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Participation of Disabled Children and Young People in Decision-Making within Social Services Departments: A survey of current and recent activities in England

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Abstract

A survey of all social services departments in England was undertaken in order to identify and investigate current work concerning the participation of disabled children within decision-making regarding their own care and in service development.

Developing a culture of, and good practice in children's participation is integral to government policy. Results demonstrate that disabled children are being involved in a range of decision-making areas, however participation is not yet embedded or sustained across all social services departments and the involvement of disabled children at a higher strategic level is still rare. The participation of disabled children needs further development including more evidence on which factors can support and promote disabled children's effective participation.

Keywords: disabled children and young people, participation, involvement, Quality Protects.

Background

In England, 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. The programme set national objectives, supported by more detailed sub-objectives and performance indicators, to improve the effectiveness of children's social services. Developing a culture of, and good practice in children's participation is fundamental to achieving the overall aim of Quality Protects, and was a requirement under Objective 8:

(Insert Fig: A)

Children's participation was also a QP priority area for action and was actively supported by the Department of Health's Children and Young People's Participation Project Team. Guidance published by the Department of Health (2001a) was unequivocal about the wish to see participation 'embedded and sustained across all QP objectives', reflecting the growing emphasis being placed on involving young service users in decisions about their own care and/or wider service planning, both in National and Local Government and the NHS (Willow, 1997, 2002; Department of Health, 1999, 2001b, 2003a; Sinclair and Franklin, 2000; Children and Young People's Unit, 2001; Cavet and Sloper, 2004).

There is a growing recognition and acceptance that children and young people should be involved in making decisions that affect them. This is reflected in law, government guidance, regulations and policy. Children's rights to expression and to receiving information are underpinned by Articles 12 and 13 of the UN Convention on

the Rights of the Child (UNCRC) (1989), which was ratified by the UK government in 1991. Article 13 is particularly 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. The Human Rights Act, 1998, (Article 10) requires central and local government to uphold a right to freedom of expression, and the Children Act 1989 requires local authorities to ascertain the wishes of children they look after or are about to look after, and to give these due consideration, subject to practicability, and the child's age and understanding. The guidance and regulations dealing specifically with 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 sharing in decision-making.

Service users 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. For example, within health national requirements for patient and public involvement place a duty on service providers to involve children and young people (Department of Health, 1999, 2001b), and the Children's National Service Framework stresses the need to consult and involve them, recommending that professionals 'adopt a systematic approach which enables children and young people to contribute to discussions about their needs, care or treatment....and express their views. This includes children with communication needs or who use non-verbal communication' (Department of Health/Department for Education and Skills, 2004, p91). 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.

The case for children and young people's participation is well documented and is often grouped into legal, political and social reasons (Sinclair and Franklin, 2000; Children and Young People's Unit, 2001; McNeish and Newman, 2002; Willow, 2002; Sinclair, 2004). Sinclair and Franklin (2000) summarise the reasons for involving children in the following way: to uphold children's rights; to fulfil legal responsibilities; to improve services; to improve decision-making; to enhance the democratic process and to promote children's protection. The benefits of participation to services and participants are often highlighted (see for example, Hennessy, 1999; Treseder, 1997). However, participation can also have negative consequences if children and young people are not listened to or their views are not taken into account (Sinclair, 2004).

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. However, evidence from generic studies suggests that the growth of participation of disabled children has been slower than that of non-disabled children (Sinclair and Franklin, 2000; Council for Disabled Children, 2000, 2003; Robbins, 2001; Department of Health, 2003). Recent reports concluded that although most councils reported on consultation this was mostly with parents of disabled children. 'Few had developed regular and on-going mechanisms for consulting disabled children' (Department of Health, 2003, p72). The Council for Disabled Children (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)....'even where the practice for consultation is good, disabled children and young people, particularly those with complex needs, are left out' (p22).

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; Sinclair 2004).

The level and nature of participation can vary. Boyden and Ennew (1997) state that there are different interpretations of the term 'participation'. It can simply mean taking part, being present, being involved or consulted. Alternatively, it can denote a transfer of power so that participants' views influence decisions. Although the second definition is primarily the concern of this study, the first is no less important or easy to achieve. Disabled children, for example, may lack the opportunity to participate in everyday activities. The social model of disability provides a framework for understanding the disabling barriers of social exclusion, prejudice and discrimination and how these can impact on participatory activities (for example, Morris 1998a, 2001; Watson and Priestley, 1999; Beresford, 2002).

A number of writers have developed typologies to illustrate participation. These generally make hierarchical distinctions between levels of participation according to the degree of power that is shared or transferred. Arnstein (1969) first developed the ladder of participation in relation to citizen involvement in community development.

Hart (1992) adapted this for children's participation and a number of variations on this have followed (Thoburn, Lewis and Shemmings, 1995; Shier, 2001). Some writers have criticised these typologies as they suggest a hierarchy with the objective being to reach the highest level (Treseder, 1997; Willow, 1997; Lardner, 2001). 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.

All of these models highlight the need to understand the term 'participation' and prompt examination of 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). How participation is translated into practical activity can take many forms each with their own characteristics, advantages and disadvantages. Within individual decision-making, most practice and research attention has been placed on participation in formal procedures such as assessments, care planning and reviews. However, involving children within decisions about their own care can also be undertaken on an informal basis. For example, through creating on-going dialogue, observation,

listening to spontaneous communication and engaging in joint activities (Kirby et al, 2003). Participation in public decision-making can be through the identification, development, provision, monitoring or evaluation of service delivery, service development and policy making both locally and nationally. This can take the form of consultation exercises, in research as respondents, advisors or 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; Sinclair, 2004).

Research on children's participation

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 (Shier, 2001; McNeish 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, reports of evaluations are scarce and we know little about the views of children themselves on their experiences of participation, which would help to inform the development of good practice.

Research on disabled children's participation

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 *et al.*, 2000; Kirby and Byson, 2002; Kirby *et al.*, 2003), less is known about additional specific factors, which could promote disabled children's participation.

Evidence to date from research and practice involving disabled children highlights the importance of identifying disability-related needs for participation and of adopting creative and flexible approaches in meeting these (Beresford, 1997; Ward, 1997; Morris, 1998b, 2003; Russell, 1998; Marchant *et al.*, 1999; The Children's Society, 2001). Some materials have now been developed to support the process of obtaining disabled children's views (Kirkbride, 1999; Triangle/NSPCC, 2001; Mencap, 2003). However, little information has been gathered on their use, it is not yet known for example, to what extent these resources are used in practice. Badham (2004) provides a useful example of an evaluation of a disabled young people's participation project, 'Ask Us!' initiated under Quality Protects, however, this is a rare example. 'Ask-Us!' was a national peer research project which used multi-media to consult with over 200 disabled children and young people. It culminated in the production of CD-Roms on exclusion and rights. The evaluation concluded that multi-media provided a

successful inclusive method of involvement and that changes had occurred in the attitudes and actions among those who had purchased the CD-Roms.

The research reported here is investigating disabled children and young people's participation within decision-making, to establish factors which can support and promote good practice in terms of the process and outcomes of participation. The first stage of the study, results of which are reported here, was a survey of all social services department in England. A further stage undertakes a qualitative case-study approach with children and young people (using verbal and non-verbal methods to facilitate communication), parents and professionals in a sample of five local authorities to find out 'what works' in order to make participation meaningful, effective and sustainable in respect of the processes and outcomes of disabled children's participation.

Methods

The survey was carried out during the summer of 2003 in order to identify and investigate current work concerning disabled children's participation. A two-stage approach was taken. A screening letter was sent to all Assistant Directors of Children and Families within Social Services departments in order to find out if participation work with disabled children was currently being undertaken or had been undertaken during the last twelve months, and, if so, to supply a contact name of someone who could complete a detailed questionnaire. This received a response rate of 86 per cent, identifying 102 social services departments who had involved disabled children in decision-making. Twenty-seven authorities indicated that they had not undertaken any work of this nature during the last year. 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 all participation activity. A detailed questionnaire was sent to the 102 authorities, a total of 71 were completed, a response rate of 70 per cent. The questionnaire was designed to investigate in detail participation activity, in particular the process as well as the outcomes of disabled children's involvement in decision-making. The questions were categorised around seven themes: the nature of participation, characteristics of the children and young people involved, characteristics of the participation activity, methods of involvement, support for children, young people and staff, outcomes and lessons learnt.

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 areas/teams. 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. For brevity, we have used the term 'children' to refer to people aged under 18 years.

Findings

Nature of disabled children's participation

Responses from the 71 authorities indicated that 60 per cent were involving disabled children and young people in both service development and decision-making regarding their own care. Forty per cent indicated involvement of disabled children within just one of these processes, with equal numbers involved in each decision-making area.

Within decisions regarding their own care, disabled children and young people were more likely to be involved in their review than in any other decision-making process, with over 80 per cent of respondents who involved children in decisions about their own care stating that they involve children in reviews. The least likely areas of involvement were within child protection conferences or their own health plans.

Within aspects of service development, disabled children were most likely to be participating in consultations concerning their views on play and/or leisure services (see Table 1). This is a similar theme throughout where disabled children and young people are in the main being asked for their opinions on tangible issues within their own experience, such as activities, equipment, toys, décor and changes to buildings/gardens within respite care, resource centres and short breaks rather than more abstract issues such as developing new forms of service. The responses also suggest the emergence of youth forums as a mechanism of participation, with 11 (16 per cent) of the 70 initiatives being youth forums. These forums were involved in a wide variety of activities including training and interviewing social services staff, consulting with other young people, producing newsletters and general consultation

work around service developments such as transition. From the information supplied, it appears that a number of the forums are being run by the voluntary sector, and some appear to be more embedded into local authority decision-making structures than others. Of the 11 youth forums, the data suggest that seven were formed specifically for the involvement of disabled young people, while disabled and non-disabled young people within the looked after population participated in three, and one respondent did not supply details of the forum's composition.

(Insert Table 1)

Characteristics of children and young people participating

The numbers of disabled children and young people involved in any one area varied from less than ten to over 50. Nearly a third of service development initiatives only involved up to ten young people, and 17 per cent of respondents involved fewer than ten young people within decisions regarding their own care.

Participation of disabled young people peaks around the age of 14 – 16. Although 90 per cent of respondents involved young people from the age of 11 in decisions about their own care, the corresponding figure for service development was 65 per cent (Figure B).

(Insert Figure B)

Responses suggest that the involvement of disabled children who are often described as being 'difficult to reach' is evident within both areas of decision-making.

The survey data illustrated that within decisions about their own care, 71 per cent of respondents were involving children 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. Within 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. These groups of children are the focus of later stages of this research.

Funding and partnership working

Just over half of respondents indicated that they had dedicated funding to promote disabled children's involvement in tailoring individual packages of care. A substantial number were benefiting from QP funding, which was being used to fund Children's Rights Officers, Advocacy Workers, complaints services and some participation and listening workers. In many areas, voluntary agencies were undertaking this work.

Within the area of service development, dedicated funding was reported in 64 per cent of initiatives. Funding was coming from a wide range of sources including QP, The Children's Fund, Health Action Zones, Single Regeneration Budgets, and New Opportunities Fund. Only a couple of respondents mentioned joint agency funding across education, health and social services, and one mentioned joint funding across adult and children's social services departments. Eighty per cent of these initiatives involved partnership working, with the voluntary sector featured in just under half of all projects (see Table 2). Nearly a quarter of service development initiatives were

single one-off exercises, just over a quarter were arrangements lasting over a year, with nearly a further quarter being permanent arrangements.

(Insert Table 2)

Methods of involvement

A wide variety of written, verbal, visual, computer/IT and arts based methods were being adopted to involve disabled children and young people. A number of authorities were developing their own materials, such as review consultation forms, to facilitate involvement, while others were making use of the published resources available such as the 'I'll Go First Toolkit' (McBride, 1999). In addition, artistic methods such as role-play, drama and puppets were also being used in a few cases.

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'. The survey data show that this is an area requiring further development. Eighty-three per cent of respondents provided support for disabled children and young people to enable them to participate in decisions about their own care, although comments suggest that this support can be minimal and variable. Seventy-six per cent of service development initiatives provided support. Across both decision-making areas the most likely forms of support were assistance with communication, transport and access to venues. Advocacy was quite widely available however, there were still low levels of training for children and young people and little information about the

authority's decision-making processes, both of which may encourage fuller participation and empowerment.

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. Results from this survey found that for the vast majority of respondents, training for staff had centred on communication and communication methods and was accessed predominantly through voluntary agencies. A number of respondents reported that they felt that training for staff had been limited, and identified this as an area of concern.

"There is a need for workers experienced in communication, social work staff do not practise the skills regularly enough to develop them"

The data indicate that there were 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.

"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"

Feedback given to children and young people

Good practice guidelines on participation indicate a need to provide feedback to children and young people involved in decision-making processes. 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). The findings from this survey indicate that 17 per cent of respondents involving disabled children within their own care did not provide any feedback to those involved. Where feedback was provided, this was mainly verbal through a social worker or advocate. When written information was provided, it was invariably provided to parents rather than children. Within service development, a third of the initiatives were not providing any feedback to the disabled children and young people participating, 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 from the survey data whether this was occurring within the longer-term initiatives.

Outcomes

There has been little published research examining the outcomes of children's participation *per se*, and there is scant information 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 benefit service users, maximization of resources, increased access and utilization of services, and increased participatory practice. In addition, outcomes include 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).

Findings from the survey showed that 44 per cent of service development initiatives (n=31) indicated that there had been changes to services as a result of disabled children and young people's involvement. However, for the majority, it was too early in the project to indicate any outcomes. Table 3 shows that most changes to service provision had been through altering activities and/or changes to décor, reflecting the finding that a large number of initiatives had been consultations about this topic.

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.

(Insert Table 3)

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.

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. This is not an exhaustive picture of participation, it can only provide a snapshot of current activity. In addition, it only provides information from services, rather than more in-depth information on the processes and outcomes of participation from the point of view of children, young people and parents themselves. The qualitative methods adopted in the later stages of this research will enable a more detailed exploration of the complexity of participation. For example, motivations behind adopting certain methods and level of involvement, organisational, structural and attitudinal barriers, resource implications and the personal experiences of all parties involved. The limitations of a survey method has meant that disabled children have been treated as a homogenous group, although it is well known that children's lives are shaped by many intertwining factors such as age, gender, ethnicity, culture and disabling barriers such as prejudice, discrimination and social exclusion (see for example, Shakespeare and Watson, 1998; Davis *et al.*, 2003; Jones, 2003).

The latter stages of this research will allow a more detailed examination of for example, the equitability of disabled young people's participation, in particular the multi-faceted barriers faced by young people with communication impairments within decision-making processes.

The results presented here suggest that disabled children and young people are being involved in decision-making both within their own care and service development, however participation of disabled children is not yet embedded and sustained across all social services departments. Not all authorities were involving disabled children and young people, and the numbers of those who are being involved varied considerably across areas. 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 are being asked to and can accurately represent all disabled children and young people's views, particularly if they are not being adequately supported. The results reaffirm that some disabled children have not been afforded their full participation rights under the Children Act 1989 or UNCRC (Cavet and Sloper, 2004). On a positive note, the involvement of children with communication impairments and complex needs appears to be increasing, very little evidence of involvement had

been found in the earlier study on Quality Protects (Council for Disabled Children, 2003). The survey data does not allow us to establish the numbers of children involved, however, given the low numbers of disabled children being involved *per se* it might be assumed that these figures are small. The next stage of this research will examine through case-studies the processes and outcomes of the participation of these groups of children within decision-making.

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 were being involved in different decision-making areas, although it would appear that quite a majority 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 it 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 forums 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 joint forums? Sinclair (2004) raises the issue of representativeness and this is particularly pertinent to youth forums. Questions need to be asked as to if/how the young people involved are representing the wider community of disabled young people. Have young people been prepared for the concept of representation? This can be a complex concept, have the young people been given enough information to understand this?

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 broad range and variety of methods were being employed to involve disabled children and young people, with some areas developing methods or making good

use of the resources available. However, little is known about which methods work best and in which situations, and there is some evidence to suggest that authorities were duplicating work, for example, a number reported developing their own review consultation instruments. Further research should examine whether there are resource gaps and what else will help facilitate disabled children and young people's involvement.

Existing literature has reported a need for increased support for those involved in participation and this survey reiterated this, with support for staff and young people appearing patchy. Respondents reported a need for skills development and training, with 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 rights, empowerment, the terminology of participation and increased awareness of resource implications.

Another area requiring further development is the provision of feedback to children and young people. Better mechanisms for feedback are required, 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 et al., 2000; Kirby *et al.*, 2003; Beresford, 1997; Ward, 1997; Morris, 1998b, 2003; Russell, 1998; Marchant *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 were 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 these outstanding questions, and provide more detailed information through undertaking case-studies within five local authorities across England.

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References

Arnstein, S. (1969) A Ladder of Citizen Participation in the USA. *Journal of the American Institute of Planners*, **35**, **4**, pp216-224.

Badham, B. (2004) Participation for a Change: Disabled Young People Lead the Way. *Children and Society*, **18**, pp 143-154.

Beresford, B. (1997) *Personal Accounts: Involving disabled children in research*, London, The Stationery Office.

Beresford, B. (2002) 'Preventing the Social Exclusion of Disabled Children', in McNeish, D, Newman, T and Roberts, H. (eds) *What Works for Children?*, Buckingham, Open University Press.

Boyden, J. and Ennew, J. (1997) *Children in Focus. A manual for participatory research with children*, Stockholm, Rädda Barnen.

Cavet, J. and Sloper, P. (2004) Participation of disabled children in individual decisions about their lives and in public decisions about service development. *Children and Society*, **18** (**4**), pp278-290.

Children and Young People's Unit. (2001) *Learning to Listen: core principles for the involvement of children and young people*, London, Department for Education and Skills.

Cohen, J. and Emanuel, J. (1998) *Positive Participation: Consulting and involving young people in health-related work: a planning and training resource*, London, Health Education Authority.

Council for Disabled Children. (2000) *Quality Protects: second analysis of management action plans with reference to disabled children and families*, Department of Health, London.

Council for Disabled Children. (2003) *Fourth Analysis of the Quality Protects Management Action Plans: Services for Disabled Children and their Families*, London, Council for Disabled Children.

Davis J, Watson, N, Corker M and Shakespeare T. (2003) 'Reconstructing Disability, Childhood and Social Policy in the UK', in Hallett, C and Prout, A. (eds) *Hearing the Voices of Children: Social Policy for a New Century*. London, Falmer.

Department of Health. (1991) *The Children Act 1989 Guidance and Regulations: Volume 6 Children with Disabilities*, London, Department of Health.

Department of Health. (1999) *Patient and Public Involvement in the new NHS*, London, Department of Health.

Department of Health. (2001a) *The Quality Protects Programme: transforming children's services*, 202-3, LAC (2001), 28, London, Department of Health.

Department of Health, (2001b) *The Expert Patient: A new approach to chronic disease management for the 21st century*, London, Department of Health.

Department of Health, (2003) *Transforming Children's Services: An Evaluation of Local Responses to the Quality Protects Programme. Year 4*, London, Department of Health.

Department of Health/Department for Education and Skills (2004) *National Service Framework for Children, Young People and Maternity Services: Care Standards*, London, Department of Health.

Franklin, A. and N, Madge. (2000) *In Our View: Children, teenagers and parents talk about services for young people*, London, National Children's Bureau.

Hart, R. (1992) *Children's Participation: From tokenism to citizenship*, Florence, UNICEF.

Hennessy, E (1999) Children as Service Evaluators. *Child Psychology and Psychiatry Review*. **4**, pp153-161.

Jones, B (2003) *Childhood Disability in a Multicultural Society*. Oxon, Radical Medical Press.

Kilgour, K. (2002) *Circus Skills: A Training, Support and Development Needs Survey of Participation Workers*, London, Carnegie Young People Initiative.

Kirby, P and Bryson, S. (2002) *Measuring the Magic? Evaluating and Researching Young People's Participation in Public Decision-Making*, London, Carnegie Young People Initiative.

Kirby P, Lanyon C, Cronin K and Sinclair R. (2003) *Building a culture of participation: Involving children and young people in policy, service planning, delivery and evaluation. Research report*, London, Department for Education and Skills.

Kirkbride, L. (1999) *I'll Go First: Planning and Review Toolkit for use with disabled children*, London, The Children's Society.

Lardner, C. (2001) *Exploring good practice in youth participation: A critical review*, Edinburgh, Clarity.

Lightfoot, J and Sloper, P. (2002) *Having a Say in Health: Involving Children and Young People with a Chronic Illness or Physical Disability in Local Health Services Development*, York, Social Policy Research Unit, University of York.

Marchant R, Jones M, Julyan A and Giles A. (1999) *Listening on all Channels: consulting with disabled children and young people*, Brighton, East Sussex County Council and Triangle.

McNeish, D. (1999) Promoting participation for children and young people: some key questions for health and social welfare organisations, *Journal of Social Work Practice*, **13(2)**, pp191-203.

McNeish D, Downie A, Newman T, Webster A and Brading J. (2000) *Review of young people's participation in Lambeth, Southwark and Lewisham*, London, Lambeth, Southwark and Lewisham Health Action Zone.

McNeish, D and Newman T. (2002) Involving Children and Young People in Decision making, in McNeish D, Newman T, Roberts H (ed). *What Works for Children?* Buckingham, Open University Press, pp186-204.

MENCAP. (2003) *Listen Up. Helping Children with a Learning Disability Complain about the Services they use*, London, MENCAP.

Morris, J. (1998a) *Still Missing? Volume 1 The Experiences of Disabled Children and Young People Living Away from their Families*, London, The Who Cares? Trust.

Morris, J. (1998b) *Don't Leave Us Out: Involving disabled children and young people with communication impairments*, York, Joseph Rowntree Foundation.

Morris, J. (2001) Social Exclusion and Young Disabled People with High Levels of Support Needs. *Critical Social Policy*, **21 (2)**, pp161-183

Morris, J. (2003) Including all Children: Finding Out About the Experiences of Children with Communication and/or Cognitive Impairments. *Children and Society*, **17 (5)** pp337-348.

Rabiee P, Priestley M and Knowles J. (2001) *Whatever next? Young Disabled People Leaving Care*, York, York Publishing Services.

Robbins, D. (2001) *Transforming Children's Services: an evaluation of local responses to the Quality Protects Programme Year 3*, London, Department of Health.

Russell, P. (1998) *Having a Say! Disabled Children and Effective Partnership in Decision-Making. Summary Report*, London, Council for Disabled Children.

Shakespeare, T and Watson, N (1998) 'Theoretical Perspectives on Research with Disabled Children', in Robinson, C and Stalker, K (eds), *Growing up with Disability*. London, Jessica Kingsley.

Shier, H. (2001) Pathways to participation: Openings, opportunities and obligations. A new model for enhancing children's participation in decision-making, in line with Article 13.1 of the United Nations Convention on the Rights of the Child, *Children and Society*, **15 (2)** pp107-117.

Sinclair, R and Franklin A. (2000) *Young People's Participation, Quality Protects Research Briefing*, No.3, London, Department of Health.

Sinclair, R. (2004) Participation in Practice: Making it Meaningful, Effective and Sustainable. *Children and Society*, **18**, pp 106-118.

Stone, E. (2001) *Consulting with Disabled Children and Young People*, York, Joseph Rowntree Foundation.

The Children's Society. (2001) *Ask Us: A Children's Society multi-media guide to consultation for the Quality Protects initiative*, London, The Children's Society.

Thoburn J, Lewis A and Shemmings, D. (1995) *Paternalism or Partnership? Family Involvement in the Child Protection Process*, London, HMSO.

Treseder, P. (1997) *Empowering Children and Young People*, London, Children's Rights Office/Save the Children.

Triangle/NSPCC. (2001) *Two Way Street: communicating with disabled children and young people video pack*. Leicester, NSPCC.

United Nations (1989) *Convention on the Rights of the Child*. Geneva, United Nations.

Ward, L. (1997) *Seen and Heard: Involving disabled children and young people in research and development projects*, York, Joseph Rowntree Foundation.

Watson, N and Priestley M (1999) *Life as a Disabled Child. A Qualitative Study of Young People's Experiences and Perspectives, Final Project Report to ESRC.*
Leeds: Disability Research Unit, University of Leeds.

Willow, C. (1997) *Hear! Hear! Promoting children and young people's democratic participation in local government*, London, Local Government Information Unit.

Willow, C. (2002) *Participation in Practice: Children and Young People as Partners in Change*, London, The Children's Society.

Figure A: Objective 8 of the Quality Protects Programme

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 are:

- 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.*

Table 1: 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.

Figure B: Age of children involved in the initiatives

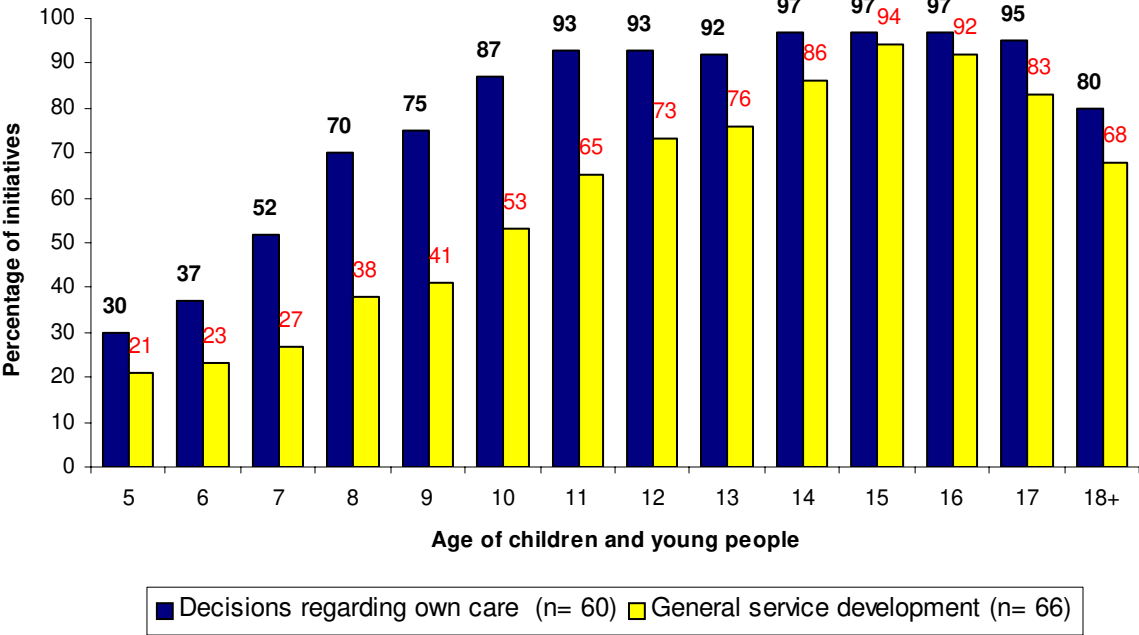


Table 2: Partner agencies involved in young people’s decision-making within service development (n=70)

	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 when ‘education’ was mentioned as a partner 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 eg. PCT or NHS Trust.

Table 3: 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

*NB an initiative could have more than one outcome.