

## Research Highlights

### Topic: Positive Behavior Support

Turnbull, A.P., & Ruef, M. (1997). Family perspectives on inclusive lifestyle issues for individuals with problem behavior. *Exceptional Children*, 63(2), 211-227.

**Bottom Line:** Data were collected through in-depth telephone interviews with 17 families of children, youth, and adults with challenging behavior. This exploratory study focused on inclusion, the lifestyle that goes along with it, and the importance of these issues to families. The study's results were organized into categories that emerged from the qualitative data analysis. The prevalent themes are family life, friendship issues, school issues, community inclusion, and supported living or supported employment issues. The study found that supports that are in place for children and adults with disabilities and/or challenging behavior and their families to encourage inclusion are extremely insufficient and inadequate. None of the people with problem behavior in this study live an inclusive lifestyle. The authors recommend expanding family support and setting priorities for future topics for research and training that can help to make inclusion a reality.

### Tips

- Develop a plan for positive behavior support (PBS) for the benefit of the individual with the disability, including a functional behavior assessment (FBA) and any behavior interventions that are needed. These must aim straight at the problem behavior, but intrude as little as possible.
- Change the environment or events for an individual with problem behavior, not the individual (fix the setting, not the person.)
- To avoid isolation, be proactive in making connections with others, such as creating opportunities for a child with disability to be in inclusive settings.
- Find ways to participate in community settings and activities.
- Create alliances with people who can help fight for inclusion, for instance faculty members living in a university community.
- Pay strong attention to the value of friendship and try to nurture it. The development of emotional connections may help to forge bonds that lead people to connect with one another.

## Key Findings

- Lifestyle issues related to inclusion include:
  - ◆ family life, including relationships with siblings and the extended family, home routines, and access to participation in religious activities.
  - ◆ friendships among children or adults, if or when they exist.
  - ◆ schools: considering teachers and administrative issues, as well as inclusion in the classroom and activities.
  - ◆ participation in the community.
  - ◆ supported living and supported employment.
- Teachers capable of providing the highest level of support are energetic, open to change, enthusiastic, and positive.
- Families' concerns about school administrators include
  - ◆ inadequate access to resources for their child.
  - ◆ a perceived push for an increasingly restrictive as opposed to inclusive setting.
  - ◆ a possible lack of full-scale implementation of IDEA (Individuals with Disabilities Education Act).
  - ◆ placement concerns.
- Families are both concerned about a lack of necessary facilities and training for teachers and administrators.
- Families expressed their firm belief in the benefits of inclusion for not only the child, but also his or her family, and others.
- Family members often spend lots of time and energy to obtain inclusion for their sons and daughters with disabilities or challenging behavior. They are usually the prime catalysts for change and the most engaged advocates for inclusion.
- Of all groups of people with disabilities, people with problem behavior likely have the greatest obstacles to finding and maintaining employment. New work opportunities must be created, and training for the transition from school to work must go hand in hand with this effort.
- Families, teachers, and others benefit from access to research findings and information about best practices.

## Method

- Data were collected through in-depth telephone interviews of an average 70 minutes per call for a period of about 5 months with 17 families of children, youth, and adults with challenging behavior.
- Purposive sampling was achieved by selecting participants who had a family member with mental retardation and who met set criteria concerning problem behavior. The sample was also diverse in terms of socio-economic background, education, and housing.
- Multiple researchers participated together on the same parts of the study, and draft paper summaries were given to research participants and family leaders for their review and input.

## Related Publications

Carr, E.G., Horner, R.H., Turnbull, A.P., Marquis, J.G., Magito-McLaughlin, D., McAtee, M.L., Smith, C.E., Ryan, K.A., Ruef, M.B., & Doolabh, A. (1999). *Positive behavior support as an approach for dealing with problem behavior in people with developmental disabilities: A research synthesis*. Washington, DC: American Association on Mental Retardation.

Turnbull, A.P., & Turnbull, H.R. (1999). Comprehensive lifestyle support for adults with challenging behavior: From rhetoric to reality. *Education and Training in Mental Retardation and Developmental Disabilities*, 34(4), 373-394.

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 Behavior Interventions*, 1(1), 43-58.

Sailor, W., Scott, T. M., Nelson, C. M., Freeman, R., Smith, C., Britten, J., & McCart, A. (2000). Using information technology to prepare personnel to implement functional behavioral assessment and positive behavioral support. *Exceptionalities*, 8(3), 217-230.

Ruef, M., & Turnbull, A.P. (2001). Stakeholder opinions on accessible informational products helpful in building positive practical solutions to behavioral challenges of people with mental retardation and/or autism. *Education and Training in Mental Retardation and Developmental Disabilities*, 36(4), 441-456.

*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.