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Supporting the Participation of Disabled Children and Young People in Decision-making

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Abstract

Increasing children's and young people's participation in decisions, about their own care and about service development, is a policy priority. Although in general participation is increasing, disabled children are less likely to be involved than non-disabled children and it is unclear to what extent children with complex needs or communication impairments are being included in participation activities. This article presents research exploring factors to support good practice in participation and discusses policy and practice implications.

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Introduction

Since the late 1990s, there have been a number of policy developments to increase the involvement of children in decision-making processes concerning their own care and service development. These include the Government's responsibilities to fulfil the requirements of the Children Acts (1989 and 2004), Article 12 of the UN Convention on the Rights of the Child (CRC) (1989) and the Human Rights Act (1998). (For brevity, the term children is used to cover children and young people aged up to 18 years.) Quality Protects, launched in 1998, set national objectives for social services for children in need, one of which focused specifically on children's participation (Department of Health, 2001). The government also announced commitment to involving children in all aspects of its work (Department of Health, 2002).

The Children Act guidance and regulations relating to disabled children (Department of Health, 1991) make it clear that disabled children cannot be assumed to be incapable of sharing in decision-making and arrangements must be made to establish their views. For people aged over 16, the Mental Capacity Act 2005 states that a person must be assumed to have decision-making capacity unless it is established that they lack capacity. Capacity is seen as decision-specific, and should be assessed for a particular decision at a particular time. The Act also protects those who are unable to make their own decisions. In addition, Article 13 of the CRC grants children the right to receive and express all kinds of information and ideas in a variety of forms. This is particularly important for disabled children who may use communication methods other than speech. A central theme of the National Service Framework for Children, Young People and Maternity Services (NSF) in England stresses the need to consult and involve children. Standard 8 for disabled children and those with complex health needs states:

Professionals should ensure that disabled children, especially children with high communication needs, are not excluded from the decision-making process. In particular professionals should consider the needs of children who rely on communication equipment or who use non-verbal communication such as sign language.

(Department of Health/Department for Education and Skills, 2004: 29)

Evidence suggests that while children are increasingly being involved in decision-making, growth has been slower in respect of disabled children (Council for Disabled Children, 2003; Sinclair and Franklin, 2000). A review of literature (Cavet and Sloper, 2004) concluded that the participation of disabled children needs further development, with little available evidence of good practice. Some disabled children have not been afforded their full participation rights under the Children Act 1989 or the CRC, for example, due to a lack of availability of communication aids for those children who rely on them (Morris, 1998; Rabiee *et al.*, 2001), and many disabled young people are not adequately involved in decision-making around their transition process

(Beresford, 2004). Marchant and Jones (2003) noted the linguistic and cultural barriers to involvement faced by disabled children from ethnic minority groups.

A study of 30 children living in residential settings found that they had not been consulted about their care (Morris, 1998). Morris concluded that where children had very limited or no use of speech, or were seen as having high levels of impairment, little effort was made to find alternative methods of communication.

There is a small body of evidence providing examples of disabled children who have learning difficulties and/or communication impairments expressing their views about services (see for example, Lewis, 2001; Marchant and Crisp, 2001; Marchant *et al.*, 1999). These studies highlight some of the challenges involved and illustrate that adequate preparation, commitment, resources, flexibility and skilled, trained facilitators are required. The Council for Disabled Children is currently engaged in mapping participation activity, with a view to sharing good practice and increasing levels of disabled children's participation.

The literature suggests that a number of barriers prevent effective participation for all children, especially disabled children. McNeish and Newman (2002) summarise that involving children in decision-making processes takes time, involves developing new skills for adults and children, requires investment of resources, can entail major shifts in attitude in organisations and like any process of negotiation, can make decision-making slower. Barriers also include attitudes of adults where there is a prevalent view of children as incompetent and in need of protection. The complexity and bureaucratic nature of organisations has been identified as hampering participation (Kirby *et al.*, 2003; Matthews, 2001). A lack of training and support for adult facilitators and children, and of research evidence to support participatory activities has also been highlighted (Cavet and Sloper, 2004; Kirby and Bryson, 2002).

Despite a growing body of literature on involving children in general, less is known about specific factors which could promote disabled children's participation. This research explored factors to support good practice in the participation of disabled children. The research had a particular focus on children with complex needs who may be seen as 'hard to reach' in participation: children with communication impairments, autistic spectrum disorders or complex health needs.

Methods

The research involved two stages. First, a survey of all social services departments in England to identify the range and nature of disabled children's participation, reported elsewhere (Franklin and Sloper, 2006).

Stage 2, reported here, consisted of case studies of six areas to explore the processes and outcomes of participation activity within social care from the points of view of professionals, parents/carers and disabled children involved. Two areas focused on involving children in decisions about their own care through the review process; three focused on activities, for example youth forums, which aimed at involving children in service development; and one area undertook both types of involvement. Selection criteria included: participation was current or very recently completed; participation had an outcome or appeared to have a likely outcome; 'hard to reach' groups of disabled children had been included or there were significant plans for their involvement. Additionally across the sample, examples were sought that reflected a range of ages, methods and partnership working.

Seventy-six professionals, 24 parent/carers and 21 disabled children, aged 5-18, were interviewed. The majority of children interviewed had a learning difficulty, ranging from mild to severe, and six children had a communication impairment. The varied nature of the case studies required a flexible approach to the interview schedules; however, the following areas were explored: for staff, details on funding arrangements, job role, training, factors which influence participation, processes and outcomes of participation and reflections on their experiences. Interviews with parents and children concentrated on the benefits and disadvantages of participation, methods of involvement, information about participation and any outcomes of participation. The majority of children interviewed took part in a verbal face-to-face interview. For those who participated in events, photographs were used to stimulate discussion and memory. For interviewees with learning difficulties and/or communication impairments, verbal questioning was supplemented with a visual tool adapted from 'Talking Mats' (Murphy, 1998; Rabiee *et al.*, 2006). A series of cards were produced, with a written question, e.g. 'Were you listened to?', and accompanying pictorial BoardmakerTM symbols. Children could choose from a series of responses on separate cards which could be stuck on the question card. These cards included words and symbols. All interviews were analysed using the 'framework' method of analysis (Ritchie and Spencer, 1994).

Discussion of findings

Nature and extent of disabled children's participation

The literature points to a need for a wide range of methods of involvement and for these to be flexible and tailored to the participant (Cavet and Sloper, 2004; Kirby and Bryson, 2002; Lightfoot and Sloper, 2003). However, this study found that across the case studies similar methods were adopted to facilitate children's involvement, with areas choosing to develop one method of participation and adopting, at least at this stage, a 'one-model fits all' method. Within individual decision-making, all authorities developed questionnaires/booklets to be used in children's reviews. There were

some differences in the format, one area created a glossy, cartoon style review booklet with a written question and answer format, another developed a questionnaire with written questions and Widge symbols, another area developed a review pack for social workers to use which contained photographs, questions and 'feelings faces' for children to indicate, 'happy', 'ok' or 'sad'.

In service development, two areas commissioned a youth forum/advisory group and two chose to undertake larger scale events. There was limited evidence of children influencing the choice of methods. However, in one area a children's advisory group had been set up in response to the request made in a consultation exercise for more opportunities to influence decision-making. Only one area engaged in multimedia and creative arts to facilitate involvement.

Supporting the earlier survey findings of this study (Franklin and Sloper, 2006), the case studies illustrated that the numbers of disabled children participating in decision-making were small, suggesting that not all children and young people are being involved in decisions regarding their individual care and that, in the main, only small numbers are being involved in service development. Professionals reported that there was limited involvement of disabled children within their reviews, as one social worker explained, 'I've worked for the team for four years and in the whole of the four years I think I have managed to do it with three clients'. The majority of parents interviewed reported that their children had never been involved in decision-making processes concerning their care.

'Hard to reach' disabled children and young people

This research aimed at focusing on the involvement of children who have been identified as being particularly difficult to reach and all case studies were selected on the basis of their plans to involve children with these conditions. However, despite the research tracking areas for nearly two years, there was only limited evidence of this occurring. In some areas plans to include these groups of children did not come to fruition because of lack of resources. There were examples of children with these conditions taking part in and enjoying larger scale events (a participation activity day and creative workshops linked to the creation of a DVD), although their level of involvement was limited. The DVD itself, however, potentially provided a tool for developing the skills and experience of children in these groups to become involved in decision-making. The DVD's interactive game enables children to practise decision-making and understand choice in a fun way.

Two areas which achieved greater involvement of children with these conditions started from the premise that they would find the means to facilitate the involvement of all children. Both areas made use of research evidence to support their work. They prioritised the training and resources required and demonstrated confidence, expertise, determination and a 'can-do' attitude:

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

The findings suggested that unless explicit attention is placed on these specific groups of children, then the small numbers of disabled children participating will continue to be the easiest to reach, most able to communicate and the most articulate and confident. Within service development, questions need to be asked as to whether a narrow sample of children can adequately represent the views of other disabled children and if so, are they being adequately supported in their role as representatives. Equally within decision-making regarding their own care, few disabled children appear to be involved, yet they all have the right to participate in these decisions.

Views on participation

Results suggested that although most professionals and parents/carers were committed to participation, saw the importance of it and the potential benefits, a minority were not convinced. In addition, although committed, many interviewees questioned how this could be achieved in a meaningful way, particularly for children with more complex needs.

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

A number of respondents raised concerns over the capabilities of children with cognitive impairments to understand the concepts of decision-making, the process of weighing up options and choosing, abstract concepts and timeframes. In addition, apprehension was expressed about interpretation, both in terms of knowing whether a child had fully understood the process or questions being asked, and also how to interpret a child's response, particularly if the method of communication was new to a social worker, the social worker did not know the child well, or they were relying on an 'interpreter', normally the child's parent/ carer.

Interviews with some social workers suggested that there was a concept of 'ideal participation' based on the mainstream agenda, and this did not appear to have been translated successfully to be meaningful for some disabled children. There sometimes appeared to be a notion that anything less than a child taking part in a review meeting and contributing to complex decision-making processes was not valid.

For example, when the views of children with learning difficulties had been sought, it might have been at a level of 'what I like' and 'what I do not like' about respite, and this was sometimes viewed as limited, with a few social workers questioning its validity.

Participation is a continuum along which the type of participation activity should be determined according to the circumstances and the participating children (Kirby *et al.*, 2003). Alderson and Montgomery (1996) defined levels at which children can participate: being informed, expressing a view, influencing the decision-making process and being the main decider. These levels are useful in understanding the meaning of participation for disabled children. For example, for disabled children with cognitive impairments their participation may be at a level of choosing between two different options, as illustrated in the DVD produced by one area where children were given simple choices such as what they want for breakfast. This should be seen as a valid means of participation and afforded equal status and priority with other levels of participation. For some children choosing between two options may be the only level at which they are able to participate, but for others this might be the starting point from which to build. In order to facilitate this, children and young people need to be given the opportunities to gain experience and develop their skills, and information to support their participation.

Clearly there is a need for more understanding of what participation can mean for disabled children and of a continuum of participation. Examples of practice explored in this study highlighted how social workers, when trained and properly equipped and supported, gathered children's views on their experience of respite care and successfully used this within the review process. As one practitioner explained, small changes can make a difference to the quality of a child's experience at a respite centre:

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

A number of social work respondents raised the issue of choice and the importance this has in children's participation. Some reported difficulty in reconciling children's participation in decision-making with a lack of choice in terms of service provision. However, one manager explained how despite limited choice, a young person could still be involved and make a valid contribution to transition planning:

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

to make this the same for him.

Questioning participation

Some social workers were concerned that parents might feel that their child's participation was 'more interference', 'a waste of time and resources' or 'a backdoor route to cutting services'. Parents interviewed did not express those concerns but had concerns about how their child could be involved given their communication difficulties and cognitive impairments, and/or questioned the ability of their social worker to obtain the child's view:

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

Parents/carers wanted to be part of the process and required information about what participation is, what it is trying to achieve and examples of successful participation so that they could see the benefits it might have. Parents may need the opportunity to talk through their concerns about how their child will contribute, and reassurance about service provision.

However, in general, parents were pleased with the results when their child participated. Some parents had been surprised at the level of response their children had given, for some their initial scepticism had averted and two had witnessed their children making a valid contribution to their reviews.

However, another parent provided a useful reminder that participation is more than just listening, it also requires follow up action:

It's all right asking our opinion, and asking our children's opinion, but if that feeds into a document that's just filed away then there's not much point in it really. If it actually feeds back into action then you feel as if you've actually been effective in attending.
(Parent)

Children's views on participation

Although gathering the views of disabled children with experience of participation had been a central aim of this study, the small numbers actually participating within decision-making processes impinged upon the amount of data that could be collected. However, all children who had been involved in any level of participation within the

case study areas were invited to take part. Their key messages include they:

- often had limited contact or rapport with social workers;
- had few opportunities to express their views about services;
- often had a limited understanding of what they had been involved in, either they had received no explanation or information had not been given to this in accessible formats;
- enjoyed taking part, being listened to and being able to make choices;
- particularly enjoyed methods which were creative and fun;
- enjoyed the socialising associated with being part of a youth forum;
- would like more opportunities to undertake participation, and be kept informed of what happens.

Facilitators and barriers to participation

Clarity about objectives, processes and possible outcomes

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

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

It should be noted that there were no examples of children devising objectives themselves, this was led by adults.

Fragility of disabled children's participation

The fragility and fragmented nature of participation activity was evident throughout the research. Much practice resting on a few key, dedicated professionals and in their absence work ceased or was frozen. Staff turnover also negatively affected participation activity. For example, one area had undertaken authority-wide training in participation methods for social workers and had purchased participation toolkits. However, it was reported that a significant number of those who had undertaken the training were no longer in post and the resources were 'gathering dust'.

There were also practical barriers impeding participation. Within one case study a youth forum had to be disbanded for months because of a loss of their meeting venue and a lack of alternative accessible places to meet. This resulted in a loss of

momentum and interest by a number of children.

Embedding practice

Participation activity appeared not to be embedded in the culture of the organisations studied and to be carried out in isolation from other activities. However, the difficulties of moving from ad hoc activities to embedded practice were considerable: as one manager commented, a whole culture change was needed whereby disabled children's participation and communication with children, by whatever means suits each child, was an expectation.

Likewise, Sinclair (2004) argued that if children's participation in decision-making is to be meaningful and effective in influencing change, it is necessary to move beyond one-off or isolated participation and consider how participation becomes embedded as an integral part of adults' relationships with children. Kirby *et al.* (2003) indicated how organisations can start building cultures of participation, through seeing participation as a process and not an isolated event: changing attitudes, procedures and styles of working across all levels; creating champions of participation to support change across the whole organisation; and developing a shared vision and understanding of participation. Key to this is senior management support and mainstreaming of practice.

One area had initiated that all induction courses contain an element highlighting the importance of communication, so that 'you are starting that culture as soon as someone steps forth, you are creating an expectation'.

Staff turnover, lack of funding for participation (especially longer term), the rapidly changing environments, the length of time that participation can take and the fact that the outcomes of this work may not be identifiable in the short term, all hindered embedding of participation.

Partnership working

Case study areas involved in service development benefited from partnership working. Adopting a wide definition of partners appeared to assist partnership working, so that children, parents and the wider community of professionals are seen as partners and given a clear understanding of the objectives, processes and possible outcomes of participation. This led to a better understanding of participation, and might lead in the longer term to a more participatory climate. Working in partnership also brought benefits such as expertise, ideas and funding. Case studies indicated that joint understanding, shared ownership between organisations rather than individual representatives, information and task sharing were vital.

The research suggested that participation would benefit from greater partnership with schools and education. Many social workers and parent/carers spoke of the need for working with those who were expert in communication methods. Social workers reported the difficulties they faced with not seeing a child regularly enough to develop

a close relationship and understanding of their communication method, and identified that schools were best placed to assist with facilitating participation. Social workers and parents/carers were often not aware of techniques and systems being used within schools or skilled in using the child's communication method. There was a reported need for more information sharing and partnerships between schools, education, parents/carers, social workers and the wider network of professionals working with disabled children, around communication methods. This study was unable to draw on examples of this in practice, but it would appear to be an area that would benefit from closer examination. However, a number of social workers reported that partnership working was still difficult with some professional boundaries still in place, and varying degrees of willingness and ability to work in partnership. Others had different experiences, a manager stated:

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

Training, support and resources

The need for training and staff development is a common theme in the published literature (Cavet and Sloper, 2004; Kirby and Bryson, 2002; Lightfoot and Sloper, 2003; McNeish and Newman, 2002). This research reconfirmed this, whereby more training was needed for staff to enable them to support children's participation, including training in methods of communication with children who do not use speech. Many social workers spoke of not having the skills, knowledge, training, confidence and experience for consulting disabled children. They also reported a need for more training, resources and support in IT and creative skills, to develop and adapt participation methods, and also training in the theory and methods of participation with particular reference to disabled children. Involving disabled children in decisions takes time: to get to know a child, understand the children's communication and prepare them to express views. Many workers reported that there needs to be recognition that additional time is required when working with some disabled children, particularly if a child uses a non-verbal means of communication. Repeat visits may be required for some children who may be ill, unsettled or tired on the day or whose concentration levels are limited. Preparation time may also be greater if social workers are required to adapt materials into symbols or alternative communication systems, undertake observation work with a child, or identify and work in partnership with other professionals who are familiar with a child's communication system. Where appropriate tools were developed, social workers were given the training and confidence to use the tools and senior management championed the process and monitored practice, participation was achieved, even for 'hard to reach' groups.

Likewise, children may also need support and training if participation is to be meaningful and successful (Kirby *et al.*, 2003; Treseder, 1997). For many of the children in the case studies, this was their first experience of expressing their views

about services. Clearly children need to be supported in undertaking this role and in developing the skills and confidence required. There also appears to be a lack of information designed for disabled children which would help their understanding of decision-making processes.

Feedback

This study indicated that often feedback was not provided to the children involved. Yet this is vitally important if children are to feel their views are valued and are to be supported in developing their skills. The data suggest that often feedback was only given to parents/carers or, if given to young people, was verbal. Children were rarely provided with an accessible permanent record to which they could refer, for instance during the period between reviews. A few parents/carers reported that when given a record of their views their child looked at it repeatedly, some seeing it as a record of achievement.

Outcomes of disabled children's participation

When participation did take place, it was viewed as a very positive experience by those interviewed. There were examples of children influencing decisions made in their reviews and changes to service provision as a direct result of children's views. One reported outcome, although difficult to measure, appeared to be a change in attitude towards participation and a raised awareness of its potential. Other outcomes highlighted by children and parents were the positive effects of children feeling that they were listened to and valued, gaining confidence and learning new skills. However, there were few examples of disabled children directly influencing service commissioning, service priorities or service evaluation.

The measuring and documentation of the outcomes of participation activity is still an underdeveloped area, and even though some of the case studies were monitored for nearly two years there was limited evidence of measurable outcomes. None of the case study areas had in place systematic procedures for recording, monitoring or evaluating the activities undertaken.

Implications for policy and practice

The results of the research provide some indications of where development of policy and practice on disabled children's participation is needed:

- a broader understanding of the meaning of the term 'participation' for disabled children, with an emphasis on the validity of children participating at whatever level is appropriate for them;
- recognition that disabled children communicate in mediums other than speech, including recognition that observation can be a valid means of ascertaining the views of some disabled children with profound and multiple disability;
- an individualised approach to participation, with attention placed on children's communication methods where appropriate;

- more attention and resources placed on developing the participation of wider range and number of disabled children;
- more recognition of the resources, time and support required to facilitate successful participation;
- more training, support and skills development for staff and children;
- the development of more partnership working to facilitate participation;
- opportunities for those engaged in disabled children's participation to share information, support and skills development, both locally and nationally;
- more emphasis placed on feedback to those involved;
- the importance of ensuring that in individual decision-making, children's views are taken into account in developing and reviewing care plans, and that where views cannot be acted upon, it is explained to the child and family why this is so;
- in service development initiatives, ensuring that mechanisms are put in place for children's views to be fed into decision-making and, again, that children are kept aware of what is happening, and the reasons why developments may not be taking place;
- the need for monitoring and evaluation of participation to feed into future development of practice.

Further areas of research

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

Little attention has been placed on the evaluation of participation activity. More evaluation and attention placed on defining and measuring outcomes of participation, coupled with more detailed examination of the resource implications of participation, would help services to plan participation more effectively. So far, most research and participation attention has focused on formal mechanisms such as reviews, yet much could be learnt from a closer examination of informal approaches to participation which may be more appropriate for some disabled children. More information on what might be changing for disabled children as a result of participation activity would also help to create greater understanding of the meaning of participation for disabled children, and might also help to convince those not yet committed to this way of working.

Research examples of partnership working in participation across social care and other partners are also limited and as already highlighted, evidence on partnerships between education, schools and social care is one particular area requiring attention. Much could be learnt from an examination of the literature on supporting disabled

adults' decision-making. So far this body of knowledge has remained rather polarised from that of children's participation (see for example, Edge, 2001; Porter *et al.*, 2001; Ware, 2004).

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