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The participation of disabled children and young people: a social justice perspective.

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Abstract

There is an increasing expectation that children, young people and their parents should participate in decisions that affect them. This includes decisions about their health and social care and collective or public decisions about the way in which such services are designed, delivered and evaluated. Indeed this has become a policy priority across the UK (Franklin and Sloper, 2009). The participation of disabled children and young people, however, has been slow to develop in the UK and concerns have been expressed about progress in this area. Drawing on the results of an ESRC funded, mixed methods study, the aim of this article is to explore the participation of disabled children and young people through a social justice lens. Participants, recruited by purposeful sampling, included 18 disabled children and young people, 77 parents and 90 professionals from one Health and Social Care Trust in Northern Ireland. Results showed that for most disabled children and young people, decision making was firmly grounded in a family centred model. However, when children and young people were drawn into participatory processes by adults and recognised as partners in interactions with professionals they wanted more say and were more confident about expressing their views. However, choices and resources were at times limited and this had a key impact on participation and the lives of these children, young people and their parents. The article concludes by exploring implications for practice and services. The need for a two pronged, social justice approach is recommended as a mechanism to advance the participation agenda forward.

Key words: participation, disabled, children, young people, decisions, social justice.

Introduction

The concept of participation has received much attention within academic, policy and practice arenas. Despite continuing debate and discussion on the subject, there is little agreement as to how it should be defined (Clark and Percy-Smith 2006; Winter, 2006; Lansdown, 2010). In general, it is has been associated with varying degrees of involvement

in decision making and indeed the terms participation and involvement have traditionally been used synonymously within the literature (McNeish and Newman, 2002; Cavet and Sloper, 2004). Such involvement is thought to span a continuum from merely being present (Alderson and Morrow, 2004; 2011), to actively influencing decision making denoting a shift or redistribution of power (Franklin and Sloper, 2006; Lansdown, 2006). Essentially, it has been influenced by many factors including the modernisation of health and social care across the UK, the increased emphasis on the involvement of service users in the planning and delivery of services, the children's rights agenda and current legislation, policy and associated guidance. The most influential of these has been the United Nations Convention on the Rights of the Child (UNCRC), ratified in the UK in 1991 with Article 12 being frequently singled out as the most important (Fortin, 2003):

'States parties shall assure to the child who is capable of forming his or her own views the right to express those views freely in all matters affecting the child, the views of the child being given due weight in accordance with the age and maturity of the child.' (Article 12, para. 1)

Many authors have proposed conceptual frameworks or typologies of children's participation that lend themselves to a range of contexts, including health and social care (Hart, 1992; Shier, 2001; Treseder 1997; Kirby *et al.* 2003; Lundy, 2007; Wright *et al.* 2006; Thomas, 2007). Despite much debate about whether or not models should be hierarchical or non-hierarchical in nature, the earliest hierarchical model by Hart (1992) remains prevalent.

In contrast to these typologies of participation, children and young people do not always want to make all decisions by themselves. Often, particularly within the context of health and social care, children want and need the support of adults in decision making, most commonly their parents or carers (Coyne *et al.* 2006; Winter, 2006). Previous studies have demonstrated that disabled children and young people, in particular, want the support of their parents in decision making (see for example, Mitchell 2012a). Indeed, the rights and duties of parents are clearly highlighted within the UNCRC (Articles 2,3,5 and 18) in terms of helping children realise their rights and to achieve their full potential and this has particular currency where disabled children are concerned.

Participation and disabled children and young people

Active participation can be a challenge for all children; however, disabled children and young people can face additional barriers because of professionals' inadequacies in dealing with their individual ways of communicating along with wider societal attitudes towards their participatory rights and disability in general. These issues are addressed in two of the UNCRC's provisions, specifically Article 13, that children may provide information in any medium that they so wish; and Article 23 which states that disabled children should have access to information and enjoy a full life whereby self-reliance is promoted. However, in its most recent Concluding Observations on submitted reports by Great Britain and Northern Ireland, the Committee on the Rights of the Child (CRC, 2008) stated that, although progress had been made, insufficient action had been taken to ensure that disabled children's participatory rights were upheld. The ratification of the Convention on the Rights of Persons with Disabilities (CRPD) on 8th June 2009 in the UK may go some way in further promoting disabled children and young people's participation. Lansdown (2009) points out that the aim of the CRPD is not to create new rights, but to ensure that existing human rights are strengthened and enacted for disabled people, including children and young people. Article 7 reads as follows:

'States Parties shall ensure that children with disabilities have the right to express their views freely on all matters affecting them, their views being given due weight in accordance with their age and maturity, *on an equal basis with other children*, and to be provided with *disability and age-appropriate assistance* to realize that right.'

(Article 7, para. 3) (emphasis added)

Recent research shows that the participation of disabled children and young people in decisions about health and social care is multifaceted and very much influenced by: the availability (or otherwise) of resources (Franklin and Sloper, 2006; Badger, 2009 and Rabiee and Glendinning, 2010); the actions and attitudes of parents (Slade *et al.* 2009; Hyde *et al.* 2010); the practices and attitudes of professionals (Badger, 2009; Greco and Beresford, 2009); the provision of information (NICCY, 2008; Mitchell, 2012b); and adequate preparation for decision making and ongoing support (Pilnick *et al.* 2010). Parents also have

a key role to play in ensuring that disabled children and young people can access the services they need and respecting the evolving capacity of their child to make decisions for themselves. Participation fosters greater competence and confidence and this itself enhances levels of greater participation (Lansdown, 2009). This is, however, particularly challenging for parents of disabled children and young people who are often protective of them and may find it difficult to 'let go' (Murray, 2002). Achieving a balance between the child's right to be protected and their right to be heard can be difficult for all families (Archard and Skivenes, 2009) but particularly so in this context. Thus, while on the surface achieving the standards set out in the CRPD seems straightforward, it is in fact much more complex.

With this in mind, in this paper, I argue, that a social justice perspective may be useful in order to further understand and explicate what participation means for disabled children, young people and their families and what more needs to be done to advance the participation agenda.

Methods

The discussion presented here is based upon an ESRC funded, mixed method doctoral study that aimed to explore the meaning, experience and outcomes of the participation of disabled children, young people and their parents in health and social care decisions. Participants were 77 parents, 18 disabled children and young people (half of whom belonged to a local participation group – the DCYPPP and half who did not belong to such a group) and 90 health and social care professionals from one Health and Social Care Trust in Northern Ireland. Children and young people were aged from six years through to young adulthood and had a range of physical, cognitive, sensory and communication impairments. It was not always possible to interview both parents and their children in the study as some chose not to take part or were recruited using 2 different mechanisms. Thus opportunities for an in depth analysis of family or three-way decision making between parents, their children and specific professionals was not possible in this study. There were four phases of data collection: parent and professional surveys, parent and child/young person interviews using participatory and creative methods to engage with children and young people, and a focus group with professionals. This research was informed by two service user groups, including valuable input from two disabled young adults who were consulted at various stages of the research

process. Ethics committee approval was obtained from the University ethics committee, the Office of Research Ethics and the Health and Social Care Trust.

Social Justice

The term justice is most often associated with the legal system and issues such as fairness and equity. Social justice is a broader concept, retaining these issues but involving the individual, family, community and wider society. In recent child participation literature, reference to recognition theory has begun to emerge (Fitzgerald *et al.* 2010 and Graham and Fitzgerald, 2010; Thomas, 2012). Following the feminist tradition, Fraser's work is concerned with equality and social justice in terms of the oppression of certain groups within society. It is wide ranging in terms of *recognition* as the equal status of social actors in their interactions and relationships with others, the cultural norms of social institutions and the *distribution* of resources within a larger social frame. Fraser proposes a two dimensional conception of social justice, referred to as the status model (Fraser, 1996).

The status model

For Fraser, recognition is a question of social status equality and participation parity, a situation where social arrangements permit individuals to interact with each other as peers. When social actors (for example, disabled children, young people and their parents) are viewed as peers, *reciprocal recognition and status equality* result. However, when social actors are seen as inferior, are excluded or are rendered invisible within social interactions, *misrecognition and status subordination* are inevitable:

'To view recognition as a matter of status means examining institutionalized patterns of cultural value for their effects on the relative standing of social actors...To be misrecognised, accordingly, is not simply to be thought ill of, looked down upon or devalued ...It is rather to be denied the status of a full partner in social interaction, as a consequence of institutionalised patterns of cultural value that constitute one as comparatively unworthy of respect or esteem.'

(Fraser, 2000:107)

Thus, according to the status model, recognition is played out through the workings of social institutions and cultural norms, rather than resting with an individual or group, the importance of which is also emphasised within Thomas's social relational model of disability. According to Fraser (2000), injustice occurs when such institutions and cultural values perceive some individuals as less than full members of society and hinders them from participating as peers. For Fraser, injustice encompasses non-recognition, disrespect and cultural domination.

A second, and equally important, aspect of Fraser's work is the notion of *maldistribution*. This includes income inequality in addition to exploitation, deprivation (being denied an adequate material standard of living) and marginalisation from the labour market. In order to remedy maldistribution, Fraser uses the term 'redistribution' :

'For the politics of redistribution, the remedy for injustice is economic restructuring of some sort. This might involve redistributing income, reorganising the division of labour, democratizing the procedures by which investment decisions are made or transforming other basic economic structures'.

(Fraser, 1996:7)

Misrecognition (and social injustice) for Fraser cannot be seen in terms of status subordination alone, or in isolation from economic arrangements in contemporary society. For Fraser, status subordination is linked also to resources or what she calls distributive injustice. Fraser argues that material resources must be fairly distributed in such a way to ensure participants' independence and voice. Previous research has demonstrated that disabled children and their families of disabled children experience financial hardship (Contact a Family, 2012), fewer opportunities for employment and further education (Kelly, 2013) and limited social activities (Mencap, 2007). In order to remedy social injustice, Fraser proposes an approach where both recognition and the equal distribution of resources are inter-dependent and both need to be addressed.

Recognition or Misrecognition?

In this study, the extent to which disabled children and young people experienced recognition during interactions with health and social care professionals varied. Overall, it was clear that professionals played a very important part in the lives of disabled children and young people. Children and young people in this study reported positive relationships with professionals,

particularly those who included them, made efforts to build relationships with them and communicated well.

Findings from this study suggested that, where decision making was concerned, many disabled children and young people (in particular younger children and those with cognitive impairment) were generally happy for adults they trusted to take the lead. However, it was very important to children and young people that professionals provided them with information, established their views and whether or not they want to be involved. Evidence from this study suggest that this is, at times, lacking, as reported in previous studies conducted with disabled children and young people (Turner, 2003; Kelly, 2005; Haydon, 2007).

In this study, some professionals went to great lengths to spend time with children and young people and learn to communicate with them; however others communicated solely with parents, particularly when children and young people lacked verbal skills or professionals assumed that they would be difficult to understand or unable to contribute. Previous research has demonstrated that children with cognitive impairments are often not included in the decision making process because professionals do not have advanced skills and training to elicit their views (Rabiee *et al.*, 2005; Franklin and Sloper, 2006) and this was also, at times, evidenced in this study. According to Fraser's (1996) social justice perspective, this renders disabled children and young people invisible in interactions and results in misrecognition and status subordination. Some children and young people with limited verbal communication wanted professionals to talk to them more and wanted to be more involved in decision making processes. Professionals and parents who do not find ways of facilitating the involvement of these children and young people are in danger of creating disabling barriers as exclusion from communication with others also impacts detrimentally on children's self-esteem and self-determination. Disabled children and young people have said that being respected and included can positively influence their well-being (Foley *et al.* 2012). Furthermore, a lack of involvement in interactions or decision making with professionals caused anxiety for a small number of individuals, for example, Orla¹, who communicated using eye pointing:

¹ Throughout this paper, pseudonyms are used to replace the actual names of research participants to protect their anonymity.

Interviewer: And how does it make you feel when the nurse talks to your mum and not you?

Orla: [eye points to bored symbol]

Interviewer: Bored. And does it make you feel anything else [referring to the other symbols]?

Orla: [eye points to worried symbol]

Interviewer: Worried?

Orla: [indicates yes].

[Orla: 13 year old with physical and communication impairment]

Parents reported that professionals did not always communicate with children and young people at an appropriate level and they had to interpret for their child. One mother of a 16 year old described her experience in hospital as 'groundhog day', as despite advising professionals about communicating in basic, single words or phrases with her autistic son, her advice was ignored. In some cases, children and young people gave professionals the impression that they understood what was said or that they agreed to a certain treatment regime or course of action. However, once professionals were out of the room the child or young person asked the parent what was going to happen, or made it clear that they did not agree to what had been discussed. Self-confidence was an issue for many children and young people, who found it difficult to ask questions of professionals or tell them that they did not understand. However, when children and young people got to know professionals well, sometimes over years, they were more likely to take an active part in decision making or express their opinions.

For children and young people in this study, the attitudes of parents and parenting practices either facilitated or hindered their participation in health and social care decisions, a finding also reported in previous studies (Allen, 2005; Slade *et al.* 2009; Hyde *et al.* 2010). They had a key role in encouraging their child to participate in decision making and reinforcing the fact that their views were important, or, in cases where professionals did not involve them, encouraging professionals to involve them more:

When I first took Suzanne there [to the regional hospital], she would sit with her head down and he [doctor] asked me something about Suzanne ...and he turned round to me and he goes can she understand that, can she talk? And I said yes! And I turned round to the doctor and said Suzanne 'say hello to the doctor', cause the speech is actually very, very good. In fact too good sometimes!

[Mother of a 15 year old young person with physical, cognitive, sensory impairment and autism]

While some parents made conscious efforts to do this, others took the lead as their child's advocate. It was clear that some parents felt that they should always make decisions for their child, even when children became older or were able to make their views known. Thus from a social justice perspective, parents did not always recognise the importance of involving their child and affording them increasing status in their interactions with professionals. While many parents did assume that, in their parental role, they would take responsibility for decision making, it was important to them that professionals engaged with their child directly and got to know them in order to be able to communicate with them and accurately assess their needs. The approach taken by professionals was often decided by that taken by parents i.e. whether parents assumed that they would communicate with professionals and make all the decisions for their child, or whether they actively fostered their children's participation, a finding also reported by Badger, (2009). From a children's rights perspective, Burke (2005) notes the importance of hearing the voice of the child themselves rather than depending on those of parents and professionals.

For many children and young people, a lack of participation was compounded by not being informed about their impairment or diagnosis. It was evident that not telling children and young people their diagnosis was not always underpinned by parental concern that their child would worry about their prognosis but by fears that the child would feel different or inferior to others. While parental protectionism is a complex issue, this potentially also reflects the prevalence of the medical model of disability in parental thinking and wider society along with the fear of status subordination. In fact, in previous studies, disabled children and young people indicated that while they are aware of impairment effects and disabling attitudes of others, they tend to stress similarity rather than difference when comparing themselves to others (Macarthur and Kelly, 2004; Connors and Stalker, 2007; Lewis *et al.* 2007; Singh and Ghai, 2009). This again relates back to Fraser's social justice perspective. If disabled

children and young people were afforded equal status by others, parents might not have such concerns. As a result of the attitudes and practices of others, disabled children and young people are not always recognised as valued peers in social interactions, and are afforded a subordinate status.

In relation to access to appropriate information, the CRC (2006) general comment on the rights of disabled children and young people states that:

'Children with disabilities and their caregivers should have access to information concerning their disabilities so that they can be adequately educated on the disability, including its causes, management and prognosis. This knowledge is extremely valuable as it does not only enable them to adjust and live better with their disabilities, but also allows them to be more involved in and to make informed decisions about their own care.'

(CRC, 2006:11)

However, the reality is more complex, not only because of parents' attitudes and desire to protect their children, but also because of the ethical issues (i.e. the potential for doing more harm than good) surrounding truth telling where child may have life-limiting impairment or other serious illness (Price and Cairns, 2009; Coyne and Harder, 2011). Such conversations with children do not solely involve the delivery of information, but rather entail appropriate preparation and support during and after its provision. Negotiating the balance between a child's right to be protected and their right to be heard is not new (Archard and Skivenes, 2009 and Coyne and Harder, 2011), although this features little in relation to the additional issues that arise when a child is disabled. Not telling disabled children and young people about their impairment prevents them from participating as partners in interactions with professionals and potentially affords them a subordinate status. In the absence of such information, previous studies have demonstrated that disabled children and young people develop knowledge about their impairment from others which may or may not be accurate or appropriate (Kelly, 2005) and this has also been evidenced in this study. Disabled children and young people have a right to develop a clear and positive sense of identity and not telling them about their impairment may heighten the risk of them internalising negative messages from others.

Parents also played an important part in information giving. Children and young people were given varying amounts of information by parents before they went to see professionals.

Some spent time explaining and preparing their child for what would happen, while others

did not tell children and young people why they were going at all regardless of the nature of their impairment or level of understanding. Few children and young people interviewed could identify why they were going to see professionals or why professionals had come to see them at home:

Interviewer: So who else comes out to your house? The behaviour nurse comes, doesn't she?

Catherine: Yeah

Interviewer: And what does she do?

Catherine: She just talks.

Interviewer: And what does she help you with?

Catherine: I dunno.

[Catherine: 15 year old with physical and cognitive impairment]

The wider beliefs and attitudes of parents and professionals, as members of society, also impacted on the participation of disabled children and young people in this study. Parents varied in their own attitudes towards disability and the expectations they had for their disabled child and this had an impact on how much they encouraged the participation of their child in three-way communication. In all but one of the parent interviews, children and young people had a cognitive impairment and /or autism and there was a general consensus that there was limited value in professionals giving their child information because they would not be able to understand it. Some parents also did not expect professionals to learn how to communicate effectively with their child. There was an assumption that because their children did not communicate verbally or used little verbal communication, professionals would not understand them and parents would therefore need to take on an interpretative role on an ongoing basis.

Recognition Over Time

As demonstrated in other studies (Rabiee and Glendinning, 2010), some children and young people who took part in this research wanted to be more involved as they reached their teenage years and beyond. That said, a key finding from this research was that while many

children and young people were happy for adults to make decisions, when they were made aware of their rights (such as those belonging to the DCYPPP) they expressed a desire to have more of a say. Regardless of age or degree of cognitive impairment, it was very evident that children and young people who belonged to the DCYPPP were generally more confident and more likely to interact with professionals and make their views heard, than those not belonging to the group. This also engendered support from their parents who developed an understanding of their son/daughter's ability to speak up for themselves and engage in decision making with professionals, an important factor in encouraging participation. This study provides important evidence to support the continued development of such groups where disabled children and young people are recognised as peers in interactions with professionals and policy makers alike.

Most parents accompanied young people to appointments with professionals well into their young adult lives. Some parents, however, recounted that they involved their son or daughter in decisions with professionals or 'took a back seat' as they got older. Despite the finding that parents unequivocally worried about the future (when they could no longer look after their child), only a minority spoke about actively fostering their child's participation in decisions that affected them as a mechanism for developing their confidence and future independence. For most, meeting their child's needs was all consuming and a major part of their role as a parent was to advocate and make decisions for their child. If professionals did not involve the child or young person, most parents took the lead and spoke to their son or daughter afterwards.

In the survey, professionals indicated that young people were more involved in decisions about their care once they entered adult services. All professionals in adult services said that young adults had either 'some' or 'a lot of influence' on decisions made, whereas in children's services, 15% of professionals surveyed said that they had no influence and 21% answered 'other'. Issues identified in this category mainly centred on the child or young person's level of understanding, capacity or age. For example, professionals working with children less than 5 years old said they were too young to participate in decisions and one professional suggested that children were more involved when they were 10 years old. The need for professionals to be creative in order to better involve disabled children and young people of any age was identified but in general, professionals found that involving children and young people with 'communication difficulties' was challenging. Only one professional said that she would use alternative methods of communication, such as determining from the child's

behaviour if they enjoyed their placement. Several commented that in reality, choices about how to communicate or participate were very limited.

Maldistribution

The second part of Fraser's status model concerns the equal distribution of resources in achieving social justice. Fraser (2000) maintains that full participation cannot take place if there is a lack of sufficient resources to enable social actors to interact with each other as peers. Thus, failing to provide resources is, for Fraser, a source of social subordination and injustice, placing the issue of recognition within a wider socio-political and structural frame. Many parents in this study felt that they had to fight for services to meet their disabled child's needs, a common finding in recent research (Bennett, 2009; Slade *et al.* 2009; Pilnick *et al.* 2011; Resch *et al.* 2010; Care Quality Commission, 2012). The language used by several parents, such as 'feeling like the enemy' or 'experiencing a victory', suggested that they felt they were engaged in a battle. The need to fight for their child was threaded throughout many parental accounts of participating in decision making. This was perceived as long-term and at times exhausting, both physically and emotionally, for parents:

...the day you give birth to a child with a disability is the day you fight. You start a fight and the fight goes on and on and on for everything...

[Mother of a 15 year old with physical, cognitive, sensory impairments and autism]

Parents reported feeling frustrated at the length of time it took to access the resources they required (for example, equipment or short breaks) and there was a sense that they had to keep 'pushing' for whatever they got. Waiting lists also meant that families had to wait for services that they perceived as more urgent than service providers. Whilst most parents reported very positive relationships with professionals, several parents reported being made to feel like a 'neurotic mother' and recounted having to 'change their personality' to engage in the fight for their child. These parents said that they had to become more assertive and 'toughen up':

... I would've been the sort before, I would have nearly sat back and people could have walked all over me and I would have nearly lay down and said 'go on ahead, how many times do you want to do it?', but not anymore.

[Mother of a 15 year old with cognitive, sensory and communication impairments and autism]

This fight for their child was associated with a great deal of stress. An exploration of the stress associated with having a disabled child was not an objective of this study, as it is extensively covered elsewhere (Redmond and Richardson, 2003; Woolfson and Grant, 2006; Lawrence, 2008; Parkes *et al.* 2009). However, it was very apparent that while children were highly valued and precious members of the family, mothers, in particular, experience high levels of stress. This has been a recurring theme within the literature despite significant new models of service provision targeted at this group. A social justice approach may help to explain this finding, as unless there is more investment and a redistribution of resources, parents of disabled children will continue to experience insufficient services. Mothers in previous studies have identified that the most stressful part of bringing up a disabled child is dealing with professionals (Read, 2000) and so, at a relational level, by actively listening to parents and by recognising their expertise, professionals may alleviate some of the stress they experience. However, if resources are not available, or perceived to be in short supply, then social justice will not be achieved. Professionals shared parental frustration about not being able to secure services for families and they also commented on the lack of resources:

Generally a lack of resources will hinder the ability to involve parents' opinions. Ninety percent of parents will request services that can't be provided.

[Professional survey 55]

Professionals also felt under time pressure, which may partly account for the finding that relationships with professionals were, at times, less than optimal. Parents in this study felt that resources were limited given the recent 'cuts' and that sometimes they were not told about services to prevent them asking for them. Previous researchers have reported similar findings and highlight the importance of trust in professionals during decision making processes (Avis and Reardon, 2008 and Huang *et al.* 2011).

The variability of parents' awareness of post-school opportunities and social activities for their child is also noteworthy in terms of the distribution of resources. Parents in previous studies have highlighted the importance of their children's social development and wellbeing (see for example, Slade *et al.* 2009), and this is a policy priority for disabled people in Northern Ireland (DHSSPS, 2012a, b). The finding that some children had very active social

lives while others did not is of concern as children needing one to one assistance may lose out. Parents of children and young people with more complex health needs or those requiring one to one assistance, required detailed information about what was available for their child. When information became available for summer schemes, for example, it was often too late to organise the provision or training of carers within the required time frame. Many parents were concerned about the lack of information about social activities for their child, which they saw as important for engendering their social development and building confidence. **Discussion: Social Justice and Participation**

The aim of this article was to explore the participation of disabled children and young people through a social justice lens. In her status model, Nancy Fraser maintains that institutional patterns of cultural values can deny social actors the status they deserve, view them as lesser members of society and prevent them participating with others as peers. For Fraser social justice will only occur when this situation is remedied along with a redistribution of resources. Thus, Fraser is clear that social justice cannot be achieved by recognition alone but *both* aspects of the status model, recognition and redistribution. In the context of this study, recognition for disabled children and young people in social interactions with professionals is not enough; it must be paired with a redistribution of resources and opportunities to have their needs are met so that they are not disadvantaged and their voices are truly heard. For participation parity to be achieved, these two aspects need to be superimposed.

At the very heart of the first of these two elements lies the relationship between disabled children and young people, their parents and professionals. The relational basis of participation has received some attention in recent literature (Fielding, 2007; Mannion, 2007; Thomas, 2007) and this resonates clearly with Fraser's (1995) approach. Not to develop relationships with children and young people or afford them the opportunity to participate in decision making, and not to recognise them as experts in their care potentially constitutes misrecognition within the status model.

The absence of any substantial discussion around alternative means of communication or mechanisms that would enable professionals to better communicate with some children and young people was notable in this study. Recognising the importance of services for children and young people with speech, language and communication needs, the Department for Education in England has been instrumental in developing a 'Communication Council' along

with a 'Communication Champion' to advise and support government ministers in the improvement and monitoring of this aspect of service provision. A similar model would be beneficial in Northern Ireland.

The attitude of adults, both professionals and parents, is key to social justice. Adults need to recognise children and young people's agency to meaningfully participate in decisions that affect them. In this research, few parents expected their child ever to be able to participate in decisions (either independently or with their support) and many saw this as something that they would continue to do on their behalf. It must be acknowledged that some children and young people with profound cognitive impairments may not be able to be the 'main decider' as articulated by Alderson and Morrow (2004). However, at times, it appeared that they could have been more involved and their exclusion constituted misrecognition. Previous studies have discussed the role of the parent in three-way communication between children, professionals and parents, the majority focusing on barriers such as parent or professional preoccupation with protecting disabled children or parents speaking as proxies for their children (Moore and Kirk, 2010; Coyne and Harder, 2011; Kilkelly and Donnelly, 2011; Gallagher *et al.* 2012). However, the role of the parent in actively encouraging and facilitating their disabled son or daughter's participation (specifically detailed, practical advice on how to achieve this and addressing additional challenges for those with impairments) has not featured much in current literature and is an important finding of this study. Encouraging such participation may be challenging for some parents of children with significant cognitive impairment or no speech, as their natural response is to speak for their child. Clearly, however, if disabled children and young people are to participate more communication patterns need to change.

In this study, professional attitudes to involving disabled children and young people varied between child and adult services in this study. Professionals in children's services need to be aware of the importance of involving children in decisions as they develop and mature in order to prepare them for increased responsibility for decision making within adult services. This needs to be planned and supported by parents as well as children and young people. Some guidance has been recently developed about involving children and young people in decisions (RCPCH, 2010) but there is none specifically about involving and supporting them in decisions about their health and social care. The development of such guidance may help to further develop participatory practices between children and young people and professionals.

The findings of this study demonstrate that, at times, disabled children and young people do not have the information they need to participate meaningfully in decisions that affect their lives. A number of written information resources are available for parents however specific guides for disabled children and young people would be a useful addition. There were several limitations to this study that should be addressed in future research. While it is acknowledged that the number of participants in this study was relatively small, generalisability to the population as a whole was not the aim of this study. Rather, some important findings have been uncovered in this research that warrant further enquiry. The response rate from the parent survey (24%) was less than optimal and therefore caution is required when interpreting the findings. The number of professionals from adult services who took part in the study was relatively small when compared with those from children's services and therefore findings drawing comparisons between the two should be interpreted with caution. Likewise, it was difficult to recruit professionals for focus group discussions with the findings of just one focus group reported. This may account for the lack of data around children's competence as decision makers.

Conclusion

This paper started by ascertaining that, like all children, disabled children are rights holding individuals who have the right to express their views and have these views given due weight when decisions are being made. However, disabled children and young people face additional barriers to their participation as evidenced here in addition to previous literature. The link between recognition theory and participation has begun to emerge in the literature and this link has been further demonstrated here. It is imperative that disabled children and young people are afforded the recognition they deserve and are drawn in to decision making processes in their interactions with health and social care professionals. This will only happen if parents and professionals actively encourage participatory practices, if children and young people have the information they need and if professionals further develop the necessary communication skills to meet the needs of individuals. Wider societal attitudes will only improve towards disabled children and young people when their views are actively sought and respected and their ability to exercise agency in their own lives is recognised. This study adds weight to claims that participation and recognising the expertise of children and young people goes hand in hand with the development of self-determination and self-

confidence as demonstrated by young people belonging to the DCYPPP. However, securing optimal resources remains an issue for families and this creates much stress. For Fraser (1995) the struggle for recognition goes hand in hand with material inequality and the need for the redistribution of resources. Clear investment is needed to develop services and opportunities for disabled children and young people to ensure that they reach their potential.

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