

Consulting with disabled children and young people

Recent legislation and guidance across education, health, leisure and social services strengthens the expectation that professionals will consult with children and young people about decisions that affect them, including disabled children and young people. The 'Ask Us' project (led by The Children's Society) used a multi-media approach to involve disabled children and young people in influencing policy development on Quality Protects. 'Two Way Street' (led by Triangle and NSPCC) produced a training video for practitioners to build confidence and skills in communicating with disabled children who do not use speech or language. An overview of the two projects demonstrates that:

- f** Disabled children and young people had strong views about the society they live in, how they are treated, services they receive, their education, health and leisure. They wanted to be respected and to have a say in things that affect them.
- f** Disabled children and young people wanted resources, equipment and support so they could access everyday things which most children take for granted:
 - going out with friends;
 - belonging to youth and sports clubs;
 - going to pubs and clubs;
 - going to the local park.
- f** The children and young people involved in 'Two Way Street' wanted to challenge the negative assumptions they felt that many professionals have about disabled children and young people. They felt that too often, the focus is on young people's impairments and not on the real barrier: adults who do not listen and do not try to communicate 'on all channels'.
- f** The experience of those involved in the projects was that all children can be included and enabled to express their wishes and feelings. However, this needed sensitivity and openness to different ways of communicating, and also required time and a willingness to try a range of approaches.
- f** Multi-media tools provided an effective way to consult with disabled children and young people about a range of issues, including government policy. Both young people and staff who were new to the technology learned the necessary skills quickly.
- f** Some disabled children rely on communication aids and/or people who know how they communicate. But these aids and people are not always available in all parts of their life (e.g. leisure time as well as at school) or when they move or leave school. Young people in the projects felt this was against their human right to express their views.

Background

Listening to and involving children is a key principle across a wide range of initiatives, policy and practice guidance, including:

- Revised Code of Practice for children with Special Educational Needs (SEN);
- Quality Protects programme in England, Children First in Wales and the forthcoming Strategic Framework for Children's Services in Scotland;
- Valuing People (White Paper on learning disability);
- SEN Programme of Action;
- Sure Start Partnerships;
- Children's Fund;
- Connexions;
- NHS Plan;
- Framework for Assessment of Children in Need and their Families.

Consulting with children and young people has also been promoted in good practice guides across a range of government initiatives, including Early Years Child Care and Development Partnerships. The importance of designing policies around the *needs* and *priorities* of young people has also been recognised (it is a key strategic issue for the Children and Young People's Unit).

Recent legislation and guidance across education, health and social services has strengthened the expectation that professionals will consult with children and young people about issues that affect them. Yet previous research has suggested that many professionals fail to consult with or involve disabled children, even where statutory duties require authorities to ascertain children's wishes and feelings, as in The Children Act 1989, The Children (Northern Ireland) Order 1995, and The Children (Scotland) Act 1995. In addition, disabled children and young people are often excluded from wider consultations around local policy and planning, their neighbourhoods and communities.

'Ask Us' and 'Two Way Street' set out to address some of these issues through supporting disabled children and young people to have their say in policy, and through producing a training video for practitioners on communication.

'Ask Us' : a multi-media consultation on children's services

In 1999, The Children's Society was approached to find a way to enable disabled children and young people to influence Quality Protects, the Government's programme for transforming children's services in England. Importantly, the starting point of the consultation was the wishes and feelings of groups of disabled young people, rather than their views on proposals already worked out by adults. The result was 'Ask Us', a model of multi-media consultation that involved over 200 disabled children and young people across England, aged between 4 and 24 years old. Many of the children

and young people who participated have labels of severe learning disabilities and challenging behaviour. Some do not use speech or sign language; they express their wishes and feelings in other ways.

What did the consultation process involve?

The consultation happened over 3 months in the summer to allow strong relationships to build between young people and staff. Children and young people were consulted around five questions: What do you enjoy? What do you want more of? What are your experiences of consultation? What are your experiences of participation and of services? What do you understand by inclusion? Audio-tapes, videos and digital cameras were used to record the young people's work before transferring it onto CD-ROM using Powerpoint software.

Six projects run by the Children's Society were involved (see Box 1). Each was provided with a budget to allow flexibility. This resulted in a dynamic mix of processes, such as:

- Young people as researchers working on specific topics;

Box 1: Examples of the 'Ask Us' projects

St. Christopher's Solihull: three young people led their own research on the usefulness of helplines in local authority complaints leaflets. They got some training on basic research methods, and led the research at all stages. In the same project, four disabled children and five of their non-disabled friends did an access audit on eight local parks over one weekend. They called it "Can we go to the park, mom?" and used videos, digital cameras and pictures to record the results. The audit highlighted the inequalities experienced by disabled children in accessing everyday opportunities and local facilities.

Glenfield and Melton: workers used the resources to take children and young people places - a barge trip, the local swimming pool, the beach and the park - and record their responses when they were there. Part of the money was used to pay a professional to adapt young people's communication aids so they could take part more fully. This was 'on the spot' consultation. It enabled children who do not use speech or language to have their views included on the CD-ROM.

Space: young people helped to organise an Inclusion Festival over 2 days. They invited all the children from the local respite unit as well as children from local special schools. The Festival offered a wide choice of media and activities, such as archery, art, music, dancing, song-writing, camping and a graffiti wall. Two young researchers were 'roving reporters', asking other young people at the festival for their views about inclusion.

- Young people asking other young people for their views;
- Creative workshops with drama, animation, art and music;
- Song-writing and using recording studios;
- Puppetry;
- Video diaries;
- Discussions led by young people;
- Leisure activities and visits.

Lessons from 'Ask Us'

- It was important to give each project resources to use flexibly and creatively.
- Young people were often involved in all stages of the consultation.
- Given appropriate tools and support, all children, including those who were labelled as having 'severe or profound disabilities' and 'challenging behaviour', were able to express their views, wishes and feelings.
- Using the multi-media approach has enabled the children and young people to get their views across to a wider number of people, nationally and in the areas they live.
- The approach meant children and young people living away from their families could be included as well as those living in their own communities.
- Young disabled people who were paid as researchers described feeling valued and responsible; they enjoyed the work and felt they benefited from meeting other disabled people and hearing their stories.
- Careful monitoring of children's willingness to be involved was needed where the difficulties of getting informed consent from some children had to be balanced with not excluding them from taking part.

What disabled children and young people say in "Ask Us"

Children and young people identified a wide range of issues that were important to them: leisure, friendships, social workers, review meetings, growing up, bullying, discrimination and respect. A common theme was that disabled children and young people enjoyed the same things as other children and young people of a similar age. Yet they were often denied these experiences through a lack of support, resources and access, and through other people's attitudes.

Other important messages were:

- Disabled children and young people wanted adults to ask and wanted adults to listen. They wanted to have a say in things which affect them. They worried when they did not understand what was happening.
- Disabled children and young people regularly experienced bullying, exclusion and discrimination. They wanted to be treated with respect. They wanted to be part of their communities.

- Some disabled children relied on communication aids and/or people who know how they communicate. But these aids and people were not always available in all parts of their life (e.g. leisure time as well as at school) or when they moved or left school. Young people felt this denied them their right to speak.

'Two Way Street': training for practitioners

'Two Way Street' is a unique training video on communication for all professionals who encounter children and young people through their work. The video shows children and young people (aged 3 to 19 years old) communicating with each other and with adults in different ways, such as through behaviour, sign, symbols, body language, eye pointing, facial expression, gesture, play, use of art, objects of reference, speech, vocalisation and physical movement. Professionals talk about the barriers to communication, and reflect on their own experiences and early anxieties about working with disabled children who do not use speech. Young disabled people share their experiences, some good and some bad, and give advice to professionals on how to communicate better.

How was 'Two Way Street' developed?

'Two Way Street' took just over one year to produce. A consultative group involving nine disabled young people was involved throughout: in the initial development of ideas; in deciding how to approach other children to take part, and in preparation work in the different settings in which filming took place. Most members of the consultative group chose to take part in the video, in editing, designing and launching the pack. One of the two project workers was a disabled young woman who represented the consultative group, and brought to the video her knowledge of disability rights, media, and direct experience of many of the issues the video aimed to address.

Lessons from 'Two Way Street'

- Some young people had found it hard to get their views heard by professionals, especially if they did not use speech or if their speech was difficult to understand. They wanted to use the video to assert the value of different communication methods.
- The children and young people's consultative group and the employment of a young disabled woman as a project worker were crucial in shaping the video and deciding the important messages to convey. There were times when the views of the young people conflicted with those of the adults and advisory group.
- It was difficult to find ways to make the process of thinking about, making and then editing a video accessible to all those in the consultative group.
- Including children who use sign language in a video about disabled children had to be done

sensitively to respect deaf politics and identity as a cultural and linguistic minority.

- It was felt important to include disabled children and young people from a range of minority ethnic backgrounds in the project and on the video.
- Filming took a long time and careful preparation. Building strong relationships between the children and those involved in the project was important. Ensuring the film crew were sensitive to the needs of the children and the issues helped make the project successful.

What disabled children and young people say in 'Two Way Street'

The children and young people involved in 'Two Way Street' wanted to challenge negative assumptions that many professionals have about disabled children and young people. They felt that communication should be a 'two-way street' (see Box 2); that too often, the focus is on young people's impairments and not on the real barrier: adults who do not listen and do not try to communicate 'on all channels'.

About the projects

'Ask Us': a national co-ordinator, Lynette Partington, developed the methodology and ensured a consistent approach. The six projects were based in Merseyside, Leicestershire, Yorkshire, Suffolk, Kent and the West Midlands. The work was led by The Children's Society with joint funding from the Joseph Rowntree Foundation. Close links were maintained throughout with the JRF/Department of Health Quality Protects (Disabled Children) Reference Group.

Box 2: Hints and tips from young disabled people on communicating

"Don't blame us or have a go at us"

"We do have feelings"

"We're just like other children"

"Show respect, and don't patronise us"

"Take your time and make sure you understand"

"Talk directly to us, not just our parents, or our carers"

"Don't be scared to ask questions"

"Really listen and understand"

"Make sure you really understand us because I have seen carers, parents and other people who didn't even know or can't be bothered to find out how we say yes or no."

Sometimes people say later, later, because they think we're asking for attention"

"Keep calm and get on with it"

"Don't be scared"

"Learn from young people"

"Show an interest in us, make it more than just a job"

'Two Way Street': the work was led by Triangle and NSPCC (National Society for the Prevention of Cruelty to Children) with joint funding from the Joseph Rowntree Foundation. Triangle offers Training and Consultancy on services for children with complex needs. The pack was piloted with training groups across different disciplines.

This overview of the two projects has been prepared by Dr Emma Stone, JRF Senior Research Manager, Social Care and Disability.

How to get further information

Ask Us CD-ROM – copies are available at £5 each (plus 50p postage and packing per copy) from The Children's Society, Publishing Department, Edward Rudolph House, Margery Street, London WC1X 0JL. Tel: 020 7841 4415; Fax: 020 7841 4500; order online at www.childrensociety.org.uk. A second stage of the work to produce a resource pack on doing multi-media consultations is now in progress. For further information on current work and on using the CD-ROM contact: Margaret Hart, Social Work Manager, The Children's Society, 8, Vine Street, Kersal, Salford M7 3PG; Tel: 0161 705 7000; Fax: 0161 708 9482.

Two Way Street: Training video and handbook about communicating with disabled children and young people – copies are available at £55 (inclusive) from NSPCC National Training Centre, 3 Gilmour Close, Beaumont Leys, Leicester LS4 1EZ. Tel: 0116 234 7223; Fax: 0116 234 0464; or by email: sferran@nspcc.org.uk. For further information on Triangle services and consultancy: Tel: 01273 241015 or email: info@triangle-services.co.uk or visit the Triangle website: www.triangle-services.co.uk.