

# Participation of Disabled Children and Young People in Decision-Making within Social Services Departments in England

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RESEARCH FINDINGS FROM THE  
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Developing a culture of, and good practice in children's participation is fundamental to achieving the overall aim of the *Quality Protects* (QP) programme. QP sets national objectives to improve the effectiveness of children's social services. In this study, we investigated participation work which includes disabled children and young people. A national survey of all social services departments in England was carried out. The main findings were:

- Disabled children are being involved in a range of decision-making areas concerning their own care and within service development. However, participation is still patchy and involvement at a higher strategic level is rare.
- Of authorities who reported involving disabled children and young people, 60 per cent involved them in both service development and tailoring individual packages of care; 40 per cent indicated involvement of disabled children within just one of these processes.
- The numbers of disabled children involved varied considerably suggesting that not all children and young people are being involved in decisions about their own care and only small numbers are being involved in service development.
- Dedicated funding to facilitate participation was not always available, although a high level of partnership working with other agencies was reported amongst service development initiatives.
- There was a reported need for more support, skills development and training for children and staff involved.
- Further development is required to ensure feedback is given to the children and young people participating.
- Some respondents reported changes to service provision as an outcome of participation, however, a more systematic collection of evidence on outcomes is required.

## Background

The Quality Protects (QP) programme was launched in 1998 with the aim of transforming the management and delivery of social services for children. Objective 8 of the QP programme has a requirement to actively involve users and carers in planning services and tailoring individual packages of care. Evidence suggests that while in general children are increasingly involved in decision-making, growth has been slower in respect of disabled children and young people. While emerging literature has general lessons for those wishing to involve children, less is known about additional specific factors which could promote disabled children's participation. This survey was carried out as part of a wider study identifying participation work and exploring both the process and outcomes of disabled children's participation.

## Findings

### Nature of disabled children's participation

Information was received from 71 local authorities. Sixty per cent reported involving disabled children and young people in both service development and in decision-making regarding their own care; 40 per cent indicated involvement in just one of these processes. Information covered 65 teams involving children in their own care and 70 service development initiatives.

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 area of involvement was 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. This is a similar theme throughout, where disabled children and young people are in the main being asked for their opinions of activities, equipment, toys, décor and changes to buildings/gardens within respite care, resource centres and short breaks. The responses suggest the emergence of youth forums as a mechanism of participation, however, involvement at a higher strategic level of service planning is still rare.

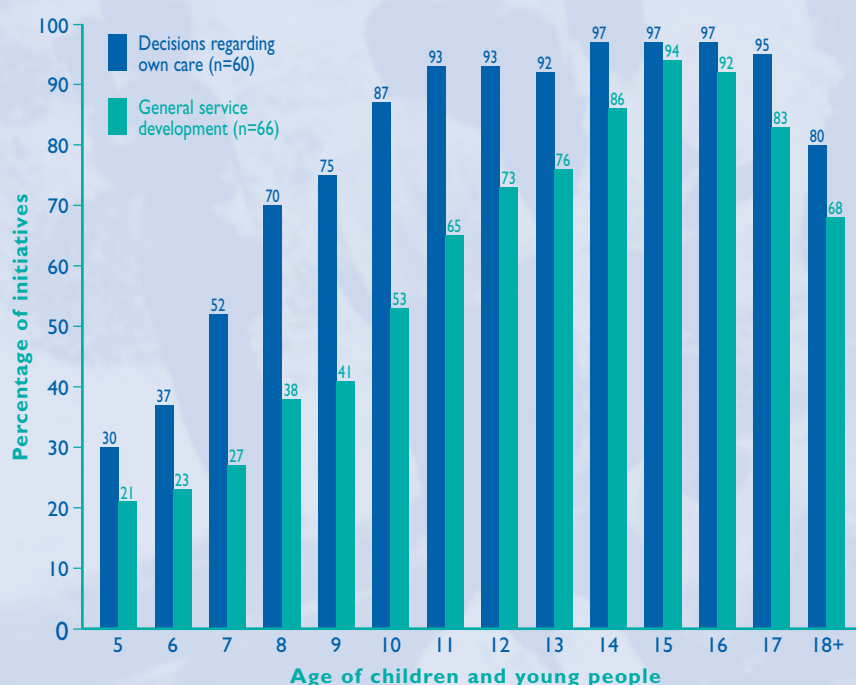
### Characteristics of children and young people participating

The numbers of disabled children involved in any one area varied from less than ten to over 50. Nearly a third of service development initiatives only involved up to 10 young people. Seventeen 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 1)

Responses suggest that the involvement of disabled young people who are often described as being "difficult to reach" is growing. Children and young people with communication impairments, degenerative conditions, autistic spectrum disorders and complex health needs were participating within the majority of authorities. These children are the focus of later stages of this project where detailed information will be gathered.

**Figure 1:**  
Age range of children involved in the initiatives



## 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, Children's Fund, Health Action Zones, Single Regeneration Budgets and New Opportunities Fund. Eighty percent of these initiatives involved partnership working with other agencies, with the voluntary sector featured in just under half of all projects. 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.

## Methods of involvement

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.

## Support and training

The survey explored support and training for both children and young people and staff. The 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.

Training for staff had centred mainly on communication and communication methods and was often accessed 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.

## Feedback

Good practice guidelines on participation indicate a need to provide feedback to children and young people involved in decision-making processes. However, 17 per cent of respondents involving children within their own care indicated that they 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.

## Outcomes

Forty-four per cent of projects indicated that there had been changes to services as a result of disabled children and young people's participation. For the majority of the other respondents, it was too early in the process to indicate any outcomes. Table 1 shows that most changes to service provision have been through altering activities and/or changes to décor, reflecting the finding that a large number of initiatives had been consultations about this topic.

**Table 1:**  
**Changes to services as an outcome of children's participation (n=31\*)**

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

\*Note: From the 57 authorities involving disabled children and young people in service development, information was collected about 70 different initiatives, 31 of whom reported changes to services.

## Implications

The results of the survey suggest that disabled children and young people are being involved in a wide range of decision-making both within decisions about their own care and within service development, however, involvement is still patchy and requires further development.

Not all authorities are involving disabled children and young people, and the numbers of those who are being involved varied considerably across areas. Younger children are least likely to be participating. Many methods are being used to facilitate involvement, but more work is required to increase participation at a higher strategic level within service development, and to increase participation beyond play/leisure consultations into a much wider sphere of activity.

A high level of partnership working must be viewed as positive. However not all respondents had dedicated funding to develop participation work with disabled children. The resource implications of participation should not be underestimated and without adequate funding or long term planning what can be achieved is greatly reduced.

Support for staff and young people is inconsistent, as is feedback to the children involved. Both areas need further development and more emphasis placed on their importance in the participation process.

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 it is too early to judge, however, more evaluation built into participation activity is required.

The final stage of this research will attempt to examine some of these outstanding questions.

## Methods

This survey forms part of a larger study funded by the Department for Education and Skills *Quality Protects* Research Initiative. The full study is due to be completed in 2005.

The survey was carried out during the summer of 2003. A two-stage approach was undertaken. A screening questionnaire 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, asking them 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. Enquiry about participation was restricted to the last twelve months in order to provide a snapshot of up to date evidence. A detailed questionnaire was sent to the 102 authorities, 71 returned this – a response rate of 70 per cent. The questionnaire was designed to investigate the participation activity in detail, in particular the process as well as the outcomes of disabled children's involvement in decision-making.

### Further information

This research is funded by the Department for Education and Skills. The full study is due to be completed in 2005.

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Copies of the full report, Franklin, A. and Sloper, P. 'Participation of disabled children and young people in decision-making within social services departments in England' DH1995 02.04, are available from SPRU Publications Office (price £7). Contact Ruth Dowling on **01904 433608** or email **spruinfo@york.ac.uk**.

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