

Few Parents Plan For Future Of Children With Disabilities, Study Finds

by Courtney Perkes | February 22, 2018



Jessica Clark, right, who has Down syndrome and is also legally blind, reaches in to hug her mother Joann Clark in the kitchen of the home they share in Glen Mills, Pa. Joann Clark is worried about what will happen to her daughter after she is gone. (Michael Bryant/The Philadelphia Inquirer/TNS)

Many parents of those with intellectual and developmental disabilities are not doing enough to prepare for the prospect of their children outliving them, according to a new University of Illinois study.

Nearly 400 parents of children ages 3 to 68 responded to a national survey on what steps they've taken to ensure future care for them. Only 3.6 percent of parents had completed a full list of 11 tasks that researchers asked about including establishing legal guardianship, power of attorney and securing a residential placement. While 32 percent had done a moderate amount of preparation, 12 percent had taken no action, the survey showed.

"We know that individuals with intellectual and developmental disabilities are having longer lives and beginning to outlive their parents," said lead author Meghan Burke, a professor of special education in Champaign, Ill. "When a parent can no longer provide care or passes away, that's a crisis situation for the family. We have to start planning for the future and that transition."

The survey found that barriers to long-term care plans included cost, lack of time and stress. The biggest reason, cited by 61 percent of parents, was a lack of residential, employment and recreational services.

"I've had parents contact me and say, 'One of the reasons why I haven't planned is because there are no services,'" Burke said. "You can't just keep putting the onus on parents. We also need some systemic changes in our delivery service system."

Burke, who has an adult brother with Down syndrome, said other concrete planning steps can range from writing a letter of intent describing protocols and routines for care to establishing a special-needs trust. Among the tasks that parents were asked about, locating a knowledgeable attorney was the most commonly taken step, with 58 percent of parents reporting doing so.

Brian Rubin, a Buffalo Grove, Ill. attorney who specializes in special needs planning, said making preparations can be overwhelming for parents because their lives are often so hectic.

“You are dealing with what’s going on tomorrow at school,” said Rubin who has a 37-year-old son with autism. “I’ve got this doctor and this therapy. You’re dealing with the day-to-day and it’s not so much intentional that you would have your head in the sand, but there’s only so many hours in the day.”

Thirty-nine percent of parents reported a lack of information as a barrier to future planning. Rubin said he recommends that parents attend free talks put on by nonprofits such as The Arc to help them get started.

“Where is this child going to be living and with whom can be the hardest question for some parents,” Rubin said. “Is this child going to be living independently with some assistance? When we try to determine how much money they’re going to need, it depends on where they’re living.”

Burke said children should also be included in the planning process.

“We’ve been encouraging families to talk to their family member with a disability and not just make it about the parents and the siblings,” she said. “Maybe just talking about it informally at first because it’s such a big, loaded topic.”

The study will be published in the April edition of the journal *Intellectual and Developmental Disabilities*.