Understanding Caregiver Preferences for Treating Children with Intellectual and Cognitive Disabilities and a Mental Illness

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What was the research about?
Children with intellectual and cognitive disabilities often have problems with reasoning, learning, and problem solving. With such challenges, caregivers may have to make choices for their children about their health care and treatments. These children may need such help into young adulthood.

In this study, the research team wanted to find out what matters most to caregivers about their children's care. Caregivers had children with an intellectual or cognitive disability plus a mental health condition, such as depression or anxiety. The team interviewed caregivers about their preferences. Then the team used this information to design a survey. A larger group of caregivers filled out the survey.

What were the results?
In the interviews, the research team found that four results mattered most to caregivers when making care decisions. These included their children's ability to

- Function in school
- Form relationships with others
- Live on their own as an adult
- Not cause trouble in the home or hurt others

Caregivers who took the survey ranked two treatment results as most important. These were that their children

- Not hurt themselves or others
- Live on their own as an adult

Also, caregivers who took the survey preferred

- Having their children in a special program for children with disabilities in a public school or alternative school, rather than a regular classroom in a public school
- Caring for their children at home instead of someone else caring for their children
- Choosing a medicine that would not change their children’s personality much

Who was in the study?
The study included caregivers of children with an intellectual or cognitive disability. The children also had a mental health condition. Children were age 26 or younger. Caregivers spoke English or Spanish.

To create the survey, the research team interviewed 58 caregivers.

Then the team gave the survey to 413 caregivers. In this group, 71 percent were a child's mother, 22 percent were a child's father, and 6 percent were another relation. In addition, 56 percent were white, 24 percent were Hispanic, 13 percent were black, 4 percent were Asian, and 3 percent were another race. Also, 32 percent made more than $75,000 per
year, 75 percent had at least a college degree, and 80 percent were married.

**What did the research team do?**
First, the research team interviewed 58 caregivers. The team used what they learned from these interviews to create an online survey. The team then sent the survey by e-mail to another 413 caregivers.

Eight staff from advocacy groups and support groups helped the research team. Four caregivers of children with an intellectual or cognitive disability and a mental health condition were research team members. They helped design the survey, collect the data, and present the findings.

**What were the limits of the study?**
In this study, most caregivers were mothers. Most had gone to college and were married. They also had higher incomes. Results might be different if the study had more caregivers with less education, who were single, who were fathers, or who had lower incomes. The study results may not be the same for children with only an intellectual or cognitive disability, or only a mental health condition.

Future studies could see whether using care preferences improves a child’s health. Future research could also study caregivers with different traits, such as being single or having lower levels of education and income.

**How can people use the results?**
Knowing about these preferences can help caregivers and doctors discuss and plan a child’s care.

*To learn more about this project, visit* [www.pcori.org/dosReis124](http://www.pcori.org/dosReis124).