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Family Quality of Life: A Qualitative Inquiry

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RESEARCH HIGHLIGHTS

Family Quality of Life

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BOTTOM LINE

In this qualitative inquiry, the authors investigated the conceptualization of family quality of life. Focus groups and individual interviews were conducted with 187 participants. Ten domains of family quality of life resulted from the qualitative analysis: advocacy, emotional well-being, health, physical environment, productivity, social well-being, daily family life, family interaction, financial well-being, and parenting. Sub-domains, indicators, and key points raised by the participants are identified for each of the 10 domains. These domains will be used as the basis of a long-term goal of developing a psychometrically sound scale for measuring family quality of life.

Beach Center on Disability

Making a Sustainable Difference in Quality of Life



TIPS

- Think about how family life is complex and that what occurs in one area of life, for example a child's education, has an impact on other areas of family life, for example the interaction among family members.
- Consider using a family quality of life framework to develop family support plans.

KEY FINDINGS

- Based on participant descriptions of their families, the authors propose the following definition of “family”: A family includes the people who think of themselves as part of the family, whether related by blood or marriage or not, and who support and care for each other on a regular basis.
- The data suggested a domain structure with two parts: domains with an individual orientation and domains with a family orientation.
- The six individual domains include advocacy, emotional well-being, health, physical environment, productivity, and social well-being. These domains represent the idiosyncratic ways that the quality of life of individual family members has an impact on the quality of life of other family members and on the family as a whole.
- Within the six individually-oriented domains, the most substantial differences in perspective of families of children with and without disabilities occurred in the domains of advocacy, emotional well-being, and social well-being.
- The four family-oriented domains include daily family life, family interaction, financial well-being and parenting. Domains with a family orientation occur at the family unit level rather than at the individual family member level. Typically, all family members tend to experience more similarity in the family-oriented domains as contrasted to the individually-oriented domains.
- Within the four family-oriented domains, the major differences between the perspectives of families of children with and without disabilities occurred in the family interaction and parenting domains.
- The 10 domains will form the basis for developing a scale to measure family quality of life.

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METHOD

- A participatory action research process involving collaboration with family members, service providers, administrators, and researchers was used to insure maximum rigor and relevance.
- Focus groups and individual interviews were used for data collection in 3 states. The 187 participants included 78 family members of children with disabilities, 18 parents who use English as a second language, 33 parents of children without disabilities, 8 individuals with disabilities, and 50 professionals.
- The constant comparative method was used to analyze transcript data to generate categories, subcategories and codes as well as to interpret patterns and themes.

NEXT STEPS FOR RESEARCHERS

- Proceed into future phases of research with the long-term goal of developing a psychometrically-sound scale for measuring family quality of life.
- Use the psychometrically sound scale to gain the perspectives of all family members regarding a rating of importance and satisfaction.
- Explore alternative methods for aggregating scores of individual family members in order to obtain the score at the family unit of analysis.
- Explore similarities and differences in the response patterns of various family members.
- Explore use of the scale in agencies both at the individual family level and at the program evaluation level.
- Develop a family-friendly survey that can be used collaboratively with families in planning for the delivery of family-centered services and supports.
- Match the rhetoric of family-centered services and the enhancement of family outcomes with the conceptual framework of family quality of life as a guide.

RELATED PUBLICATIONS

Park, J. (2001). How to define and measure outcomes of early intervention: An examination of family quality of life. Unpublished doctoral dissertation, University of Kansas, Lawrence, KS.

Park, J., Hoffman, L., Marquis, J., Turnbull, A., Poston, D., Mannan, H., & Wang, M. (2003). Toward assessing family outcomes of service delivery: Validation of a family quality of life survey. *Journal of Intellectual Disability Research*, 47 (4/5), 367-384.

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- Schalock, R.L., Brown, I., Brown, R., Cummins, R.A., Felce, D., Matikka, L., Keith, K.D., & Parmenter (2002). Conceptualization, measurement, and application of quality of life for persons with intellectual disabilities: Report of an international panel of experts. *Mental Retardation*, 40(6), 457-470.
- Turnbull, A.P., Brown, I., & Turnbull, H.R. (in press). *Family quality of life: An international perspective*. Washington, DC: American Association on Mental Retardation.

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