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PARTICIPATION OF DISABLED CHILDREN AND YOUNG PEOPLE IN DECISION-MAKING WITHIN SOCIAL SERVICES DEPARTMENTS

Quality Protects Research Initiative

A survey of current and recent activities in Social Services in England

Interim Report - February 2004

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1. Background

Quality Protects

The Quality Protects (QP) programme 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. (In this report we focus on Objective 8 concerning children's participation (Figure 1.1, p2).) The Department of Health has 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).

Since January 1999, Management Action Plans (MAPs) have been submitted annually to the Social Services Inspectorate (SSI). The MAPs report 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 will now be integrated into the mainstream SSI performance assessment system. In addition, 2003-04 will be the last year with ring-fenced funding to support the QP programme, from April 2004 QP funding will be mainstreamed.

Children's participation and Quality Protects

Developing a culture of, and good practice in children's participation is fundamental to achieving the overall aim of Quality Protects. A key component of Objective 8, children's participation, is also a QP priority area for action and is 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) is unequivocal about the wish to see participation 'embedded and sustained across all QP objectives' (Department of Health 2001a). This work reflects the growing 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 1997,2002; Department of Health 1999, 2001b, 2003; Sinclair and Franklin 2000, Cavet and Sloper 2004).

The Government's pledge to involving young service users is increasingly being illustrated within policy. They underlined their commitment by the publication of a framework of core principles for children and young people's involvement across all Government Departments, along with the 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). (See website http://www.cypu.gov.uk)

> 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.
> (CYPU, 2001, p2)

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 continues to grow (Department of Health 2003).

What is meant by participation?

The term 'participation' covers a broad continuum of involvement and is a multi-layered concept, with the term being used to describe many different processes. Kirby *et al.* (2003) consider participation under six dimensions: the level of participation; the focus of decision-making; the content of decision-making; nature of the participation activity; frequency and duration of participation; the children and young people involved.

The level and nature of participation can vary. Boyden and Ennew (1997) state that there are two 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 and knowing that one's actions and views are going to make a difference and may be acted upon, thus leading to empowerment.

A number of writers have developed typologies to illustrate this. These generally make hierarchical distinctions between levels of participation according to the degree of power that is shared or transferred. These ladders of participation are adapted from Arnstein (1969) to relate to children's participation (See Table 1.1).

Table 1.1   Ladders of participation

Arnstein (1969)	Hart (1992)	Thoburn, Lewis & Shemmings (1995)	Shier (2001)
Citizen control	Child-initiated, shared decisions with adults	Delegated power Involvement in service design	Children share power and responsibility for decision-making
Delegated power	Child-initiated and directed		
Partnership	Adult initiated, shared decisions with adults	Partnership participation	Children are involved in decision-making processes
Placation	Consulted and informed	Involvement Consultation	Children's views are taken into account
Consultation	Assigned but informed	Keep fully informed	Children are supported in expressing their views
	Tokenism		Children are listened to
Therapy	Decoration	Placation	
Manipulation	Manipulation	Manipulation	

(Sinclair and Franklin 2000)

Some writers have criticised these ladders of participation as it suggests a hierarchy with the objective being to reach the top rung of the ladder (Treseder 1997; Lardner 2001). Shier's model (2001) 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. More recently, Kirby et al (2003) have developed a non-hierarchical model of participation, where no one level is assumed to be better than another, instead the type of participation activity will be determined according to the circumstances (See Figure 1.2).

Figure 1.2   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.*, 2003, p22)

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

The focus of children's participation can also vary, with children and young people participating in matters which affect them as individuals (personal or individual decisions) and those that relate to them as a group (public 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. This can be exercised around procedures such as assessment, care planning and reviews, child protection conferences or complaints. Within this area, early statutory requirements included the 1975 Children Act where there was a requirement to ascertain the wishes and feelings of the child when making decisions about them.

This was reinforced in the Children Act 1989 and has led to a greater involvement of children in decision-making. Guidance and regulations addressing specifically disabled children (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 being involved in decision-making.

Children's participation in matters that relate to them as a group can be through the identification, development, provision, monitoring or evaluation of services and policy, 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)

Why children's participation?

There is a growing recognition and acceptance that children should be involved in making decisions that affect them which is reflected in law, government guidance, regulation and policy. This new thinking has emerged from several parallel developments: our changing views on childhood, the children's rights agenda and the increasing influence of the consumer.

Views of childhood

Since the late 1980s academic research has forced us to look beyond childhood as a period of socialisation and to view it as socially constructed where children can and do actively shape the structures and processes around them (James and Prout, 1990, 1997; James *et al.*, 1998). Research has questioned why children were seen as 'invisible', mostly identified within the family or institution to which they belonged and rarely asked for their own opinions or views (Qvortrup, 1990). Concerns were raised as to why adult interpretations of children's needs and wishes determined services and influenced research and policy. Increasingly children began to be identified as a group in their own right, and there developed an increasing understanding of the competences that children have to be involved in decision-making, including children and young people with severe illness or disability and very young children (Alderson, 1993; Clark and Moss, 2001).

Children's Rights

During the same time frame children and young people began to gain legal rights to be involved in decision-making. The UK ratified the UN Convention on the Rights of

the Child (UNCRC) in 1991 and this granted children and young people under 18 years old participatory rights. 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)

This does not necessarily mean that children and young people make decisions autonomously but rather that adults involve them in the process in ways appropriate to their abilities and understanding. Indeed Morrow's study (1999) illustrated that children did not want absolute decision-making but preferred a relative position where they wanted to have a say and contribute to decisions rather than make the decisions themselves.

Article 13 is also pertinent to promoting the participation of disabled children and young people 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)

Consumer rights

Consumers are now given more power in exercising choice and influencing the nature and quality of the services they receive, this also includes children and young people as consumers. For example, within health 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, 2003), and the Children's National Service Framework stresses the need to consult and involve them: the standard for hospital services states that 'children, young people and their parents will participate in designing NHS and social care services that are readily accessible, respectful, empowering, follow best practice in obtaining consent and provide effective response to their needs' (Department of Health, 2003, p9). Local authorities, under the Local Government Act 1999 are required to undertake Best Value reviews of all their services, these should incorporate the wishes and priorities of local people, including children and young people.

Research on children's participation

While descriptive research and practice literature on children and young people's involvement in public service decision-making is now emerging, reports of evaluations are as yet scarce (Kirby and Bryson 2002). 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). Slowly, the literature is moving on from this to study broader questions such as what facilitates a participatory culture (Kirby *et al.*, 2003), 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. In particular, we know little about the views of children themselves on their experiences of participation, which would help to inform the development of good practice. More work is required to ensure that participation is meaningful, effective and sustained. Too often participation activity is one-off and isolated, the result of a single or small group of dedicated people, 'champions of participation', rather than being embedded within agencies. Participation has come a long way in a relatively short space of time, further research is now needed to reflect on what has been achieved and what still needs to be done.

Research on 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). 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 (Morris, 1998a; Stone, 2001; Rabiee *et al.*, 2001)

While the emerging 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 and Downie *et al.*, 2000; Kirby and Byson, 2002; Kirby *et al.*, 2003), 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, 1998b; Russell, 1998; Marchant and Jones *et al.*, 1999; 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), and a training video and handbook to build practitioners' confidence and skills in communicating with disabled children who do not use speech (Triangle/NSPCC, 2001). More recently, MENCAP have developed resources to help children with a learning disability complain about the services they use (MENCAP, 2003). A collection of these resources is available on the Department of Health website (www.doh.gov.uk/integratedchildrenssystem). However, little information has been gathered on their use. It is not yet known for example, whether use of these resources is widespread in practice.

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; DoH, 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' (DoH, 2003b, p72). This report also documents 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 '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)….'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). This report highlighted the growing use of 'consultation tools' such as 'I'll Go First', Viewpoint or Widget (See Appendix A).

It would appear 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 in the process of participation or indeed what should be the outcomes of their involvement. Little evidence exists about the outcomes of disabled children's participation in terms of its likely 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 under QP, and indeed other government policy, and it is these gaps that this research study seeks to address.

2. The Research Study

This report describes one stage of a research project funded by the Department of Health Quality Protects Research Initiative.

The overall aim of the research is to improve knowledge about the effective participation of disabled children and young people under Quality Protects. The study will investigate both the process of disabled children's participation and outcomes in respect of the impact of disabled children's views on service development and/or tailoring individual packages of care. Particular attention will be paid to specific groups of disabled children who have 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 are to:
a)   Identify participation work which includes disabled children and young people.
b)   To establish factors which can support and promote good practice in the process of disabled children and young people's effective participation.
c)   To 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.

Methodology

The research is being carried out in three stages. The results from stage two are reported here. The final stage will be completed in early summer 2005 and will culminate in the distribution of guidelines to support Social Services Departments and others in promoting disabled children's participation.

Stage One consisted of analysis of Year 4 QP Management Action Plans (MAPs), 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.

At the outset of the research, a survey of Social Services Departments had not been envisaged. However, our analysis found 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 and of value. The survey 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.

Survey findings are also being used to select a sample of differing types of participation activity to explore in greater detail in Stage Three. This final stage consists of qualitative research in a sample of five local authorities. Through gaining the views of children, parents and staff, the research will investigate 'what works' in respect of the processes and outcomes of disabled children's participation. These views will directly inform the guidelines to support social services departments.

This report focuses on the findings of the analysis of the survey of Social Services Departments.

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.
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 selected for more in-depth investigation would still be in the memories of children, young people, parents and staff whom 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 were not currently, or had not within the last 12 months, involved disabled children with 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= 150)

	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. The questions were categorised around seven themes:

1)   **Nature of participation** (whether 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.

Piloting

This questionnaire was based on the one used for 'Having A Say in Health' research (Lightfoot and Sloper, 2002) and had been successfully completed by a large number of practitioners therefore extensive piloting was not deemed necessary. However the questionnaire was examined by two Social Services Departments and discussed at their team and management meetings.

Response rate

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

3.   Results

Results below refer to 71 Social Services departments who reported involving disabled children in some way and who completed the detailed questionnaire.

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

The first question sought to distinguish participation which affected disabled children as individuals and those 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 3.1   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 Table 3.1 illustrates, within the last 12 months, 60 per cent of social services departments who responded were involving or have 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.

Characteristics of children and young people participating

Table 3.2 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 per cent 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, 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 3.2   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 3.1 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 3.1: **Age range of children involved in the initiatives**
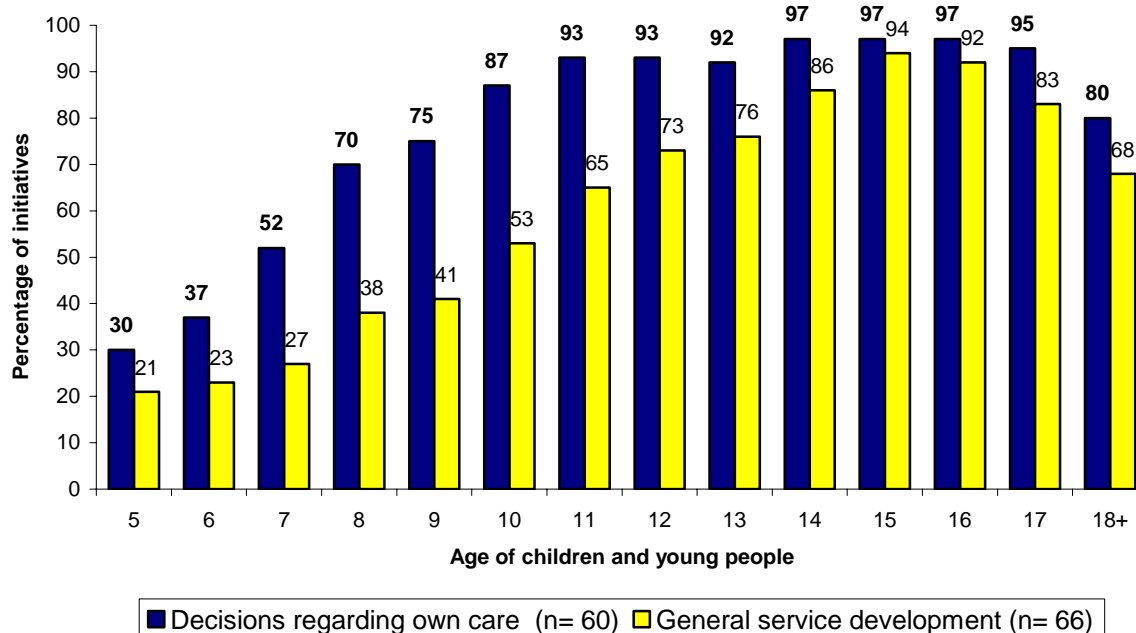
Questions were asked about the involvement of young people with the four conditions which have been identified within the QP MAPs as being particularly difficult to reach. The survey data illustrated that within decisions about their own care, 71 per cent of respondents were involving children and young 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 3.2).

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 do 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.

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Figure 3.2   Participation of "difficult to reach" disabled children and young people
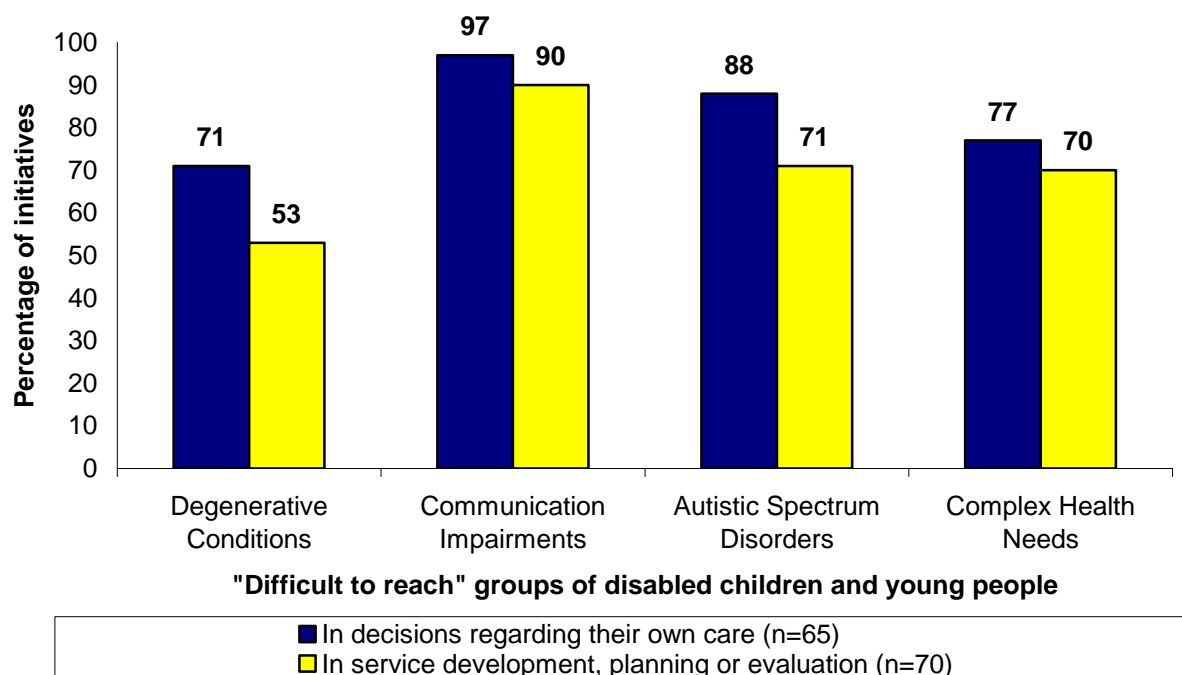
The survey data do not allow us to establish how many young people with these conditions have been involved in decision-making, however, given the low numbers of disabled children being involved per se it might be assumed that these figures are small. In addition, the survey does not offer any detailed insights into the methods being used to involve these groups of children or the equitability of their involvement. However, these questions are the focus of stage three of this project.

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 3.3 illustrates the range of areas that disabled children were being involved in.

Figure 3.3 **Participation of disabled children and young people within individual packages of care** (n= 65)

Type of decision-making process
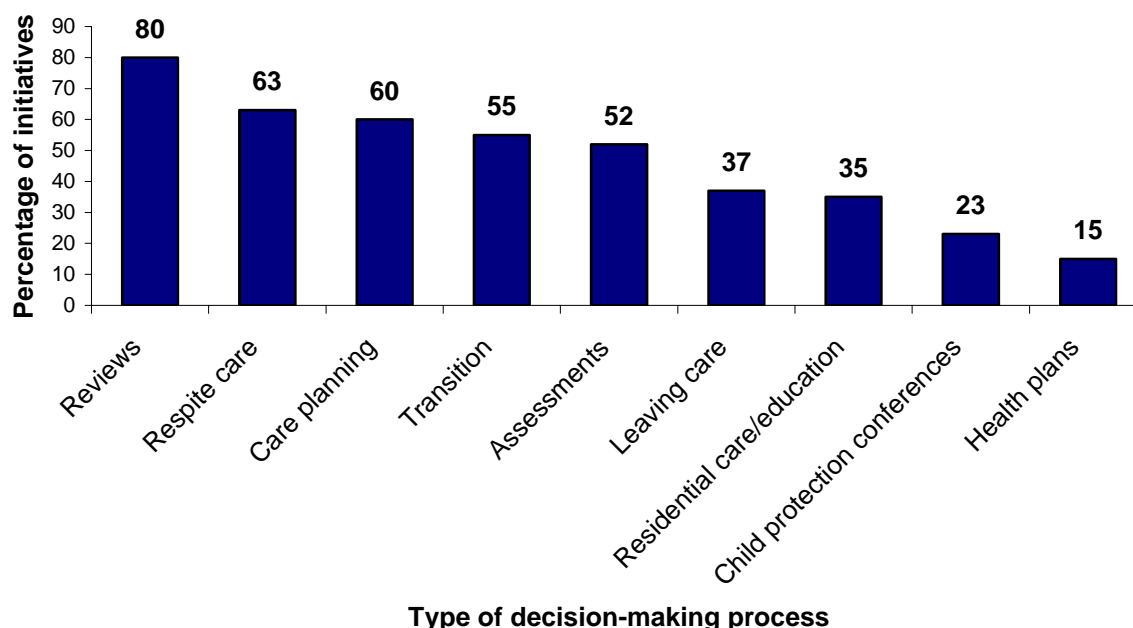
As Figure 3.3 shows disabled children and young people were more likely to be involved in their reviews than in any other decision-making process, with 80 per cent of respondents stating that they involve disabled children and young people. Over six in ten respondents reported involving children and 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.

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.

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 3.3 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 newletters 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 suggests 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 forums 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 will use the prize money to facilitate the involvement of children and young people with complex disabilities.

One young person'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 3.3   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 learning disabled young people 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 31).

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.

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, however, 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.

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 3.4). 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 association 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 joint 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 3.4   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.

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 3.5). However, no one method should be seen as superior to the other, both group and individual consultation have merits and disadvantages.

Table 3.5   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 3.6 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 3.6   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 3.7   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 documents	12 (n =4)	-
- Graffiti wall	-	5 (n= 2)
- Minutes of meetings	-	5 (n = 2)
- Missing data	41(n = 14)	53 (n = 20)
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 3.7 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 per cent 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 3.8   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 reviews	5 (n =3)	-
- Missing data	39 (n =22)	38 (n = 23)

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

Table 3.8 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 3.9   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'. 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 Widget and Viewpoint.

Table 3.10   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.

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 decision regarding their own care, 54 (83 per cent) stated that they provide support for children and young people to facilitate their involvement, although a couple of authorities wrote that this support was minimal. One authority 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 3.11 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.

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 were 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 particular 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.

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, 'Widget' 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 Widget, 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 authorities 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.

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.

Table 3.12   Support provided by authority 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)	63 (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 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 indicates 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.

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, 2002). 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 invariable 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.

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. Many supply anecdotal evidence which suggests that there are considerable practical benefits to services such as development of services better suited to service users, maximisation of resources, increased access and utilisation 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.*, 2003).

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. An outcome should not necessarily just be seen in terms of service provision, and an examination of other outcomes will be the subject of the final stage of this 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 on pages 20 - 22. Table 3.13 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 it meant that the authority 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 3.13 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

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.

Information was not sought 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. However, this is not an area that should be neglected and this will be explored within latter parts of the research study.

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 feel 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.

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 just 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.

Discussion

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. However, the limitations of this research must be acknowledged. 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. However, 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 is not an exhaustive picture of participation, it can only provide a snapshot of current 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 at this time.

The numbers of disabled children involved varied considerably 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. This echoes early findings that participation is still patchy and requires further development (Sinclair and Franklin, 2000; Council for Disabled Children, 2000, 2003; Cavet and Sloper, 2004). Indeed, 27 authorities reported that they were not undertaking any participation activity at all, and only 60 per cent of the 71 social service departments that responded involved disabled children and young people within both decision-making areas. In one-third of service development initiatives only up to ten young people were involved. Questions need to be asked as to whether these small numbers of disabled young people are the easiest to reach, most able to communicate, most articulate and confident, and whether they can accurately represent other disabled children and young people's views, particularly if they are not being adequately supported.

The age range of disabled children and young people involved varied, although involvement was greater for adolescents. Further research is needed to examine why disabled younger children are less likely to be taking part in decision-making, and what can be done to support younger children.

Encouragingly, disabled children are being involved in a range of decision-making areas, although it would appear that quite a lot of children's involvement in service development so far has centred on what could be termed 'children's issues' – activities, equipment or décor which are more concrete concepts and within a child's own experience. Involvement of disabled children and young people at a higher strategic level still seems to be rare. Such participation can involve more abstract concepts and so may be more difficult to involve, for example, children with learning disabilities. Within the area of service development, youth forums emerge as a popular mechanism for involving young people. The establishment of these might

indicate an attempt to increase the involvement of disabled young people in service developments and offer a mechanism into strategic planning arenas, however, many are newly formed and those that have been established longer have in the main represented looked after children and have only just started to address the participation of disabled young people. Further evidence needs to be gathered on the processes adopted by youth forums, how are they feeding into decision-making processes, how much weight is being given to their opinions and the outcomes of their formation. Questions remain as to which type of forum is most appropriate, for example, should forums be designed for both disabled and non-disabled young people or are forums for only disabled young people preferable? How inclusive are mixed forums?

A high level of reported partnership working between different agencies must also be viewed as positive, as much of the literature points out that disabled children's needs do not fall neatly within the boundaries of single agencies. Eighty per cent of service development initiatives were working with partners. However, only just over half of teams/areas had dedicated funding to facilitate children and young people's involvement within decisions about their own care, and only 64 per cent of service development initiatives had such funding. The resource implications of participation should not be underestimated and without adequate funding or long term planning what can be achieved is greatly reduced.

A huge range and variety of methods are being employed to involve disabled children and young people, with some areas developing methods or making good use of the resources available. However, questions remain unanswered as to which methods work best and in which situations, and are some authorities duplicating work? For example, a number reported developing review consultation instruments. Are there resource gaps and what else will help facilitate disabled children and young people's involvement?

Support for staff and young people appears patchy and respondents report a need for skills development and training. It would appear from respondents' comments that training is necessary for not only those young people and workers 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 terminology of participation and increased awareness of resource implications.

An area requiring further development is the provision of feedback to children and young people. Better mechanisms and more emphasis needs to be placed on providing appropriate feedback, and to creating a continued dialogue with children and young people involved in longer term projects.

The involvement of disabled children and young people within decision-making is an emerging area and there is a real need to share the experiences and skills which are

being developed. Evidence needs to be gathered on the outcomes of this work, some respondents reported positive outcomes in service development whilst for others only time will tell, however, more evaluation built into participation activity is required to increase our knowledge base.

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 and Downie *et al.*, 2000; Kirby *et al.*, 2003; Beresford, 1997; Ward, 1997; Morris, 1998b; Russell,1998; Marchant and Jones *et al.*, 1999; 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 currently being provided in participation work with disabled young people under the auspices of social services departments.

The final stage of this research will attempt to examine some of the outstanding questions and provide more detailed information. The survey has not allowed an examination of, for example, the equitability of young people's participation, an area that will be explored in more detail, particularly with regard to the involvement of 'hard to reach' groups of disabled children. The research will be looking to establish what factors can support and promote good practice in both the process and outcomes of disabled children's participation both within service development and/or tailoring their individual packages of care.

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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.
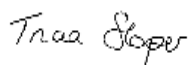
This research study is funded under the Department of Health Quality Protects Initiative, and will provide evidence to assist Social Services Departments to involve disabled children and young people in decisions about their own care and wider service planning. Our study will produce practical guidelines 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

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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) _____

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

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