

Research Highlights

Topic: Positive Behavior Support

Ruef, M.B., & Turnbull, A.P. (2002). The perspectives of individuals with cognitive disabilities and/or autism on their lives and their problem behavior. *Research & Practice for Persons with Severe Disabilities*, 27(2), 125-140.

BOTTOM LINE

Based on focus groups with nine individuals with disabilities with cognitive disabilities and/or autism, key themes focus on the conditions/barriers that they perceive cause problem behavior (for example, communication difficulties), possible solutions (for example, employment), and informational strategies (for example, easier access to relevant information). They clearly indicated a preference for more active involvement in and control over the interventions and supports that involve them.

TIPS

- Enable persons with disabilities to give key input regarding what they value and act upon this input. A collaborative approach needs to be used to support persons with disabilities.
- Listen to the perspectives of individuals with problem behavior to further delineate personalized quality of life variables.
- Expand opportunities for employment, preferred living situations, recreation/leisure opportunities, personal relationships, and opportunities for self-help.
- Provide more information to individuals with disabilities in the formats that they prefer.

KEY FINDINGS

- Some conditions/barriers that cause problem behavior include
 - ◆ Experiencing difficulty communicating with others.
 - ◆ Living in environmental circumstances that they dislike and that limit their freedom and privacy.
 - ◆ Being a recipient of programs that they found to not be helpful such as institutional placement.
- In order build practical, positive solutions to problem behavior, more important areas include
 - ◆ Having quality of life enhancements related to employment, living situations, recreation, relationships, and self-help.
 - ◆ Having helpful environmental supports such as sensory integration and stress management.
 - ◆ Having opportunities to learn through effective teaching.
 - ◆ Having other supports such as flexible funding and information.
- Preferences for information of products that would be helpful include learning through doing rather than reading and receiving information from people they know and trust.

METHOD

- Face-to-face focus groups and interviews were the source for data collection.
- There were nine focus group participants representing two subgroups:
 - ◆ Five participants were in group one diagnosed with having cognitive disabilities.
 - ◆ Four participants in group two were diagnosed with autism.
- All participants met the following criteria:
 - ◆ Minimum 13 years old
 - ◆ Engaged in problem behavior in the last 12-19 months. (Problem behavior is defined as: any serious episode requiring direct intervention.)
- Information was systematically coded using state-of-art qualitative procedures.

RELATED
PUBLICATIONS

- Biklen, S.K., & Mosely, C.R. (1988). "Are you retarded?" "No, I'm Catholic": Qualitative methods in the study of people with severe handicaps. *Journal of the Association for Persons with Severe Handicaps*, 13, 155-162.
- Freedman, R.I., & Fesko, S.L. (1996). The meaning of work in the lives of people with significant disabilities: Consumer and family perspectives. *Journal of Rehabilitation*, 62(3), 49-55.
- Goode, D.A. (1986). Who is Bobby? Ideology and method in the discovery of a Down syndrome person's competence. In P.M. Ferguson, D.L. Ferguson, & S.J. Taylor (Eds.), *Interpreting disability: A qualitative reader* (pp. 197-212). New York: Teachers College Press.
- Ruef, M.B., Turnbull, A.P., Turnbull, H.R., & Poston, D. (1999). Perspectives of five stakeholder groups: Challenging behavior of individuals with mental retardation and/or autism. *Journal of positive Behavioral Interventions*, 1, 43-58.
- Schubert, A. (1997). "I want to talk to everyone": On the use of multiple means of communication. *Mental Retardation*, 35, 347-354.

This research was conducted in collaboration with the Beach Center on Disability. It was funded by the Rehabilitation Research and Training Center on Families of Children with Disabilities of the National Institute on Disability Rehabilitation and Research (H133B30070) and private endowments. For more information, contact the Beach Center on Disability at 1200 Sunnyside Avenue, 3111 Haworth Hall, The University of Kansas, Lawrence, KS 66045-7534. Phone: 785-864-7600. Email: Beachcenter@ku.edu. Website: www.beachcenter.org.

Permission granted to reproduce and distribute this research brief.
Please credit the Beach Center on Disability.