Current Research on Family Research
National Designated Resource Person
Dr. Hasheem Mannan
National Institute for Intellectual Disability
Trinity College Dublin
Email: mannanh@tcd.ie

Research Update on Family Research: Winter 2008

Introduction:
This is the third in the series of updates on family research literature. The following is a selection from research literature on parents' perspectives on: future of their children with disabilities, transition and self-determination.

1. Blue-Banning, M., Turnbull, A.P., & Pereira, L. (2002). Hispanic youth/young adults with disabilities: Parents' visions for the future. *Research and Practice for Persons with Severe Disabilities, 27*(3), 204-219.

Abstract:
The rapid increase of culturally and linguistically diverse populations in the United States has important implications for service delivery. Addressing the needs of individuals transitioning from adolescence to adulthood and their families requires that outcomes of service recognize the cultural differences of people with disabilities. The Hispanic population is one of the fastest growing of the culturally and linguistically diverse populations in the United States. To provide effective support services, a clearer understanding is needed of the perspectives of Hispanic parents of youth/young adults with disabilities concerning their hopes and expectations for their child's future. To address this issue, focus group interviews were conducted with 38 Hispanic parents of youth/young adults with developmental disabilities. The findings suggest that Hispanic parents have a diversity of hopes and expectations concerning future living, employment, and free-time options, for their children with disabilities. Key recommendations focus on the implications for education and human service systems as well as directions, for future research.

2. Kyeong-Hwa, K., & Turnbull, A. (2004). Transition to adulthood for students with severe intellectual disabilities: Shifting toward person-family interdependent planning. *Research & Practice for Persons with Severe Disabilities*, *29*(1), 53-57.

Abstract:
The transition from high school to adulthood is a major life change for most young adults and their families, and generally it is depicted as an especially stressful time for young people with disabilities and their families. Adequate planning is required to address the challenging impact of this stage of life on families. The purposes of this paper are to provide a general overview of person centred planning and family-centred planning and to suggest merging these two approaches into person family interdependent planning to better meet the needs of this challenging time.

3. Turnbull, A., & Turnbull, R. (2001). Self-determination for individuals with significant cognitive disabilities and their families. *JASH, 26*, 56-62.
Abstract:
Two key issues in self-determination for people with significant cognitive disabilities and their families are addressed. The first issue is the inadequate attention given to the influence of significant cognitive disabilities on the achievement of self-determination. The second issue concerns the culture values that influence definitions of self-determination.
For action steps, findings, methods, steps for future research see attachment 3.
The attachments were produced by the Beach Centre on Disability, University of Kansas and used here with their permission.

Beach Center on Disability, University of Kansas, Haworth Hall, Room 3136, 1200
Sunnyside Avenue, Lawrence, KS 66045-7534, Phone: 785-864-7600, Fax: 785-864-7605
TTY: 785-864-3434

Research Update on Family Research: Autumn 2008

Introduction:

This is the second in the series of updates on family research literature. The following is a selection from research literature on the role of families in advocacy (1); preparing families for transition (2); what does research tell us about transitions (3);

1. **Stille, C. J., Primack, W. A., McLaughlin, T.J., Wasserman, R. C. (2007). Parents as information intermediaries between primary care and specialty physicians. *Pediatrics, 120,* 1238-1246.**

Abstract:

This research study examined parents' and physicians'perceptions of parents as communicators of medical information between general care physicians and specialty physicians. The role of parents as communicators was not explicitly defined, but it appears that parents either played an active role (e.g., taking an active role in communicating about their child's condition between physicians) or primary role (e.g., being the primary way their child's physicians communicated with one another). In terms of the active role, parents reported that they perceived this role as more important than primary care and specialty physicians perceived parents' role as active communicators; specialty physicians rated parents' active role as the least important among the three respondents. While parents usually felt comfortable in the active role, they were less comfortable being the *primary* communicator of information. Both primary care physicians and specialty physicians were less comfortable with parents as the primary communicator of medical information. Parents' comfort level was related to the number of visits to their child's specialty doctor. Consistent with family-centered practice, these authors recognize the importance of shared partnerships between physicians and families, and that families should not be expected to be the primary communicator of information among their child's physicians.

2. **Rous, B., Myers, C.T., & Stricklin, S.B. (2007). Strategies for supporting transitions of young children with special needs and their families. *Journal of Early Intervention, 30*(1), 1-18.**

Abstract:

This paper presents strategies recommend for successful transition by practitioners, administrators, faculty, researchers, and families reported the. The two most important strategies are interagency collaboration and effective transition practices.

3. **Rosenkoetter, S., & Schroeder, C. (2008).** ***What does the research tell us about early childhood transition?*** **Lexington: University of Kentucky, Human Development Institute, National Early Childhood Transition Centre.**

Abstract:

This literature review includes 58 studies with 33 focusing on children, 18 on families, and 8 on policy. Across child, family, and policy areas, research to date has not lead to the identification of research-based practices. The best available research on family issues underscores the importance of strong communication between families and program staff, as well as the importance of families receiving information responsive to their questions. Extensive experience-based knowledge and policy exists to support active family-professional partnerships in planning for transition. Overall, research needs to be improved in its scientific rigor and in the clarity and specificity in which it is reported.

For action steps, findings, and methods see attachment 3.

The attachments were produced by the Beach Center on Disability, University of Kansas and used here with their permission.

Beach Center on Disability

The University of Kansas 1200 Sunnyside Avenue, 3111 Haworth Hall ● Lawrence,
Kansas 66045 Telephone: 785.864.7600 ● TTY: 785.864.3434 www.beachcenter.org

Research Update on Family Research: Summer 2008

Introduction:

This is the first in a regular selection from the family research literature and the following is a selection of reading in the field of family research focusing on family quality of life. It includes qualitative as well as quantitative studies carried out in this area of research and includes conceptualization of the concept of family quality of life (1,2); validation and establishing psychometric properties of the family quality of life survey (3,4); family outcomes in early childhood programs (5); impact of advocacy in family quality of life (6); severity of disability and income as predictor of family quality of life (7); relationships between service adequacy, family quality of life, and quality of parent-professional interaction (8); impact of deafness on family quality of life (9); an international study on family quality of life (10); and fathers and mothers perceptions on family quality of life (11).

1. Denise, P., Turnbull, A., Park, J., Mannan, H., Marquis, J., & Wang, M. (2003).Family quality of life: A qualitative Inquiry. *Mental Retardation*, 41(5), 313-328.

Abstract:

In this qualitative inquiry the authors investigated the conceptualization of family quality of life. Focus groups and individual interviews were conducted with 187 individuals: family members (e.g., parents, siblings) of children with a disability, individuals with a disability, family of children without a disability, service providers, and administrators. Data were collected in urban and rural settings to elicit the participants' understanding of family quality of life. Ten domains of family quality of life were identified and described in terms of subdomains, indicators, and key points raised by participants. Implications are discussed in terms of future directions for research and family support.

2. Summers, J. A., Poston, D. J., Turnbull, A. P., Hoffman, L., Mannan, H., & Wang, M. (2005). Conceptualizing and measuring family quality of life. *Journal of Intellectual Disability Research,* 49(10), 777-783.

Background: Increasing emphasis on family-centred approaches to services and supports for families of children with disabilities has surfaced the issue of accountability for family outcomes. The authors present a review of literature about the impacts of children with disabilities on families as a backdrop to proposing family quality of life as a concept that encompasses impacts of disability and one that can be used to assess the impact of supports and services on families.

Method: The authors briefly introduce the Beach Centre Family Quality of Life Scale, providing information about its factor structure, reliability, and convergent validity.

Results: The Beach Centre Family Quality of Life Scale contains 25 items assessing family ratings of importance and satisfaction with five domains: Family interaction, Parenting, Emotional well-being, Physical/material well-being and Disability-related supports.

Conclusion:

The authors present a framework for utilizing a measure of family quality of life as a long-term outcome in concert with other short-term measures of service outcomes for families

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

Abstract:

The concept of family quality of life emerged as an important outcome of service delivery for individuals with disabilities and their families. In this article, the authors describe the process of developing a tool to measure family quality of life. A total of 1,197 respondents participated in the national field test. Through factor analysis, the survey was refined in several ways: (a) the preliminary 10-domain structure was reduced to 5-domain structure, (b) a total of 41 items were selected for the revised survey, and (c) wordings were clarified. Implications for future research and practices are provided.

4. Hoffman, L., Marquis, J., Poston, D., Summers, J. A., & Turnbull, A. (2006). Assessing family outcomes: Psychometric evaluation of Beach Centre family quality of life scale. *Journal of Marriage and Family 68,* 1069-1083.

Abstract:
There is currently a lack of reliable scales with which to assess the construct of family quality of life, particularly for families who have children with disabilities. The current work presents 2 studies, including a total of 488 families with children with disabilities, which were conducted to complete the development of a scale to assess family quality of life. The measure was refined through confirmatory factor analyses into 25 items that assess 5 domains of Family Quality of Life: Family Interaction, Parenting, Emotional Well-Being, Physical/Material Well-Being, and Disability-Related Support. Each subscale was found to be unidimensional and internally consistent. An initial examination of test-retest reliability and convergent validity is also presented. Implications for future research, scale use, and policy are discussed.

5. Mannan, H., Summers, J. A., Turnbull, A. P., & Poston D. (2006). Family outcomes in early childhood programs: A review of outcome measures. *Journal of Policy and Practice in Intellectual Disabilities,* 3(4), 219-228.

Abstract:

The authors undertook a review of measures available for assessing outcomes of early childhood services for children with disabilities and their families. With principles of family-centred practice mandating the inclusion of both family and child outcome measures in effective evaluation plans, the review examined measures with established psychometric properties for (a) documenting the effectiveness of partnerships with families, and (b) documenting the effectiveness of services and supports for families. Constructs and their associated measures related to partnerships include satisfaction with the overall program and empowerment. The constructs for outcomes of supports and services include social support, parenting, and family quality of life. The authors reviewed measures for each of the five constructs. They note that the selection of appropriate measures to assess the outcomes of family support and services depends on the specific configuration of support services provided by the program and that each program may have to be explicit about the outcomes it wants to impact and therefore measure.

6. Wang, M., Mannan, H., Turnbull, A. P., Poston, D., & Summers, J. A. (2004). Parents' perceptions of advocacy and its impact on family quality of life. *Research & Practice for Persons with Severe Disabilities,* 29(2), 144-155.

Abstract:

The concept of family quality of life has emerged as an important outcome of service provision for children with disabilities and their families. In this article, the authors report families' perceptions of their advocacy efforts and the impact of these efforts on their family quality of life. A total of 104 family respondents participated in focus groups and individual interviews. Through qualitative analysis the authors identified two themes related to parents' perceptions about their advocacy actions: advocacy as an obligation and advocacy as a means to improve services. Three themes also emerged regarding parents' perceptions of the impact of their advocacy actions: advocacy enhances coping, advocacy involves struggle, and advocacy causes stress. The authors discuss issues related to these themes as well as two factors (the quality of their partnerships and of their child's education) that may mediate the impacts of parental advocacy. They also discuss the implications for practice and provide tips for educators to improve their practices to better support families in their advocacy efforts.

7. Wang, M., Turnbull, A. P., Summers, J.A., Little, T.D., Poston, D., Mannan, H., & Turnbull, R. (2004). Severity of disability and income as predictors of parents' satisfaction with their family quality of life during early childhood years. *Research &Practice for Persons with Severe Disabilities,* 29(2), 82-94.

Abstract: The field of early intervention has recognized a growing need to study contributing factors of family outcomes such as family quality of life (FQOL). This study of 130 fathers and 234 mothers of families in early childhood programs explores the associations between family income and severity of disability, and fathers' and mothers' satisfaction with their FQOL. The results reveal that severity of disability is a significant predictor of fathers' and mothers' satisfaction ratings of FQOL; that family income is a significant predictor of mothers' satisfaction ratings of their FQOL, but not of fathers; and that there is no interaction effect of family income and severity of disability with respect to fathers' and mothers' satisfaction ratings of FQOL.

8. Summers, J. A., Marquis, J., Mannan, H., Turnbull, A. P., Fleming, K., Poston, D., Wang, M., & Kupzyk, K. (2007). Relationship of perceived adequacy of services, family-professional partnerships, and family quality of life in early childhood service programs. *International Journal of Disability, Development and Education.* 54(3), 319-338.

Abstract:

This study applied three family measures (ratings of service adequacy or implementation, satisfaction with the family–professional partnership, and family quality of life) to a sample of families of young children in one Midwestern U.S. state. The results suggest that: (a) families more often believe they are receiving adequate amounts of services for their child, but tend to believe they are not receiving adequate amounts of services for their family; (b) respondents tend to be satisfied with their partnerships with their primary service provider, with lower satisfaction ratings for the provider's ability to meet their child's individual needs and to provide information about services; and (c) respondents tended to be more satisfied with their family's material well-being and less so with their family's emotional well-being. Finally, the authors found that service adequacy ratings were a significant predictor of family quality of life, and that partnerships partially mediated this effect. They discuss the research, service, and policy implications of these findings.

9. Jackson, C. W. & Turnbull, A. (2004). Impact of deafness on family life. *Topics in Early Childhood Special Education 24(1),* 15-29.

Abstract:

The presence of deafness in a family has the potential to affect all areas of family life. An understanding of the impact on family life is critical to addressing all components of the family system in early intervention. This review synthesizes the literature on deafness as it relates to four domains of family quality of life, including family interaction, family resources, parenting, and support for the child who is deaf. Implications for future research are discussed.

10. Brown, I., Anand, S., Fung, W.L. A., Issacs, b. & Baum, N. (2003). Family quality of life: Canadian results from an international study. *Journal of Developmental and Physical Disabilities, 15(3),* 207-230.

Abstract:

The quality of life of families that have a son or daughter with a disability has been an area overlooked by quality of life researchers until recently. The purpose of this study

was to gather preliminary data on family quality of life and to report the findings of one part of an international study. The parents of 34 children and adults with intellectual disabilities were interviewed using the Family Quality of Life Survey, a measurement and assessment tool developed by a team of international researchers. Quantitative and qualitative data were collected for four concepts—opportunities available, initiative to access opportunities, attainment, and satisfaction—for each of the 9 key areas of family quality of life. In general, careers, spiritual and cultural beliefs, and family relationships were rated highly, while support from others and support from disability related services were rated quite low. Results provide a baseline for further research into the needs of these families, which is imperative for developing public policies and approaches to family-centred supports.

11. Wang, M., Summers, J. A., Little, T., Turnbull, A. P., Poston, D., & Mannan, H. (2006). Perspectives of fathers and mothers of children in early intervention programmes in assessing family quality of life. *Journal of Intellectual Disability Research, 50(12),* 977-988.

Background: Family quality of life (FQOL), as a family outcome measure of early intervention and other services, has increasingly drawn attention of researchers, policymakers and service providers. Developing an index of *family* QOL requires a measure suitable for use with multiple family members. The purpose of this study was to test whether mothers and fathers similarly view the conceptual model of FQOL embodied in one measure. *Method* This study involved fathers and mothers of families who have a young child (birth to five) with a disability enrolled in an early intervention programme. Data from couples completing the Beach Centre FQOL measure were analysed using structural equation modelling (SEM) to determine similarities or differences between fathers and mothers with respect to their assessment of FQOL.

Results: The analysis of measurement invariance of the FQOL construct across the father and mother groups indicates that the Beach Centre FQOL Scale measures equally the underlying FQOL construct across fathers and mothers in this sample. Fathers do not differ from mothers in perceived importance of factors related to FQOL items, nor did they differ in their overall satisfaction with FQOL.

Conclusion: These results suggest that fathers and mothers respond similarly to the latent constructs within the Beach Centre FQOL Scale; therefore, it holds promise for use with both fathers and mothers in assessing FQOL across multiple family members. Further implications for research and practice are discussed.