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# Research in Developmental Disabilities



## Family quality of life among families with a child who has a severe neurodevelopmental disability: Impact of family and child socio-demographic factors



Mitchell Schertz<sup>a,\*</sup>, Yael Karni-Visel<sup>a</sup>, Ada Tamir<sup>b</sup>, Jacob Genizi<sup>c</sup>, Dana Roth<sup>d</sup>

<sup>a</sup> Child Development & Pediatric Neurology Service, Meuhedet-Northern Region, Simtat Atlit 6, Haifa, Israel

<sup>b</sup> Rappaport Faculty of Medicine, Technion Israel Institute of Technology, Haifa, Israel

<sup>c</sup> Department of Pediatrics, Bnei Zion Hospital, Haifa, Israel

<sup>d</sup> Beit Issie Shapiro, Ra'anana, Israel

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### ABSTRACT

We aimed to examine family quality of life (FQOL) of Northern Israeli families having a child with a severe neurodevelopmental disability and its relation to socio-demographics. The cohort included caregivers of 70 children ages (mean  $\pm$  standard deviation)  $5.36 \pm 3.53$  years. Families were two-parent (85.7%), lived in the periphery (67.1%) and included Jews (60%), Muslims (18.6%), Druze (14.3%) and Christians (7.1%). Religiosity included: secular (38.6%), traditional (31.4%), religious (30%). Children's diagnosis included autistic spectrum disorder (41.4%), intellectual disability (21.4%), cerebral palsy (17.1%), genetic syndromes (17.1%) and sensorineural hearing loss (2.9%). Degree of support (1-minimal,5-greatest) required by the child was  $3.67 \pm 1.28$  for physical and  $3.49 \pm 1.36$  for communication. Primary caregivers completed the FQOL Survey. Domain scores were highest for family relations and lowest for financial well-being. Dimension scores were highest for importance and lowest for opportunities. Overall FQOL approximated average. Jewish families and residents of a major urban area reported higher and more religious families reported lower overall FQOL. Regression analysis found ethnicity contributing to overall FQOL and domain scores with residence contributing to support from services. Ethnicity and child dependence contributed to dimension scores. Northern Israeli families having a child with a severe neurodevelopmental disability report average FQOL scores. However, family and child dependence characteristics affect FQOL scores. Professionals working with these families should consider FQOL information when making recommendations.

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### What this paper adds

This paper expands our understanding regarding the use of the FQOL measure in a number of ways. Locally it adds specific socio-demographic information to that previously known about the Israeli population in those families having a child with a severe neurodevelopmental disability. Of interest to the larger audience is the examination of the relationship between FQOL

*Abbreviations:* FQOL, family quality of life; ASD, autistic spectrum disorder; ID, intellectual disability; CP, cerebral palsy; SNHL, sensorineural hearing loss; GMFCS, gross motor function classification scale; MACS, manual ability classification scale.

\* Corresponding author. Tel.: +972 4 8612300; fax: +972 4 8612301.

E-mail address: [mitch\\_s@meuhedet.co.il](mailto:mitch_s@meuhedet.co.il) (M. Schertz).

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scores and child and family characteristics. We found both of these to impact on the FQOL scores reported. Finally this is one of the few studies to date reporting on the use of the FQOL in a neurodevelopmental medical model service where both initial diagnosis and intervention are provided.

## 1. Introduction

### 1.1. Family quality of life (FQOL)

Children with a disability are best served in the context of their family life (Parish, Pomeranz, Hemp, Rizzola, & Braddock, 2001) and professionals working in partnership with families are better able to meet the needs of the child with a disability (King, Teplicky, King, & Rosenbaum, 2004; Dunst, Trivette, & Hamby, 2007). Yet a child with disability places a burden, both in health and economic terms, on the entire family (Lin et al., 2009; Neikrug, Roth, & Judes, 2011). Furthermore, the quality of life for a child with disability is influenced by the caregiver's psychological and family related factors (Chen, Tseng, Shieh, Lu, & Huang, 2014).

All of the above have led to a change in how service provision to children with disabilities and their families are performed. Families of children with disabilities are now becoming partners in the treatment process using what is termed family-centered service (King et al., 2004) with strong evidence supporting such an approach (Rosenbaum, 2011). Yet given multiple studies demonstrating increased maternal depression (Singer, 2006) and parental stress (Pisula, 2011) in those having a child with a disability, much of the focus to date has been on improving parental function via direct treatment to the parent (Shaw, Connell, Dishion, Wilson, & Gardner, 2009), and providing parental guidance of on effective manners of intervention to the child (Barlow, Coren, & Stewart-Brown, 2014; McConachie & Diggle, 2007; Kaminski, Valle, Filene, & Boyle, 2008).

The recognition of family outcomes as being important to the family having a child with disability has further evolved with the development of the construct of family quality of life (FQOL). Earlier definitions of FQOL (Olson & Barnes, 1982), used a subjective conceptualization that were further expanded on by Park et al., (2003) who defined FQOL as a "family's sense of the fit between themselves and their environment". More recently, Wang and Kober (2011) reported on a definition of FQOL that the authors saw as representing an emerging consensus on this topic. It reads as follows: "Family quality of life is a dynamic sense of wellbeing of the family, collectively and subjectively defined and informed by its members, in whom individual and family-level needs interact".

These conceptualizations of FQOL have been followed by the development of systematic measures that examine this construct (see Samuel, Rillotta, & Brown, 2012 for a review). To date, two different instruments measuring FQOL have been developed: the Beach Center FQOL Scale (Hoffman, Marquis, Poston, Summers, & Turnbull, 2006) and the family quality of life survey (FQOLS-2006) (Brown et al., 2006). These instruments gather comprehensive information from key areas affecting family life such as health, financial well-being, family relationships, support from other people and services, values and leisure involvement.

### 1.2. FQOL and socio-demographic affects

Implicit in the construct and the different aspects examined in FQOL, is the consideration of the environment in which the child and family live. The concept of environment is multidimensional, including not only the physical space that a family resides in but the social, cultural, ethnic and religious milieu as well (Bronfenbrenner, 1986). Park et al., (2003) noted that inclusion of unique perspectives from families with different cultural and ethnic backgrounds may also be a relevant issue when measuring quality of life outcomes for families who have a member with a disability.

Environments with multiple resources available to parents, such as in major urban centers, might lead to very different outcomes in family quality of life in those having a child with disability than those where such services are either more limited or less accessible due to the need to travel long distances for services. Supporting this, is research suggesting that rural environments have impacts, among others, on quality of life (Rapley & Hopgood, 1997) including access to health care (Brundisini, Giacomini, DeJean, Vanstone, Winsor, & Smith 2013; Li, Essex, & Long, 2014).

While FQOL data has been published on numerous cohorts, the literature that has specifically examined the effect of child and family characteristics on FQOL data is limited (Wang et al., 2004; Davis & Gavidia-Payne, 2009; Hu, Wang, & Fei, 2012). As such, it is instructive in examining them in some detail. The study by Hu and colleagues (Hu et al., 2012) examined the effect of demographic factors on FQOL, although they limited their examination to the dimension of *satisfaction*. They reported that improved housing conditions and personal transportation was associated with physical well-being of satisfaction. Family income and severity of disability while being significant predictors of families' satisfaction together only accounted for 1.6% of the variance of FQOL family's perceived satisfaction.

The study by Davis and Gavidia-Payne (2009) was notable in its comprehensiveness of measures employed that were used to examine how family and child characteristics *and* parental perception of a family centered approach impact on family quality of life. They found that severity of disability was not associated with FQOL satisfaction, and that caregiver education and family income was correlated with FQOL importance. Of interest was their finding that intensity of child behavior problems, family support, and parental report of good family centered service all positively correlated with FQOL satisfaction.

Wang et al. (2004) reported on the effect of family income and severity of disability on FQOL. Findings were mixed with both higher family income and less severity of disability showing significant positive associations with mothers' satisfaction

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