

Research Highlights

Topic: Family Quality of Life

Poston, D. J., & Turnbull, A. P. (2004). Role of spirituality and religion in family quality of life for families of children with disabilities. *Education and Training in Developmental Disabilities*, 39(2), 95-108.

BOTTOM LINE

Results from a qualitative inquiry investigating conceptualization of family quality of life are provided. Focus groups and individual interviews were composed of 187 individuals that included family members (e.g., parents, siblings) of children with a disability, eight individuals with a disability, family members of children without a disability, service providers, and administrators of education and social service agencies. Families described the importance of spirituality in their lives, how spirituality helped them make sense of the presence of disability in their lives, and how they participated in religious communities. Discussion and implications include strategies to enhance family spiritual well-being, to provide spiritually sensitive supports, and to promote inclusive religious communities for children with mental retardation and developmental disabilities (MR/DD) and their families.

TIPS

- Steps families can take to enhance/improve participation in their religious community:
 - ◆ Set aside time for spiritual or religious practice.
 - ◆ Ask your religious community for support.
 - ◆ Ask disability organizations or the child's school for support.
- Activities religious organizations may explore to support a child with a disability and their family:
 - ◆ Implement a lay ministry program (such as Stephen's Ministries).
 - ◆ Model a new program after successful ones, such as health care workers in the congregation providing information and support.
 - ◆ Solicit help from community resources such as disability organizations, parents of a child with a disability, educators, etc.

TIPS (cont.)

- Efforts schools and disability organizations can make to support full participation of families in religious activities
 - ◆ Develop IEP goals and objectives that will enhance the ability of families to participate in religious communities.
 - ◆ Hire outreach staff to work specifically with religious communities and activities.
 - ◆ Include spirituality and religious awareness in professional development programs.
- Access resources such as books, websites, journals, and organizations dedicated to supporting individuals with disabilities in spiritual activities (see <http://www.aamr.org/Groups/div/RG/index.php>)

KEY FINDINGS

- Many participants identified spiritual beliefs as a contributor to their emotional and overall family quality of life in three areas:
 - ◆ Having **faith** – believing in something greater than themselves. From faith they gain strength and make sense of life events.
 - ◆ Using **prayer** – a way to communicate with God and to access their faith.
 - ◆ Attributing **meaning** to disability – using faith as a way to make sense of having a child with a disability.
- Religion and spirituality play a major role in the lives of many families. Comments reflected a sense of strength gained from spiritual well-being and participation in religious activities.
- Responses were divided equally regarding acceptance of the child with a disability into a religious community.
 - ◆ Some respondents described their religious community as a place of acceptance and unconditional love.
 - ◆ Others indicated difficulties and that lack of acceptance of the child with a disability impeded their full participation.
- Families who participated in this study appear to be looking for three things from a religious community:
 - ◆ Acceptance of their child with a disability.
 - ◆ Spiritual and emotional support for themselves.
 - ◆ Supports for their child during services so that the child and the family can participate meaningfully.
- Religious leaders need a resource person, someone to contact for information, training, and support to be responsive to the needs of children with a disability and their families.

METHOD

- A Participatory Action Research (PAR) group was implemented to ensure maximum relevance.
- Semi-structured focus groups, averaging one-and-a-half hours, were held in three locations (urban and rural) and included 187 families with a child with a disability, families without a child with a disability, service providers, administrators, and a group of people with a disability. Follow-up focus groups were held three to four months later.
- Individual interviews for speakers of languages other than English included parents (N=18), service providers (N=10) to families with English as a second language, and siblings (N=3).
- Sampling strategies included purposive, maximum variation, intensity, and convenience.
- The constant comparative method was used for interview data analysis to generate categories, subcategories, and codes, as well as to interpret patterns and themes and to ensure rigor.

RELATED PUBLICATIONS

- Canda, E. R. (1999). Spiritually sensitive social work: Key concepts and ideals. *Journal of Social Work Theory and Practice*, 1(1), 1-15.
- Gaventa, W. C. (2001). Defining and assessing spirituality and spiritual supports: A rationale for inclusion in theory and practice. *Journal of Religion, Disability, and Health*, 5, 29-48.
- Poston, D. J., Turnbull, A. P., Park, J., Mannan, H., Marquis, J., & Wang, M. (2003). Family quality of life outcomes: A qualitative inquiry. *Mental Retardation*, 41, 313-328

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 (H133B980050) 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.