

Box 3: Phases of Childhood and Developmental Milestones

[3a] Parent participant (10021): *"I was talking to the dietician about green beans, and she said, 'Well, once he's taking more than a few tablespoons at a time, I'm going to have to know how much he had so I can take some protein away from him out of the formula.' I really thought, 'Man, this is the easy part. Mixing formula every day and measuring, that's been easy compared to knowing specifically what's going in his mouth.'"*

[3b] Provider participant (20011): *"The cadence of care for these kids is they have catastrophic episodes. Then they have a little honeymoon. Then they're about roughly six months to a year old when they don't have much happen to them because you control everything that goes into them. Then you start feeding them. They get a little rockier. Then they're up and down, and up and down."*

[3c] Provider participant (20006): *"Having to deal with unpalatable medications, how to get their kids to take them, and I think dealing with compliance for a long-term, complex, medical condition is difficult, especially with – hard as toddlers, and then it gets a little bit easier, and then you have an adolescent who wants to have some control over their lives, and refuses to take their medicine, or says they do and don't, and things. I think those are a lot of things that our families struggle with."*

[3d] Parent participant (10019): *"She went to a preschool classroom two days a week, but if any of the kids were sick or if she was not feeling 100%, she was probably not there as much as half the time. She missed a lot because we just constantly had to monitor certain things."*

[3e] Parent participant (10023): *"The doctor made it pretty clear that she probably won't go to a normal school. Yeah, the diet poses serious challenges if she's going to be going to a school. We haven't figured that problem out yet."*

[3f] Parent participant (10019): *"If she would've missed one of her doses of medicine before her transplant, that was a guaranteed ticket to Hopkins. As she became older, and she didn't need mom and dad to shove medicine in her mouth anymore, and it became her job, for sure, I thought about that and worried about that, probably more as a teenager."*

[3g] Parent participant (10014): *"It's just a new chapter in our lives. In order for [my daughter] to – the possibility of her being able to maybe go to college and – I'd like for her to be able to go to college and maybe go away to college someday...just be able to think about things like that. I don't know. If we can't get it under control now, I don't know how we're going to be able to get it under control in the next couple of years."*

[3h] Provider participant (20005): *"Especially with the older children, are you getting older, and who's going to take care of this – who's going to manage the child who doesn't have a liver transplant after you're dead and gone or if you become incapacitated? If life goes on, you never know what's going to happen around the corner. With the younger patients, I usually don't take that approach, but as the patients get into their teenage years, it's a question of, well, who is going to manage this, a sibling, and are they willing to do it? That's something that really is important to think about."*