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QUALITY OF LIFE OF FAMILIES WITH CHILDREN WHO HAVE SEVERE DEVELOPMENTAL DISABILITIES: A COMPARISON BASED ON CHILD RESIDENCE

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ABSTRACT

This study measured the quality of life of two groups of families with children who had severe developmental disabilities–families whose child lived at home and families whose child lived in a residential facility. Participants were 54 primary caregivers of children who had severe intellectual disabilities and who lacked the ability to both ambulate without assistance and communicate conversationally. Participants completed the *Family Quality of Life Scale* (Hoffman, Marquis, Poston, Summers, & Turnbull, 2006). Analyses revealed that both groups rated their family quality of life (FQOL) as exemplary. FQOL was higher in the family home group than in the residential facility group in all areas. Seven items from the *family interaction* and *parenting* subscales were statistically different between the groups. Implications for families, service providers, and policymakers are discussed.

Key Words: Multiple and severe disabilities, parental perceptions, quality of life, child residence, residential facilities.

QUALITY OF LIFE OF FAMILIES WITH CHILDREN WHO HAVE SEVERE DEVELOPMENTAL DISABILITIES: A COMPARISON BASED ON CHILD RESIDENCE

There is general understanding within the developmental disabilities field that disability affects both the individual and his or her family (Turnbull, et at., 2005). It is typically assumed that the relationship between the individual and the family is linear; that is, services that affect the individual with a developmental disability affect the family as well, and vice versa (Turnbull, Beegle, & Stowe, 2001). It follows, then, that policies designed to have a positive impact on the individual with a developmental disability should likewise have a positive impact on the family. In the area of public disability policy, however, this last assertion has not been adequately investigated.

Public disability policy from the 1930s to the present makes it clear that the government recognizes a responsibility for promoting the welfare of and for providing resources and services to individuals with special needs and their families (McFelea, 2007). It suggests that the family home is the preferred residence for individuals who have developmental disabilities, especially if those individuals are children. Although some do not agree wholeheartedly with this position (Bruns, 2000; Blacher, 2001), most authors and/or researchers believe that families should be actively encouraged to raise their children in the family home (Baker & Blacher, 2002). Further, it is also believed that it is best for the child that they do so (Blacher, Baker, & Feinfeld, 1999). Little is known, however, about the impact of current public disability policy on the quality of life of families with children who have severe developmental disabilities. It is possible that the best option for the child and the best option for the family differ.

The quality of life of families that include a child who has a severe developmental disability has received scant attention from researchers (McFelea, 2007). This is possibly due, in part, to the unavailability of a psychometrically sound and user-friendly measurement tool for quantifying a family's quality of life within that population. With the recent publication of the *Family Quality of Life Scale* (*FQOL Scale*) (Hoffman, Marquis, Poston, Summers, & Turnbull, 2006), this measurement obstacle may have been abridged.

The *FQOL Scale* assesses the quality of life of families with children who have disabilities. The authors developed a scale capable of assessing family outcomes, which were defined as the positive and negative impacts that result from services and supports provided to families and their children who have a developmental disability.

Since an acceptable instrument for measuring family quality of life is now available, a reasonable next step is to use it to investigate the impact of aspects of public disability policy on family quality of life. The purpose of the present study was to measure responses of primary caregivers of children with severe developmental disabilities to the *FQOL Scale*. Two different groups were compared – families whose child lived at home and families whose child lived in a residential facility. It was hypothesized that, if differences were found, this information would be important to service providers and public disability policymakers as they attempt to meet the needs of all stakeholders of public disability policy.

METHOD

PARTICIPANTS

The participants were 54 self-identified primary caregivers of children designated as having severe to profound intellectual disabilities and who lacked the ability to both ambulate without assistance and communicate conversationally. Twenty-five respondents whose child lived in the family home and 29 families whose child lived in a residential facility participated. Caregivers whose child lived at home were primarily female, indicated that they were the child's parents, designated their race as black, were between 30-49 years of age, were high school graduates, were married or cohabitating, and were employed either part- or full-time. Respondents whose child lived in the residential facility were primarily female, indicated that they were the child's parents, designated their race as white, were between 30-49 years of age, were high school graduates, were married or cohabitating, and were employed either part- or full-time. The participants' information is shown in Table 1.

INSTRUMENT

The 25-item *FQOL Scale* is comprised of five internally consistent and uni-dimensional domains: *disability-related support, emotional well-being, family interaction, parenting,* and *physical/material well-being*. The *disability-related support* and *emotional well-being* domains are composed of four items each. The *family interaction* and *parenting* domains each contain six items. The *physical/material well-being* domain is comprised of five items.

Administration of the scale requires the primary caregiver of the family to indicate, on a five-point scale, the importance of 25 statements which describe his

Table 1.

Participant Demographic Information ($n = 54$)

Characteristic	*n*	%, FH	%, RF
Gender			
Male	7	4.0	20.7
Female	47	96.0	79.3
Relationship to Child			
Parent (Adoptive, Biological, Foster, or Step)	44	79.2	89.3
Other Relative	8	20.8	10.7
Race			
Black	24	64.0	27.6
White	28	32.0	69.0
Other	2	4.0	3.4
Age in Years			
20-29	2	0.0	6.9
30-39	18	29.2	37.9
40-49	24	50.0	41.4
>50	9	20.8	13.7
Education Level			
No Degree	7	25.0	3.4
High School Graduate	32	50.0	69.0
College Degree (Associate, Bachelor's, Graduate)	14	25.0	27.5
Marital Status			
Married / Cohabitating	33	68.0	55.2
Not Married / Cohabitating	21	32.0	44.8
Employment Status			
Full-Time for Pay / Profit for a Company / Family Business	26	43.5	59.3
Part-Time for Pay / Profit for a Company / Family Business	6	8.7	14.8
Not Employed	18	47.8	25.9

or her family's current quality of life. Each respondent is then asked to indicate, on a five-point scale, the degree to which the caregiver is satisfied that the condition described has been met in his or her family within the past six months.

The *FQOL Scale* has been found to have reasonably acceptable internal consistency, test-retest reliability, and construct validity, for both importance and satisfaction ratings, when used to assess family quality of life in a number of populations (Hoffman et al., 2006). It is psychometrically sound when used to assess the quality of life of families with children between birth and 12 years of age with disabilities that range from mild to what was described as very severe (Hoffman et. al., 2006). McFelea (2007) showed that the instrument was reliable and valid when used to measure quality of life of families with school-aged children whose developmental disabilities are severe. She also demonstrated that the *FQOL Scale* is fairly reliable when used to measure quality of life of families whose school-aged children with severe developmental disabilities live outside the family home.

PROCEDURE

Study participants were recruited from four school districts and one residential facility located in southeastern Virginia. Each school district was provided with survey packets that were mailed to all families on their rosters with a child between the ages of 6-21 years whose special education category designation was that of "severe disability". The packets contained a letter of support from the applicable school district, an introductory letter about the study, a description of the method by which responses would be kept confidential, and information about obtaining a $25 honorarium for completing the Family *Quality of Life Scale (FQOL Scale).* Families were provided with a pre-addressed, stamped envelope for returning the surveys. A local residential agency licensed to serve individuals with intellectual disabilities followed the same procedure and mailed the survey packets to the families of its residents who met the study criteria. Completed surveys were assigned an identifying number in order of their return and data were entered into a statistical analysis software program (SPSS). Two weeks after the survey return deadline, a second packet was mailed in order to increase the number of returns.

DATA IMPUTATION

Seven respondents did not provide importance ratings for four of the 25 statements and 12 respondents did not provide satisfaction ratings for six of the 25 statements. The item-mean substitution method was employed to replace the missing raw data. It has been found to be an acceptable alternative

Table 2.

Imputed Values

Item	Number of Missing	Imputed Value
04, Importance Rating	3	4.07
04, Satisfaction Rating	4	3.73
06, Satisfaction Rating	1	4.33
08, Importance Rating	1	4.44
08, Satisfaction Rating	1	4.21
11, Importance Rating	1	4.39
11, Satisfaction Rating	1	4.02
17, Importance Rating	2	4.54
17, Satisfaction Rating	3	4.04
21, Satisfaction Rating	2	4.13

to omitting data from participants who do not address all items within a scale given two conditions, both of which were met with this study: (1) > 80% of the participants completed all scale items; and (2) > 80% of the participants provided responses to each scale item (Downey & King, 1998).

In essence, the mean importance ratings (IR) and satisfaction ratings (SR) for each of the 25 scale items were computed and those values were used as an estimate for the missing data. For example, since one participant did not provide an IR for the eighth scale item, her missing value was replaced by the mean of the ratings given by the remaining participants. The imputed values are presented in Table 2.

SCORE COMPUTATION

Since the *FQOL Scale* does not provide a scoring method, a technique for calculating a FQOL score was developed based on that used by Raphael, Brown, Renwick, and Rootman (1996). Their theoretical model of quality of life and related instrumentation, the Quality of Life Instrument Package, collects individual-specific quality of life data from persons who have developmental disabilities. They computed a quality of life score based on the interaction between participants' importance and enjoyment ratings. Similarly, for this study, a family's quality of score was computed based on the interaction between each of the 25 IR and SR ratings. First, item scores (IS) were computed as follows: IS = (IR/3) × (SR − 3). The application of this formula produced a range of scores from −3.33 (very important areas with very low satisfaction) to +3.33 (very important areas with very high satisfaction). These IS were converted to a scale of 0-5 to facilitate understanding by applying the formula Converted Item Score (CIS) = (IS + 3.33) × 0.75 (Raphael et al., 1996). For example, CIS given an importance rating of three and a satisfaction rating of four is: $[(3/3)(4 - 3) + 3.33]0.75 = [(1)(1) + 3.33]0.75 = (1 + 3.33)0.75 = (4.33)0.75 = 3.25$.

Subscale scores were then obtained by averaging the scores for the items contained within each of the five subscales of the *FQOL Scale*. Each individual's FQOL score (FQOLS) was obtained by averaging the scores of the 25 scale items.

SCORE INTERPRETATION

FQOLS were interpreted according to the classification offered by Raphael et al. (1996). Specifically: (1) < 1.37 = very problematic; (2) 1.37 to 2.11 = problematic; (3) 2.12 to 2.86 = adequate; (4) 2.87 to 3.61 = very acceptable; and (5) > 3.61 = exemplary.

RESULTS

FAMILY HOME (FH) GROUP

Global family quality of life and quality of life relative to each of the five *Family Quality of Life Scale* (*FQOL Scale*) subscales were exemplary. In fact, a ceiling effect (McHorney & Tarlov, 1995; Hobart & Thompson, 2001) with regard to the *disability-related support* subscale was produced in that 32% ($n = 8$) of the 25 participants obtained scores of 5.00. Additionally, quality of life for each of the 25 *FQOL Scale* items ranged from very acceptable to exemplary.

All 25 scale items received the highest possible score (5.00) from at least one respondent. The lowest possible score (0.00) for 24% ($n = 6$) of the 25 scale items was received for two items within the *disability-related support* and *emotion well-being* subscales and one each within the family interaction and physical/material well-being subscales.

Ranges and medians for the family quality of life score (FQOLS), subscale scores, and item scores are presented in Table 3. Interquartile ranges were omitted in order to promote clarity. These data are available upon request.

RESIDENTIAL FACILITY (RF) GROUP

Global family quality of life and quality of life relative to each of the five *Family Quality of Life Scale* (*FQOL Scale*) subscales ranged from very acceptable to exemplary. Additionally, quality of life for each of the 25 *FQOL Scale* items ranged from very acceptable to exemplary.

All 25 scale items received the highest possible score (5.00) from at least one respondent. The lowest possible score (0.00) was received for 72% ($n = 18$) of the 25 scale items. One item was located within the *disability-related support* subscale and three others were located within the *emotional well-being* subscale. All six items of the *family interaction* subscale, plus five items within the *parenting* subscale and three items within the *physical/material well-being* subscale, received a score of 0.00 from at least one participant.

Ranges and medians for the FQOLS, subscale scores, and item scores are presented in Table 2. Again, interquartile ranges, which were omitted in order to promote clarity, are available upon request.

FAMILY HOME AND RESIDENTIAL FACILITY GROUP COMPARISON

Data from the two groups were statistically compared via the Mann-Whitney U-Test, necessary due to the asymmetry of the data's distribution. Analyses revealed that the *FQOL Scale* median scores of the family home group (FHG) and the residential facility group (RFG) were statistically equivalent. The median scores of the two groups on the *disability related support, emotional well-being, parenting,* and *physical/material well-being* subscales were also statistically equivalent. The *family interaction* median score of the FHG was considerably higher than the median score of the RFG and this difference was statistically significant. The precise *p*-value is given in Table 3.

Analyses via the Mann-Whitney U-Test also revealed seven *FQOL Scale* items which were higher at a statistically significant level in the FHG than in the RFG. Four of these items were from the *family interaction* subscale and the remaining three were contained within the *parenting* subscale. *P*-values of all statistically significant findings are presented in Table 3.

DISCUSSION

The present study compared the scores on the *Family Quality of Life Scale* (*FQOL Scale*) of 25 families whose child with severe developmental disabilities lived at home with those of 29 families whose child lived in a residential facility. All respondents were the primary caregivers of children designated as having severe to profound intellectual disabilities and who lacked the ability to both ambulate without assistance and communicate conversationally. Family quality of life was found to be exemplary in both groups. A comparison of the median scores of the two groups revealed that, for the most part, family quality

Table 3.

FQOL Scores Family Home and Residential Facility Group Comparison ($n = 54$)

FQOL Scale, Subscales, and Items	FH		RF	
	Range	Median	Range	Median
FQOL Scale	**2.49–4.88**	**3.95**	**1.46–5.00**	**3.84**
Disability-Related Support	2.90–5.00	4.31	2.12–5.00	4.06
My family member with a disability has support to accomplish goals at home	1.25–5.00	5.00	0.00–5.00	3.75
My family member with a disability has support to accomplish goals at school or workplace	0.00–5.00	5.00	1.50–5.00	3.75
My family member with a disability has support to make friends	0.00–5.00	3.75	1.50–5.00	3.75
My family has good relationships with the service providers who provide services and support to our family member with a disability	1.00–5.00	5.00	1.25–5.00	5.00
Emotional Well-Being	1.25–5.00	3.62	0.31–5.00	3.56
My family has the support it needs to relieve stress	1.00–5.00	4.00	0.00–5.00	3.25
My family members have friends or others who provide support	0.50–5.00	3.25	0.00–5.00	3.50
My family members have some time to pursue their own interests	0.00–5.00	3.75	1.00–5.00	3.50
My family has outside help available to take care of special needs of all family members	0.00–5.00	3.50	0.00–5.00	3.75
*Family Interaction** ($p = 0.009$)	1.50–5.00	4.33	0.83–5.00	3.75
My family enjoys spending time together	1.25–5.00	5.00	0.00–5.00	3.75
My family members talk openly with each other* ($p = 0.005$)	1.50–5.00	5.00	0.00–5.00	3.75
My family solves problems together	1.25–5.00	3.75	0.00–5.00	3.50
My family members support each other to accomplish goals* ($p = 0.019$)	0.00–5.00	5.00	0.00–5.00	3.25
My family members show they love and care for each other* ($p = 0.018$)	2.50–5.00	5.00	0.00–5.00	4.00

Table 3. contd.

	FH		RF	
FQOL Scale, Subscales, and Items	Range	Median	Range	Median
My family is able to handle life's ups and downs* ($p = 0.039$)	1.25–5.00	3.75	0.00–5.00	3.50
Parenting	2.62–4.83	4.16	0.21–5.00	3.71
My family members help the child(ren) learn to be independent* ($p = 0.043$)	1.00–5.00	4.50	0.00–5.00	3.50
My family members help the child(ren) with school work and activities	2.50–5.00	3.75	0.00–5.00	3.50
My family members teach the child(ren) how to get along with others* ($p = 0.050$)	2.50–5.00	4.50	2.50–5.00	3.75
Adults in my family teach the child(ren) to make good decisions	2.50–5.00	3.75	1.25–5.00	3.75
Adults in my family know other people in the child(ren)'s lives (friends, teachers, etc.)	1.25–5.00	3.75	0.00–5.00	3.75
Adults in my family have time to take care of the individual needs of each child* ($p = 0.042$)	1.25–5.00	3.75	0.00–5.00	3.50
Physical/Material Well-Being	2.50–5.00	4.00	1.45–5.00	3.86
My family members have transportation to get to the places they need to be	0.00–5.00	4.00	2.50–5.00	5.00
My family gets medical care when needed	2.50–5.00	5.00	0.00–5.00	5.00
My family gets dental care when needed	1.75–5.00	3.75	0.00–5.00	3.50
My family has a way to take care of our expenses	1.25–5.00	3.75	0.00–5.00	3.75
My family feels safe at home, work, school, and in our neighborhood	1.25–5.00	4.50	1.75–5.00	3.75

* $p < 0.05$

of life was rated higher by respondents whose child lived at home than by respondents whose child lived in a residential facility.

The primary caregivers whose children lived at home rated their family quality of life as it related to *disability-related support, emotional well-being, family interaction, parenting,* and *physical/material well-being* as exemplary. These families scored within the very acceptable and exemplary ranges on all items.

The primary caregivers whose children lived in a residential facility rated their family quality of life as it related to *disability-related support, family interaction, parenting,* and *physical/material well-being* as exemplary. These families scored within the very acceptable range on the *emotional well-being* subscale as well as within the very acceptable (n = 10) and exemplary (n = 15) ranges on all items. The median score for the majority of the scale items (n = 15) fell within the exemplary range and the median scores for the remaining 10 items fell within the very acceptable range.

It was unexpected and yet interesting that both family groups rated their quality of life as exemplary. This is surprising because the majority of published literature tends to focus on the negative aspects that a child with a developmental disability creates within a family (Hastings & Taunt, 2002). Some professionals have suggested that service providers and policymakers may fail to recognize the many positive benefits derived from a child born with a severe developmental disability (Raver, Michalek, & Gillespie, in press). It is probable that this skewed focus causes many to underestimate the resilience of many families. This study suggests that families of children with multiple and severe intellectual and physical disabilities, as a whole, are able to balance the challenges of caring for their child with the joys that that child brings to the family. It is possible that the exemplary quality of life reported by this sample of families whose child lived in a residential facility was directly linked to the fact that residential placement was available to the families and they chose to take advantage of that option. This study can neither support nor refute that possibility.

A comparison of the median scores between the two groups reveals that, for the most part, scores on the *FQOL Scale* were higher in families whose child lived in the family home than it was in families whose child lived in a residential facility. The median score for three scale items, however, were higher in the RFG than in the FHG. Two are contained in the *emotional well-being* subscale and the third is in the *physical/material well-being* subscale: "Family members have friends or others who provide support", "Family has outside help available to take care of special needs of all family members", and "Family members have transportation to get to the places they need to be." That the median scores for the first two items were highest in the RFG is not surprising – residential placement provides families a great deal of support in that it assumes responsibility for providing the child's day-to-day care. The median score for the third item may be highest in the RFG because the residential facility rather than the family provides transportation to/from medical appointments, school, and recreational activities, thereby perhaps freeing a vehicle and driver for the child's other family members.

There are eight statistically significant differences in family quality of life scores between the two groups. The *family interaction* subscale score was significantly higher in families whose child lived in the family home than it was for families whose child lived in the residential facility. At first glance this finding seems intuitive in that the ability of family members to interact with each other is surely enhanced by their living together. When the same rationale is applied to the *parenting* subscale, however, the logic falters in that there is no statistically significant difference between the groups with respect to that subscale. Further examination of the data reveals that the remaining statistically significant differences in scores between the two groups consist of individual items contained within either the six-item *family interaction* ($n = 4$) and the six-item *parenting* ($n = 3$) subscales. In each case, the FHG scored higher than did the RFG. In an attempt to understand why the groups differ in terms of *family interaction* but not *parenting,* one might be tempted to conclude that the number of items geared toward families whose child lived in the family home is greater in the *family interaction* subscale than in the *parenting* subscale. However, the reverse appears to be case. Five of the six *family interaction* items appear to favor the FHG rather than the RFG whereas all six parenting items appear to favor the FHG (refer to Table 3 for item descriptions). Further, the score for the one *family interaction* item that appears neutral (that is, “My family is able to handle life’s ups and downs”) was found to be statistically significantly higher in the FHG when compared to the RFG.

Service providers support families whose child lives in a residential facility by building and maintaining a strong sense of the family unit in spite of the physical separation between the family members that comprise that unit. According to this study, however, primary caregivers whose child lives in a residential facility experience less satisfying family interactions and are less fulfilled in their parenting roles than are primary caregivers whose child lives at home. This source of relative dissatisfaction may be due to a combination of three factors. First, opportunities to interact with family members are certainly less frequent than would be possible were the child living in the family home. This relative lack of opportunity may weaken parent-child and sibling-child relationships, which could in turn decrease the willingness of parents and/or siblings to take advantage of interaction opportunities. Second, necessary requirements of the residential facility no doubt hinder the spontaneity and variety of interactions that would likely take place were the child living in the family home. And third, physical constraints such as distance from the family home and privacy for family interactions within the residential facility itself might hinder family interactions, especially those of siblings and extended family members such as grandparents, aunts and uncles, cousins, and others.

The *FQOL Scale* scores for individual items that received the lowest possible score, 0.00, differed between the two groups. Only two of the 22 items that received a score of 0.00 did so for both groups: “My family has outside help available to us to take care of special needs of all family members” and “My family members support each other to accomplish goals”. This information suggests the possibility that, although the *FQOL Scale* is reliable and valid for the two family groups, the subscales and/or individual items may not be as psychometrically sound. One may question whether or not the *FQOL Scale* captures the entire construct of family quality of life for families with children who have severe developmental disabilities regardless of the child’s living arrangement.

STUDY LIMITATIONS

One limitation of the current study pertains to the homogeneity of the sample. The children of both groups of participants all attended schools that were subject to the same Department of Education rules and regulations. These rules and regulations govern the types and amounts of education and related services children receive through school districts, and these services have a direct bearing on the quality of life of the child and his or her family. Similarly, the children of the residential facility group all lived in the same residential facility and, therefore, had access to the same medical, recreational, and other resources that would have a bearing on their quality of life and that of their families.

Another possible limitation pertains to the instrument used to measure family quality of life. Although deemed psychometrically sound for use with individual families with children who have severe developmental disabilities, its potential for use to compare the quality of life of different groups of families has not been fully investigated. The asymmetrical distribution of the data and the fact all items received the highest possible score from at least one of the participants might lead one to question the tool’s sensitivity. Additionally, many respondents declined to answer at least one of the scale’s items, which may indicate that all items are not applicable to each family’s situation.

A final limitation was the inability of the authors to speak directly with the participants of the study. Privacy was of utmost concern to the agencies involved, and although the researchers indirectly invited participants, through correspondence mailed by agency personnel, to contact them, the researchers were not permitted to contact participants directly. More detailed caregivers’ feedback would have, no doubt, enriched the discussion.

FUTURE RESEARCH

More research is needed to determine the state of possible differences among the quality of life of families based on child residence. Further study of this issue may begin a process that will enhance service providers' and public disability policymakers' abilities to better align their efforts toward meeting families' most immediate and pressing needs. More investigation of the ability of the *FQOL Scale* to measure the quality of life of families with children who have multiple and severe developmental disabilities, especially for those whose children live outside the family home, is warranted. It may be that child residence creates vastly diverse family needs and that any single tool may not be sufficient to help service providers identify an individual family's needed supports.

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