

Study: Many parents of children with disabilities don't make care plans

February 9 2018, by Sharita Forrest



Fewer than half of parents of children with disabilities develop plans to ensure that their child's needs will be met in the event of the parent's or other caregiver's death, University of Illinois special education professor Meghan Burke found in a recent nationwide survey. Credit: L. Brian Stauffer

Fewer than half of parents of children with intellectual and developmental disabilities make long-term plans about who will take over their child's care if the parent or other relative providing care dies or becomes incapacitated, a new study suggests.

More than 380 [parents](#) - primarily mothers - of individuals with [disabilities](#) participated in a web-based national survey about planning for their children's care. The parents who responded to the survey ranged in age from 40 to 83, and their offspring with disabilities were ages 3 to 68.

Parents in the study were asked whether they had completed 11 items related to planning for their [child's](#) long-term needs, such as identifying a successor to the current [family](#) caregiver, researching residential programs or establishing a special-needs trust.

More than 12 percent of the parents who participated reported that they had taken none of these actions to ensure that their child's needs would be met if the parent or other caregiver died or was otherwise unable to continue assisting the adult or minor child with disabilities.

Because people with disabilities are living longer, they are increasingly outliving their parents, and planning for their future care should begin as early as possible, said the study's lead author, Meghan Burke, a professor of special education at the University of Illinois.

Adults with intellectual or [developmental disabilities](#) are significantly more likely to be placed in institutional settings if care plans are not in place when the parent providing care dies or becomes too old or too ill to continue, Burke said.

"It affects everyone in the family when you don't have plans in place," said Burke, who has an adult sibling with Down syndrome. "You are

more likely to face a crisis situation where the person has to move out of the family home, be uprooted and have their routines disrupted. A sibling, most likely, will have to jump in and pick up the reins caring for the person with disabilities - while, at the same time, both siblings are having to face their parent's mortality."

More than 77 percent of the individuals with disabilities in the study lived with their parents or with another relative, while 17 percent lived independently with support and 6 percent lived in group homes.

Some parents indicated that their planning efforts were thwarted by interpersonal conflicts - such as disagreements with the other parent about what should happen - or by [family members](#)' refusal to discuss alternative arrangements. According to more than 7 percent of the parents in the survey, the topic was too "emotionally loaded" or stressful for family members to talk about.

While more than half of the parents had engaged in three planning activities, such as locating an attorney and discussing future care plans with the child or other family members, their actions were aspirational rather than conclusive, Burke said.

Conclusive actions included making residential arrangements or writing a letter of intent to guide future caregivers or legal guardians in making decisions about the types of care the person with disabilities ought to receive.

Financial constraints were significant barriers to succession planning for more than 46 percent of families; however, an even greater problem, according to more than 61 percent of parents in the study, was the dearth of residential, employment and recreational services that suited their child's particular needs and abilities.

"In Illinois alone, there are more than 20,000 people with disabilities on waiting lists for services," Burke said. "Nationally, 75 percent of people with intellectual and developmental disabilities don't have access to formal services. It may be that many families think why plan for services when there are no services currently available to them."

A large number of parents - more than 39 percent of those in the survey - said their greatest impediment was simply obtaining information on developing a care plan for their child with disabilities.

Unlike systemic problems such as a lack of services, access to information is a problem that's relatively simple and inexpensive to fix, Burke said.

Training programs on developing long-term care plans for people with disabilities already exist that could be adapted to different languages and provided to families over the web, Burke said.

"We can make some really positive changes here without spending a lot of money to do it," she said.

Catherine K. Arnold, the director of community education, disability and human development, and Aleksa Owen, a visiting research specialist, both at the U. of I. at Chicago, were co-authors of the study.

The study has been accepted for publication in the April edition of the journal *Intellectual and Developmental Disabilities*.

More information: "Identifying the correlates and barriers of future planning among parents of individuals with intellectual and developmental disabilities" *Intellectual and Developmental Disabilities*, 2018.

Provided by University of Illinois at Urbana-Champaign

Citation: Study: Many parents of children with disabilities don't make care plans (2018, February 9) retrieved 23 April 2024 from

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