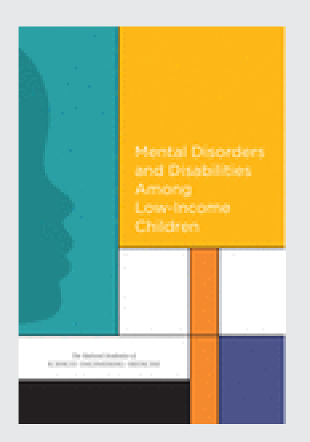

Mental Disorders and Disabilities Among Low-Income Children

DETAILS

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Committee to Evaluate the Supplemental Security Income Disability
Program for Children with Mental Disorders

Thomas F. Boat and Joel T. Wu, *Editors*

Board on the Health of Select Populations

Board on Children, Youth, and Families

Institute of Medicine

Division of Behavioral and Social Sciences and Education

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Reviewers

This report has been reviewed in draft form by individuals chosen for their diverse perspectives and technical expertise. The purpose of this independent review is to provide candid and critical comments that will assist the institution in making its published report as sound as possible and to ensure that the report meets institutional standards for objectivity, evidence, and responsiveness to the study charge. The review comments and draft manuscript remain confidential to protect the integrity of the deliberative process. We wish to thank the following individuals for their review of this report:

Christina Bethell, Johns Hopkins University, Bloomberg School of Public Health
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Daniel Pine, National Institute of Mental Health
Mark A. Stein, University of Washington, Seattle Children's Hospital
Leslie R. Walker, University of Washington, Seattle Children's Hospital

Although the reviewers listed above have provided many constructive comments and suggestions, they were not asked to endorse the conclusions or recommendations nor did they see the final draft of the report before its release. The review of this report was overseen by **Alan Leshner,** Rutgers University, and **Robert S. Lawrence,** Johns Hopkins University. They were responsible for making certain that an independent examination of this report was carried out in accordance with institutional procedures and that all review comments were carefully considered. Responsibility for the final content of this report rests entirely with the authoring committee and the institution.

Preface

Four decades ago, disability and functional impairment in children was recognized as a national challenge, leading to responsive federal legislation through the Social Security Act in the 1970s. The Supplemental Security Income (SSI) program was created within the Social Security Administration (SSA), initially to provide need-based monetary support for elderly adults and adults with disabilities. It was rapidly extended to include the families of children with severe impairments owing to disabling conditions. The program has grown to provide more than $10 billion of support for families of severely impaired children. Over the years, a growing number of child SSI benefit recipients have been impaired as a consequence of mental, emotional, or behavioral disorders, and in the last decade, parity was reached between the proportion of recipients of SSI benefits for physical and mental disorders. Despite this growth, the consensus committee found it highly likely that a sizable number of families that include a child with a disabling mental disorder are not supported by SSI benefits.

The SSI benefits program for children is positioned to mitigate the mutually reinforcing connection between childhood disability and family poverty. As addressed in this report, the costs and employment limitations of parents who care for children with severe disabilities are widely recognized. In addition, the occurrence and severity of disability is magnified by family poverty. Breaking the poverty–disability cycle is an important goal of the childhood SSI program, and, in the opinion of many, the current $10.5 billion annual investment provides a sizable return. To put this figure in perspective, the $10.5 billion expenditure represents only 5 to 6 percent of all disability benefits provided to U.S. citizens by the SSA.

In our federal expenditures–conscious society, questions have been raised about the growth of SSI benefits directed to children with mental disorder–related disabilities. To better address the questions raised, the SSA sponsored this Institute of Medicine (IOM) consensus study to gather and analyze data that could better illuminate the relationship between the growth of the SSI benefits program for childhood mental disorders and trends in mental disorder diagnoses within the general population of U.S. children. The latter data are limited and have significant drawbacks when used for comparisons with the SSI data. These drawbacks are meticulously addressed in the report, and they led the committee to seek other comparison populations. Two such populations were identified—namely, all U.S. children living in families with an income under 200 percent of the federal poverty level, and children enrolled in the Medicaid program. Both have the advantage of matching family income with that of children who are enrolled in the SSI program. The committee's task included the gathering and analysis of data on childhood mental disorders in aggregate and also for the major contributing mental disorder diagnoses, some of which (such as attention deficit hyperactivity disorder) have been the object of pointed public questions. All of these tasks required the committee to obtain new data sets and review them de novo.

Thus, our efforts included the collection and review of large amounts of data from the SSI program and from comparison populations, in contrast to many other consensus committee efforts which have reviewed published literature. The committee was assisted by a team from Rutgers University which generated and analyzed data from the Medicaid program under a contractual arrangement. The analytical as well as the review functions of our task created a demand on committee members and staff that translated to an extraordinary commitment of time, effort, and expertise. We trust that the data, findings, and conclusions from this committee will be informative not only to the study sponsor (the SSA), but also for the future shaping of public opinion and policy. Children with disabilities in the United States, particularly those with mental, emotional, or behavioral disorders, are deserving of the highest level of planning and implementation for family support programs. Both at-risk families and society as a whole stand to benefit.

The committee was instructed not to address SSI processes for the adjudication of claims, and it was careful not to do so. However, in the course of committee deliberations it became clear that there is extensive state-to-state variation in family access to SSI benefits for childhood mental disorder disability. It was also noted that there may be opportunities for analysis of the adjudication process, and the committee suggests that these areas be considered for future quality improvement efforts.

As chair of this consensus committee, I wish to acknowledge the broad and high-level capabilities of committee members, spanning a spectrum of expertise from childhood impairment to disorder-specific disabilities, and across key disciplines such as child psychiatry and psychology, pediatric medicine, epidemiology, economics, population health, mental health program management, and health services organization and improvement. A special thank-you goes to the liaison members from the IOM Standing Committee of Medical Experts to Assist Social Security on Disability Issues, Drs. Howard H. Goldman and Ruth E. K. Stein, who made many tangible as well as conceptual contributions. The IOM staff for this project worked tirelessly and productively to capture committee inputs, organize and execute a huge data management and analysis effort, and formulate committee findings and conclusions. With oversight by Dr. Rick Erdtmann, director of the Board on the Health of Select Populations, Mr. Joel Wu, our study director, managed with great skill the many interfaces required by the committee task, insightfully translated committee findings to report text, and encouraged conversations about tough topics with grace and good humor, all in the context of extended hours and workweeks. My great appreciation goes to all who contributed.

Thomas F. Boat, M.D., *Chair*
Committee to Evaluate the Supplemental
Security Income Disability Program for
Children with Mental Disorders

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Beyond the work of the committee and the Institute of Medicine (IOM) project staff, this report reflects contributions from numerous other individuals and groups. The committee takes this opportunity to recognize those who so generously gave their time and expertise to inform its deliberations.

This study was sponsored by the U.S. Social Security Administration. We wish to thank Gina Clemons, Robin Doyle, Joanna Firmin, Marianna LaCanfora, Scott Marko, Virginia Reno, Melissa Spencer, Jim Twist, and Cheryl Williams and their staff for their guidance and support.

For their collaboration and support in developing the analysis of Medicaid data contained in the report, the committee would also like to extend special thanks to the staff of the Rutgers University Institute for Health; the Center for Health Services Research on Pharmacotherapy, Chronic Disease Management, and Outcomes; and the Center for Education and Research on Mental Health Therapeutics, including Scott Bilder, Stephen Crystal, and Cassandra Simmel.

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Many staff within the IOM provided support in various ways to this project. The committee would like to thank E. Lorraine Bell, Laura DeStefano, Chelsea Frakes, Greta Gorman, Karen Helsing, Maureen Mellody, Patti Simon, and Julie Wiltshire.

Contents

APPENDIXES

Acronyms and Abbreviations

AACAP	American Academy of Child and Adolescent Psychiatry
ADD	attention deficit disorder
ADDM	Autism and Developmental Disabilities Monitoring
ADHD	attention deficit hyperactivity disorder
APA	American Psychological Association
ASD	autism spectrum disorder
AUD	alcohol use disorder
BA	Broadman area
BD	bipolar disorder
BPD	borderline personality disorder
BP-NOS	bipolar disorder not otherwise specified
CD	conduct disorder
CDC	Centers for Disease Control and Prevention
CDR	Continuing Disability Review
CNS	central nervous system
CPT	current procedural terminology
CRC	Convention on the Rights of the Child
CRS	Congressional Research Service
DDS	disability determination services
DISC	Diagnostic Interview Schedule for Children
DMDD	disruptive mood dysregulation disorder

DSM	American Psychiatric Association's *Diagnostic and Statistical Manual of Mental Disorders*
ECLP	Early Childhood Longitudinal Program
FAS	fetal alcohol syndrome
GAO	Government Accountability Office
HIV	human immunodeficiency virus
ICD	*International Classification of Disease*
ICF	International Classification of Function
ICF-CY	International Classification of Function for Children and Youth
ID	intellectual disability
IDEA	Individuals with Disabilities Education Act
IOM	Institute of Medicine
IQ	intelligence quotient
K-SADS	Schedule for Affective Disorders and Schizophrenia for School Age Children
LD	learning disorder
MAOI	Monoamine oxidase inhibitor
MD	major depression
MDD	major depressive disorder
NAMCS	National Ambulatory Medical Care Survey
NCMRR	National Center for Medical Rehabilitation Research
NCS-A	National Comorbidity Survey-Adolescent Supplement
NCS-R	National Comorbidity Survey-Replication
NEMESIS	Netherlands Mental Health Survey and Incidence Study
NHIS	National Health Interview Survey
NRC	National Research Council
NSCH	National Survey of Children's Health
NS-CSHCN	National Survey of Children with Special Health Care Needs
ODD	oppositional defiant disorder

ODDRS	Oppositional Defiant Disorder Rating Scale
PBD	pediatric bipolar disorder
PDD	persistent depressive disorder
PDD	pervasive developmental disorder
PIQ	performance intelligence quotient
PRWORA	Personal Responsibility and Work Opportunity Reconciliation Act
RTI	response to treatment intervention
SGA	substantial gainful activity
SNRI	selective serotonin and norepinephrine reuptake inhibitor
SSA	Social Security Administration
SSI	Supplemental Security Income
SSRI	selective serotonin reuptake inhibitor or serotonin-specific reuptake inhibitor
SUD	substance use disorder
TBI	traumatic brain injury
TCA	tricyclic antidepressant
UN	United Nations
VIQ	verbal intelligence quotient
WHO	World Health Organization
WIAT	Wechsler Individual Achievement Test
WISC	Wechsler Intelligence Scale for Children
WRAT	Wide Range Achievement Test

Summary

Since 1975 the Social Security Administration (SSA) has paid benefits to children with disabilities in low-income households through the Supplemental Security Income (SSI) program. In 2013 there were approximately 1.3 million children who received SSI disability benefits. Approximately 50 percent of those recipients had disabilities primarily due to a mental disorder. An increase in the number of children who were recipients of SSI benefits due to mental disorders has been observed from 1985 through 2010. Less than 1 percent of children in the United States are recipients of SSI benefits for a mental disorder.

There has been considerable and recurring interest in the growth and sustainability of the SSI program for children. In response, the SSA asked the Institute of Medicine (IOM) to identify trends in the prevalence of mental disorders among children in the United States and to compare those trends to changes observed in the SSI childhood disability population. The IOM was also tasked with providing an overview of the diagnosis and treatment of mental disorders in children, and of impairments caused by mental disorders in children. Within these broad objectives, the SSA articulated details for the completion of the task order, including two goals and six tasks. Box S-1 contains the committee's statement of task.

In following the statement of task and the SSA's direction, this consensus committee report includes evidence-based findings and conclusions concerning trends in the prevalence of mental disorders in children and also the diagnosis and treatment of these children. Of note, the committee's charge did not include a review of the SSA's standards and procedures for determination of disability and for the classification of impairments in the

BOX S-1
Statement of Task

The task order objective is to

- Identify past[a] and current trends[b] in the prevalence and persistence of mental disorders[c] for the general U.S. population under age 18 and compare those trends to trends in the SSI childhood disability population.
- Provide an overview of the current status of the diagnosis and treatment of mental disorders, and the levels of impairment, in the U.S. population under age 18.

To accomplish this objective, the committee shall

1. Compare the national trends in the number of children with mental disorders under age 18 with the trends in the number of children receiving SSI on the basis of mental disorders and describe the possible factors that may contribute to any differences between the two groups.
2. Identify current professional standards of pediatric and adolescent mental health care and identify the kinds of care documented or reported to be received by children in the SSI childhood disability population.

To perform the above activities, the committee shall do the following with respect to the two child populations:

1. Identify national trends in the prevalence of mental disorders in children and assess factors that influence these trends (for example, increased awareness or improved diagnosis).
2. Identify the average age of onset and the gender distribution and assess the levels of impairment within age groups.
3. Assess how age, development, and gender may play a role in the progression of some mental disorders.
4. Identify common comorbidities among pediatric mental disorders.
5. Identify which mental disorders are most amenable to treatment and assess typical or average time required for improvement in mental disorder to manifest following diagnosis and treatment.
6. Identify professionally accepted standards of care (such as diagnostic evaluation and assessment, treatment planning and protocols, medication management,[d] and behavioral and educational interventions) for children with mental disorders.

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[a] For at least the last 10 years.

[b] In the context of current trends in child health and development, and in pediatric and adolescent medicine.

[c] Including disorders such as attention deficit and hyperactivity disorder, autism and other developmental disorders, intellectual disability, learning disorders, and mood and conduct disorders.

[d] Including appropriateness of how medications are being prescribed.

SSI program. As a result, this report does not contain recommendations to the SSA regarding the administration of the SSI program. However, the committee makes several conclusions to address issues or limitations identified in the process of conducting this study, including the availability of data on children with disabilities, and policy issues that are out of this committee's scope of work.

This summary contains the major findings and conclusions of the committee. Since there are a large number of findings and conclusions, this summary begins with six overarching "Key Conclusions" that are informed by all the evidence compiled in this report, and summarize the major findings and conclusions of this study (see Box S-2). The remainder of the summary includes findings and conclusions specific to each element of the task order, including trends observed in the SSI program for children with mental disorders, clinical characteristics of mental disorders in children, and estimates of the prevalence of mental disorders in children.

NATIONAL TRENDS IN THE SSI PROGRAM FOR CHILDREN WITH DISABILITIES

The committee conducted a review of the trends in the number and proportion of all children in the United States who were allowed and received SSI disability benefits nationally, from 2004 to 2013. This analysis included a review of the trends in the number of children who received SSI disability benefits for all causes as well as reviews of the trends in childhood disability attributed to 10 major mental disorders, both individually and in aggregate. The 10 major mental disorders selected for review included attention deficit hyperactivity disorder (ADHD), autism spectrum disorder (ASD), intellectual disability (ID), mood disorders (depression and bipolar disorder), learning disorder (LD), organic mental disorders, oppositional defiant disorder (ODD), conduct disorder (CD), anxiety related disorders, and borderline intellectual function. The committee's findings and conclusions based on this review are the following:

Conclusions

- Overall, the likelihood that an application for benefits was allowed on the basis of a mental disorder decreased from 2004 to 2013. The proportion of all disability determinations for the major mental disorders that resulted in a finding of disability decreased from year to year.
- Generally, each year, the number of suspensions, terminations, and age-18 transitions out of the child SSI program was less than the

BOX S-2
Key Conclusions

1. Information about trends in the rates of mental disorders, and the disability associated with mental disorders, among children in the United States is limited. In addition, it is difficult to directly compare these trends to trends in the number of allowances and recipients[a] of SSI benefits for child mental disorders. Information about the severity, comorbidities, treatment, outcomes, and other characteristics (including race and ethnicity) of children who are SSI recipients is also limited.
2. While the number of children allowed (that is new beneficiaries of) SSI benefits for mental disorders has fluctuated from year to year between 2004 and 2013, over the 10-year period, the percentage of children in low-income households who are allowed SSI benefits for mental disorders has decreased.
3. After taking child poverty into account, the increase in the percentage of children in low-income households receiving SSI benefits for mental disorders, (from 1.88 percent in 2004 to 2.09 percent in 2013) is consistent with and proportionate to trends in prevalence of mental disorders among children in the general population.
4. The trend in child poverty was a major factor affecting trends observed in the SSI program for children with mental disorders during the study period. Increases in numbers of children applying for and receiving SSI benefits on the basis of mental health diagnoses are strongly tied to increasing rates of childhood poverty because more children with mental health disorders become financially eligible for the program when poverty rates increase.
5. Better data about diagnoses, comorbidities, severity of impairment, and treatment, with a focus on trends in these characteristics, are necessary to inform improvements to the SSI program for children. The expansion of data collection and analytical capacities to obtain critical information about SSI allowances for and recipients with mental disorders should be given consideration by the SSA and related stakeholders.
6. Important policy issues identified during this study, but outside of the scope of this committee's statement of task, include improving methods for the evaluation of impairment and disability in children, effects of SSI benefits for children on family income and work, and state-to-state variation within the SSI program. Further investigation of these topics, building on the findings and conclusions of this report, could provide expert policy advice on how to improve the SSI program for children.

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[a] An allowance is determination by the disability determination service, an administrative law judge, or the Appeals Council that an applicant meets the medical definition of disability under the law. A recipient is an individual who receives SSI benefits.

number of allowances and "reentries" from suspension, which has led to increasing numbers of total recipients.

- A substantial proportion of child disability allowances are on the basis that applicants "functionally equal" the SSA's "Listing of Impairments."[1] There is a substantial pool of children who experience severe disability due to conditions that are not formally described in the Listings and who subsequently cannot be reliably or accurately characterized using the Listings alone. Therefore, the impairments typically associated with primary diagnostic listing may not be the sole impairments experienced by the child. As a consequence, it is not possible to precisely identify the pool of children who are SSI recipients based on a specific mental disorder. That said, the committee concluded that the data contained in this report for each of the 10 major childhood mental disorders arethe best available approximation of specific diagnosis prevalence in the SSI beneficiary population.

Findings

- In 2013, approximately 1.8 percent of U.S. children (ages 0–18) were recipients of SSI benefits. This had increased from 1.35 percent in 2004.
- Approximately half of all children who are recipients of SSI disability benefits receive benefits due to mental disorders. The percentage of all U.S. children who were recipients of SSI disability benefits for the 10 major mental disorders grew from 0.74 percent in 2004 to 0.89 percent in 2013.
- Among the children who applied for SSI, the proportion whose SSI applications were allowed (i.e., met SSI disability criteria) each year for all disabilities did not increase from 2004 to 2013.
- The proportion of children whose applications were allowed annually for the 10 major mental disorders out of all allowances for children did not increase. Approximately half of all allowances for child disability benefits were for the 10 major mental disorders.
- The number of suspensions and terminations varied considerably over the period from 2004 to 2013. Changes in the number of children who annually are found to no longer have a severe disability contributed to the variation in number of suspensions and terminations.

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[1] The "Listing of Impairments" is a regulatory list of medical conditions and medical criteria produced by the SSA that serve as a standard for a determination of disability.

- Trends in the number and proportion of allowances and recipients varied by type of mental disorder. Some diagnoses, such as ASD, showed substantial increases over the period. Some, such as intellectual disability (ID), showed considerable decreases. For each year from 2004 to 2013, the ADHD category was the largest in terms of the numbers and proportions of child SSI disability allowances and recipients.

STATE-TO-STATE VARIATION OBSERVED IN THE SSI PROGRAM FOR CHILDREN WITH MENTAL DISORDERS

The data requested from the SSA by the committee included the numbers of SSI child disability benefit allowances and recipients for mental disorders within each state. Because the SSI program is administered at the state level, the committee concluded that a review of state-level data would help to ascertain whether national trends generally reflect state trends or whether the national trend obscures variations that occur at the state level. Based on the review of state-specific SSI program data, the committee concluded the following:

Conclusion

- Variation among states indicates that the likelihood of a child with a disability becoming a recipient of SSI varies depending on the state of residence. Although studies have shown state variations in prevalence rates for children's mental health disorders, these prevalence variations cannot fully explain differences in state allowances or recipients.

Finding

- There is considerable state-to-state variation in the rates at which children are allowed SSI disability benefits for mental disorders. There is also variation in the rate at which children receive SSI for mental disorders.

POVERTY AND CHILDHOOD DISABILITY

SSI eligibility criteria require that a child have a disability and come from a low-income household. The committee observed that these eligibility criteria select for a high-risk population of children due to the interaction of poverty and disability. As a result, the committee decided that an analysis of the effect of poverty on disability and the SSI program would be necessary to understand and effectively characterize the unique population of children who are potentially eligible to receive SSI benefits. Based on this review, the committee's findings and conclusions are the following:

Conclusions

- Poverty is a risk factor for child disability, including disability associated with mental disorders. At the same time, child disability is a risk factor for family poverty. In times of economic hardship in the United States, more children with mental disorder–related disabilities will qualify for benefits because they meet the income eligibility threshold.
- Children living in poverty are more likely than other children to have mental health problems, and these conditions are more likely to be severe. Low-income families containing a child with a disability may be particularly vulnerable in times of economic hardship. Access to Medicaid and income supports via the SSI disability program may improve long-term outcomes for both children with disabilities and their families.

Findings

- The total number of U.S. children changed very little during the 2004–2013 decade, but both the number and percentage of all children who lived in impoverished households increased. The major increase occurred from 2008 to 2010 and coincided with a time of economic recession.
- The biggest percentage increase of children in in low-income households between 2004 and 2013 occurred in those families with incomes less than 100 percent of the federal poverty level (FPL). A small increase was documented for children in families whose income was between 100 percent and 200 percent of the FPL.
- The proportion of all children who are identified as having a disability in the United States has steadily increased each decade since the 1960s.
- The definition of disability has evolved to encompass a variety of factors that influence impairment due to biomedical factors and contextual factors such as poverty as well as functional limitations and barriers to effective participation in usual childhood activities.
- The number of families with an SSI recipient who are living below the FPL when SSI benefits are not included in calculating income increased by 46 percent between 2002 and 2010. In 2010 more than 45 percent of those families were raised above the FPL after

receiving SSI benefits, potentially reducing both economic stresses and the risk of worsening child disability.

- Neither the total number of child mental disorder allowances of SSI benefits nor the rate of allowances among children in poverty increased during the 2004–2013 decade. In fact, the total number of allowances was approximately 10 percent lower in 2013 than in 2004.
- Despite the decrease in allowances, the number of recipients increased steadily during the 2004–2013 decade. Total recipients as a percentage of all children in households below 200 percent of the FPL increased by approximately 11 percent. Recipient rates increased for all levels of poverty.
- Allowance and recipient rates per 100,000 children were higher for families below the FPL than for those above, and they increased with progressively more severe levels of poverty.

CLINICAL CHARACTERISTICS OF MENTAL DISORDERS IN CHILDREN

Pursuant to the statement of task, the committee conducted focused reviews of the clinical characteristics and treatment of the six selected mental disorders, chosen due to their prevalence and the severity of disability attributed to those disorders within the SSI disability program. These include ADHD, ODD/CD, ASD, ID, LD, and mood disorders. Findings drawn from reviews of each disorder are summarized below.

Findings Regarding the Clinical Characteristics of ADHD

- Diagnosis requires a detailed, comprehensive clinical assessment. Adherence to diagnostic guidelines is variable. There are no laboratory tests to identify ADHD.
- The diagnosis of ADHD usually occurs during the early elementary school years.
- Boys are diagnosed with ADHD approximately twice as frequently as girls.
- The functional impairments caused by ADHD may change as a child matures; however, a childhood diagnosis of ADHD can often mean persistent impairments into adulthood.
- ADHD co-occurs with another mental, emotional, or behavioral disorder very frequently—in approximately 70 percent of cases. Children with ADHD and co-occurring conditions have more significant functional impairments.

- Evidence-based treatments benefit many children with ADHD. However, there is also evidence that many children with ADHD do not receive optimal, evidence-based treatment.

Findings Regarding the Clinical Characteristics of ODD and CD

- The diagnosis of ODD or CD requires a comprehensive diagnostic evaluation. There are no biological markers for ODD or CD.
- There is insufficient evidence of trends in the distribution of ODD and CD by either sex or age. Differences in the rate of diagnosis by sex have not been uniformly documented.
- ODD and CD tend to be persistent problems. The conversion of ODD to CD may account for at least some of the remissions of ODD cited in the literature.
- The disruptive behavior disorders of childhood (ODD and CD) frequently co-occur with other mental disorders in children, in particular, ADHD, mood disorders, and anxiety disorders. The co-occurrence of these disorders with other mental disorders causes significant functional impairment in many children who are SSI recipients.
- Early preventive interventions show promise for reducing ODD occurrence. Psychosocial interventions involving both parents and child are documented to provide the greatest therapeutic benefit.

Findings Regarding the Clinical Characteristics of ASD

- The diagnosis of ASD requires a comprehensive behavioral and medical evaluation by experts, including a clinical evaluation and the use of disorder-specific screening and diagnostic instruments. The role of genetic testing is limited, apart from a small number of well-characterized single-gene conditions.
- The age of onset for ASD is in early childhood. Individuals diagnosed with ASD are likely to have functional impairments throughout their lives; however, the severity of these impairments can vary greatly, from profound to relatively mild. The diagnosis of ASD can be made in most children with great certainty by age 3.
- ASD is more common in males by more than three- to fivefold.
- Unlike other mental disorders, ASD is diagnosed less often in children living in poverty, although most population studies indicate equal rates among children living in low-income households, suggesting disparities in access to early identification.

- ASD is associated with an increased risk of intellectual disability.
- Significant impairment usually persists into adolescence and adulthood.
- Early diagnosis and the application of evidence-based interventions increase the likelihood that a child will have better outcomes and reduced functional impairments. The goals of treatment are to minimize disruptive effects and to improve adaptive functioning.

Findings Regarding the Clinical Characteristics of IDs

- Historically, intellectual disability has been defined by significant cognitive deficits, typically established by the testing of IQ and adaptive behaviors. There are no laboratory tests for ID; however, many specific causes and genetic factors for ID can be identified through laboratory tests.
- Males are more likely than females to be diagnosed with ID. Poverty is a risk factor for ID, especially for mild ID.
- The functional impairments associated with ID are generally lifelong. However, there are functional supports that may enable an individual with ID to function well and participate in society.
- As a diagnostic category, IDs include individuals with a wide range of intellectual functional impairments and difficulties with daily life skills. The levels of severity of intellectual impairment and the need for support can vary from profound to mild.
- Comorbidities, including behavioral disorders, are common.
- Treatment usually consists of appropriate education and skills training, supportive environments to optimize functioning, and the targeted treatment of co-occurring psychiatric disorders.

Findings Regarding the Clinical Characteristics of LDs

- LDs are diagnosed in educational and clinical settings. Standardized instruments are available as diagnostic aids.
- The diagnosis is usually made in school-aged children.
- Boys are more often identified as having an LD than girls.
- Academic and employment success can be challenging for those with LDs.
- Comorbidities are common and add to the likelihood of functional impairment.
- Appropriate accommodations in educational settings enhance the opportunities for children with LDs to achieve academically and develop real-life skills that allow them to do well as adults.

Findings Regarding the Clinical Characteristics of Mood Disorders

- Diagnosis requires a comprehensive psychiatric diagnostic evaluation. Screening tools are available to detect symptoms of depression, particularly in adolescents. There are no well-established laboratory tests for mood disorders.
- Mood disorders of childhood may occur in children of all ages. However, the risk of mood disorders increases during adolescence, especially among girls. A younger age of onset is a risk factor for increased severity and duration.
- While symptoms may wax and wane, mood disorders cause significant functional impairment that often persists or recurs through childhood and into adulthood.
- Mood disorders frequently co-occur with other mental disorders.
- There is evidence for the effectiveness of medication treatment and psychotherapies for mood disorders. Improvements in functional impairments are enhanced with a combination of evidence-based psychotherapy and medication.
- Bipolar disorder in children and youth is classified by the *Diagnostic and Statistical Manual of Mental Disorders, 5th Edition* (DSM-5) as a diagnosis distinct from depression. Severe impairments in functioning are very common and frequently persist, even with treatment.

PREVALENCE OF MENTAL DISORDERS IN CHILDREN

As prescribed in the task order, the committee completed focused reviews of prevalence estimates for six major mental disorders from SSI data, from the general population of youth, and from Medicaid childhood populations. Findings and conclusions drawn from reviews of each disorder are summarized below.

Prevalence of ADHD

Conclusions

- The available evidence on the prevalence of ADHD in children shows (1) increasing rates where diagnoses are based on actual or parent-reported clinician judgment and (2) no evidence of increasing rates (from a meta-regression analysis) where diagnoses are based on parent- and/or child-reported symptoms. The implication of these findings is that the increase in ADHD observed within the SSI program is consistent with an increase in the diagnosis of

ADHD in the general population, but not necessarily an increase in the rates of children who have symptoms that meet various criteria for ADHD.

- The frequency of ADHD diagnoses relative to that of other mental disorders (and, in particular, mood disorders and oppositional defiant disorder/conduct disorder) is greater in the SSI population than in the general population. A possible explanation is that ADHD serves as a catch-all diagnostic category for children with multiple and unspecified mental disorders within the SSI program.
- Based on 2012 estimates of the number of children below 200 percent of the FPL and the prevalence of moderate to severe ADHD in children nationally, it appears that only a small proportion of children who were potentially eligible for SSI benefits due to ADHD were in fact recipients.

Findings

- Prevalence estimates for ADHD in the general population of youth fall into the 5 percent or greater range, depending on the source of the estimate and survey methodology.
- Estimates of the prevalence of ADHD that apply diagnostic criteria based on assessment of a child's symptoms are lower than estimates derived from parent reports of health care provider diagnoses of ADHD. There is no evidence of an increase in the prevalence of ADHD based on assessments of a child's symptoms; however, there is evidence of an increase in the frequency of diagnoses for ADHD based on parent report and from Medicaid billing records.
- The increase in the prevalence of ADHD diagnoses found by the national surveys based on parent interviews approaches that of the increase in the number of youth with ADHD in the SSI recipients group (approximately 60 percent over 10 years). Similarly, the cumulative percentage increase in the percentage of ADHD diagnoses in child Medicaid enrollees from 2004 to 2010 is similar to the increase in the percentage of poor children who are recipients of SSI benefits for ADHD.

Prevalence of ODD and CD

Conclusion

- Based on rough approximations of the prevalence of moderate to severe behavioral and conduct problems among children in households below 200 percent of the FPL, in 2011 and 2012 only an estimated 4 percent of children who were potentially eligible for SSI benefits on the basis of ODD/CD disorders were actually recipients.

Findings

- Estimates of the prevalence of ODD and CD range from 3 to 5 percent. A recent meta-analysis estimated the combined prevalence of ODD/CD to be 6.1 percent.
- Currently there are no population- or national-level data on the prevalence trends of ODD and CD among U.S. children.
- While ODD/CD constitutes a small number of mental disorder cases in SSI, from 2004 to 2013 the rates of allowances among children in low-income households for ODD increased slightly, while the rates of allowances among poor children for CD decreased. Over the same period, the rate of SSI recipients for both ODD and CD increased.

Prevalence of ASD

Conclusion

- Based on current prevalence estimates of autism and on estimates of the number of children in low-income households in this country, there is significant evidence that not all children in low-income households who would be eligible for SSI benefits due to ASD are currently recipients of these benefits. Depending on the prevalence estimate, only 20 to 50 percent of potentially eligible children received SSI benefits. However, unlike the case with other mental disorders, the evidence shows higher rates of ASD identification in children in middle- and high-income households, and lower rates of identification among children in low-income households. This suggests ASD children may be under-identified and underestimated.

Findings

- Recent prevalence estimates for ASD in the general population under age 18 range from 1.5 to 2 percent.
- An increasing trend in the prevalence of ASD has been observed across all data sources, including national surveys, epidemiologic studies, special education service use counts, and Medicaid reimbursements. The trends in the rate of child SSI recipients for ASD among children in low-income households are consistent with

trends in the rate of ASD observed in both the general population and others.

- There is evidence of diagnostic substitution between ASD and ID in both the general population data and SSI program data. From 2004 to 2013, decreases in the rate and number of recipients of SSI for ID were similar to decreases in the rate of special education service use for ID in the general population; significant increases in the rate and number of recipients of SSI for autistic disorder are similar to increases in the rate of special education services for ASD in the general population.
- The trend in ASD diagnoses among Medicaid-enrolled children was similar to general population trends between 2001 and 2010. The yearly prevalence estimates of ASD diagnoses among children enrolled in Medicaid were similar to estimates based on special education child counts, but lower than ASD prevalence estimates from surveillance and survey data for the general population.

Prevalence of IDs

Conclusion

- Rough estimates of the number of children in low-income households with moderate to severe ID suggest that less than 60 percent of children who are likely eligible for SSI benefits due to ID are recipients of these benefits.

Findings

- Estimates of the prevalence of ID in the general population have varied somewhat over time, but have remained largely unchanged. These estimates range from 8.7 to 36.8 per 1,000 children.
- The number of and proportion of children in low-income households who are receiving SSI benefits for ID is decreasing. The decreasing trend is consistent with trends observed in the rates of special education service utilization for children with ID and may relate to diagnostic substitution with ASD.
- The rates of children diagnosed with ID among all child Medicaid enrollees did not appear to decrease between 2001 and 2010. The percentage of children diagnosed with ID who are on Medicaid on the basis of SSI eligibility may have increased slightly.

Prevalence of LDs

Conclusions

- Rough estimates of the number of children in low-income households with moderate to severe LD suggest that less than 24 percent of children who are likely eligible for SSI benefits due to LD are recipients of these benefits.
- There is no evidence that the trends observed in the proportion of children receiving SSI benefits for LD are inconsistent with the prevalence trends observed in the general or Medicaid populations.

Findings

- Prevalence estimates for LD in the general population range between 5 and 9 percent.
- Prevalence in the general population is stable, but from 2003 to 2012 the number of children receiving special education services based on an LD diagnosis decreased.
- Within the SSI program, trends in both the number of LD allowances and the rate of LD allowances in children in low-income households is decreasing. From 2004 to 2013, the number of SSI recipients for LD was stable.
- Among children enrolled in Medicaid on the basis of SSI eligibility, the rate of children with an LD diagnosis appears to be increasing. Among all children enrolled in Medicaid, there does not appear to be an increase in the rates of LD diagnoses.

Prevalence of Mood Disorders

Conclusion

- Conservative estimates of the prevalence of moderate to severe depression among children and adolescents (i.e., 1 percent) applied to the population of these children and adolescents who are below 200 percent of the FPL suggest that only a small proportion, approximately 3 percent, of those who are potentially eligible for SSI benefits on the basis of mood disorders are actually recipients.

Findings

- Prevalence estimates for child and adolescent depression in the general population range from 2 to 8 percent. Because pediatric bipolar disorder is uncommon, additional research is needed to more robustly estimate the prevalence rates using standardized diagnostic criteria among children in nationally representative samples.

- The prevalence of depression among children and adolescents in the general population does not appear to be increasing. The trends in the prevalence of pediatric bipolar disorder remain unknown.
- From 2004 to 2013 the allowance rates for SSI benefits for mood disorders decreased, while the percentage of children in low-income households who were recipients of SSI benefits for mood disorders increased modestly.
- The trend for SSI mood disorder recipients is upward among both SSI and Medicaid enrollees.

PREVALENCE AND TREATMENT OF MENTAL DISORDERS IN CHILDREN ENROLLED IN MEDICAID

The committee concluded that another comparison population of children with mental disorders in low-income families would add value to its analysis of trends based on SSI data and would allow for an analysis of the types of treatments documented for children with mental disorders in the SSI population. Medicaid data are the most efficient source of continuously collected data that simultaneously include information on a child's SSI status, mental disorder diagnoses, and health services utilization. The findings and conclusions from this study are summarized below.

Conclusions

- The number of ADHD diagnoses among all Medicaid enrollees in the study nearly tripled during the decade of our inquiry. Increases in SSI benefits for ADHD during this decade are therefore expected in view of this growth rate in the Medicaid population of children who have received paid Medicaid services.
- Child Medicaid enrollment increased from 2001 to 2010. The growing numbers of all Medicaid enrollees during the study period likely reflect increases in childhood poverty as well as policies that encouraged the enrollment of eligible children in Medicaid.

Findings

- The percentage of All Medicaid enrollees with a mental disorder diagnosis increased from 7.9 percent in 2001 to 11.1 percent in 2010, a growth rate similar to the increase observed for asthma diagnoses. The percentage of SSI Medicaid enrollees with a mental disorder diagnosis increased from 29.2 percent in 2001 to 38.6 percent in 2010.

- There are high rates of co-occurring or comorbid mental disorder diagnoses among children enrolled in Medicaid. The frequency of co-occurring mental diagnoses among children with disabilities enrolled in Medicaid is higher than the frequency of co-occurring mental disorder diagnoses in all children enrolled in Medicaid.
- The rates of treatment with medication, psychotherapy, or combinations of the two varied depending on the specific mental disorder diagnosis.
- All Medicaid enrollees with ADHD experienced increased rates of treatment with medications, psychotherapy, or a combination of the two. This increase suggests improving adherence to guidelines by providers serving the Medicaid population.
- The number of SSI Medicaid enrollees with ADHD with no recorded paid claims for treatment declined by almost 50 percent during the period, consistent with the other indicators of increased frequency of treatment.
- Combination therapy for mental disorders was used with increasing frequency from 2001 to 2010, but was documented in only about one-quarter of the total mental disorder diagnoses by 2010.

Part I

Background and Context of the Supplemental Security Income Disability Benefit Program for Children

1

Introduction

BACKGROUND

The Social Security Administration (SSA) pays disability benefits to children with disabilities in low-income households through the Supplemental Security Income (SSI) program. The SSI program, created in 1972, is designed to provide monetary support to individuals with disabilities with limited income and resources. Out of the approximately 73.6 million children under age 18 living in the United States, every month approximately 1.8 percent of them, or 1.3 million children, receive SSI benefits (U.S. Census Bureau, 2014). There are approximately 63 million (in 2013) total recipients of Social Security and SSI payments in the United States (SSA, 2013). Of those 63 million individuals receiving benefits administered by the SSA, 2 percent are children receiving SSI (SSA, 2013). In 2012 the annual federal payments for SSI children totaled approximately $9.9 billion, or approximately 19.6 percent of all payments made to the SSI population ($51 billion), 5.5 percent of all disability benefits administered by the SSA ($191 billion), and 1.2 percent of all payments ($840 billion) administered by the SSA (SSA, 2013).

As has been the case with other entitlement programs, there has been considerable and reoccurring interest in the growth, effectiveness, accuracy, and sustainability of the SSI program for children. Since 2010 Congress and the media have posed questions about the changes observed in the SSI program involving pediatric and adolescent mental disorders. The attention paid to this issue has included periodic coverage in the press and, subsequently, consideration in congressionally directed studies and hearings.

For example, in December 2010 the *Boston Globe* published a series of articles by Patricia Wen that described the experiences and challenges of families that either were currently receiving or else sought to become eligible to receive SSI benefits for their children.[1] In this series of articles, Wen covered a range of issues, including the growth of the SSI program for children and the increasing number of children receiving benefits for behavioral, mental, or learning disorders. The articles also questioned the influence of medication use in the determination of eligibility, the impact of the SSI benefits on long-term outcomes for recipients, and the role of SSI within the broader system of public benefits. Additional related press attention included an editorial article by Nicholas Kristoff in the *New York Times*[2] in December 2012, and an investigative piece by Chana Joffe-Walt for NPR[3] in March 2013. These articles suggested that the growth of the disability benefit program, and in particular growth in the SSI program for children with mental disorders, may not be helpful to recipients and their families, and may be the result of incentives that are not related to increases in the true prevalence of disability in children.

Partially in response to the issues raised in the *Boston Globe* series, in early 2011 several members of Congress directed the U.S. Government Accountability Office (GAO) to conduct an assessment of the SSI program for children. Congressional members instructed the GAO to assess three aspects of the SSI program for children with disabilities: (1) trends in the rate of children receiving SSI payments due to mental impairments over the past decade; (2) the role that medical and nonmedical information, such as medication use and school records, plays in the initial determination of a child's eligibility; and (3) steps that SSA has taken to monitor the continued medical eligibility of these children (GAO, 2012). The GAO assessment was conducted from February 2011 to June 2012. Midway through the GAO assessment, on October 27, 2011, the Subcommittee on Human Resources of the House Ways and Means Committee convened a hearing on SSI for children, including an interim report by the GAO on its findings regarding the SSI program for children.

The GAO found that the number of children making claims for and receiving SSI benefits based on mental impairments had increased. Between 2000 and 2011, the number of children applying for SSI benefits increased from 187,052 to 315,832; of these applications, 54 percent were denied

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[1] "The Other Welfare," available at http://www.boston.com/news/health/specials/New_Welfare (accessed May 7, 2015).

[2] "Profiting from a Child's Illiteracy," available at http://www.nytimes.com/2012/12/09/opinion/sunday/kristof-profiting-from-a-childs-illiteracy.html (accessed May 7, 2015).

[3] "Unfit for Work: The Startling Rise of Disability in America," available at http://apps.npr.org/unfit-for-work (accessed May 7, 2015).

(GAO, 2012). In addition, the GAO found that mental impairments constituted approximately 65 percent of all child SSI allowances and that the three most prevalent primary mental impairments for children found eligible were attention deficit hyperactivity disorder (ADHD), speech and language delays, and autism/developmental delays (GAO, 2012). From December 2000 to December 2011, the number of children receiving SSI benefits for mental disorders increased by almost 60 percent, from approximately 543,000 to approximately 861,000 (GAO, 2012). Secondary impairments were present for many of those found medically eligible. GAO also estimated that, in 2010, 55 percent of allowances had an accompanying secondary impairment recorded. Of those secondary impairments recorded, 94 percent were mental disorders (GAO, 2012).

In the report, the GAO suggested that several factors may contribute to changes observed in the size of the SSI program for children, including

- Fewer children leaving the disability program prior to age 18;
- Increased numbers of children living in poverty in the United States;
- Increased awareness and improved diagnosis of certain mental impairments;
- A focus on identifying children with disabilities through public school special education services; and
- Increased health care insurance coverage of previously uninsured children.

In addition to these factors, the rates of disability from mental health disorders in children may have increased (Halfon et al., 2012). In the chapters that follow, this report will address these factors as well as other factors that may also contribute to the changes observed in the SSI program for children. Chapter 3 briefly addresses the rates of children leaving the disability program prior to age 18. Chapter 5 is devoted to addressing the effect of poverty on childhood disability. Part II of the report (Chapters 6 through 11) will review diagnostic criteria and guidelines for the assessment and treatment of major mental disorders.[4] Part III of the report (Chapters 12 through 17) will present findings on the prevalence trends of specific mental disorders and will address some potential factors that may affect prevalence trends, including awareness and diagnosis of the condition, the role of special education services for certain mental disorders, and how rates of diagnosis mental disorders in children may be related to access to health care insurance.

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[4] Major mental disorders include attention deficit hyperactivity disorder, autism spectrum disorders, intellectual disabilities, mood disorders, learning disorders, oppositional defiant disorder, and conduct disorders.

BOX 1-1
Statement of Task

The task order objective is to

- Identify past[a] and current trends[b] in the prevalence and persistence of mental disorders[c] for the general U.S. population under age 18 and compare those trends to trends in the SSI childhood disability population.
- Provide an overview of the current status of the diagnosis and treatment of mental disorders, and the levels of impairment, in the U.S. population under age 18.

To accomplish this objective, the committee shall

1. Compare the national trends in the number of children with mental disorders under age 18 with the trends in the number of children receiving SSI on the basis of mental disorders and describe the possible factors that may contribute to any differences between the two groups.
2. Identify current professional standards of pediatric and adolescent mental health care and identify the kinds of care documented or reported to be received by children in the SSI childhood disability population.

To perform the above activities, the committee shall do the following with respect to the two child populations:

1. Identify national trends in the prevalence of mental disorders in children and assess factors that influence these trends (for example, increased awareness or improved diagnosis).
2. Identify the average age of onset and the gender distribution and assess the levels of impairment within age groups.
3. Assess how age, development, and gender may play a role in the progression of some mental disorders.
4. Identify common comorbidities among pediatric mental disorders.
5. Identify which mental disorders are most amenable to treatment and assess typical or average time required for improvement in mental disorder to manifest following diagnosis and treatment.
6. Identify professionally accepted standards of care (such as diagnostic evaluation and assessment, treatment planning and protocols, medication management,[d] and behavioral and educational interventions) for children with mental disorders.

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[a] For at least the last 10 years.

[b] In the context of current trends in child health and development, and in pediatric and adolescent medicine.

[c] Including disorders such as attention deficit and hyperactivity disorder, autism and other developmental disorders, intellectual disability, learning disorders, and mood and conduct disorders.

[d] Including appropriateness of how medications are being prescribed.

A review of trends in the prevalence of mental disorders in children in the United States was outside of the scope of the GAO report. However, a review of national trends would provide essential and fundamental information for considering changes in the SSI program for children. Therefore, SSA asked the Institute of Medicine (IOM) to review the national prevalence rates and trends of mental disorders in individuals under the age of 18, how those rates compare to the trends observed in the SSI program, what factors might be related to any changes and differences, and the characteristics of mental disorders in children in the United States, including how childhood and adolescent mental disorders are treated. See Box 1-1 for the committee's statement of task. This report represents the committee's efforts to provide the SSA insight into changes in the number of children who are diagnosed with mental disorders nationally relative to changes in the number of children who receive SSI benefits for mental disorders, based on the best data currently available.

STUDY CHARGE, SCOPE, AND APPROACH

Study Charge

In 2013 the SSA Office of Disability Policy requested that the Institute of Medicine convene a consensus committee to (1) identify past and current trends in the prevalence and persistence of mental disorders for the general U.S. population under age 18 and compare those trends to trends in the SSI childhood disability population, and (2) provide an overview of the current status of the diagnosis and treatment of mental disorders, and the levels of impairment, in the U.S. population under age 18. See Box 1-1 for the committee's statement of task.

Study Scope

The statement of task from the SSA is narrowly focused. The agency asked for the best available current information about mental health conditions of children that are relevant to the SSI program, including specifically: demographics, diagnosis, treatment, and expectations for the disorder time course, both the natural course and under treatment. The agency also asked the committee to provide an analysis of prevalence trends for these disorders in the U.S. childhood population and to compare SSI data for childhood mental health determinations and recipients with data of the U.S. childhood population. Each section of this report has been developed to meet a specific requirement of the statement of task. This report is not intended to be a comprehensive discussion of these mental disorders in children, but rather to provide the SSA with basic information directly relevant to the administration of the SSI program for children with mental disorders. The following paragraphs describe how the committee used the statement of task as a guide to complete its review and analysis and to determine whether to include or exclude related or noteworthy topics.

Inclusion and Exclusion of Mental Disorders for Review Within the Report

There is substantial variation in the rates of pediatric and adolescent mental disorders within the SSI program, ranging from 0 percent for substance abuse disorders to approximately 21.9 percent for ADHD (unpublished data set provided by the SSA). Rather than review every mental disorder category in the SSI program, the committee made the decision to focus its descriptive and analytic work on the most frequent SSI determinations by primary diagnosis.

Although claims for "speech and language impairment" constitute a significant proportion (21.3 percent) of the disability observed in the SSI program for children with primary mental disorders, this diagnostic category has been specifically excluded from review in this report at the direction of the SSA (unpublished data set provided by the SSA). The SSA determined that a separate committee is needed to investigate trends in the rates of speech and language impairment in children, and it has engaged an independent IOM consensus report committee to complete that work.

After excluding speech and language impairment, the top 10 mental disorder impairment codes by allowance, at the initial level,[5] arranged from those with the highest to the lowest frequency in 2013, are

1. **Attention deficit disorder/attention deficit hyperactivity disorder** (ADHD) — 21.9 percent of all mental disorder allowances in 2013
2. **Autistic disorder and other pervasive developmental disorders** (ASD) — 21.19 percent
3. **Intellectual disability** (ID) — 11.29 percent
4. **Mood disorder** — 7.61 percent
5. **Learning disorder** (LD) — 4.09 percent
6. **Organic mental disorders** — 2.98 percent
7. **Oppositional defiant disorder** (ODD) — 2.78 percent
8. **Anxiety related disorders** — 1.78 percent
9. **Borderline intellectual function** (BIF) — 1.4 percent
10. **Conduct disorder** (CD) — 1.33 percent

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[5] Unpublished data set provided by the SSA.

The review and analysis of trends in the SSI program for mental disorders will include only these 10 major disorders.

Furthermore, the in-depth review of the clinical characteristics, treatment, and trends in prevalence will be focused on six mental disorders that are of significant relevance to the SSI program: ADHD, ASD, mood disorders, ID, LD, and ODD/CD. These disorders have been specifically selected for in-depth review and analysis because of the high rates of disability caused by these disorders and because the rates of these diagnoses have been subject to change over the past decade. Two disruptive behavior disorders of childhood, ODD and CD, have been grouped and are specifically selected for in-depth review because of the high rate of co-occurrence with ADHD and the severity of impairment that is frequently the result of these conditions. Organic mental disorders have been excluded from further in-depth review because the term "organic" mental disorders is no longer recognized as a meaningful diagnostic category and the use of the term in practice has been in decline (Ganguli et al., 2011). Developmental and emotional disorders of infants are excluded because the diagnosis of mental disorders at that stage of early childhood development is inconsistent and involves disorders and impairments that are distinct from the mental disorders of that occur later in childhood development. Although anxiety disorders occur with some frequency in the under-18 population, because this diagnosis represents a relatively small percentage of SSI allowances, it is excluded from review in this report. BIF is not reviewed because the rates of the condition are relatively low and have not exhibited significant change over the time period of interest.

The other remaining mental disorder impairment codes[6] excluded entirely from review and analysis in this report are

1. **Schizophrenic/delusional (paranoid), schizo-affective, and other psychotic disorders** — 1.05 percent
2. **Developmental and emotional disorders of newborn and younger infants (under 1 year of age)** — 0.96 percent
3. **Personality disorders** — 0.28 percent
4. **Eating and tic disorders** — 0.05 percent
5. **Somatoform disorders** — 0.02 percent
6. **Psychoactive substance dependence disorders (drugs)*** — 0 percent
7. **Psychoactive substance dependence disorders (alcohol)*** — 0 percent
   *Substance dependence disorders cannot be allowed as a primary impairment by law.

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[6] Unpublished data set provided by the SSA.

Assessment of Childhood Poverty Rates

A criterion for childhood SSI benefit eligibility is a documentation of the family's poverty status. Therefore, a significant part of this report is devoted to exploring the interaction of childhood poverty rates and the changes observed in the SSI program for children with mental disorders. Additional data are provided in this report that allow for comparisons and analyses of SSI determination, allowances, and the total number of childhood SSI recipients as a percentage of impoverished populations within the United States. This discussion can be found in Chapter 5 of this report.

Limitation of Review of the SSI Program to Children Under 18 Years Old

As noted in the statement of task, this review is limited to studying children under age 18. This is because children under age 18 are the population served by the SSI childhood program. Once they reach age 18, SSI recipients must be reevaluated to see if they qualify to receive SSI disability benefits as an adult.

Exclusion of In-Depth Analysis of State-to-State Variation in the SSI Program

The adjudication of applications for SSI benefits is managed at the state level. Through an examination of the evidence, the committee became aware that there is considerable variation from state to state in the number and rate of applications leading to determinations as well as in the rate of allowances. However, state-to-state variation does not affect the national-level prevalence and trends data required to respond to the SSA statement of task for the committee. Some state-level data are included in this report to provide some overall perspective, but the committee does not explore the potential factors contributing to state-to-state variation in the rates of SSI disability. The discussion of state-to-state variation can be found in Chapter 4.

Limitation of the Use of Recommendations Within the Report

The committee was not asked to provide recommendations on the SSI program for children, but rather it was tasked with gathering information on and reporting on the current state of knowledge concerning the diagnosis, prognosis, and treatment of mental disorders in children as well as on trends in the prevalence of mental disorders in children. This report will document those efforts and communicate the consensus findings and conclusions of the committee, which were based on the information gathered and analyzed.

Study Approach

The study committee included 12 members with expertise in pediatric and adolescent psychiatry, pediatric and adolescent psychology, pediatrics, and epidemiology; see Appendix H for biographies of the committee members. The study committee also benefited from the participation and input of two additional liaisons from the concurrent IOM Standing Committee of Medical Experts to Assist Social Security on Disability Issues, who offered specialized expertise in disability policy as well as in pediatric disabilities and chronic disease.

A variety of sources informed the committee's work. The committee met in person six times; three of those meetings included public workshops intended to provide the committee with input from a broad range of experts and stakeholders, including experts in childhood disability and public benefit policy, examiners and executives from the SSA Disability Determination Services, and childhood disability and mental disorder advocacy organizations. In addition, the committee conducted a review of the literature in order to identify the most current research on the etiology, epidemiology, and treatment of pediatric mental disorders. Finally, the committee commissioned a supplemental study using Medicaid data to create an approximate national comparison group for the SSI childhood population. (See Chapter 18 and Appendixes F and G for detailed information about this study.)

Related IOM Reports of Interest

The following are IOM reports with related topics that may be of interest:

- *The Future of Disability in America* (2007)
- *Improving the Social Security Disability Decision Process* (2007)
- *Preventing Mental, Emotional and Behavioral Disorders Among Young People: Progress and Possibilities* (2009)

Structure of the Report

Part I of the report focuses on the background and context of the SSI disability benefit program for children: Chapter 2 covers the SSI program for children; Chapter 3 discusses national level trends in the SSI program for children with mental disorders, from 2004–2013; and Chapter 4 looks at state variation in the SSI program, while Chapter 5 discusses poverty and childhood disability.

Part II of the report covers clinical characteristics of the six selected mental disorders: ADHD (Chapter 6), ODD and CD (Chapter 7), ASD (Chapter 8), ID (Chapter 9), LD (Chapter 10), and mood disorders (Chapter 11).

Part III of the report focuses on the trends in prevalence of the six selected mental disorders in the general population, in Medicaid, and in the SSI program for children; ADHD (Chapter 12), ODD/CD (Chapter 13), ASD (Chapter 14), ID (Chapter 15), LD (Chapter 16), and mood disorders (Chapter 17).

Finally, Part IV of the report discusses the results of the Medicaid Analytic eXtract (or MAX) study, which was commissioned by the committee and performed by Rutgers University.

REFERENCES

Ganguli, M., D. Blacker, D. G. Blazer, I. Grant, D. V. Jeste, J. S. Paulsen, R. C. Petersen, and P. S. Sachdev. 2011. Classification of neurocognitive disorders in DSM-5: A work in progress. *American Journal of Geriatric Psychiatry* 19(3):205–210.

GAO (U.S. Government Accountability Office). 2012. Supplemental Security Income: Better management oversight needed for children's benefits. GAO-12-497. http://purl.fdlp.gov/GPO/gpo25551 (accessed May 7, 2015).

Halfon, N., A. Houtrow, K. Larson, and P. W. Newacheck. 2012. The changing landscape of disability in childhood. *The Future of Children* 22(1):13–42.

SSA (Social Security Adminstration). 2013. Annual statistical supplement to the Social Security Bulletin, 2012. www.ssa.gov/policy/docs/statcomps/supplement/2012/supplement12.pdf (accessed May 7, 2015).

U.S. Census Bureau. 2014. Current population reports: Number of children (in millions) ages 0–17 in the United States by age, 1950–2014 and projected 2015–2050. www.childstats.gov/americaschildren/tables/pop1.asp (accessed May 7, 2015).

2

The SSI Program for Children

The Supplemental Security Income (SSI) program for children is an important and unique part of the country's social safety net. The administration of this benefit program is complex; it is the product of numerous legislative, judicial, and regulatory decisions accumulating over the past 50 years. An understanding of the history and administration of SSI for children is essential background for understanding trends observed in the program. This chapter will provide background information on the SSI program for children and will discuss the committee's approach to the use and interpretation of SSI program data. There are six sections in this chapter. The first section will provide a brief overview of the purpose and history of the SSI program for children. The second section is a list of key terms and definitions for this report. The third section provides a description of the process for determining whether an applicant is eligible to receive SSI benefits. The fourth section offers a description of the process for an applicant to appeal an unfavorable determination of eligibility, suspensions and terminations of benefits, and recurring reviews of disability. The fifth section gives a description of the SSI data, and of the sources of SSI data used in this report. The sixth and final section provides an explanation of how the committee approached the interpretation and use of the SSI data in order to be responsive to the committee's task order.

PURPOSE AND HISTORY OF THE SSI PROGRAM FOR CHILDREN

Purpose

SSI is a national needs-based public benefit program established in 1972 to provide assistance to individuals with limited income and resources who are age 65 or older, blind (any age), or disabled (any age). Funded through general tax revenues, the SSI program provides monthly cash benefits to recipients to meet basic needs for food, shelter, and clothing (SSA, 2014j). In 2014 the SSI program provided a maximum monthly cash benefit of $721.00 for an individual (SSA, 2014h). In September 2014, an average child SSI benefit was $632.24 (SSA, 2014i).

In order to receive benefits through the SSI program, an individual must (1) be age 65 or older, blind, or disabled; (2) be a U.S. citizen or have qualified alien status; (3) reside in one of the 50 states, the District of Columbia, or the Northern Mariana Islands[1]; (4) have limited income and resources; and (5) file an application (SSA, 2012b).

In addition to cash benefits, SSI eligibility may also grant eligibility for Medicaid. In 33 states and the District of Columbia, the SSI application is also the Medicaid application, so Medicaid eligibility starts during the same month as SSI eligibility (SSA, 2015c). Seven states and the Northern Mariana Islands require a separate application for Medicaid but use the same rules for the determination of eligibility as SSI (SSA, 2015c). Ten states require the completion of a different application with different standards to be eligible for Medicaid on the basis of disability and financial criteria (SSA, 2015c).

The following section discusses the history of the SSI program for children and, in particular, the evolution of the standard for eligibility.

History

Created by the Social Security Amendments of 1972 (Public Law 92-603), the SSI program came into effect in 1974 and was developed to replace disparate state-based benefit programs for the needy aged, blind, and disabled. The program was intended to provide another form of income support to particularly disadvantaged households.

The standard of eligibility for children has evolved in three distinct phases. From 1974 to 1990, the standard for children's eligibility was essentially an extension of the adult standards; unlike the adult rules, however, the rules for children did not include an assessment of a child's functioning comparable to the medical-vocational assessment of an adult's

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[1] Effective January 9, 1978.

employability. From 1990 to 1996, following an order by the Supreme Court in *Sullivan v. Zebley*, the Social Security Administration (SSA) wrote new childhood regulations that based the determination of disability on an individualized functional assessment (IFA). From 1996 to the present, the Personal Responsibility and Work Opportunity Reconciliation Act (PRWORA, Public Law 104-193) narrowed the definition of disability for children, including elimination of the IFA, and set new criteria for the determination of eligibility. Each of these phases is described in greater detail in the sections that follow.

Childhood Disability Eligibility Standards from 1974 to 1990

From 1974 to 1990 the Social Security Act set a "comparable severity standard" for the determination of a child's eligibility for the SSI benefit program, meaning that the standard for determining whether a child was disabled enough to receive SSI benefits would be comparable to the adult standard for disability. Specifically, the statute stated that a child would be eligible for benefits "if he suffers from any medically determinable physical or mental impairment of comparable severity" to one that would disable an adult (SSA, 1991a).

The five sequential steps used in the adjudication of "adults" include (1) a determination of whether an applicant is currently engaged in "substantial gainful activity" (SGA; see definition in the Key Terms and Definitions section); (2) a medical screen to determine whether or not the applicant has a medically determinable impairment that is "severe" in that it has more than a minimal impact on basic work-related functional abilities and is not due to an acute condition of short duration; (3) further determination that the impairment meets or medically equals criteria articulated in the Listing of Impairments (Listings; see definition in the Key Terms and Definitions section) and meets the duration requirement; (4) an assessment of the applicant's "residual functional capacity" (RFC) used to determine the ability to perform past relevant work; and (5) a determination of the applicant's ability to do any work in the national economy using the same RFC and considering the applicant's age, education, and work experience.

The child disability determination of impairment severity was based on the adult standard. In practice, the adult standard had other steps for determining impairment severity beyond the medical criteria in the listings. When an adult's impairment did not meet or equal the medical criteria in the listings, his or her RFC was considered in steps 4 and 5. These steps included a functional assessment and compared it to the physical and mental demands of the adult's past relevant work. Children were not evaluated using a functional assessment and instead were evaluated using medical criteria alone.

In 1983 a class-action complaint was filed in Pennsylvania to challenge the listings-only, medical criteria–based policy of evaluating disability for children. The complaint alleged that children were held to a stricter standard than adults because functional assessments, which were used for adult disability claims, were not used for child disability claims. When the Third Circuit Court found the statute's "comparable severity standard to be too restrictive and preclusive of an individualized assessment of a child's functional impairment," the SSA filed a petition requesting a review by the Supreme Court (SSA, 1992). In *Sullivan v. Zebley*, decided in 1990, the Supreme Court held that the listings-only policy for determining disability in children was inconsistent with the statutory standard of "comparable severity" to adult standards in the Social Security Act and therefore required functional assessments for children when determining disability (SSA, 1992). The Supreme Court subsequently ordered SSA to conduct "individualized functional analysis contemplated by the statute and provided to adults" (SSA, 1991b).

Childhood Disability Eligibility Standards from 1990 to 1996

In following the Supreme Court's order, the SSA wrote new regulations that based the determination of disability for children on an IFA. The IFA assessed a child's day-to-day functioning in several domains while considering the child's age. If an IFA showed that impairments substantially reduced a child's ability to function independently, appropriately, and effectively in an age-appropriate manner and also that the impairments met the duration requirement, then the SSA would find that the child had an impairment of comparable severity to one that would disable an adult. The child would then be determined eligible for benefits.

At around the same time as the *Sullivan v. Zebley* decision in 1990, the SSA published updated medical listings for adult and child mental disorders. In the revised listings for children, seven new listings were added:

- anxiety disorders (112.06);
- somatoform, eating, and tic disorders (112.07);
- personality disorders (112.08);
- psychoactive substance dependence disorders (112.09);
- autistic disorder and other pervasive developmental disorders (112.10);
- attention deficit hyperactivity disorder (112.11); and
- developmental and emotional disorders of newborn and younger infants (112.12) (Cowles, 2005).

In the early 1990s, following the *Sullivan v. Zebley* ruling which allowed for the consideration of a child's functioning and SSA's publication of seven new mental disorder listings, an increase in child SSI beneficiaries was observed. Between 1991 and 1996, SSI child beneficiaries more than doubled from 397,000 to 955,000, with a portion of awards being given to children with mental disorders (SSA, 2006b; Tambornino et al., 2015).

Childhood Disability Eligibility Standards from 1996 to the Present

In 1996, as part of a series of welfare reform legislative actions, Congress passed the PRWORA, which changed the statutory standard for childhood eligibility for SSI benefits from "comparable severity" to "marked and severe functional limitations," eliminated reference to "maladaptive behavior" in the childhood mental listings, and eliminated the "individualized functional assessment" (SSA, 2012a).

The PRWORA created a new definition of disability for children and mandated changes to the disability determination process for children (SSA, 1997). The "comparable severity" portion of the act was replaced with the new definition: "An individual under the age of 18 shall be considered disabled for the purposes of this title [XVI] if that individual has a medically determinable physical or mental impairment, which results in marked and severe functional limitations, and which can be expected to result in death or which has lasted or can be expected to last for a continuous period of not less than 12 months" (SSA, 1997).

The SSA implemented interim final rules in 1997 for the determination of eligibility for children, which established a three-step sequential evaluation process:

- Step 1: Is the child working and performing SGA?
- Step 2: Does the child have a severe medically determinable impairment?
- Step 3: Does the severe impairment meet a listing, medically equal a listing, or functionally equal the listings?

Following these changes to the disability determination process and the stricter definition of disability, a temporary decline in the number of awards for new beneficiaries was observed (Bazelon Center, 2012).

Additionally, after PRWORA was passed, existing child SSI recipients who were originally evaluated using IFAs were reevaluated for eligibility based on the new criteria. Reevaluations for these recipients led to the termination of SSI payments for more than 90,000 children, further decreasing the number of beneficiaries (Coe and Rutledge, 2013). SSI awards for children with mental disorders began rising again after 1997 (SSA, 2006b).

KEY TERMS AND DEFINITIONS

The following set of definitions for the key administrative terms and procedures used in the SSA's determination of an applicant's eligibility for SSI benefits will be used throughout the remainder of this chapter and report. SSA field offices (FOs), located in communities throughout the country, administer the nondisability criteria of citizenship or alien status, residency, employment, income, and resources. State disability determination services (DDSs) administer the disability eligibility criteria at the initial and reconsideration levels.

1. **Adjudication:** For the purposes of this report, adjudication is a decision process by which the SSA first determines whether or not an applicant is eligible for disability benefits after taking into account the citizenship or alien status, residency, income, and resources criteria and then engages in a detailed analysis of specific disability criteria as outlined in the regulations. A final determination or decision can be made at various levels during the adjudication process: at the initial level, reconsideration level, or administrative hearing level. If a claimant is dissatisfied with the outcome of the case, he or she can appeal a hearing-level decision to the SSA Appeals Council, which is the last administrative level of review within the SSA. If a claimant is dissatisfied with the actions taken by the Appeals Council, he or she can appeal to the federal district court.
2. **Allowance:** A determination by the disability determination service, an administrative law judge, or the Appeals Council that an applicant meets the medical definition of disability under the law.
3. **Allowance rate:** The percentage of allowed disability applications in a given time period calculated as the number of medically allowed applications divided by the total number of applications with a medical decision. (An allowance rate provides a narrower view of the disability program than does an award rate because it excludes nonmedical determinations from its base.)
4. **Applicant:** For purposes of this report, an applicant refers to a child under age 18 who has submitted an application to receive benefits through the SSI program.
5. **Award:** An administrative determination that an individual is eligible for an SSI benefit; that is, an applicant has met both the disability and the nondisability (citizenship or alien status, residency, work, income, and resource) eligibility criteria and may receive benefits.
6. **Continuing disability review (CDR):** An evaluation of an individual's impairment(s) to determine whether the person is still

disabled within the meaning of the law for purposes of eligibility for SSI benefits. (A CDR is a periodic review to determine if an individual who was previously found disabled and eligible for SSI benefits is still disabled. If an individual is determined to be no longer disabled, eligibility for benefits will stop. Individuals who are determined to still be disabled will continue to be eligible to receive disability benefits.)

7. **Deeming:** A complex process by which a portion of a child applicant's parents' or stepparents' income and resources is counted as available to the child when determining eligibility for SSI benefits or payment amount.
8. **Denial:** For purposes of this report, a denial is a determination by a DDS that an applicant does not meet the SSI disability criteria and is not disabled (i.e., the applicant's impairment does not meet a listing, medically equal a listing, or functionally equal the listings). (Denials may also occur based on other, nondisability criteria.)
9. **Determination:** For purposes of this report, a determination made by the DDS on whether an applicant is disabled. Within a given year, the number of determinations in that year is equal to the sum of all allowances and denials in that year. An individual may have multiple determinations within the same year. For example, an applicant may have two determinations in 1 year if the applicant is denied at the initial level in January, and then allowed at the reconsideration level in September. In this report, we only evaluate determinations made at the initial level to avoid a skewing of the allowance rates caused by multiple denials within one year. Also, for the purposes of this report, the number of determinations can be understood as a proxy for the number of applications among children who are in poverty; specifically, determinations will be the number of children for whom applications for SSI benefits have been submitted and who have already been found to meet the nondisability eligibility criteria.
10. **Disability:** According to the Social Security Act, Section 1614(a)(3)(C)(i), "An individual under the age of 18 shall be considered disabled for the purposes of this title if that individual has a medically determinable physical or mental impairment, which results in marked and severe functional limitations, and which can be expected to result in death or which has lasted or can be expected to last for a continuous period of not less than 12 months."
11. **Functional limitation:** Functional limitations are the primary criteria on which the SSA based a determination concerning disability. A "medical impairment," or the existence of a "medically determinable impairment" alone, is not sufficient to make one eligible

for SSI; marked and severe functional limitations resulting from the impairments must be established by evidence.

12. **Impairment:** An impairment results from anatomical, physiological, or psychological abnormalities that can be shown by medically acceptable clinical and laboratory diagnostic techniques. A physical or mental impairment must be established by medical evidence consisting of signs, symptoms, and laboratory findings, not only by an applicant's statement of symptoms.
13. **Listing of impairments (listings):** The listings are a regulatory list of medical conditions and criteria, produced by the SSA, that serve as a standard for a determination of disability. An in-depth description of the listings can be found in Box 2-1.

BOX 2-1
The Child Mental Disorders Listings

The Listing of Impairments was developed to ease the administrative burden of determining the functional capacity of each claimant and was revised in 1977 to include criteria that would apply to children under age 18 applying for SSI (IOM, 2007). For children, the listings contain specific medical severity criteria describing impairments severe enough to cause marked and severe functional limitations (SSA, 2015b).

SSA uses the listings to identify medically obvious cases of individuals with disabilities, thereby avoiding the time-consuming medical–vocational review (IOM, 2007). The listings allow the SSA to process a high number of cases more quickly. In addition, because SSA uses a specific set of medical criteria to guide each disability determination, the listings help promote equal treatment and adjudicative consistency for applicants (IOM, 2007).

The Listing of Impairments consists of Part A, which is primarily for adults, and Part B, which is for children only. The parts are organized into 14 major body systems for adults and 15 major body systems for children. The listings for each body system begin with an introduction containing definitions of key terms and concepts that describe the diagnosis and severity of impairment. Each major body system and its corresponding diagnostic categories are numbered. The childhood (Part B) body system for mental disorders is identified as 112.00, and its listings are arranged in 11 diagnostic categories, which are

1. Organic mental disorders (112.02);
2. Schizophrenic, delusional (paranoid), schizo-affective, and other psychotic disorders (112.03);

14. **Medically determinable impairment:** A medically determinable impairment is a physical or mental impairment that is established by medical evidence consisting of symptoms, signs, and laboratory findings from acceptable medical sources, not based only on an individual's statement of his or her symptoms.
15. **Nondisability criteria:** Nondisability criteria refer to citizenship or alien status, residency, work, income, and resources criteria that must be met.
16. **"Poor" and "poverty":** For the purposes of this report, poor and poverty refer to a family income less than 200 percent of the federal poverty level (FPL). An in-depth description of poverty can be found in Chapter 5.

3. Mood disorders (112.04);
4. Intellectual disability (112.05);
5. Anxiety disorders (112.06);
6. Somatoform, eating, and tic disorders (112.07);
7. Personality disorders (112.08);
8. Psychoactive substance dependence disorders (112.09);
9. Autistic disorder and other pervasive developmental disorders (112.10);
10. Attention deficit hyperactivity disorder (112.11);
11. Developmental and emotional disorders of newborn and younger infants (112.12).

Each listing, except for listings 112.05 and 112.12, is followed by paragraph A criteria which outline a set of medical findings and paragraph B criteria which outline a set of impairment-related functional limitations (SSA, 2015b). Criteria in both paragraphs must be satisfied in order for an impairment to meet a listing (SSA, 2015b).

It should be noted that there are no listings for learning disorder (LD) and borderline intellectual functioning (BIF). Although there are no listings, there are SSA impairment codes (see Table 2-2). These impairment codes are used when a child's functioning is found to be of listing-level severity primarily due to LD or BIF. However, since there is no listing, no determination of disability can be made for LD or BIF based on meeting.

The complete SSA childhood mental disorders listings are reproduced in Appendix B. Additional information on the origin, design, and structure of the medical listings can be found in Appendix C, which contains Chapter 5 of the Institute of Medicine report *Improving the Social Security Disability Decision Process* (IOM, 2007).

17. **Recipient:** An individual who receives SSI benefits. The total number of recipients at a point in time (or within a specified period) is the total number of individuals who are receiving benefits, regardless of the date on which they became eligible to receive benefits.
18. **Substantial gainful activity (SGA):** Work activity is "substantial" if it involves doing significant physical or mental activities and is "gainful" if it is usually done for pay or profit.
19. **Suspension:** An ineligibility status that causes the nonpayment of benefits for a period of anywhere from 1 to 12 months for any of a number of reasons. (Payments can resume if the recipient reestablishes eligibility during the suspension reinstatement period. If a recipient does not become eligible again within the 12 months, benefits will be terminated.)
20. **Termination:** Cessation of benefits, which can occur for a number of reasons, including death, medical improvement, or a period of suspension lasting longer than 12 months. (Once benefits are ceased, an individual cannot receive benefits without filing a new application.)

REQUIREMENTS FOR SSI ELIGIBILITY

For a child to receive SSI benefits, two basic conditions must be met: (1) the child must meet citizenship or alien status, residency, work, income, and resource criteria; and (2) the child must be found to have a severe impairment that meets the statutory and regulatory standards for disability. State agencies, which are fully funded by the federal government, working under the guidance and rules of the Social Security Administration are responsible for making disability determinations (SSA, 2007). The process for becoming eligible for child SSI benefits begins when an individual files an application for benefits with the SSA. The adjudication process proceeds through multiple steps, as illustrated in Figure 2-1. Each step in the process is discussed in detail below.

It should be noted that while this report and the committee describe the adjudication process as proceeding through four steps, the SSA formally describes the process as a three-step process, but with step 3 composed of two parts, step 3a and step 3b. Step 3 in this report is the same as step 3a in the SSA regulations, and step 4 in this report is the same as step 3b in the SSA regulations.

Step 1: Work and Income

Determination of employment status and financial eligibility is the first step in the determination of a child's eligibility for SSI disability benefits.

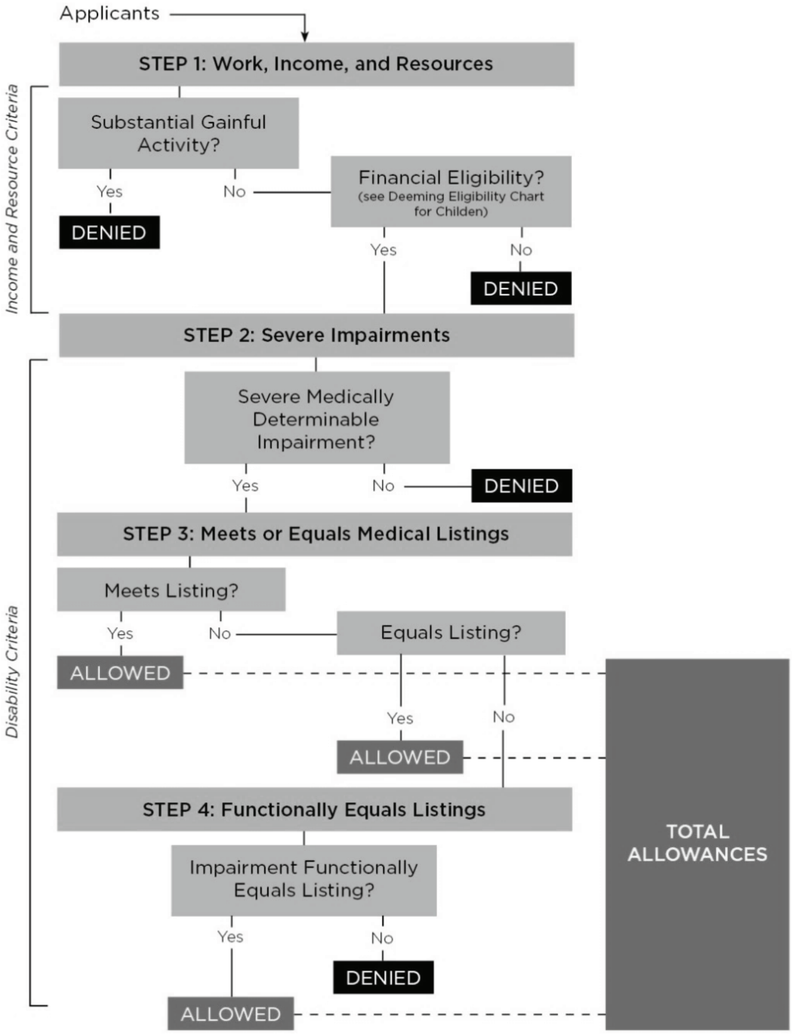

FIGURE 2-1 For purposes of this report, the SSI adjudication process.
SOURCE: Wixon and Strand, 2013.

The work, income, and resource eligibility criteria must be met prior to any evaluation of disability.

After an application for child SSI benefits is filed, the SSA field offices will first determine whether the child is engaged in SGA. SGA[2] is defined as work that involves doing significant and productive physical or mental duties and that is done (or intended) for pay or profit (SSA, 2014a). If a child engages in SGA, the claim will be denied.

If a child is not employed, FOs will proceed to evaluate financial eligibility based on the child's income and the parents' and stepparents' income and resources (Wixon and Strand, 2013). Until a child attains age 18, a portion of his or her parents' and stepparents' income is used to determine financial eligibility through a complex process known as deeming. A certain portion of the parents' and stepparents' income and resources is "deemed" to be available to the child as a member of the household and therefore counted toward eligibility. Some types of parental income and resources are deemed, and others are not.

Income that is not deemed includes Temporary Assistance for Needy Families, pensions from the Department of Veterans Affairs, general assistance, foster care payments for an ineligible child, and income used to make court-ordered support payments (SSA, 2014g). Resources that are not deemed may include the primary residence, one vehicle used primarily for transportation, and pension fund money (SSA, 2014g). The SSA's Deeming Eligibility Chart for Children for 2015 is reproduced in Appendix A.

If the employment, income, and resources criteria are met, the case will proceed to the second step. It should be noted that, because of the deeming process, the SSI income eligibility criteria do not necessarily predict the level of poverty of the household. After deeming exclusions are applied, children eligible for SSI may come from households with income above 100 percent of the FPL. As reported in Chapter 5, three-quarters of children receiving SSI benefits were in households with income less than 200 percent of the FPL, without taking into account the income from the SSI benefit (Bailey and Hemmeter, 2014).

Step 2: Medically Determinable Impairment, Severity, and Duration

In the second step, the DDS evaluates whether an applicant has a "severe medically determinable impairment" as required by the Social Security Act, and the claim will be denied if the child does not have a severe medically determinable impairment as defined by statute and in the Code of Federal Regulations (SSA, 2011a).

The SSA defines a medically determinable physical or mental impairment

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[2] The monthly SGA amount for nonblind individuals with disabilities for 2015 is the SGA amount for 2000 multiplied by the ratio of the national average wage index for 2013 to that for 1998, or, if larger such SGA amount for 2014 ($1,070). If the amount so calculated is not a multiple of $10, we round it to the nearest multiple of $10 (SSA, n.d.).

as an impairment that results "from anatomical, physiological, or psychological abnormalities which can be shown by medically acceptable clinical and laboratory diagnostic techniques" (SSA, 2013c). A medically determinable impairment must be established by medical evidence that includes symptoms, signs, and laboratory findings (SSA, 2013c). Furthermore, the medical evidence used to support a medically determinable impairment must come from an SSA-approved list of medical sources, which includes licensed physicians and psychologists (SSA, 2013b). If there is not sufficient medical evidence to support a finding of a medically determinable impairment, the claim will be denied.

Applicants will also be denied if the impairment is not considered severe. The SSA defines a nonsevere impairment as an impairment or combination of impairments that does not "cause more than a minimal limitation in the individual's ability to function in an age-appropriate manner" (SSA, 2014e).

Applicants will also be denied if their impairment is not expected to cause death or has neither lasted 12 months, nor can be expected to last for a continuous period of 12 months or more (SSA, 2000).

If the DDS finds that the claimant has a severe, medically determinable impairment, the claim will proceed to step 3.

Step 3: The Listings

In the third step, the DDS will perform a medical screen to determine if the child has one or more severe impairments that "meet" or "medically equal" the criteria articulated within the listings, published by the SSA (Wixon and Strand, 2013). The relevant definitions are as follows:

- *Meets a listing*: If the evidence in a case establishes the presence of all the criteria required by one of the listings and meets the duration requirement, then the claimant's impairment meets that specific listing (SSA, 2013d).
- *Medically equals a listing*: If a claimant's impairment is not found to meet the exact requirements of a specific listing, the claimant can still be found disabled if the impairment is at least equal in severity and duration to the criteria of any listed impairment, as established by the relevant evidence in the claimant's case record (SSA, 2013d).

If a child's impairment meets or medically equals a listing, benefits will be awarded. Otherwise, the claim will proceed to step 4.

Box 2-1 provides a discussion of the purpose and structure of the Child

BOX 2-2
112.11 Attention Deficit Hyperactivity Disorder Criteria

ADHD: Manifested by developmentally inappropriate degrees of inattention, impulsiveness, and hyperactivity.

The required level of severity for these disorders is met when the requirements in both A and B are satisfied.

A. Medically documented findings of all three of the following:
   1. Marked inattention; and
   2. Marked impulsiveness; and
   3. Marked hyperactivity; and

B. For older infants and toddlers (age 1 to attainment of age 3), resulting in at least one of the following:

   1. Gross or fine motor development at a level generally acquired by children no more than one-half the child's chronological age, documented by:
      (1) An appropriate standardized test; or
      (2) Other medical findings; or
   2. Cognitive/communicative function at a level generally acquired by children no more than one-half the child's chronological age, documented by:
      (1) An appropriate standardized test; or
      (2) Other medical findings of equivalent cognitive/communicative abnormality, such as the inability to use simple verbal or nonverbal behavior to communicate basic needs or concepts; or
   3. Social function at a level generally acquired by children no more than one-half the child's chronological age, documented by:
      (1) An appropriate standardized test; or

Mental Disorders Listings, which serve as a standard for determination of disability.

Box 2-2 contains Listing 112.11 for attention deficit hyperactivity disorder, which describes the set of medical findings and impairment-related functional limitations that are considered when determining disability for a child (SSA, 2015b).

Step 4: Functional Equivalence

In the fourth step, the DDS will evaluate whether the impairment functionally equals the listings (Wixon and Strand, 2013), i.e., whether the child's impairment is of listing-level severity, which means it must result in

    (2) Other medical findings of an equivalent abnormality of social functioning, exemplified by serious inability to achieve age-appropriate autonomy as manifested by excessive clinging or extreme separation anxiety; or
4. Attainment of development or function generally acquired by children no more than two-thirds of the child's chronological age in two or more areas covered by a., b., or c., as measured by an appropriate standardized test or other appropriate medical findings.

C. For children (age 3 to attainment of age 18), resulting in at least two of the following:

1. Marked impairment in age-appropriate cognitive/communicative function, documented by medical findings (including consideration of historical and other information from parents or other individuals who have knowledge of the child, when such information is needed and available) and including, if necessary, the results of appropriate standardized psychological tests or, for children under age 6, by appropriate tests of language and communication; or
2. Marked impairment in age-appropriate social functioning, documented by history and medical findings (including consideration of information from parents or other individuals who have knowledge of the child, when such information is needed and available) and including, if necessary, the results of appropriate standardized tests; or
3. Marked impairment in age-appropriate personal functioning, documented by history and medical findings (including consideration of information from parents or other individuals who have knowledge of the child, when such information is needed and available) and including, if necessary, appropriate standardized tests; or
4. Marked difficulties in maintaining concentration, persistence, or pace.

"marked" limitations in two domains of functioning or "extreme" limitation in one domain (Wixon and Strand, 2013).

Six Activity Domains

When determining functional equivalence, the SSA considers how a child functions in activities in terms of six domains. The domains are broad areas of functioning that depict activities that children can and cannot do at home, at school, and in the community compared to typical children the same age who do not have impairments (IOM, 2010). Information concerning functioning in the six domains is collected from medical sources, parents, teachers, and others who can describe functioning at home, in childcare, at school, and in the community (SSA, 2015a). The SSA may also request a consultative exam if the medical evidence provided is not adequate (SSA, 2015a).

The first domain, “Acquiring and using information,” refers to how well a child can acquire or learn information and use the information that was learned (SSA, 2015a). An example of limited functioning in acquiring and using information is having difficulty remembering things that were learned in school the previous day (SSA, 2015a).

The second domain, “Attending and completing tasks,” involves how well a child can focus and maintain attention throughout activities and finish the activities (SSA, 2015a). A child with limited functioning in this domain is repeatedly distracted from activities (SSA, 2015a).

The third domain, “Interacting and relating with others,” concerns how well a child can “initiate and sustain emotional connections with others, develop and use the language of the community, cooperate with others, comply with rules, respond to criticism, and respect and take care of the possessions of others” (SSA, 2015a). When a child is unable to form close friendships, he or she is limited in interacting and relating with others (SSA, 2015a).

The fourth domain, “Moving about and manipulating objects,” concerns gross and fine motor skills that include a child’s ability to move from one place to another and his or her ability to move and manipulate things (SSA, 2015a). Difficulty climbing up and down stairs shows limitation in this domain (SSA, 2015a).

The fifth domain, “Caring for yourself,” refers to how well a child can maintain a healthy emotional and physical state, including how well a child can get his or her physical and emotional wants and needs met in appropriate ways, how a child copes with stress and changes in his or her environment, and whether a child takes care of his or her own health, possessions, and living area (SSA, 2015a). A child with limitations in this domain may not dress or bathe themselves appropriately when accounting for age (SSA, 2015a).

The sixth domain, “Health and physical well-being,” involves the “cumulative physical effects of physical or mental impairments and their associated treatments and therapies on functioning” (SSA, 2015a). A child who has frequent seizures related to his or her impairment will have a limitation in the domain for health and physical well-being (SSA, 2015a).

Marked and Extreme Limitations

To functionally equal the listings, a child’s impairment must result in “marked” limitation in two domains or “extreme” limitation in one domain (SSA, 2011b). When deciding whether a child has marked or extreme limitation, SSA considers functional limitations of the child’s impairments and their interactive and cumulative effects (SSA, 2014f). Relevant information in the child's case record, such as signs, symptoms, laboratory findings, and parental and teacher descriptions of function, is used to determine functioning (SSA, 2014f). Medical evidence such as formal testing is also used to provide developmental and functional information, and the standard scores from the formal tests along with standard deviations of scores are used with the information obtained regarding functioning to determine whether a child exhibits marked or extreme limitation in a domain (SSA, 2014f).

Marked Limitation

When a child has marked limitation, his or her impairment interferes seriously with the ability to independently initiate, sustain, or complete activities (SSA, 2014f). Marked limitation can be described as "more than moderate" but "less than extreme" (SSA, 2014f). The impairment can affect day-to-day functioning by seriously limiting only one activity, or the impairment's interactive and cumulative effects can limit several activities (SSA, 2014f). For children of any age, marked limitation will be decided if a valid score on a comprehensive standardized test designed to measure ability or functioning in a domain is two standard deviations or more below the mean but less than three standard deviations (SSA, 2014f). The test should be designed to measure ability or functioning in that particular domain, and the child's day-to-day functioning in domain-related activities should be consistent with the score (SSA, 2014f). For children who have not yet reached age 3 and cannot be tested, marked limitation will generally be decided if they are functioning at a level that is more than one-half but not more than two-thirds their chronological age (SSA, 2014f).

Extreme Limitation

A child has extreme limitation when the impairment interferes very seriously with the ability to independently initiate, sustain, or complete activities (SSA, 2014f). Extreme limitation is also described as "more than marked" (SSA, 2014f). The impairment can effect day-to-day functioning by very seriously limiting only one activity, or its interactive and cumulative effects can limit several activities (SSA, 2014f). As mentioned above, comprehensive standardized test scores may be used for determining extreme limitation (SSA, 2014f). A valid score for extreme limitation is three standard deviations or more below the mean (SSA, 2014f). Children who have not yet attained age 3 will generally be considered to have extreme limitation if they are functioning at a level one-half of their chronological age or less (SSA, 2014f).

Benefits will be awarded if it is found that a child's impairment results in limitations that functionally equal the listings; otherwise, the application for benefits will be denied.

THE APPEALS PROCESS, SUSPENSIONS AND TERMINATIONS, AND RECURRING REVIEWS

The Appeals Process

A claimant has the right to appeal a determination, decision, or dismissal after any step of the disability determination process and can present additional evidence to support his or her case or appoint a representative to

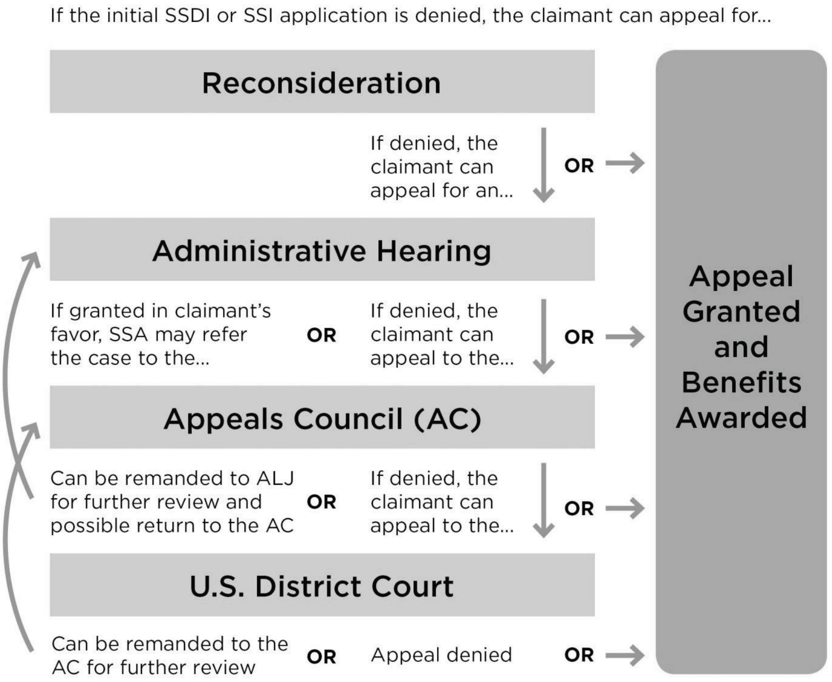

FIGURE 2-2 The SSI appeals process.
NOTE: Under the disability redesign prototype model, SSA eliminated the reconsideration step of the appeals process in the following states: Alabama, Alaska, California (Los Angeles North and Los Angeles West DDS offices), Colorado, Louisiana, Michigan, Missouri, New Hampshire, New York, and Pennsylvania. ALJ refers to an administrative law judge.
SOURCE: Morton, 2014.

do so (Morton, 2014). The appeals process has three levels of administrative review with the SSA before it can be appealed to the U.S. court system (Morton, 2014) (see Figure 2-2).

- Step 1: *Reconsideration.*[3] Claimants who are dissatisfied with the initial determination may request reconsideration in writing within 60 days after receiving the initial determination notice (SSA, 2014b). A different disability examiner will review the evidence from the initial determination and any additional evidence and notify the claimant in writing of the determination (Morton, 2014).
- Step 2: *Administrative hearing*. Claimants who are dissatisfied with the reconsideration determination (or initial determination in states using the disability redesign prototype model) may request a hearing before an administrative law judge in writing within 60 days following receipt of the determination notice (SSA, 2013e). The administrative law judge will make a de novo decision based on the evidence, including testimony from the claimant and any witnesses, such as a medical or vocational expert, and will adjudicate the request for hearing (Morton, 2014). Following the hearing, the claimant is notified in writing of the decision.
- Step 3: *Appeals Council*. Claimants who are dissatisfied with the administrative law judge decision or dismissal may request an Appeals Council review in writing within 60 days following receipt of the hearing decision or dismissal (SSA, 2014c). The Appeals Council may deny or dismiss the request, or it may grant the request and either issue a decision (favorable or unfavorable) or remand the claim to an administrative law judge (SSA, 2014c). The claimant is notified in writing of the Appeals Council action.
- Step 4: *U.S. District Court*. Claimants who are dissatisfied with the Appeals Council decision or its denial of the request for review may file a civil action with the U.S. District Court which may issue a decision, remand the case to the Appeals Council (Morton, 2014), or dismiss the case.

As shown in Table 2-1, from year to year it is consistently the case that the majority—over 90 percent—of allowances for children are made at the initial determination level. On average, only 3.3 percent of allowances are made at reconsideration, and 4.5 percent of allowances are made at the

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[3] Under the disability redesign prototype model, SSA eliminated the reconsideration step of the appeals process in the following states: Alabama, Alaska, California (Los Angeles North and Los Angeles West DDS offices), Colorado, Louisiana, Michigan, Missouri, New Hampshire, New York, and Pennsylvania.

TABLE 2-1 Percentage of Child Applications Allowed at the Various Levels of the Adjudication Process, 2004-2012

Calendar Year of Filing	Percent Allowed at Initial	Percent Allowed at Recon	Percent Allowed Beyond Recon
2004	91.5%	3.3%	5.3%
2005	91.3%	3.4%	5.3%
2006	90.5%	3.5%	6.1%
2007	90.4%	3.4%	6.2%
2008	90.3%	3.6%	6.1%
2009	90.6%	3.6%	5.8%
2010	92.0%	3.7%	4.3%
2011	95.8%	3.3%	0.9%
2012	98.0%	1.9%	0.1%
Average (9-yr)	92.3%	3.3%	4.5%

SOURCE: SSA, 2013a.

administrative hearing level, the Appeals Council level, or at the federal court level.

Suspensions and Terminations

Recipients' benefit payments may be suspended or terminated when they are no longer eligible for benefits. Suspensions of benefit payments occur when a recipient is found to no longer be eligible for a number of reasons, including having excess income or resources, whereabouts being unknown, residing in a Medicaid facility or public institution, or no longer being disabled. Suspensions can last up to 12 months. Payments can be reinstated if, within 12 months after a recipient's payments are suspended, the recipient's circumstances revert to being consistent with the eligibility criteria.

A termination of SSI benefits occurs when a recipient is ineligible for 12 consecutive months; the terminated recipient cannot receive disability benefit payments without submitting a new application. Terminations can occur when a recipient dies, or after 12 consecutive months of suspension.

Recurring Reviews

Continuing Disability Reviews

CDRs are performed at regular intervals to determine whether a child continues to be eligible for SSI benefits (SSA, 1986). The frequency of reviews depends on whether the impairment is expected to improve and whether the disability is permanent (SSA, 2006a). For impairments expected to improve, CDRs are completed in intervals of 6 to 18 months following the most recent determination or decision (SSA, 2006a). When a disability is not considered permanent and medical improvement for an impairment cannot be predicted, a CDR is conducted at least once every 3 years (SSA, 2006a). When a disability is considered permanent, a CDR is conducted no less than once every 7 years and no more than once every 5 years (SSA, 2006a).

Transitioning into the Adult SSI Disability Standard

The standards for SSI disability benefits for children under 18 are different than the standards for adults 18 and older. As a result, when a recipient turns 18 years old, he or she must be reevaluated to determine eligibility for benefits under the adult standard. These evaluations are known as "age-18 redeterminations" (Morton, 2014). Subject to some exceptions, a recipient's eligibility for child SSI benefits stops at age 18.

As a result, recipients who turn 18 are no longer part of the child SSI program. These children will leave the child SSI recipient pool and transition either into the adult SSI program or else be terminated if they do not meet the adult disability standards. Those who meet adult standards and go on to be recipients of adult SSI benefits are not counted as terminations from the child SSI program, even though they are no longer recipients of child SSI benefits. Those who do not meet the adult standards at redetermination are counted as terminations.

DESCRIPTION OF SSI DATA

This section describes the sources and types of data used in this report. Our report relies primarily on two measures produced by the SSA: allowances and recipients. SSI allowance and recipient data were provided by two different divisions within the SSA, the Office of Disability Policy Management Information (ODPMI) for allowances and the Office of Research, Evaluation, and Statistics for recipients.

Allowances

ODPMI tracks information on the outcomes of the SSI adjudication process. Specifically, SSA records information on whether or not an applicant is eligible according to the nondisability criteria (citizenship or alien status, residency, work, income, and resource; step 1), and the disability criteria (steps 2, 3, and 4). The emphasis of the committee's task order was the trends in the rates of disability caused by mental disorders; therefore, denials due to nondisability criteria are not included in the analysis in this report; rather, information specifically about determinations of disability, specifically allowances at the initial level, is prioritized. Administrative information regarding the outcome of a determination of disability is recorded on a standard form called the SSA-831 Disability Determination and Transmittal form. Allowance data included in this report are from the SSA-831 file.

As previously discussed in the chapter, an allowance is defined as a determination by a DDS (or a decision by an administrative law judge or the Appeals Council) that an applicant meets the statutory and regulatory criteria for disability. An individual applicant may have multiple determinations due to multiple denials at different levels of adjudication. For example, within the same year an individual applicant may be denied at the initial and reconsideration levels, but is subsequently allowed at the administrative law judge level. As a result, there would be three adjudications on the record for this individual applicant—two denial determinations and one allowance decision. However, once an allowance has been made, there is no subsequent readjudication of the disability criteria, and therefore, generally, there are no multiple allowances for applications. For the purposes of this report, since we only consider determinations made at the initial level, each determination can only have one outcome: either an allowance or a denial. Subsequent denials or allowances at reconsideration or thereafter, a relatively infrequent occurrence, are not analyzed in this review of the SSI program, and as such, adjusting for multiple determinations and denials for individual applicants is not necessary.

Data on determinations collected by the SSA also include information on three important aspects of every determination: (1) a medical diagnosis associated with the determination, (2) the level of adjudication at which the allowance was made, and (3) the regulation basis code (or regulatory basis) for the allowance. These three key data elements are discussed in the following sections.

Diagnostic Categories for Determinations of SSI Benefits

The SSA Program Operations Manual System (POMS), which provides instructions on completing the SSA-831, requires that the diagnosis or medical basis for the applicant's disability that is most pertinent to the determination be recorded. The SSA collects information on a primary diagnosis and an optional secondary diagnosis for each determination. According to the POMS DI 26510.015, "The primary diagnosis for an allowance refers to the basic condition that rendered the individual disabled, or in (the case of) a denial, the one which the evidence shows to have the most significant effect on the individual's ability to work" (SSA, 2014d). A secondary diagnosis is defined as the "most significant diagnosis following the primary diagnosis in severity" (SSA, 2014d).

The SSA disability examiners are required to record an "impairment code" for every disability determination. The SSA's impairment codes are numeric codes loosely informed by the *International Classification of Diseases, 9th Revision* (ICD-9) which are used to classify medical diagnoses that are the basis for disability claims. Each impairment code is linked to a diagnostic category within the SSA "Listing of Impairments," based in part on the *Diagnostic and Statistical Manual of Mental Disorders, 3rd Edition* (DSM-III-R) (SSA, 2010). For each allowance that meets or medically equals a listing, the examiner is required to record the correlated impairment code. For every allowance that functionally equals the listings, examiners must record the impairment code that most closely matches the impairment in the applicant's case file and that serves as the basis of his or her disability. For denials, examiners are instructed to record an impairment code for the diagnosis that has the most effect on the claimant's function, or a code for "none established" if there is no diagnosis or when the medical evidence in the file is not sufficient to establish a diagnosis. The analysis of the trends in rate of mental disorders in the SSI program in this report is based on impairment codes recorded only for primary diagnoses.

Table 2-2 shows what the SSA uses to link the childhood mental disorders listings to 18 mental disorder impairment codes. Codes included in this review of the SSI program are denoted with an asterisk (*).

SSI Secondary Impairment Data

Data on secondary diagnoses and impairments are excluded from this review. During public information gathering meetings with the SSA, the SSA staff informed the committee that secondary impairment codes are neither consistently nor accurately recorded by examiners, and recommended that the committee avoid use of the secondary impairment data. Additional information on the rates of secondary impairments for mental disorders in children and also on the reliability and consistency of secondary impairment data can be found in the U.S. Government Accountability Office (GAO) report *Supplemental Security Income: Better Management Oversight Needed for Children's Benefits* (GAO, 2012). The GAO conducted a case file review of initial determinations where the initial impairment was ADHD, speech and language delay, or autism. Of the determinations that resulted in an allowance, 55 percent had a secondary impairment recorded. Of those secondary impairments, 94 percent were mental impairments. The GAO also found that in 27 of 80 allowances, examiners coded secondary impairments that were alleged by claimants, but were not relevant to the determination.

TABLE 2-2 Childhood Listing Impairment Codes

Mental Disorder Listing	Diagnostic Category Label	Impairment Code
112.02	Organic mental disorders	2940*
112.03	Schizophrenic, delusional (paranoid), schizo-affective, and other psychotic disorders	2950
112.04	Mood disorders	2960*
112.05	Intellectual disability	3180*
112.06	Anxiety disorders	3000*
112.07	Somatoform disorders	3060
112.07	Eating and tic disorders	3070
112.08	Personality disorders	3010
112.08	Conduct disorder	3120*
112.08	Oppositional/defiant disorder	3138*
112.09	Psychoactive substance dependence disorders (alcohol)	3030
112.09	Psychoactive substance dependence disorders (drugs)	3040
112.10	Autistic disorder and other pervasive developmental disorders	2990*
112.11	Attention deficit disorder/attention deficit hyperactivity disorder	3140*
112.12	Developmental and emotional disorders of newborn and younger infants	3150
	Learning disorder (LD)[a]	3152*
	Speech and language impairment	3153
	Borderline intellectual functioning[b]	3195*

NOTE: Childhood listings are based in part on the revised third edition of the *Diagnostic and Statistical Manual of Mental Disorders* (SSA, 2010). Impairment codes are based on the *International Classification of Diseases, 9th Revision, Clinical Modification* (SSA, 2013f). Codes included in this review of the SSI program are denoted with an asterisk (*).

[a] The learning disorder impairment code 3152 does not have a corresponding mental disorder listing, so it cannot be used for an allowance based on meeting a listing.

[b] The borderline intellectual functioning impairment code 3195 does not have a corresponding mental disorder listing, so it cannot be used for an allowance based on meeting a listing.

The lack of reliable secondary impairment data is a significant limitation. Information about the rates and patterns of comorbidity among children who are applying for and being awarded SSI benefits cannot be evaluated, and comorbidity patterns within the SSI program cannot be compared to comorbidity patterns observed in the general population.

Level of Adjudication

The SSA also collects information on the level of adjudication at which a determination is made. In this report only those determinations made at the initial level are reported and analyzed.

Regulation Basis of Determinations

The SSA keeps records on whether allowances are for impairments that meet a listing, that medically equal a listing, or that functionally equal the listings. Chapter 3 includes an analysis of the trends in the number of allowances by regulation basis code (or regulatory basis) from 2004 to 2013.

Race and Ethnicity Data

Race and ethnicity data are not available from the SSI administrative data. The SSA does not collect any information on race or ethnicity at any point during the adjudication process.

Recipients

A recipient is a child who is receiving SSI disability benefit payments. The number of recipients reflects the total number of individuals who have previously been found to be eligible for benefits and who remain eligible for benefits. The SSA collects and maintains data on the number of individuals who receive SSI benefit payments. These data are known as the "Supplemental Security Record" (SSR). The SSR is a record of the number of individuals who apply for SSI disability benefits, the number of applicants who become eligible for benefits under both the nondisability (citizenship or alien status, residency, work, income, and resource) and disability criteria (awards[4]), and the number of individuals who are currently recipients of SSI disability benefits payments. The recipient data in the SSR refer to the number of recipients within a time period, specifically within the month of December of the year. All recipient data included in this report are from the SSR. There cannot be more than one recipient count per individual.

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[4] An award is an administrative status that indicates that an applicant has met both disability and nondisability (work, income, and resource) eligibility criteria. Because awards include nondisability criteria, they are not used in this report. Generally, the numbers of allowances and awards are very similar.

INTERPRETATION AND USE OF SSI DATA FOR PREVALENCE TRENDS

Restatement of the Task Order Requirements

The task order stipulates that the committee must compare estimates of trends in the prevalence of mental disorders generated by surveys of the general population with trends observed in the SSI program for children with mental disorders. The following sections discuss the committee's approach to completing this aspect of the task order. Specifically, the following three sections explain first, what is meant by a prevalence trend; second, what "prevalence" in the SSI program is for the purposes of this task order; and third, the challenges of comparing general population estimates of prevalence trends with SSI "prevalence" trends.

What Is a Prevalence Trend?

When we talk about how many people in the population have an illness, we often use the term "prevalence." By "prevalence" we usually mean *point prevalence:* the proportion of a population that has a given illness or condition at a *certain point in time*. Other measures of prevalence are *period prevalence*, the proportion of the population who have been cases within a *given period of time*, such as the past year, and, in particular, *lifetime prevalence*, the proportion of the population who have been cases *over their lifetime*. As described below, data from the SSI program mainly allow statements about point prevalence—the proportion of children who are SSI recipients in December of each calendar year.

As a proportion, prevalence estimates are based on two values: (1) the number of cases identified (numerator) and (2) the population in which these cases occur (denominator). Again, for the SSI program, our estimated number of "cases" is based on national and state counts of SSI recipients, and the eligible population includes those who are eligible for SSI benefits, such as families who qualify based on lower incomes. Comparing prevalence trends from the SSI program to those in the general population requires that we take into consideration several key factors, including (1) the basis or criteria by which cases are identified (numerator), (2) the definition and enumeration of the relevant population (denominator), (3) the type of prevalence reported (point prevalence or period prevalence), (4) information quality, and more. As detailed below, the sources of data regarding the prevalence of mental disorders in the general population and in the SSI population can differ on all of these factors, adding considerable challenges to their comparisons.

In order to look at trends in prevalence as required by the task order, it is necessary to have multiple estimates of prevalence over a period of time. If these estimates are arranged in order of date, they produce a trend line. Changes in prevalence over time (or the prevalence trend line) can be influenced by many factors, some substantive and some methodological. "*Substantive" changes in prevalence trends* may result from increases in the risk for a disease (such as increases in lung cancer due to smoking during the late 20th century) or decreases following the introduction of a vaccine or environmental improvements. *Methodological factors* can include a variety of topics, such as differences in methods of case identification, differences in diagnostic criteria, or changes in the makeup of the population being studied. For example, some wonder whether reported increases in prevalence trends for autism and autism spectrum disorder (ASD) may result from new, broader, and more inclusive diagnostic criteria. Differences in prevalence trends resulting from altered case identification are of concern when studying psychiatric illness because definitions have changed over time; there are no routine, standardized tests for the disease; and many individuals with the disorder may never see an expert diagnostician. Furthermore, methodological difficulties are compounded when information about cases of mental disorders are not routinely monitored or collected by state or national agencies. We know how many cases of measles or rabies occur because reporting is required; however, no official, nationwide record is kept of the number of cases of ADHD or ASD. In comparing SSI prevalence trends to comparable information from the general population we draw on multiple sources of prevalence data, which are discussed below.

Administrative Data

Examples Individuals with Disabilities Education Act (IDEA) data on learning disabilities

IDEA mandates that schools should identify, serve, and report children with specific learning disabilities. The number of children served varies widely between states, depending upon the stringency of the methods used to determine eligibility. Individual state data are reported to the federal government who then track the estimated prevalence of learning disabilities based upon this information.

Advantages

- Inexpensive means of monitoring number of children served in educational settings over time.
- Available information on entire population of school-aged children permitting prevalence estimates.
- Permits annual comparisons over time.

Disadvantages

- Inconsistent criteria for identifying students with learning disabilities.
- Criteria for service eligibility may not be consistent with diagnostic criteria. Children who receive services may not have symptoms that meet diagnostic criteria.

Surveillance Systems

Examples Metropolitan Atlanta Developmental Disabilities Surveillance Program (MADDSP), Autism and Developmental Disabilities Monitoring (ADDM) Network

These two programs are funded by the Centers for Disease Control and Prevention to estimate the number of children with selected developmental disabilities in Atlanta (MADDSP) and the number of children with ASD and other developmental disabilities in a range of communities throughout the United States (ADDM). They are examples of programs using reviews of administrative records. The process is labor intensive. MADDSP identifies children through a process known as active record review (CDC, 2015). Records are reviewed for all children in metropolitan Atlanta who are in contact with multiple health and educational settings, such as clinics and schools that evaluate and provide services to children with developmental disabilities (CDC, 2015). The reviews occur every other year for children who are or will turn 8 years of age within the year of interest and who live with a parent or guardian who is a resident of one of the five counties in which data are tracked (CDC, 2015). Trained abstractors review records and abstract detailed information (CDC, 2015). The abstracted information from all sources for a given child is then reviewed by a trained clinician (CDC, 2015). The ADDM Network consists of between 11 and 14 sites (depending on the survey year) around the United States. All collect data using the same methods, which are modeled after those of MADDSP. Additional information on surveillance systems that collect data on mental disorders is included in Appendix D.

Advantages

- All potential cases identified have been brought to the attention of health or education service providers as being in need of help; this indicates a level of severity.
- All cases are evaluated using the same criteria by trained study personnel.

Disadvantages

- There may well be cases that are not brought to the attention of service providers.
- Data collection is erratic when communities opt into or out of the program, for example, in the ADDM Network.
- If membership in the network is voluntary, there may be bias in the types of communities that opt in or out, so the sampling does not represent the whole country.
- Variability may be caused by changes in official criteria for use of a service setting or access to benefits such as Medicaid, rather than by changes in the rates of a disorder in the population.

National Surveys Involving Direct Assessment or Parent Report

Examples National Survey of Children's Health (NSCH), National Health and Nutrition Examination Survey (NHANES), National Health Interview Survey (NHIS)

Some sources of data on prevalence trends for psychiatric disorders are based on surveys that involve house-to-house sampling or sampling from existing databases, such as school or telephone listings for a given geographic area. These databases are used to recruit individuals into a random sample who are interviewed in person or by telephone. The NHANES is an example of a national survey that then conducts direct interviews with and assessments of children; the NHIS is a national survey in which information on child mental disorders is obtained through parent reports to an interviewer. Additional information on surveys that collect data on mental disorders is included in Appendix D.

Advantages

- Can be used to generate representative random samples.
- Can be used to oversample subgroups of interest.

Disadvantages

- Can be expensive to generate a sample.
- Can be difficult to get access to the information (e.g., the name, address, age, and sex of each member of the whole population) needed to recruit a truly representative sample, either because there are no records or because permission to use such records is denied (e.g., school registers).
- In the case of the NSCH, data reflect parents' understanding rather than documented diagnoses or direct assessment of a child's symptoms; e.g., such questions from the NSCH as "Please tell me if a

doctor or other health care provider ever told you" the [child's name] had [the disorder].
- If done repeatedly in the same area to measure trends, changes in the local population rather than changes in the rate of disorder may result in changes in prevalence rates.

Meta-Analyses: Synthesis of Published Research Studies

If studies have been published over a period of time it may be possible to identify a trend in the observed prevalence rates. For child and adolescent psychiatric disorders we are limited by the fact that reliable, standardized measures of childhood mental illnesses were first developed in the 1970s. By the end of the 20th century, however, population surveys using either interviews or questionnaires were much more common.

In order to calculate estimates of "true" prevalence, meta-analytic reviews can control for the methodological variability. For example, Polanczyk and colleagues conducted a meta-analysis of ADHD that found no increase in the population prevalence of the disorder over three decades (Polanczyk et al., 2014). Similarly, a survey of studies of depression showed no increase in rates of depression since the 1970s (Costello et al., 2006). As SSI benefits rely on diagnosed cases, the prevalence of benefits in the SSA database can increase even though "true" prevalence is static. It is not possible to use this method to estimate trends in ASD because the diagnosis has changed, and it was rarely included in population surveys until very recently.

Advantages

- Will include large numbers of subjects.
- Can sometimes be used to look at age, sex, or race/ethnic differences or family income level.
- Can be used to study prevalence rates over a considerable period of time.
- Can deal statistically with methodological issues such as the different time frames of the interviews.

Disadvantages

- Is dependent on information from published studies, which may lack certain necessary data (e.g., may not specify the age or sex of the participants).
- Studies tend to vary in how they group diagnoses; e.g., ASD may be included with developmental disabilities.

Medicaid Data

The Medicaid Analytic eXtract (MAX) is a set of data files organized at the person level on Medicaid eligibility, service utilization, and payments. The MAX data are pulled from the Medicaid Statistical Information System and are generated by data submitted from state Medicaid files. These data sets are the largest repository of Medicaid claims, but not all states submit data, and in many states the data for children enrolled in Medicaid managed care are not included or not accurate. Still, MAX data provide a strong source of trend data across years on cases that are diagnosed or treated because Medicaid accounts for a large portion of all child health care. MAX data are particularly useful for analyzing trends for children who qualify for Medicaid because of poverty since there is no impairment or condition requirements for eligibility. MAX data are organized into annual calendar year files. For this report, we analyzed trends in annual diagnosis of specific mental disorders and in the provision of specific mental health treatments.

Advantages

- Closest estimate for national trends in diagnosis and treatment of mental disorders for children and adolescents.
- Eligibility for poor children similar to SSI eligibility.
- Clear delineation of psychiatric drug use and diagnosis.

Disadvantages

- Clinician diagnosis may reflect best reimbursement rather than the most accurate medical condition. Clinician diagnosis is also subject to error; there is evidence that children who receive treatment may not meet diagnostic criteria.
- Psychotherapy treatments may be omitted in claims systems.
- Data are often delayed by 2 to 3 years and so may not reflect recent shifts.

What Is a Prevalence Trend in the SSI Program?

The trends observed in the SSI program are a product of variation in the cases of disability that lead to an application for benefits and subsequent selection by the disability adjudication process. Only children whose families have applied for benefits on their behalf and who sequentially meet all of the eligibility criteria can become recipients of SSI benefits.

As shown in Figure 2-1, an allowance is a finding that a child who applied for disability benefits is eligible based on the disability criteria, after having previously met the income and resource criteria. Therefore, the total number of allowances (the dark gray box in Figure 2-1 within a time period

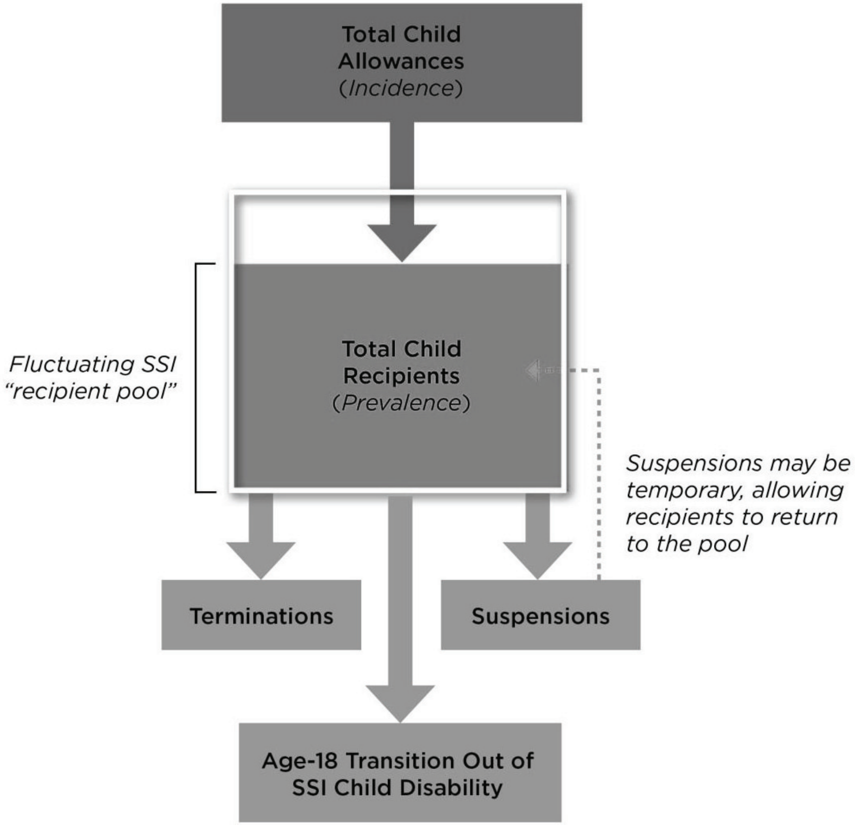

FIGURE 2-3 SSI relationship of allowances, recipients, terminations, and suspensions.

can be understood as the total number of new cases of disability among children in low-income households whose families applied for benefits within that time period.

Nearly all applications that result in allowance will also result in the applicant becoming a recipient of SSI benefits (dark gray allowance boxes in Figures 2-1 and 2-3). Within the SSI program, the term "recipients" can be understood as the current number of cases receiving benefits (recipient box in Figure 2-3). Once a child becomes a recipient of SSI benefits, he or she will continue to receive benefits until suspended or terminated or until he or she turns 18. As previously explained, a termination or suspension occurs when a recipient is found to no longer be eligible. Loss of eligibility can occur when a child no longer meets the income and resource criteria or

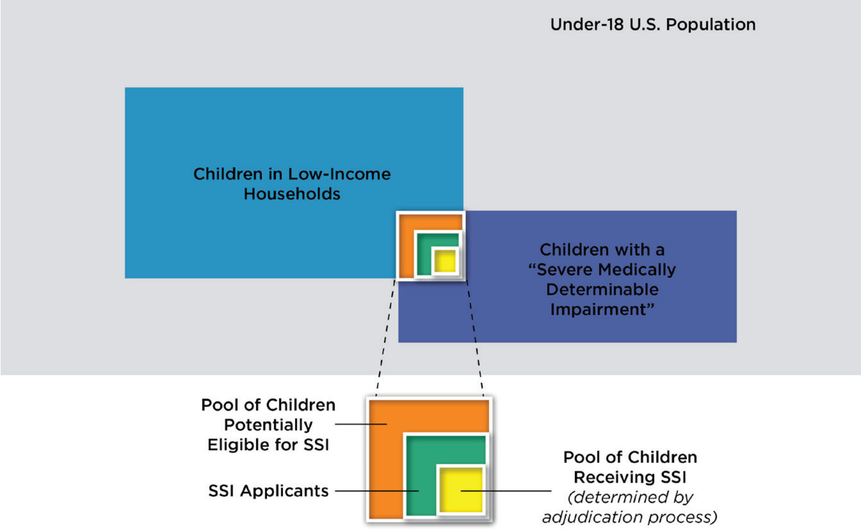

FIGURE 2-4 Subpopulations of children eligible for SSI.

is no longer disabled. Suspended individuals can reenter the recipient pool if their status changes before they are terminated.

The number of child SSI recipients at any given point in time will be a function of the number of allowances, terminations, age-18 transitions out of the child SSI program, suspensions, and reentries of suspended individuals, indicated by the yellow box in Figure 2-4. Generally, the number of recipients of the SSI benefits can be understood as the number of poor children who are identified as currently disabled by the SSI system. There will be a certain number of recipients who are, in fact, no longer disabled but have not been reevaluated and identified as such. The total number of recipients will fluctuate from year to year, depending on the number of allowances, terminations, age-18 transitions out of the child SSI program, suspensions, and reentries from suspension for that year. If the number of allowances exceeds the number of terminations and suspensions from year to year, the total number of recipients will increase. Because the adjudication process only evaluates children for disability after they meet the income and resource criteria, the identified cases of disability are only among poor children.

As illustrated by the yellow box in Figure 2-4, SSI recipients are a small subset of children in the United States who are simultaneously in low-income households and meet the requirements of having a "severe, medically determinable impairment." (Medically determinable impairment

BOX 2-3
Prevalence in the SSI Program

For the purposes of this report, SSI prevalence is the proportion of children in low-income households in the United States who are recipients of SSI benefits for the selected mental disorders, individually and in aggregate. The yearly estimated prevalence of children in low-income households who are recipients is based on counts of the number of children who are SSI recipients in December of each year.

generally can be understood to mean children with access to health care services who have evidence to support a diagnosis for their condition.) Within the group of children who are potentially eligible (orange box in Figure 2-4), only those children whose families apply for benefits on their behalf (green box in Figure 2-4), and only those who are adjudicated as disabled become recipients, the group of children represented by the yellow box in Figure 2-4. SSI prevalence can be understood as the ratio of the number of children in the yellow box to the number of children in the blue "children in low-income households" box. The amount of time that a child receives benefits can be understood as the duration of time, or persistence of disability. See Box 2-3 for the definition of prevalence in the SSI program for children.

Challenges for Comparing SSI "Prevalence Trends" to Other Prevalence Trends in the General Population

To accomplish the goals of the task order, the committee compared trends in the prevalence, as illustrated by Figure 2-5. Here we briefly

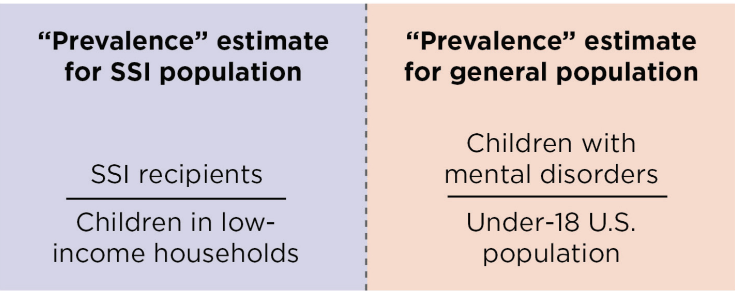

FIGURE 2-5 Comparison of "prevalence" estimate for SSI population to "prevalence" estimate for general population.

describe significant issues for interpreting the trends observed for the SSI program.

Differences Between the General Population and the SSI Population

An important difference between estimates of prevalence produced by the national surveys and prevalence of mental disorders ascertained by the SSI program is in the composition of the populations surveyed. National surveys are designed to estimate the prevalence of mental disorders *among all children*, regardless of their income, and regardless of the severity of their disease. In contrast, the SSI adjudication process restricts eligibility for the SSI benefits to those children who meet the income and resource criteria and also meet the requirements of having a severe, medically determinable impairment.

To reduce the effect of real differences on comparisons between the SSI and general populations, the committee compared SSI prevalence data with the U.S. data for children in families meeting poverty criteria (discussed further in Chapter 5). Furthermore, the committee also commissioned a study of Medicaid data, which allowed an analysis of trends in the diagnosis of mental disorders within the population of children who have met criteria for having low income. The Medicaid study also allows a comparison of trends in the rates of mental disorder among all children enrolled in Medicaid with children who are enrolled in Medicaid on the basis of receiving SSI disability benefits.

Other Potential Methodological Concerns

There are various other methodological concerns. First, the SSI taxonomies and categories for disorders are different. The SSI listings criteria are not the same as the diagnostic criteria articulated in the DSM or the ICD. The SSI listings only roughly approximate diagnostic criteria.

Second, the way in which the diagnostic categories in the SSI program are assigned to a determination of disability has significant implications. For every determination that meets or equals a listing, the examiner must record the correlated impairment code. The first listing that can be supported by the evidence in an applicant's file will be selected by the examiner as the basis for the allowance. For example, an applicant may submit an application alleging disability due to asthma; however, if the examiner finds more evidence supporting an allowance on the basis of ADHD, the applicant's SSI diagnosis would be ADHD.

For every determination that functionally equals the listings, an examiner is required to record an impairment code. Allowances that functionally equal the listings, by definition, do not meet criteria for a condition

TABLE 2-3 Challenges in Comparing SSI Prevalence Trends with Prevalence Trends in the General Population

SSI Recipients	General Under-18 Population	Medicaid Population
Key differences in the composition of populations surveyed (The "denominator" in prevalence)		
Only poor children.	Children of all income levels.	Primarily children in poverty or in other disadvantaged populations.
Only children with "severe, medically determinable impairments."	All children, regardless of the presence of any impairment.	Children enrolled in Medicaid who have either two outpatient visits or one inpatient visit.
Key differences between the cases identified (The "numerator" in prevalence)		
SSI data rely on SSI listings and impairment codes. The SSI listings and impairment codes are not currently consistent with the DSM and ICD or any other current taxonomy for mental disorders in children.	General population surveys rely on a wide range of methodologies and taxonomies for identifying and classifying cases. These vary depending on the survey/study.	Diagnoses are based on physician assignment of a diagnosis, based on the ICD, for billing and reimbursement purposes.
SSI classification is based on a review of a range of materials provided by parents, clinicians, and schools to the DDS.	Diagnoses can be based on parent report (e.g., NSCH or NHIS), direct assessment (e.g., NHANES), review of medical records (e.g., ADDM), or assessment for service eligibility (e.g., IDEA).	Diagnoses are based assessment of a patient by a clinician in a clinical setting.

in the listings; however, examiners must still record an impairment code that closely matches a diagnosis in the applicants file. Allowances that functionally equal the listings may be caused by a condition or a combination of conditions that are not in the SSA's listings or impairment codes. An impairment code would still be assigned with that allowance, regardless of whether the impairment code fully reflects the underlying causes of the child's disability. Because of these administrative requirements, the impairment codes associated with an allowance may not accurately reflect the child's mental disorder. Table 2-3 recaps the challenges encountered in comparing prevalence estimates in the SSI and general populations.

SUMMARY

With these caveats in mind, the committee set out to compare prevalence rate and prevalence rate trends in the SSI and general (total and impoverished) populations of children. Recognizing the limitations of these comparisons, the committee is of the opinion that helpful inferences can be drawn from analyzing data presented in this report. Furthermore, comparing SSI with Medicaid prevalence and trends provides an opportunity to test whether SSI prevalence and trends data deviate substantially from a second comparison population.

FINDINGS

- For a child (0–17 years of age) to be eligible to receive the SSI disability benefits, the child must meet statutory requirements for having a severe medically determinable impairment, must not be employed, and must come from a household that does not exceed a certain level of income and resources.
- The majority of children who are recipients of SSI benefits come from households at or below 200 percent of the FPL.

CONCLUSIONS

- Childhood SSI recipients represent a population of children whose families have applied for benefits and who also have had the resources to supply the necessary evidence to support a successful application for SSI benefits. Many severely impaired or disabled children in the United States are recipients of SSI benefits. Most children who are recipients of the SSI benefits will have severe impairments and will come from an impoverished household.
- Comparisons between trends in the prevalence of mental disorders in the general population and trends in the SSI population are complicated because of differences in the composition of the populations surveyed (the denominator in the prevalence) and differences in the cases identified (the numerator in the prevalence). Differences in the populations surveyed include income and the severity of impairments. Differences in cases identified also include differences in how disorders are classified for the SSI program versus in national surveys or clinical settings.
- For the purposes of this report, SSI prevalence is either the proportion of children in low-income households, or the proportion of all children in the United States who are recipients of SSI benefits for the selected mental disorders.

REFERENCES

Bailey, M. S., and J. Hemmeter. 2014. Characteristics of noninstitutionalized DI and SSI program participants, 2010 update. www.ssa.gov/policy/docs/rsnotes/rsn2014-02.html (accessed July 7, 2015).

Bazelon Center. 2012. Children's SSI: Enrollment trends in perspective. Judge David L. Bazelon Center for Mental Health Law. http://www.bazelon.org/LinkClick.aspx?fileticket=eZaz6hw6dxI%3D&tabid=40 (accessed July 7, 2015).

CDC (Centers for Disease Control and Prevention). 2015. Metropolitan Atlanta Developmental Disabilities Surveillance Program (MADDSP). http://www.cdc.gov/ncbddd/developmentaldisabilities/MADDSP.html (accessed July 16, 2015).

Coe, N. B., and M. S. Rutledge. 2013. What is the long-term impact of *Zebley* on adult and child outcomes? Center for Retirement Research and Boston College Working Paper No. 2013-3. http://crr.bc.edu/wp-content/uploads/2013/01/wp_2013-3-508.pdf (accessed July 7, 2015).

Costello, E. J., A. Erkanli, and A. Angold. 2006. Is there an epidemic of child or adolescent depression? *Journal of Child Psychology and Psychiatry* 47(12):1263–1271.

Cowles, A. L. 2005. A history of the disability listings. www.ssa.gov/history/pdf/Listings_History.pdf (accessed July 7, 2015).

GAO (U.S. Government Accountability Office). 2012. Supplemental Security Income: Better management oversight needed for children's benefits. GAO-12-497. http://purl.fdlp.gov/GPO/gpo25551 (accessed July 7, 2015).

IOM (Institute of Medicine). 2007. *Improving the social security disability decision process*. Washington, DC: The National Academies Press.

IOM. 2010. *HIV and disability: Updating the Social Security listings*. Washington, DC: The National Academies Press.

Morton, W. R. 2014. Primer on disability benefits: Social Security Disability Insurance (SSDI) and Supplemental Security Income (SSI). http://fas.org/sgp/crs/misc/RL32279.pdf (accessed October 28, 2014).

Polanczyk, G. V., E. G. Willcutt, G. A. Salum, C. Kieling, and L. A. Rohde. 2014. ADHD prevalence estimates across three decades: An updated systematic review and meta-regression analysis. *International Journal of Epidemiology* 43(2):434–442.

SSA (Social Security Administration). 1986. Code of Federal Regulations 416.989: We may conduct a review to find out whether you continue to be disabled. www.socialsecurity.gov/OP_Home/cfr20/416/416-0989.htm (accessed August 15, 2014).

SSA. 1991a. II-4-1-1. Supplemental Security Income; determining disability for a child under age 18. www.ssa.gov/OP_Home/hallex/II-04/II-4-1-1.html (accessed July 7, 2015).

SSA. 1991b. SSR 91-7c: Section 1614(a)(3)(a) of the Social Security Act (42 U.S.C. 1382c(a)(3)(a)) Supplemental Security Income—disability standards for children. www.ssa.gov/OP_Home/rulings/ssi/01/SSR91-07-ssi-01.html (accessed May 8, 2015).

SSA. 1992. I-5-4-28 Sullivan v. Zebley. www.socialsecurity.gov/OP_Home/hallex/I-05/I-5-4-28.html (accessed August 17, 2014).

SSA. 1997. I-5-4-30-a. Processing supplemental security income childhood disability cases based on Pub. L. 104-193. www.ssa.gov/OP_Home/hallex/I-05/I-5-4-30-A.html (accessed August 17, 2014).

SSA. 2000. Code of Federal Regulations 416.906: Basic definition of disability for children. www.socialsecurity.gov/OP_Home/cfr20/416/416-0906.htm (accessed August 8, 2014).

SSA. 2006a. Code of Federal Regulations 416.990: When and how often we will conduct a continuing disability review. www.socialsecurity.gov/OP_Home/cfr20/416/416-0990.htm (accessed August 15, 2014).

SSA. 2006b. *Trends in the Social Security and Supplemental Security Income Disability programs*. SSA Publication No. 13-11831. Washington, DC: SSA.

SSA. 2007. Code of Federal Regulations 416.903: Who makes disability and blindness determinations. www.socialsecurity.gov/OP_Home/cfr20/416/416-0903.htm (accessed August 15, 2014).

SSA. 2010. 20 CFR parts 404 and 416: Revised medical criteria for evaluating mental disorders; proposed rule. www.gpo.gov/fdsys/pkg/FR-2010-08-19/pdf/2010-20247.pdf (accessed August 15, 2014).

SSA. 2011a. Code of Federal Regulations 416.924: How we determine disability for chidren. www.socialsecurity.gov/OP_Home/cfr20/416/416-0924.htm (accessed August 15, 2014).

SSA. 2011b. Code of Federal Regulations 416.926a: Functional equivalence for children. www.socialsecurity.gov/OP_Home/cfr20/416/416-0926a.htm (accessed August 15, 2014).

SSA. 2012a. Program Operations Manual System (POMS): DI 11070.001 Public Law (P.L.) 104-193. https://secure.ssa.gov/poms.nsf/lnx/0411070001 (accessed October 20, 2014).

SSA. 2012b. Program operations manual system (POMS): SI 00501.001: Eligibility under the Supplemental Security Income provisions. https://secure.ssa.gov/apps10/poms.nsf/lnx/0500501001 (accessed August 8, 2014).

SSA. 2013a. 2013 annual report of the SSI program: Table v.C2.—disabled child claims: Disposition of applications for SSI disability benefits by year of filing and level of decision. www.socialsecurity.gov/oact/ssir/SSI13/V_C_AllowanceData.html#197399 (accessed April 24, 2015).

SSA. 2013b. DI 22505.003: Medical and other evidence of an individual's impairment(s). https://secure.ssa.gov/poms.nsf/lnx/0422505003#a (accessed January 30, 2015).

SSA. 2013c. DI 25205.005: Evidence of a medically determinable impairment. https://secure.ssa.gov/poms.nsf/lnx/0425205005 (accessed January 30, 2015).

SSA. 2013d. POMS DI 22001.020: Impairment(s) meets or medically equals a listing. https://secure.ssa.gov/poms.nsf/lnx/0422001020 (accessed July 7, 2015).

SSA. 2013e. Program operations manual system (POMS): SI 04030.020 requests for SSI hearing. https://secure.ssa.gov/apps10/poms.nsf/lnx/0504030020 (accessed August 15, 2014).

SSA. 2013f. SSI annual statistical report, 2013. www.ssa.gov/policy/docs/statcomps/ssi_asr/2013/glossary.html (accessed April 3, 2015).

SSA. 2014a. Code of Federal Regulations 416.972: What we mean by substantial gainful activity. www.ssa.gov/OP_Home/cfr20/416/416-0972.htm (accessed August 15, 2014).

SSA. 2014b. Code of Federal Regulations 416.1409: How to request reconsideration. www.socialsecurity.gov/OP_Home/cfr20/416/416-1409.htm (accessed August 15, 2014).

SSA. 2014c. Code of Federal Regulations 416.1467: Appeals Council review—general. www.ssa.gov/OP_Home/cfr20/416/416-1467.htm (accessed August 15, 2014).

SSA. 2014d. DI 26510.015: Completing item 16a and 16b on the SSA-831 disability determination and transmittal. https://secure.ssa.gov/poms.nsf/lnx/0426510015 (accessed April 23, 2015).

SSA. 2014e. DI 26510.045: Completing item 22 (regulation basis code) on the SSA-831. https://secure.ssa.gov/poms.nsf/lnx/0426510045 (accessed February 2, 2015).

SSA. 2014f. Program Operations Manual System (POMS): DI 25225.020: How we define "marked" and "extreme" limitations (Section 416.926a(e)). https://secure.ssa.gov/poms.nsf/lnx/0425225020 (accessed December 30, 2014).

SSA. 2014g. Spotlight on deeming parental income and resources—2014 edition. www.socialsecurity.gov/ssi/spotlights/spot-deeming.htm (accessed December 29, 2014).

SSA. 2014h. SSI federal payment amounts. www.ssa.gov/oact/cola/SSIamts.html (accessed December 31, 2014).

SSA. 2014i. SSI federally administered payments. www.ssa.gov/policy/docs/statcomps/ssi_monthly/2014-09/table07.pdf (accessed April 22, 2015).

SSA. 2014j. Supplemental Security Income home page—2014 edition. www.ssa.gov/ssi/ (accessed April 23, 2015).

SSA. 2015a. Section 416.926a. Functional equivalence for children. www.ssa.gov/OP_Home/cfr20/416/416-0926a.htm (accessed February 2, 2015).

SSA. 2015b. Disability evaluation under Social Security: 112.00 Mental disorders–childhood. www.ssa.gov/disability/professionals/bluebook/112.00-MentalDisorders-Childhood.htm#112_11 (accessed January 12, 2015).

SSA. 2015c. SI 0175.010 Medicaid and the Supplemental Security Income (SSI) program. https://secure.ssa.gov/poms.nsf/lnx/0501715010 (accessed April 23, 2015).

SSA. n.d. Determinations of substantial gainful activity (SGA). www.socialsecurity.gov/oact/cola/sgadet.html (accessed August 11, 2015).

Tambornino, J., G. Crouse, and P. Winston. 2015. National trends in the child SSI program. http://aspe.hhs.gov/hsp/15/ChildSSI/rb_ChildSSI.pdf (accessed April 21, 2015).

Wixon, B., and A. Strand. 2013. Identifying SSA's sequential disability determination steps using administrative data. Research and Statistics Note No. 2013-01. Social Security Administration, Office of Retirement and Disability Policy. http://www.ssa.gov/policy/docs/rsnotes/rsn2013-01.html (accessed July 7, 2015).

3

National-Level Trends in the SSI Program for Children with Mental Disorders, 2004–2013

This chapter reviews national-level data generated by the Supplemental Security Income (SSI) disability program for children under age 18 for 10 major mental disorder categories (hereinafter referred to as the "10 major mental disorders") from 2004 to 2013. As described in Chapter 1, these 10 major mental disorders are

- attention deficit disorder/attention deficit hyperactivity disorder (ADHD),
- autistic disorder and other pervasive developmental disorders (ASD),
- intellectual disability (ID),
- mood disorders,
- learning disorder (LD),
- organic mental disorders,
- oppositional/defiant disorder (ODD),
- anxiety disorders,
- borderline intellectual functioning (BIF), and
- conduct disorder (CD).

The quantitative overview provided in this chapter of the SSI disability benefits program for children with mental disorders provides context for the rest of the report in two ways. First, it demonstrates the relative size of the SSI program for children in the United States and the proportion of SSI benefits administered to youth that are based on disability due to mental disorders. Second, it illustrates the trends and trajectories of specific mental disorder–related determinations of disability and receipts of SSI benefits from 2004 to 2013.

The chapter contains a review of SSI data for the 10 major mental disorders in aggregate and individually from 2004 to 2013. The chapter begins with an aggregate review of the 10 major mental disorders in which recipient and allowance data for the 10 major mental disorders are compared with data on the size of the entire SSI program for children and the size of the under-18 U.S. population. The remainder of the chapter is devoted to a review of the individual 10 major mental disorders, with trends described in the number of allowances, determinations, allowance rates, and recipients. Additional tables with data concerning initial allowances, initial determinations, allowance rates, and recipients for the 10 major mental disorders are included in Appendix E. In-depth reviews of six selected high-priority individual mental disorders are discussed in Part II and Part III of this report.[1]

AGGREGATE REVIEW OF 10 MAJOR MENTAL DISORDERS

Recipients

In 2013 approximately 654,370 children were recipients of SSI disability benefits for one of the 10 major mental disorders (see Table 3-1). This represents about half (49.51 percent) of all child SSI recipients and 0.89 percent of the entire population of children in the United States in 2013. In 2013 approximately 1.32 million children in the United States were recipients of SSI disability benefits, representing about 1.8 percent of all U.S. children under the age of 18.

As shown in Table 3-1 and in Figures 3-1 and 3-2, from 2004 to 2013 both the number and the proportion of all children who were recipients of SSI disability benefits increased. The number of child SSI recipients increased from 993,127 in 2004 to 1,321,681 in 2013. The percentage of the U.S. under-18 population that received SSI disability benefits increased from 1.35 to 1.8 percent.

However, as the number of children receiving SSI benefits increased, the proportion of SSI children who were recipients of SSI benefits due to the 10 major mental disorders gradually decreased, from 54.38 percent in 2004 to 49.51 percent in 2013. As shown in Figures 3-1 and 3-2, from 2004 to 2013 the increase in both the number and percent of children who were recipients of SSI disability benefits for the 10 major mental disorders was

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[1] As discussed in Chapter 1, speech and language disorders are the basis of a large amount of disability in the SSI program, but they are not included in this analysis and are being independently studied by another Institute of Medicine committee, at the request of the Social Security Administration.

TABLE 3-1 SSI Child Recipient Numbers

Year	Total # of Child SSI Recipients	# of Child SSI Recipients for 10 Major Mental Disorders	# of Child SSI Recipients for All Other Disorders	Percent of Child SSI Recipients with the 10 Major Mental Disorders	U.S. Child Population	Percent of U.S. Child Population Receiving SSI Benefits
2004	993,127	540,051	453,076	54.38%	73,297,735	1.35%
2005	1,036,498	562,402	474,096	54.26%	73,523,669	1.41%
2006	1,078,977	577,091	501,886	53.49%	73,757,714	1.46%
2007	1,121,017	583,947	537,070	52.09%	74,019,405	1.51%
2008	1,153,844	587,618	566,226	50.93%	74,104,602	1.56%
2009	1,199,788	600,115	599,673	50.02%	74,134,167	1.62%
2010	1,239,269	615,772	623,497	49.69%	74,119,556	1.67%
2011	1,277,122	631,602	645,520	49.46%	73,902,222	1.73%
2012	1,311,861	647,555	664,306	49.36%	73,708,179	1.78%
2013	1,321,681	654,370	667,311	49.51%	73,585,872	1.80%

SOURCES: SSA, 2014; U.S. Census Bureau, 2014; unpublished data set provided by the Social Security Administration (SSA).

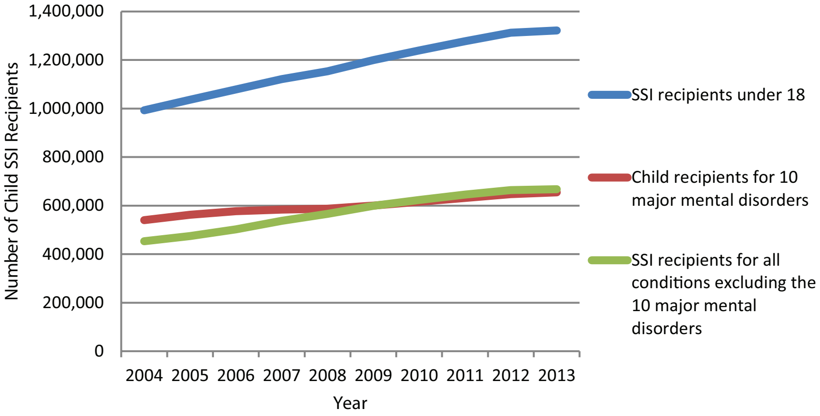

FIGURE 3-1 Numbers of child SSI recipients, 2004–2013.
SOURCES: SSA, 2014; unpublished data set provided by the SSA.

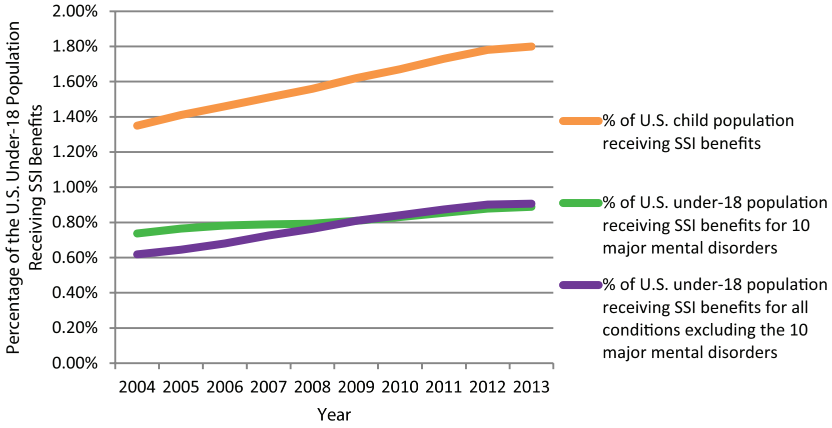

FIGURE 3-2 Percentage of the U.S. under-18 population that received SSI benefits, 2004–2013.
SOURCES: SSA, 2014; U.S. Census Bureau, 2014; unpublished data set provided by the SSA.

surpassed by the increase in the number and percent of recipients for all other disorders. Growth in SSI for children, therefore, is not due primarily or disproportionately to mental illness (excluding speech and language disorders).

Allowances

Allowances are the most direct measure of new cases of disability in the SSI population. The percentage of U.S. children being allowed SSI disability benefits at the initial level did not increase considerably over the 10-year period; the percentage of children being allowed the SSI disability benefits between 2004 and 2013 decreased from 0.24 to 0.23 percent (see Table 3-2). Similarly, the percentage of child allowances attributable to the 10 major mental disorders did not increase over that time period. From 2004 to 2013, slightly more than half of allowances were for one of the 10 major mental disorders, and the percentage of all U.S. children being allowed benefits for one of the 10 major mental disorders also remained largely unchanged from 2004 to 2013, ranging from 0.13 percent in 2004 to 0.11 percent in 2013. These observations suggest that the rate of new cases of severe disability attributable to mental disorders among children applying for SSI benefits did not increase between 2004 and 2013.

Suspensions and Terminations

For every year from 2004 to 2013, excess income or resources was the basis for the largest number of suspensions and terminations of SSI benefits to children who had been current recipients. The total number of suspensions, but not terminations, has increased over the decade, suggesting that a sizable number of suspended children are reinstated.

Over the 10-year period, substantial variation was observed in the numbers of children suspended or terminated because they were found to no longer be disabled. The number of suspensions of children who were no longer disabled decreased from 27,600 in 2004 to 5,800 in 2008 and then increased again to 25,484 in 2013. A similar pattern is seen in terminations: 18,550 terminations in 2004, decreasing to 4,478 in 2008, and increasing to 18,432 in 2013.

It should be noted that changes in the number suspensions or terminations for no longer being disabled are mostly likely not caused by a decrease in the rates of disability in the SSI population, but rather by a change in the utilization rates of continuing disability reviews (CDRs). It is improbable that for the years where the number of children who are terminated or suspended as no longer being disabled, there is a real decrease in the number of children who are no longer disabled. Rather, it is most likely that fewer recipients of disability benefits are undergoing CDRs and therefore fewer children who are no longer disabled are being identified. A reduction in the number of CDRs may result in a decrease in the number of suspensions and terminations, as the children who are no longer disabled but who do not undergo CDRs will remain recipients.

TABLE 3-2 SSI Child Initial Allowances

Year	Total # of Child SSI Allowances at the Initial Adjudicative Level	# of (Initial) Child Allowances for 10 Major Mental Disorders	# of Child Allowances for All Physical and Other Mental Disorders	Percent of Child Allowances for the 10 Major Mental Disorders	Under-18 Population	Percent of U.S. Child Population Allowed SSI Disability Benefits
2004	179,240	93,401	85,839	52.11%	73,297,735	0.24%
2005	175,944	90,554	85,390	51.47%	73,523,669	0.24%
2006	167,521	83,707	83,814	49.97%	73,757,714	0.23%
2007	164,943	80,465	84,478	48.78%	74,019,405	0.22%
2008	174,634	85,447	89,187	48.93%	74,104,602	0.24%
2009	187,854	91,739	96,115	48.84%	74,134,167	0.25%
2010	196,831	97,778	99,053	49.68%	74,119,556	0.27%
2011	197,473	98,571	98,902	49.92%	73,902,222	0.27%
2012	189,080	93,132	95,948	49.26%	73,708,179	0.26%
2013	171,574	84,307	87,267	49.14%	73,585,872	0.23%

SOURCES: U.S. Census Bureau, 2014; unpublished data set provided by the SSA.

TABLE 3-3 Total SSI Recipients Under 18 Who Were Suspended

Year	No Longer Disabled	Excess Income or Resources	Other	Total
2004	27,600	84,900	65,800	178,300
2005	22,400	85,180	56,270	163,850
2006	11,845	82,062	51,817	145,724
2007	6,588	80,409	56,591	143,588
2008	5,800	89,563	67,079	162,442
2009	9,073	88,031	75,578	172,682
2010	14,721	96,165	81,721	192,607
2011	16,572	102,161	90,184	208,917
2012	25,353	96,647	85,949	207,949
2013	25,484	95,138	98,485	219,107

NOTE: Other reasons for suspensions include whereabouts unknown; in Medicaid facility; in public institution; failed to furnish report; outside United States; presumptive disability; no representative payee.
SOURCE: SSA, 2013a.

Excluding the possibility of variations in the rates of suspensions and terminations due to no longer being disabled, no clear trend in the number and proportion of terminations on the basis of other causes is apparent.

Finally, it should be emphasized that the numbers of suspensions and terminations of under-18 SSI recipients (see Tables 3-3 and 3-4) do not include the number of children who transition out of the child SSI program when they turn 18, are found eligible under the adult standard, and go on to be recipients of SSI benefits as an adult. Suspension and termination data for the 10 major mental disorders were not available to the committee, nor were data on the number of SSI child recipients who turn 18, and whose payments are continued, if found disabled using the adult rules, or ceased, if found not disabled using the adult rules. Furthermore, trends in the number of under-18 recipients include both the changes in the number of allowances and changes in the numbers of suspensions, terminations, and transitions into the adult SSI program.

Summary of Aggregate Review of 10 Major Mental Disorders

Figure 3-3 shows the number of initial allowances, initial determinations, and recipients for the 10 major mental disorders from 2004 to 2013. The number of children who were receiving SSI benefits for the 10 major mental disorders continuously increased over that decade, while the

TABLE 3-4 Total SSI Recipients Under 18 Who Were Terminated

Year	No Longer Disabled	Excess Income and Resources	Death	Other	Total
2004	18,550	28,270	5,500	12,950	65,270
2005	16,747	29,347	5,051	11,531	62,676
2006	17,536	31,498	5,236	10,862	65,132
2007	9,516	30,384	5,488	9,759	55,147
2008	4,478	34,045	5,194	8,986	52,703
2009	4,528	31,858	5,041	11,940	53,367
2010	5,720	35,528	4,824	11,543	57,615
2011	11,152	36,772	4,805	12,507	65,236
2012	13,103	34,522	4,686	12,575	64,886
2013	18,432	32,825	4,484	11,341	67,082

NOTE: Other reasons for terminations include whereabouts unknown; in public institution; failed to furnish report; outside United States.
SOURCES: SSA, 2006, 2013b.

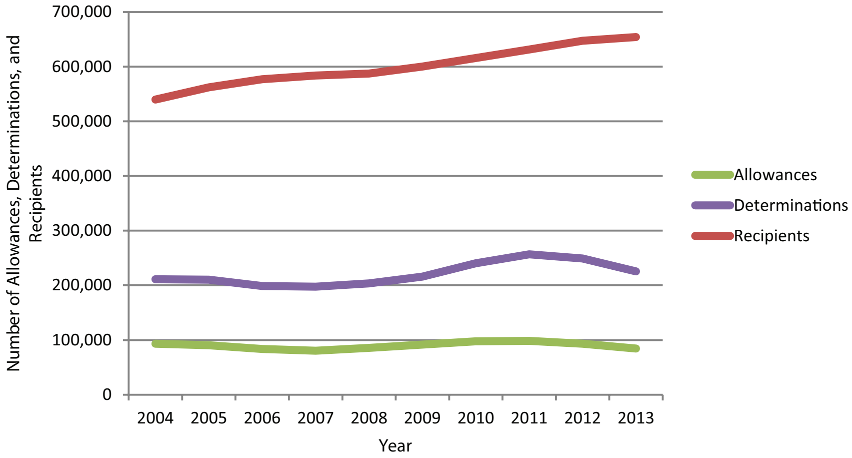

FIGURE 3-3 Initial allowances, initial determinations, and recipient trends for 10 major mental disorders, 2004–2013.
SOURCE: Unpublished data set provided by the SSA.

number of children who were allowed benefits each year did not increase. This figure also shows that approximately half of the determinations of disability for the 10 major mental disorders resulted in denials. These trends indicate that the number of children being allowed benefits and reinstated

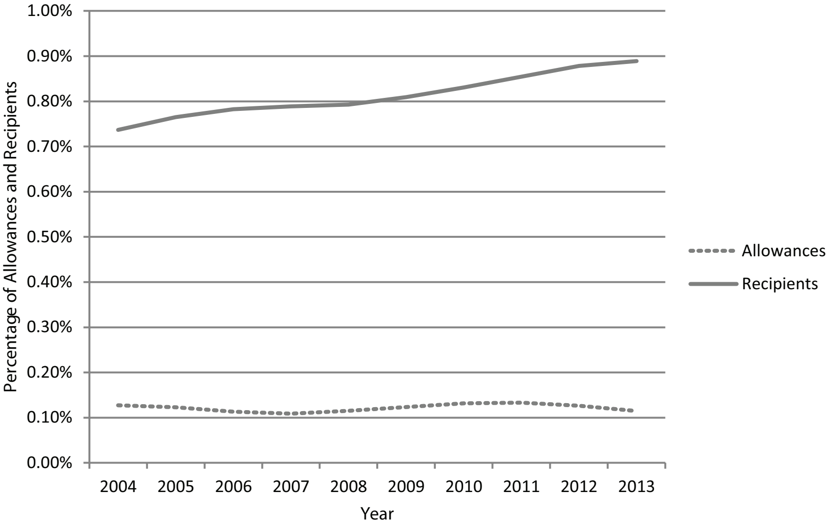

FIGURE 3-4 Percentage of allowances and recipients for SSI benefits adjusted to under-18 population for the 10 major mental disorders, 2004–2013.
SOURCE: Unpublished data set provided by the SSA.

as a recipient from the suspended pool exceeded the number of children who were suspended, terminated, or "aged out" from receiving benefits each year. The number of children who are recipients will continue to rise as long as the number of allowances and reinstatements exceeds the number of suspensions, terminations, and "age-outs."

A caveat to these conclusions is that the allowance numbers that we report are initial allowances. The total number of allowances resulting from successful appeals is not known to the committee and is thought to be relatively small.

Figure 3-4 shows the percentages of children in the United States who received SSI benefits for the major mental disorders and were allowed SSI benefits for the major mental disorders at the initial level. After adjusting for changes in the population of U.S. children, the same pattern emerges: From 2004 to 2013 the proportion of children who were allowed SSI benefits for the major mental disorders did not increase, while the proportion of children who were recipients did increase.

REVIEW OF INDIVIDUAL MAJOR MENTAL DISORDERS

The numbers of recipients and allowances for all major mental disorders presented in the previous section show the overall trends in the SSI program, but they also obscure important dynamics and trends at the level of individual disorders. The following four sections will analyze the trends in the number of allowances, determinations, allowance rate, and recipients for the major mental disorders individually.

Allowances

Of the major mental disorders, ADHD is the basis for the largest number of initial allowances across the entire decade. In 2013 there were 24,181 allowances for ADHD, which was the lowest number of annual allowances at any time from 2004 to 2013 (see Figure 3-5). The number of allowances for ASD continuously increased from 2004 to 2012, from 9,677 to 24,159, or a 150 percent increase. By 2013 the number of allowances for ASD nearly equaled the number of allowances for ADHD. By contrast, the number of allowances for ID continuously decreased, from 24,602 to 12,470, a 50 percent decrease over the 10-year period. The remaining seven mental disorders do not exhibit any trends of similar magnitude, although the number of allowances does appear to have decreased over that time

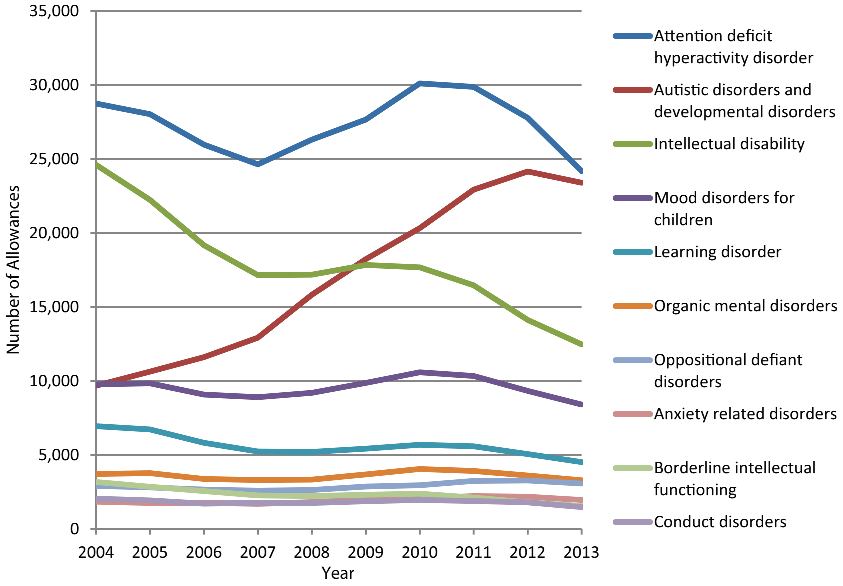

FIGURE 3-5 Number of allowances for major mental disorders for all children under 18, at the initial level, 2004–2013.
SOURCE: Unpublished data set provided by the SSA.

period for LD, BIF, and CD. The trend in the number of ADHD allowances appears to be sensitive to changes in the rate of child poverty, as are several other mental disorders. A large majority of the children who are allowed benefits for the major mental disorders received those benefits for ADHD, ASD, and ID. In 2013, 28.68 percent of allowances were for ADHD, 27.75 percent were for ASD, 14.79 percent were for ID, 9.96 percent were for mood disorders, and 5.35 percent were for LD.

Determinations

From 2004 to 2013 the number of determinations for ADHD was substantially greater than for any of the other major mental disorders (see Figure 3-6). During that period the total annual determinations for any of the nine major mental disorders other than ADHD never exceeded 30,000, while the total annual determinations for ADHD ranged from a low of 87,765 in 2006 to a high of 124,215 in 2011, and ADHD accounted for no less than 42 percent of all determinations for the major mental disorders in each year between 2004 and 2013. However, as previously noted, only

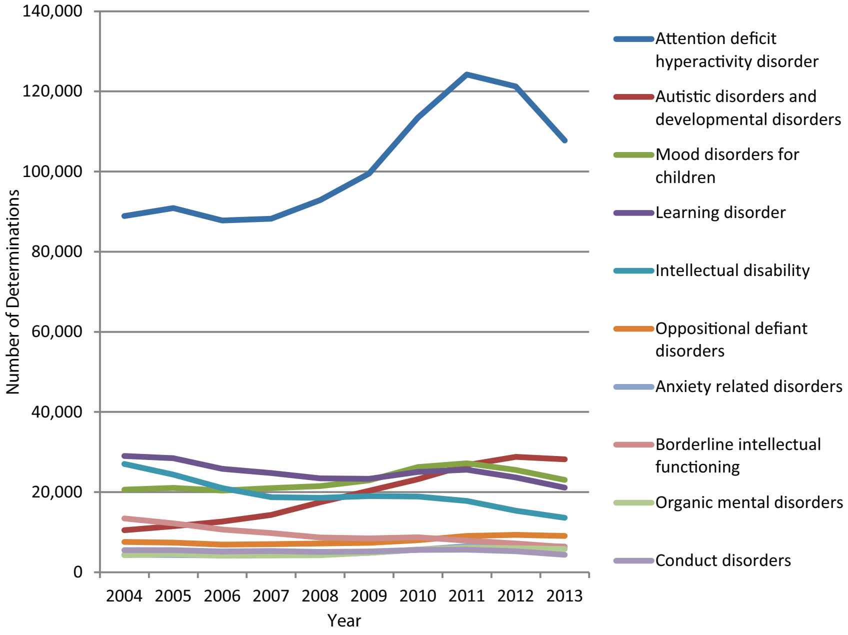

FIGURE 3-6 Number of determinations for the major mental disorders for all children under 18, at the initial level, 2004–2013.
SOURCE: Unpublished data set provided by the SSA.

about 29 percent of allowances are for ADHD, which indicates that a large proportion of all ADHD determinations result in denials.

The opposing trends in the number of determinations of ID and ASD are similar to the trends observed in the numbers of allowances for those two disorders. The number of ID determinations decreased from 27,037 in 2004 to 13,613 in 2013, while the number of ASD determinations increased from 10,486 to 28,192. As a portion of total determinations for the 10 major mental disorders, the percentage of determinations for ASD increased between 2004 and 2013 from 4.97 to 12.49 percent, and the percentage of determinations for ID decreased from 12.8 to 6.03 percent (see Table 3-5).

About one-half of children who are applying for SSI disability benefits are being determined on the basis of ADHD. This indicates that applicants are claiming impairment on the basis of ADHD at a higher rate than they claim impairment on the basis of other mental disorders and also that disability examiners are assigning ADHD as the basis for allowances and denials at a greater rate than they do for other mental disorders, or both. Furthermore, ADHD determinations decreased in the past 2 years of the 10-year period.

Allowance Rate

Figure 3-7 shows the allowance rates for the 10 major mental disorders for all children under age 18 from 2004 to 2013. The highest allowance rates between 2004 and 2013 were observed for ID (90.99 to 91.60 percent) and ASD (92.28 to 83.00 percent). The persistently high rate of ID allowances likely can be explained by the use of an objective measure, the IQ test, for determining an allowance. While ADHD had the highest number of allowances, the allowance rate of ADHD has been low, between 32.32 and 22.40 percent. The ADHD category may be a catch-all for the categorization of applications that are denied because of inadequate severity or applications that lack adequate evidence. The LD category also has a relatively low allowance rate (23.91 to 21.40 percent), potentially indicating that determinations on the basis of LD are associated with applications by families of children who are less disabled. The allowance rate of organic mental disorders decreased from 87.12 percent in 2004 to 56.6 percent in 2013, which may have been related to an overall decrease in the recognition of the diagnostic category by mental health professionals. Overall, the combined yearly allowance rate for the 10 major mental disorders decreased from 52 percent in 2004 to 43 percent in 2013. This indicates that the probability of an applicant being found to be disabled by SSI criteria for the major mental disorders—and subsequently eligible for SSI benefits—actually decreased over the decade of interest. Changes in the allowance rate over time could be explained by changes in the adjudicative

TABLE 3-5 Percentage of Determinations for the Major Mental Disorders for All Children Under 18, at the Initial Level, 2004–2013

	2004	2005	2006	2007	2008	2009	2010	2011	2012	2013
ADHD	42.10%	43.21%	44.13%	44.65%	45.63%	46.10%	47.17%	48.36%	48.66%	47.75%
LD	13.74%	13.54%	12.99%	12.53%	11.53%	10.81%	10.41%	9.97%	9.49%	9.36%
Mood	9.76%	10.02%	10.26%	10.62%	10.56%	10.62%	10.91%	10.58%	10.26%	10.22%
ID	12.80%	11.60%	10.56%	9.48%	9.12%	8.80%	7.86%	6.93%	6.16%	6.03%
ASD	4.97%	5.48%	6.38%	7.26%	8.59%	9.43%	9.65%	10.41%	11.55%	12.49%
BIF	6.35%	5.80%	5.36%	4.95%	4.28%	3.91%	3.64%	3.09%	2.88%	2.79%
ODD	3.59%	3.53%	3.48%	3.55%	3.53%	3.40%	3.33%	3.53%	3.76%	4.01%
CD	2.61%	2.63%	2.62%	2.68%	2.50%	2.41%	2.32%	2.20%	2.11%	1.94%
Anxiety	2.06%	2.04%	2.12%	2.15%	2.18%	2.26%	2.34%	2.54%	2.70%	2.84%
Organic	2.02%	2.14%	2.09%	2.12%	2.08%	2.26%	2.37%	2.39%	2.43%	2.57%

SOURCE: Unpublished data set provided by the SSA.

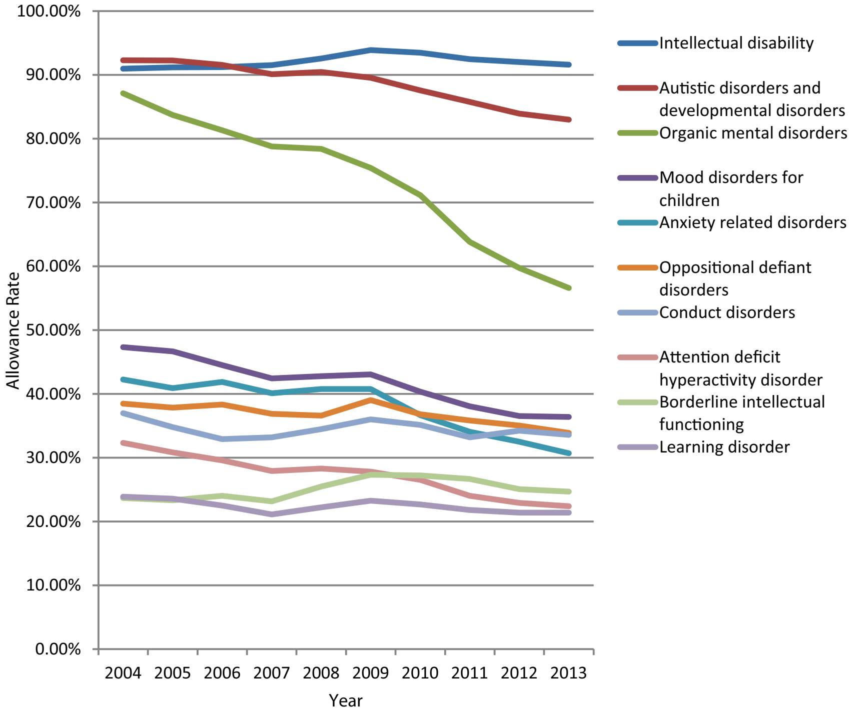

FIGURE 3-7 Allowance rate for the major mental disorders for all children under 18, at the initial level, 2004–2013.
SOURCE: Unpublished data set provided by the SSA.

standards applied by the SSA, changes in the profile of the population of children applying for SSI, or, most likely, both.

Recipients

The number of recipients grew between 2004 and 2013 for 8 of the 10 major mental disorders (see Figure 3-8). There was substantial growth in the number of recipients for ADHD, from 138,921 in 2004 to 226,363 in 2013, and also for ASD, increasing from 43,628 in 2004 to 134,310 in 2013. One of the two exceptions to the trend was the number of ID recipients, which decreased from 215,709 in 2004 to 120,248 in 2013. Overall, as shown in Figure 3-9, the combined number of recipients for the 10 major mental disorders increased each year during the 10-year period, growing from 540,051 recipients to 654,370.

Of the major mental disorders, ADHD, ASD, and ID made up the

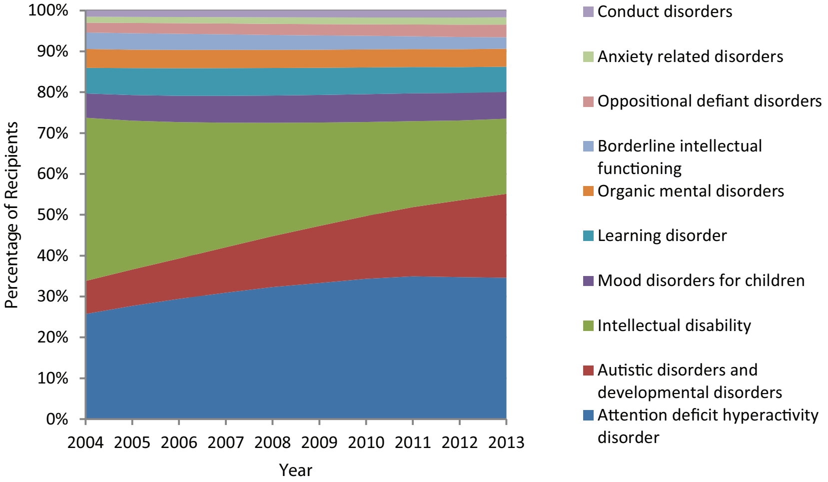

FIGURE 3-8 Percentage of recipients for each of the major mental disorders, 2004–2013.
SOURCE: Unpublished data set provided by the SSA.

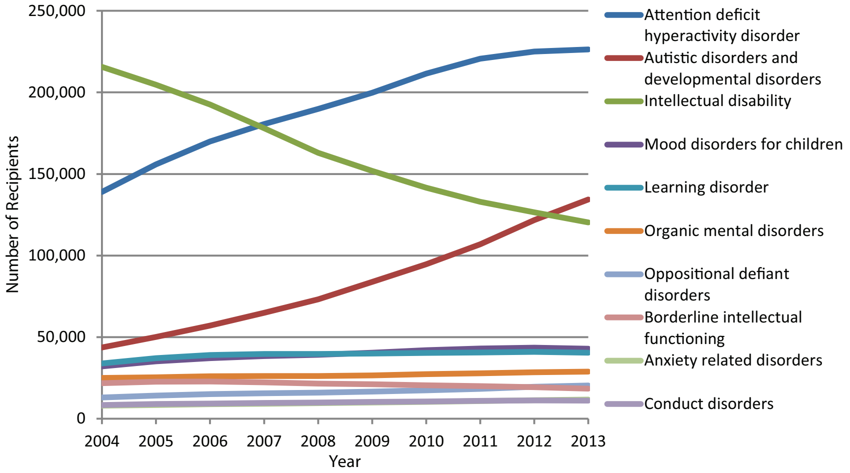

FIGURE 3-9 Number of recipients for the major mental disorders for all children under 18, at the initial level, 2004–2013.
SOURCE: Unpublished data set provided by the SSA.

highest percentage of recipients between 2004 and 2013. In 2013, 34.59 percent of recipients of the major mental disorders were for ADHD, 20.53 percent for ASD, and 18.38 percent for ID. A striking increase in the percentage of recipients was observed for ASD—from 8.08 percent in 2004 to 20.53 percent in 2013. Although the proportion of recipients with ID decreased from 39.94 to 18.38 percent over the 10 years, in 2013 the proportion of recipients for ID was still the third-largest of the 10 major mental disorders. The first year that the number of recipients for ASD exceeded the number of recipients for ID was 2013.

The number of recipients for the other seven major mental disorders did not exhibit changes to the same degree. There was a decrease in the number of recipients for BIF, from 21,749 in 2004 to 18,420 in 2013. The number recipients for organic mental disorders increased from 24,987 in 2004 to 28,793 in 2013, despite a major decrease in the allowance rate. The number of recipients for mood disorders increased from 32,078 in 2004 to 42,826 in 2013; for anxiety related disorders from 7,890 in 2004 to 11,613 in 2013; for CD from 8,280 to 11,077; for ODD from 12,976 to 20,259; and for LD from 33,833 to 40,461.

SSI Regulatory Basis for Allowances from 2004 to 2013

As explained in Chapter 2, benefits can be allowed by four regulatory categories: meets the listings, medically equals the listings, functionally equals the listings, and other allowances. For all 10 years from 2004 to 2013, the majority of allowances for the 10 major mental disorders at the initial level either met the listings or functionally equaled the listings (see Figure 3-10). From 2004 to 2009 the numbers of child allowances for the major mental disorders that met the listings were greater than the number of allowances that functionally equaled the listings. From 2009 to 2013 the numbers of allowances that functionally equaled the listings exceeded the number of allowances that met the listings. Combined with the observation that allowance rates are decreasing, these trends may indicate that the children who are being determined for the SSI benefits on the basis of the major mental disorders are less severely impaired and may not have supporting evidence that meet the listings criteria. However, these findings may simply indicate that the way DDS are adjudicating claims has changed in a way that prefers or prioritizes functional equivalence. The data provided here do not include enough information to support conclusions about the causes of these changes in regulation basis.

The initial allowances by regulation basis for ID and ADHD are shown below in Figures 3-11 and 3-12 to illustrate that the proportion of

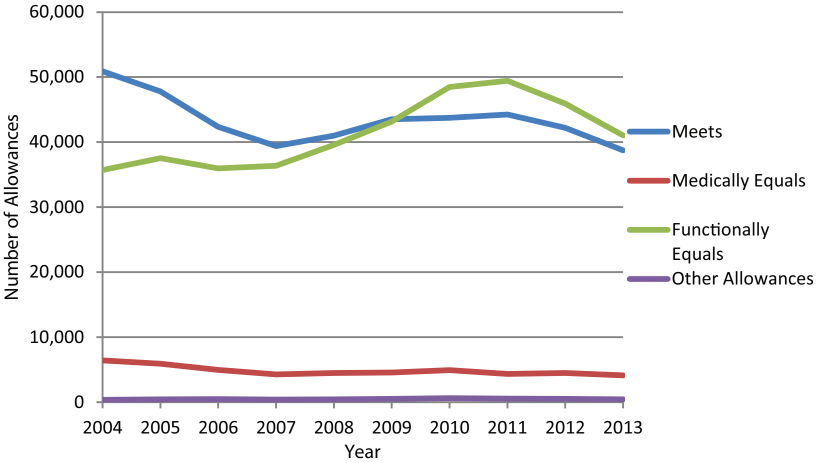

FIGURE 3-10 Initial allowances for the 10 major mental disorders, by regulation basis, 2004–2013.
SOURCE: Unpublished data set provided by the SSA.

allowances by regulation basis can vary considerably among the individual mental disorder categories.

Figure 3-11 shows the percentage of initial allowances for ID by regulation basis for all children under age 18 from 2004 to 2013. A high percentage—more than 80 percent—of allowances meets the listings for the decade. This is likely because of the type of evidence (IQ scores) specified by the listing and generally involved in making a diagnosis. Applicants with a diagnosis and a score within the range of the listing level requirements will be found to meet the listing. However, it is not clear what criteria are used to allow the approximately 15 percent of ID applicants who are based on a functionally equals basis.

Figure 3-12 shows the percentage of initial allowances for ADHD by regulation basis. In 2004, 50 percent of ADHD allowances functionally equaled the listings, and 44 percent met the listings. Between 2004 and 2010 the proportion of allowances that met the listings decreased, and the proportion of allowances that functionally equaled the listings increased. From 2010 to 2013 approximately 26 percent of ADHD allowances met the listings, and 70 percent functionally equaled the listings.

In contrast to the case for ID, since 2010 the majority of ADHD allowances have been for allowances that functionally equal the listings. This is likely due to differences in the nature of the listings criteria and also in the characteristics of the children whose applications are being assigned

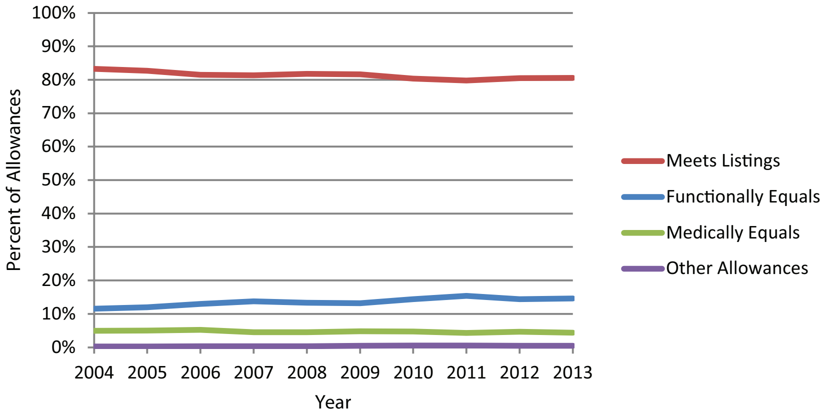

FIGURE 3-11 Percent of initial allowances for ID by regulation basis, 2004–2013.
SOURCE: Unpublished data set provided by the SSA.

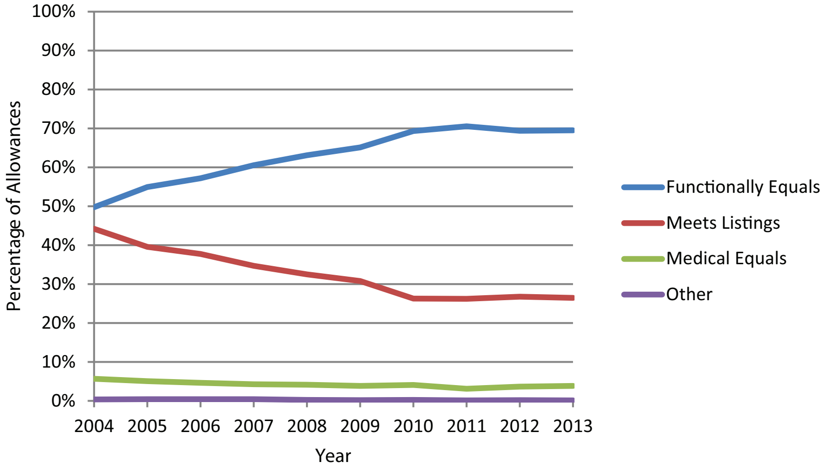

FIGURE 3-12 Percent of initial allowances for ADHD by regulation basis, 2004–2013.
SOURCE: Unpublished data set provided by the SSA.

the impairment code of ADHD by examiners. In contrast to the ID listings which specify IQ test scores, the ADHD listings only specify that there be "medically documented" findings of marked inattention, marked impulsiveness, and marked hyperactivity.

FINDINGS

- In 2013, approximately 1.8 percent of U.S. children (ages 0–18) were recipients of SSI benefits. This had increased from 1.35 percent in 2004.
- Approximately half of all children who are recipients of SSI disability benefits receive benefits due to mental disorders. The percentage of all U.S. children who were recipients of SSI disability benefits for the 10 major mental disorders grew from 0.74 percent in 2004 to 0.89 percent in 2013.
- Among the children who applied for SSI, the proportion whose SSI applications were allowed (i.e., met the SSI disability criteria) each year for all disabilities did not increase from 2004 to 2013.
- The proportion of children whose applications were allowed annually for the 10 major mental disorders out of all allowances for children did not increase. Approximately half of all allowances for child disability benefits were for the 10 major mental disorders.
- The number of suspensions and terminations varied considerably over the period from 2004 to 2013. Changes in the number of children who annually are found to no longer have a severe disability contributed to the variation in number of suspensions and terminations.
- Trends in the number and proportion of allowances and recipients varied by type of mental disorder. Some diagnoses, such as ASD, showed substantial increases over the period. Some, such as ID, showed considerable decreases. For each year from 2004 to 2013, the ADHD category was the largest in terms of the numbers and proportions of child SSI disability allowances and recipients.

CONCLUSIONS

- Overall, the likelihood that an application for benefits was allowed on the basis of a mental disorder decreased from 2004 to 2013. The proportion of all disability determinations for the major mental disorders that resulted in a finding of disability decreased from year to year.
- Generally, each year, the number of suspensions, terminations, and age-18 transitions out of the child SSI program was less than the number of allowances and "reentries" from suspension, which has led to increasing numbers of total recipients.
- A substantial proportion of child disability allowances are on the basis that applicants "functionally equal" the SSA's "Listing of

> Impairments."[2] There is a substantial pool of children who experience severe disability due to conditions that are not formally described in the Listings and who subsequently cannot be reliably or accurately characterized using the Listings alone. Therefore, the impairments typically associated with primary diagnostic listing may not be the sole impairments experienced by the child. As a consequence, it is not possible to precisely identify the pool of children who are SSI recipients based on a specific mental disorder. That said, the committee concluded that the data contained in this report for each of the 10 major childhood mental disorders are the best available approximation of specific diagnosis prevalence in the SSI beneficiary population.

REFERENCES

SSA (Social Security Administration). 2006. *SSI annual statistical report, 2006*. Table 51: Recipients terminated, by age and reason for termination, 1998–2005. http://www.ssa.gov/policy/docs/statcomps/ssi_asr/2006/sect10.html#table51 (accessed July 1, 2015).

SSA. 2013a. *SSI annual statistical report, 2013*. Table 76: Recipients suspended, by age and reason for suspension, 2004–2013. www.ssa.gov/policy/docs/statcomps/ssi_asr/2013/sect11.html (accessed July 1, 2015).

SSA. 2013b. *SSI annual statistical report, 2013:* Table 77: Recipients terminated, by age and reason for termination, 2006–2013. www.ssa.gov/policy/docs/statcomps/ssi_asr/2013/sect11.html (accessed May 8, 2015).

SSA. 2014. SSI monthly statistics: Table 2: SSI federally administered payments recipients by eligibility category and age, 2004–2013. www.ssa.gov/policy/docs/statcomps/ssi_monthly/index.html (accessed May 8, 2015).

U.S. Census Bureau. 2014. Total population by child and adult populations. http://datacenter.kidscount.org/data/tables/99-total-population-by-child-and-adult-populations?loc=1&loct=1#detailed/1/any/false/35,18,17,16,15/39,41/416,417 (accessed November 14, 2014).

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[2] The "Listing of Impairments" is a regulatory list of medical conditions and medical criteria produced by the SSA that serve as a standard for a determination of disability.

4

State Variation in the SSI Program for Children

There are substantial interstate variations in the Supplemental Security Income (SSI) program for children with mental disorders. These variations from state to state have not been closely studied and are not well understood; however, they are important because these variations mean that the probability of applying for and receiving disability benefits for a child with disabilities may differ depending on the state in which he or she lives. Furthermore, analysis of aggregate trends at the national level may obscure different trends at the state level. State-level analysis is necessary to determine whether the national trends are representative of all states, or whether trends in individual states have different trends with potentially different causes. This chapter reviews the state variation in the rates of reported mental health disorders; the variation in the numbers of determinations, in the numbers of recipients, and in the allowance rates across states in 2013; and the changes in the number of determinations between states from 2004 to 2013.

STATE VARIATION IN THE RATES OF REPORTED MENTAL HEALTH DISORDERS

Some studies have shown substantial state-to-state variations in the rates of reported mental health disorders among children and adolescents. *The Mental and Emotional Well-Being of Children*, a publication of the Maternal and Child Health Bureau (2010), detailed substantial variations in the presence of mental health conditions by state, ranging from a prevalence of 8.1 percent in Hawaii to 16.0 percent in North Carolina.

Ghandour and colleagues used the 2007 National Survey of Children's Health and found that almost 8 percent of all children ages 6 to 17 years had had a diagnosis of depression or anxiety and 5.4 percent a behavior or conduct disorder (Ghandour et al., 2012). The study found wide state-to-state variations in these diagnoses, with about a threefold difference between highest and lowest reported rates (Ghandour et al., 2012). For example, depression/anxiety rates varied from 4.8 percent in Georgia to 14.4 percent in Vermont (Ghandour et al., 2012). This study also found higher rates of reported diagnoses among children in lower-income households and among children reported as having poor or fair health (Ghandour et al., 2012). In an older study of state-to-state variation in rates of attention deficit hyperactivity disorder (ADHD), children were more likely to have the diagnosis if they lived in the South than in the West (Fulton et al., 2009). Additionally, medication use varied between states (Fulton et al., 2009). This study found that the number of physicians in a state was associated with both diagnostic rates and medication prescriptions, but educational policies were not associated with either (Fulton et al., 2009). A more recent study by the Centers for Disease Control and Prevention found significant variations in the diagnosis of and medication use by children for ADHD by state (Visser et al., 2013). Nationally in 2007, 7.2 percent of children were diagnosed with ADHD; Nevada had the lowest prevalence (3.7 percent), and North Carolina had the highest prevalence (12.8 percent) (Visser et al., 2013). This study also found that 66 percent of children with ADHD were treated with medication, but the state-based rates varied from a low of 33 percent to a high of 79 percent (Visser et al., 2013).

State-to-state variations in reported prevalence exist for all types of health conditions as well as for overall child health status. Nationwide, 84.2 percent of children are in excellent or very good health, but only 77.6 percent of California's children are, compared with 91.7 percent of children in South Dakota (NSCH, 2012a). Among children with special health care needs with functional limitations, the degree to which children are affected varies by state. The District of Columbia has the lowest reported percentage of severely affected children (52.5 percent) and New York has the highest (78.0) (NSCH, 2012b). The causes of the state variations in the prevalence of reported health conditions are likely to be multifactorial and could explain some of the variations in SSI findings concerning children's mental health conditions. One important factor is the rate of poverty in each state since child health in general and child mental health in particular both track with poverty.

STATE-TO-STATE VARIATION IN 2013

Number of Determinations and Allowances

In fiscal year (FY) 2013, disability determination services (DDSs) made more than 225,000 initial determinations involving the 10 mental impairments addressed by this report. By state, the number of initial determinations ranged from 153 in Wyoming to 26,513 in Texas (see Figure 4-1).

A few DDSs adjudicated most of the initial determinations in FY 2013. The Texas DDS, for example, performed more than 10 percent of the national total (see Figure 4-1). Eight states—California, Florida, Georgia, Michigan, New York, Ohio, Pennsylvania, and Texas—accounted for just more than half (50.6 percent).

The raw number of determinations and allowances will naturally vary between states because of differences in the populations of children in low-income households in each state. However, even after controlling for the number of children in low-income households within each state, in FY 2013 the rate of SSI child initial determinations from a state's population of children in low-income households varied significantly. Using children under 18 in families with income less than 200 percent of the federal poverty level (FPL) as a proxy for the number of children who are income- and asset-eligible for SSI, the rate of claims for the 10 mental impairments varied by a factor of 5.7, from a low of 252 per 100,000 in Nevada to a high of 1,441 per 100,000 in Pennsylvania (see Figure 4-2). As can be seen within Figure 4-2, the ratio of allowances to denials varies from state to state as well. This variation in the ratio of allowances to determinations is addressed in additional detail below. Figure 4-3 shows the variation in the rate of determinations among children in low-income households geographically. There appears to be a gradient in the rates of determinations in children in low-income households, with the rates of determinations in Western states lower than those in Eastern states.

It is useful to compare the raw numbers of determinations by state with the rate of determinations within children in low-income households by state. In particular, some states with high numbers of determinations appear to actually be evaluating a smaller proportion of the state's children in low-income households for disabilities than are evaluated in other states. For example, consider Texas, which in 2013 had the highest number of determinations and number of allowances. After adjusting the numbers of determinations and allowances for the estimated number of children in low-income households in the state, Texas is actually the 21st highest state. The disparate rates of determinations within state-specific populations of children in low-income households indicate that across the United States,

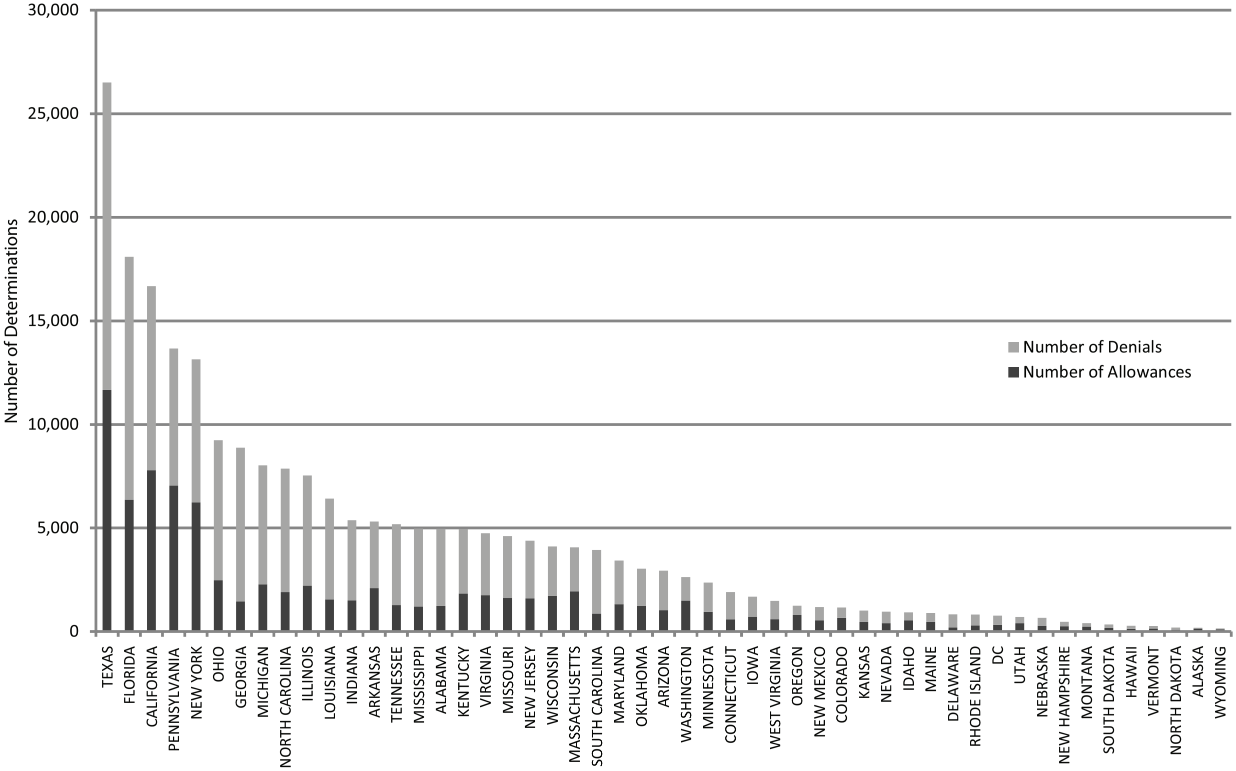

FIGURE 4-1 Number of determinations, broken down by allowances and denials, for 10 selected mental disorders, per state, for 2013.

SOURCE: Unpublished data set provided by the SSA.

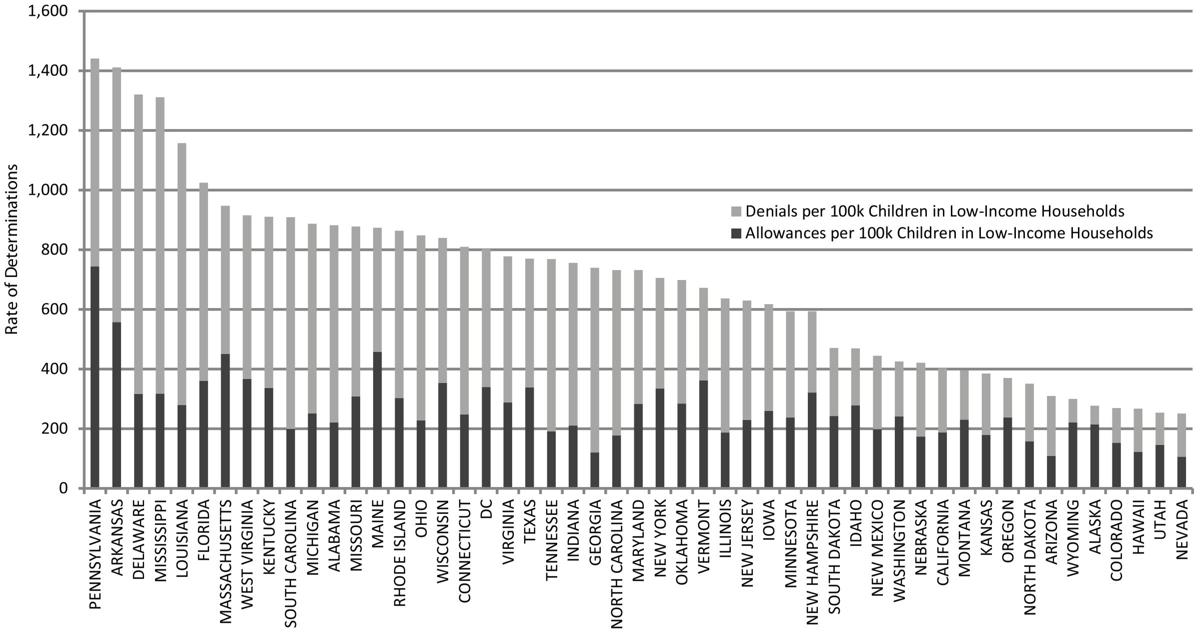

FIGURE 4-2 Rates of SSI child initial determinations for 10 select mental impairments, by state: fiscal year 2013 (per 100,000 children in families with income less than 200 percent of the federal poverty level).

NOTE: The Current Population Survey table creator was used to generate numbers of children below 200 percent of the federal poverty level. Parameters used to generate the numbers include get count: of persons in poverty universe (everyone except unrelated individuals under 15) from years 2004 to 2013; Census 2010 weights; row variable: age; column variable: income-to-poverty ratio; and customized formatting: income-to-poverty ratio percent cutoff of 200 percent.

SOURCES: U.S. Census Bureau, 2015; unpublished data set provided by the SSA.

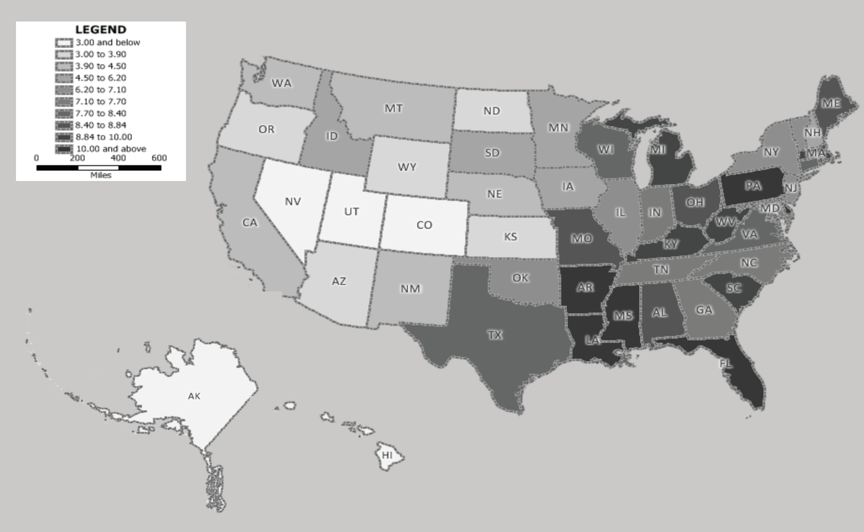

FIGURE 4-3 Rates of the SSI child initial determinations for 10 select mental impairments, by state: fiscal year 2013 (per 100,000 children in families with income less than 200 percent of the federal poverty level).
SOURCES: U.S. Census Bureau, 2015; unpublished data set provided by the SSA.

some children in low-income households are far more likely to be determined for disability benefits than others.

Differences in Allowance Rates

There is substantial variation in initial allowance rates from state to state, i.e., in the percentage of determinations in which the applicant is found to be disabled. In 2013, for example, the combined initial allowance rate for child SSI claims with the 10 selected mental impairments ranged from 16 percent in Georgia to 78 percent in Alaska. Nationally, the initial allowance rate averaged 37 percent, but it was more than 50 percent in 13 states and less than 25 percent in 7 states (see Figure 4-4).

The reasons for the wide differences in allowance rates from DDS to DDS are not fully understood. According to an SSA analysis of 1990s program data for the SSI adult claimants, about half the variation in the allowance rate from the national mean could be explained by factors external to the SSA, including application rates, economic factors such as the poverty rate, disability prevalence rates, demographic factors, and health indicators such as insurance coverage (Strand, 2002). No similar study has

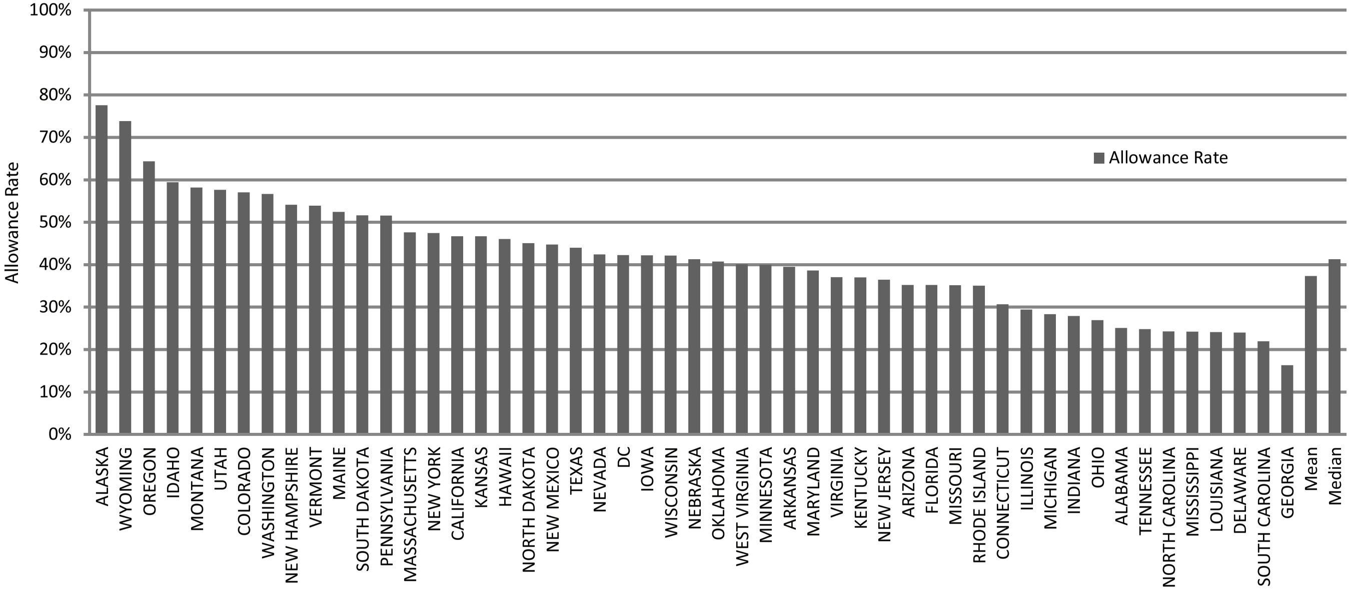

FIGURE 4-4 Child SSI initial allowance rate for 10 selected mental impairments, by disability determination service: fiscal year 2013 (percentage).
SOURCE: Unpublished data set provided by the SSA.

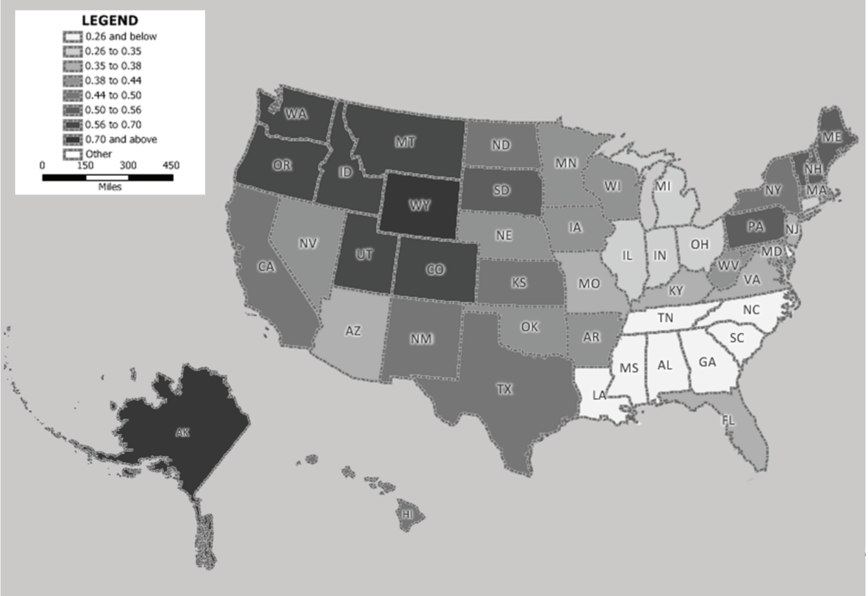

FIGURE 4-5 Child SSI initial allowance rate for 10 selected mental impairments, by disability determination service: fiscal year 2013 (percentage).
SOURCE: Unpublished data set provided by the SSA.

been done of the SSI child allowance rates. As illustrated by Figure 4-5, another potential factor could be related to geography: A cluster of states with low determination rates appears in the Southeast, and states with high allowance rates appear to cluster in the Northwest and West.

Recipients

There are also significant variations in the percentage of children who receive SSI benefits for the 10 selected mental disorders between states. In 2013, 0.7 percent of children in low-income households in Hawaii were recipients of such benefits, while 5.3 percent of children in low-income households in Pennsylvania were, a percentage that was approximately 7.6 times as great as the percentage in Hawaii (see Figure 4-6). Because recipients are the children who cumulatively have been allowed and remain currently eligible for benefits, the percentage of poor children who are recipients within a state can serve as an indication of the coverage of the SSI program for children with mental disorders in that state. The variation in the rates of poor children who are recipients for SSI benefits for the selected mental disorders strongly suggests that there are state-specific DDS differences

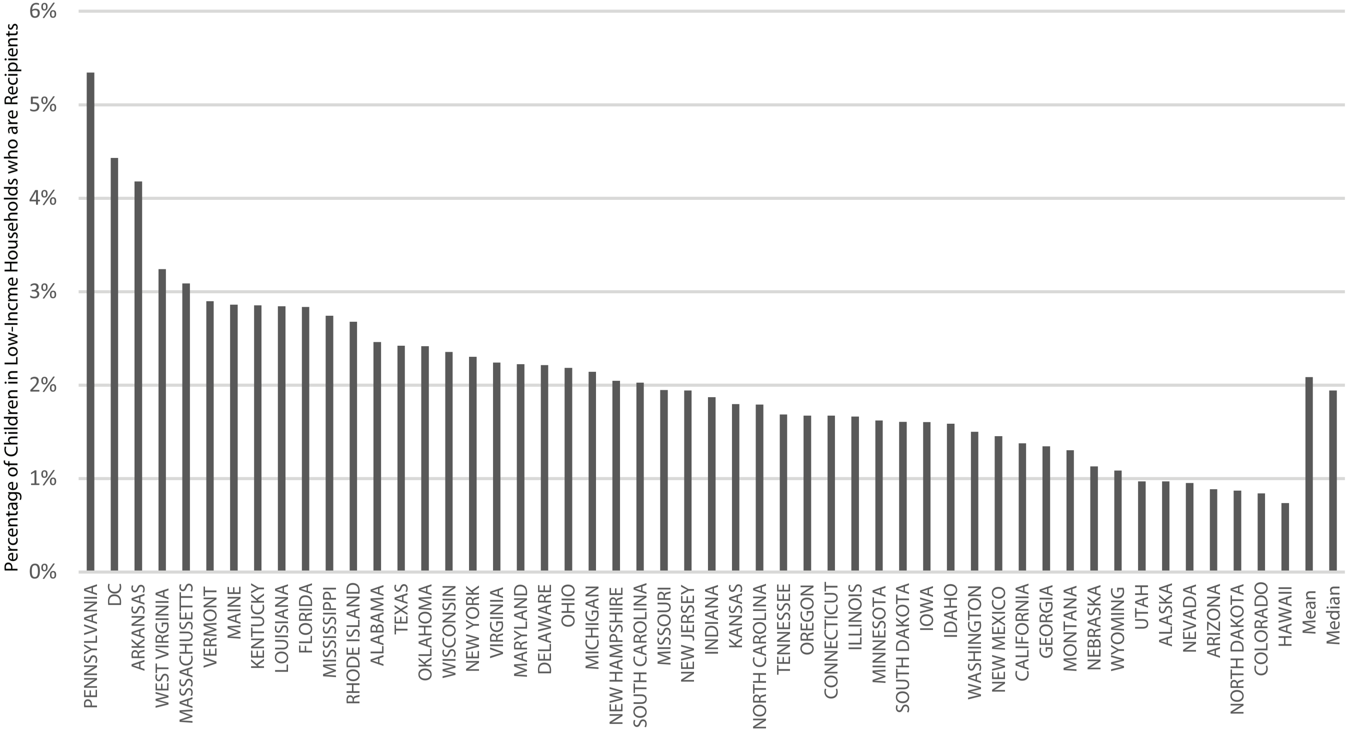

FIGURE 4-6 Percentages of children in low-income households in each state who are recipients of SSI benefits for the 10 selected mental disorders.
SOURCE: Unpublished data set provided by the SSA.

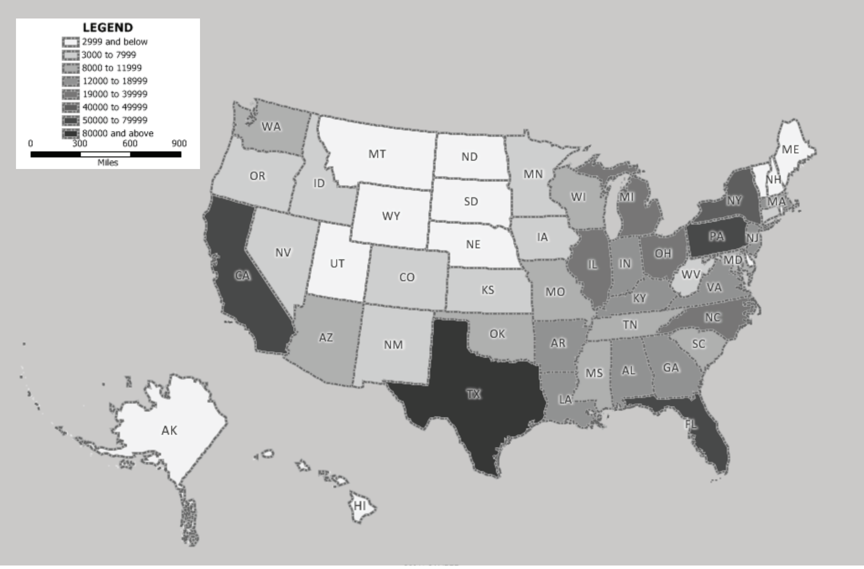

FIGURE 4-7 Numbers of recipients for the 10 selected mental disorders in 2013, by state.
SOURCE: Unpublished data set provided by the SSA.

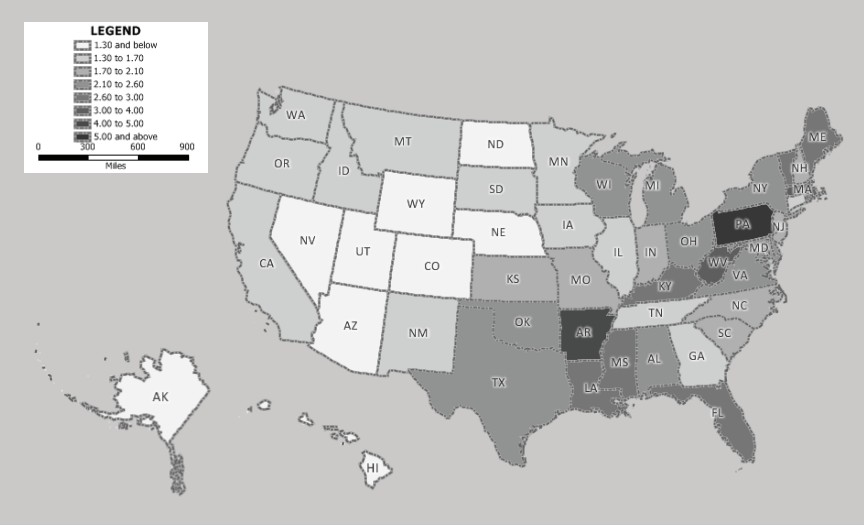

FIGURE 4-8 Percentages of children in low-income households who are recipients of SSI benefits for the selected mental disorders, by state, for 2013.
SOURCES: U.S. Census Bureau, 2015; unpublished data set provided by the SSA.

influencing the likelihood that a potentially eligible child with a mental disorder will receive SSI benefits. This is further illustrated by Figures 4-7 and 4-8. Figure 4-7 shows the number of under-18 SSI recipients for the 10 selected mental disorders in 2013; Figure 4-8 shows the rate of recipients for the selected mental disorders in families that are under 200 percent of the FPL. A significant difference is observed for California, which has a high raw number of recipients but a low rate of recipients among children in low-income households. In contrast, Arkansas has a relatively low number of recipients but a high percentage of children in low-income households who are recipients. Pennsylvania appears to be an outlier in having both high numbers of recipients and high rates of recipients among children in low-income households.

CHANGE IN STATE-SPECIFIC DETERMINATION RATES IN CHILDREN IN LOW-INCOME HOUSEHOLDS BETWEEN 2004 AND 2013

For the nation as a whole, the average rate of determinations in children in low-income households decreased 2 percent from 2004 to 2013; however, this national level statistic obscures state variations in the specific rate of determinations. For example, between FY 2004 and FY 2013, the rate of determinations in Rhode Island increased by 48 percent, from 584 per 100,000 to 864 per 100,000. Other states with substantially higher determination rates in 2013 than in 2004 included Utah and Texas (32 percent) and Connecticut (31 percent) (see Figure 4-9). In other states, the determination rate decreased substantially between FY 2004 and FY 2013. In Minnesota, North Dakota, Kansas, and Nevada, the rate decreased by one-third or more from 2004 to 2013. These changes in the number of determinations between states also indicate that there are changes occurring within states over time that result in either increasing or decreasing rates of determinations for disabilities caused by the selected mental disorders in children.

SUMMARY OF STATE VARIATIONS IN 2013

The state-to-state variation in the numbers and rates of children being determined for, being allowed, and receiving SSI disability benefits for the selected mental disorders is a significant and concerning observation. A number of factors could contribute to these disparities, including state-to-state variation in the rates of disability caused by the selected mental disorders; however, the degree of between-state variation observed in the SSI program cannot be reasonably explained solely, or even in substantial part, by a variation in the rates of disabilities and mental disorders between

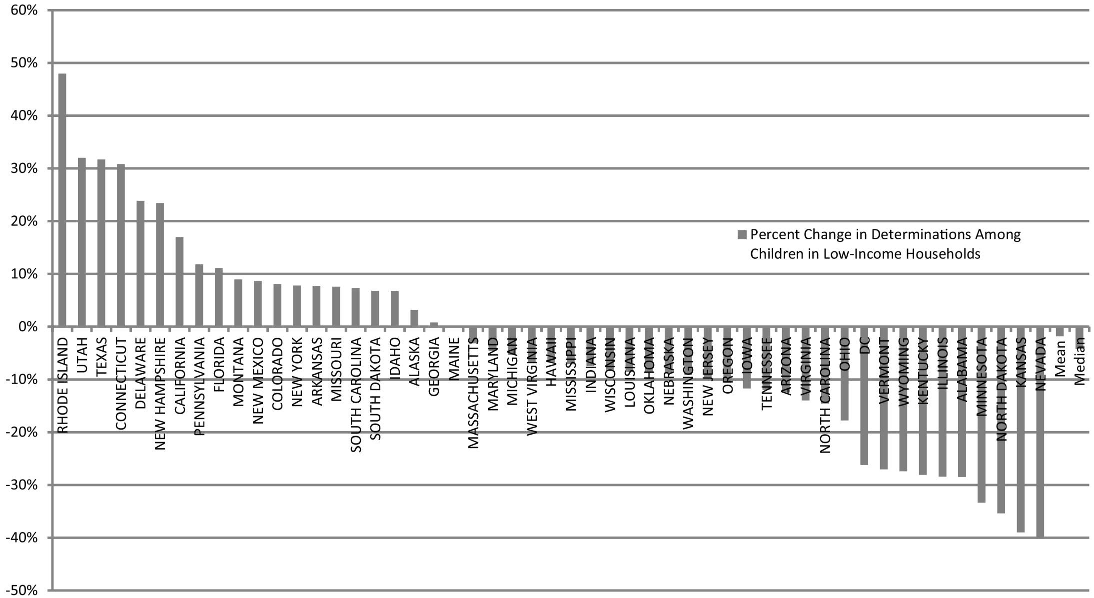

FIGURE 4-9 Percent change in rate of determinations among children in households below 200 percent of the federal poverty level, by state, from 2004 to 2013.

NOTE: The Current Population Survey table creator was used to generate numbers of children below 200 percent of the federal poverty level. Parameters used to generate the numbers include get count of: persons in poverty universe (everyone except unrelated individuals under 15); years: 2004 to 2013; Census 2010 weights; row variable: age; column variable: income-to-poverty ratio; and customized formatting: income-to-poverty ratio percent cutoff of 200 percent.

SOURCES: U.S. Census Bureau, 2015; unpublished data set provided by the SSA.

states. State-specific variations in the population of children in low-income households may contribute to disparities observed in the SSI program; however, those variations have been controlled for in the preceding analyses, and they cannot reasonably be thought to be the cause of the magnitude of variation observed. After controlling for changes in the state-specific populations of children in low-income households, there is still significant state-to-state variation.

A recent analysis from the Office of the Assistant Secretary for Planning and Evaluation (ASPE) at the Department of Health and Human Services examined geographic variation in the child SSI program growth and participation between 2008 and 2013 and confirmed this variation (Wittenburg et al., 2015). The analysis looked at the ratio of child SSI caseloads to number of children by state and found that regional, state, and local factors play a crucial part in the geographic variation in program growth during this period (Wittenburg et al., 2015). Notably, Pennsylvania and Texas experienced substantial state-level growth between 1998 and 2013, and these two states along with Florida and California account for half of the aggregate child SSI caseload increase (Wittenburg et al., 2015). According to ASPE, possible significant factors that lead to state variation include the following:

- Advocacy groups, program administrators, and policy officials vary in outreach levels to eligible children.
- Differences in state economies and in policy and program environments affect the opportunities of youth and their parents to obtain public assistance, employment, and education.
- The demographic and income characteristics of youth vary by state.
- DDSs must follow federal policy in eligibility determinations, but they have flexibility in DDS review process management, the compensation and hiring of disability examiners, and the use of private contractors.

Overall, however, there was not a single state or local trend or a singular demographic, economic, or other factor that explained the variations (Wittenburg et al., 2015).

It is the committee's consensus that state-to-state variation cannot be solely or substantially attributed to variation in the rates of mental disorders among states. Other factors that likely contribute to the observed variation include state-specific benefit policies and state-specific approaches to the implementation of public benefit programs, such as substituting SSI benefits (which are federal dollars) for Temporary Assistance for Needy Families benefits (which use state dollars). State-specific changes over time reinforce a conclusion that state program management is a variable and fluid factor in SSI benefits access and assignment. However, an analysis and discussion of these factors is outside the scope of this committee's task, and the factors will not be discussed further in this report.

FINDING

- There is considerable state-to-state variation in the rates of children allowed SSI disability benefits for mental disorders. There is also variation in the rates of children who are recipients of SSI for mental disorders.

CONCLUSION

- Variation among states indicates that the likelihood of a child with a disability becoming a recipient of SSI varies depending on the state of residence. Although studies have shown state variations in prevalence rates for children's mental health disorders, these prevalence variations cannot fully explain differences in state allowances or recipients.

REFERENCES

Fulton, B. D., R. M. Scheffler, S. P. Hinshaw, P. Levine, S. Stone, T. T. Brown, and S. Modrek. 2009. National variation of ADHD diagnostic prevalence and medication use: Health care providers and education policies. *Psychiatric Services* 60(8):1075–1083.

Ghandour, R. M., M. D. Kogan, S. J. Blumberg, J. R. Jones, and J. M. Perrin. 2012. Mental health conditions among school-aged children: Geographic and sociodemographic patterns in prevalence and treatment. *Journal of Developmental and Behavioral Pediatrics* 33(1):42–54.

Maternal and Child Health Bureau. 2010. *The mental and emotional well-being of children: A portrait of states and the nation, 2007*. Rockville, MD: U.S. Department of Health and Human Services, Health Resources and Services Administration, Maternal and Child Health Bureau.

NSCH (National Survey of Children's Health). 2012a. National Survey of Children's Health 2011/12. Data query from the Child and Adolescent Health Measurement Initiative. www.childhealthdata.org (accessed April 14, 2015).

NSCH. 2012b. National Survey of Children with Special Health Care Needs 2009/10. Data query from the Child and Adolescent Health Measurement Initiative. www.childhealthdata.org (accessed April 14, 2015).

Strand, A. 2002. Social Security disability programs: Assessing the variation in allowance rates. www.ssa.gov/policy/docs/workingpapers/wp98.html (accessed June 30, 2015).

U.S. Census Bureau. 2015. CPS table creator. www.census.gov/cps/data/cpstablecreator.html (accessed July 13, 2015).

Visser, S. N., S. J. Blumberg, M. L. Danielson, R. H. Bitsko, and M. D. Kogan. 2013. State-based and demographic variation in parent-reported medication rates for attention-deficit/hyperactivity disorder, 2007–2008. *Preventing Chronic Disease* 10:20073.

Wittenburg, D., J. Tambornino, E. Brown, G. Rowe, M. DeCamillis, and G. Crouse. 2015. ASPE research brief: The child SSI program and the changing safety net. http://aspe.hhs.gov/hsp/15/ChildSSInet/rb_ChildSSInet.pdf (accessed April 21, 2015).

5

Poverty and Childhood Disability

One requirement of the task order for this committee was to compare trends in the prevalence of mental disorders in the population of children who receive disability benefits with trends in the prevalence of mental disorders in the general U.S. population, aged 0 through 17 years. This task is complicated by the facts that both poverty and having a disability are eligibility criteria for disability benefits, while the majority of children in the general population comparison group neither live in poverty nor have a disability. In addition, disability is generally more common among children living in poverty than among those not living in poverty. Therefore, in addition to comparing trends in the prevalence of mental disorders among those receiving SSI benefits to trends of these disorders in the general child population, this chapter and the remainder of the report present trends in the prevalence of mental disorders that take into account the population of children who are living in poverty. Parts III and IV of this report present trends in an additional comparison group that is socioeconomically more comparable to the Supplemental Security Income (SSI) population, namely, children receiving Medicaid benefits.

An additional caveat in comparing populations stems from the fact that information on trends in the frequency of mental disorders among children in the general population is dependent on engagement of affected children with the health care system or on parent recall of relevant diagnostic information and reporting of that information in surveys. It is known that various disparities in health care access exist, and such disparities may cause some subpopulations of youth with mental disorders to be misrepresented by general surveys or analyses of medical or other service system data.

Furthermore, parental reports may not accurately capture the disability associated with mental health diagnoses. Therefore, while some information on the prevalence of mental health conditions is available from numerous studies, information on the functional impact of these conditions on children who are affected is not. In contrast, the data for monitoring trends in mental disorder prevalence in SSI beneficiaries is dependent on selection criteria for eligibility, specifically, poverty and disability. The large majority of SSI recipients live in families that are "poor," that is, with a family income less than 200 percent of the federal poverty level (FPL). Families under 200 percent FPL represent more than 40 percent of the general population (DeNavas-Walt and Proctor, 2014). Furthermore, the number of families with incomes less than 200 percent of the FPL is not static. As economic conditions deteriorate, more families join the ranks of those with incomes at or below a defined poverty level. This most recently occurred following the 2008–2009 "Great Recession," or economic downturn, in the United States. As a result, more children with disability owing to mental disorders would have met the poverty criterion for SSI benefits. This means that an increase in the percentage of children with mental health disorders on SSI may not reflect an increase of mental health disorders, but may instead arise from an increased percentage of children with these disorders meeting the poverty threshold for SSI eligibility.

Differences between the general population and the population of children receiving SSI or Medicaid benefits are further compounded by the facts that poverty itself is a risk factor for mental disorders in children and that functional impairment is more severe for children diagnosed with a mental disorder who live in poverty than for those diagnosed with such a disorder who do not (see the section in this chapter on the interactions of poverty and disability) (Parish and Cloud, 2006). Furthermore, the presence of a child with disability is itself a risk factor for family poverty (Wolfe and Hill, 1995).

Thus, it is difficult to make direct comparisons of prevalence trends between all children in the general population with a mental disorder and children with a mental disorder in the SSI or Medicaid beneficiary population, and data presented in this report must be interpreted with this in mind. In subsequent sections of this report the committee has attempted to mitigate population differences by using the number of children in households under 200 percent FPL each year as a proxy for the SSI income-eligible population of children. In response to the task order, this report focuses on comparisons of the trends in the prevalence of mental disorders over time, rather than on differences in prevalence among the populations.

CHILDHOOD POVERTY

Rates of poverty among children can be measured—and the year-to-year trends in those rates determined—using objective standards established by the government. The most common measure of poverty being used in the United States is whether a child lives in a household whose income is below an absolute poverty level (the FPL). This poverty measure has been calculated in nearly the same way since the mid-1960s. The level is based on the cost of a minimum food diet multiplied by a factor of 3 to allow for all other family expenditures. In 2013, the poverty threshold for a family of three with two children was $18,769, and for a family of four with two children it was $23,624 (DeNavas-Walt and Proctor, 2014). Official national figures on poverty are based on the Annual Social and Economic Supplement to the Current Population Survey. Table 5-1 presents the absolute number of children under age 18 in poverty and the percentage of children who were below the FPL annually from 2004 to 2013. The pattern shows that the percent of children in poverty increased after 2006, peaked in 2010, and declined afterward, although by 2013 it was still well above the 2006 level.

In addition, another 5.7 percent of children were living near poverty (100 to 125 percent of the FPL) in 2012 (Hokayem and Heggeness, 2014).

Other sources provide similar estimates. For example, the American Community Survey provides a higher estimate for the percentage of children living in poverty—22.2 percent in 2013—but this is not the official measure. In addition, the National Center for Children in Poverty tracks the

TABLE 5-1 U.S. Children in Poverty (less than 100 percent of the FPL), 2004–2013 (numbers in thousands)

		Below Poverty	
Year	Total	Number	Percent
2004	73,241	13,041	17.8
2005	73,285	12,896	17.6
2006	73,727	12,827	17.4
2007	73,996	13,324	18
2008	74,068	14,068	19
2009	74,579	15,451	20.7
2010	73,873	16,286	22
2011	73,737	16,134	21.9
2012	73,719	16,073	21.8
2013	73,625	14,659	19.9

SOURCE: DeNavas-Walt and Proctor, 2014.

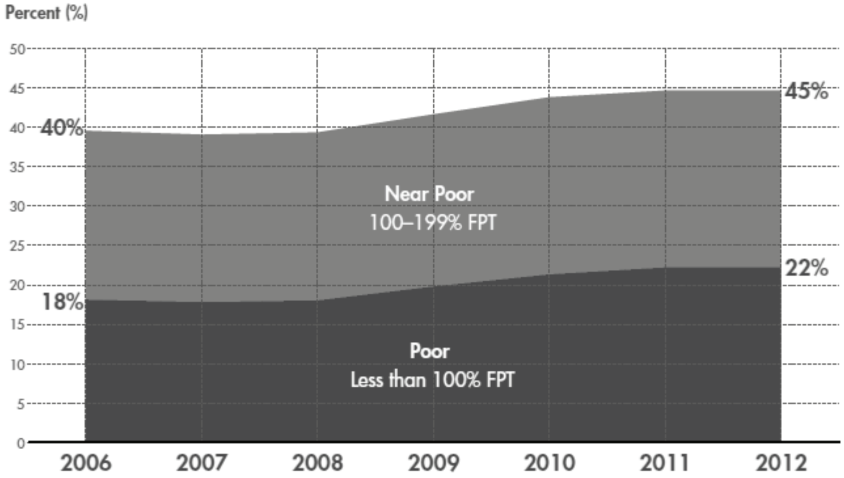

FIGURE 5-1 Children living in near poor (low-income) and poor families, 2006–2012.
SOURCE: Jiang et al., 2014.

number of children who live in "low-income families or families with incomes below 200 percent of the FPL" (Jiang et al., 2014). Figure 5-1 shows the percentage of children living below 100 percent of the FPL (poor) and below 200 percent of the FPL (low-income or near poor and poor) from 2006 to 2012. The numbers in both groups show a steady increase beginning in 2008. The absolute percentages are consistent with the American Community Survey data.

The patterns, regardless of source, suggest that there was an increasing pool of children who would be eligible for income-conditioned programs during the Great Recession of the 21st century.

How Child Poverty Is Represented in the SSI Program for Children with Disabilities

Because of income and resource eligibility criteria, nearly all children who are recipients of SSI disability benefits come from households that are poor or near poor. The Social Security Administration (SSA) does not regularly collect data on the degrees of poverty represented among child SSI recipients; however, the SSA does produce yearly data on the size of benefit payments administered to recipients, and it has also conducted occasional studies of the economic characteristics of households of the child SSI recipients.

TABLE 5-2 Number and Percentage of Families with SSI Recipients Under Age 18, by Poverty Status Minus SSI Payments, 2002 and 2010

Family Income, Excluding SSI Payments, as a Percentage of Poverty Threshold	Number of Families with a Child Receiving SSI Benefits	
	2002	2010
Under 100 percent of the FPL	475,194 (53)	692,696 (58)
100–150 percent of the FPL	213,773 (24)	187,481 (16)
150 percent or more of the FPL	205,959 (23)	313,670 (26)
Total	894,924	1,193,848

SOURCES: Bailey and Hemmeter, 2014; DeCesaro and Hemmeter, 2008.

Every year in the SSI annual statistical report, the SSA reports the amount of money administered to disability benefit recipients. The 2013 SSI annual statistical report indicated that 62.6 percent of child SSI recipients received the maximum SSI benefit payment of $710.00 per month and therefore were living in households that had no "countable income"[1] that could reduce the maximum SSA benefit payment each month.

In 2008 and in 2014 the SSA published research and statistics notes on the characteristics of noninstitutionalized disability insurance and SSI program participants in the years 2002 and 2010, respectively. To generate better information on the economic characteristics of SSI recipients, the SSA used validated Social Security numbers to match SSI disability administrative records to data from the Census Bureau's Survey of Income and Program Participation (SIPP). By matching SSI recipients to SIPP households, the SSA was able to obtain more detailed estimates of the rates and severity of poverty for children who were recipients of SSI disability benefits. Data from these publications are summarized in Tables 5-2 and 5-3.

Table 5-2 shows the number and percentage of families with SSI recipients under age 18 who were below 100 percent FPL, between 100 and 150 percent FPL, and above 150 percent FPL excluding SSI payments, for 2002 and 2010. As the table shows, in 2010 approximately 58 percent of families with SSI recipients under age 18 were below 100 percent of the FPL. Another 16 percent of families with children receiving SSI payments were between 100 and 150 percent FPL.

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[1] An individual's SSI benefit payment is calculated by subtracting the family's "countable income" from the SSI federal benefit rate. The family's countable income is calculated by subtracting income that is not counted by exclusionary SSI criteria from the family's total income. Every additional dollar of countable income reduces the individual's SSI payment. For more detail, see www.socialsecurity.gov/ssi/text-income-ussi.htm (accessed March 27, 2015).

Table 5-3 shows the number and percentage of families with SSI recipients under age 18 whose incomes were raised from below to above 100 percent FPL by the receipt of SSI payments. In 2010, 315,440 families were brought above the FPL by SSI payments, an increase from 175,394 in 2002. The percentage of SSI recipient families brought above the FPL also increased, from 36.9 percent in 2002 to 45.5 percent in 2010. As will be discussed further in the remainder of this chapter, poverty exacerbates negative outcomes in children with disabilities and their families.

These data show that a large majority of SSI recipients are from low-income households and that this was increasingly true over the period 2002–2010. Changes in the rates of poverty will directly affect the number of households that would be eligible for SSI and also the need for additional income supports. As such, an increase in the rates of poverty could reasonably be expected to precede or predict an increase in the rates of applications and determinations for disability benefits. Figure 5-2 shows the number of allowances and determinations for the 10 major mental disorders from 2004 to 2013; Figure 5-3 shows the number of children (in thousands) under 100 percent and 200 percent of the federal poverty guidelines.

As would be expected, the trends in the rate of child poverty from 2004 to 2013 coincided with the trends in the rates of SSI disability determinations and allowances over the same time period. The period of time where

TABLE 5-3 Number and Percentage of Families with SSI Recipients Under Age 18, by Poverty Status with and Without SSI Payments, 2002 and 2010

	Number of Families with a Child Receiving SSI benefits	
	2002	2010
Total number of families with a child receiving SSI benefits	894,924	1,193,848
Number (percent) of families with incomes less than 100 percent FPL when SSI payments are excluded	475,194 (53.1%)	692,696 (58.0%)
Number (percent) of family with incomes less than 100 percent FPL when SSI payments are included	299,800 (33.5%)	377,256 (31.6%)
Number of families raised above 100 percent FPL by SSI payments	175,394	315,440
Percent of SSI recipients below the FPL, brought above 100 percent FPL by receipt of SSI benefits	36.9%	45.5%

SOURCES: Bailey and Hemmeter, 2014; DeCesaro and Hemmeter, 2008.

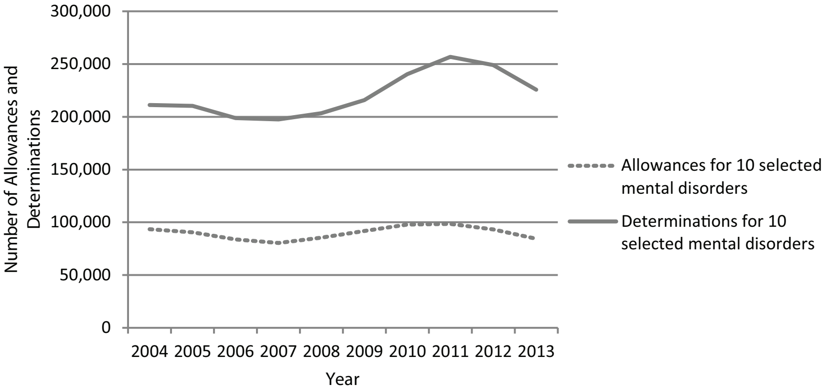

FIGURE 5-2 Allowances and determinations for 10 major mental disorders, 2004–2013.
SOURCE: Unpublished data set provided by the SSA.

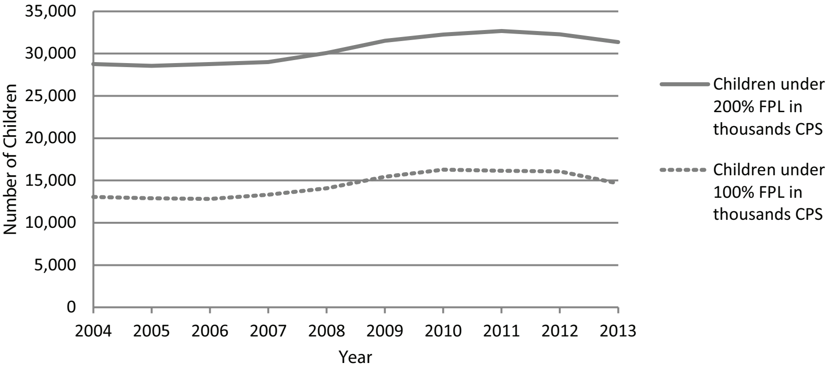

FIGURE 5-3 Estimated number (in thousands) of children in families under 100 percent and 200 percent of the federal poverty level by year, 2004–2013.
NOTE: The Current Population Survey table creator was used to generate numbers of children below 100 percent and 200 percent of the federal poverty level. Parameters used to generate the numbers include get count of: persons in poverty universe (everyone except unrelated individuals under 15); years: 2004 to 2013; Census 2010 weights; row variable: age; column variable: income-to-poverty ratio; and customized formatting: income-to-poverty ratio percent cutoffs of 200 percent and 100 percent.
SOURCE: U.S. Census Bureau, 2015.

there were increases in the rates of allowances and determinations (2008–2011) coincided with a period of serious recession in the U.S. economy. In 2014 the U.S. Census Bureau published a brief analysis that showed trends in poverty among children from 1999 to 2013. Figure 5-4 shows trends in both the number of children in poverty and the child poverty rate as a percentage of all children from 1999 to 2013, with the periods of recession highlighted. The Census Bureau's analysis found that the first statistically significant decline in child poverty since 2000 was observed between 2012 and 2013, when the child poverty rate dropped from 21.8 to 19.9 percent (DeNavas-Walt and Proctor, 2014). This is consistent with trends observed in the SSI program; the numbers of allowances and determinations for the major mental disorders peaked in 2011 and then decreased through at least 2013.

Any analysis of the potential causes of the change observed in the SSI program for mental disorders in children should account for the variation in the number of children living in poverty. Calculating allowances, determinations, and recipients as a percentage of the number of children in low-income households for each year is a simple way of controlling for the effects of variations in child poverty rates on the SSI program. Year-to-year changes observed in the SSI program after controlling for poverty

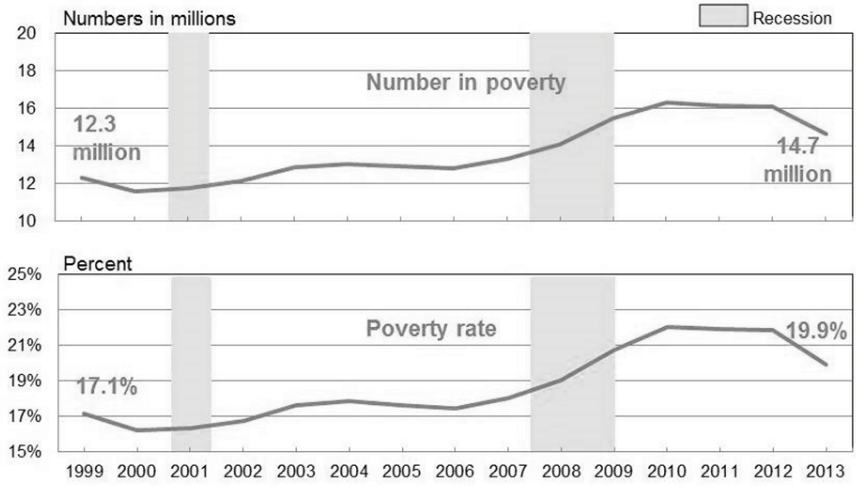

FIGURE 5-4 Child poverty rate and number of children in poverty.
SOURCE: Renwick, 2014.

will be due to factors such as variations in the rates of disability, changes in diagnostic practice, and changes in adjudicative standards or practices.

The last three columns of Table 5-4 show the results of calculating the rate of allowances, determinations, and recipients as a percentage of the number of children in households under 200 percent FPL.

From 2004 to 2013 there was a decrease in the percentage of allowances for the 10 major mental disorders among children in households under 200 percent of the FPL, from 0.32 to 0.27 percent. Furthermore, there was no overall increase in the percentage of determinations of disability among children in households under 200 percent FPL, though there was some variation during the period. The percentage of recipients among children increased, from 1.88 percent in 2004 to 2.09 percent in 2013. As was previously described in Chapter 3, the increase in recipients is likely to have been the result of the number of allowances and reentries from suspensions exceeding the number of suspensions, terminations, and transitions from child SSI to adult SSI.

After adjusting for changes in the number of children in low-income households in the United States, the rates of allowances and determinations for mental disorders did not increase over this time period. In addition, these figures illustrate the relatively small percentage of children in households under 200 percent FPL whose mental disorders are evaluated for SSI eligibility and the even smaller proportion that are found eligible.

Figures 5-5 and 5-6 further illustrate the effect of differences in the severity of child poverty on the rate of allowances and recipients for the 10 major mental disorders. Figure 5-5 shows that the rate of allowances is higher for applicant families that have less income and resources. As expected, the frequency of allowances is highest among the families that are at or below 100 percent FPL. The figure also shows that the rate of allowances among children at all levels of poverty decreased from year to year. The decrease was particularly noticeable for the period 2004–2007, but the entire period 2004–2013 appears to have seen a decrease. The percent change from 2004 to 2010 for children at or below 100 percent FPL was –20 percent, for those at or below 150 percent FPL it was –21 percent, for those at or below 200 percent FPL it was –21 percent, and for all children was –17 percent. The percentage point change between 2004 and 2010 (i.e., the difference between the percentage in 2004 and the percentage in 2010) for children at or below 100 percent FPL was –14 percent, for those at or below 150 percent FPL it was –12 percent, for those at or below 200 percent FPL it was –10 percent, and for all children it was –6 percent. Consistent with these decreases, the rate of allowances for all children in the general population decreased slightly from 2004 to 2013. The decrease in the rate of allowances over time among families in low-income households is likely due to a steady increase in the number of children who

TABLE 5-4 Rate of Allowances, Determinations, and Recipients as a Percentage of the Number of Children in Households Under 200 Percent FPL

Year	# of (initial) Child Allowances for 10 Major Mental Disorders	# of (initial) Child Determinations for 10 Major Mental Disorders	# of (initial) Child Recipients for 10 Major Mental Disorders	# of Children in Households Under 200 Percent FPL	Percent of Children Under 200 Percent FPL Allowed SSI for 10 Major Mental Disorders	Percent of Children Under 200 Percent FPL Determined for 10 Major Mental Disorders	Percent of Children Under 200 Percent FPL Recipients of SSI Benefits for 10 Major Mental Disorders
2004	93,401	211,191	540,051	28,753,000	0.32%	0.73%	1.88%
2005	90,554	210,316	562,402	28,539,000	0.32%	0.74%	1.97%
2006	83,707	198,857	577,091	28,757,000	0.29%	0.69%	2.01%
2007	80,465	197,612	583,947	28,999,000	0.28%	0.68%	2.01%
2008	85,447	203,522	587,618	30,064,000	0.28%	0.68%	1.95%
2009	91,739	215,813	600,115	31,505,000	0.29%	0.69%	1.90%
2010	97,778	240,506	615,772	32,254,000	0.30%	0.75%	1.91%
2011	98,571	256,867	631,602	32,678,000	0.30%	0.79%	1.93%
2012	93,132	249,152	647,555	32,269,000	0.29%	0.77%	2.01%
2013	84,307	225,667	654,370	31,364,000	0.27%	0.72%	2.09%

NOTE: The Current Population Survey table creator was used to generate numbers of children below 200 percent of the federal poverty level. Parameters used to generate the numbers include get count of: persons in poverty universe (everyone except unrelated individuals under 15); years: 2004 to 2013; Census 2010 weights; row variable: age; column variable: income-to-poverty ratio; and customized formatting: income-to-poverty ratio percent cutoff of 200 percent.

SOURCES: U.S. Census Bureau, 2015; unpublished data set provided by the SSA.

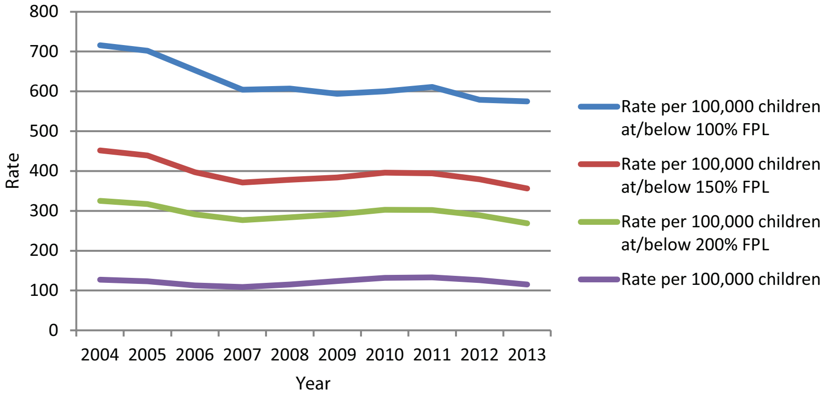

FIGURE 5-5 Rate of SSI child allowances for the 10 major mental disorders per 100,000 children under 100 percent FPL, under 200 percent FPL, and for the total U.S. under-18 population.
NOTE: The Current Population Survey table creator was used to generate numbers of children below 200 percent of the federal poverty level. Parameters used to generate the numbers include get count of: persons in poverty universe (everyone except unrelated individuals under 15); years: 2004 to 2013; Census 2010 weights; row variable: age; column variable: income-to-poverty ratio; and customized formatting: income-to-poverty ratio percent cutoffs of 200 percent, 150 percent, and 100 percent.
SOURCES: U.S. Census Bureau, 2015; unpublished data set provided by the SSA.

are in households that are at or near the FPL (i.e., a steady increase in the denominator). In contrast, the frequency of allowances among all children (i.e., the numerator) did not vary substantially over the period because there was little change in the number of allowances relative to the overall number of children.

Figure 5-6 shows how the rate of recipients of SSI benefits for the 10 major mental disorders in children in low-income households is sensitive to differences in the severity of child poverty. The proportion of all U.S. children receiving SSI benefits for the 10 major mental disorders increased from 2004 to 2013. This increase is reflected in all poverty groups. The dip in rates observed during 2008–2011 in the 100 percent or below FPL population, and also to a lesser degree in the 150 percent and 200 percent FPL or below populations, may be attributed in part to the increased rates of child poverty following the period of recession in 2008.

The rate of recipients among all children in the United States increased gradually from year to year for the entire decade, from approximately 737 per 100,000 children in 2004 to 889 per 100,000 children in 2013. This

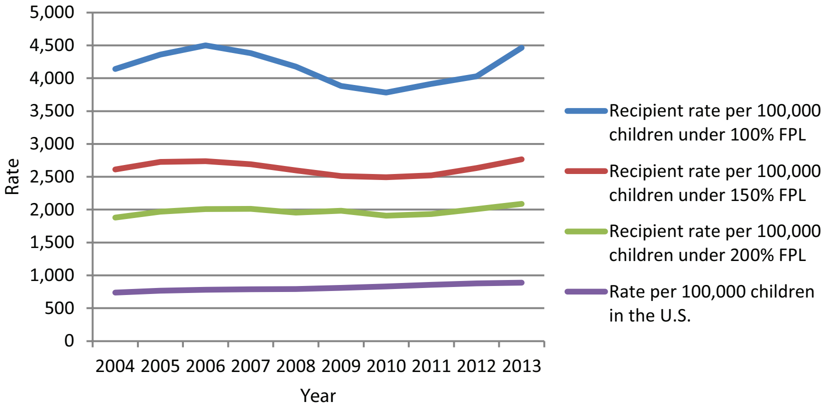

FIGURE 5-6 Rate of SSI child recipients for 10 major mental disorders per 100,000 children under 100 percent FPL, under 200 percent FPL, and for the total U.S. under-18 population.
NOTE: The Current Population Survey table creator was used to generate numbers of children below 100 percent, 150 percent, and 200 percent of the federal poverty level. Parameters used to generate the numbers include get count of: persons in poverty universe (everyone except unrelated individuals under 15); years: 2004 to 2013; Census 2010 weights; row variable: age; column variable: income-to-poverty ratio; and customized formatting: income-to-poverty ratio percent cutoffs: 200 percent, 150 percent, and 100 percent.
SOURCES: U.S. Census Bureau, 2015; unpublished data provided by the SSA.

was a 21 percent increase, and an increase of 0.15 percentage points in the rate per 100,000. In contrast, the rate of recipients among children in households at or below 100 percent FPL varied over the decade, with an increase in rates from 2004 to 2006, a decrease from 2006 to 2010, and then another period of increases from 2010 to 2013. Over the entire 10-year period the rate of recipients within children in households at or below 100 percent FPL increased from 4,141 per 100,000 children in 2004 to 4,464 per 100,000 children in 2013, with a high of 4,499 per 100,000 in 2006 and a low of 3,781 per 100,000 in 2010. Among children at or below 100 percent FPL, the percentage increase from 2004 to 2010 was 8 percent, while the percentage point increase was 0.32 percent.

Figure 5-6 illustrates two findings. First, the rate for receipt of benefits is greatest for the poorest families. Second, the total relative increase in the rate of recipients from 2004 to 2013 was the least for the lowest-income families (100 percent and 150 percent FPL). The variations observed in the rates of recipients are affected by changes in the rates of child poverty. When child poverty is taken into account, there was little or no overall increase in the rates of recipients from 2004 to 2013.

CHILDHOOD DISABILITY

The identification of disability in children is perhaps a more complex and dynamic process than the measurement of poverty. This is in part because children develop new skills as they age and the expectations for their functioning increase dramatically with time. Additionally, the way in which disability is framed has changed substantially in recent decades. In health care and in the determination process of disability by the SSA, disability is understood to be a personal attribute that is the consequence of health-related conditions. The consequences are impairments that limit the activities that a person is able to do. The SSA evaluates how well a child can perform activities in six domains: acquiring and using information, attending to and completing tasks, interacting and relating with others, moving about and manipulating objects, caring for himself or herself, and maintaining health and physical well-being. Newer models of disability blend the "medical model" with an understanding that the experience of disability is contextualized by the world in which a person lives. Models proposed by Nagi in the 1960s and 1970s, by the Institute of Medicine in 1991, by the World Health Organization in 2001 as the International Classification of Functioning, Disability and Health, and by the United Nations Convention in 2006 solidified the definition of disability as the outcome of interactions between persons with impairment and attitudinal and/or environmental barriers that hinder full and effective participation (Stein, 2007).

Data on childhood disability suggest that the proportion of children experiencing disability is steadily increasing, regardless of the definition used. In 1980, 3.8 percent of U.S. children had health-related limitations of activity (Newacheck at al., 1986). Thirty years later, 7.9 percent of children had an activity limitation (Houtrow et al., 2014). In addition, the health conditions associated with disability are shifting. A recent study by Olfson anc colleagues showed a decrease in the percentage of young people with severe mental health impairment; at the same time there were increases in the rates of mental health treatment (Olfson et al., 2015). Between 2000–2001 and 2010–2011 there was a 21 percent increase in disability related to mental health and a 12 percent decline in disability owing to physical conditions (Houtrow et al., 2014). The SSA process for determining disability has changed little over the years, although the populations to which the definitions are applied have changed. Thus, the SSA process for the determination and classification of disability (see Chapter 2) differs from the determination and classification or diagnosis of disability in other contexts, such as determinations for clinical treatment, for the provision of support services, or for epidemiologic surveillance and research. For this reason, shifts in the SSA determination outcomes have not, and in the future may not, reflect the changes reported by surveys of disability in the general childhood population.

The Relationship Between Childhood Disability and Poverty

The relationship between childhood disability and poverty is best described as complex and interactive (Lustig and Strauser, 2007). Poor health and disability are strongly associated with poverty (Stein and Silver, 2002). This relationship is thought to be a linear one, in which income or socioeconomic status and parental education (which are highly correlated) are correlated with health both within and across societies (Marmot et al., 1987). The same is true for disabilities associated with mental health disorders: children living in or near poverty have higher rates of disability associated with mental health disorders than other children (Houtrow et al., 2014). Poverty has also been shown to be a source of a gradient for overall child health (Brooks-Gunn and Duncan, 1997; Fletcher and Wolfe, 2012; Lubotsky et al., 2002; Starfield et al., 2002). It is clear that poverty is also associated with other social disadvantages, such as minority status, single parenthood, and poor education, which have a cumulative effect on child health and disability (Bauman et al., 2006; Evans, 2004).

Children who are born to mothers in low-income households are more likely to be born pre-term, to have worse birth outcomes, and to demonstrate higher proportions of developmental disadvantage as well as poorer health outcomes (NRC and IOM, 2000). Even when preterm babies have an identical medical status, their prognosis is heavily influenced by their socioeconomic status, with those from less advantaged backgrounds being more likely to experience poorer outcomes (Escalona, 1982; Stein et al., 2010). Furthermore, children who grow up in poverty are less likely to be treated for their conditions, as they generally have more limited access to care, and even those with insurance may face additional barriers and consequently have poorer health outcomes (Van Cleave et al., 2010).

In general, children and youth who live in poverty have increased rates of most chronic health conditions, more severe conditions and complications, and poorer access to care. Thus, for example, children in low-income households with acute lymphocytic leukemia (the most common leukemia in childhood) have higher rates of mortality than middle-income children with the same disease. Similar findings exist for a wide range of childhood conditions, such as cystic fibrosis, spina bifida, and congenital heart disease. Among higher-prevalence conditions, such as obesity and asthma, although these conditions affect children in all socioeconomic status groups, the prevalence is higher and the course of the disorder more severe in lower-income households. The data for mental health conditions may be less well developed than those for other conditions, but here too there is moderate to strong evidence that these conditions (e.g., attention deficit hyperactivity disorder and depression, conduct disorder) occur more commonly among poor children and likely with greater severity, with the possible exception of Autism (Houtrow and Okumura, 2011).

Furthermore, children who live in low-income households experience more food insecurity, more parental depression and other mental health disorders, and more housing instability and are more likely to live in neighborhoods where there are more environmental hazards which may be associated with higher rates of injury and exposure to traumatic events (Merikangas et al., 2010). As a result, children who live in low-income households are more likely to experience toxic stress, which has been shown to affect long-term health and well-being (Shonkoff et al., 2012).

Additionally, having a child with a disability places financial and other stress on families and may increase the chances of the family becoming poor. There are both direct and indirect effects. Households with children with chronic health conditions face higher costs for caring for the children as well as decreased household income when parents leave the workforce or decrease their paid workload to care for a child with a disability (National Commission on Childhood Disability, 1995). Families with a child with disabilities are also more likely to incur increased out-of-pocket expenses, for example, for childcare or for transportation to locations with specialized medical care (Kuhlthau et al., 2005; Newacheck and Kim, 2005). The time and energy required to take care of such a child and the strain on financial resources often affect parents' opportunities for advancement in life by interfering with their educational aspirations or promotion in employment (Anderson et al., 2007). These parents' lives are often interrupted unexpectedly by the need to deal with a child's condition. Until the passage of the Affordable Care Act, there also was a great likelihood that families with private health insurance would find it difficult to insure children with disabilities, leading to considerable medical expenses and work loss and sometimes to employment discrimination. There has also been evidence that, for some families, parents had to work more in order to secure health insurance, leading to reduced time spent with children (Gould, 2004). The net result is that many families with children with disabilities experience either a lack of economic advancement or decreased overall resources relative to other families and are therefore more likely to enter and remain in poverty.

A number of studies have shown that parents—both fathers and mothers—raising children with disabilities have lower rates of employment than parents with similar characteristics who have children without ongoing health conditions (Kuhlthau and Perrin, 2001; Kuhlthau et al., 2005). Another study documented much higher rates of stopping or decreasing employment as well as lower household income among mothers 6 months after their children's first hospitalization for a chronic health condition when compared with mothers of children with acute hospitalizations (Thyen et al., 1999).

In conclusion, children living in poverty are more likely than other children to have mental health problems, and their conditions are more likely to be severe. This too will have an upward effect on numbers of determinations and, perhaps, allowances. When analyzing SSI data and finding comparables for trend examination, the impact of poverty should be factored into the analyses. The committee has attempted to do this in the remainder of the report, and it suggests that prospective acquisition of data by SSI similarly should take poverty into account.

FINDINGS

- The total number of U.S. children changed very little during the 2004–2013 decade, but both the number and percentage of all children who lived in impoverished households increased. The major increase occurred from 2008 to 2010 and coincided with a time of economic recession.
- The biggest percentage increase of children in poor families between 2004 and 2013 occurred in those families with incomes less than 100 percent of the FPL. A small increase was documented for children in families whose income was between 100 percent and 200 percent of the FPL.
- The proportion of all children who are identified as having a disability in the United States has steadily increased each decade since the 1960s.
- The definition of disability has evolved to encompass a variety of factors that influence impairment due to biomedical factors and contextual factors such as poverty as well as functional limitations and barriers to effective participation in usual childhood activities.
- The number of families with an SSI recipient who are living under the FPL when SSI benefits are not included in calculating income increased by 46 percent between 2002 and 2010. In 2010 more than 45 percent of those families were raised above the FPL after receiving SSI benefits, potentially reducing both economic stresses and the risk of worsening child disability.
- Neither the total number of child mental disorder allowances of SSI benefits nor the rate of allowances among children in poverty increased during the 2004–2013 decade. In fact, the total number of allowances was approximately 10 percent lower in 2013 than in 2004.

- Despite the decrease in allowances, the number of recipients increased steadily during the 2004–2013 decade. Total recipients as a percentage of all children in households under 200 percent of the FPL increased by approximately 11 percent. Recipient rates increased for all levels of poverty.
- Allowance and recipient rates per 100,000 children were higher for families under the FPL than for those above, and they increased with progressively more severe levels of poverty.

CONCLUSIONS

- Poverty is a risk factor for child disability, including disability associated with mental disorders. At the same time, child disability is a risk factor for family poverty. At times of economic hardship in the United States, more children with mental disorder–related disabilities will qualify for benefits because they meet the income eligibility threshold. In this situation, the number of SSI determinations and allowances would be expected to increase, unless the SSI determination process becomes more stringent, the income eligibility criteria are changed, or there is a coincidental change in the characteristics of the population applying for SSI benefits.
- Children living in poverty are more likely than other children to have mental health problems, and these conditions are more likely to be severe. Low-income families with a child who has a disability may be particularly vulnerable at times of economic hardship. Access to Medicaid and income supports via the SSI disability program may improve the long-run outcomes for both children with disabilities and their families.

REFERENCES

Anderson, D., S. Dumont, P. Jacobs, and L. Azzaria. 2007. The personal costs of caring for a child with a disability: A review of the literature. *Public Health Reports* 122(1):3–16.

Bailey, M. S., and J. Hemmeter. 2014. Characteristics of noninstitutionalized DI and SSI program participants, 2010 update. Research and Statistics Note No. 2014-02. www.ssa.gov/policy/docs/rsnotes/rsn2014-02.html (accessed July 1, 2015).

Bauman, L. J., E. J. Silver, and R. E. Stein. 2006. Cumulative social disadvantage and child health. *Pediatrics* 117(4):1321–1328.

Brooks-Gunn, J., and G. J. Duncan. 1997. The effects of poverty on children. *Future of Children* 7(2):55–71.

DeCesaro, A., and J. Hemmeter. 2008. Characteristics of noninstitionalized DI and SSI program participants. Research and Statistics Note No. 2008-02. www.ssa.gov/policy/docs/rsnotes/rsn2008-02.html (accessed July 1, 2015).

DeNavas-Walt, C., and B. D. Proctor. 2014. *Income and poverty in the United States: 2013*. U.S. Census Bureau current population reports, P60-249. Washington, DC: U.S. Government Printing Office. www.census.gov/content/dam/Census/library/publications/2014/demo/p60-249.pdf (accessed July 1, 2015).

Escalona, S. K. 1982. Babies at double hazard: Early development of infants at biologic and social risk. *Pediatrics* 70(5):670–676.

Evans, G. W. 2004. The environment of childhood poverty. *American Psychologist* 59(2):77–92.

Fletcher, J., and B. L. Wolfe. 2012. Increasing our understanding of the health–income gradient in children. National Bureau of Economic Research Working Paper No. 18639. www.nber.org/papers/w18639 (accessed July 1, 2015).

Gould, E. 2004. Decomposing the effects of children's health on mother's labor supply: Is it time or money? *Health Economics* 13(6):525–541.

Hokayem, C., and M. L. Heggeness. 2014. *Living in near poverty in the United States: 1966–2012*. U.S. Census Bureau current population reports, P60-248. Washington, DC: U.S. Government Printing Office. www.census.gov/prod/2014pubs/p60-248.pdf (accessed July 1, 2015).

Houtrow, A. J., and M. J. Okumura. 2011. Pediatric mental health problems and associated burden on families. *Vulnerable Children and Youth Studies* 6(3):222–233.

Houtrow A. J, K. Larson, L. M. Olson, P. W. Newacheck, and N. Halfon. 2014. Changing trends of childhood disability, 2001–2011. *Pediatrics* 134(3):530–538.

Jiang, Y., M. Ekono, and C. Skinner. 2014. Basic facts about low-income children: Children under 18 years, 2012. National Center for Children in Poverty, Columbia University, February. http://www.nccp.org/publications/pdf/text_1089.pdf (accessed July 1, 2015).

Kuhlthau, K. A., and J. M. Perrin. 2001. Child health status and parental employment. *Archives of Pediatric and Adolescent Medicine* 155(12):1346–1350.

Kuhlthau, K., K. Hill, R. Yucel, and J. Perrin. 2005. Financial burden for families of children with special health care needs. *Maternal and Child Health Journal* 9(2):207–218.

Lubotsky, D., C. Paxson, and A. Case. 2002. Economic status and health in childhood: The origins of the gradient. *American Economic Review* 92(5):1308–1334.

Lustig, D. C., and D. R. Strauser. 2007. Causal relationships between poverty and disability. *Rehabilitation Counseling Bulletin* 50(4):194–202.

Marmot, M. G., M. Kogevinas, and M. A. Elston. 1987. Social/economic status and disease. *Annual Review of Public Health* 8:111–135.

Merikangas, K. R., J.-P. He, M. Burstein, S. A. Swanson, S. Avenevoli, L. Cui, C. Benjet, K. Georgiades, and J. Swendsen. 2010. Lifetime prevalence of mental disorders in U.S. adolescents: Results from the National Comorbidity Survey Replication-Adolescent Supplement (NCS-A). *Journal of the American Academy of Child & Adolescent Psychiatry* 49(10):980–989.

National Commission on Childhood Disability. 1995. *SSI disability benefits for children: Supplemental Security Income for children with disabilities*. Report to Congress of the National Commission on Childhood Disability, October, Washington, DC. www.ssa.gov/history/reports/SSI/ChildhoodDisabilityReport.html (accessed July 1, 2015).

Newacheck, P. W., and S. E. Kim. 2005. A national profile of health care utilization and expenditures for children with special health care needs. *Archives of Pediatric and Adolescent Medicine* 159(1):10–17.

Newacheck, P. W., N. Halfon, and P. P. Budetti. 1986. Prevalence of activity limiting chronic conditions among children based on household interviews. *Journal of Chronic Diseases* 39(2):63–71.

NRC and IOM (National Research Council and Institute of Medicine). 2000. *From neurons to neighborhoods: The science of early childhood development.* Committee on Integrating the Science of Early Childhood Development. Jack P. Shonkoff and Deborah A. Phillips, eds. Board on Children, Youth, and Families, Commission on Behavioral and Social Sciences and Education. Washington, DC: National Academy Press.

Olfson, M., B. G. Druss, and S. C. Marcus. 2015. Trends in mental health care among children and adolescents. *New England Journal of Medicine* 372(21):2029–2038.

Parish, S. L., and J. M. Cloud. 2006. Financial well-being of young children with disabilities and their families. *Social Work* 51(3):223–232.

Renwick, T. 2014. Child poverty down—Income of families with children up. *Random Samplings*, September 16. U.S. Census Bureau blog. http://blogs.census.gov/2014/09/16/child-poverty-down-income-of-families-with-children-up (accessed July 1, 2015).

Shonkoff, J. P., A. S. Garner, and the Committee on Psychosocial Aspects of Child and Family Health, Committee on Early Childhood, Adoption, and Dependent Care, and Section on Developmental and Behavioral Pediatrics. 2012. The lifelong effects of early childhood adversity and toxic stress. *Pediatrics* 129(1):232–246.

Starfield, B., J. Robertson, and A. W. Riley. 2002. Social class gradients and health in childhood. *Ambulatory Pediatrics* 2(4):238–246.

Stein, M. A. 2007. A quick overview of the United Nations Convention on the Rights of Persons with Disabilities and its implications for Americans with disabilities. *Mental and Physical Disability Law Reporter* 31(5):679–683.

Stein, R. E., and E. J. Silver. 2002. Comparing different definitions of chronic conditions in a national data set. *Ambulatory Pediatrics* 2(1):63–70.

Stein, R. E., M. J. Siegel, and L. J. Bauman. 2010. Double jeopardy: What social risk adds to biomedical risk in understanding child health and health care utilization. *Academic Pediatrcs* 10(3):165–171.

Thyen, U., K. Kuhlthau, and J. M. Perrin. 1999. Employment, child care, and mental health of mothers caring for children assisted by technology. *Pediatrics* 103(6):1235–1242.

U.S. Census Bureau. 2015. CPS table creator. www.census.gov/cps/data/cpstablecreator.html (accessed July 13, 2015).

Van Cleave, J., S. L. Gortmaker, and J. M. Perrin. 2010. Dynamics of obesity and chronic health conditions among children and youth. *JAMA* 303(7):623–630.

Wolfe, B. L., and S. C. Hill. 1995. The effect of health on the work effort of single mothers. *Journal of Human Resources* 30(1):42–62.

Part II

Clinical Characteristics of Selected Mental Disorders

The Social Security Administration recognizes 11 different disorders in the mental health category that will qualify families of children and adolescents for disability benefits if they meet the Supplemental Security Income (SSI) program diagnostic or functional criteria. Part II of this report provides background information concerning the clinical characteristics of the mental disorders that most often form the basis for SSI childhood disability benefits. Information about these selected disorders is not comprehensive and is not intended to provide clinical guidance. Rather, the discussion of the clinical characteristics of selected mental disorders in the following chapters is tailored to address the objectives of the committee's charge, which was to provide information on factors, such as diagnosis, treatment, and prognosis, which influence trends in the numbers of children who qualify for SSI disability benefits. This introduction provides background information relevant for interpretation of the chapters included in Part II of this report.

AGE OF ONSET OF SYMPTOMS VERSUS AGE OF DIAGNOSIS OF SYMPTOMS FOR MENTAL DISORDERS IN CHILDREN

Most mental disorders in children are diagnosed after they reach school age, and in the majority of cases they are not diagnosed for months or often years after the onset of symptoms (NRC and IOM., 2009). The age at which a child is formally diagnosed can vary depending on the mental disorder and on the circumstances in which symptoms of the mental disorder are manifested (e.g., at home, at school, or in a clinical setting).

Conditions such as developmental difficulties, including autism spectrum disorder (ASD) and intellectual disability (ID), are more commonly diagnosed earlier in a child's life, whereas conditions such as depression more commonly appear and are diagnosed in adolescence. Obtaining mental disorder diagnoses for children is complicated by a number of barriers. These include family recognition of the problem, concern about stigma, limited access to mental health services, costs associated with obtaining a diagnosis, and variations in diagnostic standards.

RISK FACTORS FOR MENTAL DISORDERS IN CHILDREN

Risks and correlates for mental disorders may be genetic, environmental, or a combination of both. These factors may include poverty, childhood trauma and adverse experiences (such as abuse and neglect, or living with an impaired parent), stressful and unstable living conditions, hunger and food insecurity, homelessness, obesity, sleep deprivation, exposure to neurotoxins, chronic illness, reduced access to health care services, adverse school experiences (such as bullying), and substance use. It should be noted that many of these factors are also risk factors for disability and poverty, thereby complicating analyses of risks. They are also factors that can interfere with access to and adherence to treatment for the conditions.

Because many of these factors are more prevalent in socioeconomically disadvantaged families, children living in inner cities and poor rural areas are more vulnerable to acquiring mental disorders and are less likely to be identified and treated at an early stage. Evidence is accumulating from animal and human studies that epigenetic changes to the expression of DNA as the result of stressful life exposures at various points—before conception (to either parent), during pregnancy (to the mother), or after birth (to the child)—can contribute to the risk for mental disorders. Similarly, resilience factors play a role in mental health outcomes. These factors can also be genetic, epigenetic, or environmental; examples include nurturing homes and school success. However, mental disorders generally have no laboratory test or biologic marker to guide diagnosis.

DIAGNOSIS AND CLASSIFICATION OF MENTAL DISORDERS IN CHILDREN

Diagnoses of mental disorders are made by a variety of health professionals. Many children are identified as needing mental health services as the result of an assessment by a child psychologist, psychiatrist, pediatrician, family physician, or counselor. Pediatricians and family medicine physicians are increasingly are making diagnoses such as attention deficit hyperactivity disorder (ADHD), and they are frequently the individuals who first identify severe behavioral disturbances.

There are no clear measures or standards for assessing the severity of mental disorders. Severity is in part contextual, with some environments and situations aggravating symptoms and interfering with coping. Other, more supportive contexts may reduce the severity and dysfunction of children with specific diagnoses.

Developmental issues may modify presenting manifestations and make diagnosis difficult. In fact, diagnoses may change with age, as the expression of each disorder evolves with a child's maturation. Symptoms may wax and wane. In addition, the response to treatment varies from one point in a child's development to another, and from one individual to another. Not infrequently, as the subsequent chapters in this report will attest, a child will have several concurrent or sequential mental diagnoses or may have a mental disorder co-occurring with a physical disorder. Those diagnoses that appear to be the main cause of impairment are usually described as a primary mental disorder and those that co-occur are labeled as secondary disorders.

Diagnoses are usually made using a complex set of criteria, which are set out in a series of manuals such as the *Diagnostic and Statistical Manual of Mental Disorders* (DSM) published by the American Psychiatric Association. There have been multiple versions of the DSM, the most recent being the DSM-5, which was published in 2013 and which was preceded by the DSM-IV-TR (2000), the DSM-IV (1994), the DSM-III-R (1987), and the DSM-III (1980). The sets of criteria vary in substantial ways, and with a new diagnostic standard, changes in diagnostic categories will be encountered. Almost all of the criteria involve both a set of symptoms and some evidence of impairment, although not necessarily the level of impairment that would qualify for designation as severely or moderately impaired according to the SSI definitions. The SSI mental health listings for children are roughly based on the DSM-III. How the subsequent evolution of diagnostic criteria affected SSI determinations is unknown.

In interpreting the available data concerning children with mental health problems, it is important to understand the uses and limitations of a "primary diagnosis." Diagnostic labels vary depending on their intended use (e.g., clinical, research, or public health). Official systems of diagnosis such as the DSM or the *International Classification of Diseases* are categorical in nature; either a child does or does not have a particular diagnosis (APA, 2013; WHO, 1992). As a practical matter, clinicians treat the individual and his or her presenting problems rather than the "diagnosis." Diagnoses are provided to facilitate billing, and in the absence of a definitive laboratory or blood test, the accuracy of the label can vary tremendously. Nevertheless, there are some diagnoses that can be made more consistently (e.g., ASD, ID) and others that require multiple respondent perspectives (e.g., ADHD) to enhance accuracy. As a result of these issues, the concept of a "diagnosis" needs to be understood as an evolving phenomenon (Jensen and Hoagwood, 1997).

FUNCTIONAL IMPAIRMENT FOR CHILDREN WITH MENTAL DISORDERS

There can be a range of impairments within a diagnosis. For example, the level of impairment may be objectively measured in the case of intellectual disability (e.g., with an IQ test), but the determination will be more subjective in the case of ADHD. It must be noted that to qualify for SSI benefits, every condition or combination of impairments must meet the statutory and regulation-specified level of impairment. Furthermore, it must be emphasized that the prevalence of a diagnosis or condition is not the same as the prevalence of a disability related to that condition. For example, while several studies show that the frequency of ADHD diagnosis has increased in the population, there is simultaneous evidence that the prevalence of disability due to ADHD has decreased (Houtrow et al., 2014).

COMORBIDITY AND CO-OCCURING MENTAL DISORDERS IN CHILDREN

Mental disorders in children very frequently co-occur. The presence of one disorder may predispose the child to other problems. For example, a child with ADHD might also exhibit conduct problems. Similarly, in children with autism there is an increased risk of intellectual disability. Furthermore, in early childhood the impairments caused by speech, language, and communication disorders may not be distinguishable from autism or intellectual disability. Multiple co-occurring diagnoses may make treatment decisions more challenging.

Mental disorders and physical disorders may also co-occur. The high rates of co-occurring mental and physical health conditions with complicated causal connections are well documented, especially in adults (Druss and Walker, 2011). Having a disability increases the risk of mental health problems; and having a mental health disorder increases the risk of having health problems and that a health problem will be disabling (Honey et al., 2010). There are also numerous studies of comorbid physical and mental health problems in children. Data from Canada's Bergen Child Study show increased rates of emotional and behavioral problems among children with various types of chronic health problems and an increased probability of psychiatric diagnoses (Hysing et al., 2009). Using data from the Neurodevelopmental Genomics Cohort Study, Merikangas and colleagues found that the prevalence of mental health disorders is higher among children with moderate to severe physical conditions compared to children without physical conditions or with mild physical conditions (Merikangas et al., 2015). Children enrolled in Medicaid with severe mental health problems were significantly more likely to have chronic physical health problems than other children (Combs-Orme et al., 2002). The presence of both physical and mental health problems were found to be negatively associated with general health status and functioning (Combes-Orme et al., 2002). In a study of Florida Medicaid-enrolled children, 35 percent of children with physical disabilities had mental health problems and 42 percent of children with mental health disabilities had other health problems (Boothroyd and Armstrong, 2005). The risk factors for having comorbid physical and mental health problems include poverty and social disadvantage (Honey et al., 2010). These children are at high risk for unmet needs which can further worsen their health and functioning (Boothroyd and Armstrong, 2005).

As noted in Chapter 2, the SSI data on comorbidity are unavailable. For the purposes of SSI determinations—and therefore for the purposes of this report—a single diagnosis is chosen as the primary cause of impairment. When there are multiple diagnoses that contribute to marked impairment, either physical or mental, the condition most easily assessed as meeting the standards of disability in the SSI system is frequently the one that is selected with the diagnosis. Due to the limitations of the SSI data, patterns of comorbidity within the SSI program cannot be assessed and compared to patterns of comorbidity observed in the general population.

LIMITATIONS IN OBTAINING ACCESS TO SERVICES FOR CHILDREN WITH MENTAL DISORDERS

As noted earlier, diagnoses are provided in part to facilitate access to services and billing for these services, as is exemplified by the Medicaid data reviewed in Parts III and IV of this report. However, access to services itself is influenced by a host of factors that are quite independent of diagnosis. These factors include recognition and activation by the parent or caregiver to seek out services, the availability of providers, adequate insurance coverage, and, importantly, the stigma associated with mental disorders. Thus, it is important to note, diagnosis is a necessary but not a sufficient step in improving children's mental health outcomes.

TREATMENT OF MENTAL DISORDERS IN CHILDREN

The response to treatment is also highly variable for many of the mental disorders. Treatment modalities generally fall into two categories: behavioral therapies and medication. For a number of disorders, the use of both modalities may be superior to either alone in effecting a beneficial treatment response. There are many psychotropic medications, and, historically, treatment benefits have been identified by trying one or more drugs. A medication's side effects not infrequently complicate and delay a beneficial response. The ability to predict a response and its timing or durability over time is limited. In cases in which there are benefits to treatment, a major determinant of the treatment outcomes is adherence to the prescribed therapy. Factors that interfere with adherence include the cost of the treatments, a lack of family organizational capacity, and the perception that the drugs produce adverse reactions.

Psychotherapy, including cognitive behavioral therapy, and parental education and therapy are often indicated. However, reimbursement for diagnosis or treatment by public or private third-party payers is often at a level that is not accepted by providers of mental health care, and many families are unable to afford these costs. There are many barriers to full participation in a therapeutic intervention. The mitigation of risk factors is often important for achieving therapeutic benefit, but families with limited resources are often unable to do what is necessary to reduce risk factors. This challenge for socioeconomically disadvantaged families is of particular concern for benefit programs such as the SSI, because the likelihood of improvement is reduced and the mental disorder–caused impairment is less likely to improve.

While effective treatments, as noted above, do exist for the majority of childhood mental disorders, few service providers have been trained to deliver effective and evidence-based services. Consequently, even if a child is diagnosed accurately and his or her family is able to overcome the many barriers to accessing services, the likelihood that he or she will receive an effective and evidence-based service is low. One study summarized this situation as a “20/20/2” problem: About 20 percent of children and adolescents will have a mental disorder during their lifetime; of those only 20 percent will be able to receive mental health care; and of those only 2 percent will receive an evidence-based service (HHS, 1999; New Freedom Commission on Mental Health, 2003; U.S. Public Health Service, 2000). Although actual estimates differ considerably depending on how the data are collected, there is broad consensus that most children are not treated and that, of the children who are treated, most are not receiving evidence-based treatment.

EFFECTS OF MENTAL DISORDERS IN CHILDREN

As a group, children and adolescents with mental disorders fall behind their peers in the areas of school success, social engagement, family integration, personal relationships, and ability to secure employment. Their problems may interfere substantially with family functioning, parental employment, and the coping ability of siblings. This adverse impact on the family is a barrier to providing for the needs of the child with a mental disorder. As youth move into adulthood, these mental disorders are often a barrier to achieving financial and functional independence. Many of these youth are placed in foster care or end up in the juvenile justice system. Neither system is well equipped to deal with the child's mental disorder in an optimal fashion. For all of these reasons, many childhood mental disorders are lifetime problems, either recurrently or persistently.

In the general population, approximately half of all children with a psychiatric diagnosis will be free of their initial childhood difficulties by early adulthood, and many may be within the normal range in the areas of health, educational and career achievements, social functioning, and avoidance of criminal or dangerous behavior (Costello and Maughan, 2015). However, many childhood psychiatric disorders lower a young person's chances of a normal life as an adult. Because these youths are more likely, once they reach adulthood, to experience a recurrence of the same disorder or the onset of a different one, the adult prevalence rate for mental disorders is higher among them than among adults with no psychiatric history. In addition, evidence is beginning to accumulate that, even in those grown youth with no adult diagnosis, having experienced a disorder in childhood or adolescence increases their risk of poor "real-world" outcomes in the areas of educational and work achievement, of conflicts with law enforcement and the legal system, of social isolation and suicidality, and of physical frailty and ill health. Children with high impulsivity have many problem behaviors, and as adults they are more likely to die young (before age 46) than children low on these measures, with the risk for children in the highest quartile of impulsivity and related externalizing behavior more than double that of children in the lowest quartile (Jokela et al., 2009). There are, however, very limited or no specific data on what proportion of children with mental health conditions meet the SSI's level of impairment in childhood or on what the adult outcomes are for these children. Overall, one would expect their outcomes to be somewhat worse than the outcomes among all children who receive a psychiatric or mental health diagnosis because many of those children would not have met the level of impairment necessary to be eligible for the SSI benefits.

It is still unclear how often the untreated course of a disorder results in an acceptable outcome, e.g., how many adults with a history of childhood mental illness succeed in compensating for the ensuing functional disabilities. More than half of the children with psychiatric disorders identified in epidemiologic studies have received no specialty mental health care (Burns et al., 1995, 1997; Merikangas et al., 2010, 2011).

Environmental and contextual factors can have a significant effect on the identification, expression, and outcome of mental disorders in children.

Adverse conditions can exacerbate and worsen outcomes for children; however, appropriate treatment and supports such as the SSI benefits enhance a child's opportunity to succeed in school, participate in the community, and live a healthy life (Costello et al., 2010).

REFERENCES

APA (American Psychiatric Association). 2013. *Diagnostic and statistical manual of mental disorders, 5th edition*. Washington, DC: APA.

Boothroyd, R. A., and M. I. Armstrong. 2005. Comorbidity and unmet service needs among Medicaid-enrolled children with identified disabilities. *Journal of Emotional and Behavioral Disorders* 1(13):43–51.

Burns, B. J., E. J. Costello, A. Angold, D. Tweed, D. Stangl, E. M. Z. Farmer, and A. Erkanli. 1995. Childrens mental health service use across service sectors. *Health Affairs* 14(3):147–159.

Burns, B. J., E. J. Costello, A. Erkanli, D. L. Tweed, E. M. Z. Farmer, and A. Angold. 1997. Insurance coverage and mental health service use by adolescents with serious emotional disturbance. *Journal of Child and Family Studies* 6:89–111.

Combes-Orme, T., C. A. Heflinger, and C. G. Simpkins. 2002. Comorbidity of mental health problems and chronic health conditions in children. *Journal of Emotional and Behavioral Disorders* 10(2):116–125.

Costello, E. J., and B. Maughan. 2015. Optimal outcomes of child and adolescent mental illness. *Journal of Child Psychology and Psychiatry* 56:3324–3341.

Costello, E. J., A. Erkanli., W. Copeland, and A. Angold. 2010. Association of family income supplements in adolescence with development of psychiatric and substance use disorders in adulthood among an American Indian population. *JAMA* 303(19):1954–1960. doi: 10.1001/jama.2010.621.

Druss, B. G., and E. R. Walker. 2011. Mental disorders and medical comorbidity. *The Synthesis Project: Research Synthesis Report* (21):1–26.

HHS (U.S. Department of Health and Human Services). 1999. *Mental health: A report of the Surgeon General.* Rockville, MD: HHS, Substance Abuse and Mental Health Services Administration, Center for Mental Health Services, National Institutes of Health, National Institute of Mental Health.

Honey, A., E. Emerson, G. Llewellyn., and M. Kariuki. 2010. Mental health and disability. In *International Encyclopedia of Rehabilitation,* edited by J. H. Stone and M. Blouin. http://cirrie.buffalo.edu/encyclopedia/en/article/305 (accessed on July 15, 2015).

Houtrow, A. J., K. Larson, L. M. Olson, P. W. Newacheck, and N. Halfon. 2014. Changing trends of childhood disability, 2001–2011. *Pediatrics* 134(3):530–538.

Hysing, M., I. Elgen., C. Gillberg., and A. J. Lundervold. 2009. Emotional and behavioural problems in subgroups of children with chronic illness: results from a large-scale population study. *Child: Care, Health and Development* 35(4):527–533.

Jensen, P. S., and K. Hoagwood. 1997. The Book of Names: DSM-IV in Context. *Development and Psychopathology* 9(2):231–249.

Jokela, M., J. Ferrie, and M. Kivimäki. 2009. Childhood problem behaviors and death by midlife: The British National Child Development Study. *Journal of the American Academy of Child and Adolescent Psychiatry* 48(1):19–24.

Merikangas, K. R., J. P. He, D. Brody, P. W. Fisher, K. Bourdon, and D. S. Koretz. 2010. Prevalence and treatment of mental disorders among U.S. children in the 2001–2004 NHANES. *Pediatrics* 125(1):75–81.

Merikangas, K. R., J. P. He, M. Burstein, J. Swendsen, S. Avenevoli, B. Case, K. Georgiades, L. Heaton, S. Swanson, and M. Olfson. 2011. Service utilization for lifetime mental disorders in U.S. adolescents: Results of the National Comorbidity Survey-Adolescent Supplement (NCS-A). *Journal of the American Academy of Child and Adolescent Psychiatry* 50(1):32–45.

Merikangas, K. R., M. E. Calkins, M. Burstein, J. P. He, R. Chiavacci, T. Lateef, K. Ruparel, R. C. Gur, T. Lehner, H. Hakonarson, and R. E. Gur. 2015. Comorbidity of physical and mental disorders in the neurodevelopmental genomics cohort study. *Pediatrics* 135(4): e927–e938.

New Freedom Commission on Mental Health. 2003. *Achieving the promise: Transforming mental health care in America. Final report*. DHHS Pub. No. SMA-0303832. Rockville, MD: HHS.

NRC and IOM (National Research Council and Institute of Medicine). 2009. *Preventing mental, emotional, and behavioral disorders among young people: Progress and possibilities*. Washington, DC: The National Academies Press.

U.S. Public Health Service. 2000. *Report of the Surgeon General's Conference on Children's Mental Health: A national action agenda*. Washington, DC: HHS.

WHO (World Health Organization). 1992. *The ICD-10 classification of mental and behavioural disorders: Clinical descriptions and diagnostic guidelines*. Geneva: WHO.

6

Clinical Characteristics of Attention Deficit Hyperactivity Disorder

DIAGNOSIS AND ASSESSMENT

Attention deficit hyperactivity disorder (ADHD) has been diagnosed with increasing frequency over the past several decades (see Chapter 12 for an in-depth review). Most diagnoses are made in school-aged children and often based on teacher and parent concerns about school and home performance and behaviors. Diagnoses are made by a range of health professionals, including primary care physicians, psychologists, and child psychiatrists. A number of organizations have developed diagnostic and treatment guidelines, including the American Academy of Pediatrics (AAP, 2011) and the American Psychiatric Association (APA, 2011), but adherence to guidelines is inconsistent, particularly for uncomplicated cases (Garner et al., 2013).

The current diagnostic criteria outlined in the *Diagnostic and Statistical Manual of Mental Disorders, 5th Edition* (DSM-5) require that a child's behavior be developmentally inappropriate (i.e., the child's behavior is substantially different from other children of the same age and developmental level) and that the symptoms must begin before age 12 and be present for at least 6 months; must be present in two or more settings; must cause significant impairments in home, school, occupational, or peer settings; and must not be secondary to another disorder (APA, 2013). There are three different presentations of ADHD that are identified in the DSM-5. The first is ADHD, predominantly inattentive; the second is ADHD, predominantly hyperactive-impulsive; and the third is ADHD, combined. Symptoms may vary from motor restlessness and aggressive, disruptive behavior, which is common in preschool-aged children, to disorganized, distractible, and inattentive symptoms, which are more typical in older adolescents and adults. ADHD is often difficult to diagnose in preschoolers as distractibility and inattention are within the range of developmental norms during this period (APA, 2013).

A diagnosis of ADHD is made primarily in clinical settings after a thorough evaluation which includes a careful history and clinical interview to rule in or to identify other causes and contributing factors, behavior rating scales, a physical exam, and any necessary or indicated laboratory examinations. It is important to systematically gather and evaluate information from a variety of sources, including the child, parents, teachers, physicians, and, when appropriate, other caretakers (APA, 2013). Though the evaluation of impairment in ADHD is thought to be more subjective than in that of intellectual disability, there are objective measures of impairments that are increasingly used in ADHD (Gordon et al., 2006), such as the measures of adaptive functioning in general and specific ADHD impairment measures (Biederman et al., 1993; Fabiano et al., 2006).

Clinical interviews allow for a comprehensive analysis of whether or not the symptoms meet the diagnostic criteria for ADHD. During an interview, information pertaining to the child's history of the presenting problems, overall health and development, and social and family history should be gathered. Moreover, an interview should emphasize factors that might affect the development or integrity of the central nervous system or reveal the presence of chronic illness, sensory impairments, or medication use that might affect the child's functioning. Disruptive social factors, such as family discord, situational stresses, abuse, or neglect may result in hyperactive or anxious behaviors. Finally, a family history of first-degree relatives with ADHD, mood or anxiety disorders, learning disability, antisocial disorder, or alcohol or substance abuse may indicate an increased risk for ADHD and comorbid conditions (Larsson et al., 2013). In addition to performing a clinical interview, health care providers should assess the number and severity of ADHD symptoms within the home and school settings, using parent and teacher behavior checklists. Behavior rating scales are useful in establishing the magnitude and pervasiveness of the symptoms but are not sufficient by themselves to make a diagnosis of ADHD. Nonetheless, there are a variety of well-established behavior rating scales that reliably discriminate between children with ADHD and controls as well as between ADHD and other childhood psychiatric disorders (APA, 2013).

Currently, there are no laboratory tests available to identify ADHD in children. Although genetic and neuroimaging studies are able to discriminate between subjects with ADHD and normal subjects, these findings apply to differences among groups and are not sufficiently precise to identify single individuals with ADHD. Competing medical and biological explanations for ADHD must first be ruled out. Thus, the presence of hypertension, ataxia, or thyroid disorder should prompt further diagnostic evaluations. Fine motor coordination delays and other "soft signs" are common but are not sufficiently specific to contribute to a diagnosis of ADHD. Vision or hearing problems should also be evaluated. Children with ADHD may also have histories consistent with exposure to neurotoxins such as lead, infections such as meningitis, or prenatal exposure to alcohol. It is important to note that behavior in a doctor's office or in a structured laboratory setting may not reflect the child's typical behavior in the home or school environment. Therefore, a reliance on observed behavior in a physician's office may result in an incorrect diagnosis. Similarly, computerized attention tasks and electroencephalogram assessments cannot be used to make the diagnosis. Standard office tests for vision and hearing are an essential part of the overall examination in order to rule out such factors as contributing causes (APA, 2013).

DEMOGRAPHIC FACTORS AND DURATION OF THE DISORDER

A diagnosis of ADHD is most frequently made during elementary school years. The demands for attentiveness and orderly behavior are increased in an educational environment, and children with an inability to control their hyperactivity and impulsiveness and an inability to stay focused on the educational lesson become more noticeable because their behaviors can disrupt the classroom environment. In general, ADHD symptoms do not wax and wane, but rather they tend to be consistent up until early adolescence, when the symptoms of hyperactivity may be less obvious, but the inattentive and unmindful characteristics persist, as do the problems with restlessness and impulsiveness.

Age

Clinical manifestations of ADHD may change with age (APA, 2013). A childhood diagnosis of ADHD often leads to persistent ADHD throughout the lifespan. Sixty to 80 percent of children diagnosed with ADHD will continue to experience symptoms in adolescence, and up to 40 to 60 percent of adolescents exhibit ADHD symptoms into adulthood (APA, 2013). Symptoms such as inattention, impulsivity, and disorganization exact a heavy toll on young adult functioning. In addition, a variety of risk factors can affect untreated children with ADHD as they become adults. These factors include engaging in risky behaviors (sexual, delinquent, substance use), educational underachievement and employment difficulties, and relationship difficulties.

Sex

Boys are more likely to be diagnosed with ADHD than girls. Estimates of prevalence have consistently put the rate of reported ADHD diagnoses in male children at approximately twice the rate of ADHD diagnoses in female. In the 2011 National Health Interview Survey, the estimated prevalence of ADHD in males was 12 percent; by contrast, in females the estimated prevalence was only 4.7 percent (Perou et al., 2013). Similarly, a recent meta-analysis of 86 studies of ADHD in children estimated that the ratio of male to females diagnoses for all subtypes of ADHD ranges from 1.9-to-1 to 3.2-to-1 (Wilcutt, 2012).

Race/Ethnicity

Recent population-based studies have found no clear evidence for racial/ethnic differences in the rates of ADHD diagnoses in children. In some estimates of prevalence, the rate of ADHD diagnoses appears to be higher in white than in African Americans or Hispanic Americans; however, this may be due to a lag in clinical identification of nonwhite children who have ADHD (Miller et al., 2009; Morgan et al., 2013). In addition, there may be cultural differences in the attitudes toward or the interpretation of children's behaviors; cultural differences in acceptance of an ADHD diagnosis in children are another barrier to convincing some parents to seek treatment for their children and to comply with that treatment (Bailey et al., 2010).

COMORBIDITIES

Although ADHD is primarily thought of in terms of impairments in attention, impulse control, and motor activity, there are a number of other psychiatric disorders that regularly appear alongside it. Research studies based on clinical populations have shown that 15 to 25 percent of children with ADHD also experience learning disabilities; 30 to 35 percent of children with ADHD also have language disorders; 5 to 20 percent of children with ADHD are also diagnosed with mood disorders; and 20 to 33 percent of these children have coexisting anxiety disorders. Children diagnosed with ADHD may also have co-occurring sleep disorders, memory impairment, and decreased motor skill function (APA, 2013; MTA Cooperative Group, 1999). A diagnosis of oppositional defiant disorder (ODD) co-occurs in approximately 50 percent of children with ADHD (Gillberg et al., 2004). Conduct disorder (CD) is seen in conjunction with about 7 to 20 percent of the patients with ADHD. The 2009 National Research Council and Institute of Medicine report *Preventing Mental, Emotional,* *and Behavioral Disorders Among Young People* presented findings from a meta-analysis showing significant odds ratios (ORs) for ADHD to co-occur with ODD and CD (OR greater than 10), depression (OR greater than 5), and anxiety disorders (OR greater than 2).

Comorbid diagnoses may lead to diagnostic and treatment complications (and may also lead to greater functional impairments, as discussed below). Biederman and colleagues demonstrated that the baseline rates of depression among children with ADHD increase from an initial rate of approximately 30 percent to 40 percent at 4-year follow-up, in contrast to a 5 percent base rate in control subjects (Biederman et al., 2006). Those with comorbid ADHD and depression also manifested additional disorders, including bipolar disorders and anxiety, more hospitalizations, and lower ratings on a global assessment of functioning.

FUNCTIONAL IMPAIRMENT

The relationship between ADHD symptoms and functional impairments takes a wide variety of forms. Symptoms may be present without any functional impairments, particularly among those with ADHD and no co-occurring disorders (about 30 percent of children; Jensen et al., 2001a,b). ADHD symptoms can also be viewed dimensionally; there is evidence that externalizing symptoms are associated with more functional impairment and differentially associated with impairment (Evans et al., 2005; Zoromski et al., 2015). Approximately one in five children with ADHD has extremely severe impairment across all of their life contexts and even with optimally delivered medications and intensive behavioral interventions may continue to show pronounced disabilities (APA, 2013; Jensen et al., 2001b).

Seventy percent of children with ADHD also have one or more co-occurring mood, anxiety, learning, and oppositional and conduct disorders. The many difficulties such children face result in substantial functional impairment (Jensen et al., 2001a,b). Symptoms may cause impairments at some points in development and not at others. Impairments result from a complex interplay of risk and protective factors; thus impairment will vary across contexts and will be observed and reported differently by youth, parents, teachers, and clinicians.

Delays in speech, language, motor, and social development are common in youth with ADHD, and they can lead to the common findings of impairments in academic performance and the development of comorbid learning disabilities. In addition, irritability, low frustration tolerance, and affect dysregulation are often present in youth with ADHD, resulting in similar consequences for a wide range of social and interpersonal outcomes, including difficulty forming friendships and participating in social activities, and often leading to an increasing accumulation of diagnoses and functional impairments. The core ADHD symptom of impulsivity has been linked to numerous other functional impairments, including engagement in risk behaviors that affect health and safety, such as poor driving performance and accidents, arrests, alcohol and substance abuse, smoking, acquisition of sexually transmitted diseases, and early pregnancies.

Barkley, in particular, has noted that the correlations between ADHD diagnosis and any particular functional impairment tend to be modest, but that the construction of omnibus impairment scales that can sum across different life domains demonstrates much more robustly the risk of untoward outcomes for youth with ADHD (Barkley, 2012). Functional consequences across domains are more visible to parents, teachers, and other observers than to self-reporting youth.

A recent large study (Garner et al., 2013; N = 5,663) used parent and teacher ratings of child or adolescent impairment across domains in the International Classification of Functioning, Disability and Health as well as symptoms of ADHD and comorbid disorders and then carried out hierarchical regression analyses to identify predictive relationships between specific symptoms and functional outcomes. Notably, symptoms of inattention best predicted academic functioning, while symptoms of hyperactivity/impulsivity predicted disruptive classroom behavior, even after accounting for learning disabilities and oppositional behaviors (Garner et al., 2013). Oppositional and aggressive symptoms were significantly involved; however, ADHD symptoms account for minimal variance in the outcomes of interpersonal functioning and ability to participate in organized activities.

The emerging area of executive functioning (Barkley, 2012) shows promise for elucidating core neuropsychological variables which may be particularly affected by or in ADHD, leading to varied and striking functional impairments. For example, Sjöwall and Thorell have demonstrated that reduced working memory is particularly implicated in the acquisition of language skills, while variability in reaction time and working memory are predictors of difficulties in acquiring mathematical skills (Sjöwall and Thorell, 2014). Furthermore, the ability to regulate anger is a significant predictor of peer problems for children with ADHD, independent of comorbid oppositional defiant or conduct disorder diagnoses.

TREATMENT AND OUTCOMES

Treatment for ADHD generally falls into two categories, either behavioral and psychosocial or medication treatments. This section offers a review of behavioral and psychosocial treatments for ADHD, followed by a review of standards for medication treatment.

Behavioral and Psychosocial Treatment for ADHD

Once the diagnosis of ADHD has been established, parents and children should be educated about the ways in which ADHD can affect learning, behavior, self-esteem, social skills, and family function. Treatment goals for the family should be to enhance parenting skills, improve the child's interpersonal relationships, develop the child's study skills, and decrease the child's disruptive behaviors.

Families are profoundly affected by children with ADHD diagnoses, including having increased stress and a higher occurrence of health and mental health problems in both parents and siblings. Divorce rates among parents of children with ADHD under age 8 have been found to be nearly twice that of comparable age cohorts (22.7 percent versus 12.6 percent), with a number of factors increasing the risk for divorce even further, including the child having more severe symptoms and comorbid oppositionality, the family members being minorities, the father having a history of antisocial or criminal behavior, and the mother having a lower level of education (Wymbs et al., 2008). Families are often in acute need of assistance in managing the disruptive behaviors associated with ADHD in the home context, and they are also critical contributors to their children's success in school and community venues (Power et al., 2012). A model program developed by Power and colleagues, the Family School Success (FSS) program, demonstrated that parental involvement and strong school–family relationships improve both academic performance and social skills (Power et al., 2008). Building upon the behavioral intervention utilized in the National Institute of Mental Health (NIMH) Multimodal Treatment of ADHD (MTA) studies, FSS utilizes a systematic partnership model using structured, collaborative problem solving (conjoint behavioral consultation) and more focused attention to homework performance using a daily report card shared between home and school. While these interventions place substantial demands on families, they also create an additional venue of support and greater environmental consistency for the child.

The goal of behavioral treatment is to target behaviors that create impairment (e.g., disruptive behavior, difficulty in completing homework, failure to obey home or school rules) for the child to work on progressively improving. Parents and teachers should be guided in establishing a clear communication of expectations and strategies for effective teaching, as well as contingency management, in order to help the child succeed. Federally funded studies performed on large-scale multisite randomized controlled trials lasting up to 24 months have found that, while both behavioral treatments and stimulants improve outcomes, when they are used alone, stimulants are more effective than behavioral treatments, with behavioral interventions alone being only modestly successful at improving behavior (Hechtman et al., 2004a,b; MTA Cooperative Group, 1999). The most severely impaired children with ADHD (usually with co-occurring conditions) benefit the most from the combination of carefully managed medication and behaviorally oriented therapy (Jensen et al., 2001a). The relative effectiveness of the two therapeutic modalities remains an area of some controversy. One recent meta-analysis of large-scale randomized trials found psychotherapeutic interventions to have little to no benefit on core ADHD symptoms (Sonuga-Barke et al., 2013), but it did provide evidence that these interventions were effective in reducing oppositional defiant and conduct disorder symptoms. Others researchers, citing many smaller studies with different study designs (e.g., single case designs), have argued that behavioral therapy may be more effective than generally assumed by most ADHD researchers (Fabiano et al., 2009).

The American Academy of Pediatrics treatment guideline for ADHD (AAP, 2011) clearly states that a care plan should include behavioral treatment along with any prescribed medication. In the MTA, the major NIMH reference study examining the effects of multimodal treatment for ADHD, combined treatment was found to be usually superior to medication alone or behavioral intervention alone on specific measures of anxiety, academic performance, oppositionality, parent–child relations, and social skills (APA, 2013; Jensen et al., 2001b; MTA Cooperative Group, 1999). These are precisely the comorbid conditions and functional impairments that routinely complicate the course—and the treatment—of ADHD symptoms.

Research studies have documented the potential benefits of such academic interventions as task modifications, reinforcement for on-task behaviors by teachers, organizational skills training, and homework strategies with parents' involvement (APA, 2013). However, the most commonly provided school-based accommodations (e.g., allowing the child extended time to take tests) have not shown evidence of helping children with ADHD (APA, 2013). Studies of well-diagnosed clinical populations indicate that more than a quarter of children identified with ADHD receive special education services (APA, 2013). Similarly, national surveys have documented that a relatively high prevalence of children with ADHD (more than one-third) receive special education and that children with ADHD make up the majority of those in the Other Health Impairment and Emotional Disturbance categories of disability under the Individuals with Disabilities Education Act (APA, 2013).

Medication Treatment for ADHD

The most widely researched medicines used in the treatment of ADHD are the psychostimulants, including methylphenidate (e.g., Ritalin, Concerta, Metadate), amphetamine, and various dextroamphetaminic preparations

(Dexedrine and Adderall) (APA, 2013). Longer acting, once-daily forms of each of the major types of stimulant medications are available and appear to facilitate adherence. A stimulant treatment, either methylphenidate or an amphetamine-based compound, should be prescribed. As suggested by the results of the NIMH MTA study, the careful monitoring of medication is a necessary component of treatment in children with ADHD (APA, 2013). Optimal treatment in most instances will require somewhat higher doses than routinely prescribed in routine practice settings (Garner et al., 2013). Four or more medication follow-up visits should be offered (APA, 2013).

Evidence suggests that the majority of children who receive careful medication management accompanied by frequent treatment follow-ups, all within the context of an educative, supportive relationship with the primary care provider and appropriate behavioral interventions and supports, are likely to experience behavioral gains for up to 24 months (APA, 2013).

It is worth noting that, with proper treatment, the risks associated with ADHD can be significantly reduced in nearly two-thirds of children (Swanson et al., 2001), although "treatment as usual" (as delivered across the United States by most health care providers) has not been shown to yield lasting benefits. This unfortunate outcome for many youth has numerous roots: Youth and young adults with ADHD usually stop taking medications; clinicians tend to deliver medications in a nonoptimal fashion (e.g., doses being too low, failing to regularly monitor progress, etc.); and primary care referral to and coordination with providers of behavioral interventions is often lacking (APA, 2013). Sixteen-year follow-up data from the MTA study indicate that by ages 23–27, 40 percent of adults with ADHD diagnosed between ages 7 and 10 years old continue to experience significant impairment, despite early intensive treatment. While intensive interventions (carefully managed medication and behavioral therapy) do ameliorate most symptoms in most children with ADHD, these intensive treatments are not generally provided in the community (Jensen et al., 2001a). Nonetheless, three randomized controlled trial follow-up studies indicate that optimal treatments (i.e., usually the combination of carefully titrated and monitored stimulant medication, plus intensive behavior therapy services) substantially reduce functional impairment in up to two-thirds of children compared to less intensively treated control subjects (Abikoff et al., 2004a,b; Gilberg et al., 1997; MTA Cooperative Group, 1999; Swanson et al., 2001). Within the United States, nearly all children with ADHD generally receive "some" treatment, so the outcomes of untreated children have become increasingly difficult to fully assess. For the majority of cases, monotherapy is described although in the community it is more likely that children receive combination and intensities of psychosocial and pharmacological treatment (dosReis et al., 2005), and very little is known about how to sequence these interventions (Foster et al., 2007).

In a study of the 1996 Medical Expenditure Panel Survey, Chan and colleagues examined total costs of care for children with ADHD, children with asthma, and the general population. They found that total yearly costs were $1,151 for ADHD, $1,091 for asthma, and $712 for the general population. These differences persisted after adjustment for multiple sociodemographic characteristics. The ADHD population did not have higher hospital discharge rates than the general population, although out-of-pocket expenses were substantially higher for the ADHD group, at $386 per year, compared with asthma at $246 and the general population at $202 (Chan et al., 2002). In general hospitalization rates for children and youth with ADHD are not higher than in the general population; however, children with ADHD hospitalized for injuries have more severe injuries than other children, are more likely to receive intensive care, and have longer length of stay (DiScala et al., 1998).

FINDINGS

- Diagnosis requires a detailed, comprehensive clinical assessment. Adherence to diagnostic guidelines is variable. There are no laboratory tests to identify ADHD.
- The diagnosis of ADHD usually occurs during the early elementary school years.
- Boys are diagnosed with ADHD approximately twice as frequently as girls.
- The functional impairments caused by ADHD may change as a child matures; however, a childhood diagnosis of ADHD can often mean persistent impairments into adulthood.
- ADHD co-occurs with another mental, emotional, or behavioral disorder very frequently—in approximately 70 percent of cases. Children with ADHD and co-occurring conditions have more significant functional impairments.
- Evidence-based treatments benefit many children with ADHD. However, there is also evidence that many children with ADHD do not receive optimal, evidence-based treatment.

REFERENCES

AAP (American Academy of Pediatrics, Subcommittee on Attention-Deficit/Hyperactivity Disorder, Steering Committee on Quality Improvement and Management). 2011. ADHD: Clinical practice guideline for the diagnosis, evaluation, and treatment of attention-deficit/hyperactivity disorder in children and adolescents. *Pediatrics* 128(5):1007–1022.

Abikoff, H., L. Hechtman., R. G. Klein, R. Gallagher, K. Fleiss, J. Etcovitch, L. Cousins, B. Greenfield, D. Martin, and S. Pollack. 2004a. Social functioning in children with ADHD treated with long-term methylphenidate and multimodal psychosocial treatment. *Journal of the American Academy of Child and Adolescent Psychiatry* 43(7):820–829.

Abikoff, H., L. Hechtman, R. G. Klein, G. Weiss, K. Fleiss, J. Etcovitch, and S. Pollack. 2004b. Symptomatic improvement in children with ADHD treated with long-term methylphenidate and multimodal psychosocial treatment. *Journal of the American Academy of Child and Adolescent Psychiatry* 43(7):802–811.

APA (American Psychiatric Association). 2011. *American Psychiatric Association practice guidelines 2011*. Edited by APA: Psychiatry. Washington, DC: American Psychiatric Association.

APA. 2013. *Diagnostic and statistical manual of mental disorders, fifth edition*. Washington, DC: APA.

Bailey, R. K., S. Ali, S. Jabeen, H. Akpudo, J. U. Avenido, T. Bailey, J. Lyons, and A. A. Whitehead. 2010. Attention-deficit/hyperactivity disorder in African American youth. *Current Psychiatry Reports* 12(5):396–402.

Barkley, R. A. 2012. *Barkley functional impairment scale—Children and adolescents (BFIS-CA)*. New York: Guilford Press.

Biederman, J., S. V. Faraone, and W. J. Chen. 1993. Social Adjustment Inventory for Children and Adolescents: Concurrent validity in ADHD children. *Journal of the American Academy of Child and Adolescent Psychiatry* 32(5): 1059–1064.

Biederman, J., M. C. Monuteaux, E. Mick, T. Spencer, T. E. Wilens, J. M. Silva, L. E. Snyder, and S. V. Faraone. 2006. Young adult outcome of attention deficit hyperactivity disorder: A controlled 10-year follow-up study. *Psychological Medicine* 36(2):167–179.

Chan, E., C. Zhan, and C. J. Homer. 2002. Health care use and costs for children with attention deficit/hyperactivity disorder. *Archives of Pediatrics & Adolescent Medicine* 156:504–511.

DiScala, C., I. Lescohier, M. Barthel, and G. Li. 1998. Injuries to children with attention deficit/hyperactivity disorder. *Pediatrics* 102:1415–1421.

dosReis, S., J. M. Zito, D. J. Safer, J. F. Gardner, K. B. Puccia, and P. L. Owens. 2005. Multiple psychotropic medication use for youths: A two-state comparison. *Journal of Child & Adolescent Psychopharmacology* 15(1):68–77.

Evans, S. W., J. Allen, S. Moore, and V. Strauss. 2005. Measuring symptoms and functioning of youth with ADHD in middle schools. *Journal of Abnormal Child Psychology* 33(6): 695–706.

Fabiano, G. A., W. E. Pelham, Jr., D. A. Waschbusch, E. M. Gnagy, B. B. Lahey, A. M. Chronis, and L. Burrows-Maclean. 2006. A practical measure of impairment: psychometric properties of the impairment rating scale in samples of children with attention deficit hyperactivity disorder and two school-based samples. *Journal of Clinical Child and Adolescent* 35(3):369–385.

Fabiano, G. A., W. E. Pelham, Jr., E. K. Coles, E. M. Gnagy, A. Chronis-Tuscano, and B. C. O'Connor. 2009. A meta-analysis of behavioral treatments for attention-deficit/hyperactivity disorder. *Clinical Psychology Review* 29(2):129–140.

Foster, E. M., P. S. Jensen, M. Schlander, W. E. Pelham, L. Hechtman, L. E. Arnold, J. M. Swanson, and T. Wigal. 2007. Treatment for ADHD: Is more complex treatment cost-effective for more complex cases? *Health Services Research* 42(1):165–182.

Garner, A. A., B. C. O'Connor, M. E. Narad, L. Tamm, J. Simon, and J. N. Epstein. 2013. The relationship between ADHD symptom dimensions, clinical correlates, and functional impairments. *Journal of Developmental and Behavioral Pediatrics* 34(7):469–477.

Gillberg, C., P. Rasmussen, B. Kadesjo, and H. Soderstrom. 2004. Supplement 13. *European Child and Adolescent Psychiatry* I80–I92.

Gordon, M., K. Antshel, S. Faraone, R. Barkley, L. Lewandowski, J. J. Hudziak, J. Biederman, and C. Cunningham. 2006. Symptoms versus impairment: The case for respecting DSM-IVs Criterion D. *Journal of Attention Disorders* 9(3):465–475.

Hechtman, L., H. Abikoff, R. G. Klein, B. Greenfield, J. Etcovitch, L. Cousins, K. K. Fleiss, M. Weiss, and S. Pollack. 2004a. Children with ADHD treated with long-term methylphenidate and multimodal psychosocial treatment: Impact on parental practices. *Journal of the American Academy of Child and Adolescent Psychiatry* 43(7):830–838.

Hechtman, L., H. Abikoff, R. G. Klein, G. Weiss, C. Respitz, J. Kouri, C. Blum, B. Greenfield, J. Etcovitch, K. Fleiss, and S. Pollack. 2004b. Academic achievement and emotional status of children with ADHD treated with long-term methylphenidate and multimodal psychosocial treatment. *Journal of the American Academy of Child and Adolescent Psychiatry* 43(7):812–819.

Jensen, P. S., S. P. Hinshaw, J. M. Swanson, L. L Greenhill, C. K. Conners, L. E. Arnold, H. B. Abikoff, G. Elliott, L. Hechtman, B. Hoza, J. S. March, J. H. Newcorn, J. B. Severe, B. Vitiello, K. Wells, and T. Wigal. 2001a. Findings from the NIMH Multimodal Treatment Study of ADHD (MTA): Implications and applications for primary care providers. *Journal of Developmental and Behavioral Pediatrics* 22(1):60–73.

Jensen, P. S, S. P. Hinshaw, H. C. Kraemer, N. Lenora, J. H. Newcorn, H. B. Abikoff, J. S. March, L. E. Arnold, D. P. Cantwell, C. K. Conners, G. R. Elliott, L. L. Greenhill, L. Hechtman, B. Hoza, W. E. Pelham, J. B. Severe, J. M. Swanson, K. C. Wells, T. Wigal, and B.Vitiello. 2001b. ADHD comorbidity findings from the MTA study: Comparing comorbid subgroups. *Journal of the American Academy of Child and Adolescent Psychiatry* 40(2):147–158.

Larsson, H., Z. Chang, B. D'Onofrio, and P. Lichtenstein. 2013. The heritability of clinically diagnosed attention-deficit/hyperactivity disorder in children and adults. *Psychological Medicine* 10:1–7.

Miller, T. W, J. T. Nigg, and R. L. Miller. 2009. Attention deficit hyperactivity disorder in African American children: What can be concluded from the past ten years? *Clinical Psychology Review* 29(1):77–86.

Morgan, P. L., J. Staff, M. M. Hillemeier, G. Farkas, and S. Maczuga. 2013. Racial and ethnic disparities in ADHD diagnosis from kindergarten to eighth grade. *Pediatrics* 132(1):85–93.

MTA (Multimodal Treatment of ADHD) Cooperative Group. 1999. A 14-month randomized clinical trial of treatment strategies for attention-deficit/hyperactivity disorder. *Archives of General Psychiatry* 56(12): 1073–1086.

Perou, R., R. H. Bitsko, S. J. Blumberg, P. Pastor, R. Ghandour, J. C. Gfroerer, S. L. Hedden, A. E. Crosby, S. N. Visser, L. A. Schieve, S. E. Parks, J. E. Hall, D. Brody, C. M. Simile, W. W. Thompson, J. Baio, S.Avenevoli, M. D. Kogan, and L. N. Huang. 2013. Mental health surveillance among children—United States, 2005–2011. *Morbidity and Mortality Weekly Report* 62(2):1–35.

Power, T. J., J. L. Karustis, and D. F. Habboushe. 2008. *Homework success for children with ADHD: A family–school intervention program*. Princeton, NJ: Recording for the Blind & Dyslexic.

Power, T. J., J. A. Mautone, S. L. Soffer, A. T. Clarke, S. A. Marshall, J. Sharman, N. J. Blum, M. Glanzman, J. Elia, and A. F. Jawad. 2012. A family–school intervention for children with ADHD: Results of a randomized clinical trial. *Journal of Consulting and Clinical Psychology* 80(4):611–623.

Sjöwall, D., and L. B. Thorell. 2014. Functional impairments in attention deficit hyperactivity disorder: The mediating role of neuropsychological functioning. *Developmental Neuropsychology* 39(3):187–204.

Sonuga-Barke, E. J., D. Brandeis, S. Cortese, D. Daley, M. Ferrin, M. Holtmann, J. Stevenson, M. Danckaerts, S. van der Oord, M. Döpfner, R. W. Dittmann, E. Simonoff, A. Zuddas, T. Banaschewski, J. Buitelaar, D. Coghill, C. Hollis, E. Konofal, M. Lecendreux, I. C. Wong, J. Sergeant, and European ADHD Guidelines Group. 2013. Nonpharmacological interventions for ADHD: Systematic review and meta-analyses of randomized controlled trials of dietary and psychological treatments. *American Journal of Psychiatry* 170(3):275–289.

Swanson, J. M., H. C. Kraemer, S. P. Hinshaw, L. E. Arnold, C. K. Conners, H. B. Abikoff, W. Clevenger, M. Davies, G. R. Elliott, L. L. Greenhill, L. Hechtman, B. Hoza, P. S. Jensen, J. S. March, J. H. Newcorn, E. B. Owens, W. E. Pelham, E. Schiller, J. B. Severe, S. Simpson, B. Vitiello, K. Wells, T. Wigal, and M. Wu. 2001. Clinical relevance of the primary findings of the MTA: Success rates based on severity of ADHD and ODD symptoms at the end of treatment. *Journal of the American Academy of Child and Adolescent Psychiatry* 40(2):168–179.

Willcutt, E. G. 2012. The prevalence of DSM-IV attention-deficit/hyperactivity disorder: A meta-analytic review. *Neurotherapeutics* 9(3):490–499.

Wymbs, B. T., W. E. Pelham, Jr., B. S. Molina, E. M. Gnagy, T. K. Wilson, and J. B. Greenhouse. 2008. Rate and predictors of divorce among parents of youths with ADHD. *Journal of Consulting and Clinical Psychology* 76(5):735–744.

Zoromski, A. K., C. E. Brady, S. W. Evans, and J. S. Owens. 2015. Identifying ADHD symptoms most associated with impairment in early childhood, middle childhood, and adolescence using teacher report. *Journal of Abnormal Child Psychology* 43(7):1243–1255.

7

Clinical Characteristics of Oppositional Defiant Disorder and Conduct Disorder

DIAGNOSIS AND ASSESSMENT

Disruptive behavior disorders (DBDs) of childhood include attention deficit hyperactivity disorder (ADHD) (discussed in Chapter 6), oppositional defiant disorder (ODD), conduct disorder (CD), intermittent explosive disorder, and disruptive behavior not otherwise specified. Some nomenclatures have added a new condition labeled "disruptive mood dysregulation disorder" as well, although almost no formal epidemiological data exist on this recent addition. Formally, behaviors and associated consequences that "violate the rights of others and/or that bring the individual into significant conflict with societal norms or authority figures" qualify children or adolescents for the diagnosis of DBD (APA, 2013, p. 461). Other than ADHD (which is addressed in Chapter 6), the two most commonly studied of these disruptive behavior disorders are ODD and CD, and the remainder of this section will deal only with these two as they are the only DBD categories of any significance to the Social Security program other than ADHD. ODD is defined both by the American Psychiatric Association and the World Health Organization as a longstanding pattern of hostile, defiant, or disobedient behavior. CD is also considered "disruptive" in that youths with CD have antisocial behaviors such as lying and stealing which can result in criminal, educational, and family consequences in addition to the impairment associated with these behaviors.

Because they share some antecedent risk factors and are both defined by challenging interactions with parents and other authority figures, ODD and CD are often linked as a single category in prevalence and epidemiologic studies. However, several authors suggest that significant distinctions exist between the two; for example, there are inconsistent findings about gender differences in ODD, but CD has a very marked male-to-female risk ratio. These authors thus recommend reporting and studying these conditions separately (Burke et al., 2002; Maughan et al., 2004). In item analysis on risk scales, ODD and CD have a great deal of overlap, but they still appear to be separate constructs (Cavanagh et al., 2014).

The latest guidelines for assessing ODD/CD in children were issued in 2007 and 1997, for ODD and CD, respectively, by the American Academy of Child and Adolescent Psychiatry (Steiner et al., 1997, 2007). The diagnosis of ODD/CD requires a comprehensive diagnostic evaluation, which includes interviews with the child or youth, the primary caregiver, and collateral informants, such as teachers. Standardized reporting tools are recommended for gathering complete data from diverse informants, but no tool is thought to be specific, nor are there any biological markers for these disorders. It is not clear if the distinction between ODD and CD is important for the care of individual patients. It is important to note that because the ODD/CD diagnoses and symptoms are enmeshed in families and social interactions, the recommendations emphasize the importance of the clinicians' relationships with both the family and patient in assessment and treatment.

A diagnosis of ODD/CD is made when children or adolescents present with aggression or related behaviors that result in persistent problems, including legal and social consequences, and when other causes are not present. These conditions generally do not remit quickly, and often present along a continuum, so ongoing care and follow-up is necessary.

The risk factors for ODD and CD are not well understood; however, it appears that genetic, environmental, and family factors all contribute. Therefore, a review of a child's history should involve prenatal exposures, exposure to adverse childhood experiences, and cognitive or other developmental problems. It is also essential to assemble a history of the current illness, including age of onset, the environmental situations in which the symptoms are manifest, the duration of the symptoms, and any precipitating events or situations, and persons, places, or events that ameliorate or exacerbate the behavior problems should be noted. An assessment for other psychiatric problems, such as substance abuse, trauma-related symptoms, and ADHD, should also be conducted.

Because ODD and CD are known to cluster in families, it is important to obtain a family history of psychiatric disorders and medical conditions. In addition, the role of the family emotional, communicative, interactional, and coping styles and resources should be assessed.

Information about a child's functioning in a school setting should be obtained from the appropriate staff, such as the principal, teacher, school psychologist or counselor, and nurse, once a release of information is granted. Teacher reports of behavior that use structured forms are often very helpful. Suspected disabilities in intellectual functioning, communication abilities, or motor skills should be evaluated. ODD and CD are, by definition, conditions that often involve social service agencies, such as foster care and juvenile justice. Agency reports of both symptoms and consequences are essential to proper diagnosis and treatment.

A thorough physical evaluation is needed to rule out medical causes. Medical conditions that cause agitation, aggression, or impulsive anger need to be considered. Routine laboratory tests (i.e., blood counts, renal and liver functions, thyroid functions, a toxicology screen, a pregnancy test, and urinalysis) are usually not indicated unless specific history or examination findings suggest the need. However, preventive screening for HIV, depression, and substance abuse are all indicated when age appropriate.

DEMOGRAPHIC FACTORS AND DURATION OF THE DISORDER

Age and gender trends in ODD are not pronounced, with some studies finding that boys are more likely to report symptoms consistent with ODD than are girls, but others showing no gender differences (Nock et al., 2007). In one of the largest and most representative samples, boys were much more likely to have ODD, but most of the additional symptoms reported for males were by teachers who have not been used in many epidemiologic studies (Maughan et al., 2004). This same study also noted that the typical decline in ODD reported in many studies is almost entirely contingent on whether ODD and CD are made exclusive because the symptoms do not decline, but CD diagnoses replace ODD.

Age

Age influences the prevalence rates of CD as well, although in some subtle ways. ODD is often shown to remit with age as CD rises with age; because these conditions are usually considered exclusive in prevalence estimates, this may simply be the result of reclassifications. Moreover, it is not clear if CD symptoms increase with age, but the severity of symptoms and aggression may increase as youths age. From cross-sectional data in three distinct samples, Copeland and colleagues estimated that 3 percent of preschoolers may be affected (Copeland et al., 2013).

Neither of these conditions is thought to be short-lived. ODD remits in roughly half of the population after 3 years (Biederman et al., 2008; Bunte et al., 2014), although the conversion to CD in these cases may not have been taken into account.

Socioeconomic Status

Both ODD and CD symptoms are more pronounced in children in low-income households and adolescents. In fact, neighborhood and environmental factors may play a strong role in producing such symptoms, with the poorest and most violent neighborhoods having the highest prevalence rates of ODD and CD behaviors (Loeber et al., 2000). Low parental educational attainment and low household income are independently associated with higher rates, and these demographic characteristics are thought to influence prevalence through disciplinary practices, scarcity, food insecurity, and their influence on access to peer support (CDC, 2013). Less clear is whether or not these findings extend to rural areas.

Race/Ethnicity

Race and ethnicity may or may not influence prevalence rates, depending on the extent to which income, urban residence, and parenting practices are taken into account. Nock suggests that race does less to influence total prevalence of CD and more to influence subtypes of CD, although these subtypes are not universally recognized (Nock et al., 2006).

COMORBIDITIES

Unfortunately, neither of these conditions occurs often in isolation. Both have extremely high rates of comorbidity, particularly with ADHD and mood and anxiety disorders (Chen et al., 2013). Children with ODD not only have high rates of comorbid mood disorders, but they even retain some of these other diagnoses when their ODD remits (Nock et al., 2007). According to parent and teacher reports, ODD almost always has associated mood, anxiety, or posttraumatic stress disorder symptoms (Angold et al., 1999; Cavanaugh et al., 2014; Copeland et al., 2013; Loeber et al., 2000). A meta-analysis by Angold and colleagues found that the odds ratio of ADHD co-occurring with CD is 10.7, the odds ratio of CD co-occurring with depression is 6.6, and the odds ratio of CD co-occurring with anxiety disorder is 3.1. Substance abuse disorders are also frequently occur with DBDs and are also one of the symptoms of CD (Angold et al., 1999).

Because of the frequent clinical appearance of mood symptoms in association with behavioral problems, the *Diagnostic and Statistical Manual of Mental Disorders, 5th Edition*, includes disruptive mood dysregulation disorder, a new condition that requires both behavioral and mood symptoms. Limited information on prevalence is available at this time.

FUNCTIONAL IMPAIRMENT

The assessment of impairment in ODD/CD is challenging for several reasons. As already noted, DBDs seldom occur in isolation, and it is not usually possible in the clinical setting to determine the contribution of ODD/CD to an impairment separately from the contribution from the comorbid conditions. Second, impairment in relationships and functioning in usual roles is a core part of the definition and symptoms of ODD/CD. Thus, there is a tautology to discussing the extent to which these disorders cause impairment because the definitions are composed by the extent of impairment. Finally, the extent of impairment in ODD/CD is most reliably reported by parents and teachers rather than patients. However, these individuals often have involved and highly charged and damaged relationships with the patient. Consequently, the reporting of impairment may not be independent of the emotional involvement of the reporter.

Regardless of these factors, it is clear that impairment in ODD/CD, especially when left untreated, is marked. Children with ODD experience greater school failure and more suspensions and expulsions. Their home relationships are often disrupted, and they are less successful at peer relationships. With increasing age, symptoms shift from impairment and disruption of family and school life, to societal infractions and encounters with the legal system. Adolescents with CD demonstrate higher levels of aggression and more school failure, drug abuse, and arrests than adolescents without CD (Biederman et al., 2008; Burke et al., 2014; Johnson et al., 2015). The extent of these impairments is largely contingent on the number of risk and resiliency factors in the environment, such as positive peer relationships and consistent availability of supports and services in the home or school setting.

TREATMENT AND OUTCOMES

Preventive interventions are known to be effective in reducing the intensity and frequency of ODD/CD. However, the effective interventions studied to date are broad-based classroom and community interventions that have long-term preventive effects. They are discussed further in other Institute of Medicine documents (NRC and IOM, 2009).

Treatment for ODD/CD involves psychotherapeutic interventions or psychopharmaceutical agents, or both. The Agency for Healthcare Research and Quality (AHRQ) has compiled the most recent review of the efficacy of both types of interventions. In general, psychosocial interventions are the most widely studied in the United States and elsewhere, have the largest effects documented, and are even more effective when both child and parent are the targets of interventions.

AHRQ identified 58 studies that met the criteria for rigorous methods examining psychosocial interventions (AHRQ, 2014). These studies fell into two categories: preschool ODD intervention studies and adolescent CD intervention trials. For the former, the three primary interventions studied were Incredible Years, Parent Child Interaction Therapy, and the Positive Parenting Program. Each of these interventions was associated with moderate to large effect sizes, with more intensive participation yielding greater improvements in parent–child relationships, decreased parental distress, improved classroom behavior, reduced frequency of anger and outbursts, and reductions in overall behavior symptom scores (Dretzke et al., 2005; Fossum et al., 2008). For CD, multisystemic therapy and brief strategic family therapy were the most frequently studied interventions. The effect sizes were less impressive for older children with CD than for younger children, but psychosocial interventions such as multi-systemic therapy and Functional Family Therapy, among several similar programs, consistently produced reductions in adolescent aggression, legal problems, and parental conflict as well as improvements in school function and other prosocial behaviors. No significant negative side effects of these psychosocial interventions were identified for either group of psychosocial interventions.

Most studies of pharmaceutical agents were industry funded and short term. Results were mixed. They included trials of antipsychotics, antiepileptics, and ADHD agents, but no agent achieved consistent positive effects, and no high-quality studies of combinations of pharmaceutical agents and psychosocial interventions were identified. Several of the psychotropic medications had significant side effects in the trials of ODD/CD treatment.

Findings

- The diagnosis of ODD or CD requires a comprehensive diagnostic evaluation. There are no biological markers for ODD or CD.
- There is insufficient evidence of trends in the distribution of ODD and CD by either sex or age. Differences in the rate of diagnosis by sex have not been uniformly documented.
- ODD and CD tend to be persistent problems. The conversion of ODD to CD may account for at least some of the remissions of ODD cited in the literature.
- The disruptive behavior disorders of childhood (ODD and CD) frequently co-occur with other mental disorders in children, in particular, ADHD, mood disorders, and anxiety disorders. The co-occurrence of these disorders with other mental disorders causes significant functional impairment in many children who are Supplemental Security Income recipients.

- Early preventive interventions show promise for reducing ODD occurrence. Psychosocial interventions involving both parents and child are documented to provide the greatest therapeutic benefit.

REFERENCES

AHRQ (Agency for Healthcare Research and Quality). 2014. Psychosocial and pharmacologic interventions for disruptive behavior disorder. *Evidence-based Practice Center Systematic Review Protocol*. http://effectivehealthcare.ahrq.gov/ehc/products/555/1932/disruptive-behavior-disorder-protocol-140701.pdf (accessed on July 20, 2015).

Angold, A., E. J. Costello, and A. Erkanli. 1999. Comorbidity. *Journal of Child Psychology and Psychiatry* 40(1):57–87.

APA (American Psychiatric Association). 2013. *Diagnostic and statistical manual of mental disorders, fifth edition*. Washington, DC: APA.

Biederman, J., C. R. Petty, C. Dolan, S. Hughes, E. Mick, M. C. Monuteaux, and S. V. Faraone. 2008. The long-term longitudinal course of oppositional defiant disorder and conduct disorder in ADHD boys: Findings from a controlled 10-year prospective longitudinal follow-up study. *Psychological Medicine* 38(7):1027–1036.

Bunte, T. L., K. Schoemaker, D. J. Hessen, P. G. van der Heijden, and W. J. Matthys. 2014. Stability and change of ODD, CD and ADHD diagnosis in referred preschool children. *Journal of Abnormal Child Psychology* 42(7):1213–1224.

Burke, J. D., R. L. Loeber, and B. Birmaher. 2002. Oppositional defiant and conduct disorder: A review of the past 10 years, part II. *Journal of the American Academy of Child & Adolescent Psychiatry* 41(11):1275–1293.

Burke, J. D., R. Rowe, and K. Boylan. 2014. Functional outcomes of child and adolescent oppositional defiant disorder symptoms in young adult men. *Journal of Child Psychology and Psychiatry* 55(3):264–272.

Cavanagh, M., D. Quinn, D. Duncan, T. Graham, and L. Balbuena. 2014. Oppositional defiant disorder is better conceptualized as a disorder of emotional regulation. *Journal of Attention Disorders*, January 30 [Epub ahead of print]. http://jad.sagepub.com/content/early/2014/01/30/1087054713520221 (accessed July 3, 2015).

CDC (Centers for Disease Control and Prevention). 2013. Mental health surveillance among children, United States, 2005–2011. *Morbidity and Mortality Weekly Report Supplement* 62(2):1–35.

Chen, M. H., T. P. Su, Y. S. Chen, J. W. Hsu, K. L. Huang, W. H. Chang, T. J. Chen, and Y. M. Bai. 2013. Higher risk of developing mood disorders among adolescents with comorbidity of attention deficit hyperactivity disorder and disruptive behavior disorder: A nationwide prospective study. *Journal of Psychiatric Research* 47(8):1019–1023.

Copeland, W. E., A. Angold, E. J. Costello, and H. Egger. 2013. Prevalence, comorbidity, and correlates of DSM-5 proposed disruptive mood dysregulation disorder. *American Journal of Psychiatry* 170(2):173–179.

Dretzke, J., E. Frew, C. Davenport, J. Barlow, S. L. Stewart–Brown, J. Sandercock, S. Bayliss, J. Raftery, C. Hyde, and R. Taylor. 2005. The effectiveness and cost-effectiveness of parent training/education programmes for the treatment of conduct disorder, including oppositional defiant disorder, in children. *Health Technology Assessment* 9(50):1–250.

Fossum, S., B. H. Handegård, M. Martinussen, and W. T. Mørch. 2008. Psychosocial interventions for disruptive and aggressive behaviour in children and adolescents. *European Child & Adolescent Psychiatry* 17(7):438–451.

Johnson, V. A., A. H. Kemp, R. Heard, C. J. Lennings, and I. B. Hickie. 2015. Childhood- versus adolescent-onset antisocial youth with conduct disorder: Psychiatric illness, neuropsychological and psychosocial function. *PLoS ONE* 10(4):e0121627.

Loeber, R., J. D. Burke, B. B. Lahey, A. Winters, and M. Zera. 2000. Oppositional defiant and conduct disorder: A review of the past 10 years, part I. *Journal of the American Academy of Child & Adolescent Psychiatry* 39(12):1468–1484.

Maughan, B., R. Rowe, J. Messer, R. Goodman, and H. Meltzer. 2004. Conduct disorder and oppositional defiant disorder in a national sample: Developmental epidemiology. *Journal of Child Psychology and Psychiatry* 45(3):609–621.

Nock, M. K., A. E. Kazdin, E. Hiripi, and R. C. Kessler. 2006. Prevalence, subtypes and correlates of DSMV conduct disorder in the National Comorbidity Survey Replication. *Psychological Medicine* 36:699–710.

Nock, M. K., A. E. Kazdin, E. Hiripi, and R. C. Kessler. 2007. Prevalence, correlates and persistence of oppositional defiant disorder: Results from the National Comorbidity Survey Replication. *Journal of Child Psychology and Psychiatry* 48(7):703–713.

NRC and IOM (National Research Council and Institute of Medicine). 2009. *Preventing mental, emotional, and behavioral disorders among young people: Progress and possibilities.* Washington, DC: The National Academies Press.

Steiner, H., AACAP Work Group on Quality Issues, J. Dunne, W. Ayeres, V. Arnold, E. Benedek, R. S. Benson, G. A. Bernstein, W. Bernet, O. Bukstein, J. Kinlan, H. Leonard, and J. McClellan. 1997. Practice parameter for the assessment and treatment of children and adolescents with conduct disorder. *Journal of the American Academy of Child and Adolescent Psychiatry* 36(10 Suppl):12S–139S.

Steiner, H., L. Remsing, AACAP Work Group on Quality Issues, V. Arnold, J. Beitchman, R.S. Benson, W. Bernet, O. Bukstein, J. Kinlan, D. Rue, J. Shaw, U. Schoettle, S. Stock, and H. Walter. 2007. Practice parameter for the assessment and treatment of children and adolescents with oppositional defiant disorder. *Journal of the American Academy of Child and Adolescent Psychiatry* 46(1):126–141.

8

Clinical Characteristics of Autism Spectrum Disorder

DIAGNOSIS AND ASSESSMENT

Autism, or autism spectrum disorder (ASD), first described in 1943 (Kanner, 1943), is a neurodevelopmental disorder characterized by impairments in social interaction and communication, along with repetitive or stereotyped patterns of behaviors and often restricted interests.

The diagnosis of ASD is typically made during childhood, based on comprehensive behavioral evaluations by specialists in child psychiatry or psychology or by those in behavioral and developmental pediatrics. ASD was not officially recognized until DSM-III, the third edition of the *Diagnostic and Statistical Manual of Mental Disorders*, in 1980 (APA, 1980; Kanner, 1943). The current version of the DSM introduced in 2013, DSM-5, is the first edition of the DSM to use the term “autism spectrum disorder.” This version does not distinguish subtypes such as “autistic disorder” or “Asperger syndrome,” and the diagnostic criteria specified in the DSM-5 for ASD are somewhat narrower than used previously. DSM-5 criteria require that a child has persistent impairment in social communications and interactions across multiple contexts as well as restricted or repetitive patterns of behavior, interests, or activities; that symptoms should present in early childhood and cause significant functional impairments; and that the impairments are not better explained by intellectual disability (APA, 2013).

DSM-5 introduced major change by eliminating subcategories and providing an overall approach to the diagnosis of ASD (Volkmar et al., 2014a). Concerns about individuals losing services prompted the addition of a "grandfather clause" in DSM-5 granting continued diagnostic assignment to cases previously diagnosed under DSM-IV.

Although experienced clinicians can diagnose ASD by the age of 2 years in many affected children, and while the diagnosis of ASD can usually be made very clearly by age 3, population-based studies in the United States have shown the median age at first diagnosis of ASD to be older than 5 years (Maenner et al., 2013; Shattuck et al., 2009). The process of obtaining a diagnosis of ASD often requires a referral from a pediatrician or other primary care provider to a clinical center or care provider experienced in ASD diagnosis. Once a referral has been made, families can face wait times of 6 to 12 months or longer for the first available appointment. At each step of the diagnostic process, financial and cultural barriers can delay the identification of ASD, especially for socioeconomically disadvantaged children (Magaña et al., 2013).

Several sets of practice guidelines are now available to provide guidance on screening and diagnosis (McClure, 2014). Current practice guidelines suggest that there should be a comprehensive assessment involving structured observations of the child's behavior; extensive parental interviews; testing of cognition, speech and language, hearing, vision, and motor function; a physical examination; and a collection of medical and family history information (Millward et al., 2008; Nye and Brice, 2005; Reichow et al., 2010, 2013). The assessment may also involve genetic testing, neuroimaging, or other studies.

Early screening is recommended beginning at 18 months and during the preschool years. In general, ASD is an early-onset disorder, but early screening may miss a minority of cases where parents report regression after some period of normal development; in other instances symptoms may be missed on early screening in more cognitively able children. Early diagnosis and assessment are important to optimize the potential for a good outcome (McClure and Melville, 2007; Volkmar et al., 2014a). A family history of ASD (e.g., in a sibling) should prompt higher levels of clinical concern.

Clinical evaluation is indicated to look for symptoms and signs of associated conditions (notably seizure disorder or epilepsy). Although sometimes associated with single-gene conditions (notably fragile X and tuberous sclerosis), the genetics of ASD appears to be very complex, with potentially many different genetic pathways being associated with ASD (Geschwind, 2011). The role of genetic factors in etiology has been increasingly recognized in recent years, although genetic testing remains limited, apart from certain well-recognized single-gene conditions. More extensive genetic testing may be indicated based on clinical presentation or family history. Guidelines for genetic testing are now available (Schaefer et al., 2013).

A range of tests are used to assess developmental levels and the need for occupational and physical therapy. A number of screening and diagnostic instruments are available (see Volkmar et al., 2014a). It is common for the assessment of cognition and communication to reveal multiple areas of difficulty. Unusual styles of learning in ASD lead to problems in generalization, which can cause difficulty with adaptive skills. Therefore, the ability to apply knowledge to real-world settings should be assessed.

DEMOGRAPHIC FACTORS AND DURATION OF THE DISORDER

Age

ASD is an early-onset disorder. The average age of diagnosis is 3.1 years old, and the diagnosis of ASD is made with great certainty by age 3 (Mandell et al., 2005). Prior to that age, social-communication difficulties may be present but the characteristic behaviors and restrictions may not clearly emerge until around age 3. The combination of mandates for services in early intervention programs and school with greater public awareness and mandates for screening has led to earlier identification (McClure, 2014; Reichow et al., 2010).

By the time they reach school age, children with ASD become more socially aware, but behavioral problems may also increase. In adolescence some individuals make major gains in functioning, while a smaller number lose skills. Improved access to treatment and earlier case detection appear to be associated with a significant shift in outcome, with many more adults now achieving independence and more attending college and becoming employed, although even with good treatments, not every individual makes major gains (Howlin et al., 2014). Some individuals may not need services as adults and may blend into the general population (Fein et al., 2013).

Overall, the most predictive factors for a diagnosis of ASD relate to the presence of communicative and nonverbal abilities before the age of 5 (Howlin et al., 2013). However, as Kanner and Eisenberg (1953) noted, these issues are complex, with some children making major gains, and others experiencing losses during the developmental period, particularly in adolescence (see Howlin et al., 2014, for a discussion).

Sex

ASD is more common in males by a factor of 3 to 5. In lower-IQ groups gender difference is much less pronounced, while in high-IQ cases it is much more pronounced. There is some suggestion that higher rates of impairment (overall) in females may reflect a higher genetic risk (Howlin et al., 2014).

Race/Ethnicity

Epidemiologic studies in the United States consistently report a lower prevalence of ASD among black non-Hispanic and Hispanic children than among white non-Hispanic children (Baio, 2012). Studies based on reporting by schools reveal marked and unexpected variations in rates, suggesting possible reporting bias. Parental beliefs about diagnosis and health care, cultural barriers, and discrimination may affect diagnosis and prevalence estimates by race/ethnicity (Kogan et al., 2009; Magaña et al., 2012; Mandell et al., 2009).

Socioeconomic Status

From the very first reports of ASD, the data have suggested that ASD is mainly a disorder among children whose parents have high levels of education and occupational status; however, this was likely due to the barriers to accessing diagnostic and therapeutic services experienced by children from low-income families (Bhasin and Schendel, 2007; Cuccaro et al., 1996; Durkin et al., 2010; Kanner, 1943; Wing, 1980). In this respect, ASD differs from other forms of childhood mental disorder or developmental disability, which tend to be associated with socioeconomic disadvantage rather than advantage. In a paper published in 1980, Wing argued that children of highly educated parents are more likely to have the resources to be aware of and to obtain a diagnosis of ASD (Wing, 1980). One indication that Wing was correct is a recent study from Sweden, a country with universal health care and access to comprehensive diagnostic and treatment services, which found no excess of ASD among children of high socioeconomic status and in fact found that the prevalence of ASD decreased slightly with increasing socioeconomic status (Rai et al., 2012). Cultural issues have received little attention. While ASD symptoms appear similar in cases from around the world, there may be major differences in the way the disorder is conceptualized and treated (Magaña and Smith, 2013; Mandell et al., 2009; Rogers et al., 2012; Volkmar et al., 2005). It does appear that within the United States there may be some tendency for more affluent families to seek a diagnosis of ASD to ensure more access to services and also that families from poverty may be less aware of the condition and their school districts less likely to assign an ASD diagnosis (Mandell and Novak, 2005; Mandell et al., 2009; Pinborough-Zimmerman et al., 2012).

COMORBIDITIES

Issues of comorbidity are complex, particularly in individuals without spoken language (Matson and Nebel-Schwalm, 2006). One thing that is clear, however, is that ASD is associated with an increased risk of intellectual disability (Simonoff et al., 2008; White et al., 2009). Furthermore, epilepsy co-occurs with as many as 20 percent of cases, with peak periods of onset in both early childhood and adolescence (Volkmar et al., 2014b). It remains unclear whether the poor outcomes are the result of a common underlying cause for both epilepsy and ASD or the result of side effects from anticonvulsant treatments (Howlin et al., 2014). For school-age children with ASD, attentional difficulties and irritability are relatively common (Volkmar et al., 2014a). By adolescence, particularly for more cognitively able individuals, the risk for mood disorders (particularly depression) and anxiety-related problems increases. The association of ASD with anxiety and mood problems in older individuals appears to be relatively strong.

In younger children, ASD raises the risk for nonfatal and fatal injuries to double the rates in the general population. Bolting (running away) is a frequent problem and cause of injury or death. Having ASD at least doubles the risk of being bullied, which can exacerbate other issues such as anxiety and depression (Cappadocia et al., 2011). In the past, there was a strong co-occurrence of ASD and intellectual disability (ID). While early diagnosis and intervention has decreased this association, a minority of patients still have co-occurring diagnoses of ASD and ID. Given that ASD is a disorder involving communication, it is unusual (but not impossible) for a child with ASD to exhibit comorbid language conditions.

FUNCTIONAL IMPAIRMENT

Functional (adaptive) skills are invariably impaired in ASD and are an important impediment to adult self-sufficiency (Paul et al., 2004). These functional impairments are typically highlighted in practice guidelines as a major focus of intervention (McClure, 2014; Volkmar et al., 2014a). Deficits may be severe and persistent and result from problems in the overall learning style associated with ASD as well as from difficulties in generalization. Functional impairments stem from the basic and fundamental deficits in social interest and motivation that causes problems with learning, organization, multitasking, and generalization (executive functions). These difficulties in organizational and executive function lead to major problems in dealing with new situations as well as with situations that require the generalization of knowledge across settings. Even for the most cognitively able individuals with ASD, problems with the generalization of knowledge into real-life situations are a source of considerable impairment, and deficits in functional skills have frequently been included as a defining feature of the condition (Klin et al., 2007).

A number of excellent assessment instruments of adaptive and functional skills are available and have consistently documented deficits in multiple areas of functioning, such as social skills, communication, and activities of daily living (Goldstein et al., 2009). In spite of the availability of assessment instruments, the severity of impairment in autism remains complex, because expressions of the syndrome change with age, particularly in early childhood and in adolescence, where some individuals make major gains while others lose skills. Furthermore, no single convention exists for classification of difference in ability levels or severity of impairment. For example, the terms "high functioning" or "low functioning" are frequently used, but primarily refer only to cognitive ability or IQ. In reality, many individuals with high IQ have severe impairment in adaptive skills. For example, an individual may have an IQ above 140, but the social skills of a 4-year-old child (Klin et al., 2007). Further complicating the assessment of severity is that major differences in various sub-indices of IQ can exist, with differences up to 70 points (Volkmar et al., 2005). As a practical matter, the severity of impairment in multiple areas, regardless of IQ, is the major source of disability.

TREATMENT AND OUTCOMES

Early approaches to treatment in ASD focused on psychotherapy, but over time it became apparent that children with ASD were more likely to improve with structured, special education interventions (Bartak et al., 1977). Other important contributions to more effective treatment included the advent of the Education for All Handicapped Children Act, which mandated education as a right for children with special needs, including those with ASD (NRC, 2001), and the official recognition of ASD in 1980. The early interest in behavioral approaches has now expanded into the field of applied behavior analysis, which has repeatedly been shown to be an effective evidence-based approach (Smith, 2010). A review by the National Research Council on early intervention for ASD reported a range of programs and models, each of which had some empirical support; the literature on evidence-based treatments has not increased substantially in subsequent years (NRC, 2001).

A number of meta-analyses and reviews of the available treatment literature are now available (Reichow et al., 2010). It is important to note that the treatment literature is of variable quality and that noteworthy gaps remain. However, this literature has been increasingly included in the various official guidelines for practice (McClure, 2014).

Comprehensive treatment programs fall into four types. One group of treatment programs employs a developmental approach, notably the Rogers "Denver" model and the less-well-researched Greenspan "Floortime" approach (Greenspan et al., 2008; Rogers et al., 2012). A second group of treatment programs is more behaviorally focused and includes most of the programs employing applied behavior analysis (Smith et al., 2007). A third group of treatment programs is exemplified by the state-wide TEACCH model used in North Carolina, which is more eclectic in nature (Schopler et al., 1995). A fourth group of treatment programs uses a combination of behavioral and developmental approaches, as exemplified by pivotal response therapy (Koegel and Koegel, 2006).

Generally, the goal of all treatment programs is to minimize the disruptive effects of ASD on learning, while maximizing more normative processes. Treatment goals change with age and developmental level but typically include a focus on social, language, and adaptive (self-help) skills. Educational and behavioral treatments draw on the expertise of a range of professionals. Specialists in communication focus on expanding the range of the child's communicative ability beyond vocabulary. Children who lack verbal language can be helped through augmentative strategies (e.g., manual signing, picture exchange, and new computer-based technologies). Behavioral techniques help with management of disruptive behavior and facilitate learning. Given the unusual learning style of children with ASD, a focus on the generalization of skills into functional activities is important. Social skills teaching is an important aspect of treatment programs (Reichow et al., 2012).

Pharmacological interventions may be very helpful with behavioral problems and comorbid conditions, but they do not affect the central social and communicative aspects of ASD. The newer atypical neuroleptics can help with the management of agitation and stereotypic behaviors, and other agents can help with issues of mood, anxiety, and attention (Volkmar et al., 2014a); however, side effects of medication sometimes limit their usefulness (McDougle et al., 2005). For more cognitively able individuals, medication use can be combined with supportive psychotherapy, and several models of treatment are available (Scarpa et al., 2013).

A number of studies, including independent meta-analyses, have been conducted of treatment effects in ASD. The available literature varies, reflecting major differences in research that arise from a large number of different professional disciplines involved in the treatment of ASD. A review of five meta-analyses by Reichow reported effect sizes for psychosocial, early intensive behavioral interventions ranging from 0.38 to 1.19 for IQ and 0.3 to 1.09 for adaptive behavior (Reichow et al., 2012). A meta-analysis of cognitive-behavioral therapy for children by Sukhodolsky and colleagues, reported effect sizes of 1.19 and 1.21 for clinician- and parent-reported outcome measures of anxiety, respectively. A review of five randomized controlled trials of social skills training reported treatment effect sizes for a number of outcomes, including an effect size of 0.47 for improved social competence and 0.41 for friendship quality (Reichow et al., 2012). Similar effect sizes have been shown for pharmacological treatments. Arnold and colleagues and McCracken and colleagues reported effect sizes of 1.2 for behavioral irritability treated with atypical neuroleptics like Risperidone. A large number of alternative/complementary treatments have been proposed for ASD and are widely used by parents (Levy and Hyman, 2015). These typically lack an empirical foundation, but it is important that service providers be aware of their use.

It is important to emphasize that, with earlier diagnosis and intervention, many (though not all) children make substantial gains. More and more individuals now seek post–high school education or vocational training, or both (Howlin et al., 2013; Vanbergeijk et al., 2008).

FINDINGS

- The diagnosis of ASD requires a comprehensive behavioral and medical evaluation by experts, including a clinical evaluation and the use of disorder-specific screening and diagnostic instruments. The role of genetic testing is limited, apart from a small number of well-characterized single-gene conditions.
- The age of onset for ASD is in early childhood. Individuals diagnosed with ASD are likely to have functional impairments throughout their lives; however, the severity of these impairments can vary greatly, from profound to relatively mild. The diagnosis of ASD can be made in most children with great certainty by age 3.
- ASD is more common in males by more than three- to fivefold.
- Unlike other mental disorders, ASD is diagnosed less often in children living in poverty, although most population studies indicate equal rates among children living in low-income households, suggesting disparities in access to early identification.
- ASD is associated with an increased risk of intellectual disability.
- Significant impairment usually persists into adolescence and adulthood.
- Early diagnosis and the application of evidence-based interventions increase the likelihood that a child will have better outcomes and reduced functional impairments. The goals of treatment are to minimize disruptive effects and to improve adaptive functioning.

REFERENCES

APA (American Psychiatric Association). 1980. *Diagnostic and statistical manual of mental disorders, 3rd edition*. Washington, DC: APA.

APA. 2013. *Diagnostic and statistical manual of mental disorders, 5th edition*. Washington, DC: APA.

Baio, J. 2012. Prevalence of autism spectrum disorders: Autism and developmental disabilities monitoring network, 14 sites, United States, 2008. *Morbidity and Mortality Weekly Report* 61(SS03):1–19.

Bartak, L., M. Rutter, and A. Cox. 1977. A comparative study of infantile autism and specific developmental receptive language disorders, III: Discriminant function analysis. *Journal of Autism and Childhood Schizophrenia* 7(4):383–396.

Bhasin, T. K., and D. Schendel. 2007. Sociodemographic risk factors for autism in a U.S. metropolitan area. *Journal of Autism and Developmental Disorders* 37(4):667–677.

Cappadocia, M. C., D. Pepler, and J. A. Weiss. 2012. Bullying experiences among children and youth with autism spectrum disorders. *Journal of Autism and Developmental Disorders* 42(2):266–277.

Cuccaro, M. L., H. H. Wright, C. V. Rownd, R. K. Abramson, J. Waller, and D. Fender. 1996. Professional perceptions of children with developmental difficulties: The influence of race and socioeconomic status. *Journal of Autism and Developmental Disorders* 26(4):461–469.

Durkin, M. S., M. J. Maenner, F. J. Meaney, S. E. Levy, C. DiGuiseppi, J. S. Nicholas, R. S. Kirby, J. A. Pinto-Martin, and L. A. Schieve. 2010. Socioeconomic inequality in the prevalence of autism spectrum disorder: Evidence from a U.S. cross-sectional study. *PLoS ONE* 5(7):e11551.

Fein, D., M. Barton, I. M. Eigsti, E. Kelley, L. Naigles, R. T. Schultz, M. Stevens, M. Helt, A. Orinstein, M. Rosenthal, E. Troyb, and K. Tyson. 2013. Optimal outcome in individuals with a history of autism. *Journal of Child Psychology and Psychiatry* 54(2):195–205.

Geschwind, D. H. 2011. Genetics of autism spectrum disorders. *Trends in Cognitive Sciences* 15(9):409–416.

Goldstein, S., J. A. Naglieri, and S. Ozonoff. 2009. Assessment of autism spectrum disorders. *Assessment of autism spectrum disorders*. New York: Guilford Press. Pp. xiv, 384.

Greenspan, S. I., T. B. Brazelton, J. Cordero, R. Solomon, M. L. Bauman, R. Robinson, S. Shanker, and C. Breinbauer. 2008. Guidelines for early identification, screening, and clinical management of children with autism spectrum disorders. *Pediatrics* 121(4):828–830.

Howlin, P., P. Moss, S. Savage, and M. Rutter. 2013. Social outcomes in mid- to later adulthood among individuals diagnosed with autism and average nonverbal IQ as children. *Journal of the American Academy of Child & Adolescent Psychiatry* 52(6):572–581.

Howlin, P., S. Savage, P. Moss, A. Tempier, and M. Rutter. 2014. Cognitive and language skills in adults with autism: A 40-year follow-up. *Journal of Child Psychology and Psychiatry* 55(1):49–58.

Kanner, L. 1943. Autistic disturbances of affective contact. *Nervous Child* 2:217–250.

Kanner, L., and L. Eisenberg. 1953. Notes on the follow-up studies of autistic children. *Proceedings of the Annual Meeting of the American Psychopathological Association* 1954–1955:227–239.

Klin, A., C. A. Saulnier, S. S. Sparrow, D. V. Cicchetti, F. R. Volkmar, and C. Lord. 2007. Social and communication abilities and disabilities in higher functioning individuals with autism spectrum disorders: The Vineland and the ASOS. *Journal of Autism and Developmental Disorders* 37(4):748–759.

Koegel, R. L., and L. K. Koegel. 2006. *Pivotal response treatments for autism: Communication, social, and academic development*. Baltimore, MD: Paul H. Brookes.

Kogan, M. D., S. J. Blumberg, L. A. Schieve, C. A. Boyle, J. M. Perrin, R. M. Ghandour, G. K. Singh, B. B. Strickland, E. Trevathan, and P. C. van Dyck. 2009. Prevalence of parent-reported diagnosis of autism spectrum disorder among children in the U.S., 2007. *Pediatrics* 124(5):1395–1403.

Levy, S. E., and S. L. Hyman. 2015. Complementary and alternative medicine treatments for children with autism spectrum disorders. *Child and Adolescent Psychiatric Clinics of North America* 24(1):117–143.

Maenner, M. J., L. A. Schieve, C. E. Rice, C. Cunniff, E. Giarelli, R. S. Kirby, L. C. Lee, J. S. Nicholas, M. S. Wingate, and M. S. Durkin. 2013. Frequency and pattern of documented diagnostic features and the age of autism identification. *Journal of the American Academy of Child & Adolescent Psychiatry* 52(4):401–413.

Magaña, S., and L. E. Smith. 2013. The use of the autism diagnostic interview—revised with a Latino population of adolescents and adults with autism. *Journal of Autism and Developmental Disorders* 43(5):1098–1105.

Magaña, S., S. L. Parish, R. A. Rose, M. Timberlake, and J. G. Swaine. 2012. Racial and ethnic disparities in quality of health care among children with autism and other developmental disabilities. *Intellectual and Developmental Disabilities* 50(4):287–299.

Magaña, S., K. Lopez, A. Aguinaga, and H. Morton. 2013. Access to diagnosis and treatment services among Latino children with autism spectrum disorders. *Intellectual and Developmental Disabilities* 51(3):141–153.

Mandell, D. S., and M. Novak. 2005. The role of culture in families' treatment decisions for children with autism spectrum disorders. *Mental Retardation and Developmental Disabilities Research Reviews* 11(2):110–115.

Mandell, D. S., M. M. Novak, and C. D. Zubritsky. 2005. Factors associated with age of diagnosis among children with autism spectrum disorders. *Pediatrics* 116(6):480–1486.

Mandell, D. S., L. D. Wiggins, L. A. Carpenter, J. Daniels, C. DiGuiseppi, M. S. Durkin, E. Giarelli, M. J. Morrier, J. S. Nicholas, and J. A. Pinto-Martin. 2009. Racial/ethnic disparities in the identification of children with autism spectrum disorders. *American Journal of Public Health* 99(3):493–498.

Matson, J. L., and M. S. Nebel-Schwalm. 2007. Comorbid psychopathology with autism spectrum disorder in children: An overview. *Research in Developmental Disabilities* 28(4):341–352.

McClure, I. 2014. Developing and implementing practice guidelines. In *Handbook of autism and pervasive developmental disorders, fourth edition*, edited by F. R. Volkmar, R. Paul, S. J. Rogers, and K. A. Pelphrey. Hoboken, NJ: John Wiley & Sons. Vol. 2, Ch. 44.

McClure, I., and C. A. Melville. 2007. Early identification key in autism spectrum disorders. *Practitioner* 251(1697):31, 33–35.

McDougle, C. J., L. Scahill, M. G. Aman, J. T. McCracken, E. Tierney, M. Davies, L. E. Arnold, D. J. Posey, A. Martin, J. K. Ghuman, B. Shah, S. Z. Chuang, N. B. Swiezy, N. M. Gonzalez, J. Hollway, K. Koenig, J. J. McGough, L. Ritz, and B. Vitiello. 2005. Risperidone for the core symptom domains of autism: Results from the study by the autism network of the research units on pediatric psychopharmacology. *American Journal of Psychiatry* 162(6):1142–1148.

Millward, C., M. Ferriter, S. Calver, and G. Connell-Jones. 2008. Gluten- and casein-free diets for autistic spectrum disorder. *Cochrane Database of Systematic Reviews* 2(2):CD003498.

NRC (National Research Council). 2001. *Educating children with autism*. Washington, DC: National Academy Press.

Nye, C., and A. Brice. 2005. Combined vitamin B6–magnesium treatment in autism spectrum disorder. *Cochrane Database of Systematic Reviews* (4):CD003497.

Paul, R., S. Miles, D. Cicchetti, S. Sparrow, A. Klin, F. Volkmar, M. Coflin, and S. Booker. 2004. Adaptive behavior in autism and pervasive developmental disorder-not otherwise specified: Microanalysis of scores on the Vineland Adaptive Behavior Scales. *Journal of Autism and Developmental Disorders* 34(2):223–228.

Pinborough-Zimmerman, J., A. V. Bakian, E. Fombonne, D. Bilder, J. Taylor, and W. M. McMahon. 2012. Changes in the administrative prevalence of autism spectrum disorders: Contribution of special education and health from 2002–2008. *Journal of Autism and Developmental Disorders* 42(4):521–530.

Rai, D., G. Lewis, M. Lundberg, R. Araya, A. Svensson, C. Dalman, P. Carpenter, and C. Magnusson. 2012. Parental socioeconomic status and risk of offspring autism spectrum disorders in a Swedish population-based study. *Journal of the American Academy of Child & Adolescent Psychiatry* 51(5):467–476.

Reichow, B., P. Doehring, D. V. Cicchetti, and F. R. Volkmar. 2010. *Evidence-based practices and treatments for children with autism*. New York: Springer Science & Business Media.

Reichow, B., A. Steiner, and F. Volkmar. 2012. Social skills groups for people aged 6 to 21 years with autism spectrum disorders (ASD). *Cochrane Database of Systematic Reviews* 7:CD008511.

Reichow, B., A. M. Steiner, and F. Volkmar. 2013. Cochrane review: Social skills groups for people aged 6 to 21 with autism spectrum disorders (ASD). *Evidence-Based Child Health: A Cochrane Review Journal* 8(2):266–315.

Rogers, S. J., A. Estes, C. Lord, L. Vismara, J. Winter, A. Fitzpatrick, M. Guo, and G. Dawson. 2012. Effects of a brief early start denver model (ESDM)-based parent intervention on toddlers at risk for autism spectrum disorders: A randomized controlled trial. *Journal of the American Academy of Child & Adolescent Psychiatry* 51(10):1052–1065.

Scarpa, A., S. W. White, and T. Attwood. 2013. *CBT for children and adolescents with high-functioning autism spectrum disorders*. New York: Guilford Press.

Schaefer, G. B., N. J. Mendelsohn, and Professional Practice and Guidelines Committee. 2013. Clinical genetics evaluation in identifying the etiology of autism spectrum disorders: 2013 guideline revisions. *Genetics in Medicine* 15(5):399–407.

Schopler, E., G. B. Mesibov, and K. Hearsey. 1995. Structured teaching in the TEACCH system. In *Learning and cognition in autism*, edited by E. Schopler and G. B. Mesibov. New York: Springer. Pp. 243–268.

Shattuck, P. T., M. Durkin, M. Maenner, C. Newschaffer, D. S. Mandell, L. Wiggins, L.-C. Lee, C. Rice, E. Giarelli, and R. Kirby. 2009. Timing of identification among children with an autism spectrum disorder: Findings from a population-based surveillance study. *Journal of the American Academy of Child & Adolescent Psychiatry* 48(5):474–483.

Simonoff, E., A. Pickles, T. Charman, S. Chandler, T. Loucas, and G. Baird. 2008. Psychiatric disorders in children with autism spectrum disorders: Prevalence, comorbidity, and associated factors in a population-derived sample. *Journal of the American Academy of Child & Adolescent Psychiatry* 47(8):921–929.

Smith, T. 2010. Early and intensive behavioral intervention in autism. In *Evidence-based psychotherapies for children and adolescents*, edited by O. I. Lovas and T. Smith. New York: Guilford Press. Pp. 312–326.

Smith, T., D. Mozingo, D. Mruzek, and J. Zarcone. 2007. Applied behavior analysis in the treatment of autism. In *Clinical manual for the treatment of autism*, edited by E. Hollander and E. Anagnostou. Washington, DC: American Psychiatric Publishing. Pp. 153–177.

Vanbergeijk, E., A. Klin, and F. Volkmar. 2008. Supporting more able students on the autism spectrum: College and beyond. *Journal of Autism and Developmental Disorders* 38(7):1359–1370.

Volkmar, F. R., R. Paul, A. Klin, and D. J. Cohen (eds.). 2005. *Handbook of autism and pervasive developmental disorders, Vol. 2*. Hoboken, NJ: John Wiley & Sons.

Volkmar, F., M. Siegel, M. Woodbury-Smith, B. King, J. McCracken, and M. State. 2014a. Practice parameter for the assessment and treatment of children and adolescents with autism spectrum disorder. *Journal of the American Academy of Child & Adolescent Psychiatry* 53(2):237–257.

Volkmar, F. R., B. Reichow, and J. C. McPartland. 2014b. *Adolescents and adults with autism spectrum disorders*. New York: Springer.

White, S. W., D. Oswald, T. Ollendick, and L. Scahill. 2009. Anxiety in children and adolescents with autism spectrum disorders. *Clinical Psychology Review* 2(3):216–229.

Wing, L. 1980. Childhood autism and social class: A question of selection? *British Journal of Psychiatry* 137(5):410–417.

9

Clinical Characteristics of Intellectual Disabilities

DIAGNOSIS AND ASSESSMENT

Intelligence is the general mental capacity that involves reasoning, planning, solving problems, thinking abstractly, comprehending complex ideas, learning efficiently, and learning from experience (AAIDD, 2010). Historically, intellectual disability (previously termed "mental retardation") has been defined by significant cognitive deficits—which has been established through a standardized measure of intelligence, in particular, with an IQ score of below 70 (two standard deviations below the mean of 100 in the population)—and also by significant deficits in functional and adaptive skills. Adaptive skills involve the ability to carry out age-appropriate daily life activities. Two different systems for classifying intellectual disability (ID) used in the United States are that of the American Association on Intellectual and Developmental Disabilities (AAIDD) and the *Diagnostic and Statistical Manual of Mental Disorders, 5th Edition* (DSM-5), which is published by the American Psychiatric Association. Both of these systems classify severity of ID according to the levels of support needed to achieve an individual's optimal personal functioning (see Table 9-1).

DSM-5 defines intellectual disabilities as neurodevelopmental disorders that begin in childhood and are characterized by intellectual difficulties as well as difficulties in conceptual, social, and practical areas of living. The DSM-5 diagnosis of ID requires the satisfaction of three criteria:

1. Deficits in intellectual functioning—"reasoning, problem solving, planning, abstract thinking, judgment, academic learning, and learning

from experience"—confirmed by clinical evaluation and individualized standard IQ testing (APA, 2013, p. 33);

2. Deficits in adaptive functioning that significantly hamper conforming to developmental and sociocultural standards for the individual's independence and ability to meet their social responsibility; and
3. The onset of these deficits during childhood.

The DSM-5 definition of ID encourages a more comprehensive view of the individual than was true under the fourth edition, DSM-IV. The DSM-IV definition included impairments of general mental abilities that affect how a person functions in conceptual, social, and daily life areas. DSM-5 abandoned specific IQ scores as a diagnostic criterion, although it retained the general notion of functioning two or more standard deviations below the general population. DSM-5 has placed more emphasis on adaptive functioning and the performance of usual life skills. In contrast to DSM-IV, which stipulated impairments in two or more skill areas, the DSM-5 criteria point to impairment in one or more superordinate skill domains (e.g., conceptual, social, practical) (Papazoglou et al., 2014).

Classifications of Severity

The terms "mild," "moderate," "severe," and "profound" have been used to describe the severity of the condition (see Table 9-1). This approach has been helpful in that aspects of mild to moderate ID differ from severe to profound ID. The DSM-5 retains this grouping with more focus on daily skills than on specific IQ range.

Mild to Moderate Intellectual Disability

The majority of people with ID are classified as having mild intellectual disabilities. Individuals with mild ID are slower in all areas of conceptual development and social and daily living skills. These individuals can learn practical life skills, which allows them to function in ordinary life with minimal levels of support. Individuals with moderate ID can take care of themselves, travel to familiar places in their community, and learn basic skills related to safety and health. Their self-care requires moderate support.

Severe Intellectual Disability

Severe ID manifests as major delays in development, and individuals often have the ability to understand speech but otherwise have limited communication skills (Sattler, 2002). Despite being able to learn simple daily routines and to engage in simple self-care, individuals with severe ID

TABLE 9-1 Classifications of Intellectual Disability Severity

Severity Category	Approximate Percent Distribution of Cases by Severity	DSM-IV Criteria (severity levels were based only on IQ categories)	DSM-5 Criteria (severity classified on the basis of daily skills)	AAIDD Criteria (severity classified on the basis of intensity of support needed)	SSI Listings Criteria (The SSI listings do not specify severity levels, but indicate different standards for meeting or equaling listing level severity.)
Mild	85%	Approximate IQ range 50–69	Can live independently with minimum levels of support.	Intermittent support needed during transitions or periods of uncertainty.	IQ of 60 through 70 *and* a physical or other mental impairment imposing an additional and significant limitation of function
Moderate	10%	Approximate IQ range 36–49	Independent living may be achieved with moderate levels of support, such as those available in group homes.	Limited support needed in daily situations.	A valid verbal, performance, or full-scale IQ of 59 or less
Severe	3.5%	Approximate IQ range 20–35	Requires daily assistance with self-care activities and safety supervision.	Extensive support needed for daily activities.	A valid verbal, performance, or full-scale IQ of 59 or less
Profound	1.5%	IQ <20	Requires 24-hour care.	Pervasive support needed for every aspect of daily routines.	A valid verbal, performance, or full-scale IQ of 59 or less

need supervision in social settings and often need family care to live in a supervised setting such as a group home.

Profound Intellectual Disability

Persons with profound intellectual disability often have congenital syndromes (Sattler, 2002). These individuals cannot live independently, and they require close supervision and help with self-care activities. They have very limited ability to communicate and often have physical limitations. Individuals with mild to moderate disability are less likely to have associated medical conditions than those with severe or profound ID.

Evaluation of Severity

Currently AAIDD publishes a framework for evaluating the severity of ID, the Supports Intensity Scale (SIS), which focuses on the types and intensities of supports needed to enable an individual to lead a normal and independent life, rather than defining severity in terms of deficits. The SIS evaluates the support needs of an individual across 49 life activities, divided into six categories: home living, community living, life-long learning, employment, health and safety, and social activities.

DSM-5 notes that intellectual functioning reflects several different components: verbal comprehension, working memory, perceptual reasoning, quantitative reasoning, abstract thought, and cognitive efficacy (APA, 2013). Accurate measurement requires an instrument that is psychometrically valid, culturally appropriate, and individually administered. In the absence of appropriate measurement instruments, screening instruments are still able to assist in the identification individuals who need further testing. IQ test results fall along the normal (bell-shaped) curve, with an average IQ of 100, and individuals who are intellectually disabled are usually two standard deviations below the average (IQ below 70). Various issues (e.g., co-occurring communication problems, sensory or motor difficulties) can affect assessment, and psychologists must address these in considering which tests to use. IQ scores are usually reported with an associated confidence interval which indicates a range within which the "true" score is likely to fall.

A frequently used IQ measure for children in the United States is the Wechsler Intelligence Scale for Children (WISC-V). It historically measured verbal IQ, performance IQ, and full performance IQ (Wechsler et al., 2004). In its most recent edition, the WISC-V provides an overall IQ score as well as five other scores for verbal comprehension, visual spatial skills, fluid reasoning, working memory, and processing speed (Pearson Education, 2015). Because IQ scores have been constantly rising since the 1930s, standardized

IQ tests have been periodically renormed based on the current population (Flynn, 1987).

Etiology

Environmental factors such as exposure to toxic substances (e.g., prenatal alcohol exposure, prenatal or postnatal lead exposure), nutritional deficiencies (e.g., prenatal iodine deficiency), brain radiation, childhood brain infections, traumatic brain injury, and maternal infections (e.g., rubella, cytomegalovirus) can lead to ID. Additionally, prenatal and postnatal complications—e.g., complications of prematurity such as hypoxemia and periventricular hemorrhage—may cause brain injury resulting in ID (Gustafsson, 2003).

Genetic factors play a major role in ID. Different genetic causes may lead to ID. Down syndrome (trisomy 21) is the most common genetic cause of ID in the United States, occurring approximately once every 700 live births (Parker et al., 2010). Fragile X syndrome is the most common known inherited cause of ID, and it affects approximately 1 per 5,000 males (Coffee et al., 2009). Many cases of ID in the population are of unknown etiology.

Because of the varied causes and consequences of ID, an initial evaluation should address intellectual and life skills, the identification of genetic and nongenetic etiologies, and the diagnosis of conditions that need treatment (e.g., epilepsy and phenylketonuria). Prenatal and perinatal medical histories, a physical examination, genetic evaluations, and metabolic screening and neuroimaging assessment may aid in the determination of characteristics that may influence the course of the disorder.

DEMOGRAPHIC FACTORS AND DURATION OF THE DISORDER

ID begins in the first two decades of life. The age and characteristics of onset depend on the cause of the disability and the severity of the neuropsychiatric dysfunction. The identification of children with more severe ID (what previously would have been termed severe and profound mental retardation) typically occurs early in life. These children often have dysmorphic features and associated medical conditions and higher rates of behavioral and psychiatric disturbances. Individuals with severe intellectual disability may show delayed motor, language, and social accomplishments within the first 2 years of life. Individuals with mild intellectual disability may not be recognized until early school age because that is when their difficulties with academic learning become apparent.

Depending on its cause, ID may be stable and nonprogressive or it may worsen with time. After early childhood, the disorder is chronic and usually lasts an individual's lifetime; however, the severity of the disorder may change with age. For example, visual or hearing difficulties, epilepsy, childhood psychological or head trauma, substance abuse, and other medical conditions may affect the course of the disorder. Conversely, an early intervention may improve adaptive skills.

Sex

Males are more likely than females to be diagnosed with ID. According to the National Health Interview Survey, from 1997 to 2008 the prevalence of ID was 0.78 percent in boys and 0.63 percent in girls (Boyle et al., 2011). Overall, studies of prevalence show a male excess in the prevalence of ID, which is partially explained by x-linked causes of the disability, such as fragile X syndrome (Durkin et al., 2007).

Race/Ethnicity

In the United States, the prevalence of ID varies by race/ethnicity, probably due to confounding by socioeconomic status (SES). Black non-Hispanic children are approximately twice as likely, and Hispanic children approximately one and a half times as likely, to be diagnosed with ID as white non-Hispanic children (Bhasin et al., 2006; Boyle and Lary, 1996; Boyle et al., 2011; Camp et al., 1998; Van Naarden Braun et al., 2015). Language differences and poverty likely contribute to the racial and ethnic differences in performance on cognitive tests and to the corresponding disparities in prevalence. Even after taking the effects of SES into account, there is evidence that test bias and diagnostic bias affects the rates of the diagnosis of ID (Jencks and Phillips, 1998).

Socioeconomic Status

Poverty is one of the most consistent risk factors for ID (Cooper and Lackus, 1983; Durkin et al., 1998; Stein and Susser, 1963). Boyle and colleagues reported that in the United States between 1997 and 2008, the prevalence of ID among children below 200 percent of the federal poverty level (FPL) was 1.03 percent, while for those above 200 percent FPL the rate was 0.5 percent (Boyle et al., 2011). Similarly, Camp and colleagues found the prevalence of ID among children of low SES to be more than twice as high as that among middle- or high-SES children (Camp et al., 1998). The association between low SES and poverty is considerably stronger for mild than for more severe levels of ID (Drews et al., 1995; Durkin et al., 1998).

COMORBIDITIES

Many neurodevelopmental, psychiatric, and medical disorders co-occur with ID, especially communication disorders, learning disabilities, cerebral palsy, epilepsy, and various genetically transmitted conditions (APA, 2013). Estimates of the rates of psychiatric coexisting conditions vary. For many years there was an underestimation of the increased risk for development of comorbid conditions ("diagnostic overshadowing"). As research was conducted, it became clear that the risk for comorbid conditions is greater than previously believed. For example, Rutter and colleagues reported rates of 30 to 42 percent of psychopathology in children with "mental retardation" compared with 6 to 7 percent in children without the disability (Rutter et al., 1970). Gillberg and colleagues reported that 57 percent of subjects with mild and severe "mental retardation" met diagnostic criteria for affective, anxiety, conduct, schizophrenia, and somatoform disorders and attention deficit hyperactivity disorder (ADHD) (Gillberg et al., 1986). Most studies indicate a four- to fivefold increase in mental health problems among individuals with ID. In general, at least 25 percent of persons with ID may have significant psychiatric problems, with the population experiencing, in particular, significantly increased rates of schizophrenia, depression, and ADHD (Bouras and Holt, 2007; Fletcher et al., 2007).

FUNCTIONAL IMPAIRMENT

The diagnosis of ID requires evidence of impairments in real life (adaptive) skills; thus all people with ID demonstrate functional impairment. These adaptive abilities relate to such things as understanding rules, the ability to navigate the tasks of daily living, and participation in family, school, and community activities. Various assessments of such skills are available, such as the Vineland Adaptive Behavior Scales which is a widely used instrument (Sparrow et al., 2005). Assessment of these skills helps to plan remediation, i.e., teaching specific skills and working on generalization of skills.

TREATMENT AND OUTCOMES

Treatments for ID generally fall into three main categories: (1) treatments that address or mitigate any underlying cause of ID, such as restricting phenylalanine in the diet of patients who have phenylketonuria; (2) treatments of comorbid physical and mental disorders with the aim of improving the patient's functioning and life skills, such as targeted pharmacologic treatments of behavioral disorders among children with fragile X syndrome (Hagerman and Polussa, 2015); and (3) early behavioral and cognitive interventions, special education, habilitation, and psychosocial supports (Szymanski and Kaplan, 2006).

Guidelines for the assessment and management of ID generally focus on psychosocial interventions. Challenges vary with the age of the individual and the level of impairment as well as with the presence of other associated conditions (Curry et al., 1997; Moeschler et al., 2006; Shevell et al., 2003; Szymanski and King, 1999). Because individuals with ID can manifest the full range of psychiatric disorders, medications can sometimes help manage these disorders (Reiss et al., 1982). However, the cognitive and verbal limitations of patients with ID make the psychiatric diagnostic process difficult. These disorders frequently respond to standard psychiatric treatment, i.e., medication and psychosocial support, although in the main ID makes treatment more complex.

FINDINGS

- Historically, intellectual disability has been defined by significant cognitive deficits, typically established by the testing of IQ and adaptive behaviors. There are no laboratory tests for ID; however, many specific causes and genetic factors for ID can be identified through laboratory tests.
- Males are more likely than females to be diagnosed with ID. Poverty is a risk factor for ID, especially for mild ID.
- The functional impairments associated with ID are generally lifelong. However, there are functional supports that may enable an individual with ID to function well and participate in society.
- As a diagnostic category, IDs include individuals with a wide range of intellectual functional impairments and difficulties with daily life skills. The levels of severity of intellectual impairment and the need for support can vary from profound to mild.
- Comorbidities, including behavioral disorders, are common.
- Treatment usually consists of appropriate education and skills training, supportive environments to optimize functioning, and the targeted treatment of co-occurring psychiatric disorders.

REFERENCES

AAIDD (American Association on Intellectual Developmental Disabilities). 2010. *Intellectual disability: Definition, classification, and systems of supports*. Washington, DC: AAIDD.

APA (American Psychiatric Association). 2013. *Diagnostic and statistical manual of mental disorders, fifth edition*. Washington, DC: APA.

Bhasin, T. K., S. Brocksen, R. N. Avchen, and K. V. N. Braun. 2006. Prevalence of four developmental disabilities among children aged 8 years: Metropolitan Atlanta Developmental Disabilities Surveillance Program, 1996 and 2000. *Morbidity and Mortality Weekly Report* 55(SS01):1–9.

Bouras, N., and G. Holt. 2007. *Psychiatric and behavioural disorders in developmental disabilities and mental retardation*. Cambridge, UK: Cambridge University Press.

Boyle, C. A., and J. M. Lary. 1996. Prevalence of selected developmental disabilities in children 3–10 years of age: The metropolitan Atlanta developmental disabilities surveillance program, 1991. *Morbidity and Mortality Weekly Report* 45(SS-2):1–14.

Boyle, C. A., S. Boulet, L. A. Schieve, R. A. Cohen, S. J. Blumberg, M. Yeargin-Allsopp, S. Visser, and M. D. Kogan. 2011. Trends in the prevalence of developmental disabilities in U.S. children, 1997–2008. *Pediatrics* 127(6):1034–1042.

Camp, B. W., S. H. Broman, P. L. Nichols, and M. Leff. 1998. Maternal and neonatal risk factors for mental retardation: Defining the “at-risk”child. *Early Human Development* 50(2):159–173.

Coffee, B., K. Keith, I. Albizua, T. Malone, J. Jowrey, S. L. Sherman, S. T. Warren. 2009. Incidence of fragile X syndrome by newborn screening for methylated FMR1 DNA. *American Journal of Human Genetics* 85(4):503–514.

Cooper, B., and B. Lackus. 1983. The social-class background of mentally retarded children: A study in Mannheim. *Social Psychiatry* 19(1):3–12.

Curry, C. J., R. E. Stevenson, D. Aughton, J. Byrne, J. C. Carey, S. Cassidy, C. Cunniff, J. M. Graham, M. C. Jones, M. M. Kaback, J. Moeschler, G. B. Schaefer, S. Schwartz, J. Tarleton, and J. Opitz. 1997. Evaluation of mental retardation: Recommendations of a consensus conference. *American Journal of Medical Genetics* 72(4):468–477.

Drews, C. D., M. Yeargin-Allsopp, P. Decouflé, and C. C. Murphy. 1995. Variation in the influence of selected sociodemographic risk factors for mental retardation. *American Journal of Public Health* 85(3):329–334.

Durkin, M. S., N. Schupf, Z. A. Stein, and M. W. Susser. 1998. Mental retardation. In *Public health and preventive medicine*, edited by R. Wallace. Stamford, CT: Appleton & Lange. Pp. 1049–1058.

Durkin, M. S., N. Schupf, Z. A. Stein, M. W. Susser. 2007. Mental retardation. In *Public health and preventive medicine*, 15th ed., edited by R. Wallace. Stamford, CT: Appleton & Lange. Pp. 1173–1184.

Fletcher, R. J., E. Loschen, C. Stavrakaki, and M. First (eds.). 2007. *Diagnostic manual-intellectual disability: A textbook of diagnosis of mental disorders in persons with intellectual disability*. Kingston, NY: NADD Press.

Flynn, J. R. 1987. Massive IQ gains in 14 nations: What IQ tests really measure. *Psychological Bulletin* 101(2):171–191.

Gillberg, C., E. Persson, M. Grufman, and U. Themner. 1986. Psychiatric disorders in mildly and severely mentally retarded urban children and adolescents: Epidemiological aspects. *British Journal of Psychiatry* 149:68–74.

Gustafsson, C. 2003. Intellectual disability and mental health problems: Evaluation of two clinical assessment instruments, occurrence of mental health problems and psychiatric care utilisation. Acta Universitatis Upsaliensis. Comprehensive summaries of Uppsala dissertations from the Faculty of Medicine. Uppsala. https://uu.diva-portal.org/smash/get/diva2:163146/FULLTEXT01 (accessed July 5, 2015).

Hagerman, R. J., and J. Polussa. 2015. Treatment of the psychiatric problems associated with fragile X syndrome. *Current Opinion in Psychiatry* 28(2):107–112.

Jencks, C., and M. Phillips (Eds.). 1998. *The Black-white test score gap*. Washington, DC: The Brookings Institution.

Moeschler, J. B., M. Shevell, and the American Academy of Pediatrics Committee on Genetics. 2006. Clinical genetic evaluation of the child with mental retardation or developmental delays. *Pediatrics* 117(6):2304–2316.

Papazoglou, A., L. A. Jacobson, M. McCabe, W. Kaufmann, and T. A. Zabel. 2014. To ID or not to ID? Changes in classification rates of intellectual disability using DSM-5. *Intellectual and Developmental Disabilities* 52(3):165–174.

Parker, S. E., C. T. Mai, M. A. Canfield, R. Rickard, Y. Wang, and R. E. Meyer. 2010. Updated national birth prevalence estimates for selected birth defects in the United States, 2004–2006. *Birth Defects Resesearch, Part A, Clinical and Molecular Teratology* 88:1008–1016.

Pearson Education. 2015. WISC-V. www.wiscv.com (accessed May 4, 2015).

Reiss, S., G. W. Levitan, and J. Szyszko. 1982. Emotional disturbance and mental retardation: Diagnostic overshadowing. *American Journal of Mental Deficiency* 86(6):567–574.

Rutter, M., P. J. Graham, and W. Yule. 1970. *A neuropsychiatric study in childhood*. London: Heinemann Medical Books.

Sattler, J. M. 2002. *Assessment of children: Behavioral and clinical applications*. San Diego: J.M. Sattler.

Shevell, M., S. Ashwal, D. Donley, J. Flint, M. Gingold, D. Hirtz, A. Majnemer, M. Noetzel, R. D. Sheth, Quality Standards Subcommittee of the American Academy of Neurology, and Practice Committee of the Child Neurology Society. 2003. Practice parameter: Evaluation of the child with global developmental delay: Report of the Quality Standards Subcommittee of the American Academy of Neurology and the Practice Committee of the Child Neurology Society. *Neurology* 60(3):367–380.

Sparrow, S. S., D. A. Balla, D. V. Cicchetti, and E. A. Doll. 2005. *Vineland-II: Vineland Adaptive Behavior Scales: Survey forms manual*. Circle Pines, MN: AGS Publishing.

Stein, Z., and M. Susser. 1963. The social distribution of mental retardation. *American Journal of Mental Deficiency* 67:811–821.

Szymanski, L., and B. H. King. 1999. Practice parameters for the assessment and treatment of children, adolescents, and adults with mental retardation and comorbid mental disorders. *Journal of the American Academy of Child & Adolescent Psychiatry* 38(12):5S–31S.

Szymanski, L. S., and L. C. Kaplan. 2006. Mental retardation. In *Essentials of child and adolescent psychiatry*, edited by M. Dulcan and J. M. Wiener. Arlington, VA: American Psychiatric Publishing. Pp. 121–154.

Van Naarden Braun, K., D. Christensen, N. Doernberg, L. Schieve, C. Rice, L. Wiggins, D. Schendel, and M. Yeargin-Allsopp. 2015. Trends in the prevalence of autism spectrum disorder, cerebral palsy, hearing loss, intellectual disability, and vision impairment, metropolitan Atlanta, 1991–2010. *PLoS ONE* 10(4):e0124120.

Wechsler, D., E. Kaplan, D. Fein, J. Kramer, R. Morris, D. Delis, and A. Maerlender. 2004. *The Wechsler intelligence scale for children—fourth edition integrated technical and interpretative manual*. San Antonio, TX: Harcourt Assessment, Inc.

10

Clinical Characteristics of Learning Disabilities

DIAGNOSIS AND ASSESSMENT

Learning disabilities (LDs) are diagnosed using both educational and medical perspectives (Cortiella and Horowitz, 2014). From an educational perspective, the most commonly used definition is found in the federal special education law, the Individuals with Disabilities Education Act (IDEA). The medical perspective on LDs is reflected in the *Diagnostic and Statistical Manual for Mental Disorders* (currently the DSM-5 and previously the DSM-IV) published by the American Psychiatric Association (APA, 2013). There is considerable overlap in the definition of LD used by professionals in educational and medical settings (Cortiella and Horowitz, 2014).

Individuals with Disabilities Education Act

IDEA defines a specific learning disability as

> a disorder in one or more of the basic psychological processes involved in understanding or in using language, spoken or written, which disorder may manifest itself in the imperfect ability to listen, think, speak, read, write, spell, or do mathematical calculations. This term includes conditions such as perceptual disabilities, brain injury, minimal brain dysfunction, dyslexia, and developmental aphasia. Specific learning disabilities are not primarily the result of visual, hearing, motor disabilities, mental retardation, emotional disturbance, or of environmental, cultural, or economic disadvantage. (DOE, 1995)

Children are typically diagnosed using the IDEA criteria in school settings as a prerequisite to receiving educational interventions and accommodations (Cortiella and Horowitz, 2014). A challenge presented by the IDEA definition is the use of diagnostic nomenclature, such as "perceptual disabilities" and "minimal brain dysfunction," that are no longer recognized. Among the major forms of learning disabilities, some evidence suggests that dyslexia, or difficulty with reading, may be the most common form (Ferrer et al., 2010). Other major types of specific disabilities include dyscalculia (difficulties with mathematical calculations), dysgraphia (difficulties with writing), and others. In studies where every student is examined, as many as 21.5 percent are found to be dyslexic; in contrast, schools report less than 4 to 5 percent (Ferrer et al., 2010).

Diagnostic and Statistical Manual for Mental Disorders

According to DSM-5, the diagnosis of a specific learning disorder includes the following symptoms:

1. Persistent difficulties in reading, writing, arithmetic, or mathematical reasoning skills during formal years of schooling. Symptoms may include inaccurate or slow and effortful reading, poor written expression that lacks clarity, difficulties remembering number facts, or inaccurate mathematical reasoning.
2. Current academic skills must be well below the average range of scores in culturally and linguistically appropriate tests of reading, writing, or mathematics. Accordingly, a person who is dyslexic must read with great effort and not in the same manner as those who are typical readers.
3. Learning difficulties begin during the school-age years.
4. The individual's difficulties must not be better explained by developmental, neurological, sensory (vision or hearing), or motor disorders and must significantly interfere with academic achievement, occupational performance, or activities of daily living (APA, 2013).

Of note, the fourth edition of the DSM (i.e., DSM-IV-TR) did not use a broad category of LD; instead it included several diagnoses specific to impairments in reading, mathematics, and written expression (APA, 2000).

In DSM-IV-TR, LD is diagnosed "when the individual's achievement on individually administered standardized tests is substantially below that expected for age, schooling, and level of intelligence" (APA, 2000). The DSM-IV-TR approach recognizes three explicitly defined diagnostic categories: reading disorders, mathematics disorders, and disorders of written expression. A residual category, learning disabilities not otherwise specified, is also provided. These terms are commonly used as equivalent, overall, to the term for learning disability in federal regulations.

The DSM-IV approach, now more than 20 years old, was based on methods that relied on discrepancy scores; that is, a learning difficulty was said to exist in a particular area such as reading when the scores in that particular area were significantly below what would be expected judging by the individual's overall cognitive ability. The *International Classification of Diseases, Ninth Revision*, definition of these conditions is rather similar but includes an explicit requirement that the school environment is appropriate to the child's ability to learn the skill. Sensory deficits can be present, although the additional learning difficulty is diagnosed only when the achievement delays are even greater than would be expected.

DSM-5 has taken a different approach to LDs by broadening the category into a single overall diagnosis. It does not limit the diagnosis to reading, math, or written expression but more generally describes problems in achieved academic skills with the potential for specification of the more traditional areas (APA, 2013). A diagnosis is made based on a clinical review of an individual's history, teacher reports and academic records, and responses to interventions. Difficulties must be persistent, scores must be well below the range on appropriate measures, and the problems cannot be better explained by other disorders. A significant interference in achievement, occupation, or activities of daily living must be present.

Dyslexia, a term that antedates LD, refers specifically to difficulties with accurate or fluent word recognition, poor spelling, and deficits in coding abilities (International Dyslexia Association, 2015). It continues to be used in both clinical and research contexts and is included under the single DSM-5 umbrella diagnosis of LD.

Standardized Instruments for Assessment

A number of well standardized instruments are available for the assessment of LDs. A measure of cognitive ability, such as the newly developed Weschler Intelligence Scale for Children, is commonly used (Prifitera et al., 2005). Other frequently used measures include Woodcock–Johnson IV, the Wechsler Individual Achievement Test II, and the Wide Range Achievement Test III. Specialized tests are also available, such as the comprehensive test of phonological processing and assessments of fluency such as the Test of Word Reading Efficiency. Assessment results assist with diagnosis, planning for intervention, and identifying any additional comorbid conditions or problems that may interfere with treatment. Children growing up in different cultures should be assessed with different instruments, with the instruments matched to the culture.

Response to Treatment Intervention

An awareness of the potential problems with diagnosis led to the introduction of a new concept, response to treatment intervention (RTI), in the 2004 amendment of IDEA. The RTI approach has emerged as a possible alternative to the discrepancy-based diagnostic approach (Vaughn and Fuchs, 2003). This model combines aspects of assessment with intervention, and its approach includes an emphasis on early screening and closer follow-up to clarify the need for additional intervention. Several types of interventions are used, ranging from less to more intensive. The LD diagnosis is made only if these various attempts to modify the child's regular classroom and program have not been successful or if problems remain with the child's absolute performance or rate of skill gains. This diagnostic process can be prolonged.

Alternatives to the RTI approach use annual testing to identify students whose skills have not progressed as would be expected and thus who might need more intensive and directed intervention. Another approach uses normalized references to establish which child scores below a preestablished threshold. These issues continue to be widely debated in the field. School districts vary considerably in their approaches to these issues.

DEMOGRAPHIC FACTORS AND DURATION OF THE DISORDER

Age

The National Health Interview Survey (NHIS) estimates the prevalence of any parent-reported LD from 1997 to 2008 to be 5 percent among children 3 to 10 years old, and 9.3 percent for children from 11 to 17 years old (Boyle et al., 2011). LD is a lifelong condition and is unlikely to resolve after a child graduates, although many individuals learn to successfully accommodate for their LDs.

Sex

Multiple sources indicate that the rates of LD are higher among males than females. The 2010 data indicate that for children ages 6 to 17, 2.8 percent of males have an LD, while 1.6 percent of females have an LD. Similarly, IDEA data indicate that 66 percent of students identified with LD are male. The NHIS has consistently shown that males are more likely than females to be diagnosed by a school or health professional as having an LD (Pastor and Reuben, 2008). The NHIS survey estimates the prevalence of any parent-reported learning disabilities from 1997 to 2008 among boys (3–17) to be approximately 9 percent, and among girls to be 5 percent

(Boyle et al., 2011). However, when the identification depends not on teacher identification and parent reports, but rather on direct cognitive assessments of the child, the prevalence of males and females is almost equivalent. Teachers may use the more active and potentially disruptive behavior of males as a factor in a student's referral for evaluation (Shaywitz, 1990).

Race/Ethnicity

Racial disparities have been observed in the rates of LD among children in some but not other studies. According to NHIS data, the prevalence of LD among black children is generally higher than the prevalence of LD in white or Hispanic children; in 2010, for example, the prevalence of LD among school-aged children was 1.7 percent in white non-Hispanic children, 1.9 percent in black non-Hispanic children, 0.9 percent in Asian children, and 1.2 percent in Latino/Hispanic children. According to the 2011/2012 National Survey of Children's Health (NSCH), the estimated prevalence of mild LD by race was 3.4 percent for Hispanic children, 4.4 percent for white children, 3.9 percent for black non-Hispanic children, and 3.6 percent for other non-Hispanic children. The NSCH-estimated prevalence for severe LD by race was 3.8 percent for Hispanic children, 3.9 percent for white non-Hispanic children, 5.7 percent for black non-Hispanic children, and 3.2 percent for other non-Hispanic children. Variations in the rates of LD by race must be cautiously interpreted. Even after taking into account the effect of socioeconomic status, there is some evidence that test bias and diagnostic bias contributes to disparities observed between racial or ethnic categories in the identification of children with LD (Coutinho et al., 2002; Jencks and Phillips, 1998).

Socioeconomic Status

Differences in the rates of LD by race and ethnicity must take into account the role of poverty. Studies have consistently shown that the risk of LD is higher among children in poverty. U.S. national data from 2010 indicated that for children of ages 5 to 17, the prevalence of LD was 2.6 percent among children below the federal poverty level (FPL), while the prevalence of LD was 1.5 percent among children above the poverty line. Results of the 2011/2012 NSCH show a direct relationship between poverty and the rates of severe LD. The prevalence rate of severe LD for children in households at 0 to 99 percent FPL is 6.7 percent, at 100 to 199 percent FPL is 4.2 percent, at 200 to 299 percent FPL is 3.3 percent, and at 400 percent FPL or higher is 2.6 percent.

COMORBIDITIES

LDs are frequently associated with certain other conditions, and it is important to consider these conditions in assessing impairment and planning interventions. The recognition of these associated difficulties varies depending on the age of the child and the severity and extent of the learning problems. The recognition of an LD may occur as the child enters school, but the LD may have been preceded by a language delay which does increase the risk of subsequent LDs. LDs are also associated in complex ways with a range of other problems, including attention deficit hyperactivity disorder and disruptive behavior disorders such as conduct disorder. For children with more difficulty, repeated school failure may be associated with the onset of anxiety and depression in middle childhood and adolescence. There may also be an increased risk for bullying, being bullied, or both. Although learning difficulties often do persist into adulthood, many individuals are able to develop compensatory strategies and can do well as adults.

LDs are commonly associated with many medical conditions. A multitude of genetic and congenital conditions have LDs as a frequent phenotypic finding (Kodituwakku, 2007; Mazzocco, 2001; Murphy et al., 2006; Wernovsky et al., 2005). For example, children with spina bifida often have math-related learning difficulties (Barnes et al., 2006; English et al., 2009). Children born prematurely are also at increased risk for LDs, as are children with cerebral palsy (Aarnoudse-Moens et al., 2009; Beckung and Hagberg, 2002). Children with epilepsy and other neurologic conditions often have concurrent LDs which may be easily identified or overlooked because of the complexity of the primary neurologic problem (Prince and Ring, 2011). Additionally, children may manifest LDs as findings that are associated with an unrecognized or newly recognized medical condition such as sleep apnea (Lewin et al., 2002; Sadeh et al., 2002).

FUNCTIONAL IMPAIRMENT

Learning difficulties, including dyslexia, result in significant functional impairments in important life skills such as reading and learning. Recent IDEA data show that children with LD are more likely to experience challenges in academic performance and negative school outcomes, including below-average test scores, lower grades, and higher rates of course failure. The same data show that approximately one-third of children with LDs have been held back a grade in school at least once. Only about 68 percent of children with LDs graduate with a regular diploma, with 19 percent dropping out and 12 percent receiving a certificate of completion. Adults with LDs are less likely to enroll in post-secondary education than individuals without LDs, and adults with LDs are less likely to be employed than adults without LDs (Spencer et al., 2014).

At the same time, many of these individuals may have reasonably good real-life, or adaptive, skills. The presence of additional, comorbid diagnoses raises the likelihood of disruptions in multiple areas and of impaired functional skills. Even in the absence of a comorbid disorder, some learning difficulties can present challenges for the child in important functional areas, notably in the area of peer interactions. Increased family attention and participation in remedial efforts is an added burden.

In some ways the spectrum of possible early interventions has complicated the data on potential functional impairment. In addition, the largest body of research has focused on the most prevalent and clearly delineated LD, dyslexia, rather than on the outcomes of other areas of impairment.

TREATMENT AND OUTCOMES

Given the various federal mandates for service, many children with significant LDs now receive special help. Most of the available information on treatment and outcome specifically addresses dyslexia or another specific learning disorder. Even in the instances in which students who are dyslexic have received effective interventions, there are no data indicating a closure of the fluency gap; these individuals remain slow readers, although they are often very good thinkers and, with individualized accommodations, can succeed academically.

Many different intervention strategies and accommodations are now available and can help children, adolescents, and adults with LDs. The What Works Clearinghouse, sponsored by the Institute of Education Sciences of the U.S. Department of Education, offers a good source of information concerning which programs are evidence based. No matter how intelligent an affected individual is, dyslexia will impede fluency, so these individuals require extra time to complete reading and writing assignments and to work on examinations. There are also various forms of assistance that can be used to accommodate these individuals, ranging from low tech to very high tech, e.g., visual aids, schedules, organization software, and text-to-speech software.

Treatment planning should be comprehensive, addressing areas of weakness but also recognizing areas of strength. The range of services provided in school can vary from a very intensive level of support, e.g., individualized interventions or special educational classes, to less intensive support, such as additional help in the mainstream classroom or with homework and special tutoring. Support is often also provided through special lesson plans, with individuals grouped according to achievement levels, and frequent assessment and more intensive teacher involvement. Modification in the classroom setting—e.g., in the placement of the child, modifications in homework, modified test requirements, or extra time on tests—can be helpful. Electronic and other resources, such as the use of computers with spell check, text-to-speech or speech-to-text, and specialized games and learning materials, are also used. There are few data concerning the effectiveness of many of these procedures within the regular classroom.

For students who qualify, the provision of resource room support or special classes along with an individualized education plan is often the most helpful approach. It is important that the school focus on areas of strength as well as weakness, e.g., helping the child achieve in areas such as sports or music as well as in traditional academic areas (Shaywitz, 1990).

Other treatment approaches have been concerned with addressing what are presumed to be underlying problems in information processing, such as attention. LDs often present the child with challenges in other areas, including peer interaction. Support for programs in these areas, as well as the more specifically academic challenges, can be helpful.

While many individuals with learning difficulties lead active and productive lives as adults, others have learning challenges that lead to early withdrawal from school and lower levels of occupational attainment.

FINDINGS

- LDs are diagnosed in educational and clinical settings. Standardized instruments are available as diagnostic aides.
- The diagnosis is usually made in school-aged children.
- Boys are more often identified as having an LD than girls.
- Academic and employment success can be challenging for those with LDs.
- Comorbidities are common and add to the likelihood of functional impairment.
- Appropriate accommodations in educational settings enhance the opportunities for children with LDs to achieve academically and develop real-life skills that allow them to do well as adults.

REFERENCES

Aarnoudse-Moens, C. S., N. Weisglas-Kuperus, J. B. van Goudoever, and J. Oosterlaan. 2009. Meta-analysis of neurobehavioral outcomes in very preterm and/or very low birth weight children. *Pediatrics* 124(2):717–728.

APA (American Psychiatric Association). 2000. *Diagnostic and statistical manual of mental disorders, 4th edition, text revision*. Washington, DC: APA.

APA. 2013. *Diagnostic and statistical manual of mental disorders*. Washington, DC: APA.

Barnes, M. A., M. Wilkinson, E. Khemani, A. Boudesquie, M. Dennis, and J. M. Fletcher. 2006. Arithmetic processing in children with spina bifida: Calculation accuracy, strategy use, and fact retrieval fluency. *Journal of Learning Disabilities* 39(2):174–187.

Beckung, E., and G. Hagberg. 2002. Neuroimpairments, activity limitations, and participation restrictions in children with cerebral palsy. *Developmental Medicine & Child Neurology* 44(5):309–316.

Boyle, C. A., S. Boulet, L. A. Schieve, R. A. Cohen, S. J. Blumberg, M. Yeargin-Allsopp, S. Visser, and M. D. Kogan. 2011. Trends in the prevalence of developmental disabilities in US children, 1997–2008. *Pediatrics* 127:1034–1042.

Cortiella, C., and S. H. Horowitz. 2014. The state of learning disabilities: Facts, trends, and emerging issues. https://www.ncld.org/wp-content/uploads/2014/11/2014-State-of-LD.pdf (accessed August 13, 2014).

Coutinho, M. J., D. P. Oswald, and A. M. Best. 2002. The influence of sociodemographics and gender on the disproportionate identification of minority students as having learning disabilities. *Remedial and Special Education* 23(1):49–59.

DOE (U.S. Department of Education). 1995. *Individuals with Disabilities Education Act Amendments of 1995: Reauthorization of the Individuals with Disabilities Education Act (IDEA)*. Washington, DC: DOE.

English, L. H., M. A. Barnes, H. B. Taylor, and S. H. Landry. 2009. Mathematical development in spina bifida. *Developmental Disabilities Research Reviews* 15(1):28–34.

Ferrer, E., B. A. Shaywitz, J. M. Holahan, K. Marchione, and S. E. Shaywitz. 2010. Uncoupling of reading and IQ over time: Empirical evidence for a definition of dyslexia. *Psychological Science* 21(1):93–101.

International Dyslexia Association. 2015. Definition of dyslexia. http://eida.org/definition%20of%20dyslexia/?gclid=Clrl-MHMqMUCFFdgUc (accessed July 6, 2015).

Jencks, C., and M. Phillips. 1998. *The black-white test score gap*. Washington, DC: Brookings Institution Press. http://site.ebrary.com/id/10224504 (accessed July 1, 2015).

Kodituwakku, P. W. 2007. Defining the behavioral phenotype in children with fetal alcohol spectrum disorders: A review. *Neuroscience & Biobehavioral Reviews* 31(2):192–201.

Lewin, D. S., R. C. Rosen, S. J. England, and R. E. Dahl. 2002. Preliminary evidence of behavioral and cognitive sequelae of obstructive sleep apnea in children. *Sleep Medicine* 3(1):5–13.

Mazzocco, M. M. 2001. Math learning disability and math LD subtypes: Evidence from studies of Turner syndrome, fragile X syndrome, and neurofibromatosis type 1. *Journal of Learning Disabilities* 34(6):520–533.

Murphy, M. M., M. M. Mazzocco, G. Gerner, and A. Henry. 2006. Mathematics learing disability in girls with Turner syndrome or fragile X syndrome. *Brain and Cognition* 61(2):195–210.

Pastor, P. N., and C. A. Reuben. 2008. Diagnosed attention deficit hyperactivity disorder and learning disability: United States, 2004–2006. National Center for Health Statistics. *Vital and Health Statistics* 10(237). http://www.cdc.gov/nchs/data/series/sr_10/sr10_237.pdf (accessed June 6, 2015).

Prifitera, A., D. H. Saklofske, and L. G. Weiss. 2005. *WISC-IV clinical use and interpretation: Scientist–practitioner perspectives*. New York: Academic Press.

Prince, E., and H. Ring. 2011. Causes of learning disability and epilepsy: A review. *Current Opinion in Neurology* 24(2):154–158.

Sadeh, A., R. Gruber, and A. Raviv. 2002. Sleep, neurobehavioral functioning, and behavior problems in school-age children. *Child Development* 73(2):405–417.

Shaywitz, S. E. 1990. Prevalence of reading disability in boys and girls. *JAMA* 264(8):998–1002.

Spencer, T. J., S. V. Faraone, L. Tarko, K. McDermott, and J. Biederman. 2014. Attention-deficit/hyperactivity disorder and adverse health outcomes in adults. *The Journal of Nervous and Mental Disease* 1.

Vaughn, S., and L. S. Fuchs. 2003. Redefining learning disabilities as inadequate response to instruction: The promise and potential problems. *Learning Disabilities Research & Practice* 18(3):137–146.

Wernovsky, G., A. J. Shillingford, and J. W. Gaynor. 2005. Central nervous system outcomes in children with complex congenital heart disease. *Current Opinion in Cardiology* 20(2):94–99.

11

Clinical Characteristics of Mood Disorders

The Social Security Administration (SSA) Listing of Impairments for mood disorders includes within the same diagnostic category criteria for the following diagnoses: major depressive syndrome, manic syndrome, and bipolar or cyclothymic syndrome. However, according to the *Diagnostic and Statistical Manual of Mental Disorders, Fifth Edition* (DSM-5) (APA, 2013), the mood disorders that may have a childhood onset are (1) major depression, (2) persistent depressive disorder (PDD), and (3) disruptive mood dysregulation disorder (DMDD). In a departure from DSM-IV, DSM-5 treats bipolar disorders as a separate category. Pediatric bipolar disorder (PBD) will be addressed separately following a discussion of depression.

DEPRESSION

Diagnosis and Assessment

Major depression is defined by DSM-5 as the presence of all five symptoms including feeling—or being observed to feel—sad, empty, or hopeless most of the day (depressed mood); having markedly diminished interest in most activities (anhedonia); or having severe, recurrent verbal or behavioral outbursts of temper three or more times per week. Irritability may be a substitute for symptoms of persistent depression for children, but irritability alone is not a sufficient criterion for major depression in children (Stringaris et al., 2013). Chronicity is the most easily observed feature of PDD, which may include children diagnosed with subthreshold depression (formerly known as dysthymia) as well as those diagnosed with chronic major depression. There is no lower age limit for the diagnosis of either major depressive disorder or persistent depressive disorder, but the latter is specified as "early onset" if the first episode occurs before age 21. Disruptive mood dysregulation disorder is applicable only to children between the ages of 6 and 18 years. DMDD is a new diagnosis that was developed to reduce the risk of misclassifying children with nonepisodic and chronic irritable mood as having bipolar disorder (Roy et al., 2014). Given that PDD and DMDD are new diagnostic categories, estimates of prevalence, clinical characteristics, and course may change as these criteria are applied in future research.

The most important difference between DSM-IV and DSM-5 in the diagnosis of mood disorders is that "depressive disorders" have been separated from "bipolar and related disorders." In general, the differences between depressive disorders in DSM-IV and DSM-5 are very small and unlikely to have a great effect on estimates of prevalence or incidence.

The diagnosis of a childhood-onset depression disorder requires a comprehensive psychiatric diagnostic evaluation, including interviews with the child, primary caregivers, and collateral informants such as teachers (Birmaher et al., 2007). Although screening tools to detect depressive symptoms are available, findings from these are not a substitute for a clinical diagnosis (Birmaher et al., 2007).

There are no well-established biologic markers for these diagnoses. Research on the biologic correlates of child depression include studies examining contributing factors such as genetics, sleep, neuroendocrine, inflammatory, metabolic, and neurotrophic factors. These factors as well as neural networks are in the exploratory phase of research development (Li et al., 2013a,b; Miller and O'Callaghan, 2013; Mills et al., 2013; Nivard et al., 2015; Palagini et al., 2013; Penninx et al., 2013; Rao, 2013; Schmidt et al., 2011; Schneider et al., 2011). Early findings using brain neuroimaging, for example, have suggested that alterations in the developmental trajectories of limbic and striatal regions may increase the risk of adolescent-onset depression (Whittle et al., 2014). Luking and colleagues found an attenuated relationship between the amygdala and cognitive control regions, consistent with the hypothesis of altered regulation of emotional processing in early childhood–onset major depression (Luking et al., 2011). Preliminary studies using neuroimaging also raise questions about whether changes in brain white and gray matter differentiate between early onset unipolar and bipolar depressive disorders (Serafina et al., 2014). None of these research advances are as yet employed diagnostically.

Demographic Factors and Duration of the Disorder

Age

The age of onset for depression among children and youth is variable because the expression of depressive symptoms may differ by development stage. Irritability, for example, may be more prominent among younger depressed children (Birmaher et al., 2009). Preschool children with depressive syndrome may manifest subthreshold diagnostic criteria for depression of shorter duration (Luby et al., 2014). These early depressive symptoms are significant because in clinical samples they are predictive of major depressive disorder in later childhood even after controlling for a maternal history of depression and other risk factors (Luby et al., 2014). Furthermore, this relationship may persist because subthreshold depressive symptoms have also been found to be predictive of major depressive disorder (MDD) onset in young adulthood (Klein et al., 2013). Some of the best established risk factors for MDD include childhood anxiety and parental depression (Thapar et al., 2012).

Sex

The risk for early-onset depression among children (i.e., 12 years or younger) does not vary by gender; however, during adolescence the risk among girls substantially increases. Findings from most studies on children suggest that there are no differences in the rates of depression between boys and girls or only a slight elevation in boys compared to girls (Brooks-Gunn and Petersen, 1991; Costello et al., 1996; Garrison et al., 1989; Lewinsohn et al., 1998b; Nolen-Hoeksema et al., 1991; Petersen et al., 1991; Rutter et al., 1986; Wesselhoeft et al., 2014). In contrast, during adolescence the rate of depression among girls almost always exceeds that of boys (Avenevoli et al., 2015; Costello et al., 2003; Ferrari et al., 2013; Lewinsohn et al., 1998b; Offord et al., 1989), and this trend persists into early adulthood (Costello et al., 2003; Ferrari et al., 2013; Rao et al., 1999; Rohde et al., 2013). There is evidence that hormonal, rather than psychological or sociological, reasons account for the appearance of this adolescent gender difference, which persists until menopause (Angold et al., 1998).

Race/Ethnicity

The findings regarding differences in rates of depression among youth by race or ethnicity are mixed, and the variation is likely due to differences in study design, target populations, and how depression was identified. Among a nationally representative sample of adolescents, major depression based upon youth-reported symptoms did not vary by race or ethnicity (Avenevoli et al., 2015). Using data from the National Health and Nutrition Examination Survey (NHANES) for children ages 8 to 15 years, a study found no differences in the prevalence of mood disorders by race or ethnicity, possibly because of the small sample size (Merikangas et al., 2010). In contrast, an analysis of data from the National Comorbidity Study-Adolescent Supplement (NCS-A) found higher rates of mood disorders among Hispanic adolescents than among non-Hispanic whites (Merikangas et al., 2010). Furthermore, findings from the National Longitudinal Study of Adolescent Health indicated that youth from racial or ethnic minority backgrounds were more likely to report depressive symptoms than non-minority youth (Rushton et al., 2002). This finding is consistent with that of a study that examined the variation in prevalence rates of depression among children and youth enrolled in Medicaid (Richardson et al., 2003).

Socioeconomic Status

Although studies of adults suggest that depression is associated with lower social class (Kessler et al., 2003), results from studies of children and adolescents are inconsistent (Merikangas et al., 2009). Some studies report a lack of association between depressive and anxiety disorders and social class (Costello et al., 2003), whereas others report a significant association, at least for the most impoverished groups (Costello et al., 1996; Gilman et al., 2003; Reinherz et al., 2003). There are also data on lifetime risk of depression that indicate that a low socioeconomic status (SES) in childhood is related to a higher risk of depression later in life (Gilman et al., 2002). Consequently the precise nature of the relationship between mood disorders in children or adolescents and poverty is unknown.

Duration

Childhood-onset depression is a chronic disorder, with an estimated average duration of 6 months. Among a longitudinal cohort of 816 high school students (ages 14 to 18) with depression, the mean age of onset was 15 years, and the mean duration of a major depressive episode was 26 weeks, but the duration varied widely, from 2 to 520 weeks (Rohde et al., 2013). The risk factors related to longer depressive episodes were earlier onset (age 15 years and younger), suicidal ideation, and seeking mental health treatment (Rohde et al., 2013). These findings are consistent with the NCS-A, which found the mean duration of a major depressive episode to be 27 weeks among a nationally representative sample of U.S. youth (Avenevoli et al., 2015). The median duration of major depressive episodes among clinically referred samples has been found to be considerably longer, most likely reflecting the greater clinical severity among children who access and receive continuous mental health care. In such samples, the median duration of depression ranged from 7 to 9 months, which was more than three times longer than that found in a community-based sample (Kovacs, 1996).

Adolescent depression also tends to recur. A recent review of outcomes of childhood depression reached the following conclusions (Costello and Maughan, 2015): (1) One in two children with a diagnosis of depression had one or more further episodes as an adult; (2) depression alone has a much better prognosis than depression accompanied by any of the following: anxiety disorders, oppositional defiant disorder, or substance use disorder; and (3) family conflict predicts continuity of depression into adulthood. Among adolescents in the community who recovered from a depressive episode, 5 percent experienced another major depression within 6 months, 12 percent within 1 year, and approximately 33 percent within 4 years (Rohde et al., 2013). Within clinically referred samples, an estimated 70 percent of depressed young patients had at least one recurrence within 5 or more years (Kovacs, 1996). These findings are consistent with international studies that suggest that children and adolescents with depression are more likely to suffer major depression and to manifest suicidal tendencies as adults (Fergusson et al., 2005; Harrington et al., 1990).

Comorbidities

Comorbid disorders are common among children and youth with depressive disorders, and childhood onset may increase the risk for comorbidity (Fernando et al., 2011). Children and youth with depression are more likely to suffer from anxiety disorders, conduct disorder, oppositional defiant disorder, and attention deficit hyperactivity disorder (ADHD) as well as alcohol and drug abuse (Costello et al., 2003; Fleming and Offord, 1990; Hipwell et al., 2011; Meinzer et al., 2013). Among a community-based cohort of adolescents with major depressive disorder, 43 percent also had a lifetime occurrence of another mental disorder. Of those teens with major depression, for example, 20 percent had an anxiety disorder, 13 percent abused alcohol, 18 percent abused drugs, 4 percent had conduct disorder, 3 percent had oppositional defiant disorder, 3 percent had ADHD, 8 percent had core symptoms of bipolar disorder, and 30 percent reported smoking cigarettes daily (Lewinsohn et al., 1998b). In a study following older teens into adulthood, the rates of comorbid major depression and of alcohol abuse or dependence were both only 2 percent during adolescence, but they increased in early adulthood to 11 and 7 percent, respectively (Briere et al., 2014). Compared to major depression only (i.e., without other diagnoses), the prognosis for youth with combined depression and substance use disorders is poorer. Youth with both disorders are at higher risk for alcohol dependence, suicide attempt, impaired role functioning, academic problems, life dissatisfaction, and less treatment utilization (Briere et al., 2014; Lewinsohn et al., 1998b).

Functional Impairment

A large proportion of children and adolescents with mood disorders have significant levels of functional impairment, defined as a reduced capacity to meet normal expectations in their roles at home, at school, and with peers and adults. Based on the NCS-A, 63 percent of youth with past-year major depression reported significant disability in at least one domain of functioning (Avenevoli et al., 2015). These findings are consistent with the 2001–2004 NHANES, which found that about half of children with a depressive diagnosis also showed significant functional impairment (Merikangas et al., 2010). Further, among a large epidemiologic sample, The Great Smoky Mountains Study of youth aged 9 to 13 found that 73 percent of a community sample with depression had significant functional impairment (Costello et al., 1996).

In addition, children with depression run a high risk of impaired functioning that continues into adulthood (Costello and Maughan, 2015). In the Great Smoky Mountains Study, four areas of functioning were defined as contributing to functional impairment in adulthood: (1) health, (2) education and income (SES), (3) social relationships, and (4) criminality or self-injurious behavior (Copeland et al., 2015). In all four areas, participants with early depression were significantly worse off than those with no psychiatric history, and they were the most likely of any diagnostic group to perform poorly as adults. Results from international studies are also consistent with these findings. In a Swedish sample (Jonsson et al., 2011) depressed adolescent females grew into adults who were more likely than other adults to be divorced, to be single parents, to have miscarried, to have experienced intimate partner violence, or to have had a sexually transmitted disease. In the Brisbane birth cohort study (Keenan-Miller et al., 2007), even after controlling for adult depression, early adolescent depression continued to be associated with poorer interviewer-rated health, poorer self-perceived general health, higher health care utilization, and increased work impairment due to physical health.

Treatment and Outcomes

Treatments for mood disorders among children and adolescents include evidence-based psychotherapies and psychotropic medications that may be administered alone or in combination, depending on the clinical severity, the prior history of treatment response, and parent (or older youth) preference. For mild or brief depression, education, supportive therapy for 4 to 6 weeks, and case management to address environmental factors may be sufficient (AACAP, 2007).

For moderate to severe depression, the possible evidence-based psychotherapies for adolescents include cognitive behavioral therapy (CBT) (Compton et al., 2004; Harrington et al., 1998) and interpersonal psychotherapy (IPT) (Mufson et al., 1999, 2004; Rossello and Bernal, 1999). These therapies are typically delivered in six to eight weekly sessions. CBT helps adolescents recognize negative thoughts and unwanted behavioral patterns and gives them strategies to change their thoughts and actions (AACAP, 1998, 2007). Interpersonal therapy focuses on strategies to cope with problems in relationships (i.e., family disputes) that may exacerbate depressed mood (AACAP, 1998, 2007).

For persistent depression that is not improved by psychotherapy alone or for more severe depression, antidepressant medication is recommended. The medication class commonly used is selective serotonin reuptake inhibitors (SSRIs), and within this class only a few medications are approved by the Food and Drug Administration (FDA) for use with children or adolescents. In 2004 the FDA issued a public warning (i.e., a "black box warning") about an increased risk of suicidal thoughts or behavior in children and adolescents treated with SSRI antidepressant medications. In 2007 findings from a comprehensive review of pediatric trials conducted between 1988 and 2006 suggested that the benefits of antidepressant medications likely outweigh their risks to children and adolescents with major depression and anxiety disorders (Bridge et al., 2007).

The results of research on the effectiveness of treatment are mixed but promising. Younger adolescents respond better to acute treatment than older or multiply comorbid adolescents (Curry et al., 2006). Within community-based treatment settings, psychotherapy for acute treatment of depressed youth is only modestly effective (AACAP, 2007; Weisz et al., 2006). Findings from randomized clinical trials comparing the efficacy of combined CBT and antidepressant medication with medication or psychotherapy alone are mixed (Curry et al., 2006; Goodyer et al., 2007; Kratochil et al., 2006; March et al., 2004, 2006; Melvin et al., 2006).

Antidepressant medications from the SSRI class are commonly used. Fluoxetine (Prozac) is the only SSRI approved by the FDA for use in treating depression in children ages 8 and older. Escitalopram (Lexapro) is also FDA approved for early-onset depression, but approval is restricted to youth ages 12 and older. The other SSRI medications and the SSRI-related antidepressant venlafaxine have not been approved for treatment of depression in children or adolescents, but they may be prescribed on an "off-label" basis. Table 11-1 summarizes the commonly used antidepressant medications for adolescents with depression.

TABLE 11-1 Commonly Prescribed Antidepressant Medications for Depressive Disorders Among Adolescents

	Generic Name	Brand Name
SSRI	Fluoxetine	Prozac
	Sertraline	Zoloft
	Citalopram	Celexa
	Escitalopram	Lexapro
	Fluvoxamine	Luvox
SNRI	Venlafaxine	Effexor

NOTE: SNRI = selective serotonin and norepinephrine reuptake inhibitor; SSRI = selective serotonin reuptake inhibitor.
SOURCE: AACAP, 1997.

Overall, the phases of treatment for depressive disorders are conceptualized as acute, continuation, and maintenance and are defined by the goal to be achieved. The goal of the acute phase is to achieve response (i.e., the patient having no symptoms or a significant reduction in symptoms for at least 2 weeks) and, ideally, full symptomatic remission (i.e., a period of at least 2 weeks and less than 2 months with no or few depressive symptoms) (AACAP, 2007). Continuation treatment is required for all depressed youths in order for them to avoid relapses (AACAP, 2007). This phase typically lasts 6 to 12 months. The goal of the maintenance phase is to avoid recurrences, especially among youth with depression of greater clinical severity. This phase may last 1 year or longer, and little research is available to guide national recommendations for when treatment during the maintenance phase should end (AACAP, 2007).

PEDIATRIC BIPOLAR DISORDER

Diagnosis and Assessment

DSM-5 conceptualizes bipolar and related disorders as a distinct diagnostic group which includes (1) bipolar I disorder, (2) bipolar II disorder, (3) cyclothymic disorder, and (4) other specified. The hallmark characteristic of bipolar I disorder is meeting criteria for a manic episode. Bipolar II disorder is characterized by a history of at least one major depression and at least one hypomanic episode. Given the chronicity of depression and mood instability, teens with bipolar II disorder may also experience serious impairment in social, academic, and occupational functioning (APA, 2013). The diagnosis of cyclothymic disorder is given to persons who experience both hypomanic and depressive periods without ever fulfilling the criteria for mania, hypomania, or major depression (APA, 2013). The latest guidelines for diagnosing bipolar disorder in children were issued in 2007 by the American Academy of Child and Adolescent Psychiatry, and they are currently being updated to reflect new DSM-5 criteria. The diagnosis of PBD requires a comprehensive psychiatric diagnostic evaluation, including a psychiatric interview with the child or youth, the primary caregiver, and collateral informants, such as teachers. There are no well-established biologic markers for PBD. Pediatric bipolar disorder is a rare condition in childhood but it can lead to significant impairments (Goldstein, 2012).

A thorough evaluation is needed to rule out organic conditions. A pediatric examination should include a thorough neurological evaluation, especially in the presence of either psychotic symptoms or catatonia. Medical conditions that mimic either mania or depression, such as metabolic, endocrine, or infectious disorders or acute intoxication or withdrawal, need to be evaluated as indicated.

Comorbidities

Comorbid disorders among teens with bipolar disorder are common and include ADHD, anxiety disorders, oppositional defiant disorder, and substance use disorders (Bernardi et al., 2010; Birmaher et al., 2009; Jolin et al., 2008; Masi et al., 2006; Pini et al., 2006; Sala et al., 2014; Stephens et al., 2014). In a national household sample, rates of ADHD and alcohol use were three times higher among adolescents with bipolar disorder who received treatment than among those who received no treatment; those who received treatment often had much more severe bipolar disorder (Khazanov et al., 2015). Among youth hospitalized for their first manic episode, the rate of comorbid substance abuse is high. In one study, almost one-half (48 percent) of youth hospitalized for bipolar disorder had a substance use disorder either at baseline or within the following year (Stephens et al., 2014). Furthermore, early onset of mania may increase a youth's risk for substance abuse (Gao et al., 2010), and combined bipolar and substance use disorders is associated with legal and academic difficulties, pregnancy, and suicidality (Goldstein and Bukstein, 2010).

Functional Impairment

The extent of functional impairment among children with pediatric bipolar disease is influenced by the severity of the child's illness and by the complexity of the disorder. Because PBD is a chronic and serious disorder, severe impairments in functioning are very common. Youth with PBD have documented impairments in academic functioning and achievement due to executive functioning deficits (Biederman et al., 2011; Perlman et al., 2013).

Research also shows that children and adolescents with PBD have difficulties reading facial expressions (Schenkel et al., 2012; Whitney et al., 2013), which is key to effective social functioning. Current longitudinal studies underway (see Findling et al., 2010 will elucidate the extent of functional impairments associated with this diagnosis.

Treatment and Outcomes

Treatment for bipolar disorder includes psychotherapy and medication. Recommended evidence-based psychotherapies are family-focused therapy (FFT), CBT, and IPT. FFT has a strong evidence base and targets reduction of highly charged emotions and stressors while promoting family problem-solving and conflict resolution (AACAP, 2009). FFT in combination with mood-stabilizing medications has been found to improve symptoms of mania, depression, and behavior problems (Miklowitz et al., 2006). CBT helps adolescents avoid stressful situations that may trigger mania (AACAP, 2009) and develop strategies to change thoughts and actions. IPT focuses on strategies to improve the stability of daily routines, such as maintaining a regular sleep schedule; it may also reduce a teen's vulnerability to new episodes of mania (AACAP, 2009).

Medications for bipolar disorder in older children and youth include mood stabilizers and atypical antipsychotic medication (see Table 11-2).

Although the short-term efficacy of recommended first-line mood stabilizers and antipsychotic medication treatment has been established, there are few, if any, studies examining the long-term efficacy of medication treatment. Among a cohort of 263 children and adolescents with bipolar spectrum disorders, approximately 70 percent recovered from their index episode, but 50 percent had at least one syndromal recurrence, particularly

TABLE 11-2 Commonly Prescribed Medications for Bipolar Disorder in Adolescents

	Generic	Brand Name
Mood stabilizers	Lithium	Eskalith, Lithobid
	Valproate	Depakote, Depakene
	Carbamazepine	Tegretol
	Oxcarbazepine	Trileptal
	Lamotrigine	Lamictal
Atypical antipsychotics	Risperidone	Risperdal
	Aripiprazole	Abilify
	Olanzapine	Zyprexa

depressive episodes (Birmaher et al., 2006). Clinically, the extent of improvement is likely influenced by clinical severity and complexity (i.e., comorbid substance abuse), timely access to care, treatment adherence, and environmental factors such as social support, family functioning, and schooling.

The duration of treatment for this chronic disorder also varies from individual to individual. Common short-term goals for treatment usually include a reduction in target symptoms. Longer-term goals include improvement in social and academic functioning, which may include a reduction in high-risk behaviors such as substance abuse.

FINDINGS

- Diagnosis requires a comprehensive psychiatric diagnostic evaluation. Screening tools are available to detect symptoms of depression, particularly in adolescents. There are no well-established laboratory tests for mood disorders.
- Mood disorders of childhood may occur in children of all ages. However, the risk of mood disorders increases during adolescence, especially among girls. A younger age of onset is a risk factor for increased severity and duration.
- While symptoms may wax and wane, mood disorders cause significant functional impairment that often persist or recur through childhood and into adulthood.
- Mood disorders frequently co-occur with other mental disorders.
- There is evidence for the effectiveness of medication treatment and psychotherapies for mood disorders. Improvements in functional impairments are enhanced with a combination of evidence-based psychotherapy and medication.
- Bipolar disorder in children and youth is classified by the DSM-5 as a diagnosis distinct from depression. Severe impairments in functioning are very common and frequently persist, even with treatment.

REFERENCES

AACAP (American Academy of Child and Adolescent Psychiatry). 1997. Practice parameters for the assessment and treatment of children and adolescents with bipolar disorder. *Journal of the American Academy of Child & Adolescent Psychiatry* 36(10, Suppl):157S–176S.

AACAP. 1998. Practice parameters for the assessment and treatment of children and adolescents with depressive disorders. *Journal of the American Academy of Child & Adolescent Psychiatry* 37(10, Suppl):63S–83S.

AACAP. 2007. Practice parameter for the assessment and treatment of children and adolescents with depressive disorders. *Journal of the American Academy of Child & Adolescent Psychiatry* 46(11):1503–1526.

AACAP. 2009. Parents' medication guide for bipolar disorder in children & adolescents. http://www.parentsmedguide.org/bipolarmedicationguide.pdf (accessed November 12, 2014).

Angold, A., E. J. Costello, and C. M. Worthman. 1998. Puberty and depression: The roles of age, pubertal status and pubertal timing. *Psychological Medicine* 28(1):51–61.

APA (American Psychiatric Association). 2013. *Diagnostic and statistical manual of mental disorders, 5th edition*. Washington, DC: APA.

Avenevoli, S., J. Swendsen, J. P. He, M. Burstein, and K. R. Merikangas. 2015. Major depression in the national comorbidity survey-adolescent supplement: Prevalence, correlates, and treatment. *Journal of the American Academy of Child & Adolescent Psychiatry* 54(1):37–44.e2.

Bernardi, S., S. Cortese, M. Solanto, E. Hollander, and S. Pallanti. 2010. Biploar disorder and comorbid attention deficit hyperactify disorder: A distinct clinical phenotype? Clinical characteristics and temperamental traits. *World Journal of Biological Psychiatry* 11(4):656–666.

Biederman, J., C. R. Petty, J. Wozniak, T. E. Wilens, R. Fried, A. Doyle, A. Henin, C. Bateman, M. Evans, and S. V. Faraone. 2011. Impact of executive function deficits in youth with bipolar I disorder: A controlled study. *Psychiatry Research* 186(1):58–64.

Birmaher, B., D. Axelson, M. Strober, M. K. Gill, S. Valen, L. Chiappetta, N. Ryan, H. Leonard, J. Hunt, S. Iyengar, and M. Keller. 2006. Clinical course of children and adolescent with bipolar spectrum disorders. *Archives of General Psychiatry* 63(2):175–183.

Birmaher, B., AACAP Work Group on Quality Issues, D. Brent, W. Bernet, O. Bukstein, H. Walter, R. S. Benson, A. Chrisman, T. Farchione, L. Greenhill, J. Hamilton, H. Keable, J. Kinlan, U. Schoettle, S. Stock, K. K. Ptakowski, and J. Medicus. 2007. Practice parameter for the assessment and treatment of children and adolescents with depressive disorders. *Journal of the American Academy of Child & Adolescent Psychiatry* 46(11):1503–1526.

Birmaher, B., D. Axelson, M. Strober, M. K. Gill, M. Yang, N. Ryan, B. Goldstein, J. Hunt, C. Esposito-Smythers, S. Iyengar, T. Goldstein, L. Shiapetta, M. Keller, and H. Leonard. 2009. Comparison of manic and depressive symptoms between children and adolescents with bipolar spectrum disorders. *Bipolar Disorder* 11(1):52–62.

Bridge, J. A., S. Iyengar, C. B. Salary, R. P. Barbe, B. Birmaher, H. A. Pincus, L. Ren, and D. A. Brent. 2007. Clinical response and risk for reported suicidal ideation and suicide attempts in pediatric antidepressant treatment: A meta-analysis of randomized controlled trials. *JAMA* 297:1683–1696.

Briere, F. N., P. Rohde, J. R. Seeley, D. Klein, and P. M. Lewinsohn. 2014. Comorbidity between major depression and alcohol use disorder from adolescence to adulthood. *Comprehensive Psychiatry* 55(3):526–533.

Brooks-Gunn, J., and A. Petersen. 1991. Studying the emergence of depression and depressive symptoms during adolescent. *Journal of Youth and Adolescence* 20(2):115–119.

Compton, S. N., J. S. March, D. Brent, A. M. Albano, V. R. Weersing, and J. Curry. 2004. Cognitive behavioral psychotherapy for anxiety and depressive disorders in children and adolescents: An evidence based medicine review. *Journal of the American Academy of Child & Adolescent Psychiatry* 43:930–959.

Copeland, W. E., D. Wolke, L. Shanahan, and E. J. Costello. 2015. Adult functional outcomes of common childhood psychiatric problems: A prospective, longitudinal study. *JAMA Psychiatry* 72(9):892–899.

Costello, E. J., and B. Maughan. 2015. Annual research review: Optimal outcomes of child and adolescent mental illness. *Journal of Child Psychology and Psychiatry* 56(3):324–341.

Costello, E. J., A. Angold, B. J. Burns, D. Stangl, D. L. Tweed, A. Erikanli, and C. M. Worthman. 1996. The Great Smoky Mountains Study of Youth. *Archives of General Psychiatry* 53:1129–1136.

Costello, E. J., S. Mustillo, A. Erkanli, G. Keeler, and A. Angold. 2003. Prevalence and development of psychiatric disorders in childhood and adolescence. *Archives of General Psychiatry* 60:837–844.

Curry, J., P. Rohde, and A. Simons. 2006. Predictors and moderators of acute outcomes in the Treatment for Adolescents with Depression Study (TADS). *Journal of the American Academy of Child & Adolescent Psychiatry* 45:1427–1439.

Fergusson, D. M., L. J. Horwood, E. M. Ridder, and A. L. Bearutrais. 2005. Subthreshold depression in adolescent and mental health outcomes in adulthood. *Archives of General Psychiatry* 62:66–72.

Fernando, K., J. D. Carter, and C. M. Frampton. 2011.Childhood, teenage, and adult-onset depression: Diagnostic and individual characteristics in a clinical sample. *Comprehensive Psychiatry* 52(6):623–629.

Ferrari, A. J., F. J. Charlson , R. E. Norman, S. B. Patten, G. Freedman, C. J. Murray, T. Vos, and H. A. Whiteford. 2013. *PLoS Medicine* 10(11):e1001547.

Findling, R. L., E. A. Youngstrom, M. A. Fristad, B. Birmaher, R. A. Kowatch, L. E. Arnold, and T. W. Frazier. 2010. Characteristics of children with elevated symptoms of mania: The Longitudinal Assessment of Manic Symptoms (LAMS) study. *The Journal of Clinical Psychiatry* 71(12):1664–1672.

Fleming, J. E., and D. R. Offord. 1990. Epidemiology of childhood depressive disorders: A critical review. *Journal of the American Academy of Child & Adolescent Psychiatry* 29(4):571–580.

Gao, K., P. K. Chan, M. L. Verduin, D. E. Kemp, B. K. Tolliver, S. J. Ganocy, S. Bilali, K. T. Brady, R. L. Findling, and J. R. Calabrese. 2010. Independent predictors for lifetime and recent substance use disorders in patients with rapid-cycling bipolar disorder: Focus on anxiety disorders. *The American Journal on Addictions/American Academy of Psychiatrists in Alcoholism and Addictions* 19(5):440–449.

Garrison, C. S., M. D. Schluchter, V. J. Schoesnbach, and B. K. Kaplan. 1989. Epidemiology of depressive symptoms in young adolescents. *Journal of the American Academy of Child & Adolescent Psychiatry* 28:343–351.

Gilman, S. E., I. Kawachi, G. M. Fitzmaurice, and S. L. Buka. 2002. Socioeconomic status in childhood and the lifetime risk of major depression. *International Journal of Epidemiology* 31(2):359–367.

Gilman, S. E., I. Kawachi, G. M. Fitzmaurice, and L. Buka. 2003. Socio-economic status, family disruption and residential stability in childhood: Relation to onset, recurrence and remission of major depression. *Psychological Medicine* 33(8):1341–1355.

Goldstein, B. I. 2012. Recent progress in understanding pediatric bipolar disorder. *Archives of Pediatrics & Adolescent Medicine* 166(4):362–371.

Goldstein, B. I., and O. G. Bukstein. 2010. Comorbid substance use disorders among youth with bipolar disorder: Opportunities for early identification and prevention. *Journal of Clinical Psychiatry* 71(3):348–358.

Goodyer, I. M., B. Dubicka, and P. Wilkinson. 2007. A randomized controlled trial of SSRIs and routine specialist care with and without cognitive behavior therapy in adolescent with major depression. *British Medical Journal* 335:142–146.

Harrington, R., M. Rutter, A. Pickles, and J. Hill. 1990. Adult outcomes of childhood and adolescent depression: I. Psychiatric status. *Archives of General Psychiatry* 47:465–473.

Harrington, R., F. Campbell, P. Shoebridge, and J. Whittaker. 1998. Meta-analysis of CBT for depression in adolescent. *Journal of the American Academy of Child & Adolescent Psychiatry* 37:1005–1007.

Hipwell, A. E., S. Stepp, and X. Feng. 2011. Impact of oppositional defiant disorder dimensions on the temporal ordering of conduct problems and depression across childhood and adolescence in girls. *Journal of Child Psychology and Psychiatry* 52(10):1099–1108.

Jolin, E. M., E. B. Weller, and R. A. Weller. 2008. Anxiety symptoms and syndromes in bipolar children and adolescents. *Current Psychiatry Reports* 10(2):1213–1219.

Jonsson, U., H. Bohman, L. von Knorring, G. Olsson, A. Paaren, and A. L. von Knorring. 2011. Mental health outcome of long-term and episodic adolescent depression: 15-year follow-up of a community sample. *Journal of Affect Disorders* 130(3):395–404.

Keenan-Miller, D., C. L. Hammen, and P. A. Brennan. 2007. Health outcomes related to early adolescent depression. *Journal of Adolescent Health* 41(3):256–262.

Kessler, R. C., P. Berglund, O. Demler, R. Jin, D. Koretz, K. R. Merikangas, A. J. Rush, E. E Walters, and P. S. Wang. 2003. The epidemiology of major depressive disorder: Results from the National Comorbidity Survey Replication (NCS-R). *JAMA* 289(23):3095–3105.

Khazanov, G. K., L. Cui, K. R. Merikangas, and J. Angst. 2015. Treatment patterns of youth with bipolar disorder: Results from the National Comorbidity Survey-Adolescent Supplement (NCS-A). *Journal of Abnormal Child Psychology* 43(2):391–400.

Klein, D. N., C. R. Glenn, D. B. Kosty, J. R. Seeley, P. Rohde, and P. M. Lewinshohn. 2013. Predictors of first time lifetime onset of major depressive disorder in young adulthood. *Journal of Abnormal Psychology* (122):1–16.

Kovacs, M. 1996. Presentation and course of major depressive disorder during childhood and later years of the life span. *Journal of the American Academy of Child & Adolescent Psychiatry* 35(6):705–715.

Kratochil, C., G. Emslie, S. Silva, S. McNulty, J. Walkup, J. Curry, M. Reinecke, B. Vitiello, P. Rohde, N. Feeny, C. Casat, S. Pathak, E. Weller, D. May, T. Mayes, M. Robins, J. March, and TADS Team. 2006. Acute time to response in the Treatment for Adolescents with Depression Study (TADS). *Journal of the American Academy of Child & Adolescent Psychiatry* 45:1412–1418.

Lewinsohn, P. M., P. Rohde, and J. R. Seeley. 1998b. Major depressive disorder in older adolescents: Prevalence, risk factors, and clinical implications. *Clinical Psychology Review* 18(7):765–794.

Li, B., L. Liu, K. J. Friston, H. Shen, L. Wang, L. L. Zeng, and D. Hu. 2013a. A treatment-resistant default mode subnetwork in major depression. *Biological Psychiatry* 74(1):48–54.

Li, J. J., M. S. Berk, and S. S. Lee. 2013b. Differential susceptibility in longitudinal models of gene–environment interaction for adolescent depression. *Development and Psychopathology* 25(4 Pt 1):991–1003.

Luby, J. L., M. S. Gaffrey, R. Tillman, L. M. Arpirl, and A. C. Belden. 2014. Trajectories of preschool disorders to full DSM depression at school age and early adolescent: Continuity of preschool depression. *American Journal of Psychiatry* 171:768–776.

Luking, K. R., G. Repovs, and A. C. Belden. 2011. Functional connectivity of the amygdala in early-childhood-onset depression. *Journal of the American Academy of Child & Adolescent Psychiatry* 50(10):451–459.

March, J., S. Silva, and S. Petrycki. 2004. Fluoxetine, cognitive behavioral therapy, and their combination for adolescents with depression: Treatment for Adolescents with Depression Study (TADS) randomized controlled trial. *JAMA* 292:807–820.

March, J. S., S. Silva, and B. Bitiello. 2006. The Treatment for Adolescents with Depression Study (TADS): Methods and message at 12 weeks. *Journal of the American Academy of Child & Adolescent Psychiatry* 45:1393–1403.

Masi, G., G. Perugi, S. Millepiedi, M. Mucci, C. Toni, N. Berini, C. Pfanner, S. Berloffa, and C. Pari. 2006. Developmental difference according to age at onset in juvenile bipolar disorder. *Journal of Child and Adolescent Psychopharmacology* 16(6):679–685.

Meinzer, M. C., P. M. Lewinsohn, J W. Pettit, J. R. Seeley, J. M. Gau, A. Chronis-Tuscano, and J. G. Waxmonsky. 2013. Attention-deficit/hyepractivy disorder in adolescent predicts onset of major depressive disorder through early adulthood. *Depression and Anxiety* 30(6):546–553.

Melvin, G. A., B. J. Tonge, N. J. King, D. Heyne, M. S. Gordon, and E. Klimkeit. 2006. A comparison of cognitive-behavioral therapy, sertraline, and their combination for adolescent depression. *Journal of the American Academy of Child & Adolescent Psychiatry* 45(10):1151–1161.

Merikangas, K. R., E. F. Nakamura, and R. C. Kessler. 2009. Epidemiology of mental disorders in children and adolescents. *Dialogues in Clinical Neuroscience* 11(1):7–20.

Merikangas, K. R., J. P He, D. Brody, P. W. Fisher, K. Bourdon, and D. S. Koretz. 2010. Prevalence and treatment of mental disorders among U.S. children in the 2001–2004 NHANES. *Pediatrics* 125(1):75–81.

Miklowitz, D. J., A. Biuckians, and J. A. Richards. 2006. Early-onset bipolar disorder: A family treatment perspective. *Development and Psychopathology* 18(4):1247–1265.

Miller, D. B., and J. P. O'Callaghan. 2013. Personalized medicine in major depressive disorder—Opportunities and pitfalls. *Metabolism* 62(Suppl 1):S34–S39.

Mills, N. T., J. G. Scott, N. R. Wray, S. Cohen–Woods, and B. T. Baune. 2013. The role of cytokines in depression in adolescents: A systematic review. *Journal of Child Psychology and Psychiatry* 54(8):816–835.

Mufson, L., M. M. Weissman, D. Moreau, and R. Garfinkel R. 1999. Efficacy of interpersonal psychotherapy for depressed adolescents. *Archives and General Psychiatry* 56(6):573–579.

Mufson, L., K. P. Dorta, P. Wickramaratne, Y. Nomura, M. Olfson, and M. M. Weissman. 2004. A randomized effectiveness trial of interpersonal psychotherapy for depressed adolescents. *Archives of General Psychiatry* 61(6):577–584.

Nivard, M. G., C. V. Dolan, K. S. Kendler, K. J. Kan, G. Willemsen, C. E. M. van Beijsterveldt, R. J. L. Lindauer, J. H. D. A. van Beek, L. M. Geels, and M. Bartels. 2015. Stability in symptoms of anxiety and depression as a function of genotype and environment: A longitudinal twin study from ages 3 to 63 years. *Psychological Medicine–London* 45(5):1039–1049.

Nolen-Hoeksema, S., J. S. Girgus, and M. E. P. Seligman. 1991. Sex differences in depression and explanatory style in children. *Journal of Youth and Adolescence* 20(2):233–245.

Offord, D. R., M. H. Boyle, and Y. Racine. 1989. Ontario Child Health Study: Correlates of disorder. *Journal of the American Academy of Child & Adolescent Psychiatry* 28(6):856–860.

Palagini, L., C. Baglioini, and A. Ciapparelli. 2013. REM sleep dysregulation in depression: State of the art. *Sleep Medicine Reviews* 17(5):377–390.

Penninx, B. W., Y. Milaneschi, F. Lamers, and N. Bogelzangs. 2013. Understanding the somatic consequences of depression: Biological mechanisms and the role of depression symptoms profile. *BMC Medicine* 11:129.

Perlman, S. B., J. C. Fournier, G. Bebko, M. A. Bertocci, A. K. Hinze, L. Bonar, J. R. Almeida, A. Versace, C. Schirda, M. Travis, M. K. Gill, C. Demeter, V. A. Diwadkar, J. L. Sunshine, S. K. Holland, R. A. Kowatch, B. Birmaher, D. Axelson, S. M. Horwitz, L. E. Arnold, M. A. Fristad, E. A. Youngstrom, R. L. Findling, and M. L. Phillips. 2013. Emotional face processing in pediatric bipolar disorder: Evidence for functional impairments in the fusiform gyrus. *Journal of the American Academy of Child & Adolescent Psychiatry* 52(12):1314–1325.e3.

Petersen, A. C., P. A. Sarigiani, and R. E. Kennedy. 1991. Adolescent depression: Why more girls? *Journal of Youth and Adolescence* 20:247–271.

Pini, S., J. D. Maser, L. Dell'Osso, M. Abelli, M. Muti, C. Gesi, and G. B. Cassano. 2006. Social anxiety disorder comorbidity in patients with bipolar disorder: A clinical replication. *Journal of Anxiety Disorders* 20(8):1148–1157.

Rao, U. 2013. Biomarkers in pediatric depression. *Depression and Anxiety* 30:787–791.

Rao, U., C. Hammen, and S. Daley. 1999. Continuity of depression during the transition to adulthood: A 5-year longitudinal study of young women. *Journal of the American Academy of Child & Adolescent Psychiatry* 38(7):908–915.

Reinherz, H. Z., A. D. Paradis, R. M. Giaconia, C. K. Stashwick, and G. Fitzmaurice. 2003. Childhood and adolescent predictors of major depression in the transition to adulthood. *American Journal of Psychiatry* 160:2141–2147.

Richardson, L. P., D. DiGiuseppe, M. Garrison, and D. A. Christakis. 2003. Depression in Medicaid-covered youth: Differences by race and ethnicity. *Archives of Pediatric and Adolescent Medicine* 157(10):984–989.

Rohde, P., P. M. Lewinsohn, D. N. Klein, J. R. Seeley, and J. M. Gau. 2013. Key characteristics of major depressive disorder occurring in childhood, adolescence, emerging adulthood, adulthood. *Clinical Psychological Science* 1(1):41–53.

Rossello, J., and G. Bernal. 1999. The efficacy of cognitive–behavioral and interpersonal treatments for depression in Puerto Rican adolescents. *Journal of Consulting and Clinical Psychology* 67:734–745.

Rushton, J. L., M. Forcier, and R. M. Schectman. 2002. Epidemiology of depressive symptoms in the National Longitudinal Study of Adolescent Health. *Journal of the American Academy of Child & Adolescent Psychiatry* 41(2):199–205.

Rutter, M., C. E. Izard, and P. B. Read. 1986. *Depression in young people: Developmental and clinical perspectives*. New York: Guilford Press.

Sala, R., M. A. Strober, D. A. Axelson, M. K. Gill, J. Castro-Fornieles, T. R. Goldstein, B. I. Goldstein, W. Ha, F. Lio, S. Iyengar, S. Yes, H. Hower, J. Hunt, D. P. Dickstein, N. D. Ryan, M. B. Keller, and B. Birmaher. 2014. Effects of comorbid anxiety disorders on the longitudinal course of pediatric bipolar disorders. *Journal of the American Academy of Child & Adolescent Psychiatry* 53(1):72–81.

Schenkel, L. S., A. M. Passarotti, J. A. Sweeney, and M.N. Pavuluri. 2012. Negative emotion impairs working memory in pediatric patients with bipolar disorder type I. *Psychological Medicine* 42(12):2567–2577.

Schmidt, H. D., R. C. Shelton, and R. S. Duman. 2011. Functional biomarkers of depression: Diagnosis, treatment, and pathophysiology. *Neuropsychopharmacology* 36(12): 2375–2394.

Schneider, B., D. Prvulovic, and V. Oertel-Knochel. 2011. Biomarkers for major depression and its delineation form neurodegenerative disorders. *Progress in Neurobiology* 95(4):703–717.

Serafina, G., M. Pompili, S. Borgwardt, J. Houenou, P. A. Geoffroy, R. Jardri, P. Girardi, and M. Amore. 2014. Brain changes in early-onset bipolar and unipolar depressive disorders: A systematic review in children and adolescents. *European Child & Adolescent Psychiatry* 23(11):1023–1041.

Stephens, J. R., J. L. Heffner, C. M. Adler, T. J. Blom, R. M. Anthenelli, D. E. Fleck, J. A. Welge, S. M. Strakowski, and M. P. DelBello. 2014. Risk and protective factors associate with substance use disorders in adolescent with first-episode mania. *Journal of the American Academy of Child & Adolescent Psychiatry* 53(7):771–779.

Stringaris, A., B. Maughan, W. S. Copeland, E. J. Costello, and A. Angold. 2013. Irritable mood as a symptom of depression in youth: Prevalence, developmental, and clinical correlates in the Great Smoky Mountains Study. *Journal of the American Academy of Child & Adolescent Psychiatry* 52(8):831–840.

Thapar, A., S. Collishaw, D. S. Pine, and A. K. Thapar. 2012. Depression in adolescence. *Lancet* 379(9820):1056–1067.

Weisz, J. R., C. A. McCarty, and S. M. Valeri. 2006. Effects of psychotherapy for depression in children and adolescents: A meta-analysis. *Psychological Bulletin* 132(1):132–149.

Wesselhoeft, R., C. B. Pedersen, P. B. Mortensen, O. Mors, and N. Bilenberg. 2014. Gender–age interaction in incidence rates of childhood emotional disorders. *Psychological Medicine* 11:1–11.

Whitney, J., M. Howe, V. Shoemaker, S. Li, E. M. Sanders, C. Dijamco, T. Acquaye, J. Phillips, M. Singh, and K. Chang. 2013. Socio-emotional processing and functioning of youth at high risk for bipolar disorder. *Journal of Affect Disorders,*148(1):112–117. doi: 10.1016/j.jad.2012.08.016.

Whittle, S., R. Lichter, M. Dennison, N. Vijayakumar, O. Schwartz, M. L. Byrne, J. G. Simmons, M. Yücel, C. Pantelis, P. McGorry, and N. B. Allen. 2014. Structural brain development and depression onset during adolescent: A prospective longitudinal study. *American Journal of Psychiatry* 171(5):564–571.

Part III

Prevalence of Selected Mental Disorders

The task order requires the committee to compare trends in the prevalence of mental disorders in children in the United States with trends in the Supplemental Security Income (SSI) childhood disability population. Part III of the report responds to the task order by providing information on the population-based prevalence estimates and prevalence trends of selected childhood mental disorders which are the most frequently reported cause of disability in the SSI program. The data presented here represent a selection of the data that are directly relevant to the fundamental issue that confronts the SSI disability benefit program for children: whether or not the trends that are being observed in the SSI program are out of line with trends observed in the general population. This introduction provides background information relevant for interpretation of the chapters included in Part III of this report.

COMPARING PREVALENCE TREND DATA WITH SSI DATA

As described in Chapter 2, the trends in the SSI program are not directly comparable to prevalence trends otherwise generated from the general population. Comparisons of SSI trends with any of the data included in the following chapters should take into consideration the major differences outlined in Chapter 2, including the differences between the composition and characteristics of the SSI population versus the general population and the methodological differences in ascertainment and classification of cases of mental disorders in children.

The availability and quality of prevalence trend data for mental disorders in children vary depending on the specific mental disorder. Unfortunately, for many conditions neither cross-sectional prevalence data nor prevalence trend data are available. Each of the following chapters will reference some of the best available population-based data that can be compared to trends in the SSI program for children with mental disorders. As briefly explained in Chapter 2, the sources of relevant data in this report include administrative data, surveillance data, national surveys involving direct assessment or parent report, published meta-analyses, and Medicaid data. Also as explained in Chapter 2, the characteristics of the prevalence data used in this report vary depending on their source.

Generally, prevalence trend data for pediatric mental disorders, based on direct neuropsychological assessment or other systematic measurement of a child's symptoms, is unavailable. In addition, data on patterns and trends of the severity of mental disorders in children are unavailable. With a few exceptions the data referenced in Part III of the report rely on proxies for determining whether a child has a mental disorder, such as parent report of whether a not a child has received diagnosis, whether a child is receiving treatment, or whether the child is receiving special education services for a disorder. As discussed in more detail in Chapter 2, because these methods for identifying cases of a disorder do not directly assess the symptoms of a child, they can be susceptible to error or bias, depending on how cases are ascertained. For example, data based on the receipt of treatment can be biased, because many children who receive treatment may not meet the diagnostic criteria for having a disorder, or conversely many children who have the disorder may not receive treatment. As a result, use of these data sources as a reference to the frequency of a disorder within the population has some limitations. These limitations are discussed in Chapter 2. Additional information about, and references for the methods used in, the national surveys can be found in Appendix D.

In spite of these limitations, the committee concluded the data reviewed in Part III are necessary to meet the requirements of the task order for several reasons. First, the information reviewed by disability examiners during the adjudication process is similar to the information referenced in this report. In particular, the use of special education services and parent reports of diagnoses and symptoms are the same types of data frequently referenced by disability examiners during the adjudication process. Second, disability examiners are not clinicians or researchers, and do not directly assess the symptoms of applicants. Rather, disability examiners are the Social Security Administration (SSA) staff trained to apply regulatory standards to evidence provided by applicants and other medical experts who may directly examine the applicant. The disability adjudication process more closely resembles survey methodology than a clinical assessment. Finally, since no other data are available, every resource should be included to provide the best available information for the SSA's use.

COMORBIDITY DATA

As discussed in Chapter 2, the SSI data contain no usable comorbidity data. As a result, patterns of comorbidity within the SSI population cannot be reliably assessed and cannot be compared with the general population. Descriptions of comorbidity patterns for individual mental disorders in children can be found in Part II of the report. An analysis of the comorbidity within the SSI-eligible population of child Medicaid enrollees with mental disorders is included in Part IV of the report.

RACE AND ETHNICITY DATA

As discussed in Chapter 2, there are no data available from SSA about the race and ethnicity of child SSI recipients. As result, trends in the rates of mental disorders, by race and ethnicity, are not discussed in Part III of the report. Data on the rates of mental disorder diagnoses, by race and ethnicity, among children with disabilities enrolled in Medicaid in 2010, are briefly discussed in Part IV of the report.

MEDICAID DATA

Special notice should be paid to the Medicaid data included in this report. Appendixes F and G contain a report and analysis commissioned by the Institute of Medicine committee and performed by the Center for Health Services Research on Pharmacotherapy, Chronic Disease Management, and Outcomes and the Center for Education and Research on Mental Health Therapeutics at the Rutgers University Institute of Health. The Medicaid report contains an analysis of Medicaid eligibility, service use, and payment data that provides novel insight into the rates of mental disorder diagnoses and treatment among all children who are enrolled in Medicaid as well as among the children who are enrolled in Medicaid on the basis of qualifying for and receiving SSI disability benefits. Each of the following chapters in Part III of the report will reference findings contained in the Medicaid report.

As described in Chapter 2, the Medicaid Analytic eXtract (MAX) provides estimates for national trends in the diagnosis and treatment of mental disorders for children and adolescents living in low-income households. The impetus for the Medicaid analysis came from committee deliberations, where committee members identified several challenges posed by the task order. One issue, as previously articulated in Chapters 2 and 5, is that the vast majority of the SSI population consists of children in families who are near or below the federal poverty level, while the general population is not. The committee determined that MAX data could potentially provide a unique perspective because Medicaid is a means-tested program and, as such, the socioeconomic status of the population of children who are enrolled in Medicaid will be more directly comparable to the socioeconomic status of the population of children who are on SSI.

Each of the following chapters in Part III includes four sections:

1. A review of estimates of prevalence of the mental disorder from the general population.
2. An analysis of trends from the Medicaid report.
3. A summary of trends of allowances and recipients for the mental disorder in question from 2004 to 2013.
4. Conclusions and findings, including a rough estimate of the proportion of potentially eligible children and those who are recipients of SSI benefits.

12

Prevalence of Attention Deficit Hyperactivity Disorder

Attention deficit hyperactivity disorder (ADHD) is important for the Social Security Administration (SSA) and related stakeholders because it tops the list of mental health diagnoses for Supplemental Security Income (SSI) determinations, allowances, and recipients (see Chapter 3) in the under-18 population. While the number of recipients for ADHD increased by more than 60 percent during the 2004–2013 decade, the percent of recipients for ADHD among all recipients for the 10 major childhood mental disorders increased more modestly, from 26 to 34 percent, and plateaued in the final 3 years of the decade. Because allowances did not increase over the decade, the conclusion must be that the average duration of time spent as a child recipient of SSI benefits for ADHD has increased, and the corollary is that allowances and reentries exceeded suspensions, terminations, and age-18 transitions on an annual basis. Another inference from the data in Chapter 3 is that growth in ADHD SSI benefits as a percentage of all SSI benefits may be reaching a steady state or even peaking as the result of gradual restriction of SSI ADHD allowances.

Questions have been raised publicly about the validity of ADHD as a major reason for the increases in SSI benefits for mental health conditions in children. While the large ADHD contribution is a fact, it should be noted that ADHD allowances usually include a comorbid condition that may have a substantial effect on functional impairment in the SSI disability program. ADHD may be listed as the primary diagnosis, but it is often not the sole reason for functional impairment (GAO, 2012).

ESTIMATES OF ADHD PREVALENCE AND PREVALENCE TRENDS FROM THE GENERAL POPULATION

The information available on changes in the prevalence of ADHD in children varies in quality depending on the data source. There are no population-wide, longitudinal epidemiologic studies of the prevalence of ADHD in the United States in the under-18 population; however, there are several cross-sectional national surveys that have produced estimates of the prevalence of ADHD in children over several different years, relying on either diagnostic interviews (National Health and Nutrition Examination Survey [NHANES]) or parental reports of diagnoses (National Health Interview Survey {NHIS], National Survey of Children's Health {NSCH]).

Prevalence of ADHD

Prevalence of ADHD Based on National Surveys of Parents

The prevalence of ADHD has been reported from several nationally representative surveys, but rarely using clinical criteria, which require multiple informants, a range of symptoms, and significant functional impairment (Birmaher et al., 2007). The survey that meets these criteria most closely was the 2001–2004 NHANES (N = 3,042 aged 8–15), based on parent reports using the Diagnostic Interview Schedule for Children (Froehlich et al., 2007; Merikangas et al., 2010). The prevalence of ADHD with impairment over the past 12 months was 7.8 percent (8.6 percent if impairment was not considered).

Other nationally-representative surveys have tended to use one or two questions that do not ask about specific symptoms or directly assess the child. The Centers for Disease Control and Prevention's NSCH in 2007 (91,642 children aged 0–17) and 2011/2012 (95,677 children aged 0–17) used a sequence of questions directed to parents to evaluate whether a child had ADHD (Blumberg et al., 2012). The first question in the survey was, "Has a doctor or health professional ever told you that (child's name) has Attention Deficit Disorder or Attention Deficit Hyperactive Disorder, that is, ADD or ADHD?" If the parent responded yes to the first question, then several follow-up questions were asked: "Does (child's name) currently have the condition?" "Would you describe his/her condition as mild, moderate, or severe?" and "Is (child's name) currently taking medication for ADD or ADHD?" (Visser et al., 2014). Results of the 2007 and 2011–2012 NSCH are summarized in Table 12-1.

Since 1997, the NHIS has included a question assessing ADHD in children (National Health Interview Survey and National Center for Health Statistics, 2010). Parents of children aged 2–17 are asked, "Has a doctor

TABLE 12-1 NSCH, Parent Report of Children Who Currently Have ADHD

Source	Year	Question	Percent of Children with ADHD	Age Range
NSCH, 2007	2007	Current ADHD	6.4% (CI 6.0–6.8%)	2–17
NSCH, 2012a	2011/2012	Current ADHD, no current medication treatment	2.5 (CI 2.2–2.7%)	2–17
NSCH, 2012a	2011/2012	Current ADHD, current medication treatment	5.4% (CI 5.1–5.7%)	2–17
Visser et al., 2007	2007	Current ADHD, no current medication treatment	7.8% (95% CI 7.4%–8.1%)	4–17
Visser et al., 2007	2007	Current ADHD, current medication treatment	4.3% (95% CI 4.1%–4.6%)	4–17
Visser et al., 2014	2011	Current ADHD and current medication treatment	8.8% (CI 8.4–9.3%)	4–17
Visser et al., 2014	2011	Current ADHD, no current medication treatment	6.1% (CI 5.7–6.5%)	4–17
Perou et al., 2013	2007	Current ADHD and current medication treatment	6.8% (C.I. 6.4–7.2%)	3–17

NOTE: CI = confidence interval.
SOURCES: NSCH, 2007, 2012a; Perou et al., 2013; Visser et al., 2007, 2014.

or health professional ever told you that [the child] had attention-deficit/hyperactivity disorder (ADHD) or attention deficit disorder (ADD)?" (Perou et al., 2013). Findings from the NHIS are summarized below, in Tables 12-2 and 12-3.

As discussed in Chapter 2, survey data from NHIS and NSCH identify those children thought by a parent to have been diagnosed with ADHD, and may not accurately reflect the prevalence of those whose symptoms have been directly assessed or diagnosed by a professional. The NHIS data include some evidence of potential bias and error in the ADHD survey results. Beginning in 2001, the NHIS included questions from the Strengths and Difficulties Questionnaire (SDQ), which is a screening tool for identifying emotional and behavioral problems in children (Goodman, 1997).

TABLE 12-2 NHIS Parent Reports of Children Who Have Ever Received a Diagnosis or Have Ever Had a Doctor or Health Professional Tell Them That Their Child Has ADHD

Source	Year	Percent of Children with ADHD	Age Range
Boyle et al., 1996	1997–1999	5.70%	(3–17)
Boyle et al., 2011	2000–2002	6.70%	(3–17)
Boyle et al., 2011	2003–2005	6.80%	(3–17)
Boyle et al., 2011	2006–2008	7.60%	(3–17)
Perou et al., 2013	2007–2008	7.6% (CI 7.1–8.2%)	(3–17)
Perou et al., 2013	2009–2010	8.5% (CI 8.0–9.0%)	(3–17)
Perou et al., 2013	2011	8.4% (CI 7.8–9.1%)	(3–17)

NOTE: CI = confidence interval.
SOURCES: Boyle et al., 1996, 2011; Perou et al., 2013.

TABLE 12-3 Percentage of Children Ages 3 to 17 Reported to Have Ever Been Diagnosed by a School or a Health Professional as Having ADHD: 1997–2013

Year	1997	1998	1999	2000	2001	2002	2003	2004
Total	5.5	5.9	5.6	6.6	6.4	7.2	6.4	7.4
Sex								
Male	8.3	8.5	8.4	9.3	9.1	10.3	9.0	10.2
Female	2.6	3.2	2.7	3.8	3.5	4.0	3.6	4.5
Race/Hispanic origin								
Non-Hispanic white	6.5	7.0	6.7	8.0	7.4	8.3	7.5	8.7
Non-Hispanic black	4.3	4.9	4.3	5.0	5.7	7.8	6.0	8.1
Hispanic	3.3	3.5	2.7	3.8	3.5	3.7	3.7	4.0
Non-Hispanic other	2.4	2.2	3.8	2.1	3.7	1.8	3.1	2.6
Age group								
Ages 3–4	0.5	0.7	0.6	1.0	0.8	1.0	0.7	1.9
Ages 5–11	5.9	6.1	5.3	6.5	6.3	6.8	6.3	6.5
Ages 12–17	6.8	7.5	7.7	8.6	8.3	9.6	8.3	10.3
Poverty status								
Below federal poverty level (FPL)	–	6.7	7.7	7.0	7.1	9.7	7.0	7.5
At or above the FPL	–	6.0	5.8	7.3	6.5	7.2	6.8	7.7
100–199% of the FPL	–	–	–	–	–	–	–	–
Above 199% of the FPL	–	–	–	–	–	–	–	–

SOURCE: Child Trends, 2014; used with permission.

The SDQ questions used in the NHIS were related to attention span and concentration. A study of the NHIS results from 2001 to 2007 showed that approximately 50 percent of children who either had a high score on the SDQ or had serious overall difficulties as reported by parents, also had a diagnosis of ADHD as reported by the same parents (Pastor et al., 2012). In addition, there is also evidence that health care professionals frequently do not fully comply with accepted guidelines for diagnosis (Epstein et al., 2014). There is also evidence that children who are treated for ADHD may not meet the diagnostic criteria for ADHD in many cases (Zima et al., 2010).

Prevalence of ADHD Based on Direct Interviews of Adolescents

The nationally representative National Comorbidity Survey-Replication Adolescent Supplement (NCS-A) generated estimates of the prevalence of ADHD based on face-to-face surveys of more than 10,000 adolescents, ages 13–17. ADHD was assessed using a modified version of the World Health

2005	2006	2007	2008	2009	2010	2011	2012	2013
6.6	7.4	7.3	8.0	8.6	8.4	8.4	9.5	8.8
9.2	10.7	10.0	11.1	11.8	11.2	12.0	13.5	12.0
3.8	4.0	4.3	4.8	5.3	5.5	4.7	5.4	5.5
7.4	8.6	8.4	9.8	10.0	9.9	10.0	9.4	10.7
7.1	7.5	7.9	8.4	10.6	10.7	8.6	5.7	8.4
4.6	5.0	4.0	4.2	5.0	4.3	5.6	11.7	6.3
2.4	2.4	4.7	3.5	2.3	2.8	3.8	5.1	3.0
0.7	0.6	2.0	2.0	1.5	1.7	1.8	1.7	1.7
6.1	7.4	5.9	7.3	7.6	7.6	7.5	9.5	8.6
8.9	9.7	10.5	11.1	12.2	11.6	11.9	12.1	11.4
7.9	9.4	9.0	10.1	10.5	10.5	10.4	12.3	11.6
6.7	7.7	7.6	8.3	8.2	7.4	8.1	9.2	8.1
–	–	–	–	10.5	10.5	7.0	9.6	8.5
–	–	–	–	7.3	7.3	8.6	9.0	8.0

Organization Composite International Diagnostic interview. The NCS-A survey produced a 30-day estimate of 4.5 percent, and a 12-month estimate of 6.5 percent (Kessler et al., 2012). The NCS-A survey also produced a lifetime estimate of 8.7 percent, where 4.2 percent of adolescents with ADHD had severe impairment (Merikangas et al., 2010).

Prevalence Trends of ADHD Based on Assessments of a Child's Symptoms

The most recent review of prevalence trends is Polanczyk and colleagues' 2014 meta-regression analysis of 135 studies using *Diagnostic and Statistical Manual of Mental Disorders* (DSM) or *International Classification of Diseases* criteria for ADHD. The review incorporates a test of whether there has been evidence of changing rates of ADHD over time, by year of assessment (or year of publication if year of assessment was not provided). This study may be the best available scientific effort to assess the trends in the prevalence of ADHD while controlling for variations in survey methodology and survey population. The studies were published between 1985 and 2012, and controlled for several methodological factors that contribute to variation in estimates, including geographic location. The mean prevalence estimate was just over 5 percent, and this did not vary significantly between 1985 and 2012. Studies using DSM-IV produced higher rates than those using other taxonomies. Estimates are, however, widely varied, for reasons that are both methodological and based on differences among populations sampled. For example, variation in educational policies may influence local rates of ADHD (Fulton et al., 2015).

TRENDS IN THE RATES OF ADHD AMONG SSI AND MEDICAID POPULATIONS

This section of the report presents data on trends in the rates of ADHD in the SSI program for children from 2004 to 2013 and in Medicaid from 2001 to 2010.

SSI

Table 12-4 presents the SSI administrative data on ADHD in children. Column 1 shows the number of child allowances made on the basis of ADHD at the initial level for each year. Column 2 shows the number of child recipients who received SSI benefits on the basis of ADHD in December of each year. Column 3 shows the estimated number of children in households with family income below 200 percent of the federal poverty level (FPL) for each year. To control for the changes in the magnitude of child poverty, the numbers shown are for the allowances and recipients as a percentage of the number of children in households under 200 percent FPL

TABLE 12-4 SSI Child Initial Allowances and Recipient Numbers for ADHD

	1	2	3	4	5
Year	# of Child SSI Allowances for ADHD	# of Child SSI Recipients for ADHD	# of Children in Households Under 200% FPL	% of Children Under 200% FPL Allowed SSI Benefits for ADHD	% of Children Under 200% FPL Who Are Recipients of SSI Benefits for ADHD
2004	28,739	138,921	28,753,000	0.10%	0.48%
2005	28,023	155,847	28,539,000	0.10%	0.55%
2006	25,959	169,863	28,757,000	0.09%	0.59%
2007	24,630	180,665	28,999,000	0.09%	0.62%
2008	26,303	189,868	30,064,000	0.09%	0.63%
2009	27,668	199,866	31,505,000	0.09%	0.63%
2010	30,106	211,478	32,254,000	0.09%	0.66%
2011	29,871	220,708	32,678,000	0.09%	0.68%
2012	27,772	225,035	32,269,000	0.09%	0.70%
2013	24,181	226,363	31,364,000	0.08%	0.72%

NOTE: The Current Population Survey table creator was used to generate numbers of children below 200 percent of the federal poverty level. Parameters used to generate the numbers include get count of: persons in poverty universe (everyone except unrelated individuals under 15); years: 2004 to 2013; Census 2010 weights; row variable: age; column variable: income-to-poverty ratio; and customized formatting: income-to-poverty ratio percent cutoff of 200 percent.

SOURCES: U.S. Census Bureau, 2015; unpublished data set provided by the SSA.

for each year. Column 4 shows the percentage of children in households under 200 percent FPL who were allowed benefits for ADHD (i.e., were found to be severely impaired with a primary diagnosis of ADHD) in each year. Column 5 shows the percentage of children in households under 200 percent FPL who were recipients of SSI payments for ADHD in December of each year. Figure 12-1 plots the percentages from columns 4 and 5 along with the 10-year average of the percentages of allowances and recipients for ADHD as a visual reference point.

Over the 10-year period from 2004 to 2013, the rate of child SSI ADHD recipients increased, while the rate of child SSI ADHD allowances may have decreased. The rate of child ADHD allowances among children in households under 200 percent FPL between 2004 and 2013 decreased from 0.10 to 0.08 percent, a 23 percent decrease. In contrast, the rate of child ADHD recipients between 2004 and 2013 increased from 0.48 to 0.72 percent, a 50 percent increase.

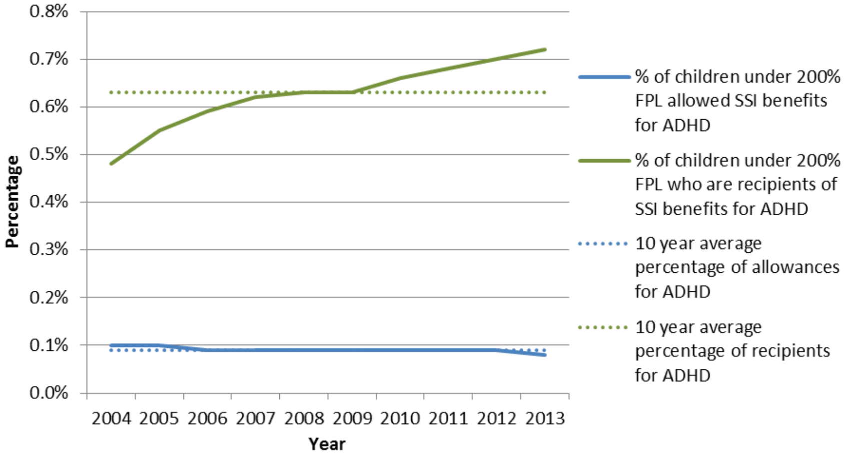

FIGURE 12-1 Percentages of SSI child initial allowances and recipients for ADHD under 200 percent FPL.
NOTE: The Current Population Survey table creator was used to generate numbers of children below 200 percent of the federal poverty level. Parameters used to generate the numbers include get count of: persons in poverty universe (everyone except unrelated individuals under 15); years: 2004 to 2013; Census 2010 weights; row variable: age; column variable: income-to-poverty ratio; and customized formatting: income-to-poverty ratio percent cutoff of 200 percent.
SOURCES: U.S. Census Bureau, 2015; unpublished data set provided by the SSA.

Trends in the number of ADHD allowances and recipients should be interpreted cautiously, keeping in mind that the ADHD impairment code contributes by far the largest number determinations every year in the SSI program. As mentioned in Chapter 3, the ADHD impairment code is 40 to 50 percent of all determinations each year, and more than triple any other mental disorder impairment code reviewed in this study. In addition, the allowance rate for the ADHD impairment code is low, approximately 22 percent, and the approximately 70 percent of ADHD allowances are allowances that functionally equal the listings. Several conclusions might be drawn from these findings. First, it might be the case that the majority of the child SSI applications for mental disorders include either evidence of ADHD or a record of a diagnosis for ADHD. Second, it might be the case that disability examiners use the ADHD impairment code as a catch-all category, assigning the impairment code to cases where the other impairment codes may not fit. The use of ADHD as a catch-all category may be both for denials and for allowances. In the case of allowances, it may be the

TABLE 12-5 Percentage of Child Medicaid Enrollees and SSI Medicaid Enrollees Diagnosed with ADHD

Year	1 % of All Child Medicaid Enrollees with ADHD Diagnosis	2 % of Child SSI Medicaid Enrollee Subpopulation with ADHD Diagnosis
2001	3.0%	10.7%
2002	3.2%	11.3%
2003	3.5%	12.3%
2004	3.9%	13.1%
2005	4.2%	14.4%
2006	4.3%	14.2%
2007	4.7%	14.5%
2008	5.1%	15.7%
2009	5.4%	17.3%
2010	5.5%	17.7%

SOURCE: MAX data.

case that the ADHD listing is the most flexible or permissive, and may accommodate cases where the applicant has unspecified or comorbid mental disorders that result in severe impairment, but do not fit within any other listing. Currently, there are no data available from the SSI program to further elucidate the role of comorbidity in ADHD allowances and recipients.

Medicaid

Table 12-5 shows the percentage of children who were diagnosed with ADHD in two different groups of Medicaid enrollees for each year from 2001 to 2010. Column 1 shows the percentage of ADHD diagnoses among all Medicaid enrollees[1] for each year. Column 2 shows the percentage of ADHD diagnoses among the smaller subpopulation of Medicaid enrollees who were eligible to be enrolled in Medicaid on the basis of receiving SSI benefits.[2]

As shown in Figure 12-2, the rates of ADHD diagnoses among all child Medicaid enrollees and among child SSI-eligible Medicaid enrollees both increased between 2001 and 2010. The rate of ADHD diagnoses among all Medicaid enrollees increased by 81 percent from 2001 to 2010; the absolute increase was 2.5 percentage points. The rate of ADHD diagnoses

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[1] Refer to Appendix F for Rutgers methods section.

[2] Ibid.

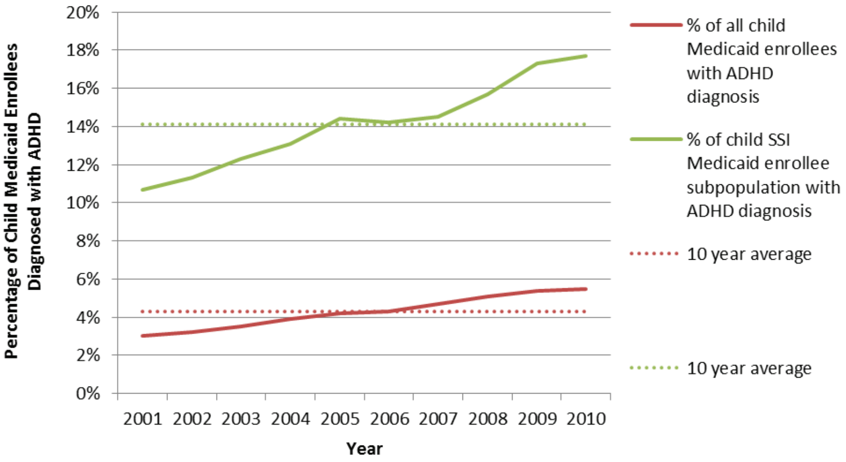

FIGURE 12-2 Percentage of child Medicaid enrollees and SSI Medicaid enrollees diagnosed with ADHD.
SOURCE: MAX data.

among the SSI-eligible subpopulation of Medicaid enrollees increased by 66 percent; the absolute increase was 7 percentage points. The greater frequency of ADHD in the SSI-eligible subpopulation is expected, because that subpopulation is defined by being disabled, while many in the general Medicaid population are not disabled.

For the years in which the Medicaid data and the SSI administrative data overlapped, 2004–2010, the rate of ADHD diagnoses among all Medicaid-enrolled children increased by 40 percent; the rate of ADHD diagnoses among SSI-eligible Medicaid-enrolled children increased by 35 percent; and the rate of SSI recipients for ADHD among children in households under 200 percent FPL increased by 38 percent. These trends are remarkably similar and confirm that the numbers of children who received SSI benefits on the basis of an ADHD diagnosis have not grown faster than comparison populations.

DISCUSSION

The consensus committee assessed changes or trends in prevalence of ADHD seen in the SSI data and compared these with trends in the Medicaid population (using billing data) and in the general population (using surveys and interviews with parents and/or children). The data presented in this chapter demonstrate two trends: (1) increasing rates where diagnoses are based on actual or parent-reported clinician judgment and (2) no evidence of increasing rates (from the meta-regression analysis) where diagnoses are based on parent- and/or child-reported symptoms. There are no studies of Medicaid or SSI populations that use diagnoses based on parent- and/or child-reported symptoms.

To be clear, some surveys ask parents whether a professional has told them that the child has ADHD, and these show increased prevalence over time, while the meta-analysis of direct parent/child interviews indicates that the prevalence of ADHD is not increasing after controlling for a number of variables, including methodological differences. The increases observed within the SSI program, within the Medicaid population, and in some surveys of the general population may be related to changes in diagnostic access and practices that are leading to children being identified as having ADHD at a higher frequency. Since the SSI program requires a "medically determinable impairment" and relies on a diagnosis—or diagnoses, in the case of comorbid conditions—from an "acceptable medical source," changes in medical diagnostic practice will directly affect the rates of disorders in the SSI program. In other words, the changes in diagnostic access and practices that have resulted in an increase in the number of ADHD diagnoses will be observed in the Medicaid data, and reflected in the national survey data and SSI program, because these latter two sources rely on reports of a diagnosis from a health care provider. The meta-regression data do not rely on diagnoses from health care providers, but rather on assessment of a child's symptoms, and therefore do not show the same increase. The implication of these findings is that the increase in ADHD observed within the SSI program is consistent with an increase in the diagnosis of ADHD in the general population, but not necessarily an increase in the rates of children who have symptoms that meet various criteria for ADHD.

Furthermore, based on general population estimates of ADHD and the rate of child poverty, it may be the case that the SSI program is providing benefits to a relatively small proportion of the population of children who would otherwise be eligible to receive benefits. The NSCH 2011–2012 estimate of the prevalence of children (age 2–17) with severe or moderate ADHD, as reported by parents, was 4.6 percent (NSCH, 2012b). The estimated number of children under 200 percent FPL in 2012 was 32,269,000 (U.S. Census Bureau, 2015).[3] Therefore, the estimated number of children with current moderate to severe ADHD under 200 percent FPL would be

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[3] The Current Population Survey table creator was used to generate numbers of children below 200 percent of the federal poverty level. Parameters used to generate the numbers include get count of: persons in poverty universe (everyone except unrelated individuals under 15); years: 2004 to 2013; Census 2010 weights; row variable: age; column variable: income-to-poverty ratio; and customized formatting: income-to-poverty ratio percent cutoff of 200 percent.

1,484,374. (This probably underestimates the number, because the NSCH estimate is for the whole population, and ADHD occurs in higher frequencies in low-income populations.) In 2012 there were 225,035 child recipients of the SSI benefits for ADHD. Based on these assumptions, approximately 15 percent of children in low-income households with moderate or severe ADHD were recipients of SSI benefits for ADHD in 2012. Figure 12-3 illustrates these relationships.

FINDINGS

- Prevalence estimates for ADHD in the general population of youth fall into the 5 percent or greater range, depending on the source of the estimate and survey methodology.
- Estimates of the prevalence of ADHD that apply diagnostic criteria based on assessment of a child's symptoms, are lower than estimates derived from parent reports of health care provider diagnoses of ADHD. There is no evidence of an increase in the prevalence of ADHD based on assessments of a child's symptoms; however, there is evidence of an increase in the frequency of diagnoses for ADHD based on parent report and from Medicaid billing records.
- The increase in the prevalence of ADHD diagnoses found by the national surveys based on parent interviews approaches that of the increase in the number of youth with ADHD in the SSI recipients group (approximately 60 percent over 10 years). Similarly, the cumulative percentage increase in the percentage of ADHD diagnoses in child Medicaid enrollees from 2004 to 2010 is similar to the increase in the percentage of children in low-income households who are recipients of SSI benefits for ADHD.

CONCLUSIONS

- The available evidence on the prevalence of ADHD in children shows (1) increasing rates where diagnoses are based on actual or parent-reported clinician judgment and, (2) no evidence of increasing rates (from the meta-regression analysis) where diagnoses are based on parent- and/or child-reported symptoms. The implication of these findings is that the increase in ADHD observed within the SSI program is consistent with an increase in the diagnosis of ADHD in the general population, but not necessarily an increase in the rates of children who have symptoms that meet various criteria for ADHD. The frequency of ADHD diagnoses relative to that of other mental disorders (and, in particular, mood disorders and oppositional defiant disorder/conduct disorder) is greater in the SSI

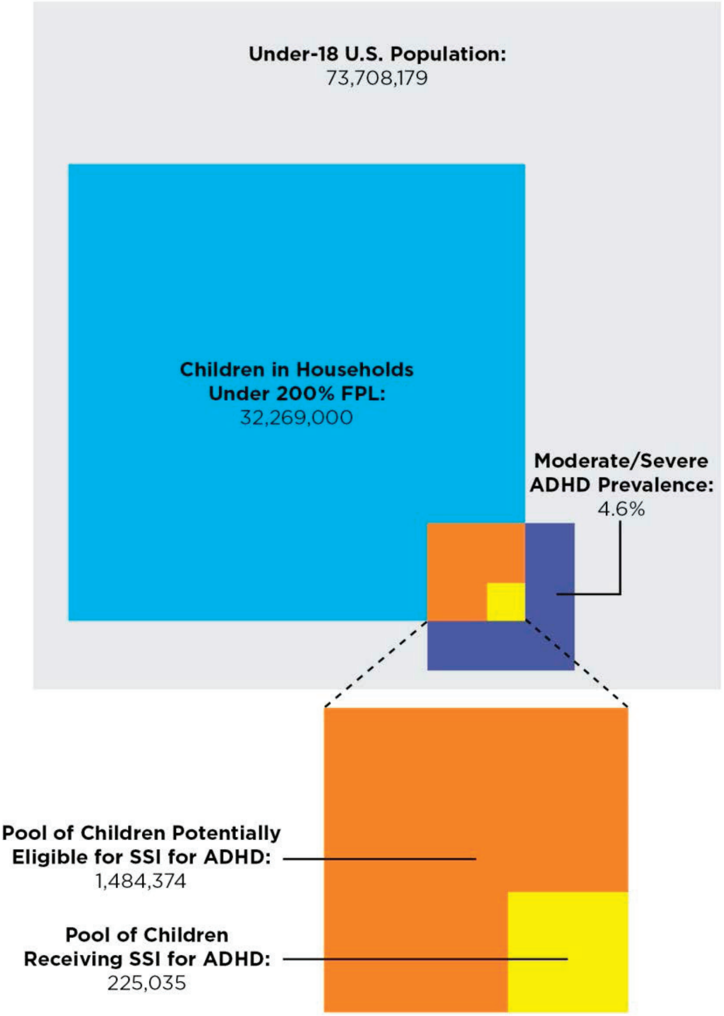

FIGURE 12-3 Children potentially eligible for SSI for ADHD versus children receiving SSI for ADHD in 2012, according to the NSCH.
NOTE: The Current Population Survey table creator was used to generate numbers of children below 200 percent of the federal poverty level. Parameters used to generate the numbers include get count of: persons in poverty universe (everyone except unrelated individuals under 15); years: 2004 to 2013; Census 2010 weights; row variable: age; column variable: income-to-poverty ratio; and customized formatting: income-to-poverty ratio percent cutoff of 200 percent.
SOURCES: NSCH, 2012b; U.S. Census Bureau, 2014, 2015; unpublished data set provided by the SSA.

population than in the general population. A possible explanation is that ADHD serves as a catch-all diagnostic category for children with multiple and unspecified mental disorders within the SSI program.

- Based on 2012 estimates of the number of children below 200 percent of the federal poverty level and the prevalence of moderate to severe ADHD in children nationally, it appears that only a small proportion of children who were potentially eligible for SSI benefits due to ADHD were in fact recipients.

REFERENCES

Birmaher, B., D. Brent, W. Bernet, O. Bukstein, H. Walter, R.S. Benson, A. Chrisman, T. Farchione, L. Greenhill, J. Hamilton, H. Keable, J. Kinlan, U. Schoettle, S. Stock, K. K. Ptakowski, and J. Medicus. 2007. Practice parameter for the assessment and treatment of children and adolescents with depressive disorders. *Journal of the American Academy of Child & Adolescent Psychiatry* 46(11):1503–1526.

Blumberg, S. J., E. B. Foster, A. M. Frasier, J. Satorius, B. J. Skalland, K. L. Nysse-Carris, H. M. Morrison, S. R. Chowdhury, and K. S. O'Connor. 2012. Design and operation of the National Survey of Children's Health, 2007. National Center for Health Statistics. *Vital and Health Statistics* 1(55):1–149. http://purl.fdlp.gov/GPO/gpo46838 (accessed July 15, 2015).

Boyle, C. A., M. Yeargin-Allsop, N. S. Doernberg, C. C. Murphy, and D. E. Schendel. 1996. Prevalence of selected developmental disabilities in children 3–10 years of age: The Metropolitan Atlanta Developmental Disabilities Surveillance program, 1991. *Morbidity and Mortality Weekly Report* 45(SS-2):1–14.

Boyle, C. A., S. Boulez, L. A. Schieve, R. A. Cohen, S. J. Blumberg, M. Yeargin-Allsopp, S. Visser, and M. D. Kogan. 2011. Trends in the prevalence of developmental disabilities in U.S. children, 1997–2008. *Pediatrics* 127(6):1034–1042.

Child Trends. 2014. Original analysis by Child Trends of National Health Interview Survey data 1997–2013. ADHD. www.childtrends.org/?indicators=ADHD (accessed July 11, 2015).

Epstein, J. N., K. J. Kelleher, R. Baum, W. B. Brinkman, J. Peugh, W. Gardner, P. Lichtenstein, and J. Langberg. 2014. Variability in ADHD care in community-based pediatrics *Pediatrics* 134(6):1136–1143.

Froehlich, T. E., B. P. Lanphear, J. N. Epstein, W. J. Barbaresi, S. K. Katusic, and R. S. Kahn. 2007. Prevalence, recognition, and treatment of attention-deficit/hyperactivity disorder in a national sample of US children. *Archives of Pediatrics & Adolescent Medicine* 161(9):857–864.

Fulton, B. D., R. M. Scheffler, and S. P. Hinshaw. 2015. State variation in increased ADHD prevalence: Links to NCLB school accountability and state medication laws. *Psychiatric Services* 66(10):1074–1082.

GAO (U.S. Government Accountability Office). 2012. *Supplemental Security Income: State trends in applications, allowances, and benefit receipts for children with mental impairments (GAO-12-498SP, June 2012), an e-supplement to* GAO-12-497. Washington, DC: GAO. http://purl.fdlp.gov/GPO/gpo25627 (accessed July 11, 2015).

Goodman, R. 1997. The Strengths and Difficulties Questionnaire: A research note. *Journal of Child Psychology and Psychiatry* 38(5):581–586.

Kessler, R. C., M. Petukhova, N. A. Sampson, A. M. Zaslavsky, and H.-U. Wittchen. 2012. Twelve-month and lifetime prevalence and lifetime morbid risk of anxiety and mood disorders in the United States. *International Journal of Methods in Psychiatric Research* 21(3):169–184.

Merikangas, K. R., J. P. He, M. Burstein, S. A. Swanson, S. Avenevoli, L. Cui, C. Benjet, K Georgiades, and J. Swendsen. 2010. Lifetime prevalence of mental disorders in US adolescents: Results from the National Comorbidity Survey Replication-Adolescent Supplement (NCS-A). *Journal of the American Academy of Child & Adolescent Psychiatry* 49(10):980–989.

National Health Interview Survey and National Center for Health Statistics. 2010. *National Health Interview Survey*. Hyattsville, MD: The Center.

NRC and IOM (National Research Council and Institute of Medicine). 2009. *Preventing mental, emotional, and behavioral disorders among young people: Progress and possibilities*. Washington, DC: The National Academies Press.

NSCH (National Survey of Children's Health). 2007. Data query from the child and adolescent health measurement initiative. www.childhealthdata.org/browse/survey/results?q=1208 (accessed July 29, 2015).

NSCH. 2012a. Data query from the child and adolescent health measurement initiative. www.childhealthdata.org/browse/survey/results?q=2482&r=1 (accessed July 29, 2015).

NSCH. 2012b. Data query from the child and adolescent health measurement initiative. http://childhealthdata.org/browse/survey/results?q=2484&r=1 (accessed July 29, 2015).

Pastor, P. N., C. A. Reuben, and C. R. Duran. 2012. Identifying emotional and behavioral problems in children aged 4–17 years: United States, 2001–2007. *National Health Statistics Reports* (48):1–17.

Perou, R., R. H. Bitsko, S. J. Blumberg, P. Pastor, R. M. Ghandour, J. C. Gfroerer, S. L. Hedden, A. E. Crosby, S. N. Visser, L. A. Schieve, S. E. Parks, J. E. Hall, D. Brody, C. Simile, W. W. Thompson, J. Baio, S. Avenevoli, M. D. Kogan, and L. N. Huang. 2013. Mental health surveillance among children—United States, 2005–2011. *Morbidity and Mortality Weekly Report* 62(2):1–35.

Polanczyk, G. V., E. G. Willcutt, G. A. Salum, C. Kieling, and L. A. Rohde. 2014. ADHD prevalence estimates across three decades: An updated systematic review and meta-regression analysis. *International Journal of Epidemiology* 43(2):434–442.

U.S. Census Bureau. 2014. Total population by child and adult populations. http://datacenter.kidscount.org/data/tables/99-total-population-by-child-and-adult-populations?loc=1&loct=1#detailed/1/any/false/35,18,17,16,15/39,41/416,417 (accessed November 14, 2014).

U.S. Census Bureau. 2015. CPS table creator. www.census.gov/cps/data/cpstablecreator.html (accessed July 13, 2015).

Visser, S. N., C. A. Lesesne, and R. Perou. 2007. National estimates and factors associated with medication treatment for childhood attention-deficit/hyperactivity disorder. *Pediatrics* 119(Suppl 1):S99–S106.

Visser, S. N., M. L. Danielson, R. H. Bitsko, J. R. Holbrook, M. D. Kogan, R. M. Ghandour, R. Perou, and S. J. Blumberg. 2014. Trends in the parent-report of health care provider-diagnosed and medicated attention-deficit/hyperactivity disorder: United States, 2003-2011. *Journal of the American Academy of Child and Adolescent Psychiatry* 53(1):34–46.

Zima, B. T., R. Bussing, L. Tang, L. Zhang, S. Ettner, T. R. Belin, and K. B. Wells. 2010. Quality of care for childhood attention-deficit/hyperactivity disorder in a managed care Medicaid program. *Journal of the American Academy of Child and Adolescent Psychiatry* 49(12):1225–1237.

13

Prevalence of Oppositional Defiant Disorder and Conduct Disorder

Among the selected mental disorders, disruptive behavior disorders (DBDs) of childhood (oppositional defiant disorder and conduct disorder, or ODD/CD) are the basis for a relatively small percentage of Supplemental Security Income (SSI) allowances and for a relatively small percentage of the children who are receiving SSI benefits. Of the selected mental disorders for all years between 2004 and 2013, approximately 5 percent of the allowances were for either ODD or CD. The DBDs were the basis for 4.8 percent of all child SSI recipients in 2013, up from 4.9 percent in 2004. In 2009 a meta-analysis reported by an Institute of Medicine consensus committee estimated that the childhood prevalence of any DBD was 6.1 percent[1] (confidence interval [CI] 5.4–7.3 percent) (NRC and IOM, 2009). The prevalence of CD was estimated to be 3.5 percent[2] (CI 2.7–4.7 percent), and the prevalence of ODD was estimated to be 2.8 percent[3] (CI 2.1–3.7 percent) (NRC and IOM, 2009).

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[1] Prevalence estimates for DBD, CD, and ODD were retrieved from Table 2-2 in *Preventing Mental, Emotional, and Behavioral Disorders Among Young People: Progress and Possibilities* (NRC and IOM, 2009). Table 2-2 presents the results of a meta-analysis of data on the prevalence of mental, emotional, and behavioral disorders in young people from more than 50 community surveys around the world, published in the past 15 years (updated from Costello et al., 2003). The analysis controlled for sample size, number of prior months that subjects were asked about in reporting their symptoms, and age of participants (NRC and IOM, 2009). A list of the data sets used in the meta-analysis is included in the above-mentioned report (NRC and IOM, 2009).

[2] Ibid.

[3] Ibid.

Although the DBDs represent a relatively small portion of all the SSI disability in children, they likely play an important and significant role in causing disability as a co-occurring or comorbid condition. As discussed in Chapter 7, CD and ODD rarely occur in isolation, and both have very high rates of comorbidity with attention deficit hyperactivity disorder (ADHD) and mood and anxiety disorders. However, due to the nature of the adjudication process (see Chapter 2), and the type of data and quality of data that are collected about SSI allowances, it is not possible to evaluate the amount and severity of disability caused by ODD or CD as a secondary disorder within the SSI program. Nevertheless, an understanding of the prevalence of ODD and CD will be important for the SSI disability benefit program for children because of the relationship between DBDs and other mental disorders in children (in particular ADHD and depression) and because of the nature and severity of the impairments that can be caused by CD/ODD, both independently and in combination with others disorders.

ESTIMATES OF ODD AND CD PREVALENCE AND PREVALENCE TRENDS FROM THE GENERAL POPULATION

Prevalence of ODD and CD

As is the case with other psychiatric disorders of children, prevalence estimates of ODD and CD in the general population primarily employ surveys of parents, children, or both to arrive at diagnoses within a cohort and weights that estimate to the larger population. Some of these surveys, such as the National Comorbidity Survey, gather lifetime prevalence estimates among adults, while others focus on point-in-time estimates using parent surveys with or without teacher surveys and child interviews (Kessler, 2013).

The lifetime prevalence of ODD was 10.2 percent in an adult community sample, with men at 11.2 percent and women at 9.2 percent (Nock et al., 2007). Almost all respondents with ODD reported comorbid mood, anxiety, or drug disorders, but, for the most part, the ODD occurred prior to the onset of other symptoms. The median duration of symptoms was 5 to 6 years. The adolescent replication of the National Comorbidity Study provided higher estimates of lifetime prevalence, with 12.6 percent of the sample positive for ODD (6.5 percent severe) and 6.8 percent positive for CD (Merikangas et al., 2010). Point prevalence estimates of ODD in children from community samples range from 2 to 16 percent, but most estimates from stratified community samples range from 1 to 3 percent.

Cross-sectional prevalence varies by study design, ascertainment, and analyses, but the Centers for Disease Control and Prevention employed the National Survey of Children's Health (NSCH) to provide a combined prevalence estimate for ODD and CD. In 2007, parent-reported data asking

TABLE 13-1 Prevalence of ODD and CD According to the National Survey of Children's Health

Source	Year	Question	Percent of Children with Behavioral or Conduct Problems	Age Range
NSCH (2007)	2007	Currently have behavioral or conduct problems?	3.3 (C.I. 3.0–3.6)	2–17
Perou et al. (2013)	2007	Current	3.5 (C.I. 3.1–3.8)	3–17
Perou et al. (2013)	2007	Ever	4.6 (C.I. 4.3–5.0)	3–17
NSCH (2012a)	2011/2012	Current behavioral or conduct problems such as ODD or CD?	3.2 (C.I. 2.9–3.5)	2–17

NOTE: CI = confidence interval.
SOURCES: NSCH, 2007, 2012a; Perou et al., 2013.

about prior diagnoses and conditions identified 4.6 percent (CI of 4.3–5.0 percent) of children aged 3–17 years with ODD or conduct disorder. An estimated 3.5 percent (CI of 3.1–3.8 percent) had a current condition (Perou et al., 2013). Boys were twice as likely as girls to have these conditions. Age was associated with an increased reporting of ODD and CD. There was no regional variability in parent-reported prevalence. Results from the 2007 and 2011–2012 NSCH are summarized in Table 13-1. Results of the survey are organized by the question that parents were asked regarding whether their child currently or ever had behavioral or conduct problems. Further information about the limitations of these data can be found in Chapter 2, and additional methodological information can be found in Appendix D.

Prevalence Trends

It is important to acknowledge that there are no perfect sources of data for evaluating trends in the prevalence of ODD and CD in the United States. An ideal source that would allow evaluation of trends over time might be generated by large-scale, nationally representative, population-based epidemiologic studies conducted periodically, and using validated and comparable methods and diagnostic criteria over time. No such data source exists.

However, there are cross-cultural studies. In a review of 25 studies, meta-regression analyses found no remarkable differences across countries and geography. The majority of differences in prevalence estimate were due to methodological differences in disorder assessment or calculation (Canino et al., 2010). Several of these methodological differences are worth highlighting because they underscore why estimates of prevalence do vary across studies. For example, one of the largest factors influencing prevalence rates of CD across countries in the cross-cultural comparison was the intensity of impairment required. Studies of significant impairment had low prevalence rates, but studies with no impairment had much higher rates of prevalence for CD. Maughan notes that the prevalence of conduct disorder varies by the survey of parent, child, teacher, or combinations of the aforementioned (Maughan et al., 2004). Parents and teachers often provide different ratings of ODD symptoms in children (O'Laughlin et al., 2010). Similarly, the strong predilection for males means that samples with larger portions of boys have higher rates.

In 2000, Loeber and others examined several studies and concluded that trend data over several decades were suspect because of an increase in prevalence over time due to rising arrest rates and the use of retrospective recall studies (Loeber et al., 2000). They noted that recall studies might favor a trend toward greater recent prevalence. Since that time, arrest rates have actually declined for many crimes.

In an effort to respond to studies postulating longitudinal increases in the prevalence of these conditions and other mental disorders, de Graaf and a team in the Netherlands looked at trends over time in the Netherlands Mental Health Survey and Incidence Study (NEMESIS) I and II (de Graaf et al., 2012). In the mid-1990s and again 10 years later, two cross-sectional surveys of adults were carried out that assessed lifetime prevalence of mental disorders in the Dutch population. The Dutch team found almost no changes in prevalence of any disorders that reached statistical or clinical significance. Their 2006 estimate of CD prevalence was 5.6 percent, and their estimate for ODD was 2.9 percent, with exclusivity between the two categories. They concluded that the prevalence of mental disorder was stable in the Dutch population over time, a conclusion echoed in the American population by Glied and colleagues (2010), although they did not look specifically at ODD and CD in children.

TRENDS IN THE RATES OF ODD AND CD AMONG SSI AND MEDICAID POPULATIONS

This section of the report presents data on trends in the rates of ODD and CD in the SSI program for children from 2004 to 2013 and in Medicaid from 2001 to 2010.

SSI

Table 13-2 presents the SSI administrative data on ODD in children. Column 1 shows the number of child allowances made on the basis of ODD at the initial level for each year. Column 2 shows the number of child recipients who received SSI benefits on the basis of ODD in December of each year. Column 3 shows the estimated number of children in households under 200 percent of the federal poverty level (FPL) for each year. To control for the changes in child poverty, allowances and recipients are also presented as a percentage of the number of children in households under 200 percent FPL for each year. Column 4 shows the percentage of children in households under 200 percent FPL who were allowed benefits for disabilities associated with a diagnosis of ODD in each year. Column 5 shows the percentage of children in households under 200 percent FPL who were recipients of SSI payments for ODD in December of each year. Figure 13-1

TABLE 13-2 SSI Child Initial Allowances and Recipient Numbers for ODD

	1	2	3	4	5
Year	# of Child Allowances for ODD	# of Child SSI Recipients for ODD	# of Children Under 200% FPL	% of Children Under 200% FPL Allowed SSI Benefits for ODD	% of Children Under 200% FPL Who Are Recipients of SSI Benefits for ODD
2004	2,913	12,976	28,753,000	0.010%	0.045%
2005	2,807	14,158	28,539,000	0.010%	0.050%
2006	2,653	14,967	28,757,000	0.009%	0.052%
2007	2,590	15,501	28,999,000	0.009%	0.053%
2008	2,628	15,919	30,064,000	0.009%	0.053%
2009	2,860	16,570	31,505,000	0.009%	0.053%
2010	2,950	17,293	32,254,000	0.009%	0.054%
2011	3,252	18,281	32,678,000	0.010%	0.056%
2012	3,281	19,588	32,269,000	0.010%	0.061%
2013	3,072	20,259	31,364,000	0.010%	0.065%

NOTE: The Current Population Survey table creator was used to generate numbers of children below 200 percent of the federal poverty level. Parameters used to generate the numbers include get count of: persons in poverty universe (everyone except unrelated individuals under 15); years: 2004 to 2013; Census 2010 weights; row variable: age; column variable: income-to-poverty ratio; and customized formatting: income-to-poverty ratio percent cutoff of 200 percent.

SOURCES: U.S. Census Bureau, 2015; unpublished data provided by the SSA.

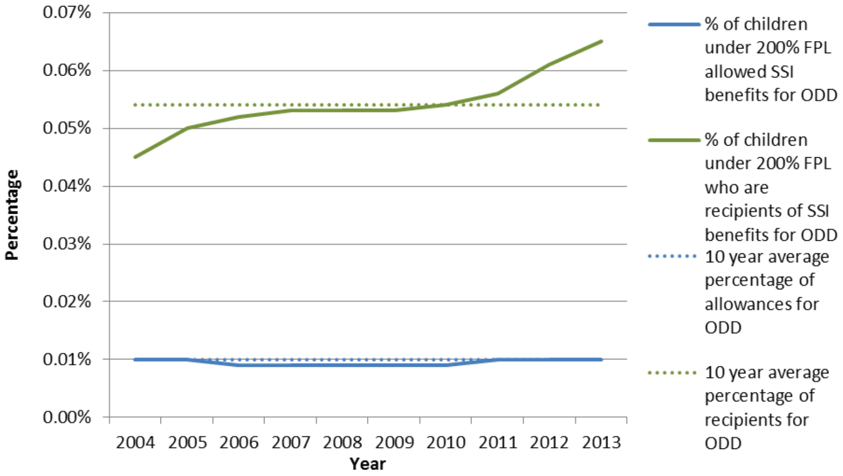

FIGURE 13-1 Percentages of SSI child initial allowances and recipients for ODD under 200 percent FPL.
NOTE: The Current Population Survey table creator was used to generate numbers of children below 200 percent of the federal poverty level. Parameters used to generate the numbers include get count of: persons in poverty universe (everyone except unrelated individuals under 15); years: 2004 to 2013; Census 2010 weights; row variable: age; column variable: income-to-poverty ratio; and customized formatting: income-to-poverty ratio percent cutoff of 200 percent.
SOURCES: U.S. Census Bureau, 2015; unpublished data provided by the SSA.

plots the percentages from columns 4 and 5 of Table 13-2 along with the 10-year average of the percentage of allowances and recipients for ODD as a visual reference point.

Over the 10-year period from 2004 to 2013, the rate of child SSI ODD recipients increased, while the rate of child SSI ODD allowances was flat. There was no change in the rate of allowances for ODD from 2004 to 2013. The rate of child ODD recipients increased by almost 43 percent between 2004 and 2013, from 0.045 to 0.065 percent. Table 13-3 presents the SSI administrative data on CD in children. Table 13-3 is organized identically to Table 13-2. Figure 13-2 plots the percentages from columns 4 and 5 of Table 13-3 along with the 10-year average of the percentage of allowances and recipients for CD as a visual reference point.

Over the 10-year period from 2004 to 2013, the rate of the child SSI CD recipients increased by 23 percent, from 0.029 to 0.035 percent, while the rate of the child SSI CD allowances decreased slightly, by 34 percent, from 0.007 in 2004 to 0.005 in 2013.

TABLE 13-3 SSI Child Initial Allowances and Recipient Numbers for CD

Year	Child SSI Allowances for CD	Child SSI Recipients for CD	# of Children Under 200% FPL	% of Children Under 200% FPL Allowed SSI Benefits for CD	% of Children Under 200% FPL Who Are Recipients of SSI Benefits for CD
2004	2,041	8,280	28,753,000	0.007%	0.029%
2005	1,927	8,907	28,539,000	0.007%	0.031%
2006	1,717	9,256	28,757,000	0.006%	0.032%
2007	1,761	9,577	28,999,000	0.006%	0.033%
2008	1,753	9,884	30,064,000	0.006%	0.033%
2009	1,873	10,202	31,505,000	0.006%	0.032%
2010	1,959	10,561	32,254,000	0.006%	0.033%
2011	1,880	10,889	32,678,000	0.006%	0.033%
2012	1,802	11,203	32,269,000	0.006%	0.035%
2013	1,469	11,077	31,364,000	0.005%	0.035%

NOTE: The Current Population Survey table creator was used to generate numbers of children below 200 percent of the federal poverty level. Parameters used to generate the numbers include get count of: persons in poverty universe (everyone except unrelated individuals under 15); years: 2004 to 2013; Census 2010 weights; row variable: age; column variable: income-to-poverty ratio; and customized formatting: income-to-poverty ratio percent cutoff of 200 percent.
SOURCES: U.S. Census Bureau, 2015; unpublished data provided by the SSA.

Medicaid

Tables 13-4 and 13-5 show the percentage of children who were diagnosed with ODD and CD, respectively, in two different groups of Medicaid enrollees for each year from 2001 to 2010. For both tables, column 1 shows the percentage of ODD or CD diagnoses, respectively, among all Medicaid enrollees[4] for each year, while column 2 shows the percentage of either ODD or CD diagnoses among the smaller subpopulation of Medicaid enrollees who were eligible to be enrolled in Medicaid on the basis of receiving SSI benefits.[5]

As shown in Figure 13-3, the rate of ODD diagnoses among all child Medicaid enrollees and among child SSI-eligible Medicaid enrollees both increased between 2001 and 2010. The rate of ODD diagnoses among all Medicaid enrollees increased by 69 percent, from 0.8 to 1.4 percent,

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[4] Refer to Appendix F for Rutgers methods section.

[5] Ibid.

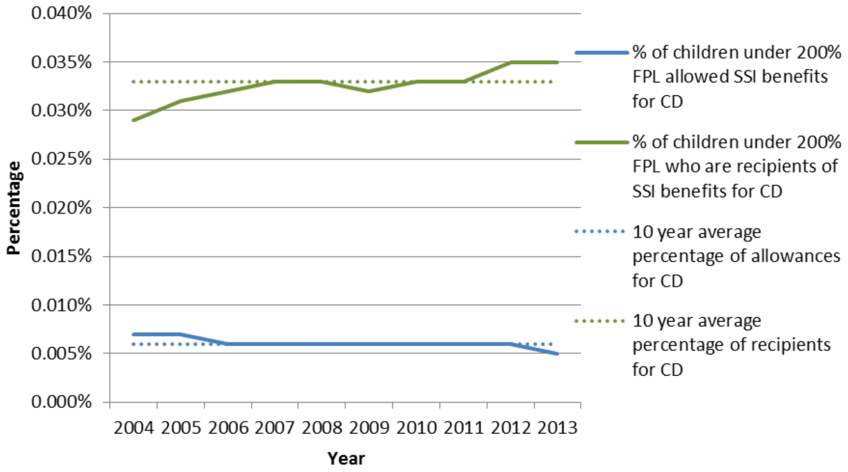

FIGURE 13-2 Percentages of SSI child initial allowances and recipients for CD under 200 percent FPL.
NOTE: The Current Population Survey table creator was used to generate numbers of children below 200 percent of the federal poverty level. Parameters used to generate the numbers include get count of: persons in poverty universe (everyone except unrelated individuals under 15); years: 2004 to 2013; Census 2010 weights; row variable: age; column variable: income-to-poverty ratio; and customized formatting: income-to-poverty ratio percent cutoff of 200 percent.
SOURCES: U.S. Census Bureau, 2015; unpublished data set provided by the SSA.

while the rate of ODD diagnoses among the SSI-eligible subpopulation of Medicaid enrollees increased by 63 percent, from 2.7 to 4.5 percent.

As shown in Figure 13-4, the rate of CD diagnoses among all child Medicaid enrollees and among child SSI-eligible Medicaid enrollees both increased between 2001 and 2010. The rate of CD diagnoses among all Medicaid enrollees increased by 29 percent, from 1.1 to 1.4 percent. The rate of CD diagnoses among the SSI-eligible subpopulation of Medicaid enrollees increased by 33 percent, from 3.5 to 4.6 percent.

For the years where the ODD Medicaid data and the SSI administrative data overlapped, that is, 2004–2010, the rate of ODD diagnoses among all Medicaid-enrolled children increased by 56 percent, the rate of ODD diagnoses among SSI-eligible Medicaid-enrolled children increased by 50 percent, and the rate of SSI recipients for ADHD among children in households under 200 percent FPL increased by 20 percent. For CD over the same time

TABLE 13-4 Percentage of Child Medicaid Enrollees and SSI Medicaid Enrollees Diagnosed with ODD

	1	2
Year	% of All Child Medicaid Enrollees with ODD Diagnosis	% of Child SSI Medicaid Enrollee Subpopulation with ODD Diagnosis
2001	0.8%	2.7%
2002	0.9%	2.9%
2003	0.9%	3.0%
2004	0.9%	3.0%
2005	1.1%	3.5%
2006	1.2%	3.7%
2007	1.4%	4.0%
2008	1.4%	4.2%
2009	1.5%	4.6%
2010	1.4%	4.5%

SOURCE: MAX data.

TABLE 13-5 Percentage of Child Medicaid Enrollees and SSI Medicaid Enrollees Diagnosed with CD

	1	2
Year	% of All Child Medicaid Enrollees with CD Diagnosis	% of Child SSI Medicaid Enrollee Subpopulation with CD Diagnosis
2001	1.1%	3.5%
2002	1.1%	3.7%
2003	1.1%	3.8%
2004	1.2%	4.0%
2005	1.2%	4.0%
2006	1.2%	3.9%
2007	1.3%	3.9%
2008	1.3%	4.2%
2009	1.4%	4.7%
2010	1.4%	4.6%

SOURCE: MAX data.

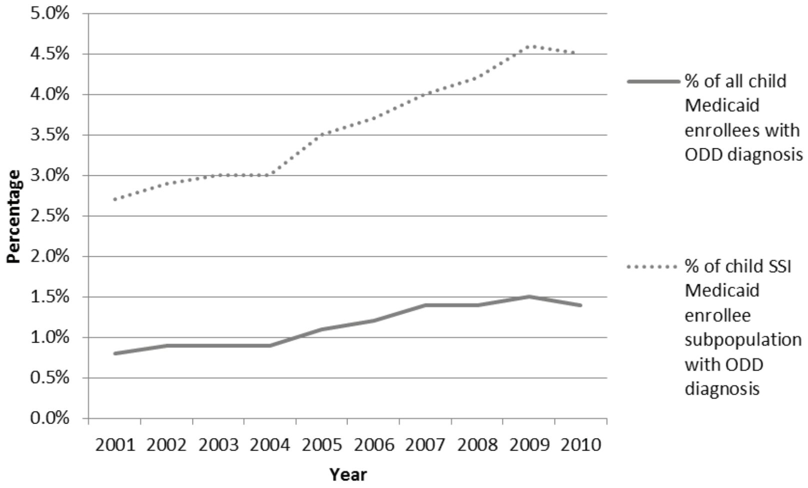

FIGURE 13-3 Percentage of child Medicaid enrollees and SSI Medicaid enrollees diagnosed with ODD.
SOURCE: MAX data.

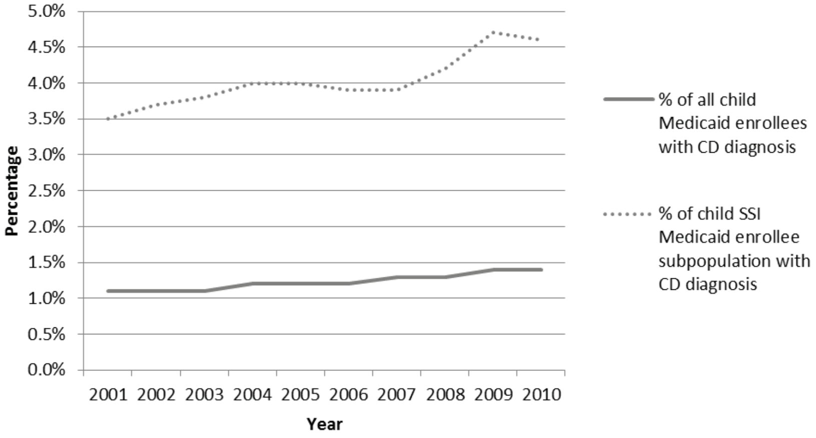

FIGURE 13-4 Percentage of child Medicaid enrollees and SSI Medicaid enrollees diagnosed with CD.
SOURCE: MAX data.

period, 2004–2010, the rate of CD diagnoses among all Medicaid-enrolled children increased by 17 percent, the rate of CD diagnoses among SSI-eligible Medicaid-enrolled children increased by 15 percent, and the rate of SSI recipients for ADHD among children in households under 200 percent FPL increased by 14 percent.

DISCUSSION

Generally speaking, there are limited data on national or population trends in the rates of the disruptive behavioral disorders of childhood. As a result, direct comparisons with the SSI disability program trends are not possible. Some comparisons can be made between trends observed in the SSI population with trends observed in the broader Medicaid population. Both the SSI program data and the Medicaid data suggest that the rates of the diagnosis of ODD and CD are increasing among low-income children. A notable observation is that the rates of ODD are higher than the rates of CD in the SSI population, while the rates of CD are slightly higher than the rates of ODD in the Medicaid population. It is unclear why this difference exists.

Overall, the modest increases in the numbers of recipients with ODD and CD in the SSI program for children are consistent with trends observed among children enrolled in Medicaid. The reported growth rate is not the result of more inclusive SSI allowance rates, which actually decreased during the analysis period. Given that the reported median duration of benefits is approximately 6 years, low rates of terminations from the SSI program during childhood might explain the expanding recipient population.

Based on general population estimates of ADHD and the rate of child poverty, it may be the case that the SSI program is providing benefits to a relatively small proportion of the population of children who would otherwise be eligible to receive benefits. In 2011–2012, the NSCH estimate of the prevalence of children ages 2–17 with moderate or severe “behavioral or conduct problems,” as reported by parents, was 2.2 percent (NSCH, 2012b). The estimated number of children under 200 percent FPL in 2012 was 32,269,000. Therefore, the estimated number of children with combined moderate and severe ODD and CD living in households with income under 200 percent FPL would be 709,918. In 2012 there were 11,203 child recipients of SSI benefits for CD. In 2012, there were 19,588 child recipients of SSI benefits for ODD. Combined, there were 30,791 child recipients for ODD/CD. Figure 13-5 illustrates these relationships.

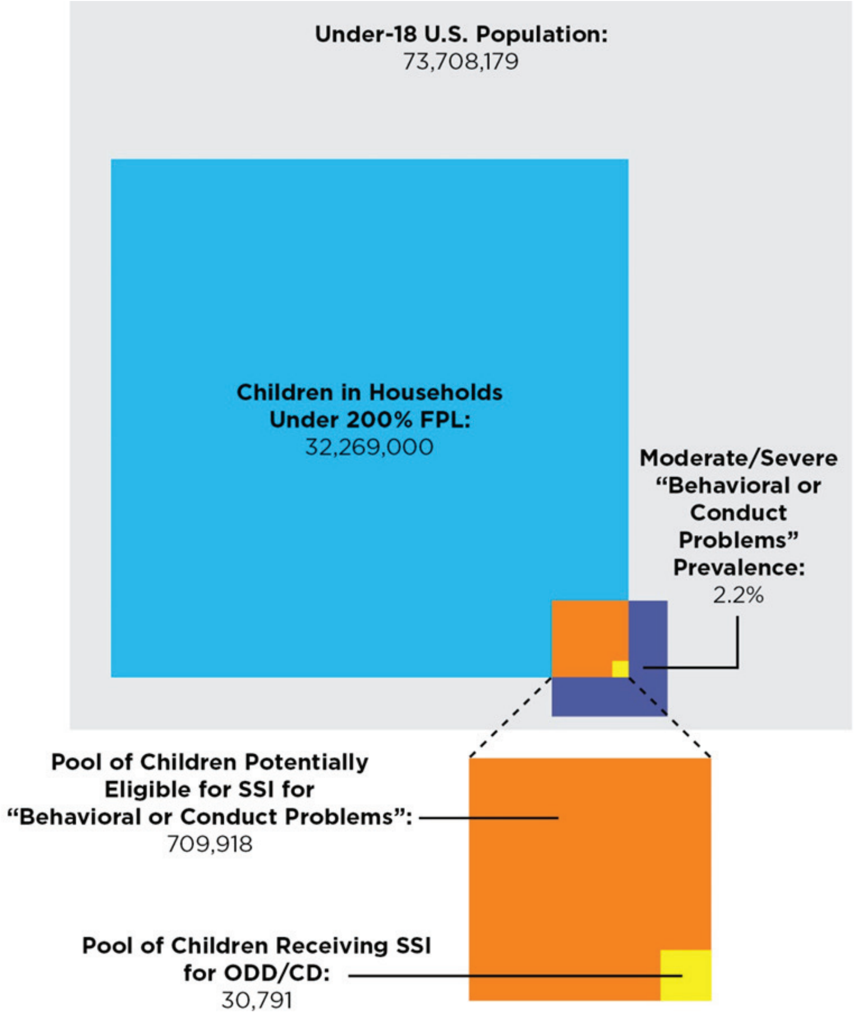

FIGURE 13-5 Children potentially eligible for SSI for "behavioral or conduct problems" versus children receiving SSI for ODD/CD in 2012, according to the National Survey of Children's Health.
NOTE: The Current Population Survey table creator was used to generate numbers of children below 200 percent of the federal poverty level. Parameters used to generate the numbers include get count of: persons in poverty universe (everyone except unrelated individuals under 15); years: 2004 to 2013; Census 2010 weights; row variable: age; column variable: income-to-poverty ratio; and customized formatting: income-to-poverty ratio percent cutoff of 200 percent.
SOURCES: NSCH, 2012b; U.S. Census Bureau, 2014, 2015; unpublished data provided by the SSA.

FINDINGS

- Estimates of the prevalence of ODD and CD range from 3 to 5 percent. A recent meta-analysis estimated the combined prevalence of ODD/CD to be 6.1 percent.
- Currently there are no population- or national-level data on the prevalence trends of ODD and CD among U.S. children.
- While ODD/CD constitutes a small number of mental disorder cases in SSI, from 2004 to 2013 the rates of allowances among poor children for ODD increased slightly, while the rates of allowances among children in low-income households for CD decreased. Over the same period, the rate of SSI recipients for both ODD and CD increased.

CONCLUSION

- Based on rough approximations of the prevalence of moderate to severe behavioral and conduct problems among children in households below 200 percent FPL, in 2011 and 2012 only an estimated 4 percent of children who were potentially eligible for SSI benefits on the basis of ODD/CD disorders were actually recipients.

REFERENCES

Canino, G., G. Polanczyk, J. J. Bauermeister, L. A. Rohde, and P. J. Frick. 2010. Does the prevalence of CD and ODD vary across cultures? *Social Psychiatry and Psychiatric Epidemiology* 45(7):695–704.

Costello, E. J., S. Mustillo, A. Erkanli, G. Keeler, and A. Angold. (2003), Prevalence and development of psychiatric disorders in childhood and adolescence. *Archives of General Psychiatry* 60:837–844.

de Graaf, R., M. ten Have, C. van Gool, and S. van Dorsselaer. 2012. Prevalence of mental disorders and trends from 1996 to 2009: Results from the Netherlands Mental Health Survey and Incidence Study-2. *Social Psychiatry and Psychiatric Epidemiology* 47(2):203–213.

Glied, S., K. Herzog, and R. Frank. 2010. Review: The net benefits of depression management in primary care. *Medical Care Research and Review* 67(3):251–274.

Kessler, R. C. 2013. National Comorbidity Survey-Adolescent Supplement (NCS-A), 2001–2004. www.icpsr.umich.edu/icpsrweb/HMCA/studies/28581/version/4 (accessed July 13, 2015).

Loeber, R., J. D. Burke, B. B. Lahey, A. Winters, and M. Zera. 2000. Oppositional defiant and conduct disorder: A review of the past 10 years, part I. *Journal of the American Academy of Child & Adolescent Psychiatry* 39(12):1468–1484.

Maughan, B., R. Rowe, J. Messer, R. Goodman, and H. Meltzer. 2004. Conduct disorder and oppositional defiant disorder in a national sample: Developmental epidemiology. *Journal of Child Psychology and Psychiatry* 45(3):609–621.

Merikangas, K. R., J. P. He, M. Burstein, S. A. Swanson, S. Avenevoli, L. Cui, C. Benjet, K. Georgiades, and J. Swendsen. 2010. Lifetime prevalence of mental disorders in U.S. adolescents: Results from the National Comorbidity Survey Replication-Adolescent Supplement (NCS-A). *Journal of the American Academy of Child & Adolescent Psychiatry* 49(10):980–989.

Nock, M. K., A. E. Kazdin, E. Hiripi, and R. C. Kessler. 2007. Lifetime prevalence, correlates, and persistence of oppositional defiant disorder: Results from the National Comorbidity Survey Replication. *Journal of Child Psychology and Psychiatry* 48(7):703–713.

NRC and IOM (National Research Council and Institute of Medicine). 2009. *Preventing mental, emotional, and behavioral disorders among young people: Progress and possibilities.* Washington, DC: The National Academies Press.

NSCH (National Survey of Children's Health). 2007. Data query from the Child and Adolescent Health Measurement Initiative. http://childhealthdata.org/browse/survey/results?q=1213 (accessed August 3, 2015).

NSCH. 2012a. Data query from the Child and Adolescent Health Measurement Initiative. http://childhealthdata.org/browse/survey/results?q=2409&r=1 (accessed August 3, 2015).

NSCH. 2012b. Data query from the Child and Adolescent Health Measurement Initiative. http://childhealthdata.org/browse/survey/results?q=2413&r=1 (accessed August 3, 2015).

O'Laughlin, E. M., J. L. Hackenberg, and M. M. Riccardi. 2010. Clinical usefulness of the oppositional defiant disorder rating scale (ODDRS). *Journal of Emotional and Behavioral Disorders* 18(4):247–255.

Perou, R., R. H. Bitsko, S. J. Blumberg, P. Pastor, R. M. Ghandour, J. C. Gfroerer, S. L. Hedden, A. E. Crosby, S. N. Visser, and L. A. Schieve. 2013. Mental health surveillance among children—United States, 2005–2011. *Morbidity and Mortality Weekly Report* 62(Suppl 2):1–35.

U.S. Census Bureau. 2014. Total population by child and adult populations. http://datacenter.kidscount.org/data/tables/99-total-population-by-child-and-adult-populations?loc=1&loct=1#detailed/1/any/false/35,18,17,16,15/39,41/416,417 (accessed November 14, 2014).

U.S. Census Bureau. 2015. CPS table creator. www.census.gov/cps/data/cpstablecreator.html (accessed July 13, 2015).

14

Prevalence of Autism Spectrum Disorder

Autism spectrum disorder (ASD) is an important mental impairment for the Social Security Administration (SSA) as well as for stakeholders in the health care system and disability community, due in part to the considerable and continuous growth in the rates of disability attributed to ASD. From 2004 to 2013, the ASD and developmental disorders category grew more than any other mental disorder in the Supplemental Security Income (SSI) program. As reported in Chapter 3, over that decade the ASD category had the largest increase in the number of allowances per year, the largest increase in the number of determinations per year, the largest increase in the number of recipients, and the largest increase in the recipient proportion of all selected mental disorders—from 8.08 percent due to autistic disorder in 2004 to 20.53 percent in 2014. In addition, the autistic disorders category has the second highest allowance rate. These findings are of particular significance since there seems to be little or no indication of when growth in the number of children applying for and receiving SSI benefits for ASD will abate.

This chapter addresses the question of whether trends in the disability attributed to autistic disorders in the SSI program for children are consistent with trends observed in the general population of children in the United States and in the Medicaid child population.

ESTIMATES OF AUTISM PREVALENCE AND PREVALENCE TRENDS FROM THE GENERAL POPULATION

Prevalence of Autism

The first studies of the prevalence of autism, which were conducted in the 1960s and 1970s in Europe and the United States, reported prevalence estimates in the range of 2 to 4 cases per 10,000 children (Lotter, 1966; Rutter, 2005; Treffert, 1970). This led to the impression that autism was a rare childhood disorder. The earliest prevalence studies also found a consistent sex difference, with boys being three to four times more likely to have autism than girls. Following an expansion of diagnostic criteria for autism that occurred in the late 1980s and 1990s, autism prevalence studies around the world showed dramatic increases (Fombonne, 2009; Rice, 2013; Rutter, 2005). The association between rising autism prevalence estimates and changes in the criteria for diagnosing autism can be seen in Figure 14-1.

By 2002, estimates of the prevalence of autism in the United States were in the range of 6 to 7 per 1,000 children, more than a 30-fold increase from the first studies of autism prevalence (Fombonne, 2009; Lotter, 1966; Rice et al., 2007; Treffert, 1970). These studies also found the prevalence of ASD to be three to four times higher in boys than girls.

It is likely that the rise in autism prevalence during the latter decades of the 20th century, based on epidemiologic studies, can be attributed largely

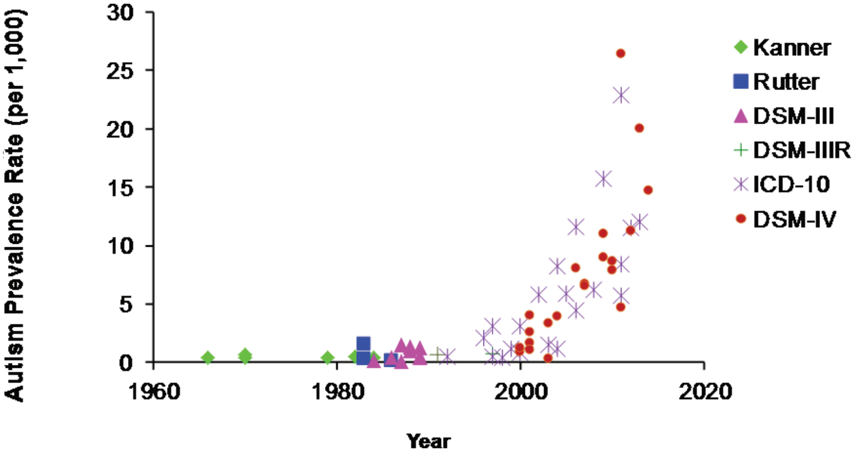

FIGURE 14-1 Evolution and expansion of diagnostic criteria for ASD.
SOURCE: Rice, 2013.

to the expansion of diagnostic criteria and the adoption of the concept of autism as a spectrum of impairments (ASD) that occurred during this period (Fombonne, 2009; King and Bearman, 2009; Rice, 2013; Wing and Potter, 2002). It is also possible that other factors, including improvements in screening and services for children with ASD and increases in specific risk factors for ASD (such as increases in the proportion of births to older parents) have also contributed to increases in the prevalence of ASD over time (Durkin et al., 2008; Grether et al., 2009; Rice, 2013; Rice et al., 2013; Schieve et al., 2011).

Prevalence Trends

We describe recent trends in the frequency of ASD in the United States based on four types of data sources: (1) epidemiologic studies, (2) special education "child counts," (3) administrative data on developmental services from the state of California, and (4) national surveys based on parental reports. For purposes of this review of ASD prevalence among children in the United States, which focuses on the years 2000–2012, it is important to emphasize that no formal changes in diagnostic criteria were introduced or adopted between the years 2000 and 2012. Thus, changes in the prevalence of ASD during this period cannot be readily explained by the evolution of diagnostic criteria, though the gradual adoption and increasing application of diagnostic criteria introduced in the 1990s could have affected prevalence trends during the 2000–2012 period.

It is important to acknowledge that there are no perfect sources of data for evaluating trends in the prevalence of autism in the United States. An ideal source that would allow evaluation of trends over time might be generated by large-scale, nationally representative, population-based epidemiologic studies conducted periodically, and using validated and comparable methods and diagnostic criteria over time. No such data source exists. The data sources used for the purposes of this study have complementary strengths and weaknesses. For example, the epidemiologic data source described below, from the Centers for Disease Control and Prevention's (CDC's) Autism and Developmental Disabilities Monitoring (ADDM) Network, has the advantages of being population-based, including large and diverse populations of U.S. children, relying on validated methods for classifying cases of ASD that were comparable over a multiple-year period (2000–2010), and allowing evaluation of trends over time. The ADDM Network data are, however, not nationally representative and they rely on administrative records of developmental and/or educational assessments. In contrast, special education "child count" data have the advantages of being nationally representative and available annually, but do not necessarily rely on standard case definitions or diagnostic criteria that are comparable over time and across states and school districts. Administrative data from the California Department of Developmental Services (CDDS) have the advantages of representing one large, U.S. state and allowing monitoring of annual trends in the number of children in the state receiving services for autism, but the disadvantage of not being nationally representative. The national survey data have the advantage of being based on national probability samples, but the disadvantages of relying on parental reports rather than diagnostic assessments and standard criteria, and of response rates less than 100 percent. Despite the limitations of each data source, taken together they provide valuable and complementary evidence for evaluating trends over time in the frequency of ASD in U.S. children.

Trends Based on Epidemiologic Studies

Since 2000, the ADDM Network of the CDC has conducted surveillance of ASD among 8-year-old children in multiple U.S. sites every 2 years using methods that have been comparable over time and that are based on the diagnostic criteria from the *Diagnostic and Statistical Manual of Mental Disorders, 4th Edition* (DSM-IV-TR; APA, 2013). The ADDM Network ASD prevalence estimate for the year 2000 was 6.7 per 1,000. As shown in Table 14-1, by 2010, the most recent year for which data are available, the prevalence had more than doubled, to 14.7/1,000 or 1.5 percent (95

TABLE 14-1 Prevalence of ASD in the United States, Based on ADDM Network Studies Published from 2007 to 2014 (surveillance years 2000–2010)

Surveillance Year	Birth Year	Total Population Aged 8 Years Under Surveillance	ASD Prevalence per 1,000 (95 percent confidence interval)	Approximately 1 in *x* Children
2000	1992	187,761	6.7 (6.3, 7.1)	1 in 150
2002	1994	407,578	6.6 (6.4, 6.9)	1 in 150
2004	1996	172,335	8.0 (7.6, 8.4)	1 in 125
2006	1998	307,790	9.0 (8.6, 9.3)	1 in 110
2008	2000	337,093	11.3 (11.0, 11.7)	1 in 88
2010	2002	363,749	14.7 (14.3, 15.1)	1 in 68

SOURCE: Adapted from http://www.cdc.gov/ncbddd/autism/data.html (accessed July 15, 2015).

percent confidence interval [CI] 1.43–1.51 percent) (Baio, 2012, 2014; Rice, 2009; Rice et al., 2007).

Although ASD can be diagnosed before age 2 years in some children and is typically a lifelong condition or disability, population-based studies have shown that the median age at which children receive a formal diagnosis or ASD classification is 5.2 to 5.7 years (Maenner et al., 2014; Shattuck et al., 2009). The ADDM Network approach to monitoring ASD prevalence assumes that most children in the United States with ASD will have received a developmental assessment or a special educational assessment providing documentation of ASD diagnostic criteria by the age of 8 years (Durkin et al., 2014). For this reason, the ADDM Network monitors the prevalence of ASD at the single year of age 8 as the most efficient way to monitor trends over time. Because children who have ASD at the age of 8 years most likely have this condition throughout childhood, the prevalence at age 8 can provide an estimate of ASD prevalence among children of all ages.

An important caveat about the ASD prevalence estimates from ADDM Network data is that the sites represented in the network are selected in a competitive process and do not provide a probability sample of U.S. children (Baio, 2014). For this reason, the resulting prevalence estimates cannot be generalized to the nation. However, the ASD prevalence estimates from the ADDM Network are population based in the sense that efforts are made at each participating site to count every 8-year-old child with ASD in the defined populations rather than just counting those who receive care through a particular health care provider or who receive special education services for autism (Baio, 2014; Durkin et al., 2014).

A consistent finding in virtually all epidemiologic studies of ASD is the excess prevalence among boys relative to girls (Fombonne, 2009). This can be seen in the trend lines from the ADDM Network prevalence findings shown in Figure 14-2, which also show that the rise in ASD prevalence from 2000 to 2010 was somewhat steeper for boys than girls, resulting in an increase in the sex ratio (boys to girls) from 3.5 in 2000 to 4.5 in 2010 (Baio, 2012, 2014; Rice, 2009; Rice et al., 2007).

Persistent racial and ethnic disparities in ASD prevalence as determined by the ADDM Network are seen for each surveillance year between 2002 and 2010, with the prevalence being highest among white non-Hispanic children and lowest among Hispanic children (see Figure 14-3). The trend of rising prevalence of ASD over time occurred for all racial and ethnic subgroups monitored (Baio, 2012, 2014; Rice, 2009; Rice et al., 2007).

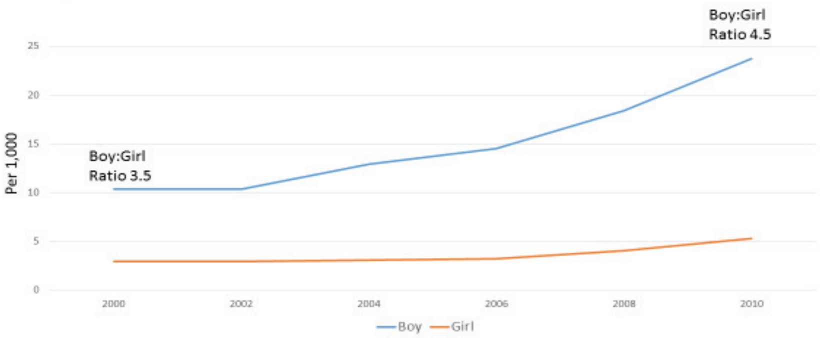

FIGURE 14-2 Prevalence of autism from 2000 to 2010 by sex.
SOURCE: ADDM Network ASD prevalence reports published in *Morbidity and Mortality* Reports, 2007–2014.

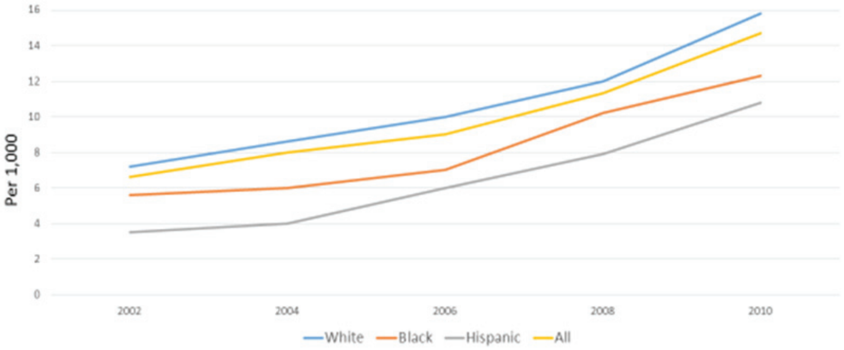

FIGURE 14-3 Trends in the prevalence (per 1,000) of ASD among 8-year-old children by race and ethnicity, U.S. ADDM Network Surveillance Sites, 2002–2010.
SOURCE: ADDM Network ASD prevalence reports published in *Morbidity and Mortality* Reports, 2007–2014.

Trends Based on the Number of Children Receiving Special Educational Services for ASD

In 1992, 15,556, children (ages 6 to 22 years) in the United States received special education services for ASD. By 2011 this number had increased by more than 25-fold, to 406,957. Figure 14-4 shows the increasing trend between 2001 and 2012 in the number per 1,000 of U.S. children, ages 6–17 years, who received special educational services under the ASD

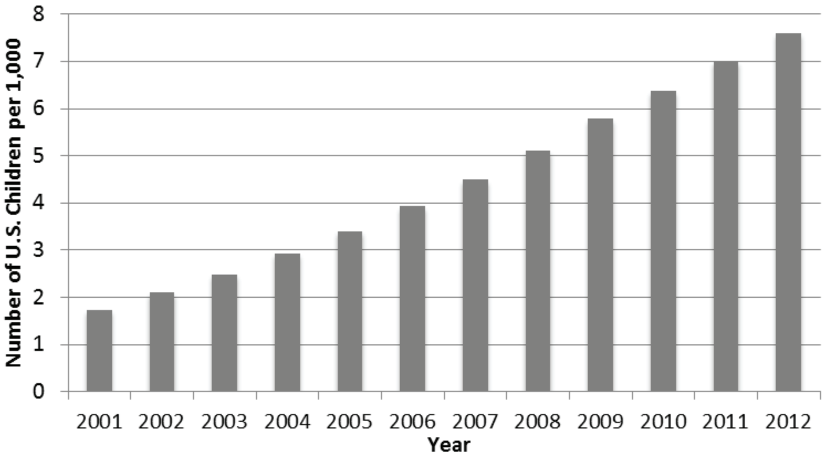

FIGURE 14-4 Trend in the number of U.S. children per 1,000 receiving special education services for autism, ages 6 to 17 years, 2001–2012.
NOTE: Denominators of child population were obtained for ages 5–17 for the years 2001–2012. Numerators were obtained from Part B child count data for autism for the 50 states, Washington, DC, and Puerto Rico, ages 6–17 for the years 2001–2011. Numerator was obtained for autism for the 50 states, Washington, DC, and Puerto Rico for ages 6–17 for year 2012.
SOURCES: U.S. Census Bureau, 2011, 2015a; U.S. Department of Education, 2013, 2014.

disability category. This number increased from 1.7 per 1,000 in 2001 to 7.6 per 1,000 in 2012.

Trends Based on the Number of Children Receiving Disability Services with an Autism Diagnosis in California

The state of California provides support and services to individuals with developmental disabilities. The determination of eligibility is administered by the CDDS. Eligibility for services from the CDDS is determined through a systematic evaluation of diagnostic elements and the functional level for the majority of children aged 3 and above. In 2007 the CDDS published data collected on the agency's caseload due to autistic disorder from 1987 to 2007. This source of data has unique strengths. Each case is based on the application of some diagnostic and functional criteria for the determination of eligibility for state-administered supports and services. In addition, this program reaches most individuals in the state of California, California has a large and diverse population, and the program has continuous data available over two decades. Below are two figures from the 2007 report. The first figure (see Figure 14-5) shows the approximately 12-fold increase in the number of people in California who have autism. The second figure (see Figure 14-6) shows the percent growth from year to year among the four primary diagnostic categories for eligibility in the state program. The frequency of ASD in California grew more than 1,100 percent from 1987 to 2007. ASD grew nine times more than the other diagnostic categories between 2002 and 2007 (Cavagnaro, 2007).

Trends Based on National Surveys of Parents

National Health Interview Survey In each of four national surveys conducted between 1997 and 2008, the National Health Interview Survey (NHIS) asked parents from a probability sample of noninstitutionalized U.S. children if a health professional had ever told them their child had ASD (Boyle et al., 2011). As shown in Table 14-2, the results of these surveys show a nearly fourfold increase in the estimated prevalence of autism among children ages 3–17 years, from 1.9 per 1,000 in 1997–1999 to 7.4 per 1,000 in 2006–2008.

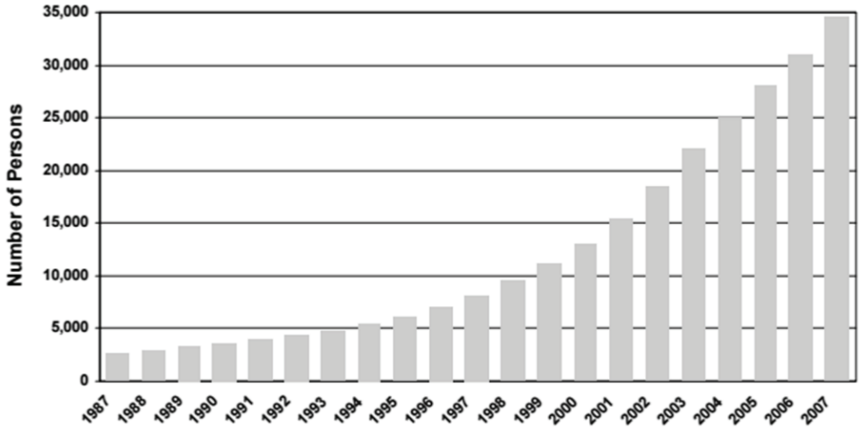

FIGURE 14-5 Annual frequencies of persons with autism from June 1987 to June 2007.
SOURCE: Cavagnaro, 2007.

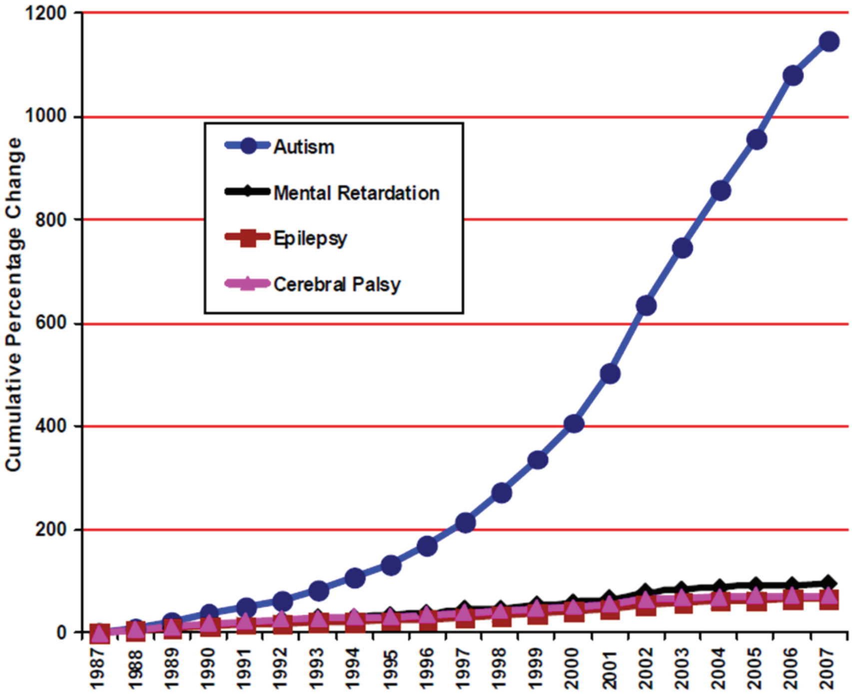

FIGURE 14-6 Cumulative percentage change of autism, cerebral palsy, epilepsy, and mental retardation over two decades.
SOURCE: Cavagnaro, 2007.

TABLE 14-2 Trends from the NHIS, Parent Report, Ever Told If Child Had Autism

Year (Age Range)	Prevalence Estimate
1997–1999 (3–17)	1.9 per 1,000
2000–2002 (3–17)	3.5 per 1,000
2003–2005 (3–17)	5.9 per 1,000
2006–2008 (3–17)	7.4 per 1,000

SOURCE: Boyle et al., 2011.

National Survey of Children's Health The National Survey of Children's Health (NSCH) has included questions about ASD in three survey years: 2003–2004, 2007, and 2011–2012 (Blumberg et al., 2013). Between 2003–2004 and 2007, the frequency with which parents reported that their child had ever been diagnosed with ASD increased from 5.5 to 11.6 per 1,000

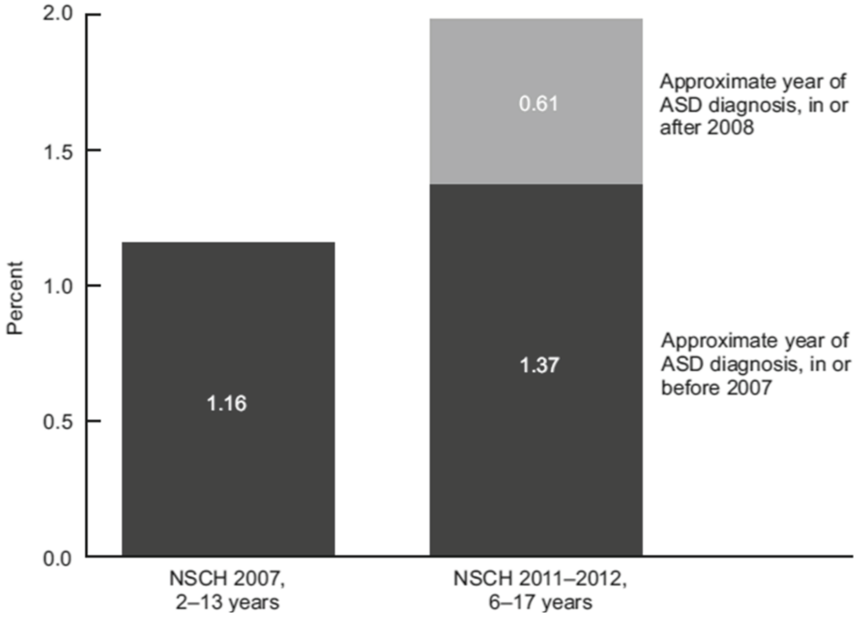

FIGURE 14-7 The frequency of autism spectrum disorder based on parent surveys: The National Survey of Children's Health.
SOURCES: Blumberg et al., 2013; Schieve et al., 2006.

(see Figure 14-7). By 2011–2012, it had increased to 20 per 1,000 or 2 percent. Note that the age ranges for children included in these surveys differed over time. In the 2003–2004 survey it was 4–17 years, in 2007 it was 2–13 years, and in 2011–2012 it was 6–17 years (Blumberg et al., 2013).

POTENTIAL EXPLANATIONS FOR THE RISING PREVALENCE OF AUTISM

ASD was first introduced as a category for receiving special education in the United States in 1991. The gradual adoption and use of this reporting category by school districts has led to a gradual increase in the number of children identified with autism in school settings. Children with autism, who might have been served under the intellectual disability (ID) category or another disability category in the past, are increasingly being served under the autism category, a process referred to as "diagnostic substitution" (Shattuck, 2006). Evidence of diagnostic substitution of autism for ID can be seen in the special education data shown in Figure 14-8. Additional

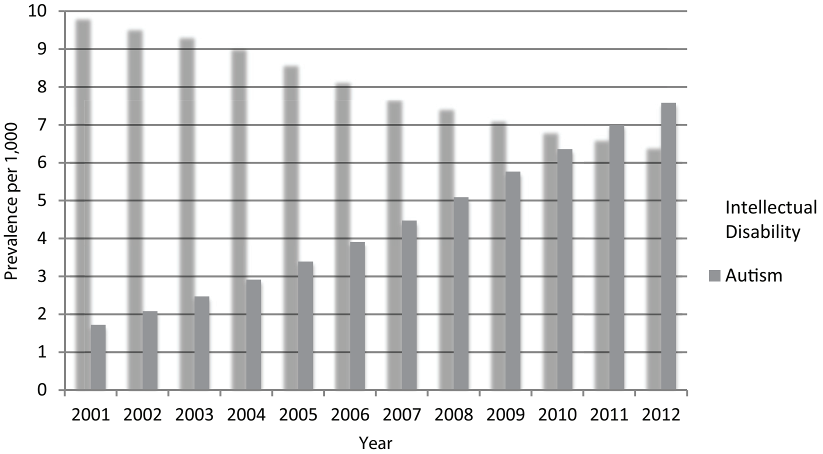

FIGURE 14-8 Evidence of diagnostic substitution. Trends in the prevalence per 1,000 of receipt of special education services for intellectual disability and autism, ages 6–17 years, United States, 2001–2012.
NOTE: Denominators of child population were obtained for ages 5–17 for the years 2001–2012. Numerators were obtained from Part B child count data for autism and intellectual for the 50 states, Washington, DC, and Puerto Rico, ages 6–17 for the years 2001–2011. Numerators were obtained for autism and intellectual disability for the 50 states, Washington, DC, and Puerto Rico for ages 6–17 for year 2012.
SOURCES: U.S. Census Bureau, 2011, 2015a; U.S. Department of Education, 2013, 2014.

evidence of this can be seen in epidemiologic data for 8-year-old children in metropolitan Atlanta, which showed a decline in ID without co-occurring ASD between 1996 and 2010 and also showed corresponding increases in ASD (with and without co-occurring ID) during the same period (Braun et al., 2015). Figure 14-9 shows this relationship.

Other factors that have likely contributed to the increasing numbers of children identified as having ASD include increased awareness of autism due to media attention and advocacy; increased training of clinicians and the increased availability of standard screening and diagnostic tools for identifying ASD; new policies for routine pediatric screening for ASD during well-child examinations; an increase in the assignment of co-occurring diagnoses among children with developmental disabilities, a process referred to as "diagnostic accrual" (King and Bearman, 2009); and the frequent requirement that a child first receive a diagnosis of ASD in order to receive needed services (Rice, 2013).

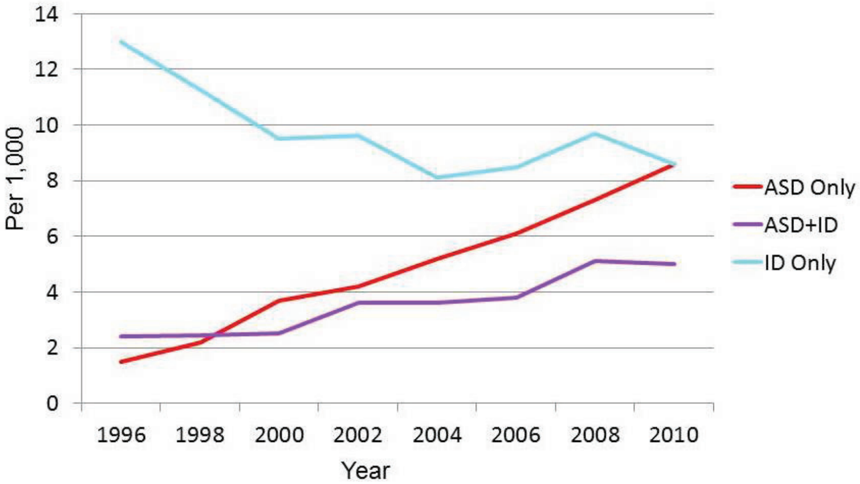

FIGURE 14-9 Contrasting trends in the prevalence of ASD and ID.
SOURCE: Braun et al., 2015.

A recent study from Sweden provides some evidence that the rise over time in autism diagnoses in that country among children born between 1993 and 2002 was steeper than the increase observed during the same period in the frequency of autism behavioral characteristics reported in telephone surveys of parents (Lundstrom et al., 2015). The authors concluded that the increase in autism diagnoses could not be fully explained by the corresponding increase in reported autism behavioral characteristics in the population.

As previously discussed, changes in the frequency of risk factors for ASD in the population, including changes in known or suspected risk factors, such as parental age, maternal obesity, and in vitro fertilization, may contribute to variations in trends, but they are unlikely to explain much of the observed increase.

Association Between Socioeconomic Status and ASD Prevalence in the United States and Potential Under-Identification of ASD Among Low-Income Children

In the United States, the prevalence of ASD as identified in both the ADDM Network surveillance system and in the National Health Interview Survey increases with increasing socioeconomic status (SES) (Boyle et al., 2011; Durkin et al., 2010). This SES gradient in ASD prevalence could be

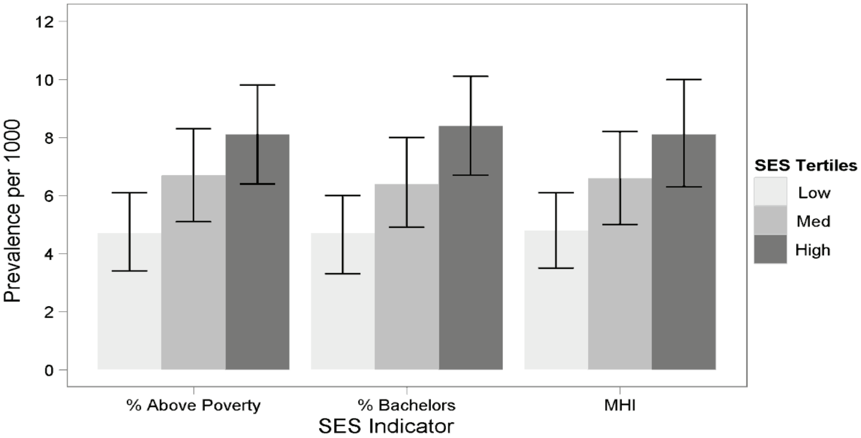

FIGURE 14-10 Prevalence per 1,000 of ASD by three SES indicators based on census block group of residence.
NOTE: Thin bars indicate 95 percent confidence intervals. MHI refers to median household income.
SOURCE: Durkin et al., 2010.

due to disparities in access to services. Figure 14-10 displays the results of an analysis of ADDM Network data showing the prevalence of ASD to be nearly twice as high in children in the highest SES tertile compared with those in the lowest SES tertile. Similarly, the NHIS data show a dose–response association between maternal education and the prevalence of reported ASD in children, which ranged from 2.5 per 1,000 among offspring of mothers with less than a high school education to 6.1 per 1,000 among offspring of mothers with a bachelor's degree (Boyle et al., 2011). This SES gradient suggests that low-income children with ASD might be underidentified and less likely to be receiving ASD-related services than middle- and high-income children with ASD. This observation is relevant for the SSA, as applications for benefits may continue to rise for children in low-income families.

TRENDS IN THE PREVALENCE OF ASD AMONG SSI AND MEDICAID POPULATIONS

This section of the report presents data on trends in the rates of ASD in the SSI program for children from 2004 to 2013 and in Medicaid from 2001 to 2010.

SSI

Table 14-3 presents SSI administrative data on ASD in children from 2004 to 2013. Column 1 shows the number of new child allowances made each year on the basis of ASD. Column 2 shows the number of child recipients who received SSI benefits on the basis of ASD in December of each year. Note that the number of recipients includes both new allowances and existing cases. Column 3 shows the estimated number of children in households with income less than 200 percent of the federal poverty level (FPL) for each year. To control for the changes in the magnitude of child poverty, allowance and recipient rates are shown as a percentage of the number of children in households under 200 percent FPL for each year. Column 4 shows the frequency of children in households under 200 percent FPL who were allowed benefits for ASD (i.e., were found to be severely impaired with

TABLE 14-3 SSI Child Initial Allowances and Recipient Numbers for ASD

	1	2	3	4	5
Year	# of Child SSI Allowances for ASD	# of Child SSI Recipients for ASD	# of Children in Households Under 200 % FPL	Children Under 200 % FPL Allowed SSI Benefits for ASD per 1,000	Children Under 200% FPL Who Are Recipients of SSI Benefits for ASD per 1,000
2004	9,677	43,628	28,753,000	0.3	1.5
2005	10,626	50,078	28,539,000	0.4	1.8
2006	11,613	56,976	28,757,000	0.4	2.0
2007	12,925	64,883	28,999,000	0.4	2.2
2008	15,812	73,161	30,064,000	0.5	2.4
2009	18,231	83,801	31,505,000	0.6	2.7
2010	20,317	94,606	32,254,000	0.6	2.9
2011	22,931	106,910	32,678,000	0.7	3.3
2012	24,159	121,699	32,269,000	0.7	3.8
2013	23,398	134,310	31,364,000	0.7	4.3

NOTE: The Current Population Survey table creator was used to generate numbers of children below 200 percent of the federal poverty level. Parameters used to generate the numbers include get count of: persons in poverty universe (everyone except unrelated individuals under 15); years: 2004 to 2013; Census 2010 weights; row variable: age; column variable: income-to-poverty ratio; and customized formatting: income-to-poverty ratio percent cutoff of 200 percent.

SOURCES: U.S. Census Bureau, 2015b; unpublished data set provided by the SSA.

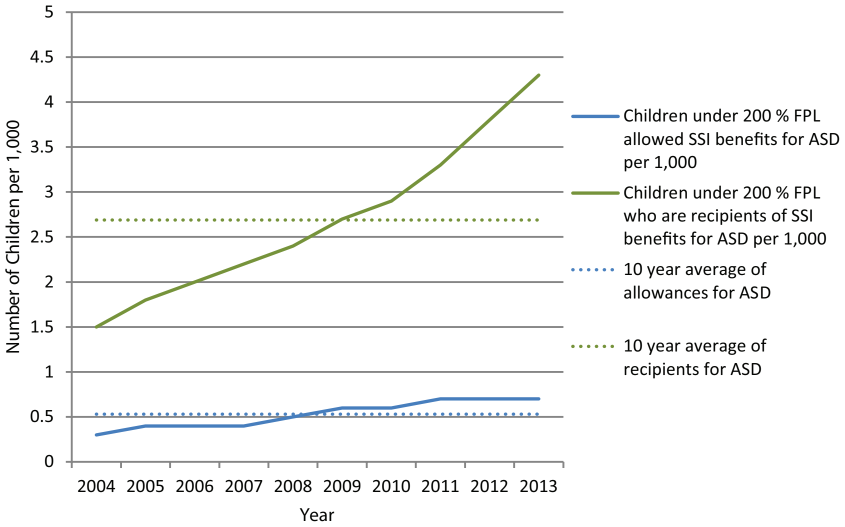

FIGURE 14-11 Numbers of SSI child initial allowances and recipients for ASD under 200 percent FPL per 1,000.

NOTE: The Current Population Survey table creator was used to generate numbers of children below 200 percent of the federal poverty level. Parameters used to generate the numbers include get count of: persons in poverty universe (everyone except unrelated individuals under 15); years: 2004 to 2013; Census 2010 weights; row variable: age; column variable: income-to-poverty ratio; and customized formatting: income-to-poverty ratio percent cutoff of 200 percent.

SOURCES: U.S. Census Bureau, 2015b; unpublished data provided by the SSA.

a primary diagnosis of ASD) in each year, per 1,000 children. The numbers in Column 4 can be interpreted as the incidence rate (per 1,000) of new allowances for ASD each year. Column 5 shows the frequency of children in households under 200 percent FPL who were recipients of SSI payments for ASD in December of each year, per 1,000 children. These numbers can be interpreted as the prevalence each year of children under 200 percent FPL receiving SSI benefits for ASD per 1,000 children. Figure 14-11 graphs the column 4 and 5 data.

Figure 14-11 plots the rate from columns 4 and 5 along with the 10-year averages of the percentages of allowances and recipients for ASD as visual reference points. Over the 10-year period from 2004 to 2013, the rates of child SSI ASD allowances and recipients both increased. During that same period, the incidence of child ASD allowances among children in households under 200 percent FPL more than doubled, from 0.3 to 0.7

TABLE 14-4 Prevalence of Child Medicaid Enrollees and SSI Medicaid Enrollees Diagnosed with ASD

	1	2
Year	Prevalence of All Child Medicaid Enrollees with ASD Diagnosis per 1,000	Prevalence of Child SSI Medicaid Enrollee Subpopulation with ASD Diagnosis per 1,000
2001	2	22
2002	2	24
2003	3	27
2004	3	30
2005	4	38
2006	5	42
2007	6	49
2008	6	57
2009	7	60
2010	7	67

SOURCE: MAX data.

per 1,000. The prevalence of child ASD recipients nearly tripled during the same period, from 1.5 to 4.3 per 1,000.

Medicaid

Table 14-4 shows the prevalence of children who were diagnosed with ASD per 1,000 in two different groups of Medicaid enrollees for each year from 2001 to 2010. Column 1 shows the prevalence of ASD diagnoses per 1,000 among all Medicaid enrollees[1] for each year. Column 2 shows the prevalence of ASD diagnoses per 1,000 among the smaller subpopulation of Medicaid enrollees who were eligible to be enrolled in Medicaid as an SSI beneficiary.[2]

As shown in Figure 14-12, the rate of ASD diagnoses among all child Medicaid enrollees and among child SSI-eligible Medicaid enrollees increased more than threefold between 2001 and 2010. The frequency of ASD diagnoses among all Medicaid enrollees increased from 2 per 1,000 in 2001 to 7 per 1,000 in 2010. The frequency of ASD diagnoses among the SSI-eligible subpopulation of Medicaid enrollees increased from 22 to

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[1] Refer to Appendix F for Rutgers methods section.

[2] Ibid.

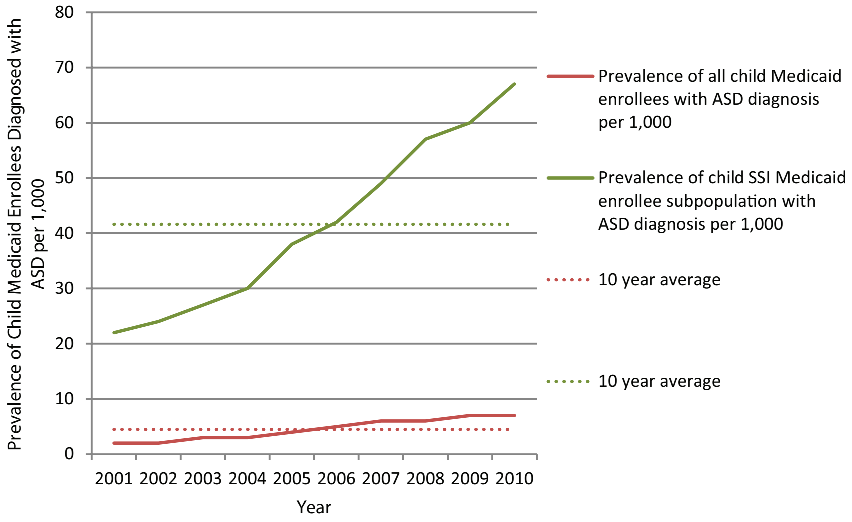

FIGURE 14-12 Prevalence of child Medicaid enrollees and SSI Medicaid enrollees diagnosed with ASD.
SOURCE: MAX data.

67 per 1,000 during the same period. The greater frequency of ASD in the SSI-eligible subpopulation is expected since having a disability is an eligibility criterion for the SSI, while the general Medicaid population includes children with and without disabilities.

For the years in which the Medicaid data and the SSI administrative data overlapped, 2004–2010, the rate of ASD diagnoses among all Medicaid-enrolled children increased by 133 percent; the rate of ASD diagnoses among the SSI-eligible Medicaid-enrolled children increased by 123 percent, and the rate of SSI recipients for ASD among children in households under 200 percent FPL increased by 93 percent. These findings confirm that recipients of SSI benefits on the basis of an ASD diagnosis have not grown faster than comparison populations.

DISCUSSION

The increasing trend in the rate of ASD observed in the SSI program for children is consistent with trends in the prevalence estimates of ASD in the general population. The data presented in this chapter uniformly indicate an increase in the frequency of ASD diagnosis or identification among children in the United States, regardless of the population studied or the methods for identifying a case of ASD. Increases in the rates are observed in data from active surveillance efforts, from national surveys, from administrative records on service utilization for ASD, and from among children enrolled in Medicaid. Some of these categories may be more sensitive than others to variations caused by changes in diagnostic practices or standards. The consistency observed across all the data sources supports a finding that the trends observed in the SSI program are not unexpected.

A notable pattern observed in both the SSI data and the special education service utilization data is the increase in the frequency of ASD and the concurrent decrease in the frequency of ID over the time period from 2004 to 2013 (see Figure 3-5 and Figures 14-13 and 14-14). These patterns could be explained in part by diagnostic substitution (Shattuck, 2006). Special education service use data and SSI data might be particularly sensitive to diagnostic substitution because both are benefit programs that generally require a diagnosis as a prerequisite for benefit or for service eligibility. The data presented here do not provide additional evidence to support a conclusion that diagnostic substitution is, in fact, a cause of the observed trends, but the trends observed in the SSI program are consistent with the possibility that there are children with developmental/cognitive/social impairments who were previously eligible for services or benefits on the basis of a diagnosis of ID or MR but who are more recently deemed eligible on the basis of a diagnosis of ASD.

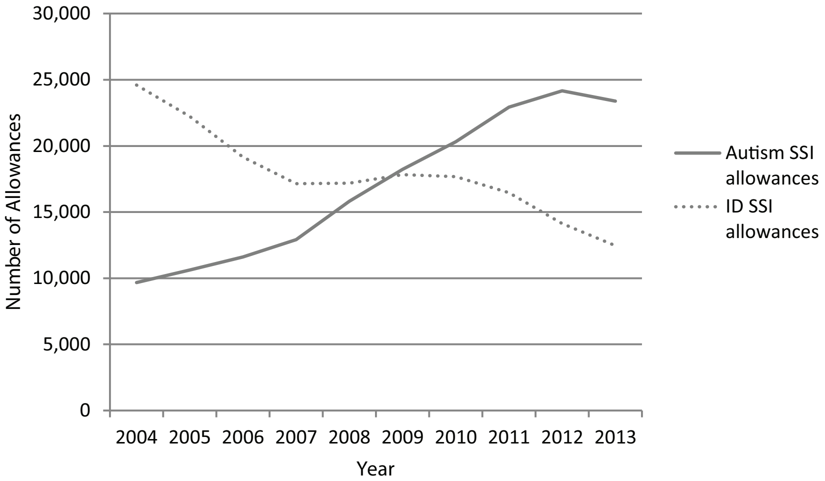

FIGURE 14-13 Autism and intellectual disability initial allowances for SSI.
SOURCE: Unpublished data set provided by the SSA.

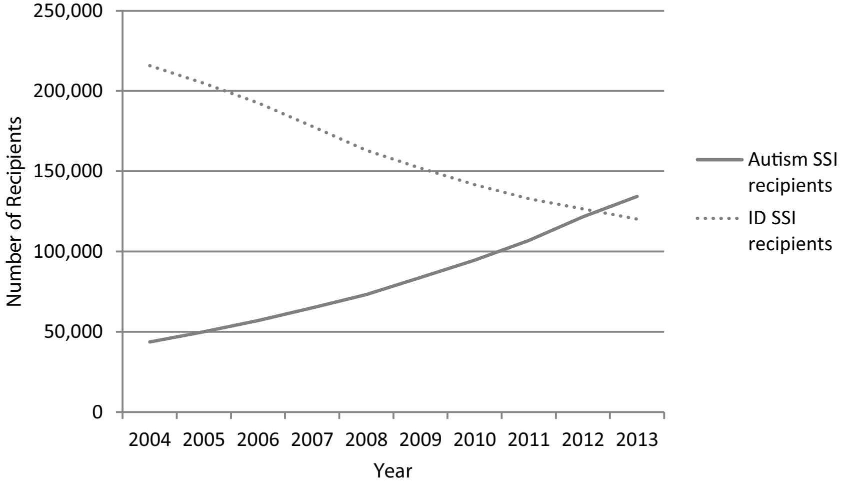

FIGURE 14-14 Autism and intellectual disability recipients for SSI.
SOURCE: Unpublished data set provided by the SSA.

Based on the National Survey of Child Health estimates for 2011–2012, the prevalence of severe or moderate ASD among U.S. children of ages 2–17 years was 0.8 percent, or 8 per 1,000 (NSCH, 2012). Severity determinations were based on parental ratings. After 2008, parents rated 41.7 percent of ASD cases as moderate or severe. The estimated number of children below 200 percent FPL in 2012 was 32,269,000. Therefore, the expected number of children with severe or moderate autism living in families below 200 percent FPL would be 258,152. By comparison, in 2012 there were 121,699 child recipients of the SSI benefits for autism, fewer than half the number expected based on the NSCH estimate. Figure 14-15 illustrates these relationships.

Based on national special education child counts, the estimated prevalence of ASD among school-aged children in the United States in 2012 was 0.76 percent, or 7.6 per 1,000. Applying this prevalence estimate to the number of children below 200 percent FPL in 2012, the expected number of children in low-income households with ASD would be 245,244, similar to the expected number based on the NSCH data and more than double the number of child recipients of SSI benefits for autism in 2012.

The ADDM estimated that the prevalence for ASD in 2010 among 8-year-old children was 1.47 percent or 14.7 per 1,000 (CDC, 2015). In 2010 the estimated number of children below 200 percent FPL was 32,254,000. Applying the ADDM prevalence estimate for 2010 to children

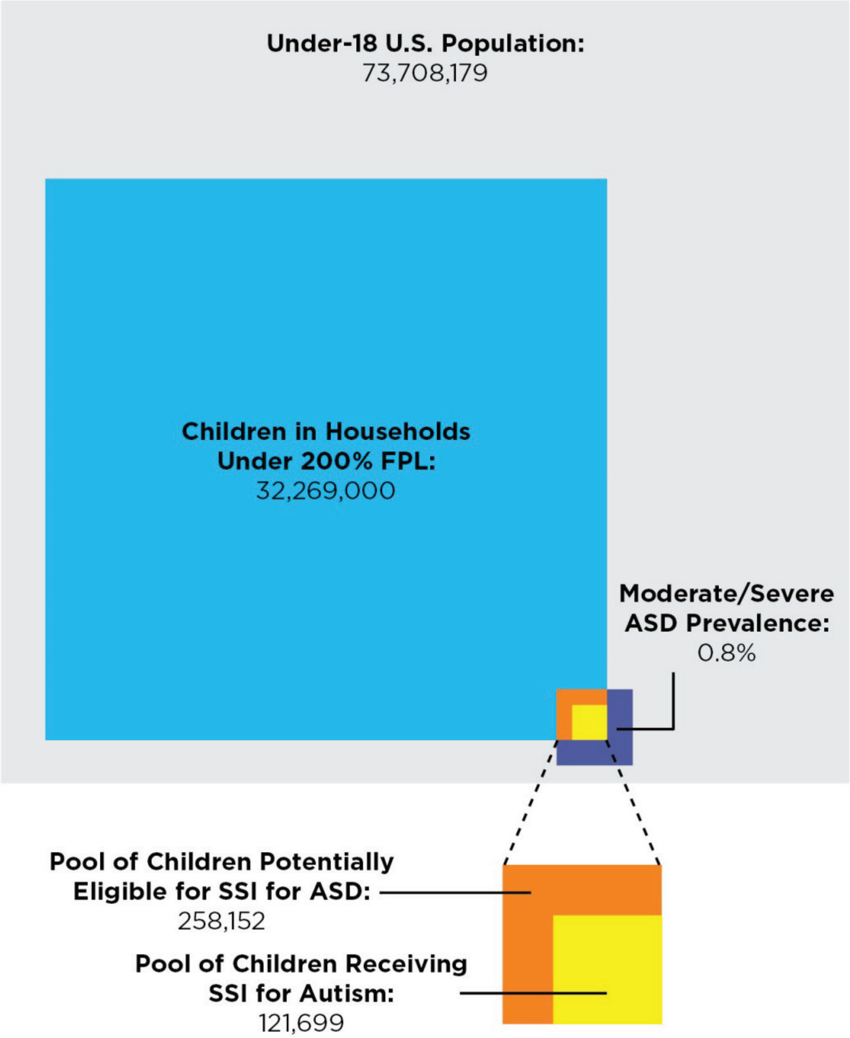

FIGURE 14-15 Children potentially eligible for SSI for ASD versus children receiving SSI for ASD in 2011–2012, according to the NSCH.
NOTE: The Current Population Survey table creator was used to generate numbers of children below 200 percent of the federal poverty level. Parameters used to generate the numbers include get count of: persons in poverty universe (everyone except unrelated individuals under 15); years: 2004 to 2013; Census 2010 weights; row variable: age; column variable: income-to-poverty ratio; and customized formatting: income-to-poverty ratio percent cutoff of 200 percent.
SOURCES: NSCH, 2012; U.S. Census Bureau, 2014, 2015b; unpublished data provided by the SSA.

below 200 percent FPL, the expected number of children in low-income households with ASD in 2010 would be 474,133. However, recognizing the much lower prevalence of diagnosed ASD in children in low-income households, compared to middle- or upper-socioeconomic-class children, this estimate of the number of children in low-income households with ASD may be a substantial overestimate. In 2010, there were 94,606 recipients of SSI benefits for ASD. It is likely that the high rate of allowances for ASD in the SSI system has considerably closed the gap between potential and actual recipients of benefits. Figure 14-16 illustrates these relationships.

Prevalence of ASD

Findings

- Recent prevalence estimates for ASD in the general under-18 population range from 1.5 to 2 percent.
- An increasing trend in the prevalence of ASD has been observed across all data sources, including national surveys, epidemiological studies, special education service use counts, and Medicaid reimbursements. The trends in the rate of the child SSI recipients for ASD among children in low-income households are consistent with trends in the rate of ASD observed in both the general population and others.
- There is evidence of diagnostic substitution between ASD and ID in both the general population data and the SSI program data. From 2004 to 2013, decreases in the rate and number of recipients of SSI for ID were similar to decreases in the rate of special education service use for ID in the general population; significant increases in the rate and number of recipients of SSI for autistic disorder are similar to increases in the rate of special education services for ASD in the general population.
- The trend in ASD diagnoses among Medicaid-enrolled children was similar to general population trends between 2001 and 2010. The yearly prevalence estimates of ASD diagnoses among children enrolled in Medicaid were similar to estimates based on special education child counts, but lower than ASD prevalence estimates from surveillance and survey data for the general population.

Conclusion

- Based on current prevalence estimates of autism and on estimates of the number of children in low-income households in this country, there is significant evidence that not all children in low-income

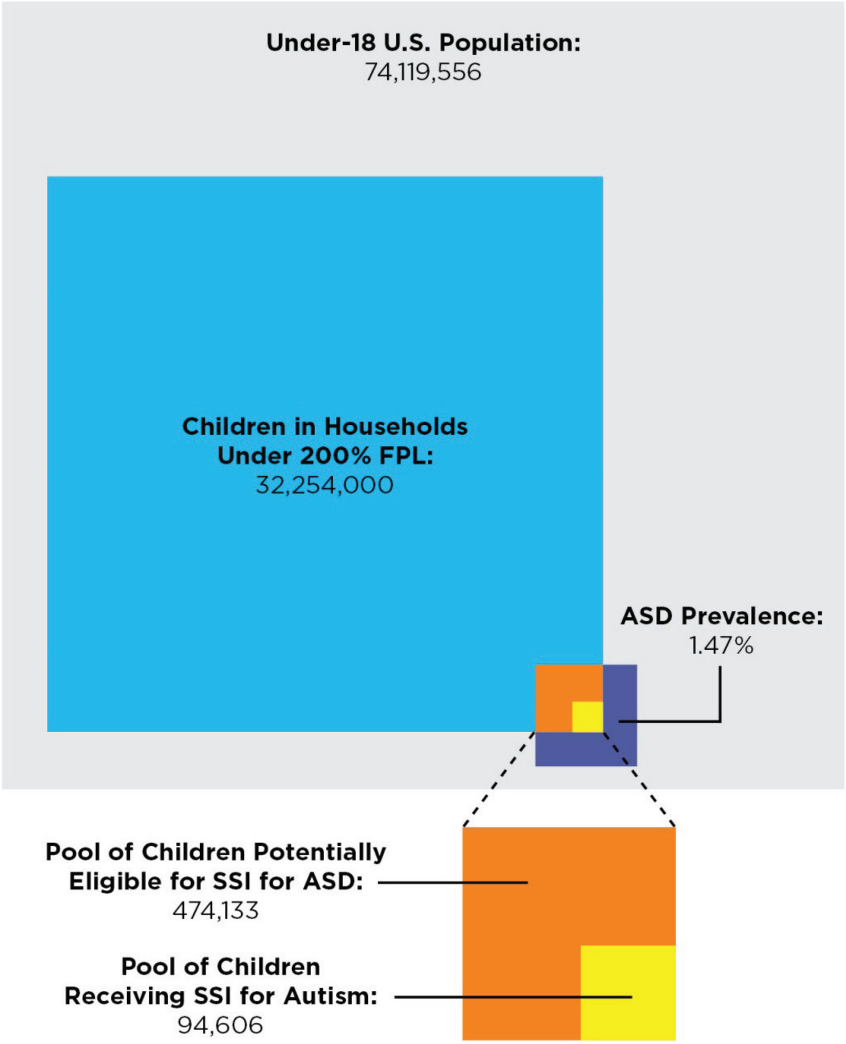

FIGURE 14-16 Children potentially eligible for SSI for ASD versus children receiving SSI for ASD in 2010.
NOTE: The Current Population Survey table creator was used to generate numbers of children below 200 percent of the federal poverty level. Parameters used to generate the numbers include get count of: persons in poverty universe (everyone except unrelated individuals under 15); years: 2004 to 2013; Census 2010 weights; row variable: age; column variable: income-to-poverty ratio; and customized formatting: income-to-poverty ratio percent cutoff of 200 percent.
SOURCES: CDC, 2015; U.S. Census Bureau, 2014, 2015b; unpublished data provided by the SSA.

households who would be eligible for SSI benefits due to ASD are currently recipients of these benefits. Depending on the prevalence estimate, only 20 to 50 percent of potentially eligible children received SSI benefits. However, unlike the case with other mental disorders, the evidence shows higher rates of ASD identification in middle- and high-income children, and lower rates of identification among low-income children. This suggests ASD in low-income children may be under-identified and underestimated.

REFERENCES

APA (American Psychiatric Association). 2013. *Diagnostic and statistical manual of mental disorders, fifth edition*. Washington, DC: APA.

Baio, J. 2012. Prevalence of autism spectrum disorders: Autism and developmental disabilities monitoring network, 14 sites, United States, 2008. *Morbidity and Mortality Weekly Report* 61(SS03):1–19.

Baio, J. 2014. Prevalence of autism spectrum disorder among children aged 8 years: Autism and developmental disabilities monitoring network, 11 sites, United States, 2010. *Morbidity and Mortality Weekly Report* 63(SS02):1–21.

Blumberg, S. J., M. D. Bramlett, M. D. Kogan, L. A. Schieve, J. R. Jones, and M. C. Lu. 2013. Changes in prevalence of parent-reported autism spectrum disorder in school-aged U.S. children: 2007 to 2011–2012. *National Health Statistics Reports* 65(20):1–12.

Boyle, C. A., S. Boulet, L. A. Schieve, R. A. Cohen, S. J. Blumberg, M. Yeargin-Allsopp, S. Visser, and M. D. Kogan. 2011. Trends in the prevalence of developmental disabilities in U.S. children, 1997–2008. *Pediatrics* 127(6):1034–1042.

Braun, K. V. N., D. Christensen, N. Doernberg, L. Schieve, C. Rice, L. Wiggins, D. Schendel, and M. Yeargin-Allsopp. 2015. Trends in the prevalence of autism spectrum disorder, cerebral palsy, hearing loss, intellectual disability, and vision impairment, metropolitan Atlanta, 1991–2010. *PLoS ONE* 10(4):e0124120.

Cavagnaro, A. 2007. *Autistic spectrum disorders: Changes in the California caseload. An update: June 1987-June 2007*. California Health and Human Services Agency. www.dds.ca.gov/Autism/docs/AutismReport_2007.pdf (accessed July 15, 2015).

CDC (Centers for Disease Control and Prevention). 2015. Autism and Developmental Disabilities Monitoring (ADDM) Network. www.cdc.gov/ncbddd/autism/addm.html (accessed August 3, 2015).

Durkin, M. S. M., J. Matthew, C. J. Newschaffer, L.–C. Lee, C. M. Cunniff, J. L. Daniels, R. S. Kirby, L. Leavitt, L. Miller, W. Zahorodny, and L. A. Schieve. 2008. Advanced parental age and the risk of autism spectrum disorder. *American Journal of Epidemiology* 168(11):1268–1276.

Durkin, M. S., M. J. Maenner, F. J. Meaney, S. E. Levy, C. DiGuiseppi, J. S. Nicholas, R. S. Kirby, J. A. Pinto-Martin, and L. A. Schieve. 2010. Socioeconomic inequality in the prevalence of autism spectrum disorder: Evidence from a U.S. cross-sectional study. *PLoS ONE* 5(7):e11551.

Durkin, M. S., D. A. Bilder, S. Pettygrove, and W. Zahorodny. 2014. The validity and usefulness of public health surveillance of autism spectrum disorder. *Autism* 19(1):118–119.

Fombonne, E. 2009. Epidemiology of pervasive developmental disorders. *Pediatric Research* 65(6):591–598.

Grether, J. K., N. J. Rosen, K. S. Smith, and L. A. Croen. 2009. Investigation of shifts in autism reporting in the California Department of Developmental Services. *Journal of Autism and Developmental Disorders* 39(10):1412–1419.

King, M., and P. Bearman. 2009. Diagnostic change and the increased prevalence of autism. *International Journal of Epidemiology* 38(5):1224–1234.

Lotter, V. 1966. Epidemiology of autistic conditions in young children. *Social Psychiatry* 1(3):124–135.

Lundstrom, S., A. Reichenberg, H. Anckarsater, P. Lichtenstein, and C. Gillberg. 2015. Autism phenotype versus registered diagnosis in Swedish children: Prevalence trends over ten years in general population samples. *British Medical Journal* 350:h1961. doi: http://dx.doi.org/10.1136/bmj.h1961.

Maenner, M. J., C. E. Rice, C. L. Arneson, C. Cunniff, L. A. Schieve, L. A. Carpenter, K. Van Naarden Braun, R. S. Kirby, A. V. Bakian, and M. S. Durkin. 2014. Potential impact of DSM-5 criteria on autism spectrum disorder prevalence estimates. *JAMA Psychiatry* 71(3):292–300.

NSCH (National Survey of Children's Health). 2012. Data query from the Child and Adolescent Health Measurement Initiative. http://childhealthdata.org/browse/survey/results?q=2408&r=1 (accessed August 3, 2015).

Rice, C. 2009. Prevalence of autism spectrum disorders: Autism and Developmental Disabilities Monitoring Network, United States, 2006. *Morbidity and Mortality Weekly Report* 58(SS10):1–20.

Rice, C. 2013. Time trends in diagnosis. In *Encyclopedia of autism spectrum disorders*, edited by F. Volkmar. New York: Springer. Pp. 3120–3125.

Rice, C., K. V. N. Braun, Autism and Developmental Disabilities Monitoring Network, and Centers for Disease Control and Prevention. 2007. *Prevalence of autism spectrum disorders—Autism and developmental disabilities monitoring network, six sites, United States, 2000; Prevalence of autism spectrum disorders—Autism and developmental disabilities monitoring network, 14 sites, United States, 2002; and Evaluation of a methodology for a collaborative multiple source surveillance network for autism spectrum disorders—Autism and Developmental Disabilities Monitoring Network, 14 sites, United States, 2002*. Washington, DC: U.S. Government Printing Office.

Rice, C. E., M. Rosanoff, G. Dawson, M. S. Durkin, L. A. Croen, A. Singer, and M. Yeargin-Allsopp. 2013. Evaluating changes in the prevalence of the autism spectrum disorders (ASDs). *Public Health Reviews* 34(2):1–22.

Rutter, M. 2005. Aetiology of autism: Findings and questions. *Journal of Intellectual Disability Research* 49(4):231–238.

Schieve, L. A., C. Rice, C. Boyle, S. N. Visser, and S. J. Blumberg. 2006. Mental health in the United States: Parental report of diagnosed autism in children aged 4–17 years—United States, 2003–2004. *Morbidity and Mortality Weekly Report* 55(17):481–486.

Schieve, L. A., C. Rice, O. Devine, M. J. Maenner, L.-C. Lee, R. Fitzgerald, M. S. Wingate, D. Schendel, S. Pettygrove, and K. van Naarden Braun. 2011. Have secular changes in perinatal risk factors contributed to the recent autism prevalence increase? Development and application of a mathematical assessment model. *Annals of Epidemiology* 21(12): 930–945.

Shattuck, P. T. 2006. The contribution of diagnostic substitution to the growing administrative prevalence of autism in U.S. special education. *Pediatrics* 117(4):1028–1037.

Shattuck, P. T., M. Durkin, M. Maenner, C. Newschaffer, D. S. Mandell, L. Wiggins, L.-C. Lee, C. Rice, E. Giarelli, and R. Kirby. 2009. Timing of identification among children with an autism spectrum disorder: Findings from a population-based surveillance study. *Journal of the American Academy of Child & Adolescent Psychiatry* 48(5):474–483.

Treffert, D. A. 1970. Epidemiology of infantile autism. *Archives of General Psychiatry* 22(5): 431–438.

U.S. Census Bureau. 2011. National intercensal estimates (2000–2010): Table 1 Intercensal estimates of the resident population by sex and age for the United States: April 1, 2000 to July 1, 2010. www.census.gov/popest/data/intercensal/national/nat2010.html (accessed July 28, 2015).

U.S. Census Bureau. 2014. Total population by child and adult populations. http://datacenter.kidscount.org/data/tables/99-total-population-by-child-and-adult-populations?loc=1&loct=1#detailed/1/any/false/35,18,17,16,15/39,41/416,417 (accessed November 14, 2014).

U.S. Census Bureau. 2015a. Annual estimates of the resident population for selected age groups by sex for the United States, states, and counties, and Puerto Rico Commonwealth and municipios: April 1, 2010 to July 1, 2014. http://factfinder.census.gov/faces/tableservices/jsf/pages/productview.xhtml?src=bkmk (accessed July 15, 2015).

U.S. Census Bureau. 2015b. CPS table creator. www.census.gov/cps/data/cpstablecreator.html (accessed July 13, 2015).

U.S. Department of Education. 2013. Thirty-fifth annual report to Congress on the implementation of the Individuals with Disabilities Education Act, Parts B and C. 2013: Part B data descriptions and data files. http://www2.ed.gov/about/reports/annual/osep/2013/parts-b-c/part-b-data/index.html (accessed July 28, 2015).

U.S. Department of Education. 2014. 2012 IDEA part B child count and educational environments. https://inventory.data.gov/dataset/2012-idea-part-b-child-count-and-educational-environments/resource/a68a23f3-3981-47db-ac75-98a167b65259?inner_span=True (accessed August 3, 2014).

Wing, L., and D. Potter. 2002. The epidemiology of autistic spectrum disorders: Is the prevalence rising? *Mental Retardation and Developmental Disabilities Research Reviews* 8(3):151–161.

15

Prevalence of Intellectual Disabilities

This chapter reviews recent evidence on the prevalence of intellectual disability (ID) in the general population of children in the United States and compares this to trends in the frequency of ID allowances and recipients in the Supplemental Security Income (SSI) program as well as trends in ID prevalence among children enrolled in Medicaid.

ESTIMATES OF INTELLECTUAL DISABILITY PREVALENCE AND PREVALENCE TRENDS FROM THE GENERAL POPULATION

Prevalence of Intellectual Disabilities

Estimates of the prevalence of ID among children in the United States based on epidemiologic studies range widely, from 8.7 to 36.8 per 1,000 (Boyle and Lary, 1996; Camp et al., 1998) (see Table 15-1). A major source of this wide range in prevalence is variation in the inclusion of mild ID (often defined to include individuals with IQs in the range of 50–70 and deficits in adaptive behavior).[1] While the prevalence of serious ID (IQ <50 with deficits in adaptive behavior) in the United States and other developed countries is consistently found to be in the range of 2.5 to 5 per 1,000 children, that of mild ID ranges from as low as 2 to more than 30 per 1,000. The risk of mild ID is highest among children of low socioeconomic status (Durkin et al., 2007; Maulik et al., 2011). From the evidence reviewed, disparities in the rates of ID by race and ethnicity are also reported.

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[1] See Chapter 9 for further discussion on the classification of severity of intellectual disabilities.

TABLE 15-1 Prevalence of Intellectual Disability per 1,000 Children

Reference	Year	Location	Age Range	Mild	Severe ID	All	Comments
Camp et al., 1998	1966–1972	U.S. multisite birth cohort	7 years	N/A	Not provided	36.8	Prevalence higher in black children (55.0/1,000) than white children (17.0/1,000), and in children of low SES (70.0/1,000) than middle or high (28.0/1,000) SES.
Boyle and Lary, 1996	1991	Atlanta, GA	3–10 years	5.7	0.9	8.7	Overall prevalence higher in black children (13.2/1,000) than white children (6.1/1,000).
Bhasin et al., 2006	1996	Atlanta, GA	8 years	10.0	4.3	15.5	Prevalence higher in black children (22.7/1,000) than white children (9.8/1,000) and higher in boys (19.1) than girls (11.8).
Bhasin et al., 2006	2000	Atlanta, GA	8 years	7.3	3.3	12.0	Prevalence higher in black children (16.9/1,000) than white children (7.0/1,000) and higher in boys (14.0) than girls (9.9).
Van Naarden Braun et al., 2015	2010	Atlanta, GA	8 years	9.4	3.8	13.6	Prevalence of ID without co-occurring ASD declined from 13.0 in 1996 to 8.6 in 2010. Prevalence of ID with co-occurring ASD increased from 2.4 in 1996 to 5.0 in 2010.

NOTES: ASD = autism spectrum disorder; N/A = not applicable; SES = socioeconomic status. The sum of mild and severe ID prevalence may be less than the overall ID prevalence due to some cases of undetermined severity.

SOURCES: Bhasin et al., 2006; Boyle and Lary, 1996; Camp et al., 1998; Van Naarden Braun et al., 2015.

TABLE 15-2 NHIS Prevalence of Intellectual Disability/Mental Retardation

	1997–1999	2000–2002	2003–2005	2006–2008
ID/Mental Retardation Prevalence	6.8/1000	7.3/1000	7.5/1000	6.7/1000

SOURCE: Boyle et al., 2011.

Socioeconomic status is a confounder for these disparities; however, there is also evidence that test bias and diagnostic bias contribute to these differences (Jencks and Phillips, 1998).

In addition to epidemiologic studies, evidence from the Metropolitan Atlanta Developmental Disabilities Surveillance Program (MADDSP) and two national surveys, the National Health Interview Survey (NHIS) and the National Survey of Children's Health (NSCH) as well as receipt of special education services will be discussed.

National Health Interview Survey

The NHIS provides national-level data on the frequency of ID among children (ages 3–17 years) in the United States for the period 1997 to 2008. The NHIS data, which are based on parent-reported diagnoses of "mental retardation" or ID, are summarized in Table 15-2.

National Survey of Children's Health

The NSCH began collecting information on the prevalence of ID or mental retardation in the 2011–2012 survey. Previous versions of the NSCH did not ask any questions about ID or mental retardation. The NSCH-estimated prevalence of children (2–17 years) who currently had the condition in 2011–2012 was 1.1 percent (confidence interval [CI] 0.9–1.2) (NSCH, 2012a).

Prevalence Trends for Intellectual Disabilities

It is important to acknowledge that there are no perfect sources of data for evaluating trends in the prevalence of ID in the United States. An ideal source that would allow evaluation of trends over time might be generated by large-scale, nationally representative, population-based epidemiologic studies conducted periodically, and using validated and comparable methods and diagnostic criteria over time. No such data source exists. The data sources used for the purposes of this study have complementary strengths and weaknesses. For example, the epidemiologic data source described below, from the Centers for Disease Control and Prevention's (CDC's) MADDSP, has the advantages of being population-based, including one large and diverse populations of U.S. children, relying on validated methods for classifying cases of ID that were comparable over a multiple-year period (1991–2010), and allowing evaluation of trends over time. The MADDSP data are, however, not nationally representative and they rely exclusively IQ scores recorded in the records of health care providers or schools, without incorporating information on adaptive behavior. In contrast, the national survey data have the advantage of being based on national probability samples, but the disadvantages of relying on parental reports rather than diagnostic assessments, and of response rates less than 100 percent. Special education "child count" data have the advantages of being nationally representative and available annually, but do not necessarily rely on standard case definitions or diagnostic criteria that are comparable over time and across states and school districts. Despite the limitations each data source, taken together they provide valuable and complementary evidence for evaluating trends over time in the frequency of ID in U.S. children.

Metropolitan Atlanta Developmental Disabilities Surveillance Program

MADDSP, which is funded by the CDC, has monitored the prevalence of ID among children in the five counties of metropolitan Atlanta since 1991, and it recently published findings that allow an evaluation of trends in ID prevalence over time (Van Naarden Braun et al., 2015). The earliest estimate of the prevalence of ID from this program—for surveillance year 1991—was 8.7 per 1,000 children of ages 3–10 years (see Table 15-1) (Boyle and Lary, 1996). Subsequent estimates were restricted to 8-year-old children, as 8 years is the peak age for identification of ID. For the surveillance year 1996, MADDSP reported an ID prevalence of 15.5 per 1,000 8-year-old children, and for surveillance year 2000 the comparable estimate was 12.0 (see Table 15-1) (Bhasin et al., 2006). The most recent estimate, for surveillance year 2010, found the overall prevalence of ID among 8-year-old children to be 13.6 per 1,000 shown in Table 15-1 (Van Naarden Braun et al., 2015).

Special Education Services

As reported previously in comparison with prevalence trends for autism spectrum disorder, the rate of the receipt of special education services for ID among school-aged children in the United States declined steadily from 9.1 per 1,000 in 2004 to 6.6 per 1,000 in 2012. Table 15-3 shows the decreasing trend in the rate of children receiving special education services for ID from 2004 to 2012.

TABLE 15-3 Prevalence of Receipt of Special Education Services for Intellectual Disability in Children of Ages 6–17 Years, per 1,000 Children in the United States, 2004–2012

Year	2004	2005	2006	2007	2008	2009	2010	2011	2012
Prevalence	9.1	8.6	8.2	7.7	7.5	7.2	6.9	6.7	6.6

NOTE: Denominators of child population were obtained for ages 5–17 for the years 2004 to 2012. Numerators were obtained from Part B child count data for intellectual disability (called mental retardation before 2010) for the 50 states, Washington, DC, and Puerto Rico, ages 6–17 for the years 2004–2011. Numerator was obtained for intellectual disability for the 50 states, Washington, DC, and Puerto Rico for ages 6–17 for year 2012.
SOURCES: U.S. Census Bureau, 2011, 2015a; U.S. Department of Education, 2013, 2014.

TRENDS IN THE RATES OF INTELLECTUAL DISABILITY AMONG SSI AND MEDICAID POPULATIONS

This section of the report presents data on the trends in the rates of intellectual disability in the SSI program for children from 2004 to 2013 and in Medicaid from 2001 to 2010.

SSI

Within the SSI program, the number of allowances and recipients for ID substantially and continuously decreased between 2004 and 2013. The proportion of allowances and recipients attributable to ID among the 10 major mental disorders also decreased. In spite of these decreases, in 2013 ID was the basis for the third highest number of allowances (12,470) of the major mental disorders, the fifth highest number (13,613) of determinations, and the third highest number (120,248) of recipients. In addition, the allowance rate for ID remained above 90 percent for each year from 2004 to 2013, indicating that nearly all children with ID who applied for benefits were deemed eligible. Based on these findings, it appears that fewer children are being adjudicated as having a disability due to ID. The decreasing numbers of ID allowances and recipients is unique; decreasing trends of similar magnitude are not observed for any of the other selected mental disorders.

Table 15-4 presents the SSI administrative data on ID in children. Column 1 shows the number of child allowances made on the basis of ID at the initial level for each year. Column 2 shows the number of child recipients who received SSI benefits on the basis of ID in December of each year. Column 3 shows the estimated number of children in households with incomes under 200 percent of the federal poverty level (FPL) for each year. To control for the changes in the magnitude of child poverty, allowances and recipients are shown as a percentage of the number of children in

TABLE 15-4 SSI Child Initial Allowances and Recipient Numbers for Intellectual Disability

	1	2	3	4	5
Year	# of Child SSI Allowances for ID	# of Child SSI Recipients for ID	# of Children in Households Under 200% FPL	% of Children Under 200% FPL Allowed SSI Benefits for ID	% of Children Under 200% FPL Who Are Recipients of SSI Benefits for ID
2004	24,602	215,709	28,753,000	0.09%	0.75%
2005	22,237	204,755	28,539,000	0.08%	0.72%
2006	19,161	192,566	28,757,000	0.07%	0.67%
2007	17,152	178,042	28,999,000	0.06%	0.61%
2008	17,182	163,007	30,064,000	0.06%	0.54%
2009	17,831	151,887	31,505,000	0.06%	0.48%
2010	17,680	141,618	32,254,000	0.05%	0.44%
2011	16,456	132,906	32,678,000	0.05%	0.41%
2012	14,128	126,520	32,269,000	0.04%	0.39%
2013	12,470	120,248	31,364,000	0.04%	0.38%

NOTE: The Current Population Survey table creator was used to generate numbers of children below 200 percent of the federal poverty level. Parameters used to generate the numbers include get count of: persons in poverty universe (everyone except unrelated individuals under 15); years: 2004 to 2013; Census 2010 weights; row variable: age; column variable: income-to-poverty ratio; and customized formatting: income-to-poverty ratio percent cutoff of 200 percent.

SOURCES: U.S. Census Bureau, 2015b; unpublished data set provided by the Social Security Administration (SSA).

households under 200 percent FPL for each year. Column 4 shows the percentage of children in households under 200 percent FPL who were allowed benefits for ID (i.e., were found to be severely impaired, with a primary diagnosis of ID) in each year. Column 5 shows the percentage of children in households under 200 percent FPL who were recipients (including newly allowed and existing recipients) of SSI payments for ID in December of each year. Figure 15-1 plots the percentages from columns 4 and 5, along with the 10-year average of percentage of allowances and recipients for ID as a visual reference point.

Over the 10-year period from 2004 to 2013, the rates of child SSI ID allowances and recipients were decreasing. The rate of child ID allowances among children in households less than 200 percent FPL decreased between 2004 and 2013 by approximately 56 percent, from 0.09 to 0.04 percent.

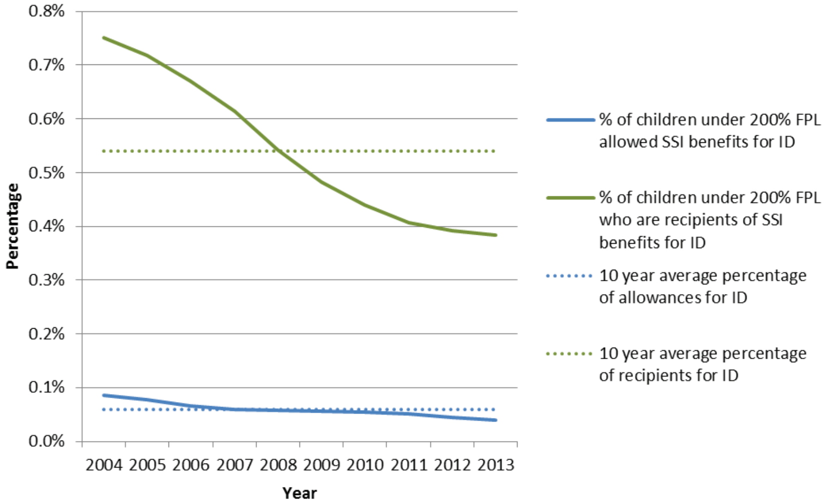

FIGURE 15-1 Percentages of SSI child initial allowances and recipients for intellectual disability below 200 percent FPL.
NOTE: The Current Population Survey table creator was used to generate numbers of children below 200 percent of the federal poverty level. Parameters used to generate the numbers include get count of: persons in poverty universe (everyone except unrelated individuals under 15); years: 2004 to 2013; Census 2010 weights; row variable: age; column variable: income-to-poverty ratio; and customized formatting: income-to-poverty ratio percent cutoff of 200 percent.
SOURCES: U.S. Census Bureau, 2015b; unpublished data set provided by the SSA.

Similarly, the rate of child ID recipients decreased between 2004 and 2013 by 49 percent, from 0.75 to 0.38 percent.

Medicaid

Table 15-5 shows the percentage of children who were diagnosed with ID in two different groups of Medicaid enrollees for each year from 2001 to 2010. Column 1 shows the percentage of ID diagnoses among all Medicaid enrollees[2] for each year. Column 2 shows the percentage of ID diagnoses among the smaller subpopulation of Medicaid enrollees who were eligible to be enrolled in Medicaid on the basis receiving SSI benefits.[3]

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[2] Refer to Appendix F for Rutgers methods section.

[3] Ibid.

TABLE 15-5 Percentage of Child Medicaid Enrollees and SSI Medicaid Enrollees Diagnosed with Intellectual Disability

	1	2
Year	% of All Child Medicaid Enrollees with ID Diagnosis	% of Child SSI Medicaid Enrollee Subpopulation with ID Diagnosis
2001	0.60%	6.60%
2002	0.60%	6.50%
2003	0.60%	6.20%
2004	0.50%	6.20%
2005	0.50%	6.40%
2006	0.60%	6.40%
2007	0.60%	6.80%
2008	0.60%	7.10%
2009	0.60%	6.60%
2010	0.50%	6.40%

SOURCE: Medicaid Analytic eXtract (MAX) data.

As shown in Figure 15-2, the rate of ID diagnoses among all children enrolled in Medicaid was mostly flat, remaining very close to the 10-year average each year. The rate of ID diagnoses among all Medicaid enrollees decreased by 16.67 percent from 2001 to 2010, from 0.6 to 0.5 percent. The rate of ID diagnoses among the SSI-eligible subpopulation of Medicaid enrollees decreased by –3.03 percent, from 6.6 to 6.4 percent. There was a peak in the rates of ID diagnoses among SSI-eligible Medicaid enrollees in 2008 which does not seem to appear in any of the other trends observed.

For the years in which the Medicaid data and the SSI administrative data overlapped, 2004–2010, there was no change in the rate of ID diagnoses among all Medicaid enrolled children, the rate of ID diagnoses among SSI eligible Medicaid enrolled children increased 3.23 percent, and the prevalence of SSI recipients for ID among children in households below 200 percent FPL decreased by 41 percent. A clear decreasing trend is observed in the SSI program, while no clear decreasing trend is observed in the Medicaid population.

DISCUSSION

SSI data and special education service utilization data show a uniformly decreasing trend in ID prevalence for the time period roughly between

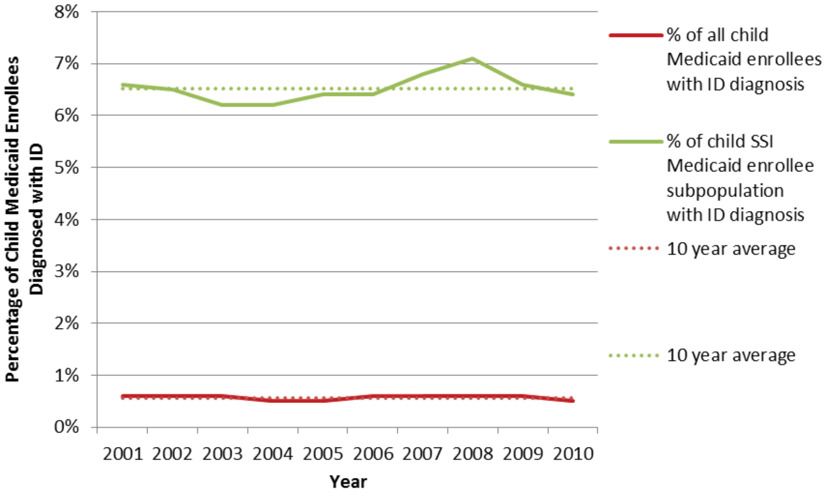

FIGURE 15-2 Percentage of child Medicaid enrollees and SSI Medicaid enrollees diagnosed with intellectual disability.
SOURCE: MAX data.

2001 and 2013. Epidemiologic data also suggest a decline in ID prevalence between the 1960s and 2000 (Bhasin et al., 2006; Camp et al., 1998). On the other hand, available national survey data and Medicaid data show no evidence of a change in the frequency of ID in recent decades. A possible explanation for the differences in the observed trends is that the data based on SSI allowances and recipients, special education, and epidemiologic surveillance are secondary uses of diagnostic categories that are required for benefit and service eligibility, while the Medicaid and population survey data are based, respectively, on the use of clinical or treatment services and on parent reports. As discussed in Chapter 14, diagnostic substitution may contribute to the decrease in ID observed in the SSI program and in special education service use data. The use of the autism spectrum disorder diagnostic category may be incentivized—and therefore preferentially used—due to the availability of more or better services and supports or because of less social stigma. In contrast, the diagnostic criteria used in a clinical setting might be less prone to substitution.

The similarity of the decreasing trends observed in the SSI program and in the Individuals with Disabilities Education Act data does provide some confirmation that the trends observed in the SSI program are not unexpected or inconsistent with trends in the general population.

Based on general population estimates of ID and the rate of child poverty, it may be the case that the SSI program is providing benefits to a relatively small proportion of the population of children who would otherwise be eligible to receive benefits. The NSCH 2011–2012 estimate of the prevalence of children (ages 2–17) with severe or moderate ID, as reported by parents, was 0.7 percent (NSCH, 2012b). The estimated number of children below 200 percent FPL in 2012 was 32,269,000 (U.S. Census Bureau, 2015b).[4] Therefore the expected number of children with current moderate to severe ID below 200 percent FPL would be 225,883. In 2012 there were 126,520 child recipients of SSI benefits for ID, less than 60 percent of the expected number. Figure 15-3 illustrates these relationships.

FINDINGS

- Estimates of the prevalence of ID in the general population have varied somewhat over time, but have remained largely unchanged. These estimates range from 8.7 to 36.8 per 1,000 children.
- The number of children and the proportion of children in low-income households who are receiving SSI benefits for ID is decreasing. The decreasing trend is consistent with trends observed in the rates of special education service utilization for children with ID and may relate to diagnostic substitution with ASD.
- The rates of children being diagnosed with ID among all child Medicaid enrollees did not appear to decrease between 2001 and 2010. The percentage of children diagnosed with ID who are on Medicaid on the basis of SSI eligibility may have increased slightly.

CONCLUSION

- Rough estimates of the number of children in low-income households with moderate to severe ID suggests that less than 60 percent of children who are likely eligible for SSI benefits due to ID are recipients of SSI benefits for ID.

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[4] The Current Population Survey table creator was used to generate numbers of children below 200 percent of the federal poverty level. Parameters used to generate the numbers include get count of: persons in poverty universe (everyone except unrelated individuals under 15); years: 2004 to 2013; Census 2010 weights; row variable: age; column variable: income-to-poverty ratio; and customized formatting: income-to-poverty ratio percent cutoff of 200 percent.

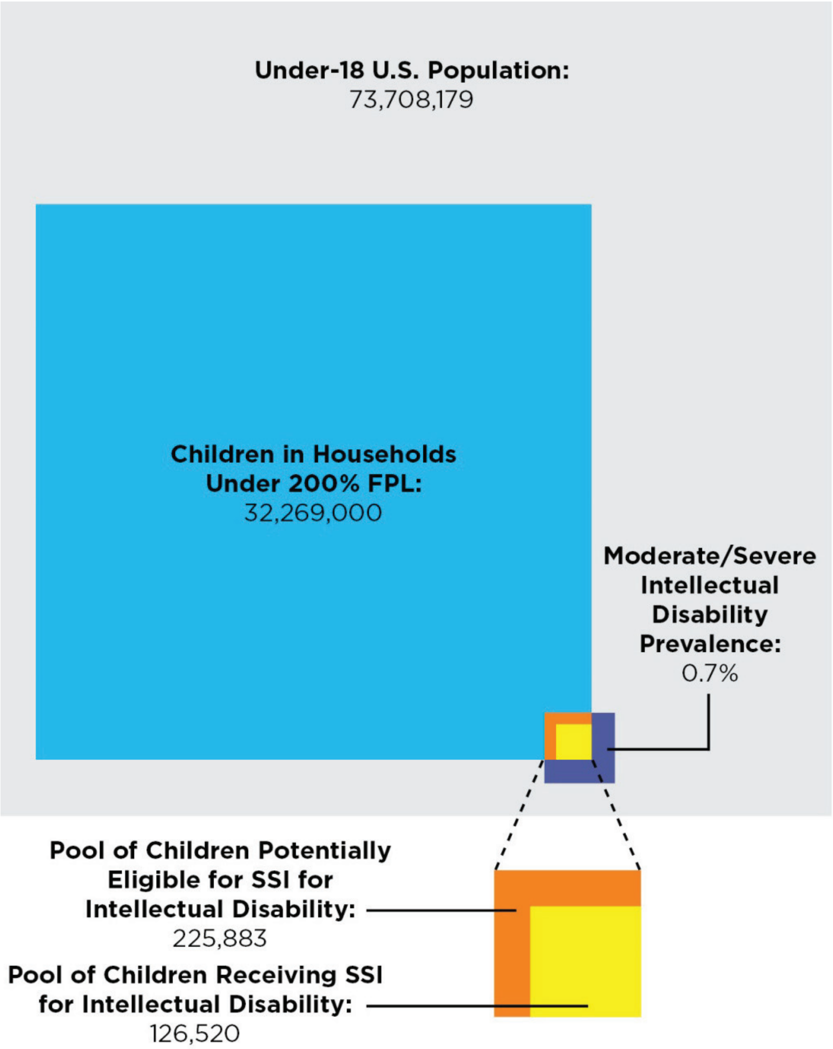

FIGURE 15-3 Children potentially eligible for SSI for intellectual disability versus children receiving SSI for intellectual disability in 2012, according to the NSCH.
NOTE: The Current Population Survey table creator was used to generate numbers of children below 200 percent of the federal poverty level. Parameters used to generate the numbers include get count of: persons in poverty universe (everyone except unrelated individuals under 15); years: 2004 to 2013; Census 2010 weights; row variable: age; column variable: income-to-poverty ratio; and customized formatting: income-to-poverty ratio percent cutoff of 200 percent.
SOURCES: NSCH, 2012b; U.S. Census Bureau, 2014, 2015b; unpublished data provided by the SSA.

REFERENCES

Bhasin, T. K., S. Brocksen, R. N. Avchen, and K. V. N. Braun. 2006. Prevalence of four developmental disabilities among children aged 8 years: Metropolitan Atlanta Developmental Disabilities Surveillance Program, 1996 and 2000. *Mordity and Mortality Weekly Report* 55(SS01):1–9.

Boyle, C. A., and J. M. Lary. 1996. Prevalence of selected developmental disabilities in children 3–10 years of age: The Metropolitan Atlanta Developmental Disabilities Surveillance Program, 1991. *Morbidity and Mortality Weekly Report* 45(SS02):1–14.

Boyle, C. A., S. Boulet, L. A. Schieve, R. A. Cohen, S. J. Blumberg, M. Yeargin-Allsopp, S. Visser, and M. D. Kogan. 2011. Trends in the prevalence of developmental disabilities in U.S. children, 1997–2008. *Pediatrics* 127(6):1034–1042.

Camp, B. W., S. H. Broman, P. L. Nichols, and M. Leff. 1998. Maternal and neonatal risk factors for mental retardation: Defining the "at-risk" child. *Early Human Development* 50(2):159–173.

Durkin, M., N. Schupf, Z. Stein, and M. Susser. 2007. Mental retardation. In *Public health and preventive medicine*, edited by R. Wallace. Stamford, CT: Appleton & Lange. Pp. 1173–1184.

Jencks, C., and M. Phillips. 1998. The black-white test scope gap: Why it persists and what can be done. *The Brookings Review* 24–27.

Maulik, P. K., M. N. Mascarenhas, C. D. Mathers, T. Dua, and S. Saxena. 2011. Prevalence of intellectual disability: A meta-analysis of population-based studies. *Research in Developmental Disabilities* 32(2):419–436.

NSCH (National Survey of Children's Health). 2012a. Data query from the child and adolescent health measurement initiative. http://childhealthdata.org/browse/survey/results?q=2530&r=1 (accessed July 16, 2015).

NSCH. 2012b. Data query from the child and adolescent health measurement initiative. http://childhealthdata.org/browse/survey/results?q=2533&r=1 (accessed August 3, 2015).

U.S. Census Bureau. 2011. National intercensal estimates (2000–2010): Table 1 Intercensal estimates of the resident population by sex and age for the United States: April 1, 2000, to July 1, 2010. www.census.gov/popest/data/intercensal/national/nat2010.html (accessed July 28, 2015).

U.S. Census Bureau. 2014. Total population by child and adult populations. http://datacenter.kidscount.org/data/tables/99-total-population-by-child-and-adult-populations?loc=1&loct=1#detailed/1/any/false/35,18,17,16,15/39,41/416,417 (accessed November 14, 2014).

U.S. Census Bureau. 2015a. Annual estimates of the resident population for selected age groups by sex for the United States, states, and counties, and Puerto Rico Commonwealth and municipios: April 1, 2010, to July 1, 2014. http://factfinder.census.gov/faces/tableservices/jsf/pages/productview.xhtml?src=bkmk (accessed July 15, 2015).

U.S. Census Bureau. 2015b. CPS table creator. www.census.gov/cps/data/cpstablecreator.html (accessed July 13, 2015).

U.S. Department of Education. 2013. Thirty-fifth annual report to Congress on the implementation of the Individuals with Disabilities Education Act, Parts B and C. 2013: Part B data descriptions and data files. http://www2.ed.gov/about/reports/annual/osep/2013/parts-b-c/part-b-data/index.html (accessed July 28, 2015).

U.S. Department of Education. 2014. 2012 IDEA part B child count and educational environments. https://inventory.data.gov/dataset/2012-idea-part-b-child-count-and-educational-environments/resource/a68a23f3-3981-47db-ac75-98a167b65259?inner_span=True (accessed August 3, 2014).

Van Naarden Braun, K., D. Christensen, N. Doernberg, L. Schieve, C. Rice, L. Wiggins, D. Schendel, and M. Yeargin-Allsopp. 2015. Trends in the prevalence of autism spectrum disorder, cerebral palsy, hearing loss, intellectual disability, and vision impairment, metropolitan Atlanta, 1991–2010. *PLoS ONE* 10(4):e0124120.

16

Prevalence of Learning Disabilities

The chapter begins by reviewing recent estimates of the prevalence of learning disabilities (LDs), followed by trend estimates from the general population. The chapter concludes with a comparison of trends for LD in the Supplement Security Income (SSI) program, in the Medicaid population, and in the subpopulation of children who are enrolled in Medicaid by virtue of being SSI recipients.

ESTIMATES OF LEARNING DISABILITY PREVALENCE AND PREVALENCE TRENDS FROM THE GENERAL POPULATION

The committee identified multiple potential data sources that address the prevalence of and trends for rates of learning disabilities in the United States. From these, we identified two data sets judged (1) to be of the highest quality to examine current prevalence estimates of learning disabilities and (2) to characterize trends over the past decade. We selected the National Survey of Children's Health (NSCH) and the Early Childhood Longitudinal Study (ECLS) (Cortiella and Horowitz, 2014; Dhuey and Lipscomb, 2009) as the strongest sources of information on current prevalence. For trend data, we selected the Individuals with Disabilities Education Act (IDEA) data and the National Health Interview Survey (NHIS) (Cortiella and Horowitz, 2014; Dhuey and Lipscomb, 2009). It is notable that these four data sources have produced different forms of data, with attending strengths and limitations, discussed in Chapter 2. This includes administrative data on service receipt maintained by individual school departments (IDEA), national surveys based largely upon parent report, both by telephone (NSCH) and in person (NHIS), and a large longitudinal research project involving direct assessment of children with high-quality research measures (ECLS). While there are certainly limitations with each of these imperfect data sources (e.g., errors in parent reports, differences in awareness and available funds across different school districts, attrition in longitudinal cohorts) we are comforted by the set of results that converge through the use of these multiple data sources, on which we base our conclusions that (1) prevalence estimates for LD in the general population range between 5 and 9 percent and (2) prevalence in the general population does not appear to be rising.

Prevalence of Learning Disabilities

Prevalence Estimates from National Survey of Parents

The purpose of the National Survey of Children's Health is to estimate the national- and state-level prevalence of a variety of physical, emotional, and behavioral child health indicators. It is a random-digit dialing telephone survey and had sample sizes for 2007 and 2011–2012 of 91,642 and 91,800 children, respectively. The question used in the 2007 and 2011–2012 surveys asked, "Has a doctor, health care provider, teacher, or school official ever told you that your child had a learning disability?" Interviews were conducted with parents or guardians of one child randomly selected from each household. There were several questions that assessed not only parent reports that the child had a learning disability, but also, for those who reported learning disabilities, the severity of and services used for this impairment. (Questions assessing the prevalence of learning disabilities were not included in the 2003 survey.) The estimate for current learning disabilities among children of ages 3–17 years in 2007 was 7.8 percent, with 3.7 percent rated as mild and 4.0 percent rated as moderate or severe (NSCH, 2007a,b). The estimate for learning disabilities in 2011–2012 was 8.0 percent for children of ages 3–17, with 4 percent rated as mild and 4 percent rated as moderate or severe (NSCH, 2012a). The percentage of learning disabilities by severity and race/ethnicity is displayed in Figure 16-1. The percentage of learning disabilities by severity and poverty level is displayed in Figure 16-2. With the exception of an apparent increase in moderate to severe LD in the black non-Hispanic group, there are no race/ethnicity differences. In contrast, there is a clear poverty-related gradient for LD.

Prevalence Based on the Early Childhood Longitudinal Studies

The ECLS consists of three cohorts—the birth cohort (ECLS-B), the kindergarten class 1998–1999 (ECLS-K), and the kindergarten class

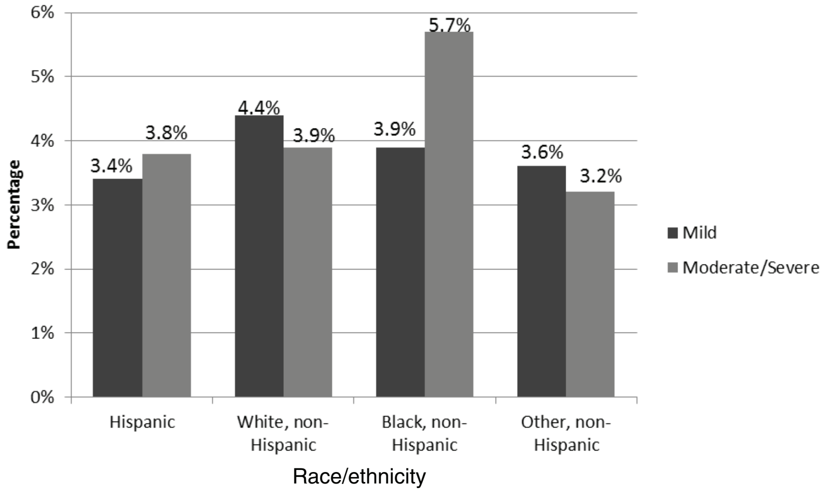

FIGURE 16-1 Percentage of children with learning disabilities by severity and race/ethnicity.
SOURCE: NSCH, 2012b.

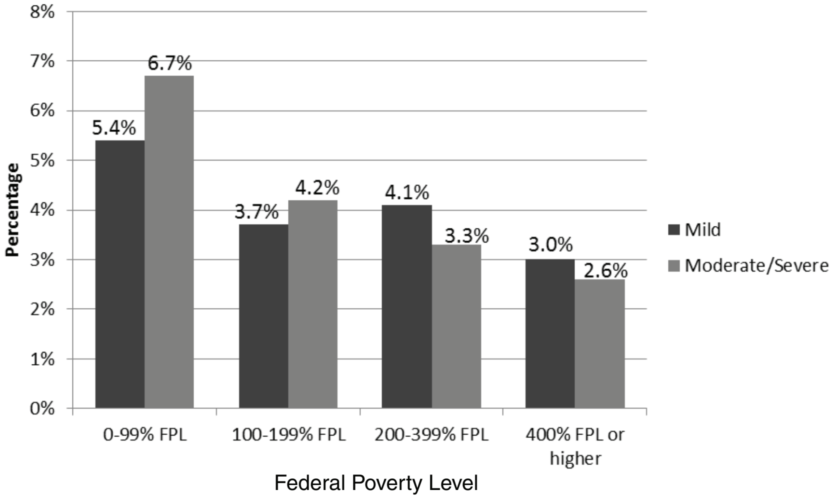

FIGURE 16-2 Percentage of children with learning disabilities by the federal poverty level (FPL).
SOURCE: NSCH, 2012c.

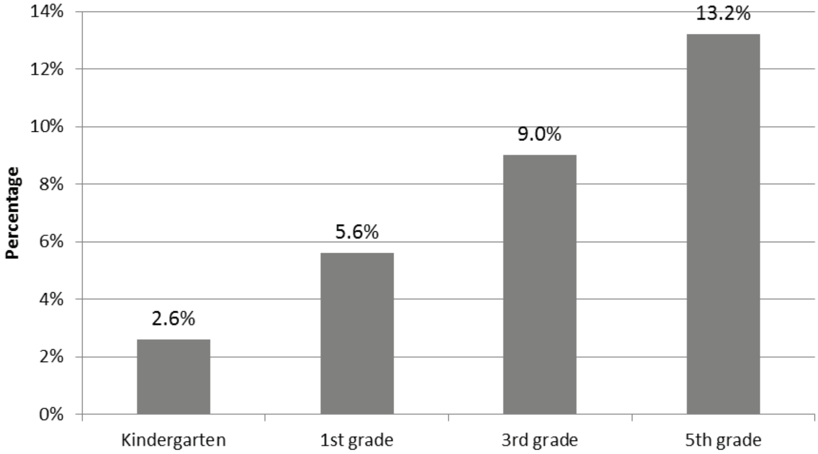

FIGURE 16-3 Ever diagnosed with learning disability: ECLS-K, 1998–2004.
SOURCE: Dhuey and Lipscomb, 2009.

2010–2011 (ECLS-K:2011)—that are used to examine child development, school readiness, and early school experiences (Dhuey and Lipscomb, 2009; Livermore et al., 2011). All three studies have large sample sizes (ECLS-B: 14,000 children; ECLS-K: 21,387; ECLS-K:2011: data collection ongoing) and use several sources of data, including child assessments, interviews, and records (Dhuey and Lipscomb, 2009; Livermore et al., 2011). Results from the ECLS-K indicate that the prevalence of ever being diagnosed with a learning disability increased across the age spectrum from 2.6 percent (kindergarten) to 13.2 percent (5th grade) (see Figure 16-3).

Prevalence Trends

The committee also sought to identify two data sets that would provide the most accurate information on trends in the rates of learning disabilities over recent years. For trend estimates, the committee focused on the IDEA data and the NHIS (Cortiella and Horowitz, 2014; Dhuey and Lipscomb, 2009).

Since 1975, IDEA has provided public access to state-supplied administrative records about children and youths with disabilities up to the age of 21. The data available from IDEA include information on the number and distribution of students served under this law and on the services utilized. Trend estimates for learning disabilities have been measured from 1976 to 2012. As shown in Figure 16-4, from 2004 to 2012, the percentage of school children identified as having learning disabilities, reported through the IDEA system, decreased steadily from 5.8 percent in 2003–2004 to 4.7 percent in 2011–2012.

The NHIS is the principal source of information on the health of the civilian noninstitutionalized population of the United States. It produces statistical information on the prevalence, distribution, and effects of illness and disability in the United States and on the services rendered because of such conditions. This nationally representative survey has been conducted annually since 1957 and samples approximately 35,000 households containing 87,500 individuals each month (Halfon et al., 2012). From each family in the NHIS, one sample adult and one sample child (if any children are present) are randomly selected, and information on each is collected. Since 1997 the question used in the NHIS for ascertaining LD has been, "Has a representative from the school or a health professional ever told you that [survey child] has a learning disability?" Over the period of interest, from 2004 to 2013, the percent fluctuated between 6.9 and 8.2 percent, with no clear evidence of an increasing or decreasing trend. More detailed information on the NHIS estimated prevalence of LD can be seen in Table 16-1.

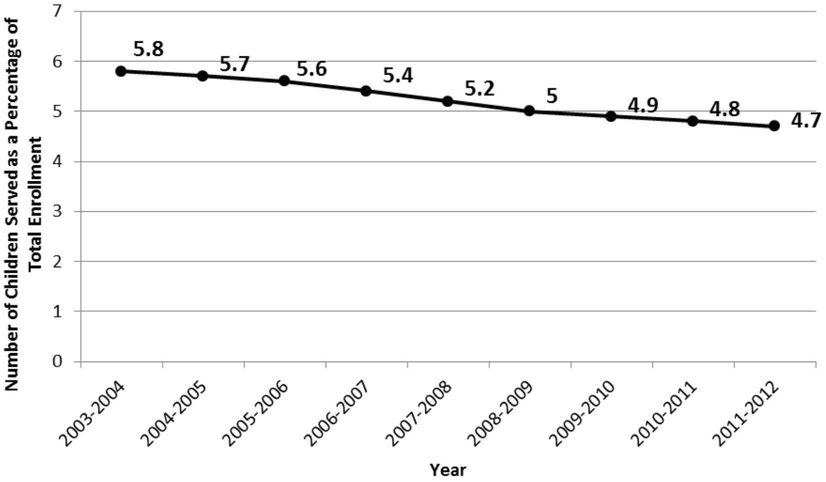

FIGURE 16-4 Children with LD, ages 3–21 served under IDEA, as a percentage of all school children, 2003–2012.
SOURCE: NCES, n.d.

TABLE 16-1 Percentage of Children, Ages 3–17, Reported to Have Ever Been Diagnosed by a School or a Health Professional as Having a Learning Disability

	1997	1998	1999	2000	2001	2002	2003
Total	7.8	7.5	7.2	7.9	7.7	8.1	7.5
Gender							
Male	10.1	9.5	9.8	9.9	9.7	10.1	9.2
Female	5.3	5.4	4.5	5.7	5.5	6.0	5.6
Race/Hispanic origin							
Non-Hispanic white	8.5	7.5	7.6	8.3	7.8	8.5	8.0
Non-Hispanic black	7.6	9.7	7.7	9.2	9.0	10.7	7.6
Hispanic	5.7	6.1	5.5	6.1	6.5	5.8	6.1
Non-Hispanic other	4.1	4.1	5.1	4.2	5.3	3.2	4.8
Age group							
Ages 3–4	1.8	2.7	1.1	2.3	1.5	1.0	2.0
Ages 5–11	7.2	6.6	6.9	7.4	7.4	8.0	7.1
Ages 12–17	10.5	10.2	9.6	10.3	10.0	10.5	9.6
Poverty status							
At or above poverty	—	6.9	6.8	8.0	7.3	7.5	7.6
Below poverty	—	11.4	11.9	10.7	12.6	14.1	9.7

NOTE: Reproduced with permission.
SOURCE: Child Trends Databank, 2014.

With the exception of a recent increase in the percent of all 3- to 4-year-olds reported to have LD, there are no clear gender, race/ethnicity, age, or economic status trends during this 17-year period.

TRENDS IN THE RATES OF LEARNING DISABILITY AMONG SSI AND MEDICAID POPULATIONS

This section of the report presents data on trends in the rates of LD in the SSI program for children from 2004 to 2014 and in Medicaid from 2001 to 2010.

SSI

Within the SSI program for children with mental disorders, LD is the basis for a relatively small but still substantial number of allowances, determinations, and recipients for SSI benefits.

Table 16-2 provides the SSI administrative data on LD among children. Column 1 shows a decreasing number of child allowances made on the basis of LD. Column 2 shows little variation in the total number of child

2004	2005	2006	2007	2008	2009	2010	2011	2012	2013
8.0	6.9	7.8	7.5	8.1	8.2	7.9	7.5	8.0	7.5
9.5	8.7	9.6	9.6	10.0	10.6	9.3	9.2	10.0	9.0
6.4	5.1	5.9	5.3	6.1	5.7	6.4	5.7	6.0	5.9
8.5	7.0	8.6	8.0	9.1	8.7	8.1	8.1	8.7	7.5
9.6	8.4	7.9	7.7	9.1	9.6	10.3	8.5	8.2	9.5
5.6	7.0	6.3	6.7	5.8	7.1	6.5	6.3	7.0	7.2
4.8	2.5	2.7	2.6	4.3	3.9	4.2	4.5	5.2	3.2
2.5	1.5	2.1	2.1	2.3	2.8	3.2	2.6	2.4	3.2
7.4	6.5	7.2	6.7	8.8	7.6	8.0	7.0	8.1	7.8
10.5	9.2	10.2	10.2	9.4	10.8	9.3	9.8	9.7	9.3
7.9	6.5	7.6	7.4	7.9	7.7	7.1	6.8	7.4	6.4
11.3	11.0	10.7	9.3	12.4	11.4	12.3	9.8	11.8	11.9

recipients who received SSI benefits on the basis of LD, particularly if 2004 data are excluded. Column 3 shows the estimated total number of children in households with incomes under 200 percent of the federal poverty level (FPL) for each year. To control for the changes in the magnitude of child poverty, as displayed in column 3, columns 4 and 5 show the rates of allowances and recipients as a percentage of the number of children in households under 200 percent FPL. Column 4 shows the percentage of children in households under 200 percent FPL who were allowed benefits for LD, meaning they were found to be disabled due to a diagnosis of LD. Column 5 shows the percentage of children in households under 200 percent FPL who were recipients of SSI payments for LD in December of each year. Figure 16-5 plots the percentages from columns 4 and 5 along with the 10-year average of the percentages of allowances and recipients for LD as a visual reference point.

As shown in Figure 16-5, over the 10-year period from 2004 to 2013 the proportion of children under 200 percent FPL who were child SSI LD recipients increased from 2004 through 2007, decreased through 2011, then increased slightly through 2013. No overall trend is noted. Over the same time period, the rate of child SSI LD allowances gradually and

TABLE 16-2 SSI Child Initial Allowances and Recipient Numbers for LD

	1	2	3	4	5
Year	# of Child SSI Allowances for LD	# of Child SSI Recipients for LD	# of Children in Households Under 200% FPL	% of Children Under 200% FPL Allowed SSI Benefits for LD	% of Children Under 200% FPL Who Are Recipients of SSI Benefits for LD
2004	6,940	33,833	28,753,000	0.024%	0.118%
2005	6,720	37,118	28,539,000	0.023%	0.130%
2006	5,811	38,934	28,757,000	0.020%	0.135%
2007	5,230	39,597	28,999,000	0.018%	0.137%
2008	5,211	39,619	30,064,000	0.017%	0.132%
2009	5,428	39,868	31,505,000	0.017%	0.127%
2010	5,681	40,278	32,254,000	0.018%	0.125%
2011	5,590	40,533	32,678,000	0.017%	0.124%
2012	5,061	40,924	32,269,000	0.016%	0.127%
2013	4,513	40,461	31,364,000	0.014%	0.129%

NOTE: The Current Population Survey table creator was used to generate numbers of children below 200 percent of the federal poverty level. Parameters used to generate the numbers include get count of: persons in poverty universe (everyone except unrelated individuals under 15); years: 2004 to 2013; Census 2010 weights; row variable: age; column variable: income-to-poverty ratio; and customized formatting: income-to-poverty ratio percent cutoff of 200 percent.
SOURCES: U.S. Census Bureau, 2015; unpublished data set provided by the SSA.

continuously decreased. The rate of child LD allowances among children in households under 200 percent FPL decreased by 40.4 percent, from 0.024 percent in 2004 to 0.014 percent in 2013. Despite these declining annual allowance rates, the total number of recipients each year increased throughout this period, from 0.118 percent in 2004 to 0.129 percent in 2013, an increase of 9.6 percent, although if the 2004 number were excluded, the 9-year change would be downward.

Medicaid

Table 16-3 shows the percentage of children who were diagnosed with LD in two different groups of Medicaid enrollees for each year from 2001 to 2010. Column 1 shows the percentage of all Medicaid enrollees who had a diagnosis of LD, by year. Column 2 shows the percentage of LD diagnoses among the smaller subpopulation of Medicaid enrollees who

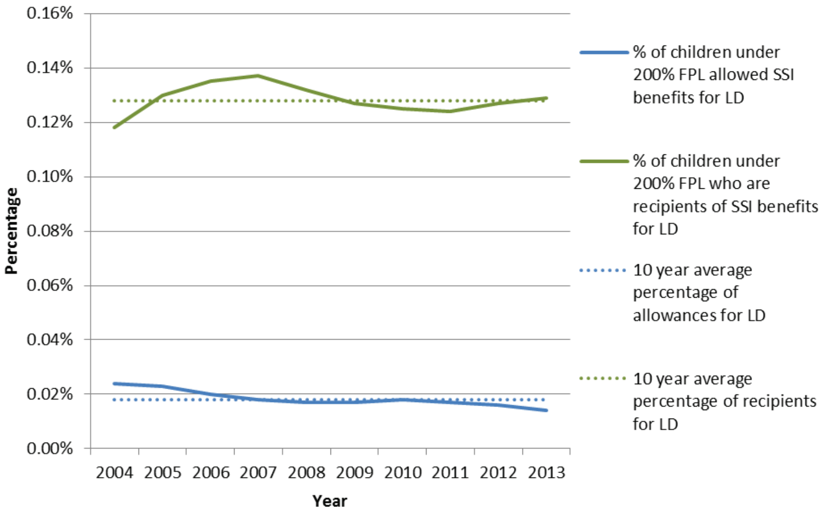

FIGURE 16-5 Percentages of SSI child initial allowances and recipients for LD under 200 percent FPL.
NOTE: The Current Population Survey table creator was used to generate numbers of children below 200 percent of the federal poverty level. Parameters used to generate the numbers include get count of: persons in poverty universe (everyone except unrelated individuals under 15); years: 2004 to 2013; Census 2010 weights; row variable: age; column variable: income-to-poverty ratio; and customized formatting: income-to-poverty ratio percent cutoff of 200 percent.
SOURCES: U.S. Census Bureau, 2015; unpublished data set provided by the SSA.

were eligible to be enrolled in Medicaid on the basis of their eligibility to receive SSI benefits.

The rate of LD diagnoses among all child Medicaid enrollees stayed essentially unchanged between 2001 and 2010 (see Figure 16-6). However, during the same period the proportion of child SSI-eligible Medicaid enrollees with a diagnosis of LD increased from 5.6 to 6.8 percent (an increase of 21.4 percent), with most of the increase occurring between 2008 and 2010.

For the 6-year period of overlap between the Medicaid and SSI administrative data sets, from 2004 to 2010, the rate of LD diagnoses among all Medicaid-enrolled children increased by 20 percent, while the rate of LD diagnoses among SSI-eligible Medicaid-enrolled children increased by 15.25 percent. There was a 9.6 percent increase in the rate of SSI recipients for LD among children in households under 200 percent FPL.

TABLE 16-3 Percentage of Child Medicaid Enrollees and SSI Medicaid Enrollees Diagnosed with LD

	1	2
Year	% of All Child Medicaid Enrollees with LD Diagnosis	% of Child SSI Medicaid Enrollee Subpopulation with LD Diagnosis
2001	1.20%	5.60%
2002	1.10%	5.70%
2003	1.10%	5.80%
2004	1.00%	5.90%
2005	1.00%	5.90%
2006	1.10%	6.00%
2007	1.10%	5.70%
2008	1.10%	5.80%
2009	1.10%	6.00%
2010	1.20%	6.80%

SOURCE: MAX data.

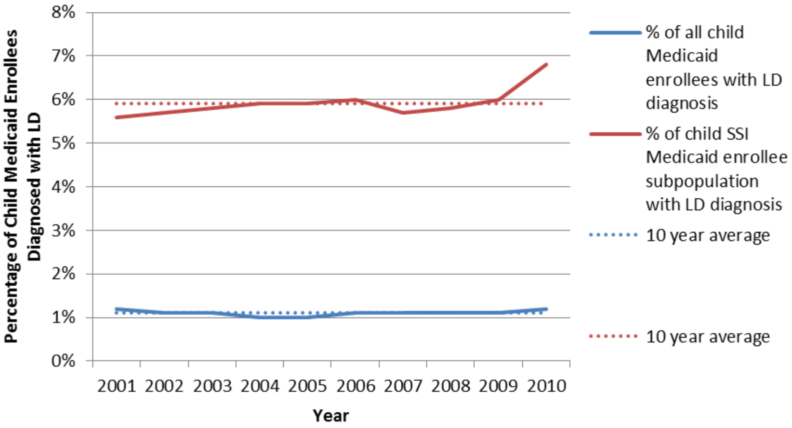

FIGURE 16-6 Percentage of child Medicaid enrollees and SSI Medicaid enrollees diagnosed with LD.
SOURCE: MAX data.

DISCUSSION

The trends in the estimated prevalence of LD among children vary depending on the population studied and on the ways that cases of LD are identified. Overall, the trends in the SSI program are generally consistent with trends generated from surveys of the general population, special education service use, or diagnoses among children in the Medicaid population.

The estimates of prevalence from the population surveys suggest no clear trend, either increasing or decreasing, from 2004 to 2013. The NHIS results showed no clear trend, with the prevalence of LD fluctuating between 6.9 and 8.2 percent, with no increase or decrease between 2004 and 2013, of the percentage of children of ages 3–17 reported to have ever been diagnosed by a school or health professional as having a learning disability. IDEA special education service utilization data showed that the rates of special education use for LD decreased from 5.8 percent in 2004 to 4.7 percent in 2011–2012, a decrease of 18.96 percent. The results of studies that show difference by race and ethnicity must be cautiously interpreted, since there is evidence of diagnostic and test bias for children with LD, even after taking into account the effects of socioeconomic status (Coutinho et al., 2002; Jencks and Phillips, 1998).

The SSI data from 2004 to 2012 indicate that a gradually decreasing percentage of children under 200 percent FPL are being allowed SSI disability benefits for LD. Over the same time period, the percentage of children under 200 percent FPL who were recipients of SSI benefits for LD fluctuated, showing an increase from 2004 to 2007, a decrease from 2007 to 2011, and then another increase from 2011 to 2013; over the 10-year period the total increase was 0.011 percent.

The trends in the rate of LD diagnoses among all child Medicaid enrollees from 2001 to 2010 remained flat. The trends in the rate of LD diagnoses among children enrolled in Medicaid based on SSI eligibility also remained flat from 2004 to 2009; however, a marked increase in the rates of diagnoses occurred in 2010. It is not clear why this increase was observed.

In 2012, there were approximately 32 million children under age 18 living at or below 200 percent of the federal poverty level. Of these, approximately 21 million were of school age (ages 6–17 years). Recent U.S. prevalence data suggest that approximately 4 percent of the child population were diagnosed with a moderate or severe learning disorder (NSCH, 2012a). This suggests that there are approximately 840,000 school-aged children below 200 percent FPL with a severe learning disability, an estimate that is likely to be quite conservative. By contrast, in 2012, 40,924 children received SSI benefits with a diagnosis of learning disability, or approximately 5 percent, which was well below the estimated eligible number. Figure 16-7 illustrates these relationships.

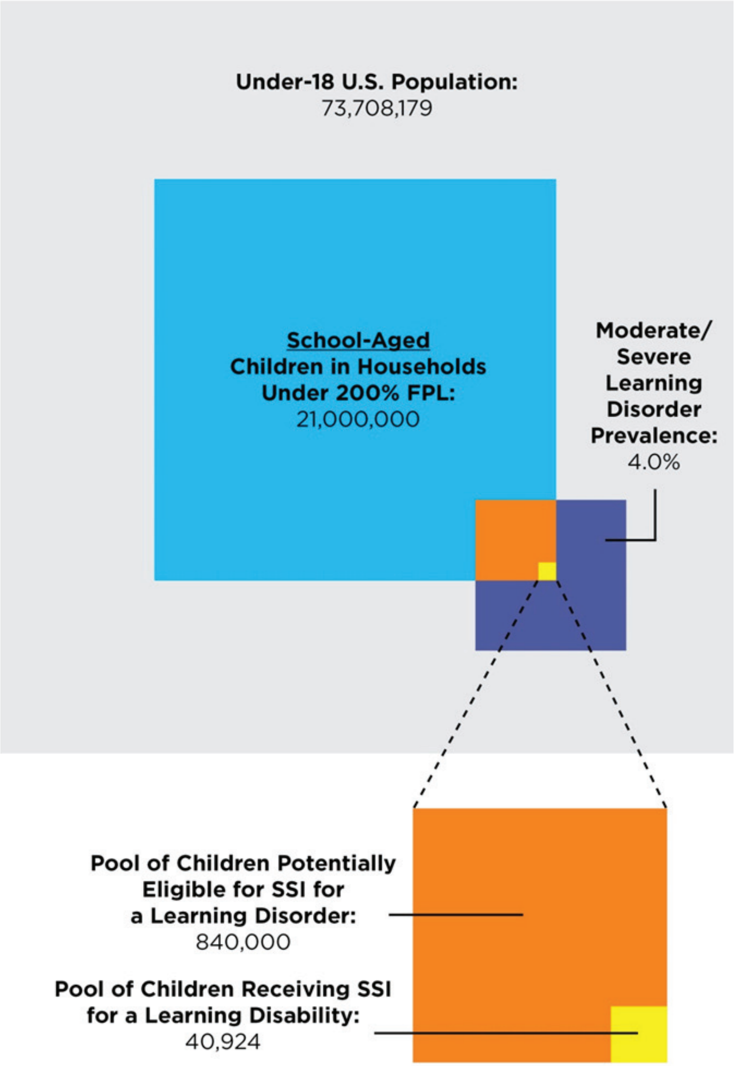

FIGURE 16-7 Children potentially eligible for SSI for LD versus children receiving SSI for LD in 2013, according to the NSCH.
NOTE: The Current Population Survey table creator was used to generate numbers of children below 200 percent of the federal poverty level. Parameters used to generate the numbers include get count of: persons in poverty universe (everyone except unrelated individuals under 15); years: 2004 to 2013; Census 2010 weights; row variable: age; column variable: income-to-poverty ratio; and customized formatting: income-to-poverty ratio percent cutoff of 200 percent.
SOURCES: U.S. Census Bureau, 2014, 2015; NSCH, 2012a; unpublished data set provided by the SSA.

FINDINGS

- Prevalence estimates for LD in the general population range between 5 and 9 percent.
- Prevalence in the general population is stable, but from 2003 to 2012 the number of children receiving special education services based on an LD diagnosis decreased.
- Within the SSI program, trends in both the number of LD allowances and the rate of LD allowances in children in low-income households is decreasing. From 2004 to 2013, the number of the SSI recipients for LD was stable.
- Among children enrolled in Medicaid on the basis of SSI eligibility, the rate of children with an LD diagnosis appears to be increasing. Among all children enrolled in Medicaid, there does not appear to be an increase in the rates of LD diagnoses.

CONCLUSIONS

- Rough estimates of the number of children in low-income households with moderate to severe ID suggest that less than 24 percent of children who are likely eligible for SSI benefits due to ID are recipients of these benefits.
- There is no evidence that the trends observed in the proportion of children receiving SSI benefits for LD are inconsistent with the prevalence trends observed in the general or Medicaid populations.

REFERENCES

Child Trends Databank. 2014. Learning disabilities. www.childtrends.org/?indicators=learning-disabilities (accessed August 4, 2015).

Cortiella, C., and S. H. Horowitz. 2014. *The state of learning disabilities: Facts, trends, and emerging issues, 3rd edition*. New York: National Center for Learning Disabilities. http://www.ncld.org/wp-content/uploads/2014/11/2014-State-of-LD.pdf (accessed July 16, 2015).

Coutinho, M. J., D. P. Oswald, and A. M. Best. 2002. The influence of sociodemographics and gender on the disproportionate identification of minority students as having learning disabilities. *Remedial and Special Education* 23(1):49–59.

Dhuey, E., and S. Lipscomb. 2009. Disabled or young?: Relative age and special education diagnoses in schools. *Economics of Educational Review* 29:857–872.

Halfon, N., A. Houtrow, K. Larson, and P. W. Newacheck. 2012. The changing landscape of disability in childhood. *Future of Children* 22(1):13–42.

Jencks, C. and M. Phillips. 1998. The black-white test scope gap: Why it persists and what can be done. *The Brookings Review* 24–27.

Livermore, G., D. Whalen, S. Prenovitz, R. Aggarwal, and M. Bardos. 2011. *Disability data in national surveys*. Washington, DC: Office of Disability, Aging, and Long-Term Care Policy, U.S. Department of Health and Human Services.

NCES (National Center for Education Statistics). n.d. Table 204.30: Children 3 to 21 years old served under Individuals with Disabilities Education Act (IDEA), Part B, by type of disability: Selected years, 1976–77 through 2011–12. Digest of Education Statistics. http://nces.ed.gov/programs/digest/d13/tables/dt13_204.30.asp (accessed July 16, 2015).

NSCH (National Survey of Children's Health). 2007a. Data query from the child and adolescent health measurement initiative. http://childhealthdata.org/browse/survey/results?q=1219 (accessed August 4, 2015).

NSCH. 2007b. Data query from the child and adolescent health measurement initiative. http://childhealthdata.org/browse/survey/results?q=1235 (accessed August 4, 2015).

NSCH. 2012a. Data query from the child and adolescent health measurement initiative. http://childhealthdata.org/browse/survey/results?q=2542&r=1 (accessed August 4, 2015).

NSCH. 2012b. Data query from the child and adolescent health measurement initiative. http://childhealthdata.org/browse/survey/results?q=2542&r=1&g=456 (accessed August 4, 2015).

NSCH. 2012c. Data query from the child and adolescent health measurement initiative. http://childhealthdata.org/browse/survey/results?q=2542&r=1&g=458 (accessed August 4, 2015).

U.S. Census Bureau. 2014. Total population by child and adult populations. http://datacenter.kidscount.org/data/tables/99-total-population-by-child-and-adult-populations?loc=1&loct=1#detailed/1/any/false/35,18,17,16,15/39,41/416,417 (accessed November 14, 2014).

U.S. Census Bureau. 2015. CPS table creator. www.census.gov/cps/data/cpstablecreator.html (accessed July 13, 2015).

17

Prevalence of Mood Disorders

Within the Social Security Administration (SSA) Listing of Impairments, mood disorders are recognized as an individual diagnostic category. In 2013 mood disorders represented the fourth largest group of Supplemental Security Income (SSI) recipients, after attention deficit hyperactivity disorder, autistic disorder, and intellectual disability. The medical criteria listed within the mood disorder listing include criteria for major depressive syndrome, manic syndrome, and bipolar or cyclothymic syndrome; however, as previously explained, current diagnostic criteria outlined in the *Diagnostic and Statistical Manual of Mental Disorders, Fifth Edition*, treat depression and bipolar as separate categories.

This chapter includes separate reviews of estimates of the prevalence of pediatric depression and of pediatric bipolar disorder in the United States. Individual epidemiologic studies using structured diagnostic interviews provide the best prevalence estimates; these exist for depression and have been done over time, thus yielding data on trends (Angold et al., 2012). National survey data that do not use structured diagnostic interviews exist for depression, but these estimates vary widely and should be interpreted cautiously. With respect to pediatric bipolar disorder, no individual epidemiologic studies using structured diagnostic interviews exist, and only one national survey exists. However, this targeted adolescents only (not children). Thus, estimates of the prevalence of pediatric bipolar disorder must be interpreted cautiously.

These reviews are followed by a discussion of trends in the rates of depression and bipolar disorder observed in the Medicaid Analytic eXtract (MAX) study. The chapter concludes with a discussion comparing these estimates with trends in the rate of allowances and recipients of SSI benefits for children with mood disorders.

ESTIMATES OF DEPRESSION PREVALENCE AND PREVALENCE TRENDS FROM THE GENERAL POPULATION

Findings from epidemiologic studies of depression among children and youth vary widely, but the overall prevalence rate has remained relatively constant over four decades. The prevalence estimates from various individual epidemiologic studies ranged from 0.3 to 18 percent of children, and the predominant variation in these estimates was by the period of time examined (e.g., 1 month, 3 months, 6 months, and lifetime) and by the instrument used to detect depression (Angold et al., 2012). A meta-analysis of 51 published studies of children born during various periods between 1954 and 2005 found an overall prevalence rate of 3.8 percent with no appreciable change over time (Angold et al., 2012). Figure 17-1 shows the estimated prevalence rates by approximate assessment date, with a linear trend line. When the meta-analysis was updated to include the 18 most recent studies published since 2004, a somewhat lower estimate (2.7 percent) was found,

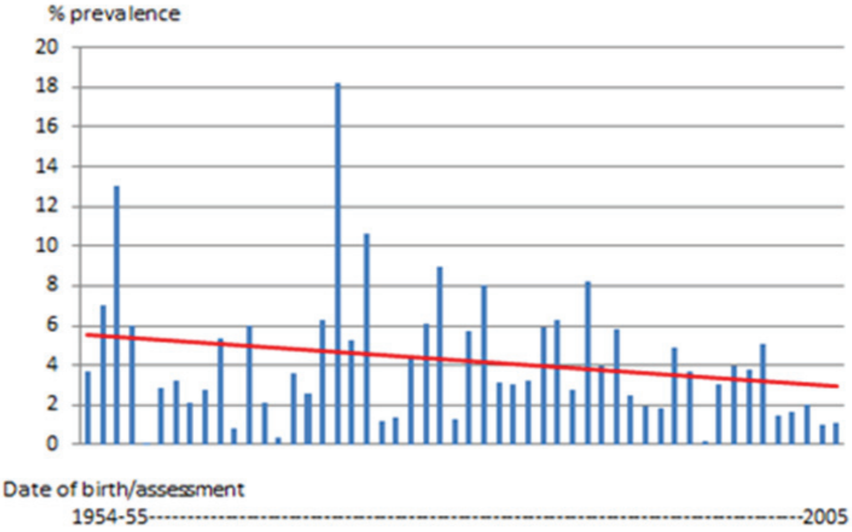

FIGURE 17-1 Prevalence of depression or dysthymia.
SOURCE: Angold et al., 2012.

but these findings further support a conclusion that the prevalence rates of child and youth depression has not increased over time (Angold et al., 2012). In addition, findings from a meta-analysis of more than 50 community surveys between 1994 and 2009 found that the estimated prevalence of depression in children and adolescents had remained relatively constant, at 5.2 percent (confidence interval 4–7 percent) (NRC and IOM, 2009).

Prevalence estimates of pediatric mood disorders based on national surveys should be interpreted with caution. The national surveys that have included questions about the symptoms or diagnosis of depression are the National Health Interview Survey (NHIS), the National Survey of Children's Health (NSCH), the National Survey on Drug Use and Health (NSDUH), the National Comorbidity Survey-Adolescent Supplement (NCS-A), and the National Health and Nutrition Examination Survey (NHANES) (NCHS, 2012; NHANES and CDC, 2010; NHIS and NCHS, 2007; NSDUH, 2002). However, the data available to estimate changes in the prevalence of depression from 2004 to 2013 are very limited because the surveys use different methods and are administered in different years. In addition, survey items, even when they are the same from year to year, often assess changes in parental awareness of a child receiving a diagnosis of depression or changes in primary care provider detection of depressive symptoms in children. Within a survey, the language used to assess depression often varies across years. For example, the NSCH included questions for parents about their children receiving diagnoses for depression in 2003 and in 2007, but the questions varied slightly. The results of these recent estimates of child and youth depression are summarized in Table 17-1.

ESTIMATES OF BIPOLAR DISORDER PREVALENCE AND PREVALENCE TRENDS FROM THE GENERAL POPULATION

Although there is a general consensus that pediatric bipolar disorder is an uncommon and serious mental illness, it is sufficiently rare to go unmeasured in most epidemiologic surveys. The 12-month prevalence for bipolar disorder I or II among adolescents, as reported in the NCS-A, was 2.1 percent, and the 30-day prevalence 0.7 percent (Kessler et al., 2012). A meta-analysis that included studies reporting rates for mania or hypomania in community epidemiologic samples with participants up to 21 years of age found the overall prevalence of bipolar disorder to be 1.8 percent (Van Meter et al., 2011).

According to medical data, the rates of bipolar diagnoses among youth have risen dramatically. According to the National Ambulatory Medical Care Survey, the estimated annual number of office-based visits for youth with a diagnosis of bipolar disorder increased from 25 (1994–1995) to 1,003 (2002–2003) visits per 100,000 population, representing a 40-fold

TABLE 17-1 Prevalence Estimates of Depression Based on Household Surveys

Source	Year	Question	Estimate	Age Range
NSCH (2003)	2003	Parent report Has a doctor or health professional ever told you that (child's name) has depression or anxiety problems?	4.2%	2–17
NSCH (2007a)	2007	Parent report In the 2007 NSCH parents are asked whether they have ever been told that their child has a specific condition, from a list of 16 conditions. If they answer "yes," they are then asked if the child currently has the condition. Current depression	2.0%	2–17
NSCH (2007a)	2007	In the 2007 NSCH parents are asked whether they have ever been told that their child has a specific condition, from a list of 16 conditions. If they answer "yes," they are then asked if the child currently has the condition. Had depression at some point, but not currently	1.7%	2–17
NSCH (2012)	2011/ 2012	Parent report Same as 2007 Current depression	2.2%	2–17
NSCH (2012)	2011/ 2012	Parent report Same as 2007 Had depression at some point, but not currently	1.6%	2–17
NHIS (Perou et al., 2013)	2007	Parent report Received a diagnosis of depression during past 12 months	3.0%	4–17
NHANES (Perou et al., 2013)	2007–2010	Child report Current depression during past 2 weeks (child report, score of ≥10 on PHQ-9)	6.7%	12–17
NSDUH (Perou et al., 2013)	2010–2011	Child report Major depressive episode during past 12 months	8.1%	12–17

NOTE: PHQ-9 = Patient Health Questionnaire 9.
SOURCES: NSCH, 2003, 2007a, 2012; Perou et al., 2013.

increase over 10 years (Moreno et al., 2007). These findings should be interpreted with caution. However, claims-based diagnoses may differ from clinical diagnoses (Youngstrom et al., 2015).

The reported rates of pediatric bipolar disorder have also varied between the United States and Europe. Using hospital discharge data from the English National Health Service Hospital Episode Statistics data set and the U.S. National Hospital Discharge Survey from 2000 to 2010, James and colleagues found a 72.1-fold difference in discharge rates for pediatric bipolar disorder between the United States and England (James et al., 2014). After controlling for cross-national differences in the length of stay, pediatric bipolar disorder discharges remained 12.5 times higher in the United States than in England (James et al., 2014). These findings are directionally consistent with an earlier study that examined the incidence of childhood-onset bipolar illness among a cohort of 500 adult outpatients with bipolar illness. In that study, more than 60 percent of U.S. patients reported onset of symptoms during childhood or adolescence versus only 30 percent in the Netherlands or Germany (Post et al., 2010). Although some of this variation has been attributed to differences in diagnostic criteria (Dougherty et al., 2014), substantive questions have been raised about the validity of this diagnosis in children (Demeter et al., 2008; Duffy et al., 2007; Horst, 2009).

TRENDS IN THE RATES OF MOOD DISORDERS AMONG SSI AND MEDICAID POPULATIONS

This section presents data on trends in the rates of mood disorders in the SSI program for children from 2004 to 2013 and among child Medicaid enrollees from 2001 to 2010. The Medicaid data are presented as a rough approximation of the population living in poverty from which SSI recipients are drawn. Comparisons across these data sources as well as comparisons with earlier findings from epidemiologic studies should be made with caution because of their methodological differences. National prevalence estimates from epidemiologic studies for mood disorders vary because they are influenced by differences in study methods, such as how the children were selected, how the presence of the diagnosis was identified, the time period over which data were taken concerning symptoms (i.e., lifetime, past 6 months), and the respondent (i.e., parent, youth). The diagnoses listed for SSI determinations are those that most strongly support eligibility for benefits, and they may be influenced by the extent to which documentation is available to the evaluator and may be prioritized according to which symptoms contribute most to a child's disability. The prevalence estimates of children with mood disorders based on Medicaid data are based on encounter coding and billing which can reflect efforts to optimize reimbursement rather than accuracy of clinical diagnosis. With these caveats, findings from these data sources are described by source. The proportion of children with mood disorders identified in the SSI administrative data is described within the context of national poverty trends among U.S. children. Findings from the Medicaid data are stratified to compare the proportion of children with mood disorders who are receiving SSI with all children receiving Medicaid.

SSI

Table 17-2 examines the SSI administrative data on mood disorders in children. Column 1 shows the number of child allowances made on the basis of mood disorders at the initial level for each year. Column 2 shows the number of child recipients who received SSI benefits on the basis of

TABLE 17-2 SSI Child Initial Allowances and Recipient Numbers for Mood Disorders

	1	2	3	4	5
Year	# of Child SSI Allowances for Mood Disorders	# of Child SSI Recipients for Mood Disorders	# of Children in Households Under 200% FPL	% of Children Under 200% FPL Allowed SSI Benefits for Mood Disorders	% of Children Under 200% FPL Who Are Recipients of SSI Benefits for Mood Disorders
2004	9,760	32,078	28,753,000	0.034%	0.11%
2005	9,835	35,184	28,539,000	0.034%	0.12%
2006	9,084	37,112	28,757,000	0.032%	0.13%
2007	8,907	38,280	28,999,000	0.031%	0.13%
2008	9,199	39,164	30,064,000	0.031%	0.13%
2009	9,869	40,444	31,505,000	0.031%	0.13%
2010	10,588	41,932	32,254,000	0.033%	0.13%
2011	10,339	42,936	32,678,000	0.032%	0.13%
2012	9,331	43,508	32,269,000	0.029%	0.13%
2013	8,400	42,826	31,364,000	0.027%	0.14%

NOTE: The Current Population Survey table creator was used to generate numbers of children below 200 percent of the federal poverty level. Parameters used to generate the numbers include get count of: persons in poverty universe (everyone except unrelated individuals under 15); years: 2004 to 2013; Census 2010 weights; row variable: age; column variable: income-to-poverty ratio; and customized formatting: income-to-poverty ratio percent cutoff of 200 percent.

SOURCES: U.S. Census Bureau, 2015; unpublished data set provided by the SSA.

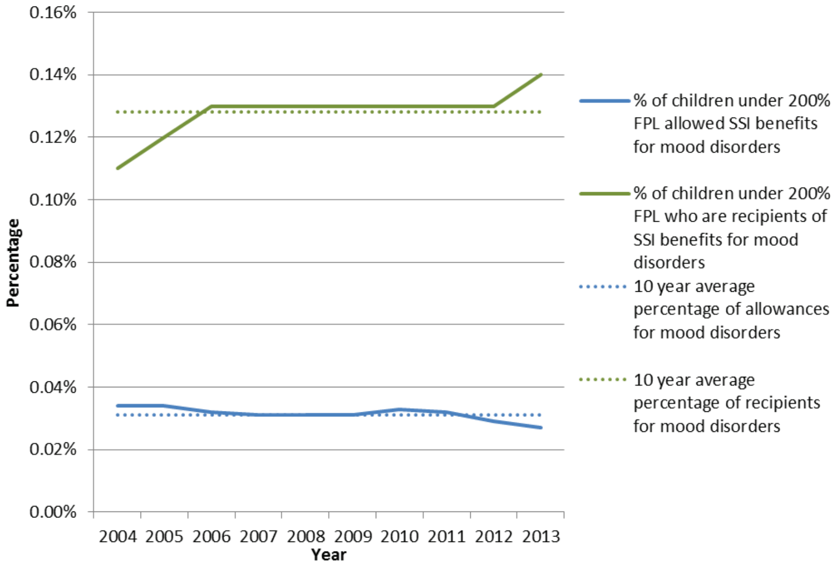

FIGURE 17-2 Percentages of SSI child initial allowances and recipients for mood disorders under 200 percent FPL.
NOTE: The Current Population Survey table creator was used to generate numbers of children below 200 percent of the federal poverty level. Parameters used to generate the numbers include get count of: persons in poverty universe (everyone except unrelated individuals under 15); years: 2004 to 2013; Census 2010 weights; row variable: age; column variable: income-to-poverty ratio; and customized formatting: income-to-poverty ratio percent cutoff of 200 percent.
SOURCES: U.S. Census Bureau, 2015; unpublished data set provided by the SSA.

mood disorders in December of each year. Column 3 shows the estimated number of children in households with incomes under 200 percent of the federal poverty level (FPL) for each year. Columns 4 and 5 show the rate of allowances and recipients based on all mood disorders as a percentage of the number of children in households under 200 percent FPL for each year. Figure 17-2 plots the average of the percentages of allowances and recipients for mood disorders from columns 4 and 5 and illustrates deviations from the 10-year average for each.

As shown in Chapter 3, between 2004 and 2013, approximately 10 percent of SSI allowances for children were on the basis of mood disorders, and, of these, the allowance rate decreased from 47 to 36 percent. The decreasing allowance rate corresponds to a slight decrease in the number of allowances; however, the absolute number of recipients for mood disorders has gradually risen. Between 2004 and 2013, allowances decreased from 9,760 to 8,400, while the number of recipients rose from 32,078 to 42,826. Among children in households under 200 percent FPL in the same time period, the rate of child mood disorder allowances decreased by approximately –21 percent, from 0.034 to 0.027 percent. Between 2004 and 2013 the rate of child mood disorder recipients increased by approximately 22 percent, from 0.11 to 0.14 percent.

Medicaid

Table 17-3 shows the percentage of children who were diagnosed with depression in two different groups of Medicaid enrollees from 2001 to 2010. Column 1 shows the percentage of depression diagnoses among all Medicaid enrollees for each year. Column 2 shows the percentage of depression diagnoses among the smaller subpopulation of Medicaid enrollees who are eligible to be enrolled in Medicaid based on their eligibility to receive SSI benefits. Figure 17-3 visually displays the upward trends for each set of percentages.

Overall, during this time period the proportion of children receiving Medicaid-funded services for depression among all child Medicaid beneficiaries was roughly one-half the proportion of children who received care

TABLE 17-3 Percentage of Child Medicaid Enrollees and SSI Medicaid Enrollees Diagnosed with Depression

	1	2
Year	% of All Child Medicaid Enrollees with a Depression Diagnosis	% of Child SSI Medicaid Enrollee Subpopulation with a Depression Diagnosis
2001	1.70%	4.00%
2002	1.70%	4.30%
2003	1.90%	4.50%
2004	2.00%	4.60%
2005	1.90%	4.50%
2006	1.90%	4.40%
2007	2.00%	4.40%
2008	2.10%	4.80%
2009	2.20%	5.40%
2010	2.20%	5.50%

SOURCE: MAX data.

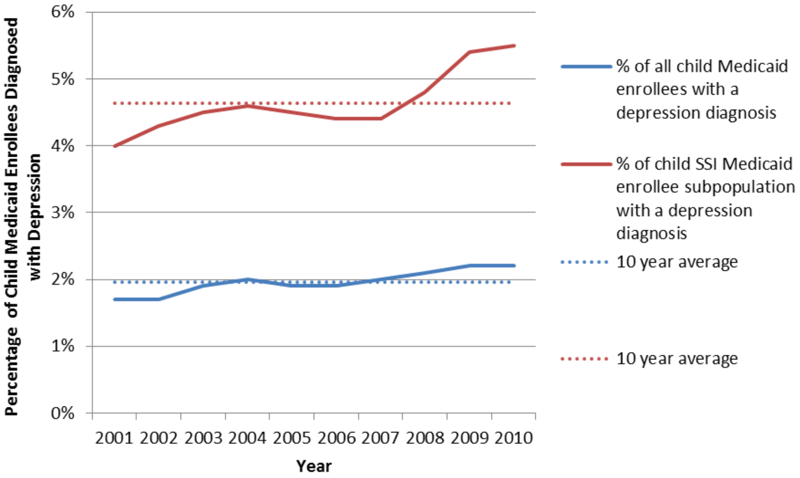

FIGURE 17-3 Percentage of child Medicaid enrollees and SSI Medicaid enrollees diagnosed with depression.
SOURCE: MAX data.

for depression among all children eligible for Medicaid through SSI. It is worth noting that between 2001 and 2010 the proportion of children with depression diagnoses in these two groups increased. In the SSI subpopulation, starting in 2008, a relatively large increase in the proportion of children with depression diagnoses was observed, likely corresponding to the onset of the economic recession. Between 2001 and 2010 the proportion of children with depression diagnoses among all Medicaid enrollees increased by 29.4 percent, from 1.7 to 2.2 percent. The proportion of children with depression diagnoses among the SSI-eligible subpopulation of Medicaid enrollees increased by 37.5 percent, from 4 to 5.5 percent.

Table 17-4 and Figure 17-4 summarize the Medicaid data for children receiving care that is linked to the diagnosis of bipolar disorder. Overall, the annual proportion of children receiving Medicaid-funded services for bipolar disorder among all child Medicaid beneficiaries was roughly 20 percent of the proportion of children who received care for depression among children eligible for Medicaid through SSI. In addition, the proportion of children with a bipolar diagnosis among these two increased between 2001 and 2009, although it plateaued for the entire Medicaid population from 2006 to 2010 and decreased in 2010 for the Medicaid SSI subgroup. From 2001 to 2010 the proportion of children with a bipolar diagnosis among all Medicaid enrollees increased by 100 percent, from 0.3 to 0.6 percent.

TABLE 17-4 Percentage of Child Medicaid Enrollees and SSI Medicaid Enrollees Diagnosed with Bipolar Disorder

	1	2
Year	% of All Child Medicaid Enrollees with a Bipolar Diagnosis	% of Child SSI Medicaid Enrollee Subpopulation with a Bipolar Diagnosis
2001	0.3%	1.4%
2002	0.3%	1.7%
2003	0.4%	1.9%
2004	0.5%	2.3%
2005	0.5%	2.4%
2006	0.6%	2.5%
2007	0.6%	2.7%
2008	0.6%	2.8%
2009	0.6%	3.0%
2010	0.6%	2.8%

SOURCE: MAX data.

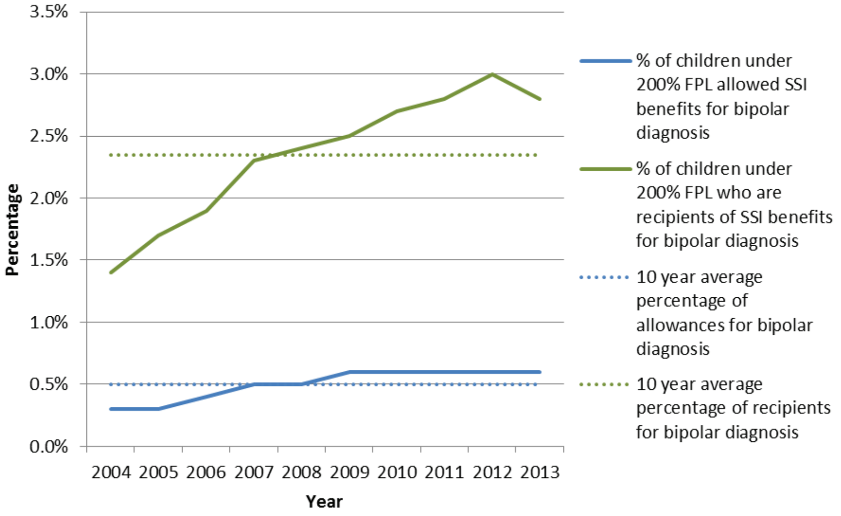

FIGURE 17-4 Percentage of child Medicaid enrollees and SSI Medicaid enrollees diagnosed with bipolar disorder.
SOURCE: MAX data.

TABLE 17-5 Percent Increases of Depression, Bipolar Disorder, and Mood Disorder for Medicaid Enrollees, Medicaid SSI Enrollees, and SSI Disability Recipients

	Medicaid All Enrollees		Medicaid SSI Enrollees		SSI Disability Recipients
	Depression	Bipolar disorder	Depression	Bipolar disorder	Mood disorders
Percent increase from 2004 to 2010	10%	25%	19.6%	25%	27.3%

SOURCE: MAX and unpublished data set provided by the SSA.

The proportion of children with a bipolar diagnosis among the SSI eligible subpopulation of Medicaid enrollees also increased by 100 percent, from 1.4 to 2.8 percent.

Table 17-5 compares percent increases from 2004 to 2010 in the proportions of children in the two Medicaid populations and the SSI disability population who were identified as having depression or bipolar disorder—or both in the case of SSI disability children. This is the time period—from 2004 to 2010—for which the available Medicaid and SSI data overlapped. Among children receiving Medicaid because they were eligible through SSI, the percentage increase in the proportion of children with depression was roughly twice the percentage increase in the proportion of all children receiving Medicaid. The increase for the SSI combined mood disorders recipient population was similar to that for the Medicaid SSI group. The percent increase in the proportion of children with bipolar disorder diagnosis was similar between the two groups, but this finding should be interpreted with caution because smaller numbers of children received this diagnosis. The limitations in comparing percentage increases across these two different data sources were detailed earlier in this chapter. Diagnoses in the Medicaid data are based on billing, whereas SSI disability data are based upon the evaluator's determination following SSA disability guidelines and agency final decisions related to receipt.

DISCUSSION

The task order directed the committee to compare trends observed in the SSI disability program for children with mental disorders with trends in the prevalence of mental disorders among children in the general population. This chapter focused on trends in the percentage of children who are recipients of the SSI disability benefits on the basis of the mood disorder diagnostic category, which includes major depressive syndrome, manic syndrome, and bipolar or cyclothymic syndrome. The SSI mood disorders diagnostic category thus presents challenges for comparing prevalence estimates with findings from national epidemiologic studies and Medicaid data because depression and bipolar disorder are distinct diagnostic groups in these data sources. Comparisons between the SSI trend data by disorder to either the general population data or Medicaid data are also problematic because the data sources differ starkly in their main purpose and in how a disorder is identified. To satisfy the task order while safeguarding against erroneous interpretation of the data, the committee chose to present available data and point out apparent differences and trends while also noting caveats to their interpretation.

Prevalence estimates of depression in the general population between 2004 and 2013 indicate that there was no increase in depression among children. In addition, pediatric bipolar disorder is relatively rare, and there are few data available with which to estimate population-level trends for this disorder. Within this 10-year period, a small increase was observed in the proportion of the child SSI recipients for mood disorders, while a slight decrease was observed in allowances. From 2001 to 2010 a slight increase was observed in the proportion of children receiving care for depression and bipolar disorder among all children enrolled in Medicaid, which was similar to that among children eligible for Medicaid through SSI.

Overall, trends in the proportion of children receiving SSI on the basis of mood disorders are consistent with trends in depression observed in the general and Medicaid population. When the poverty level is taken into account, the proportion of children allowed SSI and receiving SSI for mood disorders is relatively constant, with a 2-year increase that corresponds with the onset of an economic recession.

Depression may be underdiagnosed in children living in poverty, and the pool of children potentially eligible for SSI benefits based on mood disorders is estimated to be large. The NSCH prevalence estimates of children and adolescents (ages 2–17) with moderate or severe depression for 2007, as reported by parents, was 1.0 percent (NSCH, 2007b). The estimated number of children under 200 percent FPL in 2007 was 28,999,000. Therefore, the estimated number of children with moderate or severe depression (not including bipolar) under 200 percent FPL would be expected to be 289,990. In contrast, in 2007 there were 8,907 child recipients of SSI benefits for mood disorders. Figure 17-5 illustrates these relationships. A final consideration relates to questions about bipolar disorder diagnoses in children. Until widespread adoption of standardized diagnostic criteria is achieved, questions will remain about the prevalence and its trends for this disorder. However, this concern does not mitigate the possibility that, even

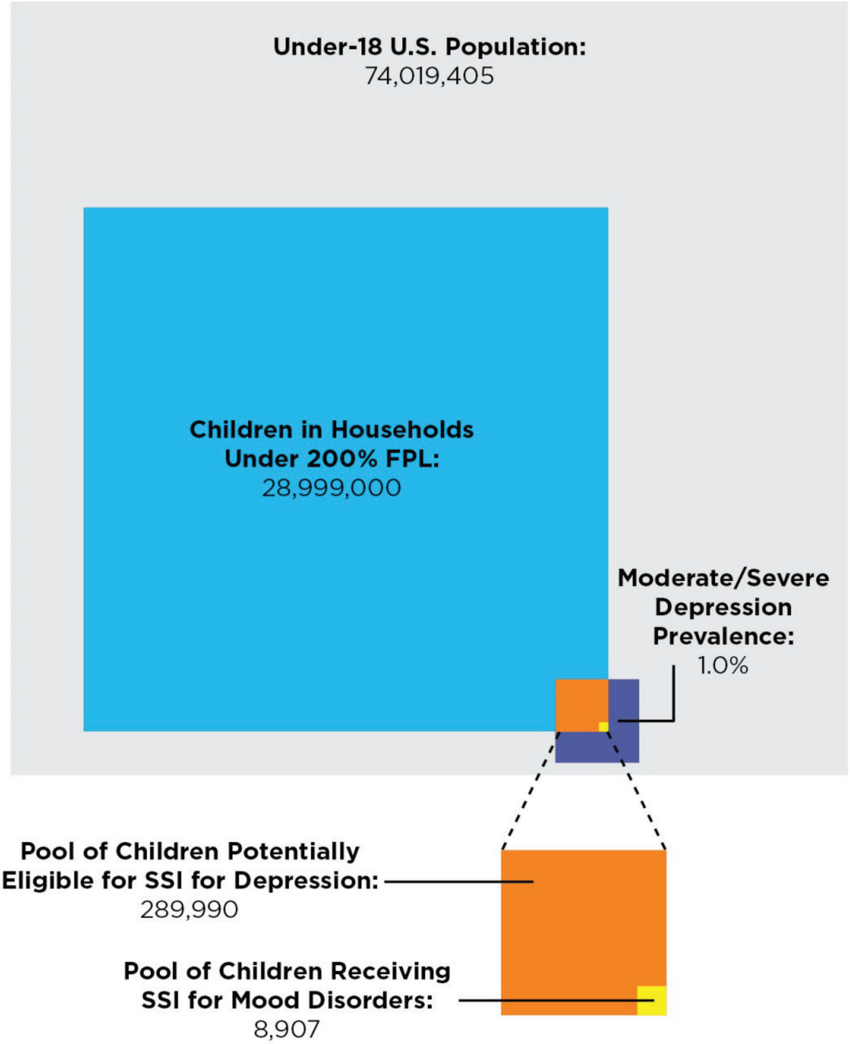

FIGURE 17-5 Children potentially eligible for SSI for depression versus children receiving SSI for mood disorders in 2007, according to the NSCH.
NOTE: The Current Population Survey table creator was used to generate numbers of children below 200 percent of the federal poverty level. Parameters used to generate the numbers include get count of: persons in poverty universe (everyone except unrelated individuals under 15); years: 2004 to 2013; Census 2010 weights; row variable: age; column variable: income-to-poverty ratio; and customized formatting: income-to-poverty ratio percent cutoff of 200 percent.
SOURCES: NSCH, 2007b; U.S. Census Bureau, 2014, 2015; unpublished data set provided by the SSA.

if misdiagnosed, many children currently labeled with bipolar disorder are likely to qualify for SSI based on moderate or severe disability.

FINDINGS

- Prevalence estimates for child and adolescent depression in the general population range from 2 to 8 percent. Because pediatric bipolar disorder is uncommon, additional research is needed to more robustly estimate the prevalence rates using standardized diagnostic criteria among children in nationally representative samples.
- The prevalence of depression among children and adolescents in the general population does not appear to be increasing. The trends in the prevalence of pediatric bipolar disorder remain unknown.
- From 2004 to 2013 the allowance rates for SSI benefits for mood disorders decreased, while the percentage of children in low-income households who were recipients of SSI benefits for mood disorders increased modestly.
- The trend for SSI mood disorder recipients is upward among both the SSI and Medicaid enrollees.

CONCLUSION

- Conservative estimates of the prevalence of moderate to severe depression among children and adolescents (i.e., 1 percent) applied to the population of these children and adolescents who are below 200 percent FPL suggest that only a small proportion, approximately 3 percent, of those who are potentially eligible for SSI benefits on the basis of mood disorders are actually recipients.

REFERENCES

Angold, A., A. Erkanli, W. Copeland, R. Goodman, P. W. Fisher, and E. J. Costello. 2012. Psychiatric diagnostic interviews for children and adolescents: A comparative study. *Journal of the American Academy of Child & Adolescent Psychiatry* 51(5):506–517.

Demeter, C. A., L. D. Townsend, M. Wilson, and R. L. Findling. 2008. Current research in child and adolescent bipolar disorder. *Dialogues in Clinical Neuroscience* 10(2):215–228.

Dougherty, L. R., V. C. Smith, S. J. Bufferd, G. A. Carlson, A. Stringaris, E. Leibenluft, and D. N. Klein. 2014. DSM-5 disruptive mood dysregulation disorder: Correlates and predictors in young children. *Psychological Medicine* 44(11):2339–2350.

Duffy, A., M. Alda, L. Crawford, R. Milin, and P. Grof. 2007. The early manifestations of bipolar disorder: A longitudinal prospective study of the offspring of bipolar parents. *Bipolar Disorders* 9(8):828–838.

Horst, R. 2009. Diagnostic issues in childhood bipolar disorder. *Psychiatric Clinics of North America* 32(1):71–80.

James, A., U. Hoang, V. Seagroatt, J. Clacey, M. Goldacre, and E. Leibenluft. 2014. A comparison of American and English hospital discharge rates for pediatric bipolar disorder, 2000 to 2010. *Journal of the American Academy of Child & Adolescent Psychiatry* 53(6):614–624.

Kessler, R. C., S. Avenevoli, E. J. Costello, K. Georgiades, J. G. Green, M. J. Gruber, J. P. He, 2012. Prevalence, persistence, and sociodemographic correlates of DSM-IV disorders in the National Comorbidity Survey Replication Adolescent Supplement. *Archives of General Psychiatry* 69(4):372–380.

Moreno, C., G. Laje, C. Blanco, H. Jiang, A. B. Schmidt, and M. Olfson. 2007. National trends in the outpatient diagnosis and treatment of bipolar disorder in youth. *Archives of General Psychiatry* 64(9):1032–1039.

NCHS (National Center for Health Statistics). 2012. Design and operation of the National Survey of Children's Health, 2007. *Vital and Health Statistics* 1(55). http://purl.fdlp.gov/GPO/gpo46838 (accessed July 17, 2015).

NHANES (National Health and Nutrition Examination Survey) and CDC (Centers for Disease Control and Prevention). 2010. *The National Health and Nutrition Examination Surveys from the National Center for Health Statistics*. Atlanta, GA: CDC.

NHIS (National Health Interview Survey) and NCHS (National Center for Health Statistics). 2007. *National Health Interview Survey*. Hyattsville, MD: The Center.

NRC (National Research Council) and IOM (Institute of Medicine). 2009. *Preventing mental, emotional, and behavioral disorders among young people: Progress and possibilities*. Washington, DC: The National Academies Press.

NSCH (National Survey of Children's Health). 2003. Data query from the child and adolescent health measurement initiative. www.childhealthdata.org/browse/survey/results?q=559 (accessed August 19, 2015).

NSCH. 2007a. Data query from the child and adolescent health measurement initiative. www.childhealthdata.org/browse/survey/results?q=1214 (accessed August 19, 2015).

NSCH. 2007b. Data query from the child and adolescent health measurement initiative. http://childhealthdata.org/browse/survey/results?q=1230 (accessed August 4, 2015).

NSCH. 2012. Data query from the child and adolescent health measurement initiative. www.childhealthdata.org/browse/survey/results?q=2432&r=1 (accessed August 19, 2015).

NSDUH (National Survey on Drug Use and Health). 2002. *Results from the National Survey on Drug Use and Health*. Rockville, MD: Department of Health and Human Services, Substance Abuse and Mental Health Services Administration, Office of Applied Studies. http://purl.access.gpo.gov/GPO/LPS77253 (accessed August 19, 2015).

Perou, R., R. H. Bitsko, S. J. Blumberg, P. Pastor, R. M. Ghandour, J. C. Gfroerer, S. L. Hedden, A. E. Crosby, S. N. Visser, and L. A. Schieve. 2013. Mental health surveillance among children—United States, 2005–2011. *Morbidity and Mortality Weekly Report* 62(Suppl 2):1–35.

Post, R. M., G. S. Leverich, R. W. Kupka, P. E. Keck, Jr., S. L. McElroy, L. L. Altshuler, M. A. Frye, D. A. Luckenbaugh, M. Rowe, H. Grunze, T. Suppes, and W. A. Nolen. 2010. Early-onset bipolar disorder and treatment delay are risk factors for poor outcome in adulthood. *Journal of Clinical Psychiatry* 71(7):864–872.

U.S. Census Bureau. 2014. Total population by child and adult populations. http://datacenter.kidscount.org/data/tables/99-total-population-by-child-and-adult-populations?loc=1&loct=1#detailed/1/any/false/35,18,17,16,15/39,41/416,417 (accessed November 14, 2014).

U.S. Census Bureau. 2015. CPS table creator. www.census.gov/cps/data/cpstablecreator.html (accessed July 13, 2015).

Van Meter, A. R., A. L. Moreira, and E. A. Youngstrom. 2011. Meta-analysis of epidemiologic studies of pediatric bipolar disorder. *Journal of Clinical Psychiatry* 72(9):1250–1256.

Youngstrom, E. A., S. Choukas-Bradley, C. D. Calhoun, and A. Jensen-Doss. 2015. Clinical guide to the evidence-based assessment approach to diagnosis and treatment. *Cognitive and Behavioral Practice* 22(1):20–35.

Part IV

Medicaid Analytic eXtract Study

Part IV of the report summarizes the results and data interpretation of a 10-year multistate analysis using Medicaid service encounter and pharmacy claims data (hereafter referred to as the Medicaid Analytic eXtract [MAX] data and the "Medicaid study"). This study was commissioned by the committee and performed by researchers at the Rutgers University Institute for Health, Center for Health Services Research on Pharmacotherapy, Chronic Disease Management, and Outcomes, and the Center for Education and Research on Mental Health Therapeutics.[1]

The Medicaid study was commissioned by the committee in response to two elements of the task order. The first was the requirement to compare trends in the number of children with mental disorders in the Supplemental Security Income (SSI) program with trends in the prevalence of mental disorders observed among children in the general U.S. population. The second was the requirement to describe the kinds of treatments reported or documented to be received by children with mental disorders in the SSI population.

After extensive deliberation, the committee decided to commission an analysis of Medicaid data for the following reasons. First, the committee came to the conclusion that another comparison population of children with mental disorders in low-income families would add value to its analysis of trends based upon SSI data. Children who are SSI recipients and those enrolled in Medicaid are from low-income households; the comparison of trends in mental disorder diagnoses between these groups holds

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[1] Scott Bilder, Cassandra Simmel, and Stephen Crystal (director).

socioeconomic status relatively constant. This approach addresses a key limitation of comparing prevalence estimates for children receiving SSI with those for children in the general population. In addition, studying trends in the mental health diagnoses in the Medicaid population, stratified by basis of eligibility (i.e., SSI, foster care, or other, including low income) provides an additional data source with which to validate trends in the frequency of mental disorder diagnoses observed in the SSI disability program for children. Trends in the frequency of mental disorder diagnoses within the subpopulation of children on SSI and enrolled in Medicaid would be expected to align with trends observed in the SSI benefit population.

Second, the information currently available in either the Social Security Administration (SSA) administrative data or the published literature on the treatment of children in the SSI population for mental disorders was not adequate to fully complete the task order. The Medicaid data are the best available and the most efficient source of continuously collected data that simultaneously include information on a child's SSI status, mental disorder diagnoses, and health services utilization. Further discussion about the relative strengths and weaknesses of the MAX data can be found in Chapter 2.

Finally, the Medicaid data provide additional information on the characteristics of children with disabilities that are not available from the SSI administrative data. As previously discussed in Chapter 2, the SSA does not have reliable information on the secondary impairments of SSI recipients, and does not collect any information on the race and ethnicity of SSI applicants or recipients. The Medicaid data can provide information on Medicaid enrollees with multiple diagnoses, as well as their race and ethnicity. Since this information is not available from the SSI data, the Medicaid data may also provide the best available data about mental disorder comorbidity among SSI enrollees, and the distribution of mental disorder diagnoses among different racial or ethnic categories.

In Part IV, comparisons will be made among three different populations from two different data sources:

MEDICAID DATA

- ***"All Medicaid enrollees"*** This population includes all children (ages 3–17 years) who met the Medicaid Study criteria. This includes children who are enrolled in Medicaid on the basis of SSI, foster care, and for other reasons, including "Low-Income Families," "Mandatory Poverty Level," and "Medically Needy Children Under 18" (CMS, n.d.). For the purposes of this report, this population is here after referred to as "all Medicaid enrollees."

- ***"SSI Medicaid enrollees"*** This population includes children who are eligible to be enrolled in Medicaid because they receive SSI disability benefits. This is a specific subset of all Medicaid enrollees that includes only the SSI-eligible children and excludes children eligible for Medicaid because of foster care status or other reasons. We hereafter refer to this group as "SSI Medicaid enrollees."

SSA ADMINISTRATIVE DATA

- ***"SSI recipients"*** This population includes children who receive SSI disability benefits. It should be noted that practically all children who receive SSI are *eligible* for Medicaid, but only an estimated 90 percent of SSI recipients are *enrolled* in Medicaid (Ireys et al., 2004).

This report on the Medicaid study is divided into five sections. Section 1 describes the design and methods of the Medicaid study. Section 2 summarizes the 10-year trends observed for the prevalence of all common childhood mental disorders using cerebral palsy and asthma as comparison groups. (Note that trends in the prevalence of specific diagnoses of attention deficit hyperactivity disorder [ADHD], oppositional defiant disorder and conduct disorder, autism spectrum disorder, intellectual disability, learning disability, and mood disorders from the Medicaid study are discussed in Part III of the report with other information on those specific disorders.) Section 3 summarizes 10-year trends observed for the prevalence of secondary comorbid mental disorders among children with a primary diagnosis of ADHD. Section 4 summarizes the prevalence of mental disorders by racial and ethnic category, for 2010. Section 5 summarizes the 10-year trends in treatment by modality (i.e., none, medication, psychotherapy, combined) for ADHD as well as variations in treatment modalities by specific mental disorders for 2010. Details about the methods are in Appendix F, and the complete results are in Appendix G.

REFERENCES

CMS (Centers for Medicare & Medicaid Services). n.d. List of Medicaid eligibility groups. www.medicaid.gov/Medicaid-CHIP-Program-Information/By-Topics/Waivers/1115/Downloads/List-of-Eligibility-Groups.pdf (accessed July 17, 2015).

Ireys, H., D. Kasprzyk, A. Takyi, and J. Gillcrist. 2004. *Estimating the size and characteristics of the SSI child population: A comparison between the NSCF and three national surveys*. Mathematics Policy Research Paper No. 8671-980. www.ssa.gov/disabilityresearch/documents/nscf/finalcomparison/nscf-comparison-final.pdf (accessed July 17, 2015).

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Medicaid Analytic eXtract Study

STUDY DESIGN AND METHODS

Study Population

The study population included all Medicaid-eligible youth aged 3–17 years in a selected subset of states for the years 2001–2010. The year 2010 is the most recent year that Medicaid Analytic eXtract (MAX) data were made publicly available. Enrollee age, for the purposes of inclusion in analyses, was computed as of July 1 of each year. Eleven months (not necessarily consecutive) of Medicaid eligibility in the year were required for inclusion in the study. The 20 states selected for inclusion were those that we and others found, in internal analyses as well as in published work, to provide relatively complete diagnosis and treatment detail (Byrd and Dodd, 2012; Nysenbaum et al., 2012).

Data Sources

The primary data source consisted of Medicaid enrollment, claims, and prescription drug-fill data from the MAX. The MAX data provide a set of research files constructed from mandated periodical data submissions by the state Medicaid programs, compiled and processed by the Centers for Medicare & Medicaid Services (CMS). Enrollment data include information on beneficiary characteristics such as age, sex, and race/ethnicity; Medicaid eligibility class; managed care participation; and other details that affect how care is organized and paid. Claims are provided separately for inpatient, long-term care, and other (primarily outpatient) services and include details on diagnoses received and services delivered. A prescription drug file provided records for each filled prescription, allowing researchers to identify which medications were received, when the prescriptions were filled, how much of the drug was provided, and for how long. Drug data are not directly linked to specific inpatient or outpatient visits. The prescription drug records were linked to the First Data Bank National Drug Data File (NDDF), which provides the means to look up drug details using the national drug codes provided in the MAX data. Prescription medications were extracted from the MAX data by their generic names.

Database Construction and Analysis

The preliminary MAX data analyses included 44 states and the District of Columbia. A subset of 20 states was then identified that in 2009 either (1) had predominantly fee-for-service youth Medicaid populations or (2) had been identified as having relatively complete and usable managed care encounter data for that population (Byrd and Dodd, 2012; Nysenbaum et al., 2012). Key variables included in these data sets were sociodemographic characteristics (age, sex, race/ethnicity), month-by-month eligibility data, diagnoses recorded, services received, and prescriptions filled. The few youth with dual Medicaid–Medicare eligibility were excluded from analyses because records from Medicare, which is the first payer for many services, were not observable.

Enrollees were assigned to one of three basis-of-eligibility (BoE) groups following examination of their eligibility records: Supplemental Security Income (SSI)/Medicaid, foster care, and other (including a large group eligible solely because of household income). In general, households eligible for Medicaid through income are poor or near poor (<200 percent of the federal poverty level). Analyses were stratified by this grouping variable. We used each enrollee's last observed BoE category in each year to assign her or him an overall status for the year. This was necessary in order to establish mutually exclusive eligibility categories. Preliminary analyses revealed 96 percent consistency throughout the year for the focal SSI/Medicaid group, suggesting that our method of assigning BoE categories on the basis of the last observation of the year did not distort these enrollees' eligibility histories. The mappings from MAX BoE categories to these three groupings are detailed in Appendix F, Part A. The presence of ADHD and other diagnoses was identified using the multiple diagnosis fields in the MAX claims files, excluding long-term care claims. A threshold of either one or more inpatient claims or two or more outpatient claims on different dates was used to establish the presence of the following conditions for each enrollee for each year of analysis (via codes from the *International Classification of Diseases, Ninth Revision, Clinical Modification* [ICD-9-CM]):

1. Attention deficit hyperactivity disorder (ADHD; both alone and comorbid with other conditions)
2. Conduct disorder (CD)
3. Emotional disturbances
4. Oppositional defiant disorder (ODD)
5. Mood disorders (depression)
6. Mood disorders (bipolar disorders)
7. Anxiety disorders
8. Autism spectrum disorder (ASD)
9. Intellectual disorders (IDs)
10. Speech and language disorders
11. Hearing disorders
12. Learning disorders (LDs)
13. Cerebral palsy (control)
14. Asthma (control)

Cerebral palsy and asthma were selected as control conditions in order to judge whether data for mental health disorders were distinctly different from data for other fairly frequent MAX conditions. The ICD-9-CM codes used to establish diagnoses are listed in Appendix B.

Pharmacological treatments were identified via generic drug names associated with filled prescriptions in the linked MAX/NDDF data and reported using the following categories of medications: ADHD medications (which include stimulants, atomoxetine, alpha agonists, bupropion, and three tricyclic antidepressants), antipsychotic medications, antidepressants, anxiolytic/hypnotic medications, and mood stabilizers. The generic drug names for each category are listed in Appendix F, Part C. Nonpharmacological treatments were identified via procedure codes recorded in the MAX claims (using Current Procedural Terminology codes and detailed in Appendix F, Part D).

Once enrollees' eligibility, sociodemographic characteristics, diagnoses, prescriptions, and services were identified, analyses were performed to track diagnosis and treatment trends between 2001 and 2010.

10-YEAR TRENDS IN THE PREVALENCE OF COMMON CHILD MENTAL DISORDERS AMONG CHILDREN ENROLLED IN MEDICAID

Trends in the Number and Proportion of Children Enrolled in Medicaid by Basis of Eligibility

Table 18-1 summarizes the 10-year trends for the total number of children enrolled in Medicaid and the proportion of children within the three eligibility groups: SSI/disability, foster care, and other. Overall, the total number of child Medicaid enrollees among the 20 states increased by 57 percent, from approximately 5.23 million in 2001 to 8.21 million in 2010. For all SSI Medicaid enrollees, the total number of enrollees increased by 33 percent, from 361,106 to 478,822 (see Table 18-3b) during this time period. However, relative to the total number of all Medicaid enrollees, the percentage of the total population representing SSI Medicaid enrollees decreased by 16 percent (6.9 to 5.8 percent) from 2001 to 2010. Within this same time period, the proportion of children eligible for Medicaid due to foster care status also decreased by more than 30 percent (4.8 to 3.3 percent).

Trends in the Diagnosis of Mental Disorders Among All Medicaid Enrollees and Among SSI Medicaid Enrollees

Tables 18-2a and 18-2b summarize the number of mental disorder diagnoses, speech/language and hearing diagnoses, asthma diagnoses, and cerebral palsy diagnoses among all Medicaid enrollees and SSI Medicaid enrollees, respectively. In this analysis, children received Medicaid-funded care, and were also diagnosed for one or more disorders during the index year. For example, a child could receive paid treatment for more than one mental disorder or for at least one mental disorder and for a speech and language or hearing disorder during the index year.

Tables 18-3a and 18-3b summarize the 10-year trends in the estimated prevalence of mental disorders, speech/language and hearing disorders, asthma, and cerebral palsy diagnoses among all Medicaid enrollees and SSI Medicaid enrollees, respectively. A prevalence estimate for each diagnosis was generated by dividing the number of diagnoses by the number of all Medicaid enrollees within each year. The denominator was the total number of all Medicaid enrollees for each year, designated by the row labeled "N." The numerator was the number of diagnoses.

The proportion of all Medicaid enrollees with a diagnosis of any one of the mental disorders included in the Medicaid study (see Table 18-3a) (ADHD, CD, emotional disturbances, ODD, depression, bipolar, anxiety

TABLE 18-1 Medicaid Basis of Eligibility (BoE) for All Medicaid Enrollees

Basis of Eligibility	2001	2002	2003	2004	2005	2006	2007	2008	2009	2010
Foster care	4.8%	4.7%	4.5%	4.4%	4.3%	4.4%	4.4%	4.2%	3.6%	3.3%
Other	88.3%	88.8%	89.1%	89.2%	89.4%	89.2%	89.1%	89.4%	90.2%	90.9%
SSI/Disability (Medicaid)	6.9%	6.5%	6.4%	6.4%	6.3%	6.4%	6.6%	6.4%	6.2%	5.8%
Total	100%	100%	100%	100%	100%	100%	100%	100%	100%	100%
N (total # of all medicaid enrollees)	5,232,083	5,749,809	6,144,784	6,356,411	6,658,353	6,630,423	6,593,490	6,899,748	7,545,081	8,208,507

NOTE: Inclusion criteria: youth ages 3–17 with 11+ months of Medicaid eligibility and no dual eligibility in the year, in the last month of observation for the enrollee.

SOURCE: Medicaid Analytic eXtract (MAX) data for 20 states: AK, AL, AR, CA, FL, ID, IL, IN, LA, MI, MS, MT, NC, ND, NH, NM, SD, VA, VT, WY.

TABLE 18-2a Number of Diagnoses Among All Medicaid Enrollees

Diagnosis	2001	2002	2003	2004
ADHD	157,867	181,400	217,970	248,157
Conduct disorder	56,189	63,443	69,909	73,841
Emotional disturbances	72,318	78,655	86,569	94,186
Oppositional defiant disorder	44,399	49,045	54,325	59,301
Depression	88,177	100,314	114,817	124,624
Bipolar disorders	15,923	19,417	24,416	29,740
Anxiety disorders	26,957	31,009	35,776	40,385
Autism spectrum disorders	11,746	13,465	16,373	18,753
Intellectual disorders	33,110	33,856	33,877	33,811
Learning disorders	62,126	64,606	66,378	66,428
Any of the above[a]	411,670	458,502	515,838	561,252
Speech and language disorders	82,362	90,749	100,442	113,563
Hearing disorders	257,026	279,457	311,864	275,211
Cerebral palsy	27,694	28,937	31,612	32,373
Asthma	117,849	141,537	171,114	185,860

[a] Any of the above means a child with any one of the diagnoses, including if the child had comorbid diagnoses. A child with multiple co-occurring diagnoses would still be counted only once for this estimate of prevalence.

disorders, ASD, ID, and LD) increased by 41 percent (from 7.9 to 11.1 percent; also see Figure 18-1), even as the total number of children increased from 5,232,083 to 8,208,507. Across this time period, the most common mental health diagnosis was ADHD. The percentage of children enrolled in Medicaid with a diagnosis of ADHD rose by 83 percent, from 3.0 to 5.5 percent. In 2010 the prevalence of other specific mental health diagnoses ranged from 0.5 to 2.2 percent, with depression being the second most common mental health diagnosis across the years.

Of note, the substantial percent increase in the prevalence of asthma among all Medicaid enrollees was the same as that among children with ADHD (83 percent, from 2.3 percent in 2001 to 4.2 percent in 2010) (see Figure 18-1). In contrast, the percentage of All Medicaid enrollees with a diagnosis of cerebral palsy decreased by 20 percent, from 0.5 to 0.4 percent across the 2001–2010 decade.

As can be seen in Table 18-3b, among SSI Medicaid enrollees the percentage of children with a diagnosis of any one of the mental disorders

2005	2006	2007	2008	2009	2010
280,223	286,997	306,834	349,037	405,795	448,796
76,985	78,507	82,497	92,676	107,546	113,367
98,804	103,241	110,256	121,807	137,217	145,629
74,345	82,324	90,149	99,998	113,359	118,009
126,300	128,527	131,713	145,324	167,063	182,931
34,189	36,616	40,266	43,427	46,999	48,018
54,941	62,256	66,570	77,325	91,666	105,234
28,486	32,772	38,155	44,804	49,699	57,758
35,988	36,553	39,146	42,123	42,346	43,137
68,794	72,325	69,711	75,656	85,646	101,565
612,024	626,073	659,001	731,818	831,780	907,731
131,657	138,423	134,313	151,430	177,688	222,132
310,570	305,634	316,366	355,360	432,264	446,534
33,028	33,582	34,440	35,134	35,811	36,488
214,890	215,554	225,655	254,077	323,083	342,512

increased by 32 percent (from 29.2 to 38.6 percent; also see Figure 18-2), even as the total number of children increased from 361,106 to 478,822. The most common mental health diagnosis was ADHD, with a 65 percent prevalence increase (from 10.7 to 17.7 percent) across this 10-year period, from 38,466 children in 2001 to 84,519 children in 2010. The second most common mental health disorder was learning disorders (6.8 percent), followed by autism spectrum disorder (6.7 percent), and intellectual disability (6.4 percent) in 2010.

The percent increase among children with asthma and ADHD among SSI Medicaid enrollees was roughly the same as among all Medicaid enrolled children in the study states (see Figure 18-2). The percentage of SSI Medicaid enrollees with an asthma diagnosis increased by 61 percent (from 4.9 to 7.9 percent), corresponding to an increase from 17,622 children in 2001 to 38,034 children in 2010. The percentage of SSI Medicaid enrollees with a diagnosis of cerebral palsy decreased by 8 percent (from 6.2 to 5.7 percent).

TABLE 18-2b Number of Diagnoses Among SSI Medicaid Enrollees

Diagnosis	2001	2002	2003	2004
ADHD	38,466	42,603	48,485	53,357
Conduct disorder	12,473	14,083	15,228	16,226
Emotional disturbances	15,180	16,534	17,907	19,168
Oppositional defiant disorder	9,884	10,902	11,781	12,412
Depression	14,478	16,198	17,769	18,745
Bipolar disorders	5,211	6,337	7,640	9,206
Anxiety disorders	2,916	3,150	3,557	3,970
Autism spectrum disorders	8,072	9,075	10,859	12,273
Intellectual disorders	23,872	24,371	24,499	25,079
Learning disorders	20,266	21,352	22,941	23,992
Any of the above[a]	105,298	113,586	122,609	131,420
Speech and language disorders	22,787	24,742	27,333	30,509
Hearing disorders	30,919	32,074	33,438	30,981
Cerebral palsy	22,426	23,212	24,956	25,610
Asthma	17,622	19,885	22,719	24,144

[a] Any of the above means a child with any one of the diagnoses, including if the child had comorbid diagnoses. A child with multiple co-occurring diagnoses would still be counted only once for this estimate of prevalence.

Comparing Trends Between Medicaid and SSI Recipients from 2004 to 2010

Making direct comparisons of trends observed in the Medicaid population with trends observed in the full SSI program is possible only from 2004 to 2010 because the SSI program data were generated and delivered by the Social Security Administration (SSA) for the committee for the years specified in the study contract, from 2004 to 2013, and Medicaid data are only available up to 2010.

As shown in the left-hand sections of Table 18-4 and detailed above, among all Medicaid enrollees, there is a steady increase over time in the proportion of children who are diagnosed with a mental disorder—rising from 8.8 percent in 2004 to 11.1 percent in 2010, an increase of 26.1 percent over this interval. SSI Medicaid enrollees all have some qualifying disability by definition. Of these, 32.2 percent were diagnosed with a mental disorder in 2004, and 38.6 percent in 2010, an increase of 19.8

2005	2006	2007	2008	2009	2010
59,756	60,492	62,787	69,149	81,051	84,519
16,788	16,478	16,730	18,506	21,835	22,067
19,628	20,184	21,117	22,702	25,464	25,870
14,565	15,840	17,246	18,639	21,331	21,320
18,576	18,669	19,004	21,295	25,213	26,251
10,167	10,693	11,511	12,364	13,846	13,550
5,117	5,677	6,295	7,234	8,522	9,473
15,685	18,056	21,284	25,203	28,132	31,876
26,506	27,407	29,515	31,153	30,956	30,563
24,758	25,742	24,419	25,650	28,195	32,546
140,233	141,913	146,859	158,246	177,280	184,856
35,141	37,667	37,256	41,885	48,361	57,106
31,853	32,106	33,110	35,497	40,537	40,861
25,598	25,953	26,504	26,872	27,266	27,361
26,243	26,893	28,078	30,708	37,307	38,034

percent. Thus, among the sizable population of children who are eligible for Medicaid (more than 8 million in 2010), there is a growing trend of diagnoses of mental disorders. The rise in the prevalence of mental disorders observed among the SSI recipients is exceeded by the increasing prevalence among the entire Medicaid population, thus reflecting a larger secular trend. This observation is further supported by data shown in the two right-hand columns in Table 18-4. Drawing on data described in Chapter 3, we present estimates of the entire eligible U.S. population of youth who were SSI recipients for mental disorders in 2004 and in 2010. Here too we observe a small increase between 2004 and 2010, supporting the view that an increasing number of U.S. families are receiving SSI benefits due to mental disorders. However, the rates of SSI receipt for mental disorders among the U.S. population lag behind the increase in diagnoses for mental disorder among Medicaid enrollees. We interpret this pattern of results as indicating a growing demand for mental health services among low-income families (Medicaid enrollees), which is, to a lesser extent, reflected by increases in SSI recipients with mental disorders.

TABLE 18-3a Estimated Prevalence Among All Medicaid Enrollees

Diagnosis	2001	2002	2003	2004
ADHD	3.0%	3.2%	3.5%	3.9%
Conduct disorder	1.1%	1.1%	1.1%	1.2%
Emotional disturbances	1.4%	1.4%	1.4%	1.5%
Oppositional defiant disorder	0.8%	0.9%	0.9%	0.9%
Depression	1.7%	1.7%	1.9%	2.0%
Bipolar disorders	0.3%	0.3%	0.4%	0.5%
Anxiety disorders	0.5%	0.5%	0.6%	0.6%
Autism spectrum disorders	0.2%	0.2%	0.3%	0.3%
Intellectual disorders	0.6%	0.6%	0.6%	0.5%
Speech and language disorders	1.6%	1.6%	1.6%	1.8%
Hearing disorders	4.9%	4.9%	5.1%	4.3%
Learning disorders	1.2%	1.1%	1.1%	1.0%
Any of the above[a]	7.9%	8.0%	8.4%	8.8%
Cerebral palsy	0.5%	0.5%	0.5%	0.5%
Asthma	2.3%	2.5%	2.8%	2.9%
N (total # of all medicaid enrollees)	5,232,083	5,749,809	6,144,784	6,356,411

[a] Any of the above means a child with any one of the diagnoses, including if the child had comorbid diagnoses. A child with multiple co-occurring diagnoses would still be counted only once for this estimate of prevalence.

Discussion of Trends Observed in the Medicaid Study

Overall, these data indicate an increasing prevalence of mental disorder diagnoses among children enrolled in Medicaid which exceeds the growth rate among SSI recipients between 2001 and 2010. Additionally, the trend direction for mental disorder prevalence observed in the SSI program for children is consistent with overall trends among all Medicaid enrollees as well as among the subset of SSI Medicaid enrollees. However, while these global mental disorder trend comparisons are useful, comparisons of disorder specific trends may show different patterns. Disorder-specific trends are reviewed in Part III of the report.

Trend findings from the MAX data support several conclusions. First, the number of child Medicaid enrollees grew substantially between 2001 and 2010. This growth may reflect increases in child poverty as well as

2005	2006	2007	2008	2009	2010
4.2%	4.3%	4.7%	5.1%	5.4%	5.5%
1.2%	1.2%	1.3%	1.3%	1.4%	1.4%
1.5%	1.6%	1.7%	1.8%	1.8%	1.8%
1.1%	1.2%	1.4%	1.4%	1.5%	1.4%
1.9%	1.9%	2.0%	2.1%	2.2%	2.2%
0.5%	0.6%	0.6%	0.6%	0.6%	0.6%
0.8%	0.9%	1.0%	1.1%	1.2%	1.3%
0.4%	0.5%	0.6%	0.6%	0.7%	0.7%
0.5%	0.6%	0.6%	0.6%	0.6%	0.5%
2.0%	2.1%	2.0%	2.2%	2.4%	2.7%
4.7%	4.6%	4.8%	5.2%	5.7%	5.4%
1.0%	1.1%	1.1%	1.1%	1.1%	1.2%
9.2%	9.4%	10.0%	10.6%	11.0%	11.1%
0.5%	0.5%	0.5%	0.5%	0.5%	0.4%
3.2%	3.3%	3.4%	3.7%	4.3%	4.2%
6,658,353	6,630,423	6,593,490	6,899,748	7,545,081	8,208,507

other policy or program changes that affect child Medicaid enrollment. The large increases in the number of enrollees observed from 2008 to 2010 coincide with the period of recession and growth in child poverty. In addition, the numbers of uninsured children decreased during the 10-year period, as the numbers enrolled in Medicaid and the Children's Health Insurance Program increased, likely the result of policies incentivizing the enrollment of eligible children in Medicaid (HHS, 2010).

Second, among Medicaid enrollees, the percentage with SSI coverage or foster care eligibility decreased over the decade, indicating that from 2001 to 2010 the number of children eligible due to low income increased more quickly than the number of children in foster care or with SSI.

Third, mental disorder diagnoses increased at roughly similar rates among all eligibility categories and at rates that paralleled increases in

TABLE 18-3b Estimated Prevalence Among SSI Medicaid Enrollees

Diagnosis	2001	2002	2003	2004
ADHD	10.7%	11.3%	12.3%	13.1%
Conduct disorder	3.5%	3.7%	3.8%	4.0%
Emotional disturbances	4.2%	4.4%	4.5%	4.7%
Oppositional defiant disorder	2.7%	2.9%	3.0%	3.0%
Depression	4.0%	4.3%	4.5%	4.6%
Bipolar disorders	1.4%	1.7%	1.9%	2.3%
Anxiety disorders	0.8%	0.8%	0.9%	1.0%
Autism spectrum disorders	2.2%	2.4%	2.7%	3.0%
Intellectual disorders	6.6%	6.5%	6.2%	6.2%
Speech and language disorders	6.3%	6.6%	6.9%	7.5%
Hearing disorders	8.6%	8.5%	8.4%	7.6%
Learning disorders	5.6%	5.7%	5.8%	5.9%
Any of the above[a]	29.2%	30.2%	31.0%	32.2%
Cerebral palsy	6.2%	6.2%	6.3%	6.3%
Asthma	4.9%	5.3%	5.7%	5.9%
N (total # of SSI medicaid enrollees)	361,106	376,196	395,718	407,703

[a] Any of the above means a child with any one of the diagnoses, including if the child had comorbid diagnoses. A child with multiple co-occurring diagnoses would still be counted only once for this estimate of prevalence.

asthma diagnoses. Children in low-income households have higher rates of both mental disorders and asthma; thus, the finding of increased rates of asthma reinforces the importance of poverty as a factor contributing to the increasing rates of mental disorders in children.

Findings from Table 18-4 raise four other points of relevance. First, a very low percentage of all children living in poverty receive SSI for mental disorders, even though a substantial minority of all Medicaid-enrolled children have mental disorder diagnoses. While the SSI eligibility requirement for a severe medically determinable impairment likely accounts for much of this difference, the marked discrepancy raises questions about the number of children in poverty with mental disorders who may be eligible for SSI but who do not receive benefits.

Second, the much higher rates of mental disorder diagnoses observed among SSI Medicaid than among all Medicaid enrollees is likely explained

2005	2006	2007	2008	2009	2010
14.4%	14.2%	14.5%	15.7%	17.3%	17.7%
4.0%	3.9%	3.9%	4.2%	4.7%	4.6%
4.7%	4.7%	4.9%	5.2%	5.4%	5.4%
3.5%	3.7%	4.0%	4.2%	4.6%	4.5%
4.5%	4.4%	4.4%	4.8%	5.4%	5.5%
2.4%	2.5%	2.7%	2.8%	3.0%	2.8%
1.2%	1.3%	1.5%	1.6%	1.8%	2.0%
3.8%	4.2%	4.9%	5.7%	6.0%	6.7%
6.4%	6.4%	6.8%	7.1%	6.6%	6.4%
8.4%	8.8%	8.6%	9.5%	10.3%	11.9%
7.7%	7.5%	7.7%	8.1%	8.6%	8.5%
5.9%	6.0%	5.7%	5.8%	6.0%	6.8%
33.7%	33.3%	34.0%	36.0%	37.8%	38.6%
6.1%	6.1%	6.1%	6.1%	5.8%	5.7%
6.3%	6.3%	6.5%	7.0%	8.0%	7.9%
416,367	426,454	431,901	440,135	468,735	478,822

by the SSI eligibility criteria. Medicaid-enrolled children who receive SSI will all have significant impairments, with a substantial proportion based on mental disorders, while many other Medicaid-enrolled children will have no impairment or mental disorder diagnosis. Furthermore, the Medicaid study selection criteria include only children who had either one inpatient or two outpatient encounters; children who fail to meet those criteria were not included. As a result, the Medicaid study data may generate a higher estimate of the prevalence of mental disorders than studies that include enrollees who have not submitted claims.

Third, Table 18-4 shows a notable discrepancy between the number of SSI recipients with mental disorders and the number of SSI Medicaid enrollees with a mental disorder diagnosis. In 2010 there were 615,772 child recipients for mental disorders, while there were only 184,856 children who were enrolled in Medicaid and on SSI with a mental disorder diagnosis.

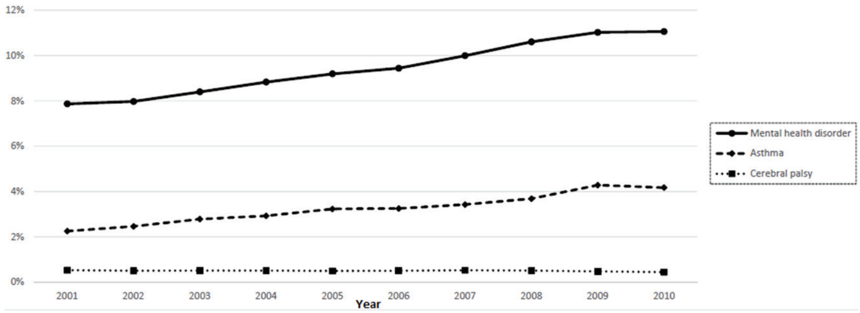

FIGURE 18-1 Diagnoses among all Medicaid enrollees, 2001–2010.
NOTES: Mental health disorder: ADHD, conduct disorders, emotional disturbances, oppositional defiant disorder, depression, bipolar disorders, anxiety disorders, intellectual disorders, learning disorders, autism spectrum disorders. Inclusion criteria: youth age 3–17 with 11+ months of Medicaid eligibility and no dual eligibility in the year. A diagnosis was established based on the presence of one or more inpatient or two or more non-inpatient claims with qualifying ICD-9-CM codes.
SOURCE: MAX data for 20 states: AK, AL, AR, CA, FL, ID, IL, IN, LA, MI, MS, MT, NC, ND, NH, NM, SD, VA, VT, WY.

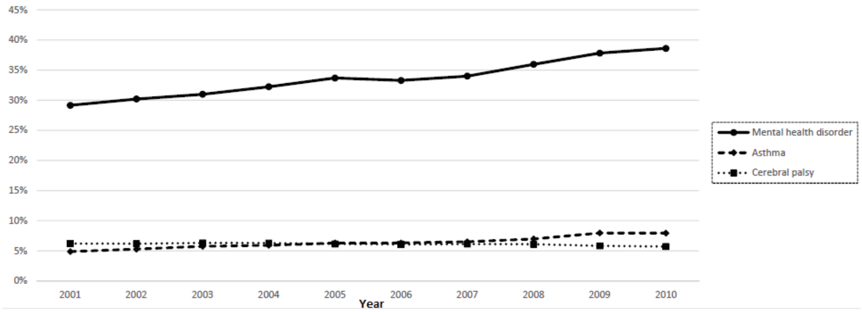

FIGURE 18-2 Diagnoses among SSI Medicaid enrollees, 2001–2010.
NOTES: Mental health disorder: ADHD, conduct disorders, emotional disturbances, oppositional defiant disorder, depression, bipolar disorders, anxiety disorders, intellectual disorders, learning disorders, autism spectrum disorders. Inclusion criteria: youth age 3–17 with 11+ months of Medicaid eligibility and no dual eligibility in the year. A diagnosis was established based on the presence of one or more inpatient or two or more non-inpatient claims with qualifying ICD-9-CM codes.
SOURCE: MAX data for 20 states: AK, AL, AR, CA, FL, ID, IL, IN, LA, MI, MS, MT, NC, ND, NH, NM, SD, VA, VT, WY.

TABLE 18-4 Change in Prevalence Estimates of Mental Disorders from 2004 to 2010 Among Children Enrolled in Medicaid and on SSI

	All Medicaid Enrollees		SSI Medicaid Enrollees		SSI Medicaid Enrollees	
	Percent Diagnosed with Any of the 10 Mental Disorders	Number of All Medicaid Enrollees Diagnosed with Any Mental Disorder	Percent Diagnosed with Any Mental Disorder	Number of SSI/Disability Enrollees Diagnosed with Any Mental Disorder	Percent of Children from Households Under 200% FPL with Any of the 10 Major Mental Disorders	Number of SSI Recipients with Any of the 10 Major Mental Disorders
2004	8.80%	561,252	32.20%	131,420	1.88%	540,051
2010	11.10%	907,731	38.60%	184,856	1.91%	615,772
Percentage increase in the % of children with a mental disorder diagnosis	26.1%		19.8%		1.6%	

NOTE: FPL = federal poverty level.

Similarly, in 2010 the total number of child SSI recipients was 1,239,269, while the total number SSI Medicaid enrollees included in the study for 2010 was 478,822. Several issues contribute to this difference. First, the Medicaid study includes only 20 states, while the SSI program includes all 50 states. Second, the Medicaid study likely underestimates the number of children who are both SSI recipients and enrolled in Medicaid because only children meeting study criteria for continuous enrollment for each index year were included. One inclusion criterion was that an individual must have had 11 months of Medicaid eligibility within 1 year. As such, enrolled individuals who submitted one or no claims or who lost Medicaid coverage during an index year would be excluded from the study.

Fourth, the proportion of children with a mental health diagnosis may be underestimated in the Medicaid study because a child was identified as receiving Medicaid paid care for an index disorder if the individual had at least one inpatient claim or two or more outpatient claims on different dates for the same mental health diagnosis. As such, children who dropped out of care after one outpatient visit would be excluded from the study.

Finally, the difference between the large 2004–2010 growth in numbers of children in the Medicaid population who have mental disorder diagnoses and the much smaller growth in numbers of children with a mental disorder diagnosis in the SSI recipient population (see Table 18-4) cannot be definitively explained by the information at hand. Two potential contributing factors, worthy of future analyses, are (1) an increasing rate of diagnosis of mental disorders for children who are Medicaid enrollees and who do not meet the moderate to severe impairment SSI criteria, and (2) stricter SSI adjudication processes for mental disorder impairment during this 7-year window.

Given that the number of impoverished and Medicaid-eligible children has increased over the period of interest, and given that the prevalence of mental disorder diagnoses within the child Medicaid population increased at a rate commensurate with SSI recipients with mental disorders over the same period, it is likely that there is a substantial and growing population of children who are eligible to receive SSI benefits for mental disorders but who are not recipients.

COMORBIDITY

Although no comparable comorbidity data are available from the SSI data, findings from the Medicaid study are consistent with those from epidemiologic studies that suggest high rates of comorbidity among children with mental disorders. Upon close reading of Tables 18-2a and 18-2b, findings suggest that there is a high rate of comorbidity between mental disorder diagnoses in the child Medicaid population. In these tables, the “Any of the Above" row corresponds to a child who received Medicaid-funded care, and also had one or more of these diagnoses recorded related to an episode of care during the index year as well as may include children who may have more than one mental disorder diagnosis recorded during a service encounter. The number of children with any one diagnosis is therefore much smaller than the sum each individual diagnosis in each row above. For example, of SSI Medicaid enrollees in 2010, there were approximately 184,856 enrollees with at least one of the clinically treated diagnoses, but each of the clinically treated diagnoses sum to nearly 300,000. This indicates that there are at least approximately 115,000 additional diagnoses among the 184,856 children with at least one diagnosis.

In addition, the Medicaid study included an analysis of the frequency of co-occurring mental disorder diagnosis among children with a diagnosis of ADHD. The committee recommended a more detailed descriptive data analysis describing comorbidity among children receiving Medicaid-funded care for ADHD because it was the most common mental disorder among all Medicaid and SSI enrollees and has high rates of comorbidity clinically. Tables 18-5a and 18-5b summarize the 10-year trends in the proportion of children with a comorbid mental disorder, speech and language disorder, hearing disorder, cerebral palsy and asthma among children with ADHD, among all Medicaid and SSI enrollees, respectively. In both 2001 and 2010, the most common comorbid mental disorders among all Medicaid enrollees who received paid treatment for ADHD were emotional disturbances (2001, 11.6 percent; 2010, 13.4 percent), oppositional defiant disorder (2001, 9.4 percent; 2010, 11.7 percent), and depression (2001, 9.3 percent; 2010, 11.2 percent). Among SSI Medicaid enrollees with paid treatment for ADHD, emotional disturbances (2001, 13.5 percent; 2010, 16.7 percent) and oppositional defiant disorder (2001, 11.2 percent; 2010, 14.9 percent) were the top two comorbid disorders. In 2001, the third most common comorbid disorder was conduct disorder (10.2 percent), but in 2010 depression rose to the rank of the third most common comorbid disorder (13.4 percent). Tables 18-6a and 18-6b summarize the 10-year trends in the proportion of children receiving Medicaid-funded care for ADHD who have any comorbid mental health or developmental disorder and any externalizing behavior disorder (defined as oppositional defiant disorder or conduct disorder) among all Medicaid and SSI enrollees, respectively. Overall, the rates of comorbidity were high. Among all Medicaid enrollees, the proportion of children with ADHD and any comorbid mental or developmental disorder rose 12 percent between 2001 and 2010 (38.2 to 43.3 percent). The rates of comorbid externalizing behavior problems among children with ADHD rose by 14 percent during this same time period (15.8 to 18.3 percent). Among SSI Medicaid enrollees, the overall rates of comorbidity were higher. The proportion of children with ADHD and any comorbid

TABLE 18-5a Comorbid Diagnoses, All Enrollees with ADHD

Diagnosis	2001	2002	2003	2004
ADHD				
Conduct disorder	8.1%	8.0%	7.9%	7.8%
Emotional disturbances	11.6%	11.4%	11.2%	10.9%
Oppositional defiant disorder	9.4%	9.4%	9.3%	9.1%
Depression	9.3%	9.1%	9.5%	9.8%
Bipolar disorders	3.4%	3.6%	4.0%	4.6%
Anxiety disorders	2.7%	2.7%	3.0%	3.1%
Autism spectrum disorders	1.0%	1.1%	1.2%	1.3%
Intellectual disorders	2.1%	2.0%	1.8%	1.6%
Learning disorders	4.1%	4.1%	3.8%	3.7%
Speech and language disorders	4.5%	4.4%	4.7%	4.9%
Hearing disorders	7.7%	7.6%	7.9%	6.9%
Cerebral palsy	0.5%	0.4%	0.5%	0.4%
Asthma	4.2%	4.6%	5.1%	5.4%
N	157,867	181,400	217,970	248,157

NOTE: Inclusion criteria: youth age 3–17 with 11+ months of Medicaid eligibility and no dual eligibility in the year. A diagnosis was established based on the presence of one or more inpatient or two or more non-inpatient claims with qualifying ICD-9-CM codes.
SOURCE: MAX data for 20 states: AK, AL, AR, CA, FL, ID, IL, IN, LA, MI, MS, MT, NC, ND, NH, NM, SD, VA, VT, WY.

mental or development disorder rose 17 percent (46.3 to 55.8 percent), and for ADHD and any comorbid externalizing disorder the proportion of children rose 18 percent (19.2 to 23.4 percent).

MENTAL DISORDERS BY RACE AND ETHNICITY

The SSA does not keep or provide information on the race and the ethnicity of SSI recipients. Thus, all information regarding race and ethnicity comes from other reports, mainly of characteristics of children and adolescents who receive Medicaid for disability. Table 18-7 shows the estimated prevalence of mental disorder diagnoses among SSI Medicaid enrollees, in 2010, by race and ethnicity. The analysis carried out in support of the work of this committee shows an overrepresentation of African American children in the identified SSI population (32 percent African American, 10 percent Latino, 22 percent white, with 34 percent mixed or unidentified).

Previous studies have shown varied findings regarding racial and ethnic characteristics of children with chronic conditions in general (Halfon et al.,

2005	2006	2007	2008	2009	2010
7.9%	8.4%	8.5%	8.7%	8.8%	8.6%
11.4%	12.8%	13.2%	13.4%	13.5%	13.4%
9.6%	11.1%	11.6%	11.8%	11.9%	11.7%
9.6%	10.4%	10.2%	10.4%	10.8%	11.2%
4.9%	5.4%	5.4%	5.3%	5.0%	4.7%
3.4%	3.8%	3.9%	4.2%	4.6%	5.1%
1.9%	2.2%	2.6%	2.9%	2.9%	3.2%
1.6%	1.7%	1.7%	1.6%	1.4%	1.4%
3.6%	3.8%	3.5%	3.5%	3.6%	3.9%
4.9%	5.2%	5.1%	5.3%	5.6%	6.4%
6.9%	6.6%	6.6%	6.8%	7.0%	6.7%
0.4%	0.5%	0.5%	0.4%	0.4%	0.4%
6.0%	6.1%	6.2%	6.3%	7.0%	6.9%
280,223	286,997	306,834	349,037	405,795	448,796

2012; Van Cleave et al., 2010); however, previous studies of the SSI population (usually using similar methodology to the MAX studies) have also shown a predominance of African American children (Perrin et al., 1998, 1999). There have also been several reports indicating racial and ethnic differences in diagnosis and receipt of services for mental health conditions (HHS, 2001). Some of this represents differential access to care by race and ethnicity (especially, for example, in diagnostic and treatment services for autism spectrum disorder). Others represent effects of language on diagnosis, where some diagnosticians and some commonly used tests may be limited to English-speaking children and families. Variation in prevalence of diagnoses across race and ethnic categories must be cautiously interpreted due not only to the effects of socioeconomic status and poverty, but also due to the effects of test bias and diagnostic bias.

Race and ethnicity data are generally not reliable for routine use in analyses of Medicaid claims data. First, the administrative claims forms in many states do not employ standard race/ethnicity questions across the recommended Office of Management and Budget categories that separate

TABLE 18-5b Comorbid Diagnoses, SSI/Disability Enrollees with ADHD

Diagnosis	2001	2002	2003	2004
ADHD				
Conduct disorder	10.2%	10.6%	10.8%	10.8%
Emotional disturbances	13.5%	13.6%	14.1%	13.6%
Oppositional defiant disorder	11.2%	11.5%	11.9%	11.4%
Depression	9.7%	9.9%	10.4%	10.6%
Bipolar disorders	5.4%	5.8%	6.5%	7.3%
Anxiety disorders	2.0%	2.0%	2.2%	2.5%
Autism spectrum disorders	2.6%	2.8%	3.3%	3.7%
Intellectual disorders	5.5%	5.5%	5.3%	4.8%
Learning disorders	6.3%	6.6%	6.4%	6.4%
Speech and language disorders	6.7%	6.9%	7.3%	8.1%
Hearing disorders	7.8%	7.8%	7.8%	7.0%
Cerebral palsy	1.3%	1.3%	1.4%	1.4%
Asthma	4.7%	5.5%	6.2%	6.5%
N	38,466	42,603	48,485	53,357

NOTE: Inclusion criteria: youth age 3–17 with 11+ months of Medicaid eligibility and no dual eligibility in the year. A diagnosis was established based on the presence of one or more inpatient or two or more non-inpatient claims with qualifying ICD-9-CM codes.
SOURCE: MAX data for 20 states: AK, AL, AR, CA, FL, ID, IL, IN, LA, MI, MS, MT, NC, ND, NH, NM, SD, VA, VT, WY.

race and ethnicity as separate variables. Even in the consideration of race alone, the field is missing in approximately 20 percent of the claims filed (IOM, 2009). Because these data are also missing from the SSA data fields, additional analyses on race/ethnicity were not conducted.

TREATMENT

For certain mental disorders in children, appropriate treatment, including medication and psychological services, can significantly reduce impairment and improve outcomes. Treatment among the SSI disability population may have an effect on the rates of disability; as such, the SSA directed the committee to identify the types of care documented or reported to be received by children in the SSI population. The SSI program does not systematically collect any information on treatment after adjudications of eligibility are made.

2005	2006	2007	2008	2009	2010
10.6%	11.2%	11.2%	11.4%	11.6%	11.4%
13.9%	15.8%	16.8%	17.0%	16.9%	16.7%
11.9%	13.9%	15.0%	15.2%	15.3%	14.9%
10.4%	11.3%	11.3%	12.2%	12.7%	13.4%
7.7%	8.5%	8.9%	8.6%	8.3%	8.0%
2.6%	3.0%	3.3%	3.6%	3.7%	4.2%
4.4%	5.4%	6.4%	7.4%	7.4%	8.2%
4.8%	5.3%	5.4%	5.2%	4.4%	4.4%
6.2%	6.4%	6.0%	6.1%	6.1%	6.8%
8.1%	8.7%	8.8%	9.5%	10.1%	11.5%
6.9%	6.7%	7.0%	7.1%	7.2%	6.9%
1.3%	1.5%	1.5%	1.4%	1.3%	1.3%
7.3%	7.5%	7.6%	7.9%	8.6%	8.6%
59,756	60,492	62,787	69,149	81,051	84,519

Thus, to meet the requirements of the task order the committee summarized what is known about mental health treatment among children enrolled in Medicaid (Section 2) and assessed trends in treatment by modality and mental health diagnosis using the MAX data. As previously described in Chapter 2 and earlier in this chapter, the MAX data contain administrative claims data on individual Medicaid enrollees, including information on their basis of eligibility, diagnosis, service use, and payments. The MAX data thus include rates of diagnoses and rates of adjudicated claims for medication prescriptions filled and receipt of any type of psychotherapy (i.e., individual, group, or family). As a result, the types of medication and psychotherapy services that are paid on behalf of children enrolled in Medicaid with mental disorders can be tracked over time.

TABLE 18-6a ADHD Type, All Enrollees

ADHD Type	2001	2002	2003	2004
ADHD with no other mental health/ developmental diagnosis	1.9%	2.0%	2.2%	2.4%
ADHD with one or more other mental health/developmental diagnosis	1.2%	1.2%	1.4%	1.5%
Proportion with one or more other mental health diagnoses	*38.2%*	*37.8%*	*38.4%*	*37.8%*
ADHD without externalizing disorder (CD/ODD)	2.5%	2.7%	3.0%	3.3%
ADHD with externalizing disorder (CD/ODD)	0.5%	0.5%	0.6%	0.6%
Proportion with externalizing disorder (CD/ODD)	*15.8%*	*15.7%*	*15.5%*	*15.2%*
N	5,232,083	5,749,809	6,144,784	6,356,411

NOTE: Row groups are not all mutually exclusive, but each "with/without" pair is.
SOURCE: MAX data for 20 states: AK, AL, AR, CA, FL, ID, IL, IN, LA, MI, MS, MT, NC, ND, NH, NM, SD, VA, VT, WY.

Background Information on Treatment of Children with Mental Disorders on SSI and in Medicaid

Few studies describe the treatment of children with mental disorders who also receive SSI benefits. The available literature on the treatment of children on SSI has relied on MAX data and has generally concentrated on smaller populations by region, including the mid-Atlantic states, southwestern Pennsylvania, and New York State. Studies have also focused on treatment patterns for SSI recipients compared with enrollees in foster care, Temporary Assistance for Needy Families, and the State Children's Health Insurance Program (DosReis, 2001; DosReis et al., 2011; Harman et al., 2000; Zito et al., 2005, 2013).

Treatment rates vary by Medicaid eligibility category. In one regional study, DosReis found that foster care–enrolled youths and SSI-recipient youths use significantly more mental health services than youths in other aid categories (DosReis, 2001). Some studies have focused on the trends in treatment rates among children on Medicaid. A 2013 regional cross-sectional study of Medicaid enrollees in the mid-Atlantic states found that the prevalence of antipsychotic use increased from 1997 to 2006 (Zito et al., 2013). Among children in poverty, rates of treatment often differ by both race and eligibility category (Zito et al., 2005).

2005	2006	2007	2008	2009	2010
2.6%	2.5%	2.7%	2.9%	3.1%	3.1%
1.6%	1.8%	1.9%	2.1%	2.3%	2.4%
38.7%	*41.2%*	*41.6%*	*42.2%*	*42.7%*	*43.3%*
3.5%	3.6%	3.8%	4.1%	4.4%	4.5%
0.7%	0.8%	0.8%	0.9%	1.0%	1.0%
15.7%	*17.5%*	*18.1%*	*18.4%*	*18.6%*	*18.3%*
6,658,353	6,630,423	6,593,490	6,899,748	7,545,081	8,208,507

Prior literature on the treatment of mental disorders for all children enrolled in Medicaid and the subset on SSI is predominantly regional, cross sectional, and focused almost exclusively on psychiatric drug prescriptions rather than other types of treatment. Across all prior studies, youths eligible for Medicaid through foster care or SSI have been found to have higher costs and rates of psychiatric drug prescriptions than those eligible solely based on income. Regional variations have been noted, but their cause and implications are uncertain.

Trends in ADHD Treatment Modalities from 2001 to 2010

Tables 18-8a and 18-8b summarize the treatment received by children with a diagnosis of ADHD among all Medicaid enrollees and among SSI Medicaid enrollees.

Among all Medicaid-enrolled children diagnosed with ADHD, most received some Medicaid-paid treatment for their condition, ranging from 87 percent in 2001 to 92 percent in 2010. These proportions were similar to those among children who were SSI Medicaid enrollees, which increased from 85 percent in 2001 to 92 percent in 2010. However, it should be noted that the absolute rates of treatment may be underestimated because

TABLE 18-6b ADHD Type, SSI/Disability Enrollees

ADHD Type	2001	2002	2003	2004
ADHD with no other mental health/developmental diagnosis	5.7%	6.0%	6.3%	6.8%
ADHD with one or more other mental health/developmental diagnosis	4.9%	5.4%	5.9%	6.3%
Proportion with one or more other mental health diagnoses	*46.3%*	*47.3%*	*48.3%*	*48.1%*
ADHD without externalizing disorder (CD/ODD)	8.6%	9.1%	9.8%	10.5%
ADHD with externalizing disorder (CD/ODD)	2.0%	2.2%	2.5%	2.6%
Proportion with externalizing disorder (CD/ODD)	*19.2%*	*19.8%*	*20.3%*	*19.7%*
N	361,106	376,196	395,718	407,703

NOTE: Row groups are not all mutually exclusive, but each "with/without" pair is.
SOURCE: MAX data for 20 states: AK, AL, AR, CA, FL, ID, IL, IN, LA, MI, MS, MT, NC, ND, NH, NM, SD, VA, VT, WY.

only children who were continuously enrolled in Medicaid were included and treatment provided in schools and foster care may not be captured in Medicaid claims. In addition, the direction of the selection bias may be mixed because SSI Medicaid enrollees may have greater clinical severity that could drive greater service utilization because functional impairment is part of SSI benefit eligibility criteria.

Treatment trends among SSI Medicaid enrollees were similar to those among all Medicaid enrollees. Overall, medication alone remained the most common treatment regimen over the decade, with approximately 50 percent of children diagnosed with ADHD receiving only medication treatment. Over time, however, there was a shift from medication-only treatment to combined treatment for both groups, indicating an increasing consistency with treatment guidelines. Among all Medicaid enrollees with ADHD, treatment with medication only decreased by 22 percent (from 65.2 to 53.2 percent), while combined treatment increased by 74 percent (from 18.5 to 32.1 percent). Among SSI Medicaid enrollees with ADHD, medication only treatment decreased by 35 percent (from 67.6 to 50.2 percent), while increase in combined treatment more than doubled (14.9 to 36.4 percent).

2005	2006	2007	2008	2009	2010
7.4%	6.8%	6.7%	7.1%	7.9%	7.8%
6.9%	7.4%	7.8%	8.6%	9.4%	9.8%
48.3%	*52.1%*	*53.9%*	*54.5%*	*54.5%*	*55.8%*
11.5%	11.0%	11.2%	12.0%	13.2%	13.5%
2.9%	3.1%	3.4%	3.7%	4.1%	4.1%
19.9%	*22.1%*	*23.2%*	*23.5%*	*23.8%*	*23.4%*
416,367	426,454	431,901	440,135	468,735	478,822

Treatment for SSI Children, by Mental Disorder, in 2010

Tables 18-9a and 18-9b summarize the treatment modalities received by mental disorder diagnosis among all Medicaid enrollees and SSI Medicaid enrollees in 2010. The rates of treatment varied by mental disorder among both groups.

Children with a diagnosis of either bipolar or ADHD were the most likely to receive any treatment. Among all Medicaid enrollees the rate of receipt of paid treatment for bipolar and ADHD was 95.4 and 93.1 percent, respectively; among SSI Medicaid enrollees the rate was even higher, at 96.9 percent for bipolar and 94.6 percent for ADHD. Among all Medicaid enrollees, the percentages of children receiving any treatment for depression, anxiety disorders, and ASD were 78.2, 73.8, and 71.2 percent, respectively. Among SSI Medicaid enrollees, the percentage of children with these disorders who received any treatment was 89.7, 84.7, and 69.2 percent.

Although few children with bipolar disorder were untreated, the proportion of children who received the recommended (reference) treatment among all Medicaid enrollees and SSI Medicaid enrollees in 2010 ranged,

TABLE 18-7 MAX Diagnoses by Race/Ethnicity, SSI Medicaid Enrollees, 2010

Diagnosis	White	Black/ African American	Am. Indian/ Alaskan Native	Asian	Hispanic/ Latino	More Than 1/ Unknown
ADHD	23.3%	18.8%	18.4%	4.5%	10.3%	15.7%
Conduct disorder	5.2%	5.1%	4.3%	2.1%	3.7%	4.1%
Emotional disturbances	6.9%	6.6%	7.6%	1.0%	3.2%	4.1%
Oppositional defiant disorder	5.6%	5.8%	5.7%	0.7%	2.2%	3.3%
Depression	8.0%	5.5%	8.1%	1.9%	5.2%	3.9%
Bipolar disorders	5.6%	2.2%	3.4%	0.7%	1.9%	1.9%
Anxiety disorders	3.5%	1.3%	2.8%	1.0%	2.1%	1.7%
Autism spectrum disorders	12.5%	3.7%	5.1%	11.0%	6.0%	5.8%
Intellectual disorders	10.6%	3.8%	3.5%	25.9%	11.6%	3.9%
Learning disorders	8.5%	5.5%	10.4%	5.3%	5.5%	7.3%
Speech and language disorders	14.6%	9.0%	17.1%	10.9%	8.4%	14.0%
Hearing disorders	11.4%	4.8%	10.6%	7.4%	10.1%	9.7%
Cerebral palsy	8.6%	3.3%	5.1%	12.8%	9.1%	4.9%
Asthma	6.3%	9.2%	8.5%	4.2%	7.4%	8.1%
N	104,116	152,011	5,320	3,635	49,189	161,876

TABLE 18-8a ADHD Treatment Among All Medicaid Enrollees with a Diagnosis of ADHD, 2001–2010

Treatment Status	2001	2002	2003	2004	2005	2006	2007	2008	2009	2010
Not treated	13.1%	12.2%	10.3%	8.5%	9.9%	10.0%	9.8%	9.3%	8.8%	8.0%
Treated with medication only	65.2%	66.8%	60.9%	52.6%	53.2%	52.5%	51.7%	51.8%	52.4%	53.2%
Treated with psychotherapy only	3.2%	2.9%	4.6%	6.1%	6.2%	7.0%	7.2%	7.2%	7.0%	6.7%
Treated with both medication and psychotherapy	18.5%	18.1%	24.2%	32.8%	30.8%	30.6%	31.4%	31.7%	31.8%	32.1%
N (# of children among all Medicaid enrollees with an ADHD diagnosis)	157,867	181,400	217,970	248,157	280,223	286,997	306,834	349,037	405,795	448,796

TABLE 18-8b ADHD Treatment Among SSI Medicaid Enrollees with a Diagnosis of ADHD, 2001–2010

Treatment Status	2001	2002	2003	2004	2005	2006	2007	2008	2009	2010
Not treated	15.3%	14.6%	12.6%	11.0%	11.5%	10.2%	9.5%	9.3%	8.6%	7.6%
Treated with medication only	67.6%	68.4%	60.2%	49.6%	50.7%	50.5%	48.6%	48.0%	50.1%	50.2%
Treated with psychotherapy only	2.2%	1.9%	3.6%	5.0%	5.2%	6.1%	6.6%	6.9%	6.0%	8.2%
Treated with both medication and psychotherapy	14.9%	15.1%	23.6%	34.4%	32.6%	33.1%	35.3%	35.8%	35.3%	36.4%
N (# of children among SSI Medicaid enrollees with an ADHD diagnosis)	38,466	42,603	48,485	53,357	59,756	60,492	62,787	69,149	81,051	84,519

TABLE 18-9a Mental Health Treatment Among All Medicaid Enrollees with One or More Mental Health Diagnoses in 2010

Diagnosis	Not Treated	Treated with Medication Only	Treated with Psychotherapy Only	Treated with Both Medication and Psychotherapy
ADHD	6.9%	54.3%	5.2%	33.6%
Conduct disorder	27.4%	21.7%	18.2%	32.7%
Emotional disturbances	22.8%	19.6%	19.1%	38.4%
Oppositional defiant disorder	20.6%	19.9%	18.4%	41.1%
Depression	21.8%	25.2%	14.1%	38.9%
Bipolar disorders	4.6%	35.4%	4.2%	55.8%
Anxiety disorders	26.2%	15.3%	29.5%	29.0%
Autism spectrum disorders	28.8%	31.7%	12.0%	27.5%
Intellectual disorders	42.0%	35.3%	7.3%	15.3%
Learning disorders	49.9%	19.2%	17.2%	13.8%
Any of the above[a]	24.3%	36.6%	13.9%	25.3%
Speech and language disorders	70.4%	15.1%	7.0%	7.5%
Hearing disorders	84.4%	8.3%	3.7%	3.7%

[a] *Any* of the above means a child with any one of the diagnoses, including if the child had comorbid diagnoses. A child with multiple co-occurring diagnoses would still be counted only once for this estimate of prevalence.

respectively, from 55.8 to 54.7 percent. Only slightly more than one-half of children received at least one visit for psychotherapy in any format (individual, family, group) and had at least one psychotropic medication prescription filled during the study year. A similar prevalence of combined therapies is noted for other behavioral disorders. The reasons for the gap between indicated and delivered care fall outside the scope of this study.

Limitations

The Medicaid Study treatment findings have several limitations. Medicaid claims data provide no information on the quality of the mental health care received. Appropriate use of medication cannot be determined

TABLE 18-9b Mental Health Treatment Among SSI Medicaid Enrollees with One or More Mental Health Diagnoses in 2010

Diagnosis	Not Treated	Treated with Medication Only	Treated with Psychotherapy Only	Treated with Both Medication and Psychotherapy
ADHD	5.4%	52.3%	3.6%	38.6%
Conduct disorder	16.1%	33.4%	8.9%	41.7%
Emotional disturbances	13.1%	26.3%	10.3%	50.3%
Oppositional defiant disorder	10.7%	26.0%	9.4%	54.0%
Depression	10.3%	33.5%	6.5%	49.8%
Bipolar disorders	3.1%	40.3%	1.9%	54.7%
Anxiety disorders	15.3%	26.4%	14.5%	43.9%
Autism spectrum disorders	30.8%	38.1%	7.2%	23.9%
Intellectual disorders	43.9%	39.1%	4.4%	12.6%
Learning disorders	45.9%	29.7%	10.0%	14.5%
Any of the above[a]	25.3%	41.5%	6.9%	26.3%
Speech and language disorders	56.7%	25.9%	6.2%	11.3%
Hearing disorders	61.8%	24.3%	4.6%	9.3%

[a] Any of the above means a child with any one of the diagnoses, including if the child had comorbid diagnoses. A child with multiple co-occurring diagnoses would still be counted only once for this estimate of prevalence.

because there is no information available on child clinical need for psychotropic medication. The use of evidence-based psychotherapies cannot be determined because Medicaid procedure codes do not specify the types of psychological services, such as parent training for ADHD.

The receipt of behavioral or educational interventions also may be under-reported because children with mental health conditions may receive services through special education programs or state-funded programs for persons with disabilities. Services that are not paid for by Medicaid could account for the low rates of treatment observed among children with intellectual and learning disorders. Psychotherapy may also be under-reported among children receiving mental health care in a primary care setting because priority may be placed on billing for other procedure codes (Zima et al., 2010). In short, the Medicaid study cannot provide any information about children who do not receive Medicaid-paid treatment.

As noted earlier, the Medicaid data do not allow a direct linkage of treatment use with a specific diagnosis in cases of enrollees who have multiple co-occurring mental disorder diagnoses. For example, an enrollee with co-occurring ASD and depression may receive antidepressant medication; however, the data will show reimbursement for medication treatment for both the ASD and depression diagnoses. As a result, the ASD diagnoses would be associated with medication treatment, although the treatment would be for the comorbid depression.

Finally, the Medicaid study and our other data sources cannot address the questions of whether parents seek services to increase the likelihood that their child's SSI application will be approved or whether treatment status affects adjudication eligibility.

CONCLUSIONS

- The number of ADHD diagnoses among all Medicaid enrollees in the study nearly tripled during the decade of our inquiry. Increases in SSI benefits for ADHD during this decade are therefore expected in view of this growth rate in the Medicaid population of children who have received paid Medicaid services.
- Child Medicaid enrollment increased from 2001 to 2010. The growing numbers of all Medicaid enrollees during the study period likely reflect increases in childhood poverty as well as policies that encouraged the enrollment of eligible children in Medicaid.

FINDINGS

- The percentage of all Medicaid enrollees with a mental disorder diagnosis increased from 7.9 percent in 2001 to 11.1 percent in 2010, a growth rate similar to the increase observed for asthma diagnoses. The percentage of SSI Medicaid enrollees with a mental disorder diagnosis increased from 29.2 percent in 2001 to 38.6 percent in 2010.
- There are high rates of co-occurring mental disorder diagnoses among children enrolled in Medicaid. The frequency of co-occurring mental diagnoses among disabled children enrolled in Medicaid is higher than the frequency of co-occurring mental disorder diagnoses in all children enrolled in Medicaid.
- The rates of treatment with medication, psychotherapy, or combinations of the two varied depending on the specific mental disorder diagnosis.

- All Medicaid enrollees with ADHD experienced increased rates of treatment with medications, psychotherapy, or a combination of the two. This increase suggests improving adherence to guidelines by providers serving the Medicaid population.
- The number of SSI Medicaid enrollees with ADHD with no recorded paid claims for treatment declined by almost 50 percent during the period, consistent with the other indicators of increased frequency of treatment.
- Combination therapy for mental disorders was used with increasing frequency from 2001 to 2010, but was documented in only about a quarter of the total mental disorder diagnoses by 2010.

REFERENCES

Byrd, V. L. H., and A. H. Dodd. 2012. Accessing the usability of encounter data for enrollees in comprehensive managed care across MAX 2007–2009. Mathematica Policy Research Medicaid Policy Brief No. 15. www.cms.gov/Research-Statistics-Data-and-Systems/Computer-Data-and-Systems/MedicaidDataSourcesGenInfo/Downloads/MAX_IB_15_AssessingUsability.pdf (accessed July 18, 2015).

DosReis, S. C. 2001. Mental health services for youths in foster care and disabled youths. *American Journal of Public Health* 91(7):1094–1099.

DosReis, S., Y. Yoon, D. M. Rubin, M. A. Riddle, E. Noll, and A. Rothbard. 2011. Antipsychotic treatment among youth in foster care. *Pediatrics* 128(6):1459–1466.

Halfon, N., A. Houtrow, K. Larson, and P. W. Newacheck. 2012. The changing landscape of disability in childhood. *The Future of Children* 22(1):13–42.

Harman, J. S., G. E. Childs, and K. J. Kelleher. 2000. Mental health care utilization and expenditures by children in foster care. *Archives of Pediatric and Adolescent Medicine* 154(11):1114–1117.

HHS (U.S. Department of Health and Human Services). 2001. *Mental health: Culture, race, and ethnicity—A supplement to mental health: A report to the surgeon gen*eral. Rockville, MD: U.S. Department of Health and Human Services, Substance Abuse and Mental Health Services Administration, Center for Mental Health Services.

HHS. 2010. *Connecting kids to coverage: Continuing the progress*. 2010 CHIPRA annual report. http://www.insurekidsnow.gov/professionals/reports/chipra/2010_annual.pdf (accessed July 18, 2015).

IOM (Institute of Medicine). 2009. *Race, ethnicity, and language data: Standardization for health care quality improvement*. Washington, DC: The National Academies Press.

Nysenbaum, J., E. Bouchery, and R. Malsberger. 2012. The availability and usability of behavioral health organization encounter data in MAX 2009. Mathematica Policy Research Medicaid Policy Brief No. 14. www.mathematica-mpr.com/~/media/publications/PDFs/health/MAX_IB14.pdf (accessed July 18, 2015).

Perrin, J. M., K. Kuhlthau, S. L. Ettner, T. J. McLaughlin, and S. T. Gortmaker. 1998. Previous Medicaid status of children newly enrolled in Supplemental Security Income. *Health Care Financing Review* 19(4):117.

Perrin, J. M., K. Kuhlthau, T. J. McLaughlin, S. L. Ettner, and S. L. Gortmaker. 1999. Changing patterns of conditions among children receiving Supplemental Security Income disability benefits. *Archives of Pediatrics and Adolescent Medicine* 153(1):80–84.

Van Cleave, J., S. L. Gortmaker, and J. M. Perrin. 2010. Dynamics of obesity and chronic health conditions among children and youth. *JAMA* 303(7):623–630.

Zima, B. T., R. Bussing, L. Tang, L. Zhang, S. Ettner, T. R. Belin, and K. B. Wells. 2010. Quality of care for childhood attention-deficit/hyperactivity disorder in a managed care Medicaid program. *Journal of the American Academy of Child &Adolescent Psychiatry* 49(12):1225–1237.

Zito, J. M., D. J. Safer, I. H. Zuckerman, J. F. Gardner, and K. Soeken. 2005. Effect of Medicaid eligibility category on racial disparities in the use of psychotropic medications among youths. *Psychiatric Services* 56(2):157–163.

Zito, J. M., M. Burcu, A. Ibe, D. J. Safer, and L. S. Magder. 2013. Antipsychotic use by Medicaid-insured youths: Impact of eligibility and psychiatric diagnosis across a decade. *Psychiatric Services* 64(3):223–229.

Appendixes

Appendix A

Deeming Eligibility Chart for Children

TABLE A-1 2015 SSA Deeming Eligibility Chart for Children

Gross monthly income **BELOW** the dollar amounts shown means a disabled child may be eligible for SSI benefits.
Amounts given are general guidelines only.

Number of Ineligible Children in Household	All Income Is **Earned**		All Income Is **Unearned**	
	One Parent in Household	Two Parents in Household	One Parent in Household	Two Parents in Household
0	$3,057	$3,791	$1,506	$1,873
1	$3,424	$4,158	$1,873	$2,240
2	$3,791	$4,525	$2,240	$2,607
3	$4,158	$4,892	$2,607	$2,974
4	$4,425	$5,259	$2,974	$3,341
5	$4,892	$5,626	$3,341	$3,708
6	$5,259	$5,993	$3,708	$4,075

SOURCE: SSA, 2015.

REFERENCE

SSA (Social Security Administration). 2015. *Understanding Supplemental Security Income SSI for children—2015 edition*. www.socialsecurity.gov/ssi/text-child-ussi.htm (accessed July 19, 2015).

Appendix B

SSA Childhood Mental Disorders Listing of Impairments

112.00 MENTAL DISORDERS

A. *Introduction*: The structure of the mental disorders listings for children under age 18 parallels the structure for the mental disorders listings for adults but is modified to reflect the presentation of mental disorders in children. The listings for mental disorders in children are arranged in 11 diagnostic categories: organic mental disorders (112.02); schizophrenic, delusional (paranoid), schizoaffective, and other psychotic disorders (112.03); mood disorders (112.04); intellectual disability (112.05); anxiety disorders (112.06); somatoform, eating, and tic disorders (112.07); personality disorders (112.08); psychoactive substance dependence disorders (112.09); autistic disorder and other pervasive developmental disorders (112.10); attention deficit hyperactivity disorder (112.11); and developmental and emotional disorders of newborn and younger infants (112.12).

There are significant differences between the listings for adults and the listings for children. There are disorders found in children that have no real analogy in adults, hence the differences in the diagnostic categories for children. The presentation of mental disorders in children, particularly the very young child, may be subtle and of a character different from the signs and symptoms found in adults. For example, findings such as separation anxiety, failure to mold or bond with the parents, or withdrawal may serve as findings comparable to findings that mark mental disorders in adults. The activities appropriate to children, such as learning, growing, playing, maturing, and school adjustment, are also different from the activities appropriate to the adult and vary widely in the different childhood stages.

Each listing begins with an introductory statement that describes the disorder or disorders addressed by the listing. This is followed (except in listings 112.05 and 112.12) by paragraph A criteria (a set of medical findings) and paragraph B criteria (a set of impairment-related functional limitations). An individual will be found to have a listed impairment when the criteria of both paragraphs A and B of the listed impairment are satisfied.

The purpose of the criteria in paragraph A is to substantiate medically the presence of a particular mental disorder. Specific symptoms and signs under any of the listings 112.02 through 112.12 cannot be considered in isolation from the description of the mental disorder contained at the beginning of each listing category. Impairments should be analyzed or reviewed under the mental category(ies) indicated by the medical findings.

Paragraph A of the listings is a composite of medical findings which are used to substantiate the existence of a disorder and may or may not be appropriate for children at specific developmental stages. However, a range of medical findings is included in the listings so that no age group is excluded. For example, in listing 112.02A7, emotional lability and crying would be inappropriate criteria to apply to older infants and toddlers, age 1 to attainment of age 3; whereas in listing 112.02A1, developmental arrest, delay, or regression are appropriate criteria for older infants and toddlers. Whenever the adjudicator decides that the requirements of paragraph A of a particular mental listing are satisfied, then that listing should be applied regardless of the age of the child to be evaluated.

The purpose of the paragraph B criteria is to describe impairment-related functional limitations which are applicable to children. Standardized tests of social or cognitive function and adaptive behavior are frequently available and appropriate for the evaluation of children and, thus, such tests are included in the paragraph B functional parameters. The functional restrictions in paragraph B must be the result of the mental disorder which is manifested by the medical findings in paragraph A.

We did not include separate C criteria for listings 112.02, 112.03, 112.04, and 112.06, as are found in the adult listings, because for the most part we do not believe that the residual disease processes described by these listings are commonly found in children. However, in unusual cases where these disorders are found in children and are comparable to the severity and duration found in adults, we may use the adult listings 12.02C, 12.03C, 12.04C, and 12.06C criteria to evaluate such cases.

The structure of the listings for intellectual disability (112.05) and developmental and emotional disorders of newborn and younger infants (112.12) is different from that of the other mental disorders. Listing 112.05 (intellectual disability) contains six sets of criteria. If an impairment satisfies the diagnostic description in the introductory paragraph and any one of the six sets of criteria, we will find that the child's impairment meets the listing.

For listings 112.05D and 112.05F, we will assess the degree of functional limitation the additional impairment(s) imposes to determine if it causes more than minimal functional limitations, i.e., is a "severe" impairment(s), as defined in § 416.924(c).

If the additional impairment(s) does not cause limitations that are "severe" as defined in § 416.924(c), we will not find that the additional impairment(s) imposes an additional and significant limitation of function. Listing 112.12 (developmental and emotional disorders of newborn and younger infants) contains five criteria, any one of which, if satisfied, will result in a finding that the infant's impairment meets the listing.

It must be remembered that these listings are examples of common mental disorders that are severe enough to find a child disabled. When a child has a medically determinable impairment that is not listed, an impairment that does not meet the requirements of a listing, or a combination of impairments no one of which meets the requirements of a listing, we will make a determination whether the child's impairment(s) medically or functionally equals the listings. (See §§ 404.1526, 416.926, and 416.926a.) This determination can be especially important in older infants and toddlers (age 1 to attainment of age 3), who may be too young for identification of a specific diagnosis, yet demonstrate serious functional limitations. Therefore, the determination of equivalency is necessary to the evaluation of any child's case when the child does not have an impairment that meets a listing.

B. *Need for Medical Evidence*: The existence of a medically determinable impairment of the required duration must be established by medical evidence consisting of symptoms, signs, and laboratory findings (including psychological or developmental test findings). Symptoms are complaints presented by the child. Psychiatric signs are medically demonstrable phenomena that indicate specific psychological abnormalities, e.g., abnormalities of behavior, mood, thought, memory, orientation, development, or perception, as described by an appropriate medical source. Symptoms and signs generally cluster together to constitute recognizable mental disorders described in paragraph A of the listings. These findings may be intermittent or continuous depending on the nature of the disorder.

C. *Assessment of Severity*: In childhood cases, as with adults, severity is measured according to the functional limitations imposed by the medically determinable mental impairment. However, the range of functions used to assess impairment severity for children varies at different stages of maturation. The functional areas that we consider are motor function; cognitive/communicative function; social function; personal function; and concentration, persistence, or pace. In most functional areas, there are two alternative methods of documenting the required level of severity: (1) use of standardized tests alone, where appropriate test instruments are available, and (2) use of other medical findings. (See 112.00D for explanation of these documentation requirements.) The use of standardized tests is the preferred method of documentation if such tests are available.

Newborn and younger infants (birth to attainment of age 1) have not developed sufficient personality differentiation to permit formulation of appropriate diagnoses. We have, therefore, assigned listing 112.12 for developmental and emotional disorders of newborn and younger infants for the evaluation of mental disorders of such children. Severity of these disorders is based on measures of development in motor, cognitive/communicative, and social functions. When older infants and toddlers (age 1 to attainment of age 3) do not clearly satisfy the paragraph A criteria of any listing because of insufficient developmental differentiation, they must be evaluated under the rules for equivalency. The principles for assessing the severity of impairment in such children, described in the following paragraphs, must be employed.

Generally, when we assess the degree of developmental delay imposed by a mental impairment, we will use an infant's or toddler's chronological age; i.e., the child's age based on birth date. If the infant or toddler was born prematurely, however, we will follow the rules in § 416.924b(b) to determine whether we should use the infant's or toddler's corrected chronological age; i.e., the chronological age adjusted by the period of gestational prematurity.

In defining the severity of functional limitations, two different sets of paragraph B criteria corresponding to two separate age groupings have been established, in addition to listing 112.12, which is for children who have not attained age 1. These age groups are older infants and toddlers (age 1 to attainment of age 3) and children (age 3 to attainment of age 18). However, the discussion below in 112.00C1, 2, 3, and 4, on the age-appropriate areas of function, is broken down into four age groupings: older infants and toddlers (age 1 to attainment of age 3), preschool children (age 3 to attainment of age 6), primary school children (age 6 to attainment of age 12), and adolescents (age 12 to attainment of age 18). This was done to provide specific guidance on the age group variances in disease manifestations and methods of evaluation.

Where "marked" is used as a standard for measuring the degree of limitation it means more than moderate but less than extreme. A marked limitation may arise when several activities or functions are impaired, or even when only one is impaired, as long as the degree of limitation is such as to interfere seriously with the ability to function (based upon age-appropriate expectations) independently, appropriately, effectively, and on a sustained basis. When standardized tests are used as the measure of functional parameters, a valid score that is two standard deviations below the norm for the test will be considered a marked restriction.

1. *Older infants and toddlers (age 1 to attainment of age 3)*. In this age group, impairment severity is assessed in three areas: (a) motor development, (b) cognitive/communicative function, and (c) social function.
a. *Motor development*. Much of what we can discern about mental function in these children frequently comes from observation of the degree of development of fine and gross motor function. Developmental delay, as measured by a good developmental milestone history confirmed by medical examination, is critical. This information will ordinarily be available in the existing medical evidence from the claimant's treating sources and other medical sources, supplemented by information from nonmedical sources, such as parents, who have observed the child and can provide pertinent historical information. It may also be available from standardized testing. If the delay is such that the older infant or toddler has not achieved motor development generally acquired by children no more than one-half the child's chronological age, the criteria are satisfied.
b. *Cognitive/communicative function*. Cognitive/communicative function is measured using one of several standardized infant scales. Appropriate tests for the measure of such function are discussed in 112.00D. Screening instruments may be useful in uncovering potentially serious impairments, but often must be supplemented by other data. However, in some cases, the results of screening tests may show such obvious abnormalities that further testing will clearly be unnecessary.

For older infants and toddlers, alternative criteria covering disruption in communication as measured by their capacity to use simple verbal and nonverbal structures to communicate basic needs are provided.
c. *Social function*. Social function in older infants and toddlers is measured in terms of the development of relatedness to people (e.g., bonding and stranger anxiety) and attachment to animate or inanimate objects. Criteria are provided that use standard social maturity scales or alternative criteria that describe marked impairment in socialization.

2. *Preschool children (age 3 to attainment of age 6)*. For the age groups including preschool children through adolescence, the functional areas used to measure severity are (a) cognitive/communicative function, (b) social function, (c) personal function, and (d) deficiencies of concentration, persistence, or pace resulting in frequent failure to complete tasks in a timely manner. After 36 months, motor function is no longer felt to be a primary determinant of mental function, although, of course, any motor abnormalities should be documented and evaluated.

a. *Cognitive/communicative function*. In the preschool years and beyond, cognitive function can be measured by standardized tests of intelligence, although the appropriate instrument may vary with age. A primary criterion for limited cognitive function is a valid verbal, performance, or full-scale IQ of 70 or less. The listings also provide alternative criteria, consisting of tests of language development or bizarre speech patterns.

b. *Social function*. Social functioning refers to a child's capacity to form and maintain relationships with parents, other adults, and peers. Social functioning includes the ability to get along with others (e.g., family members, neighborhood friends, classmates, teachers). Impaired social functioning may be caused by inappropriate externalized actions (e.g., running away, physical aggression—but not self-injurious actions, which are evaluated in the personal area of functioning), or inappropriate internalized actions (e.g., social isolation, avoidance of interpersonal activities, mutism). Its severity must be documented in terms of intensity, frequency, and duration, and shown to be beyond what might be reasonably expected for age.

Strength in social functioning may be documented by such things as the child's ability to respond to and initiate social interaction with others, to sustain relationships, and to participate in group activities. Cooperative behaviors, consideration for others, awareness of others' feelings, and social maturity, appropriate to a child's age, also need to be considered. Social functioning in play and school may involve interactions with adults, including responding appropriately to persons in authority (e.g., teachers, coaches) or cooperative behaviors involving other children. Social functioning is observed not only at home but also in preschool programs.

c. *Personal function*. Personal functioning in preschool children pertains to self-care; i.e., personal needs, health, and safety (feeding, dressing, toileting, bathing; maintaining personal hygiene, proper nutrition, sleep, health habits; adhering to medication or therapy regimens; following safety precautions). Development of self-care skills is measured in terms of the child's increasing ability to help himself/herself and to cooperate with others in taking care of these needs. Impaired ability in this area is manifested by failure to develop such skills, failure to use them, or self-injurious actions. This function may be documented by a standardized test of adaptive behavior or by a careful description of the full range of self-care activities. These activities are often observed not only at home but also in preschool programs.

d. *Concentration, persistence, or pace*. This function may be measured through observations of the child in the course of standardized testing and in the course of play.

3. *Primary school children (age 6 to attainment of age 12)*. The measures of function here are similar to those for preschool-aged children except that the test instruments may change and the capacity to function in the

school setting is supplemental information. Standardized measures of academic achievement, e.g., Wide Range Achievement Test-Revised, Peabody Individual Achievement Test, etc., may be helpful in assessing cognitive impairment. Problems in social functioning, especially in the area of peer relationships, are often observed firsthand by teachers and school nurses. As described in 112.00D, *Documentation*, school records are an excellent source of information concerning function and standardized testing and should always be sought for school-aged children.

As it applies to primary school children, the intent of the functional criterion described in paragraph B2d, i.e., deficiencies of concentration, persistence, or pace resulting in failure to complete tasks in a timely manner, is to identify the child who cannot adequately function in primary school because of a mental impairment. Although grades and the need for special education placement are relevant factors which must be considered in reaching a decision under paragraph B2d, they are not conclusive. There is too much variability from school district to school district in the expected level of grading and in the criteria for special education placement to justify reliance solely on these factors.

4. *Adolescents (age 12 to attainment of age 18)*. Functional criteria parallel to those for primary school children (cognitive/communicative; social; personal; and concentration, persistence, or pace) are the measures of severity for this age group. Testing instruments appropriate to adolescents should be used where indicated. Comparable findings of disruption of social function must consider the capacity to form appropriate, stable, and lasting relationships. If information is available about cooperative working relationships in school or at part-time or full-time work, or about the ability to work as a member of a group, it should be considered when assessing the child's social functioning. Markedly impoverished social contact, isolation, withdrawal, and inappropriate or bizarre behavior under the stress of socializing with others also constitute comparable findings. (Note that self-injurious actions are evaluated in the personal area of functioning.)

a. Personal functioning in adolescents pertains to self-care. It is measured in the same terms as for younger children, the focus, however, being on the adolescent's ability to take care of his or her own personal needs, health, and safety without assistance. Impaired ability in this area is manifested by failure to take care of these needs or by self-injurious actions. This function may be documented by a standardized test of adaptive behavior or by careful descriptions of the full range of self-care activities.

b. In adolescents, the intent of the functional criterion described in paragraph B2d is the same as in primary school children. However, other evidence of this functional impairment may also be available, such as from evidence of the child's performance in work or work-like settings.

D. *Documentation*:

1. The presence of a mental disorder in a child must be documented on the basis of reports from acceptable sources of medical evidence. See §§ 404.1513 and 416.913. Descriptions of functional limitations may be available from these sources, either in the form of standardized test results or in other medical findings supplied by the sources, or both. (Medical findings consist of symptoms, signs, and laboratory findings.)

Whenever possible, a medical source's findings should reflect the medical source's consideration of information from parents or other concerned individuals who are aware of the child's activities of daily living, social functioning, and ability to adapt to different settings and expectations, as well as the medical source's findings and observations on examination, consistent with standard clinical practice. As necessary, information from nonmedical sources, such as parents, should also be used to supplement the record of the child's functioning to establish the consistency of the medical evidence and longitudinality of impairment severity.

2. For some newborn and younger infants, it may be very difficult to document the presence or severity of a mental disorder. Therefore, with the exception of some genetic diseases and catastrophic congenital anomalies, it may be necessary to defer making a disability decision until the child attains 3 months of age in order to obtain adequate observation of behavior or affect. See, also, 110.00 of this part. This period could be extended in cases of premature infants depending on the degree of prematurity and the adequacy of documentation of their developmental and emotional status.

3. For infants and toddlers, programs of early intervention involving occupational, physical, and speech therapists, nurses, social workers, and special educators are a rich source of data. They can provide the developmental milestone evaluations and records on the fine and gross motor functioning of these children. This information is valuable and can complement the medical examination by a physician or psychologist. A report of an interdisciplinary team that contains the evaluation and signature of an acceptable medical source is considered acceptable medical evidence rather than supplemental data.

4. In children with mental disorders, particularly those requiring special placement, school records are a rich source of data, and the required reevaluations at specified time periods can provide the longitudinal data needed to trace impairment progression over time.

5. In some cases where the treating sources lack expertise in dealing with mental disorders of children, it may be necessary to obtain evidence from

a psychiatrist, psychologist, or pediatrician with experience and skill in the diagnosis and treatment of mental disorders as they appear in children. In these cases, however, every reasonable effort must be made to obtain the records of the treating sources, since these records will help establish a longitudinal picture that cannot be established through a single purchased examination.

6. Reference to a "standardized psychological test" indicates the use of a psychological test measure that has appropriate validity, reliability, and norms, and is individually administered by a qualified specialist. By "qualified," we mean the specialist must be currently licensed or certified in the state to administer, score, and interpret psychological tests and have the training and experience to perform the test.

7. Psychological tests are best considered as standardized sets of tasks or questions designed to elicit a range of responses. Psychological testing can also provide other useful data, such as the specialist's observations regarding the child's ability to sustain attention and concentration, relate appropriately to the specialist, and perform tasks independently (without prompts or reminders). Therefore, a report of test results should include both the objective data and any clinical observations.

8. The salient characteristics of a good test are (1) validity, i.e., the test measures what it is supposed to measure; (2) reliability, i.e., consistent results are obtained over time with the same test and the same individual; (3) appropriate normative data, i.e., individual test scores can be compared to test data from other individuals or groups of a similar nature, representative of that population; and (4) wide scope of measurement, i.e., the test should measure a broad range of facets/aspects of the domain being assessed. In considering the validity of a test result, we should note and resolve any discrepancies between formal test results and the child's customary behavior and daily activities.

9. Identical IQ scores obtained from different tests do not always reflect a similar degree of intellectual functioning. The IQ scores in listing 112.05 reflect values from tests of general intelligence that have a mean of 100 and a standard deviation of 15, e.g., the Wechsler series. IQs obtained from standardized tests that deviate from a mean of 100 and standard deviation of 15 require conversion to a percentile rank so that the actual degree of limitation reflected by the IQ scores can be determined. In cases where more than one IQ is customarily derived from the test administered, e.g., where verbal, performance, and full-scale IQs are provided in the Wechsler series, the lowest of these is used in conjunction with listing 112.05.

10. IQ test results must also be sufficiently current for accurate assessment under 112.05. Generally, the results of IQ tests tend to stabilize by the age of 16. Therefore, IQ test results obtained at age 16 or older should be viewed as a valid indication of the child's current status, provided they are compatible with the child's current behavior. IQ test results obtained between ages 7 and 16 should be considered current for 4 years when the tested IQ is less than 40, and for 2 years when the IQ is 40 or above. IQ test results obtained before age 7 are current for 2 years if the tested IQ is less than 40 and 1 year if at 40 or above.

11. Standardized intelligence test results are essential to the adjudication of all cases of intellectual disability that are not covered under the provisions of listings 112.05A, 112.05B, and 112.05F. Listings 112.05A, 112.05B, and 112.05F may be the bases for adjudicating cases where the results of standardized intelligence tests are unavailable, e.g., where the child's young age or condition precludes formal standardized testing.

12. In conjunction with clinical examinations, sources may report the results of screening tests, i.e., tests used for gross determination of level of functioning. Screening instruments may be useful in uncovering potentially serious impairments, but often must be supplemented by other data. However, in some cases the results of screening tests may show such obvious abnormalities that further testing will clearly be unnecessary.

13. Where reference is made to developmental milestones, this is defined as the attainment of particular mental or motor skills at an age-appropriate level, i.e., the skills achieved by an infant or toddler sequentially and within a given time period in the motor and manipulative areas, in general understanding and social behavior, in self-feeding, dressing, and toilet training, and in language. This is sometimes expressed as a developmental quotient, the relation between developmental age and chronological age as determined by specific standardized measurements and observations. Such tests include, but are not limited to, the Cattell Infant Intelligence Scale, the Bayley Scales of Infant Development, and the Revised Stanford-Binet. Formal tests of the attainment of developmental milestones are generally used in the clinical setting for determination of the developmental status of infants and toddlers.

14. Formal psychological tests of cognitive functioning are generally in use for preschool children, for primary school children, and for adolescents except for those instances noted below.

15. Generally, it is preferable to use IQ measures that are wide in scope and include items that test both verbal and performance abilities. However, in special circumstances, such as the assessment of children with sensory, motor, or communication abnormalities, or those whose culture and background are not principally English speaking, measures such as the Test of Nonverbal Intelligence, Third Edition, Leiter International Performance Scale-Revised, or Peabody Picture Vocabulary Test-Third Edition may be used.

16. We may consider exceptions to formal standardized psychological testing when an individual qualified by training and experience to perform such an evaluation is not available, or in cases where appropriate standardized measures for the child's social, linguistic, and cultural background are not available. In these cases, the best indicator of severity is often the level of adaptive functioning and how the child performs activities of daily living and social functioning.

17. Comprehensive neuropsychological examinations may be used to establish the existence and extent of compromise of brain function, particularly in cases involving organic mental disorders. Normally these examinations include assessment of cerebral dominance, basic sensation and perception, motor speed and coordination, attention and concentration, visual-motor function, memory across verbal and visual modalities, receptive and expressive speech, higher-order linguistic operations, problem solving, abstraction ability, and general intelligence.

In addition, there should be clinical interview geared toward evaluating pathological features known to occur frequently in neurological disease and trauma, e.g., emotional lability, abnormality of mood, impaired impulse control, passivity and apathy, or inappropriate social behavior. The specialist performing the examination may administer one of the commercially available comprehensive neuropsychological batteries, such as the Luria-Nebraska or Halstead-Reitan, or a battery of tests selected as relevant to the suspected brain dysfunction. The specialist performing the examination must be properly trained in this area of neuroscience.

E. *Effect of Hospitalization or Residential Placement*: As with adults, children with mental disorders may be placed in a variety of structured settings outside the home as part of their treatment. Such settings include, but are not limited to, psychiatric hospitals, developmental disabilities facilities, residential treatment centers and schools, community-based group homes, and workshop facilities. The reduced mental demands of such structured settings may attenuate overt symptomatology and superficially make the child's level of adaptive functioning appear better than it is. Therefore, the capacity of the child to function outside highly structured settings must be considered in evaluating impairment severity. This is done by determining the degree to which the child can function (based upon age-appropriate expectations) independently, appropriately, effectively, and on a sustained basis outside the highly structured setting.

On the other hand, there may be a variety of causes for placement of a child in a structured setting which may or may not be directly related to impairment severity and functional ability. Placement in a structured setting in and of itself does not equate with a finding of disability. The severity of the impairment must be compared with the requirements of the appropriate listing.

F. *Effects of Medication*: Attention must be given to the effect of medication on the child's signs, symptoms, and ability to function. While drugs used to modify psychological functions and mental states may control certain primary manifestations of a mental disorder, e.g., hallucinations, impaired attention, restlessness, or hyperactivity, such treatment may not affect all functional limitations imposed by the mental disorder. In cases where overt symptomatology is attenuated by the use of such drugs, particular attention must be focused on the functional limitations that may persist. These functional limitations must be considered in assessing impairment severity.

Psychotropic medicines used in the treatment of some mental illnesses may cause drowsiness, blunted affect, or other side effects involving other body systems. Such side effects must be considered in evaluating overall impairment severity.

112.01 Category of Impairments, Mental

112.02 ***Organic Mental Disorders*****:** Abnormalities in perception, cognition, affect, or behavior associated with dysfunction of the brain. The history and physical examination or laboratory tests, including psychological or neuropsychological tests, demonstrate or support the presence of an organic factor judged to be etiologically related to the abnormal mental state and associated deficit or loss of specific cognitive abilities, or affective changes, or loss of previously acquired functional abilities.

The required level of severity for these disorders is met when the requirements in both A and B are satisfied.

A. Medically documented persistence of at least one of the following:
1. Developmental arrest, delay or regression; or
2. Disorientation to time and place; or
3. Memory impairment, either short term (inability to learn new information), intermediate, or long term (inability to remember information that was known sometime in the past); or

4. Perceptual or thinking disturbance (e.g., hallucinations, delusions, illusions, or paranoid thinking); or
5. Disturbance in personality (e.g., apathy, hostility); or
6. Disturbance in mood (e.g., mania, depression); or
7. Emotional lability (e.g., sudden crying); or
8. Impairment of impulse control (e.g., disinhibited social behavior, explosive temper outbursts); or
9. Impairment of cognitive function, as measured by clinically timely standardized psychological testing; or
10. Disturbance of concentration, attention, or judgment;

and

B. Select the appropriate age group to evaluate the severity of the impairment:
1. For older infants and toddlers (age 1 to attainment of age 3), resulting in at least one of the following:
a. Gross or fine motor development at a level generally acquired by children no more than one-half the child's chronological age, documented by
(1) An appropriate standardized test; or
(2) Other medical findings (see 112.00C); or
b. Cognitive/communicative function at a level generally acquired by children no more than one-half the child's chronological age, documented by
(1) An appropriate standardized test; or
(2) Other medical findings of equivalent cognitive/communicative abnormality, such as the inability to use simple verbal or nonverbal behavior to communicate basic needs or concepts; or
c. Social function at a level generally acquired by children no more than one-half the child's chronological age, documented by
(1) An appropriate standardized test; or
(2) Other medical findings of an equivalent abnormality of social functioning, exemplified by serious inability to achieve age-appropriate autonomy as manifested by excessive clinging or extreme separation anxiety; or
d. Attainment of development or function generally acquired by children no more than two-thirds of the child's chronological age in two or more areas covered by a, b, or c, as measured by an appropriate standardized test or other appropriate medical findings.
2. For children (age 3 to attainment of age 18), resulting in at least two of the following:
a. Marked impairment in age-appropriate cognitive/communicative function, documented by medical findings (including consideration of historical and other information from parents or other individuals who have knowledge of the child, when such information is needed and available) and including, if necessary, the results of appropriate standardized psychological

tests, or for children under age 6, by appropriate tests of language and communication; or
b. Marked impairment in age-appropriate social functioning, documented by history and medical findings (including consideration of information from parents or other individuals who have knowledge of the child, when such information is needed and available) and including, if necessary, the results of appropriate standardized tests; or
c. Marked impairment in age-appropriate personal functioning, documented by history and medical findings (including consideration of information from parents or other individuals who have knowledge of the child, when such information is needed and available) and including, if necessary, appropriate standardized tests; or
d. Marked difficulties in maintaining concentration, persistence, or pace.

112.03 ***Schizophrenic, Delusional (Paranoid), Schizoaffective, and Other Psychotic Disorders*****:** Onset of psychotic features, characterized by a marked disturbance of thinking, feeling, and behavior, with deterioration from a previous level of functioning or failure to achieve the expected level of social functioning. The required level of severity for these disorders is met when the requirements in both A and B are satisfied.

A. Medically documented persistence, for at least 6 months, either continuous or intermittent, of one or more of the following:
1. Delusions or hallucinations; or
2. Catatonic, bizarre, or other grossly disorganized behavior; or
3. Incoherence, loosening of associations, illogical thinking, or poverty of content of speech; or
4. Flat, blunt, or inappropriate affect; or
5. Emotional withdrawal, apathy, or isolation;

and

B. For older infants and toddlers (age 1 to attainment of age 3), resulting in at least one of the appropriate age-group criteria in paragraph B1 of 112.02; or, for children (age 3 to attainment of age 18), resulting in at least two of the appropriate age-group criteria in paragraph B2 of 112.02.

112.04 ***Mood Disorders*****:** Characterized by a disturbance of mood (referring to a prolonged emotion that colors the whole psychic life, generally involving either depression or elation), accompanied by a full or partial manic or depressive syndrome.

The required level of severity for these disorders is met when the requirements in both A and B are satisfied.

A. Medically documented persistence, either continuous or intermittent, of one of the following:
1. Major depressive syndrome, characterized by at least five of the following, which must include either depressed or irritable mood or markedly diminished interest or pleasure:
a. Depressed or irritable mood; or
b. Markedly diminished interest or pleasure in almost all activities; or
c. Appetite or weight increase or decrease, or failure to make expected weight gains; or
d. Sleep disturbance; or
e. Psychomotor agitation or retardation; or
f. Fatigue or loss of energy; or
g. Feelings of worthlessness or guilt; or
h. Difficulty thinking or concentrating; or
i. Suicidal thoughts or acts; or
j. Hallucinations, delusions, or paranoid thinking;

or

2. Manic syndrome, characterized by elevated, expansive, or irritable mood, and at least three of the following:
a. Increased activity or psychomotor agitation; or
b. Increased talkativeness or pressure of speech; or
c. Flight of ideas or subjectively experienced racing thoughts; or
d. Inflated self-esteem or grandiosity; or
e. Decreased need for sleep; or
f. Easy distractibility; or
g. Involvement in activities that have a high potential of painful consequences which are not recognized; or
h. Hallucinations, delusions, or paranoid thinking;

or

3. Bipolar or cyclothymic syndrome with a history of episodic periods manifested by the full symptomatic picture of both manic and depressive syndromes (and currently or most recently characterized by the full or partial symptomatic picture of either or both syndromes);

and

B. For older infants and toddlers (age 1 to attainment of age 3), resulting in at least one of the appropriate age-group criteria in paragraph B1 of

112.02; or, for children (age 3 to attainment of age 18), resulting in at least two of the appropriate age-group criteria in paragraph B2 of 112.02.

112.05 ***Intellectual Disability*****:** Characterized by significantly subaverage general intellectual functioning with deficits in adaptive functioning.

The required level of severity for this disorder is met when the requirements in A, B, C, D, E, or F are satisfied.

A. For older infants and toddlers (age 1 to attainment of age 3), resulting in at least one of the appropriate age-group criteria in paragraph B1 of 112.02; or, for children (age 3 to attainment of age 18), resulting in at least two of the appropriate age-group criteria in paragraph B2 of 112.02;

or

B. Mental incapacity evidenced by dependence upon others for personal needs (grossly in excess of age-appropriate dependence) and inability to follow directions such that the use of standardized measures of intellectual functioning is precluded;

or

C. A valid verbal, performance, or full-scale IQ of 59 or less;

or

D. A valid verbal, performance, or full-scale IQ of 60 through 70 and a physical or other mental impairment imposing an additional and significant limitation of function;

or

E. A valid verbal, performance, or full-scale IQ of 60 through 70 and
1. For older infants and toddlers (age 1 to attainment of age 3), resulting in attainment of development or function generally acquired by children no more than two-thirds of the child's chronological age in either of paragraphs B1a or B1c of 112.02; or
2. For children (age 3 to attainment of age 18), resulting in at least one of paragraphs B2b or B2c or B2d of 112.02;

or

F. Select the appropriate age group:
1. For older infants and toddlers (age 1 to attainment of age 3), resulting in attainment of development or function generally acquired by children no more than two-thirds of the child's chronological age in paragraph B1b of 112.02, and a physical or other mental impairment imposing an additional and significant limitation of function;

or

2. For children (age 3 to attainment of age 18), resulting in the satisfaction of 112.02B2a, and a physical or other mental impairment imposing an additional and significant limitation of function.

112.06 ***Anxiety Disorders*****:** In these disorders, anxiety is either the predominant disturbance or is experienced if the individual attempts to master symptoms; e.g., confronting the dreaded object or situation in a phobic disorder, attempting to go to school in a separation anxiety disorder, resisting the obsessions or compulsions in an obsessive compulsive disorder, or confronting strangers or peers in avoidant disorders.

The required level of severity for these disorders is met when the requirements in both A and B are satisfied.

A. Medically documented findings of at least one of the following:
1. Excessive anxiety manifested when the child is separated, or separation is threatened, from a parent or parent surrogate; or
2. Excessive and persistent avoidance of strangers; or
3. Persistent unrealistic or excessive anxiety and worry (apprehensive expectation), accompanied by motor tension, autonomic hyperactivity, or vigilance and scanning; or
4. A persistent irrational fear of a specific object, activity, or situation which results in a compelling desire to avoid the dreaded object, activity, or situation; or
5. Recurrent severe panic attacks, manifested by a sudden unpredictable onset of intense apprehension, fear, or terror, often with a sense of impending doom, occurring on the average of at least once a week; or
6. Recurrent obsessions or compulsions which are a source of marked distress; or
7. Recurrent and intrusive recollections of a traumatic experience, including dreams, which are a source of marked distress;

and

B. For older infants and toddlers (age 1 to attainment of age 3), resulting in at least one of the appropriate age-group criteria in paragraph B1 of 112.02; or, for children (age 3 to attainment of age 18), resulting in at least two of the appropriate age-group criteria in paragraph B2 of 112.02.

112.07 ***Somatoform, Eating, and Tic Disorders*****:** Manifested by physical symptoms for which there are no demonstrable organic findings or known physiologic mechanisms; or eating or tic disorders with physical manifestations.

The required level of severity for these disorders is met when the requirements in both A and B are satisfied.

A. Medically documented findings of one of the following:
1. An unrealistic fear and perception of fatness despite being underweight, and persistent refusal to maintain a body weight which is greater than 85 percent of the average weight for height and age, as shown in the most recent edition of the *Nelson Textbook of Pediatrics*, Richard E. Behrman and Victor C. Vaughan, III, editors, Philadelphia: W.B. Saunders Company; or
2. Persistent and recurrent involuntary, repetitive, rapid, purposeless motor movements affecting multiple muscle groups with multiple vocal tics; or
3. Persistent nonorganic disturbance of one of the following:
a. Vision; or
b. Speech; or
c. Hearing; or
d. Use of a limb; or
e. Movement and its control (e.g., coordination disturbance, psychogenic seizures); or
f. Sensation (diminished or heightened); or
g. Digestion or elimination; or
4. Preoccupation with a belief that one has a serious disease or injury;

and

B. For older infants and toddlers (age 1 to attainment of age 3), resulting in at least one of the appropriate age-group criteria in paragraph B1 of 112.02; or, for children (age 3 to attainment of age 18), resulting in at least two of the appropriate age-group criteria in paragraph B2 of 112.02.

112.08 ***Personality Disorders*****:** Manifested by pervasive, inflexible, and maladaptive personality traits, which are typical of the child's long-term functioning and not limited to discrete episodes of illness.

The required level of severity for these disorders is met when the requirements in both A and B are satisfied.

A. Deeply ingrained, maladaptive patterns of behavior, associated with one of the following:
1. Seclusiveness or autistic thinking; or
2. Pathologically inappropriate suspiciousness or hostility; or
3. Oddities of thought, perception, speech, and behavior; or
4. Persistent disturbances of mood or affect; or
5. Pathological dependence, passivity, or aggressiveness; or
6. Intense and unstable interpersonal relationships and impulsive and exploitative behavior; or
7. Pathological perfectionism and inflexibility;

and

B. For older infants and toddlers (age 1 to attainment of age 3), resulting in at least one of the appropriate age-group criteria in paragraph B1 of 112.02; or, for children (age 3 to attainment of age 18), resulting in at least two of the appropriate age-group criteria in paragraph B2 of 112.02.

112.09 ***Psychoactive Substance Dependence Disorders*****:** Manifested by a cluster of cognitive, behavioral, and physiologic symptoms that indicate impaired control of psychoactive substance use with continued use of the substance despite adverse consequences.

The required level of severity for these disorders is met when the requirements in both A and B are satisfied.

A. Medically documented findings of at least four of the following:
1. Substance taken in larger amounts or over a longer period than intended and a great deal of time is spent in recovering from its effects; or
2. Two or more unsuccessful efforts to cut down or control use; or
3. Frequent intoxication or withdrawal symptoms interfering with major role obligations; or
4. Continued use despite persistent or recurring social, psychological, or physical problems; or
5. Tolerance, as characterized by the requirement for markedly increased amounts of substance in order to achieve intoxication; or
6. Substance taken to relieve or avoid withdrawal symptoms;

and

B. For older infants and toddlers (age 1 to attainment of age 3), resulting in at least one of the appropriate age-group criteria in paragraph B1 of 112.02; or, for children (age 3 to attainment of age 18), resulting in at least two of the appropriate age-group criteria in paragraph B2 of 112.02.

112.10 ***Autistic Disorder and Other Pervasive Developmental Disorders*:** Characterized by qualitative deficits in the development of reciprocal social interaction, in the development of verbal and nonverbal communication skills, and in imaginative activity. Often, there is a markedly restricted repertoire of activities and interests, which frequently are stereotyped and repetitive.

The required level of severity for these disorders is met when the requirements in both A and B are satisfied.

A. Medically documented findings of the following:
1. For autistic disorder, all of the following:
a. Qualitative deficits in the development of reciprocal social interaction; and
b. Qualitative deficits in verbal and nonverbal communication and in imaginative activity; and
c. Markedly restricted repertoire of activities and interests;
or
2. For other pervasive developmental disorders, both of the following:
a. Qualitative deficits in the development of reciprocal social interaction; and
b. Qualitative deficits in verbal and nonverbal communication and in imaginative activity;

and

B. For older infants and toddlers (age 1 to attainment of age 3), resulting in at least one of the appropriate age-group criteria in paragraph B1 of 112.02; or, for children (age 3 to attainment of age 18), resulting in at least two of the appropriate age-group criteria in paragraph B2 of 112.02.

112.11 ***Attention Deficit Hyperactivity Disorder*:** Manifested by developmentally inappropriate degrees of inattention, impulsiveness, and hyperactivity.

The required level of severity for these disorders is met when the requirements in both A and B are satisfied.

A. Medically documented findings of all three of the following:
1. Marked inattention; and
2. Marked impulsiveness; and
3. Marked hyperactivity;

and

B. For older infants and toddlers (age 1 to attainment of age 3), resulting in at least one of the appropriate age-group criteria in paragraph B1 of 112.02; or, for children (age 3 to attainment of age 18), resulting in at least two of the appropriate age-group criteria in paragraph B2 of 112.02.

112.12 ***Developmental and Emotional Disorders of Newborn and Younger Infants (birth to attainment of age 1)*****:** Developmental or emotional disorders of infancy are evidenced by a deficit or lag in the areas of motor, cognitive/communicative, or social functioning. These disorders may be related either to organic or to functional factors or to a combination of these factors. The required level of severity for these disorders is met when the requirements of A, B, C, D, or E are satisfied.

A. Cognitive/communicative functioning generally acquired by children no more than one-half the child's chronological age, as documented by appropriate medical findings (e.g., in infants 0–6 months, markedly diminished variation in the production or imitation of sounds and severe feeding abnormality, such as problems with sucking, swallowing, or chewing) including, if necessary, a standardized test;

or

B. Motor development generally acquired by children no more than one-half the child's chronological age, documented by appropriate medical findings, including if necessary, a standardized test;

or

C. Apathy, over-excitability, or fearfulness, demonstrated by an absent or grossly excessive response to one of the following:
1. Visual stimulation; or
2. Auditory stimulation; or
3. Tactile stimulation;

or

D. Failure to sustain social interaction on an ongoing, reciprocal basis as evidenced by
1. Inability by 6 months to participate in vocal, visual, and motoric exchanges (including facial expressions); or
2. Failure by 9 months to communicate basic emotional responses, such as cuddling or exhibiting protest or anger; or

3. Failure to attend to the caregiver's voice or face or to explore an inanimate object for a period of time appropriate to the infant's age;

or

E. Attainment of development or function generally acquired by children no more than two-thirds of the child's chronological age in two or more areas (i.e., cognitive/communicative, motor, and social), documented by appropriate medical findings, including if necessary, standardized testing.

REFERENCE

SSA (Social Security Administration). 2015. Disability evaluation under Social Security: 112.00 Mental disorders-childhood. www.ssa.gov/disability/professionals/bluebook/112.00-MentalDisorders-Childhood.htm#112_11 (accessed January 12, 2015).

Appendix C

5

The Listing of Impairments—Overview[1]

The Listings serve as a screening tool at the initial decision stage to expedite the identification of individuals whose impairments clearly more than equal the level of severity that defines disability in the Social Security Act. Quick identification of obvious cases deserving benefits permits the Social Security Administration (SSA) to avoid a time-consuming and resource-intensive inquiry into all of the case facts. Using the Listings as an administrative expedient, SSA is able to process more cases more quickly and cost effectively than it would otherwise. As SSA explained in a February 10, 1994, final regulation, *Revised Medical Criteria for Determination of Disability, Cardiovascular System* (59 FR 6468):

> The listings are intended to be a screening device by which we can identify and allow claims filed by the most obviously disabled individuals; they are not an all-inclusive list of disabilities under which all individuals must be found disabled.

In addition to efficiency, the Listings are intended to ensure that there is a medical basis for the disability and that all applicants receive equal treatment. As noted by SSA in a more recent regulatory notice from November 2001, *Revised Medical Criteria for Determination of Disability, Musculoskeletal System and Related Criteria* (66 FR 58010):

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[1] This appendix originally appeared as Chapter 5 in the 2007 Institute of Medicine report *Improving the Social Security Disability Decision Process.*

> The Listings contain examples of some of the most frequently encountered impairments in the disability program. The criteria include specific symptoms, signs, and laboratory findings that are considered to characterize impairments severe enough to prevent a person from doing any gainful activity. . . . The Listings help to ensure that determinations and decisions regarding disability have a sound medical basis, that claimants receive equal treatment through the use of specific criteria, and that people who are disabled can be readily identified and awarded benefits if all other factors of entitlement or eligibility are met.

In addition to providing equal treatment for all applicants, the Listings were intended to ensure adjudicative consistency:

> In the fall of 1959, only 3 years after the program was enacted, the Ways and Means Subcommittee on the Administration of the Social Security Program (the Harrison Subcommittee) held a series of hearings that focused in part on variation in decision making among the States. During these hearings, the Social Security Administration's Deputy Commissioner, George Wyman, told the Subcommittee that the objective of achieving reasonable consistency represented "a real challenge." However, as explained by former Commissioner of Social Security Robert Ball, who at that time was Deputy Director of the Bureau of Old-Age and Survivors Insurance, the agency had developed a set of medical guidelines for use in adjudication. These guides were developed for the express purpose of achieving "as high degree of equity in the application of this law across the country as possible" (SSAB, 2006:2).

The Listings are organized by 14 major body systems (e.g., musculoskeletal impairments, respiratory impairments, neurological impairments). There are separate listings for adults (part A of the Listings) and children (part B of the Listings), although the adult criteria can be applied to children if the disease processes have a similar effect on adults and children. Altogether, there are more than 100 listed impairments.

For each body system, the Listings begin with a narrative introduction that defines key concepts used in that body system. The introduction also identifies specific medical findings that may be required to show the existence of an impairment listed in that section. Symptoms alone cannot be the basis for establishing the existence of an impairment. The introduction is followed by the "Category of Impairments" section, which includes the specific criteria (medical signs, symptoms, and laboratory findings) that describe the required level of severity for each impairment listed in that body system. Although a few listings (e.g., certain cancers, amyotrophic lateral sclerosis) are evaluated based on diagnosis alone, most require a diagnosis in conjunction with some sort of assessment of impairment severity, either by the presence of specific clinical findings or by some sort of assessment of functional outcomes.

If the evidence in a case establishes the presence of all the criteria required by one of the impairment listings, then the individual "meets" (i.e., matches) that specific listing. However, even if the evidence does not show that an individual meets the exact requirements of a particular listing, the individual can still be found disabled at step 3 of the sequence if his or her impairment is equal in severity to the requirements of a listing, referred to as "medical equivalence."

Medical equivalence to a listing is established if the medical findings are at least equal in severity and duration to the listed findings. SSA compares the signs, symptoms, and laboratory findings in the medical evidence with the listing criteria for the individual's impairment (or the listed impairment most like the individual's impairment). If the individual has a combination of impairments, all of the medical findings of the combined impairments are compared to the most closely related listed impairment. However, medical equivalence cannot be established merely because an individual has many impairments. Medical equivalence is evaluated based on not only the medical evidence, but also on consideration of a designated physician's medical judgment about equivalence (20 CFR §§ 404.1526 and 416.926; Social Security Ruling 86-8: Titles II and XVI: The Sequential Evaluation Process). See Box 5-1 for an illustration of how SSA applies the Listings.

ORIGINS AND DEVELOPMENT OF THE LISTINGS

SSA's first experience with implementation of a disability benefit program occurred well before the Disability Freeze program in 1954 or the Disability Insurance Benefits Program in 1956. It came with the Civilian War Benefit (CWB) program, which was established in the early 1940s by executive, rather than legislative, action. CWB provided for payment of disability and medical benefits to civilians injured in the war effort. The disability benefit covered permanent, temporary, total, and partial disabilities. The disability evaluation policies and procedures included a list of conditions that automatically qualified an individual for permanent total disability benefits:

> Under CWB, an applicant was presumptively entitled to permanent total disability benefits if he/she suffered any of the following conditions:
>
> 1. Loss of both feet, or permanent loss of use of both feet;
> 2. Loss of both hands, or permanent loss of use of both hands;
> 3. Loss of one hand and one foot, or permanent loss of use of one hand and one foot;

Box 5-1 How SSA Uses the Listings

Listings Example—Peripheral Arterial Disease

If "Susan" applies for disability insurance benefits, alleging that she is unable to work due to the effects of peripheral arterial disease, SSA first determines whether she meets the nondisability requirements for entitlement (e.g., sufficient work credit for disability insurance coverage). Assuming that the nondisability requirements are met, SSA evaluates her disability status, using the five-step sequential evaluation process.

If she is not working at substantial gainful activity (step 1) and has an impairment that significantly limits her ability to perform basic work activities (step 2), SSA determines whether her impairment meets the requirements of the Listings.

Peripheral arterial disease is evaluated in the "cardiovascular" body system, in section 4.00 of the Listings. For peripheral arterial disease, listed in section 4.12, the specific requirements are:

4.12 Peripheral arterial disease, as determined by appropriate medically acceptable imaging (see 4.00A3d, 4.00G2, 4.00G5, and 4.00G6), causing intermittent claudication (see 4.00G1) and one of the following:

A. Resting ankle/brachial systolic blood pressure ratio of less than 0.50, OR
B. Decrease in systolic blood pressure at the ankle on exercise (see 4.00G7a and 4.00C16—4.00C17) of 50 percent or more of pre-exercise level and requiring 10 minutes or more to return to pre-exercise level, OR
C. Resting toe systolic pressure of less than 30 mm Hg (see 4.00G7c and 4.00G8), OR
D. Resting toe/brachial systolic blood pressure ratio of less than 0.40 (see 4.00G7c).

SSA compares Susan's medical records to these specific requirements. To meet these requirements, the medical records must first establish the existence of peripheral arterial disease, using "medically acceptable imaging." The listing shows, in the introductory text to the listing section, where the specific imaging requirements are to be found (in sections 4.00A3D, 4.00G2, 4.00G5, and 4.00G6). In addition, the impairment must cause "intermittent claudication." The listing also shows where in the introductory text that requirement is explained. Finally, the evidence must document one of four specific clinical findings (blood pressure readings) that indicate impairment severity, described in subsections A, B, C, and D.

If the medical records show that all these requirements are met, SSA determines that Susan is disabled without evaluating her work capacity, age, education, or work experience.

SOURCE: CFR chapter 20, part 404, subpart P, appendix 1, section 4.00.

4. Permanent loss of vision; or
5. Any disability which requires the individual to be permanently bedridden.

The rating schedule for evaluating disability was organized according to six body systems (DeWitt, 1997):

- musculoskeletal
- organs of special sense
- the nose and throat
- scars and disfigurements
- neuropsychiatric disabilities
- dental and oral disabilities

Although the full extent to which these CWB provisions served as a model for later disability evaluation procedures is unclear, there is an obvious similarity between the CWB approach and the process that eventually became know as the Listings.

Later, as SSA staff worked on procedures to process large numbers of disability applications throughout the late 1940s, they fixed on a process that involved classifying applicants into eight groups according to disability severity. The most severely impaired were assigned to Group I, and the least severely affected placed in Group VIII. Later, the number of groups was reduced from eight to six, with each group including several examples of the kinds of impairments expected in the group. For Group I, total disability was considered automatic. The list of impairment examples (cited in Cowles, 2005:5-6) was:

- advanced pulmonary tuberculosis
- congestive heart failure
- aneurysm of aorta or branches
- myocardial infarction
- bronchiectasis
- colitis
- nephritis
- tuberculosis (kidneys)
- any cardiac lesion classified under Class IV (American Heart Association grouping)
- leukemia
- cerebral accident
- multiple sclerosis
- pellagra
- inoperable malignancies

- osteomyelitis of pelvis or vertebra
- tuberculosis of hip, spine, or larynx
- bronchial asthma

Shortly after the Disability Freeze program was established by the Social Security Amendments of 1954, SSA appointed a 15-member medical advisory committee, which "recommended the issuance of evaluation guides and standards setting forth medical criteria for the evaluation of specific impairments with the degree of severity prescribed for each. The panel also suggested that factors such as age, education, training and experience may be important in the evaluation of disability, even though the law [at that time] did not specifically require consideration of these factors" (SSA, 1996). These evaluation guides later came to be known as the "Listing of Impairments."

From the beginning, the guides were conceived as a way to quickly identify allowance cases without performing a comprehensive analysis of an individual's capacity to work:

> . . . we recognized that there were going to be a vast majority of the cases that might be pretty cut and dried on the medical evidence and where you didn't have to go into vocational issues. And we wanted to find a way to get people through the listings and get them on. The listings were not intended administratively to close the case and foreclose the consideration of capacity to work and substantial activity of one kind or another. But the listings were a scrape to get people in (Hess, 1993).

There was also an expectation that the Listings would apply in the vast majority of the cases, thus allowing the most efficient adjudication of large numbers of claims, as well as uniformity in adjudication:

> . . . we are faced with the need to adjudicate more cases in a short period of time than ever attempted by insurance companies or any other disability organization, including the Federal Government. The gross numbers, coupled with the operational complexities that arise when 48 States participate in the adjudicative process, demand a method which would assure reasonable uniformity in adjudication and which lends itself to a mass process. The proposed Guide lists impairments under medical diagnostic headings with a degree of severity for each that, if met, would allow a finding that an individual not actually working is unable to work. . . . While it is recognized that some people with the scheduled disability will engage in substantial gainful activity, the severity should be pitched at a level where experience shows us the majority cannot. These standards may then permit relatively quick decisions in 85 to 90 percent of all cases. If so, the Guide will be worthwhile, because it will have screened out the cases, one way

> or the other, where it is not necessary to go deeply into individualized adjudication, beyond the medical picture (SSA, 1955:6).

Nevertheless, these guides were still supposed to allow some leeway for the exercise of professional judgment. Listings were not to be applied mechanically, and decision makers were expected to exercise judgment and arrive at decisions only after considering all the facts in the case (Cowles, 2005). Thus, the Listings were originally illustrative, rather than determinative.

The first Listings were fairly brief. They were organized into 10 categories according to body system, similar to the Veterans Administration's 1945 Schedule for Rating Disabilities:

- musculoskeletal system
- special sense organs
- respiratory system
- cardiovascular system
- digestive system
- genito-urinary system
- hemic and lymphatic system
- skin
- endocrine system
- nervous system, including neurology and psychiatry

Each section began with a general introduction, followed by the specific Listing criteria, which focused more on the clinical criteria for diagnoses than functional consequences (Cowles, 2005:9).

This focus on "objective" clinical criteria reflected some of the same concerns that framed the debate during the 1940s about establishing a disability program in the first place, and it compelled adoption of a definition of disability that relied heavily on objective medical evidence. "A strict, medically based definition of disability was considered necessary to avoid payment of unnecessary claims, thus keeping down costs; with an emphasis on objective medical evidence, as opposed to subjective symptoms, it was thought that decision making would be easier and more accurate" (Bloch, 1992:91). As explained by the 1948 Advisory Council on Social Security:

> To qualify for benefits, a disabled person would have to be incapable of self-support for an indefinite period—permanently and totally disabled. He would have to be unable, by reason of a disability medically demonstrable by objective tests, to perform any substantially gainful activity. . . .

> Benefits should be paid to an insured individual who is permanently and totally disabled. A "permanent and total disability" for the purpose of this program should mean any disability which is medically demonstrable by objective tests, which prevents the worker from performing any substantially gainful activity, and which is likely to be of long-continued and indefinite duration. . . .
>
> The definition of "disability" used in a disability program will in large part determine the feasibility of administration and the costs of the program. The proposed definition is designed to establish a test of disability which will operate as a safeguard against unjustified claims. It is an administratively practicable test and it will facilitate the evaluation of permanent and total disabilities.
>
> The Council recommends that compensable disabilities be restricted to those which can be objectively determined by medical examination or tests. In this way, the problems involved in the adjudication of claims based on purely subjective symptoms can be avoided. Unless demonstrable by objective tests, such ailments as lumbago, rheumatism, and various nervous disorders would not be compensable. The danger of malingering which might be involved in connection with such claims would thereby be avoided (Advisory Council on Social Security, 1948:71, 74).

Although the medically based Listings were a logical outgrowth of the medically based definition of disability eventually established in the 1954 Amendments to the Social Security Act (which had its origin in the 1948 advisory council report), nothing in the law has ever required SSA to have these kinds of guides or Listings. They were developed by SSA as an administrative tool to increase the efficiency of case processing. As SSA noted in a November 2001 final regulation, *Revised Medical Criteria for Determination of Disability, Musculoskeletal System and Related Criteria* (responding to a public comment that claimed that SSA's proposed listing criteria were inconsistent with the Social Security Act, in 66 FR 58027):

> The [Social Security] Act does not, in fact, make any provision for the listings at all. The listings are an administrative convenience established by regulation to identify obviously disabled individuals.

EVOLUTION OF THE LISTINGS

For many years after they were first devised in 1955, the Listings did not appear anywhere in SSA's disability regulations or other public information. Policy makers were concerned that widespread knowledge of the specific disability criteria could compromise program integrity:

> . . . we didn't want to give those listings out to the public generally . . . we told the State agencies and we ourselves said these listings are not to

> be made public because they are the key to the bank. And doctors and litigators and others would know what the listings were. And it's easy to write up a medical report. I don't mean it's a fraudulent medical report that is slanted in terms of highlighting those manifestations (Hess, 1993).

Instead, the regulations included a brief list of examples of the kinds of impairments that might be considered disabling, while the actual Listings were only contained in the agency's internal operating instructions. Following passage of the Freedom of Information Act in 1966, SSA began making the Listings available to the public by publishing them in its regulations. The first such publication occurred on August 20, 1968 (33 FR 11749).

Between 1955 and 1967, when the Listings existed only in agency operating instructions, they were revised frequently, since they were "being developed based on operating experience" (Program Operations Manual System [POMS], section DI 34101.005). The last version of the Listings before their publication in the regulations (dated July 4, 1967) is still preserved in the SSA operating manual (POMS DI 34101.015). By 1967, the Listings had expanded considerably and evolved from a relatively short set of criteria that relied primarily on diagnoses and "disease specifications" to a much more elaborate set of standards that relied on specific observations, "highly-specific criteria involving signs, symptoms and laboratory findings," and functional outcomes (Cowles, 2005:9, 12, 13).

Another major development in the evolution of the Listings also occurred in 1968. The 1967 Amendments to the Social Security Act (Public Law [P.L.] 90-248) established a new disability benefit for widows and widowers age 50 and above. This benefit was based on a new, more restrictive definition of disability. To qualify, the widow or widower had to be unable to engage in any "gainful activity" (as compared with the standard for the existing disability program—inability to engage in *substantial* gainful activity). The new widows/widowers test was "based on the medical severity of the impairment and . . . not . . . on non-medical factors and work activity" (U.S. House of Representatives, 1974:118). The law required SSA to define this higher degree of severity by regulation, and SSA decided that the Listings represented the degree of severity contemplated in the law (SSA, 1968). Despite the fact that the widows/widowers disability standard was later revised to equal the degree of severity required for disability insurance benefits (in the 1990 Amendments to the Social Security Act, the Omnibus Budget Reconciliation Act of 1990 [P.L. 101-508]), "listing-level severity" has continued to represent a higher degree of severity than the statutory definition of disability (i.e., inability to engage in any gainful activity vs. inability to engage in any substantial gainful activity).

The first significant revision to the Listings after 1968 occurred in

1977, when SSA published a new set of listings criteria that would apply to children under the age of 18 who were applying for Supplemental Security Income benefits (42 FR 14705). In 1979, SSA issued a comprehensive update and revision of all the adult Listings (44 FR 18170).

In 1984, Congress directed SSA to revise its mental disorders listing criteria (Section 5(a) of P.L. 98-460, The Disability Benefits Reform Act of 1984). These revisions, which were published in the regulations on August 28, 1985 (50 FR 35038), marked the first time that SSA included an expiration date for any listing. The adult mental disorders listings were to expire three years from their effective date. As SSA explained in its *Federal Register* notice, ". . . [t]he dynamic nature of the diagnosis, evaluation and treatment of the mental disease process requires that the rules in this area be periodically revised and updated" (50 FR 35038).

Later that year, SSA updated listings for most of the remaining body systems and added expiration dates for all the other body systems. Although the law does not require SSA to periodically update the criteria in the Listings, SSA noted in its December 6, 1985, *Federal Register* notice (50 FR 50068):

> Medical advancements in disability evaluation and treatment and program experience require that these listings be periodically reviewed and updated. . . . We intend to carefully monitor these listings over the period prescribed for each body system to ensure that they continue to meet program purposes. When changes are found to be warranted, the listings for that body system will be updated in the Federal Register again. Therefore, during the periods ranging from 4 to 8 years after the date of publication of these final rules, the listings under each body system will cease to be effective on the specified dates unless extended or revised and promulgated again.

The 1985 updates (which took effect in January 1986) were the last comprehensive revision to the Listings. Since then, SSA has focused on updates that are more targeted—addressing a single body system or even individual listings. According to the Government Accountability Office (GAO), SSA's Listings update activities were curtailed in the mid-1990s due to staff shortages, competing priorities, and lack of adequate research (GAO, 2002:7).

One of the competing priorities in the mid-1990s was the agency's effort to fundamentally redesign the disability decision-making process through business process reengineering—an initiative that became known as "disability redesign." One component of the disability redesign was a project to develop a new approach to making disability decisions to replace the existing sequential evaluation process (SSA, 1994). However, by 1999, SSA had undertaken an internal reassessment of its disability initiatives and was no longer pursuing a new decision-making process. Rather, it had decided to focus on improving the current process and had resumed efforts to update the Listings (IOM and NRC, 2002).

Since that time, SSA has completed a number of revisions and updates to specific sections of the Listings, including:

- Revised Medical Criteria for Determination of Disability, Endocrine System and Related Criteria (64 FR 46122, August 24, 1999)
- Addition of Medical Criteria for Evaluating Down Syndrome in Adults (65 FR 31800, May 19, 2000)
- Revised Medical Criteria for Evaluating Mental Disorders and Traumatic Brain Injury (65 FR 50745, August 21, 2000)
- Supplemental Security Income; Determining Disability for a Child Under Age 18 (65 FR 54747, September 11, 2000) [included limited revisions to the childhood listings]
- Revised Medical Criteria for Determination of Disability, Musculoskeletal System and Related Criteria (66 FR 58009, November 19, 2001)
- Technical Revisions to Medical Criteria for Determinations of Disability (67 FR 20018, April 24, 2002)
- Revised Medical Criteria for Evaluating Amyotrophic Lateral Sclerosis (68 FR 51689, August 28, 2003)
- Revised Medical Criteria for Evaluating Skin Disorders (69 FR 32260, June 9, 2004)
- Revised Medical Criteria for Evaluating Hematological Disorders and Malignant Neoplastic Diseases (69 FR 67017, November 15, 2004)
- Revised Medical Criteria for Evaluating Genitourinary Impairments (70 FR 38582, July 5, 2005)
- Revised Medical Criteria for Evaluating Impairments That Affect Multiple Body Systems (70 FR 51252, August 30, 2005)
- Revised Medical Criteria for Evaluating Cardiovascular Impairments (71 FR 2311, January 13, 2006)

SSA has also initiated, but at the time of this report had not yet completed, several other Listings revisions, including:

- Revised Medical Criteria for Evaluating Growth Impairments (65 FR 37321, June 14, 2000 and 70 FR 53323, September 8, 2005)
- Revised Medical Criteria for Evaluating Impairments of the Digestive System (66 FR 57009, November 14, 2001, and 69 FR 64702, November 8, 2004)
- Revised Medical Criteria for Evaluating Mental Disorders (68 FR 12639, March 17, 2003)

- Revised Medical Criteria for Evaluating Immune System Disorders (68 FR 24896, May 9, 2003)
- Revised Medical Criteria for Evaluating Neurological Impairments (70 FR 19356, April 13, 2005)
- Revised Medical Criteria for Evaluating Respiratory System Disorders (70 FR 19358, April 13, 2005)
- Revised Medical Criteria for Evaluating Hearing Impairments and Disturbance of Labyrinthine-Vestibular Function (70 FR 19353, April 13, 2005)
- New Medical Criteria for Evaluating Language and Speech Disorders (70 FR 19351, April 13, 2005)
- Revised Medical Criteria for Evaluating Endocrine Disorders (70 FR 46792, August 11, 2005)
- Revised Medical Criteria for Evaluating Visual Disorders (70 FR 48342, August 17, 2005)

REFERENCES

Advisory Council on Social Security. 1948. *Recommendations for Social Security legislation. The reports of the Advisory Council on Social Security to the Senate Committee on Finance. Part 2, Permanent and total disability*. Available: www.ssa.gov/history/pdf/48advise6.pdf (accessed May 20, 2006).

Bloch, F.S. 1992. *Disability determination: The administrative process and the role of the medical professional*. West London, CT: Greenwood Press.

Cowles, A. 2005. *History of the disability listings*. Available: www.ssa.gov/history/DisabilityListings.html (accessed November 3, 2005).

DeWitt, L. 1997. *The Civilian War Benefits Program: SSA's first disability program*. Available: www.ssa.gov/history/civilwar.html (accessed November 3, 2005).

GAO (Government Accountability Office). 2002. Social Security Administration: Fully updating disability criteria has implications for program design. Testimony before the Subcommittee on Social Security, Committee on Ways and Means, House of Representatives. GAO-02-919T. July 11, 2002. Available: www.gao.gov/new.items/d02919t.pdf (accessed November 17, 2005).

Hess, A. 1993. Comments at the January 21, 1993 Disability Forum, The disability program: Its origins—our heritage. Its future—our challenge. Available: www.ssa.gov/history/dibforum93.html (accessed November 3, 2005).

IOM and NRC (Institute of Medicine and National Research Council). 2002. *The dynamics of disability: Measuring and monitoring disability for Social Security programs,* edited by G.S. Wunderlich, D.P. Rice, and N.L. Amado. Washington, DC: National Academy Press.

SSA (Social Security Administration). 1955. *Summary report: Medical Advisory Committee meeting, February 9-10, 1955*. Social Security Administration History Archives, Baltimore, MD.

SSA. 1968. SSA program circular on disability insurance. *Disability regulations—The listing of impairments*. May 6, 1968.

SSA. 1994. *Plan for a new disability claim process*. SSA Publication Number 01-005. Washington, DC: U.S. Government Printing Office.

SSA. 1996. *A history of the Social Security disability programs, January 1986*. Available: www.ssa.gov/history/1986dibhistory.html (accessed November 3, 2005).

SSAB (Social Security Advisory Board). 2006. *Disability decisionmaking: Data and materials*. Available: www.ssab.gov/documents/chartbook.pdf (accessed September 28, 2006).

U.S. House of Representatives, Committee on Ways and Means. 1974. *Committee staff report on the Disability Insurance Program*. Available: www.ssa.gov/history/pdf/dibreport.pdf (accessed November 3, 2005).

Appendix D

Surveys and Surveillance Systems That Collect Data on Mental Disorders Among Children

Name, Website, and Sponsor	Description	Method of Data Collection
Autism and Developmental Disabilities Monitoring (ADDM) Network http://www.cdc.gov/ncbddd/autism/addm.html Sponsor: Centers for Disease Control and Prevention (CDC) National Center on Birth Defects and Developmental Disabilities	The ADDM Network is a group of CDC-funded programs that determine the prevalence of autism spectrum disorders (ASDs) in U.S. communities. ADDM sites collect data using the same surveillance methods, which are modeled after the CDC Metropolitan Atlanta Developmental Disabilities Surveillance Program.	Screening and abstraction of existing health and education records containing professional assessments of the children's developmental progress at health care or education facilities

Survey Topics Related to Children	Mental Health Topics and Questions Related to Children	Populations and Periodicity
Child demographic characteristics, including sex, race/ethnicity, and year of birth Previous diagnoses of intellectual disability and cerebral palsy Use of special education services Previous and current special education exceptionality (eligibility) classification Results from standardized developmental assessments (such as IQ)	Previous diagnosis of ASD Clinical features, symptoms, and behaviors associated with ASD, intellectual disability, or cerebral palsy Age of child when first symptoms noted and at first diagnosis of ASD, intellectual disability, or cerebral palsy Other developmental and mental disorders that occur with ASD, intellectual disability, and cerebral palsy (e.g., attention deficit hyperactivity disorder [ADHD])	Selected sample based on grantees. Fourteen ADDM Network sites for 2008. Children aged 8 years with evidence documented in abstracted evaluations indicating the presence of autistic disorder; pervasive developmental disorder, not otherwise specified; or Asperger's disorder. Biennial (even years): 2000, 2002, 2004, 2006, and 2008.

Name, Website, and Sponsor	Description	Method of Data Collection
National Health and Nutrition Examination Survey (NHANES) http://www.cdc.gov/nchs/nhanes.htm Sponsor: CDC National Center for Health Statistics	NHANES is designed to assess the health and nutritional status of adults and children in the United States. The survey combines interviews and physical examinations.	In-person household interviews Nutritional assessments Laboratory tests Physical examinations DNA repository

Survey Topics Related to Children	Mental Health Topics and Questions Related to Children	Populations and Periodicity
Health care use Mental, behavioral, and emotional problems of children Numerous diseases, medical conditions, and health indicators	Age/topic/method/dates: 12+/Depression screener/(CAPI)/2005, 2006 12–19/Conduct disorders/(ACASI)/1999 on 8–19/Depression/(CDISC)/2000–2004 8–15/ADHD/(parent CDISC)/2000–2004 8–15/Conduct disorders/(parent CDISC)/2000–2004 8–15/Depression/(parent CDISC)/2000–2004 No data yet published. Use of mental health care services Activity limitations because of poor physical or mental health Mental disorder diagnosis using the National Institute of Mental Health Diagnostic Interview Schedule for Children (1999–2004: generalized anxiety disorder and panic disorder; 2000–2004: eating disorders, elimination disorders, major depression/dysthymic disorder, ADHD, and conduct disorder); ages 8–15 years, varying by module Depression screener (PHQ-9; since 2005) Mentally unhealthy days (since 2001)	Nationally representative sample. 5,000 people per year, including approximately 1,000 persons aged 12–19 years. Oversampling, which changes periodically; in 2011–2012 and 2013–2014, oversample of Hispanics, blacks, Asians, and older adults.

Name, Website, and Sponsor	Description	Method of Data Collection
National Survey of Children's Health (NSCH) http://www.cdc.gov/nchs/slaits/nsch.htm Sponsor: Health Resources and Services Administration Administrator: CDC National Center for Health Statistics	NSCH examines the physical and emotional health of children aged 0–17 years, emphasizing factors that might relate to the well-being of children.	Telephone interviews, with National Immunization Survey sampling frame

Survey Topics Related to Children	Mental Health Topics and Questions Related to Children	Populations and Periodicity
Physical, emotional, and dental health Children with special health care needs Health care access, use, and barriers	Questions asked for ADHD, depression, anxiety, oppositional defiant disorder, behavioral or conduct problems, autism, developmental delay, Tourette syndrome: Has a doctor or other health care provider ever told you that selected child (SC) had…? Does SC currently have…? Would you describe his/her … as mild, moderate, or severe? In case of ADHD, a fourth question is asked: Is SC currently taking medication for ADD or ADHD? Results not yet published. Activity, social, or learning limitation resulting from mental, emotional, or behavior problems Common acute and chronic conditions (including learning disability, ADHD, depression, anxiety, behavior and conduct disorders, ASD, Tourette syndrome, and epilepsy) Social behavior, emotional difficulties, and school engagement Mental health care treatment and services used	Representative sample nationally and within each state of households with children. Data collected from responsible adult by telephone. Approximately 95,000 children aged ≤17 years. Periodic: data collected approximately every 4 years and currently available for 2003, 2007, and 2011–2012.

Name, Website, and Sponsor	Description	Method of Data Collection
National Survey on Drug Use and Health (NSDUH) https://nsduhweb.rti.org Sponsor: Substance Abuse and Mental Health Services Administration	NSDUH data are used to provide national and state-level estimates on the use of tobacco products, alcohol, illicit drugs (including nonmedical use of prescription drugs), and mental illness in the United States	In-person household interviews

Survey Topics Related to Children	Mental Health Topics and Questions Related to Children	Populations and Periodicity
Health conditions Health care use	Designed to produce drug and alcohol use incidence and prevalence estimates and report the consequences and patterns of use and abuse in the general U.S. civilian population ages 12 and older. Since 1994, questions added on mental health and access to care. Treatment for youth ages 12–17 is defined as receiving treatment or counseling for problems with behaviors or emotions from specific mental health or other health professionals in school, home, or from other outpatient or inpatient settings in the past year A module on lifetime and past year prevalence of major depressive episode (MDE), severity of the MDE as measured by role impairments, and treatment for depression was administered to adults ages 18 or older and youth ages 12–17, from 2004 to 2006; 8.5 percent of youth had an episode of MDE in the past 12 months (see http://oas.samhsa.gov/2k8/youthDepress/youthDepress.pdf) Lifetime and past year major depressive episode Level of impairment resulting from major depressive disorder, substance use, and substance use disorder Mental health service use	State and nationally representative sample. 7,200 primary sampling units each year and approximately 70,000 respondents aged ≥12 years, including 23,000 aged 12–17 years and 23,000 aged 18–25 years. Annual and continuous since 1992. Data includes 397 *Diagnostic and Statistical Manual of Mental Disorders, Fourth Edition* (DSM-IV) diagnoses.

Name, Website, and Sponsor	Description	Method of Data Collection
National Comorbidity Survey-Adolescent Supplement (NCS-A) http://www.hcp.med.harvard.edu/ncs	National psychiatric epidemiologic survey of adolescents ages 3–17	Adolescent interviews and information was collected from a parent or a parent surrogate to obtain an additional perspective on the adolescent's mental health and its correlates

REFERENCES

Merikangas, K. R., S. Avenevoli, E. J. Costello, D. Koretz, and R. C. Kessler. 2009. National comorbidity survey replication adolescent supplement (NCS-A): I. Background and measures. *Journal of the American Academy of Child & Adolescent Psychiatry* 48(4):367–379.

Perou, R., R. H. Bitsko, S. J. Blumberg, P. Pastor, R. M. Ghandour, J. C. Gfroerer, S. L. Hedden, A. E. Crosby, S. N. Visser, L. A. Schieve, S. E. Parks, J. E. Hall, D. Brody, C. Simile, W. W. Thompson, J. Baio, S. Avenevoli, M. D. Kogan, and L. N. Huang. 2013. Mental health surveillance among children—United States, 2005–2011. *Morbidity and Mortality Weekly Report* 62(2):1–35.

Survey Topics Related to Children	Mental Health Topics and Questions Related to Children	Populations and Periodicity
	Lifetime-to-date and current prevalence, age-of-onset distributions, course, and comorbidity of DSM-IV disorders: anxiety disorders, mood disorders, behavior disorders, substance disorders Identify risk and protective factors for the onset and persistence of these disorders Describe patterns and correlates of service use for these disorders	Survey of 10,148 adolescents.

Appendix E

Initial Allowance, Initial Determination, Allowance Rate, and Recipient Data for 10 Major Mental Disorders[1]

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[1] Data source is unpublished data set provided by the Social Security Administration (SSA).

TABLE E-1 Number of Allowances for the Major Mental Disorders, for All Children Under 18, at the Initial Level, from 2004 to 2013

Year	2004	2005	2006	2007	2008	2009	2010	2011	2012	2013
ADHD	28,739	28,023	25,959	24,630	26,303	27,668	30,106	29,871	27,772	24,181
ID	24,602	22,237	19,161	17,152	17,182	17,831	17,680	16,456	14,128	12,470
ASD	9,677	10,626	11,613	12,925	15,812	18,231	20,317	22,931	24,159	23,398
Mood disorders	9,760	9,835	9,084	8,907	9,199	9,869	10,588	10,339	9,331	8,400
LD	6,940	6,720	5,811	5,230	5,211	5,428	5,681	5,590	5,061	4,513
Organic	3,714	3,776	3,376	3,303	3,326	3,683	4,048	3,911	3,612	3,288
ODD	2,913	2,807	2,653	2,590	2,628	2,860	2,950	3,252	3,281	3,072
BIF	3,177	2,847	2,564	2,265	2,221	2,307	2,382	2,115	1,802	1,551
Anxiety	1,838	1,756	1,769	1,702	1,812	1,989	2,067	2,226	2,184	1,965
CD	2,041	1,927	1,717	1,761	1,753	1,873	1,959	1,880	1,802	1,469
Total yearly allowances	93,401	90,554	83,707	80,465	85,447	91,739	97,778	98,571	93,132	84,307

NOTE: ADHD = attention deficit hyperactivity disorder; ASD = autism spectrum disorder; BIF = borderline intellectual function; CD = conduct disorder; ID = intellectual disability; LD = learning disability; ODD = oppositional defiant disorder.

TABLE E-2 Percentage of Allowances for the Major Mental Disorders, for All Children Under 18, at the Initial Level, from 2004 to 2013

Year	2004	2005	2006	2007	2008	2009	2010	2011	2012	2013	Average
ADHD	30.77%	30.95%	31.01%	30.61%	30.78%	30.16%	30.79%	30.30%	29.82%	28.68%	30.39%
ID	26.34%	24.56%	22.89%	21.32%	20.11%	19.44%	18.08%	16.69%	15.17%	14.79%	19.94%
ASD	10.36%	11.73%	13.87%	16.06%	18.51%	19.87%	20.78%	23.26%	25.94%	27.75%	18.81%
Mood	10.45%	10.86%	10.85%	11.07%	10.77%	10.76%	10.83%	10.49%	10.02%	9.96%	10.61%
LD	7.43%	7.42%	6.94%	6.50%	6.10%	5.92%	5.81%	5.67%	5.43%	5.35%	6.26%
Organic	3.98%	4.17%	4.03%	4.10%	3.89%	4.01%	4.14%	3.97%	3.88%	3.90%	4.01%
ODD	3.12%	3.10%	3.17%	3.22%	3.08%	3.12%	3.02%	3.30%	3.52%	3.64%	3.23%
BIF	3.40%	3.14%	3.06%	2.81%	2.60%	2.51%	2.44%	2.15%	1.93%	1.84%	2.59%
Anxiety	1.97%	1.94%	2.11%	2.12%	2.12%	2.17%	2.11%	2.26%	2.35%	2.33%	2.15%
CD	2.19%	2.13%	2.05%	2.19%	2.05%	2.04%	2.00%	1.91%	1.93%	1.74%	2.02%

NOTE: ADHD = attention deficit hyperactivity disorder; ASD = autism spectrum disorder; BIF = borderline intellectual function; CD = conduct disorder; ID = intellectual disability; LD = learning disability; ODD = oppositional defiant disorder.

TABLE E-3 Number of Determinations for the Major Mental Disorders, for All Children Under 18, at the Initial Level, from 2004 to 2013

Year	2004	2005	2006	2007	2008	2009	2010	2011	2012	2013
ADHD	88,913	90,884	87,765	88,233	92,869	99,484	113,437	124,215	121,225	107,751
LD	29,028	28,485	25,831	24,768	23,456	23,325	25,044	25,621	23,650	21,118
Mood	20,620	21,080	20,400	20,986	21,502	22,921	26,246	27,172	25,553	23,061
ID	27,037	24,390	21,002	18,740	18,562	18,993	18,913	17,797	15,355	13,613
ASD	10,486	11,517	12,685	14,344	17,478	20,357	23,201	26,739	28,789	28,192
BIF	13,405	12,205	10,667	9,779	8,705	8,442	8,752	7,925	7,186	6,292
ODD	7,573	7,415	6,918	7,024	7,183	7,328	8,016	9,074	9,366	9,056
CD	5,516	5,537	5,214	5,303	5,082	5,202	5,571	5,661	5,261	4,367
Anxiety	4,350	4,292	4,223	4,243	4,444	4,877	5,637	6,536	6,721	6,409
Organic	4,263	4,511	4,152	4,192	4,241	4,884	5,689	6,127	6,046	5,808

NOTE: ADHD = attention deficit hyperactivity disorder; ASD = autism spectrum disorder; BIF = borderline intellectual function; CD = conduct disorder; ID = intellectual disability; LD = learning disability; ODD = oppositional defiant disorder.

TABLE E-4 Percentage of Determinations for the Major Mental Disorders, for All Children Under 18, at the Initial Level, from 2004 to 2013

Year	2004	2005	2006	2007	2008	2009	2010	2011	2012	2013
ADHD	42.10%	43.21%	44.13%	44.65%	45.63%	46.10%	47.17%	48.36%	48.66%	47.75%
LD	13.74%	13.54%	12.99%	12.53%	11.53%	10.81%	10.41%	9.97%	9.49%	9.36%
Mood	9.76%	10.02%	10.26%	10.62%	10.56%	10.62%	10.91%	10.58%	10.26%	10.22%
ID	12.80%	11.60%	10.56%	9.48%	9.12%	8.80%	7.86%	6.93%	6.16%	6.03%
ASD	4.97%	5.48%	6.38%	7.26%	8.59%	9.43%	9.65%	10.41%	11.55%	12.49%
BIF	6.35%	5.80%	5.36%	4.95%	4.28%	3.91%	3.64%	3.09%	2.88%	2.79%
ODD	3.59%	3.53%	3.48%	3.55%	3.53%	3.40%	3.33%	3.53%	3.76%	4.01%
CD	2.61%	2.63%	2.62%	2.68%	2.50%	2.41%	2.32%	2.20%	2.11%	1.94%
Anxiety	2.06%	2.04%	2.12%	2.15%	2.18%	2.26%	2.34%	2.54%	2.70%	2.84%
Organic	2.02%	2.14%	2.09%	2.12%	2.08%	2.26%	2.37%	2.39%	2.43%	2.57%

NOTE: ADHD = attention deficit hyperactivity disorder; ASD = autism spectrum disorder; BIF = borderline intellectual function; CD = conduct disorder; ID = intellectual disability; LD = learning disability; ODD = oppositional defiant disorder.

TABLE E-5 Allowance Rate for the Major Mental Disorders, for All Children Under 18, at the Initial Level, from 2004 to 2013

Year	2004	2005	2006	2007	2008	2009	2010	2011	2012	2013	10 year avg.
ID	90.99%	91.17%	91.23%	91.53%	92.57%	93.88%	93.48%	92.47%	92.01%	91.60%	92.09%
ASD	92.28%	92.26%	91.55%	90.11%	90.47%	89.56%	87.57%	85.76%	83.92%	83.00%	88.65%
Organic	87.12%	83.71%	81.31%	78.79%	78.42%	75.41%	71.15%	63.83%	59.74%	56.60%	73.61%
Mood	47.33%	46.66%	44.53%	42.44%	42.78%	43.06%	40.34%	38.05%	36.52%	36.40%	41.81%
Anxiety	42.25%	40.91%	41.89%	40.11%	40.77%	40.78%	36.67%	34.06%	32.50%	30.70%	38.06%
ODD	38.47%	37.86%	38.35%	36.87%	36.59%	39.03%	36.80%	35.84%	35.03%	33.90%	36.87%
CD	37.00%	34.80%	32.93%	33.21%	34.49%	36.01%	35.16%	33.21%	34.25%	33.60%	34.47%
ADHD	32.32%	30.83%	29.58%	27.91%	28.32%	27.81%	26.54%	24.05%	22.91%	22.40%	27.27%
BIF	23.70%	23.33%	24.04%	23.16%	25.51%	27.33%	27.22%	26.69%	25.08%	24.70%	25.07%
LD	23.91%	23.59%	22.50%	21.12%	22.22%	23.27%	22.68%	21.82%	21.40%	21.40%	22.39%
Average yearly allowance rate for 10 mental disorders	51.54%	50.51%	49.79%	48.53%	49.21%	49.61%	47.76%	45.58%	44.33%	43.43%	

NOTE: ADHD = attention deficit hyperactivity disorder; ASD = autism spectrum disorder; BIF = borderline intellectual function; CD = conduct disorder; ID = intellectual disability; LD = learning disability; ODD = oppositional defiant disorder.

TABLE E-6 Number of Recipients for the Major Mental Disorders, for All Children Under 18, from 2004 to 2013

Year	Organic	Mood	ASD	Anxiety	CD	ODD	ADHD	LD	ID	BIF	Total
2004	24,987	32,078	43,628	7,890	8,280	12,976	138,921	33,833	215,709	21,749	540,051
2005	25,333	35,184	50,078	8,351	8,907	14,158	155,847	37,118	204,755	22,671	562,402
2006	25,910	37,112	56,976	8,786	9,256	14,967	169,863	38,934	192,566	22,721	577,091
2007	26,146	38,280	64,883	9,080	9,577	15,501	180,665	39,597	178,042	22,176	583,947
2008	26,055	39,164	73,161	9,477	9,884	15,919	189,868	39,619	163,007	21,464	587,618
2009	26,530	40,444	83,801	9,908	10,202	16,570	199,866	39,868	151,887	21,039	600,115
2010	27,223	41,932	94,606	10,293	10,561	17,293	211,478	40,278	141,618	20,490	615,772
2011	27,775	42,936	106,910	10,807	10,889	18,281	220,708	40,533	132,906	19,857	631,602
2012	28,406	43,508	121,699	11,342	11,203	19,588	225,035	40,924	126,520	19,330	647,555
2013	28,793	42,826	134,310	11,613	11,077	20,259	226,363	40,461	120,248	18,420	654,370

NOTE: ADHD = attention deficit hyperactivity disorder; ASD = autism spectrum disorder; BIF = borderline intellectual function; CD = conduct disorder; ID = intellectual disability; LD = learning disability; ODD = oppositional defiant disorder.

TABLE E-7 Percentage of Recipients for the Major Mental Disorders, for All Children Under 18, from 2004 to 2013

Year	Organic	Mood	ASD	Anxiety	CD	ODD	ADHD	LD	ID	BIF
2004	4.63%	5.94%	8.08%	1.46%	1.53%	2.40%	25.72%	6.26%	39.94%	4.03%
2005	4.50%	6.26%	8.90%	1.48%	1.58%	2.52%	27.71%	6.60%	36.41%	4.03%
2006	4.49%	6.43%	9.87%	1.52%	1.60%	2.59%	29.43%	6.75%	33.37%	3.94%
2007	4.48%	6.56%	11.11%	1.55%	1.64%	2.65%	30.94%	6.78%	30.49%	3.80%
2008	4.43%	6.66%	12.45%	1.61%	1.68%	2.71%	32.31%	6.74%	27.74%	3.65%
2009	4.42%	6.74%	13.96%	1.65%	1.70%	2.76%	33.30%	6.64%	25.31%	3.51%
2010	4.42%	6.81%	15.36%	1.67%	1.72%	2.81%	34.34%	6.54%	23.00%	3.33%
2011	4.40%	6.80%	16.93%	1.71%	1.72%	2.89%	34.94%	6.42%	21.04%	3.14%
2012	4.39%	6.72%	18.79%	1.75%	1.73%	3.02%	34.75%	6.32%	19.54%	2.99%
2013	4.40%	6.54%	20.53%	1.77%	1.69%	3.10%	34.59%	6.18%	18.38%	2.81%

NOTE: ADHD = attention deficit hyperactivity disorder; ASD = autism spectrum disorder; BIF = borderline intellectual function; CD = conduct disorder; ID = intellectual disability; LD = learning disability; ODD = oppositional defiant disorder.

Appendix F

Medicaid Analytic eXtract Methods

Design and Method

Study population

The study population comprised all Medicaid-eligible youth aged 3 to 17 in a selected subset of states for the years 2001-2010. Enrollee age, for the purposes of inclusion in analyses, was computed as of July 1 of each year. Eleven months (not necessarily consecutive) of Medicaid eligibility in the year were required for inclusion in the analytic population. The twenty states selected for inclusion in the study were those that we and others found, in internal analyses as well as in published work, to provide relatively complete diagnosis and treatment detail. The overall study population meeting the age, eligibility, and state inclusion criteria ranged from 5.2m in 2001 to 8.2m in 2010.

Data sources

The primary data source for this study consisted of Medicaid enrollment, claims, and prescription drug fill data from the Medicaid Analytic Extract (MAX). The MAX data provide a set of research files constructed from regular mandated data submissions from the state Medicaid programs and compiled and processed by the Centers for Medicare and Medicaid Services (CMS). Enrollment data include information on beneficiary characteristics such as age, sex, and race/ethnicity; as well as Medicaid eligibility; managed care participation; and other details that affect how care is organized and paid for. Claims are provided separately for inpatient, long-term care, and other (primarily outpatient) services, and include details on diagnoses received and services delivered. A prescription drug file provides records for each filled prescription, allowing researchers to identify which medications were received, when the prescriptions were filled, how much of the drug was provided, and for how long. The prescription drug records were linked to the First Data Bank National Drug Data File (NDDF), which provides the means to look up drug details using the National Drug Codes (NDCs) provided in the MAX data. Prescription medications were extracted from the MAX data by their generic names.

Database construction and analysis

Our preliminary MAX data analyses included 44 states and the District of Columbia. We then identified a subset of 20 states that in 2009 either (a) had predominantly fee-for-service (FFS) youth Medicaid populations or (b) had been identified as having relatively complete and usable managed care encounter data for that population.[1] Key variables included in these data sets were: sociodemographic characteristics (age, sex, race/ethnicity), month-by-month eligibility data, diagnoses recorded, services received, and prescriptions filled. An eligibility threshold, requiring a minimum of 11 Medicaid-eligible months in the year, was also established following preliminary analyses of the MAX enrollment data. Only data for youth age three to under 18 were included in analyses. The few youth with dual Medicaid-Medicare eligibility were excluded from analyses because records from Medicare, which is the first payer for many services, were not observable.

Enrollees were assigned to one of several basis-of-eligibility (BoE) groups following examination of their eligibility records: SSI/Disability, Foster care, and Other. Analyses were stratified or subset by this grouping variable. We used each enrollee's last observed BoE category in each year to assign her/him an overall status for the year. This was necessary in order to establish mutually exclusive eligibility categories. Preliminary analyses revealed substantial consistency throughout the year for the focal SSI/Disability group, suggesting that our method of assigning BoE categories on the basis of the last observation of the year did not distort these enrollees' eligibility histories.[2] The mappings from MAX BoE categories to our three groupings are details in *Appendix A*. Where the tables, charts, or text below refer to the full population or to subpopulations (e.g., SSI/Disability), it is implied that enrollees also met the age, eligibility, and state inclusion criteria.

Presence of ADHD and other diagnoses was identified using the multiple diagnosis fields in the MAX claims files, excluding the long-term care claims. A threshold of one or more inpatient claims, or two or more outpatient or other non-inpatient claims on different dates, was used to establish the presence of the following conditions for each enrollee for each year of analysis (via ICD-9-CM codes):

1. ADHD (both alone and complicated by other conditions)

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[1] See https://www.cms.gov/Research-Statistics-Data-and-Systems/Computer-Data-and-Systems/MedicaidDataSourcesGenInfo/Downloads/MAX_IB_15_AssessingUsability.pdf and http://mathematica-mpr.com/publications/pdfs/health/MAX_IB14.pdf

[2] We found that 96% of enrollees assigned to the SSI/Disability group on the basis of their last observation of the year had no other BoE at any point earlier in the year.

2. Conduct disorder
3. Emotional disturbances
4. Oppositional defiant disorder
5. Mood disorders (Depression)
6. Mood disorders (Bipolar disorders)
7. Anxiety disorders
8. Autism spectrum disorders
9. Intellectual disorders
10. Speech and language disorders
11. Hearing disorders (control)
12. Learning disorders (control)

Two subcategories of ADHD complicated by (1) any of the non-control conditions and (2) an externalizing disorder (conduct disorder or oppositional defiant disorder) were also identified. Cerebral palsy and asthma were identified as control conditions. The ICD-9-CM codes used to establish diagnoses are listed in *Appendix B*.

Pharmacological treatments were identified via generic drug names associated with filled prescriptions in the linked MAX/NDDF data and reported using the following categories of medications: ADHD medications, antipsychotic medications, antidepressants, anxiolytic/hypnotic medications, and mood stabilizers. The generic drug names for each category are listed in *Appendix C*. Non-pharmacological treatments were identified via procedure codes recorded in the MAX claims (using Current Procedural Terminology [CPT] codes in *Appendix D*).

Once enrollees' eligibility, sociodemographic characteristics, diagnoses, prescriptions, and services were identified, analyses were performed to track diagnosis and treatment trends over the 2001-2010 period.

Project conducted by:
Center for Health Services Research on Pharmacotherapy, Chronic Disease Management, and Outcomes, and Center for Education and Research on Mental Health Therapeutics
Institute for Health, Health Care Policy, and Aging Research
Rutgers University

Part A: Study categorizations (left) of MAX BoE groupings (right)

Current Study	CMS
N/A	NOT ELIGIBLE
Other	AGED, CASH
SSI/Disability	BLIND/DISABLED, CASH
Other	CHILD (NOT CHILD OF UNEMPLOYED ADULT, NOT FOSTER CARE CHILD), ELIGIBLE UNDER SECTION 1931 OF THE ACT
Other	ADULT (NOT BASED ON UNEMPLOYMENT STATUS), ELIGIBLE UNDER SECTION 1931 OF THE ACT
Other	CHILD OF UNEMPLOYED ADULT, ELIGIBLE UNDER SECTION 1931 OF THE ACT
Other	UNEMPLOYED ADULT, ELIGIBLE UNDER SECTION 1931 OF THE ACT
Other	AGED, MN
SSI/Disability	BLIND/DISABLED, MN
Other	CHILD, MN (FORMERLY AFDC CHILD, MN)
Other	ADULT, MN (FORMERLY AFDC ADULT, MN)
Other	AGED, POVERTY
SSI/Disability	BLIND/DISABLED, POVERTY
Other	CHILD, POVERTY (INCLUDES MEDICAID EXPANSION CHIP CHILDREN)
Other	ADULT, POVERTY
Other	INDIVIDUAL COVERED UNDER THE BREAST AND CERVICAL CANCER PREVENTION ACT OF 2000, POVERTY
Other	OTHER AGED
SSI/Disability	OTHER BLIND/DISABLED
Other	OTHER CHILD
Other	OTHER ADULT
Foster Care	FOSTER CARE CHILD
Other	AGED, SECTION 1115 DEMONSTRATION EXPANSION
SSI/Disability	DISABLED, SECTION 1115 DEMONSTRATION EXPANSION
Other	CHILD, SECTION 1115 DEMONSTRATION EXPANSION
Other	ADULT, SECTION 1115 DEMONSTRATION EXPANSION
Other	UNKNOWN ELIGIBILITY

Part B: Diagnostic groupings (ICD-9-CM)

ADHD/Attention deficit hyperactivity disorder

314.00	Attention deficit disorder, without mention of hyperactivity
314.01	Attention deficit disorder, with hyperactivity
314.2	Hyperkinetic conduct disorder
314.8	Other specified manifestations of hyperkinetic syndrome
314.9	Unspecified hyperkinetic syndrome

Conduct disorder

312.x	Disturbance of conduct, not elsewhere classified

Emotional disturbances

313.x	Disturbance of emotions specific to childhood and adolescence

Oppositional defiant disorder

313.81	Oppositional defiant disorder

Mood disorders (Depression)

296.2x	Episodic mood disorder (Major depressive disorder)
296.3x	Episodic mood disorder (Major depressive disorder)
296.9x	Other and unspecified episodic mood disorder
298.0	Depressive type psychosis
300.4	Dysthymic disorder
301.12	Chronic depressive personality disorder
309.1	Prolonged depressive reaction
311	Depressive disorder, not elsewhere classified

Mood disorders (Bipolar disorders)

296.0x	Bipolar I disorder, single manic episode
296.1x	Manic disorder, recurrent episode
296.4x	Bipolar I disorder, most recent episode (or current) manic
296.5x	Bipolar I disorder, most recent episode (or current) depressed
296.6x	Bipolar I disorder, most recent episode (or current) mixed
296.7x	Bipolar I disorder, most recent episode (or current) unspecified
296.8x	Other and unspecified bipolar disorders
301.13	Cyclothymic disorder

Anxiety disorders

293.84	Anxiety disorder in conditions classified elsewhere
300.00	Anxiety state, unspecified
300.02	Generalized anxiety disorder
300.09	Other anxiety states
309.21	Separation anxiety disorder
309.24	Adjustment disorder with anxiety
309.28	Adjustment disorder with mixed anxiety and depressed mood
313.0	Overanxious disorder

Autism spectrum disorders

299.00	Autistic disorder, current or active state
299.01	Autistic disorder, residual state
299.80	Other specified pervasive developmental disorders, current or active state
299.81	Other specified pervasive developmental disorders, residual state
299.90	Unspecified pervasive developmental disorder, current or active state
299.91	Unspecified pervasive developmental disorder, residual state

Intellectual disorders

317	Mild mental retardation
318.0	Moderate mental retardation
318.1	Severe mental retardation
318.2	Profound mental retardation
319	Unspecified mental retardation

Speech and language disorders

315.31	Expressive language disorder
315.32	Mixed receptive-expressive language disorder
315.34	Speech and language developmental delay due to hearing loss
315.35	Childhood onset fluency disorder
315.39	Other developmental speech or language disorder
438.10	Speech and language deficit, unspecified
438.19	Other speech and language deficits
784.59	Other speech disturbance

Hearing disorders

380.xx	Disorders of the external ear
381.xx	Non suppurative otitis media and Eustachian disorder
382.xx	Suppurative and unspecified otitis media
384.xx	Other disorders of the tympanic membrane
385.xx	Other disorders of the middle ear and mastoid
387.x	Otosclerosis
388.xx	Other disorders of the ear
389.xx	Hearing loss
744.0x	Anomaly of ear causing impairment of hearing

Learning disorders

313.83	Academic underachievement disorder
315.00	Reading disorder, unspecified
315.01	Alexia
315.02	Developmental dyslexia
315.09	Other specific reading disorder
315.1	Mathematics disorder
315.2	Other specific learning difficulties
315.8	Other specified delays in development
315.9	Unspecified delay in development
784.61	Alexia and dyslexia

Cerebral palsy - control condition

342.00	Flaccid hemiplegia, affecting unspecified side
342.01	Flaccid hemiplegia, affecting dominant side
342.02	Flaccid hemiplegia, affecting nondominant side
342.10	Spastic hemiplegia, affecting unspecified side
342.11	Spastic hemiplegia, affecting dominant side
342.12	Spastic hemiplegia, affecting nondominant side
342.80	Other specified hemiplegia, affecting unspecified side

342.81	Other specified hemiplegia, affecting dominant side
342.82	Other specified hemiplegia, affecting nondominant side
342.90	Unspecified hemiplegia, affecting unspecified side
342.91	Unspecified hemiplegia, affecting dominant side
342.92	Unspecified hemiplegia, affecting nondominant side
343.0	Infantile cerebral palsy, diplegic
343.1	Infantile cerebral palsy, hemiplegic
343.2	Infantile cerebral palsy, quadriplegic
343.3	Infantile cerebral palsy, monoplegic
343.4	Infantile hemiplegia
343.8	Other specified infantile cerebral palsy
343.9	Infantile cerebral palsy unspecified
348.1	Anoxic brain damage
768.5	Severe birth asphyxia
768.70	Hypoxic-ischemic encephalopathy, unspecified
768.71	Mild hypoxic-ischemic encephalopathy
768.72	Moderate hypoxic-ischemic encephalopathy
768.73	Severe hypoxic-ischemic encephalopathy

Asthma - control condition

493.00	Extrinsic asthma, unspecified
493.01	Extrinsic asthma, with status asthmaticus
493.02	Extrinsic asthma, with (acute) exacerbation
493.10	Intrinsic asthma, unspecified
493.11	intrinsic asthma, with status asthmaticus
493.12	Intrinsic asthma, with (acute) exacerbation
493.20	Chronic obstructive asthma, unspecified
493.21	Chronic obstructive asthma, with status asthmaticus
493.22	Chronic obstructive asthma, with (acute) exacerbation
493.82	Cough variant asthma
493.90	Asthma, unspecified
493.91	Asthma, unspecified type with status asthmaticus
493.92	Asthma, unspecified with (acute) exacerbation

Part C: Medication groupings, using generic names

ADHD medications
amphetamine, dextroamphetamine, dexmethylphenidate, lisdexamfetamine, methamphetamine, methylphenidate, modafinil, atomoxetine, clonidine, guanfacine, bupropion, imipramine, nortriptyline, desipramine

Antipsychotic medications
aripiprazole, asenapine, benperidol, chlorpromazine, clopenthixol, clotiapine, clozapine, droperidol, flupenthixol, fluphenazine, fluspirilene, haloperidol, iloperidone, levomepromazine, loxapine, lurasidone, mesoridazine, molindone, olanzapine, paliperidone, pericyazine, perphenazine, perphenazine, pimozide, pipotiazine, promazine, quetiapine, risperidone, thioridazine, thiothixene, trifluoperazine, triflupromazine, zuclopenthixol, and combined agents amitriptyline/perphenazine and olanzapine/fluoxetine

Antidepressants
amitriptyline, bupropion, citalopram, clomipramine, desipramine, desvenlafaxine, doxepin, duloxetine, escitalopram, fluoxetine, fluvoxamine, imipramine, isocarboxazid, levomilnacipram, milnacipram, mirtazapine, nortriptyline, paroxetine, phenelzine, selegiline, sertraline, tranylcypromine, trazadone, trimipramine, venlafaxine, and combined agents amitriptyline/perphenazine and chlordiazepoxide/amitriptyline

Anxiolytic/hypnotic medications
alprazolam, atenolol, bromazepam, buspirone, chlordiazepoxide, clonazepam, clorazepate, diazepam, flurazepam, lorazepam, oxazepam, pregabalin, propranolol, temazepam, triazolam, and combined agent chlordiazepoxide/amitriptyline

Mood stabilizers
carbamazepine, gabapentin, lamotrigine, lithium, oxcarbazepine, topiramate, valproic acid/valproate/divalproex, zonisamide

Part D: Non-pharmacological treatments (Current Procedural Terminology, CPT)*

Code	Description
90801	Psychiatric Diagnostic Interview Examination
90802	Interactive Psychiatric Diagnostic Interview Examination
90820	Interactive Medical Psychiatric Diagnostic Interview Examination
90804	Office/OP Insight, Beh. Mod., or Supportive Psychotherapy, 20-30 min.
90805	Office/OP Insight, Beh. Mod., or Supportive Psychotherapy, 20-30 min. (w/eval. and mgmt.)
90806	Office/OP Insight, Beh. Mod., or Supportive Psychotherapy, 45-50 min.
90807	Office/OP Insight, Beh. Mod., or Supportive Psychotherapy, 45-50 min. (w/eval. and mgmt.)
90808	Office/OP Insight, Beh. Mod., or Supportive Psychotherapy, 75-80 min.
90809	Office/OP Insight, Beh. Mod., or Supportive Psychotherapy, 75-80 min. (w/eval. and mgmt.)
90810	Office/OP Interactive Psychotherapy, 20-30 min.
90811	Office/OP Interactive Psychotherapy, 20-30 min. (w/eval. and mgmt.)
90812	Office/OP Interactive Psychotherapy, 45-50 min.
90813	Office/OP Interactive Psychotherapy, 45-50 min. (w/eval. and mgmt.)
90814	Office/OP Interactive Psychotherapy, 75-80 min.
90815	Office/OP Interactive Psychotherapy, 75-80 min. (w/eval. and mgmt.)
90816	IP, Partial Hosp. or Res. Insight, Beh. Mod., or Supportive Psychotherapy, 20-30 min.
90817	IP, Partial Hosp. or Res. Insight, Beh. Mod., or Supportive Psychotherapy, 20-30 min. (w/eval. and mgmt.)
90818	IP, Partial Hosp. or Res. Insight, Beh. Mod., or Supportive Psychotherapy, 45-50 min.
90819	IP, Partial Hosp. or Res. Insight, Beh. Mod., or Supportive Psychotherapy, 45-50 min. (w/eval. and mgmt.)
90821	IP, Partial Hosp. or Res. Insight, Beh. Mod., or Supportive Psychotherapy, 75-80 min.
90822	IP, Partial Hosp. or Res. Insight, Beh. Mod., or Supportive Psychotherapy, 45-50 min. (w/eval. and mgmt.)
90823	IP, Partial Hosp. or Res. Interactive Psychotherapy, 20-30 min.
90824	IP, Partial Hosp. or Res. Interactive Psychotherapy, 20-30 min. (w/eval. and mgmt.)
90826	IP, Partial Hosp. or Res. Interactive Psychotherapy, 45-50 min.
90827	IP, Partial Hosp. or Res. Interactive Psychotherapy, 45-50 min. (w/eval. and mgmt.)
90828	IP, Partial Hosp. or Res. Interactive Psychotherapy, 75-80 min.
90829	IP, Partial Hosp. or Res. Interactive Psychotherapy, 75-80 min. (w/eval. and mgmt.)
90845	Other Psychotherapy, Psychoanalysis
90846	Other Psychotherapy, Family Psychotherapy (wo/patient present)
90847	Other Psychotherapy, Family Psychotherapy (w/patient present)
90849	Other Psychotherapy, Multiple-family Group Psychotherapy
90853	Other Psychotherapy, Group Psychotherapy (other than multiple family-group)
90857	Other Psychotherapy, Interactive Group Psychotherapy
90875	Individual Psychophysiological Psychotherapy, 20-30 min.
90876	Individual Psychophysiological Psychotherapy, 45-50 min.
90880	Hypnotherapy
90882	Environ. Intervention for Medical Mgmt. Purposes
90841	Individual Medical Psychotherapy by Physician w/Continuing Diagnostic Eval. and Drug Mgmt., time unspecified (code no longer used)
90842	Individual Medical Psychotherapy by Physician w/Continuing Diagnostic Eval. and Drug Mgmt., 75-80 min
90843	Individual Medical Psychotherapy by Physician w/Continuing Diagnostic Eval. and Drug Mgmt., 20-30 min
90844	Individual Medical Psychotherapy by Physician w/Continuing Diagnostic Eval. and Drug Mgmt., 45-50 min
90855	Interactive Individual Medical Psychotherapy

* includes discontinued codes that may still appear in the claims data.

Project conducted by:
Center for Health Services Research on Pharmacotherapy, Chronic Disease Management, and Outcomes, and Center for Education and Research on Mental Health Therapeutics
Institute for Health, Health Care Policy, and Aging Research
Rutgers University

Appendix G

Medicaid Analytic eXtract Results

Table G-1a

Medicaid Basis of Eligibility (BoE)[1] - Enrollees with ADHD

BoE	2001	2002	2003	2004	2005	2006	2007	2008	2009	2010
Foster Care	13.4%	12.5%	11.6%	10.8%	12.3%	12.9%	12.4%	11.5%	9.8%	9.2%
Other	62.2%	64.0%	66.1%	67.7%	66.4%	66.0%	67.1%	68.7%	70.2%	72.0%
SSI/Disability	24.4%	23.5%	22.2%	21.5%	21.3%	21.1%	20.5%	19.8%	20.0%	18.8%
	100%	100%	100%	100%	100%	100%	100%	100%	100%	100%
N	361,106	376,196	395,718	407,703	416,367	426,454	431,901	440,135	468,735	478,822

Table G-1b

Medicaid Basis of Eligibility (BoE)[1] - Enrollees without ADHD

BoE	2001	2002	2003	2004	2005	2006	2007	2008	2009	2010
Foster Care	4.6%	4.4%	4.2%	4.1%	4.0%	4.0%	4.0%	3.8%	3.2%	3.0%
Other	89.1%	89.6%	89.9%	90.1%	90.4%	90.2%	90.1%	90.5%	91.3%	92.0%
SSI/Disability	6.4%	6.0%	5.9%	5.8%	5.6%	5.8%	5.9%	5.7%	5.4%	5.1%
	100%	100%	100%	100%	100%	100%	100%	100%	100%	100%
N	5,074,216	5,568,409	5,926,814	6,108,254	6,378,130	6,343,426	6,286,656	6,550,711	7,139,286	7,759,711

Table G-1c

Medicaid Basis of Eligibility (BoE)[1] - All enrollees

BoE	2001	2002	2003	2004	2005	2006	2007	2008	2009	2010
Foster Care	4.8%	4.7%	4.5%	4.4%	4.3%	4.4%	4.4%	4.2%	3.6%	3.3%
Other	88.3%	88.8%	89.1%	89.2%	89.4%	89.2%	89.1%	89.4%	90.2%	90.9%
SSI/Disability	6.9%	6.5%	6.4%	6.4%	6.3%	6.4%	6.6%	6.4%	6.2%	5.8%
	100%	100%	100%	100%	100%	100%	100%	100%	100%	100%
N	5,232,083	5,749,809	6,144,784	6,356,411	6,658,353	6,630,423	6,593,490	6,899,748	7,545,081	8,208,507

Inclusion criteria: youth age 3-17 with 11+ months of Medicaid eligibility and no dual eligibility in the year.
Source: Medicaid Analytic Extract (MAX) data for 20 states: AK, AL, AR, CA, FL, ID, IL, IN, LA, MI, MS, MT, NC, ND, NH, NM, SD, VA, VT, WY.

[1] In the last month of observation for the enrollee.

Table G-2a

Diagnoses - All Enrollees

Diagnosis	2001	2002	2003	2004	2005	2006	2007	2008	2009	2010
ADHD	3.0%	3.2%	3.5%	3.9%	4.2%	4.3%	4.7%	5.1%	5.4%	5.5%
Conduct disorder	1.1%	1.1%	1.1%	1.2%	1.2%	1.2%	1.3%	1.3%	1.4%	1.4%
Emotional disturbances	1.4%	1.4%	1.4%	1.5%	1.5%	1.6%	1.7%	1.8%	1.8%	1.8%
Oppositional defiant disorder	0.8%	0.9%	0.9%	0.9%	1.1%	1.2%	1.4%	1.4%	1.5%	1.4%
Depression	1.7%	1.7%	1.9%	2.0%	1.9%	1.9%	2.0%	2.1%	2.2%	2.2%
Bipolar disorders	0.3%	0.3%	0.4%	0.5%	0.5%	0.6%	0.6%	0.6%	0.6%	0.6%
Anxiety disorders	0.5%	0.5%	0.6%	0.6%	0.8%	0.9%	1.0%	1.1%	1.2%	1.3%
Autism spectrum disorders	0.2%	0.2%	0.3%	0.3%	0.4%	0.5%	0.6%	0.6%	0.7%	0.7%
Intellectual disorders	0.6%	0.6%	0.6%	0.5%	0.5%	0.6%	0.6%	0.6%	0.6%	0.5%
Learning disorders	1.2%	1.1%	1.1%	1.0%	1.0%	1.1%	1.1%	1.1%	1.1%	1.2%
Any of the above	*7.9%*	*8.0%*	*8.4%*	*8.8%*	*9.2%*	*9.4%*	*10.0%*	*10.6%*	*11.0%*	*11.1%*
Speech and language disorders	1.6%	1.6%	1.6%	1.8%	2.0%	2.1%	2.0%	2.2%	2.4%	2.7%
Hearing disorders	4.9%	4.9%	5.1%	4.3%	4.7%	4.6%	4.8%	5.2%	5.7%	5.4%
Cerebral palsy	0.5%	0.5%	0.5%	0.5%	0.5%	0.5%	0.5%	0.5%	0.5%	0.4%
Asthma	2.3%	2.5%	2.8%	2.9%	3.2%	3.3%	3.4%	3.7%	4.3%	4.2%
N	5,232,083	5,749,809	6,144,784	6,356,411	6,658,353	6,630,423	6,593,490	6,899,748	7,545,081	8,208,507

Inclusion criteria: youth age 3-17 with 11+ months of Medicaid eligibility and no dual eligibility in the year.
Source: Medicaid Analytic Extract (MAX) data for 20 states: AK, AL, AR, CA, FL, ID, IL, IN, LA, MI, MS, MT, NC, ND, NH, NM, SD, VA, VT, WY.

A diagnosis was established based on the presence of one or more inpatient or two or more non-inpatient claims with qualifying ICD-9-CM codes.

Table G-2a (Ns)
Diagnoses - All Enrollees

Diagnosis	2001	2002	2003	2004	2005	2006	2007	2008	2009	2010
ADHD	157,867	181,400	217,970	248,157	280,223	286,997	306,834	349,037	405,795	448,796
Conduct disorder	56,189	63,443	69,909	73,841	76,985	78,507	82,497	92,676	107,546	113,367
Emotional disturbances	72,318	78,655	86,569	94,186	98,804	103,241	110,256	121,807	137,217	145,629
Oppositional defiant disorder	44,399	49,045	54,325	59,301	74,345	82,324	90,149	99,998	113,359	118,009
Depression	88,177	100,314	114,817	124,624	126,300	128,527	131,713	145,324	167,063	182,931
Bipolar disorders	15,923	19,417	24,416	29,740	34,189	36,616	40,266	43,427	46,999	48,018
Anxiety disorders	26,957	31,009	35,776	40,385	54,941	62,256	66,570	77,325	91,666	105,234
Autism spectrum disorders	11,746	13,465	16,373	18,753	28,486	32,772	38,155	44,804	49,699	57,758
Intellectual disorders	33,110	33,856	33,877	33,811	35,988	36,553	39,146	42,123	42,346	43,137
Learning disorders	62,126	64,606	66,378	66,428	68,794	72,325	69,711	75,656	85,646	101,565
Any of the above	*411,670*	*458,502*	*515,838*	*561,252*	*612,024*	*626,073*	*659,001*	*731,818*	*831,780*	*907,731*
Speech and language disorders	82,362	90,749	100,442	113,563	131,657	138,423	134,313	151,430	177,688	222,132
Hearing disorders	257,026	279,457	311,864	275,211	310,570	305,634	316,366	355,360	432,264	446,534
Cerebral palsy	27,694	28,937	31,612	32,373	33,028	33,582	34,440	35,134	35,811	36,488
Asthma	117,849	141,537	171,114	185,860	214,890	215,554	225,655	254,077	323,083	342,512

Inclusion criteria: youth age 3-17 with 11+ months of Medicaid eligibility and no dual eligibility in the year.
Source: Medicaid Analytic Extract (MAX) data for 20 states: AK, AL, AR, CA, FL, ID, IL, IN, LA, MI, MS, MT, NC, ND, NH, NM, SD, VA, VT, WY.

A diagnosis was established based on the presence of one or more inpatient or two or more non-inpatient claims with qualifying ICD-9-CM codes.

Table G-2b
Diagnoses - SSI/Disability Enrollees

Diagnosis	2001	2002	2003	2004	2005	2006	2007	2008	2009	2010
ADHD	10.7%	11.3%	12.3%	13.1%	14.4%	14.2%	14.5%	15.7%	17.3%	17.7%
Conduct disorder	3.5%	3.7%	3.8%	4.0%	4.0%	3.9%	3.9%	4.2%	4.7%	4.6%
Emotional disturbances	4.2%	4.4%	4.5%	4.7%	4.7%	4.7%	4.9%	5.2%	5.4%	5.4%
Oppositional defiant disorder	2.7%	2.9%	3.0%	3.0%	3.5%	3.7%	4.0%	4.2%	4.6%	4.5%
Depression	4.0%	4.3%	4.5%	4.6%	4.5%	4.4%	4.4%	4.8%	5.4%	5.5%
Bipolar disorders	1.4%	1.7%	1.9%	2.3%	2.4%	2.5%	2.7%	2.8%	3.0%	2.8%
Anxiety disorders	0.8%	0.8%	0.9%	1.0%	1.2%	1.3%	1.5%	1.6%	1.8%	2.0%
Autism spectrum disorders	2.2%	2.4%	2.7%	3.0%	3.8%	4.2%	4.9%	5.7%	6.0%	6.7%
Intellectual disorders	6.6%	6.5%	6.2%	6.2%	6.4%	6.4%	6.8%	7.1%	6.6%	6.4%
Learning disorders	5.6%	5.7%	5.8%	5.9%	5.9%	6.0%	5.7%	5.8%	6.0%	6.8%
Any of the above	*29.2%*	*30.2%*	*31.0%*	*32.2%*	*33.7%*	*33.3%*	*34.0%*	*36.0%*	*37.8%*	*38.6%*
Speech and language disorders	6.3%	6.6%	6.9%	7.5%	8.4%	8.8%	8.6%	9.5%	10.3%	11.9%
Hearing disorders	8.6%	8.5%	8.4%	7.6%	7.7%	7.5%	7.7%	8.1%	8.6%	8.5%
Cerebral palsy	6.2%	6.2%	6.3%	6.3%	6.1%	6.1%	6.1%	6.1%	5.8%	5.7%
Asthma	4.9%	5.3%	5.7%	5.9%	6.3%	6.3%	6.5%	7.0%	8.0%	7.9%
N	361,106	376,196	395,718	407,703	416,367	426,454	431,901	440,135	468,735	478,822

Inclusion criteria: youth age 3-17 with 11+ months of Medicaid eligibility and no dual eligibility in the year.
Source: Medicaid Analytic Extract (MAX) data for 20 states: AK, AL, AR, CA, FL, ID, IL, IN, LA, MI, MS, MT, NC, ND, NH, NM, SD, VA, VT, WY.

A diagnosis was established based on the presence of one or more inpatient or two or more non-inpatient claims with qualifying ICD-9-CM codes.

Table G-2b (Ns)
Diagnoses - SSI/Disability Enrollees

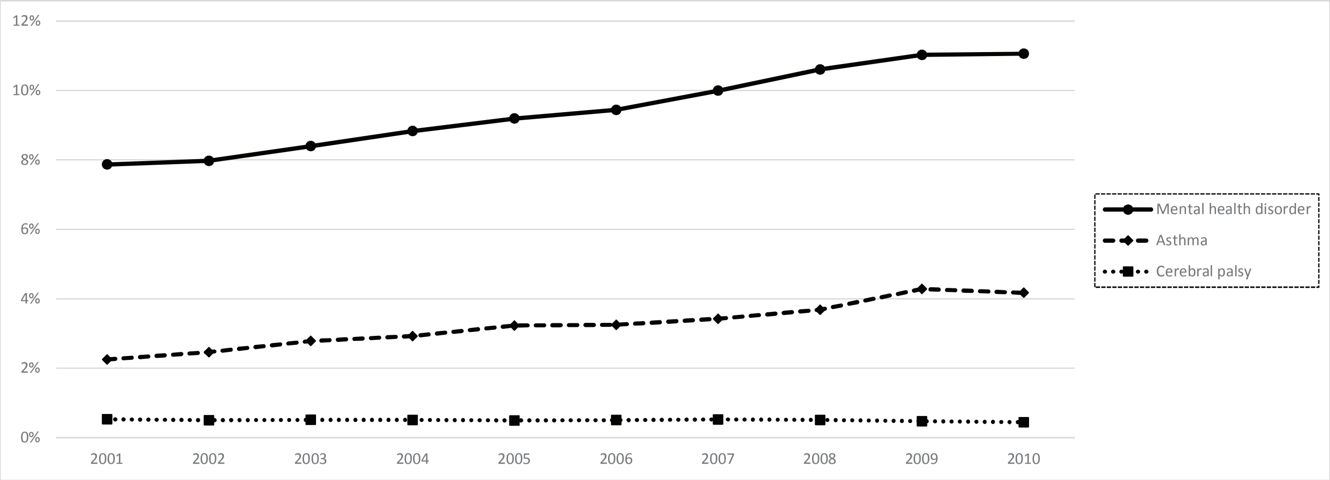
Diagnosis	2001	2002	2003	2004	2005	2006	2007	2008	2009	2010
ADHD	38,466	42,603	48,485	53,357	59,756	60,492	62,787	69,149	81,051	84,519
Conduct disorder	12,473	14,083	15,228	16,226	16,788	16,478	16,730	18,506	21,835	22,067
Emotional disturbances	15,180	16,534	17,907	19,168	19,628	20,184	21,117	22,702	25,464	25,870
Oppositional defiant disorder	9,884	10,902	11,781	12,412	14,565	15,840	17,246	18,639	21,331	21,320
Depression	14,478	16,198	17,769	18,745	18,576	18,669	19,004	21,295	25,213	26,251
Bipolar disorders	5,211	6,337	7,640	9,206	10,167	10,693	11,511	12,364	13,846	13,550
Anxiety disorders	2,916	3,150	3,557	3,970	5,117	5,677	6,295	7,234	8,522	9,473
Autism spectrum disorders	8,072	9,075	10,859	12,273	15,685	18,056	21,284	25,203	28,132	31,876
Intellectual disorders	23,872	24,371	24,499	25,079	26,506	27,407	29,515	31,153	30,956	30,563
Learning disorders	20,266	21,352	22,941	23,992	24,758	25,742	24,419	25,650	28,195	32,546
Any of the above	*105,298*	*113,586*	*122,609*	*131,420*	*140,233*	*141,913*	*146,859*	*158,246*	*177,280*	*184,856*
Speech and language disorders	22,787	24,742	27,333	30,509	35,141	37,667	37,256	41,885	48,361	57,106
Hearing disorders	30,919	32,074	33,438	30,981	31,853	32,106	33,110	35,497	40,537	40,861
Cerebral palsy	22,426	23,212	24,956	25,610	25,598	25,953	26,504	26,872	27,266	27,361
Asthma	17,622	19,885	22,719	24,144	26,243	26,893	28,078	30,708	37,307	38,034

Inclusion criteria: youth age 3-17 with 11+ months of Medicaid eligibility and no dual eligibility in the year.
Source: Medicaid Analytic Extract (MAX) data for 20 states: AK, AL, AR, CA, FL, ID, IL, IN, LA, MI, MS, MT, NC, ND, NH, NM, SD, VA, VT, WY.

A diagnosis was established based on the presence of one or more inpatient or two or more non-inpatient claims with qualifying ICD-9-CM codes.

Figure G-1

Diagnoses - All Enrollees



Mental health disorder: ADHD, conduct disorders, emotional disturbances, oppositional defiant disorder, depression, bipolar disorders, anxiety disorders, intellectual disorders, learning disorders, autism spectrum disorders.

Inclusion criteria: youth age 3-17 with 11+ months of Medicaid eligibility and no dual eligibility in the year.
Source: Medicaid Analytic Extract (MAX) data for 20 states: AK, AL, AR, CA, FL, ID, IL, IN, LA, MI, MS, MT, NC, ND, NH, NM, SD, VA, VT, WY

A diagnosis was established based on the presence of one or more inpatient or two or more non-inpatient claims with qualifying ICD-9-CM codes.

(Data for Figure G-1)

Diagnoses - All Enrollees

Diagnosis	2001	2002	2003	2004	2005	2006	2007	2008	2009	2010
ADHD	3.0%	3.2%	3.5%	3.9%	4.2%	4.3%	4.7%	5.1%	5.4%	5.5%
Other mental health disorder	6.3%	6.5%	7.0%	7.5%	7.8%	8.0%	8.5%	9.0%	9.5%	9.5%
Mental health disorder (broad)	7.9%	8.0%	8.4%	8.8%	9.2%	9.4%	10.0%	10.6%	11.0%	11.1%
Developmental disorder	7.8%	7.7%	7.9%	7.2%	7.8%	7.9%	8.1%	8.6%	9.2%	9.3%
Cerebral palsy	0.5%	0.5%	0.5%	0.5%	0.5%	0.5%	0.5%	0.5%	0.5%	0.4%
Asthma	2.3%	2.5%	2.8%	2.9%	3.2%	3.3%	3.4%	3.7%	4.3%	4.2%
N	5,232,083	5,749,809	6,144,784	6,356,411	6,658,353	6,630,423	6,593,490	6,899,748	7,545,081	8,208,507

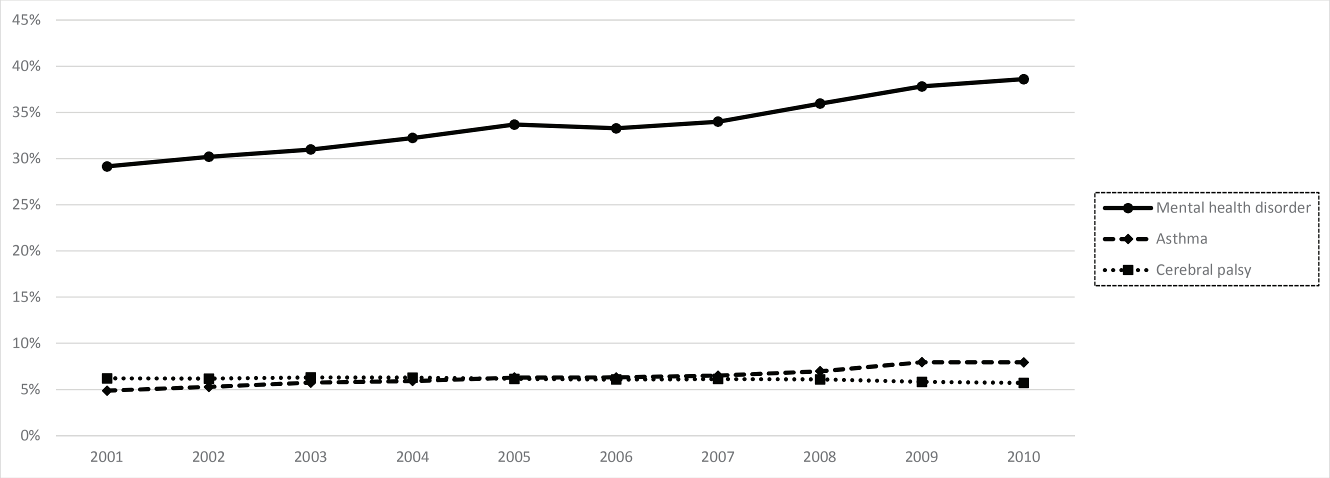
Other mental health disorder: conduct disorder, emotional disturbances, oppositional defiant disorder, depression, bipolar disorders, anxiety disorders (ADHD excluded).
Mental health disorder (broad): ADHD, conduct disorders, emotional disturbances, oppositional defiant disorder, depression, bipolar disorders, anxiety disorders, intellectual disorders, learning disorders, autism spectrum disorders.
Developmental disorder: autism spectrum disorders, intellectual disorders, speech and language disorders, hearing disorders, learning disorders.

Inclusion criteria: youth age 3-17 with 11+ months of Medicaid eligibility and no dual eligibility in the year.
Source: Medicaid Analytic Extract (MAX) data for 20 states: AK, AL, AR, CA, FL, ID, IL, IN, LA, MI, MS, MT, NC, ND, NH, NM, SD, VA, VT, WY.

A diagnosis was established based on the presence of one or more inpatient or two or more non-inpatient claims with qualifying ICD-9-CM codes.

Figure G-2

Diagnoses - SSI/Disability Enrollees



<u>Mental health disorder</u>: ADHD, conduct disorders, emotional disturbances, oppositional defiant disorder, depression, bipolar disorders, anxiety disorders, intellectual disorders, learning disorders, autism spectrum disorders.

Inclusion criteria: youth age 3-17 with 11+ months of Medicaid eligibility and no dual eligibility in the year.
Source: Medicaid Analytic Extract (MAX) data for 20 states: AK, AL, AR, CA, FL, ID, IL, IN, LA, MI, MS, MT, NC, ND, NH, NM, SD, VA, VT, WY

A diagnosis was established based on the presence of one or more inpatient or two or more non-inpatient claims with qualifying ICD-9-CM codes.

(Data for Figure G-2)
Diagnoses - SSI/Disability Enrollees

Diagnosis	2001	2002	2003	2004	2005	2006	2007	2008	2009	2010
ADHD	10.7%	11.3%	12.3%	13.1%	14.4%	14.2%	14.5%	15.7%	17.3%	17.7%
Other mental health disorder	18.5%	19.6%	20.6%	21.7%	22.7%	21.9%	22.2%	23.7%	25.8%	26.0%
Mental health disorder (broad)	29.2%	30.2%	31.0%	32.2%	33.7%	33.3%	34.0%	36.0%	37.8%	38.6%
Developmental disorder	23.8%	24.2%	24.2%	24.2%	25.4%	25.9%	26.2%	27.5%	28.3%	29.9%
Cerebral palsy	6.2%	6.2%	6.3%	6.3%	6.1%	6.1%	6.1%	6.1%	5.8%	5.7%
Asthma	4.9%	5.3%	5.7%	5.9%	6.3%	6.3%	6.5%	7.0%	8.0%	7.9%
N	361,106	376,196	395,718	407,703	416,367	426,454	431,901	440,135	468,735	478,822

Other mental health disorder: conduct disorder, emotional disturbances, oppositional defiant disorder, depression, bipolar disorders, anxiety disorders (ADHD excluded).
Mental health disorder (broad): ADHD, conduct disorders, emotional disturbances, oppositional defiant disorder, depression, bipolar disorders, anxiety disorders, intellectual disorders, learning disorders, autism spectrum disorders.
Developmental disorder: autism spectrum disorders, intellectual disorders, speech and language disorders, hearing disorders, learning disorders.

Inclusion criteria: youth age 3-17 with 11+ months of Medicaid eligibility and no dual eligibility in the year.
Source: Medicaid Analytic Extract (MAX) data for 20 states: AK, AL, AR, CA, FL, ID, IL, IN, LA, MI, MS, MT, NC, ND, NH, NM, SD, VA, VT, WY.

A diagnosis was established based on the presence of one or more inpatient or two or more non-inpatient claims with qualifying ICD-9-CM codes.

Table G-3a

ADHD Type - All Enrollees

ADHD Type	2001	2002	2003	2004	2005	2006	2007	2008	2009	2010
ADHD with no other mental health/developmental dxs	1.9%	2.0%	2.2%	2.4%	2.6%	2.5%	2.7%	2.9%	3.1%	3.1%
ADHD with one or more other mental health/developmental dxs	1.2%	1.2%	1.4%	1.5%	1.6%	1.8%	1.9%	2.1%	2.3%	2.4%
Proportion with one or more other mental health dxs	*38.2%*	*37.8%*	*38.4%*	*37.8%*	*38.7%*	*41.2%*	*41.6%*	*42.2%*	*42.7%*	*43.3%*
ADHD without externalizing disorder (CD/ODD)	2.5%	2.7%	3.0%	3.3%	3.5%	3.6%	3.8%	4.1%	4.4%	4.5%
ADHD with externalizing disorder (CD/ODD)	0.5%	0.5%	0.6%	0.6%	0.7%	0.8%	0.8%	0.9%	1.0%	1.0%
Proportion with externalizing disorder (CD/ODD)	*15.8%*	*15.7%*	*15.5%*	*15.2%*	*15.7%*	*17.5%*	*18.1%*	*18.4%*	*18.6%*	*18.3%*
N	5,232,083	5,749,809	6,144,784	6,356,411	6,658,353	6,630,423	6,593,490	6,899,748	7,545,081	8,208,507

Table G-3b

ADHD Type - SSI/Disability Enrollees

ADHD Type	2001	2002	2003	2004	2005	2006	2007	2008	2009	2010
ADHD with no other mental health/developmental dxs	5.7%	6.0%	6.3%	6.8%	7.4%	6.8%	6.7%	7.1%	7.9%	7.8%
ADHD with one or more other mental health/developmental dxs	4.9%	5.4%	5.9%	6.3%	6.9%	7.4%	7.8%	8.6%	9.4%	9.8%
Proportion with one or more other mental health dxs	*46.3%*	*47.3%*	*48.3%*	*48.1%*	*48.3%*	*52.1%*	*53.9%*	*54.5%*	*54.5%*	*55.8%*
ADHD without externalizing disorder (CD/ODD)	8.6%	9.1%	9.8%	10.5%	11.5%	11.0%	11.2%	12.0%	13.2%	13.5%
ADHD with externalizing disorder (CD/ODD)	2.0%	2.2%	2.5%	2.6%	2.9%	3.1%	3.4%	3.7%	4.1%	4.1%
Proportion with externalizing disorder (CD/ODD)	*19.2%*	*19.8%*	*20.3%*	*19.7%*	*19.9%*	*22.1%*	*23.2%*	*23.5%*	*23.8%*	*23.4%*
N	361,106	376,196	395,718	407,703	416,367	426,454	431,901	440,135	468,735	478,822

Inclusion criteria: youth age 3-17 with 11+ months of Medicaid eligibility and no dual eligibility in the year.
Source: Medicaid Analytic Extract (MAX) data for 20 states: AK, AL, AR, CA, FL, ID, IL, IN, LA, MI, MS, MT, NC, ND, NH, NM, SD, VA, VT, WY.

Row groups are not all mutually exclusive, but each "with/without" pair is.

Table G-4a

Comorbid diagnoses - All Enrollees with ADHD

Diagnosis	2001	2002	2003	2004	2005	2006	2007	2008	2009	2010
ADHD										
Conduct disorder	8.1%	8.0%	7.9%	7.8%	7.9%	8.4%	8.5%	8.7%	8.8%	8.6%
Emotional disturbances	11.6%	11.4%	11.2%	10.9%	11.4%	12.8%	13.2%	13.4%	13.5%	13.4%
Oppositional defiant disorder	9.4%	9.4%	9.3%	9.1%	9.6%	11.1%	11.6%	11.8%	11.9%	11.7%
Depression	9.3%	9.1%	9.5%	9.8%	9.6%	10.4%	10.2%	10.4%	10.8%	11.2%
Bipolar disorders	3.4%	3.6%	4.0%	4.6%	4.9%	5.4%	5.4%	5.3%	5.0%	4.7%
Anxiety disorders	2.7%	2.7%	3.0%	3.1%	3.4%	3.8%	3.9%	4.2%	4.6%	5.1%
Autism spectrum disorders	1.0%	1.1%	1.2%	1.3%	1.9%	2.2%	2.6%	2.9%	2.9%	3.2%
Intellectual disorders	2.1%	2.0%	1.8%	1.6%	1.6%	1.7%	1.7%	1.6%	1.4%	1.4%
Learning disorders	4.1%	4.1%	3.8%	3.7%	3.6%	3.8%	3.5%	3.5%	3.6%	3.9%
Speech and language disorders	4.5%	4.4%	4.7%	4.9%	4.9%	5.2%	5.1%	5.3%	5.6%	6.4%
Hearing disorders	7.7%	7.6%	7.9%	6.9%	6.9%	6.6%	6.6%	6.8%	7.0%	6.7%
Cerebral palsy	0.5%	0.4%	0.5%	0.4%	0.4%	0.5%	0.5%	0.4%	0.4%	0.4%
Asthma	4.2%	4.6%	5.1%	5.4%	6.0%	6.1%	6.2%	6.3%	7.0%	6.9%
N	157,867	181,400	217,970	248,157	280,223	286,997	306,834	349,037	405,795	448,796

Inclusion criteria: youth age 3-17 with 11+ months of Medicaid eligibility and no dual eligibility in the year.
Source: Medicaid Analytic Extract (MAX) data for 20 states: AK, AL, AR, CA, FL, ID, IL, IN, LA, MI, MS, MT, NC, ND, NH, NM, SD, VA, VT, WY.

A diagnosis was established based on the presence of one or more inpatient or two or more non-inpatient claims with qualifying ICD-9-CM codes.

Table G-4b

Comorbid diagnoses - SSI/Disability Enrollees with ADHD

Diagnosis	2001	2002	2003	2004	2005	2006	2007	2008	2009	2010
ADHD										
Conduct disorder	10.2%	10.6%	10.8%	10.8%	10.6%	11.2%	11.2%	11.4%	11.6%	11.4%
Emotional disturbances	13.5%	13.6%	14.1%	13.6%	13.9%	15.8%	16.8%	17.0%	16.9%	16.7%
Oppositional defiant disorder	11.2%	11.5%	11.9%	11.4%	11.9%	13.9%	15.0%	15.2%	15.3%	14.9%
Depression	9.7%	9.9%	10.4%	10.6%	10.4%	11.3%	11.3%	12.2%	12.7%	13.4%
Bipolar disorders	5.4%	5.8%	6.5%	7.3%	7.7%	8.5%	8.9%	8.6%	8.3%	8.0%
Anxiety disorders	2.0%	2.0%	2.2%	2.5%	2.6%	3.0%	3.3%	3.6%	3.7%	4.2%
Autism spectrum disorders	2.6%	2.8%	3.3%	3.7%	4.4%	5.4%	6.4%	7.4%	7.4%	8.2%
Intellectual disorders	5.5%	5.5%	5.3%	4.8%	4.8%	5.3%	5.4%	5.2%	4.4%	4.4%
Learning disorders	6.3%	6.6%	6.4%	6.4%	6.2%	6.4%	6.0%	6.1%	6.1%	6.8%
Speech and language disorders	6.7%	6.9%	7.3%	8.1%	8.1%	8.7%	8.8%	9.5%	10.1%	11.5%
Hearing disorders	7.8%	7.8%	7.8%	7.0%	6.9%	6.7%	7.0%	7.1%	7.2%	6.9%
Cerebral palsy	1.3%	1.3%	1.4%	1.4%	1.3%	1.5%	1.5%	1.4%	1.3%	1.3%
Asthma	4.7%	5.5%	6.2%	6.5%	7.3%	7.5%	7.6%	7.9%	8.6%	8.6%
N	38,466	42,603	48,485	53,357	59,756	60,492	62,787	69,149	81,051	84,519

Inclusion criteria: youth age 3-17 with 11+ months of Medicaid eligibility and no dual eligibility in the year.
Source: Medicaid Analytic Extract (MAX) data for 20 states: AK, AL, AR, CA, FL, ID, IL, IN, LA, MI, MS, MT, NC, ND, NH, NM, SD, VA, VT, WY.

A diagnosis was established based on the presence of one or more inpatient or two or more non-inpatient claims with qualifying ICD-9-CM codes.

Table G-5a

Diagnoses by Age, in 2010 - SSI/Disability Enrollees

Diagnosis	Age 3-5	Age 6-11	Age 12-17
ADHD	6.5%	21.9%	17.6%
Conduct disorder	3.0%	4.4%	5.3%
Emotional disturbances	1.9%	5.2%	6.8%
Oppositional defiant disorder	1.0%	4.3%	5.8%
Depression	0.6%	3.8%	8.7%
Bipolar disorders	0.2%	1.9%	4.6%
Anxiety disorders	0.7%	2.0%	2.3%
Autism spectrum disorders	7.9%	7.8%	5.2%
Intellectual disorders	2.9%	6.3%	7.6%
Learning disorders	12.1%	7.4%	4.4%
Speech and language disorders	20.7%	15.3%	5.8%
Hearing disorders	19.8%	8.6%	4.6%
Cerebral palsy	7.3%	6.0%	5.0%
Asthma	12.8%	8.8%	5.5%
N	72,940	193,479	212,403

Inclusion criteria: youth age 3-17 with 11+ months of Medicaid eligibility and no dual eligibility in the year.
Source: Medicaid Analytic Extract (MAX) data for 20 states: AK, AL, AR, CA, FL, ID, IL, IN, LA, MI, MS, MT, NC, ND, NH, NM, SD, VA, VT, WY.

A diagnosis was established based on the presence of one or more inpatient or two or more non-inpatient claims with qualifying ICD-9-CM codes.
Some sex and race/ethnicity data were missing.

Table G-5b

Diagnoses by Sex, in 2010 - SSI/Disability Enrollees

Diagnosis	Female	Male
ADHD	11.7%	20.6%
Conduct disorder	3.2%	5.3%
Emotional disturbances	4.3%	6.0%
Oppositional defiant disorder	3.4%	5.0%
Depression	5.8%	5.3%
Bipolar disorders	2.7%	2.9%
Anxiety disorders	2.2%	1.9%
Autism spectrum disorders	4.0%	8.0%
Intellectual disorders	7.1%	6.0%
Learning disorders	6.8%	6.8%
Speech and language disorders	11.1%	12.4%
Hearing disorders	10.0%	7.8%
Cerebral palsy	7.3%	4.9%
Asthma	7.9%	8.0%
N	159,270	319,549

Inclusion criteria: youth age 3-17 with 11+ months of Medicaid eligibility and no dual eligibility in the year.
Source: Medicaid Analytic Extract (MAX) data for 20 states: AK, AL, AR, CA, FL, ID, IL, IN, LA, MI, MS, MT, NC, ND, NH, NM, SD, VA, VT, WY.

A diagnosis was established based on the presence of one or more inpatient or two or more non-inpatient claims with qualifying ICD-9-CM codes.
Some sex and race/ethnicity data were missing.

Table G-5c
Diagnoses by Race/ethnicity, in 2010 - SSI/Disability Enrollees

Diagnosis	White	Black/Af. Am.	Am. Indian/AK Native	Asian	Hispanic/Latino	More than 1/Unknown
ADHD	23.3%	18.8%	18.4%	4.5%	10.3%	15.7%
Conduct disorder	5.2%	5.1%	4.3%	2.1%	3.7%	4.1%
Emotional disturbances	6.9%	6.6%	7.6%	1.0%	3.2%	4.1%
Oppositional defiant disorder	5.6%	5.8%	5.7%	0.7%	2.2%	3.3%
Depression	8.0%	5.5%	8.1%	1.9%	5.2%	3.9%
Bipolar disorders	5.6%	2.2%	3.4%	0.7%	1.9%	1.9%
Anxiety disorders	3.5%	1.3%	2.8%	1.0%	2.1%	1.7%
Autism spectrum disorders	12.5%	3.7%	5.1%	11.0%	6.0%	5.8%
Intellectual disorders	10.6%	3.8%	3.5%	25.9%	11.6%	3.9%
Learning disorders	8.5%	5.5%	10.4%	5.3%	5.5%	7.3%
Speech and language disorders	14.6%	9.0%	17.1%	10.9%	8.4%	14.0%
Hearing disorders	11.4%	4.8%	10.6%	7.4%	10.1%	9.7%
Cerebral palsy	8.6%	3.3%	5.1%	12.8%	9.1%	4.9%
Asthma	6.3%	9.2%	8.5%	4.2%	7.4%	8.1%
N	104,116	152,011	5,320	3,635	49,189	161,876

Inclusion criteria: youth age 3-17 with 11+ months of Medicaid eligibility and no dual eligibility in the year.
Source: Medicaid Analytic Extract (MAX) data for 20 states: AK, AL, AR, CA, FL, ID, IL, IN, LA, MI, MS, MT, NC, ND, NH, NM, SD, VA, VT, WY.

A diagnosis was established based on the presence of one or more inpatient or two or more non-inpatient claims with qualifying ICD-9-CM codes.

Table G-6a
ADHD Treatment - All Enrollees with ADHD

Treatment status	2001	2002	2003	2004	2005	2006	2007	2008	2009	2010
Not Treated	13.1%	12.2%	10.3%	8.5%	9.9%	10.0%	9.8%	9.3%	8.8%	8.0%
Treated with medication only	65.2%	66.8%	60.9%	52.6%	53.2%	52.5%	51.7%	51.8%	52.4%	53.2%
Treated with psychotherapy only	3.2%	2.9%	4.6%	6.1%	6.2%	7.0%	7.2%	7.2%	7.0%	6.7%
Treated with both medication and psychotherapy	18.5%	18.1%	24.2%	32.8%	30.8%	30.6%	31.4%	31.7%	31.8%	32.1%
N	157,867	181,400	217,970	248,157	280,223	286,997	306,834	349,037	405,795	448,796

Table G-6b
ADHD Treatment - SSI/Disability Enrollees with ADHD

Treatment status	2001	2002	2003	2004	2005	2006	2007	2008	2009	2010
Not Treated	15.3%	14.6%	12.6%	11.0%	11.5%	10.2%	9.5%	9.3%	8.6%	7.6%
Treated with medication only	67.6%	68.4%	60.2%	49.6%	50.7%	50.5%	48.6%	48.0%	50.1%	50.2%
Treated with psychotherapy only	2.2%	1.9%	3.6%	5.0%	5.2%	6.1%	6.6%	6.9%	6.0%	8.2%
Treated with both medication and psychotherapy	14.9%	15.1%	23.6%	34.4%	32.6%	33.1%	35.3%	35.8%	35.3%	36.4%
N	38,466	42,603	48,485	53,357	59,756	60,492	62,787	69,149	81,051	84,519

Inclusion criteria: youth age 3-17 with 11+ months of Medicaid eligibility and no dual eligibility in the year.
Source: Medicaid Analytic Extract (MAX) data for 20 states: AK, AL, AR, CA, FL, ID, IL, IN, LA, MI, MS, MT, NC, ND, NH, NM, SD, VA, VT, WY.

A diagnosis was established based on the presence of one or more inpatient or two or more non-inpatient claims with qualifying ICD-9-CM codes.

Medications are limited to those on the ADHD medication list.

Table G-7a

Mental Health Treatment - All Enrollees with One or More Mental Health/Developmental Diagnoses, in 2010

Diagnosis	Not Treated	Treated with medication only	Treated with psychotherapy only	Treated with both medication and psychotherapy	
ADHD	6.9%	54.3%	5.2%	33.6%	100%
Conduct disorder	27.4%	21.7%	18.2%	32.7%	100%
Emotional disturbances	22.8%	19.6%	19.1%	38.4%	100%
Oppositional defiant disorder	20.6%	19.9%	18.4%	41.1%	100%
Depression	21.8%	25.2%	14.1%	38.9%	100%
Bipolar disorders	4.6%	35.4%	4.2%	55.8%	100%
Anxiety disorders	26.2%	15.3%	29.5%	29.0%	100%
Autism spectrum disorders	28.8%	31.7%	12.0%	27.5%	100%
Intellectual disorders	42.0%	35.3%	7.3%	15.3%	100%
Learning disorders	49.9%	19.2%	17.2%	13.8%	100%
Any of the above	24.3%	36.6%	13.9%	25.3%	100%
Speech and language disorders	70.4%	15.1%	7.0%	7.5%	100%
Hearing disorders	84.4%	8.3%	3.7%	3.7%	100%

Inclusion criteria: youth age 3-17 with 11+ months of Medicaid eligibility and no dual eligibility in the year.
Source: Medicaid Analytic Extract (MAX) data for 20 states: AK, AL, AR, CA, FL, ID, IL, IN, LA, MI, MS, MT, NC, ND, NH, NM, SD, VA, VT, WY.

A diagnosis was established based on the presence of one or more inpatient or two or more non-inpatient claims with qualifying ICD-9-CM codes.

Medication types include: ADHD medications, antipsychotics, antidepressants, mood stabilizers, anxiolytics/hypnotics.

Table G-7b

Mental Health Treatment - SSI/Disability Enrollees with One or More Mental Health/Developmental Diagnoses, in 2010

Diagnosis	Not Treated	Treated with medication only	Treated with psychotherapy only	Treated with both medication and psychotherapy	
ADHD	5.4%	52.3%	3.6%	38.6%	100%
Conduct disorder	16.1%	33.4%	8.9%	41.7%	100%
Emotional disturbances	13.1%	26.3%	10.3%	50.3%	100%
Oppositional defiant disorder	10.7%	26.0%	9.4%	54.0%	100%
Depression	10.3%	33.5%	6.5%	49.8%	100%
Bipolar disorders	3.1%	40.3%	1.9%	54.7%	100%
Anxiety disorders	15.3%	26.4%	14.5%	43.9%	100%
Autism spectrum disorders	30.8%	38.1%	7.2%	23.9%	100%
Intellectual disorders	43.9%	39.1%	4.4%	12.6%	100%
Learning disorders	45.9%	29.7%	10.0%	14.5%	100%
Any of the above	25.3%	41.5%	6.9%	26.3%	100%
Speech and language disorders	56.7%	25.9%	6.2%	11.3%	100%
Hearing disorders	61.8%	24.3%	4.6%	9.3%	100%

Inclusion criteria: youth age 3-17 with 11+ months of Medicaid eligibility and no dual eligibility in the year.
Source: Medicaid Analytic Extract (MAX) data for 20 states: AK, AL, AR, CA, FL, ID, IL, IN, LA, MI, MS, MT, NC, ND, NH, NM, SD, VA, VT, WY.

A diagnosis was established based on the presence of one or more inpatient or two or more non-inpatient claims with qualifying ICD-9-CM codes.

Medication types include: ADHD medications, antipsychotics, antidepressants, mood stabilizers, anxiolytics/hypnotics.

Project conducted by:
Center for Health Services Research on Pharmacotherapy, Chronic Disease Management, and Outcomes, and Center for Education and Research on Mental Health Therapeutics
Institute for Health, Health Care Policy, and Aging Research
Rutgers University

Appendix H

Committee and Consultant Biographies

COMMITTEE MEMBERS

Thomas F. Boat, M.D. (*Chair*), is the dean emeritus of the College of Medicine at the University of Cincinnati and a professor of pediatrics in the Division of Pulmonary Medicine at Cincinnati Children's Hospital Medical Center. Earlier he was the director of the Cincinnati Children's Hospital Research Foundation and chairman of the University of Cincinnati College of Medicine's Department of Pediatrics. He also was physician-in-chief of Children's Hospital Medical Center of Cincinnati. He earned an M.D. at the University of Iowa. A pediatric pulmonologist by training, Dr. Boat worked early in his career to define the pathophysiology of airway dysfunction and more effective therapies for chronic lung diseases of childhood, such as cystic fibrosis. More recently he worked at local and national levels to improve child health research efforts, subspecialty training, and clinical care. He has a special interest in issues posed by children's mental health for pediatric care, research, and training, and he is working in Cincinnati and nationally to promote children's behavioral health. Dr. Boat joined Cincinnati Children's in 1993 after serving as chairman of the Department of Pediatrics at the University of North Carolina at Chapel Hill. He is a member of the National Academy of Medicine and served as co-chair of the Institute of Medicine (IOM) Forum on the Science of Health Care Quality Improvement and Implementation as well the IOM Committee on the Prevention of Mental Disorders and Substance Abuse Among Children, Youth, and Young Adults. He has continued to advocate for children at risk as a member of the Board of Children, Youth, and Families of the

National Academies of Sciences, Engineering, and Medicine. He chaired IOM committees addressing Research Training in Psychiatry Residency: Strategies for Reform and Acceleration of Research and Orphan Product Development for Rare Diseases and also the Committee on Pediatric Studies Conducted under the Best Pharmaceuticals for Children Act and the Pediatric Research Equity Act. Dr. Boat has been a member of the Association for the Accreditation of Human Research Protection Programs, Inc., board of directors, and served as its board president. He also has served as chair of the American Board of Pediatrics and president of both the Society for Pediatric Research and the American Pediatric Society.

Carl C. Bell, M.D., is currently practicing clinical psychiatry in Chicago, Illinois, at Jackson Park Hospital's Family Practice Clinic, St. Bernard Hospital's In-patient Psychiatric Unit, and the Psychosis Program in the Department of Psychiatry, College of Medicine, University of Illinois at Chicago. He is the former director of the Institute for Juvenile Research and is a clinical professor of psychiatry and public health at the University of Illinois School of Medicine. He is also former president and chief executive officer of the Community Mental Health Council Foundation. For more than 40 years Dr. Bell has practiced psychiatry. As an internationally recognized lecturer and author, he has given numerous presentations on mental wellness, violence prevention, and traumatic stress caused by violence. In 2007 he was appointed to the Institute of Medicine's Board on Children, Youth, and Families and Board on Health Care Services. These two boards sponsored the Committee on the Prevention of Mental Disorders and Substance Abuse Among Children, Youth, and Young Adults: Research Advances and Promising Interventions that he served on for nearly 3 years. That work continued until the publication of the report in 2009. The report has driven much of the prevention legislation in the nation's health care reform laws and continues to do so. Dr. Bell is also a member of the National Academy of Sciences Committee on Law and Justice. He is the author of *The Sanity of Survival: Reflections on Community Mental Health and Wellness* and co-author of *Suicide and Homicide Among Adolescents*. Dr. Bell has published more than 500 articles on mental health issues. His articles on mental health and violence prevention have appeared in the *National Medical Association and Psychiatric Services Journal*. He has addressed mental wellness and violence prevention issues on the *Today Show*, *Nightline*, *60 Minutes*, *CBS Sunday Morning*, and *Frontline*, and his campaign to prevent black-on-black violence has been featured in several publications, including *Ebony*, *Jet*, *Essence*, *Emerge*, the *New York Times*, *Chicago Tribune Magazine*, and *People* magazine. In recognition of his efforts to reduce violence, he became the first recipient of the American Psychiatric Foundation's Minority Service Award in 2004. He was presented the Special Presidential

Commendation of the American Psychiatric Association in recognition of his outstanding advocacy for mental illness prevention and for person-centered mental health awareness and recovery and presented the Agnes Purcell McGavin Award for Prevention in Child and Adolescent Psychiatry in 2012. He was a founding executive committee member of the National Action Alliance for Suicide Prevention by Pamela Hyde, administrator of the Substance Abuse and Mental Health Services Administration in 2010, and he served on the National Research Council's Committee on Assessing Juvenile Justice Reform of the Division of Behavioral and Social Sciences and Education from 2010 to 2012.

Stephen L. Buka, Sc.D., M.S., M.A., is a professor and the chair of the Department of Epidemiology and the director of the Center for Population Health and Clinical Epidemiology at Brown University. With training in epidemiology and developmental psychology, he focuses in his work on the causes and prevention of major psychiatric and cognitive disorders of children, youth, and adults. His current research includes investigations of prenatal risks for schizophrenia, attention deficit disorder, and addictive disorders, including the use of neuroimaging and molecular genetics techniques; work on the long-term effects of maternal smoking on offspring health and behavior; studies of community-level influences on youth substance use and delinquency; and the development of community-based strategies for the prevention of adolescent drinking and drug use. He directs the New England Family Study, a 50-year, three-generation longitudinal study of 17,000 infants born in New England in the 1960s. This work provides a unique opportunity to identify both environmental and genetic factors that contribute to the etiology and, ideally, the prevention of major forms of psychiatric illness, and it is supported by several major foundations and sections of the National Institutes of Health.

E. Jane Costello, Ph.D., M.A., is a professor of medical psychology in the Department of Psychiatry and Behavioral Science at Duke University. She is an adjunct professor in the Department of Psychology and Neuroscience and is on the faculty of the Center for Child and Family Policy, where she serves as associate director of research. Dr. Costello was educated at Oxford University and the London School of Economics and Political Science, where she received her Ph.D., and at the University of Pittsburgh, where she did postdoctoral work in psychiatric epidemiology. She has been on the faculty at Duke since 1988. Her work aims to integrate developmental psychopathology with epidemiology. She is the co-director of the Developmental Epidemiology Program at Duke, and for the past two decades she has been running a longitudinal, population-based study designed to examine the developmental origins and course of psychiatric and substance use disorders in young people and to study these young people's need for and access to mental health care. She is currently one of the principal investigators on the National Institute on Drug Abuse's Gene-Environment-Development Initiative, which is conducting a genome-wide association study of risk for substance use disorders in more than 12,000 youth.

Maureen S. Durkin, Ph.D., Dr.P.H., M.P.H., received her undergraduate degree and Ph.D. in anthropology from the University of Wisconsin–Madison, and her M.P.H. and Dr.P.H. degrees in epidemiology and her postdoctoral fellowship training in psychiatric epidemiology from Columbia University. Her research interests include the epidemiology, prevention, antecedents, and consequences of neurodevelopmental disabilities and childhood injuries, both globally and within the United States. She has collaborated in the development of cross-cultural methods for behavioral and developmental screening and assessment and methods for the surveillance of childhood injuries, and she has directed international studies of the prevalence and causes of childhood disabilities and mental health disorders in low-resource settings. She has also directed cohort studies of the neuropsychological outcomes of neonatal brain injuries associated with preterm birth and with metabolic disorders detected on newborn screening, and she is currently a Waisman Center investigator and principal investigator of the Wisconsin Surveillance of Autism and Other Developmental Disabilities System.

Glenace Edwall, Ph.D., Psy.D., L.P., M.P.P., is the former director of the Children's Mental Health Division at the Minnesota Department of Human Services. As the director, she oversaw Minnesota's county-administered children's mental health service system and worked on public policy issues regarding mental health benefits for children provided through Medicaid. Additionally, she is the current chair of the Minnesota Child Psychologists and the past chair of the Children, Youth and Families Division of the National Association of State Mental Health Program Directors. Her professional and scholarly focus has been on socioemotional development and its influence on children's mental health. In 2009 Dr. Edwall received the Nancy Latimer award for service and advocacy to the early childhood population. Dr. Edwall earned her Ph.D. in educational psychology from the University of Minnesota in 1983 and her Psy.D. in clinical psychology from the University of Denver in 1986. She also earned a master's degree in public policy from the Humphrey Institute at the University of Minnesota in 2001. Dr. Edwall has been credentialed by the National Register since 1993.

Kimberly Eaton Hoagwood, Ph.D., is the vice chair for research in the Department of Child and Adolescent Psychiatry at the New York University (NYU) School of Medicine. Her research portfolio focuses on four areas:

child, adolescent, and family service outcomes; parent engagement and activation; policy contexts; and quality metrics. She also works with the Division of Child, Adolescent and Family Services at the New York State Office of Mental Health. Dr. Hoagwood received her B.A. in English from American University in Washington, DC, and her M.A. in psychology from Catholic University in Washington, DC. She received her Ph.D. in school psychology from the University of Maryland, College Park. Prior to joining the faculty at NYU, Dr. Hoagwood was a professor of clinical psychology in psychiatry at Columbia University. Before that, she was the associate director for child and adolescent mental health research in the Office of the Director at the National Institute of Mental Health, where she also directed the Child and Adolescent Services Research program for 10 years. Dr. Hoagwood is the director and principal investigator of a National Institute of Mental Health–funded Advanced Center on Implementation and Dissemination Science in States for Children and Families (also called the IDEAS Center). She also co-directs the Community Technical Assistance Center, funded by the New York State Office of Mental Health. She is a principal investigator on several other major grants and subcontracts, all focused on improving the quality of services and outcomes for children and families.

Amy Houtrow, M.D., Ph.D., M.P.H., is an associate professor and vice chair in the Department of Physical Medicine and Rehabilitation for Pediatric Rehabilitation Medicine; she also serves as the director of the Accreditation Council for Graduate Medical Education–accredited Pediatric Rehabilitation Fellowship and as the chief of Pediatric Rehabilitation Medicine Services at Children's Hospital Pittsburgh. Dr. Houtrow completed her residencies in physical medicine and rehabilitation and pediatrics at Cincinnati Children's Hospital and the University of Cincinnati Medical Center in 2005; she is board certified in both disciplines with subspecialty certification in Pediatric Rehabilitation Medicine. She pursued a master's in public health in the area of health policy and management at the University of Michigan, completing those studies in 2004. From 2005 to 2012 Dr. Houtrow was assistant professor of clinical pediatrics at the University of California, San Francisco. In 2012 she earned her Ph.D. with distinction in medical sociology. Dr. Houtrow's main clinical focus is caring for children with disabling conditions and helping to improve function and quality of life. Her patients include children with spina bifida, cerebral palsy, rheumatologic disorders, brain and spinal cord injuries, and orthopaedic, musculoskeletal, and neurological disorders and conditions. Complementing her clinical focus, Dr. Houtrow's research focus is on optimizing health services for children with disabilities, with an emphasis on recognizing the impact that raising children with disabilities has on families and on developing channels to improve service delivery to reduce disparities.

Peter S. Jensen, M.D., established the REACH Institute in May 2006, following service as the founding director of the Center for the Advancement of Children's Mental Health at Columbia University. Before joining Columbia as its Ruane Professor of Child Psychiatry (where he served from 2000 to 2007), he was the associate director of child and adolescent research at the National Institute of Mental Health (NIMH). While at NIMH (1989–2000), Dr. Jensen was the lead NIMH investigator on the landmark study of multimodal treatment of attention deficit hyperactivity disorder as well as an investigator on other national multisite studies. Dr. Jensen most recently served as a professor of psychiatry and the vice chair for research, Department of Psychiatry and Psychology, at the Mayo Clinic in Rochester, Minnesota, before retiring in June 2013 to resume full-time duties at the REACH Institute. A world-renowned child psychiatrist, Dr. Jensen is a passionate advocate for children with emotional and behavioral disorders and their families. His major work and research interests include identifying, disseminating, and implementing evidence-based mental health treatments. Dr. Jensen serves on many editorial and scientific advisory boards, has authored more than 270 scientific articles and book chapters, and has written or co-edited 20 books on children's mental health. His many awards include the Norbert Reiger Award (1990–1996) and the Irving Philips Prevention Award (2011) from the American Academy of Child and Adolescent Psychiatry and the Agnes Purcell McGavin Award (1996) and the Blanche Ittleson Award (1998) from the American Psychiatric Association. He has also been honored by the American Psychological Association, the Association for Child Psychiatric Nursing, the National Alliance for the Mental Ill, and CHADD (Children and Adults with Attention-Deficit/Hyperactivity Disorder). Dr. Jensen received his bachelor's degree with high honors from Brigham Young University (1974) and his medical degree from George Washington University Medical School (1978, Alpha Omega Alpha), and he completed his postgraduate training in psychiatry and child and adolescent psychiatry at the University of California, San Francisco, and the Letterman Army Medical Center.

Kelly J. Kelleher, M.D., M.P.H., is ADS/Chlapaty Endowed Chair and a professor of pediatrics and public health in the Department of Pediatrics at the Colleges of Medicine and Public Health at Ohio State University. He is the vice president for community health and services research at Nationwide Children's Hospital and the vice president of community health services research and the director of the Center for Innovation in Pediatric Practice at the Research Institute at Nationwide Children's Hospital. He earned his M.D. in 1984 from Ohio State University, completed his pediatric residency at Northwestern University in 1987, and obtained an M.P.H. in epidemiology from the Johns Hopkins University in Bethesda, Maryland, in 1988. Dr. Kelleher's research interests focus on the accessibility, effectiveness, and quality of health care services for children and their families, especially those affected by mental disorders, substance abuse, or violence. He has a longstanding interest in formal outcomes research for mental health and substance abuse services.

James M. Perrin, M.D., is a professor of pediatrics at Harvard Medical School and a former director of the Division of General Pediatrics at the Massachusetts General Hospital (MGH) for Children and past associate chair of pediatrics for research at MGH. He founded the MGH Center for Child and Adolescent Health Policy, a multidisciplinary research and training center with an active fellowship program in general pediatrics, and directed the center for more than 15 years. He is the president of the American Academy of Pediatrics (AAP), a former chair of its Committee on Children with Disabilities, and a past president of the Ambulatory (Academic) Pediatric Association. For the AAP, he also co-chaired a committee to develop practice guidelines for attention deficit hyperactivity disorder and then a group advising the AAP on the implementation of the guidelines. His research has examined asthma, middle ear disease, children's hospitalization, health insurance, and childhood chronic illness and disabilities, with recent emphases on the epidemiology of childhood chronic illness and the organization of services for the care of children and adolescents with chronic health conditions. He heads the Autism Intervention Research Network on Physical Health, a multisite collaborative aiming to improve evidence-based care for children and adolescents with autism spectrum disorders. He also directed the Evidence Working Group reporting to the Maternal and Child Health Bureau for the Secretary's Advisory Committee on Heritable Disorders and Genetic Diseases in Newborns and Children. Dr. Perrin was the founding editor of *Academic Pediatrics* (formerly known as *Ambulatory Pediatrics*), the journal of the Academic Pediatric Association. Dr. Perrin has served on Institute of Medicine committees on Maternal and Child Health under Health Care Reform, Quality of Long-Term-Care Services in Home and Community-Based Settings, Enhancing Federal Healthcare Quality Programs, and Disability in America. He has also served on the National Commission on Childhood Disability and the Disability Policy Panel of the National Academy of Social Insurance. His experience includes 2 years in Washington, DC, working on rural primary care development and migrant health. After his fellowship at the University of Rochester, he developed and ran a rural community health center in farming communities between Rochester and Buffalo. He received a Robert Wood Johnson Foundation Investigator Award in Health Policy Research. He also served as a member of the National Advisory Council for the Agency for Healthcare Research and Quality. A graduate of Harvard College and the Case Western Reserve University School of Medicine, he had his residency and fellowship training at the University of Rochester and has also been on the faculties of the University of Rochester and Vanderbilt University.

Fred R. Volkmar, M.D., is the Irving B. Harris Professor of Child Psychiatry, Pediatrics, and Psychology at the Yale University Child Study Center, School of Medicine. A graduate of the University of Illinois, where he received an undergraduate degree in psychology in 1972, and of Stanford University, where he received his M.D. and a master's degree in psychology in 1976, Dr. Volkmar was the primary author of the autism and pervasive developmental disorders section in the American Psychiatric Association's *Diagnostic and Statistical Manual of Mental Disorders, 4th Edition* (DSM-IV). He is the author of several hundred scientific papers and chapters as well as a number of books, including *Asperger's Syndrome* (Guilford Press), *Health Care for Children on the Autism Spectrum* (Woodbine Publishing), the *Handbook of Autism* (Wiley Publishing), and *A Practical Guide to Autism: What Every Parent, Teacher and Family Member Needs to Know* (Wiley Publishing), with another three books in varying stages of production. He has served as an associate editor of the *Journal of Autism and Developmental Disorders*, the *Journal of Child Psychology and Psychiatry*, and the *American Journal of Psychiatry*. He currently serves as editor of the *Journal of Autism and Developmental Disorders*. He has served as co-chairperson of the autism/intellectual disabilities committee of the American Academy of Child and Adolescent Psychiatry. In addition to having directed the internationally known autism clinic, he also served as director of autism research at Yale before becoming chairperson of the department. Dr. Volkmar has been the principal investigator of three program project grants, including a CPEA (Collaborative Program of Excellent in Autism) grant from the National Institute of Child Health and Human Development and a STAART (Studies to Advance Autism Research and Treatment) Autism Center Grant from the National Institute of Mental Health.

Barbara Wolfe, Ph.D., is the Richard A. Easterlin Professor of Economics, Population Health Sciences, and Public Affairs and a faculty affiliate at the Institute for Research on Poverty at the University of Wisconsin–Madison. Her research focuses broadly on poverty and health issues. Her current projects examine whether housing voucher programs lead to better school performance of children in the household and increase the probability of attending postsecondary school; the effect of health shocks after individuals retire on their adequacy of resources during their first decade of retirement; how poverty influences critical brain areas among young children; and the influence of growing up with a sibling who has a developmental disability or mental illness, a sibling who is adopted, or a sibling who dies on outcomes as a young adult. Her recent work addresses the effects of welfare reform; the economics of disability; ties among income, wealth, and health; racial disparities in health; and the intergenerational determinants of success in young adults. She is a member of the National Academy of Medicine, recently serving on its standing committee on Family Planning and a committee addressing improving access to oral health care. She served as vice chair of the National Research Council/Institute of Medicine Board on Children, Youth, and Families and as a member of the Advisory Committee to the Director of the National Institutes of Health. She is a member of the National Advisory Committee for the Robert Wood Johnson Health Policy Scholars program. Dr. Wolfe's recent articles have appeared in the *Journal of Public Economics*, *Journal of Human Resources*, *Journal of Policy Analysis and Management*, *Economy Inquiry*, *Journal of Health Economics*, and *Demography*. She received her doctorate in economics from the University of Pennsylvania.

Bonnie T. Zima, M.D., M.P.H., is the associate director of the Jane and Terry Semel Institute's Health Services Research Center and a professor-in-residence in the University of California, Los Angeles (UCLA), Department of Psychiatry and Behavioral Sciences at the David Geffen School of Medicine. She is also the director of training in child and adolescent psychiatry. Dr. Zima's research focuses on the level of unmet need for mental health services among high-risk child populations with limited access to care (homeless, foster care, juvenile hall) as well as the quality of care for children served in publicly funded primary and specialty mental health care settings. She received her M.D. from Rush Medical College and her M.P.H. from the UCLA School of Public Health. In partnership with the Los Angeles County departments of mental health and probation, Dr. Zima is leading a 3-year study on the level of mental health problems, service use, and short-term outcomes among a county-wide sample of youth detained in juvenile hall. Additionally, Dr. Zima is the principal investigator for the Caring for California Initiative Project, assessing how service use and quality of care relate to key organizational and client-level characteristics of publicly funded child mental health services in selected counties. Recently, Dr. Zima was funded by National Institute of Mental Health (NIMH) to lead a 5-year study to examine the quality of care for school-aged children with attention deficit hyperactivity disorder. Dr. Zima also conducted a Robert Wood Johnson Foundation–funded study of mental health problems and service use among school-aged children and their parents living in emergency homeless family shelters in Los Angeles County. She led an NIMH study on the level of mental health problems, violence exposure, service utilization patterns, and psychotropic medication use among more than 300 school-aged children living in foster care in Los Angeles County.

CONSULTANTS

Howard H. Goldman, M.D., Ph.D., is a professor of psychiatry at the University of Maryland School of Medicine. Dr. Goldman received joint M.D./M.P.H. degrees from Harvard University in 1974 and a Ph.D. in social policy research from the Heller School at Brandeis University in 1978. He is the author or co-author of 325 publications in the professional literature. Dr. Goldman is the editor of *Psychiatric Services*, a mental health services research and policy journal published monthly by the American Psychiatric Association. He also has served on the editorial boards of several other journals, including the *American Journal of Psychiatry*, *Health Affairs*, and the *Journal of Mental Health Policy and Economics*. Dr. Goldman served as the senior scientific editor of the *Surgeon General's Report on Mental Health* from 1997 to 1999 for which he was awarded the Surgeon General's Medallion. During 2002 and 2003 Dr. Goldman was a consultant to the President's New Freedom Commission on Mental Health. In 1996 he was elected to membership in the National Academy of Social Insurance, and in 2002 he was elected to the National Academy of Medicine. Dr. Goldman has chaired the Institute of Medicine Standing Committee to Provide Medical Advice to the Disability Program of the Social Security Administration since 2009.

Ruth E. K. Stein, M.D., is a developmental–behavioral pediatrician who works in research and advocacy for children, especially those with chronic health conditions. She is a professor of pediatrics at the Albert Einstein College of Medicine/Children's Hospital at Montefiore. Her research has been supported by the Maternal and Child Health Bureau, National Institute of Mental Health, Assistant Secretary for Planning and Evaluation, Health Resources and Services Administration, and numerous foundations. Dr. Stein has received several awards for her research and lifetime achievements. She has authored or co-authored more than 200 publications and has edited four books. Dr. Stein is a past president of the Academic Pediatric Association and a member of the Research Consortium on Children with Chronic Conditions. She served on the executive committee of the board of directors of the American Academy of Pediatrics' Center for Child Health Research and its Behavioral Pediatrics Consortium and on the Board of Children, Youth, and Families of the Institute of Medicine (IOM) and National Research Council, where she co-chaired the board's study on the Evaluation of Child Health, Safety and Well-Being. She also is on the steering committee and faculty of the REACH Institute's program to teach mental health care to primary care practitioners and the steering committee of DBPNet, a research network of developmental–behavioral pediatric centers. Dr. Stein has been a member of the IOM's Standing Committee to Provide Medical Advice to the Disability Program of the Social Security Administration since 2011.