

## **Box 10: Considerations for Child's Independence**

**[10a] Parent participant (10018):** *"At one of the meetings at the Urea Cycle Foundation...they talked about...He was living on his own, and he died because his caregivers couldn't get hold of him. When they found him, he had had a high ammonia episode, and nobody was there...That made it an easy decision. We'd never let him live alone...When he'd get sick spending the night at his cousins, we were like heck, we don't want to let him spend the night anywhere. We don't want to take the chance...What kind of a life can he have if someone has to be watching him 24-hours a day?...Some of those episodes came on so fast that even if he was a normal adult, he might not have been even able to call 911 in time to manage it for himself."*

**[10b] Parent participant (10017):** *"Because [she] has done so well in school and has done so well socially, going to college...that is a very good possibility, where we never really thought that was a possibility. For her independence, a transplant is necessary...It is something that with OTC and when her ammonia level starts to rise, she can't make decisions on how to help herself. There always has to be someone there to help her identify and help her make changes to her diet and to her medication before it gets too bad. Living on her own and going away to college was not going to be an option."*

**[10c] Parent participant (10013):** *"It's a constant struggle as I'm trying to prepare her to be a young adult, understanding that in order for her to live her life, she has to be her own caregiver. That's another huge hurdle of what we're going through right now, saying, 'Okay, this was your responsibility. We're not going to be here all the time to monitor what you eat, whether you're taking your medicines,' and right now that's the biggest challenge we're having as a family...Like I tell her, if she wants to go off to college and wants to have a job, I'm not going to be there to ask her what she's eaten or whether she's done her medicine; it's all going to be on her. It's definitely a process. She's not fully aware yet, but there are signs that she's finally getting it."*

**[10d] Parent participant (10025):** *"Even right now, she's 9 and in the third grade. We're trying to transition into getting her to read food labels. Getting her to understand what everything – right now I mix up her medications, and I measure everything. We already talked about, okay, how old does she need to be before she starts getting old enough to do that? Yeah, that's our goal. We understand some day she's going to leave the nest. She's going to need to know how to do all of this. At one point do we start teaching her?"*