



Review article

Unhappy (and happy) in their own way: A developmental psychopathology perspective on quality of life for families living with developmental disability with and without autism

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ABSTRACT

Research on families living with developmental disability generally and autism specifically is dominated by a deficit view that elicits an elaborate representation of problems and risks without the benefit of considering families' potential for adaptation and resilience. A central tenet of developmental psychopathology is that the study of adaptive and maladaptive development is mutually informative. Specifically, one can examine resilience within the context of adversity and the multiple processes and pathways to adaptive and maladaptive developmental outcomes. We believe these concepts can also be extended to the study of families living with developmental disability as they transition through the family lifecycle. This paper provides an overview of the family quality of life (FQOL) construct, including its conceptualization and measurement, and a review of studies on FQOL among families of children with various developmental disabilities. Special attention is given to families of children with autism, as this is a circumstance characterized by unique adversity. We suggest benefits from adopting a developmental psychopathology perspective, and illustrate how relevant concepts can inform our methodologies as we move forward. We will demonstrate how such an integrated, systemic, and temporal approach will help generate more refined questions on FQOL among families caring for a child with developmental disability in order to provide the specific answers needed to directly inform policy and clinical practice.

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1. Introduction

Despite the historical, political and cultural divide between 19th century Russian and 21st century North American societies, Tolstoy's observations on family risk and well-being are surprisingly reminiscent of views espoused by contemporary researchers who study families caring for a child with a developmental disability (DD).¹ This research, however, is dominated by a deficit view, which elicits an elaborate representation of problems and risks without the benefit of considering families' potential for adaptation and resilience.

In this paper, we review the extant literature and attempt a more nuanced view on family functioning (with humble apologies to Tolstoy) by adopting a developmental psychopathology perspective on family quality of life (FQOL) as it relates to those caring for a child with DD. We take a family systems perspective which views individuals as interconnected parts of a system that cannot be understood in isolation from one another, but as embedded within their family. We incorporate developmental notions of risk, resilience, equifinality, and multifinality to better understand stability and change throughout the family life cycle. We present a synthesis of previous FQOL conceptualizations, measurement approaches, and findings, as well as identify existing gaps in the literature and methodological limitations. We conclude with suggestions on directions for future research, particularly with regard to autism,² and encourage researchers to contextualize families' quality of life within family systems and developmental psychopathology frameworks. We suspect that this perspective on FQOL will enrich our understanding of FQOL, as well as propel advances in methodology that may capture the full range of possible adaptive and maladaptive family outcomes.

Studies were identified by conducting a search for the terms "family quality of life" and "disability", "family quality of life" and "autism", and "family well-being" and "autism", using the Ebsco Host database and Google Scholar search engine. Additional papers were identified by reviewing the reference sections of included papers. Emphasis was placed on articles that examined the FQOL construct specifically, as opposed to those that addressed the more diversely defined 'family well-being' concept.

"This . . . makes our family closer" (Bayat, 2007, p. 709) is a quote taken from an interview with a mother who describes how the experience of raising a child with autism has brought her family together with a common purpose. In sharp contrast to this perspective, another family describes their feelings when they first realized the challenges that they were about to face: "We realized the truth, and by the end of the day we were distraught, because we knew the truth about it. It was actually the worst day of our lives, that was the day we came to terms with the fact that we had this problem" (Midence & O'Neill, 1999, p. 280). These quotes illustrate how families' responses to a child with DD may differ significantly. The quotes also reflect potential changes in a family's subjective experience at different developmental time points across the life cycle. After tackling challenging circumstances and thwarting negative outcomes a family may perceive value in the experience of raising a child with a disability. However, when the family is first faced with an unexpected diagnosis of DD the prospects may be daunting and the family may feel unprepared and concerned about what the future holds.

2. Evolution of the family quality of life construct

In recent years, the direction of disability research has shifted from a unitary focus on individual quality of life to a broadened examination of perspectives held by the entire family unit. The emergence of key theories, including Bowlby's (1969) attachment, Bronfenbrenner's (1979) ecological, and Turnbull, Summers, and Brotherson's (1984) family systems (as specifically related to families of a child with disability), have spurred a paradigmatic shift in the nature of family-related practice and policy. It is now understood that the family unit constitutes a dynamic, interconnected, and self-regulating

¹ The terms 'developmental disability' (DD) and 'intellectual disability' (ID) will be used throughout the paper. It is important to note that these refer to unique circumstances, and are not interchangeable. The former is an overarching classification under which individuals with ID fall, although 'DD' refers to both those with and without intellectual impairment. ID, on the other hand, only includes those who have intellectual impairment (i.e., IQ at or below 70) as well as significant limitations in two or more areas of adaptive behaviour (e.g., daily living, communication, and social skills).

² The term 'autism' is intended to reference the full autism spectrum of disorders, as opposed to autistic disorder specifically.

system within which each individual is understood to be influenced by a set of shared, yet also unique, contextual factors. As such, disability theorists and practitioners have broadened their unitary, child-centred perspectives, and now seek to understand, from multiple levels of analysis, how child, family, and service characteristics, as well as surrounding sociocultural contexts, interact and overlap in their contributions to family functioning. From this perspective, the significant ways in which having a child with a disability impacts all family members, including parents and siblings, can be addressed.

In addition to the theoretical knowledge that has helped to shift our attention to the family, the deinstitutionalization movement of the late 1960s (Scott, Lakin, & Larson, 2008) and medical advancements leading to longer lifespans for individuals with disabilities (R. Brown, Davey, Shearer, & Kyrkou, 2004), have had significant implications for how we consider family life. As individuals with DD were removed from residential facilities, the reliance on the family, and in particular, the mother, to simultaneously fulfil the roles of service provider, support coordinator, and advocate, increased significantly (I. Brown, Anand, Isaacs, Baum, & Fung, 2003; Cummins & Baxter, 1997). Furthermore, parents are now faced with the challenge of providing care while experiencing ageing-related difficulties themselves, and must consider long-term support options for their children that will extend beyond their own lifetimes (Rillotta, Kirby, & Shearer, 2010). To further complicate matters, adulthood is a developmental phase for individuals with exceptionalities in which few supports and services are available (Jokinen, 2006).

Such theoretical considerations and practical challenges have helped researchers and professionals to grasp the considerable impact that having a child with a DD poses for all members of the family system, and research has begun to investigate the nature of this relationship. Traditionally, however, this directional shift has been actualized through an exclusive focus on indicators of dysfunction (Poston & Turnbull, 2006; Summers et al., 2005), including resultant parental stress (i.e., Lopez, Clifford, Minnes, & Ouellette-Kuntz, 2008), poor mental health (i.e., Hamlyn-Wright, Draghi-Lorenz, & Ellis, 2007; Herring et al., 2006; Lach et al., 2009), pessimism (i.e., Esbensen, Seltzer, & Greenberg, 2006), and caregiver burden (Al-Krenawi, Graham, & Al Gharaibeh, 2011). Turnbull, Summers, Lee, and Kyzar's (2007) review of 28 articles published between 1999 and 2007 corroborates this observation. The articles were examined to explore conceptualizations of family outcomes when there is a member with an intellectual disability (ID). Despite their relatively recent release, even those studies with a seemingly broader conceptual focus, such as family well-being, adaptation, and functioning, were restricted in concentration, and focused solely on negative aspects such as burden, pessimism, and depression. Furthermore, the most frequently utilized measures contained only negative dimensions (i.e., Center for Epidemiological Studies – Depression Scale (Radloff, 1977) and Parenting Stress Index (Abidin, 1990)) and only two of the articles included qualitative components. With this research design families do not have the opportunity to express the full scope of their rich and diverse experiences.

Although the role of the family has been acknowledged in disability-related literature for some time, research specifically examining FQOL is relatively new, having only emerged within the last decade. This field builds upon the extensive literature on individual quality of life (QOL) for those with ID (i.e., Cummins, 1997; Schalock, 2005; Schalock et al., 2002), and reflects an initiative to explore the full range of positive and negative family experiences. Though researchers differ regarding the precise domains they identify as most relevant, a consensus document written by the Special Interest Research Group on Quality of Life (SIRGQOL) of the International Association for the Scientific Study of Intellectual Disabilities (IASSID) suggests that the “core” domains include emotional, material, and physical well-being, as well as interpersonal relations, personal development, self-determination, social inclusion, and rights (SIRGQOL, 2000). FQOL incorporates many of the same domains and concepts, yet extends the notion to address the inextricable relationship between an individual and his or her family, the family impact of having a member with a disability, and the ways in which various supports can function to maximize QOL for the overall family unit (I. Brown, Schalock, & Brown, 2009; Isaacs et al., 2007; Park et al., 2003; Poston et al., 2003).

The most widely cited definition is that suggested by Park et al. (2003), in which FQOL is defined as “conditions where the family's needs are met, and family members enjoy their life together as a family and have the chance to do things which are important to them” (p. 368). Zuna, Summers, Turnbull, Hu, and Xu (2010) add that FQOL “is a dynamic sense of well-being . . . collectively and subjectively defined[,] and informed by its members in which individual and family-level needs interact” (p. 262). It is important to note that in this context, the notion of ‘family’ extends beyond the traditional nuclear unit to include “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” (Poston et al., 2003, p. 319). The essential idea is that family membership is based on the sense of relationship among individuals, and not on long-established convention. According to I. Brown and Brown (2004), satisfactory FQOL comes not only when families have the same opportunities as others, but also when they are empowered (i.e., through the provision of appropriate supports and resources) to capitalize on them. The goal of FQOL research must be to identify gaps in family support and alter practice accordingly in order to ultimately set in place the necessary conditions for sustained family success (Isaacs et al., 2007).

3. Family quality of life conceptualization and measurement

There are currently two central initiatives in FQOL research, one taking place out of the Beach Center on Disability at the University of Kansas (Poston et al., 2003), and the other an international collaboration among researchers from Canada (I. Brown et al., 2003; I. Brown, Isaacs, McCormack, Baum, & Renwick, 2004), Australia (R. Brown et al., 2004), and Israel (Neikrug, Judes, Roth, & Krauss, 2004). The work of these groups has centred on four areas: (1) establishing conceptual and theoretical grounds; (2) instrument development and psychometric evaluation; (3) conducting exploratory research; and (4) examining the impact of various child, family, and support characteristics on FQOL. Table 1 provides a list of articles produced by each group that fall within the four categories.

Table 1
Articles within each category.

Category	Research centre	Reference	Article focus
(1) Establishing conceptual and theoretical grounds	Beach Center	Poston et al. (2003)	Examines varying conceptualizations of FQOL and identifies ten central domains
		Turnbull, Poston, et al. (2007) and Turnbull, Summers, et al. (2007)	Reviews papers that examine 'family outcomes,' and differentiates between family well-being, adaptation, functioning, and FQOL
	Int'l FQOL Project	Zuna et al. (2010); Zuna, Turnbull, and Summers (2009)	Proposes a unified theoretical framework to describe the FQOL construct
		R. Brown et al. (2009)	Presents a conceptual framework for organizing and applying FQOL research
(2) Instrument development and validation	Beach Center	Isaacs et al. (2007)	Describes FQOL origins, conceptualization, as well as instrument development and revision
		L. Hoffman, Marquis, Poston, Summers, & Turnbull (2006)	Examines reliability and convergent validity of revised <i>Beach Center Family Quality of Life Scale</i>
		Park et al. (2003)	Describes the development and validation of <i>Beach Center Family Quality of Life Scale</i>
		Summers et al. (2005)	Provides information about scale factor structure, reliability, and validity
	Int'l FQOL Project	Verdugo et al. (2005)	Describes the development and validation of a Spanish version of the <i>Family Quality of Life Scale</i>
		Wang et al. (2006)	Examines whether mothers and fathers differ in their ratings of FQOL
		Zuna, Selig, Summers, and Turnbull (2009)	Examines the applicability, through factor analysis, of a slightly revised <i>Beach Center Family Quality of Life Scale</i> to families of typically developing kindergarten children
(3) Conducting exploratory research	Int'l FQOL Project	Werner, Edwards, Baum, et al. (2009)	Describes an exploratory study conducted with the revised <i>FQOLS-2006</i> , and reports on internal consistency and relationships across domains
		Brown (2008)	Reports on results from research conducted in Australia, Belgium, Canada, Israel, Japan, Nigeria, Slovenia, and the United States
	Int'l FQOL Project	I. Brown et al. (2003) and I. Brown et al. (2004)	Presents results from Canadian data
		R. Brown et al. (2004)	Reports on results from studies conducted in Australia
		R.I. Brown et al. (2010)	Reports on results from research conducted in Australia, Canada, South Korea, and Taiwan
		Neikrug et al. (2004)	Reports on results from Israeli data
		Petrowski et al. (2008)	Provides a preliminary examination of FQOL using <i>FQOLS-2006</i>
(4) Examining the impact of characteristics on FQOL	Beach Center	Eskow et al. (2011)	Examines how families of children with autism who are receiving waiver services differ in terms of their FQOL and employment status from those on the waiting list
		Friend et al. (2009)	Reviews the types of family support previously identified in intervention research, and establishes potential links between identified support and FQOL domains
		Poston and Turnbull (2004)	Examines the impact of spiritual/religious beliefs and practices on FQOL
		Summers et al. (2007)	Investigates the relationship between perceived adequacy of service and FQOL
		Wang, Mannan, et al. (2004)	Explores parents' perceptions of advocacy role, and perceived impact on FQOL
	Int'l FQOL Project	Wang, Turnbull, et al. (2004)	Examines impact of family income and disability severity on FQOL
		R.I. Brown, MacAdam-Crisp, Wang, & Iarocci (2006)	Examines FQOL differences among families that have children with Down syndrome, autism, and who are typically developing
		Jokinen and Brown (2005)	Reports on the results of FQOL interviews conducted with parents of adults with intellectual disabilities
		Werner, Edwards, and Baum (2009)	Examines the impact of out-of-home residential placement on FQOL

3.1. Beach Center on disability

In commencing their exploration of FQOL, Beach Center researchers employed a participatory action research approach (i.e., focus groups and individual interviews) and sought the diverse perspectives of families of children and adolescents with and without disabilities, service providers, and individuals with disabilities (see Poston et al., 2003, for a detailed description of the research and recruitment procedures). Subsequent qualitative analysis revealed ten FQOL domains, which were grouped into two categories: those relating to individual members and their unique influence on the overall family system (Individually-Oriented), and those pertaining to the broader family unit (Family-Oriented). Individually-Oriented domains include emotional, environmental, and social well-being, as well as advocacy, health (both physical and mental), and productivity (in education, work, and leisure). Family-Oriented domains include daily family life, family interaction, financial well-being, and parenting. It is this work that forms the basis of the now widely used *Beach Center Family Quality of Life Scale* (L. Hoffman et al., 2006). Initially, different versions (adult, sibling, physical disability, and cognitive disability) were written and pilot tested with a small participant group that included family members, service providers, and researchers. After reviewing feedback and eliminating redundant items, the original versions were condensed, resulting in one form for family members and one for individuals with disabilities. The currently used versions have been extensively field tested with approximately 1200 individuals, 194 of whom had disabilities.

The *Beach Center Family Quality of Life Scale*, as it now exists, is a 25-item self-administered quantitative instrument that measures FQOL satisfaction across five domains: Family Interaction, referring to the relationships among and between family members; Parenting, meaning the kinds of activities families engage in to facilitate their child's development; Emotional Well-Being, involving perceptions of stress and support availability; Physical/Material Well-Being, referring to basic physical needs such as medical support and transportation; and Disability-Related Support, including supports across the community contexts of school, work, and home (Park et al., 2003; Turnbull, 2004; Turnbull, Poston, Minnes, & Summers, 2007). The measure's demonstrated psychometric validity (L. Hoffman et al., 2006; Summers et al., 2005; Wang et al., 2006) and ease of use has contributed to its extensive application in FQOL research (see Table 1).

3.2. International family quality of life project

The first international FQOL research initiative began in 1997 through a collaboration among researchers from Australia, Canada, and Israel. After examining relevant literature, seeking expert input, including those at the Beach Center, and ascertaining family feedback, nine domains were identified: Health of the Family, Financial Well-Being, Family Relationships, Support from Other People, Support from Disability-Related Services, Spiritual and Cultural Beliefs, Careers and Preparing for Careers, Leisure and Enjoyment of Life, and Community and Civic Involvement (R.I. Brown, Hong, Shearer, Wang, & Wang, 2010; Isaacs et al., 2007). The first version of the *Family Quality of Life Survey (FQOLS-2000)*; I. Brown, Neikrug, & Brown, 2000) was pilot tested with over 300 families residing in Australia, Canada, Israel, South Korea, and Taiwan. This version asked respondents to provide basic information about their families, and included questions pertaining to the nine domains across five concepts: Opportunities available to families that would enhance their FQOL; Initiative taken to capitalize on such opportunities; Attainment of wants and needs; Satisfaction with the various components of FQOL; and Stability, which inquired about the relative influence of domains over time (I. Brown et al., 2003). Although a formal psychometric evaluation has not been conducted, results from various studies using the survey indicate that the measure is "promising with respect to reliability and validity" (Isaacs et al., 2007, p. 181; see Isaacs et al. for a report of reliability and validity evidence from various studies using the *FQOLS-2000*).

After compiling respondent feedback, a number of changes were made, resulting in publication of the revised *Family Quality of Life Survey (FQOLS-2006)*; I. Brown et al., 2006). The most significant changes included altering the names and content of three domains, adding a sixth concept, Importance, in which respondents rated the relative weight of each domain to their general FQOL, and including questions about overall FQOL (i.e., "Are there everyday experiences that *add* to your family quality of life that we have not covered in this survey?" (I. Brown et al., 2006, p. 38)). The Spiritual and Cultural Beliefs domain was changed to Influence of Values, and includes questions about spiritual, cultural, as well as personal and religious values. Leisure and Enjoyment of Life is now known as Leisure and Recreation, and reflects the broad range of activities individuals can engage in for relaxation, entertainment, and enjoyment. Finally, Community and Civic Involvement was changed to Community Interaction to give families the opportunity to consider negative, as well as positive, community interaction experiences. Furthermore, a short-form option has been made available, in which only the six concept questions (Opportunities, Initiative, Attainment, Satisfaction, Stability, Importance) for each domain are asked (Isaacs et al., 2007).

Currently, the *FQOLS-2006* is being used in over 25 countries around the world, and has been translated into 20 languages (Samuel, Rillotta, & Brown, 2012). Although the psychometric properties are largely unknown, Werner, Edward, Baum, et al.'s (2009) exploratory study found moderate internal consistency for the six concepts across all domains, indicating that each provides unique, though broadly related, information. Global satisfaction, as measured by a single item ("Overall, how satisfied are you with your family's QOL?"), was also significantly correlated with the aggregated satisfaction ratings across all domains. Moreover, recent research provides evidence for the nine-domain survey structure; however, less support was found for the six concepts. This was attributed to high variability in both Importance and Stability (Isaacs et al., 2012). Although further work is needed to determine optimal survey structure and to establish reliability and validity, this measure

shows potential and appears to be a significant improvement over the earlier version. It is also important to consider that “optimal structure” likely differs depending on intended use (i.e., practical setting versus research, or intake interview versus outcome measure).

Rillotta et al. (2010) administered both the *FQOLS-2006* (I. Brown et al., 2006) and *Family Quality of Life Scale* (L. Hoffman et al., 2006) to 15 Australian primary caregivers of children or adults with ID. The instruments were completed via interview with the majority of individuals, though three elected to self-administer. The authors identified substantial administration differences across the two measures. The International Project instrument was significantly longer, taking about 40 min to self-complete, and required more expertise to administer and interpret, yet provided ample opportunity for qualitative elaboration. This option was not used, however, when caregivers completed it alone. Alternatively, the Beach Center Scale was quick to complete, requiring only approximately 20 min, yet detail in respondent comments were not sought. A relative area of strength for the International group's *FQOLS-2006* is that it accounts for families that have more than one member with a disability; whereas, the Beach Center Scale does not (participants are asked to consider the member who has the most impact on their lives). This may be of particular concern when including disabilities for which there is a significant heritability component, as is the case with autism (Constantino, Zhang, Frazier, Abbacchi, & Law, 2010). Rillotta et al. note that Beach Center questions are likely to be more easily understood and therefore, may be a better option if families are completing it on their own, as participants in their study had trouble understanding the *FQOLS-2006* Opportunities, Initiative, Attainment, and Stability concepts. Despite these differences, Rillotta et al. identified considerable overlap in the two measures' domain content, and examined correlations among directly related items, including the *FQOLS-2006* Health, Financial Well-Being, and Leisure and Recreation, and Beach Center Survey's “gets medical care when needed”, “has a way to take care of our expenses”, and “have some time to pursue our own interests” items, respectively. Satisfaction ratings among the examined measure dimensions were strongly and positively related (ranging from $r = .60-.84$, $p < .05$), indicating that both likely provide compatible data regarding FQOL.

3.3. Other approaches to conceptualization and measurement

Valuable work regarding FQOL has also originated outside of the Beach Center and International Project. Many researchers have utilized qualitative approaches, including interviews and group discussions (Schippers & van Boheemen, 2009; Werner, Edwards, & Baum, 2009), and have structured the dialogue around their particular focus of study (i.e., the impact of professional practices and long term residential placement). Others have utilized the International Project's *FQOLS* as a jumping off point. For example, in Jokinen and Brown's (2005) study examining FQOL in families of adults (over 40 years of age) with ID, the open-ended questions served as a source of discussion in their interviews and focus groups. Adopting qualitative approaches permits families to have free reign to discuss their perceptions, as the limitations of staying within discrete, pre-determined domains typically used in quantitative approaches, are lifted.

Quantitative methodologies have also been employed. Dunst, Trivette, Hamby, and Bruder (2006) utilized a single 10-point scale item to measure FQOL, in which families indicated their perceived relative position in terms of having the ‘best’ or ‘worst’ life possible. Others have utilized more comprehensive measures. For example, Feldman and Werner (2002) developed a questionnaire that measured FQOL across eight domains: daily activities and routines, community integration, peer relationships, learning, family stress, family social functions in and outside the home, and positive response from others. However, this instrument takes a dysfunction perspective, as it only inquires about the impact of the child's behaviour disorder on these domains, as opposed to taking a more holistic and systemic view of family life and functioning.

FQOL conceptualization in diverse cultures must also be considered, as applying measures that are culturally inappropriate and irrelevant will not yield sensitive or valuable information, nor serve the ultimate purpose of informing potential practice and policy advancements. A few, including Schmidt and Kober (2010) and Verdugo, Córdoba, and Gómez (2005), have approached this issue by adapting existing measures, whereas others have developed new tools or conducted qualitative studies to address cultural issues in the assessment of FQOL (i.e., Giné, Gràcia, Vilaseca, & Balcells, 2010; Todd, Young, Shearn, & Jones, 2004). Aznar and Castañón (2005) involved families of children with ID from 13 Latin American countries and developed an instrument appropriate to this population. Their tool examines FQOL across the following six domains: emotional and physical/material well-being, personal strength and development, cohabitation rules, family life, and interpersonal and community relations.

As with any research method, the chosen methodological approach will be accompanied by strengths and limitations. It is critical that investigators carefully weigh these in order to determine which approach is most appropriate given their research focus, and that they attempt to mitigate, to the greatest extent, any foreseeable limitations. The goal of attaining both rich and abundant data must be balanced with considerations of accessibility, particularly as they pertain to the participant group of interest. This is of chief concern for families of children with DD, as these families tend to be stretched in terms of time and resource commitments. Utilizing what Schalock (2005) refers to as “methodological pluralism” (p. 696), or simply mixed-methods approaches, may be the most appropriate way to achieve such aims.

3.4. Core concepts in the FQOL construct

Regardless of the diverse ways in which FQOL has been broken down and examined, consensus generally exists on the construct's family systems-oriented core concepts (I. Brown & Brown, 2004; Schalock, 2005; Schalock et al., 2002). As has

already been demonstrated, FQOL is best approached from a perspective that is multidimensional and holistic in nature. Both individual and collective elements are included (i.e., Poston et al.'s Individually- and Family-Oriented domains), and each is considered within the physical and sociocultural contexts in which the family lives. Furthermore, the uniqueness of each family must be at the forefront, as differences in priorities and experiences will inform ratings of FQOL. The goal of examining FQOL in research and practice must be to identify opportunities that will enhance and maximize families' functioning to achieve their goals. As family life is continuously in flux, such work must take a lifespan approach. In particular, attention must be paid to times of developmental transition, as these are points in which families must flexibly adapt to meet new demands. The ways in which such challenges are confronted have significant implications for family outcomes.

4. FQOL research: child, family and support characteristics

We know that families of children with DD tend to be less satisfied with their FQOL, across domains, than families of typically developing (TD) children (R.I. Brown et al., 2006; Poston et al., 2003), but what do we know about FQOL topography in this population? Werner, Edwards, Baum, et al. (2009) and Petrowski, Edwards, Isaacs, Baum, and Brown (2008) examined this using the *FQOLS-2006*, and found significant overlap among findings. In both studies, participants identified that they took the most Initiative, had the highest Attainment, and derived the most Satisfaction from their Family Relationships. Health of the Family was also consistently rated as most Important. Conversely, Support from Others received the lowest ratings across the concepts of Importance, Satisfaction, Initiative, Attainment, and Opportunities, and Financial Well-Being was consistently rated as lowest in terms of Stability. Further, Stability was one of the lowest rated concepts across domains, providing support for the view that FQOL is perpetually changing, and must be continually re-examined. I. Brown et al. (2003) found similar results, as Support from Others was ranked lowest in terms of Initiative taken, available Opportunities, and level of Attainment, and families were least Satisfied with Support from Services. Family Relationships was also rated highly in terms of Attainment, Initiative, and Satisfaction. As this study utilized an earlier version of the *FQOLS*, identical comparisons cannot be made, although the findings certainly reinforce the centrality of the family, and point out that support, whether instrumental or informal, is perceived as a relative area of weakness. The latter finding is consistent across research conducted by the International Project (I. Brown, 2008; I. Brown et al., 2004; R. Brown et al., 2004; R.I. Brown et al., 2010), with the exception of that carried out in Israel, where families spoke about the considerable help they received from extended family members (Neikrug et al., 2004). Others, however, have found that families are least satisfied with their Emotional Well-Being, and that Disability-Related Support is rated relatively highly (Davis & Gavidia-Payne, 2009; Summers et al., 2007).

The Beach Center and International Project have produced a substantial amount of research examining the impact of specific child, family, and support characteristics on FQOL. What follows is a review of research in these three areas.

4.1. The impact of child characteristics

Research on the relations between specific child characteristics and FQOL has focused on the impact of long-term residential placement, having an adult child with an ID, and disability severity. Werner, Edwards, and Baum (2009) interviewed families about how their FQOL changed before and after placing their adolescent or adult child with ID in a long-term primary care facility. Overall, most caregivers felt FQOL had improved, and parents' responses underscored the fundamentally interconnected nature of the construct. Families noted that if they saw their child as benefitting from the placement (i.e., improving individual QOL), this was mirrored in the broader QOL of the family. Parents had new social, vocational, and recreational freedom, and could devote more time and attention to fostering relationships with other family members. Parents' reports of decreased exhaustion, sadness, anger, and resentment, and increased happiness, peace, and hopefulness also likely contributed to a more positive home environment. Caregivers did experience heightened guilt, worry, and feelings of inadequacy; however, such concerns were likely mitigated by observations of improved overall family functioning. It is also possible that such feelings may vary as a function of the amount of time their child has resided in long-term care.

Many studies involving individuals with disabilities and their families are conducted with younger populations (Jokinen, 2006), likely due to the fact that this is a relatively easier group to seek out and involve. As such, we know less about functioning in families with an older child with a disability and about how the kinds of challenges that emerge in these later developmental stages impact the family. Jokinen and Brown (2005) attempted to shed light on such issues by conducting a mixed-methods study with parents of adults ($M = 47.1$ years, range = 41–52) with ID. Parents participated in a focus group or interview and completed an adapted version of the *FQOLS-2000*. Overall, families communicated positive perceptions regarding their FQOL. They discussed the ways in which their child had positively contributed to the family, although they also emphasized the lifelong nature of caregiving. Parents described their concerns for the future, such as who would care for their child when they no longer could and the potential impact this could have on TD siblings and their respective families. With regard to the authors' quantitative inquiry, families were highly satisfied with Leisure and Life Enjoyment and Family Relationships, and less so with Contribution to Community and Civic Affairs. As observed in previously described research, parents experienced low levels of support from individuals outside of their family (over half of parents reported that they received 'hardly any' practical help from neighbours or extended family members).

Wang, Turnbull, et al. (2004) investigated the impact of disability severity on FQOL, and found that for both mothers and fathers, disability severity demonstrated an inverse relationship with FQOL satisfaction, indicating that as disability severity

worsened, so did FQOL. It is possible, however, that this relationship was influenced by the age of the participant group. As the majority (approximately 67%) of children were between the ages of birth and three years, it is likely that many would have been newly diagnosed or in the process of determining diagnosis. This may have been a very uncertain time for participating families in which they were unsure of what supports were available and for what services they qualified. Moreover, most (approximately 86%) participants indicated that their child's disabilities were in the mild-to-moderate severity range. Those who viewed their child's disability as more severe may have perceived this as having a more significant and negative impact on overall family well-being as a function of comparisons they were making between themselves and other families. This study included data from 280 families (130 fathers and 234 mothers) across 13 early childhood centres in one American state. It is possible that participants knew other families involved in the study and may have made implicit comparisons when considering their relative FQOL. An alternate explanation may be that as severity increases, so do incidences of behaviour problems, an aspect that is negatively associated with FQOL (Davis & Gavidia-Payne, 2009).

4.2. *The impact of family characteristics*

Research in this area has focused on the influence of specific family characteristics, including income, spiritual/religious beliefs and practices, and advocacy activities. Wang, Turnbull, et al.'s (2004) study, discussed above, also examined the impact of family income on FQOL. Income was not a significant predictor of FQOL satisfaction for fathers, although it was for mothers. The authors note that we must be cautious in interpreting the former finding, as only a small number of fathers were included and family income was negatively skewed (45% of participants were from high-income families). Financial security likely does play a role in families' satisfaction ratings; however, such differences may only emerge in an appropriately diverse sample. As mothers fulfilled the role of primary caregiver in the majority of included families, it is also possible that they are more acutely aware of and concerned about the cost of intervention services.

As part of the larger Beach Center FQOL conceptualization study (Poston et al., 2003), Poston and Turnbull (2004) specifically examined the role of spiritual or religious practices and beliefs on quality of family life. As previously noted, a wide range of perspectives was sought, including families of children with and without disabilities. Families discussed the challenges associated with attending religious services and maintaining involvement with their religious community, and how their faith helped them to derive meaning from their child's disability. This was a positive attribution for some, as certain individuals referred to their child as a blessing. For others, however, this was not the case, as they spoke about understanding their child's disability to be a form of punishment. It would have been interesting to know how one's religious/spiritual belief system influenced such perceptions; however, participants were not asked to identify their religious orientation, and it was thought that for the most part, only Christianity was represented. It would also be of interest to examine how families of children with and without disabilities differentially describe the role of religion in their lives, and the discrepant impact on overall FQOL. This study underscores the importance of including questions about religious/spiritual beliefs and practices when inquiring about FQOL.

Families' perceptions regarding advocacy activities have also been examined. In Wang, Mannan, Poston, Turnbull, and Summers' (2004) qualitative study, participants discussed their feelings that engaging in advocacy was a necessary part of parenting a child with disabilities and that it could result in achieving a better fit between their child's unique needs and the professional services they received. Moreover, families discussed the resultant personal impacts. Families described the significant stress associated with such activities and spoke about how participation reduced the time available to spend with their family. On a positive note, parents felt that they gained valuable knowledge and skills, as they developed a better understanding of their child's needs, gained self-confidence, and were exposed to an expanded social support network. As with many of the other elements discussed, the impact of various characteristics on FQOL is likely largely determined by families' value perceptions. If families see that engaging in advocacy, for example, results in better services for their child, thus allowing their child to be a happier and more involved member of the family system, it is likely that family relations are eased across levels, and that overall functioning is perceived as enhanced.

4.3. *The impact of support characteristics*

The nature of the family–professional relationship has significant implications in terms of the services families have access to, the information they are given about their child's disability, and the kinds of support they receive. The family-centred philosophy is the dominant theoretical and practical model, particularly in early intervention, and is considered a best practice. Under this model, professionals adopt a strengths-based approach, address the needs of the entire family unit, and operate in individualized and flexible ways (Trivette & Dunst, 2005). Despite the support this perspective has received, little has been done to evaluate the broad impact of this movement on FQOL. Davis and Gavidia-Payne (2009) used the Beach Center Scale, along with a measure of family-centredness, to examine this relationship. Families that were most satisfied perceived that professionals partnered with them, and saw services as delivered in respectful, coordinated, and informative ways. Summers et al. (2007) found similar results, as ratings of service adequacy significantly predicted FQOL satisfaction. What may be most critical is that the support provided is well matched with families' needs and directly targets specific FQOL domains (Schippers & van Boheemen, 2009; Summers et al., 2007). For example, services such as peer support or parent training programs, as well as the provision of respite care may facilitate families' Emotional and Physical Well-Being, and fulfil Disability-Related Support needs (Friend, Summers, & Turnbull, 2009).

5. Quality of life for families of children with autism

Autism is a neurodevelopmental disorder characterized by a triad of social, communicative, and behavioural impairments (Woolfenden, Sarkozy, Ridley, & Williams, 2012), and the negative impacts experienced by families of children with autism are well established. Likely due to the associated behavioural problems (Lee, Harrington, Louie, & Newschaffer, 2008), these families experience greater levels of stress and depression, as well as decreased marital happiness and family cohesion as compared to families of children who are TD or who have other DDs such as Down syndrome (Bundy & Kuncze, 2009; Dabrowska & Pisula, 2010; Hamlyn-Wright et al., 2007; Higgins, Bailey, & Pearce, 2005; C.D. Hoffman, Sweeney, Hodge, Lopez-Wagner, & Looney, 2009; Ingersoll & Hambrick, 2011; Ingersoll, Meyer, & Becker, 2011; Totsika, Hastings, Emerson, Lancaster, & Berridge, 2011). Further, they are more likely to have unmet healthcare, family support, and service referral needs (Kogan et al., 2008). Despite these negative experiences, families describe the effect of autism on their lives as positive, and express how their families are closer as a result (Bayat, 2007). Such knowledge, along with the extremely high prevalence rates (estimated to be as high as one child per 88; Baio, 2012), provides strong justification for examining the impact of having a child with autism, exclusively, on FQOL.

R.I. Brown et al. (2006) examined FQOL in families of children with autism as compared to that of families of TD children and to families of a child with Down syndrome. Families of children with autism were most satisfied with Family Relations, and least with Community and Civic Involvement. The latter domain, however, was the lowest-rated for all three groups, indicating that this is not unique to families of a child with autism, although their ratings were much lower than those of the other two groups. Careers and Preparing for Careers as well as Leisure and Enjoyment of Life received the next lowest satisfaction rankings, both of which were significantly lower than for the Down syndrome group. It is important to note, however, that families of children with autism demonstrated lower satisfaction in all domains (*FQOLS-2000*) but one (the Down syndrome group was slightly lower in Spiritual and Cultural Beliefs). Further, for most (6 of 9) domains, less than half of participating families indicated that they were 'satisfied' or 'very satisfied'. These results indicate that FQOL-related concerns are abundant and pervasive for families of children with autism, leaving significant opportunity for support intervention.

Other research has been more exploratory and preliminary in nature. Lee et al. (2008) used National Survey of Children's Health data to examine QOL in families of children and adolescents (ages 3–17 years) with autism in comparison to families of a child with Attention-Deficit/Hyperactivity Disorder (ADHD) and to families of TD children. It must be noted that of those QOL domains assessed, only one, Caring Burden, was subjective in nature, as items inquired about parental perceptions of how difficult it was to raise their child. Other domains, including Family Outing, Family Meals, Religious Service Attendance, Quit a Job, Days of Missing School, Activity Participation, Repeated a Grade, Independence, and Community Service, required parents to provide frequency counts of how often their family or child had participated in specific activities in the recent past. Few pertained to the family context (family meals and outings), and most were child-specific (religious service attendance, days of missing school, activity participation, repeated a grade, independence, and community service). The assumed approach is somewhat in conflict with central tenets of both individual QOL and FQOL research, as these domains do not reflect a sufficiently broad representation of the individual nor address the uniqueness of each family. Few, if any, of the domains identified by the *SIRGQOL* (2000) are represented. Further, respondents were not given an opportunity to supplement their ratings and counts with their own perceptions (i.e., subjective satisfaction ratings of each domain), and the only items that were personal in nature operated from a one-sided dysfunction perspective (parents were asked to rate their feelings that their child "is much harder to care for than most children[;] ... does things that really bother them a lot[;] ... they are giving up more of their life to meet their child's needs than they ever expected" (Lee et al., 2008, p. 1149)). Moreover, the same QOL questions were not asked of each age group (3–5 years; 6–11 years; and 12–17 years), restricting the ability to make comparisons across developmental periods. Overall, families of children with autism reported poorer QOL across age and comparison groups. Although this study has limitations, this finding confirms those of other researchers (R.I. Brown et al., 2006; Eskow, Pineles, & Summers, 2011) and further emphasizes the urgent need to extend this line of work and consider how FQOL for these families can be improved.

Eskow et al. (2011) examined one way in which FQOL can be enhanced. Their research examined quality of life in families of children with autism who were receiving state- and federally funded Medicaid waiver services (i.e., "environmental access/modification; intensive individual support services; therapeutic integration; residential habilitation; family training; respite care; and supported employment ... also ... service coordination" (Eskow et al., 2011, p. 30)), as compared to those on a waitlist. Waiver families demonstrated higher FQOL, both overall and across domains (as measured by the *Beach Center FQOL Scale*). Although it is unclear as to which services accounted for the observed differences, this research provides evidence of the beneficial role that appropriately matched supports can play in families' lives, and indicates that reducing families' financial burden may have significant life quality implications. Such findings can help to inform policy makers about potentially fruitful areas in which to allocate funds.

6. Moving FQOL research forward: lessons from developmental psychopathology

Our review suggests that palatable advances have been made in the study of QOL among families living with a member with DD. Researchers have developed and refined the construct, provided important detailing of how various facets of family life are impacted, and encouraged us to think about how this research can be applied in practice to benefit families. However,

a fundamental challenge remains, as the deficit view still informs methodologies that seek to elicit themes of family risk and maladaptation, despite efforts to adopt a well-rounded approach that aligns with FQOL core concepts (I. Brown et al., 2006; Poston et al., 2003). This issue appears to be particularly prominent in autism research, and is reminiscent of the struggles faced by researchers who, decades ago, argued vehemently for a developmental approach to the study of individuals with ID when deficit views were prominent (Zigler, 1967, 1969; Zigler & Balla, 1982; Zigler & Hodapp, 1986; Zigler & Weisz, 1979). This body of work laid the foundation for the discipline of developmental psychopathology, and continues to influence developmental science as applied to persons with ID (Burack, 1997; Hodapp & Burack, 2006). Although the developmental psychopathology perspective has traditionally been applied to the study of individuals at risk, the basic tenets are amenable to the study of families at risk. The developmental psychopathology perspective embraces notions of reciprocity between typical and atypical processes and outcomes, developmental and family systems, risk and resilience, as well as the interplay between risk and protective factors that are important throughout the family life cycle and contribute to “diversity in process and outcome” (Cicchetti & Rogosch, 1996, p. 597; i.e., equifinality and multifinality). In what follows we are guided by decades of developmental psychopathology research on individuals and propose ways to borrow the ‘pearls of wisdom’ to advance the study of families living with a child with DD. We believe that concepts and methods from developmental psychopathology can be applied to advance a more comprehensive understanding of FQOL and, in turn, generate new and innovative research ideas. We use the example of families of children with autism, as the need for research on this population is dire given both the disorder’s high prevalence rates (Fombonne, 2007) and the associated and pervasive challenges experienced by their families (Ingersoll & Hambrick, 2011; Ingersoll et al., 2011; Kogan et al., 2008).

7. Conceptual considerations for FQOL research: a focus on families living with autism

7.1. Conceptualizing the family as a system

The family systems perspective is a framework that contextualizes individuals within their families, and the family within society. It helps us to think about relationships and interactions as they occur across levels, and informs us about how the “system” is in fact unique for each member. Like Bronfenbrenner’s (1979) ecological model, it can be displayed as a series of concentric circles, in which the innermost element consists of the individual, and expanding circles represent socially extended elements, such as the relationships among individuals within the family system, the influence of one’s, at times changing, role within the family (i.e., one may simultaneously fulfil the roles of child, sibling, and caretaker, as well as the notion that these change over time), and finally to external contextual factors, such as relevant sociocultural norms. Moreover, we can think of the system in temporal terms, as the system progresses in time, and must adapt to changing circumstances that arise during times of transition (McGoldrick, Carter, & Garcia-Preto, 2011). This model is based on four central principles: the family operates as a whole and this “whole is greater than the sum of its parts” (Bornstein & Sawyer, 2008, p. 382); individuals are causally related, as any change that is experienced by one member is also felt by the others; the family structure is hierarchical, meaning that role boundaries, between parent and child for example, direct interactions; and finally, families work to readjust during episodes of disruption to the system (Bornstein & Sawyer, 2008).

Family systems theory and research provides an important developmental context from which to examine the ways that families cope with typical life cycle transitions, such as the birth of a child. Additional risks and stressors must be considered, however, when there is a child with a disability, as couple, parent, and sibling relationships must be renegotiated amongst periods of unusually high stress (McGoldrick et al., 2011). For example, once a diagnosis of autism is made, families must also accomplish a variety of tasks simultaneously, such as making sense of potentially conflicting medical and other diagnostic information, procuring specialized professionals and services for their child’s special needs, and the resources to finance them (Guralnick, 2000; Minnes, 1998). It is also a time when parents may experience negative attitudes from health professionals and others in their social networks, particularly with regard to expectations about their child’s future (Virji-Babul, Eichman, & Duffield, 2004).

7.2. Risk and resilience

The family faced with the challenge of raising a child with autism is considered at risk in developmental terms because their situation is atypical and more taxing than most. Families are usually ill-prepared, overwhelmed with additional burdens, and in need of specialized support services that are in limited supply (Kohler, 1999; Lovett & Haring, 2003). Although this predicament would be described as adverse, it is precisely within this context that one would expect to find resilience. Resilience is defined as one’s ability to develop optimally despite exposure to conditions of considerable risk or adversity, whether acute or chronic (Masten & Obradovic, 2006). It is thought to be dependent on individual factors, such as the capacity to capitalize on available internal and external resources (Masten, Best, & Garmezy, 1990; Rutter & Sroufe, 2000; Waters & Sroufe, 1983), as well as contextual factors such as family support systems, and community resources. Although the concept of resilience has typically been considered in relation to individual developmental trajectories and outcomes, it also has value when applied to family trajectories and outcomes. For example, autism is a risk factor for maladaptive development primarily because those afflicted have limited abilities to communicate and relate to others, thus diminishing the individual’s quality of life. FQOL is also at risk because it is the family members who most closely witness, experience, and cope with the social and communication challenges that interfere with developing meaningful relationships. Resilience in

family relations and processes is possible, however, when high quality family support systems and community resources can buffer the effects of caring for a member with autism. Eskow et al.'s (2011) research supports this notion, as families receiving government-funded services were more satisfied with their FQOL than those on a waiting list. Research also demonstrates strong positive correlations between FQOL and high quality support characteristics, such as close partnerships, open information sharing, and respectful parent–professional relationships (Davis & Gavidia-Payne, 2009), that perceptions of service adequacy significantly predict FQOL satisfaction (Summers et al., 2007), and that families perceive support from disability-related services as a very important aspect of FQOL (Werner, Edwards, Baum et al., 2009).

Success at one period sets in place a cascade of processes in which current competence prepares the individual and family to experience continued resilience (Burack, 1997; Cox, Mills-Koonce, Propper, & Gariépy, 2010; Sroufe & Rutter, 1984). Thus, current adaptation is a product of both prevailing circumstance and developmental history (Bowlby, 1980; Rutter & Sroufe, 2000). However, it is important to acknowledge that competence in resolving issues in one developmental period does not predict future functioning in a linear or deterministic way, as resilience at one time does not guarantee that it will continue (Coie et al., 1993). As such, the goal of FQOL research must be to highlight the environmental factors that are associated with positive outcomes despite potential adversity, while keeping in mind that this is reflective of only one point in time and only one set of circumstances. Due to the multiplicity of risk factors and the complexity of the developmental process and its outcomes, both for the family and the individual with autism, these are necessary considerations in terms of family research and intervention.

7.3. Multifinality and equifinality

Individuals with autism are diverse in terms of abilities and disabilities, ethnicity, culture, socio-economic status and family characteristics, yet many share similar risk factors such as high levels of anxiety, limited social opportunities, and negative life experiences (e.g., bullying). What then can one predict about family outcomes in terms of their diversity or similarity? The developmental psychopathology concept of multifinality helps to explain how a particular risk factor can lead to any of the several developmental outcomes depending on personal predilections and the environmental supports for various symptoms. Another concept, equifinality, refers to the case whereby one can arrive at the same outcome from diverse beginnings (Cicchetti & Rogosch, 1996; Cicchetti & Toth, 2009). As applied to the family, rather than the individual, one can envision how particular coping styles, interactional patterns (family predilections), and potential risk and protective factors (i.e., access to extended family networks, strong or weak financial status, and quality of community support services) may contribute to mal/adaptive family functioning patterns, as well as how these may change across the family life cycle (Sturge-Apple, Davies, & Cummings, 2010). Within this framework, one would expect the family to be most at risk during life cycle transitions when they must flexibly readjust to changing circumstances and may require additional supports to effectively cope with increasing demands.

8. Methodological considerations for FQOL research

8.1. Group differentiation

Historically, we have learned that theoretical shifts in thinking are necessary but not sufficient for important research advances to be made. Deficit models of ID were pervasive in the early 1950s and 1960s and reflected at least two misconceptions: one being that all people with ID were deficient in their IQ as compared to their TD peers, and hence should also be viewed as deficient in other domains (Burack, Iarocci, Flanagan, & Bowler, 2004); and two, that people with ID could be grouped and studied under the same label as they all had a similar behavioural outcome, namely low IQ. Zigler and colleagues debunked these fallacies, representing a dramatic shift in both theory and research methodology, with an elegant series of studies wherein simply differentiating people with ID into two groups—those related to biologic causes and those to heritable/familial origins—and matching them with TD controls on a measure of mental rather than chronological age, uncovered important differences in their developmental trajectories (Zigler, 1967, 1969; Zigler & Balla, 1982; Zigler & Hodapp, 1986; Zigler & Weisz, 1979).

The two-group differentiation, though considered basic by today's standards, led to an important refinement in the conceptualization of ID. Developmental disability is often used as an overarching term within which individuals diagnosed with different pathologies are grouped together, even though each disorder is thought (and in some cases known) to have a different aetiology, developmental course, and prognosis. Our review indicates that the majority of FQOL findings are based on the aggregation of very diverse disabilities, including autism, ADHD, anxiety and mood disorders, hearing and speech-language impairments, and 'no specific diagnosis,' into one general 'disability' category. In general, researchers have not attempted to tease apart those within this group, but instead have looked for overall findings or general differences as compared to families of TD children. The presentation, severity, and behavioural profiles of such diagnoses are vastly different, and likely have very diverse implications for FQOL. Further, adopting an undifferentiated disability group methodology masks potentially important insights into unique circumstances of risk, resilience, and their role in a family's developmental path.

There has also been little analysis of how demographic factors, such as cultural background or marital status, influence FQOL. Although this could be due to a lack of sample variability, it would be beneficial to seek out and include diverse

populations in future work, as this may clarify existing inconsistencies (i.e., the relationship between family income and FQOL and the impact of diverse religious/spiritual beliefs). Research also indicates that disruptive events, such as divorce, are almost twice as common in families of children with autism as compared to families with TD children, and that for the former, divorce risk remains high across the child's development, not declining until after the child is 30 years of age (Hartley et al., 2010). Assessments must account for significant life events, such as divorce or family births and deaths, that occur around the time of evaluation, as these critical family transition points are likely extremely impactful to FQOL ratings.

8.2. Matching and choice of comparison groups

The challenge of selecting an appropriate and meaningful comparison group is another critical methodological issue in DD research, and is certainly not unique to the FQOL field (Burack, Iarocci, Bowler, & Mottron, 2002). A comparison group is most informative if ethnicity, socio-economic status, and type and level of disability are considered, as researchers are thus able to make more precise interpretations of their findings. Yet, the choice of comparison group and the measures on which they are matched are only beneficial to the extent that they inform about the questions of interest. In the FQOL studies reviewed, families of children with autism were compared to families of children with Down syndrome and ADHD so the unique impact of autism, versus DD in general, could be determined (R.I. Brown et al., 2006). However, the differences between these groups and autism in terms of age of diagnosis, diagnostic experience, presence of behaviour problems, and social stigma, to name only a few, are fundamental in nature, and muddy the 'comparison' waters considerably. Moreover, we are now beginning to understand the possibility that significant overlap exists between ADHD and autism, perhaps lessening the appropriateness of using these individuals comparatively (Frazier et al., 2001; Hattori et al., 2006). We know that families of children with autism have more FQOL-related concerns, and as such, it is perhaps time to move beyond confirmation of this finding, to an examination of key factors that contribute to within group differences.

8.3. A family systems methodology

Although family systems theory has generally informed the development and direction of FQOL research, a methodological implementation truly reflective of a systemic perspective has not yet been achieved. This would involve seeking input from all family members, including both parents/caregivers, TD siblings, as well as the individual with disability. Participation may also extend to those outside of the nuclear unit, as we must keep in mind that each family's composition may differ. This would assist in gaining a truly rounded and contextualized understanding of how the delicate interrelationships among family members influence the ways in which events, both significant and routine, affect FQOL in risk- or resilience-promoting ways.

Incorporating Schalock's (2005) methodological pluralism would also help to tackle such challenges. Only two of the nine studies employing quantitative approaches also included a qualitative component, thus, it is difficult for the reader to contextualize the findings. Including a qualitative piece through follow-up interviews would allow for a better understanding of how experiences may differ depending upon factors such as presence/absence of specific comorbidities or behavioural problems, or how the stress associated with the diagnostic experience uniquely impacts FQOL. Furthermore, it would allow one to examine existing practice and policy gaps, as identified by families, and make needed suggestions for change.

Research must also consider that FQOL is a dynamic and highly context dependent construct. Assessing FQOL at only one point in time provides merely a glimpse into the myriad of factors that influence the ways in which a family functions. As such, longitudinal research designs that take a family life cycle perspective may be a more appropriate method for determining how families can successfully progress through developmental transitions. This may provide a more detailed representation of the family's lifespan as a unit, illuminating equi- and multifinal processes, and highlighting how members must at times reconcile the potentially competing demands associated with being a caregiver while also fulfilling novel personal roles that come with entering new life stages (i.e., the birth of a child, leaving the home, acquiring a new professional position, or retirement).

This type of research typically seeks large samples, and may request participation through phone- and internet-based methods. As such, the use of gold standard measures, including the Autism Diagnostic Interview – Revised (ADI-R; Rutter, Le Couteur, & Lord, 2008) and Autism Diagnostic Observation Schedule (ADOS; Lord, Rutter, DiLavore, & Risi, 1999), may not be appropriate or feasible. Researchers, however, could include validated screening instruments (i.e., Autism Spectrum Rating Scales [ASRS]; Goldstein & Naglieri, 2009) as part of their research protocol in order to ensure the validity of drawn conclusions. It would also be desirable to include sufficient information regarding sample characteristics. Future studies must report comorbidity information, as well as provide data about participants' behavioural and social profiles, as this will allow researchers to determine how the presence of specific characteristics commonly observed in autism differentially impact FQOL.

9. Summary and conclusion

The birth of a child with a DD, much like other life cycle transitions, occurs within a family context of stability and change. The family can be conceptualized as a system with a stable structure (i.e., prescribed roles, rules, and relational patterns),

a common history, and interrelated function. However, unlike mechanical systems, the family is open, fluid, and perpetually adapting to changing circumstances. Significant perturbations in the system often take the form of developmental transitions such as the introduction of a new child, the initiation of the child's formal schooling, increased autonomy and peer contact in adolescence, and launching the adolescent into adulthood (McGoldrick et al., 2011). Such perturbations set in motion the process of developmental reorganization that involves both challenges and opportunities for growth within the family system. Although children with DD and the families that care for them may be referred to as 'at risk' due to the added challenges associated with parenting a child with special needs, they can also be considered for the ways in which they are resilient in successfully managing stressors and adjusting to life cycle transitions (Iarocci, Virji-Babul, & Reebye, 2006). Multiple risk and protective factors may be present in families caring for a child with DD. Consequently, multiple pathways to adaptation or maladaptation are possible. For example, families that care for a child with DD do not have the benefit of their extended family's wisdom on raising their 'unique' child, yet they may be less bound by social and cultural prescriptions on parenting. These families also often face the challenges of advocating for and acquiring resources for their child; however, this very deliberate engagement in the parenting process may lead to more mindful awareness and activity in child rearing.

FQOL research must be extended in ways that inform about families and their ability to function optimally and cohesively as a unit. The family serves as the primary developmental context for children with and without disabilities, and the individuals comprising this system provide the foundation for a child's developmental trajectory. If supports—particularly for families of children with disabilities—that maximize families' abilities to fulfil this role are not in place, the entire system is placed at unnecessary risk. At this point, research on QOL in families of children with ID is far more extensive than that for families of children with autism, even though FQOL is significantly lower in the latter group. This fact, along with rising autism awareness and prevalence (note: *not* incidence; Fombonne, 2007), as well as our knowledge of the pervasive and often adverse family impact, provides a strong rationale for devoting attention to this group, and addressing the limitations that exist within this body of work. A valuable next step will be to examine the landscape of FQOL across the lifespan of individuals with autism, from diagnosis to adulthood. This will provide an opportunity to richly examine the relative impacts of various child and family characteristics beyond what has already been done, and with the added benefit of having other developmental periods serve as a source of comparison. This will highlight the strengths and limitations of currently available supports and services, as well as indicate areas in need of enhancements.

Tolstoy's astute observations (by the scholarly standards of the time) on family well-being have helped to shape notions of family risk and its many facets. The developmental psychopathology approach can now help us to generate more refined questions wherein happiness and unhappiness are better integrated within the construct of FQOL. In turn, the answers will be more specific with regard to the 'who, what, where, when, and how' of family well-being, thus improving the impact on policy and clinical practice.

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