



## Exploring parental perspectives of participation in children with Down Syndrome

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## **I Introduction**

Down Syndrome (DS) is a visible disability which may put children at risk in relation to social acceptance. Children with DS are perceived to present with a degree of sociability and cheerfulness not demonstrated by most other group of children with intellectual disabilities (Hodcapp et al. 2003). Individuals with DS have a distinct profile of developmental outcomes (Fidler 2005) with variability in the range and level of abilities (Turner and Alborz 2003). Children with DS present with a range of physical characteristics e.g., dysmorphic facial features, broad hands, congenital heart disease, and hypotonia (Roberts et al. 2007). Children with DS also present with speech difficulties, language impairments (generally characterised by deficits in syntax and semantics), and literacy difficulties, with pragmatic skills viewed as an area of relative strength (Roberts et al. 2007; Connors 2003). Although the level of abilities varies, children with DS often function effectively in social situations (Bull and Committee on Genetics 2011). Nonetheless, children with DS, along with other children with developmental disabilities, may be at risk in relation to social exclusion, and this may be further exacerbated by speech and language difficulties.

Participation in activities in society is important because it can provide positive outcomes for children with a range of disabilities, such as benefits in relation to companionship, functional skill development, support, belonging, and emotional development (King et al. 2003; Law et al. 2007). However, there is evidence to suggest that people with intellectual disability are one of the most socially excluded groups (Ali et al. 2012). The focus of this paper is on exploring parental perspectives of participation in children with DS. There is need for speech and language therapists to listen to the perspectives of service users, including parents and children e.g., the National Strategy for Service User Involvement in Ireland (Department of Health and Children and Health Service Executive 2008) and the United Nations Convention

on the Rights of Children (UNCRC 1989). In this paper, we discuss the construct of participation, including a critique of the International Classification of Functioning, Disability, and Health (ICF) (WHO 2001) as a means of exploring participation in children with DS. We argue for the need to listen to the subjective experiences of parents in relation to their children's participation. We review what is known about participation in children with disabilities, and more specifically in children with DS, and consider the implications for practice.

### ***1 The International Classification of Functioning, Disability, and Health (ICF) (WHO 2001)***

Children with DS may be at risk in relation to well-being. Some claim that domains such as physical, psychological, cognitive, social, and economic domains, contribute to children's overall well-being (Pollard and Lee 2003; Statham and Chase 2010).

“...well-being could be defined...at the individual level within a specific domain (physical, social, cognitive, or psychological) or the environmental level by incorporating effects of the child's environmental context.” (Pollard & Lee, 2003, p.64)

One of the ways in which speech, language and communication impairments can be classified, which includes these domains, is through use of the International Classification of Functioning, Disability, and Health (ICF) (WHO 2001). The ICF and the more recent version for children and youth, the International Classification of Functioning, Disability and Health – Child and Youth Version (ICF-CY) (World Health Organisation 2007) classify health-related functioning in a holistic way taking account of biopsychosocial perspectives which may contribute to overall well-being. The ICF can assist speech and language therapists in thinking about the overall needs of clients (Threats and Worrall, 2004). The classification system comprises three lists of codes: one list of body functions and structure; one list for the domains of activity and participation; and a third list of personal and environmental factors,

which may affect functioning. In relation to activities and participation, the ICF also has two qualifiers i.e., performance and capacity. The performance qualifier describes what an individual does in his or her current environment, whereas the capacity qualifier describes the highest level of functioning and what an individual can do in an ideal environment (Morris 2009; WHO 2001).

At the level of body structures and function, children with speech and language impairments, such as children with DS, may present with difficulties in the areas of listening, speaking, hearing, and oral motor skills. They may also present with cognitive deficits and medical conditions. Activity is defined as “*the execution of a task by an individual*” and participation is defined as “*an individual’s involvement in a life situation*” (World Health Organisation 2001). At the activity and participation levels, children with speech and language impairments may have difficulty with everyday activities, such as learning and applying knowledge, difficulties communicating effectively with others, and problems with related reading and writing skills. In addition, restrictions in activities may affect the child’s participation in other areas e.g., forming and maintaining relationships, accessing the curriculum, and involvement in community activities (Washington 2007; Campbell and Sharakis-Doyle 2007; McLeod and Bleile 2004). McCormack et al. (2011) found an association between speech and language impairments (both primary and secondary diagnoses) at age 4-5 years and later performance on activity and participation outcomes at age 7-9 years. The main findings were that children with speech and language impairments were at risk for peer relationship difficulties and poor outcomes in the academic domain.

There has been support for the use of the ICF as a conceptual framework in speech and language practice because of its value as a research, clinical, and educational tool (Threats

and Worrall 2004; Threats 2006). Furthermore, Threats and Worrall (2004) claim that one of the less obvious values of the ICF is that it could be a useful social policy tool because it can be used to explore environmental barriers to inclusion, which may in turn inform policy development and legislation.

However, there have also been criticisms of the ICF (Simmons-Mackie 2004). Some claim that there is overemphasis on individuals' functioning and doing, with other important determinants of well-being, such as being, belonging, and identity less visible (Simmons-Mackie 2004; Whalley Hammel 2009; Duchan 2004). Others claim that the definitions of activities and participation are ambiguous (Simeonsson et al. 2003). One of the challenges for speech and language therapists is in relation to assessing activity and participation in ways which are meaningful and valid. For example, McCormack et al. (2011) used a range of tools to measure activities and participation, including rating scales completed by teachers, parents, and children themselves. Morris (2009) argues that when measuring participation in childhood disability, there is need to consider the construct of 'capability', which reflects the child's capacity along with the opportunities provided in everyday life. Furthermore, Duchan (2004) claims that the subjective experience is missing from the ICF. Granlund et al. (2012) argue that a third qualifier of subjective experience of involvement when performing an activity would enhance the ICF.

Participation is a multidimensional and complex construct and no single tool or measurement approach can capture the intricacies inherent in participation (Bedell et al, 2011). Further research is needed to understand the subjective experiences of participation from the perspectives of parents (Granlund et al. 2012; Morris 2009; Radermacher et al. 2010) and the children themselves (UNCRC 1989). The everyday lives of children with disabilities, in

particular those with DS are not well known or understood, with few studies qualitatively exploring how children's participation is conceptualized and given meaning (Hammel et al. 2008). The subjective dimension of parent's experiences can be explored through use of observation, self-rating scales, personal narratives, and interviews (Granlund et al. 2012; Kovarsky 2008).

## ***2 Participation in children with developmental disabilities***

The pattern of participation of children with a range of developmental disabilities can differ from that of their non-disabled peers (Bedell et al. 2011). For example, some researchers have found that children with intellectual disabilities may have fewer social contacts and friendships (Bedell et al. 2011). Children with intellectual disability may be more likely to participate in family recreational activities with less participation in leisure activities outside of the home (McConachie et al. 2006). However, others have found that children with intellectual disabilities participated and enjoyed out of school activities to the same extent as their typically matched peers, but required extra support to complete specific recreational, active-physical and skill-based activities (King et al. 2013). Ethnographic research methods have been used to explore the experiences of young people with physical disabilities (Wickenden 2010). The young people were frustrated when they were misunderstood or misrepresented by others and when their autonomy was restricted (Wickenden 2010).

More specifically in relation to children with DS, there is evidence that these children may participate less in physical activities (Oates et al. 2011; Wang and Su 2012). In a study which investigated parental reports of participation in leisure activities in children with DS, children's recreation was predominantly sedentary and solitary, and children were unlikely to participate in more than one sport or hobby (Oates et al. 2011). Study findings also revealed

that, although 14.5% of children with DS had either only one or no friends, 52.5% had two or more friends (Oates et al. 2011). There was also evidence in this study that complex factors both within *and* external to the child with DS, such as the child's functional ability and familial income status, influenced the frequency of participation in leisure activities, such as swimming (Oates et al. 2011). Likewise, Dolva et al. (2011) found that a combination of environmental adaptations and support for children with DS facilitated peer interactions in mainstream classrooms.

In the two studies described, internal and external factors can be viewed as both enabling and disabling participation. However, the social model of disability places more emphasis on the external factors and views disability as arising from societal barriers which fail to respond to people's needs (Oliver 2004; Ali et al. 2012). Physical, social and attitudinal factors across settings (e.g., home, school and community) have been identified as influencing participation in children with various disabilities, with acknowledgment that the relative impact of specific factors can vary (Bedell et al. 2011; Duchan 2001; King et al. 2003). For example, the findings of a descriptive study using parental questionnaires, indicated that children with disabilities were engaged in the same activities as their peers and this engagement was influenced by family engagement in routines (Axelsson et al. 2013). On the other hand, other researchers have found that parents reported that negative attitudes and lack of knowledge acted as barriers to participation for children with disabilities (Bedell et al. 2011). It is also important to consider that there may be cultural factors which impact on participation and the studies reviewed have been carried out in a range of countries e.g., Sweden (Granolund et al. 2012; Axelsson et al. 2013), Australia (McCormack et al., 2011; King et al., 2013), US and Canada (Bedell et al., 2011), and Taiwan (Wuang & Su, 2012).

### **3 Intervention**

Promoting children's participation in everyday life activities represents a key aim for healthcare service providers and policy makers (Hammel et al. 2008). Professionals need to understand a children's individual participation profiles, along with the opportunities provided for participation, so that tailored interventions can be planned effectively to meet children's specific needs (Chien et al. 2014). Impairment and social approaches to intervention may be required to address children's participation. Duchan (2001) defines the impairment approach as one where the speech and language therapist assesses clients to determine whether the individual has deficits in speech, language, and communication, which in turn become targets for intervention. Therapists working within a social model framework examine the nature of the speech and language needs from the client's own perspective and explore facilitators and barriers to communication in the client's social networks. The emphasis is on developing supports in the environment to maximise communicative success (Duchan, 2001). Speech and language therapists may need to use both approaches to intervention to promote participation in children with DS. Intervention may require a focus on enhancing children's speech and language skills as well as addressing barriers to participation e.g., upskilling potential communication partners, facilitating opportunities for participation, and addressing negative attitudes.

The aims of this study were:

1. To gather the views of parents of children with DS on the children's everyday lives and participation
2. To identify facilitators and barriers in relation to their children's activities and participation.

## **II Methods**

The qualitative research paradigm is appropriate in instances where insights, experiences, descriptions and clarifications are required to explore a particular topic (Creswell 2007). The aim of this study was to explore parent's views on their children's participation, with a view to providing depth and rich data. Therefore, an exploratory qualitative paradigm was considered as an appropriate methodology in terms of answering the research questions.

### ***1 Participants***

This was a small scale exploratory study. The researchers used purposive sampling to recruit the parents of children aged between five and twelve years of age with DS. The participants were members of a support group in Ireland, which was known to one of the researchers. The researcher requested that the chairperson of the group would distribute information about the study and consent forms to parents who were members of the support group. The sample size for this study was 7 with in-depth interviews conducted with each participant. The aim was not to generalise but to gain an understanding of the experiences of parents of children with DS. It is acknowledged that this sample size is small and this was the case for two reasons. Firstly, this was a small scale exploratory study and secondly the research was conducted with limited resources in a short-time scale. There is also some evidence that data saturation may be reached after 6 interviews when the sample have all experienced a particular phenomenon (Guest et al. 2006). Ethical approval was granted from ANONYMOUS (for peer review purposes) in July 2011. Written consent was obtained from all participants.

*Insert table 1 about here*

## ***2 Data Collection***

For three families, one parent attended for interview, whilst both parents from the remaining two families were interviewed (seven participants in total) by the second author. The researcher used in-depth semi-structured interviews to generate data. The interviews were conducted in the parent's homes and ranged from 45 to 60 minutes in duration. While group interviews or focus groups may have generated data, their public nature may have prevented the attainment of specific information relating to the beliefs and perspectives of each participant (DiCicco-Blom and Crabtree 2006). Interviews provided opportunities for parents to describe their children's everyday activities (King and Horrocks 2010). The researchers could also clarify meanings and follow-up on particular topics. Nonetheless the interview is not without its limitations. Generally, the interview takes place in an interpersonal context which is influenced by power and emotion. Hence, in interpreting the data, the researcher engaged in reflexivity (see Section 4) (Denscombe 2007).

The interviews were semi-structured and followed a loose topic guide (see Appendix 1). One pilot interview was carried out to hone listening and questioning skills and to refine the topic guide. The topic guide was developed based on the literature in relation to children's activities and participation in a range of contexts e.g., the home, school, and wider community. Parents were not involved in the design of the topic guide and did not see the topic guide in advance of the interviews. The parents were advised that they would be asked to talk about their child's everyday life. All interviews were recorded with parental consent. Although the researcher followed a somewhat structured topic guide, she was aware of the need to create space for the participants to raise new topics.

All interviews were transcribed verbatim by the second author using transcription conventions (Shipley and McAfee 2009). All identifying information was removed and

participants were given alternative identifiers. In addition, the researcher kept detailed field-notes during and after each interview.

### ***3 Data Analysis***

The research questions were used to guide the data analysis within a framework analysis approach (Ritchie and Spencer 1993; Spencer et al. 2006). The iterative process of data analysis was achieved through the following stages: familiarisation, identification of a thematic framework, indexing, charting and mapping and interpretation (Green and Thorogood 2004; Ritchie and Spencer 1993).

1. Familiarisation: the second researcher immersed herself in the raw data, by listening to the interviews and reading the transcripts and listed key ideas and themes from each interview (Ritchie and Spencer 1993).
2. A thematic framework was constructed which included the key research questions as overall themes, along with sub-themes (Pope and Mays 2006).
3. The first and second author then refined the initial thematic index by systematically applying the data from all five transcripts to the thematic framework. This process required continuous checking of the data against themes to find the best fit.
4. The final stages included charting and interpreting the data, which involved defining concepts and finding associations between themes in order to provide explanations for the study's findings.

### ***4 Rigour***

In order to enhance the rigour and trustworthiness in this study, the strategies of reflexivity, member-checking and multiple coding were employed. Firstly, the second author compiled a reflective log over the course of the research to reflect on how the data were generated and analysed, taking account of the positionality of the researcher as an undergraduate speech and

language therapy student. Furthermore, during data analysis, while the researcher had pre-set objectives, a conscious effort was made not to force the data to fit the apriori issues (Ritchie and Spencer 1993). Secondly, during the interviews the second author checked with the participants that her understandings matched the participant's intended meanings. At the end of each interview, the second author identified key themes and checked with each participant that the themes were representative of their views, thus ensuring that the essence of their experience was captured reliably (Kreftin 1991). Thirdly, definitions of themes were provided to the first author who cross checked the coding of data in relation to themes and the overall thematic analysis, thus strengthening reliability of the study (Barbour 2001).

### **III Findings**

The final thematic framework comprised two themes and seven sub-themes. Each of the sub-themes will be discussed in turn and illustrated with quotes from the data.

#### ***Theme 1: Value of participation***

The first theme was in relation to the parents' beliefs about the values and benefits which they considered their children gained from participation in everyday activities, such as leisure activities. These benefits included the development of skills, and promotion of well-being and belonging. They also talked about ways in which their children needed support to participate.

##### ***1.1 Sub-theme: Development of skills***

In the parent's view, participation in activities provided the children with opportunities to make choices, be responsible, and demonstrate self-determination. The parents reported that through participation in activities, their children learned valuable life-skills. For example, through self-care activities, they learned about feeding and dressing themselves. Through leisure activities they learned skills such as swimming. By participating in social activities, they learned skills such as greeting others. Parents were keen that their children were given

opportunities to develop these skills with the ultimate aim of their children engaging in meaningful, real-life situations. One parent discussed how her daughter's ability to use the cash register in the family shop transfers as an important life skill.

*“She knows the barcode on each product you scan, so she'll scan the thing and she'd ask the customer for money ... oh it's a great life skill because she knows ... she has to pay for things” (P4)*

Parents also believed that participation in everyday life situations, such as physical activities and interpersonal interactions, provided the children with opportunities to develop their communication skills, empowering the children to influence their environments.

*“She'll say ‘my turn’ ... She's decided this is my thing too I want a turn [to talk at the dinner table] ... But I suppose that's good because she is making the effort to include herself all of the time... she won't see herself left out like” (P1)*

*“Okay just because he can't really speak ... but if he decides he wants to, he uses the sign, he can get the message across all on his own terms” (P7)*

### *1.2 Sub-theme: Enhanced well-being*

This sub-theme is defined in terms of children's psychological well-being which parents considered was enhanced as a result of participating in everyday life activities. Parents talked about the children's enjoyment when participating in activities, which in turn provided the children with a sense of achievement and satisfaction. Parents also valued attending some community based activities, which they perceived as enjoyable for their children.

*“[Child's name] loves going [to play group] because she gets to meet all the other DS children” (P4)*

Moreover, the successful execution of activities was perceived by parents to have a positive impact on the child's well-being, providing them with a sense of competence. These achievements included participation in activities across a range of settings, such as home, school and community settings.

*“She’s after getting very good at that [colouring], she’s starting to stay in between the lines, she’s not going over the lines now at all” (P3)*

One parent described how the sense of achievement functioned as a motivating factor for her son's participation in activities.

*“And knows that he can do it [any activity], that’s important, when he’s well able to do it, that’s when he likes to participate, if he thinks he can’t do it he’s not bothered” (P7)*

### *1.3 Sub-theme: A sense of belonging*

This sub-theme demonstrates how parents valued their child having a connection with others in the home, school and local community. Interpersonal interactions and relationships with other individuals in these settings were perceived to positively influence the child's well-being. For all parents, the home was identified as the core setting in which the child was included in activities, interacted with others and maintained relationships. In terms of relationships, there was general consensus that the majority of the child's friendships existed within the home, with the child's siblings and cousins. This was a matter of concern for two parents.

*“Well her friends now, I don’t know whether it’s good or bad, her best friends are her cousins” (P1)*

All participants valued their children's participation in activities with peers in the school context. Some parents were satisfied that their children, who were attending mainstream school, had actively developed and maintained friendships in school.

*"So she knows everyone well from school ... and gets on there" (P1)*

*"All I could see was her falling and cutting the two knees off herself [when running in the playground with classmates] but sure look sure isn't she happy and involved ... that's all you want for them is to be with the rest" (P1)*

Within the special education context, some parents provided examples of ways in which the teacher provided opportunities for their children to interact with their peers.

*"The teacher splits them into two little groups ... the children have to take turns putting the clothes on the doll, interacting with each other and deciding, So they have to take turns instead of one person just taking over" (P3)*

The parents also valued their children's participation in their local communities.

*"She'd go away into the post office and have a conversation with the girl there ... it's across the board young and old everybody she'd talk to them" (P1)*

The parents of some children who were attending special education particularly valued their children's participation in community activities with both abled/disabled peers e.g., leisure and recreation activities.

*"She goes swimming., She is the only special needs child there., gets the chance to talk to other children her age., she can learn their way and she's not treated any differently so it's great, because in the classroom they are all special needs" (P4)*

## ***Theme 2: Barriers and facilitators to participation***

This theme concerned barriers and facilitators of participation and four sub-themes were identified i.e., child factors, attitudes and views of others, environmental modifications, and logistical barrier.

### *2.1 Sub-theme: Child factors*

Child factors were defined as the child's level of functional ability, current health status, behaviour, fatigue, and communicative ability as perceived by their parents. Factors were unique to each child and were perceived to facilitate or obstruct participation in everyday activities.

*The speech is really the big problem, he can't get his point of view across, it's like tough luck if he doesn't want to do something, it's just not proficient enough to allow him to be in there and involved all the way. (P7)*

Participants perceived a trade-off between their children's strengths and challenges.

*Like he is fit and he has great mobility, he's not hindered anyway like that ... so even though he can't really talk, he can walk and run and that allows him to take part in his own way. (P7)*

### *2.2 Sub-theme: Attitudes and views of others*

This theme reflected the parents' interpretations regarding the attitudes of individuals towards their children with DS. Generally, parents considered the attitudes of others as positive and recognised these attitudes as facilitative of their children's participation in activities.

*When it came to summer camp ... would [child's name] be able to go to summer camp? She [dance teacher] said 'yeah, no problem, there's no issues whatsoever'. (P3)*

Some experiences were less positive, whereby the parents' perception of negative attitudes resulted in their children's exclusion from or avoidance of specific activities or interactions.

*My sister would offer to take my other children on holidays, but no they wouldn't offer to take [child's name] ... that how he is different. (P5)*

Parents expressed the belief that these negative views and attitudes were barriers to their children's participation in activities. Parents also encountered situations in which other adults and children exhibited low expectations of their children's general ability, which subsequently hindered opportunities for participation.

*She wouldn't have had an awful lot to do with her two grandparents ... daddy would say things ... like [child's name] would do something or would say something and he'd say 'God there is something going on in that brain'. (P1)*

In one of the interviews with both parents, there were conflicting views in relation to the views and attitudes of others in the local community towards their child. P1 stated: *'anywhere we go in the village she'd be really well known, people make such a point ... it's fantastic to see... everybody knows her don't they?.'* However, P2's response was more sceptical because he questioned the motivation for the positive interactions *'Did that start out as sympathy towards her?'*. Nonetheless, P1 argued that these interactions, regardless of the underlying motivations, were positive because they facilitated inclusion *'It works and I don't care how it started, it's great to have it for her'*.

### *2.3 Sub-theme: Modifications to the environment*

This theme reflected parents' awareness of their children's competence and limitations in participating in everyday life situations, and of the subsequent need to make changes to the

children's physical and social/attitudinal environment to make activities and participation more accessible for their children.

Parents talked about the support which their children required to participate and this support was mainly from parents and educators. Parents adopted an active role in providing their children with opportunities to develop skills, which would enable them to participate. They adapted the demands of activities at home and in community settings to make these activities accessible for their children. Support was predominantly described in terms of verbally motivating the child to participate in activities. The levels of support provided were context-specific and depended on the child's level of competence in the specific activity.

*"What [child's name] needs is time [in school], the bit of one to one, the bit of 'come on and do it'"(P1)*

Parents reported a need to balance promotion of participation in activities with consideration for their children's health and safety.

*I'd be begging them [child's siblings] and I'd be saying come out here and do something with [child's name]. (P1)*

*She has no fear at all of danger, and that's why every window in this house is locked, that's why doors are locked and keys are up and out of the way. (P3)*

#### *2.4 Sub-theme: Logistical Barrier*

Although location of activities was not a major theme emerging from the data, some participants identified geographical location as a barrier to their children's opportunities for participation.

*Well the Special Olympics stuff is way down in [town name], it's a bit away like, sometimes we wouldn't get going... just with the distance and the time commitment.*

*(P7)*

#### **IV Discussion**

The overall aims of this study were firstly to explore parental views of their children's participation and secondly to identify barriers and facilitators in relation to participation. The findings of this small scale study add to the current literature and provide some insight into activities and participation of children with DS in the Irish cultural perspective. Parents discussed ways in which their children engaged in self-care, physical and social activities which is consistent with the findings of other studies (Oates et al. 2011; Bedell et al. 2011). Parents placed value on their children's participation in everyday life, and reported benefits arising from such participation, for example, development of new skills, enhanced well-being and a sense of belonging, findings similar to those of other studies (Law et al. 2007; Lawlor et al. 2006). Specifically in relation to communication skills, parents also valued their children's agency in that they made decisions to actively include themselves in interactions with others. The importance of agency and autonomy in well-being has been acknowledged, with some arguing that it is the perception of autonomy which is important for well-being (Bridges 2003).

Parents identified a number of factors, which influenced their children's participation including: the children's individual strengths and challenges; attitudes and views of others; and modifications which need to be made to facilitate engagement. This finding is consistent with those of other studies (King et al. 2013; Dolva et al. 2011). The children in this study tended to participate in activities within the family and extended family context to a greater extent than in activities within the community. For example, there were reports that the

majority of the friendships were with siblings and extended family members rather than with peers. These findings are consistent with other research which has also reported that children with physical and intellectual disabilities may have fewer friendships (Bedell et al. 2011) and have fewer leisure activities outside the home (McConachie et al. 2006).

Attitudinal factors influenced participation in both positive and negative ways (Bedell et al. 2011). Parents viewed negative attitudes as the barriers to their children's participation, for example, low expectations, patronising views and attitudes, and exclusion because of the disability (Ali et al. 2012). An interesting finding was the different way in which one set of parents interpreted the behavior of others, for example, the mother interpreted the behavior as inclusive whereas the father interpreted the behavior as patronizing. This highlights the complexity of the attitudinal environment, and ways in which behaviours can be interpreted in multiple ways.

Key findings from this study highlight the perceived intricacies of participation in everyday life activities for children with DS. Parents' discussion of their children's participation in everyday life went beyond the actual activities to the benefits which the children gained from participation. The interplay between the child's participation and features of the social and attitudinal environments highlights the value of the social model of disability. Within this model there is a shift from identifying the impairments towards identifying and challenging the barriers in order to maximize a person's participation (Oliver 2004). There has been support from the Government's National Disability Strategy (Department of Health and Children 2004), enshrined in the Disability Act (Houses of the Oireachtas 2005), for a focus in health care and community planning towards changing disabling environments. Similar to the findings of Law et al. (1999), these findings provide support for policy makers and service providers alike to work with parents of children with DS to collapse barriers to participation across home, community, and societal domains.

Within speech and language therapy practice there is a need to understand the child's world from the perspectives of the children and family themselves. While frameworks like the ICF have an important role in understanding disability it needs to be supplemented with personal experiences of children and others in their lives. In this way, an exploration of the child's abilities, along with opportunities available in the child's environment to participate, needs to be undertaken so that specific goals can be designed to meet individual needs (Morris, 2009). It may be useful for speech and language therapists to explore family activity patterns because these patterns may influence children's preferences with regard to participation (Axellson, 2013). Participation requires more than taking part in activities and speech and language therapists also need to explore the quality of these experiences for children. Speech and language therapists also have a role in addressing negative attitudes towards children with DS. This could involve exploring the nature of these barriers and developing strategies to address them to facilitate the child's participation across a range of contexts.

One of the strengths of this study was the use of qualitative research design, which provided insights into parents' views and perceptions. A further strength was the inclusion of the perspectives of some fathers. However, there were some limitations. In this study, the researchers explored the perspectives of parents and did not investigate the perspectives of children themselves. There is evidence to suggest that children and parental perspectives may differ (Markham et al. 2009; Markham and Dean 2006). Therefore, proxy reports may not represent the child's perspective. The researcher who conducted the interviews and the analysis was a speech and language therapy student and had a family member with DS. These factors influenced the nature of the investigation and the lens through which the data were analyzed (Malterud 2001). Further research with a larger sample size, varied age range, and the use of longitudinal and observational study research designs are needed to enhance our understandings of the everyday lives of children with DS.

In conclusion, the current study, in keeping with the findings of other studies (Bedell et al. 2011; Hammel et al. 2008), illustrates the challenge in capturing the multidimensional nature of participation in everyday activities. These findings support the arguments put forward by Granlund et al. (2012) that a third qualifier of subjective experience of involvement in activities and participation would add to the ICF framework. Others advocate for direct observations to capture the complexities of participation in everyday life situations (Simeonsson et al. 2003). The implications for practice are that speech and language therapists need to consider the subjective experience of participation from the point of view of the families and the children themselves, as well as the ICF framework as it currently exists. In addition, therapists need to consider individual child factors along with environmental factors, such as opportunities for participation, when working with children with DS.

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