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Quality of life of siblings of people with intellectual and developmental disabilities

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DOCTORAL THESIS

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Presented by	Olga Muries Cantán
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Directed by	Dr Climent Giné, Dr. Geert van Hove and Dr Alice P. Schippers

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If not to hunger for the meaning of it all
Then tell me what a soul is for?
Why have the wings unless you're meant to fly?
And tell me please, why have a mind
If not to question why?

Yentl (1983)

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Francisco, C., & Múries-Cantán, O. (2022). Are family routines a dynamic concept? Disability Studies in Nederland.

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Abstract

In recent years, interest for siblings of people with intellectual and developmental disabilities (IDD) has increased. Scholars from different backgrounds have investigated the particular experiences of siblings of all ages. However, less is known about their quality of life perceptions as siblings. The aim of this doctoral thesis is to explore siblings' quality of life perceptions from their own voice and through a family quality of life lens. A systematic review of the literature was performed to find relevant information about quality of life perceptions of siblings of people with IDD in the context of a family. It highlighted the lack of research from non-English speaking countries and research with younger siblings. Consequently, interviews and discussion groups with young siblings (5-11 years old) living in Catalonia (northeast Spain) were conducted to explore their perceptions of quality of life as siblings and the influence of family dynamics and parental performances on their quality of life. Despite the cultural, religious and linguistic characteristics of Catalonia, findings were in line with those of similar research; revealed the particularities of the experience of having a brother or a sister with IDD and the singular effect external influences might have on siblings' perceptions of quality of life. Additionally, results have shown siblings mature giving rise to critical views regarding their families. It is important then to listen to siblings of all ages and to spread awareness around the necessity that researchers, practitioners and policymakers consider siblings' views and perceptions, in order to provide siblings and their families with better services and support.

Keywords: siblings; siblings quality of life; family quality of life; intellectual disability; developmental disability; family

Resum

En els darrers anys, l'interès pels germans i les germanes de persones amb discapacitat intel·lectual i del desenvolupament (DID) ha augmentat considerablement. Però, si bé els acadèmics han investigat les experiències particulars de germans i germanes de totes les edats des de diferents constructes teòrics, encara és escassa la informació disponible pel que fa a la percepció de la qualitat de vida que tenen com a germans/es. L'objectiu d'aquesta tesi doctoral és, precisament, explorar la percepció de qualitat de vida dels germans/es escoltant la seva pròpia veu i des de la perspectiva de la qualitat de vida familiar. A tal efecte, s'ha dut a terme una revisió sistemàtica de la literatura existent per tal d'obtenir informació rellevant sobre la percepció de la qualitat de vida dels germans i les germanes de les persones amb DID en el context d'una família. Els resultats han posat de manifest la manca d'investigació en països no angloparlants i amb germans/es més petits. En conseqüència, s'ha procedit a realitzar entrevistes i grups de discussió amb germans joves (5-11 anys) residents a Catalunya (nord-est d'Espanya), per tal d'explorar la seva percepció de la qualitat de vida com a germans/es, així com les possibles influències de les dinàmiques familiars i parentals en la seva qualitat de vida. Malgrat les característiques culturals, religioses i lingüístiques de Catalunya, els resultats han confirmat el que s'ha trobat en investigacions similars: han revelat les particularitats de l'experiència de tenir un germà o una germana amb DID i l'efecte singular que les influències externes poden tenir en la percepció de la qualitat de vida dels germans/es. A més, els resultats han permès, també, recollir les perspectives crítiques i madures dels germans/es respecte les seves famílies. Esdevé, doncs, un aspecte de gran importància escoltar germans i germanes de totes les edats i sensibilitzar sobre la necessitat que els investigadors, professionals i responsables polítics tinguin en compte les seves opinions i percepcions, per tal de proporcionar als germans/es, i a les seves famílies, els millors serveis i suports.

Paraules clau: germans; qualitat de vida dels germans; qualitat de vida familiar; discapacitat intel·lectual; discapacitat del desenvolupament; família

Resumen

En los últimos años, el interés por los hermanos y las hermanas de personas con discapacidad intelectual y del desarrollo (DID) ha aumentado considerablemente. Aún así, a pesar de que los académicos han investigado las experiencias particulares de hermanos y hermanas de todas las edades desde distintos constructos teóricos, todavía es escasa la información disponible relativa a la percepción de calidad de vida que tienen como hermanos/as. El objetivo de esta tesis doctoral es, precisamente, explorar la percepción de calidad de vida de los hermanos/as escuchando su propia voz y desde la perspectiva de la calidad de vida familiar. Para ello, se ha realizado una revisión sistemática de la literatura existente para obtener información relevante sobre la percepción de calidad de vida de los hermanos y hermanas de las personas con DID en el contexto de una familia. Los resultados han puesto de manifiesto la falta de investigación en países no anglófonos y con hermanos/as más pequeños. En consecuencia, se han llevado a cabo entrevistas y grupos de discusión con hermanos jóvenes (5-11 años) residentes en Cataluña (noreste de España), con el fin de explorar su percepción de la calidad de vida como hermanos/as, así como las posibles influencias de las dinámicas familiares y parentales en su calidad de vida. Pese a las características culturales, religiosas y lingüísticas de Cataluña, los resultados han confirmado los hallados en investigaciones similares: han revelado las particularidades de la experiencia de tener un hermano o hermana con DID y el efecto singular que las influencias externas pueden tener en la percepción de la calidad de vida de los hermanos/as. Además, los resultados han permitido, también, recoger las perspectivas críticas y maduras de los hermanos/as con respecto a sus familias. Es, pues, un aspecto de gran importancia, escuchar a hermanos y hermanas de todas las edades y sensibilizar sobre la necesidad de que los investigadores, profesionales y responsables políticos tengan en cuenta sus opiniones y percepciones, para proveer a los hermanos/as y a sus familias, de los mejores servicios y apoyos.

Palabras clave: hermanos; calidad de vida de los hermanos; calidad de vida familiar; discapacidad intelectual; discapacidad del desarrollo; familia

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CHAPTER 1. Introduction

1.1 Overview of the thesis

The aim of this doctoral thesis is to explore siblings' quality of life perceptions from their own voice. Despite the important role siblings have on family life and on their brothers or sisters with intellectual and developmental disabilities (IDD)' life, their needs and voices have been often overlooked by parents, researchers and practitioners in the disability field. By exploring siblings' quality of life perceptions, this research highlights their needs and subsequently provides them with supports and resources. If siblings are given the right opportunities, information and support from the onset and throughout their whole life, their needs will be met and their quality of life improved.

To understand siblings and their perceptions, it is important to start with their family context. Siblings become siblings inside a family. Poston et al. (2003) defined family as following: "a family includes 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" (p. 319). However, in today's society, when there is widespread acceptance of a wide range of family kinds and structures, it is extremely challenging to define a family. Rillotta et al. (2011) proposed that a family is constituted by "people who are closely involved in the day-to-day affairs of the household and support each other on a regular basis; whether related by blood, marriage or by close personal relationship" (as cited in Samuel et al., 2011, p.2).

Families are constituted by relational factors and interactive dynamics that affect the well-being and development of their members. Due to its dynamic nature, any situation regarding one of the family members has the potential to affect the other members and, eventually, the whole system (Zuna et al., 2010). Zuna et al. (2010) defined Family Quality of Life (FQOL) as a "dynamic sense of well-being of the family, collectively and subjectively defined and informed by its members, in which individual and family-level needs interact" (p. 262).

From this perspective, siblings have their own perceptions on FQOL and are capable to report it as any other family member (Rillotta et al., 2012). However, to understand siblings' perspective on FQOL, it is pertinent to explore first their quality of life perceptions as being siblings.

Research has shown that individuals' quality of life and FQOL convey and interact in a continuous manner influencing each other, making it difficult to separate the reported quality of life of a single member from the general overview of FQOL (Boelsma et al., 2017). Recently, researchers have shown an increased interest on siblings and their quality of life' perceptions. However, in Catalan and Spanish' contexts, still far too little attention has been paid to siblings. Specifically, perceptions from siblings on their developmental stage (up to 21 years old) have not been properly explored.

As the main objective of this thesis is to have more in depth knowledge about siblings' quality of life perceptions, the following section provides the steps that had been done towards this goal.

1.1.1 Chapters of the Thesis

1.1.1.1 Chapter 1

First of all, there is an overview introducing the general structure and the personal reasons for conducting the research. Then, the theoretical framework that guided the whole research project is presented, highlighting the main concepts and keywords, such as family quality of life and siblings' quality of life. Furthermore, a brief explanation of the selected methodology for conducting the research reported in Chapters 2, 3 and 4 is included. Finally, the objectives that have guided the doctoral thesis are presented.

1.1.1.2 Chapter 2

The second chapter displays a systematic review of the literature based on the format of the published paper: *Siblings of people with intellectual and developmental disabilities: A systematic review on their quality of life perceptions in the context of a family* (Múries-Cantán et al., 2022). Literature published between 2003 and 2021 was critically reviewed to find relevant information about the quality of life of siblings of people with intellectual and developmental disabilities. Findings showed the richness of siblings' perceptions and experiences and highlighted their major needs, desires and concerns. Additionally, results indicated a gap in the literature referring to young siblings, as their voices were still scarcely collected. Suggestions for siblings' support and future research were given, such as the necessity to conduct research on siblings from different cultural backgrounds.

1.1.1.3 Chapter 3

The main findings of the literature review have guided the research presented in Chapter 3: *Siblings of children with intellectual and developmental disabilities: Quality of life perceptions from Catalonia* (Múries-Cantán et al., 2023). Due to the lack of papers focused on data from young siblings and from different cultural backgrounds, a group of children from 5 to 11 years old from Catalonia, an autonomous region in northeast Spain, was selected to participate in qualitative research. The main goal was to explore siblings' perceptions on their quality of life as siblings. Results presented following the nine domains of siblings' quality of life by Moyson & Roeyers (2012), showed the variability of siblings' perceptions and indicated a need to better understand siblings' experiences and to explore the influence of family dynamics on siblings' relationships.

1.1.1.4 Chapter 4

Chapter 4 introduces the paper *Is the quality of life of siblings of people with intellectual and developmental disabilities influenced by family dynamics and parental performances? Initial explorative study from young siblings' perspectives* (submitted). This research explores the influence of family dynamics and parental performances on siblings' quality of life perceptions and how this has affected their well-being and their relationship with brothers and sisters with IDD. A total of 6 eleven-year-old siblings, took part in two discussion groups. Collected data was thematically analyzed. The article has shown the relevance of family dynamics on siblings' relationships and on the views siblings hold regarding their families. More research on siblings' quality of life is required, together with the development of creative ways to keep collecting data from children and adolescent' siblings.

1.1.1.5 Chapter 5

This final chapter contains a general discussion of the main findings of the doctoral research. Some of the theoretical, methodological and practical contributions of the research are highlighted, followed by the strengths and limitations of the research. Lines for future work are suggested. Finally, conclusions and some final remarks about the research process are included, together with the list of consulted references.

1.1.2 Personal reasons for conducting this research

I would like to include here my personal reasons for exploring the theme of my thesis. Through my professional work as a psychologist and educator in different organizations that support people with disabilities and their families, I was able to come into contact with these families. I had the chance to work with the families not only in their natural environment, the family home, but also within the children's everyday schools and the recreational settings where they spend their leisure time. This professional experience allowed me to observe them in different circumstances and attitudes and to appreciate the needs and shortcomings within their functioning and environment, as well as their strengths. Altogether, it was an up-close experience with the various individuals that make up the family structure.

Thanks to this proximity, my conversations with parents were frequent and often emotionally at the same time. Parents expressed, positively and negatively, their judgements, feelings, and anxieties related to their specific situations. Remarkably, however, I had only very few opportunities to interact with the siblings. By way of accounts and some home visits, I became interested in the various attitudes from siblings, not only toward their brother or sister with a disability, but also toward their parents and myself. For instance, I detected how the youngest children were usually the ones who modified their behavior, trying to attract an attention mainly directed at the child with disabilities. Older children, the adolescents, seemed to maintain a more detached attitude, though on occasion they were also self-interested, which may have been more a result of my involvement than their siblings with disabilities. These experiences draw some similarities with various studies on the subject (Cuskelly & Gunn, 2003; Hannah & Midlarsky, 2005; Hodapp, et al., 2010).

These experiences lead me to understand how important it could be to conduct research on the quality of life of siblings of persons with IDD. Having in mind the potentialities of all members involved in the family dynamic, I would like to focus on the subsystem of siblings, their strengths and the importance of the siblings' relationship. To this end, together with my supervisors and their research groups, we have developed the present research, that was funded by the Blanquerna Research Grant (see Appendix A).

1.2. Theoretical Framework

1.2.1 Family Quality of Life

As mentioned earlier, the research followed a family quality of life approach. Research on siblings of people with IDD has been mainly descriptive and atheoretical, what ended up having a scene of unconnected information about siblings and their reality (Saxena & Adamsons, 2013). In addition, the family quality of life approach has relied mainly on mothers as main caregivers when exploring the FQOL of a certain family. This meant that, although the FQOL concept refers to a group of people -since a family consists of two or more individuals- have been mainly mothers the ones to report on the quality of life of their family. Consequently, it was clear from the onset that exploring siblings' quality of life was going beyond individual quality of life: This doctoral research explores the siblings' perspectives in the context of a family.

1.2.1.1 Origin and definition of the Family Quality of Life concept

To explain the family quality of life approach that informs this research, it is mandatory to refer first to the quality of life concept. Over the last few decades, the concept of quality of life has become a guiding principle for people with IDD related to a fulfilling, dignified life in which their needs and wishes are respected. The concept has been extended to the family system of these individuals, thanks to the contributions of researchers such as A. Turnbull, R. Brown, I. Brown and R. Schalock (Brown & Brown, 2003; Turnbull et al., 2004; Brown, et al., 2009). Together with other authors, their contributions helped to learn how families understand quality of life, to design measurement tools and strategies for better outcomes.

We would trace the origin of the international interest in FQOL back to the year 2000 with the creation of the SIRG-QOL (Special Interest Research Group) on Quality of Life within the International Association for the Scientific Study of Intellectual and Developmental Disabilities (IASSIDD). Inside the SIRG-QOL there are two sub-groups: person-centered quality of life and family-centered quality of life. Since then, there has been a growing interest in attending to the situations of families and siblings and to conduct research about their specific needs and experiences related to their family quality of life.

The subsystem of siblings constitutes one of the central components of family life, being an important element to consider when exploring quality of life, both globally and on a more specific fraternal level. However, there is little research that has been done on siblings of people with IDD from the perspective of FQOL.

Working with, attending to, or conducting research on families of persons with IDD from a perspective of FQOL means doing so while appreciating and recognizing the perceived needs and general well-being of the entire family and of all its members, in relation to their life situation and cultural context. For Brown and Brown (2014) "family quality of life is concerned with the degree to which individuals experience their own quality of life within the family context, as well as with how the family as a whole has opportunities to pursue its important possibilities and achieve its goals in the community and the society of which it is a part" (p.2195).

Authors like Turnbull et al. (2004) and Zuna et al. (2010) also consider FQOL a social dynamic construct made up of the interaction between the family members, defined in a subjective way by all of them on an individual and collective level. Accordingly, FQOL is a construct which has to do with the entire family as an entity and that is particular to each family. It is constructed nurturing the family specific characteristics, strengths and resources and evolves along with the circumstances.

The FQOL approach has an ecological and systemic foundation (Bronfenbrenner, 1987; 1998). From this perspective, what happens within a family affects all of its members. This may lead to two thoughts. First, the presence of a disability might affect the way in which family members perceive their quality of life. It is therefore necessary to give voice to all those individuals who form a part of the family unit (or those who consider themselves a part of the family despite not living in the same household) in an adapted way considering their ages and needs, to assure an intervention that truly supports and attends everyone (Schippers et al., 2015). Consequently, regarding siblings, there is no one better suited to report on their perception of quality of life as siblings than the siblings themselves. Research has shown that when adequate channels of communication can be guaranteed, youngest siblings can also express their ideas on FQOL (Bitsika et al., 2015; Luijkx, et al., 2016; Moyson & Roeyers, 2012) rather than having to do so through their parents who often provide a vision which is biased toward their own experiences (Gaal et al., 2010; Neece, et al., 2010).

Second, the enhancement of quality of life of siblings also indirectly improves that of the rest of the family (Kryzak et al. 2014; Luijkx, et al., 2016). All of this provides us with a holistic point of view to understand the work with families, in which the needs of each person and their interactions within the family context are considered, as well as those who care for and sustain the environment in which they live. From this point of view, all individual intervention is conceived considering the possible collateral effects it can have on the rest of the system. Then, it is pertinent to research specifically the characteristics or elements of siblings' quality of life perceptions.

1.2.1.2 Measuring Family Quality of Life

Nowadays, there are two main tools developed to assess FQOL: the Family Quality of Life Survey (Brown et al., 2006) and the Beach Center Family Quality of Life Scale (Hoffman et al., 2006). The latter has been validated in the Spanish context (Giné et al., 2013; Verdugo, et al., 2005). The use of scales to assess FQOL up to now has mainly gathered the opinions of parents (mostly mothers) and, in some cases, those of siblings (Balcells et al., 2011; Roth & Brown, 2016). Table 1 shows the domains of FQOL from the two main scales.

TABLE 1. FQOL domains from the FQOL Survey and the Beach Center FQOL Scale

FQOL Survey. Brown et al. (2006).	Beach Center FQOL. Hoffman et al. (2006)
Health of the family	Physical/material well-being
Financial well-being	Family Interaction
Family relationships	Parenting
Support from other people	Emotional well-being
Support from disability related services	Disability related supports
Influence of values	
Careers and preparing for careers	
Leisure and recreation	
Community interaction	

Due to the lack of a theoretical or empirical background regarding siblings' quality of life, some of these FQOL domains were selected based on its relationship with siblings' well-being and emotional experiences to guide our literature review and getting an appropriate state of the art. As it is stated in Chapter 2, these domains were: Family interaction/Family relationships, Emotional well-being, Support from other people/from disability related services, Influence of values, Leisure and recreation and Community interaction.

1.2.2 Siblings' quality of life

Different authors agreed that perceptions of quality of life differ between siblings and their parents (Kryzak et al. 2014; Moyson & Roeyers, 2012; Shivers & Dykens, 2017). Siblings have their own needs and desires which need to be known and considered for a full understanding of their behavior and to carry out specific interventions addressed to them. In the present research, siblings' quality of life perceptions from childhood to adulthood were collected (Chapter 2) and studied (Chapter 3 and 4) from a broader perspective to embrace the diversity of reported experiences.

Some characteristics of siblings' quality of life were often mentioned in the literature. First, the experience of having a brother or sister with IDD is commonly described as being ambivalent, with the co-occurrence of positive and negative moments in siblings' lives (Corsano, et al., 2016; Dansby, et al., 2018). Second, articles with adolescent and adult siblings frequently noted the changing nature of the sibling relationship and of the familiar reality over the years, something seen in the FQOL' framework (Petalas, et al., 2012; Rawson, 2010; Rossetti & Hall, 2015). Finally, the normalcy-exceptionality pair is frequently related to siblings when expressing their desire of normalcy simultaneously with their pride for having an "exceptional" brother or sister who made them better human beings (Bachraz & Grace, 2009; Cridland, et al., 2016; Flaton, 2006).

1.2.2.1 Quality of life during the life cycle

Previous research had shown that throughout their life, siblings of people with IDD report different experiences and feelings regarding having a brother or a sister with a disability. Feelings of love and care are usually reported by siblings along their life, while some feelings are most reported in relation with specific age groups. For instance, during the adolescence, a period where peer reactions and opinions have a strong influence, siblings could be worried about their peer reactions to their siblings with IDD (Corsano et al, 2016). In the following section, some of these specific experiences will be highlighted in relation to childhood, adolescence and adulthood. Transitional periods were also included due to their relevance as peak moments on siblings' life, where new challenges and opportunities may appear.

1.2.2.1.1 Childhood

Due to the nature of disability, it is usually during childhood when siblings realize their brother or sister might be different in certain ways. Current literature highlighted siblings' acceptance of their brothers or sisters as the way they are and their willingness to be related with them during their life (Pavlopoulou & Dimitriou, 2019).

Authors agreed that childhood is a crucial age for the establishment of healthy bonds between siblings. Brothers and sisters will benefit from information related to their sibling' disability and with specific support to guarantee their well-being (D'Arcy et al., 2005; Iriarte & Ibarrola- García, 2010). Research shows that younger siblings could perceive the responsibilities their parents tend to put on them as a burden or perform role reversal as a result of having to take care of their older brother or sister (Benderix & Sivberg, 2007; Gaal et al., 2010). Further, early understanding and interventions are critical for sibling's accommodation and future relationships (Luijkx et al., 2016; Petalas et al., 2012; Tozer & Atkin, 2015).

1.2.2.1.2 Adolescence

Similar to youngest siblings, adolescent siblings experience a rich variability of feelings due to having a brother or a sister with a disability. For instance, Petalas et al. (2012) reported how adolescent siblings considered funny being able to share moments and activities with their brothers or sisters with a disability. In the study by Diener et al. (2015) sisters perceived their relationships with their brothers with autism as positive and negative like any other sibling' relationship, with both moments of joy and conflict.

Adolescent siblings expressed different experiences regarding available support for having a sibling with IDD. Petalas et al. (2009) noted that siblings refer to supportive affect such as being able to ask for support to reliable friends and family members. Others, indicate the value of professional support from psychologists and other therapists (Dansby et al., 2018; Davys et al., 2016; McGraw & Walker, 2007; Tozer et al., 2013).

Data from several studies suggests that adolescent siblings have embarrassing feelings in front of their peers because of their brothers or sisters' behavior or because of the stigma associated with disability (Hastings & Petalas, 2014; Pollard et al., 2012; Skotko, et al., 2011). There are differences also in the way adolescent and adult siblings cope with their particular reality. Adolescent siblings used more emotion- focused strategies than adults and rely more on their parents and friends (Orsmond et al., 2009). Compared with children, adolescents report on higher personal and social growth (Findler & Vardi, 2009), have a more developed sense of empathy and can reconsider their brother or sister's difficulties with reflective thinking (Petalas et al., 2012). Further, adolescent siblings are able to recognize their parents' efforts to take care of both their siblings and themselves (Benderix & Sivberg, 2007; McGraw & Walker, 2007; Noonan et al., 2018; Pavlopoulou & Dimitriou, 2019).

1.2.2.1.3 Adulthood

Siblings tend to have warm and close adult relationships if they have had a good relationship during childhood (Cuskelly, 2016). However, authors referred to nonreciprocal emotional support between siblings with and without IDD, different levels of given support and difficulties to be involved in the same shared activities (Burbridge & Minnes, 2014).

Adult siblings reported caregiving as one of the main reasons of frustration and stress, especially when parents aged (Gaal et al., 2010; Rossetti & Hall, 2015). However, other siblings expressed their will to provide care to their brothers or sisters with IDD and their strong connections and feelings of joy in these relationships (Cuskelly, 2016; Rossetti & Hall, 2015). These siblings used to live closer and to have more contact with their brothers or sisters with IDD than ordinary siblings do (Doody et al., 2010; Skotko et al., 2011).

Usually, adult siblings will be the main caregivers when their parents could not take care of the person with IDD. Therefore, some authors reiterate the importance to know more about the characteristics of this kind of sibling relationships and about the changes on siblings' support needs along the lifespan (Hodapp & Urbano, 2007; Rossetti & Hall, 2015). Siblings have during adulthood different concerns about their brothers or sisters with IDD and they develop diverse ways to solve their eventual difficulties related with their sibling's disability (Petalas et al., 2012).

1.2.2.1.4 Transitional periods

Finally, regarding transitional periods, existing literature recognizes a general reduction of conflict between siblings and a positive growth during the transition from adolescence to adulthood (Floyd et al., 2016). Siblings' relationships decreased with the independence of the brother or sister with no disability and are recovered during middle adulthood (Gaal et al., 2010). Decreased contact between siblings does not mean poorer or negative relationships, it seems that they can maintain the same positive affect as during adolescence (Orsmond et al., 2009). Even so, feelings of guilt could appear on those periods (Rossetti & Hall, 2015). For instance, different authors noted that siblings could felt guilty when moving from the family home due to the established dynamics of support but also a sort of relief on account of some needed distance from their families and related responsibilities (Boelsma et al., 2017; Cridland et al., 2016 & Rossetti & Hall, 2015).

Some studies focused on adult siblings suggest as a way of increasing siblings' relationships, the provision of support to facilitate interactions in adult services, especially when siblings with no IDD have moved from the family home (Hodapp & Urbano, 2007). Others propose to influence on siblings' adapting skills to improve those relationships (Orsmond & Seltzer, 2007). Findings suggest that siblings represent an important part of family support because of their continued bond over the years (Floyd et al., 2016). It is then crucial to take siblings into consideration during decision-making processes and family- counselling sessions besides to give them information about possible challenging developmental issues related with specific disabilities (Gaal et al., 2010; Heller & Kramer, 2009; Orsmond et al., 2009; Rana & Mishra, 2015; Rossetti & Hall, 2015). Some authors recommend leisure actions like organizing special events for both siblings inside IDD services and institutions in order to involve all the family and to bolster relationships between centers and siblings (Burbridge & Minnes, 2014; Shivers & Dykens, 2017).

1.2.2.2 Nine domains of siblings' quality of life: The inspiring research by Moyson and Roeyers (2012)

A decade ago, Moyson and Roeyers published an article entitled: 'The overall quality of my life as a sibling is all right, but of course, it could always be better'. Quality of life of siblings of children with intellectual disability: the siblings' perspectives (2012). In this article, the authors explored siblings' perspectives on their quality of life perceptions. Their main goal was to examine how young siblings (from 6 to 14 years old) of children with intellectual disability define their quality of life as siblings. It was innovative research due to the selected theoretical framework and focus of interest. It ended up with nine domains to describe siblings' quality of life (see Table 2).

TABLE 2. Nine domains of sibling quality of life (Moyson & Roeyers, 2012)

1. Joint activities
2. Mutual understanding
3. Private time
4. Acceptance
5. Forbearance
6. Trust in well-being
7. Exchanging experiences
8. Social support
9. Dealing with the outside world

The authors were conducting the research from the quality of life/family quality of life framework, suggesting that siblings' quality of life may not be overlooked inside the general concept of family quality of life. For that reason, the authors were clear about the pertinence of interviewing directly the main subjects of their research: the siblings. Until then, research displayed a general tendency to collect data about siblings from parents or other proxies; retrieving information that might be different if asked directly to siblings.

This article encouraged the design and conduction of the research presented in Chapters 3 and 4. In particular, the research was nurtured by the authors theoretical discussion and some of the methodological issues they highlighted, such as interviewing the siblings on familiar environments after developing a trustful bond with them. The topic guides for the interviews and discussion groups were inspired by their interview topics. However, the followed methodological approach was different than theirs. These authors have followed the principles of grounded theory, while the research' collected data was thematically analyzed. Findings in Chapter 3 are presented following these nine siblings' quality of life domains.

The theoretical framework and the topic guide of the research were discussed with Dr. Moyson. She suggested questions like "How is it for you being a sibling in this particular family?" and the use of different resources to stimulate the conversation with siblings, like drawings, toys or tales. Finally, Dr. Moyson suggested to take a general approach on the experience of quality of life of siblings due to the lack of research on the topic, locally and internationally.

1.2.2.3 Siblings' quality of life in Catalonia

This research has been conducted in Catalonia. Nowadays, Catalonia is an autonomous region situated in the northeast of Spain. Historical and geographical reasons can help explain some of the cultural and linguistic differences from other Spanish' regions. The cultural diversity of Catalonia is rooted in the fact that their population show a strong sense of belonging despite having roots from multiple origins. The Catalan language, acting as a glue for the conglomerate of people that lives in the territory, aids to preserve the identity and customs of the Catalan people while keeping the heterogeneity of family values. These particularities, added to the significant size and diversity of the Spanish' regions, explain the focus some authors have had on the family quality of life of people living in Catalonia.

Before introducing some of the most relevant studies on FQOL in Catalonia, it is important to note that these studies were mainly reporting data collected from parents (especially mothers) regarding their perceived FQOL. Consequently, data about siblings' quality of life was not directly gathered. However, a few references to their needs and well-being are provided.

Giné et al. (2015) showed that the perceived FQOL of Catalan families was similar with the results from other FQOL' research. Specifically, Catalan families were rating high on the "family interaction" domain and low on the "health" and "financial well-being" domain. Regarding siblings' participation, this domain was rated higher in the group of families with a person with IDD over 18 years old, which is congruent with the changing roles and responsibilities siblings could have due to their parents ageing.

In previous research, Giné et al. (2011) noted the desire of parents to improve the attention and affect they show to the siblings with no IDD. Moreover, to value the siblings' views regarding issues concerning the person with intellectual disability. As support needs, families mentioned willing to know more about the siblings' needs and to have support groups for parents and siblings.

Similarly, Vilaseca et al. (2017) found that one of the most significant needs amongst families of people with intellectual disability was to have support groups for siblings. The authors highlighted: "As regards the examination of the services needed by the family (parents, siblings, other relatives and also the person with intellectual disability), our results show that the ones most needed in Catalonia are to do with informational resources and financial resources, followed by emotional resources". (p.9). The authors considered that working with families from family-centered approaches and not just focused on the person with disability, would be beneficial for the quality of life of the members of the family including siblings, which is also recommended in the study by Boelsma et al. (2017).

The present doctoral research is informed by this state of the art and is aimed to provide insights into the quality of life of siblings in a geographically situated area to contribute to the international knowledge on siblings' quality of life perceptions.

1.2.2.4 Social and scientific relevance of the study of siblings' quality of life

Research indicates that siblings tend to show different needs than their parents regarding the experience of disability, and that these needs are not usually considered when setting up resources to assist families (Bitsika et al., 2015; Connell et al., 2014; Moyson & Roeyers, 2012; Neece et al., 2010). Consequently, it is necessary to broaden the range of interventions to effectively reach all members of the family system and offer specifically designed and constructed support, ideally co-constructed with siblings. This would help to reduce or prevent adverse reactions that could pose a threat not only to the siblings' own development, but to that of their brothers or sisters with IDD, which could in the long term affect the general well-being of the family. The following reasons from the literature justify research into siblings.

First, among family relationships, the one between siblings is generally the longest-lasting (Cuskelly & Gunn, 2003; Connell et al., 2014; Rossetti & Hall, 2015). It is imperative to take advantage of the potentialities and benefits which this relationship brings not only to the siblings themselves, but to the entire family. During childhood and because they are of a similar age, siblings are often closer to children with IDD than their parents and can even better understand them, collaborating positively in their developmental process. Additionally, with the help of their siblings, a child with disabilities can enjoy more opportunities to share educational and leisure time with other children without disabilities, which not only allows them to participate in society in a more ordinary fashion, but helps foster a more inclusive society (Kryzak et al., 2014).

Second, quality of life, both on an individual and family level, improves when interventions aimed specifically at siblings are carried out (Moyson & Roeyers, 2012). For example, broadening children's understanding of the disability and the developmental problems faced by their sibling with IDD helps to facilitate a space in which they can express themselves and communicate feelings of anxiety and frustration, and so provide them with the necessary tools to cope with the situation (Smith & Perry, 2005; Lizasoain & Onieva, 2010).

Third, a recurring issue when discussing siblings of persons with IDD are the possible negative consequences having a brother or sister with IDD can bring. Findings from research vary: some authors claim that siblings see themselves as negatively affected by having a brother or sister with IDD, while others argue that there is not enough evidence available on the topic (Neece et al., 2010; Smith et al., 2013; Stoneman, 2010). Maybe the best approach is the one which evaluates the experience taking into account all the dimensions and particularities -both positive and negative- which are present in any interpersonal relationship.

Finally, as siblings are getting older, they are expected to take on more responsibilities and roles regarding their brothers or sisters with disabilities. One of the most common roles of siblings is the legal representative or guardianship role (Hall & Rossetti, 2017). Taking this role means that siblings have legally agreed to take care of their brothers or sisters’ issues regardless its type (e.g., health, finances, placements options, etc.). Authors reported how this information used to be scarce, with siblings complaining about what is expected from them to do or how to approach the different available public resources (Jacobs & Macmahon, 2016). Due to the importance of this legal role, siblings have to be well informed about their rights and obligations, as well as the different legal figures considered in the civil codes of their own countries.

1.3. Methods

The present research has followed a qualitative research design. Qualitative methods offer an effective way of exploring perceptions, experiences and other subjective views from individuals. Thus, a qualitative approach was the most suitable to meet the research’ interests.

Research on siblings and their perceptions of quality of life is a recently studied topic. Because there is an open field of research, data analysis took an inductive approach (Thomas, 2006). Themes and common subjects were highlighted throughout the data to stablish connections and to build a narrative from them. Research objectives were always guiding the analysis’ process that was backed up by the existing literature on siblings’ quality of life.

To analyze the collected data, a content analysis of the results from the systematic review (Chapter 2) and a thematic analysis of the data from the interviews (Chapter 3) and discussion groups (Chapter 4) were conducted. Following these lines, there is a brief explanation about these methods of analysis and why they were selected. In addition, some of the issues faced while researching with young children, were discussed.

1.3.1 Content Analysis

A content analysis of the data of the systematic review was chosen to inform about relevant topics related to the research question in the written pieces of text. In addition, it was important to focus the analysis to those parts of the text that were reporting information about siblings and their perceptions of quality of life. Since some of the reviewed articles were reporting not only information about siblings’ quality of life but from other related issues as well, an effort was made to focus specifically on the significant data. Qualitative content analysis involved data reduction by concentrating on particular data features which was useful to the research’ goals (Cho & Lee, 2014). Findings from the articles included in the systematic review were systematically coded and grouped into final themes. More information about the whole process is included in Chapter 2.

1.3.2 Thematic Analysis

The analysis of the collected data via the interviews and discussion groups was conducted following the description and principles of thematic analysis by Terry et al. (2017). This kind of analysis was considered as the most convenient for the collected data due to its basic underlying principles. For instance, this analysis requires a necessary engagement with the dataset to be able to develop proper themes to accurately define detected patterns of meaning. To this end, a deep and reflexive thinking about the data was consistently performed. At the same time, an iterative process of codification was conducted which resulted in the conceptualization of themes. A more detailed description of the conducted analytic process is included in Chapters 3 and 4.

1.3.3 Research with young children

Conducting research might be challenging. There are explicit steps that had to be followed for quality research, even before thinking on starting a project (Braun & Clarke, 2006). As said before, Chapters 3 and 4 present research conducted with young siblings: children from 5 to 11 years old. Ethical approval of the research was sought and granted by the Ramon Llull University Ethics Committee (see Appendix B).

Figuring out the sample, its identification, selection and recruitment could be some of the most difficult and time-consuming parts. One of the characteristics of researching with children is that their parents are the ones deciding on their participation. This is a mandatory step: parental consent must be collected prior to any data collection and, at the same time, their consent acts as one of the first filters. Parental hesitation on the participation of their children was one of the main problems faced when selecting participants. Few parents were worried about the eventual effects that their children face in participation in the study. Moreover, the selected topic was a delicate and complex one. Delicate because it was focused on young children’s reflections on the experience of having a brother or a sister with a disability; and complex because it might expose the intimacy of the family and of the family dynamics, involving emotional reactions on different family members.

A total of 28 families were contacted. Eight families declined participation on the research. Some of the reasons were related with their children' preferences to not taking part in the project, but the majority were related with parental views on the research. As an example, the answer received to an inviting email from a mother of two children:

> "I'm sorry but I don't want to coerce my daughter to an interview. I hope you have other parents more interested on this topic".

This reply stated the importance of taking care of terminology used and the way of approaching potential families. Since this email, the word "interview" was no longer used, and it was replaced by "sessions". An informal talk via telephone or a face-to-face meeting with parents, were offered to those interested to solve beforehand any questions or concerns.

Previous research has shown that young children can report their own experiences if provided with the adequate support and resources (Bachraz & Grace, 2009). Pyle (2013) argued that "recent research has demonstrated an alternative perspective that reflects the paradigm shift in the study of the sociology of childhood which recognizes that children have agency. This shift is, in part, the result of a deepening understanding of the Vygotskian constructivist perspective of children as active participants in their own learning (Stephenson, 2009)" (p. 1544). Therefore, children, as subjects, have their own voices, opinions and views and must be given the opportunity to report on them.

As noted earlier, the research topic was a sensitive one. Additionally, the research involved formal conversation with an unknown person to talk about personal experiences due to having a sibling with a disability. Therefore, an interview protocol was designed to take care about these aspects and to be able to give positive responses to the siblings' needs. Consequently, at the beginning of the sessions time was designated to establish a comfortable environment with siblings and also, some time was taken at the end to finish the interview with leisure time. This time was considered part of the interviews as well, even when the interviewer was not directly asking questions, because siblings were in this way more naturally discussing about their quality of life. All the interviews started with a reminder of the details and goals of the research and of the confidentiality of the process, all of these in a clear and understandable way for children.

Together with oral communication and following suggestions on interviewing children (Berkowitz & Jonas, 2014) a diversity of resources and materials were used to facilitate the siblings’ expression: books related with emotions (Llenas, 2012) and with emotions due to having siblings with IDD (Ponce & Gallardo, 2016), drawings or toys. The interviewer was sensitive during the whole session to detect if siblings were requiring some extra time to deal with particular emotional moments during the interviews or whether an adaptation of the questions was required. Parents were previously advised that siblings could be in a transitory emotional state immediately after the interviews or in the periods between them so they could be aware of their needs. An active and empathetic listening together with accurate answers to possible questions, were suggested and a telephone number and email address were provided in case of necessary support.

1.4. Objectives and research questions

The aim of this doctoral thesis is to explore siblings' quality of life perceptions from their own voice. This aim consequently led to the main research question: "How do siblings of people with intellectual and developmental disabilities perceive their quality of life as siblings?"

Following this aim and research question, a systematic review on the theme (Chapter 2) was conducted in order to know about the state of the art. Findings from this systematic review highlighted: (1) a gap in the literature on siblings regarding research with children and adolescents and (2) only a few articles were focused on siblings' quality of life. Consequently, empirical studies were projected, developed and conducted to explore young siblings' perceptions of their quality of life. These empirical studies are presented in two papers, respectively the Chapters 3 and 4. The main thesis aim was further operationalized in the specific objectives and research questions as shown in Table 3.

TABLE 3. Articles related with their corresponding thesis' objectives and research questions

Article Title	Objectives	Research Questions
Siblings of people with intellectual and developmental disabilities: a systematic review on their quality of life perceptions in the context of a family	1. To find relevant information about quality-of-life perceptions of siblings of people with IDD, collected on the international literature. Specifically: 1.1 To know about siblings' perceptions on quality of life 1.2 To explore what demands do siblings have regarding their quality of life as siblings of individuals with IDD	1. What are the siblings' perceptions on quality of life in the context of their family? 2. What needs and challenges do siblings have regarding their quality of life as siblings of individuals with IDD?
Siblings of children with intellectual and developmental disabilities: Quality of life perceptions from Catalonia	2. To gather young siblings' perceptions on quality of life from their point of view 3. To understand siblings' perceptions and their lived experiences.	3. How do young siblings aged 5 to 11 years old of children with IDD living in Catalonia, perceive and describe their quality of life as siblings?
Is the quality of life of siblings of people with intellectual and developmental disabilities influenced by family dynamics and parental performances? Initial explorative study from young siblings' perspectives	4. To explore the influence of family dynamics and parental performances on siblings' quality of life' perceptions	4. Have family dynamics and parental performances an influence on siblings' quality of life perceptions?

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CHAPTER 2. Siblings of people with intellectual and developmental disabilities: a systematic review on their quality of life perceptions in the context of a family

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Siblings of people with intellectual and developmental disabilities: a systematic review on their quality of life perceptions in the context of a family

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Background: Within Family Quality of Life (FQoL) research, perceptions of siblings of people with intellectual and developmental disabilities (IDD) in the setting of a family are limited studied. The aim of this systematic review is to find relevant information about quality of life perceptions of siblings of people with IDD. Two main questions guided this review: (1) what are the siblings' perceptions on quality of life in the context of their family? (2) what needs and challenges do siblings have regarding their quality of life as siblings of individuals with IDD? **Methods**: A systematic search was conducted using Scopus, PsycInfo, ERIC and Web of Science databases, involving keywords and combinations such as Intellectual and Developmental Disabilities, Family Quality of Life and siblings. **Results**: We identified a total of 48 articles. Analysis showed siblings' diverse perceptions of quality of life and their multiple experiences, needs, desires and concerns. **Conclusions**: Results contribute to knowledge about the quality of life and well-being of siblings of all ages. Suggestions for support, interventions and future research are given, such as the necessity of educating local communities regarding siblings' needs, the study of siblings' experiences in different cultural contexts or the importance of conducting research with clear theoretical frameworks and focused on the multiple components that might be influencing siblings' quality of life.

Keywords: siblings, quality of life, family quality of life, intellectual and developmental disability, systematic review

Introduction

Families provide a context where individuals can develop and influence each other. As defined by Poston *et al.* (2003), "a family includes 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" (p. 319). Given the dynamic and interactive nature of families, any situation regarding one of the family members has the potential to affect the other members and, eventually, the whole system (Zuna *et al.* 2010). Thus, the presence of a disability could influence the quality of life of the family and of its individual members (Poston *et al.* 2003).

Over the past two decades, the construct of family quality of life (FQoL) has been largely studied regarding conceptual, theoretical and measurement aspects (see Boelsma *et al.* 2017, Brown *et al.* 2006). Zuna, *et al.* (2009) defined FQoL as a "dynamic sense of well-being of the family, collectively and subjectively defined and informed by its members, in which individual and family-level needs interact." (p. 262). Individuals' quality of life and FQoL convey and interact in a continuous manner influencing each other. Consequently, it is difficult to separate the reported quality of life of a single member from the general overview of FQoL (Boelsma *et al.* 2017). The instruments used to date had primary looked at FQoL from a parent's and, particularly, mother's point of view, while the voices of other family members have been usually overlooked (Vanderkerken *et al.* 2018). As mothers responses in representation of the whole family had been worthy considered (e.g. Chiu *et al.* 2017, Samuel

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et al. 2018) this is the same with siblings. With a focus on siblings' perceptions it becomes more clear that every member of the family has its own perceptions regarding quality of life, with all of them deserving to be explored (as it is recently happening with fathers [see Schippers *et al.* 2020]). Therefore, the present review is focused on siblings' quality of life; this is the perceptions and well-being of being a sibling in a certain family.

Siblings and quality of life in the literature

Studies from the FQoL field have reported that siblings have specific needs and concerns regarding their quality of life that may differ from those expressed by their parents and from the general FQoL perceptions (Luijkx *et al.* 2016). For example, young siblings appreciate having specific information about their brother's or sister's disability and supportive friends with whom they are able to share their experiences (Moyson and Roeyers, 2011). Further, sibling's quality of life's perceptions change along the years due to the multiple and significant roles siblings play in the lives of their brothers and sisters with and without intellectual and developmental disabilities (IDD) (Tozer *et al.* 2013).

Research has provided important information on siblings' experiences regarding their particular family situation, such as the long-lasting nature of sibling relationships or the recognition that these relationships constitute a source of self-development and joy for both siblings (Stoneman 2005). The rising number of siblings who are embracing the role of carers of their brothers and sisters as a result of an increased life expectancy of people with IDD, has led to an enlargement of siblings' literature (Heller and Kramer, 2009). Many authors have been interested in siblings and their experiences with a considerable disparity of approaches and focus of interest, while their research's theoretical frameworks were not always explicit (see Stoneman 2005, for an overview).

Systematic reviews about siblings have explored their experiences, relationships or the influence that having a brother or a sister with a disability have had in their life. However, much less is known about their quality of life perceptions. For instance, previous reviews have shown that outcomes on siblings' well-being and siblings' experiences seem to be ambivalent and diverse (Orsmond and Seltzer, 2007). The meta-analysis by Rossiter and Sharpe (2001) indicated that it is not clear to what extent having a brother or a sister with a disability influences the siblings' life. Blacher *et al.* (2005)' review about families with a member with ID, detected differences in the adjustment and attachment styles of siblings while Heller and Arnold (2010) noted that influences on siblings' personal well-being were either positive and negative depending on different variables like the closeness of the siblings' relationship or the level of involvement in the siblings' life.

Nevertheless, while these reviews provided a valuable insight into siblings' reality, none of them had sibling's quality of life' perceptions as the main focus of their research nor their reported findings. That's why, in this systematic review, siblings' quality of life perceptions will be explored, as they constitute an essential but sometimes forgotten part of family life. Therefore, the focus is not on siblings' individual quality of life but on their quality of life as siblings in a family context. From the multiple identities an individual could hold, we took the one that refers to the specific place this individual is occupying inside a family; in this case, a sibling of a person with IDD.

Aim of the present systematic review

The aim of this study is to provide a more systematic review by exploring the perceptions of quality of life of siblings of people with intellectual and developmental disabilities available in the more recent literature. Two main questions guided this review: (1) what are the siblings' perceptions on quality of life in the context of their family? (2) what needs and challenges do siblings have regarding their quality of life as siblings of individuals with IDD?

Methods

Authors followed the Preferred Reporting Items for Systematic reviews and Meta-Analyses (PRISMA) guidelines by Liberati *et al.* (2009) regarding the search strategy, application of eligibility criteria, selection of included studies, data extraction, data analysis and quality assessment.

Search strategy

A keyword search strategy was conducted in May 2019 for the period 2003–2019 and actualized in December 2021, using the following specialized databases: Scopus, Web of Science (WoS), Education Resources Information Center (ERIC) and PsycInfo. Keywords related with quality of life, such as family quality of life, health-related quality of life, outcome and well-being were matched with keywords related to people with IDD such as intellectual or developmental disabilities, mental retardation[1] and learning disabilities[2]. It is noted that developmental disabilities such as autism were included (but not high functioning autism). These words were also matched to those related with siblings: brothers, sisters and 'brothers and sisters'. Truncated keywords term disab* and famil* plus 'quality of life' were likewise used to increase the chance of retrieving relevant articles. Between search terms, AND was used as a Boolean operator. The reference lists of some selected articles, together with the published article index of relevant journals in the field, were searched manually ($n = 30$). Finally, 48 articles were included in the qualitative synthesis.

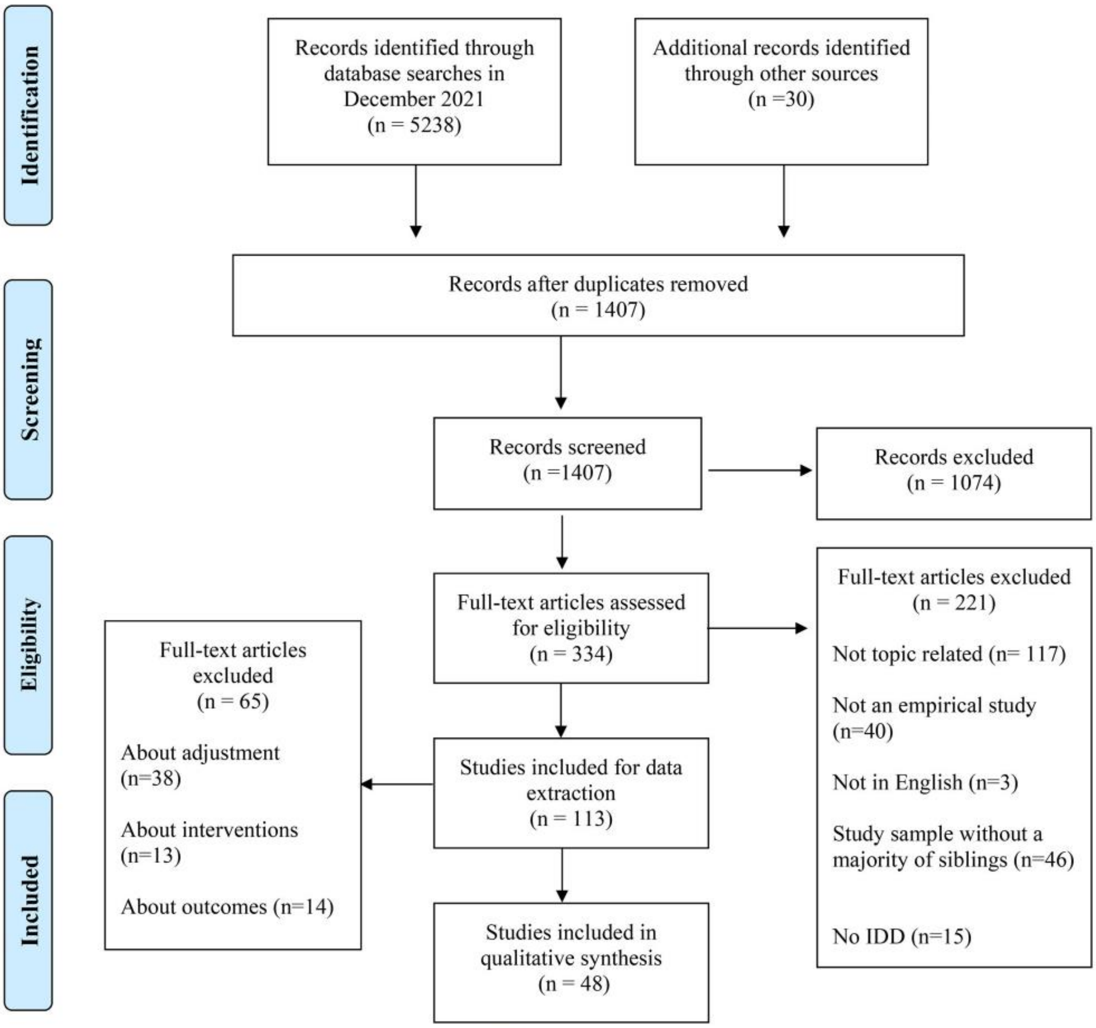

Figure 1. Study flow diagram (PRISMA, Liberati *et al.* 2009).

Eligibility criteria

Included studies met the following criteria: (a) published between 2003 (the approximate date when the concept of "family quality of life" appeared for the first time, even when aspects of living for people with ID was referred to in early years [see Park *et al.* 2003]) and 2021; (b) focus on siblings' quality of life, siblings' well-being, siblings' relationships, siblings' adjustment, and/or siblings' outcomes; (c) empirical studies; (d) English language; (e) data coming from siblings themselves; and (f) members with at least one sibling with IDD.

As noted in Saxena and Adamsons (2013) siblings of people with IDD 'has come from research that is largely cross-sectional and atheoretical' (p.300); leading to a general situation of diverse and unconnected information about siblings. The present systematic review followed the specific domains that are used in the quality of life approach when collecting data and analysing the selected articles. Considering the definition by Zuna *et al.* (2010) given above, FQoL employs a variety of domains, but only some of them were applied to siblings' perceptions. Domains from the International Family Quality of Life Project (Brown *et al.* 2006) and from the Beach Center Family Quality of Life Scale (Hoffman *et al.* 2006) were followed. Specifically, domains such as Family interaction/Family relationships, Emotional well-being, Support from other people/from disability related services, Influence of values, Leisure and recreation and Community interaction were used. However, before considerations can be made of wider characteristics of FQoL, it is necessary to know what do the individuals feel about being siblings of a person with an IDD. Therefore, information about siblings' well-being and siblings' emotional experiences were taken as a starting point in selecting the articles for this review.

Selection of the studies

Once all the records were retrieved and duplicates removed, titles and abstracts were screened. In order to ensure reliability, two reviewers used the eligibility criteria to conduct a full-text reading of the selected articles ($N = 334$) and agreed to explain their rejections during several discussions until they reached a consensus (initial agreement, 86.43%).

Data extraction and coding procedures

Relevant articles were codified in a data extraction table that was developed based on the research questions of the review. Articles were coded based on the author, title, year of publication, sample characteristics, theoretical framework, methodology, key findings, outcomes about siblings' quality of life, information reported by parents about siblings, country, and cultural values. To perform a more accurate codifying and categorizing process, Atlas-ti Scientific Software Development GmbH (v8.4.4) a computer-assisted software to analyse large amount of qualitative data was used.

After this process was completed, the authors redefined the inclusion criteria to include only those articles reporting information related to siblings' quality of life, their experiences and perceptions of being siblings. Articles focused on outcomes or interventions ($n = 65$) were finally excluded because their approach was either too narrow for the purposes of this review or presupposed a clear negative experience on siblings (see Figure 1). Two reviewers checked the extracted data and disagreements were discussed among all authors.

Data analysis and quality assessment

All but one of the selected articles had a qualitative research design. Before initiating the data analysis process, the quality of the selected articles was evaluated using the Critical Appraisal Skills Programme (2013), one of the most popular tools to evaluate the quality of qualitative articles (Long *et al.* 2020). The questions of this tool were applied to each paper (questions considered most important: "Was there a clear statement of the aims of the research?"; "Was the research design appropriate to address the aims of the research?"). Each question was scored zero, one or two depending on the accuracy of the information presented in the article, with an overall score of 20. The 47 articles achieved a score of 17 or above implying a high-quality article[3]. The quality of the quantitative article was successfully evaluated through AXIS tool (Downes, *et al.* 2016).

Articles were analysed using a qualitative content analysis. Due to the novelty of the topic, findings were coded line-by-line in an inductive process. Afterwards, data was categorized into descriptive themes such as siblings' relationships, siblings' needs and supports. These themes were then matched with the above domains of Family Quality of Life. Resultant themes and their codes were critically reviewed by the authors during reflexive meetings and discrepancies during the process were discussed until a consensus was reached. Finally, these themes were used to report the findings, after being grouped into two broad categories derived from the main questions of this review: 1) Siblings' perceptions of their quality of life; 2) Issues of concern and challenges for siblings regarding quality of life.

Results

This section presents the results of the 48 reviewed articles listed in Table 1. A total of 902 individuals participated in the selected articles. Of these, 540 were female, 276 were male, and there was no gender information for the remaining 86 individuals. The participants' age ranged from 4 to over 80 years old. Due to the presence of the discussed topics throughout the siblings' life, findings are generally reported without distinction of siblings' age. However, when specific age groups were reporting something, this was clearly stated. Articles included siblings of people with mild, severe and profound intellectual disabilities (ID), developmental disabilities (DD), learning disabilities, autism spectrum disorder (ASD), cerebral palsy (CP), Down syndrome (DS), 22q11.2 deletion syndrome, rare disorders and a combination of disabilities such as ID and ASD.

Regarding the theoretical frameworks, 11 of the 48 analysed studies named the framework used to conduct the research. The FQoL approach was one of the most referred frameworks (5; 9; 27; 30; 33; 34). Another theoretical framework was the social constructionist research paradigm (4; 31) and Thomas' (Thomas, 1999) social relational model of disability (45). McGraw and Walker (2007) used other theoretical approaches: critical feminism, symbolic interactionism, phenomenology, cultural sociology, and poststructuralism. From the adapted Lifeworld framework by Galvin and Todres (2013), Pavlopoulou and Dimitriou (2019) has followed an experience- sensitive approach constituted by 8 dimensions to understand the siblings' experiences. Finally, Pompeo (2009) used social ecology/ecological psychology, family systems theory, labelling theory, and the social model of disability.

Siblings' perceptions of their quality of life

Family interaction

Findings suggested that family interaction, like communication and daily contact, can shape siblings quality of life in both positive and negative ways. Four articles (1; 17; 35; 41) reported that siblings feel close to their family through bonds of love while holding negative feelings if family dynamics have placed their siblings with IDD at the centre of the family life. Three articles (1; 2; 27) highlighted that siblings' relationships with their brothers or sisters may be influenced by difficulties related to the disability, but these difficulties must be placed within the specific context and family dynamics. For example, as noted in one article (9) certain routines

Table 1. Characteristics of included studies.

Author(s); Year; Country	Focused on	Method		Sample		Type of IDD
		Interviews	Other data- collecting instruments	Size	Age	
1. Atkin and Tozer, 2014. UK	Siblings' perspectives on having a brother or sister with autism; how their relationships were negotiated and given meaning across the course of life	X		$n = 21$	25-67	ASD + Learning Disability
2. Bachraz and Grace, 2009. Australia	Sibling' relationships when one sibling has ASD	X	Photographs in interviews Naturalistic observations	$n = 3$	4-6	ASD
3. Benderix and Sivberg, 2007. Sweden	Experiences of siblings with a brother or sister with autism and mental retardation	X		$n = 14$	5-29	ASD + Mental Retardation
4. Bigby, Webber and Bowers, 2015. Australia	Siblings roles in the lives of older people with intellectual disability and those who live in group homes; the relationships between residents' siblings and group home staff	X		$n = 14$	50-70	ID
5. Boelsma, Caubo-Damen, Schippers, Dane and Abma, 2017. The Netherlands	The dynamics between the family members and their Quality of Life and Family Quality of Life	X		$n = 1$	23	ID and autistic-related behaviour
6. Cameron, 2010. USA	The author's own path from sibling to sibling-parent		Autoethnography	$n = 1$	Adults	ID
7. Canary, 2008. USA	How family members construct notions of ability and disability and how interactions with individuals outside the family influence those family members' constructions	X	Observations; Member validation of transcripts	$n = 12$	Children	Invisible disabilities
8. Connell, Halloran and Doody, 2016. Ireland	Sister's experience of growing up with a brother with ASD; professionals understanding of the sister's perspective		Ethnography	$n = 1$	Adults	ASD
9. Correia and Seabra-Santos, 2021. Portugal	Siblings' perspectives about the experience of having a sibling with ID and about their family quality of life (FQoL).	X		$n = 6$	17-56	ID
10. Corsano, Musetti, Guidotti and Capelli, 2017. Italy	Experiences of growing up with a brother with an ASD	X		$n = 14$	12-20	ASD
11. Coyle, Kramer and Mutchler, 2014. USA	The transition in care from parents to siblings, from the perspective of a sibling of an individual aging with IDD	X		$n = 15$	>40	DS, IDD, ASD and CP
12. Cridland et al. 2016. Australia	Experiences, roles, and responsibilities of sisters of a brother with an ASD, at school and home from the perspective of different family members	X		$n = 3$	16-17	ASD
13. Dansby, Turns, Whiting and Crane, 2018. USA	Experiences of siblings growing up alongside a brother or sister with autism		Posts from online blogs	$n = 65$	17-31	ASD
14. Davys, Mitchell and Haigh, 2016. UK	Perceptions of siblings of adults with ID regarding future wishes and family expectation of future support	X	Survey	$n = 15$	30-64	ID
15. Diener, Anderson, Wright and Dunn, 2015. USA	Sibling' relationships of students enrolled in a technology education program designed for youth with an ASD	X		$n = 7$	7-14	ASD
16. Flaton 2006. USA	Life experiences of a woman growing up with a brother with Down Syndrome	X		$n = 1$	39	DS
17. Goodwin, Alam and Campbell, 2017. UK/Australia	The interpretations of youth and adults who have a sibling with 22q11.2 Deletion Syndrome from a phenomenological epistemological position	X		$n = 5$	16-42	22q11.2 deletion syndrome
18. Gorjy, Fielding and Falkmer, 2017. Australia	How adolescent siblings of children with Autism Spectrum Conditions view their life	X		$n = 11$	12-17	ASD
19. Graff *et al.* 2012. USA	Experiences of adolescent siblings of a child with DS plus health problems	X		$n = 23$	12-19	DS+ Multiple

(*Continued*)

Author(s); Year; Country	Focused on	Method		Sample		Type of IDD
		Interviews	Other data- collecting instruments	Size	Age	
20. Hall and Rossetti, 2018. USA	Roles of siblings regarding their brothers or sisters with severe intellectual and developmental disabilities		Survey with four open-ended questions	$n = 79$	19-72	Health Problems IDD
21. Hames, 2008. UK	How and when siblings understand that they have a brother or sister with a learning disability	X		$n = 12$	12-14	Learning Disability
22. Haukeland, Fjermestad, Mossige and Vatne, 2015. Norway	Emotional experiences of siblings of children with rare disorders		Support Groups	$n = 58$	7-17	Rare disorders
23. Hwang and Charnley, 2010a. South Korea	Experiences of children living with an autistic sibling		Visual ethnographic methods/ video elicitation	$n = 9$	7-15	ASD
24. Hwang and Charnley, 2010b. South Korea/UK	The role of culture in understanding autism		Visual ethnographic	$n = 9$	7-15	ASD
25. Jacobs and MacMahon, 2017. Scotland	Experiences of young adults with a sibling with an ID placed in a residential school	X		$n = 6$	16-22	Learning Disability
26. Kao, Romero-Bosch, Plante and Lobato, 2012. USA	Experiences of Latino siblings of children with developmental disabilities	X		$n = 17$	8-14	IDD
27.Kyrkou, 2018. Australia	Practical aspects of the sibling relationship through the major developmental stages of early childhood, school years, adolescence, and the shift into adulthood		Autoethnography	$n = 1$	Adults	Unknown condition
28. Lemoine and Schneider, 2021. France	Adult siblings perceptions of their childhood relationships with brothers or sisters with DS		Online survey	$N = 120$	18-80	DS
29. Luijkx, van der Putten and Vlaskamp, 2016. The Netherlands	Experiences of having a sibling with profound intellectual and multiple disabilities		Photo elicitation interviews	$n = 18$	6-13	PIMD
30. Mascha and Boucher, 2006. UK	Experiences and feelings of siblings with a brother or sister with autism	X		$n = 14$	11-18	ASD
31. McGraw and Walker, 2007. USA	How gender and developmental disability discourses shape nondisabled women's understandings of themselves and their siblings with disabilities	X		$n = 10$	21-82	DD
32. Mouzourou, Santos and Gaffney, 2011. USA/Cyprus	Family experiences with a child with autism	X	Observations of their daily routines	$n = 3$	6,10,12	ASD
33. Moyson and Roeyers, 2011. Belgium	Siblings of children with ASD' descriptions and definitions of their quality of life	X		$n = 17$	6-14	ASD
34. Moyson and Roeyers, 2012. Belgium	Siblings definition of their quality of life as a siblings	X		$n = 50$	6-14	ID
35. Noonan *et al*. 2018. Ireland	Experiences of siblings of adults with an ASD and ID	X		$n = 8$	18-37	ASD + ID
36. Paul *et al.* 2021. USA	Experiences of siblings of people with intellectual disabilities in Latin America, Africa, and Asia-Pacific		Focus groups	$n = 22$	8-25	ID
37. Pavlopoulou and Dimitriou, 2019. UK	Unexplored factors in the life of adolescents' sisters with a brother or sister with an ASD	X		$n = 9$	12-14	ASD + ID
38. Petalas, Hastings, Nash, Dowey and Reilly, 2009. UK	Perceptions and experiences of siblings with a brother with an ASD	X		$n = 8$	9-12	ASD
39. Petalas, Hastings, Nash, Reilly and Dowey, 2012. UK	How adolescent siblings with a brother with an ASD make sense of their unique circumstances and experiences	X		$n = 12$	14-17	ASD
40. Pompeo, 2009. USA		X		$n = 5$	22-25	Disability

(*Continued*)

		Method		Sample		
Author(s); Year; Country	Focused on	Interviews	Other data- collecting instruments	Size	Age	Type of IDD
	Sisters' experiences within educational and public domains; how such experiences have shaped their personalities and career choices					
41. Rampton *et al.* 2007. USA	What is important for siblings of children with Down Syndrome		Photo elicitation interviews	$n = 16$	7-15	DS
42. Rawson, 2010. UK	Concerns young adult siblings have for the future; what support they need to develop and improve support for their siblings	X		$n = 13$	17-23	ASD + Learning Disability
43. Rossetti and Hall, 2015. USA	Siblings' relationship perceptions with brothers or sisters with severe disabilities		Survey with four open-ended questions	$n = 79$	19-72	Severe Disabilities
44. Sage and Jegatheesan, 2010. USA	Siblings' perceptions of their brothers with autism and their relationships with them	X	Video recorded observations of siblings playing	$n = 2$	7	ASD
45. Stalker and Connors, 2004. Scotland/ UK	Siblings' understandings and experiences of disability	X		$n = 24$	6-19	Disability
46. Tozer and Atkin, 2015. UK	Expectations of social care among siblings	X		$n = 21$	25-67	ASD + Learning Disability
47. Tozer, Atkin and Wenham, 2013. UK	Siblings' relationships where one of them have autism and severe learning disability	X		$n = 21$	25-67	ASD + Learning Disability
48. Vella Gera et al. 2020. Malta	The experiences of young siblings of children with disability in Malta	X	Focus group	$n = 7$	8-12	CP, DS and ASD

ASD, autism spectrum disorder; IDD, intellectual and developmental disabilities; ID, intellectual disabilities; DS, down syndrome; CP, cerebral palsy.

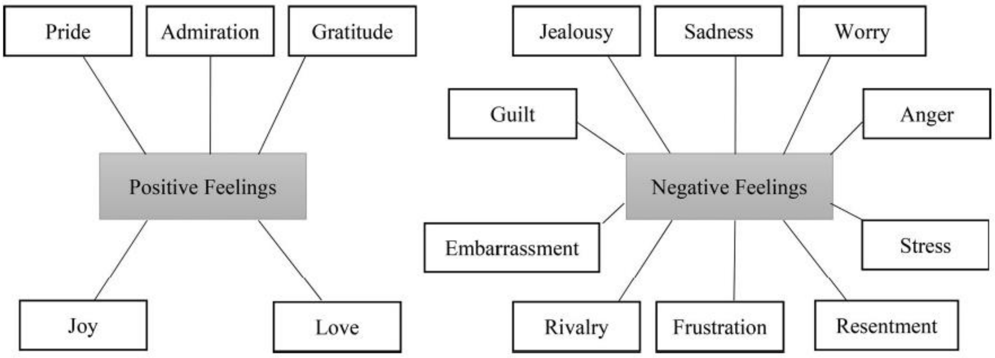

Figure 2. Positive and negative feelings experienced by siblings towards their brothers or sisters with IDD.

established by parents, like insisting their children play together, may have a negative effect on siblings' well-being if they are required to watch over their brothers or sisters when they do not wish to.

Five articles (19; 22; 25; 31; 35) reported that siblings value how family dynamics are influenced by disability by stimulating a family sense of uniqueness and togetherness. In contrast, 10 articles (12; 14; 18; 23; 31; 32; 38; 39; 46; 47) stated that disability can affect family life when distressful moments, like public outbursts of the sibling with IDD, occurred. Four articles (17; 33; 34; 45) indicated that child and adolescent siblings might prefer not to share their worries with their parents to avoid putting more pressure on them and three articles (9; 12; 30) referred how siblings appreciate opportunities to be alone with their parents. Three articles (2; 17; 27) reported that siblings understand different parental treatment towards siblings with IDD, such as giving them more attention, but 8 articles (18; 22; 28; 30; 31; 38; 40; 48) affirmed that siblings could be in conflict between accepting that difference while feeling anger or lacking parental attention.

Siblings with and without IDD' relationships

Seven articles (20; 28; 36; 43; 46; 47; 48) indicated that siblings with and without IDD share a unique and long-lasting relationship. In another five (2; 8; 15; 36; 41) siblings view these relationships as a mutual space to grow and share activities, and one article (48) reported that it goes beyond the brother or sister' disability. However, in two articles (7; 13) siblings have expressed negative sentiments toward their brothers or sisters with disability and described moments of conflict, dispute, or burden due to caregiving duties. The ambivalence of the siblings' relationship is noted in almost half of the articles (1; 6; 7; 10; 12; 13; 15; 17; 18; 19; 22; 23; 25; 30; 31; 35; 38; 39; 43; 44; 45; 46; 47). Two of them (15; 47) explained it as a common characteristic of siblings' relationships regardless of the presence of disability.

Two articles (25; 46) showed that disability influences siblings' relationships. Communication impairments, disruptive behaviour, or limited reciprocity from brothers or sisters with IDD may affect them, as noted in 14 articles (1; 10; 12; 17; 22; 33; 36; 37; 38; 39; 43; 44; 47; 48). In 10 articles (9; 19; 20; 29; 33; 35; 36; 37; 44; 48) siblings awareness of their brothers or sisters' needs lead them to adapt accordingly communication and activities.

Three articles (39; 45; 48) revealed an empathetic sense from child and adolescent siblings towards their brothers or sisters and four articles (18; 35; 43; 48) reported the use of love, humour and joy to reinforce their relationship. Hall and Rossetti (2018) indicated that, as siblings grow up, their relationship will involve higher levels of caregiving. Three articles (24; 28; 31) have referred to the gendered nature of caregiving and how sisters have had to deal with the social pressure of being a woman added to the familial obligation placed on them as sisters.

Emotional well-being

Figure 2 presents the most referred feelings from siblings related to having a brother or sister with IDD. In two articles (22; 34), the behaviour of siblings with IDD or their recurrent medical issues, were highlighted as a strong influence on child and adolescent siblings' well-being promoting feelings of compassion toward them. One article (9) reported the well-being of brothers and sisters with disability as important for siblings' quality of life.

Nine studies (9; 17; 23; 29; 31; 33; 34; 38; 39) reported that accepting the family situation has positive consequences for siblings. As stated in three articles (17; 33; 36), the pragmatic acceptance of their brothers or sisters with IDD, helps siblings to adjust and even to benefit from the relationship. In two articles (9; 48) siblings reported that parental positive views and acceptance of their child's disability, has influenced the rest of the family to accept it as well, improving their family quality of life. However, as noted in three articles (9; 39, 48),

Table 2. Siblings roles towards brothers or sisters with IDD.

Friendship role

- Providing support, experiences and leisure activities.
- Being able to understand and comprehend brothers or sisters with IDD and to perform as their translators for other people, including their parents.
- Having a protective role.
- Friendship relationship constituted by an amount of fun, confidence and trustworthiness.

Caregiving role

- More equal and flexible role than their parents.
- Starting during childhood in a natural way.
- In the adulthood, supporting brothers or sisters with IDD to deal with the decease of parents and relatives.
- Siblings' concerns about what will happen to brothers or sisters with IDD if they could not look after them anymore due to their own age-related declining or death.
- Transition in the caregiving role from parents to siblings: easier and fairer if parents and professionals value siblings' voices and opinions from the beginning and clear future care plans are established together.

Advocate role

- Standing up for brothers or sisters with IDD' interests and rights.
- May cover all areas of brothers or sisters with IDD life, including family, school or the larger community.
- Being informants and defendants of their siblings with IDD in front of peers, teachers or strangers.
- Feelings of incompetence and stress when trying to carry out similar standards of care as their parents while trying to maintain their own family life and obligations.

Legal representative role

- Legal guardians of siblings with IDD.
- Lack of information about guardianship.
- Distress when having to take some important decisions about their siblings.

IDD, intellectual and developmental disabilities.

sometimes this acceptance comes with a desire to change their brothers or sisters' behaviour or condition.

Influence on identity construction

Having a brother or a sister with IDD may influence siblings' personality and subjective decisions. In ten articles (12; 16; 18; 19; 21; 22; 25; 36; 40; 48), siblings realize how their brothers or sisters with IDD have positively shaped their personality and the way they give meaning to life, and two articles (7; 31) showed that relationships among siblings have a preponderant role on identity construction.

In another twelve (10; 14; 16; 17; 19; 28; 30; 33; 34; 36; 37; 48) siblings consider themselves more mature and patient than their peers due to circumstances of their daily life and, in seven articles (16; 17; 22; 29; 35; 40; 48) also more empathetic with others. One study (6) indicated that having a brother or sister with IDD could affect siblings' decisions about having their own children. Six articles (9; 13; 14; 16; 21; 40), also reported some siblings chose professional employment related with care professions on special educational field.

Influence of cultural and religious values

Cultural constructions about disability differ from context to context and have different effects in the siblings' lives. Three articles (25; 32; 40) from a variety of countries, noted that cultural perceptions might lead to feelings of guilt, shame, or isolation by determining the definition of "normalcy" and "exceptionality". These views are also held in other studies (31; 36; 45) and indicated how the religious views on siblings' reflections about disability could lead to the idea that the person with an IDD is someone who has to be healed, represents God's punishment or alternatively is a holy gift to their family, as collected in the study from Cyprus (32). Religion can also help families overcome tough moments, as reported in one article (9).

In the South Korean studies (23; 24) all members of the family shared a mutual commitment with the family system. Siblings' sacrifices for their brothers or sisters with autism are connected with filial obligation, experimenting pride derived from its fulfilment. Similar values were found in the articles with Latino families in the USA (26), siblings from Latin America, Africa and Asia-Pacific (36) and from Southern European countries (9; 10; 32; 48) where siblings used to have more caregiving responsibilities and reported positive and negative feelings regarding it.

Roles and responsibilities

Table 2 (structured following Hall and Rossetti 2018) summarizes the roles and responsibilities carried out by siblings. In addition, three articles (23; 26; 31) referred how the impact on the performance of roles is the way siblings are willing to be a good sibling; Coyle *et al.* (2014) stated that roles change according to age.

Community interaction

As individuals, siblings have bonds with their communities and are positively and negatively affected by them. Seven articles (9; 33; 35; 36; 37; 40; 48) reported that siblings might face challenges or difficulties because of social views regarding disability. According with Tozer *et al.* (2013) these experiences create feelings of segregation on siblings and their families while, at the same time, improve their self-confidence. In at least 13 articles (18; 24; 25; 27; 29; 32; 34; 36; 37; 38; 39; 45; 47) siblings referred to misunderstandings and negative public judgment together with the importance of being treated normally and of educating society about disability. In six articles (24; 30; 31; 33; 35; 39) behavioural

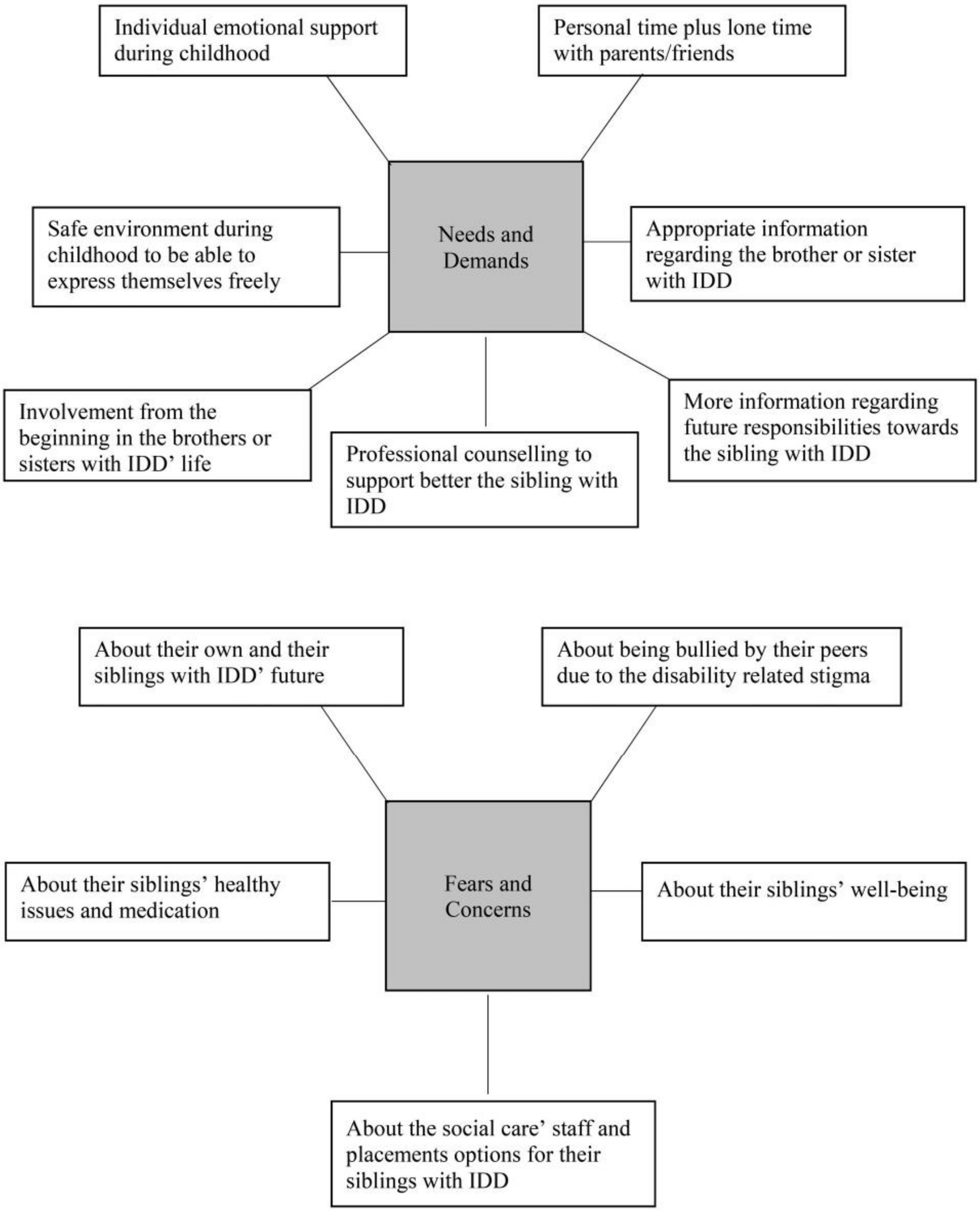

Figure 3. Siblings needs and concerns regarding having a brother or a sister with IDD.

problems and the invisibility of autism are stated by siblings of all ages as some of the most difficult situations when dealing with the outside world.

Two articles (24; 39) noted that adolescent siblings could feel shame and loneliness due to stigma. Another article (36) referred to the stigma within the family, meaning that families are not protected from negative assumptions regarding disability. However, four articles (16; 24; 25; 31) indicated that siblings succeed in having a life of quality and in building and maintaining a lifelong relationship with their siblings.

Issues of concern and challenges for siblings regarding quality of life

Siblings' needs and desires

During their lifespan, siblings have a variety of desires, needs and concerns that were reported throughout the reviewed studies. One article (36) mentioned siblings wanted to be a good model for their brothers or sisters. In six articles (10; 18; 21; 33; 34; 48) children and adolescent siblings expressed willingness to share their experiences with other siblings of people with IDD to feel understood and to learn ways to behave and relate better with their brothers or sisters with IDD. Six studies (9; 16; 26; 38; 45; 46) noted how siblings wished to enjoy neat, clear, and straight communication with their parents to obtain practical information about their siblings with IDD, discuss delicate issues, and consider how to deal with eventual circumstances.

In nine articles (8; 9; 31; 34; 38; 39; 43; 47; 48) some siblings were eager to have a 'normal' family with brothers and sisters displaying ordinary communication and behaviour. Figure 3 provides the siblings' most mentioned needs, demands, fears and concerns.

Disability related-support

Siblings expressed different experiences regarding formal and informal supports due to having a brother or a sister with IDD. In one article (36), siblings wished more and better services for their brothers or sisters. Two articles (35; 46) indicated that adult siblings felt ignored or excluded by parents and practitioners. In another two studies (42; 47) young and adult siblings noted that they were not always sure to what extent they could be involved in their siblings' lives or about how to approach the different types of available support. In contrast, seven articles (3; 8; 25; 31; 35; 38; 46) found that siblings of all ages valued respite care facilities, residential placements for brothers and sisters in adulthood, and maintaining a positive and trusting relationship with staff and service providers.

Twelve articles (9; 12; 14; 16; 17; 18; 20; 28; 31; 37; 47; 48) reported that siblings appreciate having support from other siblings, friends, parents, extended family and the larger community. Six articles (8; 9; 11; 33; 34; 38) mentioned as support leisure time without their brothers or sisters with IDD, sharing experiences and responsibilities.

Discussion

This review aimed to explore siblings' perceptions of quality of life collected in the literature. Results indicated that siblings perceptions are personally oriented and influenced by the context. Previous studies have shown that disability permeates different areas of siblings' life. Despite this, the present review revealed that the reality of disability could not by itself explain the characteristics of siblings' quality of life perceptions. Their relationship appears more extensive, variable and complex. It is important to note that the influence of established family dynamics and the social responses perceived by siblings affected their willingness to fulfil certain roles. This appears to be a complex determinant affecting siblings' perceptions of quality of life.

We have seen that during their development, siblings reported different issues affecting their perceptions of quality of life due to having a brother or a sister with IDD. During childhood and adolescence, siblings empathic feelings towards their brothers or sisters might also be linked to feelings of loneliness and shame. However, siblings used to hesitate about sharing their concerns with their parents, due to parental reactions towards disability, such as the establishment of specific dynamics and interactions in the nuclear family. Further, parental expectations towards the responsibilities siblings should take, may disturb the well-being of the siblings if not clearly explained and understood by them. This resonates with data obtained in Rillotta *et al.* (2012) where main caregivers noted that if siblings perceived themselves as being put in a second position in relation to the brother or sister with IDD, negative reactions can give rise to misbehaviour. At the same time, siblings referred to being positively influenced by their brothers or sisters with IDD resulting in greater maturity and socially sensitive and abled than their peers. As noted on the research by (Findler and Vardi, 2009) understanding what is going on with their brothers or sisters and growing alongside a person with a disability, may lead to improvement in siblings' psychological growth.

The demands on the adult sibling regarding their quality of life seems to be related to being recognized in their efforts to support their brothers or sisters with IDD. Findings showed that siblings hold multiple roles and responsibilities towards their brothers or sisters with IDD, most of them appeared to be in a positive way, but several did indicate their contribution is not valued enough by parents and services. This finding was also reported in Arnold *et al.* (2012) where siblings requested further inclusion and active participation in disability related services to improve their support for their siblings with a disability. The lack of recognition could cause supportive siblings feelings of disappointment and sorrow and affect negatively their own perceptions of well-being and quality of life. However, it appears that these reactions did not persuade them to end their involvement or their relationship with brothers or sisters with IDD; on the contrary, our findings indicated that siblings decide fiercely to keep their engagement and bond with brothers and sisters with IDD frequently involving commitment, responsibility and love towards them.

The relationships siblings have with the larger community and with their cultural context, seem to affect their perceptions of quality of life due to the influences of embedded values and social myths about disability. These results are in accordance with the unified theory of family quality of life by Zuna *et al.* (2009) that highlights the continuous interaction between individual, family and social levels and its effects on family quality of life. Indeed, the family quality of life approach has an ecological and systemic foundation (see Turnbull *et al.* 2004) and considers the influence that the interaction of these three levels have on families in order to understand their experiences and needs.

On account of the external influences on siblings' quality of life (e.g. financial wealth, availability of supports, good relationship with service providers) it is interesting to note the role that disability-related stigma can play. Stigma is constituted by culturally established ideas about what disability is or what having a relative with an IDD could be, constraining siblings' sense of normalcy (Hwang and Charnley, 2010b). These results are consistent with the work of Brown *et al.* (2019) who have discussed how new eugenics practices can negatively pervade the perceptions of quality of life of people with IDD and their families, due to a reliance on "the idea that a life with disability, especially one with severe disability, is troublesome and lacking in quality for the individual with disability and supporting family members" (p.122). Nevertheless, many siblings are able to have a meaningful life and to develop their own sense of normalcy intertwined with feelings of exceptionality.

Limitations of the review

Whilst this review has contributed to knowledge on siblings' quality of life from childhood to adulthood and about their needs and desires from their own voice, there are three factors that can limit the scope of our findings. The first one is the general lack of a clear theoretical framework in the majority of the reviewed articles. The second one is that the number of female participants in the selected articles was found to be significantly higher ($n = 540$) than the number of male participants ($n = 276$). Although this seems to be the general tendency in studies in the field, this may be a bias regarding gender, as reported in Doody *et al.* (2010). A third limitation is that the data gathered is predominantly from Western and English-speaking countries with a Judeo-Christian culture and tradition. Further, participants come predominantly from a middle and high socioeconomic status with a high educational level. Some authors referred to this homogeneity as a limitation of their studies (1; 11; 19; 20; 33; 34; 35; 37; 41; 43; 47) and recommended researching with individuals from different backgrounds, educational levels and socioeconomic status, as pointed out in the review by Heller and Arnold (2010). Community- based participatory research (CBPR) (see Pavlopoulou and Dimitriou, 2020) may result in positive outcomes by involving siblings from the first stages of the research to influence policies and services directed to enhance their quality of life.

Conclusions and directions for future research

This review contributes to a broader understanding of siblings' perceptions of quality of life when they have a brother or a sister with IDD. The family quality of life approach appears a useful approach to gathering an overall image of siblings' quality of life. The findings reported significant information regarding the varied and often positive aspects of the personal experiences of siblings, providing a global view of their quality of life' perceptions. Their needs, desires and concerns were also reported, like the importance of promoting siblings' involvement from the beginning of the lives of their brothers or sisters with IDD, including empowering them with disability related information and emotional resources from childhood into adulthood. As such this is relevant information for practitioners and policy makers in the disability field. Further research is required to better detect and understand siblings' needs in order to develop early and accurate interventions. Therefore, research with siblings from other cultural frameworks and socioeconomic status should be undertaken.

Further research may refer to the importance of educating local communities and to explore the role of siblings educating them about what is it like to be a sibling or what their needs are (Pavlopoulou and Dimitriou, 2020). Additionally, it is important to conduct research with explicit theoretical frameworks together with designs that take into account the multiple components of a system that might be influencing siblings' well-being (Correia and Seabra-Santos 2021, Kovshoff *et al.* 2017). More research is needed about the influence that having a brother or sister with IDD may have on siblings schooling experiences and later further education. Balanced narratives that recognize the nature of disability are necessary in building positive sibling relationships (Meltzer, 2018). Finally, it would be interesting to explore the experiences of siblings in related contexts, like siblings of individuals with chronic conditions or children living with parents with an intellectual disability.

Notes

1. *Mental Retardation* was included as a keyword because it was widely used until recent years.
2. *Learning Disabilities* was included because it is commonly used in the United Kingdom and other Anglo-Saxons countries to refer to ID.
3. Table with the reported information will be provided by requesting the first author (olgamc1@blanquerna.url.edu).

Conflict of interest

No conflict of interest has been declared.

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CHAPTER 3.

Siblings of children with intellectual and developmental disabilities: Quality of life perceptions from Catalonia

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Some related documents are added at the end of this dissertation:

- Recruitment letter to families (see Appendix D)
- Recruitment letter to the institutions (see Appendix E)
- Information flier to siblings (see Appendix F)
- Informed consent document for the interviews (see Appendix G)
- Demographic questionnaire (see Appendix I)

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ORIGINAL ARTICLE

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Siblings of children with intellectual and developmental disabilities: Quality of life perceptions from Catalonia

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Abstract

Siblings' interactions and shared experiences influence their perceptions of quality of life. Recently, research about siblings of children with intellectual and developmental disabilities has been significantly expanded but data from Southern European countries is still missing. This research was carried out in Catalonia (northeast Spain) a region in the Mediterranean area with its own shared culture, language and traditions that equally embraces an important diversity of ethnicities and cultures. The main aim was to collect siblings' perceptions on quality of life from siblings' own voices. Semi-structured interviews were conducted with 14 siblings aged 5–11 years old and thematically analyzed using the following domains: joint activities; mutual understanding; private time; acceptance; forbearance; trust in well-being; exchanging experiences; social support; and dealing with the outside world. Siblings reported a variety of experiences in relation to having a brother or a sister with intellectual and developmental disabilities (I/DD), including unique characteristics of their quality of life perceptions. There were also some common factors amongst the siblings' experiences, such as the importance of being able to communicate properly with their brothers or sisters with I/DD. It emerged that having their own time with their parents was an important factor in their own development. This research echoes some siblings' beliefs that society needs to provide a conscious revision of values and ideas regarding disability. Implications for research and practice are described.

KEYWORDS

developmental disability, family quality of life, intellectual disability, siblings, siblings quality of life

Abbreviations: 22q11.2, 22q11.2 deletion syndrome; 5p-, cri-du-chat syndrome; ASD, autism spectrum disorder; DS, Down syndrome; FQOL, family quality of life; FXS, Fragile X syndrome; I/DD, intellectual and developmental disabilities; ID, intellectual disability; NGO, non-governmental organization; PIMD, profound intellectual and multiple disabilities; QOL, quality of life; SMS, Smith–Magenis syndrome.

INTRODUCTION

Siblings often have a genuine, unique and powerful bond with their brothers and sisters, which is typically kept throughout the lifetime (Tozer et al., 2013). In their relationship, siblings learn to love, take care of each other and establish their own ways to communicate, play and interact (Cuskelly & Gunn, 2003; Diener et al., 2015). As Canary (2008) noted, siblings' relationships have an important role in identity construction. In fact, siblings' relationships represent the opportunity to develop skills and abilities in both siblings; promoting positive feelings like pride and joy (Vella Gera et al., 2021). However, negative feelings are also stated when one of the siblings in the dyad has intellectual and developmental disabilities (I/DD), such as guilt, jealousy or parental attention deprivation (Lemoine & Schneider, 2022). Frequently, siblings' daily interactions are influenced by different factors like parenting style, personality traits but also siblings' intellectual or developmental disability (Orsmond & Seltzer, 2007).

Families constitute in most cases the first social environment in the siblings' life promoting their development, identity construction and quality of life (Brown & Brown, 2004). Inside a family, individuals' quality of life (QOL) is in a constant interaction with the family's quality of life (FQOL) influencing and modifying each other (Zuna et al., 2010). In this dynamic interplay, the experience of disability within the family will affect the family members, their perceptions of quality of life and their interactions with the wider community (Boelsma et al., 2018).

Luijkx et al. (2016) investigated the positive and negative experiences of siblings of children with multiple disabilities, including severe intellectual disability, and suggested that having a brother or a sister with a disability affected siblings' general perceptions of quality of life. This research is aligned with other studies in the family quality of life field. For example, Moyson and Roeyers (2011) and Rillotta et al. (2012), noted the importance of investigating how siblings perceive and describe their quality of life. Moyson and Roeyers (2012) also asserted that young siblings should be asked directly to report on their experiences, in order to comprehend their quality of life. These authors, had proposed nine useful domains to describe siblings' quality of life: (1) joint activities; (2) mutual understanding; (3) private time; (4) acceptance; (5) forbearance; (6) trust in well-being; (7) exchanging experiences; (8) social support; and (9) dealing with the outside world.

In addition to the studies by Luijkx et al. (2016) and Moyson and Roeyers (2011, 2012) several studies with young siblings reported significant findings using interviews as a data collection instrument (Kao et al., 2011; Stalker & Connors, 2004). Other studies have combined siblings and parental perspectives to explore experiences regarding disability (Cebula, 2011; Chan & Lai, 2016; Diener et al., 2015) and also the views of younger and older siblings (Carter et al., 2015; Rampton et al., 2007).

Additionally, the cultural environment where siblings live also influences their quality of life. As indicated in Schippers et al. (2015), families are embedded in sociocultural frameworks with values and traditions that may affect and influence their family quality of life. Consequently, investigating families and their members' realities in different contexts appears as a key issue (Hwang & Charnley, 2010; Ravindran & Myers, 2011; Tsai et al., 2016).

A recent systematic review of the literature about siblings of people with intellectual and developmental disabilities and their quality of life (Múries-Cantán et al., 2022) has shown that: (a) published data on young siblings from a quality of life approach is still limited and (b) the majority of reviewed articles were conducted in English-speaking or Western European countries. In particular, while some research on young siblings has been carried out in different Mediterranean' countries (e.g., Findler & Vardi, 2009; Mouzourou et al., 2011) none appear to have been focused on the quality of life perceptions of young siblings in Southern Europe.

The present research was carried out in Catalonia, an autonomous region situated in the northeast of Spain. Nowadays, Catalonia has a cultural, religious and linguistic diversity that has permeated families' practices and beliefs (Giné et al., 2015). The research question that guided this research was: "How do young siblings aged 5–11 years old of children with I/DD living in Catalonia perceive and describe their quality of life as siblings? Due to the importance of family dynamics on siblings' life, parental perspectives are included to get their views on their children' relationships. Findings from this research are aimed to contribute to our understanding of siblings' perceptions and their lived experiences. Furthermore, they could be of interest for those working and researching with families of people with intellectual and developmental disabilities.

METHODS

Design

This qualitative study followed an inductive approach. The principles of thematic analysis as described in Terry et al. (2017) served as a guide in conducting the research and analyzing the data.

Participants

A review on the field of siblings of people with I/DD revealed that young children were the most under researched population group. Consequently, school-age children were selected to participate in the research. Semi-structured interviews were conducted with siblings of children with I/DD. In Catalonia and in Spain the total number of children with special needs matriculating to regular schools has been increasing due to policies promoting inclusive education. Nevertheless, still half of the students with special needs in Catalonia remain in special education schools. Participants were selected through four special education schools and two NGOs had facilitated the recruiting process. Also, a purposive sample of additional potential families was reached (Palinkas et al., 2013).

The recruitment documents sent to siblings and families were a colorful and illustrative flyer, which summarized research-related information that was comprehensible to siblings, along with an invitation letter to the parents. These documents were provided in Catalan and Spanish. The families willing to participate in the research were contacted by the first author via mail or a phone call to arrange a first meeting, which was an opportunity to meet the family and to explain more details and questions about the research. The verbal assent given by siblings and the signed consent from parents, were collected during the meeting. Afterwards, the first interview was carried out (and audio-recorded) to find out about the sibling's world and to start building a trusting relationship that would be helpful during the research process. Finally, a total of 14 siblings, 6 females and 8 males, aged from 5 to 11 years old ($M = 8$ years; $SD = 2.14$), agreed to participate in the study.

A short questionnaire to collect demographic information was completed by the parents ($N = 13$). One mother declined completing the questionnaire but agreed to her child participating. The respondents were mothers ($n = 11$) and fathers ($n = 2$); they had completed higher education, had a paid job and were living in urban areas in the same house of a partner and their children. Most of the respondents considered that the monthly income was sufficient to support the family's needs, but some reported that there was a need to increase quality of life. Along with closed questions, some open-ended questions concerning the child with I/DD and the relationship between brothers and sisters were included to get the parental' views of the nature of siblings' relationship. Data from these questions is reported at the Results section. Demographic characteristics are presented in Tables 1 and 2. Pseudonyms are used to preserve the identities of the participants.

An effort was made to select a variety of families to get a more diverse rainbow of siblings' experiences and quality of life perceptions. To this end, the institutions were selected because of the particular characteristics of their

TABLE 1 Participant and brothers/sisters with I/DD demographic information

Sibling participant ($N = 14$)				**Brothers/sisters with I/DD ($N = 13$)**		
Pseudonym	Gender	Age	Position in relation to child with I/DD	Gender	Age	Type of I/DD
Meritxell[a]	F	5	Younger	M	12	Severe ID
Xavier[a]	M	5	Younger			
Miguel	M	5	Younger	M	9	ASD
Guillem	M	7	Younger	F	11	22q11.2
Rafa	M	7	Younger	M	10	ID
Ivan	M	8	Younger	M	13	22q11.2
Nil	M	8	Older	F	6	DS
Joan	M	8	Younger	F	15	ID
Judit	F	9	Twin	M	9	ASD
Lilith	F	10	Younger	F	14	5p-
Júlia	F	10	Older	M	6	DS
Beatriz	F	11	Younger	F	13	FXS
Jordi	M	11	Younger	F	15	PIMD
Tània	F	11	Younger	M	15	SMS

Abbreviations: 22q11.2, deletion syndrome; 5p-, cri-du-chat syndrome; ASD, autism spectrum disorder; DS, Down syndrome; FXS, fragile X syndrome; PIMD, profound intellectual and multiple disabilities; SMS, Smith–Magenis syndrome.

[a] Twins.

TABLE 2 Demographic characteristics of the families

Variable	Parents ($N = 13$)
Age (n), range (years)	34–51
30–40	2
41–50	10
50–60	1
Gender (n)	
Female	11
Male	2
Relationship to sibling participant (n)	
Biological mother	11
Biological father	2
Type of family (n)	
Couple with 2–3 children	11
Large family up to 4 children	2
Education level (n)	
Less than primary education	1
Primary education	1
Secondary/higher education	4
Bachelor's degree	4
Postgraduate degree/PhD	3
Employment (n)	
Full-time or part-time	11
Others	2
Monthly income perception (n)	
Enough to support family's needs	5
Enough but could be better	3
Not enough to support family's needs	5
Type of area where living	
Urban	8
Rural	5
Cultural origin (n)[a]	
Catalan/Spanish	11
Other European countries	2
Latin America	1

[a] Some respondents indicated the cultural origin of their partners, thus the n adds up to more than 13.

focus population (i.e., higher level of students with ASD or NGOs centered on specific intellectual disabilities). Furthermore, we knew the selected schools well and this allowed us to have access to or inquire about the age range of children who we wish to interview. We went to the younger age group of people with disabilities, but this naturally led to a varied age group of siblings without I/DD, providing some variability amongst the participants who participated.

Interviews

A total of 29 semi-structured interviews were conducted with siblings at their family homes. Depending on their age, some siblings were interviewed once, others twice and some three times. For example, younger children typically had more and also shorter sessions. On average interviews lasted 41 min ranging from 10 to 85 min. At the start of each session a comfortable environment was secured and a careful reminder of the details and goals of the research and of the confidentiality of the process was made.

The interview guide (see Table 3) contained three main themes: (1) the sibling's life history; (2) perceptions on their quality of life; and (3) the meaning of their experiences. These themes were based on those that guided the interviews by Moyson and Roeyers (2012).

Previous research has noted young children's abilities to report on their experiences is improved when provided with adequate support (Bachraz & Grace, 2009; Pyle, 2013). Accordingly, a set of resources were used in carrying out the interviews. For example, content from relevant books (Llenas, 2012; Ponce & Gallardo, 2016) was used, such as short graphic stories about siblings of children with disabilities and the emotions they might feel. Siblings were invited to show their toys or beloved objects. The interviewer was sensitive to detecting whether siblings required more time to deal with particular emotionally charged moments during the interviews. Parents were previously advised that siblings could be affected emotionally following the interviews. In case parents or others had follow up questions, a telephone number and email address were provided for necessary support.

Quality procedures

To assure the adequacy of the questionnaire and the interviews guide, both were pilot tested with three families that met the eligibility criteria. Parents and sibling participants were requested to assess the questionnaire and the interviews (e.g., length, appropriateness of the questions) through open-ended questions. No significant changes were recommended. Data from these families were included in the analysis.

TABLE 3 Interview guide

1. **The sibling's life history**
   - Could you share with me some important events that happened in your life?
   - Are there some important events that happened to you because you're a sibling?
   - What do you think about having a brother/sister?
   - Do you like to spend time with your family?
   - How about the school?
2. **Perceptions on their quality of life**
   - What do you think about your brother/sister?
   - When did you realize your brother/sister was different?
   - How is it for you being a sibling in this particular family?
   - Could you tell me about moments when you like to be a sibling?
   - What do you like the most about your life?
   - Is there anything you think should be better to change in your life?
   - Do you think you and your parents have enough help and support from others?
   - How is your relationship with your brother/sister?
   - How do you used to communicate with your brother/sister?
   - How is your brother/sister relationship with your parents?
   - What do you like to do the most with your parents? How much time do you spend with them?
   - Would you like to change something about your relationship with your parents?
   - Have you ever met other brothers and sisters with siblings with I/DD?
3. **The meaning of their experience**
   - Did you ever have to do something special because you have a brother/sister?
   - Do you think having a brother/sister with I/DD has influenced your life in some way?
   - How do you feel being a sibling of a child with I/DD?
   - What do you need as a sibling to be happy?
   - Is there anything I have forgotten to ask you about?

The combination of different methods of collecting data- the parents' questionnaire, the interviews and the observational and field notes - allowed for some comparison of data between parents and siblings.

Data analysis

All the interviews with siblings were audio recorded and transcribed. We decided to use the features of Atlas.ti (2002–2019) as it was considered an easier, faster and visual method to codify our data. This computer-assisted software for analyzing large amounts of qualitative data has facilitated the coding process.

First of all, we familiarized ourselves with the collected data. We started the transcription of the interviews as soon as we initiated the data collecting process. Some of the observational notes we made during the transcription served to influence and improve the subsequent interviews with the other participants, by reformulating particular questions or giving more prevalence to some of them. At the same time, reflective and field notes made after conducting the interviews, were also taken into account. This material was used alongside the codification process and served to enrich the interviews with relevant information. Regarding the setting of the interviews, for example, the participants' various behavior during the sessions was noted and any personal information about their families that might assist the broad understanding of the collected data.

Having transcribed approximately half of the interviews, we started the codification process. We conducted a systematic and iterative process of coding any piece of data that had relevance to the research question. Codes could be a word or a short sentence highlighting the meaning of that specific piece. We generated the codes in an inductive way. Even when not required in the type of thematic analysis that we were performing, we decided to use a coding reliability measure. Thus, 10% of the interview data was subjected to an inter-coder agreement with an independent researcher, which resulted in a 79% of initial agreement. Disagreements were then discussed in order to achieve a final common view.

A first set of themes was developed from the final group of codes. Definitive themes and their interrelations were discussed between the first, second and last author until a consensus was reached. After having achieved this point on the analysis, we considered the paper by Moyson and Roeyers (2012). This seemed to represent an important background considering earlier work. From this, we adopted their nine domains of siblings' quality of life (mentioned in the Introduction), to report our findings.

Ethical issues

Ethical approval of the project was sought and granted by the Ramon Llull University Ethics Committee (reference number 1819001D). Siblings' choice to participate freely was fundamental. Consequently, their assent was verbally collected in the first meeting. Siblings were informed that they could withdraw from the research at any time without any kind of inconvenience.

Due to the sensitive nature of the discussed topics authors took time to ensure the siblings were feeling safe and comfortable throughout the data gathering process. The interviews took place in familiar environments of the parental home. The researcher and the siblings were alone and with no interruptions. The parents and children had already given consent and the parents remained in the home. Additionally, siblings were asked if there was any information they did not want to be shared with their parents. This was important as there was a debriefing session that was performed with parents after the siblings' interviews.

RESULTS

The research findings[1] are reported using the nine domains of siblings' quality of life described by Moyson and Roeyers (2012) (see Table 4).

Joint activities

A majority of siblings ($n = 10$) talked about joyful moments and activities shared with their brothers or sisters with I/DD. These activities were mainly playing, doing sports or watching TV. Four siblings indicated they did not do activities together with the sibling with a disability since they had different interests; for instance, a brother reported not being much involved with her sister with Down syndrome because "she likes to play with dolls and be bossy" (Nil, 8 years old). Only five of the 14 siblings recognized the need to adapt activities according to their siblings' interests and created funny moments for them:

> "We jump pretending to hurt ourselves and she laughs, we throw things at her and she laughs, if she breaks things or throws things at you, she laughs... we play like this" (Jordi, 11 years old)

Four siblings reported care-related tasks as joint activities, such as dressing or looking after their brothers or sisters with I/DD while outside, and one sister indicated her pleasure in doing such activities.

TABLE 4 Nine domains of sibling quality of life (Moyson & Roeyers, 2012)

1. Joint activities
2. Mutual understanding
3. Private time
4. Acceptance
5. Forbearance
6. Trust in well-being
7. Exchanging experiences
8. Social support
9. Dealing with the outside world

Mutual understanding

Almost all participant siblings ($n = 13$) developed their own way to interact and communicate with their brothers or sisters with I/DD; using words, gestural communication, pictograms or facial expressions. Two sisters referred to understanding their brothers or sisters even better than their parents:

> "I am the one in my house who understands her best. When someone does not understand her, they always ask me: What does Susana say? Susana explains it to me, and I tell them." (Beatriz, 11 years old)

Four siblings seemed to "infer" they knew what their brothers or sisters want or feel with some suggesting it is because of their shared bond.

> "She communicates but sometimes it makes me sad that she cannot express herself, she gets angry and hits herself [...] I don't know much about sign language, because there are a lot of signs...but sometimes I understand her as a sister, I mean, sometimes we are connected..." (Lilith, 10 years old)

Private time

Five siblings reported it was important to have private time and to have their own bedroom; although two sisters reported wanting to sleep with their siblings with disability at night. Three sisters valued having spaces without their brothers or sisters and spend private time with their parents:

> "Inside the house Claudia is the one who has all the attention but outside, maybe it's me." (Lilith, 10 years old)

> "For example, at the dentist where I know I'll have a bad time, I don't like him to be there because I need my mother to be just for me." (Júlia, 10 years old)

Acceptance

Siblings developed their own understanding of what is going on with their brothers or sisters with I/DD, with one sister recognizing: "I didn't know a lot, I just accepted him and that's it" (Tània, 11 years old). Three siblings reported having a "normal" relationship with their siblings with I/DD, not different from the relationship with siblings without a disability.

A sister suggested that knowing the "name" of her sister's disability has helped her to understand her sister's disability and to be able to give an answer to those asking about her. Furthermore, five sisters showed an understanding of different parental treatment towards their brothers or sisters, while craving parental attention for themselves:

> "It's like they're paying more attention to him, I understand, but they also have to pay a little bit of attention to me, you know. Because I'm not... invisible." (Judit, 9 years old)
>
> "I'm fine as a sister, what I dislike is that they leave me as a second dish." (Tània, 11 years old)

Two sisters recognized being positively influenced by their brothers or sisters with I/DD, like being more open-minded and more sensitive to other people with disabilities. None of the 14 siblings reported being influenced in a negative way.

Forbearance

Five siblings indicated needing more patience and self-control than other siblings when having a brother or a sister with disability. Different situations were mentioned, like having to give more frequent explanations to their brothers or sisters with I/DD, having to adapt themselves to their siblings needs or when dealing with specific circumstances like echolalia or tantrums.

A sister when asked about what she considered important from her experience as a sister in regard to family relationships said:

> "More than anything, I think he is a person like us [...] I treat him like a normal brother, although sometimes I have to make my parents be more attentive because he has autism, right? I also have to do special things, such as spending more time studying alone because he needs help too." (Judit, 9 years old)

Trust in well-being

Five siblings reported fearing something bad could happen to their siblings, like others taking advantage of them due to their disability, falling outside the bed, or hurting themselves. A sister mentioned being happy to share her bedroom with her sister because "I'm feeling safe that she is alright and nothing happens to her" (Beatriz, 11 years old).

Siblings with I/DD having medical issues also affect sibling's well-being, with a few siblings ($n = 3$) indicating being worried about their brothers or sisters' health but also tired of attending their brothers or sisters with I/DD' medical appointments.

> "The moment I suffered a lot was when he was 6 months old that he had a heart surgery and, of course...I cried when they told me [...]. He was my brother and I didn't want anybody to touch him. [...] Then, my parents gave me things to listen to his heart, so that I would lose my fear." (Júlia, 10 years old)

A few siblings ($n = 5$) referred to feeling sad for their brothers or sisters with I/DD because of experiences they were not able to have or difficulties they faced daily, due to their condition or limited abilities.

> "The sadness is because sometimes when we are going to do cool things, like for example cool trips, she can't join us." (Jordi, 11 years old)

Exchanging experiences

Only four siblings reported wanting to meet other brothers or sisters who had siblings with I/DD in order to share similar experiences and to feel understood by them. A brother explained why he would like to meet other siblings:

> "Because while I don't know anyone who has a brother like this, I get sad because it seems that only my brother has a problem." (Rafa, 7 years old)

Two sisters already knew other siblings of children with I/DD and noted being happy to share activities and experiences with them. Three siblings wanted to share some advice to other siblings of people with I/DD such as having patience, looking for useful resources to express their emotions and talking with their parents.

Social support

Half of the siblings reported relying on their parents to know what was going on with their brothers or sisters with I/DD. Parental explanations helped them to understand and normalize their siblings' behavior:

> "I was told that he was different from the others, that he had autism and that I don't have to be afraid if my brother would do weird things and people stare weird at him" (Judit, 9 years old)

> "Down syndrome is something that occurs inside the body, which when you are born makes it difficult for you to do things… and doesn't let you relate like others do." (Nil, 8 years old)

Few siblings ($n = 5$), mentioned support they received from extended family, like fixing toys broken by their brothers or sisters with I/DD or playing with their siblings:

> "Robert had the best relationship with my grandfather [...] I don't know why but for some reason they connect very well, you know? They are always playing together… my grandmother also plays a bit with him but is mostly my grandfather the one with whom Robert wants to play" (Júlia, 10 years old)

Two of them, specifically referred to the relationship with their cousins, involving moments of playing while taking care of the child with disability:

> "Two of us play together while one keeps an eye on Marta [...] because she could run away" (Guillem, 7 years old)

A few siblings ($n = 6$) commented that having friends to trust and feeling understood by them was important. Professional support for their brothers or sisters with I/DD was also beneficial for siblings ($n = 3$) as they could spend more time with their parents, learn new ways to communicate with their brothers or sisters or improve their knowledge about disability.

> "That's why we have this assistant so my mom can dedicate time to me" (Lilith, 10 years old)

Dealing with the outside world

Half of the siblings mentioned different types of experiences when at the school or when interacting with the larger community. Four indicated being questioned and having to give explanations about their brothers or sisters with I/DD. In this sense, one sister referred to how teachers could help siblings at school:

> "There are a lot of people who…well now not so much because now everyone knows Robert has Down Syndrome although some do not know much what it means, but well, I leave it to be. But before, they asked me a lot: "What is it?" and of course, I didn't know how to explain it to them because I'm not an expert either and, I don't know, maybe teachers could explain it a bit in order for others to get informed too." (Júlia, 10 years old)

Three siblings also reported being stared at by strangers; yet a brother from a rural city, noted that people could be nicer and respectful when going out with his sister with PIMD. For a couple of siblings, dealing with the outside worldmeant dealing with physical barriers, like narrow sidewalks or occupied special parking lots by people without disability.

Finally, a sister reflected about the stigma her brother may suffer due to the invisibility of autism, including being called bad words, not being accepted because of his interests or being stared at in the streets. That's why, she called for a collective mind-set change:

> "People also have to start understanding that there are people different from them, not only for the physical aspect but for the inner aspect." (Judit, 9 years old)

Parental' perceptions on siblings' relationships

The questionnaire answered by the parents ($N = 13$) reported significant information about parents' perceptions of their children' relationship. Almost half of the respondents ($n = 6$) commented that their children used to fight and argue.

> "They get along well and love each other a lot, but there are always a lot of fights and discussions." (Mother, 39 years old)

Five respondents reported their children had a nice relationship involving feelings of love and all the participants indicated their children used to share time and activities together. Two mothers reported feelings of jealousy by their children with no I/DD and explained this was due to different parental treatment in responding to the child with I/DD' health issues. A few respondents ($n = 3$) indicated how certain characteristics associated with the brother or sister with I/DD might impact the quality of the siblings' relationship, such as communicative disorders or the child with I/DD having a tendency to hit or invade the personal space of their siblings. Yet a few respondents ($n = 3$) noted how the difficulties of their children with no I/DD of comprehending their brothers or sisters' needs, could affect their relationship as well:

> "Although [*their relationship*] is good I think that the fact that she doesn't speak fluently, disturbs Nil and he doesn't get along well. They love each other and they are jealous of each other. They also band together and play together." (Mother, 42 years old)

The questionnaire asked about some aspects, such as interests or worries, that siblings might have regarding their brothers or sisters with I/DD. Some respondents ($n = 4$) noted different worries of siblings concerning their brothers or sisters with I/DD. For example, being worried about their well-being, their eventual death, their difficulties in doing age- related tasks and about their future after their parents decease.

Finally, during the debriefing sessions at the end of the process, a few ($n = 5$) parents commented that taking part in the interviews appears to help their children understand their brothers or sisters with I/DD. They also reported some emotional reactions on siblings after these sessions.

DISCUSSION

The aim of this study was to become more informed about the quality of life's perceptions of siblings of children with I/DD living in Catalonia. Siblings' data was enriched with the parental views on siblings' relationships- showing different feelings and perceptions.

This study makes several contributions to the literature. It is relevant to note that children in this study could relate their experience of having a brother or sister with I/DD from their own point of view. Further than relate, siblings were able to describe, in a mature and sensitive way, their inner perceptions and lived experiences of having a brother or a sister with I/DD. Barak-Levy et al. (2010) suggested that asking children themselves resulted in relevant and useful information about their own experience. In fact, interviewing siblings in the context described in this article highlights, despite their age, information about their quality of life and in this instance including their capacity of young siblings to report inner experiences. However, there are certain issues that must be taken into consideration.

First of all, it was important to develop rapport while the sibling and interviewer got to know each other. In this research this was assured by spending time with the siblings without I/DD prior to the more formal section of the study. For example, talking about their hobbies and interests using plain language, drawing and playing (Irwin & Johnson, 2005). The interview structure should be flexible enough to adapt to the circumstances that may occur during the formal interview (e.g., external interruptions, unexpected relatives' visits) and to the needs that children may have (e.g., time to get involved, movement needs).

We then followed a set of questions that served as a "guide" for the interviews, which we expected to facilitate the openness of the discussion including welcoming interjections or topics siblings might bring up (Cameron, 2005). In this sense, it was important to let the participants talk freely about whatever they considered from the interview questions. In the case of younger children, it was thought necessary to provide opportunities for drawing, games, toys and other prompts to stimulate the conversation (Cameron, 2005). This was found to be the case with the youngest participants (from 5 to 8 years old). Additionally, on some occasions the active presence of parents prior to the formal interview was useful to introduce new related topics that triggered some memories in the children (Irwin & Johnson, 2005).

The results demonstrate that children have their own voice and agency and this information should be useful to researchers, school teachers and other practitioners who could then provide support and insight which is relevant to all members of the family. Likewise, Luijkx et al. (2016) noted that siblings' reports differ from those of their parents when asked about their quality of life. This is consistent with an ongoing concern in the FQOL field that it is desirable to collect the views of all family members, since we already know that family members may have somewhat different perceptions from each other (Francisco Mora et al., 2020; Gardiner & Iarocci, 2015; Wang et al., 2006).

The social contexts where siblings live are influenced by cultural values that affect the social response to disability. For instance, when siblings report experiences linked to stigma under the "dealing with the outside world" domain, such as being stared at by strangers, or disrespectful behavior towards people with I/DD and their needs, such as occupied reserved parking lots, they are reflecting about the struggles they face when interacting with the wider community. Siblings are aware of the way their brothers or sisters do not always fit into the norms and values of society. These results are in line with those of Boelsma et al. (2017), who found that not having the support and consideration from those in the immediate family and the local society where they were living, negatively impacted their FQOL. On the other hand, good relationships within the family unit and the positive role played by the extended family were important for siblings, something noted as well in other studies conducted in Southern Europe (Mouzourou et al., 2011).

The nine domains of sibling's quality of life by Moyson and Roeyers (2012) have proved useful in reporting siblings' perceptions. Results from the present study have shown similarities with those in Moyson and Roeyers (2012) and Luijkx et al. (2016), with siblings reporting both positive and negative experiences as a result of having a brother or a sister with I/DD. The "joint activities" and the "mutual understanding" domains received the highest number of positive references from siblings, demonstrating the importance of being able to spend quality time with their brothers or sisters with I/DD and to establish successful and enriching interactions with them.

The "acceptance" domain seems to be characterized by the importance of siblings referring to knowing of their brothers or sisters' I/DD. However, it is interesting to note the ambivalence presented on sibling's reports. Even when accepting and understanding a different treatment to their brothers or sisters due to their disability, this different treatment may not be well accepted. Something similar is found in Luijkx et al. (2016), where siblings reported their difficulties in accepting their brothers or sisters' disability because of the related difficulties they might have. We can perhaps infer that the acceptance process would oscillate and evolve during the sibling's life. Regarding the "exchanging experiences" domain, just a few siblings declared willing to meet other siblings in their situation, which differs from the findings of Moyson and Roeyers (2012). However, siblings indicated on the "social support" domain the importance of receiving a diversity of support from relevant people, in line with Moyson and Roeyers (2012).

Despite the usefulness of these domains, key aspects of siblings' perceptions have not been properly addressed. Siblings reflections denote the importance of family' dynamics and family interactions on their reported well-being. As defined by Zuna et al. (2010) "family quality of life is a dynamic sense of well-being of the family, collectively and subjectively defined and informed by its members, in which individual and family-level needs interact" (p. 262). Due to this dynamic and its interactive nature, disability could not be considered as a single outcome to explain the quality of life perceptions of siblings or of the other members of the family (Boelsma et al., 2017). Further exploration of siblings' experiences, such as the influence of family dynamics on the relationship between the siblings, including the siblings' roles, is necessary.

The information from the questionnaire answered by the parents, supported to some degree the data from siblings, although there are some differences that are important to remark. For instance, respondents referred to the fights and arguments their children used to have, something that was not equally highlighted by siblings. Parents respondents indicated feelings of jealousy amongst their children while this was not seen in the siblings' data. In general, parental responses seemed to be focused on the "negative side effects" that having a brother or sister with I/DD might have on siblings, rather than the more "balanced" views that siblings reported.

Strengths and limitations of the study

One of the strengths of this study is the wide variability of diagnosis amongst the brothers or sisters with disability and simultaneously the similarities of quality of life' perceptions amongst siblings. The debriefing sessions with parents after the interviews are another strength of the study. They represented an opportunity to discuss issues concerning the siblings and to give feedback from the sessions.

This research had a relatively small purposive sample. Despite this, the reported findings add to those from Moyson and Roeyers (2011, 2012) and Luijkx et al. (2016) and, as explained in Brown (2016), when "the research is repeated in various situations in different countries and the results are similar, then the data should surely be taken seriously and acted upon" (p. 3). Consequently, the findings that we present must be considered as part of a bigger picture that is beginning to provide information on siblings' quality of life perceptions.

Another limitation is that parents were the ones deciding to participate. While this is the general norm when researching with minors, it implies that siblings' voluntary participation was not guaranteed at first. The authors had to make conscious efforts to collect siblings informed consent and to assure their willingness to participate.

This study was limited to the exploration of quality of life' perceptions of siblings without I/DD. At this stage, we did not collect the perspective of the brother or sister with I/DD. This is indeed important for further research which should be undertaken to explore their quality of life as siblings. Given their limited communicative and cognitive abilities, creative and flexible ways to get to know about their perceptions will be needed. In addition, it would be interesting to look at the perspective of the different members of one family unit, collecting the similarities and divergences that may appear.

Implications for practice and future research

These findings have important implications for families, siblings and children with I/DD. Families could be interested in knowing about the balanced perspective that siblings offer regarding the experience of disability, which should positively influence family quality of life. For siblings, knowing about how other siblings without I/DD felt about the experience of family life, might help them put things into perspective and provide support as they could discover not being alone in their feelings and circumstances. At the same time, it is a way to valorize themselves as they realize the important role they have in their families. Children with I/DD may benefit from these research findings, given the siblings' relationship power and the commitment of these young siblings towards them. This information may help parents to obtain greater insight and have a positive impact on family dynamics.

This research supports the need in the QOL/FQOL field for more research conducted with different populations and in multiple countries and situations (Brown, 2016). Although the current research has a limited scope due to its culturally situated characteristics, it is important to keep collecting the voices from those in the margins (due religious, linguistic, gender or age-related reasons) in order to depict a more realistic image of FQOL.

We have seen the importance of finding out about children's views. Accordingly, more research on this topic needs to be undertaken that leads to practical ways to collect and take into account young siblings' perceptions. Finally, it is recognized that this particular group of siblings is an important group to examine, and this needs to be further followed up across the age range because the results may differ considerably over time.

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CONFLICT OF INTEREST

No conflict of interest has been declared.

ETHICS STATEMENT

Ethical approval of the project was sought and granted by the Ramon Llull University Ethics Committee (Reference Number 1819001D).

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ENDNOTE

[1] The full list of quotes may be obtained by writing to the first author (olgamc1@blanquerna.url.edu).

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CHAPTER 4.

Is the quality of life of siblings of people with intellectual and developmental disabilities influenced by family dynamics and parental performances? Initial explorative study from young siblings' perspectives

Múries-Cantán, O., Giné, C., Brown, R. I., García-Ventura, S., & Schippers, A. P. (submitted). Is the quality of life of siblings of people with intellectual and developmental disabilities influenced by family dynamics and parental performances? Initial explorative study from young siblings' perspectives. *Journal of Intellectual & Developmental Disability.*

Some related documents are added at the end of this dissertation:

- Recruitment letter to families (see Appendix D)
- Recruitment letter to the institutions (see Appendix E)
- Information flier to siblings (see Appendix F)
- Informed consent document for the discussion groups (see Appendix H)
- Demographic questionnaire (see Appendix I)

Is the quality of life of siblings of people with intellectual and developmental disabilities influenced by family dynamics and parental performances? Initial explorative study from young siblings' perspectives

Running head: **Siblings' quality of life & family dynamics**

This article explores the influence that family dynamics and parental performance can have on the quality of life' perceptions of siblings of young individuals with intellectual and developmental disabilities (IDD). Using a qualitative approach, this study gathered data from eleven-year-old siblings via two discussion groups. Data were analyzed through an inductive thematic analysis. The results highlight the influence that family dynamics can have on two major areas on the siblings' life: the relationship with their brothers or sisters with IDD and the views they hold about their families. Further, findings suggest a considerable level of maturity amongst siblings of this age, as shown by the critical opinions they have regarding their family situation. Implications of study findings and suggestions for future research are discussed.

Keywords: siblings, intellectual and developmental disabilities, quality of life, family dynamics, relationships.

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Introduction

Family quality of life (FQOL) literature has revealed that families have their own characteristics, dynamics, and relational patterns. The natural cycle of family life causes these elements to evolve and change, modifying families' needs and desires. Due to the holistic nature of families, interactions, and relationships inside the family affect all its members (Brown & Brown, 2004). At the same time, what influences individual quality of life, may also influence the quality of life of the whole family and allied social system (Brown & Brown, 2004).

FQOL is defined by Zuna et al. (2010) as a "dynamic sense of well-being of the family, collectively and subjectively defined and informed by its members, in which individual and family-level needs interact." (p. 262). Siblings[1] represent an essential part of the family and influence and are influenced by its daily well-being. The unified theory of FQOL proposed by Zuna et al. (2010), suggests four groups of concepts that could help to influence FQOL: a) family-unit concepts, b) individual family-member concepts, c) performance concepts and d) systemic concepts.

Regarding the family- unit, two concepts were reported: family characteristics and family dynamics. The first one is associated with objective characteristics of the family, such as income or family size. As Schlebusch et al. (2018) noted, these characteristics are usually difficult or even impossible to change, even when having an important influence on FQOL' outcomes (Wang et al., 2004). The second one is defined as "aspects of interactions and ongoing relationships among two or more family members" (Zuna et al., 2010, p.263). Exploring how these interactions and relationships

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[1] Note: For clarification purposes, the word "Siblings" is capitalized when referring to siblings of people with intellectual and developmental disabilities.

may be affecting the perceptions of siblings without IDD on their own quality of life, may be useful in attempting to bring about positive change or modification.

Siblings and Quality of Life: A Critical but Understudied Topic

It is only in recent years that there is an increase in studies regarding siblings of people with intellectual and developmental disabilities. Each person experiences their family' life in subjective and particular ways. Although sharing similarities with the experiences of the whole family, roles, responsibilities, or individual personality' traits, may uniquely colour the experiences of family members. Almost two decades ago, Brown and Brown (2004) highlighted the importance of gathering the voices of all family members to know about their family quality of life.

To date, several studies have focused on adult Siblings relating to particular issues of their experience; for instance, the enlargement and multiplicity of roles Siblings perform partly as a consequence of an increased life expectancy for people with disabilities (Hall & Rossetti, 2018; Heller & Arnold, 2010). However, there is little published data focused on younger Siblings who are the focus of our study. In this line, a few authors have been interested in young Siblings quality of life perceptions and asserted the importance of asking Siblings directly about their experiences and perceptions of quality of life (Luijkx et al., 2016; Moyson & Roeyers, 2011).

There have been a few studies which use specific domains and examine these Siblings' quality of life. For example, Moyson and Roeyers (2011; 2012) developed a set of nine domains to describe Siblings quality of life: Joint Activities, Mutual Understanding, Private Time, Acceptance, Forbearance, Trust in Well-being, Exchanging Experiences, Social Support and Dealing with the outside world. Correia and Seabra-Santos (2021) reported two domains: Future and Family relationships.

Present Investigation

Research conducted by the present authors on Siblings’ quality of life (Múries-Cantán et al., 2023), suggested the importance of family dynamics on Siblings’ quality of life such as family interactions and parental communication. Following that research, the aim of the present article is to explore the possible influence of family dynamics and parental performances on Siblings’ quality of life perceptions, as reported by Siblings themselves. Particularly, in this study we examine parental interactions with the siblings without disability, their communication, and practical actions inside the family.

Methods

Study Design

This qualitative study was designed to explore the influence of family dynamics and parental performance on Siblings’ quality of life perceptions. The research was conducted taking an inductive approach and data was analyzed following the principles of thematic analysis (Terry et al., 2017).

Participants

Participants were recruited through four special education schools and three NGO. Additional potential families were purposely reached (Palinkas et al., 2013). Our main objective was not to obtain large numbers but to focus in-depth on the experiences and perceptions of a small group of Siblings.

For recruitment purposes, an invitation letter was sent to the parents along with a colorful and illustrative flier containing research- related information also comprehensible to Siblings. These documents were provided in Catalan and Spanish. The first author contacted by phone those families willing to participate in the research to arrange a meeting prior to the discussion groups. The main goals of these meetings were: (1) to explain the research in-depth, solving any inquiries about it; (2) to collect the verbal assent from Siblings and the signed consent from parents; and (3) to conduct a short and audio- recorded interview with the participant sibling. This short interview was carried out to assure Siblings have understood the purposes of the research and their role in it. At the same time, it was an opportunity for both Siblings and researcher, to get to know each other and to start establishing a trustful bond. Questions regarding themselves, their relationship with brothers or sisters with IDD and leisure time activities were included.

A total of 6 Siblings, 5 females and 1 male, all aged 11 years old with a brother or sister with intellectual or developmental disability (IDD), agreed to participate in the study. Four out of six Siblings were interviewed on their own and the interviews were transcribed and included in the analysis (14' on average). It was not possible to conduct the short interview with two participants because of time limits but it was possible to exchange information and to obtain their consent (parents and Siblings).

The parents were required to complete a short questionnaire to collect demographic information about themselves and their families. Respondents were mothers (3) and fathers (2) (two of the participants were twins, so the total does not match N=6). Ten of them had completed higher education, had a paid job and were living in urban areas in the same house of a partner and their children. Regarding the perception of monthly income, the respondents considered it enough to support the family's needs. Demographic characteristics are presented in Table 1. Pseudonyms are used to preserve the identities of the participants.

TABLE 1 PLACED ABOUT HERE

Discussion Groups

Two discussion groups were performed to gain an insight into the personal stories of the participants in a shared context. The groups were considered appropriate for 11-year-old Siblings, due to the linguistic abilities and reflexive thinking the children this age have achieved. One group was constituted of two females and one male and the other one was formed by three females. This small sampling size enabled the researchers to build a more intimate environment where Siblings could feel comfortable. Furthermore, small sized groups were considered more appropriate due to the participants' age and the sensitive content to be discussed (Moser & Korstjens, 2018).

The first group was conducted in a small classroom of the University. The other one took place in a classroom of a special education school. In both classrooms, the tables, chairs and recording material were placed in the most effective way for the young individuals' comfort and choice. The discussion groups were organized in two parts and lasted in total around 90 minutes. Each part took 40 minutes and was divided by a 10 minutes' break. That break was considered necessary to refresh the concentration levels of participants and an opportunity to share some cookies and juice while having a relaxed talk all together. Groups were videotaped from the beginning to the end, without stopping the record during breaks to obtain informal information from Siblings that could eventually enrich the findings. A summary of the main structure of the question' guide and the activities performed to stimulate the discussion, are provided in Table 2.

TABLE 2 PLACED ABOUT HERE

The groups were conducted by the first and fourth authors: the first one had an active role guiding the discussion following the question' guide and the latter was checking the recording material, tracking the question' guide to avoid the loss of important information and keeping observational notes. The question guide for the discussion groups was based on the Siblings' quality of life domains defined by Moyson and Roeyers (2012) and refined with the key findings and most repeated ideas and feelings from a previously conducted research (Múries-Cantán et al., 2023).

Quality Procedures

The triangulation of information was accomplished by combining and comparing different methods of collecting data: the parent's questionnaire, the discussion groups, and observational and field notes. Ethical approval of the project was sought and granted by the Ramon Llull University Ethics Committee (Reference Number 1819001D). Siblings' assent was verbally collected in the first meeting. Siblings were informed that they could withdraw from the research at any time. Confidentiality was provided during the sessions and the setting of a safe space and a sense of familiarity with Siblings was actively promoted.

Data Analysis

Data from the short interviews and discussion groups were codified and categorized using software on qualitative data analysis (Atlas-ti). Field notes that were taken during the collection of the data' process, served to enrich the analysis by adding information about the behavior or emotional state of the participants during the development of the short interviews and discussion groups.

Data was analyzed following the principles and phases of thematic analysis as described by Terry et al. (2017). The first author, who was already familiarized with the data, developed a first draft of descriptive codes to capture the direct meaning of Siblings expressions, and of interpretative codes to help explain what Siblings were expressing in an implicit manner. After codifying all the dataset, codes were grouped into themes and sub-themes. That list of codes and themes was then checked by the first and the second author during collective discussions until consensus was reached and definitive themes and their interrelations were established. These themes were then grouped into two major topics: (1) Focus on Siblings' relationships with brothers or sisters with IDD and (2) Focus on families. The first topic includes four themes: "attitudes towards brothers or sisters with IDD"; "interacting with siblings with IDD"; "understanding the sibling with IDD"; and "connecting with their brothers or sisters with IDD". The second, comprises two themes, namely, "critical views regarding parental' performances" and "daily life: comments on agreement and regret".

Results

Family dynamics and, specifically, parental performance appear to be influencing Siblings' views about their family and their brothers or sisters with IDD. The results are provided under two main topics: (1) Siblings' relationships with brothers or sisters with IDD and (2) Siblings' views about their family situation.

1. Siblings' Relationships with Brothers or Sisters with IDD

The relationships with brothers or sisters with IDD are found to be notably important for all participant Siblings. Siblings appear to have managed to establish a meaningful relationship with their brother or sister and a special bond. Siblings reported their relationship as being constituted by moments of affection and joy and, to a lesser extent by anger and jealousy. Siblings recognized positive aspects of their relationship with their brothers or sisters with IDD, like having a partner to share negative moments with or being able to play with them; something one sister affirmed this was due to her sister's disability despite the fact this sister was several years older.

> "What I like the most about [sister with IDD] is that she is now 16 and if she didn't have a disability, she wouldn't play with me […] I guess it's because she has a disability that she plays more with me and so I spend more time with her." (Maria)

One of the multiple ways Siblings show love towards their brothers or sisters with IDD is by adapting ways of playing so their brothers or sisters can enjoy playing as well. For example, one sister reported the way she played with her sister:

> "For instance, we play hide-and-seek and she hides behind the door and starts knocking on it. Then, you have to pretend you are a bit dumb and start asking "Where are you?" while not looking at the door. If not, it's not funny. Finally, she touches you on the back and you have to act pretending you are surprised." (Cristina)

Another example is by accepting their siblings with IDD as the way they are:

> "For me it's not necessary that he changes, because for me…everything will be the same, you know?" (Sònia)

Generally, Siblings appear to receive information about their brothers or sisters with IDD directly from their parents. The way parents talk about the disability or condition appears to help Siblings understand and apprehend their situation:

> "When I was around 2-3 years old, I realized my sister was different…my parents explained to me that she was not [different], that she was normal. Later, I saw that she was a special person, different, nicer." (Maria)
>
> "As I was growing up, I realized how my sister was, that she didn't speak; at the age when I started talking, she wasn't talking and so I was getting it […] and also because my parents explained it to me." (Carmen)

In fact, Siblings reported positive outcomes, like a better understanding of brothers and sisters due to having proper and reliable information about their disability. For instance, one participant considered his brother as "more innocent" after knowing about his condition, which helped him to behave better with his brother. Siblings described feelings of pride when helping, teaching, or understanding their brothers or sisters with IDD; something they often appeared to do even better than their parents:

"I understand [sister with IDD] so well. I think it is because we spent a lot of time together that, sometimes, I can understand her while my parents don't." (Maria)

It seems that the close contact between siblings over time, made them able to understand their speech better than other people. Consequently, Siblings reported moments when they interact with brothers or sisters with IDD without their parents' awareness, strengthening their shared bond:

> "For example, sometimes he wants to eat something, so we [she and her twin sister] became sidekicks with him and gave him what he wants" (Sònia)

Siblings appear able to regulate themselves in order to be patient towards their brothers or sisters with IDD. However, Siblings feel this patience is not valued enough by their parents if they are not witnessing their efforts:

> "We have a day-care provider and she [sister with IDD] is in love with her and so she becomes super intense […] She keeps saying: "ba ba ba" [calling the day-care provider] and there comes a point you [referring to herself] say "Shut up now!" and my parents [said]: "Be patient…" but I have spent all afternoon with her saying "ba" and she is getting up my nose!" (Cristina)

Siblings expressed their concerns regarding their brother's or sisters' future. A sister recognized being worried about her sister' academic abilities and another participant tried to figure out his sibling's future regarding his abilities to make new friends. Despite this, almost all participants trusted their Siblings’ abilities to be able to live on their own.

2. Siblings’ Views about their Family Situation

Siblings shared a critical view on their families, assessing and commenting on their parents' roles and interactions with their brothers or sisters with IDD. Witnessing certain interactions between parents and brothers or sisters with IDD may cause disturbances in Siblings’ well-being. These disturbances might be explained by a sense of unfairness reported by Siblings, like a preferential parental treatment or a lack of coherence in parental’ responses towards brothers or sisters with disability.

In this sense, Siblings were willing to do things differently regarding their Siblings with IDD than what their parents used to do. For instance, by sticking to what they have promised to their brothers or sisters or by promoting their autonomy:

> “For instance, if he wants something to eat but he has just finished dinner, [my parents] just said to him that he wouldn’t eat more; despite this, they finally give more food to him. So, no! If he is just finished, he is just finished!” (Eva)
>
> [Discussing about their relationship with their parents] “Is similar but different from the one they have with my sister. It is similar, but they have her more spoiled than me and they consent to her on more issues. For example, regarding putting the dishes in the dishwasher, she is perfectly able to do it but she never does.” (Cristina)

The last quote is an example of a general perception shared by Siblings, who see their brothers or sisters with IDD with capabilities that their parents might not think they have. However, it is not clear if this perception is always related with Siblings' positive assessment towards their brothers or sisters or with feelings of anger and jealousy due to a perceived different parental treatment.

Regarding varied approaches by parents, Siblings raise two concerns: (1) when their parents allow something that Siblings regard as not necessary at that moment or (2) when brothers or sisters with IDD are allowed to do something not permitted to the Siblings themselves. It seems that when parents are not coherent with their actions, this often does stress Siblings:

> "They don't used to reprove him but, when they do it, my father
> says to him: "Ok, today, you will not have the [computer] tablet"
> but then, the night comes and he is like "hey, would you like me to
> give you the [computer] tablet?" and I said: Dad, you have said no
> to him!" (Eva)

It is also interesting to note that Siblings understood that their brothers or sisters with IDD might require more attention due to their higher needs:

> "Because he can do less things and I can already do a lot of
> things…that's' it." (Eva)
>
> "It is because he has a disability." (Pau)

Even when understanding this difference, as clearly reported by participants, this comprehension did not keep them away from feelings of jealousy or being isolated from their parents. Despite these feelings, Siblings also showed empathy towards their brothers or sisters and were aware of the difficulties and challenges they might face, as exemplified in the quotes below:

> “Sometimes she gets really angry but, by putting myself into her shoes, I think that if I couldn’t talk, how would I communicate myself? I’ll probably scream as well” (Carmen)
>
> “When [sister with IDD] wants to explain something to us and we cannot understand her… she should feel like…oops!” (Cristina)

Discussing Siblings' self-reported position inside their families, Siblings suggested their parents used to place more responsibilities on them than on their brothers or sisters with IDD. A feeling of being in a role reversal, where younger Siblings were performing like the eldest ones, was consistently reported by Siblings. Interestingly, two participants referred to their parents and themselves as a separate entity from their Siblings with IDD, as if they were sharing responsibilities towards the member with disability. An example:

> “My sister is now at my school but we will transfer her to a special school soon. I’m worried that she could have a bad time due to being in another school”. (Carmen)

A sister related that keeping certain family rituals and traditions was something she valued and enjoyed, like watching a movie or sharing a special meal all together.

> “On Friday, Saturday and Sunday’ nights, we watch a film or series. That’s something all of us like to do. However, when I choose to watch something my sister dislikes, she can bear it or she can do another thing.” (Maria)

The way parents react to daily challenges, seems to influence Siblings’ views and to modulate their reactions. In the following extract, two participants related to a common lived situation by their family: having to deal with those who park without permission in a disability parking area. Whilst this situation may be considered excusable or inoffensive for these people, the sisters referred to the inconveniences and disturbances it causes in their families:

> “Eva: There are a lot of people who park without a card in a disabled parking area. The other day mom had an argument with a boy who said: “Hey, we have got the card.” Yes man! It was expired! [...] Sònia: Mama got out of the car and started: (shouting) “Let's see, if you don't have a disability card, why are you parking here?! The boy was not believing it and my mother asked: “Do you want me to open the car door for you and see [child with IDD]?!” (Eva & Sònia)

All participants approved their parents’ furious reactions in such circumstances, considering them coherent and with good reason.

Overall, these results provide important insights into the critical and personal- oriented views Siblings hold about their families and considering the influence of family dynamics and parental performances on their quality of life.

Discussion

The current study aimed to explore the influence of family dynamics and, particularly, parental performance on Siblings’ quality of life perceptions. Siblings’ extracts denoted that parental performance might be related with some of the Siblings’ quality of life domains described by Moyson & Roeyers (2012): Joint activities, Mutual understanding, Acceptance, Forbearance and Dealing with the outside world.

By informing Siblings about the conditions of their brothers or sisters with IDD parents may help improve the relationship between Siblings with and with no IDD, as well as their well-being. Better understanding of brothers or sisters with IDD, of their needs and realities, appears to lead to a stronger sibling' relationship. As siblings spent more time together, it became easier to understand one another, to reinforce their personal bond and to accept brothers or sisters as the way they are. However, the empathy or patience that Siblings were able to show towards their brothers or sisters with IDD are not exempt from frustration and disappointment if Siblings are not receiving parental recognition. In this sense, differences in the relationship and interactions between parents and children might be considered inequitable and resented.

Results contribute to the literature in many ways. The importance of effective relationships between the two siblings is essential to both of their lives and likewise to family relations and adaptation. Our results showed that siblings' relationships are necessarily connected to family relationships and are at times complex and giving rise to different emotions (e.g., happiness, amusement, irritation, jealousy). However, the flourishing of siblings' relationships, despite some external influences, like family dynamics or disability- related difficulties, constitutes a positive outcome that should be taken into account when exploring Siblings' quality of life. This is widely noted in studies in the field (see Diener et al., 2015; Jacobs & MacMahon, 2017; Moyson & Roeyers, 2011; Rossetti & Hall, 2015; Vella Martin & Zahra, 2021).

A further finding was noticing how family dynamics have placed the sibling with IDD in the nucleus of the family life. Siblings' statements suggested that family life revolves around the member with a disability. A differentiated parental treatment towards siblings with and with no disability, might contribute to the establishment of a certain relational pattern, working as a loop where all the members of the family play their own role. It seems that this loop may be maintained or even increase negative interaction if there is no awareness of the factors affecting it. For example, Siblings' extracts illustrate that family interactions can negatively influence their quality of life when considered unfair: causing them feelings of anger and envy. These results are consistent with those from Correia and Seabra-Santos (2021) where Siblings indicated how their brother or sister with disability have a preponderant role in their family life, leading to limitations on the ordinary family life cycle and on family' experiences. Noonan et al. (2018) also referred to this preeminent position the brother or sister with disability has in the family to the detriment of the other Siblings and highlighted how this might operate as a central connection promoting other family' members connections.

In the present research we have dealt with a particular age group of Siblings (eleven-years-old) who have demonstrated their own independent and critical views about what is going on with their families regarding disability. Taking a different perspective than their parents, Siblings spread light on their realities and self-experiences, enriching information about the always evolving family life. Consequently, it is necessary to keep collecting and reporting, not only the main caregivers, but the Siblings' voices on their quality of life.

For instance, it is important to stress the "role reversal" reported by Siblings. Siblings mentioned how their parents tended to place more responsibilities on them than on their brothers or sisters with IDD. This is in accordance with previous studies such as Hall and Rossetti (2018), Moyson and Roeyers (2012) or Jacobs and MacMahon (2017). It seems that Siblings with no disability ended up taking on duties and care-related tasks towards their brothers or sisters with IDD from early ages. Despite Siblings' sensitivity and willingness to help and support their brothers or sisters with IDD, this experience might lead Siblings to mature at an earlier stage than usual. The potential effect of that early maturation needs to be further explored.

Finally, it is relevant to note how Siblings valorize their brothers and sisters' abilities and imagine their successful future. Siblings' positive references to their brothers and sisters with IDD' achievements are commonly found in studies about siblings of individuals with different disabilities and conditions (ex: Goodwin et al., 2017; Gorjy et al., 2017; Paul et al., 2022; Sage & Jegatheesan, 2010). The main particularity of our finding is that Siblings' positive perceptions regarding their brothers or sisters' abilities seems from their words to be higher than those from their parents. It is possible, therefore, that Siblings could be promoting more situations of self-development for their brothers or sisters with IDD than their parents, which would be especially important for their future. These results are consistent with those of Noonan et al. (2018) who reported Siblings' concerns over their parents' constraining brothers or sisters' autonomy.

Limitations of the Study

The generalizability of these results is subject to certain restraints. For instance, there were only a small number of participants which may restrict the generalization of the data, though the results are consistent with other authors' findings, for example Moyson and Roeyers (2012) and Vella Martin and Zahra (2021). Future research should also consider that Siblings in different age groups or cultural backgrounds, may report on different experiences and points of view.

Finally, in this research we looked into the Siblings with no IDD' interactions with their brothers or sisters with IDD. An issue that was not addressed was the effect of the sibling with a disability on the sibling without IDD' quality of life. Further research could usefully explore the incidence of having a brother or a sister with disability on different aspects of the Sibling' life, like identity construction, the attribution of meaning of life or the development of relationships.

Conclusions and Implications

To sum up, we have seen Siblings' descriptions of the relationship they have with brothers or sisters with IDD, focusing on the attitudes and emotions displayed by Siblings together with the reported characteristics of the interactions with their brothers or sisters. Siblings referred to how receiving information from their parents about their brothers or sisters' disability resulted in positive outcomes improving their well-being. Siblings shared the multiple ways in which they relate to their brothers or sisters and reflected on the particular perceptions and concerns they have about their families. Additionally, Siblings commented on the views they hold about their families: especially regarding their parents and their daily life. Perceptions of a different parental treatment towards brothers or sisters were highlighted by Siblings together with the many interactions and roles they have in the family.

Further studies are required to understand the elements that might be affecting and either enhancing or disrupting Siblings' quality of life, like research on the influence of certain family dynamics or relational patterns on Siblings and family quality of life. More research on Siblings' particular needs and demands may strengthen the intervention of a variety of professionals, like educators, coaches, and psychologists. To this end, it is important to keep developing methods of collecting data from Siblings, particularly children and adolescents. As an example, the photovoice interview (where photos taken by the participants are used to promote and enrich the discussion) might be explored to gather data from Siblings and from other family members (Pavlopoulou & Dimitriou, 2020). More detailed studies should improve the available instruments of

FQOL (see Brown et al., 2006; Hoffman et al., 2006) or lead to the development of a parallel survey on Siblings' perceptions of their own quality of life.

Conflict of Interest

No conflict of interest has been declared.

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Table 1. Demographic Characteristics of the Families

Sibling Participant (N=6)				Brothers/ Sisters with IDD (N=5)		
Pseudonym	Gender	Age	Position in relation to child with IDD	Gender	Age	Type of IDD
Eva*	F	11	Younger	M	16	CP
Sònia*	F	11	Younger			
Cristina	F	11	Younger	F	17	ID
Carmen	F	11	Older	F	7	DS
Pau	M	11	Younger	M	13	ID+ADHD
Maria	F	11	Younger	F	16	DS

Variable	Parents (N=5)
Age (n), range (years)	43-51
41–50	4
50–60	1
Gender (n)	
Female	3
Male	2
Relationship to sibling participant (n)	
Biological mother	3
Biological father	2
Type of family (n)	
Couple with 2 to 3 children	5
Education level (n)	
Secondary/ Higher education	1
Bachelor's degree	1
Postgraduate degree/PhD	2
No reported information	1
Employment (n)	
Full-time or part-time	4
Others	1
Monthly income perception (n)	
Enough to support family’s needs	4
No reported information	1
Cultural origin	
Catalan / Spanish	5

*Twins

Note. ADHD= Attention Deficit Hyperactivity Disorder; CP= Cerebral Palsy; DS= Down Syndrome

One family declined to answer the questionnaire.

Table 2. Questions and Activities of the Discussion Groups

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1. Individually short presentation + introduction of the research
- Co-creating a story with illustrated colorful cards. Images of children with and without IDD and adults doing different activities. A wide range of emotions are represented.

2. Being a sibling
- Perceptions of having a brother or sister
    - Group discussion before & after watching a video about a sister (12) and a brother with IDD
- Spending time with family/ Participants relationship with their parents
- Positive & Negative moments about being a sibling
    - List on a clipboard. Listing elements about what they like of being siblings in front of those they dislike of being siblings
- Private time

3. Siblings' relationship
- Joint activities
- Trustworthy
- Mutual Understanding
- Acceptance
- Forbearance
- Trust in well-being

4. Siblings' well-being
- Reflection on well-being
    - Cards with Emotions to improve emotions recognition
- Needs as siblings to feel good being siblings
    - Thumbs Up or Down to get rapid feedback. Listing orally elements other siblings said about ways to improve their quality of life to get the participants reactions/point of view
- Brothers & sisters with an IDD influences on siblings' life

5. Ending Question
- Is there anything else you want to say about what we have been talking about this morning? Is there anything we have forgotten to ask you about?

6. Giving away participation certificates and candies to the participants to show our gratitude for their participation

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CHAPTER 5.

General Discussion and Conclusions

The aim of the research was to explore the quality of life perceptions of siblings of people with intellectual and developmental disabilities (IDD). To this end, three different but related studies focused on siblings' quality of life were conducted.

This chapter, divided into six parts, presents the discussion of the results and the conclusions that emerged from the whole study. This chapter is structured as follows: (1) Review of the aims of the research; (2) Summary of the main findings from the three studies; (3) Main theoretical, methodological and practical contributions of the research; (4) Strengths and limitations of the research; (5) Directions for future research; (6) Conclusions and final remarks. The full references list is also included.

5.1 Aims of the research

The main aim of the research was to explore quality of life perceptions of siblings of people with intellectual and developmental disabilities (IDD). In order to gain an understanding of siblings' experiences regarding their quality of life as a sibling of a person with IDD, the current state of the art was explored. Chapter 2 provides a systematic review of the literature on siblings and their quality of life perceptions. The findings of the review offered a general overview of siblings' perceptions on the context of their family and about the needs and challenges they had as siblings. At the same time, a gap in the literature was highlighted, namely young siblings are the most under researched group within siblings' research. Chapter 3 reports the study focused on how young siblings -aged 5 to 11 years old and living in Catalonia- describe their quality of life as siblings of a child with IDD. Following Moyson and Roeyers (2012), findings were reported using their nine domains of siblings' quality of life. From siblings' explanations it was possible to infer that family dynamics were playing an important role on their quality of life and reported well-being. Therefore, a follow-up study was focused on the impact of family dynamics and parental performances on siblings' quality of life. This study is presented in Chapter 4.

Following democratic knowledge production, it was considered important to include the voice of children in research directly. Consequently, data was collected from siblings themselves: The articles included at the systematic review were reporting data gathered directly from siblings; the presented empirical studies had siblings as the main informants. Finally, it is essential to emphasize the importance of engaging with the individuals who take part in a study as they are the best-informed interlocutors to express what they want or experience. Even when these interlocutors are young children.

5.2 Summary and reflection of the main findings

5.2.1 Richness of siblings’ perceptions of quality of life

Siblings’ quality of life perceptions shows rich and diverse experiences of having a brother or a sister with IDD. This was one of the significant results derived from the systematic review presented in Chapter 2. From experiences of learning, growing and becoming a better person to feelings of embarrassment and sadness were reported in the reviewed articles (e.g., Benderix & Sivberg, 2007; Connell et al., 2014; Flaton, 2006; Goodwin et al., 2017; Vella Gera et al., 2021). This ambivalence was also reflected in the narratives of the participant siblings as reported in Chapter 3 and Chapter 4.

Participants (Chapter 3 & Chapter 4) were siblings of brothers and sisters with IDD and different support needs. However, even when certain particularities of their experiences had been noticed, like the invisibility of autism or the visual impact of a child in a wheelchair, siblings’ reported perceptions of quality of life were intrinsically similar. These findings add to those from Moyson and Roeyers (2011; 2012) and Luijxk et al. (2016) displaying a general view of siblings’ descriptions of their quality of life as siblings.

The research has shown that young siblings (5 to 11 years old) can report about their perceptions of quality of life. From an early age, siblings are well aware of the fact that their brothers or sisters are different and start developing their own explanations about it. The variability of those explanations, shared memories and experiences while a general homogeneity in their narratives is being kept, has revealed a personal but quite similar lived experience. For instance, common feelings of love and togetherness had been encountered in the narratives of the participant siblings whilst the challenges inside the family or the siblings’ relationship had been equally noted. This finding has important implications for the field, indicating a general direction for developing resources, tools and different supports for siblings.

5.2.2 Assuming different and complex roles

Siblings tend to develop and perform a large variety of responsibilities and roles, like the advocating role (Rawson, 2010), friendship role (Hall & Rossetti, 2017) or caregiving role (Coyle, et al., 2014) towards their brothers or sisters with IDD. Generally, siblings were eager to develop different roles regarding their brothers or sisters with IDD throughout their life. This eagerness was linked to their feelings of love and commitment towards their brothers or sisters with IDD, as also reported by Benderix and Sivberg (2007) and Tozer and Atkin (2015).

However, when the siblings' bond was not properly established due to family dynamics or difficulties in the siblings' relationship, certain roles, like the caregiving role, could be seen as a burden for the siblings with no IDD. Findings suggest family dynamics might place the person with IDD in the center of the family life. Consequently, siblings with no IDD, may feel a certain level of parental attention deprivation and that their needs and desires are not properly addressed (Boelsma et al., 2017; Cridland et al., 2016). Families and practitioners must be aware of these kinds of circumstances to prevent siblings from challenges or unpleasant experiences.

5.2.3 Balanced views of siblings related to those from their parents

Siblings' views regarding the experience of having a brother or a sister with IDD seemed to be more positive than those held by their parents, which is consistent with Diener et al. (2015). This finding could be explained by the fact that siblings are situated in a peer relationship with their brothers or sisters with IDD, different from the ones parents hold regarding their offspring.

Another interesting finding was that siblings tended to promote more opportunities of development to their brothers or sisters with IDD than their parents. Interestingly, siblings might be looking to their brothers or sisters with IDD' abilities from a more encouraging point, relying on their potential capacities and promoting their autonomy. These results are in line with those of previous studies like Noonan et al. (2018). However, as noted in Chapter 4, it is not possible to affirm that these views were only related to an empowering vision of brothers or sisters with IDD' capacities. Certainly, feelings of unfair treatment reported by siblings with no IDD, cannot be overlooked. These feelings might also partly explain the opinion that their brothers or sisters with IDD are more capable than their parents think they are.

Nevertheless, it is important to consider the siblings' perceptions when working with families. Siblings are active contributors on their brothers or sisters with IDD' development and would stay so, providing enough space is left to them (Rawson, 2010). Their visions and opinions must be included in family' assessments and any intervention or support provided to the family.

5.2.4 External influences and contextual values on the reported siblings' quality of life

The sociocultural context, such as where siblings live, influence their quality of life due to its values and beliefs. One of the most powerful construction of beliefs, stigma, which has been referred throughout the research, appears to affect the well-being of siblings (Scior & Werner, 2016). Stigma is constituted by preestablished ideas of what a disability is or what having a relative with a disability could be (Hwang & Charnley, 2010b). Collected data from the interviews and discussion groups, echoes some of the findings from other studies. For instance, the stigma inside the school setting (Pompeo, 2009), the negative experience of being stared by strangers (Paul et al., 2021) or the negative views hold by society towards people with disability and its consequences on the siblings' well-being (Vella Gera, 2021).

Findings from the empirical research highlighted a normalcy - exceptionality dyad. This dyad refers to feelings mentioned by siblings of being proud and happy to have their brothers or sisters the way they are. Some of them even refer to how "special" it makes them due to having a sibling with a disability. However, when this difference makes their family "different" from the rest of the families, it is reported as something negative. Particularly, when siblings have to deal with the outside world, which could be having to relate with people from outside their family and beloved ones or being in the public space, like the street or the school (Hwang & Charnley, 2010b; Jacobs & Macmahon, 2016; McGraw & Walker, 2007).

Further, the way parents are perceiving disability will also have effect on siblings with no IDD's perceptions. This could be noted on the parental explanations regarding disability, as it is illustrated in the following quote: "I was told that he was different from the others, that he had autism and that I don’t have to be afraid if my brother would do weird things and people stare weird at him” (Judit, 9 years old; Múries-Cantán et al., 2023, p.8). This sister learnt from her parents that her brother could behave differently and that this was fine. This simple but key explanation might have helped her to be more aware of her brother’s condition and to embrace his diversity. Chapter 4, deepened in the influence of family dynamics and parental performances on sibling’ quality of life, highlighting its interactions with the siblings’ relationship and regarding the views siblings hold about their family situation.

5.3 Contributions of the Results

The following section highlights the main theoretical, methodological and practical contributions this research has had.

5.3.1 Theoretical Contributions

Some general theoretical conclusions and contributions can be drawn from this thesis. First, the combination of findings from the research provides support for the conceptual premise that siblings' quality of life cannot be separated from family quality of life. This means that siblings' quality of life is related to the general perceptions of quality of life of the system siblings are living in. When studying siblings' needs and particularities, it is not possible to overlook the contextual factors that might be influencing them, as other authors like Boelsma et al. (2018) have pointed out. That was the rationale for the systematic review (Chapter 2) that tried to look into the siblings' perceptions in the context of a family.

Second, the Siblings' Quality of Life concept proposed by Moyson and Roeyers (2011; 2012) has revealed useful for the research participants to report on their perceptions of quality of life, despite being from another cultural context and social reality. This concept is made up of nine domains of siblings' quality of life (1. Joint activities; 2. Mutual understanding; 3. Private time; 4. Acceptance; 5. Forbearance; 6. Trust in well-being; 7. Exchanging experiences; 8. Social support; 9. Dealing with the outside world).

Third, the influence of family dynamics and social related factors, such as stigma, including society' lack of awareness or disrespectful behavior towards individuals with disabilities and their families, should be considered important aspects influencing siblings' quality of life. An implication of this is the possibility that researchers and policy makers should consider the social dimension of the personal experience of disability.

Fourth, this thesis contributed to the general literature by putting the views and perceptions of young siblings in the center. This democratic and inclusive approach is still in its infancy, as it can be concluded from the conducted systematic review (Chapter 2). Most articles regarding siblings of people with IDD are about adult siblings and few have young siblings as informants. Furthermore, the level of maturity and self-awareness from the participant siblings should be acknowledged. Such findings strengthen the way forward. These include children’s voices in the context of their ability to report on their lived experiences and their knowledge.

5.3.2 Methodological Contributions

The research has evidenced the ability of children to discuss their quality of life, as noted in Chapter 3 and 4. However, the abstract concept of “quality of life” was hard to understand for young children. It required the development of an interview and discussion group’ guides (included in both chapters) with open-ended questions accompanied by a variety of supports and resources, to assist siblings in discussing their experiences of quality of life.

Additionally, interviewing young children represents a mixture of challenges and particularities that should be considered before starting the data collection process. A friendly environment for the child participants was tried to be set, following the suggestions of Cameron (2005) and Irwin and Johnson (2005), plus the reported experiences of relevant authors in the field (e.g., Luijkx et al. 2016; Moyson & Roeyers, 2012; Pavlopoulou & Dimitriou, 2020).

Question statements for the interviews and discussion groups were adapted to make them understandable for children. Other resources, such as toys, books, drawings and games were provided in order to promote siblings’ narratives and to encourage a trustful bond between the interviewee and the interviewer. As a result, it is possible to affirm that children as young as 5 years old, were able to talk and reflect on their experiences of quality of life after being provided with adequate support and a trustful environment.

Creativity is mandatory in the use of a diversity of tools and materials (e.g., photos, puppets, playdough) when interviewing children of this age. It would be interesting then, to interview even younger children (3 to 5 years old) about their quality of life. An early knowledge of pre-school siblings’ experiences might be beneficial for them and their families.

Finally, our empirical research has followed a qualitative methodology. Nevertheless, and as mentioned in Chapter 4, there are many possibilities in the field of siblings' quality of life for further progress in the development of a standardized tool to collect siblings' quality of life perceptions.

5.3.3 Practical Contributions

The findings are also relevant for practitioners in the disability field, such as teachers, psychologists and social workers. In the following paragraphs, some of the practical contributions of the findings are underscored.

First, a general eagerness by siblings in being an active part of their brothers or sisters with IDD' life is noted in the context of theoretical and empirical research. However, it seems that sibling's direct participation in their brothers or sisters with IDD' life is mostly requested by their parents in the siblings' adult years and during the transition of care from parents to siblings. Hesitations regarding the caregiving role, major questioning, anxiety and stress may be part of the scene for siblings at that moment (Coyle, et al., 2014; Rawson, 2010; Rossetti & Hall, 2015). To reduce these kinds of feelings, the improvement of siblings' participation on family support and assessment from the beginning, should be carefully considered.

Siblings without IDD can contribute to interventions or decisions their family might have to take, with knowledge from their own and unique experience, and from their views regarding their family situation. Their participation can be started naturally from their youngest ages and be enhanced throughout their life; always respecting the siblings' desired level of involvement. Then, when siblings have to take a leading role in their brothers or sisters with IDD' life, this transition could be smoother.

Second, it is important to have initiatives to promote the social awareness of disability. In this sense, the school, along with the whole educational system, plays a principal part in educating citizens towards the diversity in our societies. Schools can stimulate a diversity of proposals and activities to speak freely about disability. Younger siblings and their peers can specially benefit from practices aimed at normalizing what is often considered exceptional. Eventually, a more open and inclusive schooling system will have repercussions on decreasing the social stigma.

Another important issue to mention is the transference of knowledge. This research was inspired by the claim held by siblings of being seen, being listened to and being learnt from. The research was intended as a 'resonance chamber' for siblings' voices. Therefore, it will be worthy if it leads to different ways of exploring and improving siblings' quality of life perceptions. Consequently, as already noted, research findings need to reach a wider audience and beyond academics to make a difference. One of the several ways of doing that is by publishing short pieces of text as blogs on specialized webpages and on social media to spread awareness about disability.

On one occasion (January 2019) I was requested from Disability Studies in Nederland[2] to write an original text that answers the question “When did you feel that you made a difference with your research?”. The text, entitled ‘Little big voices’, reviews the importance it had for me as a researcher to give children a voice to properly meet their demands. ‘Little big voices’ was published at the group’s website and can be read below:

Little big voices

Around six years ago I had the opportunity to support a girl with an intellectual disability (ID) at her home. We used to do some domestic activities and went swimming afterwards twice a week. She enjoyed being in the water and I enjoyed sharing with her those joyful moments. I used to talk with her mother about some concerns and challenges she was facing together with her family because of her daughter’s disability. We also talked about positive and motivating issues related with the development and achievements of the ‘swimmer’. But I started to be curious about what the siblings think, feel or experience because of their family situation. For me, that was the starting point of an exciting and sometimes overwhelming journey that has led me to the Netherlands for the second time in four years.

Therefore, having this couple of siblings in mind, I had eagerly read a huge bunch of articles about siblings of people with intellectual and developmental disabilities (IDD) that helped me to spread light on the path I was building. For instance, I discovered that the most unstudied age group of siblings were those in their childhood. Some authors indicated a limitation on sibling’s research, the lack of information about what young

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[2] See Appendix C. Letters to justify international doctoral stage at Disability Studies in Nederland (VU)

siblings think or how they were experiencing their quality of life as siblings of children with IDD.

As I felt deeply connected with the child I was (and in a certain manner I'm still being) I rapidly decided to focus my PhD research on children with siblings with IDD. I am standing aware about the importance of letting children express themselves and listening to them. Well, not only listen, I think it is a matter of taking them seriously. That's why I was resolute not only to have children in the focus: I wanted children themselves to be the main informants in my research. So yes, I was willing to do research about children, with children and focused on what children think and want to express.

Little historical retrospective about children rights shows us that the first universal law to protect children appeared after the First World War, handled by the League of Nations. The Geneva Declaration of the Rights of the Child (1924) recognized for the first time that children have the right to wellbeing, healthy development, assistance and protection. "Humanity owes to the Child the best that it has to give" without considerations of race, nationality or religion. After the Second World War the United Nations General Assembly approved in Paris the Universal Declaration of Human Rights (1948), a milestone in the history of human rights. But it wasn't until 1959 that an improved and extended Declaration of the Rights of the Child was proclaimed. Principle 6 established that "The child, for the full and harmonious development of his personality, needs love and understanding". Standing on my research role, I strongly believe in the need of giving children the opportunity to express themselves freely.

For all these reasons, my advisors and I have decided to put children in the middle of our research. We realized that only by asking them directly we were able to know how they feel; about what they think or what they need. Personally, having time alone with children has led me to a more comprehensive view of their world, their desires and their fears. Being in a room, alone with the child participants in my research, talking about their experience of having a brother or a sister with an intellectual disability was something that moved me a lot. Children's confidence when sharing and talking with a stranger about their inner quality of life perceptions, surprised me and was a huge lesson of truth. My experience with interviewing children reinforces my perception about the importance of letting children speak for themselves in the appropriate environment (sometimes more important than the question itself), together with the child's confidence and his desire to share his story.

To sum up, the lack of children's research in the disability studies field together with the lack of information about their perceptions of quality of life from their very own voices inspired us about the purpose of our research. So, if I have to think about when I feel that I made a difference with my research or how I can contribute to society I would definitely say by spreading the voices of children.

5.4 Strengths and limitations

The most important limitations of the studies are addressed in each of the research chapters. However, in a summary of the strengths and limitations of this research as depicted in Table 4, strengths and limitations happen to be two sides of the same coin.

TABLE 4. Strengths and limitations of the thesis

	Strengths	Limitations
The chosen topic	In the intellectual and developmental disability' field, siblings of people with IDD are usually an overlooked population. Research about siblings' perceptions of their quality of life is even limited, which makes it worthy of studying it.	Due to its novelty, it was challenging at first to establish a solid theoretical background from where to start the research. Luckily, the few articles published on siblings' quality of life rooted on the family quality of life' approach, have revealed useful in building a solid path. However, further research must keep looking into the conceptualization and measurement of siblings' quality of life.
The origin of the collected data (Chapters 3 & 4)	All collected data were coming from siblings themselves. Therefore, genuine and subjective information was gathered along the research' process. Particularly, siblings from the most under-researched age group, children, were invited to talk about their experiences in first person.	When researching with children, their parents act as gatekeepers. It constitutes a limitation as it is not possible to know how many of the first contacted children wanted to participate in the research but could not do it due to their parents' disagreement. At the same time, it was necessary to make a previous effort to explore if sibling participants clearly understood the meaning of the research and really wanted to take part in the research.
The selected sample (Chapters 3 & 4)	The variability of diagnosis and intellectual disabilities is presented by brothers or sisters of the research participants. However, despite this diversity, siblings reported similar characteristics regarding their experience of quality of life. It can thus be suggested that interventions and supports based on siblings' quality of life perceptions, might be worthy for most of them no matter the condition they brothers or sisters might have.	Despite trying to get a heterogeneous sample with siblings with brothers or sisters with different IDD, the participants of this research hold some common characteristics. For instance, their socioeconomic status was certainly similar, with almost all the families being middle class. A more diverse cultural and economic origin might have led to other interesting findings regarding siblings' quality of life.

The above-mentioned points serve to highlight some of the key characteristics of this research, and identify lines for future research as will be discussed in the next section.

5.5 Directions for future research

Given the exploratory nature of the research and consequently the findings, further progress is required in exploring, learning and understanding about the quality of life of siblings of people with IDD. Along the road, and some of the faced difficulties, indicate the following directions for future research:

- *To investigate the link between the siblings' quality of life concept and the general concept of family quality of life:* Further research is required to find ways in which both concepts may be intertwined and about how the Sibling Quality of Life concept links or can be viewed as an important part of Family Quality of Life.
- *To conduct longitudinal studies on siblings' quality of life:* The findings from the systematic review presented in Chapter 2, indicated an evolution of siblings' perceptions throughout their life. Consequently, being able to study them from a lifespan perspective would depict a more complete image of their quality of life and assist in providing specific support to siblings and their families.
- *To identify key siblings' needs and concerns:* An important part of the reported quality of life of siblings was associated with the different needs and concerns they had: in relation to their brother or sisters with IDD but also to themselves and to their shared future. It is therefore necessary to be able to identify siblings' needs to promote the resources and tools they might require.
- *To study siblings' roles along the life span:* Siblings may perform different roles due to having a brother or a sister with IDD throughout their life. A close approach into those roles should inform the services and support siblings and their families might receive in order to improve siblings' well- being at different vital stages.
- *To explore siblings' quality of life in other cultural frameworks and socioeconomic status:* The empirical research was conducted in a particular region of Southern Europe and with families from a medium socioeconomic status (which was also the case of the majority of participants of the reviewed articles reported in Chapter 2). The study of siblings' quality of life perceptions in communities with other cultural and religious backgrounds and with

participants from lower socioeconomic status, must yet be conducted to gain a more complete view of siblings’ perceptions.

- *To examine the development of personal identity and life meaning because of having a brother or a sister with IDD:* The present research has made clear that having a brother or a sister with IDD affects siblings’ life in multiple ways and directions. It would be a stimulating way of knowledge to examine the influence this experience has had on self-development identity and on the attribution of meaning in life.

5.6 Conclusions

To conclude, there is an overview of the main findings using the main research question and sub-questions as defined in the general introduction of this thesis.

The main question, “How do siblings of people with intellectual and developmental disabilities perceive their quality of life as siblings?” The aim was to seek and collect significant data regarding siblings’ quality of life. This question was further operationalized in four different sub-questions that had been answered throughout the research.

1. What are the siblings’ perceptions on quality of life in the context of their family? *(Question related with Chapter 2)*

Siblings constitute an important part of family life. Siblings’ quality of life perceptions are unique and able to stand on their own. Thus, it calls for a general re-thinking of the Family Quality of Life concept to embrace the diversity and particularities of siblings’ perceptions to eventually enhance FQOL. Siblings’ participation and inclusion in the lives of their brothers or sisters with IDD, and in their collective family life, must be consistently promoted. Siblings can provide to the general well-being of the family and to its individual members with their own views and strengths.

2. What needs and challenges do siblings have regarding their quality of life as siblings of individuals with IDD? *(Question related with Chapter 2)*

Siblings’ reflections on having a brother or a sister with IDD suggest personal views, needs and challenges regarding the experience of disability as well as a unique influence on the construction of siblings’ identity. The most reported needs were related to emotional support, time alone and with their parents, appropriate information and being heard, and involved in their brothers or sisters with IDD’ life. Some of the challenges were related with personal characteristics of the siblings themselves and/or their brother or sister with IDD but predominantly with family dynamics, lack of information and social stigma.

3. How do young siblings aged 5 to 11 years old of children with IDD living in Catalonia, perceive and describe their quality of life as siblings? *(Question related with Chapter 3)*

Young siblings are able to report on their perceptions of quality of life. The provision of adequate support and resources facilitates siblings’ expression and communication of experiences, feelings and demands due to having a brother or a sister with IDD. Findings from this geographically situated research are in line with those of similar studies, suggesting common experiences of siblings. Examples are the importance of the siblings’ relationship, and the various roles and responsibilities siblings perform in relation to their family.

4. Have family dynamics and parental performances an influence on siblings’ quality of life perceptions? *(Question related with Chapter 4)*

Siblings' quality of life seems to be more influenced by family dynamics, parental performances and external circumstances- like stigma- than by the specific condition or diagnosis of brothers or sisters. Siblings' quality of life might then be improved by shaping the context. For instance, by acknowledging dynamics and relational patterns and by spreading awareness and changing attitudes regarding disability.

5.7 Personal Reflections

Finally, some final remarks regarding the process of conducting this research. For instance, some of the external factors that have influenced the quality of life perceptions of siblings have been discussed; but this research has nurtured the contextual factors and influences that had surrounded me in many ways over the years. From the opportunity to learn in different universities, from my advisors and international professors to fruitful discussions with fellow PhD' students, researchers, academics from other disciplines and non-academia related practitioners.

I would clearly advocate for an academia closer to the idea of an academy held by the ancient Greeks: a space of enriching debate and discussion guided by the love of knowledge. Additionally, I advocate for a feminist academy: one that is able to provide companionship, that is able to care, support, and give advice and guidance to its pupils. An academy that does not prioritize "publish or perish" or the mandatory solitude in so many stages of research.

The finalization of a doctoral thesis is not an easy path. It is rather a long journey full of challenges that must be met in order to move forward. It is a test of perseverance, effort, motivation and passion for what you are doing. Getting here has not been easy. Nevertheless, I have been able to enjoy a path full of wisdom, exciting opportunities and interesting people. Conducting doctoral research has taught me more than researching tools and abilities. It has provided me with the opportunity to meet myself, to grow up in an unknown environment with some odds against and to be able to conduct original research. Certainly, if the results of the research would prove valuable for siblings and their families, all the dedication and effort gathered in this dissertation will be finally worthy.

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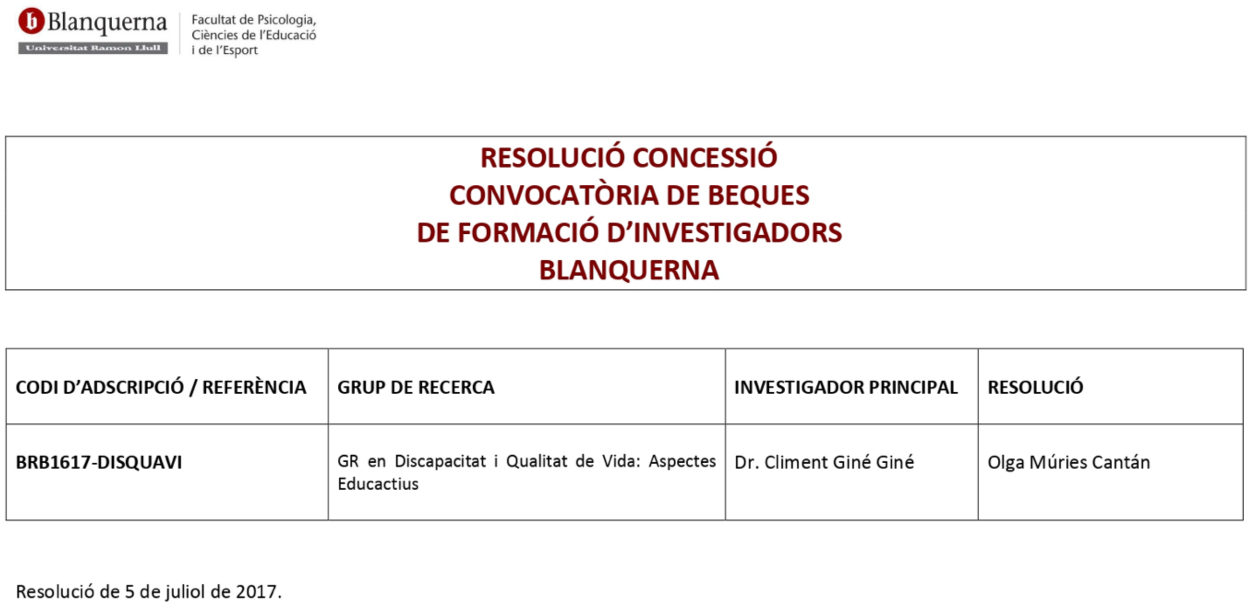
APPENDICES

Appendix A. Grant resolution of Blanquerna Research Grant



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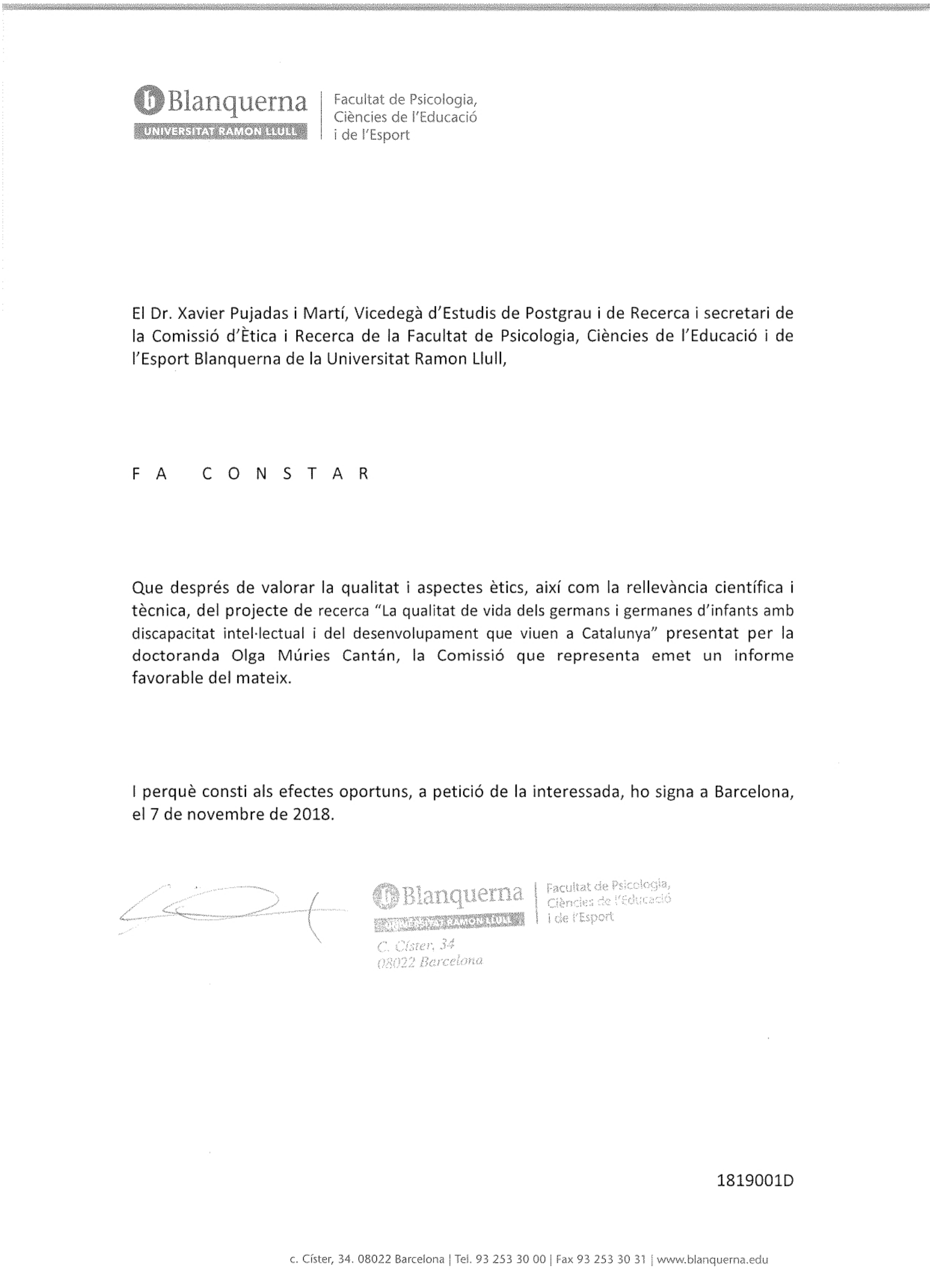
RESOLUCIÓ CONCESSIÓ
CONVOCATÒRIA DE BEQUES
DE FORMACIÓ D'INVESTIGADORS
BLANQUERNA

CODI D'ADSCRIPCIÓ / REFERÈNCIA	GRUP DE RECERCA	INVESTIGADOR PRINCIPAL	RESOLUCIÓ
BRB1617-DISQUAVI	GR en Discapacitat i Qualitat de Vida: Aspectes Educactius	Dr. Climent Giné Giné	Olga Múries Cantán

Resolució de 5 de juliol de 2017.

Appendix B. Ethical approval of the research project



Blanquerna
UNIVERSITAT RAMON LLULL
Facultat de Psicologia,
Ciències de l'Educació
i de l'Esport

El Dr. Xavier Pujadas i Martí, Vicedegà d'Estudis de Postgrau i de Recerca i secretari de la Comissió d'Ètica i Recerca de la Facultat de Psicologia, Ciències de l'Educació i de l'Esport Blanquerna de la Universitat Ramon Llull,

FA CONSTAR

Que després de valorar la qualitat i aspectes ètics, així com la rellevància científica i tècnica, del projecte de recerca "La qualitat de vida dels germans i germanes d'infants amb discapacitat intel·lectual i del desenvolupament que viuen a Catalunya" presentat per la doctoranda Olga Múries Cantán, la Comissió que representa emet un informe favorable del mateix.

I perquè consti als efectes oportuns, a petició de la interessada, ho signa a Barcelona, el 7 de novembre de 2018.

Blanquerna
UNIVERSITAT RAMON LLULL
Facultat de Psicologia,
Ciències de l'Educació
i de l'Esport
C. Císter, 34
08022 Barcelona

1819001D

c. Císter, 34. 08022 Barcelona | Tel. 93 253 30 00 | Fax 93 253 30 31 | www.blanquerna.edu

Translated for dissertation purposes

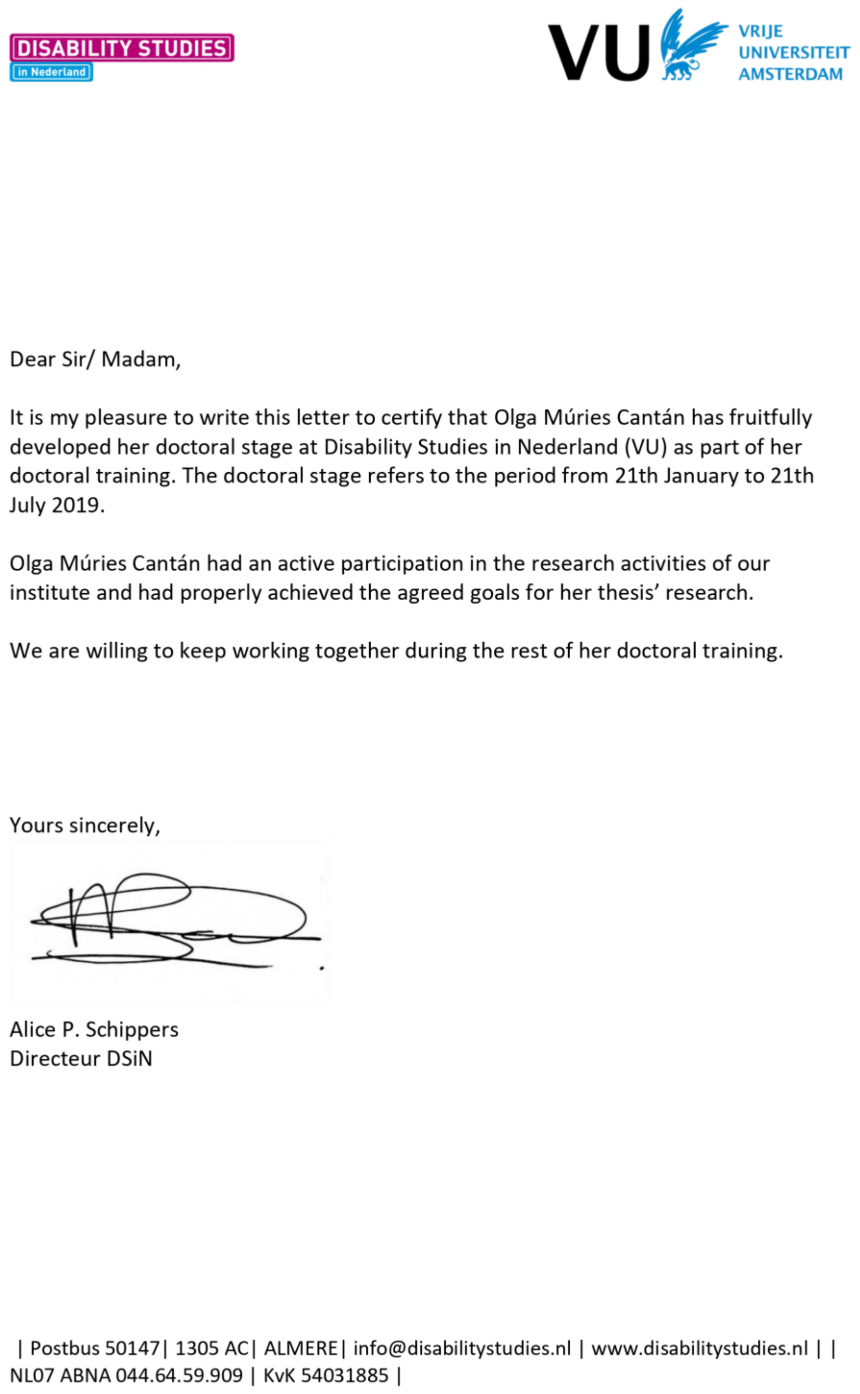
Dr. Xavier Pujadas i Martí, Vice Dean of Graduate Studies & Research and secretary of the Research Ethics Committee of the Faculty of Psychology, Education and Sports Sciences from Ramon Llull University,

STATES

That after assessing the quality and ethical aspects, as well as the scientific and technical relevance of the research project "The quality of life of siblings of children with intellectual and developmental disabilities living in Catalonia" presented by the PhD student Olga Múries Cantán, the represented commission issues a favorable report on it.

For the record, at the request of the person concerned, he signed it in Barcelona on November 7, 2018.

Appendix C. Letters to justify international doctoral stage at Disability Studies in Nederland (VU)



DISABILITY STUDIES in Nederland

VU VRIJE UNIVERSITEIT AMSTERDAM

Dear Sir/ Madam,

It is my pleasure to write this letter to certify that Olga Múries Cantán has fruitfully developed her doctoral stage at Disability Studies in Nederland (VU) as part of her doctoral training. The doctoral stage refers to the period from 21th January to 21th July 2019.

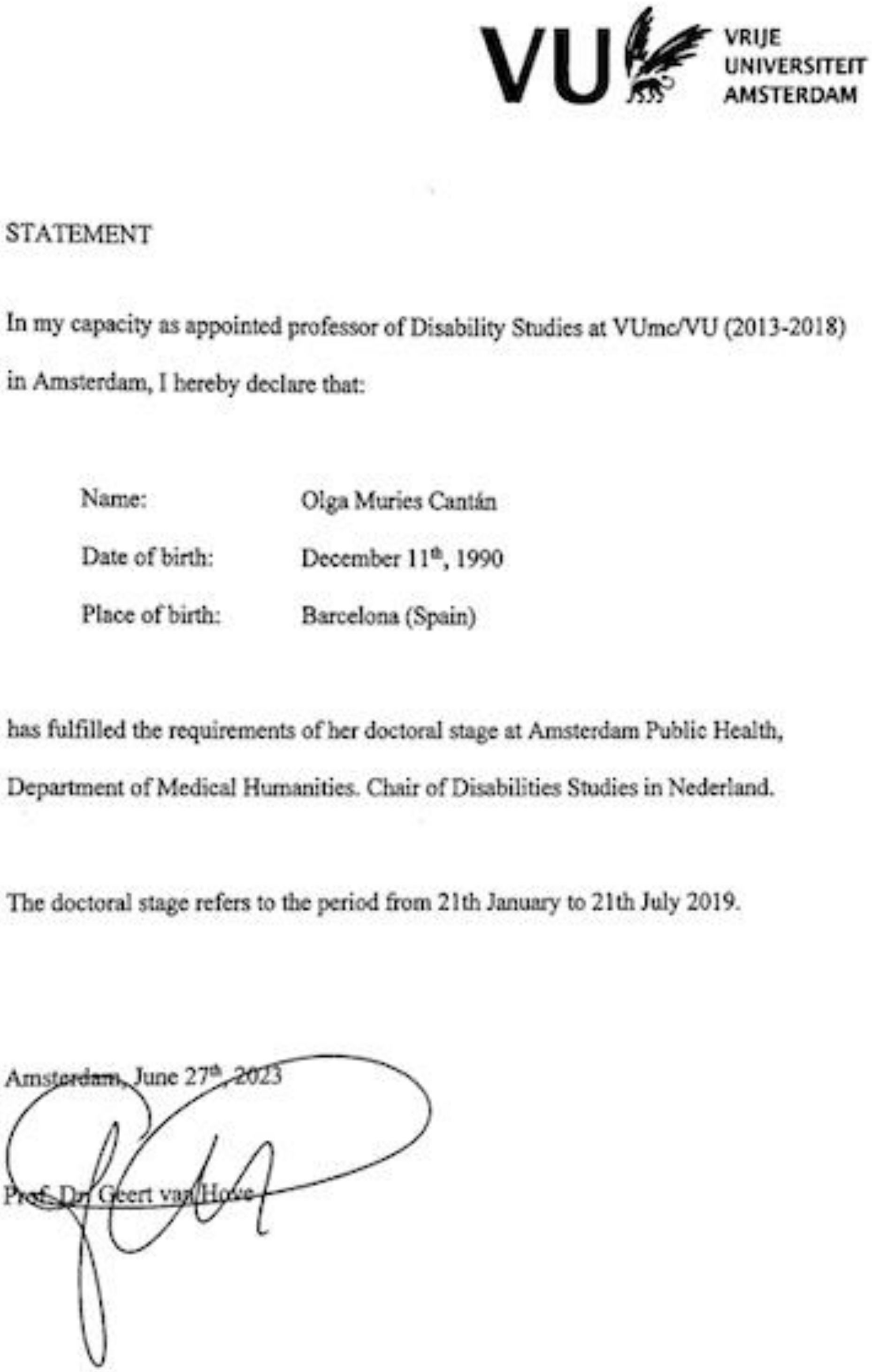
Olga Múries Cantán had an active participation in the research activities of our institute and had properly achieved the agreed goals for her thesis' research.

We are willing to keep working together during the rest of her doctoral training.

Yours sincerely,

Alice P. Schippers
Directeur DSiN

| Postbus 50147| 1305 AC| ALMERE| info@disabilitystudies.nl | www.disabilitystudies.nl | |
NL07 ABNA 044.64.59.909 | KvK 54031885 |



VU VRIJE
UNIVERSITEIT
AMSTERDAM

STATEMENT

In my capacity as appointed professor of Disability Studies at VUmc/VU (2013-2018) in Amsterdam, I hereby declare that:

Name: Olga Muries Cantán
Date of birth: December 11th, 1990
Place of birth: Barcelona (Spain)

has fulfilled the requirements of her doctoral stage at Amsterdam Public Health, Department of Medical Humanities. Chair of Disabilities Studies in Nederland.

The doctoral stage refers to the period from 21th January to 21th July 2019.

Amsterdam, June 27th, 2023

Prof. Dr. Geert van Hove

Appendix D. **Recruitment letter to families** ***(Catalan & Spanish)***

Facultat de Psicologia, Ciències de l'Educació i de l'Esport Blanquerna
Universitat Ramon Llull
VU Vrije Universiteit Amsterdam
DISABILITY STUDIES in Nederland
DISCAPACITAT I QUALITAT DE VIDA ASPECTES EDUCATIUS

Barcelona, maig del 2018

Benvolgut/da,

Des del grup de recerca Discapacitat i Qualitat de Vida: Aspectes Educatius de la Facultat de Psicologia, Ciències de l'Educació i l'Esport Blanquerna de la Universitat Ramon Llull, Barcelona, i del grup de recerca Disability Studies in Nederland de la Vrije Universiteit d'Amsterdam, Holanda, estem realitzant l'estudi "La qualitat de vida dels germans i germanes d'infants amb discapacitat intel·lectual i del desenvolupament que viuen a Catalunya".

El motiu d'aquesta carta és convidar-vos a participar en l'esmentada investigació, en la que es duran a terme entre dues i tres entrevistes individuals i/o grups de discussió amb els germans i germanes nascuts entre el gener del 2007 i el desembre del 2012 (entre 6 i 11 anys) d'infants amb discapacitat intel·lectual i del desenvolupament amb la finalitat de conèixer la percepció respecte de la seva qualitat de vida. A partir dels resultats obtinguts es pretén: (a) conèixer la percepció de qualitat de vida dels germans i germanes d'infants amb discapacitat intel·lectual i del desenvolupament que viuen a Catalunya, (b) identificar possibles necessitats o demandes dels germans i germanes en relació a la seva qualitat de vida i (c) influir positivament en les pràctiques professionals dirigides a aquests infants per tal d'augmentar la seva qualitat de vida.

Un cop acabades les sessions amb els germans/es, es farà una trobada de devolució amb els pares per tal de fer-los arribar una valoració de les percepcions i vivències dels seus fills/es.

Tota la informació que ens proporcioni serà tractada de forma confidencial i privada. Finalment els proporcionarem un document en el qual puguin atorgar, si així ho creuen, el seu consentiment per participar en aquest estudi.

Aprofitem l'ocasió per agrair la seva atenció i esperem poder comptar amb la seva participació.

Una cordial salutació,

Facultat de Psicologia, Ciències de l'Educació i de l'Esport Blanquerna
Universitat Ramon Llull

VU VRIJE UNIVERSITEIT AMSTERDAM

DISABILITY STUDIES in Nederland

DISCAPACITAT I QUALITAT DE VIDA ASPECTES EDUCATIUS

Barcelona, abril de 2018

Apreciados,

Desde el grupo de investigación Discapacidad y Calidad de Vida: Aspectos Educativos de la Facultat de Psicologia, Ciències de l'Educació i l'Esport Blanquerna de la Universitat Ramon Llull, Barcelona, y del grup de investigación Disability Studies in Nederland de la Vrije Universiteit de Ámsterdam, Holanda, estamos realizando el estudio "La calidad de vida de los hermanos/as de niños con discapacidad intelectual y del desarrollo que viven en Cataluña”.

El motivo de esta carta es invitarles a participar en dicha investigación, en la que se llevaran a cabo entrevistas individuales y grupos de discusión con los hermanos y hermanas nacidos entre enero del 2007 y diciembre del 2012 (entre 6 i 11 años) de niños con discapacidad intelectual y del desarrollo con la finalidad de conocer la percepción respecto a su calidad de vida. A partir de los resultados obtenidos se pretende: (a) conocer la percepción de calidad de vida de los hermanos y hermanas de niños con discapacidad intelectual y del desarrollo que viven en Cataluña, (b) identificar posibles necesidades o demandas de los hermanos y hermanas en relación a su calidad de vida y (c) a partir de los resultados obtenidos, influir positivamente en las prácticas profesionales dirigidas a estos niños con el fin de aumentar su calidad de vida.

Toda la información que nos proporcione será tratada de forma confidencial y privada. Finalmente les proporcionamos un documento en el que puedan dar, si así lo creen conveniente, su consentimiento para participar en este estudio.

Aprovechamos para agradecer su atención y esperamos poder contar con su participación.

Reciba un cordial saludo,

Translated for dissertation purposes

Dear families,

From the research group Disability and Quality of Life: Educational Aspects of the Faculty of Psychology, Education and Sports Sciences from Ramon Llull University, Barcelona, and from the research group Disability Studies in Nederland of the Vrije Universiteit van Amsterdam, The Netherlands, we are carrying out the study "Quality of life of siblings of children with intellectual and developmental disabilities living in Catalonia".

The reason for this letter is to invite you to participate in the aforementioned research. Two to three individual interviews and/or discussion groups will be carried out with brothers and sisters born between January 2007 and December 2012 (between 6 and 11 years old) of children with intellectual and developmental disabilities. The main purpose of this research is to know about their perceptions regarding their quality of life. It is expected that the results will provide information to: (a) know the perceptions of quality of life of brothers and sisters of children with intellectual and developmental disabilities living in Catalonia, (b) identify possible needs or demands of the siblings in relation to their quality of life and (c) positively influence the professional practices aimed at these siblings in order to increase their quality of life.

Once the sessions with the siblings are over, there will be a meeting with the parents in order to give feedback about the perceptions and experiences of their children.

All information you provide us will be treated confidentially and privately.
Finally we will provide you with a consent form in which you can give, if agree to participate in this study, your consent.

We take this opportunity to thank you for your attention and we hope to have your participation.

Yours sincerely,

Appendix E. Recruitment letter to the institutions

Barcelona, abril de 2018

Benvolgut / da,

Des del grup de recerca Discapacitat i Qualitat de Vida: Aspectes Educatius de la Facultat de Psicologia, Ciències de l'Educació i l'Esport Blanquerna de la Universitat Ramon Llull, Barcelona, i del grup de recerca Disability Studies in Nederland de la Vrije Universiteit d'Amsterdam, Holanda, estem realitzant l'estudi "La qualitat de vida dels germans i germanes d'infants amb discapacitat intel·lectual i del desenvolupament que viuen a Catalunya".

L'esmentada investigació té la finalitat de conèixer la percepció respecte de la seva qualitat de vida de germans i germanes nascuts entre el gener del 2007 i el desembre del 2012 (entre 6 i 11 anys) d'infants amb discapacitat intel·lectual i del desenvolupament. A partir dels resultats obtinguts es pretén: (a) conèixer la percepció de qualitat de vida dels germans i germanes d'infants amb discapacitat intel·lectual i del desenvolupament que viuen a Catalunya, (b) identificar possibles necessitats o demandes dels germans i germanes en relació a la seva qualitat de vida i (c) a partir dels resultats obtinguts, influir positivament en les pràctiques professionals dirigides a aquests infants per tal d'augmentar la seva qualitat de vida.

És per aquesta raó que ens adrecem a la vostra entitat amb el prec que ens puguin ajudar a trobar la mostra necessària per al bon desenvolupament de l'estudi. No cal dir que amb molt de gust compartirem les dades recollides amb cada un dels centre participants, si ho desitgen. Així doncs, en uns dies em posaria en contacte amb vostès per si fos possible comptar amb alguns infants o joves del seu centre.

Per a qualsevol informació / aclariment restem a la vostra disposició al telèfon XX o a l'adreça electrònica d'Olga Múries (olgamc1@blanquerna.url.edu).

Tot agraint la vostra atenció, aprofitem l'ocasió per a saludar-vos molt cordialment.

Atentament,

Translated for dissertation purposes

To Whom It May Concern:

From the research group Disability and Quality of Life: Educational Aspects of the Faculty of Psychology, Education and Sports Sciences from Ramon Llull University, Barcelona, and from the research group Disability Studies in Nederland of the Vrije Universiteit van Amsterdam, The Netherlands, we are carrying out the study "Quality of life of siblings of children with intellectual and developmental disabilities living in Catalonia".

The aforementioned research aims to explore the perceptions of quality of life of brothers and sisters born between January 2007 and December 2012 (between 6 and 11 years old) of children with intellectual and developmental disabilities. It is expected that the results will provide information to: (a) know the perceptions of quality of life of brothers and sisters of children with intellectual and developmental disabilities living in Catalonia, (b) identify possible needs or demands of the siblings in relation to their quality of life and (c) positively influence the professional practices aimed at these siblings in order to increase their quality of life.

It is for this reason that we are addressing your organization with the request of helping us to find the sample for the successful development of the study. It goes without saying that we will gladly share the data collected with each of the participating centers, if they wish. So, in a few days I would contact you in case it would be possible to count on some children or young people from your center.

For any information / clarification, we remain at your disposal on telephone XX or at Olga Múries' email address (olgamc1@blanquerna.url.edu).

While thanking you for your attention, we take this opportunity to greet you very cordially.

Yours faithfully,

Appendix F. Information flier to siblings

La Qualitat de Vida dels germans i germanes de nens i nenes amb discapacitat intel·lectual i del desenvolupament que viuen a Catalunya

De què parlarem?

- Història vital del germà o germana, esdeveniments importants.
- Percepcions pel que fa a la seva qualitat de vida com a germà o germana
- El significat de la seva experiència com a tal

En què consisteix la recerca?

Explorar mitjançant entrevistes i grups de discussió, com germans i germanes d'infants amb discapacitat intel·lectual i del desenvolupament (DID) descriuen la seva qualitat de vida

Quins beneficis comportarà la investigació?

- Conèixer l'experiència única i particular de germans i germanes d'infants amb DID que viuen a Catalunya
- Influir per millorar plans de suport a les famílies pel que fa a l'atenció que reben els germans/es
- Augmentar el coneixement científic internacional que es té sobre les vivències de germans/es d'infants amb DID

I per a les famílies participants?

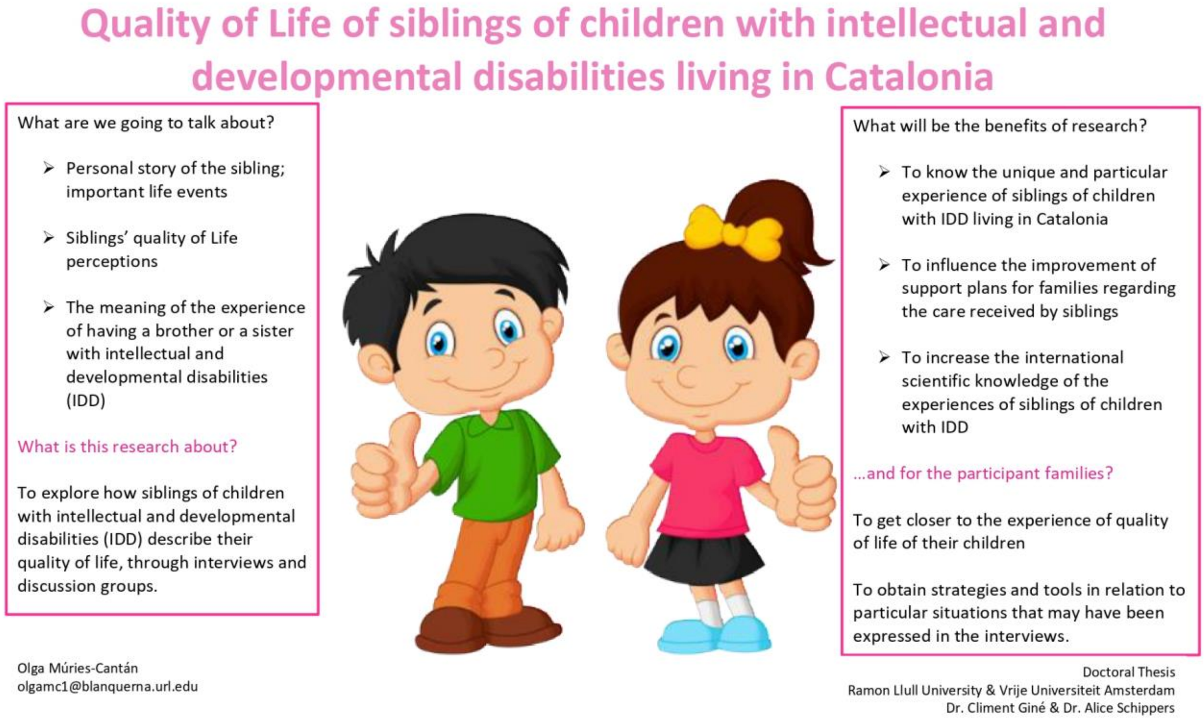
Apropar-se a l'experiència de qualitat de vida dels seus fills

Obtenir estratègies i eines en relació a situacions particulars que hagin pogut expressar en les entrevistes

Olga Múries Cantán
olgamc1@blanquerna.url.edu

Recerca de tesis doctoral
Universitat Ramon Llull & Vrije Universiteit Amsterdam
Dr. Climent Giné & Dra. Alice Schippers

Translated for dissertation purposes



Quality of Life of siblings of children with intellectual and developmental disabilities living in Catalonia

What are we going to talk about?

- Personal story of the sibling; important life events
- Siblings' quality of Life perceptions
- The meaning of the experience of having a brother or a sister with intellectual and developmental disabilities (IDD)

What is this research about?

To explore how siblings of children with intellectual and developmental disabilities (IDD) describe their quality of life, through interviews and discussion groups.

What will be the benefits of research?

- To know the unique and particular experience of siblings of children with IDD living in Catalonia
- To influence the improvement of support plans for families regarding the care received by siblings
- To increase the international scientific knowledge of the experiences of siblings of children with IDD

...and for the participant families?

To get closer to the experience of quality of life of their children

To obtain strategies and tools in relation to particular situations that may have been expressed in the interviews.

Olga Múries-Cantán
olgamc1@blanquerna.url.edu

Doctoral Thesis
Ramon Llull University & Vrije Universiteit Amsterdam
Dr. Climent Giné & Dr. Alice Schippers

Appendix G. Informed consent document for the interviews *(Catalan & Spanish)*

Facultat de Psicologia, Ciències de l'Educació i de l'Esport Blanquerna
Universitat Ramon Llull

VU VRIJE UNIVERSITEIT AMSTERDAM

DISABILITY STUDIES in Nederland

DISCAPACITAT I QUALITAT DE VIDA ASPECTES EDUCATIUS

LA QUALITAT DE VIDA DELS GERMANS I GERMANES D'INFANTS AMB DISCAPACITAT INTEL·LECTUAL I DEL DESENVOLUPAMENT QUE VIUEN A CATALUNYA. CONSENTIMENT DE LA FAMÍLIA

El/ La Sr./Sra...,
amb DNI núm...;

FAIG CONSTAR:

He estat convidat/da a prendre part en la investigació "**La qualitat de vida dels germans i germanes d'infants amb discapacitat intel·lectual i del desenvolupament que viuen a Catalunya**" que es duu a terme conjuntament en els grups de recerca Discapacitat i Qualitat de Vida: Aspectes Educatius de la Facultat de Psicologia, Ciències de l'Educació i de l'Esport Blanquerna de la Universitat Ramon Llull i Disability Studies in Nederland de la Vrije Universiteit d'Amsterdam, i se'm demana l'autorització per a la participació del meu fill/a en aquest estudi.

He conegut amb detall els objectius i procediments de l'estudi i he pogut parlar amb la investigadora que **es compromet** a mantenir de manera confidencial les dades personals dels meus fills/es i a preservar l'anonimat del que li han confiat[3].

La investigadora ens ha informat que **tenim el dret** d'abandonar l'estudi en el moment en que ho desitgem sense cap perjudici.

Atès que la informació m'ha estat donada de forma comprensible, que he pogut formular preguntes i m'han estat aclarits els dubtes presentats en llegir o escoltar la informació específica, **dono lliurement i voluntària la meva conformitat** per a que el meu fill/a participi en aquesta investigació i és per això que **ho autoritzo explícitament** en aquest full.

Data:
Firma de l'entrevistadora   Vist- i- plau del tutor legal

---

[3] De conformitat amb el Reglament (UE) 2016/679, de 27 d'abril de Protecció de Dades Personals (RGPD)

LA CALIDAD DE VIDA DE LOS HERMANOS Y HERMANAS DE NIÑOS/AS CON DISCAPACIDAD INTELECTUAL Y DEL DESARROLLO QUE VIVEN EN CATALUÑA. CONSENTIMIENTO DE LA FAMILIA

El/ La Sr./Sra..,
con DNI nº..;

HAGO CONSTAR:

He sido invitado a tomar parte en la investigación "**La calidad de vida de los hermanos y hermanas de niños/as con discapacidad intelectual y del desarrollo que viven en Cataluña"** que se lleva a cabo conjuntamente entre los grupos de investigación Discapacidad y Calidad de Vida: Aspectos Educativos de la Facultat de Psicologia, Ciències de l'Educació i de l'Esport Blanquerna de la Universitat Ramon Llull y Disability Studies in Nederland de la Vrije Universiteit de Ámsterdam, autoritzando la participación de mi hijo/a en este estudio.

He conocido con detalle los objetivos y procedimientos del estudio y he podido hablar con la investigadora que **se compromete** a mantener de manera confidencial los datos personales de mis hijos/as y a preservar el anonimato de lo que le han confiado[4].

La investigadora nos ha informado que **tenemos el derecho** a abandonar el estudio en el momento en que lo deseemos sin ningún perjuicio.

Puesto que la información me ha sido dada de forma comprensible, que he podido formular preguntas y me han sido esclarecidas las dudas presentadas al leer o escuchar la información específica, **doy libremente y voluntaria mi conformidad** para que mi hijo/a participe en esta investigación y es por eso que lo autorizo explícitamente en este documento.

Fecha:

Firma de la entrevistadora Consentimiento del tutor legal

---

[4] De acuerdo con el Reglamento (UE) 2016/679, de 27 de abril de Protección de Datos Personales (RGPD)

Translated for dissertation purposes

QUALITY OF LIFE OF SIBLINGS OF CHILDREN WITH INTELLECTUAL AND DEVELOPMENTAL DISABILITIES LIVING IN CATALONIA. FAMILY CONSENT

Mr/Ms...,
ID number...;

I STATE:

I have been invited to take part in the research **"Quality of life of siblings of children with intellectual and developmental disabilities living in Catalonia"** which is carried out jointly by the research group Disability and Quality of Life: Educational Aspects of the Faculty of Psychology, Education and Sports Sciences from Ramon Llull University, Barcelona, and from the research group Disability Studies in Nederland of the Vrije Universiteit van Amsterdam, The Netherlands. I am requested authorization for my child's participation in this study.

I have learned in detail the objectives and procedures of the study and I have been able to speak with the researcher **who is committed** to keep my children's personal data confidential and to preserve the anonymity of what they have entrusted to her[5].

The researcher has informed us that we have **the right to leave** the study at any time without prejudice.

Given that the information has been given to me in an understandable way, that I have been able to formulate questions and that the doubts presented to me when reading or listening to the specific information have been clarified, **I freely and voluntarily give my consent** for my child to participate in this research and that is why **I explicitly authorize it** on this sheet.

Date:
Interviewer signature   Tutor signature

---

[5] In accordance with Regulation (EU) 2016/679 of 27 April 2016 on the Protection of Personal Data (RGPD)

Appendix H. Informed consent document for the discussion groups *(Catalan)*

Facultat de Psicologia, Ciències de l'Educació i de l'Esport Blanquerna
Universitat Ramon Llull

VU VRIJE UNIVERSITEIT AMSTERDAM

DISABILITY STUDIES in Nederland

DISCAPACITAT I QUALITAT DE VIDA ASPECTES EDUCATIUS

LA QUALITAT DE VIDA DELS GERMANS I GERMANES D'INFANTS AMB DISCAPACITAT INTEL·LECTUAL I DEL DESENVOLUPAMENT QUE VIUEN A CATALUNYA. CONSENTIMENT DE LA FAMÍLIA

El/ La Sr./Sra..,
amb DNI núm..;

FAIG CONSTAR:

He estat convidat/da a prendre part en la investigació "**La qualitat de vida dels germans i germanes d'infants amb discapacitat intel·lectual i del desenvolupament que viuen a Catalunya**" que es duu a terme conjuntament en els grups de recerca Discapacitat i Qualitat de Vida: Aspectes Educatius de la Facultat de Psicologia, Ciències de l'Educació i de l'Esport Blanquerna de la Universitat Ramon Llull i Disability Studies in Nederland de la Vrije Universiteit d'Amsterdam, i se'm demana l'autorització per a la participació del meu fill/a en aquest estudi.

He conegut amb detall els objectius i procediments de l'estudi i he pogut parlar amb la investigadora que **es compromet** a mantenir de manera confidencial les dades personals dels meus fills/es i a preservar l'anonimat del que li han confiat[6].

La investigadora ens ha informat que **tenim el dret** d'abandonar l'estudi en el moment en que ho desitgem sense cap perjudici.

Atès que la informació m'ha estat donada de forma comprensible, que he pogut formular preguntes i m'han estat aclarits els dubtes presentats en llegir o escoltar la informació específica, **dono lliurement i voluntària la meva conformitat** per a que el meu fill/a participi en aquesta investigació en el format dels grups de discussió que seran enregistrats en vídeo i àudio i és per això que **ho autoritzo explícitament** en aquest full.

Data:
Firma de l'entrevistadora   Vist- i- plau del tutor legal

---

[6] De conformitat amb el Reglament (UE) 2016/679, de 27 d'abril de Protecció de Dades Personals (RGPD)

Translated for dissertation purposes

QUALITY OF LIFE OF SIBLINGS OF CHILDREN WITH INTELLECTUAL AND DEVELOPMENTAL DISABILITIES LIVING IN CATALONIA. FAMILY CONSENT

Mr/Ms..,
ID number...;

I STATE:

I have been invited to take part in the research **"Quality of life of siblings of children with intellectual and developmental disabilities living in Catalonia"** which is carried out jointly by the research group Disability and Quality of Life: Educational Aspects of the Faculty of Psychology, Education and Sports Sciences from Ramon Llull University, Barcelona, and from the research group Disability Studies in Nederland of the Vrije Universiteit van Amsterdam, The Netherlands. I am requested authorization for my child's participation in this study.

I have learned in detail the objectives and procedures of the study and I have been able to speak with the researcher **who is committed** to keep my children's personal data confidential and to preserve the anonymity of what they have entrusted to her[7].

The researcher has informed us that we have **the right to leave** the study at any time without prejudice.

Given that the information has been given to me in an understandable way, that I have been able to formulate questions and that the doubts presented to me when reading or listening to the specific information have been clarified, **I freely and voluntarily give my consent** for my child to participate in this research in the format of discussion groups that will be recorded in video and audio and that is why **I explicitly authorize it** on this sheet.

Date:
Interviewer signature Tutor signature

---

[7] In accordance with Regulation (EU) 2016/679 of 27 April 2016 on the Protection of Personal Data (RGPD)

Appendix I. Demographic Questionnaire *(Catalan & Spanish)*

La qualitat de vida dels germans i germanes d'infants amb discapacitat intel·lectual i del desenvolupament que viuen a Catalunya

INFORMACIÓ GENERAL SOBRE LA VOSTRA FAMÍLIA

Ens agradaria comentar-vos que fem aquestes preguntes per tal de conèixer millor les característiques de les famílies i també les percepcions dels pares pel que fa a la relació entre els vostres filles/es.

Us agrairíem que emplenéssiu aquesta secció sentint-vos lliures de deixar qualsevol pregunta sense respondre si així ho preferiu. Tanmateix, us recordem que aquesta informació és confidencial i anònima.

Comencem amb preguntes sobre vosaltres mateixos (la persona que està emplenant l'instrument):

1. **Si us plau, assenyaleu en l'apartat següent quina és la relació que teniu amb l'infant de la vostra família que no té discapacitat intel·lectual o del desenvolupament**

☐ Pare
☐ Mare
☐ Tutor legal
☐ Altres (si us plau, especifiqueu): ____________________

2. **Gènere?**

☐ Masculí
☐ Femení

3. **Data de naixement?** ____________________

4. **Quin és el vostre país de procedència?** ____________________

5. **En quina ciutat viviu?** ____________________

6. **Com és la vostra família?**

☐ Monoparental + Nombre de fills/es (si us plau, especifiqueu): ____________________

☐ En parella + Nombre de fills/es (si us plau, especifiqueu): ____________________

☐ Altres (si us plau, especifiqueu): ____________________

7. Quin lloc ocupa el vostre fill/filla sense DID que participarà en la investigació?

☐ Primogènit
☐ Mitjà
☐ Bessó
☐ Benjamí
☐ Altres (si us plau, especifiqueu): ____________________

8. Quin dia va néixer el vostre fill/filla sense DID que participarà en la investigació?____________________

9. Quina és la vostra situació laboral?

☐ Treballo a temps complet
☐ Treballo a temps parcial
☐ A l'atur, però buscant feina
☐ Altres (si us plau, especifiqueu): ____________________

10. Quin és el nivell d'educació més alt que heu completat?

☐ Alguns estudis sense aconseguir el Graduat Escolar / Certificat d'Estudis Primaris.
☐ Educació Primària - Graduat Escolar
☐ Educació Secundària (ESO; Batxillerat; FP)
☐ Diplomatura
☐ Llicenciatura / Grau
☐ Postgrau / Màster / Doctorat
☐ Altres (especifiqueu): ____________________

11. Quin és el nivell total d'ingressos familiars al mes tenint en compte totes les fonts? Assegureu-vos d'incloure els ingressos provinents de totes les fonts (per exemple, subsidi familiar, prestacions, atur, pensions, llei de dependència, etc.).

☐ Menys de 600 € al mes
☐ De 600 a 1.200 € al mes
☐ De 1.200 a 1.800 € al mes
☐ De 1.800 a 2.500 € al mes
☐ Més de 2.500 € al mes

12. Creieu que són ingressos suficients per a mantenir la família?_______________

Ens agradaria conèixer alguns aspectes sobre el vostre fill o filla amb discapacitat:

13. Quin és el gènere del vostre fill o filla amb discapacitat?

☐ Masculí

☐ Femení

14. Quin dia va néixer? ____________________

15. Quin lloc ocupa el vostre fill o filla amb DID?

☐ Primogènit
☐ Mitjà
☐ Bessó
☐ Benjamí
☐ Altres (si us plau, especifiqueu): ____________________

16. Té el vostre fill o filla amb DID algun ALTRE diagnòstic a més de discapacitat intel·lectual? (Assenyaleu TOTES les respostes que corresponguin).

☐ Trastorn per dèficit d'atenció (TDA) o Trastorn per dèficit d'atenció amb hiperactivitat (TDAH)
☐ Trastorn de l'espectre autista
☐ Trastorn emocional o de la conducta
☐ Discapacitat auditiva, incloent-hi sordesa
☐ Discapacitat visual, incloent-hi ceguesa
☐ Discapacitat física
☐ Trastorn de la parla o el llenguatge
☐ Traumatisme cranioencefàlic
☐ Problemes de salut (especifiqueu): ____________________
☐ Altres discapacitats (especifiqueu): ____________________
☐ Cap diagnòstic específic

17. Podria indicar-nos trets més rellevants del vostre fill o filla amb DID?

____

____

____

____

Voldríem preguntar-vos a continuació per la relació fraterna entre els vostres fills:

18. Podria descriure breument com és la seva relació fraterna?

____

____

____

____

19. El seu fill o filla sense DID coneix el diagnòstic del seu germà o germana?

20. El seu fill o filla sense DID coneix les dificultats que possiblement el seu germà/na tindrà quan sigui gran?

21. Com es comuniquen els seus fills o filles?

22. Els seus fills o filles comparteixen estones de joc? Amb quina freqüència?

23. Podria assenyalar alguns aspectes (interessos, preocupacions,...) relatius a com viuen els seus fills o filles el fet de tenir un germà o germana amb DID?

Moltíssimes gràcies per la vostra col·laboració!

La calidad de vida de los hermanos y hermanas de niños y niñas con discapacidad intelectual y del desarrollo que viven en Catalunya

INFORMACIÓN GENERAL SOBRE VUESTRA FAMILIA

Nos gustaría comentaros que hacemos estas preguntas con el fin de conocer mejor las características de las familias y también las percepciones de los padres sobre la relación entre vuestros hijos/as.

Os agradeceríamos que rellenéis esta sección sintiéndoos libres de dejar cualquier pregunta sin responder si así lo preferís. Asimismo, os recordamos que esta información es confidencial y anónima.

Empezamos con preguntas sobre vosotros mismos (la persona que está rellenando el instrumento):

1. **Por favor, señalad en el apartado siguiente cuál es la relación que tenéis con el niño o niña de vuestra familia que no tiene discapacidad intelectual o del desarrollo (DID)**

☐ Padre
☐ Madre
☐ Tutor legal
☐ Otros (por favor, especificad): ____________________
☐

2. **¿Género?**

☐ Masculino
☐ Femenino

3. **¿Fecha de nacimiento?** ____________________

4. **¿Cuál es vuestro país de procedencia?** ____________________

5. **¿En qué ciudad vivís?** ____________________

6. **¿Cómo es vuestra familia?**

☐ Monoparental + Número de hijos/as (por favor, especificad): ____________________
☐ En pareja + Número de hijos/as (por favor, especificad): ____________________
☐ Otros (por favor, especificad): ____________________

7. **¿Qué puesto ocupa vuestro hijo/a sin DID que participará en la investigación?**

☐ Primogénito/a
☐ Mediano/ana
☐ Gemelo/a
☐ Benjamín/a
☐ Otros (por favor, especificad): ____________________

8. **¿Qué día nació vuestro hijo/hija sin DID que participará en la investigación?** ____________________

9. **¿Cuál es vuestra situación laboral?**

☐ Trabajo a tiempo completo
☐ Trabajo a tiempo parcial
☐ En paro, pero buscando trabajo
☐ Otros (por favor, especificad): ____________________

10. **¿Cuál es el nivel de formación más alto que habéis completado?**

☐ Algunos estudios sin conseguir el Graduado Escolar / Certificado de Estudios Primarios.
☐ Educación Primaria - Graduado Escolar
☐ Educación Secundaria (ESO; Bachillerato; FP)
☐ Diplomatura
☐ Licenciatura / Grado
☐ Postgrado / Máster / Doctorado
☐ Otros (por favor, especificad): ____________________

11. **¿Cuál es el nivel total de ingresos familiares al mes teniendo en cuenta todas las fuentes? Aseguraros de incluir los ingresos provenientes de todas las fuentes (por ejemplo, subsidio familiar, prestaciones, paro, pensiones, ley de dependencia, etc.).**

☐ Menos de 600 € al mes
☐ De 600 a 1.200 € al mes
☐ De 1.200 a 1.800 € al mes
☐ De 1.800 a 2.500 € al mes
☐ Más de 2.500 € al mes

12. **¿Creéis que son ingresos suficientes para mantener la familia?** _______________

Nos gustaría conocer algunos aspectos sobre vuestro hijo o hija con discapacidad:

13. **¿Cuál es el género de vuestro hijo o hija con discapacidad?**

☐ Masculino
☐ Femenino

14. ¿Qué día nació? ____________________

15. ¿Qué lugar ocupa vuestro hijo o hija con DID?

☐ Primogénito/a
☐ Mediano/ana
☐ Gemelo/a
☐ Benjamín/a
☐ Otros (por favor, especificad): ____________________

16. ¿Tiene vuestro hijo o hija con DID algún OTRO diagnóstico además de discapacidad intelectual? (Señalad TODAS las respuestas que correspondan).

☐ Trastorno por déficit de atención (TDA) o Trastorno por déficit de atención con hiperactividad (TDAH)
☐ Trastorno del espectro autista
☐ Trastorno emocional o de la conducta
☐ Discapacidad auditiva, incluida la sordera
☐ Discapacidad visual, incluida la ceguera
☐ Discapacidad física
☐ Trastorno del habla o del lenguaje
☐ Traumatismo craneoencefálico
☐ Problemas de salud (especificad): ____________________
☐ Otras discapacidades (especificad): ____________________
☐ Ningún diagnóstico específico

17. ¿Podría indicarnos rasgos más relevantes de vuestro hijo o hija con DID?

____

____

____

____

Quisiéramos preguntaros a continuación por la relación fraterna entre vuestros hijos:

18. ¿Podría describirme brevemente cómo es su relación fraterna?

____

____

____

____

19. ¿Su hijo o hija sin DID conoce el diagnóstico de su hermano o hermana?

____

20. ¿Su hijo o hija sin DID conoce las dificultades que posiblemente su hermano/na tendrá cuando sea mayor?

____

21. ¿Cómo se comunican sus hijos o hijas?

____

____

____

____

22. ¿Sus hijos o hijas comparten ratos de juego? ¿Con qué frecuencia?

____

____

____

____

23. ¿Podría señalar algunos aspectos (intereses, preocupaciones…) relativos a cómo viven sus hijos o hijas el hecho de tener un hermano o hermana con DID?

____

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¡Muchísimas gracias por su colaboración!