



“So, I told him to look for friends!” Barriers and protecting factors that may facilitate inclusion for children with Language Disorder in everyday social settings

*Cross-cultural qualitative interviews with parents*

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## “So, I told him to look for friends!” Barriers and protecting factors that may facilitate inclusion for children with Language Disorder in everyday social settings: Cross-cultural qualitative interviews with parents

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### ABSTRACT

**Purpose:** Although researchers have explored parental perspectives on childhood speech and language disorders, this work has mostly been conducted in English-speaking countries. Little is known about parental experiences across countries. Participation in the COST Action IS1406 ‘Enhancing children’s oral language skills across Europe and beyond’ provided an opportunity to conduct cross-cultural qualitative interviews. The aims were to explore how parents construe inclusion and/or exclusion of their child and how parents involve themselves in order to facilitate inclusion.

**Method:** Parents from nine countries and with a child who had received services for speech-language disorder participated in semi-structured qualitative interviews. We used thematic analysis to analyze the data.

**Results:** Two overarching themes were identified: ‘Language disabilities led to social exclusion’ and ‘Promoting pathways to social inclusion’. Two subthemes were identified *Interpersonal relationships are important* and *Deliberate proactiveness as stepping stones for social inclusion*.

**Conclusions:** Across countries, parents report that their children’s hidden disability causes mis-understandings that can lead to social exclusion and that they are important advocates for their children. It is important that the voices and experiences of parents of children with developmental

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disabilities are understood and acknowledged. Parents' recommendations about how to support social inclusion need to be addressed at all levels of society.

## 1. Introduction

Language Disorder (LD) is used in DSM-5 to refer to children with unexplained language problems such as Specific Language Impairment and Social Communication Disorder (DSM-5, American Psychiatric Association, 2013). Bishop, Snowling, Thompson, Greenhalgh, and CATALISE consortium, 2016; Bishop, Snowling, Thompson, & Greenhalgh, 2017) proposed that the term Language Disorder be used to describe children "who are likely to have language problems enduring into middle childhood and beyond, with a significant impact on everyday social interactions or educational progress". Language Disorder may be an inherent part of biomedical and neurodevelopmental conditions such as Attention Deficit Hyperactivity Disorder (ADHD), Autism Spectrum Disorder (ASD), and intellectual disability.

The prevalence of LD in the preschool period is estimated at 7–14 percent (Law et al., 2017), and at school entry two children in each class have a LD severe enough to affect their academic progress (Norbury et al., 2016). Growing up with LD has long-term consequences for the individual's mental health (Botting, Durkin, Toseeb, Pickles, & Conti-Ramsden, 2016; Conti-Ramsden et al., 2019; Feeney, Desha, Ziviani, & Nicholson, 2012). Despite the high prevalence of LD and the potential lasting implications of the disorder, this condition is not well known compared to other, less prevalent neurodevelopmental conditions like ADHD, ASD or Dyslexia, rendering it an 'invisible' condition (Bercow, 2008, 2018; Bishop, 2010, 2013; Thordardottir, Topbas, & Working Group 3 of COST Action IS1406, 2021). Kamhi (2004) argued that some diagnostic labels such as Dyslexia and Asperger's syndrome are successful memes (i.e., ideas that catch on in society), whereas Language Disorder, due to the complexity of understanding what language is, is an unsuccessful meme and not well understood by the public. Bishop, Clark, Conti-Ramsden, Norbury, and Snowling (2012), thus characterized LD as a "neglected condition not only in research, but also in debates about policy and practices" (p. 259). One way to promote LD successfully in the meme competition may be by making it clearer what it means to have a Language Disorder (Kamhi, 2004).

Due to limitations in understanding and producing language, children with LD frequently experience emotional and social difficulties (Fujiki, Brinton, & Clarke, 2002; Nilsson & Jensen de López, 2016), and are often excluded from social interactions, or experience a poor quality of interactions and friendships (Brinton, Fujiki, Spencer, & Robinson, 1997; Durkin & Conti-Ramsden, 2007). Delayed language abilities may manifest themselves in weak competences for managing the social world and specifically in entering and interacting in groups with age-matched peers (Brinton et al., 1997; Liiva & Cleave, 2005). Social exclusion is experienced as loneliness, poor peer acceptance, few opportunities of making friends and a higher exposure to bullying compared to other children (Conti-Ramsden & Botting, 2004; Durkin & Conti-Ramsden, 2007; Knox & Conti-Ramsden, 2003; Redmond, 2011; Wadman, Durkin, & Conti-Ramsden, 2008). LD has been identified as a risk factor for social anxiety related to social interaction in adolescence and adulthood (Brownlie, Bao, & Beitchman, 2016; Voci, Beitchman, Brownlie, & Wilson, 2006). Forrest, Gibson, Halligan, and St Clair (2018) observed in a longitudinal study how early language difficulties and peer problems correspond with later emotional difficulties in adolescence. Their results suggest that positive relationships with peers may act as a protective factor against emotional difficulties in adolescents with LD. These results are in line with those obtained by Lyons and Roulstone (2018) through qualitative narrative interviews with a group of 9- to 12-year old children with speech and language disorders. These authors found that positive relations were one of the protective factors in relation to well-being.

From childhood and throughout adolescence parents play an important role in encouraging and supporting their children's social and peer relationships. Given that LD may be a long-term condition, it is important that the experiences and perspectives of parents are prioritized and understood for a number of reasons. Firstly, patient values and preferences are one of the three dimensions of evidence-based practice (EBP) (Dollaghan, 2007). There is some evidence that in the case of children with LD, professionals often overlook or disregard children's and parent's views and opinions and may not include them in the decision-making process (Rannard, Lyons, & Glenn, 2005; Roulstone, Harding, & Morgan, 2016). Parents to children with LD report that they do not feel that their expertise and knowledge of their children were recognized by practitioners.

Secondly, Ritzema, Lach, Nicholas, and Sladeczek (2018) showed that "Parent perceptions of their children's functional difficulties were differentially related to their children's well-being, depending on their perceptions of the adequacy of the formal supports and services their child and family received" (Ritzema et al., 2018 p. 244). Improved understanding of parental experiences and beliefs could inform policy and practice and enhance outcomes for the individual child.

Thirdly, in line with Kamhi (2004), information to the public in general about the concrete challenges that parents and children who live with LD experience and concrete solutions to these challenges, may help towards establishing a successful meme status for the term LD.

### 1.1. Parental involvement for children with LD

Family is one of the most important contexts for the development of socialization processes during childhood and adolescence (Palacios & Rodrigo, 1998; Rodrigo, Máiquez, Martín, & Byrne, 2008), and as such parents must fulfill different roles. The basic roles are to (1) guarantee the physical safety of their children, along with ensuring their socialization processes and the development of communicative and symbolic behaviors; (2) provide a supportive and affective environment, promoting attachment relationships; (3)

offer the necessary stimulation and be the gatekeepers for the child to access other developmental contexts. Families that have a child with a developmental disability often face additional challenges, having to engage in multiple roles, such as being an advocate for their child, being a therapist and being an educator (Safe, Joosten, & Molineaux, 2012). Young people with disabilities considered their parents as having an essential role in their engagement in community activities (DuBois, Renwick, Chowdhury, Eisen, & Cameron, 2020), reflecting the crucial role of parents of children with disabilities as gatekeepers and promoters of socialization in other contexts.

Qualitative research on the perspectives of parents towards children with LD, and the ways they empower themselves as advocates for their children in everyday settings is sparse and has mostly been conducted in English-speaking countries (Ash, Christopoulos, & Redmond, 2020; Rannard, Lyons, & Glenn, 2004; Roulstone et al., 2016). These studies have shown that parents may experience feelings of stigma, feel uncertain about the attitude of others towards their children, and worry that others may perceive their children as less intelligent (Marshall, Harding, & Roulstone, 2017; Rannard et al., 2004; Roulstone et al., 2015). British parents (Marshall et al., 2017) viewed themselves as competent facilitators of their children's language development using strategies such as starting language input early, spending time talking to their child, and giving the child opportunities to use its language through interaction and socialization.

Some parents revealed worries that perhaps they did not give their children enough attention, or that they had not been patient enough with them (Roulstone et al., 2015). Focus group studies with British parents to children with a LD have shown that desired outcomes are inclusion, social acceptance, family relations and independence, rather than outcomes specifically related to their children's communication (Markhan & Dean, 2006; Roulstone & Lindsay, 2012).

While there is literature about social inclusion in educational settings, little is known about social inclusion of children with developmental disorders in everyday settings. To our knowledge limited research has been carried out regarding how parents of children with LD construe the social inclusion of their children and the ways they actively involve themselves as advocates for their children's well-being. Furthermore, little is known regarding this type of parental experience across cultures and countries. The results of a recent set of large cross-cultural studies have shown that there is a great variability across European countries concerning how the needs of children with LD are met (Law et al., 2017; Law, Levickis et al., 2019; Thordardottir et al., 2021). These studies also show large differences in the ways LD is conceptualized, where people have heard of LD, how clinical services are delivered, and how the respective nation is organized in terms of its health and educational system. Furthermore, countries differ regarding the dominance of either the educational or the health system in decision-making about the services children with LD receive (see Law, McKean, Murphy, & Thordardottir, 2019 for detailed descriptions).

In order to understand how parents empower themselves and how they construe their children's possibilities for social inclusion, in our study we give the voice to parents as witnesses and advocates of the social inclusion of their children in everyday settings.

The authors of this paper participated in a 4-year European-funded COST Action IS1406 network 'Enhancing children's oral language skills across Europe and beyond: A collaboration focusing on interventions for children with difficulties learning their first language'. This collaboration provided a unique opportunity to conduct a cross-cultural qualitative study across nine countries. A recent cross-country study by Jensen de López et al. (2021) found that parents demonstrated contextualized understandings of their children's speech and language (dis)abilities despite not holding professional knowledge about LD. The current study describes a secondary analysis of the qualitative data of Jensen de López et al. (2021) exploring 1) how parents construe inclusion and/or exclusion of their child, 2) how parents involve themselves in order to facilitate inclusion and 3) areas of similarities in the experiences described in research questions 1 and 2 across cultures.

## 2. Method

The current study is a cross-cultural qualitative interview study which aimed to explore parental experience from the perspective of the parents themselves. We investigated how parents experience social inclusion or/and exclusion of their child in relation to their child's speech and language disorder, searching for common themes across the interviews. Qualitative interviews provide researchers with rich data that enable them to make personal experiences, beliefs, customs, and practices of participants explicit. Advantages of cross-cultural qualitative research where local researchers provide the data collection, data interpretation and data analyses are that there are reduced language barriers in understanding the data and that the findings can provide valuable insights into cultural nuances, local policies and different practice contexts (Chapple & Ziebland, 2017; Kaae et al., 2016).

We encountered cross-nation differences with regard to procedures for applying for ethics. Five countries required and obtained ethical approval to carry out the study (Appendix A, Supplementary).

### 2.1. Participants

In accordance with our aim to capture perspectives of parents across different countries, we used purposive sampling to recruit parents from 9 European countries and beyond (Croatia, Denmark, Hungary, Iceland, Ireland, Israel, the Netherlands, Norway and Spain). Parents were approached individually by telephone or face-to-face by gatekeepers (e.g., speech and language therapists, linguists). There were three inclusion criteria for participating in the study. Parents were requested to have a monolingual (speaking the societal language) child aged six to twelve years that had a speech and/or language disorder which was the primary presenting difficulty. Furthermore, the child should have received services for speech and language disorders within the last four months. A total of 10 parents participated consisting of nine mothers and one mother-father dyad. All participants gave their written consent prior to data collection and participation in the study was voluntary with the option to withdraw at any time. The study was carried out in accordance with the Declaration of Helsinki. The characteristics of the participating parents and their children are presented in

## Appendix B (Supplementary).

## 2.2. Procedure and data collection

A topic guide was developed in English by KJL and RL, and inspired by the Danish parental interview guide which focuses on how it is to be a family with a child that is growing-up with LD, and currently used at the Clinic for Developmental Communication Disorders, Aalborg University, Denmark. The guide included four topics: “Making sense of language impairment and how the parent describes it”, “Impact on the family”, “Getting help”, and “closure and verifying common understanding”. The topic guide included questions such as ‘Can you tell me about your child?’, ‘How would other people notice that your child has a language problem?’. The prompts were kept neutral to the specific situation of the family and in order to allow the parent to equally engage in positive or/and negative stories about her/his child’s situation. The topic guide, questions and prompts were discussed within the research group and topics were evaluated or/and revised to be culturally appropriate in the respective countries and to ensure the purpose of the specific questions and prompts were clear to all researchers. The interview guide was then translated into all the participating languages by respective researchers or a native speaker. In order to ensure that the meaning of words and phrases were maintained after the translation, back translation to English was carried out by independent researchers and adjustments were made; e.g., the term ‘service’ was replaced by the term ‘help’.

Interviewers held either a Master degree in speech and language pathology, developmental or/and health psychology or/and worked in the field as a researcher, and had undergone either previous formal training in qualitative research methods or extensive experience conducting qualitative research. The authors followed the Consolidated Criteria for Reporting Qualitative Research (COREQ) (Tong, Sainsbury, & Craig, 2007).

The data were collected using semi-structured interviews in the societal language of the specific country. All interviews were conducted by local researchers at a convenient location for the interviewees, such as their home or in a clinic (Appendix C, Supplementary). In accordance with the variation in ethics approvals, summer vacations and the subsequent identification of interviewees, data collection spanned over a period of eight months (during 2018). Interviews lasted from 35 to 77 minutes (median =55 min) and were audio-recorded. The recordings were transcribed verbatim by a respective member of the research team and six of the researchers made additional field notes during the interview.

## 2.3. Data analysis and reflexivity

Thematic analysis was used to analyze the interviews (Braun & Clarke, 2006). The initial analysis was guided by the research questions and we adopted an inductive (bottom up) approach in order to generate patterned meanings within the dataset. Our essential aim was to understand and describe the personal experiences, meanings and realities of the respective parents, that echoed social inclusion/exclusion of their children, while allowing for deductions (top down understandings) based on our professional perspectives as clinicians and/or researchers to influence our analysis. Critical reflections on the values, prejudices and personal positions of the individual researchers and of the group were used during the research process, in order to manage potential biases in interpreting the data (Braun & Clarke, 2006). As with all qualitative research our aim was not to document fully objective descriptions of the parent’s experiences, but through the process of scrutiny and meaning condensation to be able to reach the least biased understanding of the personal life experiences of the parents. Furthermore, the excerpts that we extracted in the final analyses were interpreted in a highly contextualized way in order to avoid misunderstandings and biases. Critical questions from the team concerning the meanings of the excerpts contributed to the management of biases. Data analyses was led by KJL, JF, IRRO and SB and through subgroup and full group discussions via teleconferences (Skype, Zoom, Teams).

The first steps in data analysis consisted of the respective researchers independently becoming familiarized with their data, reading and re-reading the transcripts and extracting meaning related to the topic of inclusion/exclusion. Following this initial process of data

Table 1

Preliminary coding framework.

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<b>STRATEGIES FOR INCLUSION</b> (incl. strategies attempted by caretakers or/and peers/family/extended family/ school/institution/after school activities). These could be physical or psychological or both
<b>SUCCESSFUL INCLUSION</b> (incl. strategies attempted by caretakers or/and peers/family/extended family/peers/ school/institution/after school activities) and that SUCCEEDED.
<b>UNSUCCESSFUL INCLUSION</b> (incl. strategies attempted by caretakers or/and peers/family/extended family/peers/ school/institution/after school activities), and that FAILED.
<b>The CHILD’s OWN strategies (agency)</b> in trying to become included; the child’s perceptions about and feelings about being included-excluded; including examples of agency. These can be conscious/explicit or unconscious/implicit strategies.
The CHILD’s OWN <b>SUCCESSFUL</b> strategies in trying to become included; its’ perceptions about and feelings about being included-excluded; including examples of agency.
The CHILD’s OWN <b>UNSUCCESSFUL</b> strategies in trying to become included; its’ perceptions about and feelings about being included-excluded; including examples of agency.
<b>DEVELOPMENTAL TRAJECTORIES OF SOCIAL INCLUSION</b> for children with <b>LD</b> (mediated by age, gender, culture, type of speech-language disorder etc.) – how do the child’s strategies change as the child becomes older in order to adapt to the challenges in society, how are these scaffolded or not by the child’s significant others (parents, teachers, extended family, teachers, pedagogues)?
Changes in the child’s strategies
Changes in the strategies opposed by others, that are clearly related to changes in the child’s development

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familiarization, the full author group discussed contextualized examples of the understandings that presented themselves in the individual data sets. Based on these discussions and due to the nature of our cross-culture data analyses KJL, JF, IRRO and SB developed an excel coding framework in English with topics addressed in the group discussions e.g., successful/unsuccessful inclusion and strategies, as well as developmental trajectories of social inclusion (see Table 1). The coding sheet was discussed within the full group and authors were asked to add examples of descriptions from their interviews that spoke to these topics. This was followed by several teleconferences where the initial coding framework was reviewed and revised.

Subgroup and full group discussions facilitated the analysis to move from code construction to generating initial themes. Analysis was thus iterative and reflexive in nature constantly moving backwards and forwards between data, analysis, codes and meanings, in the different languages and cultures as interpreted by the individual researchers. In cross-cultural and cross-language qualitative research, there is debate about when in the research process data should be translated into English (Chapple & Ziebland, 2017). In this study, the interviews and analysis were conducted in the societal language of the country. We decided not to translate excerpts of the data to English until the final stages of the analysis during which the codes and themes were generated. Through this procedure we felt that analysis of the data more closely respected the inherent meanings of the individual interviews than if we had translated the interviews to English before initiating the analysis.

### 3. Results

Two overarching themes were identified ‘language disabilities led to social exclusion’ and ‘promoting pathways to support social inclusion’. The second theme reflected parents’ direct and indirect concerns, and two sub-themes were generated within it: ‘interpersonal relationships are important’, and ‘deliberate pro-activeness as stepping stones for social inclusion’.

In the following we explain the themes, subthemes and aspects related to them, while providing excerpts from the data.

#### 3.1. Theme 1: ‘language disabilities led to social exclusion’

This theme captured the parents’ experience and reflections regarding how the language disability affected their children’s everyday life. It reflected barriers to activities and participation, situations where others did not understand the child, and thoughts about the psychological impact of LD on the child. Parents reported that others (including family, preschool teachers, and teachers) did not understand their child, e.g. ‘People just didn’t seem to understand what he was saying’ (Ireland), ‘(...) he started speaking late, and you couldn’t understand him well, he didn’t have much vocabulary (...)’ (Spain). The misunderstandings in turn impacted on the child’s ability to communicate with friends as well as her/his ability to form and maintain peer relationships, e.g. ‘She sometimes experienced small acts of teasing in the kindergarten, because of how she talks’ (Denmark).

Parents also expressed feelings of frustration because they viewed their child’s disability as a barrier to independence. In the following example excerpt, a mother expresses her sorrow and frustration on behalf of her daughter, because the baker was not able to understand the child’s attempt to place an order:

one could never..., that pride in being able to go to, that is, bringing her with one to the baker and when she says, "we would like that and that" well they, the baker couldn’t understand what she was saying and she just wanted to be allowed to try... but there wasn’t anyone that understood it (Denmark)

Turning to the psychological impact of growing up with a speech-language impairment, parents described ways in which their children were aware of their difficulties, as well as embarrassed and frustrated or upset by their language problems; e.g. ‘she knows and she is embarrassed, she can’t say the sentence’ (Israel). Parents described communication breakdowns and ways in which their children would become upset and cry when they could not be understood after multiple attempts. On the positive side, a parent reported that her child’s levels of anger had decreased and that he could now verbalize what was making him angry:

And he is not retreating any more. I mean, he goes to his room, but then I come to him... before he would angrily turn his back and he wouldn’t open up. And now he says what happened. ... He wanted many things, and we could not understand what he wants. (...) So we were guessing. So, he would start to cry after the third attempt, because we had more and more difficulties in understanding him (Croatia)

Another parent similarly reported that their child’s inability to express his needs and wishes led to aggressive behaviours: ‘It was difficult for him to express things, express what he wanted, express feelings, he would get very aggressive’ (Spain), while other parents expressed how their children demonstrated reduced self-efficacy:

He used a very few words. And when he got older, he was not able to build sentences. It was hard to understand him. He just couldn’t tell what he wanted. It was like everything was jumbled and then he just gave up telling [express his wishes, feelings, wants] and it was “Oh I can’t do this (Iceland)

Within this theme we identified, across all countries, that parents to children with LD experience similar frustrations and worries related to ways in which their child’s LD eliminates it from being included with the same ease as its peers. In the second theme we illustrate how parents react to these frustrations, and ways in which they create opportunities that may facilitate social inclusion of their children.

### 3.2. Theme 2: promoting pathways to support social inclusion

The second overarching theme covers the range of similar and different ways in which parents either directly or indirectly perceived their child as either being included or as being excluded, and the ways in which they actively create scenarios and concrete opportunities to support better inclusion of their child. Parents also expressed thoughts and worries that their child would experience social exclusion in the future. It became clear that most parents identified interpersonal relationships as important pathways for ensuring the social inclusion and well-being of their child.

#### 3.2.1. Sub-theme 1: interpersonal relationships are important

A central aspect that many parents addressed during the interviews was that *Friends are the key*. Parents seemed very conscious about the importance of friendships, and that it therefore was necessary to support their child in creating peer relationships. In some sense parents seemed to put more emphasis on peer relationships than school education. Parents also seemed to prefer peer relationships rather than adult-child or sibling-child or cousin-child relationships, which might reflect a desire for their child to have as “normal” a childhood as possible, but also mirror how they were preparing the child to become independent in the future. Some of the employed strategies were shown to be very successful, while others were difficult to implement and resulted in frustrations.

Many parents indicated the importance of ensuring the child had at least one friend to play with. A parent explicitly directed this concern to their child: ‘basically Peter did not have a friend (when he started school). So I told him to look for new friends.... he has some buddies, but he doesn’t have a real strong friendship with anyone’ (Hungary).

All parents also emphasized to different extents the desires for their child to have friends and/or to engage with others, and for some this meant putting lots of effort into creating scenarios to facilitate peer engagement. as described in the following:

... husband concerned about exclusion, made efforts to ensure inclusion. He’s no problems but my husband was kind of freaking out going oh my god he’s got no friends and no one is inviting him for play dates and I suppose we have kind of tried to you know? We try to bring friends over now, my husband takes a half day on a Friday and we’ll try and bring somebody from his class over to the house and let them play for a while and you know? Bring them off for tea or do something like that, so that he will have somebody coming like (Ireland)

Parents also expressed frustrations related to their desire for their child to independently find friends. A parent expressed this in the following way: ‘he is not able to make friends alone: I would like him to go to the park, you know, and then to have friends, but he still, he still binds to his cousins. I am worried more and more. How this is going to be in future. They cannot be together forever’ (Croatia).

It was also clear that many parents saw their child as social and with desires to be with other people: ‘She loves the kids’ company, of course’ (Israel); ‘he is very outgoing, a very social fellow. He always wants to take the stage and talk or sing. It does not make sense, does it, because he can’t sing and is not particularly good at talking either’ (Norway). Parents also worried whether the friendships established by their child were similar to those of “normally developing” children. The following quotes illustrate this:

Teachers say he has friends. Now like he does get invited to parties. He does seem to be popular. If I ask the question to the teachers is he ok? Has he someone to play with? And they’re like yes. Everyone loves him you know? (Ireland)

We are noticing that they call him for birthday parties and things, but they don’t call him for...he is always telling me “mum, let’s invite XXX to the pool” and then I have the experience of having invited the same kid 3 or 4 times, and then that kid doesn’t invite him. They don’t invite him home (Spain)

A further aspect regarding friendships was that having friends with disabilities or friends who are younger peers seemed to be one way to compensate for the child not having age-matched friends, e.g. ‘it was very helpful when they allowed him to play with the younger children and help them and teach them. He acquired the confidence that there was something that he could do. This was very helpful’ (Israel). However, not all parents perceived this type of friendship as what they mostly desired for their child. For example, the Irish mother’s experienced this type of friendship as a ‘kind of friends’ relationship indicating a partial acceptance: ‘There’s another little fella who was very sick when he was born too and had a tracheotomy for a while and is still having issues. They’re the kind of friends he has, they’re his similar little buddies like’ (Ireland).

The great importance of gaining friends also meant that at times parents felt they needed to make compromises in the demands they otherwise would have made as a parent. For example, the Croatian parent expressed the following: ‘sometimes I let him do some things that I normally wouldn’t allow, just to make him feel a bit important (in front of friends)’ (Croatia). Some parents also felt they needed to reduce the child’s exposure to everyday peer social activities that demand talk, including attending school, because the child became drained from energy and expressed psychosomatic symptoms. A parent explained this in the following way ‘but she can’t do that (participate in after school peer dinners). ... it was the film club she participated in .....well the rest of the week actually (the child said), “I have a headache, I have a stomachache”... She also stayed home today (from school due to fatigue), well it’s not that she often stays at home’ (Denmark).

Other parents expressed how their child was involved in peripheral peer relationships bridged by younger peers, cousins etc. They were concerned that this strategy made the child dependent and could become a disadvantage in the future:

However, he is dependent on his cousins. They are some kind of his pass to the society. (...) Because now, as they are still small, wherever the cousins go, maybe children would not call him, you know, for football or for something, but where his cousins go, he goes, too (Croatia)

The parents' overall concerns about how to ensure that their child had at least one playmate may reflect parent's hopes for their child to have as normal a childhood as possible. Given that most of the parents had at least one other child without an impairment, that may have served them as a reference to the ease with which children without a LD are accepted within social activities.

### 3.2.2. Subtheme 2: deliberate pro-activeness as stepping stones for social inclusion

Parents expressed a high level of proactiveness in supporting their child's well-being and ensuring that the child did not become excluded socially in different contexts. Although parents did not directly talk about specific strategies for promoting social inclusion, their concerns included active ways to facilitate interpersonal and intrapersonal opportunities that could serve as pathways to enable their child to become a true participant in age-adequate social activities. A strategy that seemed successful was to let others know about the child's disabilities in order for them to adapt and create an inclusive arena for the child to navigate. Explanations of the child's disability were deliberately provided by the parents to significant others (peers' peers', parents to peers, relatives, teachers) with the purpose of making them able to understand why the child might appear to respond differently from what might be expected for its age. For example, the Dutch parent expressed the following:

Sometimes I explain it [DLD<sup>1</sup>] to others. I mean, you don't want to put too much emphasis on it [DLD], but sometimes I do explain it. Like, Sanne has DLD so that others know...it will be nice if they can take it into account when communicating with her. That she is not able to express herself (Netherlands)

Another parent had developed the strategy of introducing the child together with her disability in order to avoid other children misunderstanding the child's behavior, when they were gathered with friends or close relatives in social settings. The parent explained this in the following way: 'always (in extended family settings) I say "do you know what? Klara"' or "just before you start playing then you just need to know that Klara talks like this or that and she had pain in her ears when she was little", that's the explanation we (the parents) normally have given' (Denmark).

Parents often felt that there was a lack of knowledge about LD within the society, e.g. 'a woman met Dana in the playground and asked "which kindergarten you are in?"' Dana was a little bit embarrassed and then I told the woman "she is in a language kindergarten". "What is a language kindergarten?" ' (the woman asked)' (Israel). Parents felt responsible for distributing adequate information about the disabilities related to growing up with a LD and put much effort into becoming experts on behalf of their child:

I really would like to have much knowledge about DLD. All the evidence, I would like to know that. And of course I looked for it on the internet, but I still don't know it completely. I'm not convinced. I still don't know everything about it [DLD] (Netherlands)

Making sure others understand the child will not grow out of its disabilities was also part of how parents informed others of what to expect of their child, e.g. 'They (other people) "say yes, yes, he will get it in the end. That is their attitude. I tried to explain to them that he is improving but that he will never be like his peers. I tried to explain it this way' (Iceland).

Parents deliberately took on responsibilities for ensuring that others understand that their child will not grow out of its disabilities and avoiding their child being excluded. This included reminding educators and other parents about the child's specific disabilities, as exemplified in the following:

He is now talking more about [the fact] that he does not understand. He did not do that before, but now he will say: "I took Icelandic class today and I don't know what the teacher was talking about. Nothing at all". And I say, "ok so be it". I am not scolding him for that. I will explain this to the teacher when I meet with him that he has difficulty understanding (Iceland)

Well, the headteacher is on our side. So she understands this problem (that the child was being teased). And so she is very much on our side... she says she realized this now and she understands it now that, indeed, Peter is being pushed on purpose to see when he slaps. Or he kicks somebody' (Hungary)

The Icelandic parent was well aware of the impact that informing others could have for her child's abilities to express agency and make decisions for himself:

I have talked to parents of his best friends and that has made a difference. One mum has told me that one time she took his son and my son to an ice-cream shop and wanted to give them ice-cream. And H, he could not tell her what he wanted. He wanted strawberry Ice Cream, with luxurious chocolate dip (ídfá). He just could not remember the name, and this was very difficult. And the mum said, "I would have gotten impatient and angry if this had been a normal child", "I would have said, what is wrong with you, tell me what you want". But because she knew that he had trouble with expressing himself she was able to show him extra patience. If he would have been a normal child then she would have decided for the child, but she did not, she gave him a chance to explain what he wanted. This time it was significant that I had explained his situation to the parent. She told me "yes, at this time it was important to know about his situation" (Iceland).

Along these lines parents found it supportive to repeatedly "translate" to others what the child said in order to ensure smoother

<sup>1</sup> DLD (Developmental Language Disorder) is used to refer to a language disorder.

communication, which in turn then could support inclusion of the child in social activities. This strategy especially seemed to be useful for younger children, e.g. the Norwegian parent commented as follows: ‘In many contexts, I tend to take over a little....I help him, and when he was younger, like at the end of kindergarten, he would say: “Mommy, say it for me” because I know what he wants to say’ (Norway). Although repeating what the child was saying mostly served as an immediate and positive strategy to allow the child to be included and understood by others, some parents also experienced this strategy leading to the child feeling that it was not being fully included, in the same way as its peers. For example, the Danish mother found that being dependent on this strategy also made the child feel different and experience a lack of agency: ‘one could see she was not happy about it [that others translated what she said]’ (Denmark).

The parents’ narratives projected the child’s educational trajectory, and many of them took active measures to assure the best possible educational setting for their child. Parents worry about how their children will be treated and excluded in kindergarten and school, and how to prepare them for what is to come, as seen in this example from Norway: ‘We are worried because we are afraid that he will not manage school. He does not have to be an academic, not at all, but he has to be able to cope in social contexts in an ok way. Otherwise he will not thrive there’ (Norway).

As a part of their efforts to improve their child’s language and school performance as a pathway to inclusion, parents worked hard on pursuing and matching the child’s interests, whether it was different kind of sporting activities like basketball, horse riding or swimming or a particular academic activity, as in the following:

He’s mad about science. So we have gone down that road now, so I try and do as many science camps with as him as I can. So Anyone for Science do, he’s doing a Halloween camp now. He did a summer camp, he did an Easter camp. He’s mad about science, loves it, will talk about it all the time if he could. Reads a load of books on it. Loves Lego. So builds Lego, every present he gets brought him to Legoland over in London. So we’ve kind of just tried to find what he actually likes (Ireland)

Parents were also concerned about teachers not demanding enough from the child because of her/his disability e.g. ‘Yes, in reality not [the teachers do not have any expectations for success]. It is pointless to make demands on these students. This is my view the teacher says he will just do what he can, and this is going to be ok’ (Iceland). From an inclusion-exclusion point of view, this attitude in teachers may be regarded as an indirect way of excluding the child. Parents also saw it as important that education should prepare the child for the future e.g. ‘Yes, exactly, because you do want to do that. You want that for her [Mother’s need for information, to be able to support her daughter]. She has to find a job in the in a while, in the future you know. I would like to make that as easy as possible for her. So that she won’t have too many challenges’ (Netherlands).

#### 4. Discussion

Our cross-cultural study explored how parents of children with LD construe inclusion and/or exclusion of their child and how parents involve themselves in order to facilitate and ensure inclusion. Researchers from nine countries conducted a semi-structured qualitative interview with a parent of a child that had recently had received services for her/his language disorder. Two overarching themes were generated; ‘language disabilities led to social exclusion’ and ‘promoting pathways to social inclusion’. We further generated two subthemes within the second theme, namely ‘interpersonal relationships are important’ and deliberate pro-activeness as stepping stones for social inclusion. Overall, our results showed common experiences among the parents. All parents experienced that their child’s language disability caused barriers to the quantity and quality of their social interactions, and that they needed to advocate for their child in different ways in order to ensure the child was not misunderstood, left out or simply overlooked by others. Constantly having to advocate for their child’s rights to be listened to and to be included in everyday activities was time-consuming for the parents. However, this also empowered them to develop successful strategies for how to be proactive as well as long-term planning that may allow the child to interact more smoothly with others, and avoid misunderstandings due to the child’s LD. The parents felt they were competent advocates for the rights of their child, which is similar to reports from British parents (Marshall et al., 2017), and that they saw it as their responsibility to fulfill this role (Davies, Marshall, Brown, & Goldbart, 2016). The worries and uncertainties expressed by British and American parents (Ash et al., 2020; Rannard et al., 2005) were also present in the group of parents participating in our study.

Regarding the theme of interpersonal relationships, parents expressed concerns that their children would not be able to fit in with peers, that they would be perceived as different and that they would fall behind in terms of becoming dependent. This concern was also raised by British parents in regarding their children’s quality of life (Markhan & Dean, 2006; Roulstone & Lindsay, 2012), and recently by American parents (Ash et al., 2020). These studies have shown that parents may experience feelings of stigma, feel uncertain about the attitude of others towards their children, and worry that others may perceive their children as less intelligent (Marshall et al., 2017; Rannard et al., 2004; Roulstone et al., 2015). Furthermore, the desires of the parents in our study for their children to be accepted in peer social interactions supports the results from the Forrest et al. (2018) and the Lyons and Roulstone (2018) studies that suggest positive social relations as being one of the protective factors in relation to the well-being of children with LD.

Our study is the first cross-cultural qualitative investigation of the views and experiences of parents of children that grow up with Language Disorder: a neuropsychological disorder with high prevalence, but low visibility. The findings illustrate that despite cultural, political, and service provision differences across countries (for descriptions see Law, McKean et al., 2019), there were many similarities among the parents regarding the way they construe their child’s possibilities and (dis)possibilities of being included in everyday social activities and across different institutional settings. Our results may be useful for practitioners and educators to consider when involving parents as valuable collaborators in the education of their child and when offering services, but also for

society in general. While the nature of semi-structured qualitative interviews and of our sample may present limitations to the generalization of the findings, it is important to underline that the goal of qualitative research is to generate insight and in-depth understanding based on purposive sampling and to evaluate the extent to which aspects of our results can be ‘transferred’ to other groups of people or contexts (Braun & Clarke, 2004). We therefore do not expect our results to reflect the exact experiences of all parents with a child growing up with LD.

An important contribution of our study is that we investigated how parents construe the inclusion and/or exclusion of their child, meaning that we left it open to parents to talk about what they felt was most important and subsequently interpreted their narratives. For example, we did not directly ask the parents to address the notion of inclusion, but simply asked them to tell us about their child and their experiences as a family. All the parents in our study spontaneously brought up narratives regarding inclusion and exclusion, and through our qualitative analyses we generated themes illustrating ways in which these experiences affected the everyday activities of the child and the family.

A limitation to our study is that it reflects the perspectives of educated parents and is restricted to a specific socioeconomic group. It would be complementary to gather parental interviews using the same methodology with other SES groups, parents of bilingual children and parents of children with other kinds of neuropsychological disorders, e.g. ASD, who struggle with social relationships for other reasons. Furthermore, children often grow up with two parents, and therefore it could be of interest to include the experiences of both parents, as well as the experiences of siblings.

Despite these limitations, the nature of qualitative interviews permitted parents across nine different countries to express ways they construe the realities of experience as a family with a child that is growing up with Language Disorder. This knowledge would not have been captured through quantitative methods. Understanding how parents and families construe their child’s LD, but also the strategies they find useful in advocating for their child’s rights to be included, may serve to make the visibility and acceptance of this condition more widespread.

## 5. Conclusions

Our findings suggest that, across European countries and beyond, parents are aware that the child’s hidden disability may cause misunderstandings that can lead to social exclusion, and that the parents are important advocates for their child. It is important that the voices, experiences and recommendations of parents of children with developmental disabilities are acknowledged. The thoughts and recommendations of best practices on how to support social inclusion for this large group of children should be addressed at all levels of society. According to Kamhi (2004), this type of insight may contribute towards establishing a meme- status for LD. Our findings indicate that attending social inclusion in peer groups as a part of or in the setting of language therapy potentially could be very useful for children and parents. It is important that the voices, experiences and recommendations of parents of children with developmental disabilities are acknowledged. The thoughts and recommendations of best practices on how to support social inclusion for this large group of children should be addressed at all levels of society. They also imply that that the child’s language and communication issues should be considered in a cross-professional perspective where SLTs work together with psychologists and social workers.

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## Appendix A. Supplementary data

Supplementary material related to this article can be found, in the online version, at doi:<https://doi.org/10.1016/j.ridd.2021.103963>.

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