DOCTOR OF PHILOSOPHY

The participation of disabled children, young people and their parents in health and social care decisions

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The participation of disabled children, young people and their parents in health and social care decisions

(Part 1)
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Abbreviations used in this thesis

PCCD Parent/Carers' Council on Disability
DCYPPP Disabled Children and Young People's Participation Project
DHSSPSNI Department of Health, Social Services and Public Safety Northern Ireland
HSCB Health and Social Care Board
OFMDFM Office of the First Minister and Deputy First Minister
NICCY Northern Ireland Commissioner for Children and Young People
RQIA The Regulatory and Quality Improvement Authority
UNCRC United Nations Convention on the Rights of the Child
CRC Committee on the Rights of the Child
UNCRPD United Nations Convention on the Rights of Persons with Disabilities
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 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 has been slow to develop and concerns have been expressed about progress in this area. This ESRC funded study aimed to explore the experience and outcomes of the participation of disabled children, young people and their parents in health and social care decisions. Participants, recruited by purposeful sampling, included 18 disabled children and young people, 77 parents and 90 professionals from the Southern Trust, Northern Ireland. This mixed methods study, that included surveys, a focus group, interviews and participatory methods of research with children and young people, was designed and informed by 2 service user groups who were consulted at various stages of the research process. Results showed that for most disabled children and young people, decision making was firmly grounded in a family centred model. However, when they were drawn into participatory processes this created a sense of independence and self-confidence. Parents in this study wanted to be fully involved in all decisions made with professionals and felt the need to protect their child on the one hand, whilst encouraging their independence on the other. Clearly the onus is on practitioners to support both children and young people and their parents during decision making, whilst acknowledging the individual needs of those concerned. Based on the findings of this research a new Family Participation Model is proposed as a mechanism for further understanding how participation operates for these particular families and guiding future enquiry around this area. Key recommendations for practice, services, policy and future research are explored.
Chapter 1: Introduction

1.0 Introduction

Simple definitions of participation suggest that it means taking part or being involved; however, in reality participation is more complex and there is no consensus as to how it might be defined or conceptualised (Clark and Percy-Smith 2006; Winter, 2006; Lansdown, 2010; Thomas, 2012). Essentially, it has been influenced by many factors including the modernisation of health care across the UK and the recent reorganisation of health and social care in Northern Ireland, the increased emphasis on the involvement of service users in the planning and delivery of services (i.e. the manner in which they are delivered), the need to recognise children as citizens in their own right, the children’s rights agenda and current legislation, policy and associated guidance, explored in chapter 2 of this thesis. While this guidance is clear, progress in the UK has been less than optimal where disabled children, young people and their families are concerned. In the Concluding Observations on the last UK report to the UN (Committee on the Rights of the Child, 2008) it was stated that ‘insufficient action has been taken to ensure the rights enshrined in article 12 are applied to children with disabilities’ (para 32). Despite their frequent use of health and social care services, evidence suggests that they are less likely to be consulted and actively to participate in decision making processes than other children (Davis and Watson, 2000; Sinclair and Franklin, 2000; Cavet and Sloper, 2004a; Franklin and Sloper, 2006; Franklin and Sloper, 2009; Mitchell et al. 2009). Although less likely, it is evident that disabled children and young people are indeed participating and some progress has been made— for example, Making Ourselves Heard (Martin, 2009) reports encouraging examples of such activity in England and similarly the Aiming High programme (Every Disabled Child Matters) details many innovative examples of consultative events with disabled children and young people. The participation of parents, while clearly important, has received less attention within the literature. Here, there has been more emphasis placed on partnership working (Goldfarb et al. 2010; Price, 2012), participation in children's physical or nursing care and treatment decisions (Coyne, 2007; Power and Franck, 2008). This first chapter summarises the gaps that this study
seeks to fill, sets out the aims and objectives of the research and outlines the structure of the thesis.

1.1 Gaps this study seeks to fill

While there is an emerging literature about participation, there are significant gaps in our current knowledge about the experiences and outcomes of participation by disabled children, young people and their parents in decisions about services, whether at the level of individual care or service provision and policy. A national survey in England showed that disabled children are less likely to be involved in decision making than non-disabled children (Franklin and Sloper, 2006), raising important issues surrounding equality. Further evidence suggests that it is the most articulate and confident disabled children who are engaged in participatory practices (Martin and Franklin, 2010). There are few evaluations of children and young people's participation that focus specifically on their experiences, or outcomes and benefits (Kirby and Bryson, 2002; Kirby et al. 2003; Carr, 2004; Cavet and Sloper, 2004a; Cavet and Sloper, 2004b; Pinkerton, 2004; Sinclair, 2004; Franklin and Sloper, 2006; Thomas and Percy-Smith, 2010) and there is much less evidence in the literature about parents' participation in decision making, particularly where parents of disabled children and young people are concerned. When parents are asked about participation it is often about their child's participation and the tensions in decision making when parents, children and young people and other key stakeholders are involved are seldom explored. As Shah (2008) points out the family, as one of the most influential institutions in society, has a crucial role in shaping children's development, aspirations and choices made for both everyday and adult life. Family centred practices within the health and social care professions continue to recognise that the lives of children, young people and their parents are inextricably linked and thus health and social care decisions must be made in the context of the family.

As Cavet and Sloper (2004a; 2004b) and Carr (2004) point out, much more is written about the process of participation rather than the outcomes. Indeed, overall there is a general lack of evaluative activity (Pinkerton, 2004; Kirby and Bryson, 2002; Sinclair, 2004) and much of what is written is based on anecdotal evidence or opinion rather than
evaluative studies. Where disabled children are concerned, there is a lack of research around both disabled children's experiences of participation (Franklin and Sloper, 2006) and its outcomes. Thus, this study fills a gap in the current literature, exploring the process (experience) as well as the intrinsic and extrinsic outcomes (what happens as a result) of the participation of disabled children and their parents. Uniquely, it places equal emphasis on both children and their parents as social actors in decisions making processes. Research around the participation of disabled children, young people and their parents in decisions about health and social care services and policy is even more scant (see chapter 3 of this thesis). Given the increasing emphasis on service user involvement within local health and social care provision and policy in Northern Ireland (DHSSPS, 2011a), this study also seeks to fill this gap. Thus, participation is explored across a number of dimensions enabling the exploration of potential links between participation in care decisions made with professionals and those made at a higher strategic level. In so doing it is acknowledged that there is only so much scope for reporting all the findings in this thesis. However, the salient points will be presented and may serve as a useful mechanism for further research in this area.

Previous research has at times focused on either health or social care decision making (see for example, Franklin and Sloper, 2006; Egilson, 2011; Mitchell, 2012a). However, this study focuses on both types of decisions given that Northern Ireland (unlike the rest of the UK) has an integrated health and social care system. Furthermore, in a UK study by Marchant et al. (2007) (that included participants from Northern Ireland), parents argued that children should be seen as a whole child and not an individual with different health, social care or education needs:

'... they keep telling me you have to separate out his educational needs and his social needs from his health needs. WELL YOU CAN'T. That's his health needs, that's his disability, that's his educational needs... I try to explain they don't come as separate bits. I don't care who pays for which bit.'

(Marchant et al. 2007:6)
Young people in the study by Marchant et al. also highlighted the importance of seeing their needs together:

‘For me, social care and health care are all bundled together. I need a balance. The social care would include football, computers, going out. The medical care would include meds and nebulisers. If I stop either one of them, the other one gets affected. If I don’t go out I get ill. If I don’t get medical care, I can’t go out.’ (22-year-old with CHCN)

(Marchant et al. 2007:5)

Thus the integrated approach taken in this research is warranted. This thesis is presented a short time after the launch of the World Health Report on Disability (World Health Organisation and World Bank, 2011) that endorses participation, along with Transforming your Care (Health and Social Care Board, 2011), a new model of service delivery in Northern Ireland. Its submission is therefore timely.

1.2 Aim and objectives of the research

The aim of this research was to explore the meaning, experience and outcomes of the participation of disabled children, young people and their parents in health and social care decisions, from the perspectives of key stakeholders. Objectives and research questions, generated from current literature and negotiated with the 2 advisory groups involved in the study, are set out in Table 1:

Table 1: Objectives of the research and associated research questions.

<table>
<thead>
<tr>
<th>Objectives</th>
<th>Research questions</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. To establish the extent to which disabled children, young people, parents and professionals share a common understanding of participation in decisions.</td>
<td>How do disabled children, young people, parents, professionals define participation that is meaningful for them?</td>
</tr>
<tr>
<td>2. To explore disabled children and young people’s experiences of participating in</td>
<td>1. To what extent do children and young people participate in decisions made with</td>
</tr>
<tr>
<td>3. To explore parents' experiences of participating in decisions about children and young people's care made with health and social care professionals about the health and social care that their son or daughter receives.</td>
<td></td>
</tr>
<tr>
<td>---</td>
<td></td>
</tr>
<tr>
<td>1. To what extent do parents participate in decisions made with professionals about their child's health and social care i.e. being informed, expressing a view, influencing the decision making and being the main decider (Alderson and Morrow, 2004)?</td>
<td></td>
</tr>
<tr>
<td>2. To what extent do parents want to participate?</td>
<td></td>
</tr>
<tr>
<td>3. What sorts of decisions do they want to make and what sorts of decisions do they want others to make?</td>
<td></td>
</tr>
<tr>
<td>4. Are some decisions more difficult than others?</td>
<td></td>
</tr>
<tr>
<td>5. What are the tensions in decision making between children and young people, parents and professionals?</td>
<td></td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>4. To explore disabled children, young people's and parents' participation in (a) decisions about the manner in which health and social care services are designed and delivered (b) decisions about associated policy.</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. Who gets involved and why do some children, young people and parents participate in this way and others do not.</td>
</tr>
<tr>
<td>2. What are children, young people's and parents' experiences of participating in decisions about the planning and provision of health and social care services and associated policy?</td>
</tr>
<tr>
<td>3. What are the tensions between service users and those who are responsible for</td>
</tr>
<tr>
<td><em>5. To find out what promotes and hinders participation in decisions across these domains.</em></td>
</tr>
</tbody>
</table>
| *6. To identify the nature of the outcomes of children, young people’s and parents’ participation in (a) decisions about children and young people's care made with health and social care professionals, in (b) decisions about service design and delivery and (c) decisions about associated policy.* | 1. What difference, if any, does participation make across the 3 domains?  
2. Are there both positive and negative outcomes of participation? |

### 1.3 Structure of the thesis

This thesis is presented in 2 volumes. Volume 1 comprises 10 chapters. This first chapter has sets out the aims and objectives of the research and defines key terms used within the thesis (see 1.4). Chapter 2 explores the context of the study in terms of health and social care structures and policy in Northern Ireland. In chapter 3, participation is defined and two literature reviews are presented: the first reports the participation of disabled children and young people and the second the participation of parents in health and social care decisions. Chapter 4 defines the key theoretical concepts that underpin this thesis. Chapter 5 sets out the methods used in the study and explores issues such as survey design, interviewing parents and creative, participatory research with disabled children and young people. Ethical issues that arose in the planning and conduct of the research are discussed in chapter 6. Chapter 7 reports the findings of the study. The following chapter, chapter 8, proposes a new Model of Family Participation. The penultimate chapter critically evaluates the findings in light of current theory, discussing the implication for practice, services and policy. The final chapter, chapter 10, presents an overall conclusion of the thesis. Volume 2 includes references and appendices.
1.4 Definition of key terms and definitions of terms for the current study

**Child**: aged less than 13 years, as defined by the National Institute for Health and Clinical Excellence (2009). It should be noted that parents who took part in the study spoke of their 'child' regardless of age and this is retained in their accounts. Although, legally, the term 'child' refers to those up to the age of 18 (and up to 21 years in some cases), it was anticipated that the term 'child' would not sit well with developing young people who were actively engaged as service users.

**Children in need**: as defined in The Children (Northern Ireland) Order 1995, Article 17: 
(a) he is unlikely to achieve or maintain, or to have the opportunity of achieving or maintaining a reasonable standard of health or development without the provision for him of services by an authority under this Part;
(b) his health or development is likely to be significantly impaired, or further impaired, without the provision for him of such services; or
(c) he is disabled.

**Young person**: aged 13-28 years. The National Institute for Health and Clinical Excellence (2009) defines a young person as those aged 13-17 years. However, this age was extended in this study as young people belonging to the Disabled Children and Young People's Participation Group (DCYPPP) were up to 28 years. However, at times, for the sake of brevity, the terms children and young people are used interchangeably in this thesis.

**Parent**: parent or carer/those with parental responsibility including mothers and fathers or significant other.

**Professional**: health or social care professional.

**Service provider**: Southern Health and Social Care Trust where the research was conducted. This term includes those with responsibility for service design and development.
Impairment: 'problems in body function or alterations in body structure— for example, paralysis or blindness' (WHO and World Bank, 2011:5).

Disability: 'Persons with disabilities include those who have long-term physical, mental, intellectual or sensory impairments which, in interaction with various barriers, may hinder their full participation in society on an equal basis with others' (UNCRPD Article 1).

Participation: involvement in decision making. The words involvement and participation are at times used synonymously in this thesis.
Chapter 2: Context of the study

2.0 Introduction

This chapter sets out the context of the study. First, the organisation of health and social care within Northern Ireland is explored, highlighting key changes over the last 10 years and current developments. The research was conducted within the Southern Health and Social Care Trust and the chapter next describes ‘Wraparound’, the model of service delivery for disabled children, young people and their parents within the Trust. The participation of children, young people and their parents strongly underpins relevant legislation, policy and associated guidance in Northern Ireland and reflects a growing emphasis, more generally, on the importance of involving service users in health and social care. Salient aspects of this guidance are summarised in this chapter, highlighting the rationale for the study and the importance of this area for health and social care service provision and more generally for children, young people and their parents.

2.1 Health and social care provision in Northern Ireland: a time of change

Northern Ireland currently has the only integrated health and social care system within the UK. It is thought that such systems and practices may help meet the rising demand for services, while at the same time reduce public expenditure and increase satisfaction with services (Cameron et al. 2012). Health and social care within the province has undergone a radical time of change and reform over the past 10 years in terms of models of care delivery, the advancement of medical and other technologies, and public health challenges, along with changing demographics. The provision of services closer to home, the shift from hospital to home care, and the care of ventilated children and young people in the community are just some of the examples of the rapid change and challenges faced by those who use and provide services. At the same time, the expectations of patients and their families have risen.
2.2 The organisation of services

In 2006, the Review of Public Administration (RPA, 2006) set out plans to streamline Health and Personal Social Services in Northern Ireland with the aim of increasing efficiency, enhancing the quality and safety of services and improving health related outcomes. Following the re-establishment of the devolved Assembly, a wide ranging consultation was conducted in 2008 about future structures of health and social care. This resulted in significant changes, most notably in the reduction of the number of Health and Social Care Boards from 4 to 1, the formation of a regional Public Health Agency, a regional Business Services Organisation and a regional Patient and Client Council (see Figure 1). The number of Trusts was also significantly reduced from nineteen to six.

Figure 1: Current structure of health and social care in Northern Ireland (DHSSPS, 2011a:7)
The Health and Social Care (Reform) Act (Northern Ireland) 2009 provided the legislative framework to support these changes to the organisation and delivery of service provision.

In 2011, following a further review of health and social care in Northern Ireland, a new model of integrated health and social care service delivery was unveiled (Health and Social Care Board, 2011). Central to this model is the individual patient or service user, who is supported in health and social care decisions that affect them, a key issue in this research. This current shift to caring and supporting individuals and families in the home will continue in this new model with services in local areas supported by the voluntary sector. Services for those with physical and/or cognitive impairment will focus on personalisation, independent living and control, 'providing the right care in the right place at the right time' (HSCB, 2011:79). Ensuring that patients and clients are actively involved in decision making is central to this process (see Figure 2).

Figure 2: Proposed model of service provision in Northern Ireland (HSCB, 2011:6)
Launching the vision of the review and new model of service delivery, the Health Minister acknowledged the difficult financial and economic climate, but claimed that the new model was about quality rather than cost cutting. That said, he pointed out that there needed to be a radical shift in how money was used. It is against the backdrop of the economic downturn that this study was conducted and many parents and a small number of young people who took part expressed their anxieties about ‘the cuts’ and how it would affect their family both in the short term and the future.

2.3 The involvement of ‘users’ in health and social care in Northern Ireland

Duffy (2008:11) defines service users as 'people who have experience of, both receiving and the potential for influencing, health and social care services'. The last decade has seen the development of a model of service delivery that embraces the participation of users of services in service design and delivery and this has been reflected in both local and national policy and legislation (Department of Health, 2000; Department of Health, Social Services and Public Safety (DHSSPS), 2004). Increasingly, service providers are calling on members of the public to provide feedback on their experiences of the relevance, adequacy and quality of services, their views about how these services might be improved and the policies that guide such services. Indeed, one of the five key themes of the current twenty year strategy for health and social care in Northern Ireland (DHSSPS, 2004) concerns involving people in services to ensure that they are at the centre of the process. Within this strategy, there is a clear emphasis on including service users’ views to actively influence decision making in relation to health and social care services at all levels.

In 2006, The Department of Health, Social Services and Public Safety in Northern Ireland (DHSSPS) produced guidance on strengthening Personal and Public Involvement (hereafter referred to as PPI) in health and social care. The aim of the guidance was to develop a more patient- and user-centred service in the light of the reforms following the Review of Public Administration. PPI is now a statutory
requirement of clinical governance arrangements and quality standards for Health and Social Care (DHSSPS, 2006).

In 2008, the Northern Ireland Social Care Council (NISCC), the Regulation and Quality Improvement Authority (RQIA) and the Social Care Institute for Excellence (SCIE) commissioned a province wide consultation (Duffy, 2008) in order to explore the current situation around user involvement and to inform a future strategy to develop user involvement in Northern Ireland. The consultation involved disabled young people from the Southern Board area. A number of themes emerged, including the need for good communication skills amongst staff along with essential core values such as respect, humanity and partnership working with service users, the need for ongoing training and feedback for service users. Subsequently, an action plan was devised in response to the recommendations made as a mechanism for taking user involvement forward within the province.

Quality assurance of services is overseen by the RQIA and the Patient and Client Council (PCC). The inclusion of the latter as a key body in the quality assurance of services, demonstrates the commitment of local government to ensuring that all service users (including children, young people and adults) participate in decisions that are made about health and social care issues. Established under Section 16(1) of the Health and Social Care (Reform) Act (Northern Ireland) 2009, the PCC aims to provide a powerful voice for health and social care users and to promote the involvement of patients, clients and carers in the design, planning, commissioning and delivery of health and social care (DHSSPS, 2011a).

Thus an emerging theme within health and social policy in recent years concerns the involvement of service users in the manner in which services are designed, planned and delivered and the need to ensure that patients and clients are actively involved in all levels of decision making. Hence the focus on both participation in decisions about health and social care and in decisions about services and policy in this research. This is arguably of particular importance to disabled people in order to acknowledge their
expertise and afford them choice, control and ultimately the option of independent living.

2.4 The Southern Health and Social Care Trust

This research was conducted in the Southern Health and Social Care Trust (see Figure 3). This Trust was selected because of its specific commitment to embracing the views of service users in service design and delivery, not least via regular stakeholder meetings with disabled children and young people, parents, professionals along those with a responsibility at Department level. There were 2 service user groups already in existence for some years who had significant involvement with health and social care services at a strategic level. Thus selecting participants from this area ensured that experiences of participation in care decisions and participation in strategic decisions could be adequately explored. Clearly the experiences of those in alternative Trusts are not reflected here by way of comparison as a regional study was beyond the remit of a PhD study.

The Southern Health and Social Care Trust covers a wide geographical area divided into three areas: Armagh and Dungannon, Newry and Mourne and Craigavon and Banbridge with 532 million pounds spent annually on health and social care. One of the core values of the Southern Health and Social Care Trust is 'to listen and learn' and their commitment to the participation of service users in decisions is clearly apparent within the Trust's Personal and Public Involvement Strategic Plan 2010-2013 (PPI).
Over the past 10 years the Southern Trust has demonstrated a continuing commitment to families who support disabled children and young people and examples of innovative thinking and good practice are frequently highlighted in both regional and national documents (see for example, Council for Disabled Children and Contact a Family, 2004a and 2004b). One early initiative was the introduction, in 2002, of the Wraparound model of service delivery aimed at disabled children, young people and their parents within the Trust. Traditionally, children were required to 'fit' in with local available services. As the name suggests the unique feature and ethos of Wraparound was that services would be 'wrapped' around the child and family's individual needs.

The Wraparound scheme

Wraparound aims to 'enable children with disabilities to have access to information, assessment and, where appropriate, services which provide the social, health and educational support necessary to maximise their potential to lead socially included lives' (Elliot et al. 2002:14). Active participation, partnership working and empowerment are key issues for Wraparound and these are engendered via stakeholder forum meetings to which children, young people, parents and service providers are invited. The role of the stakeholder forum is to ensure Wraparound takes account of a wide range of
perspectives, promotes user participation and updates and informs professionals, agencies, parents and young people about service developments, research and other relevant issues.

In line with current policy and the Trust's commitment to PPI, one of the initial unique projects funded through Wraparound was 'The disabled children and young people’s participation project' (DCYP PPP). The DCYP PPP, established in 2002, aimed to give disabled children and young people a voice in children’s service planning. To date, around 200 young people involved in this group have been proactive in shaping services (Murray, 2012), some presenting their work via local, national and international forums. In addition, young people from the 'Sixth Sense' group (the project's advocacy group) have met with government ministers to discuss their views and three members were invited to participate in the UN’s Day of General Discussion on participation in Geneva. Issues addressed to date have included wheelchair provision, transition to adult services, life-long learning and opportunities for training and employment among others. The young people involved with this group also provide training to enable new employees within the Trust to communicate effectively with disabled children and young people.

In 2005 the Parent Carers' Council on Disability (PCCD) was formed, under the auspices of Wraparound, by a group of parents of disabled children and young people. Their aim was to find new ways of working with agencies and professionals who impacted upon their lives. The group aims to support, enable and provide advocacy for other parents, to work as equal partners and to liaise with service providers on behalf of other parents. This Council now has an identified group of 'executive' parents who represent other parents and liaise closely with the Health and Social Care Board (HSCB), the RQIA, the Public Health Agency and link in with the Patient and Client Council (PCC). Currently these 2 user groups both attend stakeholders' meetings and present their work but there is no joint working between the two. Access to participants in this research was negotiated via both the DCYP PPP and the PCCD.
Disabled children and young people in Northern Ireland: prevalence

The most recent records detailing the prevalence of disabled people in Northern Ireland is the Northern Ireland Survey of People with Activity Limitations (Northern Ireland Statistics and Research Agency, 2007). This survey indicates that there are approximately 26,000 disabled children and young people in Northern Ireland up to the age of 18 years (DHSSPS, 2010). In 2008, according to NICCY (2008) there were 2,356 disabled children and young people aged 0-18 years in the Southern Board, now known as the Southern Health and Social Care Trust, where the research was conducted.

However, the complex nature of disability makes it difficult to measure (Read et al. 2009) and Northern Ireland has yet to develop a consistent approach to maintaining a register of disabled children and young people. The move to one Health and Social Care Board (as opposed to 4) may go some way to resolving this issue. Additional limitations on current data systems include the quality and variability of data kept, multiple diagnoses, an absence of diagnosis and the variability in manifestations of differing disabilities amongst individual children (The Southern Health and Social Services Board and The Institute of Public Health in Ireland, 2002). Although a number of registers exist for children with chronic illness, for example the Cerebral Palsy register, Cystic fibrosis and Cancer registry, the provision of one comprehensive and complete register for disabled children and young people in Northern Ireland has yet to be achieved, as recommended by the Children (NI) Order 1995.

Like other children, most disabled children grow up at home with their family, with mothers most often taking primary responsibility for their care (Read et al. 2006). Increasingly, the importance of fathers in parenting disabled children has received attention within the literature (Davies et al. 2004; Harrison et al. 2007; McKeever, 2008), as has the role of other close family members, for example grandparents, siblings, aunts, uncles and family friends in the provision of support (Collinson and Bleakley, 2009). However, since it is normally parents or carers and children or young people who interact directly with professionals, they are the focus of the current research.
2.5 Legislation, policy and guidance

The increased emphasis on the participation of disabled children, young people and their parents in decisions affecting them has been driven by the development of legislation, policy and associated documents that guide health and social care service provision within the UK. The children, young people and parents in this study reside in Northern Ireland and therefore the main focus of the following sections is on the legislation, policy and guidance within Northern Ireland together with relevant United Nations treaties.

United Nations Treaties

A number of United Nations Treaties have had been instrumental in shaping the participation of children, young people and disabled persons in decisions affecting them. The most influential of these has been the United Nations Convention on the Rights of the Child, ratified in the UK in 1991. Article 12 has frequently been singled out as the most important as it underlies all other articles in the Convention (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.'

This has formed the basis for growing expectation amongst service providers and policy makers that children and young people, including those who are disabled, should fully participate in decisions that affect their lives (The Children’s Society, 2007). While a specific focus on Article 12 is justified on the basis of its pivotal status, the Committee on the Rights of the Child (hereafter referred to as ‘the Committee’), in its Day of General Discussion on the child’s right to be heard (CRC, 2006), pointed out the need to consider the articles of the Convention together. Thus a number of additional articles impact on the participation of disabled children and their parents in health and social care decision (see Table 2 for summary of key articles and their relevance to this study).
As the Committee pointed out in their Day of General Discussion on the child's right to be heard (CRC, 2006a) and the General Comment on children with disabilities (CRC, 2006b), disabled children within the UK are facing barriers to enjoying their rights, not because of their impairment, but because of social and cultural attitudes towards them. Disabled children are often involved in specific decision making in relation to issues concerning disabled children rather than children's issues as a whole. The Committee's General Comment (CRC, 2006b) on children with disabilities states that:

'Like all children, disabled children should without exception be involved in parliaments, committees or forums so that they may contribute to decision making processes across a wide spectrum of activity and not simply in issues related to disability. It is therefore essential that disabled children are involved in local policy development as often it is adults with and without disabilities that are involved in policy and decision making.'

(CRC, 2006b:32)

The realisation of the rights of children and young people is not solely the responsibility of government. The rights and duties of parents are clearly highlighted within the convention (Articles 2, 3, 5 and 18) in terms of helping children realise their rights and to achieve their full potential. Parents also have a key role to play in ensuring that disabled children and young people can access the healthcare that 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 protective of them and often 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.
Table 2: Articles of the UNCRC and their relevance to the study.

<table>
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<tr>
<th>Article</th>
<th>Relevance</th>
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<tr>
<td><strong>Article 2:</strong></td>
<td><strong>Article 2:</strong></td>
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<tr>
<td>1. States Parties shall respect and ensure the rights set forth in the present Convention to each child within their jurisdiction without discrimination of any kind, irrespective of the child's or his or her parent's or legal guardian's race, colour, sex, language, religion, political or other opinion, national, ethnic or social origin, property, disability, birth or other status.</td>
<td>Every child is a rights holder and disabled children should not experience discrimination because of their impairment. In other words they should not be treated differently than other children during decision making processes.</td>
</tr>
<tr>
<td>2. States Parties shall take all appropriate measures to ensure that the child is protected against all forms of discrimination or punishment on the basis of the status, activities, expressed opinions, or beliefs of the child's parents, legal guardians, or family members.</td>
<td>Disabled children need to be protected against discrimination on the basis of their parents' views. Thus disabled children cannot be excluded from decision making processes because their parents do not believe they could have an input.</td>
</tr>
<tr>
<td><strong>Article 3:</strong></td>
<td><strong>Article 3:</strong></td>
</tr>
<tr>
<td>1. In all actions concerning children, whether undertaken by public or</td>
<td>When health and social care decisions are being made the best</td>
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private social welfare institutions, courts of law, administrative authorities or legislative bodies, the best interests of the child shall be a primary consideration.

2. States Parties undertake to ensure the child such protection and care as is necessary for his or her well-being, taking into account the rights and duties of his or her parents, legal guardians, or other individuals legally responsible for him or her, and, to this end, shall take all appropriate legislative and administrative measures.

3. States Parties shall ensure that the institutions, services and facilities responsible for the care or protection of children shall conform with the standards established by competent authorities, particularly in the areas of safety, health, in the number and suitability of their staff, as well as competent supervision.

| Article 5: |
| States Parties shall respect the responsibilities, rights and duties of parents or, where applicable, the members of the extended family or community as provided for by local custom, legal guardians or other persons legally responsible for the child, to provide, in a manner consistent with the evolving capacities of the child, appropriate direction and guidance in the exercise by the child of the rights recognized in the present Convention. |

| Article 5: |
| This article emphasises again the role of parents and the evolving capacity of the child in the realisation of children's rights. |

| Article 6: |
| 1. States Parties recognize that every child has the inherent right to life. |

| Article 6: |
| Like all children, disabled children have the right to life and to reach their full potential. |
2. States Parties shall ensure to the maximum extent possible the survival and development of the child.

**Article 12:**

1. 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.

2. For this purpose, the child shall in particular be provided the opportunity to be heard in any judicial and administrative proceedings affecting the child, either directly, or through a representative or an appropriate body, in a manner consistent with the procedural rules of national law.

**Article 12:**

Like all children, disabled children have the right to express their views when health and social care decisions are being made. The age and maturity of the child should be taken into consideration in how far their views influence the final decision. The child may express their own views in an official capacity or a representative may take on this role, for example, a guardian ad litem or other advocate. Disabled children may need assistance from a suitably trained person to help them to express their views.

**Article 13:**

1. The child shall have the right to freedom of expression; this right shall include freedom to seek, receive and impart information and ideas of all kinds, regardless of frontiers, either orally, in writing or in print, in the form of art, or through any other media of the child's choice.

2. The exercise of this right may be subject to certain restrictions, but these shall only be such as are provided by law and are necessary:

   (a) For respect of the rights or reputations of others; or

   (b) For the protection of national security or of public order (ordre
public), or of public health or morals.

**Article 18:**

1. States Parties shall use their best efforts to ensure recognition of the principle that both parents have common responsibilities for the upbringing and development of the child. Parents or, as the case may be, legal guardians, have the primary responsibility for the upbringing and development of the child. The best interests of the child will be their basic concern.

2. For the purpose of guaranteeing and promoting the rights set forth in the present Convention, States Parties shall render appropriate assistance to parents and legal guardians in the performance of their child-rearing responsibilities and shall ensure the development of institutions, facilities and services for the care of children.

3. States Parties shall take all appropriate measures to ensure that children of working parents have the right to benefit from child-care services and facilities for which they are eligible.

**Article 23:**

1. States Parties recognize that a mentally or physically disabled child should enjoy a full and decent life, in conditions which ensure dignity, promote self-reliance and facilitate the child's active participation in the community.

2. States Parties recognize the right of the disabled child to special

**Article 18:**

Both mothers and fathers have responsibility for the upbringing and development of their child. Thus both have responsibility for health and social care decision making that can have a significant impact on this. Parents require appropriate support and health and social care services to foster the development of their disabled child.

**Article 23:**

In order to realise this right disabled children need appropriate health and social care services where they receive assistance, are encouraged and enabled to exercise agency in their own lives and are involved in local communities. Again the emphasis is on self-reliance the disabled child realising their full potential and social development. The disabled child has
care and shall encourage and ensure the extension, subject to
available resources, to the eligible child and those responsible for his
or her care, of assistance for which application is made and which is
appropriate to the child's condition and to the circumstances of the
parents or others caring for the child.

3. Recognizing the special needs of a disabled child, assistance
extended in accordance with paragraph 2 of the present article shall
be provided free of charge, whenever possible, taking into account
the financial resources of the parents or others caring for the child,
and shall be designed to ensure that the disabled child has effective
access to and receives education, training, health care services,
rehabilitation services, preparation for employment and recreation
opportunities in a manner conducive to the child's achieving the
fullest possible social integration and individual development,
including his or her cultural and spiritual development.

4. States Parties shall promote, in the spirit of international
cooperation, the exchange of appropriate information in the field of
preventive health care and of medical, psychological and functional
treatment of disabled children, including dissemination of and access
to information concerning methods of rehabilitation, education and
vocational services, with the aim of enabling States Parties to
improve their capabilities and skills and to widen their experience in
these areas. In this regard, particular account shall be taken of the
needs of developing countries.

**Article 24:**

1. States Parties recognize the right of the child to the enjoyment of

**Article 24:**

Like all children, disabled children have the right to the best
possible health and access to services to help them achieve
the highest attainable standard of health and to facilities for the
treatment of illness and rehabilitation of health. States Parties shall
strive to ensure that no child is deprived of his or her right of access
to such health care services.

2. States Parties shall pursue full implementation of this right and, in
particular, shall take appropriate measures:

(a) To diminish infant and child mortality;

(b) To ensure the provision of necessary medical assistance and
health care to all children with emphasis on the development of
primary health care;

(c) To combat disease and malnutrition, including within the
framework of primary health care, through, inter alia, the application
of readily available technology and through the provision of adequate
nutritious foods and clean drinking-water, taking into consideration
the dangers and risks of environmental pollution;

(d) To ensure appropriate pre-natal and post-natal health care for
mothers;

(e) To ensure that all segments of society, in particular parents and
children, are informed, have access to education and are supported in
the use of basic knowledge of child health and nutrition, the
advantages of breastfeeding, hygiene and environmental sanitation
and the prevention of accidents;

this. Arguably good decision making is central to this outcome.

In order to achieve this both parents and children need a basic
knowledge of child health.
(f) To develop preventive health care, guidance for parents and family planning education and services.

3. States Parties shall take all effective and appropriate measures with a view to abolishing traditional practices prejudicial to the health of children.

4. States Parties undertake to promote and encourage international co-operation with a view to achieving progressively the full realization of the right recognized in the present article. In this regard, particular account shall be taken of the needs of developing countries.
Countries are required, under the auspices of the UNCRC, to submit reports to the Committee every 5 years regarding their progress on issues addressed within the treaty. In its Concluding Observations on the most recently submitted reports by Great Britain and Northern Ireland, the Committee (CRC, 2008) stated that, although progress had been made, insufficient action had been taken to ensure that disabled children's participatory rights were upheld, as specified in Article 12.

While the Convention is of benefit in critically exploring current policy and practice in terms of disabled children and young people's participatory rights, its validity as a set of standards is limited for many reasons (Kilkelly and Lundy, 2006), not least the irony that children were not directly involved in its development (Freeman, 2000). Unlike the European Convention on Human Rights, the UNCRC has not been adopted in domestic law. Despite this, there is an unspoken obligation to adhere to its standards given the large number of countries that have ratified it (Cohen and Naimark, 1991; Fortin, 2003). Therefore, although not legally binding, it may be utilised as a gold standard against which to measure current policy (Lyon, 2007) and practice.

The participation of disabled children and young people is also enshrined within the more recent Convention on the Rights of Persons with Disabilities (CRPD) and the UK has completed its first periodic report to the UN. Lansdown (2009) points out that the aim of the CRPD is not to create new rights, but to ensure that existing human rights are enacted for disabled people, including children and young people. The UK signed the Convention in 2007 (but not the optional protocol) and ratified it on 8th June 2009. 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)
Also relevant is Article 3 of the Convention of the Rights of Persons with Disabilities. This clearly sets out the need to actively involve disabled children in the development and implementation of policies. Hence this new treaty specifically addresses the participation of disabled children and young people and the mechanisms required to ensure that their voices are heard.

**Legislation in Northern Ireland**

As set out in the Children Order (NI) 1995 (hereafter referred to as ‘the Order’), disabled children are considered to be ‘children in need’. The Order therefore places a duty on Trusts to provide effective, needs-led, personal health and social services for them and their families. The Children (NI) Order 1995 Guidance and Regulations (Volume 5: Children with a disability) points out the need for professionals to achieve a balance between giving the child a voice and potentially overburdening them in decision making situations where they may have insufficient understanding without appropriate support mechanisms. It is clearly acknowledged, however, that children with severe learning disability can communicate their preferences by appropriately trained staff who understand them. This need for additional support is also addressed in s75 of the Disabled Persons (Northern Ireland) Act 1989 and the Disability Discrimination (Northern Ireland) Order 2006. In the former, public authorities have a statutory duty to promote equality between individuals who have a disability and those without, and those of differing ages. Applied to the current context, this means that disabled children and young people must be given the same opportunities to participate in decisions as adults and those who do not experience disabling barriers. Similarly, the Disability Discrimination (Northern Ireland) Order 2006, requires public authorities to have due regard to the need to encourage disabled persons to participate in public life and promote positive attitudes toward them. One way of promoting such attitudes is to involve them in the way services are planned and delivered. In response to s75 of the Northern Ireland Act, the Equality Commission for Northern Ireland has produced a resource entitled 'Let's talk, let's listen: Guidance for public authorities on consulting and involving children and young people' (Equality Commission, 2008). This sets out the
requirements for children’s participation, including disabled children, in the services that they use and a step by step guide to assist service providers and policy makers to achieve this, in addition to how to consult children within strategic planning. The need to involve children and young people has been further strengthened by the development of ‘Ask first’ (Participation Network, 2010), a set of participation standards for children and young people's involvement in public decision making in Northern Ireland.

Legal guidance for the parents as carers of disabled children and young people is set out in the Carers and Direct Payments (Northern Ireland) Act 2002. This enables parents of disabled children to request an assessment of their ability to provide ongoing care for their child and for the outcome of this assessment to influence service provision, although parents’ participation in this process is not specified. The availability of direct payments, also set out in this Act, has been influential in fostering parents’ participation in the services that their child receives. Despite this legislation, parents of learning disabled children are not always aware of their right to an assessment or the provision of direct payments. In the Review of Mental Health and Learning Disability (Northern Ireland) (Bogues, 2004), parents expressed surprise about the availability of direct payments within the province.

**Northern Ireland Policy**

The international treaties and legislation explored in the previous sections have had a direct impact on local policy, together with a number of reviews relating to the care of disabled children, young people and their families in Northern Ireland. Of these, the three most notable are: 'Care at its best' (DHSSPS, 2005), a regional inspection of services for disabled children and young people in hospital; 'Equal lives' (Bamford, 2005), a review of policy and services for those with a learning disability, and 'The nursing response to children and young people with complex physical care needs' (McConkey et al. 2007). Much work has been undertaken within Northern Ireland at Department level, culminating in the publication of a 'Physical and Sensory Disability Strategy and Action Plan 2012-2015' (DHSSPS, 2012a); a 'Learning Disability Service
The participation of children and their parents or carers in decisions is also highlighted as a key issue within the current ten year strategy for children and young people in Northern Ireland 'Our children and young people – Our Pledge 2006-2016', together with the need to support parents and carers. Two of the core values underpinning this document are the importance of seeing children and young people as holding rights as individuals (including their participatory rights) and as being active participants in society. The strategy also seeks to develop a culture in which the views of children are sought as a matter of course. The need to involve children in services is particularly highlighted:

'It is vital that we create the opportunity for all children and young people to express their views freely on all matters affecting them and for those views to be given due weight...We will seek, through implementation of the strategy, to be proactive in obtaining the views of children and young people on matters of significance to them. This will be particularly important in relation to service design and policy development.'

(OFMDFM, 2006:20)

Standards set out in this ten year strategy have shaped the new Children and young People's Plan 2011-2014, which centres around a 'whole child' model based on the work of Bronfenbrenner (1993). While emphasis is often put on 'the child' in discussing UN treaties or policy, a common thread within all the documents discussed above is importance of meeting the needs of both children and their families. This is emphasised within the current Regional Family and Parenting Strategy: Families Matter: supporting Families in Northern Ireland (DHSSPS, 2009a). Central to this strategy is the need for professionals and others to work in partnership with all parents and respect and take their views seriously. The overall aim of the strategy is to empower parents and to help and support them so that their children can reach their potential and become active citizens within society. Issues of family support and parenting education are highlighted
as one of the ways to achieve this. One of the underlying principles of the proposed parenting strategy includes the following:

'Encourage all stakeholders – statutory, voluntary, community and private sectors to work together in partnership, especially in participation and collaboration with children, young people and their families.'

(DHSSPS, 2009a:21)

It is clear that this strategy places the child firmly in the context of the family in keeping with a family centred approach.

2.6 Chapter summary

Northern Ireland has seen a radical time of change in terms of its public administration including health and social care and it is against the backdrop of such change that this study was conducted. This has been accompanied by a significant emphasis on the streamlining of services, meeting the needs of individuals and the active involvement of service users not only in their own care decisions but also in decisions about service design and delivery, key aspects of this study. The participation of disabled children, young people and their parents in decision making processes is strongly supported in current legislation, health and social care policy and associated guidance in Northern Ireland as highlighted in this chapter. Locally, the Southern Trust has for some years demonstrated its commitment to disabled children and their parents, not least by the launch of Wraparound, the establishment of 2 local service user groups and its PPI policy. The chapters that follow will examine current models and definitions of participation, set out what we know about the participation of disabled children and their parents from current literature and explore the experiences and outcomes of participation for a sample of service users within the Southern Trust. As such the reality of participatory practices will be examined.
Chapter 3: Literature review

3.0 Introduction

Despite continuing debate and discussion on the subject, there is no agreement as to how participation 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 are often used synonymously (see for example, McNeish and Newman, 2002; Cavet and Sloper, 2004b). 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; The Equality Commission for Northern Ireland, 2008). The notion of power is thought to be important in participation, for without a shift of power from the ‘powerful’ (in this case service professionals, providers and policy makers) to the ‘powerless’ (service users), participation will inevitably be little more than tokenistic. This is of particular relevance for disabled children and young people (Martin and Franklin, 2010) who, as indicated above, are considered to be ‘doubly disadvantaged’ in this regard because of their status as children or young people in addition to being disabled individuals (Beresford, 1997; Higgins et al. 2009). This chapter sets out how participation is conceptualised in this study and presents two literature reviews. The first explores the participation of disabled children and young people in health and social care decisions while the second discusses the participation of parents of disabled children and young people. Overall conclusions are drawn in the final section.

3.1 Conceptualising participation

Many authors have proposed conceptual frameworks or typologies of children’s participation that lend themselves to many contexts, including health and social care (see for example, 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. Participation has been further conceptualised in different ways: - at the individual level or group level (known as public or collective decision making), and in terms of both process (the experience of participating) and outcomes (what happens as a result) (Franklin and Sloper, 2006). Further, outcomes may be intrinsic (personal to the individual), contributing to the development of children as active citizens or extrinsic in nature, reflected in changes in services, policy or the wider community (Doel et al. 2007a). It has been argued that the process and the outcomes of participation are inextricably linked and therefore it is essential to focus on both (Ackermann et al. 2005; Doel et al. 2007b). According to Barnes and Mercer (2006), disabled people have a vested interest in both process and outcomes of participation for two reasons: firstly to help them achieve outcomes that they aspire to and, secondly, to ensure that services are delivered in a way that empowers them. This being the case, participation is conceptualised in this study as shown in Figure 4.

3.2 Joint participation

In contrast to the typologies of participation discussed earlier children and young people often do not want to make all decisions by themselves. Children do not, on the whole, purposefully exclude their parents from decisions and indeed may not wish to participate in some decisions at all. 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 (Morrow, 1999; Coyne et al. 2006; Winter, 2006; Franklin and Sloper, 2007). As Alderson and Montgomery (1996) point out, while joint or negotiated decision making between adults and professionals is generally accepted, the situation is more complex for children because of the tripartite relationship between the child, parent and professional. The dynamics within these relationships serve to further complicate decision making because of the power relationship between the child and adults and also between those who use and provide services. In a study investigating children’s experiences of participation in consultation and decision-making in hospitals in Ireland, children wanted parents to act as their advocates in the consultation process mainly
because of the inability of healthcare professionals to communicate with them effectively, but also to protect them from bad news (Coyne et al. 2006).

Figure 4: Conceptualisation of participation in this study (adapted from The Children and Young People’s Unit, 2001; Alderson and Morrow, 2004; Doel et al. 2007b).

Clearly, parents know their children well but they may need support and encouragement to give their child space to develop and exercise their autonomy as they mature into young adults, as the views of children can at times differ significantly from their parents (Beresford, 1997; McNeish and Newman, 2002). Coyne and Harder (2011) argue that, in order to balance protection of children with shared decision making, a situational
perspective may be useful. Professionals and parents adopting such a stance should recognise that children and young people's individual needs may vary according to the situation i.e. according to their illness, age, competence and type of decision to be made. This has particular currency in this study as disabled children and young people are not a homogeneous group and parents of disabled children and young people often continue to have a dominant role in health and social care decisions as their child grows up. While professionals often engage with either parents or children and young people, it is rare to find children and parents together supported in decision making (Kirby and Laws, 2010). It is useful, at this point, to discuss the nature of health and social care decisions and their representation in current literature that focuses on disabled children, young people and their parents.

3.3 Health and social care decisions

The interface between health and social care is now better appreciated, as evidenced by the resumption by local authorities of public health responsibilities, and the long-standing appreciation of the interdependence of health and social care for groups such as older people and people with disabilities. Notwithstanding this, it is also recognised that health and social care operate very separately, with distinct professional and organisational cultures, as well as underpinning structures such as different funding arrangements (the NHS being 'free at the point of entry' with much social care being rationed and charged for). One might expect that these organisational and cultural differences would impact on the approach taken to participation, and the experiences of those using services. When considering how best to organise the literature review, the original plan was to synthesise separately those studies that examined the decision-making in health care and social care, subsequently drawing out the similarities and distinctions between the two. Specifically, I anticipated that children and families would make health care decisions with health professionals (for example, doctors, nurses, health visitors, physiotherapists, occupational therapists, dietician, speech and language therapists, psychologists, psychiatrists). On the basis of previous literature and the
experience of myself and the project supervisors, it was anticipated that these decisions would be mostly related to physical care (for example, decisions about medications, nutrition, nursing or mobility needs), psychological care (for example, decisions about the management of their behaviour or psychological needs), transition to adult services healthcare services that families would receive at home or discharge from hospital. Similarly, we anticipated that social care decisions would be easily identified as those made with social care professionals, for example, social workers, family support workers or key workers, and that these decisions would relate to overall family support needs, respite care or short breaks, direct payments, transition to adult services or support services that families would receive at home. However, during the literature search and review it became apparent that many articles included health and social care decision making processes as part of participants' wider experiences of public services, an exploration of communication between children and doctors or addressed involvement in transition to adult services that concerned both health and social care professionals (see Table 3 and Table 5 for the aims of the included studies retrieved and their context in terms of health, social or other services included in the articles). While it was possible to locate the overall articles under the auspices of either health or social care (or both), at times details of the actual decision made or the professional involved were not clearly delineated. It therefore made no sense to maintain an artificial separation between the two, even for heuristic purposes. Hence, the literature reviews that follow deal simultaneously with health and social care decisions, as the experience for children and their families is often that the two are interwoven. Where possible the type of decision or the professional group concerned is reported. In line with the emphasis on the rights of children and young people discussed in the last chapter, the first literature review focuses on the participation of disabled children and young people in health and social care decisions, while the second focuses on the participation of parents.
3.4 Literature review 1: the participation of disabled children and young people in health and social care decisions

Aim of the review

The aim of this review was to establish what works in disabled children’s participation, both in terms of process and outcomes. This review updates and expands an earlier review conducted by Cavet and Sloper (2004a) that focused on the participation of disabled children and young people in social care decisions. Additionally, it explores the international literature up to and since this period, by removing Cavet and Sloper’s restriction to studies published in English, establishes if progress has been made in the reporting of the outcomes of participation, and focuses on disabled children and young people’s participation in both health and social care decisions. A protocol for the review was developed before the searches were conducted (see below).

Objectives

1. To determine disabled children and young people's experiences of participation in decisions about their health and social care, in decisions about how services are designed and delivered and about associated policy.

2. To find out what factors promote and hinder participation in the health and social care context.

3. To identify the outcomes (both extrinsic and intrinsic) of disabled children’s participation in decisions about their own care, decisions about how services are designed and delivered and about policy.

4. To determine the mechanisms of effective participation, in terms of both process and outcome
Methods

Criteria for considering studies for this review

Types of studies: Studies that reported disabled children and young people’s experiences of the process of participation in decisions about their individual care, in decisions about how services are designed and delivered and in decisions about policy development and/or the outcomes of such participation.

Types of participants: Disabled children and young people of any age with a physical, cognitive, communication or sensory impairment or a combination of these. Studies in which parents, health or social care professionals or managers who report relevant findings from their own perspectives were also included.

Type of intervention: Intervention that involved disabled children and young people in decisions about their own health or social care, in decisions about health or social care services or policy.

Outcomes of interest: In addition to children’s experiences of participation, outcomes of interest include both intrinsic and extrinsic outcomes of participation.

Search strategies for the identification of studies

Electronic searches: The following databases were searched: ASSIA (earliest to 2012), Cinahl Plus and British Nursing Index, Medline (1950-2012), PsychInfo (1984-2006 - all that was available), PsychArticles (1984-2012), ScienceDirect, ChildData, Social Care Online (Dates back to 1986-2012), ORB (from 2000), Lilacs, Zetoc (since 1993), SIGLE, Embase, Westlaw, Social Science Citation Index (1990-2012), NHS Evidence. Key words used included participation, user, involve, listen, consul, voice, choice, communication, decision, decision-making, views, consumer, child, young person, young people, adolescent, teenager, disabled, impairment, special needs, autism life-limited, blind, deaf or Deaf, delayed, learning disability with appropriate truncation.
Searching other resources: Sources of information included reference lists of articles identified in the course of conducting the review. A list of forty-five relevant voluntary and other organisations was also drawn up (see Appendix 1) in order to identify associated grey literature that may have been relevant to the review.

Selection of studies: Studies for inclusion were independently selected by the author and by Professor Geraldine Macdonald.

Data extraction and management: Data were extracted by PMCN and recorded on data extraction sheets. The following information was obtained where available: the numbers and characteristics of participants, the context and country of origin, the type and aim of the study. Data relating to the methodological aspects of the studies were also obtained (including study design, sampling, ethical procedures, place and method of data collection, analysis). A quality appraisal was conducted and the quality status of each article was recorded along with the findings.

Assessment of methodological quality

There is no consensus around quality appraisal for qualitative studies, particularly concerning ’views’ type studies. In one such a review by Harden et al. (2004) only 4 out of 35 studies met all quality assessment criteria and the remainder failed to meet basic methodological standards. Noyes et al. (2008) argue that formal appraisal tools or checklists that guide ‘in’ or ‘out’ decisions may be inappropriate for use with qualitative research. Rather, they may be better used as part of the process of exploring and interpreting findings. Keeping this in mind, studies in the current review were classified, summarised and assessed using the following quality criteria:

1. Is the study informed by or linked to an existing body of knowledge?
2. Are the aims of the study clearly stated?
3. Is the study design appropriate to the stated aims?
4. Is the sampling strategy described and adequate to explore the range of children in the particular setting?
5. Are ethical issues, such as consent, confidentiality and dissemination described and appropriate?
6. Are data collection processes adequately described and set out in sufficient detail to enable replication?
7. Were the data collection tools piloted?
8. Is the analysis explicit, replicable and justified in terms of the study design?
9. Are findings systematically reported and is sufficient original evidence reported to justify a relationship between evidence and conclusions?

These quality assessment criteria were drawn from the following guidance for the assessment of qualitative studies (Scie, no date), Medical Sociology Group (1996), Kilpatrick et al. (2008) and Harden et al. (2004). The purpose of the quality assessment was to make an informed judgement of the validity of the findings and allow direct comparison of results. In order to gain an insight into the quality of studies in the current review, studies were coded according to the following coding strategy adapted from Kilpatrick et al. (2008):

Category A: studies that meet the quality appraisal criteria with no or very few flaws, none of which threatened the overall quality of the study.
Category B: studies that meet many of the appraisal criteria, with some flaws which threatened the overall quality of the study.
Category C: Studies that include many/serious flaws that gave cause for concern about the findings.
Category D: Studies that include insufficient data on methodology to allow an appraisal of quality.

Some of these ‘flaws’ may reflect flaws in reporting, rather than the study itself.

Results

Searches were run between June and October 2010 and updated in August 2012. 6358 citations were obtained in the original 2010 search (see Figure 5). Where necessary, abstracts or full texts were read to inform decision making about inclusion in the review. In some cases, however, it was evident from the titles that articles were not relevant. For example, many articles addressed participation in sports or other community activities or referred to education. Forty-six were selected identified as being potentially relevant. Once duplicates were removed 26 were identified as being potentially relevant and the
full text of these was obtained and read. Of these 26, 14 were excluded on further examination – 4 duplicated other studies i.e. they were written as part of a larger study that was already included in the review and the other 10 did not meet the inclusion criteria. A further 10 articles were derived from alternative sources: 1 from the searches of the voluntary organisations and research units, 1 from hand searching relevant journals and 8 from the reference lists of other articles. Twenty-two studies from this search were included in the original review.

**Included studies:** 22 studies from the original search met the inclusion criteria (see figure 5). An additional 5 studies were retrieved when the review was updated in August 2012, yielding a total of 27 articles. Three studies were from the 'Choice and change' project but all are included as they reported differing perspectives (see Table 3 for details of the aim of the studies and methods used).

**Design:** 14 studies used qualitative methods, 1 used quantitative methods and 12 used a mixed method approach (see Table 3). Three studies were from the 'Choice and change' project but all are included as they reported differing perspectives.

**Quality appraisal:** The quality appraisal coding strategy was applied as described on p51. Sixteen studies were coded A, 10 coded B and 1 was coded C. Most studies were published in peer reviewed journals. Those coded B lacked a robust theoretical framework, were not placed in sufficient context in terms of current research, had small sample sizes, failed to pilot data collection tools or lacked detail about the exact method of analysis. It should be acknowledged that some of these were consultations rather than research and the word limits of particular journals may have impacted on the detail provided. The work by Badger (2009) was coded C. The author called this a 'project' rather than research per se and differing data collection workbooks recorded before and after the intervention in question potentially made direct comparison of participants' experiences reported in the document questionnable. Given the small number of studies obtained in the review, this was included in the findings of the review.
Figure 5: Study selection flowchart (original search)

Searches were run between June and October 2010. Final total= 6358 citations.

6312 discarded as irrelevant

46 citations identified as potentially relevant and full texts obtained

Total following removal of duplicates = 26

14 discarded. 10 discarded as irrelevant and 4 formed part of those already included in the review

12 articles included in the review

10 articles obtained from searches of voluntary organisations and reference lists of other articles

22 studies included in the review
Table 3: Study aims, area of service provision addressed and method.

<table>
<thead>
<tr>
<th>Study</th>
<th>Aim (verbatim)</th>
<th>Area addressed</th>
<th>Method</th>
</tr>
</thead>
<tbody>
<tr>
<td>Allen (2005)</td>
<td>To explore and describe the meaning of decision making in self-management for adolescent females and young women with mobility limiting disorders.</td>
<td>Health care, social care, education, housing, employment, advocacy, church.</td>
<td>Qualitative interviews: Transcendental phenomenology.</td>
</tr>
<tr>
<td>Badger (2009)</td>
<td>To study the impact of the Mental Capacity Act on young people who had complex needs and conditions, including intellectual disability. The study looked at the level to which a disabled young person, who lacked capacity in one particular or all aspects of their life, was involved in the decision making process.</td>
<td>Health care, social care, education, where to live, money and finances.</td>
<td>Mixed method. Author called it a project/study.</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td>Direct observation and unstructured interviews; completion of a workbook to collect quantitative data.</td>
</tr>
<tr>
<td>Burnstein et al. (2005)</td>
<td>To compare the communication patterns of paediatricians and parents of children with special health care needs and explore whether there were</td>
<td>Health care</td>
<td>Quantitative using the following scales:</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td>1. Phoenix Pediatrics Complexity Level Code: to identify if participants were Children with Special Health Care Needs. This is a 1 item scale (0-4) where the child’s rating is based on the number of organs affected and the complications that result from systems involved. Children with levels of 1-4 are identified as those with special health care needs</td>
</tr>
</tbody>
</table>

55
<table>
<thead>
<tr>
<th>Study</th>
<th>Objective</th>
<th>Methodology</th>
<th>Data Collection</th>
</tr>
</thead>
<tbody>
<tr>
<td>Carnaby <em>et al.</em> (2003)</td>
<td>Aimed initially to determine the extent to which young people with learning disabilities are involved in the transition process, and then make recommendations for enhancing this involvement. The second phase assessed ways in which the school had addressed issues raised during the first phase.</td>
<td>Health care, social care, post-education options.</td>
<td>Quantitative and qualitative data collected by means of participant observation.</td>
</tr>
<tr>
<td>Deatrick (1984)</td>
<td>To describe the characteristics, the process, and the evaluation of the decision-making process concerning surgery from the perspectives of both the adolescents and the parents.</td>
<td>Health care.</td>
<td>Qualitative; participant observation and semi-structured interviews.</td>
</tr>
</tbody>
</table>

2. Pediatrician Satisfaction Scale: 5 items rated on a 4 point scale. Scores range from 5 to 20.

3. Physician Rating Scale: a 41 item instrument that defines ideal qualities in pediatricians. Rated on a 4 point likert scale. Scores range from 41-164.

Additionally, interactions were coded into 12 mutually exclusive codes and then aggregated into 4 categories – medical related information, medical process talk, questions and social exchanges.
<table>
<thead>
<tr>
<th>Study</th>
<th>Objective</th>
<th>Domain</th>
<th>Methodology</th>
</tr>
</thead>
<tbody>
<tr>
<td>Garth <em>et al.</em> (2009)</td>
<td>To explore how the doctor-parent-child partnership is experienced and if the child patient is considered a contributor.</td>
<td>Health care.</td>
<td>Qualitative (grounded theory). Semi-structured interviews with adults and participatory methods used with children ('important' or 'not important' boxes to put statements in).</td>
</tr>
<tr>
<td>Greco and Beresford (2009)</td>
<td>To explore children’s experiences of using the service and the reasons why they were using the service.</td>
<td>Health care.</td>
<td>Mixed method. Semi-structured interviewing on 2 occasions (comparing how they felt when they started using the service) and completion of a questionnaire (the Experience of Service Questionnaire amended). Interviews took about 30 minutes and took place in the child’s home or school. Warm up activities included ‘drawing a map of people who help me’. Pre-prepared cards were used to explore a range of outcomes which the child then chose as being true for them eg ‘I don’t want to feel so angry’; or giving clinicians marks out of 10.</td>
</tr>
<tr>
<td>Harrison <em>et al.</em> (2005)</td>
<td>To find out disabled children and young people’s views and experiences about the services they currently use.</td>
<td>Health care, social care, education, respite, clubs and play.</td>
<td>Consultation. Photographs of local services and support organisations were obtained and generic photos of nurses, doctors, dentists and support equipment and feelings faces were used. Activity photos such as leisure activities, tv programmes and pets were also used.</td>
</tr>
<tr>
<td>Haydon (2007)</td>
<td>To discuss what rights participants thought they should have, if these were</td>
<td>Health care, social care, education, play and leisure, cultural</td>
<td>Consultation, meetings with children and young people.</td>
</tr>
<tr>
<td>Monteiith and Sneddon (1999)</td>
<td>1. To describe and identify gaps between existing services and need prior to the implementation of the Children (NI) Order 1995.</td>
<td>Social care, independent living, social life and community involvement, employment.</td>
<td>Mixed method – interviews with young people were in 2 parts – the first part collected sociodemographic background information (i.e. quantitative) and the second consisted of closed and open questions (qualitative).</td>
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<tr>
<td>2. To describe the experiences of young people with disabilities making the transition to adult life.</td>
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<tr>
<td>3. To identify and analyse changes in</td>
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</table>

**Kelly (2005)**

Part of a larger doctoral study which examined the provision of family support services for learning disabled children and their families.

Social care.

Qualitative. Semi-structured interviews with learning disabled children, their parents and social workers. Participatory research with children using a variety of creative methods.
| Minkes *et al.* (1994) | Part of a research project to assess the quality of services to disabled children under the Children Act. | Social care, respite, residential care services. | Qualitative. Interviews with children were conducted in school by school staff who the children knew. For children with speech, a question/answer format was used. For the others, questions were supplemented with visual cues, eg. photos of places, staff and other children, pictures of everyday objects and small books the interviewers used to build a pictorial record. |
| Monteith *et al.* (2002) | 1. To make available baseline measurement of the response of key public services to disabled children and their families, a baseline against which progress in the future and recent past can be assessed.  
2. To provide and make public some of the experiences of disabled children and their | Health care, social care, education. | Interviews with children and young people and their parents/collation of previous survey data. |
<table>
<thead>
<tr>
<th>Source</th>
<th>Methodology</th>
<th>Health and Social Care</th>
<th>Notes</th>
</tr>
</thead>
<tbody>
<tr>
<td>NICCY (2008)</td>
<td>To offer a review of systems in place to ensure the voice of the disabled child or young person is heard and offer a comparative analysis of the advocacy arrangements available to different groups of young people, e.g. those at home, in care, hospital or community settings. (additional aims within the report).</td>
<td>Health and social care.</td>
<td>Mixed method:</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td>Survey and interviews with parents</td>
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<tr>
<td></td>
<td></td>
<td></td>
<td>Children/young people were interviewed individually or in a group. Makaton/drawing used and interviews with children/young people were tailored to their individual needs.</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td>Interviews and workshops with staff from statutory and voluntary agencies.</td>
</tr>
<tr>
<td>Pilnick et al.</td>
<td>Part of a larger study that aimed to examine the impact of transition and to study how users, carers, professionals and service providers negotiate access to services for young people with ID (intellectual disability).</td>
<td>Health care, social care, education, employment, housing, transport and leisure.</td>
<td>Qualitative. Study involved repeated interviews with adults and also individual interviews or discussion groups with young people. Interactions during meetings were observed and recorded. This paper focuses on audio-tape recorded data collected from 8 multi-party meetings- 4 transition meetings and 4 leaver review meetings.</td>
</tr>
<tr>
<td>Study</td>
<td>Description</td>
<td>Field</td>
<td>Methodology</td>
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<td>------------------------</td>
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<tr>
<td>Rabiee and Glendinning (2010)</td>
<td>The paper reports the first phase of a longitudinal study looking at the priorities and importance that those participating in the study attached to choice in general and to specific choices in different areas of their lives and the reasons why particular choices were important.</td>
<td>Health and social care</td>
<td>Qualitative, semi-structured interviews with disabled people, including young people.</td>
</tr>
<tr>
<td>Simon et al. (2004)</td>
<td>To find out about children’s experiences of school, short breaks, health care, leisure, work opportunities, transition to adulthood, transport and living arrangements. The overall aim of the wider project that this forms part of is called Children’s voice and aimed to give disabled children and young people a voice in the decision-making process.</td>
<td>Health care, social care, education, short breaks, leisure, work opportunities, transition, transport, policing arrangements.</td>
<td>Qualitative/consultation. Children were visited once or twice (mostly in their own homes). 8 of the 38 children attended a group session. Researchers were matched with child/young person’s communication method. Photographs and video used as a reference, feelings faces.</td>
</tr>
<tr>
<td>Slade et al. (2009)</td>
<td>To explore parents’ experiences and views of the range of services they use in relation to their child.</td>
<td>Health care, social care, education, multiagency services.</td>
<td>Qualitative. 9 workshops were conducted with parents of disabled children and young people in each of 9 government regions. Children and young people not involved.</td>
</tr>
<tr>
<td>Study</td>
<td>Objective</td>
<td>Context</td>
<td>Methodology</td>
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<tr>
<td>Thomas (2002)</td>
<td>To explore how and the extent to which children take part in decision making processes, what factors influence, enhance or impede their participation and find out about the expectations of those involved, particularly children.</td>
<td>Social care.</td>
<td>Mixed method, ethnographic study/grounded theory. Observation of meetings, documentary analysis of records and interviews with children along with their social workers and carers and some of their parents in the qualitative part of the study. Children who were interviewed were seen twice. A range of materials were used to support the interviews. Decision charts were used with a traffic light system to indicate the extent to which individuals' had a say in specific decisions. A pots and beans activity was used in the second meeting to explore review meetings in particular. Group meetings were conducted after the individual meetings to explore issues further.</td>
</tr>
<tr>
<td>Turner (2003)</td>
<td>To elicit the views of disabled children and young people across Wales about the services they use and their recommendations for change.</td>
<td>Health services, social care services, education, leisure and recreational services.</td>
<td>Qualitative (consultation) individual and group interviews, draw and write, ranking exercises, express cards.</td>
</tr>
<tr>
<td>Ward et al. (2003)</td>
<td>Not clearly set out; however, the paper reports the experiences of young people and their families at the time of transition.</td>
<td>Health care, social care, education, leisure, housing.</td>
<td>Mixed method. Postal questionnaire sent to 370 families (283 replied – 76% response rate). 27 in-depth interviews with parents in the family home (purposefully sampled to represent a range of situations identified from the survey; sampled in terms of geographical location, good/bad experiences of transition and good/poor outcomes). 27 interviews with young people – the majority were at home with 3 taking place at residential</td>
</tr>
</tbody>
</table>
centres. Some young people used Makaton as a means of communicating. 2 young people had profound needs and time was spent with them to find out about them and their preferences. Two focus groups were held with young people with learning disabilities in order to plan the interviews with young people. Materials such as booklets, pictures, symbols, stickers and photos were extensively piloted. A4 work booklet was then produced.

Field work visits made to 10 projects across England.

<table>
<thead>
<tr>
<th>Updated review</th>
<th></th>
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</thead>
<tbody>
<tr>
<td>Care Quality Commission (2012)</td>
<td>To produce an overview of services for families in England and to provide information or organisations, commissioners or services and families.</td>
</tr>
<tr>
<td>Hyde et al. (2010)</td>
<td>To investigate the experiences of parents making decisions about cochlear implants for their deaf children.</td>
</tr>
<tr>
<td>Mitchell (2012a)</td>
<td>To explore the perspective and experiences of disabled young people with degenerative conditions as they face significant medical interventions and engage in decision-making</td>
</tr>
<tr>
<td>Mitchell (2012b)</td>
<td>To explore disabled young people's shared choice making with parents and peers.</td>
</tr>
<tr>
<td>Mitchell (2013c)</td>
<td>To explore parental perspectives on their and their child's role in choice making.</td>
</tr>
</tbody>
</table>
Location: 22 studies were conducted in the UK, 3 in the USA and 2 in Australia (see Table 4 for location of studies, sample sizes and details of participants for each study included). This reflects a continued emphasis on children's rights within the UK and possibly the fact that the USA has not signed the UNCRC.

Sample sizes: Sample sizes of children and young people varied greatly depending on whether or not others, for example, parents or professionals or managers were being asked about children and young people's participation. Samples ranged from 6 disabled young people to 283 families (numbers of disabled children and young people not specified. For example these families may have had more than 1 disabled child). Overall, however, the numbers of disabled children and young people were small. Researching with disabled children takes time in terms of preparation, time spent with the child and potentially the need to visit the child more than once. Recruitment of disabled children and young people can also be problematic as discussed in chapter 5 of this thesis.

Participants: In many studies, the perspectives and experiences of relevant others in children and young people's lives were also investigated, for example, parents and professionals. The focus of this review is the participation of children and young people in decisions that affect them and so data elicited from relevant others is only discussed where it is relevant to this. Children and young people were between birth and twenty five years (see Table 4). It is not clear from these studies when a child is considered a young person, nor when a young person is considered a young adult. Twelve studies reported the gender of these participants – there was a majority of males in eight of these (Monteith et al. 2002, Thomas 2002, Simon et al. 2004, Burnstein et al. 2005, Haydon, 2007, Mitchell 2012a, 2012b and 2012c) and a majority of females in three (Deatrick, 1984, Monteith and Sneddon, 1999, Turner, 2003). This reflects the greater incidence of impairment in the male population (Monteith and Sneddon, 1999). One study had equal males and females (Hyde et al. 2010). Only eight studies referred to the ethnicity of children and young people with the majority of participants being white. Rabiee and Glendinning (2010)
reported diversity within their sample as regards ethnicity but figures are not included for young people who took part. It is possible that language barriers prevented some families from participating in the studies and the inclusion of non white participants in similar studies requires urgent attention.

The variability in the descriptions of participants’ impairments reflects the ongoing challenges associated with defining disability and the terminologies used when referring to disabled people and their impairments (see Nicholl 2007b for a discussion of these). Terms varied from mild to severe learning difficulties, to communication impairments, sensory disabilities, mental health difficulties and chronic illness or complex needs. Many participants had a combination of these or were described as having specific conditions such as cerebral palsy or Down’s syndrome. A number of authors pointed out that they had widened the inclusion criteria for this reason so that no-one would be unintentionally excluded by gatekeepers (Turner 2003 and Franklin and Sloper, 2006). Those not of ‘normal intelligence’ and non-english speaking were excluded in one early study (Deatrick, 1984) while in another recent study the inclusion criteria was children ‘who were able to communicate’ (NICCY, 2008). In the latter case, the full meaning of this criteria was not discussed.
<table>
<thead>
<tr>
<th>Study</th>
<th>Location</th>
<th>Age/gender</th>
<th>Impairment (inclusion/exclusion)</th>
<th>Ethnicity</th>
<th>Details</th>
</tr>
</thead>
<tbody>
<tr>
<td>Badger (2009)</td>
<td>UK</td>
<td>9 young disabled people</td>
<td>Not reported.</td>
<td>Not reported.</td>
<td>Most children were Anglo American n=62, Hispanic n=2, African American n=5 and Asian n=1.</td>
</tr>
<tr>
<td>Burstein et al. (2005)</td>
<td>US</td>
<td>10 pediatricians (5 male aged between 30 and 54 years, mean age 42.5 and 5 female between the ages of 34 and 56 years, mean age 41.56).</td>
<td>2 pediatricians were Asian American and the remainder were Anglo American.</td>
<td>Family participants were 97 mothers, 21 fathers and 122 children, 25 encounters were eliminated due to inaudible/incomplete tapes.</td>
<td>Children (51 male and 41 female) were between 0 and 18 years, mean age 4.64. 5 children’s gender was unavailable.</td>
</tr>
<tr>
<td>Carnaby et al. (2003)</td>
<td>UK</td>
<td>70 learning disabilities (16-18 years)</td>
<td>Not reported.</td>
<td>Phase 1: 15 young people with a range of learning disabilities (16-18 years) and their details were not reported.</td>
<td>Category 1 students: able to speak for themselves.</td>
</tr>
</tbody>
</table>

**Table 4: Location of studies, sample sizes and details of participants.**
<table>
<thead>
<tr>
<th>Study</th>
<th>Country</th>
<th>Sample Description</th>
<th>Methodology</th>
<th>Findings</th>
</tr>
</thead>
<tbody>
<tr>
<td>Deatrick (1984)</td>
<td>US</td>
<td>24 disabled adolescents (16 female, 8 male), mean age 14 years and their parents (n=45).</td>
<td>Not reported.</td>
<td>Those not of 'normal intelligence' and non-english speaking were excluded.</td>
</tr>
<tr>
<td>Franklin and Sloper (2006)</td>
<td>UK</td>
<td>1. Survey to all social service departments in England.</td>
<td>Not reported.</td>
<td>Most children had a learning difficulty (mild-severe) and 6 children had communication impairment.</td>
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<td></td>
<td></td>
<td>2. 6 case studies: 76 professionals, 24 parents/carers and 21 disabled children aged 5-18 were interviewed in the case studies.</td>
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<tr>
<td>Garth et al. (2009)</td>
<td>Australia</td>
<td>10 children aged 8-12, 14 parents and 9 paediatricians.</td>
<td>Not reported.</td>
<td>Children with cerebral palsy: 9 children communicated verbally and 1 used yes/no responses to questions.</td>
</tr>
<tr>
<td>Greco and Beresford (2009)</td>
<td>UK</td>
<td>2 samples of children: the telelink sample (n=4; 16 and 15 years) and the main sample (n=20); 7-16.</td>
<td>Not reported.</td>
<td>Deaf children.</td>
</tr>
<tr>
<td>Harrison et al. (2005)</td>
<td>UK</td>
<td>21 children and young people (14 boys and 7 girls) between the ages of 3 and 17 years.</td>
<td></td>
<td>Children had impairments including mild and severe learning difficulties, cp, on the autistic spectrum, speech and language delay, fragile x syndrome, Downs Syndrome, hearing loss and visual</td>
</tr>
<tr>
<td>Study</td>
<td>Country</td>
<td>Sample Description</td>
<td>Sample Size</td>
<td>Notes</td>
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<tr>
<td>Haydon (2007)</td>
<td>UK</td>
<td>132 children and young people (63 female, 69 male) aged 4-25. 10 were disabled young people aged 16-24 years.</td>
<td></td>
<td>Part of a larger consultation that included children with special educational needs and disabled children and young people.</td>
</tr>
<tr>
<td>Kelly (2005)</td>
<td>UK</td>
<td>32 children their parents (n=32) and social workers (n=16).</td>
<td></td>
<td>Learning disabled children.</td>
</tr>
<tr>
<td>Monteith and Sneddon (1999)</td>
<td>UK</td>
<td>76 young people (37 male and 39 female) between the ages of 16 and 21 years. Out of the 76, 9 young people were unable to take part due to their communication difficulties and their parents acted as proxies (final total 76).</td>
<td></td>
<td>Young people had multiple disabilities – physical, learning and sensory disabilities.</td>
</tr>
<tr>
<td>Minkes et al. (1994)</td>
<td>UK</td>
<td>77 children and young people between the ages of 10 and 19 years. The interviews from the initial pilot were excluded leaving 63 participants in the main study. Parents also involved in the study but not reported here.</td>
<td></td>
<td>Children had mild to severe learning difficulties. Information about the nature of the children’s impairments was not requested but it was evident from staff comments and the results that children had a limited understanding of speech or no speech. Some used Makaton or other signs or communicated by facial expression, laughing or crying.</td>
</tr>
<tr>
<td>Monteith et al. (2002)</td>
<td>UK</td>
<td>23 parents of children/young people (5-23 years; 13 boys, 10 girls).</td>
<td></td>
<td>15 had mobility impairments, 19 personal care needs, 11 continence problems, 5 difficulty reaching and stretching, 18 had</td>
</tr>
<tr>
<td>Study</td>
<td>UK</td>
<td>Sample Description</td>
<td>Methodology/Findings</td>
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<tr>
<td>NICCY (2008)</td>
<td></td>
<td>33 children/young people and 15 parents/carers were interviewed.</td>
<td>Not reported.</td>
<td></td>
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<tr>
<td>Rabiee and Glendinning (2010)</td>
<td></td>
<td>Part of a larger study. 27 young people (13-21 years) and 34 of their parents. The study also includes 30 adults and older people with varying support needs and 20 who experienced the sudden onset of a disabling condition.</td>
<td>Diversity in the sample as regards gender and ethnicity.</td>
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<tr>
<td>Simon et al. (2004)</td>
<td></td>
<td>38 disabled children and young people (21 male and 17 female).</td>
<td>2 young people were from black and ethnic minority groups.</td>
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<tr>
<td>Slade et al. (2009)</td>
<td></td>
<td>97 parents (20 male and 77 female) of disabled children 0-19.</td>
<td>74 white, 23 BME.</td>
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</tbody>
</table>

The researcher talked to 23 children/young people about the research and 20 children/young people took part.

Sensory impairments, 14 had a learning disability, 15 had difficulties understanding the consequences of any action, 16 had behavioural problems.

Children 'who were able to communicate' and had a learning disability, physical impairment, complex needs or a combination of these.

This paper focuses on 8 young people with a moderate to profound level of disability.

Degenerative/progressive conditions.

Severe learning difficulties, profound and multiple learning difficulties and children with physical impairment aged 8-18 years.

Children and young people had a range of disabilities as defined by the DDA definition.
<table>
<thead>
<tr>
<th>Study</th>
<th>Country</th>
<th>Sample Description</th>
<th>Participation</th>
<th>Other Information</th>
</tr>
</thead>
<tbody>
<tr>
<td>Thomas (2002)</td>
<td>UK</td>
<td>225 looked after children aged 8-12 years. 64% male and 36% female. Number of disabled children and young people not specified.</td>
<td>Not reported.</td>
<td>25% had an ongoing health problem or disability. 7% learning disability.</td>
</tr>
<tr>
<td>Turner (2003)</td>
<td>UK</td>
<td>105 disabled children and young people aged 5-25 (52% female and 48% male).</td>
<td>Not reported.</td>
<td>Broad definition of disability used: children had autism, cp, ADHD, learning difficulties, Down’s syndrome, sensory disabilities, mental health difficulties and chronic illness. A significant number had multiple disabilities and complex needs.</td>
</tr>
<tr>
<td>Ward et al. (2003)</td>
<td>UK</td>
<td>283 families with young people aged 13-25 years.</td>
<td>Not reported.</td>
<td>Learning disabilities. Young people had a range of support needs and some were non-verbal, whilst others were described as articulate.</td>
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<tr>
<td><strong>Updated review</strong></td>
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<tr>
<td>Hyde et al. (2010)</td>
<td>Australia</td>
<td>247 parents of deaf children completed surveys (88.3% were mothers, 10.1% were fathers and 1.6% others eg grandparent, foster mother). 96.7% of parents were hearing, 2.8% hard of hearing and 0.4% were deaf. Children were 0.67-25 years. 27 of the 247 parents took part in telephone surveys.</td>
<td>Not reported, although 4% of parents did not use English as their main language.</td>
<td>92.7% of children had profound hearing loss pre-implantation; 6.9% had severe loss.</td>
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<tr>
<td>Study</td>
<td>Country</td>
<td>Participants</td>
<td>Characteristics</td>
<td>Conditions Discussed</td>
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<tr>
<td>Mitchell, W A (2012a)</td>
<td>UK</td>
<td>10 young people (8 male, 2 female) aged 13-21 years.</td>
<td>7 white British, 3 British Pakistani.</td>
<td>Young people had a range of conditions including DMD, SMA and cystic fibrosis.</td>
</tr>
<tr>
<td>Mitchell, W A (2012b)</td>
<td>UK</td>
<td>27 disabled young people (21 male, 6 female) aged 13-21 years (10 of whom discussed health and/or social care decisions).</td>
<td>4 British Pakistani.</td>
<td>Young people had a range of conditions including DMD, SMA, complex health needs, rare genetic neurological disorders and cystic fibrosis.</td>
</tr>
<tr>
<td>Mitchell, W A (2012c)</td>
<td>UK</td>
<td>14 parents of 11 young people (7 male and 4 female aged 14-22 years) representing 11 families.</td>
<td>One family was British Pakistani.</td>
<td>Young people had a range of conditions including DMD, SMA, complex health needs, rare genetic neurological disorders and cystic fibrosis.</td>
</tr>
</tbody>
</table>
Disabled children and young people’s experiences of the process of participation.

Children and young people’s experiences varied amongst studies. In some cases children and young people reported that they felt very much involved in decisions affecting them. Ninety-two percent (n=24) of deaf children in a study by Greco and Beresford (2009) said that they felt properly involved in consultations with professionals. Similarly disabled adolescents considering surgery were encouraged to take part in decisions in a US study, with some given the opportunity to say yes or no to surgery and others being asked their opinion with parents making the final decision (Deatrick et al. 1984). Positive aspects were also reported by Turner (2003). Badger (2009) explored the extent to which disabled young people who lacked capacity in one particular or all aspects of their life, were involved in the decision making process. At the start of the study, young peoples’ involvement in care planning or reviews was very limited. However, following staff training on the Mental Capacity Act 2005 during the second phase of the project, each young person had a care plan and most had been involved in drawing it up. Finally Mitchell (2012a) found that disabled young people participated in choices about medical interventions and their involvement ranged from full responsibility to shared decision making with parents to others (parents or professionals) taking a leading role. This varied in terms of the importance of the decision, whether it was an ongoing decision that the young person was already familiar with or whether or not the young person felt they should make the decision because they would be living with the consequences of it.

There were many instances however, when disabled children and young people’s involvement in decisions was reported to be very limited. For example, in a study by the Care Quality Commission (2012), most children and young people who took part said that they were not involved in planning their care, had little choice as to who provided their care and had little concept of complaining. Exploring the enactment of children’s rights for children and young people in Northern Ireland, Haydon (2007) found that not being involved in decisions by social workers or health professionals was a major issue for disabled participants. Disabled children and young people in this study said that social workers gave them limited choices and health professionals talked to parents
instead of young people. Turner (2003) concluded that although many of the disabled children and young people who took part in her study were able to make small day to day decisions and choices about their care, often these are made by adults. There was little evidence of disabled children and young people being involved in meetings about them, a situation that had not changed over time. Monteith and Sneddon (1999) found that although 28 young people had had a needs assessment carried out by social workers at the time of transition, only 4 said that social workers had drawn up a plan about their needs with them. None of the children in a later study by Kelly (2005), exploring the provision of family support services for learning disabled children and their families, had attended a review meeting and three quarters of social workers who took part said that children did not take part in decision making processes. Similar findings were evident in children and young people’s interactions with health professionals in 2 studies. One child in a study by Monteith et al. (2002) reported an incident where they clearly did not have the opportunity to participate in decisions about medication. A similar experience was reported by a child in the report by Simon et al. (2004) in relation to the removal of leg braces.

Children and young people’s preferences for participation in decisions.

Disabled children and young people specifically indicated that they wanted to take part in health and social care decisions in 8 studies (Turner, 2003; Allen, 2005; Harrison et al. 2005; Haydon 2007; NICCY 2008; Garth et al. 2009; Rabiee and Glendinning 2010 and Mitchell, 2012a). This was reported to vary according to age in some studies with older children and young people wanting to take increasing responsibility. Children and young people in a study by Rabiee and Glendinning (2010) generally did not talk about choice within healthcare but those who did wanted more say when they got older. Reporting disabled adolescents’ perceptions about their involvement in decisions about surgery, Deatrick (1984) found that both parents and physicians had an expectation that the young people would be more involved in decisions about surgery as they got older. Garth et al. reported that children’s preferences to be involved varied, with younger
children (8-9 years) less interested in working in partnership with professionals than older children (10-12) who felt that they had a place. NICCY (2008) reported that younger children less than 10 years were happy for their family to make important decisions for them, although older young people wanted to be kept informed about choices available to help them make informed decisions. In a survey to social services departments in England, Franklin and Sloper (2006) reported that participation in decisions about children and young people's care peaked at 14-16 years with 97% of initiatives involving this age group and similar findings were reported that related to participation in decisions about services where teenagers were involved most. Of these 8 studies, only 1 (Mitchell, 2012a) reported that age did not influence the participation of young people in this way. However, the youngest participant was 13 years old and this study reported only decisions about medical interventions. Mitchell, (2012b) reported that 6 young people did not want to take responsibility for decision making where there was an element of risk (for example, decisions about surgery) because of a fear of making the wrong decision.

The role of parents and professionals

Parents had an important role to play in their child's decision making. In a study by Hyde et al. (2010) about decisions around cochlear implantation, parents considered the decision to be largely the child's from around 10 years on but they played an important role in supporting their child (Hyde et al. 2010). One study highlighted the important role that parents played in seeing past the disability and fostering a ‘can do’ attitude in their child, encouraging them to see themselves as the same as anyone else and become independent (Allen, 2005). While one young person in this study described her mother as having a major part to play in helping her become a person who was able to make decisions about her own life, other parents emphasised what the young person could not do. Two mothers were reported to intervene in interactions with professionals to ensure that their child was involved in decision making in a study by Slade et al. (2009).
Adults in a study by Thomas (2002) identified the factors affecting children’s participation (disabled children not specified) as their personality, confidence, maturity and ability to trust among others. However, disabled children did not always display such confidence, as was evident in a study by Monteith and Sneddon (1999). Clearly parents have a key role in laying foundations upon which successful participation can be built. Having said that, there were clear examples of parents making decisions on children’s behalf and some studies evidenced a general attitude from professionals that they could not form opinions about their own needs (for example, see Turner, 2003; Kelly, 2005). Badger (2009) reported a similar finding on the basis of her observations and interviews with service users and staff where, in general, it was assumed that decisions about young peoples’ futures lay mainly with parents and then the statutory body. Where respite was concerned, Minkes et al. (1994) reported that at times disabled children were not involved in such decisions because parents needed a break from caring. Parents in another study were concerned that their child might disrupt review meetings and so judged it was better that they did not attend (Kelly, 2005). Mitchell (2012b) reported that young people without a learning or communication impairment said that parents had less input into decision making as they got older. However, Mitchell (2012c) reported that age was irrelevant for some parents, rather they thought their child's level of understanding was most important in determining the extent to which they involved their child. Regardless of age, many parents perceived that their son or daughter was still ‘a child’. The extent to which parents in this study involved their child in decision making also depended on the complexity of the choice that was being made. When parents believed that their child did not have the ability to understand the significance or consequences of a decision, they restricted their involvement. Similarly parents in this study adopted a protective role, at times limiting their involvement in decision making. However, when decisions were perceived to hold less risk, parents afforded their son or daughter more responsibility for decision making.

The ability of social workers to foster positive, trusting relationships with children was also identified by Thomas (2002) as positively influencing the involvement of children in care decisions. Harrison et al. (2007), Simon et al. (2004) and Turner (2003).
Monteith and Sneddon (1999), Deatrick (1984) and Greco and Beresford (2009) also highlight the importance of the quality of professionals' relationships with children and relationships with professionals were reported to be positive in these studies. This was influenced by the setting in one case where professionals who conducted home visits (and had no uniform) were regarded as friends, in what was perceived as the children's own space. Some children and young people felt most comfortable with community nurses and health visitors who they felt they could talk to more easily than doctors (Turner, 2004). Positive relationships with professionals were reported to have other advantages, for example, Kelly (2005) found that social workers who listened to children made them feel liked, important and happy.

However, it was evident that some professionals lacked the necessary skills to engage children and young people in participatory practices and give them the confidence to express their views. Franklin and Sloper (2006) found that successful participation was very dependent upon the individual practices of social workers, many of whom did not feel that they had the knowledge, skills, training and experience to involve children. Findings also demonstrated that when communication tools were developed and social workers received training and support, participation could be achieved. Social workers in a study by Kelly (2005) also reported a lack of knowledge about how to communicate with disabled children. Monteith and Sneddon (1999) reported that young people said that they lacked the confidence to speak to their social worker, and in the study by Turner, children referred to doctors' and nurses' lack of communication skills as they were unable to understand what they were saying.

In many cases disabled children participation was affected by the attitudes of staff. Disabled children and young people were sometimes stereotyped as those who could not speak for themselves (Allen, 2005) or who could not form opinions about their needs (Kelly, 2005). Some made blanket judgements about children's capacity to be involved (Badger, 2009). Comparing the communication patterns of paediatricians and parents and their children with and without special health care needs, Burnstein et al. (2005) found that although those with special health care needs engaged more with paediatricians than other children, they were mostly involved in social rather than
medical related conversations which were directed towards the parent. Franklin and Sloper (2006) found that both professionals and parents sometimes underestimated the ability of the child to take part before specific methods were adopted.

The positive attitudes that promoted participatory practices included discussing the young person’s needs in terms of their strengths rather than limitations imposed by others (Carnaby et al. 2003). Thomas (2002) found that professionals’ attitudes either facilitated or acted as a barrier to participation. Those who had a positive attitude to disabled children focused on the child’s ability to make themselves understood as well as their own responsibility and determination to include them. Professionals’ who felt that children’s disabilities were too profound to include them, or who couldn’t think of alternative methods to use, displayed negative attitudes that acted as a barrier to participation. Attitudes towards the appropriate level of participation was found to vary in a study by Badger (2009), who reported that staff indicated that young people had a lot of choice, however observations by the researcher showed that choices were limited to those specifically offered by staff.

**Three way interactions and decision making**

In the included studies, decision making often occurred in the context of 3 way interactions between children or young people, parents and professionals. At times professionals found it difficult to balance the needs and wishes of young people against those of their families and often it was easier to agree with parents (Badger, 2009). This situation could also be difficult for young people. Adolescents in a study by Deatrick (1984) about decision making around the need for surgery, said that they found it difficult to reconcile the opinions of different professionals and the spoken or unspoken views of their parents. While young people’s involvement in decisions made parents feel better, the responsibility for decision making was stressful for some young people. In other studies, parents or professionals controlled the involvement of children. In a study by Garth et al. (2009) children’s involvement relied to a large extent on the parents’ desire to allow the child to be exposed to the issues in question, although in most cases
children were happy with this. Paediatricians in the study acknowledged that at times they withheld information from children and young people, asking them to wait outside the room when certain issues were discussed. They also reported changing the therapeutic relationship from a dyadic one (parent and professional) to a triadic one that involved the child as they got older.

The studies indicate that, at times, children and young people felt that professionals talked to parents more than them (Kelly, 2005, Haydon, 2007). Children and young people’s preferences to be involved varied across studies. When children and young people were asked if professionals talked to children as well as staff, there were mixed reports. When Greco and Beresford (2009) asked if professionals paid attention to them or just talked to Mum or Dad, 86% of deaf children said ‘all the time’, 6% said ‘sometimes’ and 6% said ‘never’. Similarly, children in studies by Turner (2003) and Harrison et al. (2005) said that professionals talked to them as well as their parents. In other studies, this was less apparent and there was evidence that professionals talked to parents instead of the young person (Haydon, 2007, Kelly, 2005, Slade et al. 2009). Monteith and Sneddon (1999) reported equal responses between young people who felt that social workers talked more to them, more to their parent or equally.

The availability of resources

A lack of resources was seen to limit decision making in 6 studies (Turner, 2003, Ward et al. 2003, Allen, 2005, Franklin and Sloper 2006, Badger, 2009, and Rabiee and Glendinning, 2010). These related to physical resources such as housing, transport or respite facilities (Turner, 2003, Allen 2005, Badger, 2009, Rabiee and Glendinning, 2010). Turner (2003) reported that many participants felt that choices were very limited. Staffing issues were also found to hinder children and young people’s participation. Allen (2005) and Franklin and Sloper (2006) cited staff turnover as problematic and, in the latter case, a lack of time was a major issue. In this study, just 22% of those who involved disabled children and young people in decisions about their own care and 37% of those involving them in services, did so in protected time. In the
same study, parents reported that a lack of time spent with children made it difficult for social workers to explore children’s views. Similarly in the case studies in the study by Franklin and Sloper (2006), staff from social services said that a lack of time was the greatest barrier they faced in involving disabled children in decisions about their own care because of the need for additional time to build up a relationship with the child and conduct repeated visits. Children were also aware of professionals not having the time to engage with them in a study by Simon et al. (2004). According to Badger (2009) choices for disabled young people about where to live were very limited as power lay with local authorities and parents who would be paying. Thus the opportunities for decision making were dependent not only on the needs of the child or young person but also on resources provided by local services and parents.

### Preparation and support for decision making

The provision of appropriate information was discussed in a small number of studies. Children in two studies reported experiences where professionals gave clear explanations about their care. Asked if professionals explained how they were going to help, 65% of deaf children in a study by Greco and Beresford (2009) said ‘all the time’, 20% said ‘sometimes’, 10% said ‘never’ and 5% were not sure. Harrison et al. (2009:12) reported one child as saying that doctors providing information helped him to understand more. Similarly, nursing staff in a study by Deatrick et al. (1984) provided information for young people about the expectations of forthcoming surgery in a way that was realistic without being overwhelming, as well as listening and clarifying information that was given. Although information in a study by Turner (2003) was provided about children’s conditions mainly by parents, most children and young people wanted this information to come directly from professionals. Most of the young people in a study by Mitchell (2012a) did not recall receiving written information and only 2 young people had used the internet as a source of information.

Where reported, information about services was lacking. Only 9 out of 49 young people in the study by Monteith and Sneddon (1999) had been given information about
available social services in their area and 17 young people said they would like information about this. The lack of information about services was also reported by Turner (2003) and NICCY (2008). Franklin and Sloper (2006) found that although children and young people had enjoyed participatory events to inform services, they were not given information about what they had participated in – there was either no information or it was not provided in an accessible format. When asked what was the best way to get information, children and young people in the study by Turner (2003) said via videos, speaking to parents and carers, speaking to children and young people, the internet, leaflets, posters and audio tapes. Older children in a study by NICCY (2008) suggested that the use of email, web sites and chat rooms could keep them informed about choices available to them.

Preparation for decision making was identified as important for some children, particularly those who considered issues in the ‘here and now’ and found it difficult to relate to meetings that addressed past, present and future aspects of young people’s lives (Pilnick et al. 2010). Timely preparation was at sometimes lacking. Simon et al. (2004) reported that children often did not know that professionals were coming to see them at school until the actual time or day. Franklin and Sloper (2006) reported the use of recorded cards by social workers to inform children that they were visiting and would be asking about a specific thing. Forty-one percent of children and young people in a study by NICCY (2008) said that they were not given information early enough to enable them to take part in decision making. Quantitative findings of a study by Carnaby et al. (2003) demonstrated that students able to speak themselves were actively involved in transition review meetings for at least half of the time allocated to the meeting (and up to 80% of the time). Those who required moderate levels of support were excluded (32.3%) more than included (12.2%), with a lot of discussion not related to the issue in question. Students who had profound disabilities were excluded from a third (33.4%) of discussion that took place and most of the discussion that took place did not relate to the student’s transition (62.8%). Following a policy change, based on the recommendations arising from the first phase of the project, students were involved in meetings for at least 80% of the time in phase 2. During phase 2 it was evident that time had been spent with
the young person and their family prior to the meeting and inclusive methods were being employed to facilitate the process. These included holding meetings in a familiar room, showing video footage of young people engaged in activities and using symbols and photographs to show what they liked or disliked and how they spent their time at school. Students were also supported in how to have their say. Mitchell (2012a) found that parents had a key role in providing support to young people during decision making processes. Mothers, in particular, provided emotional support and listened to young people's concerns. Mothers were perceived to be more available and easier to talk to (Mitchell, 2012b), whereas fathers had a more peripheral role. Few young people identified conflicting opinions with parents who they trusted to understand them and respect their wishes. Mitchell (2012b: 628) reported that young people wanted their parents to be involved in decision making and this appeared to be 'the norm'. In this study, parental support was most important in what young people perceived as 'big decisions' (and less important where everyday decisions were concerned, p. 628). However, all of the young people (both with and without a learning and communication impairment) felt that parents would continue to support them in decision making.

Disabled children and young people's experiences of participating in decisions about services and policy.

Support was also important for those who were participating in decisions about services and policy. Young people in a study by Haydon (2007) said that they needed support to express themselves according to their needs, to represent the views of other young people and to enable them to make appropriate links with people who could make things happen. It is notable that only 1 additional study addressed disabled children and young people's participation in services or policy. Franklin and Sloper (2006) reported that they had few opportunities to participate in this way, they had limited understanding of what they had participated in, they enjoyed the social aspect of being in a youth forum and had ideas about how practice could be improved.
Outcomes of participation

The intrinsic outcomes of participation were reported in 9 of the 27 the studies. These included both positive and potentially negative outcomes for the children and young people themselves. For the main part, outcomes were generally positive with participants recounting that, as a result of their participation, children and young people felt more confident (Carnaby et al. 2003; Franklin and Sloper, 2006), assertive and resilient (Allen, 2005), valued, included and listened to (Franklin and Sloper, 2006), liked, important and happy (Kelly, 2005), important and involved (Garth et al. 2009) and more independent (Rabiee and Glendinning, 2010). However, there were also tensions and drawbacks of children and people’s involvement. For example, adolescents making final decisions about surgery found it stressful at times, particularly when they were of an age when they signed the consent form themselves (Deatrick, 1984). Finding a balance between children and young people’s protection and participation in treatment decisions was reported by Garth et al. (2009) as challenging for parents for fear of upsetting them. Professionals sometimes struggled too, to ‘get the balance right’. Pilnick et al. (2010) concluded on the basis of their study that staff felt placed in an impossible situation – between placing young people’s desires at the heart of the transition process and managing young people’s lack of competency in terms of translating their desires into reality (referring to a young person who wanted to join the police but lacked the capacity to do so). The issue of young people’s capacity was also raised in alternative studies. Although staff in a study by Badger undertaking training on the Mental Capacity Act (2005) felt that it could be beneficial in supporting vulnerable individuals in their involvement in decisions, they had a number of concerns. Staff were unsure how to address conflicts between the individuals’ choices and staff’s duty of care and had anxieties around whether or not staff would be legally accountable if they made a best interest decision that subsequently went wrong or having allowed someone in their care to make a decision that went on to have a detrimental effect on them. Although Badger recommends a consistent approach to assessing capacity when making best interest decisions with standardised forms, monitoring of assessments and direction from senior management of organisations, she acknowledges that decisions based on
capacity will always be difficult. Thomas (2002) argues that it is necessary to 'look for a process of communication that will elicit and augment the child’s actual competence, rather than to submit them to ‘tests’ of competence' (p187). Thomas concludes that children learn decisions rather than acquiring them at a certain age and this has particular currency where disabled children and young people are concerned.

The extrinsic outcomes of children and young people’s participation (outcomes that related to services, policy or the wider community) were reported in just one study (Franklin and Sloper, 2006). In a survey to social service departments in England, only 44% of initiatives involving disabled children and young people in service provision reported changes as a result. These included changes to activities, information provision, décor, best value recommendations, advocacy, new equipment, a user-friendly register, inclusion in reviews, communication packages, transition planning, the development of a disabled children’s participation strategy and changes to direct payments. Clearly the small amount of studies that addressed disabled children's participation in services or policies (2 out of 27) in part accounted for a lack of reported extrinsic outcomes. However, anecdotal evidence suggests (for example as evidenced by the 'Every disabled child matters' agenda in England and by the 'Making Ourselves Heard' initiative launched by the National Children's Bureau) that disabled children are participating in this way and yet there is a lack of research studies addressing this issue.

In reality, until government departments are required to demonstrate that they are not only engaging with disabled children and young people and produce tangible outcomes and changes that occurred as a result, this area is likely to remain largely unreported in the literature. This study seeks to address this gap in current literature.

3.5 Literature review 2: the participation of parents of disabled children and young people in health and social care decisions

Aim of the review: The aim of this review was to establish what works in parents' participation in terms of both process and outcomes.
Objectives

1. To determine parents' experiences of the process of participation in decisions about their child's health and social care, in decisions about how services are designed and delivered and about associated policy.

2. To find out what factors promote and hinder participation in the health and social care context.

3. To identify the outcomes (both extrinsic and intrinsic) of parents' participation.

4. To determine the mechanisms of effective participation, in terms of both process and outcomes.

METHODS

Criteria for considering studies for this review

Types of studies: Studies that reported parents' experiences of the process of participation in decisions about their child's care, in decisions about how services are designed and delivered and in decisions about policy development and/or the outcomes of such participation. There were no language restrictions.

Types of participants: Parents of disabled children and young people, of any age, with a physical, cognitive or sensory impairment or a combination of these.

Type of intervention: Any intervention that aimed to involve parents in decisions about their child's health or social care, in decisions about health or social care services or policy.

Outcomes of interest: In addition to parents' experiences of participation, outcomes of interest include both intrinsic and extrinsic outcomes of participation.
Search strategies for the identification of studies

**Electronic searches:** The following databases were searched: ASSIA (earliest to 2012), Cinahl Plus and British Nursing Index, Medline (1946-2012), ScienceDirect (no date restriction), ChildData, Social Care Online (dates back to 1986), ORB (From 2000), Lilacs, Zetoc (since 1993), Embase (1980-2012), Web of science/Social Science Citation Index (1990-present), NHS Evidence. Key terms used included participation, user, partnership, involving, listening, consulting, voice, choice, communication, decision, decision-making, views, consumer, parent, father, mother, carer, disabled, impairment, special needs, autism life-limited, blind, deaf, Deaf, delayed with appropriate truncation.

**Searching other resources:** Other sources of information included reference lists of articles identified in the course of conducting the review. A list of 35 relevant voluntary and other organisations were also drawn up (see Appendix 2) in order to identify associated grey literature that may have been relevant to the review.

**Selection of studies:** Studies for inclusion were selected by the author.

**Data extraction and management:** The following information was obtained where available: the numbers and characteristics of participants, the context and country of origin, the type and aim of the study. Data relating to the methodological aspects of the studies were also obtained (including study design, sampling, ethical procedures, place and method of data collection, analysis). A quality appraisal was conducted and the quality status of each article was recorded along with the findings.

**Assessment of methodological quality**

As in the first review, studies were classified, summarised and assessed using the following quality criteria:

1. Is the study informed by or linked to an existing body of knowledge?
2. Are the aims of the study clearly stated?
3. Is the study design appropriate to the stated aims?
4. Is the sampling strategy described and adequate to explore the range of children in the particular setting?
5. Are ethical issues, such as consent, confidentiality and dissemination described and appropriate?
6. Are data collection processes adequately described and set out in sufficient detail to enable replication?
7. Were the data collection tools piloted?
8. Is the analysis explicit, replicable and justified in terms of the study design?
9. Are findings systematically reported and is sufficient original evidence reported to justify a relationship between evidence and conclusions?

Again studies were coded according to the following coding strategy adapted from Kilpatrick et al. (2008):

Category A: studies that meet the quality appraisal criteria with no or very few flaws, none of which threatened the overall quality of the study.

Category B: studies that meet many of the appraisal criteria, with some flaws which threatened the overall quality of the study.

Category C: Studies that include many/serious flaws that gave cause for concern about the findings.

Category D: Studies that include insufficient data on methodology to allow an appraisal of quality.

Some of these ‘flaws’ may reflect flaws in reporting, rather than the study itself.

Results

Searches were run between June 2011 and October 2012. 5528 citations were obtained (see Figure 6). Where necessary, abstracts or full texts were read to inform decisions about inclusion in the review. In some cases, however, it was evident from the titles that articles were not relevant. For example, many articles addressed participation in the child’s nursing care rather than decision making. Fifty were selected identified as being potentially relevant. Once duplicates were removed 33 were identified as being potentially relevant and the full text of these was obtained and read. Of these 33, 2 were excluded on further examination as they did not meet the inclusion criteria. A further 3
articles were identified from the reference lists of other articles. Thirty four studies were included in the review. Three of these studies (Maddison and Beresford, 2012a, 2012b and Mitchell, 2012) were derived from the 'Choice and change project' but all are included here as they reported differing aspects.

**Included studies:** Of the thirty-four studies that met the inclusion criteria, only 13 focused specifically on decision making, with the remainder exploring wider issues such as parents' involvement in the transition process, experiences of diagnosis, having a disabled child or service provision, interactions with professionals and family support (see Table 5 for study aims, area of service provision addressed and method used). Thus, in some cases, the content relating to parental participation in decisions was minimal. This again represents a small base from which to draw firm conclusions and highlights a gap that this thesis seeks to fill. It is notable that only 3 studies addressed the participation of parents of disabled children and young people in decisions about services or policy (Flannigan and McCoy, 2006; Itzhaky and Schwartz, 2000 and Care Quality Commission, 2012), also a small number of studies from which to draw firm conclusions about this aspect and highlights a further gap that this research seeks to fill.

**Design:** Fifteen studies used qualitative methods, five used quantitative methods and fourteen used a mixed method approach (see Table 5). Few studies provided a critical analysis of 'what worked' in terms of researching with parents of disabled children and young people and this is a further gap that this thesis fills.

**Quality appraisal:** Using the quality appraisal coding strategy described on p87, twenty studies were coded A, 13 coded B and 1 was coded C. Most were published in peer reviewed journals. Those coded B lacked a robust theoretical framework, had small samples, failed to pilot data collection tools or lacked detail about the exact method of analysis. The work by Elweke and Rodda (2000) was coded C because of the authors' use of a case study approach with just 2 families: 1 family with one deaf daughter who used BSL and 1 family with 2 deaf children used the aural/oral approach. While the authors acknowledged this as a limitation, it was felt that an alternative could have been used, particularly as it was underpinned by a grounded theory approach that necessitates
the achievement of saturation in the data. This article is included here purely because of
the dearth of research in this area where parents of disabled children are concerned, the
relevance of some of the findings and ongoing controversy surrounding 'in' or 'out'
decisions when reviewing qualitative or mixed methods research.
Figure 6: Study selection flowchart

5528 citations identified

5478 discarded as irrelevant

50 citations identified as potentially relevant and full texts obtained

Total following removal of duplicates = 33

2 discarded as irrelevant

31 articles included in the review

3 articles obtained from the reference lists of other articles

34 articles included in the review
Table 5: Study aims, area of service provision addressed and method.

<table>
<thead>
<tr>
<th>Study</th>
<th>Aim (verbatim)</th>
<th>Area addressed</th>
<th>Method</th>
</tr>
</thead>
<tbody>
<tr>
<td>Braiden et al. (2010)</td>
<td>To provide an insight into parents' experiences of the diagnostic process for ASD.</td>
<td>Health care.</td>
<td>Qualitative. Semi-structured interviews.</td>
</tr>
<tr>
<td>Bjorck-Akesson and Granlund (1995)</td>
<td>To further analyse participants' typical and ideal family involvement in the habilitation process, analysing both parents' and professionals' perceptions of family involvement (habilitation = professionals supporting families to ensure that children reach their potential and achieve independent living).</td>
<td>Health care, social care.</td>
<td>Mixed method. Previously used questionnaire instruments translated into Swedish and adapted.</td>
</tr>
<tr>
<td>Burstein et al. (2005)</td>
<td>To extend our understanding of medical encounters involving families and children with special needs.</td>
<td>Health care.</td>
<td>Quantitative.</td>
</tr>
<tr>
<td>Care Quality Commission (2012)</td>
<td>To produce an overview of services for families in England and to provide information or organisations, commissioners or services and families.</td>
<td>Health care.</td>
<td>Mixed method. Questionnaires, interviews, group sessions and meetings with stakeholders.</td>
</tr>
<tr>
<td>Carnaby et al. (2003)</td>
<td>To determine the extent to which young people with learning disabilities are involved in the transition process, and then make recommendations for enhancing this involvement.</td>
<td>Health, care, social care, post-education options.</td>
<td>Mixed method. Participant observation of a number of case studies (Qualitative and quantitative data collected).</td>
</tr>
<tr>
<td>Doig et al. (2009)</td>
<td>To explore the respite care experience from the perspective</td>
<td>Social care.</td>
<td>Qualitative. In depth interviews.</td>
</tr>
<tr>
<td>Study</td>
<td>Objectives</td>
<td>Methods</td>
<td></td>
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<tr>
<td>Eweke and Rodda (2000)</td>
<td>To identify the various factors that might influence parents of children with special needs in choosing a communication mode for their children.</td>
<td>Mixed method: Case study approach; semi-structured questionnaire and a follow-up unstructured interview.</td>
<td></td>
</tr>
<tr>
<td>Gonnick et al. (2012)</td>
<td>To explore parent perception regarding facilitative factors and barriers to the transition experience in the context of the family system, the service system, the wider social and community systems.</td>
<td>Social care, education.</td>
<td></td>
</tr>
<tr>
<td>Hendrickson et al. (2000)</td>
<td>To identify the factors that prevented mothers from seeking ASD report that they are engaged in shared decision making.</td>
<td>Health care.</td>
<td></td>
</tr>
<tr>
<td>Huang et al. (2011)</td>
<td>To examine the experiences of fathers of developmentally disabled children during interactions with health professionals.</td>
<td>Health care.</td>
<td></td>
</tr>
<tr>
<td>Hyde et al. (2010)</td>
<td>To investigate the experiences of parents making decisions about cochlear implants for their deaf children.</td>
<td>Mixed methods: survey and in-depth telephone interviews lasting about 1 hour.</td>
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</tr>
<tr>
<td>Citation</td>
<td>Description</td>
<td>Methodology</td>
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<tr>
<td>Jones and Hack (2008)</td>
<td>1. To ascertain the extent to which parents are involved in commissioning services. 2. To identify the issues involved for authorities in enabling parents to commission services. 3. To make recommendations on how parents and authorities can be supported in increasing parental involvement in commissioning.</td>
<td>Social care.</td>
<td>Mixed methods. Questionnaires and interviews.</td>
</tr>
<tr>
<td>Keenan et al. (2010)</td>
<td>To report parental experiences of diagnosis and forward planning for children with ASD are reported.</td>
<td>Health care.</td>
<td>Mixed methods. Questionnaires and focus groups.</td>
</tr>
<tr>
<td>Li et al. (2003)</td>
<td>To compare the relative importance of the child’s hearing loss and parental attitudes, beliefs, values and aspirations in the decision process.</td>
<td>Term 'professionals' used but not specified.</td>
<td>Quantitative. Survey method.</td>
</tr>
<tr>
<td>Lundebey and Tossebro (2008)</td>
<td>To describe and explore situations experienced as non-listening from the parents’ perspective, to distinguish different types of situations and understandings of these situations and to point out possible traits of the service system or parent-professional relationship contributing to this experience.</td>
<td>Health care, social care.</td>
<td>Qualitative (part of a larger mixed method study). Interviews reported in this paper.</td>
</tr>
<tr>
<td>Maddison and Beresford (2012a)</td>
<td>To explore the decision making processes that take place when a disabled young person is moving on from full time</td>
<td>Social care.</td>
<td>Qualitative, longitudinal study. Parents interviewed up to 3 times.</td>
</tr>
<tr>
<td>Study</td>
<td>Objective</td>
<td>Health and social care</td>
<td>Study Design/Methodology</td>
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<td>----------------------------------------</td>
<td>---------------------------------------------------------------------------</td>
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<tr>
<td>Maddison and Beresford (2012b)</td>
<td>To explore the decision making processes that take place when a disabled young person is moving on from full time education.</td>
<td>Health and social care</td>
<td>Qualitative, longitudinal study. Parents interviewed up to 3 times.</td>
</tr>
<tr>
<td>Okubo et al. (2008)</td>
<td>To elucidate the potential benefits and risks associated with cochlear implants as perceived by parents of deaf children and to reveal the decision-making process regarding implantation surgery.</td>
<td>Health care.</td>
<td>Qualitative. Semi-structured interviews.</td>
</tr>
<tr>
<td>Pilnick et al. (2011)</td>
<td>To study how users, carers, professionals and service providers negotiate access to services for young adults with ID and more specifically how do professionals manage when parents express different views or wishes to those of the young adults they care for when decisions are being made in review meetings.</td>
<td>Health care, social care, education.</td>
<td>Qualitative, longitudinal study. Interviews with carers, staff and young people participating in 8 meetings.</td>
</tr>
<tr>
<td>Prezant and Marshak (2006)</td>
<td>To identify: the types of professional actions that parents perceive as helpful or obstructive; the specific professionals engaged in those actions and the specific actions parents would like professionals to take.</td>
<td>Health care, social care, education.</td>
<td>Quantitative. Survey.</td>
</tr>
<tr>
<td>Ryan and Salisbury (2012)</td>
<td>To identify feasible improvements to the management of primary care consultations with parents of children who might have ASD (experiences pre diagnosis).</td>
<td>Health care, education.</td>
<td>Qualitative. Interviews.</td>
</tr>
<tr>
<td>Serpentine et al. (2011)</td>
<td>To examine the perspectives of parents of children with ASD in terms of decision making about AAC.</td>
<td>Health care, education.</td>
<td>Qualitative. Interviews.</td>
</tr>
<tr>
<td>Slade et al. (2009)</td>
<td>To explore parents' experiences and views of the range of services they use in relation to their disabled child, with a</td>
<td>Health care, social care, education.</td>
<td>Qualitative. Workshops.</td>
</tr>
<tr>
<td>Study</td>
<td>Focus</td>
<td>Services</td>
<td>Methodology</td>
</tr>
<tr>
<td>-----------------------------------------</td>
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</tr>
<tr>
<td>Sperry et al. (1999)</td>
<td>To establish the unique views of parents and service providers in relation to their hopes, dreams, experiences and expectations and experiences of services for young children with ASD.</td>
<td>Health care, social care, education.</td>
<td>Qualitative. Focus groups.</td>
</tr>
<tr>
<td>Swain and Walker (2003)</td>
<td>To explore the relationship between existing services for disabled children and a local centre set up by parents and the implications for establishing an equitable partnership between parents and professionals.</td>
<td>Health care, social care, education.</td>
<td>Mixed method. Questionnaire and follow up in depth interviews.</td>
</tr>
<tr>
<td>Valentine (2010)</td>
<td>To investigate the effects, (enabling or otherwise) of choice for parents, in an environment in which choosing treatments is mandatory.</td>
<td>Health care, social care, education.</td>
<td>Qualitative. Interviews (both telephone and in person).</td>
</tr>
<tr>
<td>Ward et al. (2003)</td>
<td>To explore the experiences of young people and their families at the time of transition.</td>
<td>Health care, social care, education, housing, benefits, social opportunities.</td>
<td>Mixed method. Questionnaires and interviews.</td>
</tr>
<tr>
<td>Wodehouse and McGill (2009)</td>
<td>To provide a detailed account of support issues and increase understanding of the barriers to more effective support provision.</td>
<td>Health care, social care, education.</td>
<td>Mixed methods. Questionnaires and interviews.</td>
</tr>
<tr>
<td>Wood et al. (2009)</td>
<td>To assess satisfaction of parents of children with special health care needs with treatment by office staff, communication with the pediatrician, involvement in decision making and co-ordination of services outside the practice.</td>
<td>Health care.</td>
<td>Mixed method. Survey and focus group interviews.</td>
</tr>
</tbody>
</table>
Location: There was a wide geographical spread in terms of location. Fourteen studies were conducted in the UK, seven in the USA, two in Canada, two in Ireland, two in Australia, one in Iceland, one in Sweden, one in China, one in Israel, one in Norway, one in Japan and one in Hungary (see Table 6 for location of studies, sample sizes and details of participants for each study included).

Sample sizes: Sample sizes varied greatly from 2 families (number of parents who participated not specified) to 615 parents depending on methods used (for example, survey or interview) and, in terms of total numbers of participants, whether or not others, for example, professionals were also asked their views (see Table 6).

Participants: Where the gender of parents was specified, the proportion of mothers who participated by far outweighed the participation of fathers (Burstein et al. 2005; Doig et al. 2009; Egilson, 2011, Golnick et al. 2012; Hyde et al. 2010; Keenan et al. 2010; Lundeby and Tossebro, 2008; Maddison and Beresford, 2012a; Maddison and Beresford, 2012b; Obuko et al. 2008; Ryan and Salisbury 2012; Sperry et al. 1999 and Valentine, 2010). The number of fathers participating just exceeded mothers in only 1 study (Wood et al. 2009), although the proportions were almost equal. Three studies included the perspectives of mothers only (Braiden et al. 2010; Hendrickson et al. 2000 and Wodehouse and McGill, 2009) with only one providing a rationale for this. Hendrickson et al. (2000) stated that fathers were not invited because it was assumed that mothers were the primary caregivers. Only 2 of the 34 studies reported the experiences of fathers exclusively (Huang et al. 2011 and Serpentine et al. 2011).

Children in the studies varied in age. Only 1 study included parents of children from infancy to late adulthood (Prezant and Marshak, 2006). Children had a wide range of impairments described as autism, hearing impairments, medical conditions, degenerative conditions, intellectual disability, physical, behavioural, communication and complex needs. Nine studies included details about the ethnicity of the participants with stating that non English families were excluded because of insufficient funds (Hendrickson et al. 2000).
Table 6: Location of studies, sample sizes and details of participants.

<table>
<thead>
<tr>
<th>Study</th>
<th>Location</th>
<th>Number of participants</th>
<th>Ethnicity</th>
<th>Nature of child’s impairment (inclusion/exclusion)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Bennett (2009)</td>
<td>UK</td>
<td>615 parents of disabled children 0-19 years, including 2 carers.</td>
<td>Not reported.</td>
<td>Disabled children with a range of physical, learning, behavioural, sensory, communication or complex needs.</td>
</tr>
<tr>
<td>Bjorck-Akesson and Granlund (1995)</td>
<td>Sweden</td>
<td>73 parents 139 professionals: Physicians (n=8), psychologists (n=18); social workers (n=17); speech pathologist (n=13); Special educator (n=37); physical therapist (n=30); OT (n=11); Other (n=5). Total 212 participants.</td>
<td>Not reported.</td>
<td>Impairments not specified: disabled children.</td>
</tr>
<tr>
<td>Study</td>
<td>Location</td>
<td>Description</td>
<td>Participants/Application</td>
<td>Impairments</td>
</tr>
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</tr>
</tbody>
</table>
| Carnaby et al. (2003)        | UK       | Phase 1: 15 young people with a range of learning disabilities (16-18 years) and their families.  
Phase 2: 12 young people (16-18 years) and their families. | Not reported.             | Category 1 students: able to speak for themselves/mild learning disability  
Category 2 students: needed more support to communicate: moderate to more severe learning disabilities  
Category 3: students: those needing most support: profound and multiple disabilities. |
| Doig et al. (2009)           | Canada   | 10 participants; 7 mothers, 2 fathers and 1 grandmother.                     | 8 were caucasian.  
Other 2 not reported. | Most common condition was fetal alcohol syndrome; others were turettes, ADHD, mental retardation, learning and behavioural issues and developmental delay. |
<p>| Elweke and Rodda, (2000)     | Canada   | 2 families.                                                                  | Not reported.             | 1 family with one deaf daughter who used BSL; 1 family with 2 deaf children used the aural/oral approach. |
| Egilson (2011)               | Iceland  | 17 parents: 14 mothers and 3 fathers (40-60 years old) of children aged 7-13 years. | Not reported.             | Children had a range of impairments. |
| Flannigan and McCoy          | UK       | 87 parents (mothers and fathers; included those from ethnic)                 | Included those from ethnic | Impairments not specified. |</p>
<table>
<thead>
<tr>
<th>Study</th>
<th>Country</th>
<th>Sample Description</th>
<th>Minority Groups (Number not specified)</th>
<th>Condition</th>
</tr>
</thead>
<tbody>
<tr>
<td>Golnick et al. (2012)</td>
<td>USA</td>
<td>128 parents/carers (86% mothers; 9% fathers and the remainder other carers).</td>
<td>8.7% asian, 4.8% black, 1.6%hispanic, 77% white, 7.9% other.</td>
<td>Autism.</td>
</tr>
<tr>
<td>Hendrickson et al. (2000)</td>
<td>USA</td>
<td>13 mothers of children aged 3-5 years, 12 birth mothers, 1 child adopted. (fathers not invited as it was assumed that mothers were the primary caregivers).</td>
<td>All white. Non english families excluded as insufficient funding.</td>
<td>Five children had severe developmental delay, 4 had personality disorder, 2 autism, 1 was hearing impaired and 1 had a cognitive delay.</td>
</tr>
<tr>
<td>Huang et al. (2011)</td>
<td>China/Taiwan</td>
<td>16 fathers (32-48 years) living with their disabled child (20mths to 10 years).</td>
<td>Not reported.</td>
<td>Children had a variety of impairments including cerebral palsy, autism, down syndrome, congenital heart disease, Joubert syndrome, hydrocephaly, spinocerebellar ataxia, stroke, chromosomal abnormalities and neurological sequelae following enterovirus.</td>
</tr>
<tr>
<td>Hyde et al. (2010)</td>
<td>Australia</td>
<td>247 parents of deaf children completed surveys (88.3% were mothers, 10.1% were fathers and 1.6% others eg grandparent, foster mother). 96.7% of</td>
<td>Not reported, although 4% of parents did not use English as their</td>
<td>92.7% of children had profound hearing loss pre-implantation; 6.9% had severe loss.</td>
</tr>
<tr>
<td>Study</td>
<td>Country</td>
<td>Participants</td>
<td>Environment</td>
<td>Main Language</td>
</tr>
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</tr>
<tr>
<td>Itzhaky and Schwartz (2000)</td>
<td>Israel</td>
<td>93 parents (23-60 years). Parents were involved with services.</td>
<td>Not reported.</td>
<td>Not reported.</td>
</tr>
<tr>
<td>Jones and Hack (2008)</td>
<td>UK</td>
<td>43 parents (mothers and fathers), 6 families had more than one disabled child - overall sample included parents of 37 boys and 6 girls.</td>
<td>Not reported.</td>
<td>Not reported.</td>
</tr>
<tr>
<td>Keenan et al. (2010)</td>
<td>Ireland</td>
<td>95 parents /carers (92% female, 8% male); mean age 40 years. Children 1-16 years (80% boys, 20% girls). 10 of the parents took part in a focus group. 67 multi-disciplinary professionals including SLTs, ABA tutors, SWs, clinical psychologists, OT's, teachers, educational psychologists and learning disability nurses completed a survey.</td>
<td>Not reported.</td>
<td>78% had dual diagnoses eg ASD and intellectual disability (56%), physical and sensory disability (22%) and other concurrent diagnoses (28%).</td>
</tr>
<tr>
<td>Study</td>
<td>Location</td>
<td>Sample Size</td>
<td>Sample Description</td>
<td>Data Collection</td>
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</tr>
<tr>
<td>Li et al. (2003)</td>
<td>USA</td>
<td>83 parents.</td>
<td>All white.</td>
<td>Deaf children.</td>
</tr>
<tr>
<td>Lundeby and Tossebro (2008)</td>
<td>Norway</td>
<td>31 parents</td>
<td>14 mothers, 3 fathers, 12 mother/father couples, 1 mother stepfather, 1 foster mother of children (14 boys and 17 girls). Children were born 1993-4 or 5. In 1998 parents of pre-school children 3-5 years were interviewed. In the second round the children were 7-9 years.</td>
<td>Not reported.</td>
</tr>
<tr>
<td>Maddison and Beresford (2012a)</td>
<td>UK</td>
<td>17 out of 33 families recruited are reflected in this paper. In 11/17 cases, only mothers participated and the remainder opted for joint interviews. 18 young people aged 14-22 years represented by these parents.</td>
<td>Not reported.</td>
<td>Degenerative conditions (12/18 also had learning difficulties).</td>
</tr>
<tr>
<td>Maddison and Beresford (2012b)</td>
<td>UK</td>
<td>14 out of 33 families recruited are reflected in this paper. In 9/14 cases, only mothers participated and the remainder opted for joint interviews. 14 young people aged 14-21 years represented by these parents.</td>
<td>Not reported.</td>
<td>Degenerative conditions (9/14 also had learning difficulties).</td>
</tr>
<tr>
<td>Okubo et al. (2008)</td>
<td>Japan</td>
<td>25 parents</td>
<td>4 fathers, 21 mothers (3 couples were interviewed together and 3 parents were interviewed together at their request) and 1 grandparent of children&lt;12</td>
<td>Not reported.</td>
</tr>
<tr>
<td>Study</td>
<td>Country</td>
<td>Sample Description</td>
<td>Sample Size</td>
<td>Disability Status</td>
</tr>
<tr>
<td>------------------------------</td>
<td>---------</td>
<td>------------------------------------------------------------------------------------</td>
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<td>------------------------------------</td>
</tr>
<tr>
<td>Pilnick et al. (2011)</td>
<td>UK</td>
<td>Part of a larger study that involved 28 young people 18-19 years. This paper based on data from 8 multi-party review meetings which parents and in some cases young people attended.</td>
<td>Not reported.</td>
<td>Moderate to severe disability.</td>
</tr>
<tr>
<td>Ryan and Salisbury (2012)</td>
<td>UK</td>
<td>24 parents (6 male and 18 female) of children aged between 3 and 11 yrs. 3 interviews with both parents, the remainder with 1 parent. 3 parents had 2 children with ASC.</td>
<td>Not reported.</td>
<td>Autism (Autistic spectrum conditions).</td>
</tr>
<tr>
<td>Serpentine et al. (2011)</td>
<td>Hungary</td>
<td>10 parents (all male) of children with ASD 6-14 years old or over.</td>
<td>Not reported.</td>
<td>Autism.</td>
</tr>
<tr>
<td>Slade et al. (2009)</td>
<td>UK</td>
<td>97 Parents of children 0-19 years.</td>
<td>Included parents of mixed race.</td>
<td>Disabled children</td>
</tr>
<tr>
<td>Sperry et al. (1999)</td>
<td>USA</td>
<td>30 Parents (28 women and 2 men), including one grandparent of sons/daughters 24 months to 30 years in age (those &lt; 8 highly desired). 22 Professionals (1 male and 21 female).</td>
<td>83% of parents were caucasian, 10% hispanic and 6% other racial/ethnic backgrounds.</td>
<td>ASD</td>
</tr>
<tr>
<td>Study</td>
<td>Country</td>
<td>Participants</td>
<td>Data</td>
<td>Diagnosis</td>
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</tr>
</tbody>
</table>
| Swain and Walker      | UK      | 3 groups of participants:  
1. parents whose children attended the centre  
2. staff employed by the centre and  
3. staff from the local authority and health services who provided services to children.  
12 parents returned questionnaire and 5 were interviewed  
6 professionals from the centre returned the questionnaire and 2 were interviewed  
20 local professionals returned the survey and 6 were interviewed. | Not reported. | Disabled children. |
<p>| Valentine (2010)       | Australia | 32 Parents (30 female, 2 male) of young children with autism (modal age 3-5 years - diagnosed in previous 24 months) (6 parents had 2 children with asd); | Not reported. | Autism. |</p>
<table>
<thead>
<tr>
<th>Source</th>
<th>Country</th>
<th>Description</th>
<th>Research Sample</th>
<th>Outcomes</th>
</tr>
</thead>
<tbody>
<tr>
<td>Wood <em>et al.</em> (2009)</td>
<td>USA</td>
<td>262 parents of children with special needs</td>
<td>46.6% parents stated their child was white and 40.8% black. 12.6% classified as 'other'.</td>
<td>Special health care needs.</td>
</tr>
<tr>
<td></td>
<td></td>
<td>(54.6% male, 45.4% female) completed the questionnaire.</td>
<td>28 parents, physicians and key office staff took part in focus groups.</td>
<td></td>
</tr>
</tbody>
</table>
Parents' experiences of the process of participation

Parents in some studies found decision making for their child very stressful, often involving as it did the weighing up of risks and benefits. For example, Hyde et al. (2010) found that, in choosing cochlear implants for their very young child, parents worried that they may not have made the right decision or that their child might regret it later, a finding also reported by Obuko et al. (2008). One parent of a child with autism in a study by Valentine (2010) felt ‘terrified’ of making the ‘wrong decision’. Similarly, Beresford and Maddison (2012a) found that decision making was stressful for most parents of children with degenerative conditions, particularly in the early stages and where the child had a significant level of cognitive impairment. 'Letting go' of the child was also difficult for some parents in this study and raised mixed emotions in terms of wanting to foster independence in their child, together with the need to protect them. While choosing a residential option for their child relieved parents of their care giving role and fostered independence in their child, this was a difficult and emotional decision for parents. In two studies (Hyde et al. 2010; Beresford and Maddison 2012a), decisions were underpinned by parents' desire for their child to have a 'normal' life. Only one study reported the opposite view - parents from the Deaf community did not feel that cochlear implants and the development of speech would be beneficial since they already used Japanese sign language to communicate with their child (Obuko et al. 2008).

Maddison and Beresford (2012b) reported that parents' role in decision making was one of 'option finder' for children with degenerative conditions and at times parents found more suitable post school options than did professionals. This role involved considerable time and effort on the part of parents. It was evident from 7 studies that parents had to fight or engage in a battle for their child to obtain the services that they needed (Swain and Walker, 2003; Bennett, 2009; Doig et al. 2009; Wodehouse and McGill, 2009; Gillan and Couglan, 2010; Maddison and Beresford, 2012a; Care Quality Commission, 2012). Bennett (2009) concluded that there was an overwhelming sense from their survey respondents that parents felt that they were on their own and needed to be self-reliant in the absence of support from outside sources.
It was evident from all studies that being listened to was very important to parents, regardless of what services the family received or what decisions were made. Lundeby and Tossebro (2008) found that differences in opinions between parents and professionals did not always lead to conflict. Rather, the most important factor for parents was the fact that they were asked for their perspectives. Prezant and Marshak (2006) found that most commonly identified actions that parents perceived to be most helpful on the part of professionals centred around listening, respecting parents and recognising their expertise. The absence of such an approach was the source of much frustration for parents. In 2 studies, parents reported having to placate professionals in order to achieve what they wanted. For example in a study by Egilson (2011), parents reported having to 'keep their cool' in order to maintain relationships with professionals. Burstein et al. (2005) reported similar experiences, with parents feeling that they had to go out of their way to be pleasant and accommodating and to ingratiate themselves with the paediatrician in order to ensure that their needs were met.

The participation of fathers received little attention within the literature. In a study by Huang et al. (2011) fathers felt excluded from decisions made with medical staff who interacted only with mothers or did not ask fathers about their knowledge of their child. Fathers in this study also reported that professionals made decisions based on their own assumptions and did not involve parents.

Parents in 7 studies said that they did not always feel listened to or supported by professionals. In general parents of disabled children in the Care Quality Commission’s study (2012) did not feel that they had a voice and that professionals thought they knew better. Parents in the Lundeby and Tossebro study (2008) said that, at times, professionals appeared to believe that they were in a better position to identify the family's needs than themselves. Similarly, many parents in a study by Wodehouse and McGill (2009) said that they did not feel listened to and that their knowledge was not always taken into consideration when decisions were made. Thus, parents' expertise was not always recognised by professionals. Sperry et al. (1999) found that parents wanted more recognition as someone who knew their child best and 64% of parents in a study by Bennett (2009) (n=615) said that the recognition they received from
professionals as a carer was 'unsatisfactory' or 'poor'. Similarly, 61% of parents in a study by Bennett (2009) (n= 615) said the extent they felt listened to by professionals was 'unsatisfactory' or 'poor', while Doig et al. (2009: 240) reported one parent as saying that 'getting help from someone who is prepared to listen is your biggest battle won'. Similarly, Gillan and Couglan (2010) reported that most parents in their study felt that their involvement in decision making and planning was lacking around the time of transition and that professionals did not listen.

While the findings of all studies were mixed, more positive findings were reported in 8 studies. Eighty-five to 86% of parents of children with special needs in a study by Wood et al. (2009) were satisfied with their involvement in decisions made with their paediatricians. Those who were dissatisfied were parents of children who missed more school, experienced more pain and those who worried a lot about their child over past months. Eighty-five % of parents (n=95) of children with autism in a study by Keenan et al. (2000) had ‘always’ or ‘sometimes’ been invited to their child's forward planning review (although only half of these said that their voices were always included in the review) and 12% (n=95) said their views were never included in the review. Parents were also found to participate in review meetings in a study by Pilnick et al. (2011), whereby parents said they felt able to contribute freely and express differing opinions to those of professionals. Hyde et al. (2010) in a study exploring decision making about cochlear implantation reported a high level of satisfaction with the information, help and support they had received from professionals during the decision making process. Similarly, Burstein et al. (2005) found that parents of children with special health care needs reported high satisfaction with their interactions with paediatricians, contributing more to interactions with their paediatrician (both socially and in relation to medically based aspects) than parents of children without special needs. Bjorck-Akesson and Granlund (1995) reported that both parents and professionals rated family involvement in assessment procedures as 'moderate' (a low rating representing a model of service provision where services are led and controlled by professionals and a high rating representing a client empowerment approach). Interestingly professionals in this study viewed ideal (or optimal) parent participation in decisions as higher than did parents.
Therefore, it appears from this study that there are times when parents want professionals to take the lead where decision making is concerned, a finding also reported by Egilson (2011) and Valentine (2010). Egilson (2011) found that while many parents of children with a range of impairments wanted involvement in all aspects of decision making about their child they wanted professionals to take responsibility for some aspects of decision making. For example, they wanted professionals to have a more active role when the child was young but as they grew older parents wanted to be more involved in mutual planning. Parents of autistic children in a study by Valentine (2010) also wanted professionals to make decisions for them in the early stages following diagnosis.

**Participating in decisions at the time of diagnosis**

Around the time of diagnosis, parents often reported feeling that their concerns were perceived to be exaggerated and were not taken seriously, particularly early on. Parents in a study by Elweke and Rodda (2000) said that they had to be persistent with professionals about their concerns in order to achieve a diagnosis for their hearing impaired child. Similar findings are reported by parents of children with autism (Ryan and Salisbury, 2012), parents of children with multiple impairments (Lundeby and Tossebro, 2008) and by parents of children with special needs (Wood *et al.* 2009; Care Quality Commission, 2012). Some parents in the study by Lundeby and Tossebro (2008) felt that their views were not taken seriously until a professional had seen evidence of an issue for themselves. Braiden *et al.* (2010) found that 3 parents of children with autism found it difficult to express their concerns to their GP and, when reassured that there was nothing wrong with her child, one mother reported feeling like a hysterical mother. One parent was given the diagnosis of autism in a letter and another by phone; the experience of receiving a diagnosis by way of a letter was also reported by a parent by Keenan *et al.* (2010). Similarly, parents of children with various impairments in a study by Hendrickson *et al.* (2000) were often given false reassurances from professionals that nothing was wrong. One family saw a specialist 5 times before their concerns were recognised and one mother was made to 'feel like a paranoid mum' (p11),
a finding also reported by Slade et al. (2009). However, many parents in the study by Braiden et al. (2010) felt that their views were sought and that professionals had been transparent and honest.

The attitudes and practices of professionals

The attitudes and practices of individual professionals were the most important factors that affected parental decision making. Slade et al. (2009) reported that parents felt that it 'was down to luck' whether or not a professional was helpful and approachable and had a real desire to help. Parents reported needing to be able to trust professionals when decisions were being made about services that the child would use and this featured in several studies (Braiden et al. 2010; Gillan and Couglan, 2010; Maddison and Beresford, 2012b; Wood et al. 2009). Parents felt that professionals sometimes withheld information about services that were available for budgetary reasons (Slade et al. 2009; Wodehouse and McGill, 2009; Maddison and Beresford 2012a). Parents' perception of professionals' willingness to listen to parents, consult with them, take their views seriously and recognise their expertise was commonly viewed as a pre-requisite to participation by parents (Burstein et al. 2005; Prezant and Marshak, 2006; Lundeby and Tossebro, 2008; Bennett, 2009; Braiden et al. 2010; Keenan et al. 2010; Egilson, 2011; Gillan and Couglan, 2010; Hendrickson et al. 2000; Valentine, 2010; Pilnick et al. 2011; Ryan and Salisbury, 2012).

The need for professionals to communicate or share information with others in the team (as well as the parents) was evidenced in 5 studies (Ward et al. 2003; Slade et al. 2009; Keenan et al. 2010; Wodehouse and McGill, 2009; Care Quality Commission, 2012). Clearly, such practices are important to ensure participation. Parents in the study by Braiden et al. (2010: 383) felt 'kept in the dark' between the time of initial referral and follow up and also between diagnosis and subsequent support. Only one study reported that professionals did not always communicate with parents in a way they could understand (Care Quality Commission, 2012).
Professionals' attitudes to disability could also facilitate or hinder parental participation. For example, in one study (Huang et al. 2011), fathers reported receiving negative information and attitudes about their child that left them with a sense of hopelessness and caused them to withdraw from doctors. Similarly, parents in a study by Sperry et al. (1999) wanted professionals to recognise their child's potential rather than their deficits. In another study (Maddison and Beresford, 2012a), professionals who had a positive attitude to disability were better able to support parents in decision making. Parents in a study by Prezant and Marshak (2006) said that helpful actions by professionals included having high expectations for the child and supporting the child and parent.

Professionals' knowledge and skills about the child's impairment or about services that were available were also important factors in some studies (Bjorck-Akesson and Grandlund 1995; Hendrickson et al. 2000; Slade et al. 2009; Wodehouse and McGill, 2009; Wood et al. 2009; Care Quality Commission, 2012). For example, the parent of a child in a study by Slade et al. (2009) said that professionals needed such knowledge to signpost them to services that they could benefit from.

The attitudes and practices of parents themselves, compared to those of professionals, featured in a small number of studies. Parents' attitudes to hearing impairment influenced parental decisions about cochlear implantation in one study (Li et al. 2003). In 2 studies (Maddison and Beresford, 2012a and Carnaby et al. 2003) parents' low expectations about what would be available for their disabled child was a barrier to decision making. Both parents and professionals in a study by Sperry et al. (1999) said that some parents were 'pushy' and could advocate for their child, whilst others were unable to do so.

The provision of information

The provision of information about the child's impairment at diagnosis, about available services and professionals' roles, was said to facilitate or hinder parental participation in many studies.
Fifty nine percent of parents in the survey by Bennett (2009) (n=615) said that overall information was unsatisfactory, a finding also reported by Hendrickson et al. (2000), Swain and Walker, (2003); Ward et al. (2003); Slade et al. (2009); Wodehouse and McGill, (2009); Gillan and Couglan (2010), Keenan et al. (2010); Egilson (2011), Huang et al. (2011) and the Care Quality Information (2012). Parents in one study said that they came upon information by chance (Maddison and Beresford, 2012a). Parents in some studies did not understand professionals' roles or how services were organised (Doig et al. 2009; Braiden et al. 2010; Egilson, 2011). Parents were unsure about whom to approach for information or available options (Doig et al. 2009) and this hindered decision making.

Parents in 4 studies said that parents often obtained information from other parents in a similar situation (Wodehouse and McGill, 2009; Hyde et al. 2010; Egilson, 2011; Serpentine et al. 2011) and this often helped with their decision making. Parents also obtained information via printed literature, the internet and media sources. Parents went to great lengths to act on such information if they believed it would be beneficial for their child. Parents in a study by Valentine (2010) sold their home to pay for an Applied Behavioural Analysis program that they had sourced online.

The voluntary sector was cited as a valuable source of information in some studies (Slade et al. 2009; Hyde et al. 2010; Serpentine et al. 2011). Information was at times felt to be alternately too general or too complex (Slade et al. 2009). Parents said that they received conflicting information in just one study (Swain and Walker, 2003). Three studies reported that information was difficult for parents to absorb when they were receiving news of the diagnosis as they were often overwhelmed at that stage (Bennett, 2009; Braiden et al. 2010; Valentine, 2012).

**Resources and choices available**

A lack of resources (for example, staff numbers or turnover, services, financial support and time) and actual choices was evident in many studies and this clearly had an impact on parental participation (Bjorck-Akesson and Granlund, 1995; Elweke and Rodda, 2000; Swain and Walker, 2003; Ward et al. 2003; Lundeby and Tossebro, 2008;
Bennett, 2009; Doig et al. 2009; Slade et al. 2009; Wodehouse and McGill, 2009; Gillan and Coughlan, 2010; Egilson, 2011; Serpentine, 2011; Care Quality Commission, 2012; Maddison and Beresford, 2012a). Choices were restricted for low income families who could not afford to access additional services that they were aware of on a private basis in 4 studies (Sperry et al. 1999 (USA); Hendrickson et al. 2000 (USA); Ward et al. 2003 (England); Valentine, 2010 (Australia)).

**The outcomes of parental participation**

The outcomes of parental participation were identified as mainly intrinsic in most studies. The only negative intrinsic outcome of parental participation was the responsibility and associated stress of making decisions for their child as detailed on p105. Intrinsic outcomes of participation included parental satisfaction with service provision (Braden et al. 2010; Golnick et al. 2012), professionals being perceived as helpful (Prezant and Marshak, 2006) and parents feeling 'emotionally stronger' (Bennett, 2009). Intrinsic outcomes of non-participation in decisions included stress and frustration (Hendrickson et al. 2000; Lundeby and Tossebro, 2008; Doig et al. 2009; Maddison and Beresford, 2012a), hopelessness, powerlessness, anger, confusion and feelings of exclusion (Huang et al. 2011), feeling isolated, alone and let down (Ryan and Salisbury, 2012) and delayed diagnosis (Wood et al. 2009). Serious consequences of non-participation included a child losing her teeth due to untreated gastric reflux and, in one study a few children were reported to be close to losing their lives, although this was not elaborated upon by the authors in the study concerned (Lundeby and Tossebro, 2008).

Only 2 studies reported extrinsic outcomes of parental participation. Burstein et al. (2005) reported an increased quality of care. A further study reported an extrinsic outcome of parental non-participation. In the study by Swain and Walker (2003), non-participation resulted in parents opening and funding an independent centre in England to meet their children's needs and this created much tension with local services.
Parents' participation in decisions about services and policy

Only 3 studies reported parents' experiences of participation in decisions about services and/or policy, a further gap that this thesis seeks to fill. In a survey by Flannigan and McCoy (2006) 24% of parents who responded said that they had had the opportunity to participate in services, while 74% said they had not, and most of whom would be willing to. Parents indicated that the most effective method of participation was in a group, via a local committee in partnership with a local provider (like the Wraparound stakeholder group), rather than via surveys or responding to local consultation documents. Barriers to parental participation in this study included practical difficulties. For example, meetings that clashed with school runs, too much cost involved in travel, and difficulties in arranging childcare. A third of parents found consultation documents or questionnaires difficult to understand or too long. Similar proportions of participation in services were reported by Itzhaky and Schwartz (2000), with 26% of parents significantly involved with services. Such findings were not universal. None of the parents who took part in a survey by the Care Quality Commission (2012) had been asked their opinion about services and most had not been consulted about the provision of care or in service planning.

Only one study reported the intrinsic outcomes of parental participation in services. Itzhaky and Schwartz (2000) found that such participation as positively associated with aspects of empowerment such as coping mechanisms within the family, family relationships, self-esteem and the ability to ask for help from family members. It was also associated with parental knowledge about how to access services, a good understanding of services, good relationships with service providers, the ability to work with service providers to obtain what they were entitled to and a sense of mastery in terms of rights awareness, lobbying skills and contact with politicians.

3.6 Chapter summary

This chapter started with the assertion that there is no agreement as to how participation can be defined. Rather, it is conceptualised across a continuum from merely being present to actively influencing decision making. Evidence presented in this review
demonstrates that, while there are clear examples of disabled children and young people participating in decisions across this continuum, it is often less than optimal. While they want the support of adults, it is evident that some disabled young people want to take more responsibility for decision making, particularly as they get older. While this has common sense appeal, as Hyde *et al.* (2010) point out, participation in decision making can be a complex process that involves the processing of a large amount of sometimes complex information together with individuals' values and attitudes, and the influences of other people. This has particular currency for disabled children and young people who may need additional support to realise their participatory rights. It was evident from a small number of studies that parents continued to play an active role in their child's life well into young adulthood and they had significant influence on the degree to which the young person participated in decision making processes. Thus the role of parents in fostering and facilitating their child's participation is vitally important.

Similarly, this review has demonstrated (albeit in a small number of studies) that professionals also have an important role to play - not only in developing positive relationships with children and young people but in developing their communication skills, taking time to listen to children and young people, developing positive attitudes and inspiring confidence in children and young people so that they can make their views heard. The evidence presented here suggests that the attitudes and practices of both parents and professionals are arguably the most important factors that can either encourage or discourage the participation of disabled children and young people. However, we know little about the mechanisms surrounding how this is played out during interactions with professionals, the preferences of those involved, the tensions that may arise as a result and the additional factors that may influence such practices. Evidence presented in this chapter suggests that disabled children and young people need additional support, time and resources - for example information - to enable them to participate in a meaningful way but this is not always addressed. Again little is known about what might best facilitate participation in terms of preparation, information and support and how this might transfer into practice. Few studies document the outcomes of participation for disabled children and young people. There is a general
assumption that participation is a good thing and builds confidence and independence. However, this area is also underresearched and clearly needs further exploration. It is very evident from the discussion of current legislation and policy in chapter 2 of this thesis that like all children, disabled children and young people should participate in decisions made about their care but also in decisions about services and policy. This is a further area that is particularly underresearched in terms of their experiences and the outcomes of such participation.

Evidence presented in this review suggests that parents too varied in the extent to which they felt they were involved in decision making with professionals. Most studies provided mixed reports of being involved or otherwise and this appeared to be dependent on the attitudes and practices of individual professionals. Thus this was an issue for both children and young people and parents. However, decision making is often more complex and involves affective components and emotional reactions (Hyde et al. 2010) and this would seem more important for parents rather than children and young people. The evidence suggests that some parents feel the need to fight for the diagnosis of their child and for services their child receives in services that are perceived by parents as at times underresourced and this caused much stress. Inevitably this is an emotional process that at times underpinn decision making processes. We know little about the tensions that this may cause within parent -professional relationships and decision making processes. Overall, as someone who knew their child best, parents wanted to be involved in decision making processes. However there were times when parents wanted professionals to take the lead, often in the early stages following diagnosis. Thus it appears from the literature discussed here that some disabled children and young people and their parents want more involvement in decisions as they get older or as the years went on. Unless parents actively foster their child's participation and are prepared to hand over responsibility for decision making then this may not happen. We need to know more about the expectations and experiences of disabled children and young people as well as their parents in order to understand more about this process. The finding that the provision of information was problematic for parents is concerning, given that this has been a common feature in the literature for many years. More
research is needed around the provision and accessibility of information for families and how this can be further developed, as studies demonstrate that this can facilitate or hinder participatory practices and ultimately the services that families may use. As with children and young people the outcomes of parental participation are not well researched. These studies suggest that parental participation can increase satisfaction with services but the implications of non-participation are more widely discussed in terms of feelings of anger and frustration and delayed diagnosis or treatment. Little is known about the outcomes for parents or indeed services. Evidence presented in this review demonstrates that the area of parental participation in services or policy and the outcomes of such activity is also under researched.

The aim of this chapter was to establish 'what works' in achieving optimal participation for disabled children, young people and their parents. Given the dearth of research focusing specifically on this area this is difficult to delineate in any detail. The reviews presented here have been based on a small number of studies, many of which reported participatory practices in the context of views about services, transition, experiences of diagnosis, interactions with professionals and family support and so the evidence base is limited. In some cases disabled children and young people were part of a larger sample of children and young people and sufficient emphasis was not placed exclusively on their individual needs or those of their parents. At times studies were consultations rather than research projects per se and so the methodological quality was less than optimal. This thesis seeks to address the gaps in the literature as pointed out in the course of this chapter and make recommendations for practice, services and policy and future research.
Chapter 4: theoretical concepts

4.0 Introduction

It was anticipated at the outset of this study that a number of extant theories would be important when approaching this research. They include: perspectives on childhood, disability theory and Bronfenbrenner's social ecological model (Bronfenbrenner, 1993). There is no consensus about whether to adopt a certain theoretical framework before or after data collection and analysis. Thus it was important not to be too prescriptive at this point but rather to develop an awareness of what might underpin the data collected. The sections that follow explore these 3 theories and sets out how they may apply to the participation of disabled children, young people and their parents in health and social care decisions. The first section tracks the historical development of childhood theory, the second similarly explores the emergence of the social and later models of disability and the third sets out the social ecological model within which participation takes place. The final section summarises the key aspects and communalities of these theories and their application to the current study.

4.1 Perspectives on childhood

The first theoretical stance relevant to this study concerns how childhood is conceptualised, valued and played out in a given society. It was anticipated that this would have a direct bearing on children and young people's participation in decisions affecting them in terms of their own and adults' attitudes, including professionals and service providers. The period after the Second World War marked a time of radical change in attitudes towards childhood within the UK. Children began to be seen as 'the future' and valued and nurtured as such (Kellet et al. 2004). During this time, psychological approaches to childhood came to the fore in the work of psychologists such as Jean Piaget and Eric Erickson, who proposed a number of developmental theories that identified standards or milestones against which all children could be measured. These theories supported the notion of children as 'becomings', or 'adults in the making', and
have been widely used in practice as a mechanism for tracking children's developmental progress and introducing interventions to help children reach their potential. Arguably, however, the application of such developmental theories identifies disabled children as those failing to meet milestones and labels them as 'developmentally delayed' or failing to meet normative milestones in comparison to other children (Watson et al. 2000; Davis et al. 2003; Kelly, 2005). The prevalence of such an approach within current services explains, to some extent, why disabled children are viewed by some as a social problem, both individually and as a group (Priestly, 2003). This may also account for the finding that disabled children and young people have fewer opportunities to participate in decisions that affect them as adults' expectations of them can be less than optimal.

Rather than viewing children as adults in the making, the 'new sociology of childhood' emerged two decades ago (Tisdall, 2012), conceptualising children as competent beings, social actors capable of exercising agency in their lives and the society in which they live, rather than being perceived as incomplete or incompetent human 'becomings':

'Our twentieth century legacy is the serious recognition that children are not bundles of negative attributes, or incompletely formed persons waiting to become adults; they are who they are.'

(James et al. 1998: 14)

Mayall (2002) draws a distinction between social actors and agents, the latter being particularly relevant to this study in terms of children and young people's interactions with health and social care professionals:

'A social actor does something, perhaps something arising from a subjective wish. The term agent suggests a further dimension: negotiation with others, with the effect that the interaction makes a difference - to a relationship or to a decision, to the workings of a set of social assumptions or contraints'.

(Mayall, 2002: 21)
Thus in order to exercise agency, disabled children and young people need to be able to negotiate with professionals and service providers and to receive appropriate preparation and support to enable them to achieve this. Although widely accepted, sociological approaches to the study of childhood have been questioned and criticised. Exploring recent critiques, Tisdall and Punch (2012) argue that while there have been a multiplicity of studies exploring children's lives through the lens of childhood studies, the emergence of further theoretical debates have been slow to develop. Further they argue that there has been a move from dualist perspectives of children as beings or becomings to more flexible approaches where both may be combined. Sociological approaches to childhood have also been criticised by those researching with children. A dilemma exists for researchers in that if children are indeed competent social actors and agents then why do specific methods need to be employed by those researching children's lives? Exploring the question as to whether or not research with children should be the same or different to that with adults, Punch (2002) argues that such dicotomous stances and attitudes are too simplistic and that research with children (and indeed the lives of children) operates along a continuum, whereby a multiplicity of factors come into play, including individual differences in children, the research context and the research questions. Similarly, Uprichard (2008), criticising recent approaches to the sociology of childhood, argues that discourses of 'being' and 'becoming' need not be conflicting where children are concerned, but may complement each other. Drawing on the notion of competency, she argues that children compare themselves to others, both adults and other children, and reach conclusions about their competencies or incompetencies. Studies conducted with disabled children confirm that they do, in fact, compare themselves to their non-disabled peers and there is no doubt that children experience disabling barriers, although this is not always perceived in a negative light (Mackleprang and Altshuler, 2004; Connors and Stalker, 2007; MacArthur et al. 2007; Higgins et al. 2009). The position adopted in the current study recognises that, like all children and young people, disabled children and young people are capable of participating in decisions that affect them, and they can exercise agency where health and social care is concerned. It also acknowledges that the conduct of the research will be influenced by individual differences in children and young people, the varying competencies that they
and others perceive themselves to possess and the life experiences that they recount in engaging with health and social care professionals and services. Thus it is anticipated that perspectives on childhood will be reflected in the findings of this research.

4.2 Theorising disability

The second theory relevant to this study concerns the conceptualisation of disability. Given that the research focused specifically on disabled children and young people it was important to be aware of current theoretical thinking and models around this area. It was anticipated, for example, that the attitudes of professionals and service providers could affect the degree to which children and young people participated in decisions. Traditionally, there were two main approaches to disability. First, there is the so-called 'medical' or 'individual' model, which dominated both theory and practice up to the 1980's. Secondly, there is the social model that formally emerged in the 1980's, largely as a result of lobbying by disabled people and the work of Michael Oliver. For Oliver (1990), the medical model is based upon the oppression of disabled individuals, whereby they are considered unable to contribute to the economic growth of society. From this perspective, disability exists at the individual rather than the societal level, for it is the individual who is perceived to be lacking certain elements that affect their autonomy (Michailakis, 2003). Essentially, the medical model of disability is based upon the notion of the 'non-disabled norm', a perceived standard or ideal, against which all others, including disabled people, must be measured. In this model the professional is the perceived expert who holds the key to diagnosis, treatment and cure or rehabilitation. The model reinforces the sick role and focuses on impairments of disabled people rather than their abilities and competencies (Whyte, 2006a). The medical model has been criticised for its focus on the pathological shortcomings of individuals and for reinforcing disability as a personal tragedy, whilst neglecting the psychological and social consequences of disability (Garth and Aroni, 2003). It has also been criticised for promoting unequal power relationships between service users and professionals (Burke, 2008), suggesting that it is the role of professionals to identify an
individual’s needs and determine how these may best be met (Barnes et al. 1999), rather than affording the disabled person a say in what would be appropriate. Health and social care practices that are based on the medical model have become increasingly untenable and the rights of service users to identify their own needs and actively participate in decisions that affect them has become firmly embedded in policy and guidance that underpins practice (Barnes and Mercer, 2006).

The social model provided the starting point for disabled people to become active agents in their own lives, to participate in decisions that affected them and challenge the oppression they experienced. It maintains that disability is, in its entirety, socially constructed and that the exclusion and oppression of disabled people is attributable to the failing of society, (in terms of environmental, structural and attitudinal barriers), rather than the ‘impairments’ of disabled people. This places the onus firmly on society to change in order to accommodate disabled people, rather than expecting disabled people to adapt to society in order to participate fully (Handley, 2003). The model originated as a result of work by Paul Hunt and Vic Finkelstein and the later publication of ‘The Fundamental Principles of Disability’ (Union of the Physically Impaired Against Segregation (UPIAS), 1976) that defined impairment and disability as follows:

Impairment: ‘lacking all or part of a limb, or having a defective limb, organ or mechanism of the body’

Disability: ‘the disadvantage or restriction of activity caused by a contemporary social organisation which takes little or no account of people who have physical impairments and thus excludes them from the mainstream of social activities.’

( Oliver 1996, cited in Thomas, 1999:14)

It was not until 1983 that Michael Oliver described these definitions as the social model of disability (Flood, 2005). Thus, the term ‘impairment’ has been used by those who subscribe to the social model of disability to indicate physical or cognitive characteristics of individuals, in contrast to the term ‘disability’, which is deemed to
represent the social oppression of people with impairments. Within the social model,

disability is not perceived as the impairment itself: disability is not caused by
impairment; rather it occurs as a result of the attitudes of others and the structures
within society that serve to exclude them.

The original conception of the social model has been criticised for a number of reasons
within what has become known as Disability Studies. For example, critics have
questioned how well the social model addresses impairment experiences, the varying
identities of disabled people and the ability of the model to represent people who
experience learning disability or mental illness (Shakespeare and Watson, 1997;
Thomas, 1999; Kelly, 2005; Read et al. 2006; Thomas, 2007). The complete separation
of impairment and disability within the social model has proved problematic,
particularly for advocates of a feminist approach (for example, Morris, 1991; Thomas,
1999) who maintain that personal experience of impairment cannot be ignored and for
poststructuralists who argue that the two cannot be separated. Over the past ten years,
the term 'Critical Disability Studies' has emerged within the literature in order to move
away from traditional binary positions of impairment and disability towards a more
fluid post-modernist perspective (Watson, 2012). This acknowledges the development,
and continued development of disability theory:

'Use of CDS [Critical Disability Studies] signifies an implicit
understanding that the terms of engagement in disability studies have
changed; that the struggle for social justice and diversity continues but
on another plane of development - one that is not simply social,
economic and political but also psychological, cultural, discursive and
carnal.'

(Meekosha and Shuttleworth, 2009: 50)

4.3 Developing a theory of childhood disability

A number of authors have identified the need to develop a specific theory or model of
childhood disability, although this is still very much in its infancy. For example,
Shakespeare and Watson (1998) and Kelly (2005) suggest that combining new
perspectives on disability (that take into account children’s individual experiences of impairment) with the sociology of childhood may enhance our understanding of disability where children are concerned. In fact these two approaches share commonalities in the way in which both are socially and culturally constructed (Priestly, 2003). Building on these ideas, Connors and Stalker (2007) argue that Thomas’s social relational model (Thomas, 2004) may provide an appropriate framework from which to understand disabled children’s experiences and this is used in the proposed study.

4.4 The social relational model

The social relational understanding of disability was originally conceptualised by Finkelstein and Hunt in the 1970s. Although based on the UPIAS definition of disability quoted earlier (which focused on restrictions of activity imposed by society), the social relational model emphasises the importance of social relationships in restricting disabled people and this has particularly currency in this research. According to Thomas (1999), these socially imposed restrictions (for example, physical barriers) prevent or hinder disabled people from doing certain activities - so-called ‘barriers to doing’. However, a second mechanism operates in what Thomas calls the psycho-emotional dimensions of disablism, which contributes to how disabled people feel about themselves. This is not based on a personal tragedy perspective that focuses on the psychological problems of disabled people, but rather is imposed by others who may intentionally, or otherwise, make disabled people feel worthless or of less value than others, creating what Thomas calls barriers to ‘being’. For example, individuals may look down on disabled young people, stare or speak to others on their behalf, whilst ignoring them. Thomas (2007) acknowledges that individuals may have impairments that cause restrictions in activity but it is not the impairments per se that create barriers for disabled people. Rather it is impairment effects that constitute disablism. For example, a young person may have an impairment that restricts a certain activity; for example they may require additional assistance to use a computer. If this impairment effect leads to a difficulty in securing
employment, this then constitutes disablism. Thus, Thomas defines disability according to the social relational model as follows:

'Disability is a form of social oppression involving the social imposition of restrictions of activity on people with impairments and the socially engendered undermining of their psycho-emotional well-being.'

(Thomas, 1999: 60)

Because of their impairments and status as children, disabled children experience considerable inequality of relationships with adults and children; for example, in the school setting, disabled children experience imbalances in their power relationships with non-disabled peers, as well as adult teachers (MacArthur et al. 2007; Higgins et al. 2009). Disabled children's experiences of unequal relationships with peers, and instances of bullying that challenge their psycho-emotional well-being, have been well evidenced in research (see for example, Davis and Watson, 2001; Mackleprang and Altshuler, 2004; Kelly, 2005; Connors and Stalkers, 2007). Studies also indicate that disabled children experience social barriers to participation because of the attitudes of other children and adults, rather than as a result of their impairment (Watson et al. 2000). The fact that disabling barriers faced by children and young people are socially constructed is supported by findings that although disabled children and young people are aware of differences between themselves and others, they do not see themselves as disabled in terms of their construction of what disability means:

'I wouldn't say I was disabled. I'd say I'm not as capable as other pupils my age should be... But I wouldn't say I was disabled or anything.'

(Young person in a study by Lewis et al. 2007)
Clearly, both parents and professionals have a key role to play in shaping discourses around childhood disability (Kelly, 2005). Parents or professionals may reinforce the medical model by emphasising a 'tragedy' perspective or contribute to 'barriers to being' by not facilitating the participation of disabled children and young people in decisions that affect them. McLaughlin and Goodley (2008) maintain that in working with disabled children and families, professionals have the opportunity to be either enabling or regulative (or both). The former engenders practice that encourages disabled children, young people and their parents to exercise agency in their own lives and in relation to the support they receive. This thesis also adopts the stance offered by Read et al. (2006:11) that the experience of disability goes beyond the individual level and ‘becomes the property’ of other members of the family, for example parents. Hence, parents are considered to be an integral part of the study.

The position adopted in the current study recognises that, while they may have impairments, disabled children and young people are capable of participating in decisions that affect them. It also acknowledges that the conduct of the research will be influenced by the relationships they have with professionals and service providers, the attitudes (disabling or otherwise) of others and the degree to which various facilitators or barriers will affect their participation. Thus it is anticipated that theoretical perspectives on disability will be reflected in the findings of this research.

4.5 The social ecological model

The third theory that underpins this research is the social ecological model (Bronfenbrenner, 1979). This model has previously been used as a framework to inform enquiry around disabled children and their families and their relationships with those who support them (Seligman and Darling, 2007; Worchester et al. 2008), hence its utility here. It makes no sense to explore the experience of disabling barriers amongst children and young people and their parents in isolation, for they are part of a complex interplay of systems at an individual and group level. It was anticipated that the manner
in which children, young people and parents participate in decisions that affect them would be a direct function of their interactions with family members, health and social care providers, policy makers and wider society. Although extant research on children’s participation in decisions has focused mainly on the child or young person’s perspective, this study also seeks to report the views and experiences of key stakeholders including parents and health and social care providers. Thus the participation of disabled children and parents in decisions is explored in the context of Bronfenbrenner’s model, (Bronfenbrenner, 1979). In the ecological model, the complex interplay between the child or young person, the family and their social and physical environment is represented in a number of systems:

1. The microsystem embodies the child or young person’s immediate physical environment and the relationships between family members and other individuals that the child is in direct contact with.

2. The mesosystem links and makes connections between microsystems directly involving the child or young person, for example, home, school or the health and social care setting. According to Bronfenbrenner (1979), it is at this stage that a child becomes an active participant.

3. The exosystem, represents parents’ social worlds and the wider environment where the child or young person lives, including service delivery systems. Normally children and young people do not have direct contact with these systems; however they are affected by them.

4. The macrosystem is concerned with the wider values and belief systems of wider society, historical change and social policy and equally important for the current study, resources. This last system also includes cultural and class differences (Siegler et al. 2003; Berk, 2006; Martin and Fabes, 2006).

5. The chronosystem was added in the 1980's to take account of the effect of time and experience on human development across the lifecourse (Bronfenbrenner, 2005).

Thus, for Bronfenbrenner (1979), development is nested within a complex structure, rather like a set of Russian dolls. Bronfenbrenner himself highlights the importance of phenomenology within the ecological environment and in the conduct of research. The
position adopted in the current study recognises that disabled children and young people and their parents are capable of participating in decisions that affect them. It also acknowledges, however, that the conduct of the research will be influenced by the different systems that come into play. Thus it is anticipated that the social ecological model will also be reflected in the findings of this research.

4.6 Chapter summary

In summary, prior to data collection it was anticipated that elements of perspectives on childhood, the social relational model of disability and the social ecological model would emerge during the analysis of the findings of the research. Figure 7 combines key aspects of these theories as potentially applied to this study. Disabled children and young people are nested within not only their family where decisions are made but also within public services (health and social care services) and wider society as illustrated by the social ecological model. Decisions relating to health and social care are played out with professionals within the mesosystem where the child and/or parent may or may not be an active participant. It is here, in particular, that both the social relational model of disability and the social ecological model focus on interactions with others. Those who participate as service users at a higher strategic level within the exosystem similarly may or may not be fully involved in decision making. Beyond these levels lie the macrosystem and beliefs of wider society that may constrain or facilitate participation, not least in their attitudes to disability. Thus the social ecological model focuses more on both a micro and macro approach. At each of these levels the attitudes of others influences the participation of both children and parents as illustrated in Figure 7 as depicted by the arrows. Barriers to participation illustrated here between each system, as shown in green, may constitute 'barriers to doing', for example not being able to access a particular service or 'barriers to being' in terms of professionals' or service providers' practices or attitudes. Finally, the chronosystem is included here to potentially represent a shift in decision making processes over time. It is anticipated that parents may
participate more with time as their knowledge develops; however, as regards care decisions, this dynamic may change as the child matures and develops.

Figure 7: Summary of the relevance of 3 theories to this study
Chapter 5: Methods

5.0 Introduction

This research was funded by the ESRC and as such a short research protocol had been developed by the research supervisors in order to secure this. The original protocol set out the aim of the research in addition to specific methods that were to be used in the study. These included a systematic literature review, the use of surveys, interviews with parents and children and young people in addition to focus groups with professionals. While had no input at this stage of the study I later added the use of phenomenology as a means of explicating the lived experience of disabled children, young people and their parents. I also brought to the research my knowledge about researching with disabled children and young people and the use of participatory methods of research explored in my MRes dissertation. This chapter comprises 5 sections that set out each stage of the research process: firstly the aim, objectives and research questions, the methodological and philosophical approach, methods, data collection, and approach to data analysis. Ethical issues during the planning and conduct of the research are addressed in chapter 6. It was felt that, in this study, ethics warranted a specific chapter, as numerous ethical issues arose during the course of the research. Each section in chapter 5 details the approach taken in the current study and where relevant, a critical reflection is included in order to review ‘what worked’ in addition to the challenges that arose during the research process.

5.1 Aim, objectives and research questions.

The aim of this research was to explore the meaning, experience and outcomes of the participation of disabled children, young people and their parents in health and social care decisions. More specific objectives and associated research questions are set out in chapter 1 (Table 1, p16). The research was designed in 4 phases using a variety of research methods (see Table 7 for methods used along with the rationale for using these methods). Participants were disabled children, young people and their parents along
with professionals and policy makers involved in caring for or providing services for these families within the Southern Trust area (see Table 7 for numbers of participants for each research phase).
Table 7: Data collection methods used and rationale for choice.

<table>
<thead>
<tr>
<th>Phase</th>
<th>Participants</th>
<th>Data collection method</th>
<th>Rationale for choice</th>
</tr>
</thead>
</table>
| 1     | Parents (n=77). Health and social care professionals (n=90); 77 from children’s services, 13 from adult services. | Survey                                               | 1. This approach provided an opportunity for a large number of participants to take part in the research and thus promoted inclusion from a wide variety of perspectives.  
2. It provided a broad overview of general issues around participation from the perspectives of parents and professionals from the outset and informed the more in depth qualitative part of the study. |
| 2     | Parents (n=30)                                                              | In depth interview                                   | This provided an opportunity for parents to express their views and experiences in detail. Parents were interviewed before children and young people in order to discuss participation of their son/daughter and gather information about them and their way of communicating. Data collection tools were then personalised and tailored to their needs. |
| 3     | Children and young people aged 6-28 years (n=18)                             | In depth interviews using participatory methods       | This provided an opportunity for children and young people with various impairments to share their experiences. Individual interviews using participatory methods allowed children and young people control over the research process. Some information from the parents’ interview were used to inform the child or young person’s interview and explore issues from their son/daughter’s perspective. |
| 4     | Health and social care professionals (n=6)                                  | Focus group                                          | Professionals were able to interact and discuss participation as members of the interdisciplinary team, rather than simply as individuals. This allowed me to explore why participants felt as they did and built upon the survey in phase 1. |
5.2 Philosophical and methodological approach

Crotty (1998) sets out 4 elements that inform one another in the planning and conduct of research:

epistemology or ontology

theoretical perspective

methodology

methods

Each element is examined in the sections that follow.

Epistemology or Ontology?

As Bryman (2004) points out, different methods of social research are closely related to views about how social reality should be studied and are rooted in different ontological and epistemological assumptions. Traditionally, quantitative research has been based on epistemology (explaining how we know what we know, a natural science model) and qualitative research on ontology (the study of being). This potentially poses a problem for those using a mixed methods approach as for those who argue that research should be based on one of these. Bryman (2004) argues, however, that the divide between quantitative and qualitative research should not be conceptualised in concrete terms and
qualitative research may contain aspects of quantification. Thus, he argues that the links between epistemology and ontology and the research method employed in a given study are best considered as tendencies rather than definitive connections. Given that the aim of this study was to explore participants' experiences of participation in decisions and what it is like to 'be' a child or young person, parent or professional, the main stance taken was an ontological as opposed to an epistemological one. Bryman (2004: 20) sets out varying orientations to qualitative and quantitative research strategies as follows in Table 8:

<table>
<thead>
<tr>
<th>Epistemological orientation</th>
<th>Quantitative</th>
<th>Qualitative</th>
</tr>
</thead>
<tbody>
<tr>
<td>Natural science model; positivism</td>
<td>Interpretivism</td>
<td></td>
</tr>
</tbody>
</table>

| Ontological orientation | Objectivism | Constructionism |

Given that it is traditionally problematic for researchers to be both objectivist and constructionist (Crotty, 1998) the ontological tendency in the current research is based mainly on constructionism because of its strong links with phenomenology. Crotty (1998:42) defines constructionism as 'the view that all knowledge, and therefore all meaningful reality, is contingent upon human practices, being constructed in and out of interaction between human beings and their world, and developed and transmitted within an essentially social context'. This study explores the interactions between children, young people, their parents and service professionals and providers.

**Theoretical perspective**

The theoretical perspective used in this study is hermeneutic phenomenology. The term phenomenon originates from the Greek expression which means “to show itself”
(Heidegger, 1967) and ‘phenomenology’ has been used to refer to both a philosophy and a research methodology (Dowling, 2004). Essentially, it seeks to understand and make sense of the ‘lived experience’ or ‘life world’ of participants. Laverty (2003) points out that although the terms transcendental (or descriptive) phenomenology and hermeneutic (or interpretive) phenomenology are frequently used interchangeably, they are rooted in differing philosophies. The former is based on the work of a German mathematician and philosopher, Husserl (1964). For Husserl, phenomenology aimed to deconstruct human experiences as a mechanism for subjecting them to close scrutiny and scientific enquiry (Jones, 2001). Researchers adopting the Husserlian approach are of the opinion that context and history are largely irrelevant in terms of human experience- it is the experience that matters for the individual. Husserl believed that there were commonalities within participants’ accounts of their experiences, which he refers to as ‘essences’. These essences represent the true nature of the phenomenon of interest (Lopez and Willis, 2004). Unique to this type of phenomenology is the notion of ‘bracketing’ whereby the researcher sets aside their own preconceptions, thoughts and feelings in order to maintain objectivity and reduce bias (Kleiman, 2004; Simpson, 2007). Further, Husserl was concerned solely with the individual’s perspective on their experience and not how others experienced it (Priest, 2002). Given that the aim of the current study is to explore the experiences of key stakeholders within the context of the family, services and wider societal assumptions, such an approach was deemed inappropriate for this study. Rather, a hermeneutic approach was chosen.

The work of Husserl was later developed by Martin Heidegger (1967) in what became known as the hermeneutic (or interpretive) approach. While the focus of Husserl and many philosophers at that time was epistemological (concerned with understanding how we know what we know), Heidegger’s was ontological (what it means to 'Be'). Uncovering the understanding of what it means to 'Be' moved the phenomenological tradition beyond an objective description of the human experience to an interpretative (hermeneutic) process (see also Ricouer, 1981 and Gadamer 1976):

'The hermeneutic phenomenologist, rather than seeking purely descriptive categories of the real, perceived world in the narratives of
the participants, will focus on describing the meanings of the
individuals' being-in-the-world and how these meanings influence the
choices that they make.'

(Lopez and Willis, 2004:729)

In his seminal work ‘Being and Time’ (1967), Heidegger explored the structure of
human existence or ‘Dasein’ which literally means to exist or be there (Inwood, 1997).
An important difference between the perspectives of Husserl and Heidegger lies in their
approach to context. The term Dasein emphasises that we exist with others in the world
and it is this context that adds meaning to an experience (Simpson, 2007). Thus
Heidegger was of the opinion that it was impossible to develop an understanding of
individuals themselves without taking account of the social, cultural, temporal and
historical context (what he referred to as historicality). Laverty (2003) explains
historicality in terms of a person’s history or background, including what a culture gives
an individual during their development. This preserves ways of understanding the world
(for example, knowledge and attitudes about disability) within a given culture. The
experiences of disabled children, young people and their families are dependent on their
interactions with others within Bronfenbrenner's nested systems and, as such, context is
particularly important for this study. Hermeneutic phenomenology is both a theoretical,
philosophical approach and a methodology.

Methodology

Two methodologies were used in this study (1) survey research and (2) interpretative
(hermeneutic) phenomenology.

Survey research

According to Boynton and Greenhaigh (2008) the purpose of the survey is to gather
information about individuals' knowledge, attitudes, beliefs and/or behaviours. In this
study the aim of the survey was to generate data from both parents and professionals but
also to inform the more in depth qualitative aspect of the study. Two questionnaires
were designed, one for parents and one for professionals. The questions were designed to allow for direct comparisons between these 2 groups.

Both surveys were piloted in line with guidance by Parahoo (2006) in order to establish (1) if respondents understood each question in a similar way, (2) whether the format was appropriate for the populations of interest, (3) if the instructions were clear and determine the relevance of the questions in addition to (4) gaining feedback about the length.

Parent surveys were piloted with 4 parents. Two were personal friends who had a disabled child and 2 were the parents from the adult reference group. Two changes were made as a result. Firstly, 2 subtitles were removed from the table in question 5 (see surveys, Appendix 3) which 2 of the parents found confusing. Secondly the terminology used in the scale to indicate the importance a statement was changed from 'very important', 'fairly important', 'not very important', 'not important at all' to 'extremely important', 'very important', 'important', 'a little important', 'not important at all'. One parent felt that the former was ambiguous and unclear. One parent preferred the term 'special needs' to 'disabled' but since the term disabled was used in the names of both access groups it was retained. The survey was also discussed with the adult reference group. On their advice, additional information was provided to explain terminologies/instructions used, such as, health care, social care and policy.

The professionals’ survey was piloted with 4 educationalists, all nurses, 3 of whom currently work with disabled children/young people and their families on an occasional basis. Feedback was positive and the only changes made concerned the scale which was changed to match that of the parent survey. Although the surveys were lengthy, no one who took part in the pilots commented on this. The revised surveys (see Appendix 3) were forwarded to ORECNI and Trust ethics, constituting a minor amendment, and ethics approval was obtained.

Hermeneutic phenomenology

The second research methodology adopted in this study is based on hermeneutic phenomenology that seeks to understand, interpret and make sense of the 'lived
experience' of participants. A number of alternative potential methodologies were considered. For example, Moustakas (1994) outlines 5 models that may be used to explore the human experience: ethnography, grounded theory, empirical phenomenology, heuristics and hermeneutic phenomenology. While a detailed exploration of each approach is beyond the scope of this thesis, Table 9 summarises the principles of each and the rationale for using/not using each one. Many qualitative researchers demonstrate a commitment to exploring events and the social world through the eyes of those they are studying (Bryman, 2004) and phenomenology facilitates such an approach by investigating individuals' perceptions, attitudes, beliefs, feelings and emotions (Denscombe, 2007). It has been suggested that phenomenology is a particularly appropriate research approach to use when researching the needs and wishes of those who use services (Miller, 2003; Duffy, 2008), adding weight to its selection here. It is anticipated that interpreting and reporting service users' experiences may shape current and future service provision.
Table 9: Methodologies for researching experiences within the human sciences.

<table>
<thead>
<tr>
<th>Approach</th>
<th>Principles of the approach as identified by Moustakas (1994)</th>
<th>Rationale for using/not using the approach in the current study</th>
</tr>
</thead>
<tbody>
<tr>
<td>Ethnography</td>
<td>Involves extensive fieldwork that permits direct (and often lengthy) observations, communications and interactions with participants being studied in order to explore their experiences.</td>
<td>Such an approach has been used to explore the lives of disabled families (e.g. McLaughlin et al. 2008) but requires resources unavailable to a PhD project.</td>
</tr>
<tr>
<td>Grounded theory</td>
<td>An approach that focuses on unraveling human experience until a theory is developed, enabling the researcher to understand the meaning of an experience for research participants.</td>
<td>The current study was not designed primarily to generate theory but to explore participants’ experiences and what this meant to them.</td>
</tr>
<tr>
<td>Empirical phenomenology</td>
<td>Follows the tradition of ‘descriptive phenomenology’, letting the phenomena speak for themselves before the final interpretation of participants’ experiences (Giorgi, 1985). The researcher is must ‘bracket’ previous experience/pre-understandings and assumptions in order to explicate the essence of the human experience. Context is less important in this approach.</td>
<td>Although this approach explores relationships between individuals and situations, it was not my intention to ‘bracket’ my previous knowledge. Rather it was anticipated that my previous experience as an experienced practitioner would assist me in exploring the in depth experiences of children, young people and parents. Further, context was key in the current study.</td>
</tr>
<tr>
<td>Heuristics</td>
<td>The phenomenon is widely and deeply extricated by means of narrative descriptions, stories, poems, journals and diaries and other personal documents. This approach is concerned with in depth description of an experience rather than its interpretation.</td>
<td>This study was concerned with meaning and interpretation rather than simply in depth description.</td>
</tr>
<tr>
<td>Hermeneutic (interpretative) phenomenology</td>
<td>Involves an interplay between the description and interpretation of experience and the underlying structures and dynamics that contribute to that experience. Involves reading and re-reading participants' accounts until the intention and meaning are understood. Context and historical meanings of experience are particularly important. Rather than ‘bracketing’ pre-understandings the researcher uses these to inform the research.</td>
<td>Selected for this study because (1) the aim and objectives involved the exploration and interpretation of participants’ experiences in the context of health and social care structures and policy, along with historical and cultural perceptions of disability and childhood; (2) the research is informed by the researcher's experience.</td>
</tr>
</tbody>
</table>
Phenomenology as a research methodology

Historically, phenomenological research methodologies have largely emerged from the philosophies associated with either Husserlian or hermeneutic philosophers (such as Heidegger). The methodology used in this thesis is based on the work of Gadamer (1975) and van Manen (1990) both of whose methodologies emerged from the work of Heidegger. Gadamer (1975), maintains that in order to gain an understanding of the lived experience one must move back and forth within the data in order to achieve what he calls a 'fusion of horizons'. According to van Manen (1990:36) the aim of phenomenological research is 'to transform lived experience into a textual expression of its essence – in such a way that the effect of the text is at once a reflexive re-living and a reflective appropriation of something meaningful'. In order to achieve this, numerous methodologies and combinations of these have been developed (see Streubert and Carpenter, 2011 for examples). Traditionally, Husserlian philosophers believed that, in order to uncover the lived experience, one needed to 'bracket' or keep separate all knowledge or experience. However, from Gadamer onwards, phenomenological researchers have regarded bracketing as untenable. Rather than seeking to set aside researchers’ assumptions and preconceptions, they advocate that researchers integrate these into the research process and findings (de Witt and Ploeg, 2006). The manner in which the perspectives of the researcher and participants come together is articulated by Wojnar and Swanson (2007):

'Hermeneutic phenomenology is grounded in the belief that the researcher and the participants come to the investigation with fore structures of understanding shaped by their respective backgrounds, and in the process of interaction and interpretation, they cogenerate an understanding of the phenomenon being studied.'

(Wojnar and Swanson, 2007:175)

Here the expert knowledge of the researcher is seen as an important feature as this can be particularly useful in guiding the research (Lopez and Willis, 2004). It is often the case that the expertise and experience of researchers drives the initial conceptualisation of the research. This research was initially conceptualized by the study supervisors, in collaboration with service users. The supervisors were two social work academics and a
public health consultant, each of whom had experience of working with disabled children, young people and their families. Their experiences, along with my own experience of working with disabled children, young people and their families, guided and influenced the research process. As a children's nurse and advocate for families I came to the project with the belief that children and their parents should be valued, listened to as experts in their care and involved as partners in decision making processes. However, I also knew that in practice this did not always happen. In my new role as researcher, it was also necessary to be open to what participants were saying and develop a deeper sense of what this meant for children and parents.

As Wojnar and Swanson (2007) point out, researchers adopting the hermeneutic approach need to acknowledge that individuals' experiences are invariably affected by their family, community and wider socio-political and historical contexts. This has particular currency for disabled children, young people and their parents whose participation in decisions affecting their lives is influenced across each of these domains, as highlighted in Bronfenbrenner's model that underpins this study. Given that a key theme underpinning the objectives of this research is that these contexts add meaning to an experience (Simpson, 2007), a hermeneutic approach, based on the work of Gadamer and van Manen was deemed appropriate. Hermeneutic phenomenology is not associated with a 'method' as such, aside from engaging in the 'hermeneutic circle' (Finlay, 2011) and so the work of Dahlberg et al. (2008) was incorporated into the analysis of this research, a process explored further at the end of this chapter.

5.3 Methods

This section sets out user involvement in the research, sampling and access and recruitment of participants.

User involvement in the research

User and public involvement is now considered good practice in research, as evidenced by government funding of INVOLVE, an advisory group that aims to promote greater
involvement of the public in health and social care research. Such involvement is thought to positively enhance the ethical conduct and impact of research. Within disability studies, it is accepted that disabled people are experts in their own lives and therefore research should be done with and not on them (Goodley, 2011). Examples of studies involving disabled children and young people include Morris (1998), Marchant et al. (1999), Holme and Hanmore (2001), Stalker and Connors (2003) and Watson et al. (2006).

The involvement of service users from the outset helped to ensure that the design and conduct of this study would accurately reflect participants' experiences. The work was guided by two advisory groups. The first, an adult reference group, consisting of 5 professionals (Heads of Service involved in the delivery of health and social care within the Trust) and 2 parents of disabled young people from the Parent/carers’ Council on Disability (PCCD). While it could be argued that the adult reference group was weighted numerically in favour of professionals, in fact these 2 parents had been involved in the design of the study, were confident, articulate and used to service user groups. Parents of disabled children have many time constraints and as such 2 parents was considered sufficient. The second, a young person's advisory group, comprised two young people from the 'Sixth sense' group, the advocacy group from the Disabled Children and Young People's Participation Group (DCYPPP). The two young people were employees working with the DCYPPP and were identified by the group leader as those best placed to assist me in the conduct of the research. Both had a physical impairment along with a mild cognitive impairment. Reporting on three projects, Lewis et al. (2008) discuss the value of keeping reference groups of disabled people small (two people) so that they can make a genuine, in depth contribution.

Both groups were involved in the research from its initial conceptualisation. Davis (2009a) identifies the broad stages during which children may be involved in the research process: pre-data collection, data collection, analysis, reporting and the policy development/campaigning. This framework was used to guide user involvement by young people and adults throughout the research process (see Table 10).
The involvement of the adult advisory group

The adult advisory group met during the planning (pre-data collection) stage of the study to discuss the aims, objectives and methods employed in the study and to provide feedback on the surveys and the study protocol prior to ethical approval being sought for the study. Although they were, in principle, very supportive, there were a number of challenges. For example, managers seldom had time to read the information I sent (for example the study protocol or surveys) prior to the meeting. Often, if I was invited to a meeting by the Assistant Director of Disability Service as part of their senior management meeting, those involved in the reference group were present. However, when I called a reference group meeting, managers cancelled at the last minute, did not confirm their attendance or could only attend part of the meeting. Although the role of the adult advisory group was vital in terms of building relationships that facilitated access to participants and distribution of the surveys, their role in the study design or delivery was minimal. The most fruitful meeting was an individual meeting with the Head of Social Services who examined the survey and provided constructive comments on the design of one question which was subsequently changed as a result. Davis (2009a) points out that many issues impact on the extent to which participation in the research process is achievable and that it is often most beneficial to focus on what is realistic for a specific research project. In the current study, considerable effort was made to involve and keep the advisory group and local collaborator informed about the progress of the study. However, there was no contact with users during the data collection stage as no particular difficulties arose (see Table 10 for details of contribution of the adult and young people's advisory group at each stage).

Two parents of disabled children were involved in the study from the outset and provided invaluable feedback and advice in relation to the study design, the parent surveys and initial findings of the study.

Involvement of the young people's advisory group

The two young people from sixth sense were consulted twice during the pre-data collection stage. On the first occasion, they suggested that interviews could be held at
the centre where young people felt comfortable and were familiar with their participation work. Although I had planned to conduct the interviews with children and young people at home, this suggestion was adopted and most young people from the DCYPPP were interviewed at the centre. McLaughlin (2009) warns of the twin dangers that may rise in user involvement research: that may be tokenistic or viewed as a panacea. During the research, I took on board what individuals from the reference groups had to say but was also mindful of the aims and objectives of the research and how these would best be met. One of the young people suggested, because young people from the DCYPPP were used to working as a group, that I should start with a group activity and then see who would like to do a one to one session with me. Although a group interview would not have fulfilled the objectives of research, it seemed appropriate to respect their wishes (thereby avoiding tokenistic participation). Consequently, a discussion was conducted with the whole DCYPPP group before data collection commenced, about what they had achieved over the past year (rather than addressing the research questions). This gave me an invaluable opportunity to build rapport with the group, show a genuine interest in the work they were doing and get to know the types of activities that they were involved in. The young people also advised me about the design of the information sheets for children and young people. In particular, they favoured the development of numerous versions that would assist those with individual ways of communicating.

On the second occasion, it appeared that six members of ‘Sixth sense’ (the advocacy group of the DCYPPP) were waiting to see me, and it seemed inappropriate to exclude them from giving their expertise. They provided advice about the proposed data collection methods to be used with disabled children and young people, including the use of symbols and communication aids. All methods I had proposed were endorsed except the ‘I’ll go first toolkit’. This kit includes Boardmaker© symbols by Mayer Johnson. Boardmaker© is a design programme and set of picture communication symbols to facilitate and augment communication for those with communication impairments. This did not appeal to the young people as it contained Boardmaker©
symbols that they felt were outdated and might have caused confusion. As a result, this was not used.

Regular contact was maintained with all the young people from the participation group to remind them that the research was on-going and maintain relationships during all stages of the research. This on-going engagement proved crucial in developing my own skills of interacting with disabled children and young people in the study in a meaningful way:

NATALIE: 'I think one thing is Tricia, you know yourself, if you’re looking to participate with our group, with the likes of our group come to us ... We’ll teach you how to talk to the young people, cause sometimes they [other people] come in and they don’t know how to work with the young people ... So it’s just about knowing the group, knowing your audience and knowing how to work with them and if you know how to work, they’ll participate much easier ...

PMCN: So there needs to be a bit of background work or training before people come and ask your views.

NATALIE: Yeah, they have to come in and meet the group and see what they’ve to do ... Like Patricia you’ve built the relationship with us, so you know what way we work. If people do what you did, you know, they’d know what way to work with us. The young people know how to participate if they know what’s happening and what’s it about'.

[NATALIE: 27 year old with physical impairment]
<table>
<thead>
<tr>
<th>Advisory group</th>
<th>Pre-data collection stage</th>
<th>Data collection stage</th>
<th>Analysis stage</th>
<th>Reporting stage</th>
<th>Policy development/campaigning stage</th>
</tr>
</thead>
<tbody>
<tr>
<td>Adult advisory group</td>
<td>Involved in development of the research protocol. Consulted about questionnaire design and proposed methods of data collection.</td>
<td>Not involved at this stage.</td>
<td>Not involved at this stage.</td>
<td>Not involved at this stage.</td>
<td>Results discussed with 2 parents from the advisory group.</td>
</tr>
<tr>
<td>Young people’s advisory group</td>
<td>Involved in design of data collection. Involved in the decision about where the interviews would take place. They also advised on the design and number of information sheets.</td>
<td>Not involved at this stage.</td>
<td>Early findings of the research discussed with the young people.</td>
<td>Results presented to the DCYP group who offered to help produce a paper version of the findings for all children and young people who took part.</td>
<td>Results of the study are to be presented at the stakeholders' forum which senior Trust and Department personnel attend.</td>
</tr>
</tbody>
</table>
Sampling for all phases in the study

Purposive sampling is most frequently used in phenomenological studies as a mechanism for including participants with experience of the phenomenon of interest in research (Streubert and Carpenter, 2011). Essentially the researcher targets those with the relevant experience to answer the research questions (Bryman, 2004). In Phase 1 (the survey) all parents in the Southern Health and Social Care Trust who were either on the Parent/Carers’ Council on Disability (PCCD) database or who had recent involvement in the Disabled Children and Young People’s Participation Project (DCYPPP) were invited to participate.

In Phase 2 (the parent interviews), I had intended to ensure representation of parents with children and young people of varying ages, gender, impairment type and ethnicity who may also have been interested in taking part. However, this proved to be untenable because of small numbers of parents who agreed to take part in this phase of the study. See Tables 13 and 14 for details about the age, gender and impairments of children and young people whose parents took part in the study.

Purposive sampling was also used to identify professionals with experience of working with disabled children, young people and their families, both children’s and adult services. Again, whilst the intention was to use stratified sampling to ensure the participation of a range of professionals across geographical localities in the focus groups, only one focus group was held due to lack of participants (see p149 for professionals’ reasons for non-participation).

Access and recruitment of parents

Parent participants were accessed via the lead people for the PCCD and the DCYPPP. These groups were selected because the nature of their participation work was central to the study. Dr Brid Farrell (Health and Social Care Board) had a close working relationship with the gatekeepers of these groups and it was anticipated that they would provide access to potential participants. Generally, the parents of children and young
people from the DCYPPP were not involved in the PCCD and children and young people of those involved in the PCCD were not involved in the DCYPPP. This meant that many participants did not belong to a ‘participation group’, a point we return to later in the discussion chapter.

Details of study recruitment are shown in Figure 8. In the early stages of planning, my understanding was that the leaders of these 2 groups had agreed that all individuals on their databases would be invited to take part in the study i.e. 300 parents on the PCCD database and 200 parents on the DCYPPP database. When, following ethical approval, the gatekeepers were contacted to arrange distribution of the surveys it became apparent that they were keen only to send surveys to those currently involved in the groups, far fewer than 500. As Bryman (2004) points out there is often a need for renegotiation after gaining, in principle, access to potential participants. This was however terribly frustrating given the amount of work involved in getting to this point and a certain amount of anxiety given that this would affect the final numbers of participants. As an experienced children’s nurse I could understand their need for control over what they were responsible for. Discussion with the study supervisors also helped to resolve this situation. In the case of the PCCD, the gatekeeper felt that there would be no point in sending the survey to everyone on the database as there were only a small number of key parents who currently came to meetings and the response rate would be minimal. She suggested holding a series of open meetings and distributing surveys at the meetings or sending them to key people within the group, which would involve up to 100 parents. While I appreciated her motivation and past experience in terms of knowing how the group operated, it was necessary to stress that it was important that all members of the group were given a chance to participate, in order to avoid bias. The gatekeeper from the DCYPPP was similarly concerned that many families on the database had not been involved the group for some time; she wanted to send the surveys to the families of the 27 young people who were currently involved. Again I understood her motivation for this in terms of not sending families information when they potentially did not want it. This highlighted the need for greater clarity with all those concerned in the early stages of planning the research. It also highlights a data protection issue in that those with
access to individuals' personal information were unsure of their desire to have an on­
going association with a particular group.

When undertaking research with disabled families it is worth remembering that children may have life limiting or life threatening conditions and so the death of a child may occur during the study. One parent returned the questionnaire (completed) after her child had died. Unfortunately she had not provided contact details so I was unable to thank her for her participation and ensure that receiving the information pack had not caused her any distress. McLaughlin et al. (2008) report similar experience in terms of the deaths of 2 children during their research and one occasion when the researcher turned up at the door of one family to be told that the child had died during the night. Again the maintenance of databases should be an active process in order to protect those who volunteer personal information.

After some negotiation and diplomacy (assisted by showing the gatekeepers exactly what would be sent to potential participants and asking them to include a covering letter), surveys and information packs were sent via the gatekeepers to 220 parents on the PCCD database (all those on the database at that time) and 100 families involved with the DCYPPP. The 100 families from the DCYPPP database were selected by the gatekeeper as those who had the most recent involvement with the group. The packs contained a covering letter, information sheet about study, a reply slip and a stamped addressed envelope (see Appendix 4) along with the relevant survey. Figure 8 describes the recruitment of parents in the study.

Even after recruitment was successfully negotiated, the distribution of the packs from the PCCD took some time. The gatekeeper had kindly offered to collect the surveys from Belfast but this was hampered by a period of snow. There were additional challenges of negotiating access to participants via a parent gatekeeper. The gatekeeper was also the parent of a disabled child. Parents of disabled children and young people have many commitments, not least the caring role and, rightly, this often took priority over the research. As a result, the distribution of packs was delayed for 4 months. Again, while this was frustrating for me as a researcher I had to acknowledge the needs
of the parents involved. Parents from both databases sent the completed surveys and/or reply slip to me directly in order to ensure confidentiality.

**Access and recruitment of professionals**

Professionals involved in children’s services were accessed and recruited via Heads of Service within the Trust. The Assistant Director of Disability Services called a meeting with the Heads of Service of Wraparound which I attended. I outlined the nature and purpose of the study and distributed the surveys and information packs. Packs contained a covering letter, an information sheet about the study, a reply slip and a stamped addressed envelope (see Appendix 5) along with the relevant survey. Professionals sent the surveys/reply slips back directly to me in order to ensure that participation was entirely confidential. See Figure 8 for a flowchart of the recruitment of professionals in the study. Professionals were invited to provide a reason for non-participation. Those provided included too little time, caseload demands and too many commitments at work and at home. One respondent said she was doing a course and was ‘up to her eyes’.
Figure 8: Recruitment/consent parents and professionals

Parents

Information pack distributed to parents by post via the Parent Carers' Council (n=220) and the Disabled Children and Young People's Participation Project (n=100).

243 parents opted out.

Parent returned the survey (n=77; 16 from the DCYPPP and 61 from PCC) and reply slip, indicating that they and/or their spouse may be interested in taking part in the interview (n=34).

Parent returned the survey but 47 opted out of the interview.

Researcher contacted the parent(s) by telephone (n=34) and arranged a visit (n=28) with 1 or both parents to provide more information about the interview

Parent(s) consent to taking part in the interview (n=30).

27 interviews conducted with a total of 30 parents.

Professionals

Information packs distributed to professionals via Heads of Service internally (children's services n=191; adult services n=50).

151 professionals opted out.

Professional returned the survey (n=90; 77 from children's services and 13 from adult services) and reply slip, indicating that they may be interested in taking part in a focus group (n=7).

Professionals returned the survey but opted out of the focus group (n=83).

The date did not suit one professional who opted out. 1 professional could not be contacted and did not reply to messages left.

Researcher rang those expressing an interest in the focus group and provided information about participation. 5 agreed on to attend an organised session. An additional professional wanted to attend.

Researcher discussed information at the start of the focus group. Professionals consented to taking part (n=6).

1 focus group conducted with 6 professionals.
Access and recruitment of disabled children and young people

It is widely recognised that in order to invite children and young people to participate in research one has to approach adult gatekeepers to gain access to them (Punch, 2002). Current gatekeeping systems continue to foster a developmental approach to childhood whereby children are viewed as dependent and vulnerable (Balen et al. 2006); however this is often a necessary feature in research to ensure that children are protected. In this study, parents were the gatekeepers. Children and young people's participation was discussed with them at the end of the parent interview. Figure 9 illustrates the recruitment of children and young people to the study. Of the twenty seven parent/parent couples who agreed to be interviewed, 13 agreed for their son(s) or daughter also to be interviewed. One parent had 2 disabled sons both of whom took part in the study. Ten refused for a variety of reasons including: they would not have sufficient understanding or communication to take part (n=8) or they would be too anxious to interact with a researcher because of their autism (n= 3). One father said his son could take part ‘if pigs could fly’, even though the child was able to watch children's TV and kept looking over at me every time his name was mentioned. Out of the twenty seven interviews with parents/parent couples, thirteen had children with autism and these children and young people were the most difficult to recruit (only 5 of these children and young people (2 from the same family) took part). Similarly, Beresford et al. (2004) were able to access just 5 children with ASD out of 26 families. Such difficulties of recruiting other disabled children and young people have been reported by previous researchers (see Minkes et al. 1994; Marchant et al. 1999; Lewis, 2001; Turner, 2003; Rabiee et al. 2005; Kelly, 2007).

Additionally, in the current study, 2 children were too young (i.e. less than 4 years as per study inclusion criteria), 1 was too old (i.e. over 28, the age of the oldest member of the DCYPPP) and 3 young people did not want to take part, even though their parents gave their consent. It was decided that one young person did not have enough contact with services or professionals to participate. A total of eleven children and young people were recruited at the end of the parent interview. The remaining seven young people were recruited via the lead for the Disabled Children and Young People’s Participation project, as although their parents had been sent information about the study they did not take part
themselves or return the reply slip indicating that their son or daughter wished to consider taking part.
Figure 9: Recruitment of children and young people

Children/young people whose parents took part in the parent interview.

Parent/parent couple participates in the parent interview (n=27). Researcher discussed the possibility of their son/daughter taking part in the research (n=23).

Parent/parent couple willing to discuss their son/daughter's participation in the research with them (n=13). Parent consent obtained for their son/daughter's participation.

Researcher leaves an appropriate information pack for the child/young person and parent to discuss together.

Parent contacts the researcher indicating that their son or daughter is interested in taking part (n=10). (One parent had 2 children who took part).

Researcher visited the child/young person, discussed the information in the pack. Assent obtained—child/young person took part (n=11).

4 children/yp excluded by the researcher: too young (n=2), too old (n=1); not enough contact with services (n=1).

Parent/parent couple not willing for their son/daughter to take part (n=10). Child or young person did not take part.

Child or young person opted out (n=3).

Children/young people whose parents did not take part in the parent interview or return the reply slip indicating that the child/young person wished to take part.

All parents of cyp from the DCYP PPP sent out information in phase 1 of the study.

Leader of DCYP PPP group contacted researcher to say that 7 children/young people wished to participate in the research.

Leader sent out appropriate information pack for the child/young person and parent to discuss together. Parent consent obtained by Leader where child was <16 yrs or young person was judged as lacking the capacity to provide their own consent.

Researcher met with the child/young person, explained the information and obtained assent or consent (n=7).

Interview conducted with the child or young person.
5.4 Data collection

This section details the 4 phases of data collection including postal surveys, parent interviews, interviews with children and young people and the professionals' focus group.

**Phase 1: postal surveys to parents and professionals**

In phase 1 two postal surveys were conducted: the first to 220 parents on the Parent /Carers’ Council on Disability database and 100 parents of children on the Disabled Children and Young People Participation Project database; the second to 191 professionals from Wraparound (children and young people's services, see Table 11) and 50 to professionals working with disabled children and their families within adult services (see Table 12).

Table 11: Surveys distributed to professionals in children's services

<table>
<thead>
<tr>
<th>Discipline</th>
<th>Number of surveys distributed</th>
</tr>
</thead>
<tbody>
<tr>
<td>Social work</td>
<td>30</td>
</tr>
<tr>
<td>Community dental</td>
<td>36</td>
</tr>
<tr>
<td>Mental health</td>
<td>30</td>
</tr>
<tr>
<td>Physio and OT</td>
<td>30</td>
</tr>
<tr>
<td>CCN and Community Paediatricians</td>
<td>40</td>
</tr>
<tr>
<td>Sensory disability</td>
<td>5</td>
</tr>
<tr>
<td>Speech and language</td>
<td>25</td>
</tr>
<tr>
<td><strong>Total</strong></td>
<td><strong>191</strong></td>
</tr>
</tbody>
</table>
Table 12: Surveys distributed to professionals in adult services

<table>
<thead>
<tr>
<th>Discipline</th>
<th>Number of surveys distributed</th>
</tr>
</thead>
<tbody>
<tr>
<td>Adult learning disability (interdisciplinary)</td>
<td>27</td>
</tr>
<tr>
<td>Physical disability (social work)</td>
<td>16</td>
</tr>
<tr>
<td>Transition workers</td>
<td>3</td>
</tr>
<tr>
<td>Sensory disability (social work)</td>
<td>2</td>
</tr>
<tr>
<td>Brain injury (social work and psychology)</td>
<td>2</td>
</tr>
<tr>
<td><strong>Total</strong></td>
<td><strong>50</strong></td>
</tr>
</tbody>
</table>

**Response rate and profile of participants: parent survey**

A total of 77 parents returned the questionnaire (70 mothers and 7 fathers). While the participation of fathers in research is frequently much lower than mothers (see for example, Mitchell, 2012c), on reflection, their participation could have been encouraged in this study. Kayfitz et al. (2010) achieved equal numbers of mothers and fathers in their research by providing a separate pack and survey for each and asking them not to discuss their replies with each other. Eighty three percent (64) of parents who returned the survey had 1 disabled child and 17% (13) had 2 disabled children. The response rate for the Disabled Children and Young People's Participation Group was 16% and the response rate from the Parent/carers' Council was 28%, giving an overall response rate of 24%. The latter was augmented when, following an initial low response, a letter was sent to parents of the Council by Dr Brid Farrell from the Health and Social Care Board asking parents for their participation. An additional 29 surveys were received following this communication. While this response rate is less than optimal similar findings have
been reported in previous studies with parents of disabled children and young people. For example, Prezant and Marshak (2006) reported an 18% response rate from parents of disabled children and young people. Locally in Northern Ireland, Niccy (2008) reported an 11-33% response rate across Trusts and in a study of parents by Flannagan and McCoy (2006) only 17.6% returned the survey.

Ages of children and young people, whose parents returned the survey, is shown in Table 13. Nine parents did not provide information about their child's age.

Table 13: Ages of children and young people whose parents took part in the survey

<table>
<thead>
<tr>
<th>Age</th>
<th>Frequency</th>
<th>Percentage</th>
</tr>
</thead>
<tbody>
<tr>
<td>&lt;4 years</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>4-11</td>
<td>20</td>
<td>26</td>
</tr>
<tr>
<td>12-19</td>
<td>32</td>
<td>41</td>
</tr>
<tr>
<td>20-25</td>
<td>13</td>
<td>17</td>
</tr>
<tr>
<td>Missing data</td>
<td>9</td>
<td>12</td>
</tr>
<tr>
<td>Total</td>
<td>77</td>
<td>100</td>
</tr>
</tbody>
</table>

Children and young people had a range of impairments. Thirty-nine percent had a physical impairment, 75% had a learning disability/cognitive impairment, 27% had a sensory impairment and 25% had a communication impairment. Thirty-five percent had autism. Most children and young people had a combination of these. The category communication impairment was added by parents (i.e. it was not an available option in the survey per se) and so more children and young people may have had this type of impairment. Four parents did not provide any information about their son or daughter's impairment. One parent wrote 'who really knows?' and another, whose son had a cognitive and speech impairment said 'I wouldn't say disabled'. In other cases, parents wrote a diagnosis, for example, autism but did not tick any of the boxes to indicate the nature of their impairment. Eighty percent of parents returning the survey were married, the remainder being separated, divorced, single or widowed. One parent did not disclose
this information. In relation to ethnicity, it was clear that parents misunderstood this question as many replied 'Irish' or 'British'. Given that it was an optional question, many parents declined to answer. For those who did answer appropriately, parents were mainly white. One was Afro-Caribbean, one was mixed race and 2 were Caucasian.

Response rate and profile of participants: professionals' survey

A total of 90 professionals returned the questionnaire (see Figure 10 for occupation of these professionals). The response rate for those working in children's services was 40% and the response rate from adult services was 26%, giving an overall response rate of 37%.

Figure 10: Occupation of professionals who returned the survey
While there was representation from a wide range of professionals, no paediatricians took part. Three participants stated that they were a 'health care worker' but did not disclose more specific information.

**Phase 2: parent interviews**

Twenty-seven semi-structured interviews were conducted with 30 parents (26 mothers and 4 fathers) (see Appendix 6 for the parent interview schedule). Three couples were interviewed together and 1 father was interviewed alone. Parents who were interviewed had children and young people with a wide variety of impairments and were, primarily, between the ages of 3 and 24 years (see Table 14 for profile of children and young people whose parents were interviewed). One mother, whose son was 40 years old, wanted to take part in the interviews and, given that all parents, regardless of their son or daughter's age, referred to them as their 'child', it seemed unethical to exclude her. Sperry *et al.* (1999), in their study conducted with parents of young children with autistic spectrum disorder found that while they aimed to include parents of children less than 8 years, in reality 40% of their final sample were parents of older children who could reflect back on their experiences and were thus included.

Interviews were conducted over an 8 month period and were sometimes hampered by snow (many parents lived in a very rural area) or holiday periods. Nicholl (2007a), in her research with mothers of children with complex needs, noted that working around families' plans, schedules, school, the care needs of the child and appointments with professionals meant that data collection could be significantly delayed and this was also problematic in the current study. The needs of families were prioritised, and as a result, this phase of data collection took longer than anticipated.

**Position of the researcher in the adult interviews**

On first meeting adult participants in the study I introduced myself as having a nursing background, but having been in education for several years and conducting the research with the School of Sociology, Social Policy and Social Work. This eclectic identity
potentially allowed participants to voice their views and experiences to someone who was not from one particular professional group or service. Participants did not seem inhibited and spoke freely about all aspects of services and professionals, both positive and negative. This eclectic approach appeared to avoid pitfalls experienced by other researchers. For example, as a children’s nurse/researcher, Nicholl (2007a) recounted her experiences of being asked practical advice about the care of children with complex health needs during interviews with mothers in the conduct of her research. My previous experience as a children’s nurse was nonetheless useful. The hermeneutic approach encourages the use of the previous knowledge and experience of the researcher to uncover the true essences of the nature of the phenomenon under scrutiny (Walker, 2011). My prior insight into the issues that came to the fore meant that I was able to probe and explore issues in more depth than might otherwise have been possible. There were also disadvantages of such prior knowledge and experience. For example, often I found it difficult to listen to criticisms, in particular of nurses, as I have a pivotal role in training them and at times felt let down by my own profession.
Table 14: Profile of children and young people whose parents were interviewed (x denotes the presence of an impairment).

<table>
<thead>
<tr>
<th>Parent</th>
<th>Age (yrs) and gender of son/daughter</th>
<th>Physical Impairment</th>
<th>Cognitive Impairment</th>
<th>Sensory Impairment</th>
<th>Autism</th>
<th>Communication Impairment</th>
<th>Parent said son/daughter could take part</th>
<th>Child or young person chose NOT to take part even though parent agreed (denoted by x)</th>
</tr>
</thead>
<tbody>
<tr>
<td>P1</td>
<td>11 F</td>
<td>x</td>
<td>x</td>
<td>-</td>
<td>-</td>
<td>x</td>
<td>yes</td>
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<tr>
<td>P2 + P3</td>
<td>17 M</td>
<td>x</td>
<td>x</td>
<td>-</td>
<td>-</td>
<td>x</td>
<td>yes</td>
<td>-</td>
</tr>
<tr>
<td>P4 + P5</td>
<td>10 F</td>
<td>x</td>
<td>-</td>
<td>-</td>
<td>-</td>
<td>x</td>
<td>yes</td>
<td>-</td>
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<tr>
<td>P6</td>
<td>16 M</td>
<td>-</td>
<td>x</td>
<td>x</td>
<td>x</td>
<td>x</td>
<td>no</td>
<td>-</td>
</tr>
<tr>
<td>P7 + P8</td>
<td>19 M</td>
<td>-</td>
<td>x</td>
<td>-</td>
<td>-</td>
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<td>no</td>
<td>-</td>
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<tr>
<td>P9</td>
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<td>x</td>
<td>-</td>
<td>-</td>
<td>-</td>
<td>yes</td>
<td>-</td>
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<tr>
<td>P10</td>
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<td>x</td>
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<td>-</td>
<td>-</td>
<td>-</td>
<td>yes</td>
<td>x</td>
</tr>
<tr>
<td>P11</td>
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<td>x</td>
<td>-</td>
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<td>x</td>
<td>no</td>
<td>-</td>
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<tr>
<td>P1-P11</td>
<td>Parents from DCPPP</td>
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<td>P12</td>
<td>7 M</td>
<td>x</td>
<td>x</td>
<td>-</td>
<td>x</td>
<td>x</td>
<td>no</td>
<td>-</td>
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<tr>
<td>P13</td>
<td>9 M</td>
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<td>-</td>
<td>-</td>
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<td>6 M</td>
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<td>x</td>
<td>-</td>
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<td>-</td>
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<td>-</td>
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<td>no</td>
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<tr>
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<td>P26</td>
<td>24 F</td>
<td>x</td>
<td>x</td>
<td>-</td>
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<td>x</td>
<td>no</td>
<td>-</td>
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<td>P27</td>
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<td>-</td>
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<tr>
<td>P28</td>
<td>6 M</td>
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<td>17 M</td>
<td>x</td>
<td>x</td>
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<td>-</td>
<td>-</td>
<td>yes</td>
<td>x</td>
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<tr>
<td>P29</td>
<td>8 M</td>
<td>x</td>
<td>x</td>
<td>-</td>
<td>-</td>
<td>x</td>
<td>yes</td>
<td>-</td>
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<tr>
<td>P30</td>
<td>15 M</td>
<td>-</td>
<td>x</td>
<td>x</td>
<td>x</td>
<td>x</td>
<td>yes</td>
<td>x</td>
</tr>
<tr>
<td>P12-30</td>
<td>Parents from parent/carer council</td>
<td></td>
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</table>
Phenomenological interviewing

Interviews in phenomenological studies are used to uncover knowledge about the phenomenon of interest and are often unstructured (Clarke and Iphofen, 2006; Denscombe, 2007). Some studies use a combination of open ended and more structured questioning techniques, or a combination of these, in the form of a semi-structured interview (Maggs-Rapport, 2000). This need for a balance between flexibility and control has been emphasised by previous researchers using a hermeneutic phenomenological approach (see for example, Walker, 2011). This was the approach used in the current study in order to ensure that the objectives of the research were met, whilst also ensuring that participants could tell their story.

Dahlberg et al. (2008) point out that research interviews are like no other conversations and researchers should avoid everyday ways of conversing during the interview process. The goal of phenomenological interviewing is to support and facilitate the reflection of the phenomenon of interest. The researcher is encouraged to guide the interviewee to deeper layers of meaning, through question and response (Dahlberg et al. 2008).

According to these authors, a successful phenomenological interview is one which enlightens and deepens the understanding of the researcher, but also changes the perspective of the interviewee and enhances their own understanding of their experience. During the interviews it became apparent that parents reflected and explained their reactions and behaviour, particularly when recounting the early days of their journey and their interactions with professionals. However, it may be prudent, in future, to follow up the interviews with a telephone call to explore this further with parents or visit a smaller number of parents on 2 or 3 occasions to find out if their perspective had changed as a result of the interview.

My own perspectives were challenged and changed during the parent interviews. According to van Manen (1990:163):

'Phenomenological projects and their methods often have a transformative effect on the researcher himself or herself. Indeed phenomenological research is often a form of deep learning, leading to
a transformation of consciousness, heightened perceptiveness, increased thoughtfulness and tact…'

(van Manen, 1990:163)

While I had a wealth of experience in working with disabled children, young people and their families, my understanding of their lives very much deepened as a result of the interviews. The interview was indeed like no other conversation or interaction with parents. Because I was there to listen and find out about their experiences in an anonymous way, I found that parents did not hold anything back — they were open, honest and at times brutally frank about the challenges in their lives and their experiences with professionals and services. This was facilitated by my positioning as a researcher rather than a professional. At times, however, I found this emotionally draining, particularly towards the end of interviews or later, when transcribing interviews for weeks on end, a finding also reported by Macdonald and Greggans (2008). I was struck by challenges of the daily lives of these families and humbled by their capacity to cope with what was a difficult, ongoing situation. While positioning myself as researcher allowed parents to talk freely, it also necessarily rendered me powerless to do anything for them in a professional capacity. A number of actions on my own part helped me to deal with the emotional side of researching with these families. For example, drawing on my previous clinical experience, spacing the interviews out, not doing more than one per day, writing a summary of the interview and taking time out for a cup of coffee following the interview all helped to deal with this in addition to sharing experiences with supervisors and other researchers.

The parent interview process

Munhall (2001) suggests conducting a practice interview prior to commencing data collection. This was carried out with the parent of a disabled child that I knew, giving me the opportunity to test out my interview skills, check if the questions could be easily understood and practice using the tape recorder. This practice interview was conducted
in an office setting with one parent, but parent interviews were conducted in parents’ own homes and sometimes involved both parents.

While fathers were invited to take part in the current study, they had very limited input and their participation was often ‘policed’ by mothers who said that they had primary responsibility for the child or that their husband or partner would not have anything to contribute. When couples were interviewed it was often the mother who did all the talking, despite efforts to draw fathers into the interview. Only in one case did both parents participate equally and this may have been because this father worked from home and was very involved in his daughter's daily care.

Arskey and Knight (1999) identify 4 stages of the interview process: 'opening', 'during', 'closing' and 'after' the interview. The interview was usually opened by a friendly but polite approach with some discussion about the weather or the journey there, and thanking participants for inviting me to discuss the research. Often the parent made a cup of tea which helped to build rapport and facilitated introductions. Rapport building is an important mechanism for building trust (Irwin and Johnson, 2005) and many researchers recommend moving from more general, public issues to more personal ones during the course of the interview (see for example, Willig, 2001). This was the technique used here. For most participants, a series of open, closed or focused questions, as advocated by Walker (2011), were then used to assist parents in talking about their experiences (see parent interview schedule Appendix 6).

When conducting research, Dahlberg et al. (2008) recommend giving participants freedom to explore the phenomenon of interest. However, Arskey and Knight (1999) observe that sometimes participants insist on pursuing their own concerns rather than the issues under scrutiny and this sometimes happened in the current study. For example, rather than talking about their participation in decisions, some parents wanted just to talk about the shortcomings of services that they used. At the beginning of one interview the parents said that they had had very little contact with services or professionals but wanted to talk about the 19 years of Disability Living Allowance they had missed out on for their son. This was important to them but the parents had very little to contribute to the
research objectives. Early in another interview one mother handed me a letter from the PSNI and it became obvious that she expected me to be able to resolve her issue of a local man not being charged for sexually abusing her daughter who had Down's syndrome. I made the decision to abandon the interview and instead spent several hours listening to her talk about her situation and ongoing issues with her child. This was the only parent I contacted after the interviews to ensure that she had received appropriate support. The mother told me that she now had a new social worker who was supporting her to resolve and deal with this issue.

In the early stages of data collection I invited parents to choose the time/day of the interview. It soon became obvious that evening interviews were problematic with frequent interruptions from other family members, an issue also reported by Macdonald and Greggans (2008). Sometimes the young person was present, meaning that the parent could not speak as freely as might otherwise have been possible. It also meant that it was difficult to ask about the child or young person's communication or diagnosis as often parents said that they had not told their son or daughter about their diagnosis. Later interviews were conducted during school hours when the house was quiet and child and young people were at school or at a local centre. Sometimes this meant that fathers were less able to take part and although I often offered to return to interview them, this offer was not taken up.

Some parents became emotional during the interviews. This often occurred when parents reflected on the diagnosis of their child, the adjustment of their aspirations for their child and their gradual realization that they would not be there for them in years to come. Arskey and Knight (1999) recommend several ways to deal with this, including acknowledging and accepting any tears by maintaining eye contact; talking through the issues instead of changing the subject; sitting quietly until the interviewee has calmed down, and making a joint decision about how best to proceed. I used all of these strategies, though each situation was dealt with on an individual basis, with sensitivity and caring. If the parent seemed embarrassed to have become emotional sometimes it was better to acknowledge it and move on to something else. Often I asked if they wanted a break or would like to stop the interview, but all parents wanted to continue.
Given their experiences it was not surprising that parents' emotions came to the fore at times. Remembering that those who take part in research often find the process therapeutic and cathartic helped to keep displays of emotion in perspective (Funk and Stajduhar, 2009). Corbin and Morse (2003) note that although qualitative interviewing can cause distress, there is no evidence that this is worse than everyday life or that it requires follow up counselling. Those parents who became emotional were all receiving support from professionals within the Trust and although mechanisms had been negotiated with the Trust for dealing with parents who were struggling to cope, it was felt that, for all parents, no additional action was required.

Interviews were closed by asking parents if they had anything they wanted to add and then by thanking them for their time and for the information that they had provided. Sometimes parents asked if they had given me the right information and it was important to stress that what they had said was important for the results of the study:

PMCN: Well thank you very much that was really useful.

P19: Are you sure?

PMCN: Yes, absolutely.

[P19: parent of a 3 year old with cognitive impairment and autism]

Parents were advised that it would take some time to complete the study but that a summary of the results would be available in due course. The participation of their son or daughter was then discussed. After the interview, the parent often showed me their son or daughter’s bedroom (usually if it had been adapted) or showed me photos of the child or young person and family. It was important to end on a positive note, often responding positively to the photos and emphasizing what they and their child had achieved. After the interview, the parent was sent a card thanking them again for taking part and affirming the value of their contribution.
Phase 3: interviews with children and young people

In the third phase interviews were conducted with 18 disabled children and young people between the ages of 6 and 28 years (see Table 16, p186 for characteristics of children and young people who took part). Interviewing children is challenging, even for the experienced practitioner. Unlike the clinical interview, where the goal of questioning is to make a clinical assessment, the research interview seeks to extricate a deep understanding of the issues for the child or young person (Mack et al. 2009). Interviewing disabled children and young people is particularly challenging because of their physical limitations and their unique ways of communicating and understanding their life world.

These next sections explore the position of the researcher, the location and timing of the interviews and the preparation involved. The process of interviewing children and young people for the study is then set out.

Position of the researcher in the child and young person interviews

As discussed in chapter 4, historical and cultural influences have shaped children’s perception of their inferior position in society, in particular in relation to their interactions with adults. Clearly the onus is on researchers to break down the power imbalance that has been created (O’Kane, 2000). Cree et al. (2002) point out that some researchers attempt to remove the power differential between adult and child completely by attempting to become one of the children. Others maintain that adult power will always be present regardless of the approach used. For example, James et al. (1998) recommend what essentially amount to making friends with the child. A similar approach is proposed by Thomas (2002), based work by Fine and Sandstrom (1998), claiming that the optimum stance is that of a friend who is an adult but one who does not possess the authority of a parent, youth worker or teacher. In this study, I positioned myself as adult researcher as well as someone who could advocate for the child or young person. Renouncing all aspects of being an adult (as suggested by Mandell, 1991), as this seemed unrealistic,
unnatural and potentially confusing for children and young people. Furthermore, it
became evident during the course of the interviews with disabled children and young
people that they built relationships very quickly and befriending them (as suggested by
James et al. 1998) may have been ethically questionable as I would only have contact
with them for a very short period of time.

I introduced myself to children and young people simply as a researcher; I felt that
mentioning my nursing or teaching roles would increase the power differential. Using
participatory methods of research, giving children and young people choice and control
during the interviews and sharing information about likes and dislikes at the start of the
interaction all helped to reduce the potential power relationship. Dressing casually in
jeans and a blouse with minimal make up helped to convey the message that I was there
to listen to the child and not intimidate as might have been the case had I dressed in a
formal manner like a school teacher or professional. Likewise using an appropriate tone
of voice and asking the child or young person where they would like me to sit gave them
power and control over the situation.

Location and timing of the interviews

Eight interviews took place in a centre familiar to the young people concerned. The
remaining ten were interviewed in their own homes. Many researchers highlight the need
to visit disabled children and young people more than once in the conduct of research in
order to find out about their way of communicating and to identify optimum,
individualised methods for data collection (Beresford and Sloper, 1999; Marchant et al.
1999; Watson et al. 2000; Lewis, 2001; Crisp et al. 2002; Marchant et al. 2002; Stalker
I met children and young people belonging to the Disabled Children and Young People’s
Participation Project on several occasions prior to data collection. Because of the time
delay between introducing myself to the group at the very start of the research before
ethics approval and conducting the field work, I visited the group to remind them who I
was and to reinforce the aim of the research and that their contribution was important. By
the time they were interviewed I had gotten to know the young people and was familiar with their way of communicating.

Eight out of the 10 children and young people who were visited at home were seen twice. The remaining two children and young people were seen only once. Firstly, Suzanne, an autistic young person, communicated solely through her mother and I was unsure that she wanted to contribute to a further visit. Secondly, David, who had Down's syndrome, was keen to engage in the rapport building activities and play with me, but made it clear that he did not want to answer any of the research questions or talk about any of the professionals he met. Therefore a second visit was not warranted.

The first visit was an introductory visit to meet the child or young person, to build rapport, find out if they were interested in taking part and gain assent or consent for participation in the research. This first visit also provided an opportunity to learn about the child or young person's way of communicating and to determine which data collection tools/participatory methods were most suited to and preferred by the child. Data collection was conducted during the second visit. Visits lasted for no longer than an hour. Although this was sufficient for data collection it was at times evident that the child or young person had got tired or began to lose concentration and therefore the interview was brought to a close. Morris (1998) recommends conducting multiple visits over a short time frame so that the child remembers the purpose of the study and the researcher remembers how to communicate with the child. Kelly (2007) also points out that conducting a series of shorter, more frequent visits is ethically important in order to ensure that children do not tire and lose concentration. Thus, in the current study, follow up visits occurred within a week. The second visit started by finding out what the child or young person remembered and identifying the need to recap on what happened the last time. Although many children and young people in the study recognised me and knew my name, some had great difficulty in recalling what the study was about or why I had come to see them again, an issue also reported by Lewis (2001):

**PMCN:** Do you remember what the project's about? I know there's a few different projects at the minute?
JACK: No, I can't remember cause it's been a while.

PMCN: That's fine, so I'll tell you a bit about it.

[JACK: a 23 year old with autism]

Preparation for interviewing disabled children and young people

Effective planning and preparation are key issues when researching with disabled children and young people (Morris, 1998; Marchant et al., 1999; Holme and Hanmore, 2001; Lewis, 2001; Stalker and Connors, 2003; Kilikelly et al. 2004; Harrison et al. 2005; Rabiee et al. 2005; Kelly, 2007). In this study, information about the child or young person's communication method, their likes or dislikes and (where possible) the professionals or services that they would be familiar with was collected from parents or the leader of the DCYPPP. This prior information served 3 purposes: firstly it helped build rapport with children and young people, secondly it helped tailor the data collection tools to individual needs and thirdly it helped validate my understanding of children and young people. Lewis (2001) points out that it is important to be aware of and if possible use communication methods that the child is familiar with and currently uses, for example Makaton or BSL. A small number of parents said that their child used Makaton but this seemed to be in school only. When asked, these parents had no objection to me using Boardmaker© symbols and indeed all the children who used them in the research used them in school. Again, an individualised approach was required; one young man did not want to use the symbols as they reminded him of school. Most of the young people from the DCYPPP did not want to use symbols or any other tools as they were used to talking and they gave the impression that it would be beneath them. These symbols were not a necessary part of the data collection process per se. Rather they acted as an alternative mechanism whereby children and young people with communication impairment could express their views. Therefore it was not essential that participants used them (see Table 16 for data collection methods used by children and young people in the study).
The interview process

Because of the diversity of the children and young people, in terms of age and impairment, 3 interview schedules were prepared, a strategy used by previous researchers (see, for example, Kilkelly et al. 2004; Kelly, 2007). These schedules asked the same questions in an increasingly complex format, whilst providing a range of methods that would meet the communication and physical needs of individuals (see Appendix 7). These acted as an aide memoir, rather than a strict schedule, to preserve and foster a relaxed and natural approach to the interview. Again, both open ended and more structured questioning techniques or a combination of these were used in order to assist the child to make their views and experiences heard (Maggs-Rapport, 2000). Irwin and Johnston (2005) found that young children had difficulty with open questions, particularly at the beginning of the interview. In order to reassure children and young people that they could answer the questions, my interviews started with closed questions before moving to more open questions. Disabled children often do not use lengthy narratives to express themselves (Boylan, 2009) and this was also the case here. Prompts were used effectively to assist children and young people during the course of the interviews.

The next section addresses issues arising during the interviewing process, including building rapport, the use of participatory methods of research, understanding the children and young people, promoting choice and control, dealing with sensitive information and maintaining rigour within the course of the interviews.

Building rapport with children and young people

Children and young people had received written information and a DVD prior to my arrival (see next chapter for details of these) and so rapport building started even before I met them. Rapport was further developed during the first introductory meeting (see Lewis, 2001; Stalker and Connors, 2003; Kelly, 2007). A number of resources were also used to help build rapport during this meeting – the business cards (see Appendix 8), a
life map or poster (see Figure 11) where children or young people were asked to identify people who were important to them or pictures or photos of things they liked/disliked used with or without the like/dislike boxes (see Figure 14a). A proportion of likes or dislikes pictures, symbols and photos were based on prior information (for example about TV programmes, cartoon characters, foods, animals) gained from parents which helped me to tune into the child’s world and tailor data collection tools to the needs of individual children and young people. A certain amount of sensitivity was required here however. For example, some children were exclusively tube fed and it would not have been appropriate to ask about food likes/dislikes; those with autism often had phobias, for example about dogs or babies. In another family the pet cat had recently died causing great upset. Sometimes children or young people took the initiative– Catherine, a 15 year old young person had looked out a photo album with photos of her as a baby and her family to show me when I arrived. These strategies were highly effective and indeed it became evident just how important they were in helping to build rapport in the initial stages of the interviews. The life maps in particular shed important light on the lives of disabled children and young people. They rarely identified friends as important people in their lives – parents, siblings and close family members were most commonly identified. Many who attended the DCYPPP identified the leader of the group as an important person in their life. Similarly, when young people spoke of difficult issues it was often this person or another staff member from the group with whom the young person first discussed the issue. Finally, it was also evident that most of the young people who completed the life map had few social outlets outside their day centre or work placement and fewer than younger participants who were still at school.
Just as it was important to build rapport with the child, it was equally vital to plan for and adhere to an appropriate exit strategy as highlighted by (Lewis, 2001). On the second visit, I reminded children and young people that this was the last time I would be seeing them and this proved to be important as they were quick to form attachments:
PMCN: OK is there anything you want to ask me about it [means research]?

LAUREN: I love it. I love working with you.

PMCN: That’s great. I’m glad to hear it.

[LAUREN: a 23 year old with cognitive impairment]

In another case, David, an 8 year old boy kept asking me to stay for tea and became quite upset when I said I could not because I had to go and see another boy. When I was leaving he was still asking and his mother told him that I could stay for tea the next time, which he seemed to accept. While this pacified him at the time, I knew I would not be back.

The use of participatory research methods

Since the development of the sociology of childhood, there has been an increased onus on researchers to adopt participatory practices with children in two ways; firstly to facilitate their contribution to research agendas and secondly to ensure that they participate in research in more equal ways (Lomax, 2012). The latter has led to the development of creative methodologies that adopt the language and communication mechanisms preferred by children and young people in order to ensure that they are not passive recipients, but active participants in the research process. They are now considered to be standard practice, and have been widely discussed in research literature, for example, the use of vignettes, written or picture prompts, drawing and role play (Hill, 1997; Punch, 2002; Coad, 2007). Such materials have been positive not only in terms of eliciting children’s views in ways they prefer and can understand, but they have also gone some way to redress the power imbalance between children and adults as researchers (Barker and Weller, 2003), and this was very much in evidence in the current research.

Furthermore, using creative tools may help disabled children to express their views in a variety of ways and facilitate their communication. Previous researchers have used
Talking Mats© when eliciting the views of disabled people with little speech, no speech or a those with a degree of cognitive impairment (see for example, Preece, 2009; Mitchell, 2010, Mitchell and Sloper, 2011). Developed by speech therapists Lois Cameron and Jill Murphy (Cameron and Murphy, 2002), Talking Mats© is an interactive, communication resource that uses picture communication symbols. Consisting of 3 elements - a topic, feelings and a number of options, it represents potential views in a straightforward format.

In the current study, an activity based tool kit was compiled, based on previous research that sought the views of disabled children and young people (see Appendix 9 for summary of resources used by previous researchers eliciting disabled children and young people's views about services). The toolkit was refined in terms of children and young people's preferences and feedback from the 2 young people acting as advisers for the research. For example, children and young people did not chose certain activities that were originally available (see Table 15 for all tools planned from the outset, those not used in the study and the advantages and limitations of these). Researchers have recommended offering children a choice of multiple methods in qualitative research (see for example, Darbyshire et al. 2005; Hill, 2006; Kelly, 2007; Coyne et al. 2009), and it was evident that a 'one size fits all method' would be inappropriate. Tools used for each child or young person in the research was based upon my first meeting and interactions with them, their own preferences and on parents' advice. The advice of parents was important - while some young people wanted to use some tools geared towards much younger children this would have been inappropriate for others who did not have a cognitive impairment. It was important not to offend or patronise young people who wanted to do a talking interview.
Table 15: Toolkit developed for data collection with disabled children and young people.

<table>
<thead>
<tr>
<th>Tool</th>
<th>Utility in the study</th>
<th>Advantages</th>
<th>Limitations</th>
</tr>
</thead>
<tbody>
<tr>
<td>Art-based/creative materials/play</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Poster/life map/art materials</td>
<td>Used in a variety of ways.</td>
<td>Child or young person and I could do it together if necessary and it was enjoyable.</td>
<td>Many participants were unable engage with this due to their impairments. Boys tended to dislike art or writing activities.</td>
</tr>
<tr>
<td>'All about me' booklet</td>
<td>Not used - children and young people did not choose it.</td>
<td>Used previously to build rapport and find out about the child or young person.</td>
<td>Not appealing for some children and young people as it looks like a school based activity and potentially unsuitable for those with physical impairment.</td>
</tr>
<tr>
<td>Play house/hospital</td>
<td>Used to explore participation/ experiences at home and in hospital.</td>
<td>Fun and appealing to younger children.</td>
<td>The pieces were small rendering handling them difficult for some participants. Some children just wanted to play rather than answer questions.</td>
</tr>
<tr>
<td>Plasticine/play doh</td>
<td>Used minimally.</td>
<td>Fun for some children.</td>
<td>Again children could be distracted and simply wanted to play.</td>
</tr>
<tr>
<td>Decision making grid</td>
<td>Not used. Children and young people did not choose it.</td>
<td>Potentially provided a visual representation of participation.</td>
<td>Children and young people needed a certain level of cognitive ability in order to use it.</td>
</tr>
<tr>
<td><strong>Pictorial or verbal cues</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Photographs and pictures of services and professionals</td>
<td>Used to identify which services children and young people attended, who they met and to frame discussion.</td>
<td>Useful in terms engaging participants and providing an additional cue to support verbal communication.</td>
<td>These were not specific to each child or young person's experience as this would have been extremely time consuming given the large number of services</td>
</tr>
<tr>
<td><strong>Word choice/sentence completion using laminated cards</strong></td>
<td><strong>Used with some young people.</strong></td>
<td><strong>Provided a framework that participants could use, particularly those with little speech.</strong></td>
<td><strong>Limited in terms of few options and depth in the data.</strong></td>
</tr>
<tr>
<td>---------------------------------------------------------</td>
<td>---------------------------------</td>
<td>-------------------------------------------------</td>
<td>-------------------------------------------------</td>
</tr>
<tr>
<td><strong>Vignettes in the form of pictures</strong></td>
<td><strong>Not used as difficult to access vignettes featuring disabled children or young people and time consuming to produce.</strong></td>
<td><strong>Can be used to generate discussion.</strong></td>
<td><strong>Some disabled children or young people may not be able to make the link between the person in the picture and themselves.</strong></td>
</tr>
<tr>
<td><strong>I'll go first toolkit (The Children's Society, no date)</strong></td>
<td><strong>Not used as the 2 young people felt that the symbols were outdated.</strong></td>
<td><strong>Previously used tool that explores participation. Potentially easy to adapt to different situations.</strong></td>
<td><strong>Use of symbols that are not currently used.</strong></td>
</tr>
<tr>
<td><strong>Feelings faces</strong></td>
<td><strong>Used. It was important to provide blank spaces for other feelings to be expressed.</strong></td>
<td><strong>Encourage children and young people to express their feelings and facilitates communication in those with little or no speech.</strong></td>
<td><strong>Some symbols represent more than 1 feeling. Symbols for 'happy' and 'sad' also represent 'yes' and 'no'.</strong></td>
</tr>
</tbody>
</table>

**Resources to help children indicate likes/dislikes, yes/no and agreement/disagreement or a little/alot**

<table>
<thead>
<tr>
<th><strong>Post box</strong></th>
<th><strong>Used.</strong></th>
<th><strong>Fun activity that helped build rapport as well as data collection.</strong></th>
<th><strong>Limited in terms of depth in the data collected.</strong></th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Yes/no cards</strong></td>
<td><strong>Used.</strong></td>
<td><strong>Fun activity that helped build rapport as well as data collection.</strong></td>
<td><strong>Limited in terms of depth in the data collected.</strong></td>
</tr>
<tr>
<td><strong>Talking Mats©</strong></td>
<td><strong>Used with some participants.</strong></td>
<td><strong>Well validated tool used to assist those with</strong></td>
<td><strong>Limited in terms of depth in the data collected.</strong></td>
</tr>
<tr>
<td>Stars scale</td>
<td>Not used. Not chosen by children and young people.</td>
<td>Simple mechanism to assist children and young people to express the strength of their views.</td>
<td>Some children and young people with cognitive impairment may misinterpret this scale.</td>
</tr>
<tr>
<td>-------------</td>
<td>--------------------------------------------------</td>
<td>--------------------------------------------------------------------------------</td>
<td>----------------------------------------------------------------------------------</td>
</tr>
</tbody>
</table>
A variety of activities from the toolkit were used during the visits with children and young people. During the first, introductory visit this included the completion of a life map (see Figure 11), poster making with art materials (see Figure 12) or yes/no or like/dislike boxes (see Figure 14a) with picture/symbol cards. The child or young person was advised that I could help with any of these activities and it was important to ask so that they were not left feeling inadequate:

PMCN: Well how do you feel about doing something like this [means the life map]?

JACK: Yep, that would be fine.

PMCN: Do you want to write it or do you want me to write it?

JACK: Could you write it because my spelling's atrocious. The only thing I know how to spell is either Top Gear or something like that on U tube.

PMCN: Do you like Top Gear?

JACK: I never miss an episode

[JACK: a 23 year old with autism]

During subsequent data collection visits, one or more of the following was used: used: art or craft materials (see Figure 12), the play hospital (see Figure 13) with or without play doh, like/dislike boxes (see Figure 14a), yes, no or don't know symbols (see Figure 14b) the use of boardmaker symbols on laminated sheets (adapted from Sloper et al. 2009 -see Figure 15 and Appendix 10), Talking Mats (see Figure 16), feelings faces (see Figure 17a and 17b), or just talking. Boardmaker symbols were also used on the advice of PEAT, a local autism charity along with advice sought from Lois Cameron, who devised Talking Mats along with Joan Cameron from the University of Stirling.

Methods used for each child or young person who took part are shown in Table 16 along with their means of communication. This is described as children and young people having 'no speech' (they did not use any verbal communication), 'verbal' (they used
speech fully), 'verbal with limited expression' (they used speech but this was limited by their cognitive impairment and at times they found it difficult to articulate what they wanted to say), 'little speech' (their vocabulary was very limited and they spoke in short phrases) or 'very little speech' (single words used).

Figure 12: The use of art and craft materials.

[Picture by EOIN: a 6 year old with autism]
Figure 13: The play hospital.

Figure 14a: Like/dislike boxes.

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Figure 14b: Yes, no or don't know symbols.

Figure 15: Laminated cards with boardmaker symbols (adapted from Sloper et al. 2009).
Figure 16: Talking Mats© (Cameron and Murphy, 2002).

Figure 17a: Feelings faces.

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Figure 17b: feelings faces.

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Table 16: Data collection methods used for each child/young person in the study.

<table>
<thead>
<tr>
<th>Name</th>
<th>Age</th>
<th>Impairment</th>
<th>Communication method</th>
<th>Parent interviewed</th>
<th>Visit 1</th>
<th>Visit 2</th>
</tr>
</thead>
<tbody>
<tr>
<td>Emma</td>
<td>23</td>
<td>Cognitive</td>
<td>Verbal with limited expression</td>
<td>no</td>
<td>Life map</td>
<td>No visit</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td>Talking interview</td>
<td></td>
</tr>
<tr>
<td>Jack</td>
<td>23</td>
<td>Autism</td>
<td>Verbal</td>
<td>no</td>
<td>Life map</td>
<td>No visit</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td>Talking interview</td>
<td></td>
</tr>
<tr>
<td>Jason</td>
<td>24</td>
<td>Physical Cognitive</td>
<td>Verbal with limited expression</td>
<td>no</td>
<td>Life map</td>
<td>No visit</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td>Talking interview</td>
<td></td>
</tr>
<tr>
<td>Orla</td>
<td>13</td>
<td>Physical</td>
<td>Verbal with very little speech</td>
<td>no</td>
<td>Life map</td>
<td>No visit</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td>Talking Mats with symbols</td>
<td></td>
</tr>
<tr>
<td>Emily</td>
<td>28</td>
<td>Cognitive</td>
<td>Verbal</td>
<td>no</td>
<td>Life map</td>
<td>No visit</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td>Talking interview</td>
<td></td>
</tr>
<tr>
<td>Lauren</td>
<td>20</td>
<td>Cognitive</td>
<td>Verbal with limited expression</td>
<td>yes</td>
<td>Life map</td>
<td>No visit</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td>Talking interview</td>
<td></td>
</tr>
<tr>
<td>Suzanne</td>
<td>15</td>
<td>Physical Cognitive Autism</td>
<td>Verbal with limited expression</td>
<td>yes</td>
<td>Pictures of likes/ slikes</td>
<td>No visit</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td>Life map</td>
<td></td>
</tr>
<tr>
<td>Talking Mats with symbols</td>
<td>Life map</td>
<td>Like/dislike pictures</td>
<td>Life/Dislike boxes with pictures</td>
<td>Poster art</td>
<td>Talking Mats with feelings faces</td>
<td>Play hospital</td>
</tr>
<tr>
<td>--------------------------</td>
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<td>---------------------------------</td>
<td>-----------</td>
<td>---------------------------------</td>
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</tr>
<tr>
<td>Verbal with little speech</td>
<td>yes</td>
<td>yes</td>
<td>yes</td>
<td>no</td>
<td>no</td>
<td>no</td>
</tr>
<tr>
<td>Physical</td>
<td>20</td>
<td>15</td>
<td>12</td>
<td>27</td>
<td>23</td>
<td>18</td>
</tr>
<tr>
<td>Cognitive</td>
<td>20</td>
<td>15</td>
<td>12</td>
<td>27</td>
<td>23</td>
<td>18</td>
</tr>
<tr>
<td>Autism</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Cognitive</td>
<td></td>
<td></td>
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</tr>
</tbody>
</table>

| Michael                  |         |                       |                                 |           |                                 |              |         |                                 |
|                          |         |                       |                                 |           |                                 |              |         |                                 |
| Catherine                |         |                       |                                 |           |                                 |              |         |                                 |
|                          |         |                       |                                 |           |                                 |              |         |                                 |
| Louise                   |         |                       |                                 |           |                                 |              |         |                                 |
|                          |         |                       |                                 |           |                                 |              |         |                                 |
| Natalie                  |         |                       |                                 |           |                                 |              |         |                                 |
|                          |         |                       |                                 |           |                                 |              |         |                                 |
| Mary                     |         |                       |                                 |           |                                 |              |         |                                 |
|                          |         |                       |                                 |           |                                 |              |         |                                 |
| Mark                     |         |                       |                                 |           |                                 |              |         |                                 |

| Physical                 | 20      | 15                    | 12                              | 27        | 23                              | 18           |         |                                 |
| Cognitive                | 20      | 15                    | 12                              | 27        | 23                              | 18           |         |                                 |
| Autism                   |         |                       |                                 |           |                                 |              |         |                                 |
| Cognitive                |         |                       |                                 |           |                                 |              |         |                                 |

<p>| Michael                  |         |                       |                                 |           |                                 |              |         |                                 |
|                          |         |                       |                                 |           |                                 |              |         |                                 |
| Catherine                |         |                       |                                 |           |                                 |              |         |                                 |
|                          |         |                       |                                 |           |                                 |              |         |                                 |
| Louise                   |         |                       |                                 |           |                                 |              |         |                                 |
|                          |         |                       |                                 |           |                                 |              |         |                                 |
| Natalie                  |         |                       |                                 |           |                                 |              |         |                                 |
|                          |         |                       |                                 |           |                                 |              |         |                                 |
| Mary                     |         |                       |                                 |           |                                 |              |         |                                 |
|                          |         |                       |                                 |           |                                 |              |         |                                 |
| Mark                     |         |                       |                                 |           |                                 |              |         |                                 |</p>
<table>
<thead>
<tr>
<th>Name</th>
<th>Age</th>
<th>Diagnosis</th>
<th>Communication</th>
<th>Engaged in Activity</th>
<th>Activity Description</th>
</tr>
</thead>
<tbody>
<tr>
<td>Andrew</td>
<td>6</td>
<td>Physical, Cognitive</td>
<td>No speech BSL</td>
<td>yes</td>
<td>Like/dislike boxes with pictures</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Sensory</td>
<td></td>
<td></td>
<td>Like/dislike boxes</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td>Feeling faces</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td>Play hospital</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td>Play doh</td>
</tr>
<tr>
<td>Sinead</td>
<td>10</td>
<td>Physical</td>
<td>No speech</td>
<td>yes</td>
<td>Like/dislike boxes/symbols</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td>Talking</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td>Mats/laminated cards</td>
</tr>
<tr>
<td>Eoin</td>
<td>6</td>
<td>Autism</td>
<td>Verbal</td>
<td>yes</td>
<td>Like/dislike boxes with pictures</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td>Poster/art</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td>Like/dislike boxes</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td>Laminated cards</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td>Play hospital</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td>Play Doh</td>
</tr>
<tr>
<td>Conor</td>
<td>9</td>
<td>Autism</td>
<td>Verbal</td>
<td>yes</td>
<td>Like/dislike boxes with pictures</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td>Poster/art</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td>Did not take part in further visit</td>
</tr>
<tr>
<td>David</td>
<td>8</td>
<td>Physical, Cognitive</td>
<td>Verbal with limited expression</td>
<td>yes</td>
<td>Like/dislike boxes with pictures</td>
</tr>
</tbody>
</table>
While some researchers have developed data collection tools aimed specifically at different age groups (for example, Coad et al. 2009), disabled children and young people may find it difficult to engage with some of these activities due to their impairment. In this study, data collection tools were selected on the basis of children and young people’s preferences and, to a lesser degree, on the advice of parents. The preparation of a wide range of resources in this way facilitated flexibility and responsiveness to the needs of individual children (see Kelly, 2007). However, as reported in previous studies (see Rabiee et al. 2005), it was evident that children and young people were not used to being asked their views. It was important to be flexible in terms of using none (Watson et al. 2006), some or all of the activities.

Although these materials provided valuable data in themselves, they also provided a conduit to explore relevant issues further. Stalker and Connors (2003) maintain that such materials act as a distraction when children talk about their feelings, help maintain the child’s interest and facilitate communication with those who use alternative means of communicating. This too was evidenced in this study. Children clearly enjoyed the tools used and this helped engage them and maintain their interest in the topics explored:

PMCN: What did you like best of everything we’ve done? Did you like the boxes or the [laminated] cards or the hospital?

EOIN: I liked everything.

PMCN: You liked everything… Well do you want to do a quick drawing and I think that’s us.

EOIN: Yeah!

[EOIN: 6 year old boy with autism]

It was important that the research questions were addressed but it was also important to make the sessions fun in order to enter into the world of the child or young person and communicate with them effectively. My previous experience of working with children and young people came to the fore here with a child with very little speech:
YP picks a symbol but I can’t see it as her hand is on top of it

**PMCN**: Who’s that? Do you know who it is? You do! [laughs] Let me guess who’s missing… The nurse? Is it the nurse?

**ORLA**: [laughs]

[ORLA: 13 year old with physical impairment]

Children and young people in the study, who often faced significant challenges in their lives, often had a great sense of humour, as evidenced in this interview conducted with a young man the day after the royal wedding:

**JASON**: I’m surprised you’re not called Kate.

**PMCN**: What? [not understanding what the young person means].

**JASON**: I’m surprised that you’re not called Kate Middleton, ’cause you work at Queens [laughs].

**PMCN**: [laughs, realising what young person means] Well what did you think of the wedding then – did you watch it?

**JASON**: Yeah, I just watched the highlights [laughs]

**PMCN**: The highlights.

**JASON**: Aye [laughs].

**JASON**: 24 year old with physical and cognitive impairment

**Understanding children and young people**

Stalker and Connors (2003: 27) maintain that talking with disabled children is often no different than communicating with any other child, and the most important rule is to ‘see the child as a child first and disabled second’. Nevertheless, they reported difficulty, along with a number of other researchers (see for example, Minkes et al. 1994; Crisp et al. 2002; Preece, 2002; Marchant et al. 2002; Harrison et al. 2005; Kelly, 2007), in understanding the child or young person. Despite having undertaken additional, advanced training in communicating with disabled children and young people, at times it
was very difficult for me to understand those who took part in the study. McNeilly (2012) points out that communicating with disabled children and young people takes additional time for all those concerned and recommends the following: using a calm, unhurried approach, checking back with the child or young person if you are unsure and not pretending that you understand when you don’t and these strategies were used in this study. In the following example, a 13 year old girl with a physical impairment and very little speech insisted on doing the interview on her own and I found it difficult to make out what she was saying. It was important, within the auspices of disability theory, to accept this as my own, rather than her problem. As this was could be tiring for myself as well as the child or young person, it was necessary to check if she needed a rest or wanted to end the session:

PMCN: I think we’re doing really well but I’m quite slow at understanding you. So if you’re getting tired or you want somebody in to help will you tell me?

ORLA: [nods]

[ORLA: 13 year old with physical impairment]

A number of additional resources about communicating with children were used during the interviews. For example, Winter (2011) identifies 4 types of responding skills when communicating with children: reflecting, paraphrasing, clarifying and summarising. These strategies were invaluable during the interviews as a mechanism for checking my understanding as well as exploring children and young people’s experiences in as much depth as possible. Clarifying and reflecting, in particular, were frequently used to check my understanding of children and young people's individual way of communicating:

PMCN: And what’s your dog’s name?

ORLA: [unclear]

PMCN: Mike? [clarifying] No.

ORLA: [unclear] [unclear] [unclear]

PMCN: Are you spelling it for me?

ORLA: Yeah.
PMCN: What's the first letter again?

ORLA: R

PMCN: R? [clarifying]

ORLA: Yeah

PMCN: [writes m] What's the next letter?

ORLA: [unclear]

PMCN: I? [clarifying]

ORLA: No [unclear]

PMCN: E? [writes E] [clarifying]

ORLA: Yeah, [unclear]

PMCN: K? [clarifying]

ORLA: [unclear] [unclear]

PMCN: Do you want me to go and get someone to help?

ORLA: No [unclear]

PMCN: No [reflecting]

ORLA: [unclear]

PMCN: X? [clarifying]

ORLA: Yeah [excited]

PMCN: REX? [both excited that I have got it] [clarifying]. Brilliant! You’re great Orla! You’re very patient with me! Course it’s a dog’s name isn’t it? What sort of a dog is it is it small or big?

[ORLA: 13 year old with physical impairment]

This was also useful for tape recording and transcribing the interviews later. Paraphrasing was also used to indicate that I had understood the content of what the child or young person had said:

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[Jason talks about problems he has been experiencing]

PMCN: So you wouldn’t talk to your parents about things like that, you would rather talk to a professional [paraphrasing].

JASON: Yeah. I have come to the conclusion that I have felt like a burden on my parents at times I have, I’m very what do you call, I’m very … it’s not a good idea to let it build it up inside you…

[JASON: 24 year old with physical and cognitive impairment]

Managing the presence of others

The presence of parents during interviews with children has been discussed by a number of authors (see for example, Gardner and Randall, 2012). While parental presence can be helpful in terms of parents playing an interpretive role, particularly where disabled children and young people are concerned (see Marchant et al. 1999; Lewis, 2001, Turner, 2003) and providing support, it can also be a disadvantage. Some researchers have reported that, at times, parents dominate the interview and speak for the child (Marchant et al. 1999; Lewis, 2001) or children may censor what they say (Turner, 2003). Marchant et al. (1999) advised to continue to engage directly with the child, to ask the child to comment on what the parent said and to ask the child what they thought and this was effective in managing such situations. In their research, Lewis (2001) and Stalker and Connors (2003) explained to parents that the researchers would like to visit children on their own and this was the strategy adopted in the present study and addressed in the parent information sheet. However, I emphasised to parents that if they or their son or daughter was not happy with this arrangement then this was no problem. Most parents, children and young people had no issue with the parent not being present. All parents stayed for the first visit when their child was interviewed at home but only 6 parents stayed during data collection in the second visit because when asked the young person said they wanted their mother to be present. When parents did stay, the majority interpreted, prompted or encouraged, but without speaking for them. Orla, a 13 year old,
who had very little verbal communication (that was very difficult to understand) insisted on doing the interview on her own. I had met Orla on a few occasions and said at the start of the interview that I told her that I thought I would need help to understand her but we would see how it went. Orla made an incredible effort to help me understand her and we were able to conduct the interview without additional help. It seemed that she was proud to have taken part in the research on her own and I was also pleased that I had been able to use the tools I had brought to enable me to give young people like her a voice in the research.

Siblings were sometimes present when I arrived at the house and this required sensitive handling. Lewis (2001) noted that, in her research, siblings needed to be distracted and provided with their own activities before conducting the session. In one case, when I looked up through an open door the younger sibling was watching her sister making a picture from between the banisters of the stairs. I said to the mother that she could do a picture as well, as it was just an introductory session, and she joined in. The older sibling was also invited but preferred to just watch. I was careful to give them both a sticky badge when I was leaving. On another occasion a 12 year old sibling played an important interpretive role. Conor, a 6 year old with Down’s syndrome who was being interviewed was deaf and used signs and his mother was registered blind. Although the mother could make out the Conor’s signing movements she was unable to see the pictures or symbols I was using. The sister verified if Conor would be familiar with certain pictures and interpreted his signing. Although there were 2 sisters, I later learned that the other one hadn’t been allowed into the room. On the second visit I ensured that the second sibling helped me and both sisters were given a small gift for their contribution to the research.

**Choice and control: striking a balance**

During the interviews it was important to give children choice about which tools they wanted to use and also give them control over what came next. This was important, not only in terms of assent or consent but also to keep them engaged and interested in what we were doing. It was clear that they felt empowered by this and also felt able to say when they had had enough:
PMCN: Is there anything else you want to say about going to the doctor?

EOIN: Finished.

PMCN: That one’s all finished, ok. That’s very good. Will we do another one [picture]? Are you ready?

EOIN: Yeah, yeah one more.

PMCN: Which one? You choose.

[EOIN: 6 year old with autism]

Previous researchers have discussed issues of power and control when interviewing children (see for example, McLeod, 2007 and Macdonald and Greggans, 2008). There was, however, a limit on providing choice in this study and it was important to be clear about the purpose of the visit:

EOIN: Are we going do some of the stuff again? [sounds excited].

PMCN: We’re going do some of the stuff again but we’re going talk a wee bit about some of the people that you meet... so do you want to use the boxes again or do you want to sort into like and not like piles?

EOIN: I want to do the boxes.

PMCN: You like the boxes. So we could do the boxes with these [pictures].

EOIN: Yeah, and after we can do some pictures.

PMCN: You’d like to do some pictures.

EOIN: After.

PMCN: After, yes.

EOIN: And then we can do the play mobil.

PMCN: Yes, cause you really liked it didn’t you?-But remember that I want to ask you some questions today and that’s very important; but
it’s not like school -so it’s not right or wrong I just want to know what you think.

[EOIN: 6 year old with autism]

Dealing with sensitive information

Although the objectives of the research did not address sensitive issues as such, building rapport and spending time with disabled children and young people inevitably resulted in sensitive issues being disclosed, most often when the child or young person was interviewed alone. Those interviewing with children need to ‘expect the unexpected’ (Macdonald and Greggans, 2008:3127) and children and young people in the research at times raised sensitive issues in what appeared an offhand manner when I least expected it. At times this occurred early in the interview when they were completing the life map and I had just met them. In the following case, I gave Jack the opportunity to talk further by probing:

JACK: My Mum [PMCN writes her on life map], my mother and my dad, even though my mother and my dad are being divorced.

PMCN: They’re being divorced or they are divorced?

JACK: It’ll be final in July.

PMCN: So do they live separately then?

JACK: Yeah, my dad lives on [street] and I live on [street], plus my mother’s got a boyfriend.

[JACK: a 23 year old with autism]

Jack said he got on well with his mother’s boyfriend and I did not see any need to probe further. Davis (2009b) found that his ability to deal with sensitivities developed over the course of the research with disabled children and young people. As the interviews progressed, my interview skills developed, including dealing with difficult issues. It became evident that it was important to acknowledge what children and young people
had to say, pause to give them an opportunity to disclose further, and move on when appropriate. It was not uncommon for young people to talk about family members who had died, when completing the life map as the following example shows:

EMILY: Do you know the way, I forgot to tell you, do you know the way my dad passed away?

PMCN: Oh, I didn’t know that.

EMILY: My dad died, [foster mum’s husband] died so we were all upset.

PMCN: How long ago was that then?

EMILY: [unclear] Me and Jack had to go to [town] but we couldn’t go- we had to go to the funeral and we were all like upset [unclear].

PMCN: So that was a difficult time for you.

[EMILY: 28 year old with cognitive impairment]

It was important to explore with children and young people if they wanted these family members included on the life map and where they should be positioned. On another occasion near the start of the interview, Suzanne, a 15 year old girl said that she had been looked after by a children’s community nurse who had recently died unexpectedly. At first I didn’t make the connection from the nurse’s Christian name but her mother clarified it. When asked which professionals she had met, Suzanne indicated the following:

SUZANNE: I had [nurse].

PMCN: Ok [not recognising the significance of this].

MUM: She said she had [names nurse who died].

PMCN: Oh right [nods realising].

SUZANNE: She died.
PMCN: Yes she did- that was very sad wasn’t it?

CYP7: mm...

[SUZANNE: 15 year old with physical, cognitive impairment and autism]

This was a difficult situation for me from a personal point of view as I had known the nurse concerned, although I hadn’t considered the possibility of this arising with children or young people in the research. As the mother was present I felt that it was important to take her lead and as she didn’t pursue this further, I didn’t think it was appropriate to do so. Because of Suzanne’s autism, she communicated solely through her mother and would not make eye contact with me and this compounded the situation. On reflection I could have used the feelings faces and asked her how she felt about it. As a children’s nurse I would have been skilled to explore this with Bronagh given my previous work in the area of palliative care, however, as a researcher I felt it was beyond my role.

Other children and young people waited until near the end of the interview to share issues that they were worried about. Orla, who had very little speech, was determined to share an issue at the end of the interview, that was completely unrelated to what we had been discussing:

ORLA: My granda

PMCN: Your granda

ORLA: My Granda …have… [unclear]

PMCN: What’s the second word?

[several more attempts]

PMCN: Your granda…

ORLA: [unclear, yp really trying to tell me something]

PMCN: What’s that word at the end? Could you spell that for me?

ORLA: I.. don’t...know.
PMCN: Is it a very important word? Do you want me to get help with that or will we let it go? [really not understanding at all]

ORLA: Granda has [unclear]

PMCN: Cancer?

ORLA: Yeah

PMCN: Granda has cancer.

ORLA: Yeah

[ORLA: 13 year old with physical impairment]

This was something that was clearly worrying the Orla and yet it was difficult to explore because of my own limitations in understanding her. I used the feelings faces to explore how she felt (she was worried and sad) and ensured that she was talking to someone else about her concerns. Her mother was communicating well with her and telling her what was happening, but it was a stressful situation for Orla. Dalberg et al. (2008) suggest that, when facing anxiety provoking situations in phenomenological interviews, it is difficult to remain open despite the temptation to close off, fail to listen or turn away. This was apparent on further discussion with this young person and at times it was hard to hear what children or young people had to say. Arskey and Knight (1999) point out that even mundane research topics can elicit sensitive material and as such, researchers need to be prepared for this regardless of the research questions.

Reliability and validity

A number of techniques were used to ensure that the data collection methods used with children and young people were reliable and valid. Morris (1998) found it useful to repeat what the child communicated for the purposes of the tape recording, and this also served as a useful mechanism to check my understanding. Similarly, Kelly (2007) used
reflective techniques to ensure the response of the child matched the researcher's understanding of what was communicated.

Prior information was also used as a mechanism to ensure validity during the data collection phase, an approach previously used by Lewis (2001) and Rabiee et al. (2005). Parents were asked to identify their son or daughters' likes/dislikes and then these were used in the initial stages of the interview to check my understanding of the child or young person. For example, when children and young people placed pictures or symbols in the like/dislike boxes or sorted them using Talking Mats©, I knew that I had understood correctly and that the child or young person understood what they were required to do. Discrepancies were checked first with the child or young person and then with the parent who indicated if there were validity issues. Sometimes parents provided an alternative explanation for a discrepancy, for example that their child used to like something when they were younger but didn't now.

Being cognisant of children's body language, to ensure that it was consistent with verbal answers or cue cards, was also useful to check the validity of their responses, a technique used by Holme and Hanmore (2001). Previously, researchers have noted the effects of response set or a recency effect, whereby children consistently chose the latter of 2 options (Lewis, 2001; Preece, 2002; Rabiee et al. 2005). The order of the pictures, questions, and options were varied in the current study to avoid this issue. If it became evident that children were choosing either the like or dislike box, the position of these was swapped to check where pictures were placed. Pilnick et al. (2010) point out that disabled young people tend to display acquiescence bias or the tendency to say 'yes', as evidenced earlier with the parent of the young people involved in the DVD. If children or young people appeared to overuse the 'like' box, again, the position of the boxes was switched.

Despite best efforts to ensure reliability and validity it was obvious at times that the information that children and young people gave was inaccurate but it was important not to undermine what they had said. In the following example, I knew that the young people's participation group had only been running for 10 years:
PMCN: So you heard Rebecca talking about the group and you thought I would like to do that?

EMMA: Yes

PMCN: And how long have you been coming here? ... [no response]. What age were you when you started here?

EMMA: I started when I was ... 5.

PMCN: When you were 5 and you're 23 now. So you've been here for a few years.

[EMMA: 23 year old with cognitive impairment]

Children and young people varied in their knowledge of feelings faces and other symbols. While these were an invaluable tool, it was important to check the child or young person's knowledge of these in order to elicit reliable and valid responses:

PMCN: Do you want to use these [yes, no, don't know symbols] to tell me yes or no? [large symbols blu-tacked onto desk in front of Orla who has already indicated that she has used these before]

ORLA: Yeah

PMCN: [tests out Orla's use of symbols] So that one means yes and that one means no- can you point to 'no'?

ORLA: [touches 'no' symbol. Orla's movements very jerky but can point/touch symbols with some effort]

PMCN: Good girl and can you point to yes?

ORLA: Points to yes.

PMCN: Is that the way you want to do it?

ORLA: Nods

[ORLA: 13 year old with physical impairment]

It was also important to determine the optimal number of symbols a child could use to indicate feelings. Many children were familiar with these; however, some experienced
limitations in terms of how many they could use at a time. This was checked at the start of the interview. In the following case, although the child seemed very familiar with the symbols he could not use more than 3 symbols at the same time:

PMCN: Ok, Andrew. Let’s see if you remember what we did the last day and remember we had a look at the faces [shows feelings faces].

ANDREW: [nods]

PMCN: Wait till we see what ones you know. Alright are you ready?

ANDREW: Yeah [whispers].

PMCN: So we’ve got that one... and that one... and that one... [sets out 3 feelings faces]. So which one means sad? [child gives me sad]. Good boy, that’s very good and which one means bored? [child gives me bored]. Good boy, excellent and which one means happy? [child gives me happy]. Good boy and [swaps symbols around and replaces one] which one means bored? [hands me bored one] Good boy! And which one means scared? [hands me scared one]. Well done! That’s very good! Ok, so now we’ve got 1,2,3,4,5 [sets out 5 feelings faces]. Which one means worried? [hands me wrong one]. Ok, thankyou! Which one means happy? …[child not sure]. Which one means happy? [hands me happy]. Good boy! Which one means bored? [hands me bored]. Excellent, well done! Which one means worried [hands me the wrong one] ok [worried discarded].

[ANDREW: 6 year old with physical, cognitive impairment and no speech]

This was checked out at the start of each visit and the use of these was amended accordingly. Even though Louise seemed to know all the symbols on the first visit, she was unsure on the second visit:

PMCN: So do you remember we did the feelings faces yesterday?

LOUISE: Yeah.

PMCN: So how are you feeling today [yp points to happy]. Happy?
LOUISE: Yeah.

PMCN: Which one would you point to if you were sad [child points to sad]. Yes, which one would you point to if you were bored? [child not sure]. Which one if you were worried [child not sure] . You’re not sure about those ones, that’s ok. Which one do you think would be worried? You’re not sure about that. We’ll maybe just use these 2 – happy and sad.

[LOUISE: 12 year old girl with physical disability and no speech]

Data from the interview with Louise were not used in the analysis. I felt she did not engage during this visit – she appeared flushed and chesty, although her mother said she was fine. She was just in from school and was watching a TV programme when I arrived and, although she agreed to do the research, I wondered if she was tired would have preferred to watch her programme. In any case she seemed to lack the concentration she had demonstrated during the first visit. Unfortunately the family was emigrating in a matter of weeks and I felt it would not have been appropriate to come for a further visit.

Occasionally children and young people mistook the 'dislike' or 'don’t know' symbols for the feeling 'sad', as both of these symbols display a sad face:

PMCN: Ok, so do you remember we talked about these? [shows and tests young person’s knowledge of 'yes' and 'no' symbols]. Do you know that one? ['don’t know' symbol]

MARK: Sad

PMCN: He does look a bit sad, doesn’t he?

[MARK: 18 year old with physical and cognitive impairment]
Phase 4: focus group with professionals

The fourth stage of data collection consisted of a focus group conducted with 6 health and social care professionals, 4 from children’s services and 2 from adult services (see Appendix 11 for focus group topic guide). At the end of the survey, participants were asked to provide contact details if they were interested in taking part in a focus group. They could also provide reasons for non-participation. While 5-6 focus groups were originally planned recruiting professionals proved difficult. Reasons given by 20 professionals included caseload demands, lack of time and/or family demands. This calls into question the suitability of focus groups as a means of data collection for these type of participants. Nevertheless, the focus group consisted 1 speech and language therapist, 1 social worker, 1 dentist, 1 community children’s nurse and 2 community access officers. The focus group lasted for 1 hour 40 minutes. It was tape recorded and transcribed verbatim.

The session started by welcoming and thanking the participants for coming. Krueger and Casey (2009) provide extensive guidance about the conduct and challenges of focus groups. A number of challenges came to the fore during the session. Two professionals, in particular, tended to dominate discussions and it was necessary to actively encourage the remainder to express their views. My experience as a teacher (in large and small group teaching) helped me to be inclusive in a sensitive manner. One participant appeared very defensive and every time I reported a negative finding, she immediately responded by saying that this was not the case within her profession or caseload. It was important to reinforce at the beginning and end of the session, in particular, that disabled children and their parents had reported very positive relationships with professionals and very much appreciated their input.

5.5 Analysis framework: qualitative data

Finlay (2011) identifies approaches to the analysis specifically based on hermeneutic philosophers including Interpretative Phenomenological Analysis (IPA) (Smith and
Osbourne, 2003), the human science research approach by van Manen (1990) and the reflective lifeworld approach by Dalberg et al. (2008). IPA was considered as a research method for the current study but because of its in-depth approach, usually with a small number of participants, it was not considered suitable. While the six steps identified by van Manen (1990) could have been adopted here, it was felt that the work of Dalberg would best facilitate an in depth analysis of participation within health and social care by disabled families in this study. Dalberg et al. emphasise the importance of the lifeworld in phenomenological research and the lifeworld of disabled families has received increasing attention within the research literature (see for example, Hodge, 2008; McLaughlin and Goodley, 2008; Wongvatunya and Porter, 2008). Finlay (2011) defines it as follows:

'The lifeworld - Lebenswelt - is the taken-for-granted world as experienced; it is how our body and relationships are lived in time and space.... The lifeworld points us to the intentional relationship between the conscious, meaning-making human subjects and the external taken-for-granted, meaning-giving world.'

(Finlay, 2011:125)

Many phenomenological researchers warn against the development of strict procedural steps during the analysis phase, as this can jeopardise openness and a true understanding of the phenomenon. It is for this reason that the analysis of phenomenological research needs, to some extent, to be open ended (Dahlberg et al. 2008) and this approach was taken in the current study. While many analytical approaches abound in the literature, all allude to the need to go back and forth between the whole and the parts of the data (e.g. van Manen 1990; Mousakas, 1994) and the need to write and rewrite the results to achieve depth, an approach used in the current study. Dahlberg et al. (2008) maintain that it is this movement from the whole to parts that is one of the hallmarks of hermeneutic research, more commonly referred to as the hermeneutic circle. Citing Gadamer, How (1995) explains it thus:

'In understanding a single sentence a reader will tack back and forth between the meaning of individual words and that of the whole sentence. The individual words only have meaning in terms of the
sentence in which they are placed, while the sentence in its turn only means what those individual words allow it to mean. *In the same way reading the chapters of a novel involves us in constantly revising our understanding of the book. What we find in chapter one will lead us to anticipate a certain kind of development in chapter 2, but when we read chapter 2 we may well have to revise our understanding of chapter 1* (emphasis added).

(How, 1995:44)

The first stage of analysing any qualitative data concerns the identification of themes. Van Manen (1990) points out that themes are not simply generalisations, but represent an aspect of lived experience together with the experiential structures that make up that experience. In order to identify themes, van Manen (1990) suggests what he calls a selective approach, whereby the text is read several times and statements that reveal the phenomenon being explored are highlighted. Subsequently the meaning of these statements is identified.

Dahlberg *et al.* (2008) maintains that the emphasis should be on a search for otherness as discussed by Gadamer in *Truth and Method* i.e. a new understanding should not simply be derived from one’s pre-understanding or what we expected in advance. Although the use of pre-understanding underpins this approach, it is imperative that the researcher remains open to the data. One way of achieving this is by becoming fully emersed in the data. Van Manen (1990) highlights the importance of this:

> 'Even minor phenomenological research projects require that we not simply raise a question and possibly soon drop it again but rather that we “live” this question, that we “become this question”. Is this not the meaning of research: to question something by going back again and again to the things themselves until that which is put to question begins to reveal something of its essential nature'.

(van Manen, 1990:43)

Dahlberg *et al.* (2008) recommend the use of 5 guiding principles during the analysis of phenomenological data. It is important to emphasise that these were not used as a series of rigid steps but used as a set of principles to guide the analysis process:
1. Read the whole text, moving from the whole to the parts and vice versa in order to achieve a preliminary understanding of the phenomenon without any interpretation.

2. Create a series of themes/subthemes and establish a preliminary understanding, whilst becoming fully emersed in the data.

3. Search for meanings in order to transform something that is unknown into something that can be understood.

4. Make tentative interpretations continuing until all data relating to the research question is included using pre-understanding to make sense of phenomenon in a new way.

5. Tentative interpretations are then compared for similarity and difference working towards a new whole. It is at this stage that theoretical tools or models may be applied. Using theoretical approaches earlier in the analysis may, according to Dahlberg et al. prevent the emergence of a new understanding of the data.

Within the innermost (and most basic) level of Bronfenbrenner’s systems model lies the dyad, or two-person system, characterised by reciprocal interactions. Applied to the current research, analysis of data initially focused on parent/professional and child/young person/professional dyad. Beyond this first level lies what Bronfenbrenner calls N+2 systems, or triads, that include 3 way communication or participation in decision making between parents, children and young people and professionals. Thus triads comprised of parents, children and young people and professionals were then examined together during the analysis phase. However, as Bronfenbrenner (1979) points out, the ecological environment that affects the child extends well beyond immediate face to face interactions referred to as the microsystem. Rather it is nested within a number of complex systems discussed earlier (the mesosystem, exosystem and macro systems). Beyond the immediate interactions between parents, children and young people and professionals lay the structures of health and social care services and the social institutions enshrined in the culture where the fieldwork was conducted. Thus in the final stages of analysis, participants’ experiences were explored in the context of the complexity of their lifeworlds within these systems.
Analysing the children and young people's data

As an adult analysing and interpreting the responses of children and young people, I took care to uphold the view of disabled children and young people as competent social actors in their own right. It was also important to recognise disabled children and young people as having the right to express their views in ways that suited their individual ways of communicating, hence the wide variety of data collection tools used in this research. Although it is common for researchers to use a wide variety of data collection tools when researching with disabled children and young people, few discuss how this was managed at the analysis stage. Kilkelly et al. (2004) noted that despite the wide variety of techniques utilised in their research, there was a certain amount of structure in terms of the questions asked. Similarly in the current study, although many different tools were used to collect data with children and young people, the questions asked were essentially similar, while varying in depth in accordance with their level of understanding or communication method. For example, in some cases children and young people were simply asked if professionals listened to them and in other cases they were asked more generally about what happened when professionals came to visit them and what was discussed. Thus the mechanism of data collection was less important to how children and young people responded. Overall, in many cases and in particular where participants were young, had significant cognitive impairment or little or no speech) the responses of children and young people were at times brief, a finding also reported by Boylan (2009). While it is tempting to cite this as a limitation of the data, these are the real experiences and responses of these children and young people and an expression of their rights in so far as they can articulate them. Nevertheless, regardless of the depth of responses, the data obtained was coded in the same way as the adult data.

The use of computer assisted qualitative data analysis software

NVivo 8 was used to organise the data. First, structural or broad-brush coding (Saldana, 2009; Bazeley, 2007) was carried out to organise the data into issues relevant to the objectives of the study and set aside text that was of significance but not of direct relevance, for example, parents' experiences of having a disabled child. Next, data were
read and re-read before first cycle coding by means of annotations and memos within NVivo. This consisted of process coding, using "-ing" words, for example, feeling frustrated, and in vivo coding that used the words of the participant, for example, 'not the enemy' (Saldana, 2009). Second cycle coding was then applied, where categories and themes were derived from the codes. One of main criticisms of computer assisted data analysis packages is the concern that their use creates a distance between the researcher and the data (Bazeley, 2007). Doing phenomenology relies on movement between the whole and the parts of the data; indeed it is this movement from the whole (the original transcripts) to the parts (during the process of analysis) that generates meaning (Dahlberg et al. 2008). However, I felt that, in breaking the data down into numerous components using NVivo, I was beginning to lose a sense of the 'whole'. Therefore, following the identification and organisation of categories within the parent data, these were printed and themes were generated on paper. Given that the volume of data for the remaining objectives of the research was much less, categories and themes for the remaining objectives were also generated on paper.

At the start of the data analysis phase I felt swamped by the large amount of data I had amassed, particulary given that the parent interviews were 2 to 3 hours long. However, the structured approach described above helped me to manage the data and reduce what started as a vast amount of information into an organised and meaningful account of participants' experiences.

**Quantitative data**

Quantitative data from the surveys were entered into SPSS (PASW statistics 18) and descriptive statistics produced in tabular and graphical form.

**Reliability and validation during data analysis**

Throughout the analysis stage, a reflexive approach was adopted in order of ensure that my own views did not distort the views of participants as expressed in the data collection
phase. Bryman (2004:543) defines reflexivity as 'a term used in research methodology to refer to a reflectiveness among social researchers about the implications for the knowledge of the social world they generate of their methods, values, biases, decisions and mere presence in the very situations they investigate'. Using a reflexive approach helped to minimize the potential for researcher bias in my position as a professional. This involved continually questioning the rationale for my interpretations and ongoing discussion with the project supervisors. Two parent interview transcripts were independently analysed by two supervisors and myself to ensure rigour during the data analysis process. Analyses were shared and explored by discussion until a consensus was reached. Early results were also shared with both reference groups as a means of exploring the accuracy of the interpretations of the data collected from participants.

The notion of reflexivity has particular currency where the analysis of children and young people’s data were concerned. Davis (1998) argues that such reflexivity includes questioning one’s ability to accurately reflect the aspirations of different children in report writing. During the analysis phase, being reflexive about my academic, professional and personal preconceptions about disabled children and young people and their families helped to manage these preconceptions alongside the objective reporting of the findings. The results of the research were also discussed with the 2 young people from the reference group in order to accurately report the diversity of children and young peoples' experiences.

5.6 Chapter summary

This study used a mixed method approach to explore the participation of disabled children and young people and their parents in decision making. Both survey and interpretative phenomenology were used to explicate participants' experiences in line with the study objectives. This combination proved successful in obtaining more breadth in the data than would have been possible using qualitative techniques alone. The involvement of service users, both parents and young people, was key to the successful planning and conduct of the research and such involvement proved to be...
essential. These service users were not paid for their involvement but payment should be written in to future funding applications. It was anticipated that the survey results would inform the more in depth part of the study and this proved to be the case.

Information gained in the surveys was invaluable when meeting parents or professionals in the next phase of data collection. The survey response rate from parents in this study, while low, is in keeping with other studies. However, this raises questions about the use of the survey method where the parents of disabled children and young people are concerned. Parents spent significant amount of time participating in this study both in completing the survey and in the interviews, some of which were up to 3 hours long. Thus it was clearly a subject area that they felt was important and their time was very much appreciated. A wide variety of tools were made available in order to facilitate the participation of disabled children and young people in the research and the development of these took time. It is however essential that such time is spent in the design of such tools if disabled children and young people are to take part in research and share their experiences in a meaningful way. Equally important was time spent getting to know the child or young person over 2 or more visits and learn about their individual way of communicating. In most cases this facilitated the children or young person being interviewed on their own and potentially allowed them to speak more freely than they would otherwise have done. Given the numerous methods of data collection used in this study, it was important to draw these together in a meaningful way. Despite the different methods used and the numerous schedules for disabled children and young people, the questions asked of participants were essentially the same. Thus results were combined using the analysis framework described in this chapter.
Chapter 6: Ethical issues

6.0 Introduction

This chapter sets out the ethical conduct of the research regarding consent or 'assent', anonymity and confidentiality, data protection, debriefing and research governance. While these aspects are fundamental to research design involving adults, research with disabled children and young people brings additional challenges and warranted additional consideration in the planning stages of this research. Disabled children and young people are not a homogenous group and it is imperative that researchers provide appropriate information for them in a variety of accessible formats. This chapter explores how the information needs of children and young people were met along with adults in the study. Challenges encountered related to ethical issues that arose during the research process are critically appraised in this chapter.

6.1 Ethics approval and research governance

Ethical approval was granted from the Queen’s University Research Governance Office, the Southern Trust Research Ethics Committee and the Office of Research Ethics Committees Northern Ireland (ORECNI). In accordance with university regulations relating to research involving human participants, I also undertook Good Clinical Practice (GCP) training. Because children and young people were involved in the study, a number of additional resources were consulted in the planning of the research, for example, the 'National Children's Bureau Guidelines for research' (NCB, 2003), 'Guidelines on the ethical conduct of medical research involving children' (RCPCH, 2000) and 'Information sheets and guidelines' (National Research Ethics Service, 2011) that included advice on developing resources for children. Alderson and Morrow (2004) provide useful guidance in relation to addressing ethical issues that arise in the conduct of research with children, from the planning stage to the dissemination of findings and this also informed this study. A number of additional guides for researching with
disabled children and young people were also consulted (see for example, Lewis, 2001; Morris, 2002 and Whyte, 2006a and 2006b).

Davis (1998) points out that ethical guidelines may only become meaningful during the course of the research and this proved to be the case during the current study when the notion of 'one size fits all' was firmly refuted. Gallagher (2009:26) maintains that ethical practice should be seen as 'an on-going process of questioning, acting and reflecting, rather than the straightforward application of general rules of conduct' and a similar approach was adopted in the current study as will become apparent in the sections that follow.

6.2 The consent process

Historically, the notion of informed consent arose from the 1949 Nuremburg Code that sought to protect individuals from force, deceit and coercion (Scott et al. 2006) and the later Declaration of Helsinki updated most recently in 2002 (Neill, 2005). Research participants need to have an understanding of numerous issues, including the purpose of the research, the practical issues involved in participating, the potential benefits and risks, the manner in which the data will be used, the consent form and that they may withdraw from the research at any time (RCN, 2005). According to McCrystal (2008), the principles for obtaining consent from children are the same as those for adults; however, the practicalities are rather different and require careful consideration and planning and these are addressed in the sections that follow. In general terms valid consent is obtained from an individual where they are:

1. Acting voluntarily
2. Have sufficient information in order to facilitate decision making and
3. Capable of taking a decision (ie have capacity or are competent)

Consent: adults taking part in the study

Information sheets and consent forms were provided for all adults taking part in the study (see Appendix 4 and Appendix 5). These addressed taking part in the survey, the
focus group and the interview. One parent was registered blind and the information was provided in a size 18 font in order to make it more accessible for her. The information was given verbally and then participants were given time to read it. Questions were then invited before the parent indicated if they wanted to continue and the consent form was signed. Information was also prepared for parents about their son or daughter’s participation (see Appendix 4) and this was discussed the end of the interview. This information addressed anxieties expressed by parents in previous research, such as the child or young person not having the understanding, cognitive ability or communication to take part (Minkes et al. 1994; Marchant et al. 1999; Kelly, 2007; Rabiee et al. 2005; Turner, 2003; Lewis, 2001) or what would happen if their child criticised a service (Minkes et al. 1994; Lewis, 2001).

Consent: children and young people taking part in the study

Obtaining informed consent creates a number of dilemmas for those doing research with children, not least the common practice of gaining consent from both the parent and child (Neill, 2005; Balen et al. 2006). While the new sociology of childhood argues that children are competent social actors, capable of making their own decisions and exercising agency, it remains common practice to first gain the consent of their parents/carers before approaching issues of consent with children. Gaining consent from the parent before that of the child reflects the legal status of the child as a dependant and also recognises the child as vulnerable (Hill, 2005). This practice is evidenced in many studies conducted with disabled children (for example, see Lewis, 2001; Preece, 2002; Stalker and Connors, 2003). Kelly (2007) maintains that while approaching parents first is considered good practice, and is often in the child’s best interests, some children may not have the opportunity to participate in research as the decision is taken for them, a point also made by Coyne (2010). In the current study, ten parents who were interviewed made the decision that their son or daughter could not participate in the research. Furthermore, few parents from the DCYPPP group took part in the parent interviews or returned the reply slip to indicate that their son/daughter was interested in
taking part. In the course of discussion with the group leader, it became apparent that 7 of the young people from the group wanted to take part. In order to ensure that these young people were not denied the opportunity of participating, parents were again provided with information about their son/daughters’ participation and, where the young person was less than 16 or was judged to lack capacity (according to the group leader who knew them well) to provide their own consent, this was obtained from the parent and the assent of the child or young person was sought. The gatekeeper had a key role to play as she negotiated with the relevant parents, informing them that their child wanted to participate and obtained written consent where necessary. Parents were originally unaware that additional consent was necessary as they had already signed a consent form for the DCYPPP group to say that their son or daughter could participate in research or other consultation.

Consent or ‘assent’?

The Royal College of Paediatrics and Child Health (2000) maintains that in cases where children do not have sufficient understanding to provide consent, then ‘assent’ should be sought. Gallagher (2009) distinguishes between consent and assent, the former involving an act such as verbal or written agreement in the form of a signature and the latter denoted by the apparent willingness of the participant to take part. However, for some researchers, this approach is untenable. For example, Alderson and Morrow (2004) maintain that assent suggests that children agree to some but not all of the issues and therefore it constitutes a partly informed (and therefore invalid) consent. Moreover, they maintain that the notion of assent is used inappropriately to indicate or ‘cover’ children’s refusal.

The situation is, however, more complex when doing research with disabled children as it is often difficult to ascertain the degree to which children understand what is involved and their willingness to participate. Recognising this, Cocks (2006) maintains that securing ‘assent’ is one way of conducting research ethically with disabled children, an approach taken in the current study. She argues that the notion of assent accepts
children as they are and depends on reflexivity on the part of the researcher. As such, the researcher is required to be vigilant in relation to the child’s responses and tune in to the child’s preferred way of communicating. In the current study, the term ‘assent’ was used for those under 16 years or for whom parent consent was also obtained and the term consent was used for those young people judged to have the capacity to make their own decision to take part. Parent consent was obtained for children under the age of 16 in accordance with University guidance at the time and the assent of these children sought.

**Assessing capacity**

The DHSSPS guidance ‘Seeking consent: Working with people with learning disabilities’ (DHSSPS, 2003a) provides some useful guidance in relation to working with this client group, although the document refers to consent to treatment and care rather than research. For example, the capacity to consent depends upon what one is consenting to – while disabled people may well be able to make straightforward decisions, for example about their own care, they may not be able to make more complex decisions. Therefore, although some young people were deemed competent to make their own decision about taking part in the research, they may not have been competent to consent to surgery or other medical treatment. In the current study, the assessment of children and young people’s capacity to take part in the research was based upon guidance by Alderson and Morrow (2011). The following questions were addressed:

1. Are they able to make a choice and do they understand what it is they are making a decision about?
2. Do they know the risks and benefits and alternatives?
3. Is consent voluntary?
4. Is it informed?
5. Do they know that they can withdraw at any time?
The DHSSPS guidance 'Seeking consent: Working with children' (DHSSPS, 2003b:4) points out: 'You should never automatically assume that a child with learning disabilities is not competent to take his or her own decisions: many children will be competent if information is presented in an appropriate way and they are supported through the decision-making process'. A small number of researchers (see for example, Stalker and Connors, 2003) have provided a variety of information leaflets tailored to the needs of those they are researching. Therefore 4 levels of information were prepared along with a DVD in order to inform and support children and young people interested in taking part in the study.

Information for children and young people in the study

The provision of information is a key issue in obtaining consent and a variety of novel and imaginative resources have been used in previous studies to help children and young people understand what the research involved. Information for children and young people was provided in 2 formats in the current study—firstly in the form of a DVD and secondly in a written and/or pictorial format.

The ‘Who Decides?’ DVD

The aim of the DVD was to provide an alternative means of communicating information to children and young people about their participation in the study. A similar approach has been used in the course of the Care Pathways and Outcomes study (Institute of Child Care Research, Queen’s University Belfast). Although this DVD was commendable and indeed informed the ‘Who Decides?’ DVD, the ‘Who Decides?’ DVD aimed to show children and young people engaging in some of the activities involved in the research as well as informing them verbally about the study. Few researchers have developed alternative sources of information for children and young people for whom reading is not accessible, although in a study by Morris (1998), children were given the option to receive information in the form of video letters or audio-taped letters. The DVD was
produced by my husband, a BBC cameraman with many years’ experience of working with children and young people. This was invaluable in terms of making all those involved feel relaxed and gaining the confidence of parents and children and young people.

One of the most challenging things about producing the DVD was accessing children and young people who wanted to take part. Initial discussions with Contact a Family indicated that they were keen to help and send out the relevant information to over 700 families via email (on 2 occasions). However, this resulted in just one reply, a query, and no offers of participation. Communications with the Cedar Foundation also proved unsuccessful. Eventually it was a leader of a club run by Mencap who approached 3 specific families in person and gave them the information about the DVD (see Appendix 12 for DVD information sheets, consent forms and DVD script) to see if they would be interested in taking part and this personal communication was effective.

A meeting with the parents and children and young people was set up at a local centre. When I was discussing taking part in the DVD, 2 of the mothers grabbed the young people’s agreement forms and started ticking the boxes, saying ‘it’s ok they say yes to everything’. I felt that the young people’s understanding was very limited and made a judgement that I would be guided by their ongoing participation in the DVD as an indication of their assent. I also noted that the attention span of these 2 young people was very poor, as very quickly, they ran off to return to some of the activities at the centre.

The DVD was filmed in what was set up as a living room within the community centre, a room that the young people were familiar with. The young person who narrated the DVD, had learned the script in a very short space of time and, during the recording, often needed fewer ‘takes’ than I did. All the young people received a voucher for taking part and a copy of the DVD 2 weeks later.

It was important to provide consistent visual cues in all the information for children and young people taking part in the study, so I purposefully wore the same clothes in the DVD as was visible on the children and young people’s information sheets and wore the
same clothes again when I met them. These included a brightly coloured jacket and blouse that was both distinctive and casual.

Most children and young people saw the DVD before taking part in the research. There were advantages of the DVD for both parents and children and young people. Parents seemed to appreciate the lengths I had taken to provide a range of information for children and young people taking part in the study. It also provided an opportunity to discuss the types of participatory methods that could be used to help children and young people to express their views. It emphasised that it would not resemble the talking interview that parents had taken part in, that some children and young people would have found difficult. The cover of the DVD also illustrated some the activities and children and young people who might take part. The advantages for children and young people were that children recognised me when I met them and were well prepared. Viewing the DVD beforehand gave them some idea of what sort of things we might do when I arrived. Some children and young people were able to identify certain activities from the DVD that they wanted to do. The DVD was also useful in terms of discussing with the parent beforehand which activities might be best suited to the child, although the child or young person's preference was always upheld.

Although all children who were asked said that they liked the DVD, it also had a number of limitations. Within the time available it was not possible to make several versions for children with varying cognitive impairment. Having said that, all children and young people had the potential to recognise me and some of the activities and this appeared to be the case. Suzanne, a 15 year old young person, had watched the DVD the morning before I came and, according to her mother, did not like the activities shown. Although I had emphasised the need for parents to ensure that children and young people did not have to do any of the activities if they did not want to (i.e. that they could just talk to me if they preferred), I felt that this had put Suzanne off even before I had arrived. When I arrived she seemed reluctant to meet me although every time I asked her if she wanted to do something she said yes. This was complicated by Suzanne's autism and so she was unable to make eye contact with me and spoke through her mother. However, I later
learned that she did not like professionals coming to the house to see her and had told the last visitor to leave in no uncertain terms.

Young people from the DCYPPP had also viewed the DVD but there seemed to be a group consensus that they would not do any of the activities. Although I asked all the young people if they just wanted to talk or do some of the things shown, I felt that they were used to just talking and did not want to deviate from what they normally did. Mark's mother didn't show the DVD to him as she felt that it would be ‘over his head’. Another child watched only the start and then lost interest. Andrew, a 6 year old child, was ‘made’ to watch the DVD by his sister and I got the impression that he hadn't wanted to see it at all.

Overall, the challenges and limitations of the DVD were outweighed by the advantages for both children and young people and parents. Disabled children and young people have the right to information in a variety of mediums in line with their participatory rights and while initially time-consuming in this study, a template is now available for use in future research.

**Written information for children and young people**

A number of authors provide help in relation to designing information leaflets for children and young people (see Alderson, 1995; Marchant et al. 1999; Morris, 1998; Marchant et al. 2002; Alderson and Morrow, 2004; Gibson and Twycross, 2007) and these were used to design written information in the current study. NRES (2007) recommend that separate information should be provided for children aged 5 years and under, those 6-10 years and 11-15 years. Given the wide age range of children and young people involved in the study, together with their cognitive and/or communication impairments, a more flexible approach was warranted, that recognised the disjuncture between chronological and developmental age.

Four levels of written information were made available for children and young people. Each included a photo of me but varied in the amount of written information and use of
Boardmaker symbols (see Appendix 13 for information and agreement/consent forms). Young people aged 16 or over provided their own consent if they had the capacity to do so. Table 17 shows the level of information used by children and young people in the study with level 1 and 2 information used most commonly.

In discussion with parents or the Leader of the DCYPPP, the appropriate level of information for children and young people was selected and the gatekeeper was contacted at a later date to find out if the child or young person was interested in taking part or not. On meeting the child or young person, this information was explained. Occasionally, spending time giving information and obtaining the child or young person’s assent meant that by the time data collection started the their concentration had started to wane. Thus on many occasions the child or young person’s ongoing participation and interest in the research activities was taken as a measure of their assent, an approach taken by previous researchers (see for example, Lewis 2001).
Table 17: Information and consent for children and young people in the study.

<table>
<thead>
<tr>
<th>Name</th>
<th>Age</th>
<th>Impairment</th>
<th>Level of Information /consent form used</th>
<th>Parent consent obtained</th>
<th>Child/Young person had capacity to provide their own consent</th>
</tr>
</thead>
<tbody>
<tr>
<td>Emma</td>
<td>23</td>
<td>Cognitive</td>
<td>4</td>
<td>no</td>
<td>yes</td>
</tr>
<tr>
<td>Jack</td>
<td>23</td>
<td>Autism</td>
<td>4</td>
<td>no</td>
<td>yes</td>
</tr>
<tr>
<td>Jason</td>
<td>24</td>
<td>Physical + Cognitive</td>
<td>4</td>
<td>no</td>
<td>yes</td>
</tr>
<tr>
<td>Orla</td>
<td>13</td>
<td>Physical</td>
<td>2</td>
<td>yes</td>
<td>no</td>
</tr>
<tr>
<td>Emily</td>
<td>28</td>
<td>Cognitive</td>
<td>4</td>
<td>yes</td>
<td>no</td>
</tr>
<tr>
<td>Lauren</td>
<td>20</td>
<td>Cognitive</td>
<td>2</td>
<td>yes</td>
<td>no</td>
</tr>
<tr>
<td>Suzanne</td>
<td>15</td>
<td>Physical + Cognitive + Autism</td>
<td>3</td>
<td>yes</td>
<td>no</td>
</tr>
<tr>
<td>Michael</td>
<td>20</td>
<td>Physical + Cognitive + Autism</td>
<td>2</td>
<td>yes</td>
<td>no</td>
</tr>
<tr>
<td>Catherine</td>
<td>15</td>
<td>Physical + Cognitive</td>
<td>2</td>
<td>yes</td>
<td>no</td>
</tr>
<tr>
<td>Louise</td>
<td>12</td>
<td>Physical + Cognitive</td>
<td>1</td>
<td>yes</td>
<td>no</td>
</tr>
<tr>
<td>Natalie</td>
<td>27</td>
<td>Physical + Cognitive</td>
<td>4</td>
<td>no</td>
<td>yes</td>
</tr>
<tr>
<td>Mary</td>
<td>23</td>
<td>Physical + Cognitive</td>
<td>3</td>
<td>no</td>
<td>yes</td>
</tr>
<tr>
<td>Mark</td>
<td>18</td>
<td>Physical + Cognitive</td>
<td>1</td>
<td>yes</td>
<td>no</td>
</tr>
<tr>
<td>Name</td>
<td>Age</td>
<td>Diagnosis</td>
<td>Score</td>
<td>Has Diagnosis?</td>
<td>Treatment Needed?</td>
</tr>
<tr>
<td>--------</td>
<td>-----</td>
<td>-----------------------------</td>
<td>-------</td>
<td>----------------</td>
<td>-------------------</td>
</tr>
<tr>
<td>Andrew</td>
<td>6</td>
<td>Physical + Cognitive + Sensory</td>
<td>1</td>
<td>yes</td>
<td>no</td>
</tr>
<tr>
<td>Sinead</td>
<td>10</td>
<td>Physical</td>
<td>1</td>
<td>yes</td>
<td>no</td>
</tr>
<tr>
<td>Eoin</td>
<td>7</td>
<td>Autism</td>
<td>1</td>
<td>yes</td>
<td>no</td>
</tr>
<tr>
<td>Conor</td>
<td>10</td>
<td>Autism</td>
<td>1</td>
<td>yes</td>
<td>no</td>
</tr>
<tr>
<td>David</td>
<td>8</td>
<td>Physical + Cognitive</td>
<td>1</td>
<td>yes</td>
<td>no</td>
</tr>
</tbody>
</table>
Issues arising in relation to the consent process

It was important to be mindful that young people from the participation group had come forward themselves expressing an interest in taking part in the research, and as such the voluntariness aspect of consent was fulfilled. The remaining children and young people had been asked to take part via their parents and so it was imperative to remember that when I first met them. Although I had left a copy of the DVD and written information for them, it was important to establish that they themselves wanted to take part and that this decision was not influenced by their parents. Several issues arose around the need for proxy consent by parents and the withdrawal of assent/consent by children and young people.

Proxy consent

The children’s rights agenda, together with the UN Convention on the Rights of Persons with Disability, are clear that disabled children and young people have the right to express their views and have their views given due weight in any issue affecting them. The 2 young people from the DCYPPP who were involved in guiding the research process, felt strongly that asking parents to consent (by proxy) for children and young people’s participation was against the ethos of their group and breached their participation rights, the very subject of the research. They also questioned why parents were being involved in the study at all, as it was they who used services and not their parents. This raised a major ethical dilemma in the early stages of the research, for although they had a point, the ethics requirements of the university ethic’s guidelines were quite clear that consent of a legal guardian was required if the participant was ‘a minor’. I was impressed by the way in which the young people put forward their views in an assertive and professional manner. I also knew that ‘consultations’ by various agencies outside the Trust were frequently conducted with the young people and published with no formal consent process, either with the young people or their parents. This was a difficult issue, resolved by careful explanation of university requirements to the young people, whilst clearly respecting their views.
Christensen and Prout (2002) argue that, in the context of new approaches to childhood, ethical considerations around the conduct of research start with 'ethical symmetry' between adults and children:

'By this we mean that the researcher takes as his or her starting point the view that the ethical relationship between the researcher and informant is the same whether he or she conducts research with adults or with children.'

(Christensen and Prout, 2002:482)

However, in reality, the dilemma between safeguarding the child or young person and recognising their agency and participatory rights is a very real issue for researchers in this field. Like all children and young people, disabled children and young people have the right to express their views and are active agents in their own lives. However, the UNCRC is clear that parents also have a key role to play in their children's lives and researchers need to strike a balance between recognising the role of both during the research process.

**Withdrawing consent**

Children and young people's agreement to take part was seen an ongoing process and this was assessed during the course of visits with children, an approach taken by many researchers engaging with disabled children and young people (Morris, 1998; Beresford and Sloper, 1999; Marchant and Jones, 1999; Holme and Hanmore, 2001; Lewis, 2001; Preece, 2002; Stalker and Connors, 2003; Kelly, 2007). In previous studies, researchers have agreed with the child in advance how they might stop the session (Morris, 1998; Marchant et al. 1999; Kelly, 2007). Children and young people in the current study were asked how they would like to tell me if they wanted to end the session, for example, they could just tell me or use a 'goodbye' symbol, however, they were reluctant to do so. Some said that they would tell me, although none actually did. Some children and young people were not afraid to say when they were getting tired of a particular activity:
PMCN: OK, do you want to choose the next one? We’ve got the nurse and the dentist [symbols].

EOIN: We’re finished.

PMCN: You’re finished those ones?

EOIN: Yeah

[EOIN: 6 year old with autism]

In other cases, children or young people were more subtle in their approach to telling me that they had had enough:

PMCN: ...So that’s the hospital and you’ve been in hospital haven’t you? [no response]. Do you remember being in hospital? [no response child just wants to play]. So look -that’s the feelings faces. How do you feel when you go into hospital?... Which one? [Child points to happy]. Happy? Happy. [more play]. Well that’s very good. [more play]. [Child not in the mood to answer questions and seems to be withdrawing her assent]...

PMCN: So I think that’s us done. You can have a wee play with that if you want. That’s really good.

[LOUISE: 12 year old with physical impairment and no speech]

At times it was difficult to know if the child or young person wanted to take part or not. Suzanne, a 15 year old girl with autism, spoke exclusively through her mother and did not engage with me at all, although she seemed willing to take part in each activity. Distinguishing between a loss of concentration with one activity and the withdrawal from the research was also difficult.

The presence of parents during the interview also impacted on the assent process. Previous researchers have noted that during interviews parents can feel they are being helpful by urging the child to co-operate (Gardner and Randall, 2012). Parents were conscious that I had sometimes travelled a long distance to visit the child or young person and worried that it would be a wasted journey. It was necessary to strike a balance between respecting the child or young person’s wish to continue and not leaving
the parent feeling that they or their son or daughter had let them down. In a small number of cases parents encouraged young people to continue when it was clear they had become reluctant:

PMCN: Ok are you ready for another question?

ANDREW: Yeah.

PMCN: So do you like going to see the doctor? This one is you do like it and that one away over here you don’t like it; so if you don’t like it it goes over here. So where do you want to put the doctor? [child goes to get a drink] I think we’ll leave that mum, I think he’s had enough

MOTHER: He might be alright now that he’s got juice

PMCN: Are you going to sit down here? [Andrew doesn’t sit down]

No he’s had enough. Is that nice? [juice]

[ANDREW: 6 year old with physical, cognitive impairment and no speech]

In another case the young person kept asking if the rain had stopped and his mother was becoming agitated with him for losing concentration:

PMCN: What sort of things does she help you with or are you not sure?

MARK: Not sure.

PMCN: You’re not sure. That’s ok.

MARK: Has the rain stopped?

Mother: Not yet no.

[the rain had stopped]

PMCN: What does the physio do? Do you remember?

MARK: No.
Mother: What do they do in physio department with you, where [professional] and all is?

MARK: Getting pressure marks.

Mother: Well they stop you getting pressure marks what do they do with you [names them]? Don’t do that love [young person picking his teeth]. They take them out of the chair and what do they do with you? Come on.

MARK: Music.

Mother: They put music on and what do they do with you?

MARK: [unclear]

Mother: No, not until you’ve done this properly now come on.

PMCN: It’s ok.

[MARK: 18 year old with physical and cognitive impairment]

6.3 Anonymity and confidentiality

Anonymity refers to the notion that participants should not be identifiable within research outputs. This is generally achieved by not using participants’ names, using pseudonyms and ensuring that participants cannot be identified by any information presented (Gallagher, 2009). Parents and professionals were given a number in order to ensure that they could not be identified. Because of the small number of professionals in the focus group, individual professions could not be identified in the results of the study. A number of professional participants pointed out that they had sought their manager’s permission to attend the focus group and as such, providing information about their professional group would have denied them anonymity. This was addressed in the information leaflets where participants were also informed about the boundaries of confidentiality. Professionals were advised that what they said would be confidential unless ‘someone divulged something that could harm them or someone else’. Parents were advised that what they said was confidential unless ‘you told us something that
could harm you or anyone else’ (including their child). Several parents had, or previously had, psychological problems, some requiring admission or input from mental health services. In order to satisfy ethics requirements in the conduct of the research, it had been agreed with the Trust that if I had concerns about a parent’s wellbeing, they would be referred directly to their GP for support. Given that all parents that currently had psychological problems were receiving treatment/therapies no further action was required.

Children and young people in the current study were given a pseudonym. Many researchers maintain that it is their ethical duty to explain the limits of confidentiality to the child at the start of the research (McCrystal, 2008; Twycross et al. 2008; Gallagher, 2009). In the current study, children and young people using levels 2 -4 information were told that everything they said would be confidential unless they told me that someone had hurt them or someone else. It was judged that those needing level 1 information would not be able to understand this because of their cognitive limitations. The issue of confidentiality was important as, according to their parents (during the interviews), 4 children or young people in the study had been abused – one sexually, 1 physically in school, 1 physically at a respite centre and 1 emotionally in school. Arrangements with the trust were that, following discussion with the local collaborator (along with the study supervisors), the local Gateway (child protection) services would be contacted if I had concerns about a child or young person. Consequently the contact numbers of these services both in and out of hours were taken when visiting families. Children and young people in the study did not disclose any issues that needed such referral; however, they did take the opportunity to talk about issues that were of concern to them:

**PMCN:** The only thing I would share is if I was worried about you (and I say this to everybody that takes part all the parents, all the young people) - so if I was worried about you or if you told me that someone was hurting you or something like that then I might have to tell someone about that.
LAUREN: I have [other yp] phoning me each time. That's worrying me a lot, phoning me and phoning me and phoning me at my house and annoying [other yp] a lot.

PMCN: And who is [other yp]?

LAUREN: She used to be my friend but not anymore, annoying me that’s worrying me a lot.

PMCN: And she’s ringing you at home a lot?

LAUREN: Yeah, a lot wasting my bills on the house phone.

PMCN: Right but your mum knows all about that does she?

LAUREN: Yeah.

PMCN: Yes, so something like that- I know that’s worrying you, but I wouldn’t have to tell something like that because I know your mum knows about it and she’s dealing with it but if it was something like someone was harming you and I was worried about you...

LAUREN: and then she rang off.

PMCN: Did she and that’s annoying for you.

LAUREN: Yeah

PMCN: And is your mum sorting it out?

LAUREN: Yeah

[LAUREN: 20 year old with cognitive impairment]

Later in the interview, Lauren brought this up again and it was important to take time to listen and acknowledge that this was troubling her, while the same time acknowledging my limitations as a researcher as opposed to being a professional employed by the Trust. I was also influenced by the knowledge that her mother was very capable of dealing with this issue (having interviewed her) and was particularly supportive of her daughter, as I had interviewed her previously:

LAUREN: Can you tell my teacher? [going back to issue above]

PMCN: Tell your teacher about...
LAUREN: About [young person] annoying me?

PMCN: I think the best person to do that would be your mummy would that be right?

LAUREN: Yeah

PMCN: Cause mums are usually pretty good at that. What did your mum say about it?

LAUREN: She’s cross at it.

PMCN: And is she going to do something about it or is she hoping it’s all going to settle?

LAUREN: She’s going into school.

PMCN: Is she?

LAUREN: Yeah and with my dad to sort the whole thing out.

[LAUREN: 20 year old with cognitive impairment]

On another occasion, Orla, a 13 year old girl, with very little speech, told me at the end of the interview that her Granda had cancer and I felt it was appropriate to ask how she was feeling:

PMCN: And how do you feel about granda at the moment?

ORLA: [points to sad symbol]

PMCN: You feel sad.

ORLA: Yeah.

PMCN: And do you talk to Mummy about Granda?

ORLA: No.

PMCN: No and are you a bit worried about Granda?

ORLA: Yeah.

PMCN: And would you like your mummy to talk to you about Granda?
ORLA: No

PMCN: No and is it because you don’t want to upset her?

CYP4: Yeah ... [unclear]

[ORLA: 13 year old with physical impairment]

It is not unusual for children and young people to fail to disclose their feelings and protect their parents from additional stress in such situations (see for example, Price and Cairns, 2009). It was important, however, to ascertain that the young person was talking to someone about her concerns. It was clear that she wanted to be assured of confidentiality and I was relieved to learn that she was confiding with others with whom she had ongoing contact. Alderson and Morrow (2011) point out that while children can expect the same rights to confidentiality as adults, no one has the absolute right to confidentiality where research is concerned. Had the young person in the example above not been talking to someone else, it would have been important to encourage her to do so and possibly arrange another visit for follow up.

6.4 Data protection

Data will be stored for a minimum of 5 years following completion of the study in accordance with the requirements set out in the university’s Policy on the Ethical Approval of Research and Guidelines for Schools (2006). The Data Protection Act (1998) also provides guidance around the storage and handling of data. The Act is based upon 8 data protection principles with 3 main objectives – that data is processed for clearly defined purposes, that processing is transparent and fair and that data is up-to-date and secure (Scott et al. 2006). Applied to the current research, survey and transcribed data will only be used for the purposes of the research, will be analysed as accurately and objectively as possible and will be kept in a key-pad protected building in a room that is locked when not occupied and in a locked filing cabinet.
6.5 Debriefing

Findings of the study were presented to young people from the DCYPPP. The young people offered to help with the development of accessible information for children and young people who took part in the study and this will be compiled at the end of this study. Findings will also be presented to the parents who helped in the planning stages of the study and it is anticipated that they will advise about the further dissemination of the results to other parents who took part. The local collaborator in the Trust will be contacted to arrange presentation of the findings to service providers who provided access to professionals within the Trust and to professionals who took part.

6.6 Chapter summary

This chapter has considered the ethical requirements of the research and how these were addressed. Issues of consent or assent and confidentiality are particularly important where researching with disabled children, young people and their parents are concerned. These need careful consideration in the planning stages of the research and indeed this strategy was effective in this study. Disabled children and young people can form relationships with researchers quickly and therefore the opportunity to share information is a very real one. It is essential that researchers have experience of working with children and young people in order to manage these situations effectively. Parents in this study were under considerable stress and several already received support from counsellors or local mental health services. It is also essential therefore that researchers discuss mechanisms to deal with issues of concern with the Trust in which the research is conducted and carefully explain the conditions of confidentiality to prospective participants.
Chapter 7: Findings

7.0 Introduction

This chapter reports the findings of the study in 2 parts. Part 1 explores participants' experiences of participation in decisions about health and social care; part 2 discusses their participation in strategic decisions about services or policy. The outcomes of participation are discussed throughout. Table 18 shows themes and sub-themes generated from the qualitative data. Because there was much less data collected about participation in strategic decisions, sub-themes were not required.

Table 18: Themes and subthemes emerging from the data.

<table>
<thead>
<tr>
<th>Theme</th>
<th>Sub-theme</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Participation in decisions about health and social care</strong></td>
<td></td>
</tr>
<tr>
<td>Taking the lead</td>
<td>Fighting for the child</td>
</tr>
<tr>
<td></td>
<td>Protecting, yet preparing</td>
</tr>
<tr>
<td>Not knowing</td>
<td>Searching for a diagnosis</td>
</tr>
<tr>
<td></td>
<td>Searching and researching over the years</td>
</tr>
<tr>
<td>Getting the balance right</td>
<td>Parent or professional as expert</td>
</tr>
<tr>
<td></td>
<td>3 way communication</td>
</tr>
<tr>
<td><strong>Participation in strategic decisions</strong></td>
<td></td>
</tr>
<tr>
<td>Belonging</td>
<td></td>
</tr>
<tr>
<td>Gaining respect</td>
<td></td>
</tr>
<tr>
<td>Making a difference</td>
<td></td>
</tr>
</tbody>
</table>

7.1 Participation in decisions about children and young people's health and social care

A wide variety of decisions were made about children and young people's health and social care. This included decisions about physical care, psychological care, discharge from hospital, transition to adult services, family support needs and direct payments.
Many parents, children and young people who took part said that, in general, they did feel that professionals listened to them and involved them in decisions; however, many also recounted instances where they did not feel listened to and spoke of the considerable stress this caused, particularly for parents. Three themes emerged from the data: taking the lead, not knowing and getting the balance right.

7.2 Taking the lead

Children and young people

Often children and young people were happy for parents or professionals to take the lead in decision making. Children and young people reported positive relationships with professionals, particularly those who included them, made efforts to build relationships with them and communicated well. They felt happy, excited or proud about meeting with them and this created situations where children and young people felt that they were important and respected. Children and young people reported positive relationships with professionals who encouraged their participation, listened to their views and took them seriously. Whilst positive relationships with professionals facilitated participation, negative ones were an obvious barrier:

...like he [the dentist] would just about say hello to you when you come into the room and then just put you on the chair and just do the work type of thing and that's it... he'll just about say hello to you...like I prefer [consultant 1] because he knows me. Sometimes I thinking I'm just a number with [consultant 2]...[consultant 1] he would talk to you, he would understand and if you weren't happy. He would have a wee chat with you...

[NATALIE: 27 year old with physical impairment]
Thus, it was very important to children and young people that professionals engaged with them and built relationships, even when they looked to their parents for support and leadership in their interactions with professionals. Lauren and Michael spoke about arrangements for their work placement and how these decisions had been made by professionals who they trusted:

**PMCN:** And did you choose the café as something you thought you would like?

**LAUREN:** The school decided.

**PMCN:** Ok and would you have liked more say about that or were you happy about it?

**LAUREN:** I'm happy about it.

**PMCN:** So did you feel that was a good choice for you?

**LAUREN:** Yeah.

[LAUREN: 20 year old with cognitive impairment]

**PMCN:** Who decided that you would go to the animal rescue centre then?

**MICHAEL:** [Social worker]

**PMCN:** So were there any choices for you? Did [social worker] say you go could to the animal rescue centre or somewhere else?

**MICHAEL:** No.

**PMCN:** So she decided what would be best?

**MICHAEL:** Yeah.

**PMCN:** And how do you feel about that?

**MICHAEL:** Happy.

[MICHAEL: 20 year old young with cognitive impairment and autism]

However, overall, there was a general sense that professionals talked to children and young people as well as the parent and made at least some effort to involve them. On
the whole, nurses, medical staff, psychologists and allied health professionals explained procedures to children and young people; however, this was sometimes based on professionals' telling them what they were about to do rather than making efforts to involve them in choices, even at a basic level. There were limited examples of actual choices for children and young people:

PMCN: Did [the psychologist] involve him when she was thinking about putting him on medication?

P18: She did, yes she talked to Sean, but it was in a 'I think I'll start you on medication'. It wasn't would you want to go on it or this is the reason I think you should be going on it, but you have to...she didn't discuss it with him, she talked at him about what she wanted to do.

[P18: Mother of a 20 year old with cognitive impairment and autism]

Professionals' attitudes towards disability were also important. While these were positive in most cases, some professionals sometimes revealed more negative attitudes towards disabled children and young people:

She [speech therapist] was looking up and she says 'the trouble with these type of children', and I thought these type of children? That's the wrong sentence for me.

[P16: Mother of a 9 year old with autism]

In particular, parents of teenage children spoke of professionals being very negative in the early years when speaking about their child's development or the progress they had made. This was discussed in a more positive light by parents of younger children.

Medical staff and social workers were particularly adept at speaking to the young person first, particularly as they got older. Communications by medical staff were geared towards social interactions rather than discussing specific medical issues that needed to be addressed. Data from the younger children in the study indicated that they quickly
made judgements about professionals and that their main priority was the relationship that they had with them, rather than their involvement in decisions. With the exception of 2 girls aged 10 and 13 (from the DCYPPP group), it was not until the late teens that there was evidence that young people had an expectation that they should be more involved. However, regardless of age, children and young people with significant cognitive impairment seemed happy for parents and professionals to continue to make decisions for them. Most parents accompanied young people to appointments with professionals well into their young adult lives.

In the survey, professionals indicated that young people were more involved in decisions about their care once they entered adult services (see Figure 18). 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, there was a more even distribution and 15% of professionals surveyed said that they had no influence as determined by the first 2 categories (see Figure 18). Twenty one percent of professionals surveyed from children's services 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 said they were too young to participate in decisions. One professional said that children were more involved when they were 10 years old. Another said children often had communication difficulties, and yet another commented that decisions needed to be made by parents. One felt best placed as a professional to make decisions for the child based on best practice. The need for professionals to be creative in order to better involve disabled children and young people was identified by one professional 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 were very limited.
Although the parents interviewed indicated that the transition worker appeared to help prepare young people for increasing involvement in decisions affecting them as they got older, overall it appeared that professionals' approaches to involving young people differed to some degree between children's and adult services. In the survey and focus group data, it appeared that professionals from children's services (n=77) were working within a child and family centred model of care, where there was more of an emphasis on the participation of parents, whereas those from adult services (n=13) were focused more on person centred care where the main focus was on the young person. The emphasis from those from children's services was giving parents the relevant information and then it was up to them to make final decisions, regardless of the professionals' advice:
We'd always be explaining what best practice is. The parents might decide not to go down that route, you know, they ultimately make that decision. You might advise in the next step in pain relief and they are not ready to go there. Even with dressings, doing wound care and talking over the things with the tissue viability nurse and going back to them [the parents], you know,... it's entirely up to them.

[Professional 1: Focus group]

However, these findings should be interpreted with caution. The small number of professionals who took part from adult services may have influenced this finding and, as such, more research would be needed to fully endorse this suggestion. It appears, though, during the process of transition to adult life, young people may find themselves being asked to take responsibility for decision making without being adequately prepared for the process over a period of years.

Interestingly, professionals who took part in the survey did not rate children and young people's involvement in decisions about their care as important as parents' involvement (see Table 19). A total of 78% of professionals said that it was 'extremely' important that parents were involved and 62% said the equivalent for children and young people. Clearly, professionals' attitudes are important in facilitating or hindering their participation.

Table 19: How important is it that parents and children and young people are involved in decisions about their care? Professionals’ perceptions (%):

<table>
<thead>
<tr>
<th>How important</th>
<th>Parents</th>
<th>CYP</th>
</tr>
</thead>
<tbody>
<tr>
<td>Extremely important</td>
<td>78</td>
<td>62</td>
</tr>
<tr>
<td>Very important</td>
<td>20</td>
<td>26</td>
</tr>
<tr>
<td>Important</td>
<td>2</td>
<td>10</td>
</tr>
<tr>
<td>A little important</td>
<td>0</td>
<td>2</td>
</tr>
<tr>
<td>Not important at all</td>
<td>0</td>
<td>0</td>
</tr>
</tbody>
</table>
While most professionals made efforts to communicate with children and young people on some level, some were less adept at communicating with children and young people with little or no speech. There was little evidence that the communication aids used in the school setting were used by professionals at home and little evidence that children or young people were offered the opportunity of seeing professionals on their own. The professionals' survey indicated that overall, professionals indicated that decisions were always taken in the best interests of the child or young person and they would involve them as much as possible.

Physical barriers could also impact on the opportunity to avail of services or attend meetings. In one case, a young person had to attend a certain dentist's surgery because she thought it was only one that was accessible for wheelchair users. In another case, a young person was unable to attend a meeting about wheelchairs because the room it was held in could not be accessed by wheelchair users.

**Parents and professionals**

Parents felt strongly that they should be involved in all decisions relating to their child's care. Of those surveyed, 91% of parents indicated that it was 'extremely important' that they participated in healthcare decisions about their child and 90% said the same of social care decisions. The pattern of responses to the parent survey (90% from mothers and 10% from fathers), the uptake of parent interviews (87% mothers and 13% fathers), and data obtained during the course of the parent interviews, all strongly suggest that it was mothers who took the lead role in decision making. Fathers seemed less involved and while they attended important meetings about their child, for the main part, they left decision making to mothers and respected their opinions. Mothers' perceptions were that their main role was caring for the child while the fathers worked. However, according to the mothers, fathers played a vital supportive role. Mothers described them as 'anchors', 'a tower of strength', someone who could be relied upon to listen to them, share responsibility and play a positive role in the life of the child. This was not universal, however. One parent spoke of her husband not being able to accept their
disabled child and leaving the family home as a result and another said that her husband had been unable to bond with their son.

Most professionals who completed the survey believed that parents had some or a lot of influence on decisions made about their son or daughter's care (see Table 20). When parents were asked this question the survey response was similar, although around one fifth of parents said that they had less influence (as indicated by the first 2 categories in the Table below - 'informed but not asked their opinion' and 'asked their opinion but it had no influence'). For the main part though, from both parents' and professionals' perspectives, the majority of parents were involved in decision making about their child.

For some professionals, for example dentists or those working in adult services, decision making was clearly underpinned by legal requirements of consent and the capacity to make decisions and this provided a framework for who would take the lead in decision making. For those working in children's services, this was less clear cut and there was an overall assumption by participants that parents would make decisions for the child or young person. The types and complexity of decisions were wide ranging and professionals were sometimes involved with families over a long time frame during which the level and nature of participation in decisions varied.
Table 20: Parents' involvement in decisions about their child's care.

<table>
<thead>
<tr>
<th>% Professionals</th>
<th>% Parents (decisions about health care)</th>
<th>% Parents (decisions about social care)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Informed about the decision but not asked their opinion</td>
<td>0</td>
<td>5</td>
</tr>
<tr>
<td>Asked their opinion but it had no influence</td>
<td>6</td>
<td>14</td>
</tr>
<tr>
<td>Some influence on decisions</td>
<td>35</td>
<td>40</td>
</tr>
<tr>
<td>A lot of influence on decisions</td>
<td>53</td>
<td>41</td>
</tr>
<tr>
<td>Other</td>
<td>6</td>
<td>3</td>
</tr>
</tbody>
</table>

When asked about parents' participation in decisions, one professional added:

Difficult to generalise as I am involved in SLD children from nursery (3yrs) to transition at 19/20. As you would expect, the involvement and the types of decisions are very different.

[Professional Survey 65: PrS65]

Two subthemes emerged from the parent interviews in relation to 'taking the lead': 'fighting for the child' and 'protecting yet preparing'.

**Fighting for the child**

It was evident from parents' accounts that children and young people were highly valued and precious members of their family. It was very apparent in interviews with parents that professionals played an extremely important part in their lives. While their relationships with professionals varied, parents reported many instances of good practice and recounted stories of professionals going 'over and above' their call of duty. Positive relationships facilitated and fostered parents' participation in decisions about their child.
Parents held in high regard those professionals who were perceived to care about them, were reliable and trustworthy, who followed through on their promises, were knowledgeable and well informed and who did not compare a parent's family/situation to their own or say 'I know' or 'I understand'. They reported positive relationships with professionals who returned their calls and made efforts to get to know them as an individual and a family. In other words, they valued professionals who treated them as individuals with differing needs. These professionals did not just engage in 'box ticking' exercises but listened to them and treated them as experts in their child's care. They included and built relationships with their child who they saw as person. Where decisions about children and young people's care were concerned, parents' participation resulted in feeling valued as someone who knew their child best. It also affirmed to them that professionals cared about them and their child and formed an important part of the parent/professional relationship. For parents, the ultimate outcome of their participation was the highest possible standard of care for their child.

When professionals made little effort to build relationships, parents were less likely to engage with them or make their views heard. Often the formation of good relationships between parents and professionals depended on the good will and personality of individual professionals, and, when this was not apparent parents perceived this as a lack of caring. Professionals who did not return parents' calls or contact parents to offer support were also perceived as uncaring and this was an obvious barrier to participatory practices. Several parents spoke of wanting their child to be treated as an individual and not as 'a statistic' or 'an interesting case' or, as one parent phrased it, 'a freak of nature'. One parent stuck a photograph of her child on forms that she filled in so that people would realise that he was not a number but a little boy. The need to fight for their child was threaded throughout many parents' accounts of participating in decision making. Parents reported feeling frustrated at the length of time it took to access the resources that they required-(for example, equipment or respite) 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. Frequent changes of staff, particularly from social care, also hindered participatory practices.
because of the length of time it took for families and professionals to get to know each other and build a working relationship.

The language used by several parents, such as 'feeling like the enemy' or 'experiencing a victory', suggested that they felt they were in engaged in a battle. Several parents spoke of having had contact with local members of the legislative assembly (MLA's), the Minister for Health and Social Services, their own solicitor or the press, in order to ensure that their child's needs were met. One parent sat outside the manager's office until she was seen and threatened to commit suicide if she did not get respite, even though she said she said she would never have carried out this threat. While some parents were aware of complaints procedures within the Trust, they rarely used them as they felt that they would be ineffective. Others felt that information about how to complain was intentionally withheld, as professionals might be implicated or it might burden their caseloads.

Non-participation resulted in great frustration for parents, particularly prior to the time of diagnosis when they had initial concerns about their child. Parents not being listened to had devastating outcomes for four parents. In one case, the parent of a young person with downs syndrome was accused of neglect because her daughter had lost weight. In fact, the mother was sure that the child also had autism and this accounted for her poor dietary intake. This was later confirmed with support from the GP and the allegations were dropped. In a further case, the parent of a 24 year old young person, whose first baby was stillborn, believed that professionals not listening resulted in her second daughter being deprived of oxygen and disabled due to a delayed labour:

I went into the clinic and they did say, yes...the baby was coming and they would get the doctor to see me. This went on for 4 days... and I could feel the baby kicking down, kicking down all the time and I was saying to them this is not right. Me and my husband were pleading with them to see to me...[later when the doctor came] he put on gloves to give me an internal and he caught Sonia by the cord and the leg and pushed her back up the birth canal.

[P25: Mother of a 24 year old young person with physical, cognitive and communication impairment]
In the third case, safeguarding proceedings were commenced after a young person attacked his brother because his dental pain had not been treated in accordance with the parent's recommendations and expertise. In another case a parent and her son had to stay in hospital for a week for a blood test that would have taken a day, had staff listened to her:

PMCN: And did you not feel they were listening to you then?

P6: Absolutely not. Absolutely not. They would say, listen, we don't give sedation for something as minor as a blood test but I says this is major, and Peter is terrified of needles... they had tunnel vision, it was their way or no way.

[P6: Mother of a 16 year old young with cognitive, sensory, communication impairments and autism]

Challenging professionals' decisions was difficult for parents as they felt vulnerable and were conscious of the effects of jeopardising the relationship they had with them. There were 3 instances where parents took decisions that were against professionals' advice: firstly, in relation to a house adaptation and moving and handling equipment; secondly, when a parent refused tube feeds for her daughter, and finally where one parent had taken her son off his medication and taken him to a local healer. This young person had recently lost his sight and, following her visit with the healer, the mother believed that his sight would return.

Most professionals who took part in the focus group said that they were under constant pressure and similarly engaged in a fight or 'fire fighting' to deal with key issues that families faced.

If, you know, there's 4 people in the waiting room you don't have time to spend with that parent talking through everything that you maybe know in your mind that you should do and you usually make a note 'I'll do that the next time I see them', but it could be the same the next day they come in, you're still up to your eyes and, you know, the amount of time you have to spend with the patient is compromised.

[Professional 3: Focus group]
Professionals from the survey shared parents' frustrations 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: PrS55]

While some professionals supported the notion of parents reporting issues to MLA's, for others this was a source of frustration when the priorities of a few overshadowed the needs of less vocal parents. Professionals did encourage parents to avail of the Trust's complaints procedure, but agreed with parents that this was not as effective as other modes of action:

Yes, we do empower our clients to use the complaints procedure ninety-nine percent of the time but none of them will because, I can guarantee you that there is nothing more stimulating on a Monday morning than a parliamentary question in your in box [laughs] because it focuses the mind.

[Professional 5: Focus group]

Professionals also recounted that parents, with whom they had built up relationships over many years, did not want to complain via the Trust in case they got them into trouble and subsequently jeopardised their relationship with them.

The need for parents to fight for the child was perceived as long term and at times this was 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...

[P17: Mother of a 15 year old with physical, cognitive, sensory impairments and autism]

As already indicated, despite having to fight for services, most parents who took part in this study reported very positive relationships with professionals. However, several parents reported being made to feel like a 'neurotic mother' and recounted having to
'change their personality' to enable them to engage in the fight for their child. Parents who were timid and quiet before having their son or daughter said that they had to become more assertive, to 'toughen up' and become -as they saw it- a totally different person:

... 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.

[P30: Mother of a 15 year old with cognitive, sensory and communication impairments and autism]

Parents were not always comfortable with making these shifts; however, it was seen as necessary if they were to ensure that their child's needs were met. Over time, they gained confidence in their ability to question professionals' opinions, as one parent explained in relation to her disapproval of restricted wheelchair access and limited space for her daughter at a day care setting:

And I says 'she might want to go into another room' and he says 'what would be the purpose of going into that other room?' and I says to myself there's no way she's going to this centre; but all the professionals, the top social workers were great. There was a change they said, that we parents were actually questioning where their children's going. Years ago, they just took it for granted, you know. That's it,' she's going and that's the end of it'.

[P25: Mother of a 24 year old young person with physical, cognitive and communication impairments]

Building relationships with parents in a similar situation also helped parents to advocate and fight for their child. There was a general feeling that parents were more protective of their disabled children than their other children and they sometimes referred to their advocacy role in fighting for their disabled child:

You have to do it for her, she can't do it on her own...

[P4: Mother of a 10 year old with physical and communication impairments]
Some parents felt that certain professionals were on their side and sometimes engaged in the fight with them, and recounted how professionals sometimes shared parents' frustrations and crossed professional boundaries with families they had known for a period of time:

I had a speech therapist once and she said to me, 'I shouldn't tell you this', she says, 'but the ones that shout the loudest are the ones who get heard the most' and I've always clung to that a bit because in the first few years we were struggling.

[P14: Mother of a 19 year old with physical, cognitive and communication impairments]

While the vast majority of parents interviewed expressed the need to engage in a fight in this way, around one third of parents had no difficulty obtaining services. These parents had a positive outlook for their child and, it appeared, had accepted their situation. One parent spoke of the need to stop fighting after choosing a special school for her son:

I feel as though I can stop fighting, you know. Again with the [downs syndrome group], there's so many of them at mainstream school. They're fighting for this and they're fighting for that. It's exhausting and you know, you have to get to the stage where you're just going to love your child and forget about fighting...

[P29: Mother of an 8 year old with physical, cognitive and communication impairments]

For this parent, sending her child to a special school meant that health services were all provided within the school setting and therefore she did not have to fight for them like other parents.

Leaving-school options and choices about social activities were limited for many families, and this served as a barrier to the participation of parents and their child. This was not something that participants complained about; rather they did not appear to have the expectation that these would be widely available, particularly if a child or young person had complex health needs.
Protecting yet preparing

Parents also expressed the need to 'take the lead' by protecting their child from their diagnosis. This was a source of much anxiety for many parents who were at times unsure of what information to give children and young people and at what stage. Parents spoke of wanting to keep their son or daughter 'in a cocoon' and treading a fine line between protecting them and encouraging independence. Parents had concerns that if they told their son/daughter their diagnosis, they would feel different or lose their confidence. This was particularly difficult as, in many cases, children and young people did not view themselves as disabled:

...it was something to do with the Special Olympics and he said 'but I'm a normal boy mummy' and I want to keep things as normal as possible but I don't know how long I'll be able to do that...

[P22: Mother of 2 disabled children]

Parents spoke of needing to be strong to explain to the child the nature of their impairment or diagnosis, and some waited until their son or daughter asked them directly. There was a sense that parents needed themselves to be ready to face the diagnosis before speaking with their child. With only one exception, parents felt that they were best placed to give children and young people information about their diagnosis (or indeed to withhold it), although many struggled with how best to do this. One parent compared it to telling a child 'the facts of life' and, like many parents, spoke of giving her autistic daughter information in stages. Parents, however, did not always agree with telling the child:

When I knew she'd understand, I thought how am I going to get round to it...it was trying to make it simple and how was I going to word that?...I used to look out at that garden and say to myself how will I word this to her and her daddy would say 'don't tell her [whispers], don't tell her'. I don't believe in not telling her, I believe in telling...her.

[P16: mother of a 9 year old with autism]

Following this the parent explained to her daughter that autism was like a seed that could grow and take over her life if she did not face her fears and phobias. She had since been
able to explain to her daughter (and her sibling) why she behaved in a particular way and helped her develop coping mechanisms for everyday life, including how to stand up for herself if other children commented on her behaviour:

P16: ...but I would speak to her and every time I say to her 'it's your autism that's doing that' and I say to [sister] 'you know that's her autism making her do that' and she'll [child] say 'I know, I know, I'm trying to fight it'.

[P16: mother of a 9 year old with autism]

Some parents who had put off telling their son or daughter- because they were unsure of how to deal with it- had enlisted the help of professionals when they felt that it was time to give the child or young person information and this provided much support:

...I felt at that stage the question was coming soon as to 'what's wrong with me mummy' and I didn't know how to answer him and I didn't know if I was strong enough to give him all the facts that he needed to have and what way to word it and what level to word it at... and I asked the principal in [school] if she had any advice for me and she got the girl from the autism team to come out... and she was fantastic.

[P18: Mother of a 20 year old with cognitive impairment and autism]

Others spoke of telling their son or daughter before someone else did, and feeling safer in doing this. One parent's daughter, who had not been told about her diagnosis, took her family by surprise when she announced at a family gathering 'I'm just a Down's syndrome kid'.

Some parents whose children had less severe cognitive impairment spoke of their son or daughter wanting to make more decisions themselves as they got older; however, the assumption for many was that the young person would continue to be dependent on the parent. This was evident even when the young person indicated that they wanted to make decisions for themselves and develop a sense of independence:

...you know he'll say 'mummy, I am a man and I am an adult and this is what I want to do, is that alright?' So I think the time is coming rapidly when he'll not be looking towards me when somebody says something...the time is rapidly coming, I know it is, when it'll be 'I'll be
making the decisions' and that's alright. Good or bad he has to make them, but I don't see a time when I'll be lonely... I can't see him ever going anywhere...he might prove me wrong, but I don't think so."

[P18: Mother of a 20 year old with cognitive impairment and autism]

Parents were often reluctant to think about the future or look too far ahead. Thoughts of the future sent some into a 'full blown panic' and planning for the future was a major cause of anxiety as one mother explained:

I try not to think about it cause... you'd drive yourself insane if you look too far ahead, so I sort of try and take one year at a time...

[P12: Mother of a 7 year old with physical, cognitive, communication impairments and autism]

Regardless of age, parents referred to their son or daughter as their 'child' and there was a sense that some would never develop into adults or have any sense of independence:

...she needs to interact with other children. Oh, I keep calling them children but they're other adults. You know, she's still a child, I mean we still call it school [young person goes to a work placement].

[P10: Mother of a 22 year old with cognitive impairment]

Some parents, however, recounted that they would have to involve their son or daughter in decisions made with professionals or 'take 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. Having said that, some parents went to great lengths to explain and prepare their child for visits with professionals and ensure that they were active participants in these visits:
...if they are talking to me I then turn to [young person] and say what do you think of that Suzanne?

[P17: Mother of a 15 year old with physical, cognitive, sensory impairments and autism]

This appeared to be due to the individual preference and practices of each family but was also related to age and cognitive impairment. The parents of older children and young people and those with less cognitive impairment were more likely to actively involve their child.

Parents sometimes made assumptions that their child knew or understood more than they did. One parent talked of her son asking her if he would be coming home from school every day and realising, after a year, that he was worried in case he would be staying there and not coming home at the end of the school day.

7.3 Knowing or not knowing

Children and young people

The survey asked professionals from both children's and adult services about information for disabled children and young people. Specifically they were asked about (1) information about their impairment at the time of diagnosis, (2) information about their impairment since the time of diagnosis, (3) information relating to available services and (4) how to access these services (see Figures 19-22). Again the results differed between adult and children's services. Overall information for children was rated much less positively by those from children's as opposed to adult services. One professional from children's services noted that information was better when the young person was approaching the time of transition, (although it was aimed at parents), for example, in relation to forthcoming decisions about work placements. One professional noted that there was good written information for children and young people with autism but that this was not available for those with other impairments. Two participants commented that information was not always available in a suitable format. Around a quarter of professionals did not fill this section of the survey, commenting that they did
not know what information was available or if there was any. Some professionals said that they did not work with the children and young people at the time of diagnosis (because this normally occurred when the child or young person was younger) and therefore were unable to answer this aspect in particular.

Figure 19: Professionals views on available information for children and young people about their impairment (*children's services*).
Figure 20: Professionals views on available information for young people about their impairment (*adult services*).

![Professionals' views on information for young people about their impairment](image)

Figure 21: Professionals views on information for children and young people about *available* services.

![Professionals' views on information for children and young people about available services](image)
Providing information for children and young people was a challenge for some professionals who were unsure how to assess their level of understanding. This was compounded by meeting the needs of both the child or young person and the parents. One professional said that parents made decisions for those with cognitive impairments which often reflected their own preferences or priorities rather than those of the child or young person:

PRS55: 'no they wouldn’t like that club' actually means I’m not prepared to transport the child to your club.

[Professional Survey 55: PrS55]

Involving children and young people could present ethical challenges for professionals. One focus group participant took the decision to tell a young person that he had diabetes, even though his parents did not want him to know. The young person was provided with an appropriate diabetic diet at home without any explanation. However, the young person had access to food in his work placement and he was eating food that was not
consistent with his diabetic diet. The professional felt that she had acted in keeping with the best interests of the young person. Those from more medically driven professions (dentistry and nursing) focused on giving information to parents who then made the decisions with almost no reference to the child or young person:

...you advise a certain course of treatment and it is up to the parent to say yes or no...you give them the information and then they make the decision...if you have a 10 year old in, you are going to be talking mainly to the parent, explaining to the child after you've agreed a course of treatment with the parent whereas when the child gets older, you naturally, because age 16 in mainstream is the age of consent. You're going to be doing all the talking to the child by 16, special needs it's 18, isn't it? But it depends on the special needs person.

[Professional 3: Focus group]

Most professionals said they would always acknowledge the child or young person and talk to them, but when it came to decision making, the emphasis was clearly on the parent. Those from dentistry and adult services referred more often to young people's capacity to make decisions and this was often determined by other professionals. However, this was not a common theme throughout the findings of the research.

Although, most children and young people interviewed said that professionals explained things to them, they felt they did not always do so at an appropriate level. Therefore, explanations were not always effective and this created anxiety for some children and young people. For example, Eoin, who was given little information by the nurse prior to having a blood test done, said that he was scared as he did not know what would happen.

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

CATHERINE: Yeah

PMCN: And what does she do?

CATHERINE: She just talks.

PMCN: And what does she help you with?

CATHERINE: I dunno.

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

This was compounded by the finding that children and young people were not always aware of their diagnosis, so that explaining the roles of professionals may have invited unwanted questions. Nor did children and young people have a good understanding of professionals' roles. Several said that the dentist's job was to pull teeth out, even though this had never been done to them. Although most children and young people reported that they liked going to see the dentist, some were scared. Others were unable to say what different professionals did. Sometimes children and young people did not want to know what would happen, because of their own anxiety. Eoin said he was 'nervous' about going to see the doctor:

PMCN: and did you know that you were going to see the doctor?

EOIN: yes

PMCN: yes, and did you understand why you were going?

EOIN: shakes head [indicates no]

PMCN: no, and would you like your mum to tell you a little bit about that before you went?

EOIN: no.

[EOIN: 6 year old with autism]
Not being clear about which nurses were looking after them in the hospital setting was unnerving for young people. Lack of information at the time of admission, or at changes of shift made this difficult for children and young people. Staff turnover in the home setting meant that young people and they were unsure, at times, who would be coming to look after them in that setting:

PMCN: What about people like nurses or social workers. Have you met any of them?

JACK: Yeah, I've met some social workers.

PMCN: Nobody in particular?

JACK: No, I can't remember. I've had numerous ones and I can't remember. I can't keep up.

[JACK: 23 year old with autism]

Parents and professionals

In the surveys, both parents and professionals were asked to rate available information for parents of disabled children and young people within the Trust. Participants were asked about information relating to the child or young person's impairment at the time of diagnosis and since the time of diagnosis. They were also asked about information relating to services that were available and how to access these services. While around 90% of professionals felt that the provision to parents about their son or daughter's impairment was satisfactory, good, very good or excellent, 53% of parents said that they had not received enough information at the time of diagnosis and 27% said that they had not received enough information following the diagnosis (see Figure 23).
Parents and professionals were also asked about information for parents regarding available health and social care services and how to access these. Again, while respectively 89% and 86% of professionals surveyed felt that information about available services and access to services was satisfactory, good, very good or excellent, over a third to a half of parents surveyed (36-48%), indicated that they had not received enough information about health or social services or how to access them (see Figures 24 and 25).
Figure 24: Parents' views on available information about health services and how to access these services.

Parents' views on information about health services

<table>
<thead>
<tr>
<th>Agree</th>
<th>Neither agree nor disagree</th>
<th>Disagree</th>
</tr>
</thead>
<tbody>
<tr>
<td>80</td>
<td>10</td>
<td>10</td>
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Figure 25: Parents' views on available information about social care services and how to access these services.

Parents' views on information about social care services

<table>
<thead>
<tr>
<th>Agree</th>
<th>Neither agree nor disagree</th>
<th>Disagree</th>
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<tr>
<td>100</td>
<td>10</td>
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The situation differed somewhat depending on the age of the child. Data was explored across ages of children and young people i.e. <4 years, 4-11 years, 12-19 years and 20-25 years. Most children and young people were diagnosed at birth or in early childhood. Parents of older children and young people were better informed, while parents of children in the younger age categories said they had not received enough information either about their child's impairment or services. However, there was evidence that the provision of information about autism, in particular, had improved over time. Parents of these young people felt that, while there was very little information in the early days when their son or daughter was diagnosed, there was much more in more recent years. Parents of younger children with autism also commented positively on the availability of current information now, both verbal and written. In the survey, parents were asked where they obtained information to help them make decisions about their son or daughter's care (see Table 21).

<table>
<thead>
<tr>
<th>Sources of information for parents</th>
<th>Health care decisions</th>
<th>Social care decisions</th>
</tr>
</thead>
<tbody>
<tr>
<td>From other parents</td>
<td>68</td>
<td>68</td>
</tr>
<tr>
<td>From professionals</td>
<td>68</td>
<td>60</td>
</tr>
<tr>
<td>Voluntary organisations</td>
<td>32</td>
<td>33</td>
</tr>
<tr>
<td>The internet</td>
<td>35</td>
<td>18</td>
</tr>
</tbody>
</table>

Table 21 above, shows that the most common source of information was other parents and professionals. A third of parents obtained information from relevant voluntary organisations and one third of parents used the internet to assist them in making healthcare decisions. The internet was used less commonly to inform social care decisions.
Two sub themes emerged from the parent interviews around knowing and not knowing: searching for a diagnosis and searching and researching over the years.

**Searching for a diagnosis**

In the parent interviews, there was an overall sense that parents had to find information out for themselves about their child's condition or impairment and what services were available, even when they received regular support from professionals. Prior to diagnosis many parents were concerned and anxious about their child. Despite reassurances from professionals that nothing was wrong or that they should 'wait and see', parents were pro-active in seeking information for themselves during this stage. Some searched for information from further afield. Parents often relied on the internet at this stage when formal sources of information from professionals were not available:

> ...and I was still saying 'she's autistic, no matter what you say. She has got autism. They were just not listening and then I started reading through the side effects of lamictal [online] and Cheryl had all the side effects.

[P14: Mother of a 19 year old with physical, cognitive and communication impairment]

One parent said that searching for information at this stage was underpinned by the emotional trauma of finding out that her son had an impairment and an urgency to make their lives better. The media was also an important source of information for parents. One child's parents were watching a celebrity on television talking about his autistic son and the doctor who had diagnosed him. This confirmed their own concerns about their child, aged 2 at the time, and they subsequently attended the same doctor privately in order to get a diagnosis of autism. In 2 families, children had other existing conditions. Despite these parents' ongoing concerns, professionals attributed certain symptoms or behaviours to their original diagnosis. While most parents were desperate for information around the time of diagnosis, several were not ready to hear the news about their child or receive any associated information:
Well, when [yp] was born, they wouldn't tell me at the start. I knew the minute they handed him to me he was downs syndrome. I knew by his eyes and I couldn't accept it. I couldn't, I don't know, I just couldn't.

[P23: Mother of a 19 year old young person with physical, cognitive, sensory and communication impairment]

In another case, the parent joined the Down's syndrome Association when her child was 9 months old, where she was able to obtain information when she was ready. In another family, a parent who already had one disabled child with very complex needs did not want information about her second's son's diagnosis despite her own concerns about his development:

But what happened was, [whispers] at two and a half, there were concerns and that was whenever there was no speech and I, Patricia, I could not do it...and I remember...the doctor said to me 'I have a fair idea about Josh and I went 'don't tell me'. I couldn't hear it and I knew he was going to say autistic spectrum and I could not hear it. And I said 'no, don't tell me'. And he says 'right, that's ok'...Talk about going into denial, I couldn't get my head buried far enough... and I just thought I can't do this again, I cannot do this again...Josh was actually 8 years old before I allowed him to be diagnosed.

[P22: Mother of 2 disabled children]

Although the parent knew for years that her son had autism, she was not ready to hear it or deal with it, and this was respected by professionals. Most parents searched for information from professionals soon after diagnosis but this was often difficult to obtain in the very early stages (as indicated previously) before the child had been seen by specialist services and this created anxiety for some parents:

P13: the day he was diagnosed I went to the health visitor and I told her and she said I don't have any idea about autism... made an appointment with the GP for the following day and she said to me 'I don't know anything about autism really...that's when I started to phone round to ask for help. So I phoned early intervention and I was told oh, yes, yes I'll be coming to visit you. I phoned in March... 'Yes, I'll
be coming to see you at the end of June'...I was at the end of my tether, I really, really was.

[P13:Mother of 2 disabled children]

One professional who took part in the focus group said that it was difficult to provide information at the early stages when the implications of diagnosis were not yet apparent. She felt that it was important not to engender false hope, regardless of what the parent wanted to hear. Another said that information was, for the main part, given verbally and while there was much written information for parents about autism, this was not well established for other types of impairments.

Searching and researching over the years

The provision of timely, accurate and appropriate information could facilitate or hinder the participation of parents. Those who were well informed were empowered to make balanced decisions. There was evidence that communication and accessing information was at times difficult in terms of understanding professionals' roles, understanding the wider structures within health and social care or more broadly, what services were available and this served as a barrier to participation.

Limited contact with community-based professionals also restricted opportunities to access information for many parents:

    I only have contact from social worker twice a year at the time of the LAC review. At any other time we are unable to contact him even when family is in a crisis.

[Parent Survey PS46 – parent of 2 disabled children]

Despite having already received treatment from doctors, some parents sought out other treatments themselves, desperate to find a way to improve their situation:

    P14: ...In the first few years, we were struggling....I remember one time crossing the road [son] was in his pram, she was walking, a wee toddler and she had a seizure in the middle of the road and I'd nobody
to help me and after that I couldn't cope and I became housebound...I mean I tried a ketogenic diet. We tried everything but we were searching out all these things ourselves.

[P14: Mother of a 19 year old with physical, cognitive and communication impairment]

A small number of parents, whose children attended mainstream school, pointed out that once their son or daughter was sixteen, there appeared to be a gap in services in terms of post school options, as those attending special school attended until they were 19. In these cases, parents searched and researched options for their child. This mother sought out options for her son on leaving school at 16 as he wasn't ready for a placement normally attended by young people of 19 and older:

There was no way he was going to sit in the house, no way. I wasn't going to let that happen, no way, cause he'll be sitting in the house long enough.

[P18: Mother of a 20 year old with cognitive impairment and autism]

As indicated earlier, parents obtained most of their information from other parents or parent groups. The parent council was a highly valued source of information and support for many parents who felt that the council provided reliable information from people who understood their situation. Parents reported belonging to many parent groups, either within or outside school where they availed of information and support. The leader of the DCYPPP was also a valuable source of information for parents of those who attended this group. Parents occasionally recounted instances where professionals warned them not to use the internet and, although this was the least frequent source of information according to the survey, this was a popular source of information for those interviewed.

However, parents sometimes missed out on important information, for example, how a social worker could have supported them, about school options or the availability of benefits that may have eased financial difficulties. Despite one parent having produced written guides about service provision within the Trust and DHSSPS, other parents were not aware that such resources existed. This was not only the experience of parents.
Three professionals who took part in the focus group also spoke of instances when they later found out about services to which they could have referred families. One professional did not know that one of his clients could have attended a specialist community dental service for those with cognitive impairment. Another was not aware of a psychology service for those with needle phobias which she had tried to deal with herself. A further professional had only recently learned of health and wellbeing services that he could have accessed for his clients over the years. One suggestion to improve this situation was the introduction of a search engine for the Trust website; however, this was not straightforward:

The thing is about the search engine is that you have to know what you are looking for. Like I know there is a team that has been set up but it has changed its function several times and actually we don't know what the team's for anymore and they're not getting referrals and there was an awful lot of money set aside to put this team together and nobody knows.

[Professional 2: Focus group]

It was clear from the focus group that professionals worked very much within their own remit but did not have a good understanding of wider services that were available for families in their care.

A minority of parents felt that information was deliberately withheld from parents, to avoid increasing the demand for limited resources. Parents also sometimes found out important information by chance, for example, from a bus driver, a therapist who was treating the parent or a professional who was not involved in a particular aspect of care but who could help through their knowledge of working with other children and young people.

Parents spoke of the need for a list, one single telephone number or helpline or other information source that could be sent out to them at key points in the child's life, for example at times of transition:

...to me, like to have a central, one telephone number, where you can ring and say look I have a child...and they can say right if you live in [locality] ring this number. You ring it, you get a social worker,
instead of 'oh, you shouldn't be with us, you need to ring so and so', 'oh, it's not us, you need to ring somebody else' and you're going round and round and I've had times where I've said 'to hell with that' and I've put the phone down.

[P30: Mother of a 15 year old young person with cognitive, sensory and communication impairments and autism]

Others recommended the use of an electronic register via their GP or paediatrician that would flag up when they needed additional support or information. Some parents felt the best way to distribute information might be via special schools. The temporary or finite nature of support services made it difficult for some parents to obtain consistent sources of reliable information from professionals. Parents were often informed if a staff member was leaving and introduced to who would be supporting them. However, occasionally, parents received a letter saying that they had been 'signed off' from a particular service regardless of their perceived need for support. Support from the voluntary sector, as a source of information was invaluable to many parents, but this could also be temporary:

...there's bound to be some way of collecting those names together and sending out an email or I just don't know, I can't see why it's [voluntary agency's] responsibility to be letting me know what I'm entitled to. Well now he's finished with [voluntary service], so I don't know if anything's coming up again.

[P12: Mother of a 7 year old with physical, cognitive, communication impairments and autism]

When asked about keeping in contact with families, professionals said that it was difficult to meet the needs of individual families. Professionals spoke of a range of family support needs from those who did not want their involvement to those who wanted much more. While re-establishing nursing and allied health professional services appeared to be straightforward for parents, accessing social services could be more difficult for several parents:

Haven't seen our social worker for a few years, feel that they forget about us when the girls get a bit older. Last time I phoned our social worker she was on annual leave and the duty social worker was unable
to help us, felt they didn’t want to be bothered unless it was urgent. Cedar foundation only people who write and help to take child out.

[Parent Survey 69: PS69]

Parents requiring health care services could ring and ask for more input from a service they had used previously, whereas with social work, an in depth assessment was required again:

There's a whole process to go through if they [parents] want to come back and we toe the party line, 'there's no social worker role but you can ring in at any time and access the duty social worker who will try and assist you', but actually it goes through the whole assessment process again and I hear quite often from families 'I just want somebody to go for that, a 15 minute phone call for advice'...and I fight quite hard for families that I'm supposed to close to stay open, just for that 'as and when'.

[Professional 2: Focus group]

In social work, according to one focus group participant, it was more difficult to 'close' a case when professionals were aware that ongoing support was a common requirement for many parents of disabled children and young people. Where other professions were concerned, involvement of professionals was more clearly defined or focused on a specific course of treatment or therapy.

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. While some children and young people appeared to have a very active social life, others had very little. It emerged during the research that such opportunities were available within the Trust, but parents were not always aware of them or information was not available that provided sufficient detail to have practical utility. 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.

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One interviewee felt that parents themselves had a responsibility to find out what was available for their child. She belonged to a parent group associated with the school which was a vital source of information for her and other parents. Despite the importance of this group, it was not always well supported. For example, although there was a willingness to start a Gateway club to provide children and young people with an opportunity to have fun and develop their social skills, there was not sufficient interest in it:

... I think it's maybe a bit of a cultural thing in the country at the minute, you know, somebody else'll do it for me and you've got to take some ownership and I know they're worn out but it's not asking an awful lot.

[P14: Mother of a 19 year old with physical, cognitive and communication impairment]

7.4 Getting the balance right

Two subthemes emerged in relation to getting the balance right: parent or professional as expert and 3 way communication between parents, professionals and children and young people.

Parent or professional as expert?

As the years went by, and parents developed expertise about their child's impairment and what they could expect from services, parents grew in confidence in decision making with professionals. Some parents said that professionals, at times, were willing to act on parents' wishes, even when they had recommended an alternative or doubted their opinion. One such decision concerned choice of school where measures were taken to place a child in mainstream school (against the professionals' better judgement) despite the staff having no prior knowledge of autism or the additional health needs of the child. In a further example, a nurse was able to ensure that a 15 year old young person was admitted to a children's ward, even though the 'cut-off' was 14. One mother spoke of a consultant who biopsied a child three times because the parent continued to have concerns about him. However, this was not always the case as in the following example:
P22: He wasn't sitting at all and I tried to explain to the doctor, nine months he was and I went back at ten months and I said 'I have a real instinct that there's something not right', and he said 'I am very reluctantly going to make a referral', he says, 'but I 'm not happy about it'.

[P22: Mother of 2 disabled children]

One parent thought that professionals did not like it when parents were too well informed or challenged them, for example about waiting list deadlines. Equally frustrating for parents were professionals who implied that they knew what the parent was experiencing:

She [professional] said 'it's alright, I understand, I know' she says, 'I was a single parent' and I said 'god that must've been hard'. There was me sympathising with her, you know? And afterwards only when you go out and sit and think, well did she have a disabled child?

[P20: Mother of a 3 year old with physical, cognitive, sensory and communication impairments]

At times, despite parents' concerns, bureaucracy hampered the care of children and young people. When one parent rang the disability team, she was told that they did not accept children unless they had an IQ under 70; however, they did not test for IQ until the age of 7 years. However, the fact that the team had listened to her and said they would try and find her a social worker in another team was enough to preserve the parent's trust in professionals. In another example, when a parent said she had issues with her child at 5 o'clock in the morning, the early intervention worker came to the house at that time to get an insight into what the parent described. Professionals who actively listened to parents in this way were highly respected by parents.

On occasion, professionals positioned themselves as expert, without taking into account parents' views. This was frustrating for parents, particularly in cases where they did not have concrete evidence for their 'gut' feelings. For example, this parent thought that the side effects of her daughter's medication were causing her other symptoms:

If you put forward a theory and you haven't got anything other than your daily experiences to tell them [the doctors] and it was my gut
feeling and every time I was seeing them over x number of years it was ‘no, no, no’ and all the medical jargon and then when [the nurse] started to nod and say that other parents were saying the same I thought, great, I’m not going off my trolley.

[P14: Mother of a 19 year old with physical, cognitive and communication impairment]

Parents felt that whilst their knowledge was limited, particularly about the medical aspect of things, they knew their child best, and at times there was evidence of a power struggle:

I remember a doctor saying to me years ago, you know, it was a nurse actually, a nurse saying to me, 'don't forget mum, you know your daughter best', and I clung to that because sometimes you get bombarded with all the medical jargon and everything and I think they do that sometimes to knock you off your pedestal or to knock you back on your box, because we're getting too vocal...

[P14: Mother of a 19 year old with physical, cognitive and communication impairment]

Despite emphasising their own role, parents thought it was important that professionals made an effort to get to know their child. Parents were impressed when they went to meetings and professionals appeared to know their child, their likes and dislikes and their personality well. This gave parents some reassurance when decisions were being made as it implied that professionals cared about their child as an individual.

Professionals who knew the family well sometimes acknowledged and recognised parents' expertise and this was valued by parents:

I remember our GP was in here [at home] years ago and he sat, he nearly had his head in this hands and he said [mother] you're the expert here. All I can say to you is whatever help and support we can be to you, just phone us...

[P14: Mother of a 19 year old with physical, cognitive and communication impairment]

In one case, the parent was involved in microboarding, a mechanism for person centred planning that focuses on children and young people's hopes for the future. The parent described this as a small group of family, friends and professionals who knew the young
person. Here the parent had a pivotal role and co-ordinated the young person's care, organising all relevant meetings across education and health. This gave the parent full control over the care of the young person and was very highly regarded, although time consuming and stressful for the parent:

We have this micro board set up, so we send out minutes so everybody knows what has happened with Simon at a particular time. There's never any of this, you know, playing catch up where you go to appointments and you repeat the same thing over and over again. We're all singing from the same hymn sheet and we all know where we left off.

[P24: mother of Simon, a 16 year old with physical, cognitive impairment and autism]

While the parent had an important role, when things were particularly difficult she needed professionals to take the lead and this system worked well.

**Three way communication**

Most children and young people reported that professionals talked to them, as well as their parents, and listened to what they said. Many wanted the support of their parents when they were interacting with professionals and making decisions. There was evidence that professionals often engaged appropriately in three way communication:

**PMCN**: And would you like the nurses [in hospital] to tell you more or did the nurses tell you just the right amount?

**MICHAEL**: The right amount

**PMCN**: And who do the nurses talk to when you are in hospital, do they talk to you or your mum?

**MICHAEL**: Both of us

**PMCN**: And were you happy about that?

**MICHAEL**: Yeah.

[MICHAEL: 20 year old young person with cognitive impairment and autism]
Children and young people who were cared for by nurses said that they sometimes communicated with parents more than with them. However, social workers were reported to involve children and young people more often:

**PMCN:** And does [social worker] talk to you or your mum?

**MARK:** Me

**PMCN:** She talks to you. And do you like her to talk to you?

**MARK:** Yes.

[MARK: 18 year old with physical and cognitive impairment]

Four children and young people felt that professionals talked to their parents too much and did not involve them as much as they would have liked. One young person said that it depended on the individual. Some professionals made efforts to reduce the power relationship between them and disabled children and young people:

**NATALIE:** ...I know he's a doctor but he's more friendly and I feel confident to talk to him.

[NATALIE: 27 year old with physical impairment]

This was unusual for medical staff as most children and young people preferred, or felt happy, that medical staff talked mostly to their parents. However, a lack of involvement in interactions or decision making with professionals caused anxiety for a small number of individuals. The following quote is from an interview with a young person who could indicate a yes and no and used symbols to communicate:

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

**ORLA:** [eye points to bored symbol]

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

**ORLA:** [eye points to worried symbol]

**PMCN:** Worried?

**ORLA:** [indicates yes].
A lack of participation and understanding also resulted in children and young people becoming bored and withdrawing from being actively involved in interactions:

PMCN: And how do you feel about her [social worker] coming then?
CATHERINE: [points to bored symbol].
PMCN: Bored?
CATHERINE: Yeah.
PMCN: And why do you get bored?
CATHERINE: Because she goes on and on about things.
PMCN: She goes on and on about things?
CATHERINE: Yeah, the same things all the time.
PMCN: What sorts of things does she go on and on about?
CATHERINE: I dunno.

Clearly such withdrawal greatly reduces the opportunity for participation in decisions.

It was apparent that, when faced with children and young people with limited verbal communication, the vast majority of professionals primarily directed their communications towards parents. 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.

Parents' attitudes were of the utmost importance in either facilitating or hindering their child's participation. 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. While some parents made conscious efforts to do this, others clearly took the lead
as their child's advocate. It was clear that some parents felt that they would always have to make all the decisions for their child, even when children became older or were able to make their views known. Thus 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:

When I first took Suzanne there [to the regional hospital], [young person] 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.

[P17: Mother of a 15 year old young person with physical, cognitive, sensory impairment and autism]

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 3 way communications. In all but 1 of the parent interviews, children and young people had a cognitive impairment and/or autism and there was a general expectation that there was limited value in professionals giving children and young people information because they would not be able to understand it. There was an expectation that many would never be able to participate in decisions and that this was a role that the parent would continue to take on their behalf:

...to me Catherine would have the mentality of about a 10 year old. She still plays with dolls. She wouldn't really understand. She wouldn't be capable of making decisions...yeah, I don't think [child] will ever be capable of making decisions...

[P15: parent of a 15 year old with physical, cognitive and sensory impairment]

As reported earlier, this was compounded by the attitudes of professionals. In the survey only 62% of professionals rated children and young people's participation in decisions as 'extremely important' (as opposed to 78% for parents' participation). Some parents 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. One parent spoke of her daughter not having a voice in the court system because the prosecution would make 'mincemeat' of her as a result of her speech and other impairments.

This depended on the commitment of individual professionals in engaging in communication with the child or young person, as well as the parent, and creating opportunities for visiting the home when the child or young person was there. The ability of professionals to communicate with the child or young person, the degree to which they got to know them, and the quality of this relationship, was particularly important to parents. Indeed, in many cases, this formed the basis of parents' overall views about the quality of care that they received:

**PMCN:** And does he [the GP] talk to Alistair as well?

**P30:** Yes, and then he would ask my opinion and he would say Alistair, what do you think of that? And to me that is...and Alistair knows him, he's known him from he was a wee boy....brilliant man.

[P30: Grandmother of a 15 year old young person with autism and cognitive impairment]

Although the ultimate responsibility for decision making lay with the parent who knew the child or young person best, there was a sense that, by getting to know children and young people, professionals were working in a three way partnership with children and parents:

Now the OT who's coming at the minute is exceptional because spends an awful lot of time with him. He's building a profile of Simon to try and share it with us and help us work with him in the home as well as we can.

[P24: mother of Simon, a 16 year old young person with autism and cognitive 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 young man 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 clear that they did not agree to what had been discussed. Self-confidence was an issue for 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.

In 10 cases, both parent and child or young person took part in the study, yielding the opportunity for triadic analysis. In 1 of these cases the child withdrew their consent in the second visit when data collection took place. In another case a child with no speech appeared unwell and the data was not used as it appeared potentially unreliable. Thus 8 cases were further examined. Two children were 6 years old and all but one of these children had significant cognitive impairment, resulting in minimal data from which to extrapolate in depth, triadic analysis. However, in all 8 cases parents worked tirelessly to ensure that their child reached their potential and in all but 1 they actively fostered their child's involvement in decision making processes with professionals. In this 1 case the parent had low expectations for her child and assumed that she would never be able to participate in decisions even though she was able to tell me about what happened when she met professionals. Most of these children and young people reported positive relationships with professionals who talked to them as well as their parent. Only 2 of these children and young people said that they wanted more information and wanted professionals to talk to them more, 1 of whom belonged to the DCYPPP. Two young people did not know why professionals came to see them and many were unaware of their diagnosis.
7.5 Participation in strategic decisions

Nineteen of the thirty parents interviewed belonged to the Parent/Carers' Council on Disability (PCCD). Of those, some had a very active part in this group, whilst others had a much more peripheral role. Many belonged to other parent groups run in their own locality or via their son or daughter's special school, some of whom also participated in decisions about services and policy. The 9 young people belonging to the DCYPPP spoke about their experiences of participating in health and social care services or policy. Only 1 of the remaining 9 children or young people, Catherine, had participated in this way and this was via the school setting. This young person, whose teacher took them to Stormont to make their views heard about the withdrawal of funding for music therapy, reported that she felt happy that people had listened to her. Three themes emerged from the data relating to participation in strategic decisions: belonging, gaining respect and making a difference.

7.6 Belonging

Children and young people

All of the young people from the DCYPPP reported a firm sense of belonging to the group. It provided an opportunity for young people to make friends and access support. It was apparent during the course of the research (in particular in the completion of the life maps at the start of the interviews discussed earlier) that some disabled children and young people had fewer friends and in many cases fewer opportunities for social activities than other children their age. It was very evident that belonging to the group was an important aspect of their social lives and many of the young people identified the group leaders as important people in their lives, alongside family members. Several young people spoke of confiding in the group leaders about difficult issues in their lives and it was very evident that there were close therapeutic relationships between the young people and the group leaders. All young people reported that they very much enjoyed being part of the group and for around a third, enjoyment of social activity was much more important that the participation activities:
PMCN: And what do you like about the group [DCYPPP]?

LAUREN: Pizzas

PMCN: So the food's good. Is there anything else you like about it?

LAUREN: It gets me out of the house.

PMCN: It gets you out of the house. And what sort of things do you do here?

LAUREN: Muck about and play games.

PMCN: And is there anything else that you do here?

LAUREN: That's it.

[LAUREN: 20 year old young person with cognitive impairment]

The structure of the group meetings was such that one part focused on having fun and another on participation work, for example when someone came to ask the group for their views. While the young people clearly enjoyed the social activities associated with the group, two young people reported feeling bored with the participation work. One young person, Emma, found it difficult to recall participatory activities that she was involved in:

PMCN: Can you remember anybody else that's come [to ask the group's advice]?

EMMA: Come

PMCN: Come here. Important people who come to ask you what you think?

EMMA: It's difficult.

PMCN: It is difficult.

EMMA: It's very hard to know. All the different ones come.

[EMMA: 23 year old young person with cognitive impairment]
Parents

While some parents reported a strong sense of belonging to the PCCD, there was evidence from several parents' accounts that, over time, as the PCCD took on an executive and charitable status, (playing a key role within the Trust, the Northern Ireland Social Care Council and the Regulatory and Quality Improvement Authority), the remit of the group narrowed. Whereas in the early days, any parent could attend open meetings that addressed issues that many parents faced, meetings had become more focused, resulting in some parents feeling left out. Four parents felt that parents' participation in services and policy within the Trust was based on a very small number of individuals:

I think it's very wrong that the Trust thinks it's right that they can ask the same people questions that would be irrelevant to them. Because all the ones, their children would be in adult services now. It's irrelevant for the children's services. Their experiences happened a long time ago...things have changed now.

[P1: Mother of an 11 year old child with physical, cognitive and communication impairment]

These parents felt that the views of a small number of parents that were not representative of the 300 parents who belonged to the PCCD, a finding that was endorsed by another parent who completed the survey:

The health board ask the same few parents to be involved. What about all the other parents out there -do their opinions count?

[Parent Survey 2: PS2]

In the survey, several professionals also commented that views about services and/or policy should be widened out, and not be confined to a small number of vocal individuals:

Meetings can be hijacked by small number of vocal parents with their own specific agenda. Not all voices are heard – often the most needy are so stressed/tied up they cannot contribute.

[Professional Survey 32: PrS32]
Half of the professionals who took part in the focus group were aware of the existence of the PCCD but did not have a good understanding of its role or how parents contributed to services and/or policy design.

Other parents recounted feeling strengthened and empowered by being part of a group where they found it easier to raise issues that they knew other parents shared. Being part of a collective voice (whether within the PCCD or a different parent group) reduced feelings of isolation and helped them to develop a sense of importance, power, security, respect and control:

When it's just yourself and you're solo and you don't know, you don't have a lot of information, you're afraid to speak up or you're afraid to suggest this because you're thinking maybe that's wrong; whereas when you're with the group you can sort of banter off them and get opinions and it strengthens you.

[P29: Mother of an 8 year old with physical, cognitive and communication impairments]

One parent said it was safer to raise issues via the PCCD where they could do so anonymously or ask an advocate to act on their behalf. Those parents of who belonged to the PCCD or other parent group spoke of the benefits. The primary benefit of belonging to such a group was for social support from other parents who were in a similar situation:

I started to go to the parents' forum [previous name for the PCCD] and for the first time in my life I did not feel alone. I felt so alone for the first, goodness [child] was about 6 at that time, so for 6 years I felt nobody, nobody understood me. I didn't know anybody who had a disabled child. I was here by myself and I felt [whispers] totally alone. And then I started to go to the parents' forum, I sat - everybody in that room knew exactly what I was going through...for me it was just, it was just a light coming on...

[P22: Mother of 2 disabled children]

This mother spoke of her focus shifting from herself as, over time, she became able to support others. She felt this removed her from the 'dark place' from which she had come. One parent said that it was difficult to join such a group at the time of diagnosis,
as this required some degree of acceptance of her situation, but for many parents this was a key source of their support outside their family. The other main benefit of belonging to a parent group was the availability of information. However, for a small number of parents there were some drawbacks of belonging to the PCCD. Some felt that some of the groups were too negative and focused on parents' complaints. Some parents were frustrated when service providers spoke of meeting their targets during stakeholders' meetings, when they themselves waiting for services. Other parents felt that meetings were not always relevant to their situation and one parent found it difficult to be in the same room as a professional who had, in her opinion, broken the news of her son's impairment in an unprofessional manner.

Two parents had been actively involved in the PCCD and other parent groups but had become disheartened as they did not feel that it always made a difference and this hindered their future participation. There was no evidence of specific facilitators for parental participation in service or policy developments. Parents who contributed to service or policy initiatives were no less busy but they were highly motivated and derived much support and feelings of empowerment by being involved in this way.

7.7 Gaining respect

Children and young people

In the survey, the majority of professionals indicated that it was 'extremely' or 'very' important that children and young people were involved in decisions about services or policy, although around one third did not have a good understanding of how they did so. Professionals felt that it was equally important for disabled children to be involved in decisions about services and policy as parents (see Tables 22a and 22b).
Table 22a: Professionals' views - how important is it that parents and disabled children/young people have a say in decisions about *services* (% professionals)?

<table>
<thead>
<tr>
<th>How important is it? (Services)</th>
<th>Parents have a say</th>
<th>Disabled children and young people have a say</th>
</tr>
</thead>
<tbody>
<tr>
<td>Extremely important</td>
<td>54</td>
<td>51</td>
</tr>
<tr>
<td>Very important</td>
<td>32</td>
<td>30</td>
</tr>
<tr>
<td>Important</td>
<td>13</td>
<td>18</td>
</tr>
<tr>
<td>A little important</td>
<td>1</td>
<td>1</td>
</tr>
<tr>
<td>Not important at all</td>
<td>0</td>
<td>0</td>
</tr>
</tbody>
</table>

Table 22b: Professionals' views - how important is it that parents and disabled children/young people have a say in decisions about *policy* (% professionals)?

<table>
<thead>
<tr>
<th>How important is it? (Policy)</th>
<th>Parents have a say</th>
<th>Disabled children and young people have a say</th>
</tr>
</thead>
<tbody>
<tr>
<td>Extremely important</td>
<td>36</td>
<td>39</td>
</tr>
<tr>
<td>Very important</td>
<td>33</td>
<td>33</td>
</tr>
<tr>
<td>Important</td>
<td>28</td>
<td>21</td>
</tr>
<tr>
<td>A little important</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>Not important at all</td>
<td>0</td>
<td>1</td>
</tr>
</tbody>
</table>

When asked if the participation of children and young people made a difference, 80-90% of professionals surveyed said that it made 'some' or 'a great deal' of difference respectively. One professional who completed the survey indicated that although she was aware of the young people's work, she was sure that it did not make a difference at all. Another survey participant shared this scepticism in the following comment:

I would like to think that child's and parents' views/opinions would make a difference and influence policy making and decisions but I doubt it – especially in present financial climate.

[Professional Survey 59: PrS59]
Professionals who took part in the focus group were not aware of how disabled children and young people participated in decisions about services or policy within the Trust.

Children and young people spoke of positive feelings associated with people coming to the DCYPPP to ask their opinion, for example a sense of accomplishment, feeling happy, or feeling valued. One young person, Natalie, had a memorable experience of participating at a day of general discussion at the United Nations:

NATALIE: I goes, 'I'm going to speak' and I put up my hand like this here [gestures] and it was up that long my arm was sore... but I got saying my piece and I got a standing ovation...

PMCN: So what's it like when you're at the United Nations in Geneva and you give your speech and you get a standing ovation?

NATALIE: It was unreal, it was just... something to remember...that's the way I look at it cause I'll never forget it as long as I live...

[NATALIE: 27 year old with physical impairment]

While Natalie felt that her views were recognised in a foreign country, she felt they were not always valued locally, where she reported differing perspectives between parents and young people and professionals 'listening but not hearing'. The young people reported the importance of feedback from those who had asked them their views, affirming participation as a two way process. Feedback was a regular occurrence and gave the young people a sense of accomplishment. Young people from the DCYPPP were much more aware of their right to be heard and their capacity to be involved in decisions that affected them than those not belonging to the group:

...we are capable because we are the experts on our own lives you know, and I feel we're in this world so we should know and we should be involved in any decision making process from the start.

[JASON: 24 year old young person with physical and cognitive impairment]

An important finding from the research was that young people from the DCYPPP were more involved in decision making with professionals than other children and young people in the study. Furthermore, there were only two occasions when children and
young people said that they had disagreed with a decision that was made, both of whom came from this project. One young person, Emily, from the DCYPPP described how her father had supported her whilst making the decision that she would not have surgery. Another young person challenged a dentist when she realised that they had acted inappropriately:

EMMA: He didn't do it proper, you know the proper way. He dropped the needle on the ground and then he put it in my mouth again...[her father was waiting outside the curtain] I shouted 'Da! he's doing the wrong thing!

[EMMA: 23 year old with cognitive impairment]

Overall, young people from the DCYPPP had much more confidence and self-determination when making decisions with professionals and were more willing to take more responsibility for what happened in their lives. These young people referred to the fact that they were getting older, and had to develop their own skills and reduce the extent to which they depended on their parents. Emily said that before she came to the group she was nervous about going to see her GP; Jack said that before he came to the group he would not have had the confidence to participate in the interview for this research. Jason spoke of 'coming out of his shell' as a result of attending the group. Natalie and Mary spoke specifically about feeling generally more confident because of the group. Natalie also spoke of her hopes for independent living. There was also evidence that young people who belonged to the participation group had, as a result, developed transferable life skills, for example, presentation skills and the ability to speak out in public and the delivery of staff training sessions as a mechanism for influencing changes in practice and attitudes to disabled people. These young people (from the DCYPPP) were also more likely to tell professionals that they wanted them to speak to them, as well as their parents:

EMILY: the GP would talk to me but if he does ask my mum 'What can I do for her I'm like, there's young people here as well, not just parents. So I says 'look doc I need to talk...'

[EMILY: 28 year old young person with cognitive impairment]
Emily and Jason said that they wanted to see professionals on their own, to talk through issues that were worrying them. It became evident during the course of the research that children and young people who were interviewed alone told me about issues that were worrying them at the end of the interview, while none of those whose parents were present did. Children and young people were rarely provided with the opportunity to meet with professionals on their own. One young person from the DCYPPP, Emma, made the decision that she would attend appointments and take a lead role herself:

**PMCN:** Whenever you go and see the doctor do you go in on your own or does your mum go with you?

**EMMA:** No, I go on my own...cause you're an age now.

**PMCN:** And when did she stop going with you?

**EMMA:** I was 18.

**PMCN:** And who decided that you would go in on your own?

**EMMA:** I said I'd go on my own and I know my own thing.

[EMMA: 23 year old with cognitive impairment]

As in the example above, there was no doubt that involvement in the DCYPPP resulted in children and young people being more aware of their rights and more assertive in how these might be realised, than others, and this was an important finding of the research. Young people had the advice and support of the group leaders, while other children and young people were unaware of their participatory rights. One young person from the DCYPPP realised that in order for them to develop and gain independence, parents needed to ‘let go’:

**JASON:** I think my mum has realised now that I am capable of speaking out for myself, you know I think she found it hard to go out of that shell... you need to have that flexibility of ‘you know he can do this’ and you need to understand that I can do that... so I’m finally getting there.

[JASON: 24 year old with physical and cognitive impairment]

Jason felt that his confidence and desire to be more involved in decisions had developed as a result of his work with the DCYPPP. This developing confidence enhanced his
mother's confidence in his ability to take control of his own health and social care needs. In families where the parent actively fostered independence and involvement in decisions, young people themselves wanted to take more ownership and responsibility for decision making.

Only three parents of two young people currently involved in the DCYPPP were interviewed and asked about their son or daughter's involvement in services/policy via the DCYPPP. The parents of one young person were highly complementary about the group as a mechanism for their child's social development. One parent also spoke about the importance of the group in terms of developing independence, as it was the first time their daughter had got on a bus on her own. Because of her trust in the group leaders, she was able to leave her daughter there despite having anxieties about her pureed diet and poor swallowing reflex. However, the participation role of the group was not recognised by any of the three parents:

PMCN: And what about what the group [DCYPPP] does then? What difference do you think that makes?

P5: Let's put it this way. It would be a huge, huge loss if it wasn't there.

P4: I don't think it's the overall of what they do. I think it's the social [aspect].

[P4 and P5: parents of a 10 year old girl with physical impairinent]

Therefore, despite being sent regular newsletters about the participation activities that the young people were involved in, parents did not recognise the participation role of the group. Rather, they emphasised and valued the social aspect. Similarly, one of their daughters valued the social activities of the group. Conversely, the other daughter, who had no speech, very much valued their participatory role and the difference that this group made.
In the survey, parents were then asked how important it was that they had a say in how services were designed and delivered and about policy. In both cases, parents perceived it as much more important than professionals (see Table 23a and 23b):

Table 23a: Parents' and professionals' views - How important is it that parents have a say in decisions about services (% parents and professionals)?

<table>
<thead>
<tr>
<th>How important is it?</th>
<th>Health services</th>
<th>Social care services</th>
<th>Professionals</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Parents (%)</td>
<td>Parents (%)</td>
<td>(%)</td>
</tr>
<tr>
<td>Extremely important</td>
<td>83</td>
<td>85</td>
<td>54</td>
</tr>
<tr>
<td>Very important</td>
<td>7</td>
<td>6</td>
<td>32</td>
</tr>
<tr>
<td>Important</td>
<td>8</td>
<td>5</td>
<td>13</td>
</tr>
<tr>
<td>A little important</td>
<td>3</td>
<td>4</td>
<td>1</td>
</tr>
<tr>
<td>Not important at all</td>
<td>0</td>
<td>0</td>
<td>0</td>
</tr>
</tbody>
</table>

Table 23b: Parents' and professionals' views - How important is it that parents have a say in decisions about policy (% parents and professionals)?

<table>
<thead>
<tr>
<th>How important is it?</th>
<th>Parents (%)</th>
<th>Professionals (%)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Extremely important</td>
<td>83</td>
<td>36</td>
</tr>
<tr>
<td>Very important</td>
<td>5</td>
<td>33</td>
</tr>
<tr>
<td>Important</td>
<td>7</td>
<td>28</td>
</tr>
<tr>
<td>A little important</td>
<td>1</td>
<td>3</td>
</tr>
<tr>
<td>Not important at all</td>
<td>1</td>
<td>0</td>
</tr>
<tr>
<td>Missing data</td>
<td>3</td>
<td>0</td>
</tr>
</tbody>
</table>

When asked 44% of professionals surveyed did not have a good understanding of how parents participated in decisions about services and 53% did not have a good understanding of how parents participated in decisions about policy. Of those who did
have a good understanding, 94% of professionals said that it made some or a great deal of difference to services and 87% said that it made some or a great deal of difference to policy. Additional comments relating to the involvement of parents in services/policy were that parents could sometimes be unrealistic about what could be provided (n=1), that the views of professionals were also important (n=3) and that changes to services were often made as a result of crisis management after parents went to the press (n=1).

All parents who were interviewed believed that parental participation in service design was important, and many felt that it made at least some difference. One parent spoke of losing her identity after having a disabled child and not being recognised as a carer, but feeling a great sense of recognition from being on the PCCD. Another believed that for parent participation to be effective, it had to operate like a marriage between parents and service providers that was built on mutual trust and respect. Some felt that parents needed to be more involved. However, there was a sense that even small changes, incurred as a result of parental participation, could have a major impact on their lives.

Speaking about the stakeholders meetings within the Trust, parents who attended felt that their opinions were taken seriously and acted upon where possible, fostering a sense of control over their situation. A key element to the success of these meetings were members of the Health and Social Care Board, who parents thought listened and took parents' views seriously. Parents spoke of one person as having the right personality, being on their side, and having an in depth understanding of their lives. When asked about what was positive about her, one person replied:

Just her enthusiasm and her drive... she seems to get on well with everybody. I get the impression that she thinks outside the box - she's always looking round the next corner to see what else she can put in place.

[P11: Father of a 16 year old young person with physical, cognitive and communication impairments]

Participation in decisions about services/policy gave parents a sense of control, personal development, a sense of identity and fostered a proactive approach to ensuring that their child's needs were met. Parents spoke of feeling empowered, more confident, more self-assured and able to help other families in a similar situation. Being part of a parent
group augmented this process, given that parents felt strengthened by being part of a collective voice. Participation also had practical outcomes, as parents who were more involved in this way were more likely to ask questions or challenge decisions that professionals made about their child. Being recognised as a partner was important for parents:

PMCN: And what does mean to you as a parent [that people at Trust/Department level listen]?

P22: Well, it means everything...they were basically saying you are very important partners with us and that was sort of mind-blowing because nobody had ever done that before.

[P22: Mother of 2 disabled children]

7.8 Making a difference

Children and young people

All young people believed that people who came to the group to ask their opinion did listen to them. They wanted to speak out, make a difference and affect changes in service provision for other disabled children and young people:

PMCN: And do people come here [to the participation group] to ask your views and opinions about services?

JACK: Yeah, everybody.

PMCN: And do you think that's a good thing? Do you think that makes a difference?

JACK: Yeah, that's what we're aiming for-to make a difference.

[JACK: 24 year old young person with physical and cognitive impairment]

Although the young people themselves felt that they were making a real difference to services, one young person reported that their work was not always recognised by others, for example parents and professionals. The lack of opportunity to participate in service or policy development was also a significant barrier for some children and young
people. Only one young person who did not belong to the DCYPPP had participated in decisions about services. Parents whose children attended the DCYPPP were sceptical of the outcomes of their child's participation and so the attitudes of adults served as a barrier to the encouragement of participatory activities. One young person felt that they were consulted too late and for about one third, those who came to consult with them were unable to engage them in a way they understood and maintain their interest.

Parents

In the survey, parents were asked if they had a good understanding of how services operated in their area (see Table 24). Around one third of parents said that they did.

Table 24: Do you feel that you have a good understanding of how health or social care services in your area operate (% parents)?

<table>
<thead>
<tr>
<th></th>
<th>Health services</th>
<th>Social care services</th>
</tr>
</thead>
<tbody>
<tr>
<td>Yes</td>
<td>30</td>
<td>38</td>
</tr>
<tr>
<td>No</td>
<td>43</td>
<td>52</td>
</tr>
<tr>
<td>Not sure</td>
<td>27</td>
<td>10</td>
</tr>
</tbody>
</table>

When asked, 91% and 90% of parents said that they would like to have a better understanding of how health and social care services operated respectively. The most popular format of this information was by post, followed by online. Information via the stakeholder's forum, the current arrangement, was the least preferred format. One parent suggested that a DVD would be useful as a source of this information and another said that it would be best delivered by small groups of 6-8 parents. Twenty one percent of parents who completed the survey said that they had been asked their opinion of health services in the past 12 months and 17% said that they had been asked their opinion of social care services. Of these 5% believed their input made 'no' difference, while the remainder said that it made 'some' or 'a great deal' of difference.
It was evident that parents who were interviewed wanted honesty from service providers. One third of parents interviewed were sceptical about the degree to which the participation of parents in services or policy made any difference. Some of these parents felt that decisions were made before service providers met with parents and that involving parents was a tick box exercise:

If you go along to a meeting actually believing you are going to change anything, you are deluding yourself. Now, I can be quite cynical, I can also be quite realistic. The Trust, the Board and the Department are strapped for cash so not a lot's going to change...what they don't have is resources, but it's how they use the resources they currently have and I don't believe they have prioritised according to what parents are shouting about.

[P14: Mother of a 19 year old young person with physical, cognitive and communication impairment]

Parents were unable to identify any concrete outcomes from their participation in services/policy, however, which added to a degree of scepticism in around one third of parents interviewed:

They know they have to listen to us. They say they're going to listen and consider it but you don't actually get told...'that's a good idea, we've rethought our strategy'. I've never hear that.

[P14: Mother of a 19 year old with physical, cognitive and communication impairment]

In another case, a parent spoke of attending a meeting where she and other parents were asked their opinion but she felt that the parents' views were steered towards a predetermined outcome by a senior health service providers allocated to each table of parents. Parents emphasised the need to be involved at an early stage for meaningful participation to take place. Only two parents who were interviewed were able to identify a change that had occurred as a result of parent input, while the remainder had never had any feedback after they had expressed their views. However, the overall feeling was that it was better to make opinions known than have no input, as someone might listen.

While many parents were keen for active involvement in service design and delivery, several parents did not have the desire, time or energy to participate this way. Some said
that they were busy meeting their child's needs and had no energy to concern themselves with services while others found it difficult to find someone to look after their child when they attended meetings. Some were unable to travel to the venue of stakeholders' meetings because it was too far away and they would not be back in time for their child coming home from school i.e. structural barriers to parents' participation. That said, when parents were asked what other arrangements would suit them they were unable to offer alternatives. These parents were happy for others to take the lead on their behalf. Some parents had confidence in service providers, as experts, to do their job and felt service provision should be governed by those who received payment to do it. In other cases, 'executive' parents spoke of meetings arranged to elicit parents' views that were not well attended.

7.9 Chapter summary

The findings of this research demonstrate that there were some commonalities and differences in terms of what participation means for disabled children, young people and their parents. For most disabled children and young people in this study, participation in decisions was firmly grounded in a family centred model. Most children and young people wanted parents or professionals to take the lead in decision making (particularly those with cognitive impairment). However, when children and young people were given information and drawn into participatory processes, they participated more and had an increased desire to participate in decisions on their own and this created a sense of self-confidence and independence. For parents who took part in this study, participation meant being listened to and respected, making a positive contribution and fostering the development of their child alongside professionals and service providers. While professionals supported the principle and practice of the participation in their interactions with disabled children, young people and their parents, they were not always able to provide all the services and support that families felt they needed. Thus while the principles of participatory practices were shared, there were some differences in the perspectives of key stakeholders who took part.
Many children and young people in this study were happy for adults to take the lead in decision making and there was a general sense that professionals talked to them as well as their parent and listened to them. However, some young people wanted more information and involvement as they grew older and some children with little or no speech wanted professionals to talk to them more, instead of their parents. Regardless of their participation, the relationship they had with professionals was particularly important to children and young people. An important finding of this study is that when children and young people are made aware of their rights, and their participation is encouraged or facilitated by others, they want and do have more involvement. It was very clear that young people from the DCYPPP took a more active role in decision making as a result of being involved in this group. This builds confidence in a general sense and facilitates them in having a real voice when communicating with professionals and making decisions about their lives. Some parents felt the need to protect their child on the one hand, whilst encouraging their participation and independence on the other, while others positioned themselves as the main decision maker in the long term. Telling the child their diagnosis was a challenge for many parents who feared that this knowledge would affect their self-esteem or make them feel different to others and this has an obvious impact on decision making processes. Professionals indicated that the participation of disabled children and young people in decisions about their care was less important than the participation of parents and attitudes varied as to the importance of their participation and how this transferred into practice. This reflected wider attitudes to children and disability for these participants.

While children and young people varied in their desire to participate in decision making processes, parents wanted to be involved in all decisions about their child. The vast majority of parents indicated that they had at least some involvement. Like the children and young people, the quality of the relationship they had with professionals was key to their involvement. Many parents in this study also reported positive relationships with professionals and professionals' ability to listen to them and recognise them as experts in the care of their child. However, many parents who took part also recounted instances when they were not listened to or not sufficiently involved in decision making processes.
and this created a great deal of stress. Non-participation had serious consequences for some families in this study, highlighting the importance of actively listening to parents' concerns, even when professionals are not in agreement. While mothers took most responsibility for decision making and this could at times be stressful, fathers had an important supportive role to play. Where participation in decisions about services were concerned around a third of parents had some degree of scepticism about the difference their input made.

Factors that promoted or hindered the participation of disabled children and young people were similar: their relationships with professionals, professionals' attitudes, professionals willingness and skills to communicate with them, parents' attitudes, the provision of information, the experience of being part of a participation group and the availability of resources/opportunities. The attitudes and practices of parents and professionals are the most important factors that facilitated or hindered participation for children and young people in this study. Attitudes to disability and childhood impacted on parenting and professionals' practices, and children and young people were not always afforded the recognition they deserved as social actors in their own right. Even when parents speak for children and young people and reduce their sense of agency, professionals can take steps to involve them and this was sometimes lacking. Some professionals lacked skills in communicating with children and young people with no or very little speech. This was potentially compounded by less use of alternative methods of communication in the home or hospital setting. The availability of information for children and young people was sometimes lacking and indeed was not a major consideration for professionals, many of whom were unaware if it existed or not.

Factors that promoted or hindered the participation of parents were similar to that of children and young people and included their relationships with professionals, professionals' attitudes, professionals willingness to include them, the provision of information and the availability of resources/opportunities. For both children and young people and parents a lack of choices and opportunities hindered their participation in decisions and parents perceived that, where services were concerned, they had to 'fight' for what they could get. It was evident that professionals were not well informed about
wider services that were available for families and sometimes did not have a good understanding of impairments. The provision of information appears fragmented and while available, it was not easily accessed by parents. Over half of all parents who took part did not have a good understanding of how services operated. Parents' solutions to this issue included the use of an electronic flagging system at key periods in the child's life, one point of contact such as a list, one single telephone number or helpline. The provision of information is complex, however, as parents varied in their readiness for information. Other parents, professionals and the voluntary sector are important sources of information, with the internet the least preferred option for parents. This is an important finding given the growing emphasis on the internet as an information source.

Positive relationships facilitated participatory practices and demonstrated caring. There were examples of professionals going over and above their sense of duty and at times professionals expressed frustration about not being able to meet parents' perceived needs. Meeting the needs of their child and difficulties with travel hindered some parents' participation in decisions about services or policy.

Outcomes across all areas for disabled children and young people included the development of confidence and self-determination, although this was particularly pronounced for those who belonged to the participation group. These young people had also developed additional transferable life skills as a result of their participatory role and wanted to take a more active role in decision making. These young people were at times frustrated when their views were not sought or taken seriously. Outcomes of non-participation for those not belonging to the participation group included anxiety or withdrawal from decision making processes. Outcomes for parents included an overall satisfaction with services/professionals, feeling valued, reduced feelings of isolation, a sense of control and an ability to question professionals and ensure their son or daughter's needs were met. Outcomes of non-participation included feeling undervalued, disrespected, angry and frustrated and could have serious consequences for the child or young person.

There were additional outcomes of participation in decisions made about services and policy. Being part of a participation group fostered a sense of belonging and support for
children, young people and parents. It also developed self-confidence in those who contributed. Many mothers of disabled children give up work to care for their children and this important work gave them a sense of control, empowerment and personal development. Parents' contact with other parents of disabled children also promoted their participation. Parents felt that it was vital that they participated at this level, although professionals deemed it less important. Parents who belonged to the PCD or other parent groups who participated in this way felt strengthened and empowered by being part of a collective group. Participating parents also felt that their experience and expertise was recognised by service providers and this gave them a sense of control over their situation. However, most parents had never received feedback about the difference their participation made.

Children and young people from the DCYP PPP developed assertiveness skills and other transferable skills that impacted on other areas of their lives and on their interactions with professionals. The DCYP PPP provided an important and enjoyable social activity which, for some young people, was its most important aspect. For many children and young people, belonging to the participation group, the social aspect and sense of belonging was the most important aspect. However, in relation to their participation work, they reported feeling valued and achieving a sense of accomplishment. The group leader ensured that they received feedback. At times, however, their participation was not recognised by parents. Children and young people who did not belong to the participation group did not have such opportunities for development. Professionals who took part in the study recognised the importance of the participation of disabled children, young people and parents in service design, delivery and policy, although they attributed less importance to it than parents. Generally, stakeholders felt that the participation of disabled children, young people and their parents at service and policy level made a difference, suggesting that they believed that service providers did listen and act on their views.

The findings of this study have demonstrated that for disabled children, young people and their parents, health and social decision making is a complex and at times affective process that is played out within the family as well as within the context of health and
social care services and indeed wider society. Most children and young people take increasing responsibility for decision making as they mature and develop until they can live independently. Indeed this is often seen as a natural process. However, disabled children and young people may need additional support and their parents may need to retain at least some responsibility during decision making processes. Participation has rarely been viewed through a 'family' lens where there is emphasis on both children and parents. The findings of this study suggest that such an approach is necessary. Similarly, where decisions about service design and development are concerned, it is equally important that both children and their parents are involved as service users. Thus it is evident that a new approach, recognising the contribution of both, is warranted.
Chapter 8: A new model of family participation

8.0 Introduction

Earlier in this thesis, I argued that Bronfenbrenner's social ecological model and Thomas's social relational model of disability would be of particular relevance to disabled children, young people and their families in this study. I also argued, (based on the work of Heidegger and the philosophical stance underpinning this study), that it was impossible to develop an understanding of individuals themselves without taking account of the social, cultural, temporal and historical context. However, the findings of this research also highlight social justice issues and the work of Nancy Fraser, which is concerned with equality, recognition and social justice for oppressed and marginalised groups. In recent child participation literature, recognition theory, including Fraser’s work, has highlighted (see Fitzgerald et al. 2010 and Graham and Fitzgerald, 2010). As one of the key social justice and recognition theorists, Nancy Fraser’s work is applicable to the findings of this study because of its focus on inequality and the relational aspects of recognition, alongside an emphasis on redistributive justice to address structural levels of oppression (Garrett, 2010). It became obvious that the work of Bronfenbrenner, Thomas and Fraser could be usefully combined as a framework to discuss the findings of this research. The reader is referred back to chapter 4 at this point for a reminder of the models of Bronfenbrenner and Thomas. This short chapter describes the principles of Frasers’ status model, the creation of the new family participation model and, using some examples and a case study from the research, provides evidence for it.

8.1 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. 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, the cultural norms of social institutions and the distribution of resources within a larger social frame, all important aspects of this study. 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, a point also made 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. Parents in this study at times were denied the status of full partners in their interactions with professionals. While the Southern Trust has been proactive to promote models of service provision that embrace participatory practices, this goal it is not yet fully realised. Similarly, cultural norms have shifted towards involving parents and
other service users in decisions about service provision. However, we still do not know the extent to which they have achieved status equality. Similarly children and young people in this study were at times rendered invisible during their interactions with professionals and as such, were not afforded the recognition they deserved. While wider societal attitudes to both children and disabled people have improved in terms of their status equality, again the findings of this study suggest that there is still progress to be made.

Many disabled people join together in various groups to argue the case for their rights and raise the profile and identity of disabled people. Fraser argues that oppressed groups do not need recognition of group-specific identity but rather recognition of equal status as full partners in social interactions. Indeed, for Fraser, identity models of recognition are deeply problematic as they promote separatism and marginalisation, and do not reflect the complexity of individuals' lives (Fraser, 2001). Fraser refers to this as the problem of reification. This raises the question as to whether groups such as the PCD and the DCYPPP should be considered as distinct. Fraser does maintain, however, that in some cases, distinctiveness or group-specific identity is justified:

'In cases where misrecognition involves denying the common humanity of some participants, the remedy is universalist recognition. Where, in contrast, misrecognition involves denying some participants distinctiveness, the remedy could be recognition of difference. In every case, the remedy should be tailored to the harm. The focus should be on what sort of recognition is needed to overcome specific, existing obstacles to participation parity.'

(Fraser, 1996: 33)

A second, and equally important, aspect of Fraser's work is the notion of the 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. Thus she proposes an approach where both recognition and the distribution of resources are inter-dependent. Many parents in this study felt that they had to fight for what they could get in order to meet their disabled child's needs. Thus, it was not simply a case of professionals and service providers listening more to participants, but they also need to ensure equitable service provision and sufficient choices available. Here Fraser makes a unique approach to the theory of social justice, as traditionally these aspects have been theorised independently (Fraser, 2001). The remedy (and ensuing justice), according to Fraser, lies in the combination of both a politics of recognition and a politics of redistribution. Addressing one or other in isolation will be ineffective in promoting social justice. In summary, Fraser's status model combines two concepts of social justice: recognition and redistribution. This justice demands a parity of participation from a micro to macro level i.e. from family/private spheres to public spheres and thus resonates with Bronfenbrenner's theoretical model.

8.2 Social relations, social systems and social justice: the family participation model

This study points to a joint model of family participation in health and social care decisions (see Figure 26) that combines the work of Thomas, Bronfenbrenner and Fraser. Represented here is the child and family, nested within Bronfenbrenner's systems. In the earlier conceptual framework of participation presented in this thesis (see p. 35), it was noted that participation could operate at the intrinsic (personal to the individual) and extrinsic (services, policy and the wider community) levels as illustrated
in the model (see Figure 26 below). The participation of disabled children and young people and their parents needs to be recognised in the intrinsic sphere i.e. within the micro and mesosystems, where they interact with each other, in addition to health and social care professionals. Beyond this, in the extrinsic sphere, their participation also needs to be recognised and supported by service providers and wider society in a culture where they are afforded equal status as full partners in social interactions in keeping with Fraser's status model (see Figure 26). The absence of such recognition will result in 'barriers to being' as depicted in Thomas's social relational model. However, without appropriate distributive justice i.e. a lack of choices, opportunities or resources for participation within the extrinsic sphere, 'barriers to doing' will also ensue (see Figure 26). These barriers are represented by the green arrows in the model.

Figure 26: Family participation model (adapted from Tuukkanen et al. 2013)
It is useful to illustrate the model using the case of Sinead, a 10 year old girl with a physical and communication impairment and her parents. Sinead communicated via yes and no signals (a smile signifies yes and a movement of the head signifies no) and the use of Talking Mats©. First exploring the intrinsinc sphere, within the microsystem Sinead was an only child who lived with her parents who were highly committed to their daughter. The parents' contact with professionals within the mesosystem provoked mixed feelings. This ranged from very positive interactions with some professionals who listened to them and recognised them as experts in their child's care to other cases where they felt professionals did not have the necessary knowledge to help them make informed decisions or did not respond in a timely or favourable manner. Likewise, Sinead communicated to me (via Talking Mats©) that while she had very positive relationships with professionals she sometimes wanted more say when decisions were being made. Within the intrinsic sphere, however, Sinead experienced certain barriers to her participation in decisions affecting her as depicted by the long green arrow in Figure 26. Via Talking Mats©, Sinead communicated to me that she wanted professionals to talk to her more, rather than her mother. Sinead's parents clearly displayed a 'can do' attitude to disability and focused positively on what their child could do. However, while her mother did ensure that Sinead was involved in decision making with professionals, she was surprised to learn that Sinead wanted more say:

PMCN: And does [OT] let you decide some things?

SINEAD: Indicates no.

MOTHER: What about your pink bench?

SINEAD: Indicates no.

MOTHER: She didn't let you decide! Right!

PMCN: It mustn't have been exactly what you wanted.

SINEAD: Indicates yes.

Here we see certain barriers to participation in terms of parental and professionals' practices and attitudes in line with Thomas's social relational model. These barriers, if
sustained over time and repeated communications could constitute what Thomas calls 'barriers to being'. In other words, failing to engage with Sinead or involve her in decisions about her life could make her feel undervalued and unable to exercise agency in her own life. Similarly, where Fraser is concerned, such practices deny Sinead her right to be a full partner in interactions and decision making processes, affording her a sub-ordinate position and potentially rendering her unworthy of respect or esteem.

Moving onto the extrinsic sphere of the model (Figure 26), both Sinead and her parents have been involved in decisions made by health and social care service providers via service user groups. Here they have also experienced barriers to participation in terms of both Thomas's barriers to 'being' and 'doing' as depicted by the green arrows in Figure 26. Sinead belongs to the DCYPPP where she receives recognition for expressing her views. Potentially shaping the services that she uses and participating in decisions in this way can help to foster a sense of self worth and esteem as reported in the findings of this research and advocated by Fraser in the status model. However, both Sinead and her parents have reported barriers to 'being' and 'doing' in terms of a lack of opportunity, experienced difficulties in accessing resources and recounted an instance where they went to a meeting about wheelchair provision where there was no disabled access to the room. This provides an example where recognition alone is not enough - it is essential that there is also redistribution of resources and equal opportunities for all members of society as required by the status model. So too have they experienced barriers within the macrosystem where they recounted negative attitudes by members of the public within the wider society of the macrosystem. For many years they have had to deal with people staring, behaving inappropriately, looking down on them, talking as if Sinead was not there and a lack of access to public services such as shops and restaurants. As a family, they have struggled to maintain a sense of self-esteem and have had to fight to obtain what they believe they are entitled to. Finally, within the chronosystem, at 10 years old (and indeed Sinead appears mature for her age), it is apparent that Sinead wants to be the 'main decider' as determined by Alderson and Morrow's (2004) definition. Successful participation and minimising barriers to her participation, as set out in this model, will
potentially help Sinead to develop into an independent young woman with a bright future.

8.3 Chapter summary

Current models of participation have focused specifically on the rights of children alone. However, where decision making within health and social care is concerned a broader approach is warranted, taking parents and other adults into consideration. Disabled children and young people, in particular, often do not want to take the principle role in decision making. Rather they rely on adults (parents and professionals) to guide them through this process. However, the results of this and other studies have highlighted the importance of encouraging and fostering their participation as a mechanism for building self determination and independence. Failure to do so can render them invisible in interactions with professionals and service providers and ultimately create social injustice. Wider societal attitudes will only improve toward disabled children and young people when their views are sought and respected and their ability to exercise agency in their own lives is recognised. This chapter has introduced a new family model of participation that is used as a framework to discuss the findings of the research in the next chapter.
Chapter 9: Discussion

9.0 Introduction

Earlier in this thesis a number of gaps in current literature around participation were identified. Where disabled children, young people and their parents are concerned these gaps include: a dearth of participation research that focuses specifically on these families, relatively few studies that focus specifically on health and/or social care decisions and few that explore in detail the process and outcomes of participation, particularly around decisions about services or policy. Furthermore, we know little about what works and what might best facilitate participation in terms of preparation, information and support and how this might transfer into practice. Thus, the aim of the current research was to explore the meaning, experience and outcomes of the participation of disabled children and young people and their parents in health and social care decisions. More specific objectives were to explore their experiences of participating in decisions made with health and social care professionals about their care and in decisions about service design, development and associated policy. The study also sought to identify factors that facilitated or hindered participation and to identify the outcomes of such participation for both the individual and wider service provision. This penultimate chapter explores the findings of the research in the light of extant literature, before making recommendations for practice, services and further research. The Family Model of Participation, presented in the previous chapter is used as a framework throughout.

9.1 Social justice: participation in the intrinsic sphere

As stated on p301, for Fraser, social justice rests upon what she refers to as participation parity - a situation where social arrangements permit individuals to interact with each other as peers. When social actors 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 result. The intrinsic sphere of the Family Participation Model concerns
such interactions within the microsystem (the child's immediate physical environment and the relationships between family members and other individuals that the child is in direct contact with) and the mesosystem (interactions within the health and social care setting, including interactions with professionals).

**Social justice within the microsystem**

Bronfenbrenner's microsystem, the inner most system in the Family Participation Model, is the first system the child encounters and provides a good training ground for children's participation in decisions within the family, before they come involved in wider systems. If a child is not encouraged to exercise their own agency when smaller decisions are being made in the home setting, it is potentially much more difficult for them to engage in more important decisions made with professionals within the mesosystem.

Participation in family decision making was not an objective of this study per se. However, results of this study suggest that this could impact on the participation of disabled children and young people and their parents in wider spheres of Bronfenbrenner's model. Davey *et al.* (2010), exploring children's participation in decision making at home, found great variability in children's involvement from those who experienced very democratic households to those where children did not have a say. Children said that generally became more vocal as they grew older. Disabled children in the study by Davey *et al.*, however, were more likely than others to highlight areas where they wanted more involvement. Furthermore, they felt that their involvement in decision making and independence was restricted at home. Clearly if children and young people are not encouraged to make decisions in the home setting they are less likely to exercise their agency in other environments. Parenting styles that do not lend themselves to their child's participation in decision making may lead children to conclude that they do not have the right to participate in decisions outside the family setting.

In this study, the lead role of mothers in caring for and making decisions about their disabled child within the microsystem mirrors the findings of previous studies, such as those summarised in Read (2000). Ryan and Cole-Runswick (2008) argue that mothers
of disabled children develop specialist competencies that other mothers do not possess, and which go largely unrecognised (and indeed this provides some evidence for the need for distinctiveness of this group). This study shows that (according to the mothers and the small number of fathers who participated) mothers have the lead role in health and social care decision making where disabled children and young people are concerned.

The key role that mothers (as opposed to fathers) played in supporting their child in decision making processes has been evidenced in other studies (see for example, Mitchell, 2012a; Mitchell, 2012b) and it was clear that mothers took the lead role in both decision making with professionals and those involved in service provision at a strategic level. Thus family approaches to decision making can greatly influence the participation of others within the microsystem.

However, findings of this study also suggest that fathers play an important part in providing vital support to mothers where decision making is concerned. This role goes largely unrecognised by professionals who also may unintentionally reinforce the passivity of fathers in interactions with them and, in Fraser's terms, afford them a subordinate role. While seldom reported in previous literature, fathers of disabled children in a study by Huang et al. (2011) highlighted that professionals talked mostly to mothers, potentially excluding them from decisions that are made. Professionals therefore have an important role to play in fostering the participation of fathers and actively involving them and drawing them in to decision making processes.

Social justice for disabled children within the mesosystem

The second part of the intrinsic sphere of the Family Participation Model concerns the mesosystem which includes interactions with health and social care professionals. In order to achieve social justice, disabled children and young people require recognition and status equality as social actors in their own right. Adults that they encounter within the mesosystem need to acknowledge their capacity to participate in decision making and find out how much say they want, potentially (if desired by the child) affording them an equal status when decisions are being made. 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 (see for example, Allen, 2005; Slade et al. 2009; Hyde et al. 2010). 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 others:

'Within a children's rights framework, children need to be listened to and treated as independent individuals with rights of their own, not subsumed by those of their parents or indeed by those of professionals.'

(Burke 2005:362)

Lansdown (2005), exploring the evolving capacity of the child, points out that parents need to take into account the competency of their child when guiding them about their participatory rights. In this research, few parents expected their child ever to be able to participate (either independently or with their support) in decisions and many saw this as something that they would continue to do on their behalf. Turner (2003) and Kelly, (2005) reported similar findings where there was a general assumption that disabled children and young people could not form opinions about their own needs. 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 in Alderson and Morrow's (2004) definition (see p46). However, at times, it appeared that they could have been more involved and their exclusion constituted 'barriers to being' within the social relational (and Family Participation) model. Previous studies have discussed the role of the parent in 3 way communications between children, professionals and parents, the majority focusing on barriers such as adults' protection of children and parents speaking for children in the health and social care setting (see for example, Moore and Kirk, 2010; Coyne and Harder, 2011; Kilkelly and Donnelly, 2011; Gallagher et
However, the role of the parent in actively encouraging and facilitating their disabled son or daughter's participation (including 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. This is particularly important here, given the emphasis on empowerment and participation within the ethos of Wraparound. Many parents in this study either actively involved their son or daughter in decisions about health and social care or were of the view that they would make all the decisions for their child. Encouraging such participation may be challenging for some parents of children with significant cognitive impairment or no speech, as their most natural response is to speak for their child. As long ago as 1999, Pennington and McConachie demonstrated that communication between parents of non-speaking physically disabled children between 2 and 10 years contained high levels of maternal directiveness, with little change throughout childhood. Clearly if children and young people are to participate more these communication patterns need to change in order to address the needs of the developing young person.

The positive relationships between children and young people and professionals, as evidenced in this study, is encouraging and reflects the ethos of Wraparound. Findings from this study suggest that, overall, many disabled children and young people (in particular younger children and those with cognitive impairment) are generally happy for adults they trust to take the lead where decision making is concerned and want the support of their parents in decision making. This is in keeping with the landmark study of children awaiting surgery by Alderson (Alderson, 1993), whose definition of participation frames this study), most of whom did not want to be the 'main decider' (Alderson and Morrow, 2004). However, it is very important to children and young people that professionals talk to them, provide them with information and establish whether or not they want to be involved. Findings from this study suggest that this is, at times, lacking, a finding reported in previous studies conducted with disabled children and young people (see also Monteith and Sneddon, 1999; Turner, 2003; Kelly, 2005; Haydon, 2007).
The relational basis of participation has received some attention in recent literature (Fielding, 2007; Mannion, 2007; Thomas, 2007) and this has particular currency in this research, not least because it is the very essence of Fraser's (1995) theory of recognition, of Thomas's social relational model of disability and the family participation model proposed here. 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 constitutes psycho-emotional disabilism and misrecognition. 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 (Sinclair, 2000; Rabiee et al. 2005; Franklin and Sloper, 2006).

The ability to communicate appropriately with disabled children and young people is a key skill for all those who work with them (Children's Workforce Development Council, 2010). However, concrete training programmes, dedicated educational courses and texts are extremely limited. It is encouraging that a number of key resources and guides around communicating with disabled children and young people have recently been published in this area (see for example, Morris, 2002; Welch, 2008 and Goodwin and Jones, 2010). While the provision of such resources is positive in terms of fostering participatory practices, they need to be integrated into both undergraduate, postgraduate and continuing programmes for all professionals who work with children and young people. A positive finding of this research was that the Sixth Sense group provide training on communicating with disabled children and young people to new staff within the Trust. Such approaches clearly recognise children and young people as social actors, in their own right, fosters relationships between them and professionals and avoids 'barriers to being' within the social relational model.
Changes of staff, as reported in this study, made the maintenance of long term relationships between professionals and children and young people difficult. Winter (2009) reports similar findings relating to building relationships with young children. However, this is even more crucial where disabled children and young people are concerned, as it may take time for professionals to develop very individual ways of communicating with them. Professionals are in a unique position to build positive relationships with children and young people; however, this will only happen if professionals recognise the potential contribution of children and young people (within the auspices of social justice and the sociology of childhood), build relationships over time and communicate with them appropriately.

In this study, the provision of information for children and young people was, at times lacking. While there is a lack of studies addressing this particular issue, a small number of previous studies have identified that information provision for disabled children and young people is variable (see for example, NICCY, 2008; Greco and Beresford, 2009; Mitchell, 2012a). According to the UNCRC, disabled children and young people need to be provided with 'whatever mode of communication they need to facilitate expressing their views' (UNCRC, 2006), a point also made in the UNCRPD. However, it would appear from this research that while children and young people are provided with such resources within the school setting and in the DCYPPP, these are not used in the community by the professionals who interact with them. Stephenson and Dowrick (2005) report that while parents are not always supportive of the use of alternative and augmentative communication systems at home (citing a lack of time or invalidity of picture or symbol systems) they would encourage professionals to communicate with the child or young person directly, rather than only addressing the parent. Returning to Thomas's (1999) social relational model, some children and young people in this study experienced restrictions in communication due to impairment effects, particularly children and young people who used little or no speech. 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 to 'being' 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).

The finding that medical staff tend to engage with children and young people (with or without impairments) on a social or conversational level, rather than providing information and asking their views about medical decisions is evidenced in previous studies. Burnstein et al. (2005), exploring communication patterns of primary care paediatricians, parents and children with and without special health care needs found that children with special needs were more involved in conversations than their healthy peers. However despite this finding, in both groups of children, children talked much less than their parents and were primarily involved in social conversations. Although paediatricians talked to children, any medical information communications were directed towards parents. This may be because of current legal requirements of consent (DHSSPS, 2003a) but it does not take into account children and young people's competence as social actors in their own right. Legally, children and young people in Northern Ireland can consent to their medical treatment from age 16, but previous studies have demonstrated that much younger children and those with cognitive impairments can take part in decisions (see for example, Byrnes 2002; Garon and Moore, 2004, Alderson et al. 2006; Huizenga et al. 2007; VanTubbergen et al. 2009 and Winter, 2011). Thus a tension exists between children's agency and rights on one hand and legal requirements on the other, although the notion of Gillick competence (Gillick v West Norfolk and Wisbech Area Health Authority) bridges this gap to some extent. Young people in Northern Ireland can consent to (but not refuse) treatment from the age of 16, but may be deemed competent under the Gillick ruling. Lambert et al. (2008) proposes the concept of 'visible-ness', a continuum from 'being overshadowed' to 'being at the forefront' to explain communication systems between professionals and children in the hospital setting. Many children and young people in this study said they did not want to be at the forefront, but nevertheless some wanted to be more visible in decision making processes. If professionals do not provide children and young people with appropriate information and attempt to draw them into participatory processes, they will almost certainly be excluded from decision making and become 'overshadowed'.

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Returning to Fraser's (1996) social justice perspective, this renders disabled children and young people invisible in interactions and results in misrecognition and status subordination.

Disabled children and young people's lack of understanding of professionals' roles clearly impacted on their ability to participate in decisions, as did a lack of knowledge about who was caring for them (due to staff turnover or poor communication). Children with cognitive or communication impairments may find it difficult to retain (Larsson and Sandberg, 2008) or recall information (Beresford, 2012), but it was clear that many adults did not explain their role to children and young people, either because they did not deem it necessary or did not have (or take) the time. For many children and young people, this was compounded by not being aware of their diagnosis. There are arguments for and against telling children and young people about their diagnosis and treatment options. While there is much literature about parents' experiences of hearing about their child's diagnosis (Braiden et al. 2010; Keenan et al. 2010; Watson et al. 2011) and guides for professionals on how to share diagnostic information with parents (see DHSSPS, 2002; Price and Cairns, 2009), literature about giving disabled children or young people information about their diagnosis or impairment is notable by its absence. In relation to access to appropriate information, the UNCRC (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.'

(UNCRC, 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, 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 (see for example, 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. In the absence of information about diagnosis, previous studies have demonstrated that disabled children and young people develop knowledge about their impairment from others which may or may not be accurate appropriate (see Kelly, 2005) and this has also been evidenced in this study. It is arguable that, in relation to Thomas's social relational model, not telling children and young people about their impairment or prognosis potentially creates a 'barrier to being'. 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.

The clear difference (as determined by the survey results) between the availability of information for those in child and adult services is notable and identifies an important gap that has not been highlighted in previous literature. The finding that around a quarter of professionals from child services did not know if there was any information for children suggests that there was a feeling that this was not required and that information would be given to children by parents. Given that other services within the UK (see for example the Great Ormond Street Children's Hospital's information for children) are developing such resources, in line with new ways of thinking about children and childhood (James et al. 1998), this warrants attention. Few professionals suggested that information would need to be adapted for individual children and young people and yet this would seem key to such resources being developed and used in a meaningful way. Similarly, in all but one of the parent interviews, children and young people had a cognitive impairment and /or autism and many parents thought there was limited value in professionals giving children and young people information, because they would not be able to understand it. There was little expectation that professionals should, could or would adapt their communication skills accordingly, again reflecting parents' attitudes to disability as members of wider society.
Different attitudes and practices across child and adult services also serve to potentially facilitate or hinder the participation of disabled children which may not prepare them adequately for taking more responsibility for decision making at the time of transition. Given that decision making is the foundation of self-determination and self-confidence (Van Tubbergen et al. 2008), the apparent lack of involvement of some children and young people identified in this study is an important finding. While there were clear examples of professionals involving children and young people appropriately, some children and young people in this study said that they wanted professionals to communicate more with them, instead of their parent (particularly those from the DCYPPP who were more aware of their rights). Family and person centred practices in health and social care have incorporated the need to work in partnership with children and young people and their families (Darling, 2000; Smith and Coleman, 2009; Care Quality Commission, 2011); however it would appear that this is at times lacking. While 8 of the studies included in the literature reviews set out earlier in this thesis addressed the issue of transition (Monteith and Sneddon, 1999; Carnaby et al. 2003; Ward et al. 2003; Badger, 2009; Gillan and Couglan, 2010; Pilnick et al. 2010; Maddison and Beresford, 2012a and 2012b), the readiness of young people and preparation for increased responsibility for decision making does not feature.

There was evidence in this study that three-way participation between children or young people, parents and professionals could be achieved. Success, however, is dependent on the provision of information to the child or young person as discussed above, and the facilitative actions of professionals and parents. Coyne and Harder (2011) report that parents may intentionally or unintentionally inhibit the participation of their children by doing things like answering questions on children's behalf, asking the child to be quiet or discouraging them from interrupting. Professionals may unintentionally reinforce these actions leading to the 'double' exclusion of children from participatory practices. The specific role of the professional in promoting the participation of disabled children and young people is not clearly defined within the literature. Professionals have an important part to play in cases where parents themselves do not actively encourage their child to participate. Positive actions from professionals include spending time building
rapport with the child and developing a good knowledge of their way of communicating, redirecting a question to the child if a parent answers, maintaining eye contact with the child rather than directing communications towards the parent (especially if the child has a very individual way of communicating) and giving due consideration to the seating arrangements to ensure that children and young people are given the space to be involved (Triangle, 2009). Where participation in health and social care decisions is concerned, this study suggests that a much more active role, incorporating these issues, is required. Some parents expressed a need to protect their child and in doing so often made decisions for them. An important role of the health or social care professional is to support and be guided by parents. However, by sensitively offering the child or young person an opportunity to participate in decisions that affect them, professionals may alter communication systems in a positive way in order to uphold the rights of children, help them exercise their own agency, ensure that their expertise is recognised and ensure that they are not undermined or ignored during interactions with professionals.

Social justice for parents within the mesosystem

For social justice to ensue, the parents of disabled children and young people also need recognition as experts in their child's care and status equality during interactions with professionals within the mesosystem. Parents felt strongly that they wanted and needed to be involved in all decision making involving their child, from basic, everyday decisions to more complex ones. Such involvement fostered a sense of control and mastery over their situation (see also Jackson, 2008). This reflects current models of partnership working in both health and social care practice (Dunst et al. 1988; Darling, 2000; Smith and Coleman, 2009), based on the empowerment of service users and carers; however, parents in this study highlighted the importance of ongoing support. Many perceived professionals' lack of contact in the home setting as not caring and thus it is possible for professionals to take the empowerment approach too far and assume that parents are coping well when they are in need of support. Others appreciated that
professionals' caseloads were large rendering ongoing contact difficult (see also Hiebert-Murphy et al. 2011).

Many parents reported positive relationships with professionals within the Trust and a willingness to go 'over and above' the call of duty. This is noteworthy given the climate of change and challenges inherent within service provision in Northern Ireland in the years following the review of public administration (see chapter 2). In this study, professionals who were perceived to care, were trustworthy and reliable, worked in partnership with parents and fostered relationships based on mutual respect and open, two way communication were highly valued by parents. For Fraser, recognition relies on the status of individuals as full partners in social interactions, thinking that underpins partnership approaches to professional practice. Marchant et al. (2007) point out that the way a service is delivered is by professionals just as important as the service itself. While there were examples of professionals listening to parents' concerns, there were also times when parents were made to feel that they were over anxious or paranoid, a finding reported in previous studies (see also Hendrickson et al. 2000; Slade et al. 2009). However, while parents recounted instances when they were not listened to by particular professionals, it appeared that in many cases, the expertise of parents was recognised in keeping with Fraser's social justice perspective.

An important finding of the research was the continuing difficulty in accessing information about health and social care services, creating both 'barriers to being' and 'doing', a feature repeatedly reported within current literature (see for example, Slade et al. 2009; Resch et al. 2010; Starke, 2010; Maddison and Beresford, 2012). The finding that parents found out important information by 'accident' is reported in other studies (see for example, Redmond and Richardson, 2003; Maddison and Beresford, 2012a). A health impact assessment of the Wraparound scheme in 2002 (Farrell et al. 2004) identified the need to improve information for families. This research shows that this aspect of service provision still needs attention. A review by the Bamford monitoring group in 2011 highlighted the need to address 'the major deficit in the provision of advice and information services' (Patient and Client Council, 2011:5) for those who rely on learning disability services across Northern Ireland. It is encouraging, however, that
parents of autistic children in this participation study reported a marked increase in the availability of information about autism and available services over time. The recent Autism Act (Northern Ireland) (2011) and autism review (Maginnis, 2008) in Northern Ireland may have contributed to this finding. However, this was not apparent where other impairments were concerned. This may have improved since data collection in 2011 as the Health and Social Care Board launched the Family Support NI website in June of that year, providing online information for all families (although this is not targeted at children and young people). This website is currently being further developed and may go some way in addressing this issue. However, the internet was not widely used by parents in this study. The relatively low frequency of internet use in the survey (see p262) is surprising, given the increased emphasis on the world wide web. This aspect of information provision has featured little in current participation literature. In one UK study of 788 parents of disabled children by Blackburn and Read (2005), 75% of participants had previously used the internet. The difference in findings may be explained by the fact that the study by Blackburn and Read asked parents about general internet use, for example, emailing or shopping online as well as a source of information about caring. Some parents in this study did however turn to the internet when professionals failed to listen to their concerns. In a study by Knapp et al. (2011) in Florida, exploring internet use in parents of children with special needs, 82% of parents surveyed used the internet and 74% of these were familiar with where to find health information; however, only half of these parents could tell the difference between high quality and low quality information on which to base their decisions. Thus it appears that parents in the current study wanted reliable, face to face or written information but will use the internet to find information that is not available from other resources. Parents of disabled children also experience financial hardships (Contact and Family, 2012) and this may also have affected access to the internet for some parents in this study. Returning to the concept of social justice and redistribution, for some parents, financial hardship may have contributed to parents' lack of knowledge about what was available for their child.
Professionals' lack of knowledge about specific conditions was also apparent in this study as was their lack of awareness of what resources and services were available for families. These findings suggest that the mechanisms of information provision were not effective for either professionals or parents, and need attention. In particular professionals' lack of awareness of services may impact negatively on parental information and decision making, as children and young people's health, social care and educational needs cannot be met adequately without evidence of some degree of joined up thinking and practices, a point also made by Resch et al. (2010) and the Care Quality Commission (2012). Overall, while many services were available for families in this study, they appeared fragmented, making it difficult for parents to find out what help they could access. Previous authors have highlighted the need for greater collaboration in order to meet the needs of young disabled people, particularly as they approach the period of transition (Clarke et al. 2011).

The finding that, for around two thirds of parents, information came almost equally from professionals and parents, emphasises the strength of parents' relationships with other parents. In keeping with a social justice perspective, this adds weight to the claim that parents should be afforded more recognition for their knowledge and experience. It also highlights the potential importance of the PCD and the DCYPPP, both as mechanisms for support and information provision, as well as their core role in facilitating user involvement and promoting recognition, status equality and social justice. Jackson (2008), in a review of decision support needs of parents, also report the importance parents place on talking to other parents in the same situation as themselves in order to share experiences and knowledge, a finding also reported by Goodley and Tregaskis (2006). Equally, adequate financial investment should be available to support parent initiatives. As early as 1992, Stewart and Covington reported the inception of paid parent consultants in the care of children with special needs in the US (and mechanisms for funding). Formally employing and funding a small number of expert parents in such a role in Northern Ireland, even on a part time basis, may go some way in addressing the gaps where the provision of information is concerned and satisfy Fraser's need for recognition. Similarly, the role of the voluntary sector is pivotal in the provision of
information (see p262). Given this finding, current investment in the voluntary sector, as part of Wraparound, is indeed warranted. This was also reflected in accounts from parents who praised the local voluntary services that they had used. Children and young people in this study did not discuss a similar need for peer support and information and this warrants further enquiry.

Not all parents want information at any given time. Hyde et al. (2010) point out that decision making often has a strong affective component and the provision of information (particularly in the early stages or during periods of transition) is underpinned by parents' emotional trauma (Narramore, 2008; Eckersley, 2009; Resch et al. 2010). Several parents were not ready to seek or hear information in the early stages following the diagnosis of their child (see also Keene Reder and Serwint, 2009). Thus professionals need to be aware of the individual needs of the family and indeed several parents recounted instances where professionals were sensitive to their needs at this time.

9.2 Social justice: participation in the extrinsic sphere

For Fraser (2003), recognition may occur at the individual level, but it is equally influenced by wider cultural patterns, a point also reflected in the wider systems of Bronfenbrenner's model. Thus recognition of social actors must also occur within the wider social systems of the exosystem (in this case health and social care services) and the macrosystem (wider culture and society), as reflected in the extrinsic sphere of the Family Participation Model (see Figure 26, p 304). As stated earlier, Fraser (2003) also argues that justice requires both recognition and redistribution, neither alone is sufficient. While in the intrinsic sphere, key barriers to participation are concerned with the misrecognition of children and their parents in smaller scale interactions with professionals, in the extrinsic sphere, both aspects (recognition and redistribution of resources) are important. It is within the extrinsic sphere that families are affected by wider decision making processes made by service providers; for example, the distribution of resources and the creation of opportunities for children and young people.
to ensure that they reach their potential. Not affording children, young people and their parents opportunities for participating in strategic decisions and not providing resources may cause barriers in terms of the 2 aspects of social justice required by Fraser - a lack of recognition of their knowledge and expertise as service users and a lack of equal distribution of resources, commensurate with other families. In this section participation within the extrinsic sphere of the model is explicated and Fraser's (2003) two social justice dimensions of recognition and redistribution are considered within the exosystem and macrosystem. Finally, the influence of time (the chronosystem) is explored.

Social justice for children and young people within the exosystem

The exosystem concerns the wider environment surrounding the child and family, including service delivery systems such as health and social care. Current literature around the participation of disabled children and young people in decisions about health and social care services is scarce with only 2 studies reporting the process or outcomes of such participation (see ch 3), a gap that this study fills. Some disabled children and young people in this study, who belonged to the DCYPPP, actively participated in decisions made about health and social care services. This reflects current policy that seeks to engage with service users, particularly in the light of the proposed model of service delivery within 'Transforming your care' (see chapter 2 of this thesis). Children and young people reported a sense of empowerment and recognition by being asked for their views and they believed that this would make a difference. However, they were at times bored when service providers came to ask their views. Successful participatory practices with young people are dependent upon careful planning and novel means of communication and participation. There is much guidance available (see for example, extensive resources by produced by Participation Works) but at times such approaches were not used. The skills of those who plan and conduct participatory activities with children and young people are important and a lack of skills can create a barrier to participatory practices. The finding that children and young people who belonged to the
DCYPPP reported a firm sense of belonging to the group is significant, given the potential risk that disabled children and young people face in experiencing poor subjective well-being (Beresford, 2012). The social aspect of the group was particularly important to all participants and this reflects previous findings (and indeed data presented in this study) that disabled children and young people may not have as many social opportunities as others (Beresford and Clarke, 2009).

The finding that professionals rated children and young people's participation in services and policy the same as parents' participation is an interesting finding. It appears that professionals in this study rated children and young people's participation in decisions about their care less important than parents' participation but attributed the same importance where decisions about service and policy planning were concerned. Many professionals who took part in the study were not aware of how children and young people (or indeed parents) participated in this way, which could explain this finding. From a social justice perspective, it is encouraging that most professionals recognised their participation in this way and believed that it made a difference.

In this study, parents did not recognise children and young people's participation in the planning of services or policy, despite receiving regular newsletters from the DCYPPP outlining their contribution. This upholds traditional views of disability and childhood and refutes the notion of children and young people as competent social actors in their own right. Following Fraser (1995), the contribution of children and young people was misrecognised due to their status as children or as a disabled person. Parents may unintentionally create 'barriers to being' by not recognising their son or daughter's contribution in this way. An alternative explanation may be that parents simply do not have the time or emotional energy to consider such an approach; it is simply not their priority or due to a lack of resources (respite provision), they saw this group as an opportunity for respite and something their son or daughter could attend without their support. Their child's enjoyment in attending the group also may have been a more important aspect, as many parents in this study said their child had limited social opportunities.
Social justice for parents within the exosystem

There is a dearth of research (3 studies as detailed in ch 3) about the process or outcomes of disabled children and young people's parents in decisions about services or policy, a gap that this research also fills. Parents who were interviewed reported a firm sense of belonging to the PCD and gained much social support from it. Given that having a disabled child is often associated with social isolation (Hobson and Noyes, 2011) and helplessness that can lead to depression (Olsson and Hwang, 2001; Glenn, 2008; Kerelaaret al. 2008), this is a positive finding. Parents who were actively involved in the PCD reported feelings of empowerment, control and recognition from service providers in keeping with a social justice perspective. Affording parents equal status with service providers resulted in parents feeling valued and having a real voice in decision making processes. Recognition, for Fraser, should extend beyond the interpersonal level and into the wider structures that individuals encounter and this study confirms that this is indeed happening where health and social care provision in this area is concerned. Involving parents also ensures that they are, at least to some extent, potentially involved in the redistribution of resources, also in keeping with a social justice perspective. This strengthens the recognition of parents within health and social care, but is one area of social justice that requires further evidence. Most parents in this study could not identify how their input had a meaningful and tangible impact on services. Parents were not aware of any feedback on their participation, either from services or policy makers. Ensuring such feedback occurs might go some way towards reassuring them that their views are taken seriously, as highlighted in literature about children's participation (Percy-Smith and Thomas, 2010).

Despite the feeling of empowerment reported by parents when they engaged with service providers and policy makers and the importance they themselves attached to it, this was not always fully recognised by professionals. This may be explained by the finding that many professionals who took part in the study did not have a good understanding of how parents participated in this way. This again reflects that professionals do not have a good knowledge of how services operate. Given the emphasis on seamless, co-ordinated care within local policy (OFMDFM, 2006), this
finding is somewhat concerning. It is encouraging, however, that the vast majority of professionals believed that when parents did participate in services and policy this made a difference.

Similar to the professionals, around half of parents who took part in the study did not have a good understanding of how health or social care services operated in their locality, and the vast majority wanted a better understanding. Clearly if parents aim to participate in a meaningful way that is recognised by service providers, they need such knowledge. Around one fifth had been asked their opinion of health or social care services in the past year and it is encouraging that most parents believed that this made a difference, despite some scepticism from a small number of parents.

While many parents were happy for 'executive' parent members of the PCD to take the lead in participating in services and policy, the perception of several parents and professionals that the views of a small number of parents was not representative of all parents is of note. Some parents felt that meetings were not always relevant for their family and the inclusion of parents with children with very individual and unique needs presents a very real challenge in this context. It is important that the needs and voices of parents with a range of experiences are recognised by service providers and policy makers. Previous research has highlighted that it is the most confident and vocal disabled children and young people who participate in decisions about services and policy (Martin and Franklin, 2010) and this may also be relevant where the participation of parents is concerned. The key barrier to parents' participation in services and policy was the energy and time taken up by caring for their child. The wide geographical area meant that even when parents were willing to travel to meetings, they worried that they would not be back in time for their child coming home from school, as this varied according to transport arrangements on any particular day. Such practical challenges to parent participation have also been reported by Flannigan and McCoy (2006).
Social justice for children and young people within the macrosystem

The wider beliefs and attitudes of parents and professionals, as members of society within the macrosystem, also impacted on the participation of disabled children and young people in this study and potentially created 'barriers to being' within the Family Participation Model. 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 reflects the prevalence of the medical model of disability in parental thinking and wider society i.e. across the dimensions of the social ecological model. 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 other children (Macarthur and Kelly, 2004; Connors and Stalker, 2007; Lewis et al. 2007; Singh and Ghai, 2009). This again relates back to both Thomas's social relational model and 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 recognised as valued peers in social interactions, and are afforded a subordinate status, creating 'barriers to being' and 'doing'. Involving disabled children and young people in the health and social care services that they use can go some way in fostering self-confidence and social and emotional wellbeing, as evidenced in this and other studies (see Graham and Fitzgerald, 2011).

Professionals' wider societal attitudes and practices were also a key factor in facilitating or hindering the participation of children and young people. The finding that professionals rated parents' involvement in care decisions as much more important than that of children and young people is a stark indicator of professionals' attitudes to them as children and young people and disabled individuals. Alderson and Morrow's (2004) definition of participation, on which this thesis is based, points out that to be involved, children do not have to be the 'main deciders'. However, if professionals fail to
recognise them as social actors, in their own right, their participation will remain minimal.

**Social justice for parents within the macrosystem**

One of the strengths of Fraser's model, as applied to this study, is the importance of the attitudes of wider society in achieving social justice. Clearly professionals are influenced by their own attitudes as influenced by those around them. Parents of older children (but not those of younger ones) reported feelings of negativity from professionals when their child was not reported to be developing 'normally'. This may reflect the work by the PCD that highlighted this as an issue to those working in child development clinics. Parents from the council had reported parents' experiences to service providers before this study commenced, and this may explain why parents of younger children reported that professionals had more positive attitudes towards their disabled child. It may also be the result of the training that young people from the DCYPPP have done with all staff new to the Trust in recent years. It may be tentatively suggested that these initiatives have fostered a degree of shift away from a traditional medical of disability.

Those who dwell on the deficits of the child may reinforce dependence and vulnerability, whilst those who focus on the whole child, the experience of their family and their relationship with them may promote and reinforce the social relational model. Thus while the child may experience impairment effects, it is others' attitudes and practices that create barriers to being and doing, not the impairment itself. Professionals, in particular, have a significant role to play in shaping the discourses around childhood disability (Kelly, 2005) and this can influence attitudes of children and young people, their parents and wider society across the dimensions of Bronfenbrenner's social ecological model.

Parents, as wider members of society, varied in their own attitudes towards disability and the expectations they had for their disabled child and, in turn, this had an impact on how much they encouraged their participation. One disabled young person in this study said that when his mother came to understand his contribution to the DCYPPP and a
willingness to take more control over his life she also 'came out of her shell' and gained confidence in his abilities. When little is expected of children and young people, they too expect little, the proverbial self-fulfilling prophecy. Such attitudes can unintentionally serve to oppress disabled children and young people and lead to Thomas's psycho-emotional disablism.

Shah (2008) points out that disabled children may not be raised in the same way as their siblings due to the influence of the medical model, resulting in uncertainty amongst families as to what to expect from and for their disabled children. There is no doubt that social and cultural factors shape the experience of disabled children, young people and their families. Parents raise their disabled children within the context of a society that, at times, continues to undervalue them through a 'tragedy' lens and those parents with positive outlooks for their child may be pathologised as being in denial or unable to accept their situation (Broberg, 2011).

Social justice and redistribution within the extrinsic sphere

Fraser is clear in her status model that social justice cannot be achieved by recognition alone but both aspects of the status model, recognition and redistribution, must be upheld, an ethos not previously applied where the participation of disabled children and their parents is concerned. In the context of this study, recognising disabled children, young people and their parents as equals in social interactions is not enough; rather the equal distribution of resources need to be in place in order to ensure that their needs are met, they are not disadvantaged and their voices are truly heard. For participation parity to be achieved, these two aspects need to be superimposed. While the vast majority of parents surveyed said they had some influence on health and social care decisions they nonetheless felt a need to fight for their child to ensure that their needs were met (see also Bennett, 2009; Slade et al. 2009; Pilnickey et al. 2011; Reschet al. 2010; Care Quality Commission, 2012; Maddison and Beresford, 2012) and this 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 (see for example,
Redmond and Richardson, 2003; Woolfson and Grant, 2006; Harris, 2008; 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, appeared very stressed. This is a significant issue, given the pivotal role that they play in caring for and making important decisions for and with their child (and the fact that parents find decision making and having to 'fight' for their child emotionally challenging). This has been a recurring theme within the literature despite significant new models of service provision targeted at this group, such as Wraparound. A social justice approach may help to explain this finding, as unless there is more investment and redistribution of resources, parents of disabled children will continue to feel that there are not sufficient services for them. Mothers in previous studies have identified that the most stressful part of bringing up a disabled children is dealing with professionals (Read, 2000) and so by actively listening to mothers and by recognising their expertise, professionals can 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. It was evident from the professionals' accounts in this study that they could not always provide what parents felt they needed. In particular, professionals 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. Maddison and Beresford (2012) report similar findings and highlight the importance of trust in professionals during decision making processes (see also Avis and Reardon, 2008 and Huang et al. 2011). Not only does a perceived lack of transparency and loss of trust fuel parents' 'fight', it also challenges the ethos of current service planning in Northern Ireland (HSC, 2011) that focuses on streamlining and personalising services in order to make health and social care in Northern Ireland more efficient and cost-effective.

At times bureaucracy hindered the participation of parents, although this was not a common feature in the research. For example, parents sometimes felt powerless and frustrated when they had to wait a certain length of time to receive a service or access
specific professionals. Access to social services often required a full assessment, even when a parent wanted only advice or information, and this served as a barrier for some parents. The lack of choices or opportunities for adult life for some young people making the transition to adult services was also evident in this research, a finding also reported recently by Lundy et al. (2012).

Notable by its absence in the present study, was any substantial discussion around alternative means of communication that would enable professionals to better communicate with some children and young people. Recognising the importance of services for children and young people with speech, language and communication needs, the Department for Children, Schools and Families in England, now the Department for Education, (as part of the Aiming High for Disabled Children initiative) 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; however, it is essential that both recognition and redistribution occur to enable social justice. Thus service providers need to provide appropriate resources to enable their participation.

The variability of parents' awareness of social activities for their child and their perceived lack of such opportunities 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, Sperry et al. 1999 and Slade et al. 2009), and this is a policy priority in Northern Ireland (OFMDFM, 2006; DHSSPS, 2010). The finding that some children had very active social lives while others did not is of concern as it is clear that children needing one to one assistance may lose out. For Fraser (1995) the struggle for recognition goes hand in hand with material inequality and the need for the redistribution of resources and clear investment is needed in social opportunities for disabled children and young people along with increasing options around leaving school. Disabled people have traditionally been viewed as less
productive in the workforce and have, in the past, been accused of impeding the capitalist mode of production (Danermark and Gellerstedt, 2004). The lack of opportunities for young people reflects both a lack of recognition, along with a maldistribution of those opportunities in the wider population, potentially creating 'barriers to doing' within the Family Participation Model. In a wider sense, disabled children and young people and their families cannot participate in decision making if resources or opportunities are not available in the first instance. An interesting finding of this research was that parents appeared to accept this and had few expectations that many options would be available.

Social justice: recognition and redistribution within the chronosystem

The final element of the extrinsic sphere within the Family Participation Model concerns the chronosystem - the effect of time and experience on human development. Over time, both children and young people and their parents in this study grew in confidence around participating in decisions made with professionals. A partnership model emerged whereby at the start of their journey parents knew little about their child's impairment and needed more direction from professionals when decisions were being made. In later years their knowledge both about their child's impairment and available services had developed, reducing the need for professionals' input. Children and young people also grew in confidence with professionals they knew for a period of time and professionals also encouraged their participation as they grew older, a finding reported in previous studies (Kilkelly and Donnelly, 2011). As demonstrated in other studies (for example, Rabiee and Glendinning, 2010), some children and young people who took part in this research wanted to be more involved as they reached the 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 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 for the development of such groups.

9.3 Recommendations for practice, services, policy and further research

This section sets out the key recommendations for practice, services, policy and further research that emerge from this study.

Recommendations for practice

1. Many parents and professionals in this study assumed that adults would make health and social care decisions for disabled children and young people. While many children in this study were happy for adults to take the lead, some wanted more information and more say when decisions were being made. Regardless of the type of service, parents and professionals should be aware of avoiding a culture of acceptance that adults make all the decisions, especially when they are young and/or experience cognitive or communication impairment. Recognising children's agency and interacting with them as equals will help to foster participatory practices and lead to positive outcomes for disabled children and young people as demonstrated in this study. Parents also need encouragement and support to involve their child.

2. Professionals' attitudes to involving disabled children and young people varied between children's and adult services in this study. Professionals who work in children's services need to be aware of the growing need to involve children in decisions as they develop and mature into young adults 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 about services (see for example, Coad and Houston, 2006 and the Royal
College of Paediatrics and Child Health (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.

3. The findings of this study demonstrated that professionals' personal qualities, for example reliability, the ability to listen, good interpersonal and organisational skills and 'caring' attitudes and behaviours can go a long way in buffering the experiences of parents and their children. These do not cost money and rely on the practices of individuals; however professionals themselves need sufficient support and supervision to enable them to care for such families without the risk of burn out. Thus the onus is on service providers to ensure that such support is made available to meet the needs of both professionals and families.

4. Fathers in this study did not have a major input into decision making processes but played an important supportive role. Professionals need to recognise the important supportive role fathers play in decision making processes, in keeping with a social justice perspective, and in so doing, fathers may wish to become more involved. In particular, professionals need to direct their communications to both parents as, regardless of who makes the decisions, both are important. This may reduce responsibility and associated stress carried by mothers.

Recommendations for services

1. The findings of this study demonstrate that families are still not able to access information. Thus information on disability and available services for children and young people and parents needs urgent attention. While the recent launch of the Family Support website in Northern Ireland is positive, it is not sufficient as many parents in this study did not use the internet to source information and it is not geared towards children and young people. Written resources are still required for those who are not familiar with electronic methods or cannot afford internet access. Recommendations by Mitchell and Sloper around user friendly information for families with disabled children (2000; 2002) may inform such resources.
2. A number of written information resources for parents of disabled children and young people are available within the Trust. Specific guides for groups of children would be a useful addition, for example, while progress has been made around information about autism and associated services, less progress has been made where other impairments are concerned. Children and young people with physical health care needs have very different needs than those within a cognitive impairment as reflected in current policy (DHSSPS, 2012a and 2012b). Information needs to reflect this policy and associated organisation of services. A number of guides should be available for families; firstly a guide about useful and reliable sources of information, particularly in relation to the internet and secondly a guide based on a checklist about likely decisions that they would have to make as their child grows up. Information for children attending mainstream schools and their parents is particularly important as these families may not have the same contacts (with professionals or other parents) as those within the special school system. Information about post-school options needs to be more widely available for these families. A 'flag' system at times of transitions to nursery, primary, secondary or special school, leaving school and moving to adult services would provide a useful mechanism, alerting professionals when families are approaching such times in order to provide advice and support at key times in the child's life. Tissot (1999) provides a useful framework that may be useful to develop such a guide. While this relates to education for children with autism, it could be adapted for families who use health and social care services. Both paper and online information is required.

3. 'Health Talk Online' and 'Youth Talk Online', developed in England, provide information on parents' and young people's experiences on a range of issues. Such a model could be adapted to provide information and support to families in a Northern Ireland context. This could be coupled with an expert parent helpline run by a small number of parents trained to have an in depth knowledge of services within the regions of the Trust. While in a sense this is currently available via the Parent Council, formally maintaining this would give parents the recognition they deserve and enable further development of such a facility. While voluntary organisations play a vital role within the area, often these are focused on specific issues or types of
impairments. Providing a number of generic expert parents would help to ensure the provision of a joined up, seamless service.

4. Disabled children and young people currently provide training to all new professionals within the Trust. There is a need to extend this initiative to include the use of advanced communication skills to further develop the knowledge and skills of professionals working with these families, and for communication mechanisms used at school to be incorporated into the work of community and hospital based professionals. Further investment is needed in this area.

5. Some professionals in this study were not sufficiently aware of the rights of children when decisions are being made. Professionals need more in depth knowledge on the UNCRC and the UNCRPD than can be provided during qualifying training. The need for such education is recommended in current draft 'Northern Ireland Children and Young People's Plan 2011-2014'. This now needs to be actioned both for undergraduates and trained staff working with disabled children and young people. Knowledge is not enough however. The ability to implement these on a practical level, along with the potential challenges involved, also need to be addressed.

6. Parents in this study varied in the degree to which they encouraged their child to participate in decision making with professionals. Some parents may benefit from support and advice around nurturing decision making skills in their disabled children, not least as a mechanism for developing their self confidence and independence. Understanding the process of decision making and choice (see Beresford and Sloper, 2008) or the use of existing frameworks may help parents support their children. For example, Byrnes (2002) identifies 4 steps in decision making processes that may help to structure decision making: setting a goal, developing options to produce the goal, rank ordering these options in order of importance and selecting the highest ranking alternative. Parents have a key role in fostering decision making skills in their children and an educational programme, designed and delivered with parents, may help to develop these skills that some disabled children and young people may find challenging.

7. Children and young people who belonged to the DCYPPP group in this study were more aware of and more inclined to exercise their participatory rights. Other
children and young people need to be more aware of their rights both generally and particularly within the health and social care arena. However, awareness itself is not sufficient. Disabled children and young people need to be able to recognise specific situations where they have a right to express their views and have these views taken into account. Special schools have a key role to play in educating children and young people about their rights and also how these rights may be implemented in real life settings including health and social care.

8. Professionals in this study varied in their ability and willingness to communicate with disabled children and young people. Northern Ireland would do well to implement the development of a 'Communication council' and a 'Communication champion' as is currently available in England.

9. This research provides evidence of the benefits of active participation of disabled children and young people and the important role of participation groups such as the DCYPPP. This model needs to be further funded and developed, not only across Trusts in Northern Ireland but also within each Trust. Numerous parents in this study said that while they had heard positive reports of the DCYPPP, it was too far away for their child to attend and so there is scope for further development of this initiative.

10. Some parents and professionals in this study felt that the small number of parents actively involved with service providers and policy makers were not representative of parents within the Trust. There is a need to attract widening participation of parents within the locality. A re-launch of the PCD may go some way in achieving this in the light of the new arrangements set out in 'Transforming your care'. Focusing on the major achievements and contribution of this group, along with a vision for the future may help to achieve this. Included in these meetings should be an equal focus on a range of impairments to ensure that all parents feel included. This research supports the formation of PCD groups within the province more generally.

11. Few parents who took part in this study were aware of any changes that happened as a result of their participation in decisions about services. Like children and young people, parents also need feedback about their participation to reduce the scepticism
of some parents who participated in this study and to provide encouragement to those parents who spend considerable time and energy in helping to improve services for all families within the Trust.

**Recommendations for policy**

The participation of disabled children, young people and their parents in health and social care decisions is firmly embedded in local policy for all service users in Northern Ireland. *Transforming your care* (HSC, 2011) outlines current and future plans for health and social care, and emphasises the promotion of personalisation, partnership working and engendering independence and control for disabled people. The provision of information and better recognition of the role of carers as partners in the delivery of care are among the key issues identified. It is notable that 'good decision making', the subject of this thesis, is perceived in this document to be central to the delivery of quality health and social care services (see Figure 2, p23). The importance of service user involvement is key to the success of this model and its associated service reforms.

Similarly, the UNCRC and UNCRPD are also firmly embedded in the current Northern Ireland Children and Young People with Disabilities Draft Action Plan 2011-2014 and the plethora of very recently launched service frameworks and strategies around the lives of disabled people in Northern Ireland discussed in chapter 2 of this thesis. This highlights the commitment of the Executive to deliver on these legislative requirements. However, this must be accompanied with a financial commitment and redistribution of resources if social justice is to be achieved. The onus is also on service providers and professionals to deliver where the participation of disabled children, young people and their parents is concerned.

**9.4 Further research**

This research has highlighted the need for more work in this and related areas. In this thesis a new Family Participation Model was conceptualised. This is a high level model
and the explication of the key concepts requires further development. However, it is clear that a family focus is warranted in future research and this model could be used to frame future research proposals. Issues that warrant further enquiry include an exploration of:

1. the process and outcomes of participation in decision making by disabled children in a more general sense within the family or microsystem.
2. 3 way participation in health and social care decisions within the mesosystem (using an in depth, case study approach).
3. the sharing of diagnostic information with disabled children, young people and their siblings by parents and professionals within the micro and mesosystems.
4. professionals' knowledge and education around disability, the UNCRPD and their perceived skills in communicating with disabled children and young people within the mesosystem.
5. the information needs of disabled children, their parents and professionals as provided by service providers within the exosystem in the Northern Ireland context.
6. the distribution of resources to disabled children and their families in the context of current welfare reform, also within the exosystem.
7. a qualitative exploration of triadic attitudes to disability within the macrosystem.
8. the participation of disabled children and young people in health and social care decisions over time and following the period of transition within the chonosystem (a longitudinal study).

An exploration of the associated facilitators and barriers to participation, as represented by recognition and redistribution within the model are relevant here throughout.

9.5 Strengths and limitations of the research

Like all research, this study has strengths and limitations. As a case studentship, this study was developed in association with Dr Brid Farrell, Chair of ‘Wraparound’, parents from the PCD and children and young people involved in the DCYPPP. Thus a key strength of this research concerns the involvement of service users and providers from
its initial inception through to completion. Such practices have become a key feature of research within health and social care and ensures that research projects have utility and impact in the real world. Guidance from both reference groups was vital in this study as discussed in chapter 5 of this thesis. A further strength was the experience of the projects' supervisors both as social workers and as researchers in designing the study and guiding the research process. My own experience of working with children, young people and families as a children's nurse both in the hospital and community setting for many years was also a strength. Researching with disabled children and young people, in particular, presents many challenges to the novice researcher. A further strength of this study was the effort put into designing a variety of data collection tools and mechanisms to engage children and young people in the process of informed consent in a meaningful way. My previous work on researching with disabled children and young people, a dissertation for the MRes, was invaluable in preparing me for this work.

Alderson (2012, p238) claims that 'rights-respecting research' depends on a number of resources:

'understanding of the nature and history of rights, their origins in resistance to oppression and the 'adult' as well as their childhood literature; knowledge of research ethics, the relevant law and national and international guidelines and treaties; and researchers' keen awareness of potential harms and limitations of their work and of how their views and values may differ from those of participants'.

Given that the subject of this research is participation I believe I have met these standards. Nevertheless, this study also had limitations.

Participants for this study were recruited from two 'participation' groups and therefore may not reflect the opinions of other parents, children and young people within the Trust. That said, most parents of children and young people from the DCYPPP did not belong to the PCD and vice versa, meaning that there was a mix of participants who did and did not belong to a participation group. It was intended that participants in this research had experience of children's and adult services in order to explore a range of
participation contexts. However, current structures and organisation of services made direct comparison of these experiences difficult. On completion of this research there were plans to re-structure adults services for this client group and this may assist future research in this area. The age at which children make the transition to adult services in Northern Ireland varies considerably throughout the province and this also makes researching this area challenging. Plans have been recently outlined by the DHSSPS to reorganise child health services within Northern Ireland and this may help to streamline this process, at least to some extent (DHSSPS, 2013).

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. That said, the response rates for parents of disabled children and young people are generally low as discussed in chapter 5. This raises the question of future use of the survey method for this client group.

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 1 focus group reported. This may account for the lack of data around children's competence as decision makers.

It was not always possible to interview both parents and their children in 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 3 way decision making between parents, their children and specific professionals was not possible in this study. Likewise, the co-morbidity of children and young people's impairments did not allow for in depth analysis of specific issues for those with physical, cognitive, sensory or
communication impairments. Researching with disabled children and young people has additional challenges but this should not preclude their participation in research.

Thirteen families (17%) with more than 1 disabled child participated in this study with only one participating in the in depth interview. As such, the specific views of these families are not reported in this thesis. Overall it appears, however, that these families experience additional stress but there was not sufficient data in this study to draw firm conclusions about their experiences of decision making.

In terms of ethnic origin, a small number of parents who took part in the survey were non-white although this was not sufficient to enable comparison with other parents' experiences. Families who took part in the interviews were all white and so non white families' experiences are not reported in the findings of this thesis. Fazil et al. (2002) report the additional difficulties faced by such disabled families in accessing services. Sontag and Schacht (1994) also highlight the unique information and participation needs of ethnic minority parents who have disabled children and so this aspect warrants further enquiry.

Finally, this study necessarily reports the experiences of disabled children, young people and their parents along with professionals from their own perspectives. The observation of interactions between these groups may have provided an additional dimension to this study and warrants attention in future research by means of an ethnographic study.
Chapter 10

Concluding thoughts on relational and systemic aspects of participation and social justice

Thomas (2012) summarises recent participation theories and models. Earlier theories, he contends, are *endogenous* to the field and are mainly based on reflective practice. More recent *exogenous* participation theories or models have also drawn on political and social theory (Thomas, 2012). This thesis makes a unique contribution to participation theory as viewed through a social justice lens. Driven by the children's rights agenda, children's participation in decisions has received much attention. Parker (2006) argues that a rights-based approach alone is not sufficient to address the attitudinal and structural barriers that impede disabled people's participation in social life. For Parker, Fraser's (1995) social justice theory can, together with a rights based approach, facilitate the elimination of these barriers.

Current models of participation do not reflect the role of the parent or significant others in the child or young person's life. This is somewhat surprising, given the reference to the importance of parents within the UNCRC. This study confirms that many disabled children and young people want their parents' involvement and support in health and social care decision making processes and therefore a new model of family participation within health and social care is needed. This study presents one such model. It also acknowledges that some disabled children and young people, over time, may want to become more involved in decision making, particularly when their participation is encouraged and facilitated by others. Within this family-centred model, for participation parity to be achieved, both of Fraser's (2003) conditions of social justice must also be satisfied. Firstly, the *intersubjective condition* (Fraser, 2003) must be met where both individual and cultural values foster equal respect and opportunity for achieving social esteem and secondly, the *objective condition* focusing on the distribution of material resources to reflect equality. Thus it is clear, that successful participation in health and social care decisions, by disabled children, young people and their parents, can be achieved through an increased awareness of the role that each wants to play and the facilitation of these roles together with adequate investment in the services that they
require. The culture of participation needs to be further embraced within the health and social care arena; however it also needs further development in the wider culture of our society. This study has demonstrated that the wider attitudes of parents, professionals and service providers can impact on the participation of children and young people as disabled individuals. When children and young people in this study were made aware of their rights, they had an increased desire and confidence to participate in decisions.

Current and forthcoming health and social care policy places good decision making at the heart of services in Northern Ireland. Such policy may be instrumental in instigating real progress and fostering compliance with the UNCRC and UNCRPD to ensure that disabled children and young people reach their potential and make a meaningful contribution to society. Similarly, systems are in place within the Southern Health and Social Services Trust to embrace and give recognition to children, young people, and parents as service users and this is highly valued by those involved who believe that they do influence decision making. Health and social care professionals and service providers have a duty to work within an ethical framework that promotes the rights of patients and clients, including equal opportunities and to encourage self-determination (Sheldon and Macdonald, 2009). This was evidenced in many instances in the current study.

However, there is no room for complacency. Much more work needs to be done as evidenced by the accounts of disabled children, young people and their parents in this study. Commitment on the part of policy makers, service providers and professionals must be accompanied by the provision of services, an equal distribution of resources and associated financial investment. It is anticipated that the dissemination of the findings of this research and the realisation of the recommendations made in the last chapter will potentially raise the awareness of the importance of participation within the Southern Trust area, have a positive influence on the organisational culture in terms of attitudes to the participation of disabled children young people and their parents and inform future evidence based service development and policy making.