



Family Quality of Life in Foster and Adoptive Families of People with IDD

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RESEARCH



STOCKHOLM
UNIVERSITY PRESS

ABSTRACT

The aim of this study is to examine the family quality of life (FQoL) in foster and adoptive families of people with intellectual and developmental disabilities (IDD). Adoption or foster care and IDD can have a specific impact on families, creating particular support needs. This study assesses self-reported parent FQoL and its relations with placement and disability factors in a convenience snowball sample of 62 foster and adoptive families of children, adolescents, and young adults with IDD in Spain. The FQoL ranged between moderate and entirely satisfactory ($M = 92.2$; $SD = 16.9$). Families of people with Down Syndrome (DS) and in special placements showed higher FQoL scores than those without other diagnoses or in ordinary placements. In contrast, increased mental health needs can explain a decrease in FQoL ($\beta = -0.337$, $t = -2.729$, $p = 0.008$). These families also show specific support needs essential for FQoL, including accurate information and training processes, and particular attention and support when a disability is identified after placement.

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KEYWORDS:

adoption; foster
care; intellectual and
developmental disabilities;
special needs children; quality
of life

TO CITE THIS ARTICLE:

García-Sanjuán, Noemí, Ana
Berástegui and Rosalía Mota.
2023. "Family Quality of Life in
Foster and Adoptive Families of
People with IDD." *Scandinavian
Journal of Disability Research*
25(1):378–390. DOI: [https://doi.
org/10.16993/sjdr.975](https://doi.org/10.16993/sjdr.975)

INTRODUCTION

The Convention on the Rights of Persons with Disabilities, in Article 23, recognizes the right of all children with disabilities to have equal rights concerning family life. States shall undertake every effort to provide a family setting within the community when their immediate or extended family cannot care for them (United Nations 2007).

Adoption and family fostering are the legal processes to ensure this right, but it is not always easy to find a family for children with disabilities. Childcare services no longer consider children with IDD to be unadoptable, as in the past (Sufian 2014). However, they still consider them 'hard to place' children (Bunt 2014). International research has found an overrepresentation of these children in the childcare system; most of them are eligible to be fostered or adopted into a family (Johnson et al. 2020; Rosenberg & Robinson 2004; Welch et al. 2015). In Spain, children with IDD constitute 5.9% of the waiting children in residential care, and professionals do not expect to find a family for a significant proportion of them (López et al. 2010).

Family adjustment and the well-being of families that adopt and foster children with IDD have received scarce attention from adoption research (Good 2016). Research on IDD has neither paid enough attention to the specificity of foster and adoptive families compared to biological families, despite the higher prevalence of adopted and foster children in IDD resources such as special education, for example (Van Ijzendoorn, Juffer & Klein 2005). However, the intersection between adoption or foster care and IDD can have a relevant impact on families and therefore create specific support needs that may be unmet (Good 2016; Miller et al. 2021). Understanding the quality of family life dynamics in these families can help us promote the most appropriate services and better support them (Perry & Henry 2009).

SIMILARITIES AND DIFFERENCES BETWEEN FOSTER OR ADOPTIVE VS. BIOLOGICAL FAMILIES OF PEOPLE WITH IDD

Previous literature stresses the additional challenges of foster and adoptive parenting versus the biological parenting of children with IDD. Forbes and Dziegielewski (2003) highlight, for example, the stigmatization of foster and adoptive parenting; the grief associated with motivations such as infertility, lack of support, and understanding from the extended family; or the differential acceptance of parents in some adaptation processes. Other challenges may include managing the relationship with the biological family in foster care and open adoptions; communication about the origins and the construction of identity in the child, including the fear of abandonment (Hussey 2011); or the building of interracial families (Lazarus et al. 2002); and coping with stigmatization (Miller et al. 2021). These adoption challenges may interact with IDD challenges (Berástegui 2012; Miller et al. 2021) by boosting or overshadowing them. Conversely, the disability itself can minimize some of these adoption challenges. For example, although attachment is a particular challenge for foster and adoptive families (Berástegui 2012; Rosser & Bueno 2011; Van den Dries, Juffer, Van Ijzendoorn & Bakermans-Kraenburg 2009), Mozzi and Nuernberg (2016) show how the unique demands that stem from raising a child with IDD intensify the construction of the emotional bonds between parent and child, although this is not consistently found (Miller et al. 2021).

Foster and adoptive parenting also show certain advantages over the biological parenting of children with IDD. Foster and adoptive families of children with IDD present similar family adjustment scores to normative families of typical children (Glidden & Cahill 1998; Glidden 2000), evidencing these advantages. In addition, adoption may be a protective factor against the family and couple instability found in families with IDD children (Gibby et al. 2022). Perry and Henry (2009) highlight that prior knowledge of the disability, which occurs in adoptions and special foster care, is advantageous in becoming a family in the following aspects. First, foster and adoptive parents can make a conscious and deliberate choice to parent a child with IDD, leading to a more outstanding initial commitment to the relationship and a more significant experience of meaning (Perry & Henry 2009). Second, foster and adoptive parents can assess their own suitability to parent the child, with the help of others, and volunteer for the children who would best suit their capabilities and circumstances (Perry & Henry 2009). Finally, the previous knowledge of the child's diagnosis and needs allows foster and adoptive parents to make the relevant adjustments to prepare for parenting (such as improving/building

knowledge, preparing siblings and the extended family, or making economic or material adjustments) (Perry & Henry 2009). Furthermore, adoptive families typically do not experience the existential crisis that frequently accompanies the transition to parenthood in biological families of children with IDD (Fernández-Ávalos et al. 2020; Denby, Alford & Ayala 2011; Perry & Henry 2009). The transition to parenthood crisis can be dealt with quickly, effectively, and with a focus on problem-solving in adoptive families—due to the absence of experiences of shock, hopelessness, depression, or guilt (Brown 2016; Fernández-Alcántara et al. 2015, 2016; Glidden 1986; Van der Steen et al. 2016).

All these advantages assume that foster and adoptive families choose to parent a child with IDD, while biological families cannot. However, some biological families choose their special parenting, and some foster and adoptive families do not. The prenatal diagnosis of IDD is becoming increasingly frequent, especially in genetic conditions such as DS, which in many countries, allows the choice to continue with the pregnancy, or not (Flórez 2007). This prenatal diagnosis allows prospective parents—having initially addressed the diagnosis crisis—to assess the child's needs and capabilities to prepare and face the transition to parenting. Furthermore, the adoptions and foster care placements of children with IDD are not always previously chosen. In special adoptions, this choice does occur. However, in ordinary adoption and fostering, the disability diagnosis may occur unexpectedly after placement. Thus, we can find foster and adoptive families who are as surprised to be the parents of a child with IDD as biological parents are (Lindstrom, Voynow & Boyer 2013; Mozzi & Nuernberg 2016; Moyer & Goldberg 2017). Research has found a higher probability of failure in adoptive families when disability was previously unknown (Glidden 1991; Rosenthal 1993). Of course, these advantages cannot be used as an argument for separating children with disabilities from their biological families to place them in foster and adoptive families. However, they can encourage the search for alternative family placements when children cannot be cared for by their biological families.

VARIABILITY OF FOSTER AND ADOPTIVE FAMILIES OF PEOPLE WITH IDD

Children and young people with IDD are not a homogeneous group, and their characteristics and needs can have a complex impact on the adaptation and quality of family life (Brodzinsky & Pinderhughes 2002; Welch, Salker & Stewart 2015). The current model of disability prompts us to assess the person's support needs in different areas of functioning, rather than the severity of their limitations, as was usual from the medical model of disability (Thompson et al. 2009). Several authors have studied the influence of the degree or severity of the child's special needs on adoption outcomes (Coyne & Brown 1985; Glidden 1991; Goetting & Goetting 1993; Reilly & Platz 2004; Rosenthal, Groze & Durán 1991). Children with the most severe support needs can be successfully placed for adoption (Glidden 1991). Adoptions of children with severe or profound disabilities show low disruption rates and high parental satisfaction (Coyne & Brown 1985; Glidden 1989, 1991; Goetting & Goetting 1993).

Families show positive functioning regardless of the specific diagnosis associated with the disability (Glidden & Cahill 1998, Coyne and Brown 1985; Rosenthal & Groze 1990). Nevertheless, some studies find that adopting a child with DS has a more positive impact on family life than other disabilities, because of the belief that this disability is more benign (Glidden & Cahill 1998). This effect may express the DS advantage in adoptive families (Berastegui & Corral 2020; Corrice & Glidden 2009; Esbensen & Seltzer 2011; Hodapp 2007), due to greater knowledge and information about the needs, prognosis, and available resources (Glidden & Cahill 1998). Nevertheless, this phenomenon is still under discussion (Berástegui & Corral 2020; Glidden & Cahill 1998). By contrast, the ignorance of the etiology and its evolution, or the lack of previous experience in the parents can generate uncertainty or a mismatch in expectations, both factors having a negative effect on family life (Coyne & Brown 1985; Glidden 2000; Rosenthal, Groze & Durán 1991).

Importantly, adoption and foster care for people with IDD are not just a matter of caring for the child and adolescent, because support needs will persist throughout life. Previous studies have reported that the age of the person with IDD predicts the family's needs (Córdoba-Andrade 2007). Although the differences between biological and adoptive families disappear as the child ages in longitudinal studies (Perry & Henry 2009), studies on IDD and adoption have

rarely explored family life beyond adolescence (Glidden 2000). For this reason, Glidden (2000) highlights the importance of extending the evaluation of family well-being in the transition to adulthood, as this is a particularly stressful life stage in these people's and their families' lives (Boehm, Carter & Lunds 2015; Leonard et al. 2016).

Family adjustment is usually more significant in adoptive families than in foster families (Mulligan 2003; Triseliotis 2002). However, we are unaware of any research comparing permanent foster and adoptive families of children with IDD, and our previous study has found no differences (García-Sanjuán 2017). Similarly, although some studies show better results in international adoptions than domestic ones (Juffer & Van Ijzendoorn 2005; Levy-Shiff, Zoran & Shulman 1997), the differences are inconclusive, depending on the composition of the samples and the combination of origin and destination countries. However, there is a lack of studies evaluating the differences between domestic and international processes in special placements, particularly in children with IDD.

FAMILY QUALITY OF LIFE IN FAMILIES WITH IDD

Research on the adoption and fostering of children with IDD has been carried out mainly in the adoption research field, and has fundamentally assumed a medical model. Most of the studies are focused on the negative impact of disability and are characterized by language that is not inclusive (Bunt 2014; Good 2016). However, it is critical to address this reality from the research paradigm about quality of life and disability (Verdugo et al. 2012). Aligned with this paradigm, FQoL is becoming increasingly important as an intervention target and a success indicator of the policies and programs that aim to support people with IDD and their families (Córdoba-Andrade, Gómez-Benito & Verdugo 2008; Park et al. 2003). The FQoL approach assumes a less fragmentary, pathological, and deficit-focused vision than the predominant one up to the 1990s (Córdoba-Andrade, Gómez-Benito & Verdugo 2008).

Park et al. (2003) describe FQoL in those families whose members have their needs met, enjoy life together, and have opportunities to pursue and achieve their own goals. They propose a measure that includes the importance and satisfaction of five large domains: family interaction; parenting; health and safety; family resources; and support for the person with IDD.

This study aims to examine FQoL in a sample of foster and adoptive families of people with IDD and to explore the relationship between FQoL and its different dimensions with the characteristics of the disability (severity, etiology, and needs of the child and life stage) and the childcare placement process (special or ordinary process, foster care or adoption, domestic or international adoption, and age at the time of adoption).

METHOD

PARTICIPANTS

Participants were 62 foster and adoptive parents (77% mothers) of people with an intellectual disability in Spain. The mean age of parents was 51.46 years old ($SD = 8.65$), the youngest being 33 and the oldest 67.

Their children with IDD were 54.8% female, and their mean age was 17.79 ($SD = 8.66$). Of them, 32.7% were children (0–11 years old), 56.4% were adolescents (12–23 years old), and 10.9% young adults (24–36 years old). Most of them lived in the family home (87.1%).

All children had an IDD certificate issued by the Spanish public administration. The children's degree of disability, as reported by the parents, was mild (30.6%), moderate (43.5%), severe (22.6%), or profound (1.6%). Some of them had a specific diagnosis, including DS (23.3%), emotional or behavioral disorder (10%), attention deficit hyperactivity disorder (3.3%), autism spectrum disorder (1.7%), or others (8.3%), including Noonan syndrome or fetal alcohol syndrome.

Regarding placement factors, the mean age of children at placement was 3.37 ($SD = 3.8$); 82.3% were adoptive families, while 17.7% were foster families. Except for one case, all the foster families and 39.2% of the adoptions conducted were domestic processes, while 60.8% were intercountry adoptions. Most were ordinary placements (59.7%), while the rests were special fostering or adoptions.

INSTRUMENTS

Family quality of life

The Beach Center FQoL survey was applied (Beach Center on Disability 2005; Hoffman et al. 2006; Park et al. 2003) as adapted and validated to Spanish by Verdugo, Rodríguez and Sánchez (2009). The satisfaction section was used, which consists of 25 items with five response options (from very dissatisfied to very satisfied), evaluating five dimensions:

- a) **Family interaction:** Evaluates the family members' relationship with each other and the family's emotional climate through aspects such as interactional environment, communication, mutual support, and flexibility in planning.
- b) **Parenting:** Evaluates how family members provide care, support, or monitoring to members with IDD.
- c) **Health and safety:** Assesses the family's availability of time and support to relieve stress and meet everyone's needs.
- d) **Family resources:** Evaluates the family's access to economic, health, or social resources and a safe environment.
- e) **Support for the person with disability:** Assesses the opportunities and support available for the family member with IDD in different contexts such as education, work, free time, or home, as well as the family's relationship with the providers of this support.

The adaptation to Spanish maintains good reliability and validity indices. The satisfaction scale has acceptable reliability for the total scale ($\alpha = 0.95$) and above 0.80 for all subscales (Verdugo et al. 2005, 2009). The different factors have shown a significant correlation, strengthening the hypothesis of a single higher-order factor that explains the FQoL (Rodríguez, Verdugo & Gómez 2015). The FQoL scale shows high reliability in our study ($\alpha = 0.94$).

Sociodemographic questionnaire

The collected variables of the person with IDD were the severity of disability (mild; moderate; severe; profound), etiology reported by the parents (DS/not DS) and life stage (0–11: childhood; 12–23: adolescence, and 24–36: young adult). The variables of the placement process were special or ordinary process (i.e., the process was tailored from the beginning for children with special needs' placements or not), foster care or adoption, domestic or international adoption, and age at the time of adoption.

Support needs scale

This scale was created ad hoc to assess the support needs of the person with IDD in 10 areas (communication, use of resources, academic skills, home life, health and safety, leisure, self-care, self-direction, social relationships, and mental health), each with four response levels (0: no need for support; 1: little need for support; 2: medium need for support; and 3: high need for support). The sum of the scores (range 0–40) was used as a global measure, obtaining a good internal consistency ($\alpha = 0.86$).

PROCEDURE

The call for participation was disseminated through our entity's database to schools, special education schools, occupational centers, public entities, and associations concerned with disability or child welfare, and on social networks (Twitter, Facebook, and LinkedIn). A subsequent snowball sampling was conducted. Information on the objectives of the study, details of participation, ethical issues, and contact details was provided. The families who volunteered were called to an in-depth interview in which a self-reported questionnaire was administered. Only one parent from each family was interviewed, usually the one who made contact. The university's ethics committee approved the study, and the ethical and consent standards were scrupulously followed.

The convenience and non-probabilistic sampling is justified by the difficulties in obtaining a sampling frame that allows the extraction of a random sample (Cea D'Ancona 1999), as there is no single register of families of people with IDD in Spain. Furthermore, the fact that the population under study is new justifies using a non-probabilistic sample.

DATA ANALYSIS

The data was incorporated into the SPSS 27 tool for analysis. First, a descriptive analysis of the sample characteristics was carried out. The dimensions of the FQoL were described using the weighted mean to assess the differences between the scales. The normality assumption of the FQoL dimensions was checked using Kolmogorov-Smirnov test. A parametric test was used when the data were normally distributed, and a non-parametric test was used when the data violated the normality assumption. Therefore, for the analysis of the differences in dichotomous variables, Student's t or Mann-Whitney's U was used respectively. The effect size was evaluated with Cohen's d or Rosenthal's r, respectively. One-way ANOVA or Kruskal-Wallis was used to analyze the mean differences in variables of more than two levels. Finally, and once the application assumptions had been checked, an exploratory stepwise multiple regression analysis was carried out to identify child support needs variables that predict the global FQoL.

RESULTS

Families in our sample showed medium-high levels in the different dimensions of FQoL. Their mean scores correspond to levels between satisfied and quite satisfied in all dimensions of FQoL (Table 1). The dimension of family resources has the highest satisfaction levels on average, followed by health and safety, where they present more moderate scores. The overall quality of life, parenting, and family interaction scores show a broader dispersion. The results of the Kolmogorov-Smirnov normality test showed that all the FQoL dimensions showed a normal distribution except family interaction, parenting, and family resources scale.

	N	M	SD	DIMENSION RANGE	NUMBER OF ITEMS	WA	K	P
Family interaction	60	23.1	4.9	6-30	6	3.9	0.118	0.037
Parenting	62	21.3	5.2	6-30	6	3.6	0.116	0.042
Health and safety	62	13.2	3.1	4-20	4	3.3	0.096	0.2
Disability supports	61	14.6	3.4	4-20	4	3.6	0.107	0.80
Family resources	61	20.2	3.3	5-25	5	4.0	0.132	0.01
Total FQoL	60	92.2	16.9	25-125	25	3.7	0.072	0.2

Table 1 Descriptive statistics of the FQoL dimensions.

Note: WA = weighted average = M/Items range (1-5).

No differences were found in global FQoL regarding the severity of IDD reported by the family. Differences between groups were only found in satisfaction with parenting ($F(2.57) = 3.31$; $p = 0.044$; $d = 0.85$), satisfaction being much higher when disability is mild ($M = 22.9$) than when it is severe ($M = 18.4$).

Adoptive or foster families of children with DS showed higher levels of FQoL than those of children with other diagnoses (Table 2). These families showed moderately higher satisfaction with their family interaction ($p = 0.008$) or their parenting ($p = 0.05$), and slightly higher satisfaction in terms of disability supports ($p = 0.03$). No differences were found in the rest of the scales. Among those adopted with DS, the majority were special placements (93.8%); in the rest of families, the majority were ordinary placements (78.3%). The differences in the distribution are significant ($\chi^2(1) = 25.581$; $p < 0.001$).

The level of child support needs does not have a significant relationship with the global FQoL. However, parenting satisfaction decreases as the child's needs increase (Table 3). Parenting satisfaction also decreases as support needs at home, in health care, in self-care, or in mental health increase. Self-direction needs are slightly and positively related to satisfaction with family interaction. On the other hand, mental health and self-care needs are associated with a slight decrease in health and safety well-being; mental health needs are also associated with the decline in satisfaction with disability supports. Finally, FQoL is slightly negatively related to self-care, self-direction, and mental health needs.

The child's mental health problems appear to be a predictor variable, explaining 11.4% of the total quality of life ($R^2 = 0.114$, $F(1,58) = 7.448$, $p = 0.008$). Increased support needs due to the child's mental health problems predict a decrease in FQoL ($\beta = -0.337$, $t = -2.729$, $p = 0.008$).

	NOT DS (N = 45)		DS (N = 15)		T/U	DF	P	D/R
	M	SD	M	SD				
Family interaction	22.2	5.0	26.1	3.1	492.5	—	0.008	0.34
Parenting	20.5	5.3	23.5	4.5	-2.00	60	0.050	0.60
Health and safety	12.9	3.2	14.3	2.6	-1.52	60	0.133	0.47
Disability supports	14.0	3.5	16.1	2.5	-2.22	59	0.030	0.69
Family resources	19.8	3.3	21.3	3.2	463	--	0.089	—
Total FQoL	89.3	17.4	101.0	11.8	-2.43	58	0.018	0.79

	SN	COM	RES	ACS	HOM	HANDS	OCI	SC	SD	SR	MH
Family interaction	0.01	-0.06	0.09	0.05	0.02	-0.12	0.02	-0.13	0.33**	0.02	-0.16
Parenting	-0.31*	-0.24	—	-0.14	-0.30*	-0.31*	-0.18	-0.37**	0.18	-0.08	-0.42**
Health and safety	-0.21	-0.12	0.04	-0.08	-0.19	-0.22	-0.17	-0.26*	0.23	-0.02	-0.32*
Disability supports	-0.13	-0.21	0.04	-0.10	-0.12	-0.20	-0.14	-0.15	0.20	-0.05	-0.32*
Family resources	—	-0.08	0.06	—	0.04	-0.12	-0.04	—	0.17	0.08	-0.12
Total FQoL	-0.17	-0.17	0.04	-0.08	-0.13	-0.24	-0.11	-0.27*	0.27*	-0.03	-0.32*

We found differences between special and ordinary placements in FQoL. Families who underwent special procedures show greater satisfaction with family interaction, parenting, health and safety, disability supports, and the total score compared to families in ordinary procedures (Table 4). No differences were found in family resources.

	ORDINARY (N = 37)		SPECIAL (N = 25)		T/U	DF	P	D/R
	M	SD	M	SD				
Family interaction	21.8	5.2	25.2	3.6	597.0	—	0.009	0.34
Parenting	20.0	5.3	23.2	4.4	-2.50	60	0.015	0.66
Health and safety	12.5	3.3	14.4	2.4	-2.51	60	0.015	0.67
Disability supports	13.6	3.7	16.0	2.3	-2.82	59	0.007	0.77
Family resources	19.8	3.6	20.8	2.8	502.5	—	0.384	—
Total FQoL	87.7	18.0	99.4	12.1	-2.74	58	0.008	0.76

There are no differences in FQoL between adoption and foster care placements ($t(58) = 1.004$; $p = 0.319$), nor between national and international placements ($t(58) = 0.832$; $p = 0.409$). There is no significant relationship between the FQoL at the time of the study and the child's age at placement ($r = -0.182$; $p = 0.164$).

Table 2 Differences in FQoL depending on the IDD diagnosis (not DS/DS).

Note: T Student has been used for parenting, health and safety, disability supports, and total FQoL scales, while the Mann-Whitney U test has been used with family interaction, parenting, and family resources scales.

Table 3 Correlations between FQoL and person with IDD support needs.

Note: SN = support needs (Total); COM = communication; RES = use of resources; ACS = academic skills; HOM = home life; HANDS = health and safety; LEI = leisure; SC = self-care; SD = self-direction; SR = social relationships; MH = mental health. * $p < 0.05$; ** $p < 0.01$.

Table 4 Differences in FQoL depending on the type of placement (ordinary vs. special).

Note: T Student has been used for parenting, health and safety, disability supports, and total FQoL scales, while Mann-Whitney U test has been used with family interaction, parenting, and family resources scales.

DISCUSSION

On average, foster and adoptive families of people with IDD in our sample show medium-high levels of FQoL, not as high as those expected by adoption studies (Glidden & Cahill 1998; Glidden 2000). Nevertheless, there is an important dispersion, suggesting a majority of strongly satisfied families and a significant group of dissatisfied families. Family resources are an expected strength, as these families have been positively assessed in this domain to be considered eligible for adoption. The lowest scores are found in health and safety, showing some weakness in parents' ability to manage stress. Satisfaction with parenting and disability support have intermediate scores. Unfortunately, we do not have baseline scores to compare our families with the families of children with IDD in our context. Future research may delve into this question using graded scales or control groups.

Regarding disability characteristics, no relationship is found between the severity of the disability reported by the family and the overall FQoL. This variable is only related to satisfaction with parenting. Those who report a mild disability in their children have higher satisfaction with parenting than those with a severe one. Facing more significant and complex needs makes it more challenging to feel successful in fully covering all parenting tasks (Miller et al. 2021).

Regarding diagnosis, families whose children have DS show much higher satisfaction levels in their family interaction, moderately higher in parenting, and slightly higher in support for the member with a disability. There is no difference in family resources. These results may reflect the 'DS advantage' phenomenon for foster and adoptive families (Rosenthal & Groze 1992; Berástegui & Corral 2020). The greater social and professional knowledge of DS makes it easier to anticipate tasks and find services and support. However, it is important to interpret these data carefully because these are usually special placements and therefore, voluntarily chosen. Moreover, the significant heterogeneity of the diagnosis prevents nuances beyond comparing DS/no-DS.

The level of children's support needs is not related to FQoL, but is associated with a decrease in its parenting dimension. This decreases as support needs increase in day-to-day or physical and mental health care. Families seem more satisfied with their interaction when their children have more significant self-direction needs, which could be contrary to expectations. Perhaps, the as the family interaction times grows the lower their child's independence is. Therefore, this dimension suffers less decline in the transition to adulthood than in more autonomous children.

The increase in mental health needs is related to a reduction in most dimensions of the FQoL and is the only dimension with predictive power over global FQoL. The literature on special adoptions has repeatedly indicated that the presence of behavioral and mental health problems has a more negative impact on family adjustment than IDD itself (Miller et al. 2021; Rosenthal, Groze & Durán 1991). The intersection between the childcare system, disability, and mental health is a relevant concern that needs greater attention from research and professional interest.

Finally, contrary to expectations, no differences were found in FQoL depending on the life stage. Neither is adolescence shown as a period of particular tension, as considered by the study by Turnbull et al. (2015); nor does the transition to adult life during young adulthood seem to show a differential impact on FQoL, as shown by the results of previous research (Boehm, Carter & Lounds 2015; Leonard et al. 2016; Glidden 2000). Each life stage and its transitions, even with its challenges and characteristics, may result in comparable FQoL if the family positively copes with them. Alternatively, instruments may not be sensitive to developmental differences.

Regarding the relationship between FQoL and placement variables, no differences were found between adoptions and foster care or between domestic or international placements, in contrast to those found in families of children without IDD (Levy-Shiff, Zoran & Shulman 1997; Juffer & Van Ijzendoorn 2005). Similarly, our study draws attention to the lack of relationship between the age of placement and FQoL. The placement age has been consistently related to the child and family outcomes in foster care and adoption in association with previous adversity or the developmental challenges at placement (Palacios & Brodzinsky 2010). The lack of impact of these placement variables could reflect the main effect of IDD in shaping family life or the overshadowing of adoption and fostering challenges by disability issues (Berástegui 2012).

However, as anticipated, we found differences between ordinary or special placements. Families in special adoptions or foster care showed higher satisfaction with their family interaction, their parenting, their health and safety, their disability supports, and their overall FQoL. This factor has previously demonstrated its impact on family adjustment and stability of placement in adoption research (Asbury, Cross & Waggenspack 2003; Coyne & Brown 1985; Rosenthal 1993). This result highlights the importance of conscious and meaningful choice, adjusted expectations, preparation, anticipation of needs and resources, and a transition to parenthood free of grief and uncertainty (Perry & Henry 2009). Adoptive and foster families only show advantages over biological in special placements and therefore, voluntarily chosen ones.

Special placements are associated with better family interaction, self-efficacy in parenting, the ability to find time and support to cope with difficulties, and even the ability to mobilize specific resources on disability. We found no differences between special and ordinary placements in family resources because, as mentioned above, all families have been evaluated previously for suitability. Future research should incorporate control groups to explore the equivalence between ordinary placements and the biological parenthood of children with IDD (Glidden & Cahill 1998; Glidden 2000), and whether the unique challenges of adoption interact with or complicate coping with IDD (Berástegui 2012; Forbes & Dziwgielewski 2003). This research is a specific Spanish study on this topic, which may be interesting considering the differences that social and cultural context can make in the configuration of family relationships in foster and adoptive families, as well as in families with IDD (Van Riper et al. 2020; Verdugo et al. 2005).

This study has some limitations that should qualify the scope of the results. Firstly, the sample size is limited, and data collection is cross-sectional, which is a common problem in this research field (Glidden 2000). Moreover, the study only includes one parent's perspective, usually the mother's. Although mothers remain the primary caregivers of the family member with IDD in most cases (Córdoba-Andrade, Gómez-Benito & Verdugo 2008), it would be interesting to complement their vision with other family members' perspectives, as has been proposed in adoption research (Rosnati, Ranieri & Barni 2013). Moreover, incorporating the person with IDD as an informant is also increasingly important in disability research (Berástegui, Santos & Suárez 2021; Bigby, Frawley & Ramcharan 2014). Future research would benefit from considering a broader range of informants, including children with IDD, siblings and fathers, as well as a longitudinal follow-up of a cohort of placements across the lifespan. It would also be valuable to increase sample sizes to enable causal inferences to be tested more precisely.

CONCLUSION

This study contributes to the scarce updated knowledge of families with adopted or fostered children with IDD by providing evidence of their FQoL and related factors. To summarize, foster and adoptive families of children with IDD show good average levels of FQoL, especially those adopting children with IDD after special placements. The complexity of children's support needs impacts FQoL and partially explains the significant intragroup variability. Acknowledging the family impact of these placements is a valuable contribution, since more and more of these children are involved in foster care and adoption processes, and fostered and adopted children, adolescents, and young people are more present in the support and services for people with IDD.

IMPLICATIONS

Professionals need a greater understanding of these children's and their families' characteristics and support needs. The better outcomes of families in special placements suggest that accurate pre-placement expectations, information, and training may be key processes to enhance FQoL (Perry & Henry 2009). In addition, the attention and support of families when a disability is identified after placement are essential for family well-being.

Moreover, it is essential to include IDD as a factor in adoption studies, as well as adoption in disability studies, to improve the practice and policies that guarantee the rights of children with IDD to find a family and to support these families throughout life.


This study has been approved by the Comillas Pontifical University Ethics Committee, with reference number 2021/78, dated July 19, 2021.


COMPETING INTERESTS

The authors have no competing interests to declare.

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TO CITE THIS ARTICLE:

García-Sanjuán, Noemí, Ana Berástegui and Rosalía Mota. 2023. "Family Quality of Life in Foster and Adoptive Families of People with IDD." *Scandinavian Journal of Disability Research* 25(1):378–390. DOI: <https://doi.org/10.16993/sjdr.975>

Submitted: 06 October 2022

Accepted: 26 October 2023

Published: 27 November 2023

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Scandinavian Journal of Disability Research is a peer-reviewed open access journal published by Stockholm University Press.

