PARTICIPATION OF DISABLED CHILDREN AND YOUNG PEOPLE IN DECISION-MAKING RELATING TO SOCIAL CARE

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Key findings

Increasing children's[1] participation in decisions, both about their own care and about service development, is a key policy priority. Although in general children's participation is increasing, disabled children are less likely to be involved than non-disabled children and it is unclear to what extent children with complex needs or communication impairments are being included in participation activities. This research set out to explore factors which can support good practice in participation of these children. It consisted of national survey and case studies in six local authorities who had involved disabled children in decision making. The main findings of the research were:

- Participation at any level is only happening for a small number of disabled children. These are mainly the children who are the most able to communicate, most articulate and confident.

- Most professionals and parents/carers saw the importance of children's participation, but a broader understanding is needed of the meaning of participation for disabled children, including the importance of children participating at whatever level is appropriate to their ability.

- Participation was fragile and often rested on specific individuals. It was affected by staff turnover and sickness, and key staff having a much wider remit, so that other activities took precedence over participation.

- More training is needed for staff to enable them to support children's participation, including training in methods of communication with children who do not use speech.

- Preparing disabled children to express their views takes time and an individual approach. It should be recognised that supporting children to participate is time consuming.

- When children did participate, they viewed it as a very positive experience, and the case studies showed some examples of children influencing decisions made in their reviews and of changes to service provision as a direct result of the views children expressed.

- There were only a few examples of children being given feedback on what was happening as a result of their participation. This is important to children and needs further development.

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[1] For brevity, the term children is used to cover children and young people up to 18.

Background

The Quality Protects (QP) programme, launched in 1998, was a key policy aiming to transform the management and delivery of social services for children in need. It set national objectives for children's services, one of which focused on children's participation (see Box 1).

Box 1: Quality Protects Objective 8

> To actively involve users and carers in planning services and in tailoring individual packages of care and to ensure effective mechanisms are in place to handle complaints.
>
> Sub-objectives:
> - to demonstrate that the views of children and families are actively sought and used in planning, delivery and review of services.
> - to demonstrate that the satisfaction of users with services provided is increasing.

This policy is consistent with the United Nations Convention on the Rights of the Child (1989), in which Article 12 emphasises children's rights to express their views on matters that affects them and to have these views given 'due weight', and Article 13 grants children the right to receive and express all kinds of information and ideas in a variety of forms. This is particularly important for disabled children who may use communication methods other than speech. Children's participation is seen as important for a number of reasons, not only in upholding their rights but also in improving services and promoting children's protection. Children can influence decisions in matters that affect them as individuals and those which relate to them as a group, for example, within service planning and development or influencing policymaking.

Evidence suggests that while in general children are increasingly being involved in decision-making, growth has been slower in respect of disabled children. Equally, there is now a body of literature with general lessons for those wishing to involve children, but less is known about specific factors which could promote disabled children's participation. This research explored the process and outcomes of disabled children's participation that had been initiated under the Quality Protects programme. The aim was to establish factors which can support and promote good practice in disabled children and young people's effective participation. The research had a particular focus on children with complex needs who may be seen as 'hard to reach' in participation: those with communication impairments, autistic spectrum disorders or complex health needs.

Methods

The research comprised: a survey of all social services departments in England to identify the range and nature of disabled children's participation; and case studies of participation activity in six areas to explore in more detail the processes and outcomes of participation. In the case studies, 76 professionals, 24 parent/carers and 21 disabled children, aged 5 to 18, were interviewed. The majority of children interviewed had a learning difficulty, ranging from mild to severe, and six children had a communication impairment.

Findings

Extent of disabled children's participation

Results of a survey of social services departments in England suggested that disabled children were being involved in a wide range of decision-making both within decisions about their own care and within service development, however, involvement was still patchy and required further development.

Case studies in six areas provided more detail on the experiences of professionals, parents/carers and disabled children involved in participation activity. Two areas focused on involving children in decisions about their own care through the review process; three areas focused on activities, for example youth forums, which aimed to involve children in service development; and one area undertook both types of involvement.

Within all areas, only small numbers of children were involved in decisions about their own care. Within service development, two types of participation activity were undertaken – large scale events and youth forums. Obviously, larger numbers of disabled children took part in the large events, however, the evidence suggested that, to a certain extent, trying to accommodate large numbers can be at the expense of children expressing their views on services. Nevertheless these events were a success in terms of giving disabled children an opportunity to have new experiences. In all types of activity, participants were mostly older children, particularly teenagers, and involvement of children with complex needs was limited.

Views on participation

Professionals showed some confusion about what participation should or could mean for disabled children, particularly those with communication and/or learning impairments. There were concerns over children's competence, understanding and abilities to participate, coupled with unease about the interpretation of children's views. For some workers, there appeared to be a concept of ideal participation, based on a notion that anything less than a child taking part in a review meeting and contributing to complex decision-making processes was not valid.

Some parents also expressed concerns about how their child could be involved and/or questioned the ability of their social worker to get the child's view. However, some parents and professionals reported a change in their attitude as a result of children's participation. They had held beliefs that it would be either impossible or extremely difficult because the children had communication impairments and learning difficulties, and they reflected that they had underestimated the child and the methods being adopted.

Facilitators and barriers for participation
Clarity of aims and objectives
Interviews highlighted the importance of shared understanding of aims and objectives of participation among all those involved - staff, parents and children.

Access to communication methods
Many social workers reported that they were unsure of the communication methods of children on their case-loads.

Training, support and resources
Even when the method was known, many social workers spoke of not having the skills, knowledge, training and experience for consulting disabled children, particularly if the child used non-verbal means of communication, and questioned their abilities to facilitate participation. There was a reported need for more training, resources and support: in communication methods, IT and creative skills, to develop and adapt participation methods, and also training in the theory and methods of participation with particular reference to disabled children. Involving disabled children in decisions takes time – to get to know a child, understand the children's communication and prepare them to express views. Many workers felt that there should be more recognition of the time needed. Where appropriate tools were developed, social workers were given the training and confidence to use the tools and senior management championed the process and monitored practice, participation was achieved, even for 'hard to reach' groups.

Fragility of participation
The fragility and fragmented nature of participation activity was evident throughout the research. Much practice rested on a few key, dedicated professionals and in their absence work ceased or was frozen. Staff turnover also negatively affected participation activity. For example, one area had undertaken authority wide training for social workers in participation methods and had purchased participation toolkits using Quality Protects funding. However, it was reported that a significant number of staff who had undertaken the training were no longer in post and the resources were not being used.

Much participation activity was not embedded in the culture of the organisations concerned and appeared to be carried out in isolation from other activities. This

contributed to the fragility of disabled children's participation. However, the difficulties of moving from ad hoc activities to embedded practice were considerable: as one manager commented a whole culture change was needed whereby disabled children's participation and communication with children, by whatever means suits each child, was an expectation.

Outcomes of participation
The measuring and documentation of the outcomes of participation activity is still an underdeveloped area, and even though some of the case-studies were monitored for nearly two years there has been limited evidence of measurable outcomes, for example changes to services. None of the case-study areas had systematic procedures for the recording, monitoring or evaluation of the activities undertaking.

However, where participation did happen, all children, parents and social services staff reported positive effects. These included children feeling included in what was happening around them, feeling valued, being listened to, gaining confidence, having attention and lots of fun, and learning new skills. Parents found out from their children what they thought about respite, and gained a better understanding of what their child did there and what they enjoyed.

Feedback to children
Where feedback was provided to children on what was happening as a result of their input, this was greatly appreciated. However, feedback was by no means universal and more emphasis needs to be placed on creating an ongoing dialogue with children.

Implications for policy and practice
In order to increase disabled children's participation in decisions that affect them, a number of developments are required:
- Training and skills development for staff, and access to support and methods to facilitate participation.
- Recognition at all levels of policy and practice of the time needed to develop relationships and work effectively with children who have communication impairments and/or complex needs.
- An exploration of who is best placed to communicate with disabled children. Joint working with schools and information sharing on children's preferred communication methods should be part of facilitating disabled children's participation.
- Details of each child's method of communication should be recorded on case files.
- Participation, whether in individual decisions or in service development, should not be a one-off event. Everyday simple choices are part of the process and such choices can be used, for example, to build up a picture of a child's likes

and dislikes when at a respite centre. In addition, information from each child using a service can be collated to inform service development.

- More attention and expectation must be focused on getting the views of disabled children and this should be monitored systematically so that it becomes embedded in organisational cultures.
- Data should be gathered on outcomes of children's participation and feedback on what is happening should be provided to children.

Chapter 1: Background

1.1 Introduction

This chapter provides relevant background information and places the research within the wider body of knowledge concerning the participation of disabled children and young people within decision-making. We begin by presenting the policy and legislative context in England of children's participation with particular regard to Quality Protects, and encompassing not just social care but the wider policy climate where appropriate. This is followed by a description of the theoretical underpinning of children's participation and a discussion on relevant previous literature, where we draw attention to a number of limitations of this work. There is a paucity of research on disabled children's participation and therefore research evidence with non-disabled children is examined to provide some illustration. The final section draws these strands together and provides an overview of the rationale and aims of the research presented in this report.

1.2 Policy context

1.2.1 Quality Protects

The Quality Protects (QP) programme in England was launched in 1998 with the aim of transforming the management and delivery of services for children for whom social services has taken on direct responsibilities: children who are looked after by local authorities, children in the child protection system and other children in need requiring help or support from social services.

National objectives for children's services were set, supported by more detailed sub-objectives and performance indicators. The Department of Health had responsibility to monitor the performance of local authorities in delivering these objectives through the Performance Assessment Framework and the evaluation of Quality Protects Management Action Plans (MAPs).

Between January 1999 and 2002, Management Action Plans (MAPs) were submitted annually to the Social Services Inspectorate (SSI). The MAPs reported on local authority achievements and plans for the future across the objectives for children's services. The fourth and final MAPs were submitted in January 2002, the assessment of councils' performance was then integrated into the mainstream SSI performance assessment system. In addition, 2003-04 was the last year with ring-fenced funding to support the QP programme, from April 2004 QP funding was mainstreamed.

1.2.2 Children's participation and Quality Protects

Developing a culture of, and good practice in children's participation was fundamental to achieving the overall aim of Quality Protects. A key component of Objective 8, children's participation, was also a QP priority area for action and was actively supported by the Department of Health's Children and Young People's Participation Project Team.

Figure 1.1:   Quality Protects Objective 8

To actively involve users and carers in planning services and in tailoring individual packages of care and to ensure effective mechanisms are in place to handle complaints.

Sub-objectives:
  - to demonstrate that the views of children and families are actively sought and used in planning, delivery and review of services.
  - to demonstrate that the satisfaction of users with services provided is increasing.

Guidance for the preparation of Year 4 Management Action Plans (MAPs) was unequivocal about the wish to see participation 'embedded and sustained across all QP objectives' (Department of Health 2001a). This reflected the growing acceptance and importance being attached to involving young service users in decisions about their own care and/or wider service planning, both in Local Government and the NHS (Willow, 1997; Department of Health, 1999, 2001b, 2003a; Sinclair and Franklin, 2000). Acceptance of this principle has become manifest through the rapid increase in participation activities involving children and young people and is reflected in law, government guidance, regulations and policy.

1.2.3 Current policy context

The United Nations Convention on the Rights of the Child (1989), adopted and ratified by the UK government in 1991, created a driver towards the increased participation of children and young people. Article 12 of the Convention states that:

> State 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.
> (United Nations 1989)

Article 13 is also pertinent to promoting children's and young people's effective participation, particularly disabled children who may use a variety of communication methods. This article grants children the right to seek, receive and disseminate all kinds of information and ideas in a variety of forms. Willow (2002) states that this should serve to remind us that 'human communication takes many forms and is not confined to language alone' (p32).

Article 13 states that:
> The child shall have the right to freedom of expression: this right shall include the 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.
> (United Nations 1989)

Key requirements for children and young people's participation are contained within the Children Act 1989 which requires local authorities to ascertain the wishes and feelings of children they look after or are about to look after, and to give these due consideration, subject to practicability, plus the child's age and understanding. Similar requirements for children's involvement are also written into other formal procedures such as special education needs assessment. The revised SEN Code of Practice (Department for Education and Skills, 2001a) and associated SEN Toolkit (Department for Education and Skills 2001b) stress the importance of hearing the views of children with special educational needs (SEN). The Children Act 2004 (Her Majesty's Government, 2004) reinforces children's rights to be listened to by service providers. Joint area reviews of education and social care and performance assessment of local councils will examine the extent to which children and young people are listened to and their views taken seriously. This is applicable both within individual decision-making as well as wider service development and policy development. The act also creates a Children's Commissioner for England who will promote awareness of the views and interests of children.

Other relevant legislation includes the Human Rights Act, 1998 (Article 10) which requires central and local government to uphold a right to freedom of expression. For disabled children, Guidance and Regulations (Department of Health, 1991) make it clear that, if a child has complex needs, communication difficulties or severe learning difficulties, arrangements must be made to establish their views and that a disabled child cannot be assumed to be incapable of sharing in decision-making. Both the Children Act 1989 and the 1990 NHS and Community Care Act established a duty on the part of service providers to provide complaints procedures, and the 2002 Adoption and Children Act places a duty on local authorities to provide advocacy services to children who wish to make a complaint under the Children Act.

Even the structures and culture of central government have to some extent embraced participation with the establishment of young people's advisory

fora, and the publication of a framework of core principles for children and young people's involvement across all government departments. Alongside this is a requirement for all central government departments to produce associated Action Plans detailing how they are to involve children and young people in the decision-making of their department (Children and Young People's Unit, 2001). These action plans are subject to annual review and updates:

> The government wants children and young people to have more opportunities to get involved in the design, provision and evaluation of policies and services that affect them or which they use.
> (Children and Young People's Unit, 2001, p2)

Within health care, service users in general are being given more power in exercising choice and influencing the nature and quality of the services they receive, this also includes children and young people. For example, new national requirements for patient and public involvement place a duty on service providers to involve children and young people (Department of Health, 1999, 2001b, 2003a, 2003b, 2003c, 2004). The Department of Health documents in its action plan an expectation that children and young people will be 'routinely' involved in service development at both central government and local level and that this should not be tokenistic:

> Participation should go beyond consultation and ensure that children and young people initiate action and make decisions in partnership with adults, for example, making decisions about their care and treatment or in day to day decisions about their lives.
> (Department of Health, 2002, p4)

The National Service Framework for Children, Young People and Maternity Services (NSF) in England published in 2004 set standards aimed at raising the quality of the health and social care services that children receive. The Framework has a broad remit but a central theme stresses the need to consult and involve children. Standard 8 for disabled children and young people and those with complex health needs states:

> Professionals should ensure that disabled children especially children with high communication needs are not excluded from the decision-making process. In particular professionals should consider the needs of children who rely on communication equipment or who use non-verbal communication such as sign language.
> (Department of Health/Department for Education and Skills 2004, p29).

1.3   Defining participation

1.3.1 Why participation is important

The case for children and young people's participation is well documented and is often grouped into legal, political and social reasons (Sinclair and Franklin, 2000; Children and Young People's Unit, 2001; McNeish and Newman, 2002; Willow,

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2002). Sinclair and Franklin (2000) summarise the reasons for involving children in the following way:

> To uphold children's rights; to fulfil legal responsibilities; to improve services; to improve decision-making; to enhance democratic processes; to promote children's protection.

A number of writers have highlighted the benefits of participation for organisations and for young people themselves (for example, Treseder 1997; Cohen and Emanuel 1998; Hennessy 1999; Willow 2002; Wade and Badham 2003 and Kirby et al 2003a). They state that participation: enables resources to be targeted more effectively, improves quality, gives young people greater ownership and commitment to services and enhances skills of adults involved in planning and providing them. For children and young people, participation helps them to support and positively influence each other, provides opportunities to gain experience, skills and confidence and encourages young people to take responsibility and control of their lives. Beresford (2002) cites research evidence which repeatedly shows that for disabled young people having their views respected and being involved in decision-making are highly valued features of service provision (for example, Morris, 1999; Noyes, 1999; Crisp *et al.*, 2000; Mitchell and Sloper, 2001).

The Children and Young People's Unit (2001) published three broad reasons for why children and young people should be involved: better services, promoting citizenship and social inclusion, and personal and social education and development.

Willow (2002) argues that listening to and respecting children and young people can engage those previously deemed 'in trouble' or marginalized, leading to enhanced relationships with adults and opportunities for participants to develop their social and communication skills and increase their knowledge and learning. Willow also highlights that focusing on the benefits of participation can sometimes obscure that being listened to and taken seriously is a fundamental human right. Cutler and Frost had previously stated that:

> Participation should not be seen in purely utilitarian light – that young people will get better jobs or service providers will do their jobs better. It must be seen as a fundamental right as expressed in Article 12 of the UNCRC, and not something to be withdrawn if it fails to produce the right outputs (2001, p6).

1.3.2 What is meant by participation?

The term participation covers a broad continuum of involvement in decisions, it is a multi-layered concept, involving many different processes (Kirby *et al.*, 2003a; Sinclair, 2004). Boyden and Ennew (1997) state that there are different interpretations of the term 'participation'. It can simply mean taking part, being present, being involved or consulted. Alternatively, it can denote a transfer of power

so that participants' views have influence on decisions. Although the second definition is primarily the concern of this study, the first is no less important or easy to achieve. Disabled children, for example, may lack the opportunity even to participate in everyday activities, factors such as social and leisure needs, housing issues and transport contributing to their social exclusion, as illustrated by Beresford (2002) and Morris (1998a, 2001a, 2001b).

1.3.3 Focus of participation activity

It is important when examining participation to distinguish the focus of children's participation as this can vary. Children and young people can influence decisions in matters that affect them as individuals and those which relate to them as a group (public decision-making), for example, within service planning and development, or influencing policymaking. Both are important and not mutually exclusive, but the mechanisms to achieve involvement are likely to be different.

The focus of children's participation is illustrated within the Government's core principles for involving children and young people (See Figure1.2).

Figure 1.2:   Focus of children and young people's decision-making

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Where individual decisions are being taken about children's own lives.
For example, the Children Act 1989 says that looked after children should be involved in decisions about their care package, and statutory guidance is being developed to ensure that children and young people with special educational needs are, where possible, involved in all decisions relating to their education.

Where services for, or used by, children are being developed or provided locally.
For example, many local partnerships and local authorities have discussion groups and special consultation events to influence the design and provision of play facilities, leisure, transport and guidance services.

Where national policies and services are being developed or evaluated.
For example, where departments are producing consultation documents and using website design to seek children and young people's views on policy proposals.

(Children and Young People's Unit (2001), p4)

1.3.4 Participation within individual decision-making

Children's participation in decisions that affect them as individuals implies taking account of their wishes and feelings and including the child's perspective. In social services, most attention has been placed on children's participation in decision-making exercised around procedures such as assessment, care planning and reviews, child protection conferences or complaints. Decisions of this nature often involve several adults and sometimes the views and interests of children and young people conflict with those of parents and professionals. Little evidence has yet been collated on how these situations are handled and what are the outcomes for children.

1.3.5 Participation in public decision-making

A number of mapping exercises of public decision-making have been undertaken (Cutler and Frost, 2001; Kirby *et al.*, 2003a; Oldfield and Fowler, 2004), these identified a wide range of processes and activities. Children's participation in matters that relate to them as a group can be through the identification, development, provision, monitoring or evaluation of service delivery, service development and policy-making, both locally and nationally. This can take the form of consultation exercises; in research as respondents, advisers or as young researchers; as part of management committees, advisory groups, youth forums, community initiatives; or in delivering services by acting as mentors, counsellors, volunteers or workers (Sinclair and Franklin, 2000). McNeish and Newman (2002) note that many public decision-making initiatives have benefited from voluntary/statutory partnerships and it has been noted that voluntary agencies can have an important role as a catalyst for participation and in sustaining the developments over time (McNeish *et al.*, 2000).

1.3.6 Typologies of participation

A number of writers have developed typologies to illustrate participation. These generally make hierarchical distinctions between levels of participation according to the degree of power that is shared or transferred. Arnstein (1969) first developed a ladder of participation in relation to citizen involvement in community development, Hart adapted this for children's participation (1992, 1997) and a number of variations on this have followed (see for example, Thoburn *et al.*, 1995). Shier (2001), for example, attempts to create a 'pathway to participation' and adapts the ladder to help practitioners to explore the participation process, determine their current position and identify the next steps to be taken to increase their level of participation.

These typologies have been criticised as they suggest a hierarchy with the objective being to reach the highest level where children are the main decider (Treseder, 1997; Willow, 1997; Lardner, 2001). However, participation rights do not necessarily confer the right to be the main decider, nor do children want to exclude their parents/carers and other adults from the process. Discussion about children's participation often

raises fear that children and young people will be left to make decisions that are harmful to themselves or others. Yet this is not the basis of children's rights which advocates that children should be supported in making decisions (Lansdown, 1995; Alderson and Montgomery, 1996; Morrow, 1999). Studies have shown that children and young people recognise the limits of autonomy and accept their need for adult guidance and support (Newman, 1996; Morrow, 1999).

Recently, Kirby *et al.* (2003a) have developed a non-hierarchical model of participation, where no one level is assumed to be superior to another, instead the type of participation activity will be determined according to the circumstances and the participating children and/young people (see Figure 1.3).

Figure 1.3:   Kirby et al's model of the level of participation

	Children and young people's views are taken into account by adults	
Children and young people make autonomous decisions		Children and young people are involved in decision-making (together with adults)
	Children and young people share power and responsibility for decision-making with adults	

(Kirby *et al.*, 2003a, p22)

Models of participation help to distinguish between different levels of empowerment afforded to children and young people, highlight the need to understand the term participation and prompt examination of what kind of participation is appropriate. It is now generally accepted that the level of participation will vary depending on the objectives sought, the decision being made and the capability and choice of the children and young people. However, meaningful participation must be seen as a process, not simply an isolated activity or event (Kirby *et al.*, 2003a).

Alderson and Montgomery (1996) define four levels at which children can participate:
1)   Being informed.
2)   Expressing a view.
3)   Influencing the decision-making process.
4)   Being the main decider.

Taking Alderson and Montgomery's example, all levels are important methods of participation and the first three precede the fourth if the child is to make an informed choice. The first three levels are contained within the UNCRC and include any child who can firstly understand information, secondly form a view, and finally, is

considered to be able to form a view which can usefully inform the decision-making process.

1.4 Research literature and evidence

1.4.1 Introduction

The next section will examine evidence from existing literature in relation to two key elements of the participation process: first, the provision and need for accessible information to enable children and young people to participate successfully; and secondly, access to mechanisms which help children and young people to express their views. The section will also examine the available evidence on children and young people's participation within the Quality Protects programme and in particular disabled children and young people. Because of the limited nature of this evidence, a wider range of literature is referred to. Particular attention is paid to any evidence of outcomes of participation and to factors which facilitate or act as barriers to the successful participation of children and young people.

1.4.2 Provision and need for accessible information

Genuine participation is based on informed consent and requires that children and young people are given full and accessible information about the decisions to be made and/or the participation activity. Children cannot participate in decisions if they are not fully informed of the options available to them and the implications of those options, it is the first and vital stage of the process (Alderson and Montgomery, 1996; Beresford and Sloper, 1999). For example, children receiving medical treatment need to be informed about who is responsible for telling them what is happening, what the implications of treatment are, side effects, option that are available, implications of not having the treatment, whether it will hurt and how long it will take (Lansdown, 1995).

While it is arguable that Article 12 of the UNCRC is limited by reference to particular attributes of the child, namely their capacity, age and maturity, Article 13 grants children the right to express, seek and receive information in any medium they wish. This emphasis on provision of appropriate means of communication is of particular significance to younger children and disabled children, especially those with communication related impairments. The Department of Health states explicitly that a child who has a learning disability should not be assumed to lack competence: 'Many children will be competent if information is presented in an appropriate way and they are supported through the decision-making process' (Department of Health, 2001c, p4). Practitioners have a clear duty under Article 12 to ensure that the child has been given both the time and information they need to be helped to make an informed choice.

However, evidence on children's experience of the process of information sharing is limited, for example, little is known as to whether their information needs are met when they have been involved in decision-making. Some evidence has emerged from the field of healthcare. For example, Bradding and Horstman (1999) found that chronically ill children had information needs within four domains: diagnosis, treatment, prognosis and support. In all domains, the need for honest and accurate information given within a supportive environment was evident. Beresford and Sloper (1999) researched the information needs of young people with chronic conditions and highlighted the importance of psychosocial information such as information on dealing with the effects of their condition in social settings, as well as medical information. Within this study young people also highlighted the important role of their parents as information providers, indicating that parents' information needs must also be addressed. Danso *et al.* (2003) cite literature which indicates that children and young people within social care lack information about the reasons for social services involvement, their rights, plans for their care, reasons for decisions made about them and their entitlements particularly as care leavers (Aldgate and Statham, 2001; Cashmore, 2002; Grimshaw and Sinclair, 1997; Hill, 1997; Horgan, 1998; Utting, 1997).

Changing needs mean regular information is required, delivered in a variety of ways, appropriate to the needs of the young person. Dixon-Woods *et al.* (1999) state that there is a scarcity of evidence about how to design information materials for children. Alderson and Montgomery (1996) offer practical suggestions on the type of information which should be shared with children involved in decision-making within health care settings, although equally applicable in other settings. They suggest how practitioners might check young patients' understanding of information. For example, through the questions young patients might ask, their expression of hopes, fears and of what might be in their best interests. Brook (2000) has developed a framework for children to be involved in decisions about proposed liver transplant, again this framework could easily be adapted to other situations, including social care. The framework highlights the uniqueness of each child and their family, the necessity of keyworkers to co-ordinate information sharing and the need for an open, friendly approach which *shares* information and does not *give* information. Privacy, sensitivity and an allowance of adequate time are deemed essential.

1.4.3 Access to mechanisms to allow children and young people to voice their views

Genuine participation requires that a child's view is listened to. There is now widespread acknowledgement, particularly within the care-system, that children and young people's safety relies on them being listened to and involved in decisions, both about their own lives and also in general policy and service development (Utting, 1997; Waterhouse, 2000). Moves have been made to create structures that allow children and young people to voice issues of concern or complain about services or

treatment. Both the 1989 Children Act and the 1990 NHS and Community Care Act established a duty on the part of service providers to provide transparent complaints procedures. However, such procedures have been widely criticised for being adult orientated, inaccessible, lacking in confidentiality and difficult to negotiate without the support of an advocate (Utting, 1997; Aiers and Kettle, 1998).

Morris's (1998a) study on the experiences of young disabled people who have spent most of their childhood living away from home found that many of them did not have access to communication systems which suited their needs, did not have routine access to people who understood the ways they communicated and did not have access to independent facilitators. Morris states:

> One of the most disabling attitudes faced by children with physical or sensory impairments and particularly by children with significant learning difficulties, is the assumption that they do not have a view to express or a way of expressing it. Our society operates as if communication only takes place through written or spoken language (1998b, p36).

Patient Advice and Liaison Services (PALS) have recently been established within all English NHS (National Health Service) and Primary Care Trusts, to provide an easily accessible service for people with concerns about their care. However, research suggest that PALS have, so far, provided a generic service, and many have not provided a service that is accessible to children and young people (Heaton and Sloper, 2004). Nevertheless, there are some attempts being made to make mechanisms for complaints accessible to disabled children, for example, MENCAP (2003) have developed a resource pack to assist children with a learning disability to complain about the services they use.

Some literature points to the necessity of not only formal mechanisms through which children can participate, but also the need for informal approaches – a listening culture, where children can voice their views and be listened to at any time (see Figure 1.4), (McNeish and Newman, 2002; Lightfoot and Sloper, 2002a, 2002b,2003; Kirby *et al.*, 2003a, 2003b). Studies in the main concentrate on formal mechanisms, but Lightfoot and Sloper's study found that young people urged an informal approach, in addition to formal structures and dedicated 'participation workers' (2002a, 2002b, 2003). This is an important point to reiterate particularly for some disabled children and young people whose communication may take a number of forms. Formal structured mechanisms may not be accessible and therefore understanding that participation includes methods such as observation is often neglected. For some severely disabled children, adults observing, for example, their behaviour or body language in a number of settings can provide a wealth of information and can be used to inform the decision-making process (Morris, 1998a, 2003; Marchant *et al.*, 1999a; Marchant and Jones 2003). There is a dearth of evidence on the extent to which this kind of participation is occurring and the outcomes of it. It can be subtle and therefore not register as participation as such.

Figure 1.4   Listening Mechanisms

Informal listening	Formal Listening
- On-going dialogue - Observation - Listening to spontaneous communication - Engaging in joint activities	- Dedicated mechanisms and activities such as one-off consultations; regular group meetings; suggestions boxes

(Kirby et al, 2003a, p27)

1.4.4 Evidence of participation within Quality Protects

With regard to participation under Quality Protects, positive developments were noted in the overview report of Year 3 MAPs, which documented a trend towards more systematic, strategic planning, and evidence of more substantial participation activity. Robbins (2001) reported that there appeared an 'insistence in many MAPs that participation should be real, leading to measurable outcomes'.

Analysis of Year 4 MAPs illustrated evidence of improved participation, both on a strategic and individual level, and the extension of participation beyond looked after children, indicating that participation continued to grow (Department of Health 2003b).

1.4.5 Disabled children's participation within Quality Protects

To date there has not been an extensive examination of the participation of disabled children within Quality Protects. Studies have either undertaken a broad overview of the initiative and examined individual objectives, thus analysing participation in general (Robbins, 2001; Department of Health, 2003b), or have examined services for disabled children and families with a short chapter on participation (Council for Disabled Children, 2003).

Evidence from these studies, however, suggests that the participation of disabled children lags behind that of non-disabled children. An analysis of QP Year 2 MAPs suggested that some Local Authorities were commissioning work with innovative consultation methods and undertaking staff training to promote disabled children's participation (Council for Disabled Children 2000). However, Robbins (2001) concluded from an analysis of QP Year 3 MAPs that 'there was a wide variation in the extent to which disabled children were being involved in decisions about their care' (p9) with many authorities reporting that work to consult and involve disabled children was at an early stage. Some authorities at this time, however, reported specific initiatives to develop participation with children who have communication difficulties.

Most recent analysis of Year 4 MAPs concluded that although most councils reported on consultation this was mostly with the *parents* of disabled children: 'few had developed regular and on-going mechanisms for consulting disabled children' (Department of Health, 2003b, p72). This report also documented that two thirds of councils addressed the specific issues involved in consulting with disabled children. Such issues ranged from ensuring disabled children who are looked after were included in consultation work, through to the development of specific literature, and improving access to consultation through the use of IT packages. The Council for Disabled Children's analysis of Year 4 MAPs (2003) also concluded that, 'many councils are moving forward in their inclusion of the views of service users. However, the focus remains on gathering the views of parents rather than children, even where the practice for consultation is good, disabled children and young people, particularly those with complex needs, are left out' (p22).. 'participation in a range of circumstances for all disabled children and young people is in evidence around the country but not yet common practice' (p44). This report highlighted the growing use of 'consultation tools' such as 'I'll Go First', Viewpoint or Widget (See Appendix A).

One notable exception to the lack of participation by disabled children has been the example of 'Ask Us!', a national peer research project of disabled children and young people, undertaken by The Children's Society, and evaluated by the Joseph Rowntree Foundation. *Ask Us!* arose from the Department of Health's National Disability Reference Group for the Quality Protects programme. It consisted of a national consultation of over 200 disabled children and young people, including some with severe and multiple impairment. Six local CD Roms were produced by disabled children and young people and project staff, each focusing on different areas of exclusion such as access to play, leisure and education and relationships with friends and families. A summary CD Rom of key messages was also complied with the aim of targeting key people in local and national Government to seek wider changes in attitudes and services. A second phase, funded by the Department of Health was also undertaken with 180 disabled young people and involved eight local consultations. This resulted in a second summary CD Rom charting the practical changes needed to fulfil young people's rights (The Children's Society, 2001; Willow, 2002).

The evaluation of Ask Us! included the views and experiences of the young people who were researchers and contributors, and included an evaluation of the impact on external systems and services via questionnaires sent to those who bought, or had seen, the CD-Rom. Results illustrated that the use of multi-media had been an excellent means of enabling disabled young people to communicate their views. Locally some changes have occurred, for example, in Solihull, £30,000 worth of play equipment was secured by the children and young people involved. Attitudes toward disabled young people among social care workers, managers, parents and carers were also challenged. Badham concluded that this programme had made an impact because of sustained contact, a build up of trust, recognition of mutual benefit, time,

the young people taking charge of the medium and the message, and working within the social model of disability (2004).

1.4.6 General evidence on participation

The database on participation activity maintained by the National Youth Agency (www.nya.org.uk) and recent research for the Department for Education and Skills Children and Families Directorate (Kirby *et al.*, 2003a) identifies a vast array of participation activity, although this was by no means even across different sectors or subject areas. Kirby *et al.* found that most participation work was locally based, in small organisations or agencies and was more likely to involve generic youth work or community regeneration. The Carnegie Young People Initiative undertook a mapping exercise within the UK and concluded that, 'there is an exciting period of experimentation. There are inspiring examples of policies and mechanisms to increase participation' (Cutler and Frost, 2001, p78). Similarly, a survey on children and young people's participation within statutory and voluntary sector organisations, undertaken by the National Youth Agency and British Youth Council, reported the growth of participation work but also highlighted the limitations of activity, in terms of the range of activities being undertaken and their impact (Oldfield and Fowler, 2004).

Despite a plethora of policies the government's commitment to children's participation has been criticised by the UN Committee reviewing the UK government's implementation of the UNCRC. While recognising the increased emphasis placed on participation by the government, the Committee felt there was still more to do, especially in ensuring that participation leads to change:

> The Committee recommends that the State party, in accordance with Articles 12 and 17, take further steps to promote, facilitate and monitor systematic, meaningful and effective participation of all groups of children, including in schools… The committee further recommends that procedures be formed to acknowledge publicly the views expressed by children and the impact that they have on developing programmes and policies, and reflect how they are taken into consideration.
> (Committee on the Rights of The Child, 2002, p7, quoted in Sinclair, 2004, p110).

In addition, Badham (2004) reports that progress of government departments' action plans has been patchy, with some departments lacking dedicated resources or perceived status. Others have made some progress in the form of training for staff on the involvement of children and young people, improved consultation and feedback processes or established advisory boards and reference groups. Recent evaluations of Government programmes such as The Children's Fund (The National Evaluation of the Children's Fund, 2004) and Children's Trusts (University of East Anglia, 2005) both of which have the participation of children and young people at the core of their

work, concluded that, so far, the participation of children and young people has been variable with a lack of systematic approaches.

1.4.7 Evidence of disabled children's participation

Evidence from QP and elsewhere suggests that, while in general children are increasingly involved in decision-making, growth has been slower in respect of involving disabled children directly (Council for Disabled Children, 2000; Sinclair and Franklin, 2000; Robbins, 2001). Standard 8 of the National Service Framework for Children, Young People and Maternity Services identifies that 'disabled children are less actively involved in decision-making than children who are not disabled' (Department of Health/Department for Education and Skills, 2004, p29). A recent review of literature undertaken by Cavet and Sloper (2004) concluded that the participation of disabled children needs further development with evidence that good practice is not general. This review of literature revealed that some disabled children had not been afforded their full participation rights under the Children Act 1989 or the United Nations Convention on the Rights of the Child, for example, due to a lack of availability of communication aids to those children who rely on them. Beresford (2004) reports that research has consistently shown that many disabled young people are not adequately involved in decision-making concerning their transition process (for example, Heslop *et al.*, 2002; Cope, 2003; Ward et al, 2003) and young people with communication impairments are particularly vulnerable to being excluded from the transition process (Dee and Bryers, 2003). Heslop *et al.* (2002) undertook a survey of over 250 families and found that four out of ten disabled young people had little, if any involvement, in transition planning.

A study by Morris of 30 children and young people living in residential homes and schools found that they had not been consulted about their care (1998a). Morris concluded that where children had very limited or no use of verbal language, or were seen as having a high level of impairment, little effort had been made to find alternative methods of communication. Similarly, the Social Services Inspectorate (1998), after an inspection of services for disabled children and young people provided by eight local authorities, reported that, despite an array of local policy and guidance emphasising the importance of consulting children, in only a few cases was there evidence of this taking place. Yet the United Nations strongly states:

> Failure to respect the rights of disabled children to be heard represent a fundamental denial of their status as people. It disempowers them, it renders them vulnerable to abuse and exploitation by adults, it means their experience and knowledge fails to inform decisions that affect them and it denies them the opportunities for personal development and growth associated with the process of participating.
> (UN Committee on the Rights of the Child, 1997, p2)

There is a small body of evidence which is starting to provide examples of disabled children and young people who have learning difficulties and/or communication impairments expressing their views about services. Triangle, a voluntary organisation, have undertaken a number of small scale consultations on behalf of local authorities (see for example, Marchant *et al.*, 1999a; 1999b; Marchant and Crisp, 2001).

1.4.8 Evidence of outcomes of participation

Badham (2004) argues that it is often unclear how the process of participation is meant to link with better outcomes for the intended beneficiaries and what is actually changing for children and young people as a result of their involvement. In general, outcome measures defined by young people are still rare, although the government undertook a study to examine how children define outcomes (Sinclair *et al.*, 2002) and Rabiee *at al.* (2005) have conducted research with children and young people with complex health care needs and children who do not use speech for communication to identify their desired outcomes in terms of their quality of life.

While robust evidence is light, there is some literature emerging on perceived outcomes from a range of stakeholders. These include: better services, personal development of young people, and enhanced citizenship and social inclusion (Kirby *et al.*, 2003a). Examples of changes needed to achieve these outcomes include more accessible services – more suitable venues, opening times, accessible information; better user support, improved relations between adults and children; increased practical and communication skills for staff and increased confidence among young people (Kirby *et al.*, 2003a). However, there is little evidence that participation is having an impact on major polices and resource decisions. It is still the case that more is known about how to support young people to make participation more rewarding for them, but less about how participation can bring about change. The input of disabled children within the emerging literature remains limited.

Despite a growth in participation, there is a lack of evaluation in terms of processes and outcomes, both internally and externally (Combe, 2002; Kirby and Bryson, 2002; Cavet and Sloper, 2004; Sinclair, 2004). Some moves have been made in this direction with the Department of Health (2003c) prioritising this within their action plan and recent work funded by the Children and Young People's Unit (Kirby *et al.*, 2003a, 2003b).

1.4.9 Barriers to participation

Emerging research evidence illustrates that, despite policy and commitment to children's participation, achieving this in a sustainable and meaningful way is challenging (see for example, Alderson and Montgomery, 1996; Alderson, 2000; Willow, 2002). Studies highlight the limited number and range of children who are

participating, younger children, children from socially excluded groups, children with communication difficulties and those with minimum involvement with local agencies have all been identified as least likely participants (for example, McNeish and Newman, 2002; Cutler and Frost, 2001; Kirby and Bryson, 2002; Sinclair, 2004). Cavet and Sloper (2004) summarise studies which suggest that some disabled children are not being afforded their full rights regarding participation, in particular 'ventilator dependent' young people (Noyes, 2000), those looked after by the local authority (Morris, 1998a, 1998b) and those with severe impairments (Lightfoot and Sloper, 2003). In addition, the lack of availability of communication aids to those children who rely on them has been reported as presenting obstacles and limiting children's involvement in decision-making (Stone, 2001; Morris, 1998a, Rabiee *et al.*, 2001). Marchant and Jones (2003) note the linguistic and cultural barriers to involvement faced by disabled children from ethnic minority groups.

The published literature suggests that a number of barriers prevent effective participation. McNeish and Newman (2002) summarise that involving young people in decision-making processes takes time, involves developing new skills for adults and young people, requires an investment of resources, can entail a major shift of attitude on the part of organisations and like any process of negotiation, it can make decision-making slower. These barriers include the attitudes of adults where there exists a prevalent value base and culture to see children as incompetent and in need of protection (see for example, Lansdown, 1995; Willow, 2002; McNeish, 1999; Matthews, 2001; Bell *et al.*, 2002; Kirby and Bryson, 2002). Some writers have highlighted that the continued dominance of the medical model of disability creates barriers for disabled children's participation (Beresford, 2002; Morris 1998b). Beresford (2002) argues that the social exclusion of disabled children and young people continues because local authorities locate the problem in the disabled child rather than considering external factors such as social, physical and organisational structures that contribute. Morris states:

> It is the medical model's focus on impairment as the 'problem', as what people are suffering from, which takes attention away from the problems of disabling attitudes and unequal access…
> (1998b, p14)

Attitudinal barriers may to some extent exist because this is a new way of working and practitioners may lack the experience, capabilities and skills to facilitate participation. Publications point to very real practical barriers which need to be addressed. The complexity and bureaucratic nature of organisations has been identified as a barrier to participation by Matthews (2001), Kirby and Bryson (2002) and Kirby *et al.* (2003a, 2003b). A lack of training and support for adult facilitators and young people participating has also been highlighted by, for example, Kirby and Bryson (2002), Cavet and Sloper (2004) and a lack of research evidence to support participatory activities was noted by Dixon-Woods *et al.* (1999), Hennessy (1999) and Cavet and Sloper (2004).

1.4.10 Factors which facilitate young people's participation

Although a large numbers of guides and checklists on good practice in involving children in decision-making exist, it is not always clear where the evidence for this advice has come from. In most cases, evidence is gathered from adult facilitators of participation activity, there is little evidence from children about their experiences of involvement, although some data are emerging (Matthews, 2001; Combe, 2002; Lightfoot and Sloper, 2002b, 2003; Kirby *et al*., 2003). However, there are some common themes which can be derived from the literature and identified as being important to the success of participatory work with children and young people. These include the need for:

- *Clarity on the purpose, objectives, parameters and possible outcomes of participation* (Children's Taskforce, Department of Health, 2001; Sinclair and Franklin, 2000; Kirby and Bryson, 2002).

- *Training and development for staff* (Hennessy, 1999; McNeish *et al*., 2000; Children's Taskforce, Department of Health, 2001; Kirby and Bryson, 2002; McNeish and Newman, 2002; Lightfoot and Sloper, 2002b, 2003; Kilgour, 2002; Cavet and Sloper, 2004). Training and development programmes should address a number of objectives including attitudinal changes (Alderson and Montgomery, 1996) and communication and communication methods (Beresford and Sloper, 1999).

- *Training, support and development for young people*
  Young people may also need support and training if participation is to be meaningful and successful. They may need to increase their confidence and self-esteem and develop skills in group work or giving presentations (see for example, Treseder, 1997; Cohen and Emanuel, 1998; Combe, 2002; Kirby and Bryson; 2002; Kirby *et al*., 2003a).

- *Using flexible and appropriate methods*
  There are a number of publications that highlight the advantages and disadvantages of numerous methods of involvement and emphasise that flexibility and the use of a wide range of methods and approaches is important (for example, Cohen and Emmanuel, 1998; Kirby and Bryson, 2002, Lightfoot and Sloper, 2002a, 2003) The necessity of tailoring methods to be appropriate for the participant is emphasised, taking into account factors such as their age, ethnicity, gender, individual circumstances and support needs. Cavet and Sloper (2004) summarize the evidence surrounding inclusive approaches to involving disabled children. They highlighted from the available evidence the following as important:
  - Using a multi-media approach or variety of methods;
  - Availability of resources such as communication aids or interpreters;
  - Use of advocates or mentors;

- Multiple contacts in order to get to know the young person;
- Flexibility about how children participate and recognising that children communicate in mediums other than speaking;
- Independent facilitators so that children can give their views about services they use in confidence;
- And the need to make participation fun and rewarding.

- *Embedding practice*
  Sinclair (2004) states that if children's participation in decision-making is to be more meaningful and effective in influencing change, it is necessary to move beyond one-off or isolated participation and consider how participation becomes embedded as an integral part of adult relationships with children. The objective is to reach the position where participation is not seen just as a desirable add-on but something that is firmly embedded. Kirby *et al.* (2003a) draw on research from 29 case studies which indicates how organisations can develop the role of participation within their organisation and move from being consultation focused to participation-focused to child-focused. This study highlights ways in which organisations can start to build cultures of participation, through seeing participation as a process and not an isolated event: changing in attitude, procedures and styles of working across all levels; creating champions of participation to support change across the whole organisation; and develop a shared vision and understanding of participation. Kirby *et al.* state that the key to this is senior management support and a mainstreaming of practice.

  Hear by Right (Wade and Badham, 2003) also challenges organisations to mainstream participation, by questioning their current structures and cultures. It is recognised that the culture, structures and systems of organisations impact on participation activity (Kirby and Bryson, 2002; McNeish and Newman, 2002; Kirby *et al.*, 2003a, 2003b; Cavet and Sloper, 2004). A listening culture among staff is essential as well as genuine commitment, so that young people feel respected and confident to express their views, and have their views listened to and responded to (McNeish *et al.*, 2000; Sinclair and Franklin, 2000; Children and Young People's Unit, 2001; McNeish and Newman, 2002; Lightfoot and Sloper, 2003).

- *Resources*
  Effective participation involves a large amount of planning and preparation and may not be fruitful in terms of immediate success and quick wins. Resources are needed to provide training, support and skill development as well as to cover specific practical costs such as transport, childcare, resources and equipment for groups and, if appropriate, ensuring young people are compensated for their time and contribution. Successful participation can be extremely labour and time intensive and realistic timeframes have to be set.

Often participation work requires time for adults and children to form relationships, and get to know and trust each other. This may be particularly pertinent when considering the participation of disabled children and young people where they may communicate in non-verbal ways (Willow, 2002).

- Often the hours of preparation work to support and prepare children and young people is a hidden element in participatory work and little evidence has been collated on the cost or timetables of participatory activities (Willow, 2002; Cavet and Sloper, 2004).

1.4.11 Facilitating disabled children's participation

While the emerging participation literature has general lessons for those wishing to involve children – for example, that dedicated resources, attitudes of adults and feedback are important (Treseder, 1997; Cohen and Emanuel, 1998; McNeish, 1999; McNeish et al, 2000; Kirby and Byson 2002; Kirby *et al.*, 2003a), less is know about additional specific factors, which could promote disabled children's participation.

Evidence to date from research and practice involving disabled children (Beresford, 1997; Ward, 1997; Morris, 1998a; Russell, 1998; Marchant *et al.*, 1999a, 1999b, Morris, 2002; The Children's Society, 2001) highlights the importance of identifying disability-related needs for participation and of adopting creative and flexible approaches in meeting these. Some materials have now been developed to support the process of obtaining disabled children's views, for instance a practical 'toolkit' of cards to assist when seeking the views of disabled children about the services they receive (Kirkbride, 1999), a training video and handbook to build practitioners' confidence and skills in communicating with disabled children who do not use speech (Triangle/NSPCC 2001) and an image vocabulary for children about feelings, rights, safety, personal care and sexuality (Triangle/NSPCC 2002). More recently, MENCAP have developed resources to help children with a learning disability complain about the services they use (MENCAP 2003).

Talking Mats^{TM} is a pictorial framework that has been used as a tool for young people with learning difficulties and/or communication impairments to express their views. Talking Mats^{TM} uses picture symbols which represent topics, options and emotions. Young people place the pictures showing the possible options under appropriate emotion symbols to express their feelings. The completed mat can be photographed and kept as a record (Cameron and Murphy, 2002; Germain, 2004; Rabiee *et al.*, 2005, and in press). Some limited validation of this method has been undertaken by Germain (2004) who asked four young people to use the Talking Mats^{TM} on two separate occasions in order to compare their answers. The results showed that there were few changes made in the way the young people answered on both occasions – 92 per cent of questions were answered in the same way on both occasions, which

Germain suggests means that young people understood the significance of the different symbols.

A collection of resources to aid workers in communicating with disabled children is available on the Department of Health website (www.doh.gov.uk/integratedchildrenssystem). However, little information has been gathered on the use of these resources. It is not yet known for example, whether use of these resources is widespread in practice, and no information has been collated with regard to the outcomes of their use.

1.5   Conclusion

There has been a burgeoning publication of literature on examining why we should involve children and young people and increasing examples examining the best methods of involvement (Sinclair and Franklin 2000, Shier 2001; NcNeish and Newman 2002; Kirby and Bryson 2002). Research evidence has to date been largely exploratory and descriptive, providing accounts of different approaches to participation and their perceived advantages and disadvantages from the view point of the adult facilitators. Slowly, the literature is moving on from this to study broader questions such as what facilitates a participatory culture (Kirby *et al.*, 2003a, 2003b), whether participation is becoming sustained and embedded in practice, and to collate evidence on how participation is effecting real change (Kirby and Bryson 2002). However, there is still much to learn, with reports of evaluations scarce (Kirby and Bryson, 2002).

Within the published literature there is limited reference made to the participation of disabled children and young people. It would appear from the limited available evidence that the participation of disabled children remains patchy and research to support good practice is needed. There are still substantial gaps in knowledge about both the process and outcomes of disabled children's participation. In particular little is known about children's own experiences, and their views as to what might constitute good practice.

1.6   Rationale for present study

As noted above, little evidence exists about the processes and outcomes of disabled children's participation and factors which can support and promote good practice in respect of the impact on service planning and/or individual packages of care. Knowledge in both areas would contribute to the effective involvement of disabled children and young people and it is these gaps that this research sought to address.

The overall aim of the research was to improve knowledge about the effective participation of disabled children and young people under Quality Protects. The study

aimed to investigate the process of disabled children's participation, outcomes in respect of the impact of disabled children's views on service development and/or tailoring individual packages of care, and the impact on children themselves. Where possible, particular attention was paid to specific groups of disabled children who had been identified by service providers as posing particular concerns and/or especially 'difficult to reach': children with complex health needs, autistic spectrum disorders, communication impairments or degenerative conditions.

Specific objectives were to:
a) Identify participation work which included disabled children and young people.
b) Establish factors which can support and promote good practice in the process of disabled children and young people's effective participation.
c) Establish factors which can support and promote good practice in outcomes of disabled children and young people's participation, in respect of the impact of their views on service development and/or tailoring individual packages of care.

A combination of quantitative and qualitative methods was adopted in order to examine the breadth and depth of participation activity within social services departments:
- Stages One and Two were designed to identify the range and nature of disabled children's participation across social services departments in England, and provide information in order to identify case-study areas.
- Stage Three undertook qualitative case-studies designed to provide more in-depth understanding of the process and outcomes of participation through interviewing and seeking the views of disabled children and young people, their parent/carers and staff.

1.7 Structure of the report

The remainder of the report is structured as follows. Chapter Two describes the research design, recruitment procedures, methods and sample details. Included within this chapter is a section describing some of the practical difficulties which this study has encountered. Chapter Three presents the findings from the thematic analysis of the Quality Protects Management Action Plans. Chapter Four describes the findings of the data collected on participation of disabled children and young people collected via the survey of social services departments, while Chapter Five and Six describe and present the findings from the case-study areas selected from the survey for more detailed investigation. Chapter Seven discusses the policy and practice implications of the research findings and highlights areas for further research.

Chapter 2: Research Design and Methods

2.1   Research methods and sample

The research was carried out in three stages using a multi-method approach which included analysis of local authority QP Management Action Plans, a national survey of social services departments and case-studies within six local authority areas.

2.1.1 Stage One

This stage consisted of a thematic analysis of Objectives 6[2] and 8[3] of the Year 4 QP Management Action Plans (MAPs) (n=150), to identify participation work with disabled children, including both work concerned with service development (the design, delivery and evaluation of services) and that focusing on tailoring individual packages of care. Analysis of both objectives was undertaken as it was possible that participation of disabled children could be mentioned under either objective. The MAPs were to be used to identify case-study areas, however, the analysis showed variability in reporting and a lack of depth and clarity within the content of the MAPs. There were also concerns over the time lapse between participation work identified in the MAPs and the research. A survey of all social services departments in England was therefore deemed necessary.

2.1.2 Stage Two

A postal survey of all social services departments across England was undertaken during the summer of 2003 in order to identify current work concerning disabled children's participation and to investigate this in more detail, including the characteristics of the children involved and the nature of participation work.

A two-stage approach to the survey was undertaken. First, a screening letter and information sheet was sent to all Assistant Directors of Children and Families within social services departments in England (n=150) asking them to:
a)   Indicate if their department had undertaken any work in the last 12 months on involving disabled children and young people in decisions regarding their own care or in the design, delivery or evaluation of services.
b)   Indicate if they would be prepared to complete a questionnaire about this work.

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[2] To actively involve users and carers in planning services and in tailoring individual packages of care and to ensure effective mechanisms are in place to handle complaints.

[3] To actively involve users and carers in planning services and in tailoring individual packages of care and to ensure effective mechanisms are in place to handle complaints.

c)   Supply a contact name and address of someone who could complete the
      questionnaire and provide further details.
Copies of this screening letter are attached as Appendix B.

Enquiry about participation was restricted to the last 12 months in order to provide a
snapshot of up-to-date evidence and ensure that participation activities, identified
within the survey and selected for more in-depth investigation in Stage Three, would
still be in the memories of children, young people, parents and staff who had been
involved. In the possible absence of a designated person leading on participation
within social services departments, it was hoped that the screening letter would help
to increase the likelihood that the detailed survey would reach the person(s) with
most knowledge of the participation activity. Inevitably this method provides only a
snapshot of participation activity, and cannot claim to be a comprehensive mapping
exercise of all participation activity.

A total of 129 social services departments responded to the screening letter, a
response rate of 86 per cent (Table 2.1). Twenty-seven authorities indicated that they
did not currently, or had not within the last 12 months, involve disabled children within
decisions regarding their own care or within service development; 102 had
undertaken work and all of them indicated that they were prepared to complete a
questionnaire on the subject.

Table 2.1   Response rates for screening letter (N=50)

	Number of social services departments	Percentage of social services departments
Responded to screening letter	129	86%
Indicated participation work being undertaken	102	79%
Indicated a willingness to compete the detailed questionnaire	102	79%

Following the screening letter a detailed questionnaire was sent to those authorities
indicating that they would be willing to take part in the survey (n =102) (see Appendix
C). The questionnaire was designed to investigate the details of the participation
activity, in particular the process as well as outcomes of disabled children's
participation. Questions focused on participation of any disabled children and young
people. The questions were categorised around seven themes:

1)   **Nature of participation:** whether disabled children and young people were
      involved in decisions regarding their own care, or whether involvement was in
      general service development, planning or evaluation.

2) **Characteristics of the children and young people involved:** numbers, age range and whether the children involved have complex health needs, autistic spectrum disorders, communication impairments and degenerative conditions.

3) **Characteristics of the participation activity:** description and aim, funding, partner agencies.

4) **Methods of involvement:** written, verbal, visual and computer, whether children were consulted individually and/or in a group.

5) **Support for children, young people and staff:** type of support and any specific support tailored for disabled children and young people.

6) **Outcomes:** changes in service provision, commissioning, or in service priorities, feedback given to children and young people.

7) **Lessons learnt:** staff views on their experience on what was useful or problematic.

At the end of the questionnaire, respondents were asked whether there was a postholder in the organisation with designated responsibility for children and young people's involvement. The final question asked whether they would be willing to discuss participating in the final stage of the research.

Of the 102 departments indicating they were undertaking participation work, a total of 71 social services departments completed the detailed questionnaire, a response rate of 70 per cent.

2.1.3 Stage Three

This final stage consisted of qualitative research in a sample of six local authorities, in order to investigate 'what works' in respect of the processes and outcomes of disabled children's participation. Where possible, attention was paid to the four groups of disabled children: children with complex health needs, autistic spectrum disorders, communication impairments or degenerative conditions.

Selection of case-study sites
Survey findings were used to select an initial sample of five authorities undertaking differing types of participation activity. The inclusion criteria were:
a)   an authority indicated on their questionnaire a willingness to be involved;
b)   the work was current, in the planning stages or very recently completed;
c)   the activity had an outcome or appeared to have a likely outcome;
d)   the four groups of disabled young people had been included or there were major plans for their involvement.
And across the sample, examples were sought that reflected
e)   a range of ages;
f)   a range of methods and tools;
g)   evidence of partnership working.

Using these criteria, a shortlist of ten local authorities was identified by the researchers. Following discussion with the project's young people's advisory group (see below), five authorities were selected. All authorities agreed to be case-studies.

Disabled young people's advisory group
The research project worked with the Young Disabled Person's Forum at the Greater Manchester Coalition for Disabled People. Researchers met with the group on a number of occasions for advice on the selection of the case-study areas and on the topic areas for investigation.

The young people's criteria for selecting the case-study areas differed slightly from that of the researchers and these additional criteria were used in selecting five of the ten shorlisted authorities for case studies. The young people had very clearly defined ideas that the case-studies should have the involvement of lots of professionals with real influence, that participation should not be tokenistic, that an end result can be seen or that changes to services had already taken place, that there was a clear strategy for involvement or an area was undertaking a number of activities, thus showing commitment. They were also particularly keen to find areas that were employing disabled people to undertake participation work.

The group's ideas on relevant questions to ask during the interviewing of professionals, parents/carers and disabled children and young people were also taken on board and were reflected in the topic guides.

Professional project advisory group
The research benefited from an advisory group which consisted of local authority social services managers, voluntary sector professionals, academics, parents and Department of Health and Department for Education and Skills representatives. This group met on a number of occasions throughout the research to advise and comment on methods, progress, findings and dissemination.

Selection of two further case-studies
Within one selected case-study area, it became apparent that it would not be possible to undertake any fieldwork. This case-study area had been a popular choice with the disabled young people's advisory group, as it provided a volunteer advocacy service for children and young people with communication impairments and those with complex needs. The authority was working in partnership with a voluntary organisation who managed and supported the volunteers. It appeared from documentation that as a result of the advocacy project there had been changes to services. Unfortunately at the time of the research, there were only ten volunteers and not all of them actively supporting a young person. All ten were approached, and one volunteered for the research. The voluntary organisation had plans to recruit more volunteers but the time frame would have been outside of the research timetable. The voluntary organisation provided this advocacy service to another

authority and all four volunteers were approached within this area as well. Again only one volunteered to undertake the research interview. Such small numbers made it both impractical and unethical in terms of anonymity or confidentiality, to pursue this area.

For reasons described in section 2.2 it become necessary to recruit two additional case-study areas, both to replace the case-study area abandoned and to increase the likelihood of gathering evidence of good practice. Professional advisory group members and specialist disabled children's voluntary organisations were approached and asked to advise on authorities who were undertaking participation work with disabled children. Following their comments, a further two areas were approached and recruited. Unfortunately, because of time constraints, research within these case-studies has been somewhat limited.

Research methods for qualitative case-studies
Due to the fragmented and sometimes longitudinal element to much of the participation activities selected, it became necessary to adapt the original research design. The original methodology had encompassed a one-off interview with a sample of disabled children, young people, parents/carers and relevant staff across the case-study areas. However, a more reactive approach was adopted in order to capture a more realistic picture of participation activity. Interviews with the above people were supplemented by attendance at steering group and project meetings, observation of events and forum meetings, collection of relevant documentation such as policy and procedure manuals, reports, minutes from meetings and funding applications. Because of practical difficulties detailed in section 2.2, some authorities were monitored for nearly two years.

Interview schedule
The varied nature of the case-study areas required a flexible approach to the interview schedules which could encompass and capture the individual characteristics of each area. However, across all areas and all interviews where possible, consistency in the question areas was maintained in order to uphold the reliability of data collection. Staff questions were categorised around four main themes:

a) **Details on the individuals:** job title, full or part time post; funding of their post; job role and how disabled children's participation fits into this; training undertaken and training needs on disabled children's participation; knowledge of local authority tools, policies, procedures or strategies on involving disabled children and young people; knowledge of, and access to, resources including time, expertise, communication aids, toolkits.

b) **Information on the processes of participation:** general questions centred on factors such as what influences whether a child is involved or not, how participation was facilitated, methods or tools used, information given to

parent/carers and children and young people in advance, how children's views are fed into decision-making processes.

Within service development specific questions asked about the projects' aims and objectives, partnership arrangements, timescale, funding arrangements, how children were selected and recruited, details of support and training for young people.

c) **Information on the outcomes of participation:** What has happened as a result of participation? Have there been any changes to services, attitudes, ways of working and so on? Did there need to be any changes? Was feedback given to the children and young people involved?

d) **Reflections on their experience:** What worked well? What would you do differently? What are the barriers to participation? What would help to facilitate participation? How would you like to see disabled children and young people's participation develop in the future?

The original research design had been to interview parents/carers and children and young people who had been involved in decision-making processes and participatory activities. However, due to the small numbers of disabled children and young people participating and the practical difficulties outlined in section 2.2, interviews in Area A – Activity Two were also undertaken with those who had not been involved (parent n= 6, children and young people n = 2).

Interviews with parents/carers and children, therefore fell into two categories. When the child had not been involved, interviews with parents and children explored why they thought this was the case, what they thought would be the benefits and disadvantages of participation and how the child could be involved. If the child had been involved in participation then questions centred on the information they had received in advance, why the child had become involved, how the child had participated, what benefits did parents/carers think the child gained from involvement, what benefits did the child think they gained from involvement, what happened as a result and whether they would want to take part in the future.

The majority of disabled young people who took part in the research were willing and able to take part in a verbal face-to-face interview. For those young people who had participated in events, photographs were used to stimulate discussion and memory during interviewing. For some young people with learning difficulties, verbal questioning was supplemented with a visual tool adapted from 'Talking Mats' (Murphy,1998; see also, Rabiee *et al*., 2005 and in press). A series of A4 laminate cards were produced, which had a written question, for example, 'Were you listened to?' or 'Did you enjoy X?' and accompanying pictorial Boardmarker^{TM} symbol at the top. Children and young people could then choose from a series of possible

responses on separate smaller cards which could be stuck onto the question card. The response cards included words and symbols. The children and young people who used this method stated that they had enjoyed it and requested a copy of their laminated cards as a keepsake. In the majority of cases (14 out of the 21 children and young people) parents/carers or workers insisted that they stayed with the child during the interview. They all cited that they would be required to interpret the child's communication method, although this was rarely the case. Children and young people were given a choice by the researcher and all stated that they were happy with this arrangement.

In collaboration with parents/carers and workers, it was decided that two young people with severe cognitive impairments would not be interviewed as their level of understanding was such that they were unable to understand the reasoning behind their own participation in activities or the concepts of the research. For these young people information was gathered from the carer and others who had attended the participation activity with them. Although desired, the researchers did not attend and observe first hand as the case-study area did not inform the researchers until after the event.

Sample Size
Across the case-study areas, in total 76 professionals were interviewed mostly face-to-face. On a few occasions, mainly due to logistics, telephone interviews were held. It should be noted that a selection of key people were interviewed on more than one occasion during the course of the research.

Overall twenty-four parent/carers were interviewed. This consisted of 16 mothers, one father and two interviews where both mother and father were present, two grandparents and one carer. Twenty-one disabled children and young people and two siblings of disabled children who had attended the participation activity as well were interviewed. Table 2.2 contains a detailed breakdown of data collection within each site and Table 2.3 a breakdown of professionals interviewed.

Of the twenty-one disabled children and young people who took part, sixteen were male and five were female. Their ages ranged from five to 18, Table 2.4 provides a breakdown of their age. The majority of children and young people interviewed had a learning difficulty ranging from mild to severe, six young people had a communication impairment. Specific diagnoses included Downs Syndrome, cerebral palsy, Aspergers Syndrome, sensory impairments.

Table 2.2   Overall data collection within case-study areas

	Staff Interviews	Parent/Carer Interviews*	Children/Young People Interviews	Other methods
Area A Activity One	- 6 full interviews - 18 short interviews with stall holders / workshop organisers at event	10	- 5 disabled children/ young people - 2 non-disabled siblings who attended the event	- 42 questionnaires distributed at day event - Observation at event - Attendance at planning /debriefing meetings - Collection of minutes and planning documents - Ongoing monitoring via attendance at meetings, email and telephone.
Area A Activity Two	15	7	3	- Collection of reviewing materials - Collection of policies and procedures manuals on review process
Area B	3	-	1	- Collection of review questionnaire and end of project report written by development worker
Area C	1	-	3	- Observation of forum meetings and children's panel meetings - Collection of policy and procedure documents, minutes of forum and panel meetings, relevant documentation such as information packs given to children.
Area D	24	3	8	- Collection of all relevant policy documentation - Attendance at multi-agency planning meetings
Area E	6	2	-	- Collection of review materials and pilot feedback report
Area F	3	-	1	- Observation of disabled young people on interview panel for post of participation worker - Collection of participation workers job description, outline application for funding of project

* Note: two parent interviews contained both parents.

Table 2.3   Breakdown of professionals interviewed (N=76)

	Numbers interviewed
Development/Participation Workers	7
Social Workers	17
Managers	6
Residential Workers	16
Children's Rights Officers	2
Reviewing Officers	4
Partners from other agencies	24

Table 2.4   Ages of disabled children and young people interviewed (N=21)

	Aged 5	Aged 6	Aged 10	Aged 11	Aged 13	Aged 14	Aged 15	Aged 16	Aged 17	Aged 18
Number of children and young people interviewed	1	1	1	3	1	3	2	5	3	1

Although it is customary to report response rates for interviews, it has proved impossible to do this for this study for a number of reasons. For example, information was sent to a sample of children and young people who had been identified by the authority as having taken part in their reviews. However, it became apparent that this information was incorrect, with parents reporting that their child had not taken part, thus making it impossible to identify an accurate response rate. Due to data protection, the sending of information to children and young people had to be undertaken by staff in the case-study areas, because of staff turnover it became difficult to always guarantee that all children received the information.

2.2   Practical difficulties

Although difficulties in carrying out research often remain unreported, sharing of such information can be of benefit to those wishing to undertake similar studies. As research on participation activities will continue to grow, and anecdotal evidence suggests that the problems encountered within this study are not unusual, then what is reported here may have a potential impact on the necessary funding and timetable of future research.

Throughout the length of this study, the research has been hampered by a series of difficulties:

1) The very low number of disabled children actually participating proved a key stumbling block to achieving a sample and providing examples of what works. It also had major implications in terms of anonymity and confidentiality.

2) The fragmented nature of participation meant that often activities were delayed or abandoned. Staffing issues contributed to this in a significant way. Within case-study authorities, staff with designated responsibilities for participation or those who appeared to be driving participation forward, left or went on maternity or sick leave and were not replaced at all or for a considerable time. Some workers were seconded to a participation development role and then returned to their original roles, and recruitment to participation-type posts took a number of attempts. In a number of areas, staff with responsibilities for disabled children's participation, particularly within service development, were part-time. Their role covered the wider remit of service development for disabled children and their families, thus often other activities took precedence over disabled children's participation.

3) The length of time from planning to implementation and results of participation activities often took considerably longer than initially anticipated.

4) Despite the dedication, enthusiasm and hard work of those staff trying to achieve the participation of disabled children with decision-making, the reality was often different to what had been planned or hoped for. Within some case-study areas, the research questions had to be altered from trying to examine 'what works' to 'why did it not work' and 'what are the barriers to it working'.

These factors produced particular problems within the context of a fixed term funded research project. They resulted in very low numbers of children and young people participating and thus eligible to be interviewed for the research. Even though the project timescale was extended by four months and two additional case study sites were recruited in order to try to increase numbers and replace sites where participation activities had (temporarily) halted, it was not possible to follow many of the case-study participation initiatives through to achieving outcomes for disabled children.

2.3   Recruitment of children, young people, families and staff

In accordance with data protection, all families were approached via social services, and research information was sent on our behalf with a covering letter. Young people and their parents/carers and all professionals were provided with an invitation letter and information leaflet which described the research project (see Appendix D for an example). Young people were provided with an age appropriate written information leaflet and a copy of the leaflet containing symbols using Boardmaker^{TM}, in some cases an audio-taped version was also sent. Every effort was made to find out the

preferred communication method of the child in advance, but this information was not always available. In these cases the information leaflet stated that the researchers would make every effort to include children who did not use speech to communicate and would endeavour to meet the communication requirements of the child. This initial contact invited respondents to return a contact form if they were willing to be contacted by the research team with a view to taking part in the project. Respondents to this were then contacted, researchers answered any questions and then if they wished to take part in the research a suitable time and location for interviews was discussed.

2.4   Obtaining consent

Consent to take part in the research was obtained from the young person and their parent/carer during the first face-to-face contact, and then if necessary reconfirmed at subsequent meetings. Prior to seeking consent, the researcher confirmed with the participants that they had read (or had read to them) the research information leaflet and were aware of the implications of the research.

Children and young people's consent was re-checked prior to interview in the absence of a parent/carer. It was explained to all participants that it was acceptable to not take part, to not answer any questions they did not want to, and to withdraw at any time. The researchers took an ongoing approach to consent and on the very few occasions where it was difficult to gauge a child's consent, care was taken to observe the child's reactions and any indication that the child was reluctant to take part or wished the interview to stop.

All staff members approached during data collection were given a project sheet which explained the research and issues of confidentiality and anonymity. It was also reiterated that taking part was voluntary. Prior to interviewing, the researcher checked the consent of each staff member.

2.5   Analysis

Two computer packages were used to manage and analyse data. SPSS was used to provide descriptive statistics for quantitative data from the Stage Two Survey. NViVO was used to store and code all qualitative materials, including interview schedules, policy and practice documents and observation notes. Permission was sought from all participants to tape record interviews. A small number of interviewees did not want to be recorded, in this case permission was sought to make written notes during interview which were written up immediately afterwards. All taped interviews were fully transcribed. The 'framework' method of qualitative data analysis was adopted (Ritchie and Spencer, 1994). The first stage involves developing a coding framework – a set of analytical categories – and coding the data. Following coding, a synthesis of the verbatim coded data is entered onto a series of 'charts', with each chart

representing a theme in the data. Reading across the chart provides information about a particular subject, while reading down the chart enables comparisons to be made across the sample. Charts are then used to identify over-arching themes from the data.

Chapter 3: Findings from Stage One Analysis of QP MAPs

3.1 Introduction

This chapter presents the findings from the first stage of the research. Stage One consisted of a thematic analysis of Objectives 6 and 8 within Quality Protects Year 4 Management Action Plans (MAPs) (n=150) in order to identify participation work with disabled children, including both work concerned with service development (the design, delivery and/or evaluation of services) and that focusing on tailoring individual packages of care.

3.2 Results from analysis of Quality Protects Year 4 MAPs

As mentioned in Chapter One, generic studies of Year 4 MAPs concluded that, in the main, consultation was invariably with *parents* of disabled children, with few authorities developing regular and on-going mechanisms for consulting disabled children (Department of Health, 2003b). The Council for Disabled Children's analysis also concluded that although a range of participation activities with disabled children was in evidence, it was not yet common practice and those children with complex needs were left out (Council for Disabled Children, 2003).

Tentatively, the same conclusion could be drawn through this thematic analysis of 150 MAPs, however, a cautionary note should be made. The variability in reporting and a lack of depth and clarity in the content of the MAPs made it difficult to draw a comprehensive conclusion about the extent, processes and outcomes of disabled children's participation within the QP programme using this information alone. The information presented here illustrates that the MAPs provided a patchy overview, but contained little depth.

3.2.1 Disabled children with communication impairments and/or complex needs

Only 44 of the 150 (29 per cent) authorities specifically reported on disabled children with communication difficulties and/or complex needs. Of these, 34 stated that they would be developing this area of work. Typical statements included:

> Matter of priority, Reviewing Officers will encourage and facilitate the full participation of young people and carers, especially where additional assistance may be necessary due to disability or communication needs.

The Children's Rights Service will increase participation of disabled children and young people in particular and will develop a named friend scheme for children and young people with communication difficulties.

Methods of communication with disabled children and pre-verbal children to be explored to ensure participation at reviews and conferences.

It appeared that a few authorities had already established some provision, mostly the appointment of advocacy services commissioned through the voluntary sector:

We will continue to commission advocacy for LAC who cannot communicate verbally from the Children's Society. This ensures that they can contribute to plans for their future.

3.2.2 Advocacy

Advocacy services were mentioned by 79 authorities (53 per cent). It appeared from the limited information supplied that most advocacy services were specifically geared towards Looked After Children. However, a number were developing specialist disability advocacy worker posts, or extending their services to include specific initiatives such as advocates visiting residential units for disabled young people:

The Advocacy Officer makes regular visits to local residential establishments for disabled children and young people.

A number of authorities were working in partnership with voluntary agencies to provide an advocacy service. In particular the specialist services of NCH, The Children's Society and Voice for the Child in Care were being utilised.

Most authorities spoke of a Children's Rights Service or Officer, again it was often unclear whether their remit included disabled children and young people or just Looked After Children. However, some notable examples included:

Following placement all children, including those with disabilities receive a visit from a Children's Rights Officer.

The Children's Rights Officer for Disabled Children has embarked on a programme of visiting children with a disability placed out of borough.

3.2.3 Complaints

Objective 8 of the Quality Protects programme specifically states that authorities are to 'ensure effective mechanisms are in place to handle complaints'. Twenty-one authorities mentioned complaints within their MAPs (14 per cent). From the information supplied it was not always entirely clear whether complaints procedures or developments planned in this area were to include, or were accessible for, disabled children and young people. However, a number of authorities were specific enough for the analysis to identify that some limited progress was being made, with

some developing systems to make their complaints procedures accessible to disabled children and young people. For example:

> Social Services has involved disabled children and young people in the design and development of the children's complaints service.
>
> Developing a means of making complaints procedures accessible to disabled children. Process developed giving improved access and support to disabled children wishing to make a complaint.

3.2.4 Information

The analysis of the MAPs undertaken by the Council for Disabled Children (2003) concluded that where information was being focused on the needs of disabled children and their families the majority of authorities were at the stage of developing the service and that a high percentage of information was targeted at parents rather than disabled children and young people. This analysis supports that conclusion. Most work was in the development stage, however, worth noting was the variety in how information was going to be delivered with authorities reporting that they would be developing newsletters, websites and leaflets. The level to which this information was accessible to disabled children and young people remained unclear, although a small number of authorities appeared to be involving children and young people in the design of information.

3.2.5 Service development

It appeared that quite a number of authorities had plans for service development and that they were developing ways to enable disabled children and young people's views to be part of this process. However, in the main, specific details were not given. As already mentioned, many service development initiatives were developing advocacy services, some of which were to be available to disabled children and young people. Many authorities appeared to be undertaking consultations with disabled children and young people or their parents/carers in order to inform service development, once again specific details such as the type of service provision were not always supplied, however, respite/short break services appeared to be the most popular. For example:

> The co-ordinator of the Children's Advocacy Service is to undertake a specific piece of work with children with disabilities… to ensure their views are obtained.
>
> Significant consultation over future short breaks.

The planned development of youth forums and steering groups was also mentioned, and appeared to be a popular way of involving children and young people, however, it was not always clear if disabled children and young people were to be involved. Although a number of authorities expressed plans to make their forums inclusive.

3.2.6 Reviews

Within the area of tailoring individual packages of care, the review process appeared to be one which authorities highlighted for attention and development. Sixty authorities (40 per cent) wrote of their plans. These included:

> Matter of priority, Reviewing Officers will encourage and facilitate the full participation of young people and carers, especially where additional assistance may be necessary due to disability or communication needs.

As already mentioned, the use of advocacy services was highlighted by a number of authorities and these were being used widely within reviews. For example:

> The current LAC advocacy service is to be significantly extended to include both children with disability and Children in Need …. The service for disabled children will be permanent and will address the issue of participation of Looked After Children who receive short stays in their reviews.

Some authorities appeared to be making use of available IT packages, such as Viewpoint, or toolkits such as I'll Go First. One authority had issued disposable cameras with which disabled children could record, for example, significant events or things important to them. The authority recorded that this had been successful with young people with learning disabilities. Others were adapting reviewing documents into symbols to make them more accessible.

Overall, the involvement of disabled children and young people appeared to be an area which was in development rather than an established part of practice.

3.2.7 Training

Fifty-six (37.3 per cent) authorities mentioned that training would be provided for staff. This mainly centred on communicating with disabled children and on communication skills. For example, one authority reported that their Children with Disability Team had all received Pictorial Assessment and Communication Training (PACT). Other authorities were choosing to train staff in Makaton, Pictorial symbolisation, Total Respect or I'll Go First. However, most authorities failed to report what their training plans would entail.

3.3 Conclusion

The analysis illustrated that the MAPs did not provide sufficient detailed information to illustrate the genuine nature and extent of participation work being undertaken with disabled children. The MAPs indicated that this is an area in which many authorities were looking to develop practice, train staff and attempt to address the needs of this group of children. The MAPs had been submitted in January 2002, given the time

delay between this and the start of this research, a survey of Social Services Departments was undertaken in order to provide more detailed, current information for the research.

Chapter 4: Findings from Stage Two Survey of Social Services Across England

4.1 Introduction

This chapter presents the findings from the national survey of social services. It describes the reported nature and characteristics of participation activity; characteristics of the children and young people involved; methods of involvement; support for the disabled children, young people and staff involved; any outcomes of participation, and reflections from respondents on what was useful or problematic.

4.2 The nature of disabled children and young people's participation within social services

The first question sought to distinguish participation focusing on disabled children as individuals and that which related to them as a group. That is, involvement in decisions regarding their own care versus decisions regarding service development, planning or evaluation in general.

Table 4.1 Nature of disabled children's participation within social services departments (N= 71)

	Number of social services departments	Percentage of social services departments
Involvement in decisions regarding their own care	14	20%
General service development, planning or evaluation	14	20%
Both	43	60%

As already described, 27 authorities indicated that they did not currently, or had not within the last twelve months, involved disabled children within decision-making processes. Table 4.1 illustrates, within the last 12 months, 60 percent of social services departments who responded were currently involving or had involved disabled children and young people in both service development and within decision-making regarding their own care. Forty per cent indicated involving disabled children within just *one* of these decision-making processes.

Although 71 Social Services Departments completed questionnaires, in a number of cases separate questionnaires were received from different social work teams within a single authority, or from agencies such as the voluntary sector who had service level agreements with social service departments. Thus 57 authorities reported

involving disabled children in decisions regarding their own care, but information was collated on 65 different 'initiatives'.

In addition, several questionnaires were received from some authorities who were involving disabled children and young people in a number of service developments. Again from 57 authorities, information has been gathered about 70 different 'initiatives'.

For ease of reporting, the term 'initiative' is used to encompass both decision-making processes, however, it is recognised that decision-making might not necessarily be an 'initiative' but form part of general working practice.

4.3   Characteristics of children and young people participating

Table 4.2 details the numbers of children and young people involved in decision-making. The table shows that the numbers varied from less than ten to over 50. Nearly a third of service development initiatives only involved up to ten young people, possibly reflecting a growth in the use of youth forums as a mechanism for involvement. In addition only 14 per cent had involved more than 50 young people, illustrating that initiatives generally were not undertaking large-scale consultations.

Within decisions regarding their own care, 36 percent of respondents were involving 20 or less disabled young people, nearly a third were involving 21–50, and 17 per cent were involving more than 50. Given the legislative requirements to involve disabled young people within decisions about their care, for example within The Children Act 1989, a higher number of participants might have been expected.

Fifteen per cent of respondents did not know how many disabled children and young people were being involved in decisions regarding their own care, and within the area of service development, nine per cent of respondents were unable to supply this information.

Table 4.2   Number of children involved in the initiatives

	Percentage of initiatives	
Number of children	Involvement in decisions regarding own care (n=65)	Service development, planning or evaluation (n=70)
0-10	17 (n = 11)	32 (n= 23)
11-20	19 (n = 12)	19 (n = 13)
21-50	32 (n = 21)	23 (n = 16)
More than 50	17 (n = 11)	14 (n = 10)
Number unknown	15 (n = 10)	9 (n = 6)
Missing data	-	3 (n = 2)

Figure 4.1 illustrates the age-range of the children involved in both decision-making processes. As can be seen, participation within decisions about one's own care peaks around the age of 14, 15 and 16 years old, with 97 per cent of initiatives involving young people of this age. However, from the age of 11 years, over 90 per cent of respondents were involving disabled young people, and three in ten were involving children of five years old, within decisions about their care.

A similar pattern emerges with regard to general service development with the older age range more likely to be involved, peaking at ages 14, 15, 16 and 17. Only two in ten were involving children of age five.

Figure 4.1   Age range of children involved in the initiatives
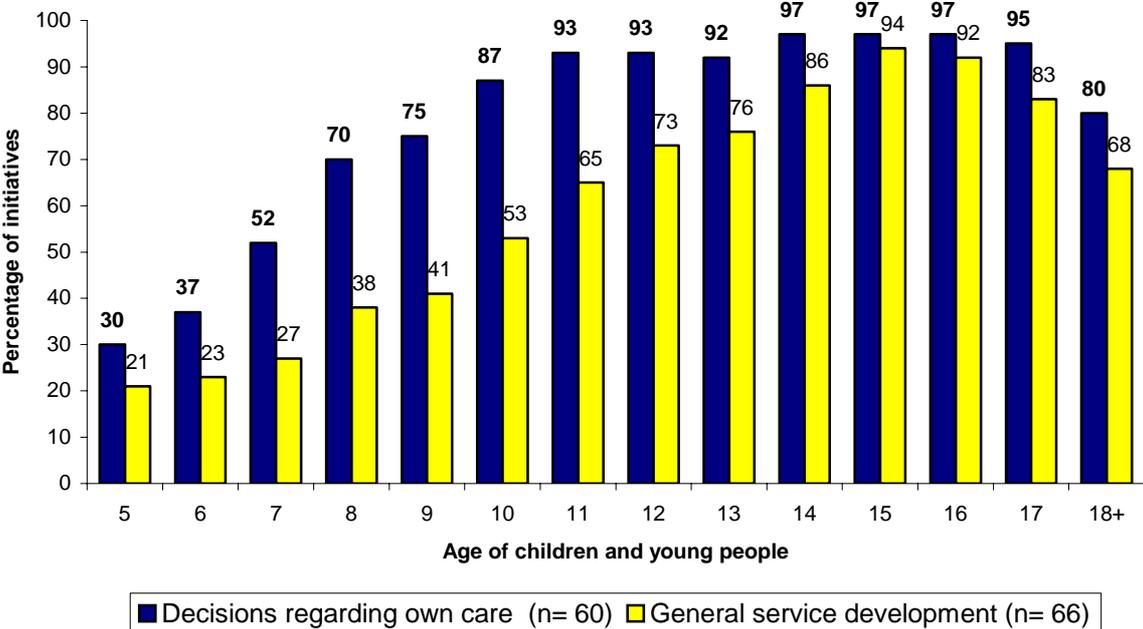
Questions were asked about the involvement of young people with the four conditions which have been identified within the QP MAPs as being particularly difficult to reach. The survey data illustrated that within decisions about their own care, 71 per cent of respondents were involving children and young people with degenerative conditions, 97 per cent with communication impairments, 88 per cent with autistic spectrum disorders and 77 per cent of them were involving children with complex health needs (Figure 4.2).

Within the area of service development the corresponding figures were 53 per cent of initiatives were involving children with degenerative conditions, 90 per cent with communication impairments, 71 per cent with autistic spectrum disorders and 70 per cent with complex health needs.

Such a high number of initiatives involving these groups of children does not concur with the information gleamed from QP MAPs 4 where there was little evidence to suggest that the involvement of children with complex needs was widespread. Either this area of work has mushroomed since the MAPs were submitted in January 2002, or more realistically there is a mismatch between the two data sources possibly due to different people completing the survey and the MAPs, or the type of information that was required for both.

Figure 4.2   Participation of 'difficult to reach' disabled children and young people
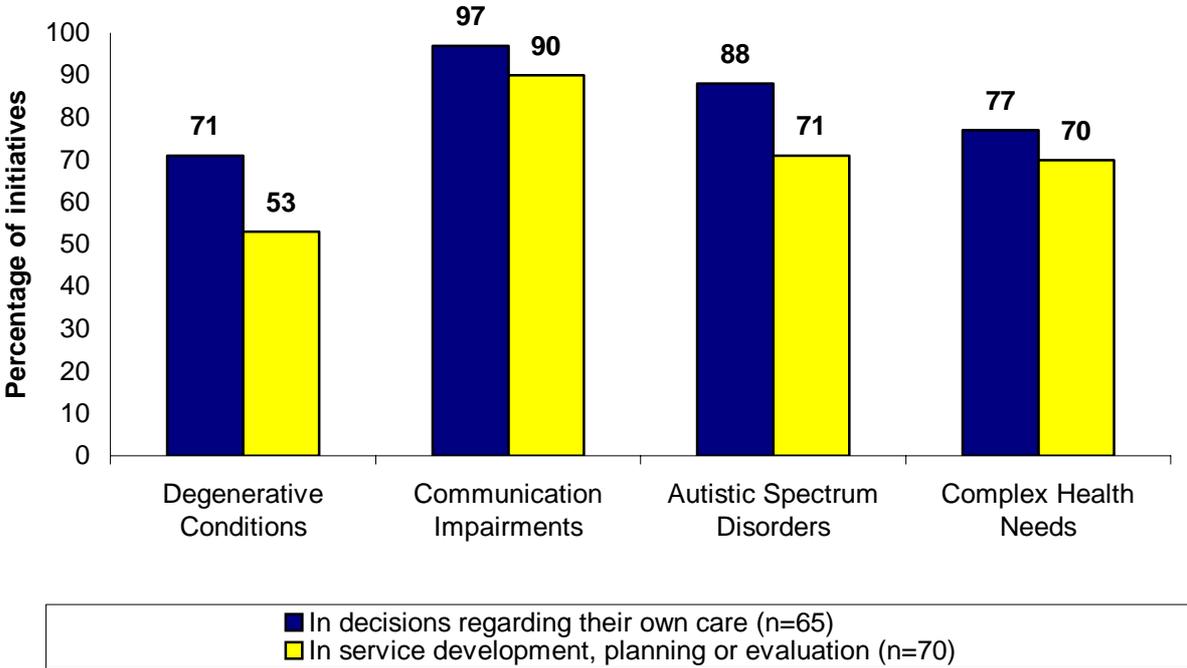
The survey data do not allow us to establish how many young people with these conditions have been involved in decision-making, however, given the low numbers of disabled children being involved per se it might be assumed that these figures are small.

4.4   Characteristics of the participation activity

Descriptive information was collected on each participation activity and relevant reports and consultation documents were sought.

Within decisions about their own care, Figure 4.3 illustrates the range of areas that disabled children were being involved in.

Figure 4.3   Participation of disabled children and young people within individual packages of care (N=65)
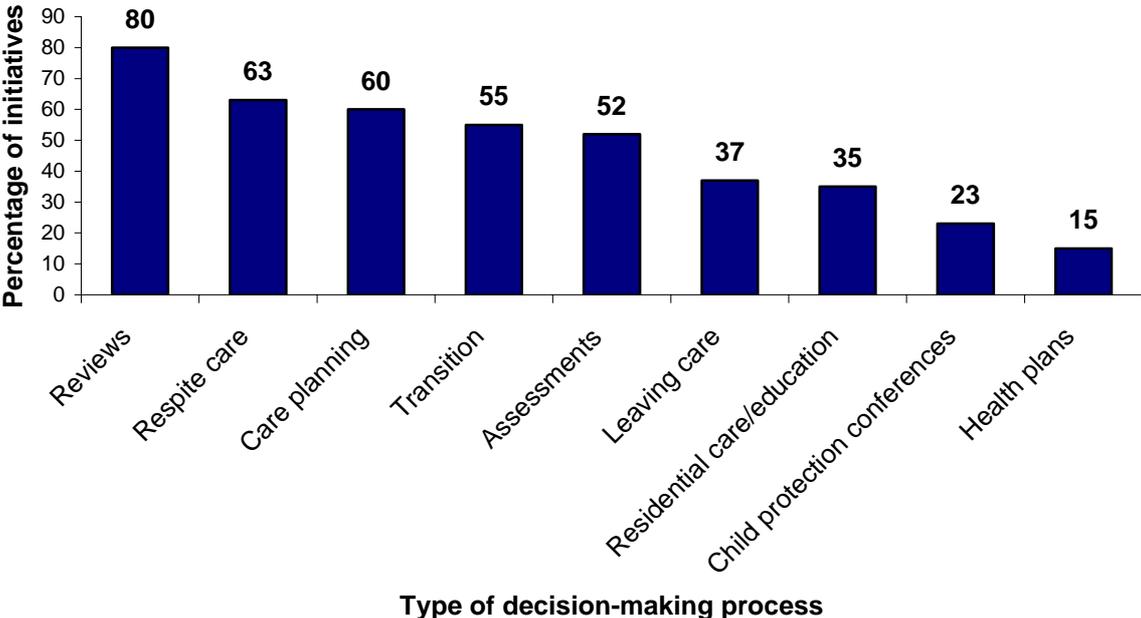
As Figure 4.3 shows, disabled children and young people were more likely to be involved in their reviews than in any other decision-making process, with over 80 per cent of respondents stating that they involve disabled children and young people. Over six in ten respondents reported involving children and young people within decisions about their respite and care planning, and over half involved children in transition planning and assessments. The least likely areas for involvement were Child Protection Conferences and health plans.

Three authorities sent examples of documentation which they had developed to support young people's involvement in their reviews. Only one of them appeared directly to have been designed for use with disabled children and young people. This example contained good practice guidelines to support social workers in using the children's consultation forms. These guidelines included information on: preparing the child/young person for their review, assisting the child/young person to make a personal report, and a checklist for both social workers and the child. Within this document there were a number of tools for social workers to use or adapt including information to give to young people prior to their review, and consultation forms specifically designed for the varying situations surrounding a child, for example, in foster care, having respite and so on. Also included was information on feeding back to the child/young person post-review. This authority was selected to be a case-study (see Area A, Activity Two, page 68).

Within aspects of service development, respondents were asked to describe the initiative, including its aims, and to provide any relevant documentation. Details were gathered on 70 different initiatives (see Table 4.3).

Eleven (16 per cent) of the 70 initiatives were youth forums. Of the 11 youth forums that have been developed, a number provided information on the kind of service development work that the forum had been undertaking and therefore have been coded in Table 4.3 both as a youth forum and with regard to their areas of work. These forums were involved in a wide variety of activities including training and interviewing social services staff, consulting with other young people, producing newsletters and general consultation work around service developments such as transition. A number stated that any service provider could and did approach the group for their views. From the information supplied, it appears that a number of the forums are being run by the voluntary sector, and some appear to be more embedded into local authority decision-making structures than others. Of the 11 youth forums, the data suggest that seven were formed for the involvement of disabled young people, while disabled and non-disabled young people within the looked after population participate in three and one respondent did not supply details of the forum's composition.

One example provided was of a youth forum especially for young disabled people receiving a service from Social Services. The forum offered a two-way communication system between the young people and service providers. The forum was set up under a Listening to Children Initiative and it is planned that elected representatives from the forum will sit on the Children's Panel. The forum has been involved in consultation about Direct Payments, they identified the need for a youth club for disabled young people and have been involved in the development work for it, and they have produced a video to inform others about their group. The forum won a SSD Quality Challenge Award and planned to use the prize money to facilitate the involvement of children and young people with complex disabilities. (This authority was selected for further study, see Case-Study Area C, section 5.4).

One young people's forum indicated that they would be undertaking their own consultation work, with the forum members consulting other young people. However, this forum had only just begun to involve disabled children and was predominantly for looked after children.

Table 4.3   Characteristics of initiatives involving disabled children and young people in service developments (N =70)

	Number of initiatives	Percentage of initiatives
Play/Leisure/Playschemes	12	17
Youth Forums	11	16
Resource centre	7	10
Transition	7	10
Respite care	5	7
Support services	5	7
Interviewing/recruiting social services staff	4	6
Information provision	4	6
Short breaks	3	4
Training social services staff	3	4
Best Value Review	3	4
Producing a newsletter/magazine	2	3
Direct Payments	2	3
Other*	12	17

* This included one of each of the following types of initiative – children's disability register, empowerment group, listening partnership, 'what would you like from a social worker?', children's rights, planning conference, youth parliament, choice of service provider, buddy-scheme for leisure and Connexions. Two respondents described multiple consultations within a single initiative but they failed to describe the nature of the consultation.

Along with youth forums, the type of initiative disabled children were most likely to be involved in was concerning play and/or leisure activities. One initiative described a focus group they had conducted on play which was being used to inform the local play strategy steering group. Another reported using 'Viewpoint' (See Appendix A) at a play scheme as a means of monitoring children's enjoyment, examining whether the scheme met the child's needs and to use this information to assist in future planning. Most reported participation work within the area of play and leisure centred on consultation on what was good, and what could be improved about play and leisure, and appeared to be one-off consultations. This is a similar theme throughout, where disabled children are in the main being asked for their opinions of activities, equipment, toys, décor, and changes to buildings or gardens within respite care, resource centres and short breaks.

Four authorities described their work involving disabled young people within the recruitment process for social services staff, and three of these authorities had taken this further by involving young people in training their staff around communicating with young people - although the extent of disabled young people's involvement within this is not always clear, as for some, groups of looked after children were their main focus.

Four authorities were undertaking participation work on information provision. Two were focused on the care system, one had produced a CD-Rom on 'Being Looked

After', and one was devising a leaflet on 'experiences of the care system'. In terms of specific disability-related information, one initiative produced a video for disabled children to provide accessible, relevant information on Short Break Residential Homes within the authority. Disabled young people were involved in the planning, filming and production of the video. The fourth initiative involved young adults with learning disabilities producing and then performing a drama production on direct payments to other disabled young people with learning disabilities in local schools.

Projects on developing information provision are interesting to see, as analysis of QP MAPs 4 indicated that a high percentage of information was still being targeted at parents rather than disabled children and young people themselves. This survey has also found that quite often feedback from disabled children and young people's participation is directed toward parents (see page 57).

A couple of authorities reported on disabled young people's involvement in Best Value reviews. One described how the involvement of young people led to major recommendations being overturned. Another authority set up a Diversity and Difference project as a result of a Best Value review. One of the objectives of this project is to facilitate disabled children's participation. The project is responding to recommendations made by disabled young people and so far, has commissioned an Arts and Drama group and is developing a Pupil Advocacy Team based in schools.

Seven initiatives were concerned with transition, two provided information on their activities. One was adopting a 'Circle of Support' model where young disabled people identify individuals to work with them to plan their future move from children's to adult services. The other was focusing on the move from compulsory schooling into further education. This authority was working with a voluntary sector organisation and was involving young people with complex physical and/or communication needs, their parents and service providers in a series of workshops to promote interagency working, foster partnerships between users and providers and facilitate a seamless transition.

4.5   Funding

Available literature on children's participation almost always points to the need for adequate resources in order to be able to undertake the work satisfactorily. Clearly any work involving disabled children and young people requires resources of some nature, for example, staff time. A question explored whether dedicated funding had been received to facilitate and/or develop participation.

Of the 65 areas/teams, 35 (54 per cent) indicated that they had dedicated funding to promote disabled children's involvement in tailoring individual packages of care. However, respondents were not always clear about the source of funding. Undoubtedly, a substantial number were benefiting from QP funding, 15 directly

mentioned QP whilst others were unsure which social services budget funds were accessed from. Respondents indicated that this money was being used to fund Children's Rights Officers, Advocacy Workers, complaints services and some participation and listening workers. Many authorities were funding voluntary organisations to undertake this work.

Within the area of service development dedicated funding was reported in 45 of the 70 initiatives (64 per cent). Funding directly from social services either via Quality Protects, Carers Grants or Disabled Children's budgets was reported in 22 cases, the Children's Fund were contributing to seven initiatives, and there was also funding being provided by Health Action Zones, SRB, NOF, and under other initiatives such as Valuing People. Only a couple mentioned joint agency funding across education, health and social services, and one mentioned joint funding across adult and children's social services departments.

4.6   Partner agencies

Nearly 20 per cent of service development initiatives did not involve partnership working, for the remaining 80 per cent a patchwork of partners existed (see Table 4.4). The voluntary sector featured highly in just under half of all projects. Barnardo's featured in nine, NCH five, The Children's Society four, and Mencap four. There were also roles for much smaller agencies such as local parent led groups, youth associations and local society groups, such as the Deaf Society.

Some initiatives were involving a wide range of partners. For example, one consisted of three local authorities' social services and education departments, five PCTs, two Hospital Trusts, Connexions and Learning Skills Councils who were jointly working on a multi-agency review of services for children and young people with a disability in order to produce a five year multi-agency improvement plan. For others, it was an arrangement with one or two partners.

Table 4.4   Partner agencies involved in young people's decision-making within service development (N=70)

	Number of initiatives	Percentage of initiatives
No partners	13	19
Voluntary sector	31	44
Education*	19	27
Health**	10	14
Children's Fund	9	13
Schools/colleges*	8	11
PCT	7	10
Connexions	6	9
NHS Trusts	5	7
Leisure	5	7
Youth service	3	4
Centre for Inclusive Living	3	4
Young people's service	2	3
Lifelong Learning	2	3

In addition the following were partners in just one project each; Housing, Learning Skills Council, Play Network, Independent Consultant, Complaints Service, Multi-agency team (not specified), Learning Disability Partnership Board, Chief Executive Department, Children's Rights Officer, Adult Learning Disability Team and Early Years Service.

*Education and schools/colleges have been coded separately as it was not always clear whether the initiative was working with individual schools or on a more strategic level with the local education authority.

** Health is coded when respondent does not specify the health agency involved e.g. PCT or NHS Trust.

4.7   Methods of involving disabled children and young people in decision-making

Involving children and young people in decision-making can take on many different forms. The survey sought information on both the range and type of methods employed to involve disabled children within decision-making as well as the duration of the activity.

The majority of service development initiatives involved children both individually and in a group which may suggest that the majority are adopting a flexible approach to the involvement of disabled children and young people (Table 4.5). However, no one method should be seen as superior to the other, both group and individual consultation have merits and disadvantages.

Table 4.5   Method of consultation for service development (N=70)

	Number of initiatives	Percentage of initiatives
Individually	9	13
In a group	16	23
Both individually and in a group	45	64

Survey respondents were asked to indicate the timescale of their service development initiative. Table 4.6 indicates that nearly a quarter were single one-off exercises, just over a quarter were arrangements lasting over one year, with nearly a further quarter being permanent arrangements suggesting possibly a more sustained approach to disabled children and young people's participation.

Table 4.6   Timescale of service development initiatives (N=70)

	Number of initiatives	Percentage of initiatives
Single, one off exercise	17	24
Up to one year	12	17
More than one year	18	26
Permanent arrangement	16	23
Various arrangements (multiple projects with varying timescales within one-initiative)	2	3
Pilot projects	2	3
Other	2	3
Missing data	1	1

Further information on the methods of involving disabled children and young people was obtained for both types of decision-making processes. Respondents were asked which methods are used to facilitate children's involvement – written, verbal, visual, Computer/IT or some other method. Although asked to specify, there was a large amount of missing data, in some cases almost half of respondents failed to provide any further details. Interpretation of these results should be treated with care.

Table 4.7   Methods of involvement within decision-making – written

	Percentage of initiatives	
	Decisions regarding own care (n= 34)	Service development (n=38)
Written		
- Questionnaires	26 (n=9)	37 (n= 14)
- Newsletters	-	5 (n = 2)
- Review forms	9 (n=3)	-
- Consultation	12 (n =4)	-
documents	-	5 (n= 2)
- Graffiti wall	-	5 (n = 2)
- Minutes of meetings	41(n = 14)	53 (n = 20)
- Missing data		

The following were each being also used by only one team/area within decision regarding own care – Makaton consultation papers, LAC contribution booklet, quality sheets, consent forms, letters, diaries and sentence completion.
Within service development initiatives – one reported using personal passports

Table 4.7 illustrates that 34 of the 65 areas/teams (52 per cent) involving disabled children within decisions about their own care were using a written method, in most cases a questionnaire or consultation form, nine percent of them mentioned a review form. Within the area of service development, 38 of the 70 initiatives (54 per cent) were using written methods, predominantly questionnaires, although some employed newsletters, graffiti walls, or distributed minutes from meetings usually at youth forums.

Table 4.8   Methods of involvement within decision-making – verbal

	Percentage of initiatives	
	Decisions regarding own care (n=57)	Service development (n=61)
Verbal		
- Interviews	42 (n =24)	36 (n =22)
- Discussion groups	-	33 (n =20)
- Meetings	-	7 (n =4)
- Workshops	-	3 (n =2)
- Advocates	25 (n =14)	8 (n =5)
- Attendance at	5 (n =3)	-
reviews	39 (n =22)	38 (n = 23)
- Missing data		

A verbal method of involvement appeared more widespread, being used in 88 per cent of initiatives for decisions regarding own care and 87per cent of service development ones.

Table 4.8 illustrates that interviews were being used widely in both decision-making arenas. Discussion groups, meetings and workshops appeared popular for service development, along with the availability of advocates for individual decision-making.

Table 4.9   Methods of involvement within decision-making – Visual

		Percentage of initiatives	
		Decisions regarding own care (n=55)	Service development (n=46)
Visual			
-	Symbols	27 (n=15)	11 (n=5)
-	Makaton	33 (n=18)	20 (n=9)
-	PECS	15 (n=8)	9 (n=4)
-	Art/drawing	31(n=17)	35 (n=16)
-	Play/games	7 (n=4)	9 (n=4)
-	Photographic diaries	16 (n=9)	11 (n=5)
-	Video	9 (n=5)	4 (n=2)
-	Signing	13 (n=7)	4 (n=2)
-	I'll go first	11 (n=6)	2 (n=1)
-	Observation	7 (n=4)	2 (n=1)
-	Missing data	33 (n=18)	50 (n=23)

The following were being each used by one team/area within decision-making regarding own care – Chailey, Boardmaker, Traffic lights and Thumbs up.
The following were each being used by one initiative within service development – Chailey, Boardmaker, Traffic lights, and Rebus.

Fifty-five of the 65 area/teams (85 per cent) involving disabled children and young people in their own care were using visual methods to facilitate involvement, in most cases using Symbols, Makaton, PECs and signing or toolkits such as 'I'll Go First' (see Table 4.9). Forty-six of the 70 service development initiatives (66 per cent) were also adopting visual methods. Art and drawing featured highly across both decision-making areas, and creative methods such as photographic diaries and videos were being employed. Observation work was also mentioned in a few cases, possibly indicating some move towards including children with severe disabilities and/or communication difficulties.

Using a computer or IT method of involvement was less common. Such technology was employed by 40 per cent of initiatives involving disabled children and young people in decisions about their own care and 33 per cent of service development projects. Within those that were harnessing IT, the majority were making use of specifically designed packages, such as Widgit and Viewpoint (Table 4.10).

Table 4.10   Methods of involvement within decision-making – computer/IT

| | *Percentage of initiatives* | |
	Decisions regarding own care (n=26)	Service development (n=23)
Computer		
- Website	-	13 (n=3)
- Widgit	23 (n=6)	17 (n = 4)
- Viewpoint	38 (n = 10)	13 (n= 3)
- Missing data	31 (n= 8)	43 (n= 10)
The following were each being used by one team/area within decision-making regarding own care – multi-media approach, writing with symbols, email and dedicated software		
The following were each being used by one initiative within service development – Powerpoint presentations, developing a CD-rom, a multi-media approach, and writing with symbols.		

Overall a wide variety of methods was being adopted to involve disabled children and young people within decision making. In addition to the above, artistic methods such as role-play, drama, and puppets were also being used in a few cases. It should also be noted that although the data have been presented using distinct categories, most authorities were combining methods.

4.8   Support for children and young people taking part

For children and young people to be properly involved in decision-making they require support so that they can understand the process and become empowered to participate effectively in what is more often than not an "adult environment".

Of the 65 respondents involving children and young people in decisions regarding their own care, 54 (83 per cent) stated that they provided support for children and young people to facilitate their involvement, although a couple of respondents wrote that this support was minimal. One respondent also described that support varied considerably according to the commitment and/or availability of social workers to facilitate it. Support varied across all areas and even across teams within a single authority.

Although information was gathered on 70 initiatives involving children and young people in service development, only 53 (76 per cent) stated that they provided any support to facilitate this involvement. Once again support varied across areas with children and young people, for example, receiving support for one initiative in an area but not another.

**Table 4.11 Support for children and young people to facilitate their
involvement**

	Percentage of initiatives	
	Decisions regarding their own care (n=54)	Service development, planning or evaluation (n=53)
Training	17 (n=9)	17 (n=9)
Information about the authority's decision-making processes	31 (n=17)	32 (n=17)
Advocacy	65 (n=35)	55 (n=29)
Assistance with communication	80 (n=43)	74 (n=39)
Access to venue(s)	52 (n=28)	72 (n=38)
Computer aided assistance	35 (n=19)	19 (n=10)
Transport (direct provision or expenses)	61 (n=33)	58 (n=31)
Other	4* (n=2)	11** (n=6)

*Access to a Children's Rights Officer and access to an Independent Visitor for Looked After Children.

** This included a residential weekend for young people involved in a forum, other comments centred on the provision of one to one support or personal care. One respondent wrote that young people also provided valuable support to each other.

Table 4.11 indicates that the forms of support most frequently offered to children and young people were assistance with communication, transport and access to venues. The increasing use of advocacy is reflected in the fact that this was available in 65 per cent of individual decision-making initiatives and 55 per cent of those concerning service development. However, there were still low-levels of training for children and young people and little information about the authority's decision-making process, both of which may help a child's understanding of the process and encourage fuller participation and empowerment.

Further information was gathered on the type of training offered to children and young people. Within decision-making for individual care, none of the nine initiatives was providing similar provision, possibly reflecting the lack of training available to help children and young people facilitate this kind of involvement. The training that was being provided included computer training provided by local FE college, group work skills and raising confidence, travel training, and specific training on communication techniques such as Makaton, BSL, and using the 'I'll Go First' package. One authority mentioned that they were training staff to be trainers, an additional authority mentioned that they were building up a bank of facilitators/ communicators.

For service development, there were nine initiatives that were providing training for young people. Most of the training within these centred on providing young people with skills to be able to work together in a forum – group work, leadership, presentation and IT skills. One authority that had developed a youth parliament was training young people in how to work with councillors. Some young people were

being trained in the use of video equipment so that they could produce a guide to Short Break Residential Homes. Three other authorities who were involving young people in training and/or recruiting social service staff were running training the trainers courses and interviewing techniques for young people.

Further details on computer-aided assistance were also sought. In terms of involving disabled children and young people in decisions about their own care, of the 19 initiatives providing this kind of support, 'Widgit' and 'Viewpoint' were mentioned by five and three respectively. Others mentioned a multi-media focus, use of symbols or just that computers were available for children and young people without providing further details. Only ten of the initiatives for service development provided computer-aided assistance. Very similar assistance was being provided, once again Widgit, Viewpoint and Symbols were mentioned, a multi-media approach was being taken by one authority, with young people having access to digital cameras, and two respondents stated that their youth forum had access to a laptop. One of these said that the laptop was being used by the young people to produce minutes, letters and information sheets.

4.9   Support for staff

Cavet and Sloper's (2004) review of literature on participation of disabled children highlighted the need for staff training and education, as well as skills development in order to promote participation. This included attitudinal changes, training about communication, disability equality and children's rights. Kilgour's (2002) survey of participation workers revealed a need amongst these workers for specialist advice, support, training and networking opportunities. This survey sought information on whether initiatives provided any training to support staff in their role (see Table 4.12).

Table 4.12   Support provided for staff taking part in initiatives

	Percentage of initiatives	
	Decisions regarding their own care (n=54)	Service development, planning or evaluation (n=43)
Training specifically on the involvement of disabled children and young people	78 (n=42)	62 (n=27)
Training on the general involvement of children and young people	44 (n=24)	42 (n=18)
Protected time	22 (n= 12)	37 (n=16)
Other	6 (n=3)	12 (n=5)

For the vast majority of respondents, training for staff had centred on communication and communication methods. With regard to training specifically for the involvement

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of disabled children and young people, a considerable amount of the training had been accessed from two voluntary organisations, namely Triangle and The Children's Society. A number mentioned Total Respect, I'll Go First, Widgit and Viewpoint training (see Appendix A) whilst others had received training in the use of communication methods such as Makaton, PECs and BSL. However, a number of respondents stated that they felt that training for staff had been minimal and limited. There did not appear to be a difference between the training received for those workers working to involve children and young people in decisions about their own care and those who are involving them in service development, although some of the processes and skills required to involve disabled children in these two different decision-making arenas would be quite different.

The data indicate that there are relatively low levels of protected time offered to workers undertaking participation work. Only 22 per cent of those involving disabled children and young people in decisions about their own care and 37 per cent of those involved in service development had protected time.

4.10 Feedback given to children and young people

Practice literature on the participation of children and young people refers to the need to provide feedback to those involved in decision-making. It is valued by the young people involved for a number of reasons including to find out the views of others, to know what is planned to change and when, and to understand the reason(s) if their ideas are not to be implemented (Lightfoot and Sloper 2002a). Evidence suggests that this does not always happen and this can have negative consequences, such as disillusionment with involvement and feelings that the process was tokenistic (Franklin and Madge, 2000). This survey sought to establish whether feedback was occurring within these participation initiatives.

Within decisions about individual care packages, 11 (17 per cent) areas/teams indicated that they did not provide any feedback to the young people who had been involved, a total of 52 (80 per cent) stated that they did but seven of these did not provide any details on how. For the remaining 45, feedback to disabled young people was mainly verbal through a social worker, keyworker or advocate, or provided during the review process. Very few had developed other means of providing feedback – when written information was provided it was invariably provided to parents.

A number of respondents wrote additional comments suggesting that feedback was not always given or given in an appropriate format. Only one respondent stated that they endeavoured to provide feedback in a communication method suited to the needs of the young person. One authority had developed with disabled young people

a written booklet for social workers to use after a review and give to a young person. This provided information about 'What was said and what people are going to do!'

Others felt that young people saw the results of their involvement by the decisions that have been implemented or services that were changed or provided. However, it should be recognised that young people may not always associate their involvement with such changes, especially if decisions are not made at the specific time of involvement or changes have taken time to initiate.

A couple of areas distributed certificates or thank you cards for young people to acknowledge their involvement.

Within involvement in service development, feedback to disabled young people was also patchy, with a number of respondents indicated that feedback was given to their parents. Twenty-three of the 70 initiatives (33 per cent) stated that they did not provide any feedback to the young people involved, many stating that it was too early in the process. Guidance on good practice within participation specifies that even within longer term participatory activities dialogue should be continuous, and young people have indicated within other studies that they like to be kept informed of developments. It is difficult to establish within the data whether this is occurring for the longer-term initiatives.

Forty-three of the 70 initiatives (61 per cent) provided some form of feedback to the disabled young people involved. Again verbal feedback appeared the most popular method, with many using their forum meetings as a way of distributing information. In addition, many forums were producing accessible minutes, some of which had been produced by forum members themselves. A couple of examples of newsletters for young people were mentioned, although it does appear that these were for looked after young people.

A few initiatives provided examples of reports being shared with young people, although it was not always clear whether these had been made accessible for young people. Some had invited participants to events such as the launch of the local play strategy or board meetings and some forums had invited service managers to meet with them.

Once again, some respondents felt that there was 'proof in the pudding' where changes had been made or that there had been outcomes of young people's involvement.

4.11 Outcomes

There has been little published research examining the outcomes of children's participation *per se*, and there has been even less on the outcomes of disabled

children's participation. Very few initiatives conduct rigorous evaluation or produce evidence to demonstrate the link between participation and presumed benefits. Kirby *et al.* (2003a) identified through their study of 29 case-studies, practical benefits to services such as development of services better suited to service users, maximization of resources, increased access and utilization of services, and increased participatory practice. In addition, outcomes have included citizenship and social inclusion of young people, improved relationships between adults and young people, personal development for the young people involved, increased confidence and self-esteem, empowerment, communication skills, group work and practical skills (Kirby *et al.*, 2003a).

With this lack of evidence in mind, respondents were asked to indicate whether the service development initiatives had led to developments in services, and if so what kinds of changes had resulted. Questions were asked on changes to service provision and changes in the commissioning or prioritising of services. It is recognised that an outcome should not necessarily just be seen in terms of service provision, however, this was the focus of questions within the confines of a postal questionnaire. A wider examination of other outcomes was adopted within the final stage of the research.

Only 31 of the 70 initiatives (44 per cent) indicated that there had been changes to service provision as a result of disabled children and young people's involvement. For the vast majority, it was too early in the project to indicate any outcomes. Some examples of outcomes have already been illustrated in section 4.4. Table 4.13 shows that most changes to service provision had been through altering activities and/or changes to décor, reflecting that the fact that a large number of initiatives had been consulting about this topic. However, this does illustrate that within these projects disabled children and young people's involvement had led to change – playschemes, holidays and awaybreaks have been altered, new equipment had been purchased and rooms made more appealing. In one case, an authority reported that as a result they were working towards developing a youth club for disabled young people.

Another reported outcome mentioned by seven initiatives was better information provision for disabled children and young people, including information on transition and a CD-Rom on being looked after. For five authorities, the involvement of disabled children and young people had informed their Best Value review recommendations. One authority appeared to have particularly embraced participation and had developed a disabled children's participation strategy which had already seen results in the formation of an advocacy service.

Table 4.13 Changes to services as an outcome of children's participation
          (N=31)*

	Number of initiatives	Percentage of initiatives
Changes to activities (leisure)	15	48
Information provision	7	23
Changes to décor	5	16
Best Value Recommendations	5	16
Advocacy service	1	3
New equipment	1	3
User-friendly register	1	3
Inclusion in reviews	1	3
Communication packages	1	3
Transition planning	1	3
Disabled children's participation strategy	1	3
Changes to Direct payments	1	3

* Note an initiative could have more than one outcome

A couple of respondents wrote additional comments suggesting that the involvement of disabled children and young people had led to change in culture, with a raised awareness that they should be more involved, and in one authority all services now had to demonstrate the involvement of young people in their development when commissioning.

Clearly it is difficult to measure some of the outcomes of participation activity and to make causal links between children and young people's involvement and the extent to which it has influenced the final decision. However, systematic evaluation is needed to ensure that participation activity is successful, appropriate and not having negative consequences.

The questionnaire did not seek information on the outcomes of disabled children's involvement in decisions about their own care as this would be variable, depending on individual cases and circumstances.

4.12 Sharing experiences

As the involvement of disabled children and young people in decision-making is still a relatively new and under researched area, and is reported to be lagging behind the involvement of other young people, the survey sought reflections from respondents on any experiences that they felt may be particularly useful to others or to identify issues that were problematic. Although analysed separately the two decision-making areas will be reported together as the responses were very similar.

The vast majority of respondents (over 80 per cent) answered this question. Most of the reported difficulties concerned lack of time and resources. Most wanted

recognition that the involvement of disabled children can be very time consuming if it is to be meaningful:

> The main issue is that it is a very time consuming process. You can only go at the young person's pace.

> Not having time to adequately prepare the child for the meeting, or to work with the child to ascertain their views and wishes.

> It takes great deal of unhurried time to include disabled children properly. Staff sadly do not have this sort of time to go in-depth.

> It can often take long periods of time to ascertain views and may require it to be done over a number of sessions due to a young person's level of interest or attention span.

The data suggest that a lack of time was a significant problem which impacted on the quality of children's involvement. Respondents reported that this meant that they did not have adequate time for their own preparation, or for listening to and preparing children, for example, for attendance at their review. Lack of time limited staff from finding or developing appropriate methods and resources, for example, adapting consultation forms, or from being able to spend sufficient time with a child in order to understand their communication method. As already mentioned, only 22 per cent of workers involving disabled children in decisions about their own care, and 37 per cent of those involving them in service development had protected time to undertake this work. As one respondent wrote this can lead to 'young people sitting in meetings which clearly are not involving them', and feelings of frustration and disillusionment.

Equally problematic was a reported need for training, skill development and experience in undertaking this kind of work. Typical comments were:

> Need for workers experienced in communication, social work staff do not practise the skills regularly enough to develop them.

> Lack of confidence for social workers in communicating with non-verbal children and an over reliance on 'forms' to do the work of the child's contribution.

A few raised the issue that staff were not always skilled in objectivity and neutrality, leading to a temptation of "putting words into young people's mouths," or skilled in interpreting and representing children's views, particularly children who do not use speech to communicate. One wrote that within service development it is not always easy for young people's views 'to carry weight within a process because young people's views cannot always be formalised'.

A number of respondents indicated difficulties that they have encountered with gatekeepers, both staff and parent/carers. A number wrote of having to persuade

them of the need to involve children in decision-making, of being prevented from accessing the views of young people, or of staff assuming children would not be co-operative. Some respondents faced 'attitudes which imply consultation cannot be made with individuals with limited communication skills', or staff being defensive, feeling that the things that young people wanted to change were aimed at them:

> Parents often need help in understanding that their children's views need to be taken into account.

> Parents do not really want to hear what their young person has to say.

Equally causing concern for some respondents was the difficulty in reconciling differing views and opinions gained from children and young people and from their parents, and the need to handle this sensitively.

There were also reported difficulties with involving particular groups of young people, those with communication difficulties, autism or severe epilepsy were mentioned. The data suggest that there is a shortage of advocates skilled in using alternative methods of communication, resulting in services still being parent led. Equally, comments indicate that many feel that the service is still very professional focused, suggesting that some participation may be tokenistic, that children's opinions are given little or no weight or that involvement is not equitable.

A couple of comments raised the issue that many disabled young people themselves lack experience and confidence in giving their views.

Although respondents did report difficulties they also wrote of the positive outcomes of involving children and young people, and indicated their increased job satisfaction and enjoyment at doing this kind of work: 'Consultation is not an easy option, but very rewarding'.

They also offered solutions and practical advice to overcome the problems.

Experience had illustrated to many that it was necessary to:
- be clear about your aims and objectives;
- be realistic and not expect too much at first;
- consider practical arrangements such as wheelchair accessibility, transport;
- undertake involvement as early as possible;
- tailor methods to each individual child – 'there is not a single solution';
- not treat disabled children as an homogenous group;
- be creative;
- use available resources such as I'll Go First, pictures, symbols, photos;
- allow sufficient time to prepare, and have protected time in order to undertake the work satisfactorily;

- allow time for young people to build up their own confidence and skills;
- build up relationships with young people in longer term service development initiatives;
- spend sufficient time with the child/young person in order to get to know them and understand their communication method;
- consider that children with complex communication methods might be best supported in their communication by someone who knows them well or that this person can offer advice;
- have sufficient funding and resources available;
- access training;
- keep information simple, jargon free;
- make sure all staff feel included;
- not make assumptions;
- be honest;
- have a positive approach;
- not be afraid!

Many felt that involving children and young people had aided planning, made provision more appropriate and helped to introduce change. Experience had shown them that often children's views or wishes are not necessarily complex, unrealistic or hard to achieve, and that with the right resources, skills and time, most children can be involved – 'even children with complex communication disorders/severe learning disabilities can be involved':

> The value of children's views and insight should not be underestimated and enhances services in practical ways – enabling better use of resources.

4.13 Responsibility for the involvement of disabled children

Given the increasing attention being placed on the involvement of children and young people in general, the survey sought information on whether there was a post-holder within each organisation with designated responsibility for children and young people's involvement. Of the 71 areas completing the questionnaire, 49 (69 per cent) stated that they had such a post. The job titles of these varied from children's rights officer, children's participation officers, consultation and information /involvement officer to service development workers. From the data it appears that it is very rare for them to have only a remit for the involvement of disabled children and young people. For many, they were covering a whole range of groups of young people and/or seemed to have a particular focus on the looked after population.

4.14 Conclusion

This survey has provided for the first time up to date details on disabled children and young people's participation within social services across England. Existing literature has identified a number of requirements for supporting and increasing children's participation in general and that of disabled children in particular (Treseder 1997, Cohen and Emanuel 1998, McNeish 1999, McNeish *et al.*, 2000, Kirby *et al.*, 2003a, Beresford 1997, Ward 1997, Morris 1998c, Russell 1998, Marchant *et al.*, 1999a, The Children's Society 2001). These include training, feedback, time, dedicated resources, positive attitudes of adults, creative and flexible approaches and identifying disability-related needs. The results of the survey provide some information on the extent to which these requirements are reported as currently being provided in participation work with disabled young people under the auspices of social services departments. These findings will be further discussed at the end of this report in the light of more detailed data from the case studies.

Chapter 5: Description of Case-Study Areas

5.1   Introduction

Within this chapter we describe the six case-study areas, the reasons for their selection, their approaches to participation and the nature of the participation activity with disabled children and young people.

5.2   Area A

Within this social services department two activities were selected for examination. One consisted of a large-scale participation activity day and the other concerned the involvement of disabled children and young people within their review process.

5.2.1   Activity one – large-scale participation activity day

This case-study was selected as it provided:
* an example of a large-scale event in service development as such events seem to be becoming popular for children in general;
* an example of an inclusive event which was to include children with severe; impairments and across the age range;
* expressed plans to be the start of a series of events and thus providing an opportunity to explore follow-up from a large scale event;
* an example of wide partnership working.

A local authority organised a free inter-agency family fun-day for disabled children and young people at a local museum in September 2003. The stimulation for organising the event came from three sources: firstly, a need to raise the profile of, and increase attendance at, the social services 'Parent Participation Group' organised by the Development Officer for Disabled Children. Second, the Social Services Disabled Champions Group for operational workers had identified the need to familiarise themselves with the whole range of services available locally and regionally for families with disabled children and to use resources to increase their confidence in communicating with disabled children directly. Finally, the authority wanted to mark the European Year of Disabled People with a fun event which would allow disabled children, their non-disabled siblings and friends, parents and schools to think about the theme of participation.

Specific aims of the day, drawn up by the multi-agency planning group, were:
* To incorporate the PSCHE (personal, social, health, citizenship education) of the school curriculum.

- Achieve better participation, inclusion and understanding.
- For professionals, services, parents and disabled children to be brought together to share information and resources.
- To act as a springboard to look at wider issues which children and parents define as important.
- To be appropriate for all ages and impairments.
- For young people to be able to attend on their own (with the help of personal assistants if required).
- To be the first of a series of events focused on participation.
- To gain wide publicity including press and TV coverage.
- To have at least 200 attendees.
- To be free for families and children/young people.

Planning and preparation

The Development Officer for Disabled Children, based within Social Services, took the lead on the planning and organising of the whole event. However, representatives at the planning meetings were encouraged to take on responsibility for individual tasks. A conference organisation company was employed from May 2003 to assist the Development Officer in the logistical organisation of the day. The company worked on the event one day a month.

Planning and organisation took 8/9 months, with the initial idea being formulated in January 2003 and the event taking place in the September. The first joint interagency meeting took place in March and then meetings were held approximately monthly until the event. Representatives came from Social Services, Education, Health, voluntary agencies and parents/carers.

The event took place on a school day. Schools were encouraged to bring along pupils and to not mark children as absent if they attended with their parents. A letter was sent to all Headteachers explaining that this had been agreed by the Strategic Manager of Children and Families and the Manager of the Attendance Team.

Invitations were sent out at the end of July with a reply slip. Families received back a confirmation letter including a parking voucher, timetable of the day and a letter to give to their child's school to confirm their attendance at the event. Invitations were sent to 650 families and 50/60 professionals as well as councillors and local dignitaries.

To encourage the maximum attendance and to ensure that the event was accessible to all, the whole day, including all workshops, was free, and free parking and a free buffet lunch was provided. Some free transport was available to those that needed it, and personal assistants were offered to try to encourage disabled young people to attend on their own. At the event, helpers dressed in a recognisable T-shirt were on

hand to care for children while their parents attended the parents debate, gathered information or took advantage of free yoga, hand massages or reiki. All of these helpers were police-checked. These details were included within the invitation sent to parents.

The organisers of the event advertised their names and contact details on the invitation so that they could be contacted if anyone had a query in advance of the day.

Description of the day
On the day almost 300 people attended, although this approximation is probably an under-estimate as the day was specifically designed to be flexible and allow a drop-in approach and not all families formally registered.

Around the edge of a main hall, there were 18 stalls mainly offering information to parents. In the centre of the hall and alongside the information stalls, activities were available for all children and young people to join in with. These included giant games, musical instruments, soft play equipment, parachute games, arts and crafts and an area of sensory lights. To one side of the hall was a smaller area where workshops of storytelling, music therapy and dance/drama therapy were available at selected times. Within the attached theatre, two parent debates were held, also available for parents was reiki, yoga, hand massages and aromatherapy.

Three local authority services had devised activities designed to gather the views of disabled children and young people. A youth organisation working in partnership with the Children's Fund provided information aimed directly at young people, this consisted mainly of information about the organisation and materials aimed at recruiting young people to join youth organisation. They also invited children and young people to draw or write on a vinyl art-mat depicting 'what and where would you like to play and what are the barriers preventing you?' After the event the vinyl artwork was handed to the Social Services Disabled Children's Team, framed and displayed in the reception area of the council's premises where many social work teams are based.

The Early Years Service used a questionnaire to gather disabled children and young people's opinions on inclusive play, such as what is important to young people about inclusive play, what would make a good inclusive play facility? When children could not complete the questionnaire because of accessibility issues, their parents were asked for their opinion. At the event, 20 questionnaires were completed.

Finally, the Transitions team displayed a graffiti wall at the event and encouraged young people to write or draw on the display giving their opinions on the work of the team, their education and what they want to get from their future.

5.2.2 Area A - activity two – specifically designed consultation forms for disabled children and young people using short overnight breaks for under 120 days

This activity was selected because it provided:
* an example of specifically designed "tools" to facilitate disabled children and young people's participation within individual care planning;
* an authority with specific policies and procedures on the involvement of disabled children and young people within their own care.

The authority designed a glossy colour cartoon style review booklet for use by disabled children receiving short breaks. Most questions within the booklet are closed offering children the option of indicating yes, no or not sure, while some questions have space for fuller answers and the booklet encourages young people to draw answers.

The booklet consists of 16 pages covering areas such as:
a) *Information about the review* – for example, who would you like to talk to after your Review? Are there any things you would like to talk about which you don't want to talk about in your Review?

b) *Staying away from home* – The good things about staying away from home. Are there any things you don't like about staying away from home? The people I like when I stay away from home are.

c) *Home, family and friends* – Who lives at home with you? Who do you see who does not live at home? The good things about being at home are. What kinds of things do you do with your friends? Does anyone come to your home to help you eat or drink, get washed etc?

d) *School* – How do you get to school? The good things about school are. Are there any things at school you don't like? Do you get extra help at school with lessons, eating or drinking etc?

e) *Health* - Do you go to the Doctors? Do you like going to the doctors? Is there someone you can tell if something happens which you don't like?

Alongside the consultation booklet, there is an accompanying feedback form designed in the same cartoon style which is to be given to children after their review. The feedback form provides details of 'what was said and what people are going to do'.

The authority has also produced other guidance material to assist social workers with involving disabled children within the reviewing process. This includes a flow chart for

action planning and guidelines for good practice, checklists for social workers and children preparing for the review, and a list of core questions that children and young people should be asked. Lists of questions are provided for children in a range of circumstances including in foster care and residential homes, placed for adoption, leaving care and respite or shared care for more than 120 days each year. In addition there are alternatives to the question/answer format with the option for children to complete a short 'smiley face' rating scale or draw a picture.

The authority's services procedures manual for review arrangements specifically states that:

> Every effort should be made to make the Review process as engaging as possible for the child/young person and, unless the child wishes otherwise, they should always be given the opportunity and choice to be present and participate in 'LIVE' Reviews. Review recommendations and the actions arising from a 'LIVE' or 'PAPER' Review should always be explained and communicated in person to the child/young person in a method they can understand [4].

The procedures manual stresses that *'social workers will need to demonstrate the efforts made to consult with the child and include them in the review'.*

5.3 Area B – involvement of disabled young people within their reviews of short break care

This authority was selected because it provided:
- an example of disabled young people being involved in the development of tools to facilitate the involvement of disabled children within their reviews of respite care;
- an example of an authority with a specific strategy directed at the involvement of disabled children which had indicated some outcomes in terms of service development.

With funding from Quality Protects, a Social Services department commissioned a voluntary agency, who provide social work support within the authority, to undertake a four month pilot study to consider ways of improving communication with disabled children and young people. A social worker was seconded to undertake the pilot project. The purpose of the work was to increase the participation of disabled children within decision-making and particularly children with communication impairments. As a focal point, the pilot work examined the participation of children and young people within their reviews at a short break residential unit, where involvement of young people was patchy and inconsistent and where young people had minimal feedback after their review.

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[4] A 'LIVE' Review is a face-to-face meeting while a 'PAPER' Review is when Review documentation is completed without a face to face meeting.

The social worker recruited two disabled young people aged 15 and 17 to be advisers to the project. The young people chose to meet twice a week with the social worker, once during lunch time at school and once after school. The young people were given gift vouchers as recognition for their input into the project.

The young people, in collaboration with the social worker, devised a series of questions which they felt were pertinent to ask a young person for their review. Topic areas included likes and dislikes, what was a good or bad day at X [the residential unit], what form of communication did they prefer, any changes they would like to make in order to make their stay more enjoyable. Respondents were encouraged to raise any issue they wanted for discussion. The questions were made into a questionnaire and Widgit symbols were placed underneath the written text. Social workers were to be encouraged to use the questionnaire with young people before their review. Accompanying the questionnaire was a list of useful resources and publications and social workers were given recommendations for good practice, these included:

- young people and their families might want access to an independent advocate;
- all children and young people's files should contain information on the child's preferred form of communication;
- children's views should be sought at an appropriate time and in an appropriate place prior to the review;
- completing the questionnaire could take numerous sessions, and children should not be expected to answer all questions if they prefer not to;
- the questionnaire should be translated into the child's preferred form of communication;
- children shall be given feedback and a chance for discussion after the review.

Staff at the residential unit were also issued with good practice guidance, this included that:

- there should be flexibility in the times of review meetings so that children could attend if they wanted to;
- there should be appropriate communication aids for the child available;
- only language appropriate to the age and understanding of the child is to be used during a review;
- a response should be made to the comments on the child's questionnaire. If the child's requests are not possible then an explanation should be given.

Six disabled young people, aged between 14 and 17 who were due to have their review of short break during the period of the pilot project were identified to trial the questionnaire.

5.4 Area C - involvement of disabled children within a youth forum and children's panel

This authority was selected because it provided:
- an example of disabled children's participation in service development;
- a youth forum which appeared to be embedded within a decision-making process;
- potential for evidence of outcomes, for example, young people developing services;
- involvement of children with autistic spectrum disorders and communication impairments;
- expressed plans to include the involvement of children and young people with severe and complex needs.

Organised and supported by the Service Development Worker for Disabled Children, a disabled young people's forum was established in September 2002. The aim of the forum was to provide a formal mechanism through which disabled young people, who receive a service from the department, can voice their opinions on service delivery and development and with whom the department can consult on matters arising. The forum was funded through a Listening to Children Budget.

Social work staff identified possible young people who they felt could be accommodated within a group setting and these were invited to join the forum. It was acknowledged at this time that without the availability of one-to-one support the inclusion of children and young people with complex needs would not be possible. However, this unmet need was recognised and was identified as an area which needed development.

The forum had defined objectives which were to:
1) Ascertain the thoughts, wishes and feelings of disabled young people with respect to the services they receive from social services.
2) Identify any areas within services for disabled children and young people generally that can be improved or developed.
3) Ensure that the views, wishes and feelings of members regarding the service provision and unmet need are fed up to senior management within the Department and to Council Members.
4) Act as a means by which the Department can consult with disabled children and young people on future service development.

The forum involved up to five disabled young people who met once a month at a Youth Café provided by Youth Services. Dates for the year were set in advance and a reminder letter was sent to each member about a week before each meeting.

Transport was provided through the voluntary transport service or young people made their own arrangements.

The forum meetings were semi-structured but allowed plenty of time for young people to socialise or raise their own issues. The 'semi-formal' meetings involved an agenda, minutes and tasks were recorded. If there were any questions/issues that the young people wanted to raise, then Departmental staff/managers were invited to the meetings. People from other organisations or wider departments were also welcomed. User-friendly minutes were distributed after every meeting, and each member of the group had their own personal file in which to collate information.

Networking and publicising the group were seen as important elements of the forum's work. This took place within and across other organisations. Activities have included performing drama and making presentations at conferences and local events. The group have also been involved in making a video publicising their work at a regional participation conference.

Funding secured from the Listening to Children budget has led to the employment of an 'Active Involvement Sessional Worker' who will assist in the running of the forum (2.5 hours per month). Information was circulated across Social Services and Education and Lifelong Learning in order to recruit someone who had experience of working with young people. The sessional worker is to be offered training and support from the Service Development Worker for Disabled Children. Young people were fully involved in the selection of the sessional worker.

The Forum won a money prize from SSD Quality Challenge and will be using the money to facilitate the involvement of children and young people with severe/complex disabilities, possibly through consulting with them through their school on issues that are important to them and how they would like to be involved in the work of the forum.

This young people's forum does not work in isolation but is one of five groups set up under a Listening to Children Initiative. Groups have been established representing disabled children and young people, children and young people looked after in foster care, children and young people looked after in residential care, young people leaving care and children and young people receiving family support.

Two representatives from each of these groups sit on a Children's Panel. These representatives were selected after a democratic election process, involving children and young people (aged 11-25) standing for election (Feb 2004). All young people receiving a service across the authority were eligible to vote. All of the young people who stood for election received a £10 voucher and certificate from the Director of Social Services. Four young people from the disabled children and young people's forum stood for election to the Children's Panel, two were elected and one of the

unsuccessful candidates has continued his involvement through making a video-diary of the development of the Children's Panel.

The Children's Panel uses the 'Youth Act' model, which aims to enable and empower young people to act as advocates for change in their communities. The model has been developed in the USA by an organisation called 'Street Law' and is being piloted in the authority by the multi-agency Cross Community Citizenship Forum of which the Children and Family Social Services Department is a member. It has a grant from the European Fund.

The Children's Panel consists of young people representatives and their adult supporters/links, the Children's Development Unit Project Officer, Councillors and the Assistant Director of Children and Families (see the organisational chart on page 75, Figure 5.1)

Following election, the young people representatives spent time getting to know each other and undertook a period of training. The Adult Supporters/Links undertook a two-day 'Youth Act' training course during July 2004. These Adult Links subsequently trained the Children's Panel members, starting with two days of activity during the school holidays. One day was spent on activities to encourage the young people to speak out about services, and gain confidence and skills in debating, listening and lobbying. They also visited the Deputy Lord Mayor. The next day all members went to a Theme Park. Their training has continued with fortnightly sessions held at the Youth Café.

Each young member of the Children's Panel has a file containing information on:
- *What's in it for me?* Explains that members will be offered a number of supports and rewards such as transport to/from meetings and refreshments, achievement awards/certificates from Social Services and school, gift vouchers, ID Badge, trips and days out. Members are encouraged to add their suggestions.

- *The Role of a Panel Member:* Explaining what is expected of them, for example, go to meetings, ask other children and young people what they think about social services and then tell everyone at panel meetings, have training, go to conferences and meetings to tell people about the panel.

- *Skills you need to be a Panel Member:* For example, talking to people and saying what you think, be able to listen to what other people have to say, be able to ask for help if you don't understand what's going on, want to learn about being in the Children's Panel, like having fun.

- *What Adult Links will do to help Panel Members*: Explains that it is the job of the Adult Link to make sure that the young people attending meetings are helped to get their ideas and those of other young people listened to and heard.

- *Active Involvement – what you need to know?* Explains how social services have guidelines for all staff which tell them how to make sure they listen to the opinions of young people when they are thinking about changing or stopping services.

- *How the Children's Panel will work:* The Organisational Chart of the Children's Panel Structure (see page 75 Figure 5.1).

- *A List of Adult Links contact names and addresses.*

The aim of the Children's Panel is to ensure that children are actively involved in service development and policy making:
1) Ensure the views and opinions of children about the services they receive are fed up to senior management and councillors.
2) Provide a ready mechanism for consultation with children and young people.
3) Assist in the role of scrutiny.

Further funding is being sought so that the panel can be firmly established, developed and ensure that all children and young people have an opportunity to be involved, including those children with severe/complex disabilities. Funding would be used to pay for more sessional workers to run the various groups, transport to and from meetings, activities and events. At present most of the Adult Link responsibilities are being carried out by two Project Officers in the Children's Development Unit. A call has been made that operational staff in Children and Families need to be identified and supported by management to take over this work. A priority is for the Active Involvement of Children and Young people to be owned by the Children and Families Division as a whole and therefore a wide range of staff need to become involved and supported by their Line Managers and Children's Development Unit.

An Active Involvement Working Group will continue to meet to oversee the development of the panel, the group will:
a) Monitor the delivery of the training programme.
b) Draw up and implement a publicity and media strategy.
c) Identify the structures and panels/forums that the panel will need to feed into.

Figure 5.1   Children's Panel Structure

Children and Young People Looked After in Foster Care	Children and Young People with Disabilities	Children & Young People Looked After in Residential Care	Young People Leaving Care	Children and Young People Receiving Family Support
⬍	⬍	⬍	⬍	⬍
Youth Forum	Youth Forum	Residents Meetings	Support Groups	Support Groups
⬆ Named Link	⬆ Named Link	⬆ Named Link	⬆ Named Link	⬆ *Named Link*
Children and Young People reps x 2	Children and Young People reps x 2	Children and Young People reps x 2	Development Workers x 2	Children and Young People reps x 2

Input from Children and Families Mangers and Staff as necessary or as requested. ➡

⬍ CHILDREN'S PANEL

Children's Planning Officer
Reps from Individual Groups with adult support if required
Councillors
Assistant Director Children and Families
Customer Care/Information Officer

⬍

Children and Young People's LSP
Representation by Development Workers on this Group

5.5 Area D – development of an information DVD on respite care

This case-study was selected because it provided an example of:
- Children and young people with complex needs, severe learning difficulties and communication impairments being involved in service development.
- Partnership working.
- Use of creative arts and a variety of methods to facilitate involvement.
- A wide age range of children and young people involved.
- A specified outcome and a plan with clear aims and objectives.

This authority worked in partnership with a multi-media company and regional dance development agency, in order to fulfil their aims of providing disabled children and young people with creative opportunities to express themselves and produce an interactive information DVD at the same time. The aim of the DVD was to provide disabled young people, who may be coming into a residential unit for an extended stay or respite care, with information on what to expect and what it might be like. Funding was secured from the authority, Connexions and the Arts Council.

Over 30 young people who have severe learning difficulties, physical impairments and who use a variety of non-verbal communications systems were involved in summer holiday workshops and activities or had the opportunity of working one-to-one with two artists in residence at their residential unit. The aim of the workshops was to provide the content material for the DVD, but also to give the participants opportunities to access art, drama, music, animation and multi-media techniques to facilitate their expression of the experiences of residential care. Workshop leaders encouraged young people to make their own choices as often as possible. The two-hour workshops were based around the theme of making choices, for example, the dance workshop involved creating movements to represent the activities that the young people liked doing and exploring ideas based around the movement of animals. Arts based activities included young people taking three of their favourite things and manipulating and exploring them. For example, using photography and computer graphics, some young people merged their own image onto their favourite characters or pop stars and became 'The Hulk', Robbie Williams or 'Tom and Jerry'. These images were then printed onto T-shirts as a permanent personal remind of their work. The artists in residence enabled a wide selection of young people to be involved and could undertake in-depth work to facilitate the involvement of young people who might need one-to-one support or who might find a workshop group environment difficult, for example, young people with autism.

At the end of each session of activities, young people's work and photographs of the young people taking part were displayed around each residential unit and parents/carers were encouraged to come in and view what their children had been undertaking.

The authority hoped that by ensuring that the content of the DVD was created by young people themselves that this will interest the young people viewing the DVD and that they will gain a young person's view of what the residential unit is like. The DVD would explain the process of coming into the residential units as well as what the young person and their family can expect. There were also plans to create a website for disabled young people. The authority envisaged that the DVD would be used as a training tool for residential workers, social workers and families to illustrate what young people's views of residential care are.

Regular steering group meetings were held at which all of the major partners attended, including representatives from the residential units, children's rights and parents. Regular information, via unit managers, was shared with all staff at the residential units involved and, via letters and personal visits, with parents and carers. Information sessions were also held at each residential unit in order to brief young people about the activities and the project manager visited the units a few days in advance in order to re-iterate with the young people what was going to be happening.

Initially three pilot dance, sound and photoshop workshops were arranged in order to gain experience, assess the skills and ability level of participants and to help inform the development of the content and delivery of the main workshops. These workshops were filmed and a video was produced of these pilots, the intention of which was to show the video to staff and parents in order to provide information about the content and style of the planned workshops and about the project's aims and objectives of producing an interactive DVD.

The DVD was launched at a major screening event held at a local theatre. The young people who had taken part in the workshops were given 'red carpet' treatment and were presented with certificates of achievements by a TV celebrity.

The content of the final DVD contains an interactive game for young people which involves the viewer following a young man through a day. At each juncture of the day, for example, getting up, having breakfast, getting dressed, watching TV etc, the viewer is required to make a choice. The commentator describes the choices, subtitles and Makaton symbols also relay the choice options, the viewer is required to make a choice and it leads onto another part of the story. The rationale behind the story and the interactive nature of the game is to put across the message that disabled young people have choices, should be given choices in their everyday life, should be encouraged to develop their skills and experience to make choices and that choices have consequences.

Alongside the interactive game on the DVD, there is also a documentary where professionals from social services and staff from the residential units explain how in reality disabled young people are encouraged during the stay to develop their communication skills, decision-making skills and the importance this has for young

people. It also tries to paint a realistic picture about balancing choice with practical implications, that choice is not always available and may sometimes be denied, for example, if there are safety issues.

Young people from the residential units act as some of the main characters in the DVD taking the roles of, for example, the young man as we follow him through the day, a bank robber or as 'themselves' enjoying a day trip out to the seaside. Throughout, the film producers encouraged the young people to make choices and to influence the content and direction of the film, however, there had to be some limits to this, as they had to balance young people's input with making sure that the film had a coherent story, was workable in terms of its interactive capacity and was of the highest quality.

Copies of the DVD have been distributed to the all the residential units in the authority, so that the young people can have access to it, and five parents who requested the DVD have been sent a copy.

5.6   Area E – pilot project to involve disabled children in their review of short stays

This activity was selected because it provided an example of:
- Children and young people with communication impairments and learning difficulties being involved in decisions regarding their own care;
- An authority focusing on training and supporting staff to undertake participation;
- An authority with a clear plan to learn from the pilot and develop practice with a wider number and range of disabled children and young people.

Within this authority, the disabled children's social work team undertook a pilot project to consider disabled children's participation within the service review process. The project manager started from the premise that this project should examine the barriers to disabled children's involvement and establish ways in which disabled children can realistically be involved in a child-centred way.

For the pilot, seven young people and their families were involved. The young people were aged between ten and 17 years, four were boys and three were girls and they had a wide range of communication impairments, five of the young people did not use speech to communicate and two had some limited speech. The young people had varying degrees of learning difficulties and complex needs.

All of the young people have regular short stays at one of the authority's residential units, and for the purposes of this developmental pilot a decision was made to seek young people's views about this service only.

The authority developed their approach in line with research evidence on some of the suggested barriers to disabled children's participation. They identified the following issues as ones which needed to be addressed:

- a failure of parents, carers and professionals to understand how young people with learning difficulties can be meaningfully involved in the reviewing process;
- a lack of understanding of the skills, knowledge and experience required of social workers and review chairs to facilitate young people's involvement;
- the time and resources required to plan and involve young people within the review process;
- the review procedure from beginning to end is largely a written exercise and thus on the whole incomprehensible by young people who have severe learning difficulties;
- the logistics of involving young people living a distance from the local authority.

The authority identified a strategy to overcome these barriers which involved devising a child-centred format for the reviewing process. The initial approach and invitation to children to invite them to their review was altered and an audio photo card was sent to the child. This attempted to make it clear to the young person that the meeting was for them, that they were the central focus of the meeting and that their attendance was seen as important. The cards allow social workers to record a brief message which is automatically played back each time the card is opened. This message can be re-recorded if necessary. Social workers recorded a message directly to the young person, typically saying, 'Hello Laura. On Thursday we would like to meet with you and talk about the time you spend at [residential unit name], and I hope you can come'.

On the front of the card there is a photograph of a typical meeting and the words 'Your Meeting'. Inside the card contains a photograph of the social worker and a photograph of the young person. Also included are instructions about how a young person could record a reply if they want to, or if they want someone to record one on their behalf. The authority were aware that this approach is not appropriate for all children, for instance, children with hearing impairments, but a personalised approach with photographs and simple writing or symbols would be used where appropriate.

A 'review pack' was developed for social workers to use and this was piloted with the seven young people. A folder was compiled which contained questions about particular aspects of the service, photographs to place the questions in context and 'feelings' faces on a scale of 'happy', 'ok' and 'sad' so that young people could indicate their level of satisfaction. Each page in the folder only contained two questions so that they could be large and clear. Alongside the folder there were separate copies of each page which were laminated individually so that they could be moved around if necessary. It was hoped that the pack would be versatile enough to

engage children with mild communication difficulties as well as those with complex needs. So, for some young people they may look at the photos and circle the feeling faces, some may pass the relevant feeling face to the adult, others may eye point to the one which best describes their view, and for some young people the feeling faces may not be appropriate and social workers were then instructed to show the young people the photographs and record the child's response whether that may be their facial expression, gesture or body language.

The review meeting itself was restructured to make it more child-centred. A first meeting was held between the parent(s), social worker and chair to discuss the agenda for the final review. The purpose of this meeting was to discuss any lengthy or contentious issues which might preclude a child taking part. The second stage involved the Social Worker meeting with the child and gathering their views via the review pack. The final stage was the actual review, where the social worker, with the young person, would feedback the young person's views and anything arising from the initial adult discussions would be recorded. It was hoped that because of prior meetings, this actual review meeting would be short and that it could be governed by the amount of time the young person was able or willing to participate.

The seven young people who took part in the pilot were selected from those young people who were due to have their review and were chosen to reflect the age range and variety of communication impairments and complex needs that the service supports. The child's designated social worker was then approached and ask to take part, thus the social workers were not 'handpicked' and varied in terms of experience, training and in their enthusiasm or scepticism for the pilot.

Social workers were asked to attend a training session where the new format of meetings, review pack and rationale behind the project were explained. They were also given guidance on communicating with young people with communication impairments.

Following the pilot and the lessons that the authority learnt from trialling this process with seven young people, they intend to expand the process to involve greater numbers of young people who use a range of different services. They also intend to establish methods of consulting with young people about aspects of their lives that cannot be easily represented in photographs or drawings and continue their training of social workers and review chairs.

5.7 Area F – voluntary sector participation project based within a disabled children's trust area

This case-study was selected as it provided:

- an example of disabled children's participation in service development;
- a youth forum which appeared to be embedded within a decision-making process and had expressed plans to include a much wider group of disabled children than those on the forum;
- an example of participation activity which was independent of statutory services, but was working in partnership with the Children's Trust;
- potential for evidence of outcomes, for example, young people developing services;
- involvement of children with autistic spectrum disorders and communication impairments and children across the age range.

A children's voluntary sector organisation, with funding from The Kings Fund, employed a Development Worker for three years, to facilitate the participation of disabled children and young people within decisions that affect their lives. The organisation had previously undertaken a consultation exercise within the area, funded through local authority Quality Protects (2003). The consultation had been with 71 disabled young people aged between three and 19 and included children and young people with complex needs, autistic spectrum disorders and communication impairments. This post was a direct response to disabled young people's request for more say in decisions.

The main activities of the Development Worker (two people job sharing) include setting up and servicing a Children's Forum which has direct links into the decision-making arena of the Children's Trust, co-ordinating a network of advocates to attend review meetings with disabled children and young people, and monitoring and evaluating all work undertaken. Although the participation project is working with the Children's Trust to bring about change, it is an independent project.

Two disabled young people aged 14 and 16 were involved in recruiting the development workers. A worker from the voluntary organisation visited the young people at their school, where information was provided on how the post came about and what the post entailed. Together they devised questions to ask of the candidates and a rating scale which would be used to score how well the candidates had answered the questions. On the interview day, candidates faced questions by the adult panel as well as a panel comprised of the two young people and the worker, who provided support to the young people such as note taking. The young people led the interview and took complete control of the scoring of candidates. Both interview panels then jointly discussed the candidates and agreed on the same person. The

young people were given gift vouchers in recognition of the considerable time and effort they had given.

Once in post, the development workers, as a starting point, organised an event to which all children and young people involved in the consultation were invited. The event was opened by a young person who spoke about the importance of participation. The event consisted of young people completing a questionnaire, containing written questions and symbols, on their likes and dislikes, what is important and what changes could be made. For some children and young people who required support, facilitators were on hand to assist with the completion of the questionnaire. After this exercise, lunch and entertainment was provided.

At the event, young people were asked if they would like to volunteer to be on an advisory group for the participation project. Twelve children and young people volunteered and these young people reflect the diversity of age and disability of the earlier consultation exercise, whereby some of the young people have severe learning difficulties, severe communication difficulties and autistic spectrum disorders. In collaboration with the development workers, the group have decided to meet on a monthly basis. They decided that their first tasks should be to vote on a name for their group and design a logo for the project and then produce publicity materials and a newsletter. A video of the group is also planned. A young person who had taken part in the original consultation and who has since completed a media studies qualification has offered to produce the video.

Alongside the young people's advisory group, the project also has an adult practitioner group which meets every four to six weeks. This consists of The Children's Trust Manager, a transitional co-ordinator, Portage worker, speech and language therapist, a social worker and a mother and a father representative. The adult group are not only supplying advice but practical support such as access to specialist communication packages and website design. The professional representatives were nominated by children and young people during the launch event.

Both the young people and adult advisory group will feed into a wider children's forum. This forum is open to all children and young people across the area, both disabled and non-disabled. This forum will be held at a local centre which has facilities for young people and is accessible for disabled people. Every six to eight weeks, the forum will meet to share ideas, information, listen and also have some fun. The forum has multiple functions in that it will provide an opportunity for dialogue with, and input from, a wider range of young people than just those on the advisory group, it provides an opportunity for service providers within the Children's Trust, councillors and others who wish to meet and consult with groups of children and young people, and it also provides an inclusive, integrated environment for disabled and non-disabled children and young people to meet, work together and share

leisure time. More opportunities for leisure, meeting people and making friends were identified as an issue for the disabled young people who took part in the consultation.

Fun days will also form part of the project, both as a reward and celebration, but also on occasions to engage with a wider audience of disabled young people. For example, the project paid for access to the disabled children's register so that they could engage with more children and young people across the authority who access services.

Whilst the project has been recruiting young people and establishing itself, the development workers have been approached on a number of occasions to undertake consultations on behalf of the local authority. On behalf of the youth service, the project gathered the views and opinions of disabled children and young people using a pilot youth group. The development workers used a combination of methods – observation, photographs, direct interviewing and a posting box in case there were private things that the young people wanted to say. The young people had many suggestions for improvements which were fed back as recommendations. Other consultations are focusing on domiciliary care and local regeneration of a park. The project, however, is very clear that although they undertook these consultations, it is now, as much as is possible, working towards the agenda of the young people on the advisory group and within the forum. If the project is approached to undertake consultancy work then a decision will be made in collaboration with the young people involved.

The project has embarked on providing advocates for disabled children and young people and has had a very positive response to the advertisements for volunteers. The voluntary sector organisation already has an advocacy scheme and training programme for advocates of looked after children, so advocacy for disabled children will link into this.

Although, the project is in its infancy, the development workers are beginning to think about the monitoring and evaluation of their work and see that the children and young people will in due course have a very important role to play in this. Plans have already been put into place to follow developments from the Youth Service consultation and to check what has happened to the recommendations that young people made. The forum will be monitored closely especially in terms of its representativeness of young people across the authority.

Chapter 6: Findings from Stage Three Case Study Areas

6.1 Introduction

The findings from the qualitative research undertaken in six case-study areas are reported in this chapter. This provides an account of the experiences of professionals, parents/carers and, where possible, disabled children and young people involved in participation activity. The chapter also draws together the range of data collected to provide a description of some of the difficulties encountered by authorities. It also highlights what interviewees have identified as 'what works' and 'what would help practice' and illustrates some positive outcomes of disabled children and young people's participation.

6.2 Professionals' views on participation

Across the case-studies a complex mixture of views and attitudes towards participation emerged from the professionals interviewed. These include:

- commitment to participation;
- different notions of what participation should mean;
- elements of not knowing how to achieve participation especially for children with learning difficulties or who use alternative forms of communication;
- concerns over children's competence, understanding and abilities to participate, coupled with unease about the interpretation of children's views;
- and sometimes a reported view that questioned participation on the basis of 'we know what is best for that child'.

6.2.1 Commitment to participation

Within all the case-study areas, interviewees were asked about their views on participation. The majority spoke of a commitment to involve disabled children and young people in decision-making but often this was qualified with questioning of how this could be achieved in a meaningful way, particularly for children with more complex needs. A small minority seemed less convinced, questioning the motives and methods and felt that this was not always practical in reality.

Commitment to participation was expressed typically in terms of ensuring that young people had a voice in decisions that affected them:

> I think it's important.. it's very much focusing on the young person's voice because it's very easy to see that, especially when young people have communication difficulties, you are often led by the main carer as to

decision-making and what happens in their life and it is very
disempowering for that young person, and you read the research and it
says, really if you do talk to young people they don't ask for the moon, it is
quite safe to talk to them and in fact it's a good thing.
(Practitioner)

You want to give it proper time and thought and not just, oh it's another tick
box exercise because that defeats the whole object of involving that young
person and the push is very much about being child focused, getting that
young person involved, which I think is brilliant and yes, I think it should be
done but you've got to do it properly.
(Practitioner)

If you are only getting out of them that they like going to the placement or
they like something at the placement and nothing else, that is sort of
seeing them as important, it is an important starting point, which I think
people might think, I've tried this and that's all I can get and it's not worth
it, but it has got to be started somewhere.
(Practitioner)

6.2.2 The meaning of participation

Despite commitment, there remained an element of uncertainty and confusion about
what participation means, what it should and should not entail, how it can be
achieved and what this means in reality for some disabled children, particularly those
with more complex needs. For example, a manager within social services explained
that confusion about participation can lead to a blurring in understanding who is
making the final decision and which decisions are open for discussion. This can lead
to concerns over young people making decisions which may not be in their best
interests, being involved in decision-making processes which are tokenistic, or
expressing a desire for a different service which is not available:

I think people get hung up about participation, what it is actually giving
young people, but you can involve a child but you're not necessarily going
to allow them to make any choices you wouldn't have done if they're in
their birth family… Social workers say, well, if you ask them if they like
something and we can't provide it, it's frustrating. If we ask them what they
want to change then we should just do it and I'll say 'Well no we shouldn't,
it's got to be in their interests'.
(Manager)

Much of the current debate and practice within children's participation does not
contain reference to, or makes only passing comment on, disabled children's
participation, and therefore there still appears to be confusion about what this
actually means for children, for example, with learning difficulties or communication
impairments. Throughout the case-studies, a number of respondents did raise
concerns over the capabilities of children with cognitive impairments to understand
the concepts of decision-making, the rational process of weighing up options and

choosing, abstract concepts and timeframes. In addition, apprehension was expressed about interpretation both in terms of knowing whether a child had fully understood the process or questions being asked, and also how to interpret a child's response, particularly if the method of communication was new to a social worker, the social worker did not know the child well, or they were relying on an 'interpreter', normally the child's parent/carer.

Interview data gathered from some social workers suggests that there appears to be a concept of 'ideal participation' which is based on the mainstream agenda, and the concepts of participation do not appear to have been translated successfully to be meaningful for some disabled children. There sometimes appeared to be a notion that anything less than a child taking part in a review meeting and contributing to complex decision-making process was not valid. For example, when the views of young people with learning difficulties had been sought, it might have been at a level of 'what I like' and 'what I do not like' about respite, and this was sometimes viewed as limited, with a small number of social workers questioning the use of this:

> I tend to find the young people I've done it with, only the concept you can get hold of is "What's your favourite things, what you like, what you don't like?, you know, so you might come to a review with 'This is what I like doing, I like music, I like going out on a bus', they are not actually saying 'Well yes, I like coming to [respite unit]' because we can't get that concept over to them. (Practitioner)

> In some cases, it can take years to get a child to use a switch to say yes or no and they've got to be able to understand the questions you're asking to be able to answer that yes or no, so I mean they might just be able to do it, 'Do you want a drink?', yes or no, so to ask them what do you think about your respite…?
> (Practitioner)

> For some children I have to be honest I don't think it is appropriate simply, because… it is a process that they're not going to grasp and that may sound unreasonable because it is SO important to get the views of children, but for some children it is pretty much impossible to get a view. You can get what you think is a response but is it a reliable response? For a profoundly disabled child who gives a blink for a yes/no response, that may be enough to record but is it reliable, do we plan? I think the point I am making is, do we make decisions on the basis of that or do we use this process as a means to give an opportunity to a child to contribute, cos if we are doing it that way, it's the way forward.
> (Practitioner)

However, as shown within the small number of examples collated from the case-studies reported on in section 6.8, through expressing these views children can make a valid contribution, when the concept and methods of participation are widely defined and understood. As one practitioner explained the 'smaller', changes can make a difference to the quality of a young person's experience at a respite centre:

There might be little things like the children they're spending time with they can't bear to be with because they're in the same class all day and they want to come in and they really don't want to see that person again.. or every time they come in, because of the way the meal menu is they always have fishfingers and they hate fishfingers.. it could be very subtle things like that.

6.2.3   Concerns over achieving participation

Although this will be explored further in section 6.7, many practitioners spoke of not having the skills, knowledge, training and experience of consulting disabled children particularly if the child used non-verbal means of communication and therefore they questioned their abilities to facilitate participation.

You are talking about skills that people don't have through their normal training.
(Manager)

It can be seen that this lack of training, particularly in terms of understanding the reasoning behind participation and methods of participation, had a direct link to some of the attitudes and concerns illustrated. A lack of understanding of the reasons for participation might also explain in part why some people reportedly held views that hampered children's participation:

Sometimes they [residential staff] say, 'Oh we know how they make their wishes known in the home, they don't need the symbols cos we generally interpret' and it's about please don't interpret for them, they've got to be able to make choices and express it.
(Practitioner)

I was getting really frustrated with one of the children's homes saying 'Oh you won't get anything out of our kids' …….. I just remember saying 'It doesn't matter, my job is to find a way to make sure they can say it'.
(Practitioner)

We do have, not many, but some staff who can't see the benefits [of participation]. They're very much like some parents, you know, well my child will never be able to communicate or, you know, why are you doing this cos they don't understand'
(Manager)

6.2.4   Choice

A number of social work respondents raised the issue of choice and the importance this has in children's participation. Some social workers reported difficulty in reconciling children's participation in decision-making with a lack of choice in terms of service provision:

We talk about giving people choices and the young people that we work with, giving them choices but.. when it actually comes down to it, would we

give them a choice if they said 'No, I don't want to do this, I want to stay at home'.. I mean we couldn't do that cos we could be putting them at risk, could be putting the family at risk.
(Practitioner)

It's ok inviting a child to a review to get their views but when they don't want to be in that placement, it's like well what else is there for that young person.
(Practitioner)

You can't give people choices if there isn't no choices.
(Practitioner)

However one manager explained how despite limited choice, a young person who had a communication impairment and severe learning difficulties could still be involved and make a valid contribution to his transition planning:

He had little control over the plans and he probably had little choice about where he was moving to but at least if he could say what he hoped would be there.. it was a start… and what was going to make him comfortable was to take his comfy chair and to set his wardrobe out and his bed.. and to make this the same for him.
(Manager)

6.2.5 Questioning participation

Some social workers also expressed concerns over how parents might feel about the participation of their child, in particular that it was 'more interference', 'a waste of time and resources', or 'a backdoor route to cutting services':

I know for parents it was, they were scared that you were going to say 'Well if your child says Oh I don't like going to so-and-so we won't bother, we'll cut that service', and they're panicking cos they think Oh God.. and it's about reassuring the parents, saying Well no, it's not about that, we just want to find out so that we can actually improve the service.
(Practitioner)

Another social worker when asked what a parent's reaction had been to their child being invited to participate recalled that the parent had been *'more than willing for it to happen but thinking that it wouldn't work with him'.*

Social workers from the pilot review project (Area E) reported that parents need to be part of the whole process and that there is a need for parents to be given information about what participation is, what it is trying to achieve and also to share some of the stories of successful participation so that they can see the benefits it might have. Parents may need the opportunity to talk through their concerns about how their child will contribute and reassurance about service provision. The pilot study had invited 40 families to take part and only 12 agreed, social workers in that area felt it was important to share the success of the pilot with families, to show what happened, that

it had potential benefits for the young people and that it is not a backdoor to reducing services:

> You do have parents who say 'what nonsense, you know, he can't speak, he's got profound learning disability, what are you on about?' But hopefully this will show that in fact even children with quite severe difficulties can be engaged and can make a valid contribution.
> (Practitioner)

Area D – the DVD project - were aware that parents/carers needed information and endeavoured to engage with them throughout the process. Parents were sent information at the outset and were offered the opportunity to talk with staff, either on the telephone or through a home visit. Some parents/carers, identified by staff as being less likely to respond, were telephoned directly or visited. Parents/carers were invited on a number of occasions to attend evening sessions at the residential centres to view the video made after the pilot workshops, view their children's work after the creative workshops at a 'show and tell' and also to the red-carpet launch of the DVD.

6.3   Parents/carers' views of participation

A neglected area within the children's participation literature and associated research is parent/carers' views on their child's participation. Participation is a new and developing concept and for some parents their child may have not been asked for their views or opinions before. One parent, when asked why she had agreed for her child to be part of the pilot review process (Area E) stated:

> You just go along with things to be honest, you just think all right, everybody's got a good idea and you come across all these good ideas and… some of them have not been good ideas but this time it worked and I was surprised and I've got to admit, I was very surprised at the outcome of the meeting, but most of the time a lot of it is just a waste of our time really.

Within this study, some parents whose children had not participated, had concerns about how their child could be involved given their communication difficulties and cognitive impairments, and/or questioned the ability of their social worker to get the child's view:

> That's my scepticism about the whole thing, because I would be very nervous about somebody who felt that they had training in recognising things then coming in and extrapolating from Michael[5] a response that I wouldn't be convinced that he'd actually made. The danger is that it's very difficult to check. On the other hand I can see what people are nervous about with parents who interpret the person's needs the whole time…
> (Parent)

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[5] All names and identifiable details have been changed.

It's a difficult thing because for me Naomi will never be able to make her own decisions unless you have somebody that's involved in that decision that knows her really well… it's just she cannot logically evaluate things and to be able to make a decision you have to logically be able, she knows what she likes, she knows what she doesn't like but…
(Carer)

Well the social worker has seen Mark about five times in five years. I don't think they have a relationship in which she's got any chance of getting any views from Mark. And you'd have to have somebody who'd spent quite a lot of time and perhaps one-to-one time, and then you'd have to have all that training and discipline which made you not imprint you own thoughts.
(Parent)

However, in general, parents were pleased with the results when children had taken part in activities or had been asked for their views. As described in more detail throughout this chapter, some parents had been surprised at the level of response their children had given, for some their initial scepticism had averted and two had witnessed their children making a valid contribution to their reviews:

She said she'd rather go out just for a walk, not necessarily go out, out anywhere but she loves going for walks and she made that clear, it would be nice instead of sitting watching telly to go out for a walk.
(Parent)

One parent whose teenage son had been involved in the review process for the first time felt that if he had been asked for his opinions from an earlier age or had repeated experiences of being involved, this might have equipped him with the skills to communicate when things are not alright for him at respite:

If he'd been more used to this sort of thing, then if he went to a respite place and there was something or somebody he didn't like, for whatever reason, he could say I don't and then you can get to the root of the problem, can't you? I think that's…for my son a good thing from the process that we've gone through.

Within the large scale events, parents/carers (Area A and Area D) reported that their children had enjoyed the events and had been given the chance to try out new activities.

However, some parents explained that the involvement of their child was not so much of a priority when the reality is that they have not had a social worker for long periods of time, when paperwork is not sent to parents and professionals in advance of reviews, and relevant professionals are not invited to attend review meetings. Another parent also remarked that participation is more than just listening, it also requires follow up action:

It's all right asking our opinion, and asking our children's opinion, but if that feeds into a document that's just filed away then there's not much point in

it really. If it actually feeds back into action then you feel as if you've actually been effective in attending.
(Parent)

6.4   Changes in attitude towards participation

Some professionals and parents reported a change in their attitude as a result of participation. Within the pilot project to involve disabled children in their review of short-stay (Area E), a number of people, both parents and professionals, reported being surprised at how successful the method had been for involving particular children and young people. They had held beliefs that it would be either impossible or extremely difficult because the children had communication impairments and learning difficulties, and they reflected that they had underestimated the child and the method being adopted. One parent said:

> I had thought what was the point really, she can't talk… but it was lovely, it was a real eye opener. I was surprised, you know, I really had negative thoughts about it but it worked out really well.

A social worker when asked what the parents reaction was to their child's involvement in the pilot project remarked, *'they were thrilled, you know, really impressed with how we'd coped with him'*.

6.5   Prevalence of participation

Despite a growth in participation activity, the available evidence suggests that in reality certain groups, including disabled children and young people, continue to be excluded from opportunities to participate (Cutlet and Frost, 2001; Kirby and Bryson, 2002; Cavet and Sloper, 2004). In addition, there has been little evidence collated on the numbers of children being involved in decision-making. This study provides some further evidence to suggest that participation is only a reality for a small number of disabled children and young people.

6.5.1   Numbers of children participating

The survey findings indicated that, the numbers of disabled children participating in decision-making were small, suggesting that not all children and young people are being involved in decisions regarding their individual care and that, in the main, only small numbers are being involved in service development. Across the case-studies, a similar picture emerged. Within service development, two types of participation activity were undertaken – large scale events and youth forums. Obviously, larger numbers of disabled children took part in the large events, however, the evidence suggests that to a certain extent trying to accommodate large numbers can be at the expense of children expressing their views and opinions on services. These events were a success in terms of giving disabled children and young people an opportunity

to have new experiences, and this is clearly an important step in developing the skills required to be involved in decision-making. Within the DVD project (Area D), children and young people expressed themselves and made choices within their creative workshops. Clearly, children and young people enjoyed this workshop experience and so did those partaking in the large-scale participation event (Area A). However, children's views and opinions on services were not gathered.

Evidence from the survey showed that youth forums had emerged as a popular mechanism for facilitating disabled children and young people's involvement in service development. However, inevitably the nature of this method means that often only a small number of children and young people are involved. In the two-case study areas which had a youth forum/advisory group, six disabled children and young people were involved within one, and twelve within the other. Although both areas had plans to consult with a wider spectrum of disabled children and young people, the forum had yet to undertake this and the advisory group was establishing the mechanisms to achieve this, through developing a large forum open to all children and young people, both disabled and non-disabled, across the authority. This forum would meet every six to eight weeks and would be a mixture of information sharing, listening, consultation, development and fun. However, it is too early to see whether this is a successful model.

Within all the case-study areas who had focused on developing individual decision-making, managers, reviewing officers and social workers reported that generally practice was poor in terms of involving disabled children and young people within their reviews and all were attempting to rectify this. The exact numbers of children being involved was impossible to gauge, although interviews with staff and parents suggest that few children were included. As one social worker explained, '*I've worked for the team for four years and in the whole of the four years I think I have managed to do it with three clients*'.

One parent reported that her son aged 15 had never been involved:
> He's never ever been involved in anything to do with an assessment... and he's never had any input whatsoever in any of his annual reviews..

The carer of another teenage young person who has not had any involvement stated:
> They ask me because as they say, 'You know Natasha better than anybody else' and that is true.. They say hello to her, they talk to her but they've never, school's done this sort of thing but Social Services never have.... They've been to school and seen what school do, yes they talk to her....and she does respond to them but they don't ask her questions that she can give a decision to.

Another parent remarked:

> When they set it up, they never sort of say well, you know, 'shall we make it at a time when Sarah can be here or shall we make it at school so Sarah can come'. The assumption is just sort of made that we'll hold it here and it will be… mid morning, lunch time to fit in with Anne, because she goes to family placement with Anne.. so Sarah's views are never sought.

One authority collated data on the numbers of disabled children involved in their reviews, and this was used to select a sample for the research of children and families who were invited to take part in the research. However, a number of families contacted researchers to inform that they had not had any involvement at all. Therefore, there can be little confidence in the numbers supplied. In the other case-study areas, only six children and young people in each had used the 'review questionnaires' developed, although it should be noted that in both authorities this had been a pilot to test the suitability of the materials being developed. One area had definite and developing plans to roll this out wider, the other ceased work after the pilot phase when the seconded worker returned to their original post and the service manager left their post.

6.5.2 Age range of disabled children and young people participating

The survey data indicated that the age range of disabled children and young people participating varied, although involvement was greater for teenagers, peaking around the ages 14 to 16. A similar pattern emerged within the case-studies, with the overwhelming majority of children and young people aged over 11 and teenagers predominantly being involved.

6.5.3 'Hard to Reach' disabled children and young people

This research had aimed to focus on the involvement of children and young people with the four conditions which have been identified as being particularly difficult to reach. Within the survey, relatively high numbers of respondents reported involving children and young people with degenerative conditions, with communication impairments, with autistic spectrum disorders and with complex health needs. Such a high number of initiatives involving these groups of children did not concur with the information gleaned from QP MAPs 4 where there was little evidence to suggest that the involvement of children with complex needs was widespread. Neither data collection method asked for the numbers of children being involved within these groups, given the small numbers being involved in general, estimations would be very low. The case studies provided an opportunity to look at this in greater detail.

All case-studies were selected because they were currently involving, or had significant plans to involve, children with these conditions. However, across the initial sample of selected case-studies there has been limited evidence of this occurring.

Children and young people with these conditions did take part in and enjoyed the experience of the larger scale events (Area A - participation activity day and Area D the creative workshops linked to the creation of the DVD). However, their level of involvement was limited. The DVD itself, however, has the potential of a providing a long-term tool for developing the skills and experience of children within these groups to become involved in decision-making. The interactive game allows children to practise decision-making and understand choice in a fun, non-threatening way.

Within the youth forum (Area C) and advisory group (Area F), a mixed pattern emerged. The youth forum had been selected because it had plans to include children with more complex needs. However, this had not come to fruition before the end of the research, mainly due to the need to finance and recruit workers to provide the one-to-one support that may be required. The advisory group, recruited at a later stage to the research, started from the premise that it would include all children regardless of their support needs and would find the means to facilitate the involvement of children within these groups and indeed, some young people within the advisory group have severe learning difficulties, communication impairments and autistic spectrum disorders. Within the timetable of the research it has not been possible to follow the progress of the advisory group, which has been slow to start due to a prolonged period when attempting to recruit the participation workers.

Within individual decision-making, the original case-studies selected provided few examples of children in these groups being involved by social workers. Evidence was collected from one authority, where a part-time Children's Rights Officer consults with disabled young people in her role as advocate. Through using pictures and photographs of activities, young people reported their likes and dislikes and this was fed into review meetings.

Case-study area E, selected later in the research, developed and piloted a method to enable children with communication impairments and learning difficulties to be involved in the review process in a way which would enable them to make sense of the process and make a contribution. From the limited evidence available, this method appeared to have been a success with the small number of young people involved, who enjoyed the process, expressed their views about respite and influenced the outcomes of the reviews, either through changes in services or maintaining the status quo. The authority is taking forward the method to a larger number of children, to encompass children with other special needs and to cover a wider range of decision-making areas. Time constraints have prevented the research from examining how and if this develops.

The two case-study areas selected later in the study (Areas E and F) have started to develop the processes to enable 'hard to reach' disabled children to be involved in meaningful ways. These areas started from the premise that they would find a means to facilitate the involvement of children within these groups, and identified the

communication needs of the child or young person. They demonstrated confidence, expertise and determination to achieve this and prioritised the training and resources required. Both areas appear to have made use of research evidence available to support their work and were drawing on, for example, the work of Triangle, a voluntary organisation dedicated to facilitating communication with disabled children.

A 'can-do' attitude was demonstrated by the participation worker within one of these case-study areas:

> I've said it time and time again, it's about being individual, children are individuals, they all have their communication needs.. so it's about finding out what system that child uses….I don't use BSL, I can't read Braille but I will access someone who can.

6.6 Nature of disabled children and young people's participation

6.6.1 Methods of involvement

Although a variety of methods were reported in the survey, the case-study areas adopted very similar methods to facilitate children's involvement. Within individual decision-making, all authorities developed questionnaires/booklets to be used in reviews, while in service development two of the four areas commissioned a youth forum/advisory group and the other two chose to undertake larger scale events. However, there was little evidence of young people choosing or influencing the choice of methods, with children in the main fitting into existing structures. Area F provided a rare example, where the advisory group had been set up in direct response to the request made in a consultation exercise for more opportunities to influence decision-making. Apart from Area D which engaged in multi-media and creative arts to facilitate involvement, there was little evidence of multiple methods being used.

6.6.2 Service development

From the survey data it appeared that disabled children were being involved in a range of decision-making areas, although evidence suggested that quite a lot of children's involvement in service development had centred on what could be termed 'children's issues' – activities, equipment or decor. The survey indicated that involvement of disabled children and young people at a higher strategic level was rare, many activities were one-off consultations and there appeared to be little evidence of the establishment of participatory cultures. This picture was somewhat reiterated within the case-study areas, although all were attempting to alter this pattern.

Within the area of service development, two case-study areas established a youth forum/advisory group in an attempt to have an established group of disabled young

people with which service providers could consult, as well as having a trained and supported group which could feed into existing adult strategic decision-making structures within the authority. The advisory group within Area F placed particular priority on the issues addressed being led by young people's ideas:

> What will take priority is what children and young people want us to work on, not what other agencies want us to do and yes, we need to work in partnership… but it is about what the children want themselves. (Participation worker)

While the other area (Area C) had spent a considerable amount of time developing structures for the forum to link into and possibly less time on issues identified by the children themselves. However, the short term nature of the research makes it difficult to compare the two models, the different approaches or outcomes. For example, Area F had a dedicated full-time worker who worked independently of, but in partnership with, the authority. The project was six months old, and appeared to have clearly defined mechanisms established to feed back and forth from the children and young people and a multi-agency professional group. The project had engaged with a wide range of disabled children and young people in terms of age and disability and had established a clear plan for wider consultation. They also had clear plans to monitor and evaluate their work and involve children and young people within this process.

Area C in contrast employed a local authority part time worker with other responsibilities. This forum had been in existence for over two years but appeared to be somewhat struggling to establish the mechanisms and structures by which children and young people could fed into decision-making areas. Their plans to develop these structures and undertake wider consultation had not, so far, come to fruition.

Within the larger events, (participation activity day (Area A) and workshops to inform the DVD (Area D)), children and young people's enjoyment was evident and could be seen as an important start to developing the knowledge required to make choices. After the event, both authorities reported that they had learnt from their experiences that in order to achieve their original aims of children with more complex needs expressing their views a much smaller consultation would be needed, where children could be supported one-to-one, and their individual needs met.

Across these case-studies what became evident was the immense amount of time required to facilitate participation in service development of any nature. Often this became the responsibility of one or two people, sometimes part-time workers, who were expected to be skilled in logistical planning, knowledge and experience of facilitating the involvement of children with complex needs, project management, devising and monitoring aims and objectives, fund raising and influencing the culture and decision-making bodies of a local authority.

The sustainability of participation in service development was an issue for some of the cases studies, with funding a concern. This was often linked to the immediate activity, rather than funding the capacity to develop on a longer term basis. No doubt this contributed to a lack of long term planning, no evaluation or monitoring and little participation work becoming embedded or linking into wider participation activities.

6.6.3 Individual decision-making

All case-study areas were developing practice around involving disabled children within their review of respite/short break care. Across the three areas similar findings emerged, even though the tools to facilitate involvement were different: Area A had developed a glossy, cartoon style review booklet with a written question and answer format, Area B had involved two disabled young people in developing a questionnaire with written questions and Widgit symbols and Area E developed a review pack for social workers to use which contained photographs, questions and 'feelings faces' for young people to indicate, 'happy', 'ok' or 'sad'.

Social workers repeatedly reported that although the tools were appropriate and would be successful with some children, these tools would need to be adapted for other children who use symbols or a different symbol language, or an alternative approach altogether, such as observation would be required, thus suggesting that an individual approach is required for some disabled children to participate. Parents and carers also remarked on this. One parent, whose child had not been involved, looked at the tools developed by the authority, her comments were:

> I'd be really keen to find a way of Melissa being able to communicate, at the moment it's usually about putting her in a situation, observing how she responds to it, and because she so clearly responds with pleasure or displeasure or lack of interest.

Although the necessity of adapting approaches, methods and tools for involvement is reported in the literature (Cohen and Emanuel, 1998; Kirby and Bryson, 2002; Lightfoot and Sloper, 2002a, 2003; Cavet and Sloper, 2004) the case-study areas have, in the first instance, invested a considerable amount of time and resources on creating uniform structures and systems or sought to fit disabled children's participation into existing ones. Social workers and managers reported that some of the advantages of uniformity are that it places disabled children's participation higher on the agenda and it gives social workers and other professionals a base from which to start, thus building up their experience and confidence of involving disabled children, often for the first time. However, one method will not meet the requirements of all children and young people or facilitate gathering their views on a variety of topics. There is still a need for methods to be made age and ability appropriate and accessible for children with, for example, visual impairments, communication impairments and learning difficulties. It should also be noted that it is not as simple as trying to create a method which is at the most basic level, so as to increase the

accessibility to a larger number of children, as this will stifle the level of involvement that some children can have and may possibly desire. As one social worker stated:

> If we take Gemma who is very able, you know, she would find this beneath her, you'd have to do it on a much more sophisticated level.

During an interview with one young person aged 16, who had been in a stable foster care placement for many years, she reported that she had been receiving through the post every six months the same 'smiley face' ticksheet. She could not see the relevance of asking the same questions each time such as 'Have you been to the dentist?' and although she thought it might be important for some children and young people to give their views, was exasperated as to why her social worker just did not talk to her!

Social workers, managers and parents alike indicated that they felt that for some disabled children the nature of their impairment required a completely different approach to facilitate their involvement. They felt it would be inappropriate and disrespectful to try to involve a child with a severe cognitive impairment within the review process which they felt would be not comprehensible to a child. Yet in one area, social workers reported that they witness this happening:

> What I've had experience of and my colleagues in the team have had the same sort of experiences as well.. you feel at school they'll wheel this young person in a wheelchair and say 'Oh this is your review, this is what we've been talking about', they haven't a clue where they are, what they are doing, what all these people are here for. Like the review has got to have some meaning for the young person.
> (Social Worker)

However, a number of parents from the same area reported that their severely disabled child receives through the post 'child-friendly' review forms from social services:

> They do send a form out for Amy to fill in but I told them she can't write so how, you know, it's very difficult..they still send them out every six months and I just don't bother filling them in. I think I did the first one and I thought well this is ridiculous, you know, because we're not filling it in how it's supposed to be filled in.
> (Parent)

It appeared that the participation of disabled children within individual decision-making was heavily reliant on the individual practice of social workers. Involvement is then dependent on an individual's positive attitude towards participation, understanding of participation theory and practice, commitment, time available to develop a relationship with the child as well as to consult, training, skills, experience, creativity to adopt and adapt involvement methods, access to resources and a variety of communication methods, a close relationship with the child in order to understand their communication needs and quite simply knowing a child's preferred communication method. At the most basic level, many social workers reported that

they did not know how children on their case-load communicated. When asked about communication methods, one social services manager stated:

> We also need to identify, and this is going to be the plan, about what does the child use in school, because astonishingly, what I've discovered when I was auditing some case files in another team, is that quite often you don't even look at that. I was astonished, you know, that there was no evidence that the social worker knew what communication method was used in the school for this child.

The case-study selected later in the study, the pilot review project (Area E) illustrated that when appropriate tools are developed, social workers are given the training and confidence to use the tools and a senior manager takes a lead on developing and monitoring practice, participation can be achieved. All interviewees reported that the pilot was a success. The pilot adapted the 'adult' meeting process to be child-centred, while still meeting the requirements of the review process for the authority and the parents/carers. One social worker involved in the pilot stated:

> This particular review process no doubt was helpful and much more informative for James, it gave him a clear understanding of why we meet to talk about [name of respite centre] and it gave him a very good opportunity to contribute to that meeting. So I think it was very successful… and absolutely something I will continue to do next year.

The recorded card was a success amongst children, parent/carers and social workers. These cards allowed social workers to record a brief message which is automatically played back each time the card is opened. Social workers recorded a direct message to each child, typically saying 'Hello, X. On Tuesday, we would like to meet with you and talk about the time you spend at X. I hope you can make it'. The card established at the outset that the child was important and that their views were going to be listened to:

> What was particularly successful I have no doubt because she spoke about it, in fact she has spoken about it a couple of times since was the card, the verbal letter, she liked that.
> (Practitioner)

Within the pilot, the authority had built in mechanisms to obtain feedback from the social workers and parents involved and thus the pilot highlighted a number of areas that needed attention particularly concerning children's interpretation of the photographs shown to them. The authority will be addressing these before they roll out the programme:

> A lot of the children .. don't have an ability to generalise very much.. so it has got to be relevant, it's got to be real. So if you want to talk about the food that you have in this residential place, you or I would recognise food on a plate. Now I'm not saying that the children don't know it's food but if the unit always uses bright yellow plates and you give them food like lamb

chops on a white plate that you've cut out of a magazine. Well that's not to do with there at the respite, that's food on a plate so it's got to connect. (Manager)

He said yes to liking other people, he was able to tell us that he found some of the other young people too noisy… The soft play area he seemed to get confused about whether that was the school soft area or at X [respite home]. He was unclear and when we talked about going out in the minibus, he gave me a story about a Chinese restaurant and Chinese food, well that didn't happen at X [respite home]. That was at school. (Practitioner)

Unfortunately, time constraints have not allowed the research to follow the progress and further developments within this area.

6.7 Key features facilitating or acting as a barrier to participation

6.7.1 Clarity and shared understanding of aims and objectives

Across the case-studies, interviewees highlighted the importance of shared clarity and understanding of the aims and objectives of participation amongst all partners in the process. This included other staff members directly or indirectly affected, parents and children and young people. There also appeared to be a need to share the 'successes and failures' both in terms of the processes and outcomes, so that lessons can be learnt and a greater understanding of disabled children's participation developed.

The service development case-studies all had written aims and objectives. However, the research showed that these were not always understood by all concerned and objectives were not always met. The participation activity day (Area A) devised aims and objectives within a multi-agency working party, and distributed them amongst a wide group planning the event. Despite this, many of the objectives were not achieved, particularly those pertaining to involving disabled children and young people in expressing their views about services and that the event should be the start of a series of events focusing on participation. A combination of factors appears to have contributed to this, including a lack of understanding of participation amongst the planning group and the wider group of people subsequently involved, time taken to organise the logistics of a large event dominating planning, no monitoring and evaluation of the aims and objectives, no long-term strategy and the development worker leaving the post after the event. In addition, the three services who had consulted with disabled children and young people at the event failed to maintain any momentum, and took no further action after the event in response to children's views.

The DVD project (Area D) also did not meet all of their aims and objectives, again the objective pertaining to involving disabled children and young people in expressing

their views about services was not met. All partners in this project shared an understanding of participation and this was carefully monitored by the development worker through regular steering groups meetings. However, the aims and objectives altered as the project developed, and it became apparent that maybe the aims had been a bit too ambitious. The group identified that further work would need to be undertaken in order to achieve the participation of children, for example, those with severe learning difficulties and those with communication needs, in expressing their views.

This case-study provided an illustration of the difficulties that can arise when creative methods are adopted and the processes and predicted results have to be flexible to allow for creative development. Such an open-ended project can make it difficult to explain to those indirectly involved what will be happening. This caused some tension with the wider group of people involved who could not fully grasp the concept, the potential benefits and the reasoning behind the project. Negativity was also expressed by some staff who thought that the project was funded through core funding at a time when cuts were being made. Despite a huge effort from the development worker to share information about the project, including that funding was not from central budgets, it appeared that this was not passed on to all staff.

Within individual decision-making, aims and objectives may seem less important, but as already illustrated, without understanding the reasoning behind participation and clarity about what the objective of participation is for each individual child, there can be confusion. A number of authorities had policy and procedure documents which stated that children should be involved in decision-making, however, these in themselves did not change practice.

It should be noted that there were no examples of young people devising aims and objectives themselves, this was led entirely by adults.

6.7.2 Fragility of disabled children's participation

The fragility and fragmented nature of participation activity was evident throughout this study. Staffing issues contributed to this in a significant way with much practice resting on a few key, dedicated professionals and in their absence work ceased or was frozen. Workers were seconded to undertake participation work and then returned to their original role and recruitment to participation-type posts took a number of attempts. In a number of areas, staff with responsibility for disabled children's participation within service development were part-time and their role covered a much wider remit than just participation, thus other activities took precedence over disabled children's participation.

It appeared that general staff turnover also affected participation activity. For example, one case study authority had invested in authority wide training in

participation methods for social workers and had purchased participation toolkits, using Quality Protects funding. However, it was reported that a significant number of those who had undertaken the training were no longer in post and the resources were 'gathering dust'.

There were also practical barriers that impeded participation and contributed to its fragile nature. For example, the youth forum within Area C had to be disbanded for a period of months because their meeting venue was allocated for other purposes by the authority, and there was difficulty in finding another accessible place to meet. This resulted in a loss of momentum and interest by a number of children.

6.7.3 Embedding practice

Developing a culture of, and good practice in children's participation was a fundamental aim of Quality Protects. It was a QP priority area for action and was a specific objective (Objective 8) of the programme. However, the difficulties of moving from the ad hoc nature of participation to embedded practice should not be underestimated. As one manager stated:

> You need to create a different culture where it will be an expectation. Because I think we have a lot of staff who feel, as many parents do, I did have a conversation with one parent who said her child could not communicate, and that's the barriers you've got to work against. You've got to change the culture and attitudes and values around how valuable it is… Communication is the key to independence.

This manager had initiated that all induction courses within the authority contain an element highlighting the importance of communication, so that with new staff *you are starting that culture as soon as someone steps forth, you are creating an expectation'*.

Within another authority, the service manager stated that in order to embed participation each disabled child would have a communication plan. When questioned how this was to be implemented and monitored, she replied:

> Well, I mean we do have a system of case file audits, although we are struggling to implement it. I suppose what I'd probably suggest is that we monitor it through supervision, because all social workers, all OTs have supervisions and within [name of residential unit], all key workers have supervision, and also through the managers. You know, we meet monthly as a group of managers so we can have that as a kind of standing item which is how far have we got with every child..

However, she went on to illustrate how difficult this is in reality:

> I've been trying for, well since I came into post 18 months, I've been trying to get [residential unit] to do some work around participation and communicating with children and it just hasn't budged.. because I haven't

been able to really get in there and influence and getting people on board, although I know that there are people committed to it.

This manager has since left and there is little evidence to suggest that the work has been taken forward.

Area B had been selected on the basis that it had a specific strategy directed at the involvement of disabled children, however, respondents were not able to provide any examples of how this was affecting practice. It appeared that the pilot project being undertaken to involve disabled children and young people within their reviews of short break care worked in isolation of any activities that might have been associated with the strategy.

Other factors impacting on practice becoming embedded appeared to be staffing issues, the rapidly changing environment where priorities and demands kept changing, the length of time that participation can take and the fact that the outcomes of this work may not be identifiable in the short-term.

Another important factor to highlight is the fact that the advisory group (Area F) was attempting to link and embed disabled children's participation into the wider elements of mainstream participation with non-disabled children. Time has not allowed this research to examine how this develops and whether this is a successful way to entrench disabled children within the growing wider agenda. For example, it would have been interesting to see whether the specific needs of disabled children become subsumed and how children with, for example, communication difficulties can be successfully included.

6.7.4 Partnership working

Within the survey findings a high level of partnership working between different agencies was reported. Eighty per cent of service development initiatives were working with partners. The case studies reported here have indicated that partnership working can bring together skills, resources and experience. Case study areas have benefited from partners with expertise in event planning, multimedia and the creative arts and professional specialists:

> One of the benefits was about getting all the voluntary organisations and statutory organisations around a table and getting to know each other basically in a way that was much more geared towards actually doing action together rather than a talking shop. We have loads of inter-agency meetings where everybody goes.. whereas in these meetings because people said 'Right I can do this and I can bring this' people got a real understanding of what each other did as organisations and it also brought us closer together.
> (Practitioner)

However, the case studies also indicate that there needs to be careful management of this through regular meetings, email updates, sharing of information, and a shared understanding of language, ways of working, responsibilities and the aims and objectives of the participation activity. There also needs to be a sense of shared ownership. To illustrate, one project suffered when designated representatives from other agencies failed to attend meetings, or left their posts and replacements were not forthcoming. Responsibility and interest fell to that one representative rather than it being on the agenda of the organisation as a whole.

Within individual decision-making there was little evidence of partnership working occurring, yet many social workers and parent/carers interviewed spoke of the need for working with those who were expert in communication methods and saw the benefits of working more closely with schools and education. Social workers reported the difficulties they faced with not seeing a child regularly enough to develop a close relationship and understanding of their communication method, and identified that schools were best placed to assist with facilitating participation. Social workers and parents/carers were often not aware of techniques and systems being used within schools or skilled in using the child's communication method. There was a reported need for more information sharing and greater partnerships between schools, education, parents/carers, social workers and the wider network of professionals working with disabled children, around communication methods:

> What we should be more proactive in doing is asking, getting the schools on board to get that info for us. Because you've got a support assistant or a teacher who works very closely with a child who knows their communication method, they are the ideal people to get their views on what's it like at respite care, what's it like at home, plus they are more independent than us.
> (Practitioner)

> Going into school, where the school has the child for however many hours per day and gets to know that child very, very well and obviously begins to understand their communication system. I often feel I would like to have more time to spend within a school situation learning from the people with that child, that would be really, really helpful.
> (Practitioner)

One parent when asked if schools could play a bigger part in accessing her child's views replied:

> Well, I'd have thought they're much better placed than social services.. you might say that, what is the most important thing that the school can give a child like Rebecca? I would say the most important thing in her however many years that she is going to be at school, is finding some way in which she can communicate.

However, a number of social workers reported that partnership working was still difficult with some professional boundaries still in place, and varying degrees of

willingness and ability to work in partnership. One social worker described a school's reaction when trying to engage the school in the reviewing process:

> This is social services, this is about respite, it's nothing to do with us, whereas our view is it is very holistic, it is about the whole care of the child in different situations. If you're starting at that difference it is quite difficult to get commitment from people.
> (Social Worker)

However a manager stated:

> We have schools who are saying 'we are able to provide some of the technology or if a child is using something that nobody knows very much about, we'll train'.. there are lots of opportunities for joint working.. I mean not all schools I have to say.

Other social workers identified that there needed to be improved collaboration with residential units, particularly in terms of communication methods. They reported that there needed to be a holistic approach to meeting a child's communication need which encompasses school, home or residential care if the child is looked after. As one social worker reported:

> Quite often, they'll come home from school with a communication system and you'll get staff in the home saying 'Oh well, there's no point doing this cos this child, you know isn't at a level of understanding to be able to learn it' and so you've got a barrier again, people's expectations of what the child is capable of, cos a lot of residential staff who have been there years and it's like 'oh no, we've tried that before'.

6.7.5 Training and support for staff, children and young people

The survey findings and case studies have both identified that support for staff and young people appears patchy and there is a reported need across the board for skills development and training. The case-studies illustrated that training is necessary for not only those young people and workers directly involved in participation activities but on a wider scale so that there is a better general understanding of, for example, children's rights, empowerment, the theory, terminology and practice of participation, interpretation of children's views and increased awareness of resource implications. More training in IT and creative methods, for example, digital photography, was also mentioned, so that social workers feel more confident in adapting and developing tools. Within any training there needs to be specific attention paid to disabled children and young people, and particularly those with communication impairments. A need for more training in communication methods was a frequent request:

> It's education, it's getting people to understand that it does actually make a difference. Because if someone can't see the sense of it or what it's going to change, they're not motivated to do it.
> (Manager)

A large number of social workers expressed that the training should really be about increasing their confidence in undertaking this kind of work. As one manager stated:

> I reckon seventy per cent is confidence, maybe 90 per cent is confidence but the confidence only comes from having some tools and understanding, get the two things together and you're away.

Typical comments from social workers were:

> More training and support for social workers so they feel more confident about doing it, I suppose it is about demystifying it and not making it scary for them so they feel comfortable about doing it.

> I think when you first start it, you think that you've got to get it right all the time, that whatever you do has got to get some results.

> It's that fear of where do you get the time to do it, and maybe we need to start off, probably it's the wrong thing to say, but my initial thought would be to do it with children that you knew would be able to handle it and then, I guess that would be the right way to do it because you build up your own confidence as well and then move on to less able children.

However, the case studies have also illustrated that one-off training events are not enough, they need to be ongoing and available to new members of staff. As already described, one authority had undertaken authority wide training of social workers in participation methods, however, it was reported that the majority of staff who had undertaken this had left their posts. Alongside the training the authority had purchased participation toolkits to facilitate involvement, respondents stated that these are no longer being used because of a lack of time, skill and confidence. However, one of the case-study authorities had placed participation and communication with disabled children and young people on their induction courses for all new members of staff.

As one social worker explained:

> It would be helpful to have refreshers and just to check out and keep up-to-date with what the current communication systems that these young people are using, and technical things like how to use scale photographs in the computer.

Support for young people also appeared patchy, although there appeared to be some attention given to developing children and young people's skills and providing support to aid their involvement within service development. For example, the children and young people's forum (Area C) set aside time during each meeting to allow the young people an opportunity to make any other comments they wanted to. The project worker stated that this can relate to, for example, something from the meeting or a general comment about what they are doing later in the week. This helped the members of the group develop confidence and skills in speaking up for themselves. On occasions the forum go on fun activities, such as to a pantomime or

a restaurant. This is a reward for their hard work but is also seen as important in terms of teambuilding, development of confidence and life skills.

Within the DVD project (Area D), it was recognised that time and effort needed to be spent in providing information to the young people involved and explaining to what would be happening in a way that was understandable. The project worker reported that:

> I am not going to go in until a couple of weeks before because they won't remember what it is about, and I'm going to speak to two or three young people at a time with a carer who knows about the DVD project as well and who can explain to the young people in a way they would hopefully understand. And by talking to parents, parents will hopefully also feed information to the young people as well. So it's going to be done gradually and drip feed the idea all the time.

6.7.6 Resources

Within the case-study areas, the need for more resources was identified constantly. A lack of time was reported across the board by social services staff as the largest barrier they face in attempting to involve disabled children, particularly in relation to decision-making about their own care, which invariably falls to individual social workers. It is reported frequently within the literature that successful participation takes time and often involves building up a relationship with the child. Some workers reported that there also needs to be recognition that additional time is required when working with some disabled children, for example, if a child uses a non-verbal means of communication. Repeat visits may be required for some children who may be ill, unsettled or tired on the day or whose concentration levels are limited. Preparation time may also be greater if social workers are required to adapt materials into symbols or alternative communication systems, undertake observation work with a child, or identify and work in partnership with other professionals who are familiar with a child's communication system. Increased time demands of recording systems in social services could militate against social workers having time to spend with children. Social workers stated:

> I think with all services in the department, a large part of our job is now paper or computer so we're spending less and less time with children and families because of the bureaucratic system that we work with.

> For the children and young people that we work with just spending some time with that person is where you get true communication.

Social workers also reported that they needed access to resources such as toolkits, communication methods and packages, IT and digital equipment, such as cameras, to aid participation:

> I think what we need is resources to know where to get certain tools if we
> need them… It's very much working together and a network of
> information.
> (Manager)

The following quote typified the response given by the vast majority of social workers:
> If you are to do it properly you've got to be given the resources to do it..
> you've got to have the tools and the equipment but you've also got to have
> the recognition that you need time, it will take extra time to do this and that
> you can't have one system to fix all children, you have to realise that you
> have to be creative in the way you're going to engage that young person
> and get their true views.
> (Social worker)

However, one manager felt that the initial investment of time and resources would
decrease as practice developed:
> I would say if you said each review has probably got an additional 3 to 4
> hours work attached to it, I think it would be fair to say that. However, I
> would also say it'll get easier because the next meeting you'll get some
> better results from it.

And a social worker identified that if there was an initial investment in development,
then the time required for individual social workers would be decreased:
> In some respects you need to have the systems in place .. like the
> photographs, once you had all the photographs you could then draw up
> the form, the background work needs to be done so that you don't have to
> reinvent the wheel every single time.

Within one authority, resources had been put into funding a specialist Disabled
Children's Rights Officer, however, this post was part-time and therefore priority was
given to disabled young people during transition. The Independent Review Team
reported that this work was 'phenomenal':
> She's taken the time to actually do the consultation over a couple of visits,
> she runs the first one identifying how they communicate, how they would
> indicate yes, no, dislike, pleasure, happiness, then they can actually go
> back with some specific questions.. but I mean that took probably just over
> two hours for that young person really and in an ideal world, she'd be able
> to go back to follow his transition through and be present six months later
> for the next review. She actually comes to the review to advocate on his
> behalf, so it's taken four hours, including travelling time to do one child.

6.8   Feedback to children, young people and parent/carers

The survey results had indicated that an area requiring further development is the
provision of feedback to children and young people involved in participation activity.
Within the case-study areas, a similar picture emerged, where children, whatever the
nature of their participation, did not receive any feedback after the event. Within the

case-study area which had developed specific cartoon style booklets to involve disabled children within their reviews (Area A), specific booklets had also been designed to provide written feedback to the children after the review and there were policies that feedback should be given. However, not enough emphasis was placed on this and it appears that this did not become an integral part of the process.

It also appeared that, within service development better mechanisms and more importance needs to be placed on providing appropriate feedback and to creating a continued dialogue with children and young people involved in longer term projects. As one young person stressed: *'it's a bit like we get involved for a week or a month but then it peters out until the next time they want us'.*

There were a couple of examples within the case-studies where time and effort had been placed on feeding back to children and young people. The DVD project (Area D) organised a major screening event at a local theatre, where everybody could celebrate what had been achieved. Attention was paid specifically to making this a special event for the young people. In addition, within the pilot review project (Area E) the booklet that the young people completed was left with the family after the review. Two parents explained that this was very positive. One parent when asked if her daughter had a copy of her review said: *'She did and she coloured it all in.. once or twice more she got it out and we would go through it again'.*

This young lady had not been asked for her opinions before and from her reaction, it would appear that it is a process she enjoyed. The feedback booklet has allowed her family to continue to develop her skills in giving her views and she will hopefully be better prepared to be involved in her next review.

6.9   Outcomes from participation

The measuring and documentation of the outcomes of participation activity is still an underdeveloped area, and even though some of the case-studies were monitored for nearly two years there has been limited evidence of measurable outcomes, for example changes to services. None of the case-study areas themselves had in place systematic procedures for the recording, monitoring or evaluation of the activities undertaking. Although one had plans to and hoped to include disabled children and young people in developing this work.

However, all professionals, parents and children interviewed, regardless of the participation activity, reported that participating had been a positive experience for the children and young people. For some young people, enjoyment was reported as coming through:
- feeling included in what was happening around them;
- being valued;

- being asked, often for the first time, for their views and opinions;
- being empowered;
- being listened to;
- gaining confidence;
- having lots of attention;
- having fun;
- undertaking activities not experienced before;
- learning new skills;
- meeting new friends;
- improved social life.

Some young people from the forum (Area C) were using their forum work to contribute towards their Millennium volunteering. Five of them received awards and a certificate from the Secretary of State for 100 hours of volunteering and they celebrated by going out to dinner.

For those children and young people who had taken part in the larger scale events (Areas A and D), they reported their enjoyment at being able to try new activities, having fun and having accessible activities available. Parents attending the participation activity day (Area A) enthused that it enabled whole families to enjoy leisure time together. One parent when asked, 'what did you enjoy about the day?' wrote:

> Atmosphere where child's disability is not an issue, another parent who took her disabled child and non-disabled child to the event wrote, 'My daughter was able to play with all the games and the smile on her face said everything. It was great that both my children who came enjoyed the activities.

All parents, children and professionals who provided feedback on the event wanted this to be repeated yearly. The event had provided information to families and a number reported finding out about services unknown to them.

The DVD (Area D) has potential benefits beyond just those gained by the young people taking part in the associated workshops. The DVD can provide other young people with learning difficulties and communication impairments the opportunity to learn and practise the skills of decision-making and experiencing the consequences of choosing. The service manager also highlighted a wider benefit in terms of illustrating to a wider audience the potential of participation:

> It's about creating the awareness amongst staff and carers that it is possible. I think sometimes whilst we can say look, you know, we have do to this, there are national standards out there, the legislation.. that supports it but unless people actually experience it and can see that it happened….

Indications of positive outcomes from participation at the individual level were also cited. In one case, a young person being involved in their review of respite for the first time influenced the outcome of the review quite significantly. Her mother reported:

> I said to them, 'It would be nice if Katie had another night' and the look on her face was, oh, now hang on a minute, you know, so of course they said to her, 'Would you like another night to come and stay?' and it was a definite no but it's all right what I'm having, she didn't want to lose the nights that she'd got, but she didn't not want to go but she certainly didn't want to go any more..

Within another case study area, a social worker explained how children's views had been listened to and attempts made to change service provision:

> I think I have had in a couple of places as well when children have given their views, 'I like doing this' and we offer parents the opportunity for them to do that and if they can't do it then we'll look at trying to fund a support worker to take them and fund them with that activity.

Social workers and parents alike within Area E reported that it had been reassuring to find out from the young people that they had found respite a generally positive experience. This method had facilitated the young people to share their likes and dislikes about being in the respite centre, and often this was the first time that the child had directly shared their views in this way. Parents had known that their child was generally happy whilst there because they returned home smiling, laughing or contented, however, this consultation had provided them with a better understanding of what their child did there and what they enjoyed and did not enjoy. As one parent said: '*I got more feedback than I ever thought I would about Laura being at X [respite unit]'.*

Through participating some young people were able to demonstrate their skills and in some instances had surprised those around them who had underestimated their abilities. As previously reported, through successful participation some people's attitudes had changed. Outcomes could also be detected such as a wish to continue to involve disabled children, create more successful participation and create more opportunities for a larger number of children or a wider range of children. A number of professional felt they had increased their skills and wanted to maintain and develop them further and parents/carers had become more knowledgeable that participation could and should be happening. Without long term monitoring it is impossible to know whether this momentum will be maintained.

A number of social workers also highlighted the importance of involving and listening to disabled children in terms of increasing disabled children's protection and safety:

> With more outreach going on, children are being taken to youth clubs supported by a carer. Now that's great but it means that those youngsters are coming into contact with more and more people and if we don't have

some sort of mechanism of, first making sure that they know that they can say 'I don't like this person, I don't feel safe with this person' in their own way and also the people that are coming in need to know that there is a means of enabling that youngster to communicate.
(Service Manager)

Also by listening to them, you're also protecting them as well because obviously in my role as a social worker with child protection you want to give them a voice. Because you know through research that they are at the highest risk, our young people, because of the number of different personal carers they have, the different settings they're coming into.. and they don't have communication as well. I think for a protective factor for those young people .. you really need to push and give them a voice really.
(Social worker)

6.10 Children and young people's views

Although gathering the views of disabled children and young people with experience of participation had been a central aim of this study, the small numbers actually participating within decision-making processes impinged upon the amount of data that could be collected. However, all children who had been involved in any level of participation within the case-study areas were invited to take part, in total twenty-one disabled children and young people were interviewed as part of this research.

The key messages that came from them include:
- they often had limited contact or rapport with social workers;
- they had few opportunities to express their views about services;
- they often had a limited understanding of what they had been involved in, either they had received no explanation or information had not been given to them in accessible formats;
- they enjoy taking part, being listened to and being able to make choices;
- they particularly enjoyed methods which were creative and fun;
- they enjoyed the socializing associated with being part of a youth forum;
- they have ideas about how practice could be improved;
- they would like more opportunities to undertake participation, and be kept informed of what happens.

For example, within Area D, the young people with severe learning difficulties expressed their enjoyment at the activities they had participated, and were proud of their artwork created within the workshops. Where possible, interviews explored issues such as whether they had felt listened to and whether they had been given choices. All young people responded positively to this and some showed the choices they had made in the design of their artwork.

Within other areas, many young people had suggestions for how practice could be improved. For example, with Area A, young people who had attended the large scale participation event had suggestions of other activities that could be available.

For young people who had not been involved in decision-making processes, it was difficult for them to comment because of their limited experience and the abstract nature of participation. In addition, all of these young people did not have regular contact with their social workers. However, they reported that they liked expressing their views, being listened to and would enjoy the attention that participation would bring. Similarly, their limited experience made it difficult for them to conceptualise the ways in which they could be involved or indeed the areas of decision-making open to them. However, their enthusiasm at being interviewed for this study and the methods used during the interview, indicate that participation would be embraced wholeheartedly by these young people.

Chapter 7: Discussion of Research Findings and Policy and Practice Implications

7.1   Introduction

This chapter discusses the research findings and examines the implications they have for policy and practice. Firstly, a brief overview of the strengths and limitations of the research is presented. This is followed by a discussion of the key issues of:

*   how participation is understood and defined in relation to disabled children and young people;
*   the picture of disabled children and young people's participation;
*   access to communication methods to facilitate participation;
*   the role of social workers and participation/development workers;
*   partnership working;
*   support, training and resources;
*   embedding practice;
*   outcomes of disabled children and young people's participation.

The chapter concludes by highlighting areas where further research is required in order to expand the evidence base to inform the development of disabled children and young people's participation.

7.2   Strengths and limitations of the research

All research needs to be seen in light of the strengths and limitations of its findings. This research undertook a multi-method approach in order to meet its objectives. The survey undertaken in Stage Two provided for the first time details on disabled children and young people's participation within social services across England. The survey ultimately depended on the return of the screening letter and on the Assistant Director of Children and Families having knowledge of disabled children's involvement. A high response rate of 86 per cent was achieved for the screening letter. In addition, the response rate to the detailed questionnaire was also high for a postal survey at 70 per cent. However, this cannot been seen as an exhaustive picture of participation, it can only provide a snapshot of activity. The picture of disabled children's participation is complicated and seemingly information is not always collated locally, which will have impinged on our results. Nevertheless, the information collected provides a useful insight into participation activity within social services.

It must be also be seen that the case-studies undertaken during Stage Three may not necessarily reflect the picture across the country. The six authorities were selected because they met defined criteria and appeared from the information gathered at the onset to be slightly more advanced in their work than others. Across the case-studies there was considerable consistency in respondents' views and experiences, and uniformity in the difficulties they faced and in the solutions they suggested. These were consistent with those reported in the survey and thus possibly indicate the case-studies were not isolated examples.

The sample of parents and children and young people who took part in this research was small. As far as can be ascertained form the interviews with staff and parents, this was because the numbers of children and young people, who were participating in decisions were small. Nevertheless, findings must be viewed in the context of these small numbers.

A key limitation of the research is that although one of the objectives was to explore outcomes of participation we have not been able to follow through many of the case-studies to the point at which outcomes, such as changes in services have happened. This was because of the delays in the case study areas and the longer than expected timetables for the initiatives.

The findings from this study, to a large extent, reflect the existing literature, however, this research has provided a much needed focus on disabled children and young people's participation and highlights how practice in this area can be further developed.

7.3 The meaning of participation for disabled children and young people

From the research findings it appears that although most professionals and parents/carers were committed to participation, saw the importance of it and the potential benefits it might have, respondents reported on a minority who were resistant. In addition, although committed, many professionals and parents questioned how some disabled children and young people could be involved successfully, if for example, they had communication impairments or learning difficulties.

As mentioned in the previous chapter, much discussion and practice literature so far has centred on participation with non-disabled children with little examination of what participation means for disabled children in particular those with severe communication impairments or learning difficulties. There are also few examples from practice on which to draw in order to create a better understanding of how this can be achieved. What appears to be needed is a better understanding and

awareness that participation for disabled children and young people should be at the level at which it is appropriate for them and with which they are comfortable with.

It is worth reflecting on the definitions of participation discussed in Chapter One. Boyden and Ennew (1997) stated that participation can mean taking part, being present, being involved or being consulted. Alternatively it can denote a transfer of power so that participants' views have influence on decisions. Participation is thus a continuum along which the type of participation activity should be determined according to the circumstances and the participating children and young people (Kirby *et al.*, 2003a). Alderson and Montgomery (1996) defined levels at which children can participate: being informed, expressing a view, influencing the decision-making process and being the main decider. These defined levels are useful in understanding the meaning of participation for disabled children. For example, for disabled children and young people with a cognitive impairment their participation may be at a level of choosing between two different options, as illustrated in the DVD produced by Area D where children were given simple choices such as what do they want for breakfast. This must be seen as a valid means of participation and afforded equal status and priority with other levels and methods of participation. For some children choosing between two options may be the only level at which they are able to participate, but for others this might be the starting point from which to build. In order to facilitate this, children and young people need to be given the opportunities to develop their skills, gain experience and be given information to support their participation.

The choices that children and young people make could be used, for example, within a review to build up a picture of a child's likes and dislikes when at the respite centre, such as undertaken by case-study Area E. This enables some elements of a child's view to be heard, and if this individual information from each child was to be collated across an area, it could be used to inform service development.

Disabled children and young people are not a homogenous group, and the need for workers to take an individualised approach became evident within the research. Clearly there is a need for a more focused examination of what participation can mean for disabled children which encompasses individualism, and the creation of a wider definition of participation than that which appears to be currently seen. More evidence needs to be gathered on the outcomes of this wider definition in order to create a greater awareness of what can be achieved. The few examples of practice illustrated within this study have highlighted how social workers, when trained and properly equipped and supported, have gathered children's views on their experience of respite care and have successfully used this within the review process.

A lack of choice in service provision was presented as a possible reason for not involving children and young people. Clearly if there are no choices available to children and young people then their participation is tokenistic. However, the issue of

choice needs to be examined. In everyday life we often have limited choices about issues such as whether we go to work, yet being listened to and having some say in decisions within the broader scenario can make a difference to situations where there are limited choices. In the same way, disabled children and young people may have limited choice about whether they attend respite provision, as it may be in their overall interests to give their parents/carers a break. In addition alternatives to a certain respite centre may be limited. However, this should not be used to preclude them from expressing a view which may make their experience, for example, more bearable or enjoyable. It should also be noted that as adults we possibly underestimate a child's understanding and the majority are probably very aware of the reasons why they attend a respite centre and that this is not really a choice. Nevertheless, enabling children to have choices within respite care, such as what they eat, which other children they stay with, can enhance their experiences and give them some sense of control.

The case-studies also indicated that it is important that everyone involved understands the aims and objectives of participation, both in a general sense, but also in relation to the particular abilities and situation of each child. This appeared vital in order for participation to be successful and have any impact on decisions being made. The importance of this has also been highlighted within the published literature (see for example, Sinclair and Franklin, 2000 and Kirby and Bryson, 2002)

7.4   The picture of participation for disabled children and young people

This research has illustrated that participation at any level is only a reality for a small number of disabled children and young people, and that the majority of those who are participating are from the older age range. This supports early findings (for example, Council for Disabled Children, 2000; Robbins, 2001; McNeish and Newman, 2002; Sinclair, 2004). The survey results highlighted that nearly a third of service development initiatives only involved up to ten young people, and within decisions regarding their own care, just over a third of survey respondents indicated that this involved twenty or less disabled children and young people. In addition, all case-study areas had been selected on the basis of their plans to include the four groups of 'hard to reach' disabled children and young people, however, there was only limited evidence of this occurring.

From the data collected within this study, it appears that unless explicit attention is placed on specific groups of young people, for example, those with communication difficulties, then the small numbers of disabled children and young people participating will continue to be the easiest to reach, most able to communicate and the most articulate and confident. Within service development, questions need to be asked as to whether such a narrow sample of young people can adequately represent the views of other disabled children and young people, and if so, are they

being adequately supported in their role as representatives. Equally within decision-making regarding their own care, few disabled children and young people appear to be involved, yet they all have the right to participate within these decisions. Sinclair (2004) argues that practitioners have to ask how the processes and mechanisms that they use can influence who gets involved and who is excluded. This study has shown that it is not only the processes and mechanisms being adopted but a lack of training, knowledge, confidence and resources combined with the low priority afforded participation, which influences who and how many disabled children and young people are participating in decision-making.

Across service development and involvement in individual decision-making, the case studies have illustrated that methods of involvement need to be multiple, flexible and tailored to the individual needs of the child. This supports much of the current guidance on good practice (see for example, Ward, 1997; Marchant *et al.*, 1999a; Lightfoot and Sloper 2002a, 2003; Cavet and Sloper, 2004). There were, however, few examples of disabled children and young people being given a choice about their participation method or how their views were to be presented. However, case study area E examined their reviewing structure and system of working and adapted it to be more child-centred. Although care should be taken with interpretation, the limited findings appeared to indicate that this was a success, with all parties enjoying the process, yet it still fulfilled the statutory functions and purpose of a review.

7.5   Access to communication methods

Before any child can participate they need to have access to mechanisms to enable them to express their views. This research has highlighted that there is a fundamental need for this to be given a higher priority as indeed did the early research of Stone (2001), Morris (1998a) and Rabiee *et al.* (2001). Many social workers reported that they were unsure of the communication methods of young people on their case-loads and managers reported that communication methods were not recorded on case-files. Even when the communication method was known, some social workers reported that they did not understand or have training in this method, or the time to develop a relationship with the child in which they could start to understand their communication. At the most basic level, children should have access to professionals who understand their communication and be given some opportunity to express their views. Not only is it a child's right but it also has implications in terms of their protection and care, particularly if they are looked after by an authority. Some case-study authorities were developing consultation tools, however, this will be in vain if attention is not placed on how a child communicates.

7.6 The role of social workers and participation/development workers

The data collected from professionals illustrated the practical difficulties that they faced in trying to facilitate the involvement of disabled children and young people. The spectrum of disability, usually contained within a large case-load or part of a wide remit for participation workers, appeared to make it difficult for workers to comprehend and become proficient in, for example, multiple methods of communication. Workers reported that they did not have the time and skills required to develop close relationships where they might begin to understand a child's communication method, abilities or specific requirements. Training and skills development is required in this area, but it might also be argued that it would be very difficult for individuals to become expert in all of this wide range of skills. The need for partnership working to bring together professionals with the required skills is one solution. Therefore, a more practical role might be for social workers and other workers to facilitate the involvement of disabled children through engaging with specialists, such as staff within schools and education, who are best placed to know the child's specific requirements. Many social workers within the case-studies would welcome such a move.

Many of the development/participation type roles had a wide remit, yet they were often expected to also have specialist skills, such as engaging with children with autistic spectrum disorders. Those engaging in service development could be expected to have skills in, for example, logistical planning, knowledge and experience of facilitating the involvement of disabled children with complex needs, project management, evaluation and the devising and monitoring of project aims and objectives, fundraising, changing the culture of complex decision-making bodies of local authorities, facilitating and maintaining partnership working, supporting staff, children, young people and parents and negotiating with gatekeepers such as parents who might be reluctant for their child to take part. Many of these workers were part-time and working in relative isolation, they reported a need for more training and support in order to manage such a wide range of tasks. Developing a network of participation workers, such as that organised by the Carnegie Young People's Initiative (see website http://www.carnegieuktrust.org.uk/cypi/home), which focuses specifically on participation of disabled children and young people might provide a useful forum for information, support and skills development.

7.7 Partnership working

A number of the case-study areas involved in service development benefited from partnership working. From their experiences adopting a wide definition of partners appeared to assist partnership working, so that children, young people, parents and the wider community of professionals are seen as partners and are given a clear

understanding of the purposes, objectives, parameters and possible outcomes of participation. This led to a better understanding of participation, and might possibly lead in the longer term to more of a participatory climate.

Case-studies illustrated that working in partnership with other agencies and organisations can bring benefits such as the joining together of expertise, ideas and funding. They also showed that a joint understanding, shared ownership between organisations rather than individual representatives, information and task sharing were vital. As already mentioned, a greater role in participation could be placed within schools and education. This study was unable to draw on examples of this in practice, but it would appear to be an area that would benefit from closer examination.

7.8   Support, training and resources

For many of the disabled children and young people who participated in the case-studies this was their first experience of expressing their views about services. Clearly children and young people need to be supported in undertaking this role and need to develop the skills and confidence required, preferably from an early age. Research has shown that for some disabled children and young people their experiences can be limited due to, for example, lack of social and leisure opportunities and accessible transport (see for example, Beresford, 2000; Morris, 1998a). Two case-studies reported here (Area A and Area D) had provided disabled children and young people with opportunities to try new activities and develop new skills, and this must be seen as important in terms of self-development and having the information and experiences that would enable them to make choices. What is vital is that this is harnessed and continued with opportunities to make choices and be involved in decisions on matters that affect them. The DVD produced within Area D could provide a long term tool for helping children and young people develop skills in making choices. In addition, the creative workshops undertaken within this project focused on the issue of choice. Children and young people were encouraged to express their choice through deciding, for example, their activity, topic area or method of creativity. For some young people with severe disabilities, their choice might have been at a level of choosing music or colour, or deciding when to stop. Staff respondents reported that this gave young people a sense of empowerment through being listened to. Young people themselves reported that they enjoyed making choices and being listened to.

There also appears to be a lack of information geared towards disabled young people which would help to aid their understanding within decision-making processes. The survey findings indicated that two authorities were developing information in terms of providing information on the care system through a CD-Rom on 'Being Looked After' and a leaflet on 'experiences of the care system'. Another authority had produced a video for disabled children on Short Break Residential

Homes within the area, and another one had involved young adults with learning difficulties performing a drama production, in local schools, on direct payments. However, under a third indicated in the survey that information was being shared with disabled children and young people about the authorities' decision-making processes. Such information is required to help a child understand the processes and encourage fuller participation and empowerment.

Preparing disabled children and young people to express their views takes time and clearly needs to be part of any policy and practice guidance. Children need to understand what is happening, what the implications are, what options are available and what will happen afterwards. For some disabled children and young people to grasp this, it will take a considerable investment of time, preparation and a personalised approach, for which there needs to be recognition. Brooks' (2000) framework for involving children in proposed liver transplants provides a useful reminder here of what might be required. The framework highlights the uniqueness of each child and their family, the necessity of keyworkers to co-ordinate information sharing, an open, friendly approach, privacy, sensitivity and an allowance of adequate time. Parents/ carers also need to be adequately prepared and informed so that they can understand the process and provide support to their child.

A lack of training was presented as a major hurdle by the overwhelming majority of staff respondents. The need for training and staff development is a common theme within the published literature and was highlighted as a necessity in a number of publications (for example, Kirby and Bryson, 2002; McNeish and Newman, 2002; Kilgour, 2002; Lightfoot and Sloper, 2003 and Cavet and Sloper, 2004). Training appeared to be important not just for those who directly engage young people in decision-making but also for the wider community of professionals involved in disabled children's lives. This research suggests that there needs to be a greater understanding of participation with specific reference to disabled children and young people, this should include:

- a wider definition of participation to encompass participation of children with more severe disabilities and recognising the importance of mechanisms such as observation and non-verbal means of communication;
- how children's views are part of a process of decision-making and not necessarily the final decision;
- that participation is a continuum and will be determined by the child's capabilities and choice, and even if a child's capabilities are limited their views can still form part of the process;
- that participation will only be successful if a child has full, accessible and appropriate information on the decision-making process and is fully supported throughout the process;
- how our attitudes and values about children and about disabled children affect the participation process;

- how to interpret children's responses and check their understanding and yours;
- how to present children's views to others and how to work successfully using an interpreter such as a parent/carer.

There is also a need for training in communication methods and communicating with children (see also Beresford and Sloper, 1999) and a greater understanding of methods of facilitating participation, such as when and how to use the various tools being developed. Workers also wanted more training in IT and creative methods, for example, digital photography, so that they felt more confident in adapting and developing methods and tools. Some workers might also benefit from a better understanding of and training in monitoring and evaluation methods, as this was an underdeveloped area of work.

The experiences from the case-study areas show that any training needs to be ongoing and cyclical to accommodate staff turnover, staff development, and changing needs such as a new case-load for a social worker.

Lack of funding was also highlighted as a problem, in particular funding to sustain activities. Funding might be granted for immediate activities, but then further funding might have to be sought, which could entail delays and momentum could be lost. The lack of assured longevity of participation activities also appeared to affect long term planning, or the implementation of monitoring or evaluation. More funding would also help to meet the calls for access to more resources and for more time to enable practitioners to develop this area of work.

As reported within the results, workers expressed that they had insufficient time to undertake participation work, particularly given that it often requires an individual approach. Time is required to get to know the child, build up a relationship, possibly get to know a child's communication method, prepare and support the child to take part, prepare materials to facilitate involvement and provide feedback to the child and their family. Clearly training and time to undertake participation work must go hand-in-hand. Although training can help workers to become more skilled in methods of communicating with disabled children, and this may mean that some time is saved, there is little point in providing more training if workers still have insufficient time to their skills into practice.

7.9   Embedding practice

The Quality Protects programme aimed to develop a culture of participation, with good practice embedded and sustained, however this research has shown, that at the time of the survey (summer 2003), 27 out of the 129 (21 per cent) social services departments who responded did not currently, or within the previous 12 months, involve disabled children and young people within decision-making processes, and only 42 of the sample of 71 social services departments who were involving disabled

children, did so within both service development and decision-making regarding their own care. Many authorities are still developing this area of work and are at very early stages of involving disabled children and young people within their decision-making processes. Even the case-studies, selected in part because they appeared to have developed their practice further than others, did not shown signs of embedding practice, and the findings from the case studies suggest that the survey figures on numbers of children participating may be rather over-optimistic.

This research has not been able to shed much light on the successful embedding of disabled children and young people's participation, as the case-studies were not yet able to demonstrate any real success in this area. Instead this research has shown the numerous barriers facing authorities trying to achieve this goal and the fragility of much participation activity. Participation often rested on individuals with dedication or a specific interest, clearly these people can be important motivators. However, without resources, support and management commitment, they alone will not be able to change working practices and the ethos of complex organisations. More attention and expectation needs to be placed on getting the views of disabled children and young people if it is to become a reality for a greater number and wider selection of disabled children and young people. Sinclair (2004) argued that if children's participation is to be successful, then participation has to become an integral part of adult and child relationships – the creation of a listening culture (see also Sinclair and Franklin, 2000; Children and Young People's Unit, 2001; McNeish and Newman, 2002, Kirby *et al.*, 2003a, 2003b and Lightfoot and Sloper, 2003).

There has been a rapid growth in participation guidance and a growth in toolkits developed to facilitate children's participation. However, while welcomed by staff respondents, it appears that this alone is not enough to embed practice. From respondents comments, access to a range of tools is vital, however, access to toolkits needs to be combined with training in how and when to use them and adequate support and time to use them.

None of the case-studies had in place systematic monitoring or evaluation systems and therefore any outcomes of participation work were often not documented including how children's views had fed into decisions. More emphasis needs to be placed on this if we are to learn from experiences and identify the impact participation might have. Workers will need to develop the necessary skills to manage this and encompass both quantity and quality measures of participation. Monitoring would also help to ensure that the few examples of poor or inappropriate practice highlighted within this report would not go unnoticed.

Through undertaking the survey of participation activity, it became apparent that information on participation activity was not always collated locally, and within local areas professionals were not always aware of other participatory activities. The sharing of local knowledge and experience would be useful to facilitate and co-

ordinate activity locally. There is also still a need for the sharing of practice nationally. Perhaps as suggested above, through a network of staff involved in developing disabled children's participation.

7.10 Feedback to young people

This study has shown that often feedback to the children and young people involved is not recognised as the final piece of the jigsaw. Yet it must be seen as a vitally important part of the process if children are to feel their views are valued, and if children are to be supported in developing their skills. The data suggest that often feedback was given to parents/carers or, if given to young people, was verbal. Very little attention was placed on providing disabled children with an accessible permanent record to which they could refer, for instance during the interim period between reviews which might only take place every six months to a year. The young respondents within this study reported on the importance this has to them, and a few parents/carers reported that their child when given a record of their views looked at it repeatedly, some seeing it as a record of achievement.

7.11 Outcomes of disabled children and young people's participation

When participation did take place, it was viewed as a very positive experience by those disabled children, young people, parents and professionals interviewed. There were examples of young people influencing the decisions being made in their reviews and changes to service provision as a direct result of what children had expressed. Within the survey, outcomes were recorded in terms of the alteration to leisure activities, information provision and changes to décor of respite or resource centres.

One reported outcome, although difficult to measure, appeared to be a change in attitude towards participation and a raised awareness of the potential of it.

Other outcomes highlighted by children and parents were the positive effects of children feeling that they were listened to and valued, gaining confidence and learning new skills.

However, in order to develop our knowledge, the gathering and sharing of this kind of data is vital. It appeared from all the data gathered through this study that there are few examples of disabled children and young people influencing directly outcomes in terms of service commissioning, service priorities or service evaluation. It would be interesting to learn from any examples of this occurring across the country.

7.12 Further areas of research

The experience of this research has demonstrated the need for flexible approaches to funding and timetables of research, particularly if the study seeks to focus on outcomes where timescales often depend on a large number of factors and results may not be seen for some considerable time.

Little attention has so far been placed on the evaluation of participation activity, yet there could be much to learn from this. Within this study, many respondents were keen to learn from the other case-study areas and clearly desired avenues to share good practice and prevent them from reinventing the wheel. The impact evaluation of Ask Us! (see page 13) is one of the few published examples on which to draw. This evaluation highlighted how sustained contact, a build up of trust, recognition of mutual benefit, time, young people taking charge of the methods and message and working within the social model of disability led to changes in services and attitude (Badham, 2004).

More evaluation and evidence of this kind, more attention placed on defining and measuring outcomes of participation, coupled with more detailed examination of the financial and time implications of participation would help service development initiatives and those engaging children in decisions about their own care to adequately resource and plan participation more effectively (see also Kirby and Bryson, 2002; Cavet and Sloper, 2004; Sinclair 2004). In addition, there is not yet a body of knowledge developed to illustrate what might be changing for disabled children and young people as a result of participation activity. Clearly this would also assist with creating a greater understanding of the meaning of participation for disabled children and young people, and assist with training activities. It might also help to win over those who are not yet convinced or committed to this way of working.

From the survey and case-study research, there appeared to be a considerable amount of time and money being invested into developing and running youth forums/advisory groups for disabled children and young people. Yet there is little evidence to support good practice both in terms of processes and how these structures effect change and influence service development. Research within this area would help the further development of this participation process and prevent reinvention of the wheel. For example, this study has shown that the youth forum and advisory group had plans to make their groups more representative of the population they are drawn from and become an integral part of decision-making bodies within their local area, but had not yet achieved this. The sharing of practice, particularly focusing on disabled children and young people would be welcomed.

As already mentioned, the parents/carers of children participating have been neglected both in terms of research and in terms of guidance published to facilitate

participation. The data collected within this study show that parents can and do influence whether a child participates, have concerns and information needs that should be addressed, and their views can sometimes conflict with those of their children. None of these issues have yet been examined in any detail and parents/carers' views have rarely been gathered, their experiences of the processes and outcomes of their child's participation are rarely documented. Yet they appear to be integral to the successful participation of children and young people. It might be that their own experiences of participation and being listened to influence their child's participation, and there has yet to be a detailed examination of the interplay of the complexities of conflicting views between parent and child and how the family is supported through this. If children's participation is to become an embedded part of practice then greater attention needs also to be placed on how this affects the child's family.

Research examples of partnership working in participation across social care and other partners are also limited and as already highlighted evidence on partnerships between education, schools and social care is one particular area requiring attention.

So far, most research and participation attention has focused on formal mechanisms such as reviews, yet much could be learnt from a closer examination of informal approaches to participation which may be more appropriate for some disabled children and young people. It might be assumed that the processes and outcomes of these methods could have a role to play within the required formal 'adult' or statutory mechanisms that might not be accessible to some disabled children and young people.

Finally, throughout the research agenda the views of those disabled children and young people who participate will need to be heard, their views have long remained unheard but they have much to offer which can influence policy and practice.

7.13 Conclusion

The results of the research provide some indications of where development of policy and practice on disabled children and young people's participation is needed:
- a broader understanding of the meaning of the term 'participation' for disabled children, with an emphasis on the validity of children participating at whatever level is appropriate for them;
- recognition that disabled children communicate in mediums other than speech, including recognition that observation can be a valid means of ascertaining the views of some disabled children with profound and multiple disability;
- an individualised approach to participation, with attention placed on children's communication methods where appropriate;
- more attention and resources placed on developing the participation of a wider range and number of disabled children and young people;

- more understanding of the resources, time and support required to facilitate successful participation;

- more training, support and skills development for staff, children and young people;

- the development of more partnership working to facilitate participation;

- opportunities for those specifically engaged in disabled children and young people's participation to share information, support and skills development, both locally and nationally;

- more emphasis and expectation placed on feedback to those involved;

- the importance of ensuring that in individual decision-making, children's views are taken into account in developing and reviewing care plans, and that where views cannot be acted upon, it is explained to the child and family why this is so;

- in service development initiatives, ensuring that mechanisms are put in place for children's views to be fed into decision-making and, again, that children are kept aware of what is happening, and the reasons why developments may not be taking place;

- the need for monitoring and evaluation of participation to feed into future development of practice.

APPENDIX A

Consultation Tools

CONSULTATION TOOLS

Taken from: www.doh.gov.uk/integratedchildrenssystem/involving1.htm

I'll Go First: The Planning and Review Toolkit for use with Children with Disabilities. Kirkbride, L. 1999. The Children's Society, London.

Tel: 020 7841 4415.
www.childrenssociety.org.uk
ISBN: 1 899783 13 X. £60.00

This is a set of 16 wipe-clean boards about situations relevant to disabled children and young people. Colour illustrations and simple sentences (with Rebus and Makaton translations) are printed on the boards, e.g. 'these are the important people in my life'. 150 re-usable stickers illustrate activities, objects, people and feelings. You can also write or draw on the boards and add the child's own photographs, and the boards can be photocopied for reviews etc. The toolkit is suitable for children who have good vision and can attribute meaning to the stickers.

Total Respect Training pack – improving participation for children looked after (2000)

CROA
Cambridge House
Cambridge Grove,
London W6 0LE,
Tel No: 0208 748 7413
Email: mail@croal.freeserve.co.uk

This training pack is for front-line staff and elected councillors and is based on materials commissioned from the Children's Rights and Advocacy Organisation (CROA) which were published in August 2000. The training materials cover most aspects of children and young people's lives in care but concentrate on:

- Children and young people's participation in individual care planning;

- Ensuring that children and young people are taken seriously when they make complaints or allegations of abuse or poor practice;

- Children's participation in local policy and service development

Viewpoint

Viewpoint Organisation Ltd,
01422 825 862
e-mail: services@vpt.org.uk

www.viewpoint-organisation.co.uk

A computer programme originally designed to facilitate confidential consultation with Looked After Children. The programme asks questions and the children answer. Viewpoint also produce a version for disabled children which is essentially the same format, the questions can be spoken by the computer and additional switches can be used.

The use of Viewpoint relies on good language skills, even if the spoken version is used.

APPENDIX B

Screening letter to Assistant Directors of children and families

AF/TS/TF

E-mail: af13@york.ac.uk

1 May 2003

Dear Colleague

Re: Department of Health Quality Protects Initiative: Participation of disabled children and young people

We are writing to ask you to take part in a national survey of Social Services, and, if possible, complete the enclosed sheet containing two questions.

This research study is funded under the Department of Health Quality Protects Initiative, and will provide evidence to assist Social Services Departments to involve disabled children and young people in decisions about their own care and wider service planning. Our study will produce practical guidelines to support Social Services Departments in involving disabled children and young people in local service development. As a first stage, the enclosed sheet will enable us to establish where and how disabled children are currently being involved. A project information sheet is enclosed containing further details.

We would be very grateful if you could please return the enclosed sheet in the prepaid envelope by **Wednesday 28 May.** If you have any questions, or would like more information about the research, please do get in touch. Thank you for your assistance.

Yours sincerely

Anita Franklin
Research Fellow
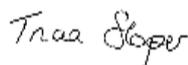
Tricia Sloper
Professor of Children's Healthcare

Enc

APPENDIX C

Questionnaire to Social Services Departments

Department of Health: *Quality Protects Research Initiative*

Participation of Disabled Children and Young People in decision-making within Social Services Departments

Survey of Current and Recent Initiatives in Social Services in England

NAME OF SOCIAL SERVICES DEPARTMENT…...

Notes:

$ The aim of the survey is to collect data about current or recent initiatives involving the participation of children and young people with a disability in decision making about social services, either with regard to their own care or to service development.

$ The phrase 'children and young people' refers to people aged under 18 years. The term 'children/young people' is used in this questionnaire for brevity.

$ The term 'current or recent' initiative means an initiative which is either on-going or which has taken place within the last **12 months.**

$ If there is more than one initiative involving children and young people in decision-making, please photocopy the relevant section and **complete one for each initiative.**

$ Please return the completed questionnaire in the pre-paid envelope provided. If you have any queries about completion, please contact:

Anita Franklin or Tricia Sloper
Social Policy Research Unit
University of York
York Y010 5DD

Tel: 01904 433608
Fax: 01904 433618
E-mail: af13@york.ac.uk/ps26@york.ac.uk

INVOLVEMENT OF DISABLED CHILDREN AND YOUNG PEOPLE

1. **Does the initiative involve disabled children in:**
    *(Please tick **one** box)*

    ❑   decisions regarding their own care *(please complete Section A and C)*

    ❑   general service development, planning or evaluation *(please go to Section B, p5)*

    ❑   both *(please complete all sections)*

SECTION A

PARTICIPATION OF DISABLED CHILDREN AND YOUNG PEOPLE IN DECISIONS REGARDING THEIR OWN CARE

(Please photocopy this section if children are involved in more than one decision-making process)

2. **How *many* disabled children/young people have been involved in decisions regarding their own care over the last 12 months?** *(Please tick **one** box)*

    ❑   0 - 10

    ❑   11 - 20

    ❑   21 - 50

    ❑   more than 50

    ❑   number unknown

3. **What is the *age range* (approximately) of the children/young people involved?**

    ☐☐ youngest age   ☐☐ oldest age

4. **Do any of the children/young people involved have**
    *(Please tick **all which apply**)*

    ☐   complex health needs

    ☐   autistic spectrum disorders

    ☐   communication impairments

    ☐   degenerative conditions

METHODS FOR INVOLVING CHILDREN AND YOUNG PEOPLE

5. **Which methods are used to facilitate the involvement of disabled children/young people in decisions concerning their individual care?** *(Please tick **all which apply**)*

   ☐ **Written methods**, for example questionnaires, sentence completion
   (please specify)⎯⎯⎯⎯⎯⎯⎯⎯⎯⎯⎯⎯⎯⎯⎯⎯⎯⎯⎯⎯⎯⎯

   ❑ **Verbal methods**, for example, interviews, use of advocacy, interpreters
   (please specify)⎯⎯⎯⎯⎯⎯⎯⎯⎯⎯⎯⎯⎯⎯⎯⎯⎯⎯

   ❑ **Visual methods**, for example use of symbols, Makaton, drawing, role play
   (please specify)⎯⎯⎯⎯⎯⎯⎯⎯⎯⎯⎯⎯⎯⎯⎯⎯⎯

   ❑ **Computer/IT methods,** (specific software e.g. Viewpoint)
   (please specify)⎯⎯⎯⎯⎯⎯⎯⎯⎯⎯⎯⎯⎯⎯

   ❑ **Any other methods**, (please specify)⎯⎯⎯⎯⎯⎯⎯⎯⎯⎯⎯⎯⎯⎯

GENERAL CHARACTERISTICS OF THE INITIATIVE

6. **What aspects of decision-making are children involved in?** *(Please tick **one** box)*
   (please enclose a copy of any documentation)
   ❑   Reviews
   ❑   Care Planning
   ❑   Assessments
   ❑   Health Plans
   ❑   Respite Care
   ❑   Residential Care/Education
   ❑   Transition
   ❑   Leaving Care
   ❑   Child Protection Conferences
   ❑   Other (please specify)⎯⎯⎯⎯⎯⎯⎯⎯⎯⎯⎯⎯⎯

7. **Do you have any dedicated funding to promote children's involvement?** *(Please tick **one** box)*

   ❑   Yes (please indicate source of funding)⎯⎯⎯⎯⎯⎯⎯⎯⎯⎯
   ⎯⎯⎯⎯⎯⎯⎯⎯⎯⎯⎯⎯⎯⎯⎯⎯⎯⎯⎯⎯⎯⎯⎯⎯⎯

❑ No

SUPPORT

8. Does your authority provide any *support for the children/young people* to facilitate their involvement? *(Please tick **one** box)*

❑ Yes

❑ No (please go to Question 10)

9. What *type(s) of support* is provided for *children/young people*? *(Tick **all which apply**)*

❑ training (please describe briefly)_____

_____

❑ information about the authority's decision-making processes

❑ advocacy

❑ assistance with communication

❑ access to venue(s)

❑ computer aided assistance (please describe briefly)_____

_____

❑ transport (whether direct provision or expenses)

❑ other (please specify)_____

10. Does your authority provide any *support for the staff* taking part in the initiative?
*(Please tick **one** box)*

❑ Yes

❑ No (please go to Question 12)

11. What *type(s) of support* is provided for *staff*? *(Please tick **all which apply**)*

❑ training specifically on the *involvement of disabled children/young people* (please describe briefly below)

_____

❑ training on the general involvement of children and young people (please describe briefly below)

_____

❑ protected time

❑ other (please specify)

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12. Do the children/young people involved receive any *feedback* on the outcomes of their involvement? *(Please tick **one** box)*

❑   Yes (please outline briefly below)

     _____

     _____

     _____

❑   No

13. From what the *staff have learned* through experience of involving disabled children/young people in decisions about their own care:

     a)   *what (if anything) would you want to pass on to others as particularly <u>useful</u>?*

         _____

         _____

         _____

     b)   *what (if anything) would you want to pass on to others as particularly <u>problematic</u>?*

         _____

         _____

         _____

(If you are not involving disabled children and young people in general service development, planning or evaluation, please go to Section C, Page 10).

SECTION B

PARTICIPATION OF DISABLED CHILDREN AND YOUNG PEOPLE IN SERVICE DEVELOPMENT, PLANNING OR EVALUATION

(Please photocopy this section if children are involved in more than one initiative)

14. How *many* disabled children/young people have been involved in the initiative over the last 12 months? *(Please tick **one** box)*

❑   0 - 10   ❑   more than 50

❑   11 - 20   ❑   number unknown

❑   21 - 50

15. What is the *age range* (approximately) of the children/young people involved?

[|]   youngest age   [|]   oldest age

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16. In this initiative, are children/young people consulted *(Please tick **one** box)*

- ☐ Individually
- ☐ In a group
- ☐ Both individually and in a group

17. Do any of the children/young people involved have *(Please tick **all that apply**)*

- ☐ complex health needs
- ☐ autistic spectrum disorders
- ☐ communication impairments
- ☐ degenerative conditions

GENERAL CHARACTERISTICS OF THE INITIATIVE

18. Please give a *brief description* of the initiative, including its *aim* (please enclose a copy of any documentation)

_____
_____
_____
_____

19. Please list any partner agencies (statutory or voluntary) involved in this initiative

_____
_____
_____
_____

20. Has the initiative received any dedicated funding? *(Please tick **one** box)*

- ☐ Yes (please indicate source of funding)

_____
_____

- ☐ No

21. **Which of the following most closely describes this initiative?** *(Please tick **one** box)*

❑   a single, 'one-off' exercise

❑   a medium term project (up to one year)

❑   a long term project (i.e. more than one year)

❑   a permanent arrangement

❑   other (please describe) _____

METHODS FOR INVOLVING CHILDREN AND YOUNG PEOPLE

22. **Which methods are used to facilitate the involvement of disabled children/young people in service development, planning or evaluation?** *(Please tick **all that apply**)*

❑   **Written methods**, for example questionnaires, sentence completion

(please specify) _____

❑   **Verbal methods**, for example, interviews, advocacy, use of interpreters

(please specify) _____

❑   **Visual methods**, for example use of symbols, Makaton, drawing, role play

(please specify) _____

❑   **Computer/IT methods,** (specific software e.g. Viewpoint)

(please specify) _____

❑   **Any other methods**, (please specify)_____

SUPPORT

23. **Does your authority provide any *support for the children/young people* to facilitate their involvement?** *(Please tick **one** box)*

❑   Yes

❑   No (please go to Question 25)

24. What *type(s) of support* is provided for *children/young people*? *(Tick all which apply)*

❑ training (please describe briefly)_____

_____

❑ information about the authority's decision-making processes
❑ advocacy
❑ assistance with communication
❑ access to venue(s)
❑ computer aided assistance (please describe briefly)_____

_____

❑ transport (whether direct provision or expenses)
❑ other (please specify) _____

25. Does your authority provide any *support for the staff* taking part in the initiative?
*(Please tick **one** box)*

❑ Yes
❑ No (Please go to Question 27)

26. What *type(s) of support* is provided for *staff*? *(Please tick **all which apply**)*

❑ training specifically on the *involvement of disabled children/young people* (please describe briefly below)

_____

❑ training on the general involvement of children and young people (please describe briefly below)

_____

❑ protected time
❑ other (please specify) _____

OUTCOMES

27. Has the involvement of children/young people resulted in any changes to service provision? *(Please tick **one** box)*

❏   Yes (please outline briefly below)

_____

_____

_____

_____

❏   No (please outline reason(s) briefly below, for example, initiative not yet complete; insufficient resources to implement children's/young people's suggestions)

_____

_____

_____

_____

28. Has the initiative resulted in any *changes in commissioning or service priorities*?
*(Please tick **one** box)*

❏   Yes (please outline briefly below)

_____

_____

_____

❏   No (please outline reason(s) briefly below, for example, initiative not yet complete; insufficient resources to implement children's/young people's suggestions)

_____

_____

_____

29. Has the initiative resulted in *any other changes* relevant to service development?
*(Please tick **one** box)*

❏   Yes (please outline briefly below)

_____

_____

_____

❏   No

30. **Have the children/young people involved received any *feedback* on the outcomes of their involvement?** *(Please tick **one** box)*

❑ Yes (please outline briefly below)

_____

_____

_____

❑ No

31. **From what the *staff have learned* through experience of this initiative in involving disabled children/young people in service development, planning or evaluation:**

a) *what (if anything) would you want to pass on to others as particularly <u>useful</u>?*

_____

_____

_____

_____

b) *what (if anything) would you want to pass on to others as particularly <u>problematic</u>?*

_____

_____

_____

_____

SECTION C

STAFF

32. **Is there a *post-holder* in the organisation with designated responsibility for children/ young people's involvement?** *(Please tick one box)*

❑ Yes (please state job title and brief outline of responsibilities)

_____

_____

_____

_____

❑ No

33. CONTACT DETAILS

In case we have any queries, please give contact details of the person completing this questionnaire:

Name: _____

Job title: _____

Work Address: _____

_____

_____

_____

Telephone number: _____

Fax number: _____

E-Mail address: _____

34. FURTHER RESEARCH

There will be a further stage of the research to look in detail at selected initiatives (see information sheet). If your initiative is selected, would you be prepared to discuss participation in Stage Two? *(Please tick **one** box)*

❑ Yes   ❑ No

Please return the questionnaire in the envelope provided

Please remember to enclose any written documentation about the initiative(s), which we will treat in confidence

Thank you for your co-operation

APPENDIX D

Information Sheets Sent to Parents and Children

HAVING A SAY IN SERVICES

**Information leaflet for parents
and guardians**

About the research

The government is trying to find out the best ways of involving disabled children and young people in decisions about the care and services they receive. They want more children and young people to have a say and to be involved in ways that are enjoyable and beneficial to them.

The Department of Health have asked researchers at York University to look at how local authorities are involving children and young people in order to get a better picture of the best ways to involve them.

A review is just one way of involving children and young people, therefore we are interested to find out what you and your child thought of your child's review, and if you have any advice for professionals who might want to involve children and young people like this in the future.

Your opinions and views will be used to produce 'guidelines' to support local authorities in promoting children and young people's involvement. Children and parents/guardians who take part in the research will receive information on these guidelines when they are produced at the end of the project.

Who is taking part?

Children, young people and their parents/guardians from five local authorities across England are being invited to take part in the research. These children will have been involved in decision-making either about their own care and the services that they receive, or have been involved in decisions about general services for disabled children and young people.

Leeds is one of the authorities selected and the researchers will be looking at a couple of ways in which children are involved within this authority. We are asking parents/guardians and their disabled child to take part in the research. In some families, both a parent and a child will want to take part, in others it may just be the child. We do not want to leave anyone out of the research because they have learning difficulties, or because they do not use speech to communicate, or because their first language is not English. We will try our best to include everyone.

What does the research project involve?
If your child, or you and your child want to take part in the research then one of the researchers will visit you somewhere convenient to you, such as your home. We find that it works best if we spend time separately with a parent/guardian and their child. In order to do this we might have to make two visits. If your child wants someone with them when we visit – that's ok. Sometimes we need another person to help us understand what a child or young person wants to tell us. They can choose whoever they want this person to be.

We find that it helps to tape-record the interviews, but we would not do this if you prefer us not to.

Confidentiality
The information collected during the research will be treated with strictest confidence, and no-one taking part in the project will be identifiable in the project report or any other publication. You can tell whomever you want about taking part in the research but we will not disclose to anyone that your child or you and your child are taking part.

Deciding to take part
You and your child do not have to take part in this research.

Your child and you can withdraw from the project at anytime without giving a reason. Whether or not you take part will not affect any services that you or your child receives.

If you and your child are happy for a researcher to contact you about the research, please complete the enclosed contact form, and send it back to us in the FREEPOST envelope provided. We will then contact you and be pleased to answer any questions you may have about the project. If you agree, we will also arrange a convenient time to visit you.

If you have any questions or would like to discuss the research project further please contact:

Anita Franklin and Tricia Sloper
Social Policy Research Unit
University of York
YO10 5DD
Tel: 01904 321950
Email: af13@york.ac.uk

THANK YOU!

HAVING A SAY IN SERVICES

Information Leaflet for Children
and Young People

What did you think about your review? Were you asked for your views? Were you listened to?

What's it all about?
The government is trying to find out the best ways of involving disabled children and young people in decisions about the care and services they receive. They want more children and young people to have a say and be involved in ways that they enjoy. Workers often want to make services better but they aren't sure what is the best way to ask children and young people what they think. Researchers at the University of York will be working with disabled children and young people, within five areas in England, who have been involved in making decisions about services to find out what they think is a good way to involve children and young people. Leeds is one of those areas.

Why me?
We would like to find out your opinions of your review. Many young people who have had a review have been asked to take part and we would also be interested in what your parents/carers have to say.

What would I have to do?
If you are interested, then we would like to meet with you to find out what it was like for you to be involved in your review. We would like to ask you questions such as what did you like and didn't like about it, were you listened to and any advice you might have for workers who want to involve children and young people in their reviews. There are no right or wrong answers, we are just interested in what **you** have to say! It would take about half an hour.

Later on… The information collected from young people in the five areas will be used to write 'guidelines' for workers about the best ways to

involve children and young people in decisions about their care and services. We would send you information about these guidelines later. We would like some young people to help design these – maybe you might be interested in that?

Who will get to know what I say?
Only the researchers will know what you say. When we write a report and produce the guidelines we will not be using any names and we will make sure that children and young people who took part cannot be identified.

What happens next?
If you are interested in taking part please fill in the 'contact form' or make contact with us by phone, letter or email. If you are aged under 16, your parent or carer will have to give permission. Please use the envelope to send the contact form back to us – you do not need a stamp. We will then contact you to answer any questions you may have, and if you still want to take part we can arrange a time to meet you. If you decide to take part and change your mind later that is ok.

If you do not want to take part. That is OK. Thank you for your time.

Who are we?
Our names are Anita Franklin and Tricia Sloper, we are researchers at the Social Policy Research Unit at the University of York. Our job is to find out from young people their opinions and views.

If you would like to ask any questions before you make a decision then please phone, email or write to us. We will phone you back to save your phone bill! Thank you for your time.

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References

Aires, A. and Kettle, J. (1998) *When Things Go Wrong: Young people's experiences of getting access to the complaints procedure*, London: NISW.

Alderson, P. (2000) *Young Children's Rights: Exploring beliefs, principles and practice*, London: Jessica Kingsley Publishers.

Alderson, P. and Montgomery, J. (1996) *Health Care Choices: Making decisions with children*, London: Institute for Public Policy Research.

Aldgate, J. and Statham, J. (2001) *The Children Act Now: Messages from research*, London: Stationery Office.

Arnstein, S. (1969) Eight rungs on the ladder of citizen participation, *Journal of American Institute of Planners* 35, 4, 216-224.

Badham, B. (2004) Participation - for a change: disabled young people lead the way, *Children and Society*, 18, 2, 143-154.

Bell, P. and Six Young People from Investing in Children Projects (2002) *Changing the View: How young people's ideas can revolutionise health services*, York: York Youth Work Project, conference presentation 'Involving Young Patients In The NHS'.

Beresford, B. (1997) Personal *Accounts: Involving disabled children in research*, London: The Stationery Office.

Beresford, B. (2002) Preventing the social exclusion of disabled children, in D. McNeish, T. Newman and H. Roberts (eds.), *What Works for Children?* Buckingham: Open University Press.

Beresford, B. (2004) On the road to nowhere? Young disabled people and transition, *Child: Care, Health and Development*, 30, 6, 581-587.

Beresford, B. and Sloper, P. (1999) *The Information Needs of Chronically Ill or Physically Disabled Children and Adolescents*, York: Social Policy Research Unit, University of York.

Boyden, J. and Ennew, J. (1997) *Children in Focus: A manual for participatory research with children* , Stockholm: Radda Barnen.

Bradding, A. and Hortsman, M. (1999) Using the write and draw technique with children, *European Journal of Oncology Nursing*, 3, 3, 170-175.

Brook, G. (2000) Children's competency to consent: a framework for practice, *Paediatric Nursing*, 12, 5, 31-35.

Cameron, L. and Murphy, J. (2002) Enabling young people with a learning disability to make choices at a time of transition, *British Journal of Learning Disabilities*, 30, 105-112.

Cashmore, J. (2002) Promoting the participation of children and young people in care, *Child Abuse and Neglect*, 26, 837-847.

Cavet, J. and Sloper, P. (2004) Participation of disabled children in individual decisions about their lives and in public decisions about service development, *Children and Society*, 18, 4, 278-290.

Children and Young People's Unit (2001) *Learning to Listen: Core principles for the involvement of children and young people*, London: Department for Education and Skills.

Children's Taskforce Department of Health (2001) *Principles for Participation of Children, Young People and Families in the Children's Taskforce*, London: Department of Health.

Cohen, J. and Emanuel, J. (1998) *Positive Participation: Consulting and involving young people in health-related work: A planning and training resource*, London: Health Education Authority.

Combe, V. (2002) *Up for It: Getting young people involved in Local Government*, Leicester: National Youth Agency.

Committee on The Rights of The Child (2002) Concluding observations of The Committee on The Rights of The Child: United Kingdom of Great Britain and Northern Ireland, 4 October 2002. Geneva, United Nations quoted in R. Sinclair (2004) Participation in Practice: Making it meaningful, effective and sustainable, *Children and Society*, 18, 106-118.

Cope, C. (2003) *Fulfilling Lives: Inspection of social care services for people with learning disabilities*, London: Department of Health.

Council for Disabled Children (2000) *Quality Protects: Second analysis of management action plans with reference to disabled children and families*, London: Department of Health.

Council for Disabled Children (2003) *Fourth Analysis of the Quality Protects Management Action Plans: Services for disabled children and their families*, London: Council for Disabled Children.

Crisp, A., Marchant, R. and Jones, M. (2000) *Quite Like Home: What you told us about Fairlawn, The Croft and Southdowns. Young people's views about residential respite care services in Kent*, Brighton: Triangle and Kent County Council.

Cutler, D. and Frost, R. (2001) *Taking the Initiative: Promoting young people's involvement in public decision making in the UK*, London: Carnegie Young People Initiative.

Danso, C., Greaves, H., Howell, S., Ryan, M., Sinclair, R. and Tunnard, J. (2003) *The Involvement of Children and Young People in Promoting Change and Enhancing the Quality of Social Care*, London: National Children's Bureau.

Dee, L. and Bryers, R. (2003) Facilitating transitions for people with profound and complex learning difficulties', *Journal of Integrated Care*, 11, 34-38.

Department for Education and Skills (2001a) *Special Educational Needs. Code of Practice*, London: Department for Education and Skills.

Department for Education and Skills (2001b) *Special Educational Needs Toolkit*, London: Department for Education and Skills.

Department of Health (1991) *The Children Act 1989 Guidance and Regulations: Volume 6 children with disabilities*, London: Department of Health.

Department of Health (1999) *Patient and Public Involvement in the New NHS*, London: Department of Health.

Department of Health (2001a) *The Quality Protects Programme: Transforming children's services*, 202-3, LAC (2001), 28, London: Department of Health.

Department of Health (2001b) *The Expert Patient: A new approach to chronic disease management for the 21st century*, London: Department of Health.

Department of Health (2001c) *Seeking Consent: Working with children*, London: Department of Health.

Department of Health (2002) Listening, *Hearing and Responding: Department of Health core principles for the involvement of children and young people*, London: Department of Health.

Department of Health (2003a) *Getting The Right Start: The National Service Framework for Children - standard for hospital services*, London: Department of Health.

Department of Health (2003b) *Transforming Children's Services: An evaluation of local responses to the Quality Protects Programme, Year 4*, London: Department of Health.

Department of Health (2003c) *Listening, Hearing and Responding*, Department of Health Action Plan 2003/4, London: Department of Health.

Department of Health/Department for Education and Skills (2004) *National Service Framework for Children, Young People and Maternity Services: Disabled children and young people and those with complex health needs*, London: Department of Health.

Dixon-Woods, M., Young, B. and Heney, D. (1999) Partnerships with children, *British Medical Journal*, 319, 778-780.

Franklin, A. and Madge, N. (2000) *In Our View: Children, teenagers and parents talk about services for young people*, London: National Children's Bureau.

Germain, R. (2004) An exploratory study using cameras and Talking Mats to access the views of young people with learning disabilities on their out-of-school activities, *British Journal of Learning Disabilities*, 32, 170-174.

Grimshaw, R. and Sinclair, R. (1997) *Planning to Care: Regulations, procedure and practice under The Children Act 1989*, London: National Children's Bureau.

Hart, R. (1992) *Children's Participation: From tokenism to citizenship*, Florence: UNICEF International Child Development Centre.

Hart, R. (1997) *Children's Participation: The theory and practice of involving young citizens in community development and environmental care*, New York: UNICEF.

Heaton, J. and Sloper, P. (2004) National survey of Patient Advice and Liaison Services (PALS) in England: children, young people and parents' access to and use of PALS, *Child: Care, Health and Development*, 30, 5, 495-501.

Hennessy, E. (1999) Children as service evaluators, *Child Psychology and Psychiatry Review*, 4, 4, 152-161.

Her Majesty's Government (2004) *Children Act 2004*, The Stationery Office.

Heslop, P., Mallett, R., Simons, K. and Ward, L. (2002) *Bridging the Divide at Transition: What happens for young people with learning difficulties and their families?* Plymbridge: British Institute for Learning Disabilities.

Hill, M. (1997) What children and young people say they want from social services, *Research Policy and Planning*, 15, 3, 17-27.

Horgan, G. (1998) Involving children and young people in care planning, *Research Policy and Planning*, 16, 3, 16-22.

Kilgour, K. (2002) *Circus Skills: A training, support and development needs survey of participation workers*, London: Carnegie Young People Initiative.

Kirby, P. and Bryson, S. (2002) *Measuring the Magic? Evaluating and researching young people's participation in public decision-making*, London: Carnegie Young People Initiative.

Kirby, P., Lanyon, C., Cronin, K., and Sinclair, R. (2003a) *Building a Culture of Participation: Involving children and young people in policy, service planning, delivery and evaluation*, research report, London: Department for Education and Skills.

Kirby, P., Lanyon, C, Cronin, K and Sinclair, R. (2003b) *Building a Culture of Participation: Involving children and young people in policy, service planning, delivery and evaluation*, handbook, London: Department for Education and Skills.

Kirkbride, L. (1999) *I'll Go First: The planning and review toolkit for use with disabled children*, London: The Children's Society.

Lansdown, G. (1995) *Taking Part: Children's participation in decision making*, London: Institute for Public Policy Research.

Lardner, C. (2001) *Exploring Good Practice in Youth Participation: A critical review*, Edinburgh: Clarity.

Lightfoot, J. and Sloper, P. (2002a) *Having a Say in Health: Guidelines for involving young patients in health services development*, York: Social Policy Research Unit, University of York.

Lightfoot, J. and Sloper, P. (2002b) *Involving Young People in Health Service Development*, Research Works, 2002 -01, York: Social Policy Research Unit, University of York.

Lightfoot, J. and Sloper, P. (2003) Having a say in health: involving young people with a chronic illness or physical disability in local health services development, *Children and Society*, 17, 277-290.

Marchant, R. and A. Crisp (2001). What We Think: Views of Children and Young People in Southwark. Brighton, Triangle.

Marchant, R. and Jones, M. (2003) *Getting It Right: Involving disabled children in assessment, planning and review processes*, Hove: Triangle.

Marchant, R., Jones, M., Juylan, A. and Martin, M. (1999a) *Listening on All Channels: Consulting with disabled children and young people*, Brighton: East Sussex County Council and Triangle.

Marchant, R., Jones, M. and Martin, M. (1999b) *'Tomorrow I Go': What you told us about Dorset Road*, young people's views about a residential respite care service, Brighton: East Sussex County Council and Triangle.

Matthews, H. (2001) Citizenship, youth councils and young people's participation, *Journal of Youth Studies*, 4, 3, 299-318.

McNeish, D. (1999) Promoting participation for children and young people: some key questions for health and social welfare organisations, *Journal of Social Work Practice*, 13, 2, 191-203.

McNeish, D., Downie, A, Newman, T., Webster, A. and Brading, J. (2000) *Review of young people's participation in Lambeth, Southwark and Lewisham*, London: Lambeth, Southwark and Lewisham Health Action Zone.

McNeish, D. and Newman, T. (2002) Involving children and young people in decision-making, in D. McNeish, T. Newman and H. Roberts (eds), *What Works for Children? Effective Services for Children and Families*, Buckingham: Open University Press.

MENCAP (2003) *Listen Up: Helping children with a learning disability complain about the services they use*, London: MENCAP.

Mitchell, W. and Sloper, P. (2001) Quality in services for disabled children and their families: what can theory, policy and research on children's and parent's views tell us? *Children and Society*, 15, 237-252.

Morris, J. (1998a) Still *Missing? Volume 1: The experiences of disabled children and young people living away from their families*, London: The Who Cares? Trust.

Morris, J. (1998b) *Accessing Human Rights. Disabled Children and The Children Act*, Ilford: Barnardo's.

Morris, J. (1998c) *Don't Leave Us Out: Involving disabled children and young people with communication impairments*, York: Joseph Rowntree Foundation.

Morris, J. (1999) *Hurtling into a Void: Transition to adulthood for young disabled people with complex health and support needs*, Brighton: Pavillion Publishing.

Morris, J. (2001a) Social exclusion and young disabled people with high levels of support needs, *Critical Social Policy*, 21, 2, 161-183.

Morris, J. (2001b) *That Kind of Life? Social Exclusion and Young Disabled People with High Levels of Support Needs*, London: Scope.

Morris, J. (2002) *A Lot to Say! A Guide for Social Workers, Personal Advisors and Others Working with Disabled Children and Young People with Communication Impairments*, London: Scope.

Morris, J. (2003) Including all children: finding out about the experiences of children with communication and/or cognitive impairments, *Children and Society*, 17, 5, 337-348.

Morrow, V. (1999) 'We are people too': children's and young people's perspectives on children's rights and decision-making in England, *International Journal of Children's Rights*, 7, 2, 149-170.

Murphy, J. (1998) Talking mats: speech and language research in practice, *Speech and Language Therapy in Practice*, Autumn, 11-14.

Newman, T. (1996) Rites, rights and responsibilities, in H. Roberts and D. Sachdev (eds), *Young People's Social Attitudes*, Barkingside: Barnardo's.

Noyes, J. (1999) Voices and Choices. *Young People Who Use Assisted Ventilation: Their health and social care and education*, London: The Stationery Office.

Noyes, J. (2000) Enabling young 'ventilator-dependent' people to express their views and experiences of their care in hospital, *Journal of Advanced Nursing*, 31, 5, 1206-1215.

Oldfield, C. and Fowler, C. (2004) *Mapping Children and Young People's Participation in England*, research report, Nottingham: Department for Education and Skills.

Rabiee, P., Priestley, M. and Knowles, J. (2001) *Whatever Next? Young Disabled People Leaving Care*, York: York Publishing Services.

Rabiee, P., Sloper, P. and Beresford, B. (2005) Desired outcomes for children and young people with complex health care needs, and children who do not use speech for communication, *Health and Social Care in the Community*, **13,** 5, 478-487.

Rabiee, P., Sloper, P. and Beresford, B. (in press) Doing research with children and young people who do not use speech for communication, *Children and Society*.

Ritchie, J. and Spencer, L. (1994) Qualitative data analysis for applied policy research, in A. Bryman and R.G. Burgess (eds), *Analysing Qualitative Data*, London: Routledge.

Robbins, D. (2001) *Transforming Children's Services: An evaluation of local responses to the Quality Protects Programme Year 3*, London: Department of Heath.

Russell, P. (1998) *Having a Say! Disabled Children and Effective Partnership in Decision-Making*, summary report, London: Council for Disabled Children.

Shier, H. (2001) Pathways to Participation: Openings, opportunities and obligations, *Children and Society*, 15, 107-117.

Sinclair, R. (2004) Participation in Practice: Making it meaningful, effective and sustainable, *Children and Society*, 18, 106 -118.

Sinclair, R., Cronin, K. Lanyon, C., Stone, V. and Hulsi, A. (2002) *Aim High, Stay Real: Outcomes for children and young people: The views of children, parents and professionals*, London: Children and Young People's Unit.

Sinclair, R. and Franklin, A. (2000) *Young People's Participation, Quality Protects Research Briefing*, No.3, London: Department of Health.

Social Services Inspectorate (1998) *Removing Barriers for Disabled Children*, inspection of services to disabled children and their families, Wetherby: Department of Health.

Stone, E. (2001) *Consulting with Disabled Children and Young People*, York: Joseph Rowntree Foundation.

The Children's Society (2001) *Ask Us: A Children's Society multi-media guide to consultation for the Quality Protects initiative*, London: The Children's Society.

The National Evaluation of The Children's Fund (2004) *Children, Young People, Parents and Carers' Participation in Children's Fund Case-Study Partnerships*, Research Report 602m, Nottingham: Department for Education and Skills.

Thoburn, J., Lewis, A. and Shemmings, D. (1995) *Paternalism or Partnership? Family Involvement in the Child Protection Process*, London: HMSO.

Treseder, P. (1997) *Empowering Children and Young People: Training Manual*, London: Children's Rights Office/Save the Children.

Triangle/NSPCC (2001) *Two Way Street: Communicating with disabled children and young people video pack*, Leicester: NSPCC.

Triangle/NSPCC (2002) *How is it: An image vocabulary for children about feelings, rights and safety, personal care and sexuality*, Leicester: NSPCC.

United Nations (1989). Convention on the Rights of the Child. Geneva, United Nations.

United Nations Committee On The Rights of The Child (1997) General Discussion Paper on Children with Disabilities, 6 October, unpublished, quoted in Beresford, B. (2002) D. McNeish, T. Newman and H. Roberts (eds), *Preventing the Social Exclusion of Disabled Children. What Works for Children?* Buckingham: Open University Press.

University of East Anglia in collaboration with the National Children's Bureau (2005) *Realising Children's Trust Arrangements: National evaluation of children's trusts*, Norwich: University of East Anglia.

Utting, W. (1997) *People Like Us: The report of the review of safeguards for children living away from home*, London: HMSO/Department of Health/Welsh Office.

Wade, H. and Badham, B. (2003) *Hear By Right: Standards for the active involvement of children and young people*, Leicester: National Youth Agency and Local Government Association.

Ward, L. (1997) *Seen and Heard: Involving disabled children and young people in research and development projects*, York: Joseph Rowntree Foundation.

Ward, L., Mallett, R., Heslop, P. and Simons, K. (2003) Transition Planning: How well does it work for young people with learning disabilities and their families? *British Journal of Special Education*, 30, 3, 132-137.

Waterhouse, R. (2000) *Lost in Care: Report of the tribunal of inquiry into the abuse of children in care in the former county council areas of Gwynedd and Clwyd since 1974*, London: HMSO.

Willow, C. (1997) *Hear! Hear! Promoting Children and Young People's Democratic Participation in Local Government*, London: Local Government Information Unit.

Willow, C. (2002) *Participation in Practice: Children and young people as partners in change*, London: The Children Society.