HYPERACTIVITY IN CHILDREN

The Gillberg affair

What drove members of a highly respected psychiatric research group to defy the Swedish courts and destroy 15 years' worth of irreplaceable data? A decade after the Gillberg affair began, **Jonathan Gornall** examines the facts

Over one weekend in May 2004, three researchers in the University of Gothenburg's department of child and adolescent psychiatry shredded tens of thousands of documents, destroying all data from a 15 year longitudinal study following 60 Swedish children with severe attention deficit disorders.

What became known as the Gillberg affair began in 1996, at a community summer party on the Swedish island of Resö. Among the guests were Leif Elinder, a paediatrician recently returned to Sweden after several years spent working abroad, and Christopher Gillberg, professor of child and adolescent psychiatry at Gothenburg University.

The men had known each other since childhood, when they had met on the island most summers. Professor Gillberg had since become a world expert in autism and attention deficit disorder and a leading proponent of deficits in attention, motor control, and perception (DAMP), a Nordic concept developed in the 1970s to describe a combination of hyperactivity, lack of attention, and clumsiness and later regarded as a subcategory of attention deficit hyperactivity disorder.

What was said at that party depends on whom you ask, but both men agree they spoke briefly about Professor Gillberg's work, that Dr Elinder wanted to meet to discuss the work further, and that he was rebuffed. Dr Elinder says Professor Gillberg wasn't interested; Professor Gillberg says he simply didn't have the time.

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Professional disagreement

While working as a paediatrician in Hamilton, New Zealand, Dr Elinder had developed doubts about the diagnosis and treatment of children with behavioural problems and he hoped to discuss this with Professor Gillberg. "We saw many wayward kids," he said, "and I felt that people expected me to label them, to give them a diagnosis, and treat them with Ritalin or amphetamines." At first, he said, "I just followed the trend, but I became sceptical."

The following March, Dr Elinder read a newspaper article cowritten by Professor Gillberg, which declared that 120 000 Swedish children (10%) had some kind of neuropsychiatric problem, including but not limited to attention deficit disorders and Asperger's and Tourette's syndrome.[1] "We are talking about a real waste of human resources," Professor Gillberg wrote, appealing for more awareness among teachers of these children and their problems. "Most things in life you can as an adult compensate for, but a ruined self-esteem and a feeling of being useless can never be repaired completely."

Professor Gillberg's estimate of the size of the problem was in step with mainstream psychiatric thinking. America's surgeon-general stated in 2001 that in the US "1 in 10 children and adolescents suffer from mental illness severe enough to cause some level of impairment."[2] Dr Elinder, however, thought Professor Gillberg's view was "absolutely wrong. Of course there is such a thing as wayward children, but you cannot diagnose an inborn, neuropsychiatric defect."

In an article published shortly afterwards in the *Swedish Medical Journal*, Dr Elinder questioned Professor Gillberg's 10% figure. In his view, "cultural handicaps" were being wrongly classed as medical conditions.[3]

Professor Gillberg's article also caught the attention of Eva Kärfve, an associate professor of sociology at Lund University. She had become more aware of attention deficit disorders, she says, when she introduced the last two of her five children to kindergarten. "I found that those working in pre-schools were suddenly talking in medical terms. Ten years earlier I had never heard this. Now they were saying, 'Has that child a defect, a dysfunction?' They were not talking about family life, a child's emotional environment, like they used to do. I felt I had to look into this."

Her concern, she says, was that such diagnoses had "a flavour of degeneration theory—that there are people who are right and people who are not. I felt it was a political movement pretending to be scientific."

Degrees of difference

It wasn't long before Professor Kärfve and Dr Elinder joined forces and, when Professor Kärfve began work on a book attacking Professor Gillberg's work, the paediatrician contributed a chapter. The book, *Brain Ghosts—DAMP and the Threat to Public Health*, published in 2000, suggested that the purpose of the diagnosis of DAMP was "to achieve no

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(Main picture) The documents were shredded at Gothenberg University. (From left) The dispute about the treatment of children with behavioural problems raged between Professor Christopher Gillberg, Dr Leif Elinder, and Professor Eva Kärfve

other permanent change than segregation."[4]

The claim outraged Professor Gillberg's camp, which accused Professor Kärfve of lies and misrepresentation and protested to Lund University that her book was "the opposite of what was true."

Professor Gillberg's supporters also suspected that the documents that had formed the basis of Professor Kärfve's book had been supplied to her by a writer linked to the Scientology movement, which has a long standing opposition to psychiatry[5 6]

The documents arose from a conference on attention deficit hyperactivity disorder that Professor Gillberg had attended in the autumn of 1999. Shortly afterwards, Janne Larsson, a journalist who writes for the Swedish chapter of the Church of Scientology's Citizens Commission on Human Rights,[7] applied to the National Board of Health and Welfare for access to the conference material. The delegates objected, maintaining the materials were working documents and not yet public property and the board rejected the application. However, a spokesperson for the board confirmed that Mr Larsson had won a court order granting him access.

Professor Kärfve originally told me that the documents from the conference had been posted to her anonymously by what she assumed to be a disillusioned insider at the board. Later, however, in an email dated 5 July 2007 she conceded: "Larsson did send me the same material, but somewhat later." She had, she insisted, "never used anything sent to me by him." Mr Larsson declined three invitations to comment.

Two months after the publication of Professor Kärfve's book, the *Journal of the American Academy of Child and Adolescent Psychiatry* published a follow-up of the participants in the Gothenburg study at the mean age of 22.8 The paper reported that 58% of 55 participants with attention deficit disorder, none of whom had received stimulant treatment, had developed personality disorders, committed serious crimes, or misused drugs or alcohol. This compared with 13% in the control group.

Professor Gillberg discussed the findings at the annual meeting of the Royal College of Psychiatrists in London in July 2001. "I was shocked," he told the conference. "These children are so much worse off in terms of education and employment than the general population. We must learn that all these children and adults are individuals and changes in attitude are more important than treatment."

The sentiment was at odds with the by now popular media view of Professor Gillberg as someone who would like to give drug treatment to all Sweden's children. Although he shares the common professional view that it is "beyond doubt that central stimulants ameliorate basic symptoms" of attention deficit disorder, Professor Gillberg is also on record as stating that drugs should not be used "unless other avenues of intervention have been entered first."[9]

Accusations of misconduct

Professional debate over the possible overdiagnosis of conditions such as attention deficit disorder and overuse of stimulants in their treatment is nothing new.[10 11] But in 2002 Professor Kärfve and Dr Elinder took the debate to another level, accusing Professor Gillberg and colleagues of research fraud and launching a series of applications to gain access to the raw data behind the Gothenburg study.

After the experience with data from the 1999 conference, Professor Gillberg's group was adamant they would not release them. As two of Professor Gillberg's Gothenburg colleagues, Elias Eriksson and Kristoffer Hellstrand, were to put it later in an appeal to the Chancellor of Justice, "The important thing is not how Kärfve and Elinder would have handled the information, but that Gillberg could not guarantee to the participants that the information would be handled correctly… much of the information they chose to propound in the media has been highly misleading or untrue."

They added: "One can attack a researcher for carrying out poor research. But when one accuses someone of deliberate dishonesty one has exceeded a clear boundary."

Professor Kärfve led the charge, writing to Professor Gillberg and colleagues in February 2002 to request access to the individual records behind all five phases of the group's longitudinal study. She was refused, on the ground that the material was confidential, and she took the case to the Administrative Court of Appeal.

On 13 April Dr Elinder wrote to Bo Samuelson, then vice chancellor of

Gothenburg University, demanding an investigation to determine "whether good ethical standards of research" had been adhered to. "How can the scientific community be persuaded that the children who were examined in 1978 were identical to the young adults who were examined in 1993?"

Dr Elinder's request was rejected by the university's ethics council, but three weeks later, Professor Kärfve demanded an inquiry, claiming: "The disposition and design of these studies entertain certain misgivings" giving rise to questions of "manufacturing and forgery of data and sources."

Like Dr Elinder, Professor Kärfve seemed to have no evidence of forgery, but only suspicions. These included surprise at the low drop-out rate, a subjective disagreement with "The treatment of the finding of 'depression' as a variable in the judgment of poor outcome," and cynicism about whether the psychiatrists who had made follow-up diagnoses throughout the study had been truly blind to the participants' original diagnosis. As the university's ethics council commented in a response on 24 February the following year, "Several of Kärfve's critical comments about the article have nothing to do with scientific misconduct, but rather deal with interdisciplinary differences of views… which Kärfve regards as fraud." The researchers had "put in a lot of effort to make the drop-out rate as low as possible" and the council concluded that Kärfve's petition "does not prove that Rasmussen-Gillberg's research is not following good scientific conduct."

An underlying motive?

The attacks continued, with Dr Elinder demanding access to the material on 9 July. Shortly after this the shadow of Scientology crossed the story again.

Professor Gillberg's group has always claimed that in the autumn of 2002, at the height of the battle to gain access to their data, Professor Kärfve attended an anti-psychiatry Scientology conference in Germany. She admits attending the meeting, but has maintained that she did so only as an observer and in her role as a sociologist. Scientology, she said, was a "scary" movement about which she had written critically.

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However, a circular for the conference, "International hearing on psychiatry labeling and drugging children," listed Professor Kärfve as a participant, alongside seven other speakers, including the presidents of the American and Italian branches of Scientology's Citizens Commission on Human Rights. Furthermore, Nicola Cramer, a spokesperson for the German branch, told me that although to her knowledge Professor Kärfve did not belong to the Scientology church, she had been "one of many guest speakers who took part in this hearing. She spoke about the Swedish psychiatric disorder DAMP."

Professor Kärfve responded in an email that she "did not lecture or 'associate' at that meeting." She said that she did talk to Nicola Cramer, but did not talk publicly, apart from giving a few replies at what she later discovered to be "a strange kind of press conference."

She could not recall how she had learnt about the meeting but was adamant that she had given no lecture there and, in any event, "I never felt it could have done me any harm to talk to people… there is always someone you can reach."

Professor Kärfve was not the only sociologist at the conference. She was accompanied by Thomas Brante, the head of her research department at the University of Lund, who has publicly backed Professor Kärfve's actions in the Gillberg affair. Professor Kärfve wrote in the same email that he could confirm that she was there to investigate Scientology and not to lecture.

Whatever the truth or wisdom of Professor Kärfve's association with Scientology, the church has eagerly exploited the Gillberg debate and Professor Kärfve's role in it. In an online article in 2005, the Swedish branch of the commission boasted of having conducted a lengthy campaign against Professor Gillberg,[12] while online the international commission quotes Professor Kärfve as saying: "The claim that ADHD is biologically caused or stems from a metabolic disturbance in the brain is not scientifically founded in any way."[13]

An account of the Gillberg affair also features in the current issue of *Freedom*, a magazine published by the Church of Scientology International.[14] The article seems to be a collection of extracts from previously published sources, none of which is attributed.

One quote, from Professor Brante, was taken from a rapid response he submitted in 2004 to a *BMJ* article about the destruction of Professor Gillberg's data: "The most rational… course of action would be to withdraw all research relying on the Gillberg data."[15]

Another passage from Brante's *BMJ* response did not appear in the *Freedom* article. "Claims have been made that Professor Kärfve is a scientologist, that she runs a personal campaign, vilifying Professor Gillberg," wrote Brante. "These are mistaken… Scientology is a church and Kärfve has no links whatsoever to it." There was, however, no mention of the trip he and Professor Kärfve had made to Munich.

Confidentiality

The year 2003 saw a series of court actions, orders, and appeals as Professor Kärfve and Dr Elinder fought to get their hands on the material, and Professor Gillberg and colleagues resisted. The study participants and their parents had opposed the release of the material, said the group, and the volume and nature of the data made anonymising impossible.

Professor Gillberg had personally guaranteed confidentiality to all the participants. One of the documents he had signed, on the instruction of the university's ethics committee, assured them that "you will never be registered in public data records of any kind and the data will be treated so that nobody apart from those of us that meet you and have direct contact with you will be able to find out anything at all about you."

Furthermore, Professor Gillberg asserts that his refusal to part with the material

was in accordance with the World Medical Association's ethical principles for research, as stated in the Declaration of Helsinki.[16]

His stance divided Swedish academe. More than 300 scientists, including Arvid Carlsson, Sweden's most recent Nobel Prize winner, signed a petition supporting him; others opposed him. Professor Gillberg was even criticised for having given assurances of confidentiality in the first place—a criticism made in the pages of his university's magazine by Björn Thomasson of the Swedish Research Council: "The problem is that Professor Gillberg has given assurances that he evidently had no right to give. One cannot promise that the material will not be scrutinised by someone outside the research group. He has simply gone too far."[17]

Gunnar Svedberg, vice chancellor of Gothenburg University, summed up the ethical dilemma facing Professor Gillberg and colleagues in a letter to Professor Kärfve and Dr Elinder in September 2003: "Professor Gillberg refers to the reasons for his refusal, among them customary ethical standards and statutory requirements that apply to medicine and to research. A large number of researchers at different universities in Sweden have written to me to state that ethical reasons prevent the release of the material concerned to outsiders without the consent of the participants."

None of the main protagonists in the affair has escaped unscathed

The legal system, however, paid no heed to Professor Gillberg's dilemma. Twice in 2003 the Supreme Administrative Court rejected his applications to appeal the decisions allowing Professor Kärfve and Dr Elinder access to the data on the ground that "he lacked any interest in the case that could be acknowledged in law as entitling him to apply for a rehearing of the issue."[18]

Destructive conclusion

The final act began on 4 May 2004, when the court overturned a last attempt by the university to demonstrate that Professor Kärfve and Dr Elinder were not acting as proper researchers and, therefore, were not entitled to examine the documents. On 6 May the university informed Professor Gillberg's department that it must make the data available. In an email reply the same day, Professor Gillberg, working in England, declared he would not cooperate. Three days later, Professor Gillberg's three colleagues informed the university's vice chancellor that they had destroyed all the data.

On 27 June 2005, just over a year after the material was shredded, Professors Gillberg and Svedberg were convicted of misuse of office. Professor Gillberg was given a conditional sentence and both men were fined and ordered to pay costs.[19] Professor Gillberg's application to appeal was rejected.

On 26 January 2006, Professors Eriksson and Hellstrand, two of Professor Gillberg's colleagues at Gothenburg who had not been part of his research group, wrote to Sweden's Chancellor of Justice to seek a judicial review. The legal process, they said, had been "exploited in the most wide-ranging slander campaign heard in current Swedish debate. That has meant that the public have been led to believe that Professor Gillberg and coworkers have committed research fraud… The manner in which public officials contributed to the success of this campaign deserves analysis." The application is under consideration.

Two months later, psychiatrists Peter Rasmussen and Carina Gillberg (Professor Gillberg's wife and one of the main researchers in the group) and unit administrator Kerstin Lamberg were convicted of destroying government documents and fined.

None of the main protagonists in the affair has escaped unscathed. In 2003, two of Professor Gillberg's colleagues accused Professor Kärfve of "scientific dishonesty" in her book and demanded an investigation by her university. They also suggested she might be linked to the Church of Scientology. Initially, Lund University rejected the complaint. Dr Rasmussen, one of the three who had destroyed the research data, then appealed to the National Agency for Higher Education, which agreed that the university should have examined the allegations in greater detail.

In March 2005, Lund invited the Swedish Research Council to evaluate the material, but the investigation stalled.

Two experts were finally found—Denny Vågerö, a professor of medical sociology and director of the Centre for Health Equity Studies at Stockholm University, and Jan-Otto Ottosson, a professor of psychiatry at Gothenburg—and by March 2006 they had made their report.

Although Professor Ottosson felt that some of Professor Kärfve's criticisms were unjustified and "sometimes based on misunderstanding," and that the tone of *Brain Ghosts* was "confrontational" and "insinuating," both men agreed that the book was polemical criticism rather than research and that, therefore, Professor Kärfve could not be guilty of breaching good research practice.

The report added that the council's review team had, therefore, taken no position on whether there was any basis for Professor Kärfve's criticisms. Furthermore, it had not concerned itself with the allegation that she was allied to Scientology.

Although exonerated, Professor Kärfve, who continues to teach at Lund, believes the accusations against her put an end to funding by the Swedish Research Council. "They will always deny it, but I realise I will never get grants any more," she says.

The council declined to comment, but confirmed that grant applications from Professor Kärfve had been rejected in 2001, 2002, 2005, and 2006.

She would not, however, hesitate to do the same again: "I am totally convinced I was right. The campaign against me made me more convinced that this was worth looking into… If they were conducting this research in a proper manner, they wouldn't have treated me like they did."

Although Dr Elinder continues to work for the Resource and Knowledge Centre of the Social Services in the city of Uppsala, he has parted company with the Försäkringskassan, the Swedish social insurance agency, for which he had worked as a medical adviser. Professor Gillberg's work continues. Research funds have continued to flow his way, and in November the Swedish Research Council awarded him a record sum for three years of study into autism.

The affair has, however, left deep scars. Professor Gillberg has lodged a grievance against the Swedish state with the European Court of Human Rights. The court cannot overturn Professor Gillberg's conviction, but it can rule that the state's actions were wrong. Professor Gillberg's five page submission to the Court of Human Rights sums up the dilemma in which he and colleagues found themselves and the sense of injustice he still feels:

"In my view," wrote Professor Gillberg in a five page submission to the Court of Human Rights, "it is unreasonable that I am first obliged to give strict promises of confidentiality by the State in order to conduct medical research, then… I am ordered by the State to break hundreds of promises of confidentiality…then am sentenced as a criminal by the State because I had not broken those promises of confidentiality.

"Something is clearly wrong in this chain of events, but it is difficult to see how the error can be mine."

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References are on bmj.com
Provenance and peer review: commissioned, peer reviewed