Journal on Developmental Disabilities
Le journal sur les handicaps du développement
JoDD
Volume 19, Number 2, 2013

Family Quality of Life of Polish Families with a Member with Intellectual Disability

Authors

Elaine Ho,[1] Nalini James,[2] Ivan Brown,[3] Anna Firkowska-Mankiewicz,[4] Ewa Zasępa,[5] Agnieszka Wołowicz,[6] Ewa Wapiennik[6]

[1] C.W. Behavioural Consulting & Therapy Services Inc., Toronto, ON

[2] Erinoakids Centre for Treatment and Development, Toronto, ON

[3] Centre for Applied Disability Studies, Brock University, St. Catharines, ON

[4] Institute of Philosophy and Sociology, Maria Grzegorzewska Academy of Special Education, Warsaw, Poland

[5] Institute of Applied Psychology, Maria Grzegorzewska Academy of Special Education, Warsaw, Poland

[6] Institute of Special Education, Maria Grzegorzewska Academy of Special Education, Warsaw, Poland

Correspondence

ivan.brown@utoronto.ca

Keywords

family quality of life, quality of life, intellectual disabilities, financial well-being, health concerns

Abstract

A Polish sample of 189 caregivers of individuals with intellectual or developmental disabilities was surveyed with the Family Quality of Life Survey-2006, as part of a larger study examining family quality of life (FQOL) across 26 countries. The survey has six outcome measures in each of nine domains. Caregivers rated the Health of the Family, Financial Well-Being, and Family Relationships domains as most important. However, Opportunity and Initiatives outcomes were lower, especially in the Support from Others and Support from Services domains. Families' initiatives and opportunities were affected by the health of family members, financial resources available, and relationships among family members. Overall, caregivers were fairly satisfied with their FQOL despite having limited opportunities to improve their FQOL.

Over the past two decades, the quality of life of people with intellectual disabilities (ID) has emerged as a topic of considerable interest and importance, and has resulted in both policy and service changes (Brown, 2010). One of the principal reasons for this is a major shift in where children and adults with ID live, and in how they live their lives. Since the 1980s, institutions began to be closed in most countries of the world and those people who lived in them were moved to communities (Brown, 1999). Governments gradually shifted financial and human resources from institutional services to services that emphasized community living (Brown, 2010; Brown, Anand, Fung, Isaacs, & Baum, 2003). Education rights for children with disabilities enabled children to continue living in their family homes throughout their school years, because they attended local schools. Improved health and medical procedures resulted in people with ID have an increased life span (Brown & Brown, 2005). Accompanying these changes was a philosophical emphasis on social inclusion in community life. A question that arose was whether people who lived in communities, in the physical and social sense, were actually part of their communities and whether they were enjoying satisfactory quality of life (Samuel, Rillotta, & Brown, 2012).

By the late 1990s, it was recognized that the expanding role of the family in the lives of their sons and daughters with ID meant that a satisfactory quality of life for people with ID was very much dependent upon the family's quality of life. Conversely, it became obvious that a family's quality of life was affected by the presence of disability (Isaacs et al., 2007, Werner et al., 2009). This suggested that family quality of life itself was an important topic to study in the broader field of ID.

As a consequence, two major family quality of life projects were initiated. The Beach Center at the University of Kansas developed and applied the Beach Center Family Quality of Life Scale (see Beach Center on Disability, 2013), and the International Family Quality of Life Project developed the *Family Quality of Life Survey 2006* (FQOLS-2006; Brown et al., 2006), which has been translated into several languages and used to gather data in more than 25 projects in 20 countries. These projects collectively provide a rich source of data for cross-country comparisons (Brown, 2010, 2012), for examining psychometric properties of the instruments (e.g., Isaacs et al., 2012), and for understanding specific aspects of family life in detail.

One aspect of understanding family life that warranted further examination (Werner et al., 2009) was to identify variables that positively influence families' experiences in order to develop policies and practices that enhance family quality of life (see Otrebski, Norway, & Mansell, 2003). The overall purpose of the present study was to guide future research in developing community strategies and services in Poland to improve the overall QOL for families who have a member(s) with a developmental disability. To begin to explore this, the specific purposes of this study were to: (1) provide key research data for developing and improving knowledge regarding the FQOL, and (2) identify factors captured within the data collection that enhance and diminish FQOL.

Method

Ethical approval for secondary analysis reported here was obtained from the University of Toronto.

Participants

The participants comprised a convenience sample (i.e., the participants were selected by available volunteers) of members of the Polish Association for Persons with Mental Handicap. Main caregivers of 189 families that had at least one family member with ID participated. The main caregivers included 163 mothers, 18 fathers, 3 siblings, 1 daughter, 1 mother and son, as well as 1 mother and daughter participating together. Of all the families, 142 were two-parent families, 43 were single-parent families, and 3 were neither of these family types. With regard to the individuals with ID, more than half were male (55%) and their mean age was 15.88 (*SD* = 7.15; range 1-36). Ninety-eight percent lived at home. The diagnoses reported by the main caregivers for these individuals were Unknown Cause (*n* = 100), Down syndrome (*n* = 52), Cerebral palsy (*n* = 17), Rett syndrome (*n* = 7), autism spectrum disorder (*n* = 6), William syndrome (*n* = 1), and other diagnosis (*n* = 1). Fifteen individuals had more than one diagnosis.

Procedures

This study was carried out as secondary data analysis using the original data collected by researchers at the Maria Grzegorzwska Academy of Special Education in Warsaw, Poland (see Zasępa & Wołowicz, 2010 for a report on the study). The database was made available, with permission from the researchers, to complete various analyses. The original data was obtained by an experienced research team in Poland that was part of an International Family Quality of Life Project, and was collected according to procedures of the authors of the FQOLS-2006 (Surrey Place Centre, 2009).

Measure

Data was collected using the FQOLS-2006 (Brown et al., 2006), described in detail elsewhere (Isaccs, et al., 2007; Samuel et al., 2012). The FQOLS-2006 takes single ratings of six measurement concepts in nine family life domains (see results section below for a full listing) using a five-point likert-type scale. For each domain, there are also a number of items that gather additional information. For example, in the Health of the Family domain, items ask if there are major health concerns for the family member with the disability or any other member of the family and, if so, what those concerns are. There are also opportunities throughout the survey to provide qualitative information in the form of additional comments. The final section of the survey asks respondents to rate their overall quality of life, and satisfaction in a global way, and also provides them with an opportunity to comment on other things that add to or detract from their family quality of life.

Analyses

Data analyses explored the mean ratings on the six main outcome measures and the relationships among the outcome measures using correlation, and the relationships between the various descriptive variables and the outcome measures within each of the nine family domains using one-way analysis of variance and *t*-test. All analyses were conducted using SPSS 16.0.

Results

Main Family Quality of Life Outcomes

The six outcome measures (Importance, Opportunities, Initiative, Stability, Attainment, and Satisfaction) were examined individually for each of the nine family life domains of the FQOLS-2006 (Figure 1; Health of the Family, Financial Well-Being, Family Relationships, Support from Other People, Support from Disability-Related Services, Influence of Values, Careers and Preparing for Careers, Leisure, and Community Involvement). Importance was rated higher than the other five measures for all nine domains of the FQOLS-2006, with Health of the Family, Financial Well-Being, and Family Relationships particularly high. Opportunities (opportunities available to the family) and Initiative (initiative taken by the family) were rated similarly for all domains, except Financial Well-Being, where Opportunities was rated much lower than Initiative, although Opportunities and Initiative ratings correlated positively for all nine domains ($r = .21\text{-}.56$, $p < .01$). Stability mean ratings (amount of change expected in the future) were also similar to those of Opportunities and Initiative in all domains except Financial Well-Being; however, lack of significant correlation between Stability and either Opportunities or Initiative in most domains suggested a more complex relationship. Attainment and Satisfaction mean ratings were also similar across the nine domains and positively correlated ($r = .49\text{-}.80$, $p<.01$), except for Family Relations where Satisfaction was rated considerably higher.

Variables Related to Main Outcome Measures

Numerous variables of the FQOLS-2006 were examined to determine possible relationships they might have to the main family quality of life outcome measures (Satisfaction and Attainment). The five variables where significance was reached were all two-category variables, and thus outcome measures for these were contrasted by *t*-test.

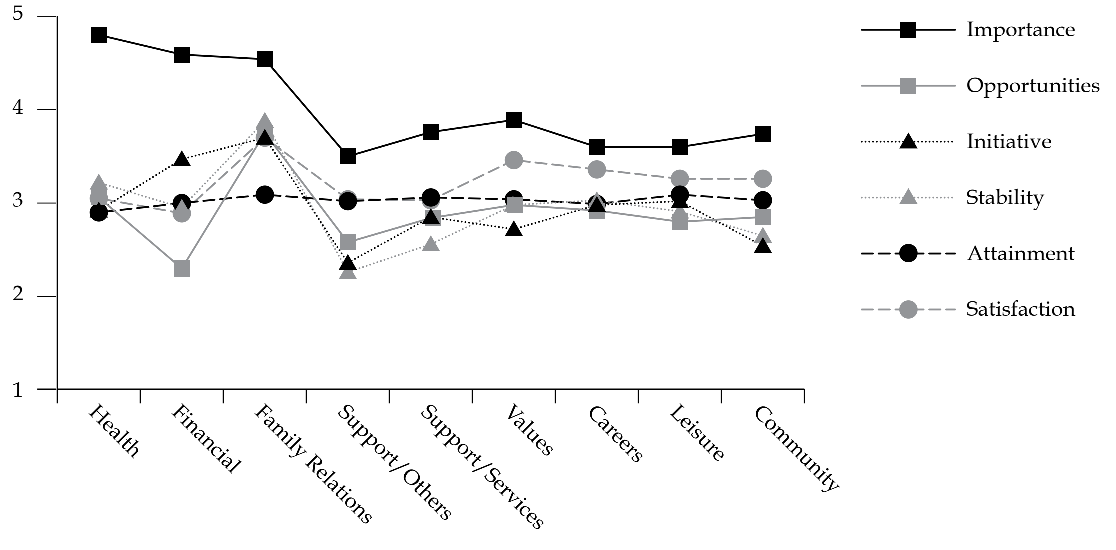

Figure 1. Mean ratings of six FQOL outcomes for nine family life domains.

Caregivers with and Without Health Concerns

Not surprisingly, caregivers with no major health concerns (n = 89) rated their family's Attainment and Satisfaction for the domain Health of the Family higher than families with major health concerns (n = 69) ($t_{(170)}$ = 2.63, p = .009 and $t_{(170)}$ = -3.11, p = .002 respectively). As might be expected, though, ratings of Initiative were significantly lower for caregivers with no major health concerns than for those with major health concerns ($t_{(170)}$ = 3.02, p = .002).

People with ID with and Without Health Concerns

Where the person with ID had major health concerns, the main caregivers' ratings of family Attainment, Stability, and Satisfaction for the domain Health of the Family were significantly higher for those households where no health concern was indicated (n = 117) than for households with health concerns (n = 55) ($t_{(156)}$ = -4.87, p < .001; $t_{(156)}$ = -4.87, p < .001, and $t_{(156)}$ = -4.73, p < .001 respectively).

Households with and Without Discretionary Income

Ratings of Opportunities, Initiative, Attainment, and Satisfaction in the domain Financial Well-Being were significantly lower for families with no discretionary income (n = 117) than for families with discretionary income (n = 71) ($t_{(186)}$ = 9.24, p < .001; $t_{(186)}$ = 3.61, p < .001; $t_{(186)}$ = 10.61, p < .001; and $t_{(187)}$ = 4.89, p < .001 respectively).

Families Receiving and Not Receiving Disability Services They Need

Ratings of Importance and Initiative in the domain Support from Services were significantly higher for families not receiving disability related services they need (n = 131) than for families who are receiving disability related services they need (n = 47) ($t_{(177)}$ = 4.03, p < .001 and $t_{(176)}$ = 2.15, p < .033 respectively). In contrast, ratings of Opportunities and Satisfaction were significantly lower for families not receiving disability related services they need than for families who are receiving disability related services ($t_{(176)}$ = 2.36, p = .022 and $t_{(177)}$ = 4.89, p < .001 respectively).

Caregivers Giving up and Not Giving up Education or Career to Care for Person with ID

Ratings of Importance in the domain of Careers and Preparing for Careers were significantly lower for families with members who have not given up their careers and education to care for the family member(s) with a disability (n = 105) than for those who have given up their careers or education (n = 73) ($t_{(176)}$ = 2.08, p < .039).

Discussion

The present study examined six outcome measures for each of the nine family life domains of the FQOLS-2006. Overall, the findings were quite similar to those of other family quality of life studies worldwide, a consistency that suggests that families might be more similar than different across several countries in their perception of family quality of life (Brown, 2010, 2012). Importance was rated higher than the other outcome measures, indicating that all domains are relevant and important for families. Opportunity was rated lowest of all the measures, and were especially low for Support from Others and Support from Services, indicating a worrisome lack of practical support from others and services in Poland that presents a challenge to families and service providers. Attainment and Satisfaction mean ratings were all below 4, suggesting a general lack of positive feeling for family quality of life among the main caregivers in this study.

The five variables significantly related to outcome measures suggest, for the provision of quality services, that (1) particular attention should be given by family services to caregivers who have major health concerns, (2) support needs to be provided to the whole family when the family member with ID has a major health concern because it adversely affects family quality of life, (3) support to families needs to recognize that families that do not have discretionary income have negative feelings about their financial well-being, (4) families who are not receiving the disability supports they need understandably see this situation as important and unsatisfactory, and (5) caregivers who have given up their careers or education to care for a family member with ID think of careers and education as particularly important, perhaps signifying some regret.

There are four main limitations to this study. First, the analysis was constrained by the structure of the FQOLS-2006, although this instrument does allow for data collection of a great many variables. Second, due to restrains in time and resources, the qualitative data could not be translated by a knowledgeable translator, and computer-generated translation programs proved to be highly inaccurate. Thus, the explanations that might have been used to clarify the ratings could not be used in this analysis. Third, there may be other information specifically about Poland that might be helpful to a full explanation of family quality of life. Finally, it is recognized that this study provides no comparative data, that is, information on the quality of life of families in Poland that do not have family member(s) with an ID. On the other hand, this database does provide a great deal of information about the quality of life of a sample of Polish families with a member with ID, and this provides excellent baseline information for future family quality of life research.

The present study examined the FQOL for caregivers who had a family member(s) with an ID. It would be interesting to know if the FQOL as perceived by the main caregiver is shared by other significant adults in the family, such as older siblings who are still living with the family and contributing to the overall family income, or members of the extended family such as grandparents, uncles, aunts, or cousins who may be providing support for the family either directly or indirectly. The present study could be extended to include all adult members who constitute the family unit to perhaps get a better representation of the family voice on FQOL. The convenience sample was derived from an urban area in Poland and represented families who receive some level of support for their family member(s) with a disability. It would be interesting to study the FQOL of a representative sample of families in other urban and rural areas of Poland, to compare the differences in the FQOL, and to identify domains that may positively and negatively impact the FQOL.

Caregivers' responses indicated that they were quite satisfied with the degree of quality of life attained. They rated all nine FQOL domains to be important. However, three domains were identified as particularly important to FQOL: Family Relationships, Health of the Family, and Financial Well-Being. Families appeared to have limited opportunities to pursue the nine domains and in turn the initiatives taken by them were low. Of special consideration were low opportunities to access support from agencies providing support for their family member(s) with a disability and support from other members in the community, indicating that families with a member(s) with a disability may view themselves as being somewhat alienated from other families in the community. Families took more initiatives to access services when the families had additional health concerns than those who did not. Families with discretionary income had more opportunities to improve the financial well-being of their family and took greater initiatives to do so than families without. Caregivers who gave up their careers in order to take care of their family member(s) with a disability viewed their careers to be more important than caregivers who did not. This analysis points to the view that specific attention should be paid to three domains in particular – Health of the Family, Financial Well-Being, and Family Relationships – in order to improve the overall FQOL of families with a family member with disabilities.

Acknowledgement

The first three authors express their gratitude to Professor Anna Firkowska-Mankiewicz for providing permission for use of the database used in this study. The original research in Poland was carried out by Professor Anna Firkowska-Mankiewicz, Professor Ewa Zasępa, Doctor Agnieszka Wołowicz, and Doctor Ewa Wapiennik, and was supported by a grant from Maria Grzegorzewska Special Education Academy in Warsaw (BST09/07-II).

Key Messages From This Article

People with disabilities: The two most important things to make you and your family happy are: (1) look after your health, and try to be as healthy as you can; and (2) get along well with people in your family, and try to enjoy your time together as much as you can.

Professionals: When considering what makes family life successful and happy, having sufficient income, being healthy, positive family relationships, and positive values are important. The burden of care and sacrifice made by parents, and women in particular, need to be acknowledged in our field by research and by services for individuals with disabilities and families

Policymakers: If the current trend toward having adults with developmental disabilities continue to live with their families is to continue successfully, policy needs to be adapted to ensure that: (1) family members, including the person with disabilities, have sufficient time to engage in meaningful and enjoyable activities together, as this is the highest-ranking positive source of family quality of life; (2) the health needs of all family members are being addressed; (3) families have at least some discretionary income to spend on positive family activities, as lacking this is associated with negative family quality of life.

References

Beach Center on Disability. (2013). *Beach Center on Disability: Positive contributions.* Retrieved from http://beachcenter.org/default.aspx?JScript=1

Brown, I. (1999). Embracing quality of life in times of spending restraint. *Journal of Intellectual and Developmental Disability, 24*(4), 299–308. doi:10.1080/13668259900034061

Brown, I. (2010). *Family quality of life: a comparison of trends in eight countries.* In V. P. Prasher (Ed.), *Contemporary issues in intellectual disabilities* (pp. 255–264). Birmingham, UK: Nova Publishers.

Brown, I. (2012). *Family quality of life: Comparisons of 19 studies in 14 countries.* Paper presented at the World Congress of the International Association for the Scientific Study of Intellectual and Developmental Disabilities, Halifax, Canada, July 9–14, 2012.

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

Brown, I., Brown, R. I., Baum, N. T., Isaacs, B. J., Myerscough, T., Neikrug, S., et al. (2006). *Family quality of life survey: Main caregivers of people with intellectual or developmental disabilities.* Toronto, ON: Surrey Place Centre.

Brown R. I., & Brown, I. (2005). The application of quality of life. *Journal of Intellectual Disability Research, 49*(10), 717–727.

Isaacs, B. J., Brown, I., Brown, R. I., Baum, N., Myerscough, T., Neikrug, S., et al. (2007). The international family quality of life project: Goals and description of a survey tool. *Journal of Policy and Practice in Intellectual Disabilities, 4*(3), 177–185.

Isaacs, B. J., Wang, M., Samuel, P., Ajuwon, P., Baum, N., Edwards, M., et al. (2012). Testing the factor structure of the Family Quality of Life Survey – 2006. *Journal on Intellectual Disability Research, 56*(1), 17–29. doi:10.1111/j.1365-2788.2011.01392.x

Otrebski, W., Norway, R., & Mansell, I. (2003). Social policy in people with intellectual disability in Poland. *Journal of Learning Disabilties, 7*(4), 363–374.

Samuel, P. S., Rillotta, F., & Brown, I. (2012). Review: The development of family quality of life concepts and measures. *Journal of Intellectual Disability Research, 56*(1), 1–16.

Surrey Place Centre. (2009). *International quality of life project.* Retrieved from http://www.surreyplace.on.ca/Education-and-Research/research-and-evaluation/Pages/International-Family-Quality-of-LifeProject.aspx

Werner, S., Edwards, M., Baum, N., Brown, I., Brown, R. I., & Isaacs, B. J. (2009). Family quality of life among families with a member who has an intellectual disability: An exploratory examination of key domains and dimensions of the revised FQOL Survey. *Journal of Intellectual Disability Research, 53*(6), 501–511.

Zasępa, E., & Wołowicz, A. (2010). *Quality of life of families with persons with intellectual disability* [Jakość życia rodzin osób z niepełnosprawnością intelektualną]. Warsaw, APS.