

# Supporting the Participation of Disabled Children and Young People in Decision Making

Anita Franklin and Patricia Sloper

R  
E  
S  
E  
A  
R  
C  
H  
F  
I  
N  
D  
I  
N  
G  
S

RESEARCH FINDINGS FROM THE  
SOCIAL POLICY RESEARCH UNIT

S | P | R | U

THE UNIVERSITY *of* York

JANUARY 2007  
no.2007-01

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

## Key findings

- Participation at any level was only happening for a small number of disabled children. These are mainly the children who are the most able to communicate, most articulate and confident.
- Most professionals and parents/carers saw the importance of children's participation, but a broader understanding is needed of the meaning of participation for disabled children, including the importance of children participating at whatever level is appropriate to their ability.
- Participation was fragile and often rested on specific individuals. It was affected by staff turnover and sickness, and key staff having a much wider remit, so that other activities took precedence over participation.
- More training is needed for staff to enable them to support children's participation, including training in methods of communication with children who do not use speech.
- Preparing disabled children to express their views takes time and an individual approach. It should be recognised that supporting children to participate is time consuming.
- When children did participate, they viewed it as a very positive experience, and the case studies showed some examples of children influencing decisions made in their reviews and of changes to service provision as a direct result of the views children expressed.
- There were only a few examples of children being given feedback on what was happening as a result of their participation. This is important to children and needs further development.

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

## Background

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

This policy is consistent with the United Nations Convention on the Rights of the Child (1989), in which Article 12 emphasises children's rights to express their views on matters that affects them and to have these views given 'due weight', and Article 13 grants children the right to receive and express all kinds of information and ideas in a variety of forms. This is particularly important for disabled children who may use communication methods other than speech. The Children Act 2004 reinforces children's rights to be listened to by service providers, as does the National Service Framework for Children, Young People and Maternity Services. Children's participation is seen as important for a number of reasons, not only in upholding their rights but also in improving services and promoting children's protection. Children can influence decisions in matters that affect them as individuals and those which relate to them as a group, for example, within service planning and development or influencing policymaking.

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

## Findings

### Extent of disabled children's participation

Results of a survey of social services departments in England suggested that disabled children were being involved in a wide range of decision-making both within decisions about their own care and within service development. However, involvement was still patchy and required further development (see *Research Works* 2004–02).

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

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

### Views on participation

Professionals showed some confusion about what participation should or could mean for disabled children, particularly those with communication and/or learning impairments. There were concerns over children's

### Box 1

#### Quality Protects Objective 8

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

#### Sub-objectives:

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

competence, understanding and abilities to participate, coupled with unease about the interpretation of children's views. For some workers there appeared to be a concept of ideal participation, based on a notion that anything less than a child taking part in a review meeting and contributing to complex decision-making processes was not valid.

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

### Facilitators and barriers for participation

**Clarity of aims and objectives** Interviews highlighted the importance of shared understanding of aims and objectives of participation among all those involved – staff, parents and children.

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

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

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

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

### Outcomes of participation

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

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

## Feedback to children

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

## Implications for policy and practice

In order to increase disabled children's participation in decisions that affect them, a number of developments are required:

- ▼ Training and skills development for staff, and access to support and methods to facilitate participation.
- ▼ Recognition at all levels of policy and practice of the time needed to develop relationships and work effectively with children who have communication impairments and/or complex needs.
- ▼ An exploration of who is best placed to communicate with disabled children. Joint working with schools and information sharing on children's preferred communication methods should be part of facilitating disabled children's participation.
- ▼ Details of each child's method of communication should be recorded on case files.
- ▼ Participation, whether in individual decisions or in service development, should not be a one-off event. Everyday simple choices are part of the process and such choices can be used, for example to build up a picture of a child's likes and dislikes when at a respite centre. In addition, information from each child using a service can be collated to inform service development.
- ▼ More attention and expectation must be focused on getting the views of disabled children and this should be monitored systematically so that it becomes embedded in organisational cultures.
- ▼ Data should be gathered on outcomes of children's participation and feedback on what is happening should be provided to children.

## Methods

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

## Further information

The research was funded by the Department for Education and Skills Quality Protects Research Initiative.

This publication should be cited as: Franklin, A. and Sloper, P. (2006) Supporting the participation of disabled children and young people in decision making, *Research Works*, 2007–01, Social Policy Research Unit, University of York, York.

Copies of the full report, Franklin, A. and Sloper, P. *Participation of Disabled Children and Young People in Decision-making Relating to Social Care*, can be downloaded from the SPRU website: <http://www.york.ac.uk/inst/spru/pubs/pdf/decision.pdf>

We can send an email notification to you when each new issue of **Research Works** is posted on the website.

**To register for this service please email us at [spruinfo@york.ac.uk](mailto:spruinfo@york.ac.uk) with the following information:**

**Name (Mr/Ms/Mrs/Dr etc.);  
Job Title; Organisation;  
Address (including Postcode);  
Tel/Fax/Email**

**T**he Social Policy Research Unit is an independent research organisation at the University of York. Established in 1973, SPRU has an international reputation for excellence in key areas of social policy, especially health and social care, poverty, social security and employment. Its Director is Professor Gillian Parker. For further information about SPRU contact the Director or the Information Office, or visit our website at <http://www.york.ac.uk/spru/>

Social Policy Research Unit,  
The University of York, Heslington,  
York YO10 5DD, United Kingdom.  
**Telephone +44 (0)1904 321950**  
**Fax +44 (0)1904 321953**  
**Text +44 (0)1904 321951**  
**E-mail [SPRU@york.ac.uk](mailto:SPRU@york.ac.uk)**