# Speech, language and communication needs

# User involvement and consultation

| Type of paper | Commissioning Support Programme paper exploring ways of improving speech, language and communication outcomes for children and young people |
| --- | --- |
| Primary audience | Lead members, directors of children's services, strategic commissioning teams, children's partnership boards, head teachers, GP commissioners, health and well-being boards, service providers, children's centres, schools and colleges, parents, carers and young people |
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# Contents

**The tools in this suite:**

# 1. About this tool

This tool is designed to provide information and guidance to commissioners of speech, language and communication services when considering their approach to involving children, young people and their parents or carers.

The Bercow Review[1] highlighted that commissioning services for children and young people with speech, language and communication needs is complex. It requires organisations to work with service users and practitioners to:

- understand – understand the needs of the local population and the resources available to meet those needs, set priorities and agree outcomes

- plan – map and plan sustainable and diverse services to deliver outcomes

- do – procure and develop services based on the plan

- review – monitor and evaluate service delivery of outcomes and take remedial action if necessary.
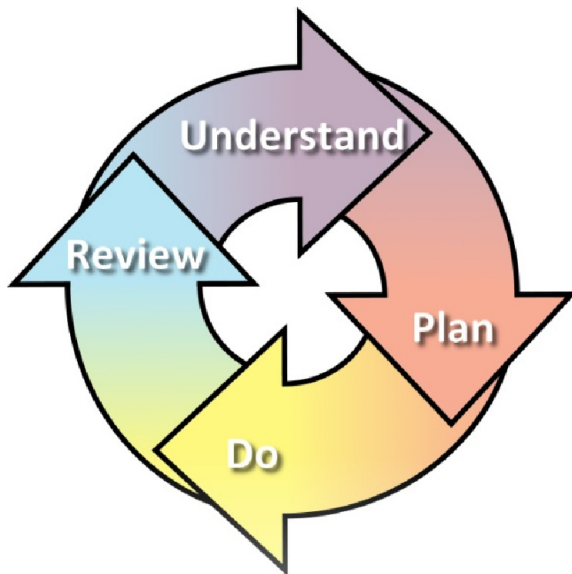


This tool outlines how commissioners can involve users at each stage in the commissioning process. The tool aims to help commissioners of speech, language and communication services to:

- identify desired outcomes from the involvement of children, young people and parents or carers

- answer some key questions about the process such as who you might involve, why, how and when

- understand what supporting strategies are required to make involvement meaningful and effective in bringing about change.

The tool will also help commissioners and providers of services which are not exclusively targeted on this group to make sure that their approaches to participation are inclusive, and that children with speech, language and communication needs are not 'disenfranchised' because of their impairment.[2]

The tool is not intended to be prescriptive, but it will provide you with information on some of the approaches available and guidance on which approaches might be appropriate in which circumstances. It draws on experience from commissioners who have successfully involved users, and gives information on where to look for further support.

This tool is part of a suite of tools for commissioners of speech, language and communication services. It should particularly be read in conjunction with the Needs Assessment and Evaluating Outcomes tools.

1   Bercow J (2008) *The Bercow Report: A review of services for children and young people (0-19) with speech, language and communication needs*. Nottingham: DCSF www.dcsf. gov.uk/bercowreview/docs/7771-DCSF-BERCOW.PDF

2   A good general guide for commissioners and providers of mainstream services is *How to involve children and young people with communication impairments in decision-making*. Available from the National Children's Bureau, www.ncb.org.uk/cdc/home.aspx

# 2. The purpose of user involvement

## Why involve users?

All children and young people can communicate, and children and young people with speech, language and communication needs (SLCN) are as able as other children to contribute to decisions about the services that affect their lives. But they may need extra help in making their voices heard.

Being involved in decisions that affect you is a basic human right, which is enshrined in legislation including the Disability Discrimination Act 1995 and 2005, and the United Nations Convention on the Right of the Child. It is also essential in making sure that services are responsive to needs.

Sinclair and Franklin[3] identified the reasons for involving children and young people in making decisions about the services that affect them as follows:

- uphold children's rights
- fulfil legal responsibilities
- improve services
- improve decision making
- enhance democratic processes
- promote children's protection
- enhance children's skills
- empower and enhance self-esteem.

It is important to be clear about the purpose of user involvement in order to be able to plan it appropriately. An initial activity might be to develop a consensus statement about the purposes and remit of user involvement in services in your locality. This will help to build a culture in which there is a commitment to take the results of involvement seriously. You will also need to think more specifically about the purpose of each engagement exercise when you start to plan it (see section 5).
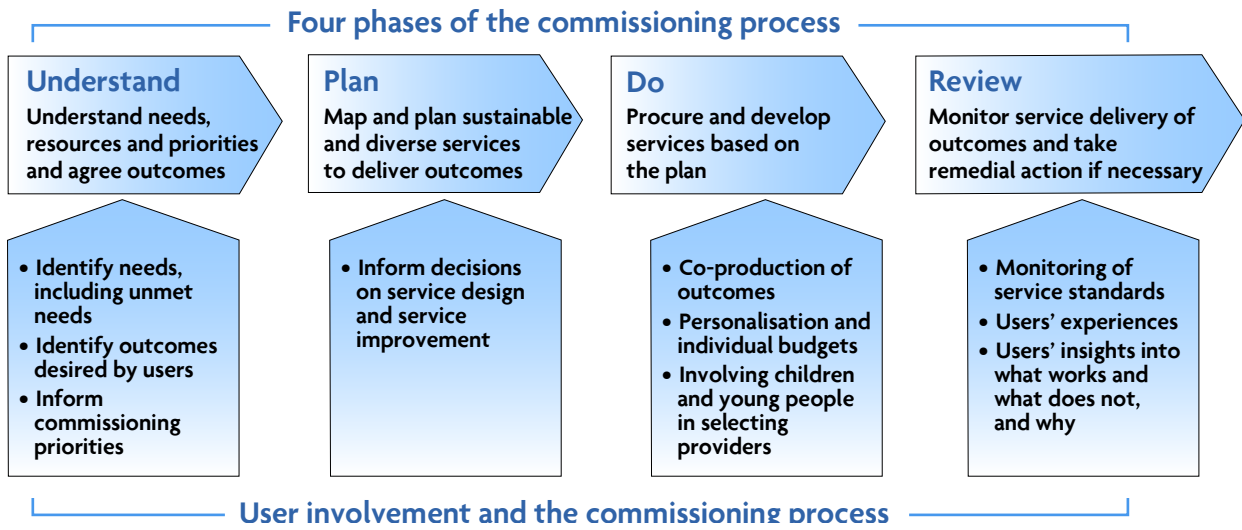
## User involvement in commissioning

Involving users can help commissioners to:

- understand needs. Are there any needs which current services are not addressing adequately? What outcomes would users like to see as a result of services?

- set priorities. Which services do users most value, and why? Which outcomes do they prioritise?

- understand users' experiences of services. What worked for them, what did not work and why?

- develop ideas for improving services. How would children, young people and families like to see services improved?

- tackle difficult service issues. Service users may have innovative solutions to controversial or knotty problems. They will certainly have a view on any solutions that you may have so it is important to find out what they think of your solutions.

- set and monitor standards. What do users think of the standards that have been set for the service? How well do they think you are keeping to these standards?

- evaluate the impact of services. What is users' perception of the outcomes of services?

Figure 1, on the next page, shows the role of user involvement at each stage in the commissioning cycle. This is elaborated on later in this paper (see Table 2 on page 19). Keeping this diagram in mind will help you to think about when you need to involve users, and the purpose of involvement at that particular stage in the commissioning process.

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3   Sinclair R, and Franklin A (2000) A Quality Protects Research Briefing: *Young People's Participation*. Department of Health, Research in Practice and Making Research Count: London.

**Figure 1: User involvement and the commissioning cycle**

Four phases of the commissioning process

**Understand**
Understand needs, resources and priorities and agree outcomes

**Plan**
Map and plan sustainable and diverse services to deliver outcomes

**Do**
Procure and develop services based on the plan

**Review**
Monitor service delivery of outcomes and take remedial action if necessary

- Identify needs, including unmet needs
- Identify outcomes desired by users
- Inform commissioning priorities

- Inform decisions on service design and service improvement

- Co-production of outcomes
- Personalisation and individual budgets
- Involving children and young people in selecting providers

- Monitoring of service standards
- Users' experiences
- Users' insights into what works and what does not, and why

User involvement and the commissioning process

# 3. The basics of user involvement

## A strategic approach to participation

Commissioners should consider their overall approach to participation and what can be done to make participation as meaningful as possible. In particular, you will find it helpful to do the following:

- Think carefully about how you can promote the involvement of children, young people, parents and carers.

- Make sure children, young people, parents and carers are involved in all stages of the commissioning process.

- Encourage the development and support of organisations that promote the involvement of or advocate on behalf of children, young people, parents and carers.

- Take steps to ensure your approach to involvement is equitable. Ensure that all communities, including those who may be hard to reach and whose voices are seldom heard, are involved.

- Make sure you have direct and regular access to users and carers. Even though participation activities are likely to be delegated to others, there is no substitute for hearing users' voices at first hand.

- Take some time to think about the skills you and your colleagues need to work effectively with children, young people, parents and carers.

Above all, if participation is to be effective in bringing about change it needs to be sustained and embedded as an integral part of relationships with users – not simply a one-off exercise. This means recognising and enabling the wider changes in attitudes, behaviour and power that are required.

## The ladder of participation

We can identify a 'ladder' of increasingly meaningful and active involvement, with increasing levels of reflection and dialogue:

- informing: providing information to children, young people parents and carers about the services that are available and planned

- consulting: obtaining user feedback on their needs and experiences

- involving: working directly with users to ensure that concerns and aspirations are consistently understood and considered

- collaborating: working in partnership with users in each aspect of commissioning, including the development of alternatives and the identification of the preferred solution; involving children and young people in the governance of commissioning and services

- empowering: placing decision-making in the hands of users; co-production of outcomes and self directed budgets.

(See figure 2 on )

It is very important to be clear about where on this ladder any particular participation activity and your participation programme as a whole sit.

The Bercow Report highlighted that even at the most fundamental level of providing information, the system is currently failing children and young people with SLCN and their families. Most localities are thus starting from a very low base.

# Co-producing outcomes

Co-production involves treating children and young people not primarily as consumers of services but rather as co-producers of outcomes along with service providers.

> **'Co-production emphasizes doing things 'with children' as opposed to doing things 'to children' or 'for children'. It is a strengths-based approach, which recognises that all children, young people and their families have their own sets of skills, knowledge and experiences which they can bring to the table.**
>
> **Engaging with children in the co-production of services goes beyond consultation in decision-making processes. A co-production approach sees the purpose of engagement to provide children and young people with the opportunity to 'be the change'. To achieve this, it focuses on children as part of their own solution.' (Action for Children and NEF, 2009)**

Co-production ensures services are as relevant and effective as possible, makes public resources go further, and helps users to understand and contribute to tough decisions about resource allocation.

Individual budgets and self directed support are a special case of co-production.[4] For speech, language and communication practitioners this means participating in the team round the child and in a single planning process in which families and young people are respected partners. More children and young people will have a lead practitioner to work with parents and coordinate a number of services including speech and language support or therapy (see the Whole System Mapping and Design tool).

However, the main focus of this tool is on involving users in decisions about the overall shape of services.

A co-production approach can also be taken to user involvement, for instance:

- users undertaking research into needs and experiences, or jointly running consultation exercises
- users taking part in mystery shopping exercises
- users sitting on panels to select contractors
- users being included on panels to design performance indicators.

The work being done by the Hounslow pathfinder (see ) is a good example of this approach.

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4   Individual budgets involve individuals, with or without help, assessing their own needs and identifying the 'indicative budget' that they could access; securing help from a support planning and service brokerage, if required; developing a support plan and budget and negotiating it with the local authority; purchasing support; living their lives; and reviewing their needs and support.

# Some fundamental principles

Although involving children and young people with speech, language and communication needs entails some special considerations, set out in section 4, there are some basic principles which apply to all programmes to involve children, young people and families.

- Ensure that all involved in the process are committed to involving children, young people and parents in a meaningful way. They must be willing to listen, be influenced by what they hear, and – in so far as they can – act on it, while bearing in mind that there will often be conflicting considerations.

- Effective involvement requires appropriate levels of resourcing which should be specifically identified within the commissioning strategy. Specialist skills may be required, which may have to be brought in from outside the organisation.

- Make the most of existing information and evidence. Do not repeat consultation that other agencies have already done; do not disregard previous feedback from children, young people and parents; look at complaints and compliments as well as feedback from specific activities and events where possible. Try to assimilate your engagement activities into other initiatives, such as public consultations, Youth Parliament, and so on.

- Build on evidence from past performance, including inspection recommendations and management information. Relevant information from performance management processes should be fed into the participation process so that children, young people and parents can participate in informed decision-making.

- Give services a chance to consolidate and to be evaluated by children, young people and parents – do not keep changing what is commissioned.

- Support children and young people to look into the future and take account of continuing and developing needs, and any trends such as population change or wider activity that might impact on services.

- Establish clear boundaries and realistic expectations with all involved at the beginning of the process.

- Plan. Start slowly, proceed carefully, draw on good practice in other areas.

- Set up feedback processes that keep all involved up to date with the commissioning process, and in particular enable users to see how their views were taken into account.

# 4. Involving users across the SLCN spectrum of need

One of the main challenges relating to the involvement of children and young people with speech, language and communication needs is the meaningful involvement of groups across the whole of the needs spectrum. This is a particular issue for individuals and families from the most vulnerable groups, who by the nature of their difficulties find communication a struggle and may require specialist expertise to facilitate discussion.

The complexity of the issues faced means that commissioners will need to work closely with others who have specialist expertise in this area. These will include local partners providing services to children and young people with speech, language and communication needs, such as schools and voluntary organisations. Commissioners may also need to draw on expertise and best practice from national organisations such as Afasic and ICAN which have extensive experience in this area. These agencies can help commissioners identify who they need to consult with, and how best to do it. Further information about where to access support and guidance can be found in section 6.

The National Children's Bureau identifies the following barriers to participation faced by children and young people with communication impairments:

- the assumption that speech is the only or best way to communicate

- the assumption that a child or young person who has some verbal language has age appropriate communication

- staff may not understand communication impairments or feel they have the right skills

- communication impairments may not always be immediately visible

- children and young people not having access to their communication system

- not allowing enough time

- expecting children and young people to 'fit in' to adult models of participation

- low expectations

- inaccessible activities

- lack of previous involvement in decision-making.[5]

Factors such as these often result in children and young people with speech, language and communication needs being excluded from mainstream user participation

processes. They highlight the importance of developing a culture of inclusion throughout the system. Children and young people with speech, language and communication needs should be involved in making decisions not only about speech, language and communication services, but about all the services that affect them.

Involving children and young people with speech, language and communication needs has a number of specific challenges. They may find it difficult to interact in a group context, to work as a team, or to relate to unfamiliar people. They will often have limited vocabulary and low literacy levels, and find it hard to understand complex ideas or ideas expressed verbally. Reflecting, remembering or talking about past events, expressing their ideas, or projecting into the future, may all be challenging for them. They may have a short attention span and limited concentration. They may have difficulty understanding the basic idea that they have special needs.

These challenges pose issues for involvement, and standard techniques of involvement may prove ineffective with many users. However, there are possible solutions, some of which are outlined in table 1 below.

Not all children will face the same or equal challenges, and careful consideration will need to be given to targeting and modifying involvement approaches for different sub-groups.

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5    National Children's Bureau (2009) *How to involve children and young people with communication impairments in decision-making.* www.ncb.org.uk/cdc/home.aspx

**Table 1: Challenges, issues and possible solutions in involving children\* with SLCN**

| Challenge | The issue for involvement | Possible solutions |
|---|---|---|
| Interacting in a group context | Within a focus group, the child may not be able to concentrate or listen to or respond to what other children are saying. | – Small groups of four or less or a high adult-to-child ratio are needed, whereby the additional adults can facilitate the individual child's responses. It is still better to have a single adult leading the session to keep the overall direction and flow of the session intact. |
| Working as a team | Child may be unable to co-operate and engage with other children to achieve agreement or to work towards a desired end point. | – Create opportunities to interview children individually. |
| Relating to unfamiliar people – adults or children | This may make one-off sessions difficult, for example where children are seen by an interviewer or as part of a group for a single session only. | – Where possible, use existing groups of children who know each other already; where possible see children over an extended period, give them time to build up a relationship with their interviewers or co-workers.<br>– Where this is impossible, create social and play contexts that facilitate easy and relaxed communications, for example by providing snacks, relaxed seating arrangements, child-friendly rooms, non-school contexts. |
| Literacy levels | Written materials may be inaccessible. | – Written materials may need picture and symbol support, use of short sentences, checked for literacy difficulty level. |
| Understanding complex ideas or ideas expressed verbally; limited vocabulary | The basic concepts to be discussed may be too difficult; words may have a very particular meaning for a child – words that we use every day may have negative connotations for children. | – Check the children's levels of language and understanding well before meetings in order to prepare relevant materials and ensure that you have facilitators with appropriate skills; expressing ideas simply in simple sentences with picture, symbol or signed support; using strategies to repeat ideas, rephrase and check children's understanding.<br>– Follow children's lead in the discussion and listen carefully to their use of words.<br>– Pacing of activities can be challenging – move fast enough to keep it interesting; allow a pace that children can understand and keep up. |
| Reflecting, remembering or talking about past events | A child may not be able to focus on services they have received in the past, may not remember what personnel they have received, may not remember them by name or designation. | – Have visual prompts available, for example, photographs of people they have worked with, places they have received services, activities they have carried out and real materials that they have worked with.<br>– Focus consultations on current services. |
| Expressing their ideas | Whilst these children may have views about what has happened to them, they may have limited means to express them. | – Establish their means of communication in advance; develop a range of possible response mechanisms including drawing, use of pictures and symbols and multiple choice answers represented visually. Wherever possible keep discussions to concrete and current ideas. |
| Projecting into the future | Children may have difficulties thinking about what they would like to happen in the future, how they would like things to be different. | |
| Short attention span, limited concentration | Long workshops or group sessions or activities that are lengthy will risk losing children's interest and attention. | – Have a range of activities available and be prepared to change if children do not understand or do not attend to any particular activity; always have more activities than you think you'll need; keep activities simple and visual; include opportunities for physical activity, such as moving around the room to place answers in boxes or to hang responses on washing lines. Children need a balance between activities which are quiet and thoughtful and activities which are fun and require movement and action. |

| Challenge | The issue for involvement | Possible solutions |
|---|---|---|
| Understanding the basic idea that they have special needs | Even where adults have discussed the reason for services with a child, we cannot assume that because a child is receiving services, they have necessarily understood why they receive that service, or that adults perceive them to have a difficulty with their speech, language or communication. | − Start from a premise that the children may not believe/perceive/ understand that they have a 'problem'. |
| * Please note: 'child' or 'children' is used throughout the table but is used to refer to both children and young people. | | |
| Source: This table has been developed as part of the *Better Communication Research Programme* by Roulstone, Coad, Hambly and Merrick and is due to be used in the publication of results. | | |

The table underlines that involving children and young people with speech, language and communication needs takes time and resources. Workshops and group activities or even individual interviews take careful planning and preparation, and high ratios of adults to children will be required to run events. Workshops need facilitators who are skilled at communicating with children and young people who have communication impairments. Commissioners will need to ensure that involvement activities are adequately resourced, or they risk being ineffective and tokenistic.

However, it is important not to focus only on the difficulties: all these challenges can and should be overcome. Although they come from young people with a range of disabilities, the 'hints and tips' on the right, are equally relevant to children with speech, language and communication needs.

## 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.'

'Learn from young people.'

'Talk directly to us, not just our parents, or our carers.'

'Don't be scared to ask questions.'

'Really listen and understand.'

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

'Keep calm and get on with it.'

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

The case study from Buckinghamshire, overleaf, is an example of good engagement of children and young people with speech, language and communication needs.

## Buckinghamshire Children and Young People's Participation

'Involving children and young people to help inform the commissioning of services in Buckinghamshire is a key priority of the Children and Young People's Trust[1]. Our objective for this project was to gather views and ideas on the support and services young people receive and need for their SLCN to inform the needs analysis and development of the speech and language therapy service specification.

'No known engagement had previously taken place with young people with SLCN in the county and therefore a group of young people were identified that represented a mixture of ages, differing language and communication needs and from a range of different schools and geographical areas across the county.

'To make the consultation session attractive and fun to the young people we held it during the daytime on a Saturday at an accessible outdoor education centre where lunch was provided along with an activity in the afternoon – a drumming workshop in a yurt! A creative and practical tool based on 'the perfect pizza'[2] was used to draw out what young people felt was important to them regarding services to meet their SLCN needs where each pizza topping represented a key element of a good service.

'The same group of young people are continuing to work with commissioners to help with the tender evaluation process by having their own 'interview panel' and coming up with their own questions.'

1   Buckinghamshire Children and Young People's Trust, *Involving Children and Young People in Commissioning: Guidance Document*, www.buckinghamshirepartnership. gov.uk/partnership/CYPT/joint_commissioning.page?

2   Adapted from: Shephard C (2002) *Participation Spice it Up!: Practical Tools for Engaging Children and Young People in Planning and Consultations*, Save the Children

## Summary of 'the perfect pizza'

Young people understand how and where the service is going to be delivered. For example, it should be somewhere quiet.

Young people understand how therapy can help them. For example, set goals that are achievable.

Build good relationships with young people. For example, be someone they can trust

Understand young people's needs. For example, speak clearly.

Young people are involved in their own therapy. For example: 'I want to improve on ...'
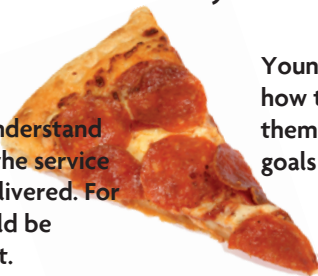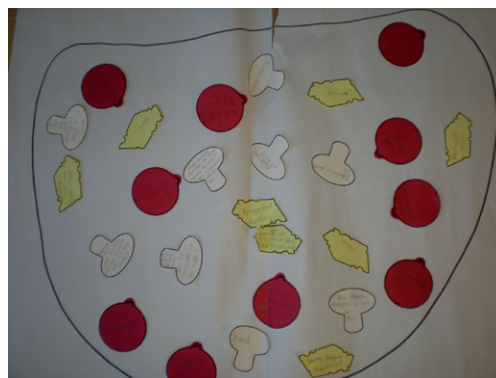
Therapists have good skills, for example a good understanding of language, words and communication.

Children and young people can access the service easily, for example at home or at school.



(Central image produced by participants at the Buckinghamshire workshop)

# 5. How to involve children, young people and their families

## Deciding whom to involve

It is important first of all to agree who the users of services for children with speech, language and communication needs are. This will vary according to locality and to care pathway. Asking this question in collaboration with an existing user group such as a local Parent Partnership establishes a principle of developing a system that is accessible and meaningful to your users.

Users will include:

- children

  – with different types of impairment or disability

  – from a range of age groups

  – from a range of contexts (schools, children's centres, nurseries, clinics, hospitals)

  – supported at universal/targeted/specialist levels

- parents and carers of children and young people with speech, language and communication needs, reflecting the above range. Parents can be powerful advocates for their children. However, they may need support in this role, or the children of less well informed and articulate parents could be at a disadvantage.

Depending on the purpose of your involvement activity, you may need to involve users across the whole spectrum of speech, language and communication services, or users of a specific service. You may also want to involve potential users. If you are involving users with a wide spectrum of needs, you may need to consider different involvement activities for different sub-groups.

Other groups may also need to be involved:

- voluntary and community sector organisations and individual volunteers

- the general public

- professionals and other practitioners such as referring agents or other partners and collaborators in the delivery of the whole SLCN service.

Although they are sometimes mentioned in the examples which follow, this tool is not concerned with these groups – its focus is on involving children and young people themselves and their families.

A successful involvement strategy will identify which approaches are appropriate for the range of audiences to be targeted, and – for each audience – what are the most suitable methods of involvement. The primary aim must be inclusivity. This will involve designing approaches so that all those concerned are encouraged and enabled to

participate, and making particular efforts to involve the 'hard to reach' – for instance children and young people with severe communication impairments, and families whose first language is not English.

Being clear about who the users of the service are and the purpose of their involvement at this stage in the commissioning cycle will help you think about how you want to involve them, as the following examples show.

## Who to involve, why, and how – examples

The examples on the following pages illustrate potential approaches in different circumstances. They are not intended to be prescriptive, but to stimulate thinking about the relationships between audience, purpose and approach, and suggest some of the considerations in each case. You might find this a helpful framework in your initial planning.

## Involving users in service development

| User | Purpose/question | Aspect of the system |
|---|---|---|
| Children, parents and teachers in secondary schools | (Re)designing the service to secondary schools. Understanding what users want from interventions with this age group | Developing outcome-based interventions |

**Activity:**
A series of one-off workshops in secondary schools in the locality/county; these might consist of a series of activities designed to explore views on signs of progress, aspirations, valued outcomes, desired results.

**Considerations:**
Secondary schools cover a wide age range – do you need to split the groups by age? Do you need different workshops (possibly locality-wide) for young people with different impairments? Participation events for parents of this age group may need to be in the evenings.

You will probably need separate events (or separate discussion groups within the same event) for teachers, to minimise the risk of professional domination. However, it would be useful for teachers to hear the views of young people and parents – can you use teachers to help with facilitation?

How will you feed back to participants how their views were used in service improvement?

## Monitoring access

| User | Purpose/question | Aspect of the system |
|---|---|---|
| All parents of children who have been identified as having SLCN needs | Experiences with a view to identifying problems and monitoring standards | Access<br><br>This might include pre-access information about the service, identification process, referral, waiting times, initial assessment |

**Possible activities:**
For the next six months, send a questionnaire to every family who has been referred and offered an appointment, whether or not they attended.

Invite every family who has been offered a first appointment during the last 12 months to attend a focus group.

**Considerations:**
Those who have failed to attend appointments, whose child no longer needs intervention or who was not offered intervention are less likely to respond to a questionnaire or attend an event. A special approach might be needed for these such as a home visit or a telephone interview. It will be particularly important to find out the reasons for non-attendance.

This raises the more general issue of making sure that those who attend are a fair reflection of the entire relevant population. How will you reach parents whose first language is not English, or who are not functionally literate?

How could you turn this into a regular process that is a routine part of the service? How could the results of these processes be collated for regular reporting for commissioners?

## Involving users in service evaluation

Please also refer to the Evaluating Outcomes tool.

| User | Purpose/question | Aspect of the system |
|---|---|---|
| Primary aged children with specific language impairment | To observe children's ideas about their own talking | Impact of intervention across an episode of care |

**Activity:**
At key stages in an intervention, ask children to 'draw yourself talking'*; this might be at the initial assessment, at the end of an episode of care or at follow-up. Ask the child to tell you about their picture; annotate the picture with their comments. At the end of any episode of care provide a summary description of the pictures and how they have changed, and themes that emerge from the child's descriptions.

**Considerations:**
The focus is on what has changed. With older and less impaired children, you may be able to ask them to reflect on how their talking has changed, and how the intervention helped.

* See Holliday E, Harrison L J and McLeod S (2009). Listening to children with communication impairment talking through their drawings. *Journal of Early Childhood Research*, vol. 7, 3: pp. 244-263.
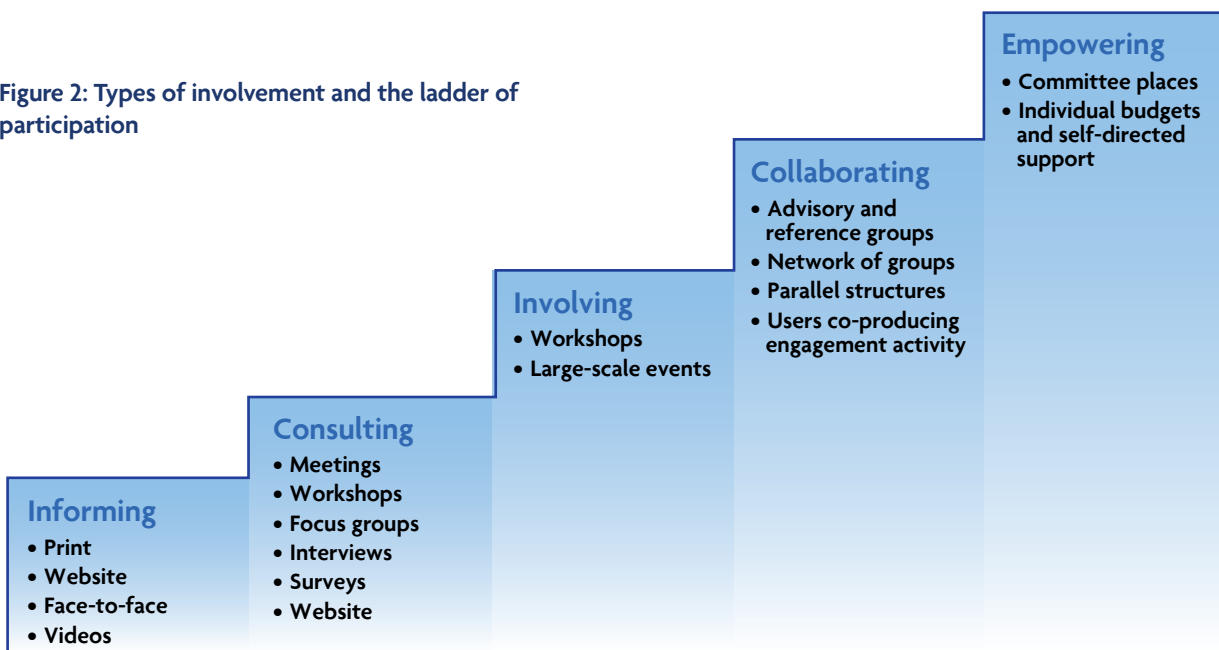
| User | Purpose/question | Aspect of the system |
|------|------------------|----------------------|
| Parents of children with SLCN | To establish parents' views on the progress their child has made | Evaluation of outcomes from a parent perspective |

**Activity**:

Develop a questionnaire which asks a parent to rate change in key aspects of their child's communicative functioning that are targeted by the particular care pathway or type of intervention. For example: confidence in holding conversations; intelligibility; making friends.

Ask the parent to say whether their child has made no progress, a little progress, quite good progress, fantastic progress in the different areas and ask parents to make a comment about what they attribute that progress to.

These questionnaires can be sent to a central point once a month for collation and analysis.

**Considerations**:

How will you collect questionnaires? Try to find a way that is not onerous for parents, to encourage their continued participation.

How will you reach parents whose first language is not English, or who are not functionally literate?

This potentially generates quite a lot of work for both parents and those who will analyse the results. Keep the questionnaire simple. But at the same time it will be important to give parents a 'free space' to make any comments they want to, and to make sure that these comments are taken into account.

# Types of involvement activity

In section 3 we introduced the concept of a ladder of participation. The following section provides information on various types of involvement activities that you may wish to use with examples from each of the different stages of the ladder. The order in which these are presented roughly reflects their position on the spectrum of informing to empowering. Figure 2 places these, with other potential mechanisms, on the ladder of participation.

There is no single best approach to participation: a combination of approaches is likely to be required, depending on who you are involving and why, and the resources available.

**Figure 2: Types of involvement and the ladder of participation**



**Empowering**
- Committee places
- Individual budgets and self-directed support

**Collaborating**
- Advisory and reference groups
- Network of groups
- Parallel structures
- Users co-producing engagement activity

**Involving**
- Workshops
- Large-scale events

**Consulting**
- Meetings
- Workshops
- Focus groups
- Interviews
- Surveys
- Website

**Informing**
- Print
- Website
- Face-to-face
- Videos

## Informing

### Providing clear and accessible information

All parents need timely and relevant information which helps them access the services and support they need to care for their children. Examples of how to produce clear and accessible information for parents, explaining why information matters, how to ensure that written information reaches parents, and some practical guidelines for producing flyers, leaflets and newsletters have been produced by Together for Disabled Children (see section 6).

The more informed that parents are, the more they will feel confident and able to make appropriate choices for their children and families.

### Website for children, young people and parents

Websites can help children, young people and their parents and carers access information about specific services and plans, resources and funding, agencies and organisations and they can be used to pose questions and issues for debate and discussion, giving a means for direct, immediate feedback.

| Strengths | Limitations |
|---|---|
| Potential numbers involved | Needs dedicated and skilled input |
| Multi-purpose | Needs a specific and adequate budget |
| Building on existing resources | Needs extensive publicity to make it known |
| Cost-effective | |
| Fun and engaging | Exclusive – not everyone has access to the internet |
| Children and young people can be involved in the web design | Needs commitment to use information and give feedback |
| Can be used through schools and youth clubs | Adults' views may be gained unintentionally |
| Examples of good practice or sources of further information: | |
| Speak up Salford | |
| Cornwall Youth Forum | |
| Young Lambeth | |

## Consulting

### Consultation approaches

These are one-off or short-term pieces of work that focus on obtaining the views of children, young people and parents. Examples include gaining users' views on their main concerns and priorities or on a particular service, and checking draft plans with them. Consultations can happen through meetings and workshops, focus groups, interviews, and postal, telephone or web-based surveys. Each of these mechanisms has its own strengths and limitations which you will need to consider very carefully in relation to the target audience and purpose of the consultation.[6] The table below gives an overview which generalises across all mechanisms.

| Strengths | Limitations |
|---|---|
| Targeted and focused | May be exclusive or unrepresentative (only the most vocal turn up to meetings, not everyone has internet access) |
| Time limited | |
| Cost effective | Lack of follow up |
| Immediate relevance | Lack of ownership |
| Provides answers to the questions commissioners want answered | No momentum |
| | Seen as a quick fix |
| Examples of good practice or sources of further information: | |
| www.teachernet.gov.uk/docbank/index.cfm?id=7561 This evaluation of The Communication Aids Project includes guidance on undertaking interviews with children who use communication aids | |

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6   For a discussion of the strengths and limitations of different mechanisms (in relation to adult audiences), see *Making Consultation Real. A toolkit for health and social care*. OPM/NHS Wales (2006) www.wales.nhs.uk/sites3/Documents/420/Makingconsultationreal.pdf..

## Seeking the views of service users and professionals in York

Following the Bercow Review, the City of York's Strategic Partnership for Integrating Services for Disabled Children commissioned a review of services for children with speech, language and communication needs, which involved a substantial consultation with parents and with professionals.

Special Educational Needs Coordinators (SENCOs) in ten schools were asked to give a questionnaire to parents of children with speech, language and communication needs. More detailed discussion was undertaken with parents whose child had received support from a specialist Teaching Assistant, and with a group of twenty parents at an Aiming High for Disabled Children consultation day. The aim of the consultation was to find out what support for children with speech, language and communication needs was working well, and what areas of support parents felt needed to be improved. Asking parents about the support their children received also provided an opportunity to see what interventions they were aware of and check if they were getting enough information and feedback.

The professionals consulted included:

>> health services – a paediatrician, health visitors, early support key workers

>> a range of support services including Connexions, the youth offending team, a dyslexia centre and others

>> early years settings – Area SENCOs, practitioners from different types of provision, children's centre teams

>> school staff in twelve primary and three secondary schools.

Professionals were given the following prompts:

>> Please describe the impact of speech, language and communication needs on the lives of children and young people.

>> Thinking about the needs of these young people, please can you describe what support/intervention works well within your own setting?

>> Please describe the support children and young people receive from other services for SLCN.

>> What would you like to do to improve support for children with speech, language and communication needs?

The findings from the consultation provided useful information to providers of speech, language and communication services, both in confirming the value placed on their work and highlighting areas where more could be done, for example a need to increase information for parents.

For commissioners, the consultation identified strengths in current provision to meet the continuum of speech, language and communication needs – such as the resource centre in a mainstream schools, speech and language therapy services to children's centres, and a pilot programme to train and support specialist teaching assistants in mainstream primary schools. It suggested a need to commission more training for mainstream school staff from the speech and language therapy service, and more support for school staff in running groups for children with less severe speech, language and communication needs. It also flagged the need to consider how provision for secondary age pupils could be developed to fill a current gap.

## Involving

### Large scale events

Rather than only drawing on the interest of the few, you may want to consider a larger event which either brings together a particular user group across the locality, or allows an exchange of views amongst a wider range of groups. This may give more flexibility in influencing and shaping ideas, priorities and direction and reaching agreement on contentious issues. The event can also be used for the children and young people to elect representatives to be on smaller advisory or committee structures.

| Strengths | Limitations |
|---|---|
| More inclusive | Needs highly skilled design and facilitation |
| Shared identity and purpose | Preparation and planning |
| Fun and energy | Time and money |
| Accountability | Raises the stakes; higher risk |
| Sharing different perspectives | Needs good follow up |
| A lot of work quickly | Needs commitment to action |
| | May be intimidating for some children and young people |

Example of good practice

Large events for children and young people should be designed to ensure complete safeguarding and the use of a range of approaches which enable children and young people from diverse backgrounds to actively contribute their experiences, concerns and ideas.

For example, OPM conducted an extensive deliberative process for the General Teaching Council for England (GTC) on the value and values of teaching, which informed the GTC's Code of Conduct and Ethics framework. The project involved several small and large-group events with children and young people of primary and secondary school age. The process was designed to cover:

– informed consent: close liaison with young people and their parents to ensure the project objectives and processes were clear and children felt they had chosen to participate

– safeguarding: transport planning and supervision and assignment of groups of children/young people to a group facilitator who supported each group and was responsible for their well-being throughout the process

– a variety of engagement activities which combined discussion, reflection, story-telling, visual expression and the use of other creative/projective techniques

– feedback and reflection of key messages and validation/ elaboration from participants

The inputs from children and young people, together with those from other stakeholders significantly informed the GTC's revised code of conduct. A sub-group of children and young people also participated in a closing multi-stakeholder event which brought together parents, teachers, head teachers and governors, other professions, and young people.

## Collaborating

### Advisory and reference groups

A group of children, young people and/ or their parents or carers advise and inform those commissioning services at the analysis, planning, delivering or reviewing phases. There is a series of meetings during the lifetime of the service.

| Strengths | Limitations |
|---|---|
| Influencing development | Time consuming and drawn out |
| Ownership | Can just be a 'rubber stamp' |
| Representative | Irregular meetings and attendance |
| Established and ongoing | No authority |
| | Needs to be backed up by mechanisms to seek the views of the wider population of users, to ensure that the views expressed really are representative |

Examples of good practice or sources of further information:

TreeHouse, Telford and Wrekin – Parents Open Doors (PODS): www.treehouse.org.uk/promoting-change/parent-participation-project/telford-and-wrekin

### Network of groups

A network of strategically-linked groups of children and young people and/or parents is set up that meets regularly with a support worker. Operating from their own territory and on their terms, the children and young people and/or parents are assisted to give their views on services or to raise their own issues, and these are addressed by the support worker.

| Strengths | Limitations |
|---|---|
| Links and supports hard to reach groups | A lot of staff support time needed |
| Regular, consistent involvement | No direct authority |
| Safe, familiar environment | Must keep short chain of communication |
| Ongoing for reviewing change | Change may seem remote |

Examples of good practice or sources of further information:

1Voice is a parent and family-led organisation for children and young people who use AAC. Further information can be found at: www.1voice.info

## Parent forums

One way of establishing and securing permanent parent participation is through Parent Forums. Over the last 10 years, there has been a large increase in the number of parent forums, often with specific roles in feeding directly into commissioning processes. Local service providers are obliged to consult with parents and many parent forums are springing up in response. Together for Disabled Children have put together some information on how to set them up.

## Involving users in research

Enabling children, young people and parents to participate in or lead research to find out the views of other users can produce new insights as well as being empowering. OPM has produced a toolkit on how to do this (see box below). The Hounslow case study (see page 17) describes how they involved parents in scrutinising SEN services.

### An online research toolkit produced by young people – WeCan2

The WeCan2 research report (OPM, 2010) is a strong example of leading edge practice. The research and reporting were undertaken by young people in youth decision-making groups, including a number with learning disabilities. The young people worked on their research for a year and produced a various outputs, including: a report, a website toolkit (to help include young people with a learning disability) and traffic-light cards (to be used to control the pace of meetings).

The aims of this project were to: develop the young people's research skills, collect evidence about what it is like to take part at youth decision-making meetings, to use the findings to build a website toolkit and to look at changes in youth decision-making meetings following publication of findings.

WeCan2 is leading-edge in a number of ways. As the research was wholly undertaken by children and young people it goes further than much work in this area. It is also innovative in that it was undertaken by, and produced for, people with learning difficulties who are often less heard than other groups. The project used video to record meetings attended by the young people. This allowed them to add a detailed observational analysis to their analysis of the language and procedural factors that needed to be addressed to enable young people with learning disabilities to participate fully in meetings. Analysis of the tapes contributed to the development of the website toolkit.

## Empowering

### Parallel structures

A youth body is set up to run alongside the adult-led decision-making processes to provide advice, or act as a sounding board. Examples include a shadow committee at any level in an organisation.

| Strengths | Limitations |
|---|---|
| Elected membership and mandate | What real authority and power? |
| Confidence and authority | Who elects members, and how? |
| Influencing organisational policy | Divisive |
| Ongoing involvement | Poor range of representation |
| Promotes informed and reflective discussion | Fractures from adult organisations |
| Examples of good practice or sources of further information: | |
| Buckinghamshire – young people's tender evaluation panel (see case study on page 9) | |

### Committee places

Children and young people and/or parents are elected or selected to be part of committees, steering groups, boards or other governing bodies. There may be specific spaces reserved for them.

| Strengths | Limitations |
|---|---|
| Direct access to governance | Not treated as equals |
| Long-term influence | Tokenism |
| Knowledge and expertise | Used to represent views of all young people, rather than in own right |
| Continuous input | Demanding of skills and commitment |
| Overcoming misunderstandings | Pressure to be seen to be successful |
| Requires change in attitudes of adults, representing a significant cultural shift for an organisation | Lose touch with peers |
| | Significant resources, staff support |
| Examples of good practice or sources of further information: | |
| Brighton and Hove Amaze Parent Carers Council www.amazebrighton.org.uk/editorial.asp?page_id=181 | |

The Hounslow case study on the following pages illustrates effective engagement with the parents of children with SEN. This engagement has been sustained, and involved a genuine sharing of power with parents.

## Engaging with Parents – Experiences from the Hounslow Pathfinder

The Hounslow pathfinder has used a number of techniques to engage with parents. For example, they have developed films aimed at parents, they have disseminated top talking tips for parents and carers, and they have supported parents to carry out their own research into issues such as best practice in the statement annual review process in Hounslow schools.

However, the main thrust has been a huge investment in relationship-building with the key Special Educational Needs (SEN) parent support organisation in the borough. The pathfinder has increased efforts to develop and build on the relationships they had already worked hard to establish and are investing still further time and energy in getting parents more involved.  In the Hounslow pathfinder project the focus is on schools as commissioners – so the intention is to make sure that parents are part of those commissioning discussions around the outcomes for their children. Essentially this is about changing concepts of power, and shifting to a more shared understanding of responsibility for outcomes – in the style of co-production.

### Who was involved: the role of scrutiny

One of the recommendations from the Lamb Inquiry was that scrutiny committees look at outcomes for SEN, with a reminder to scrutiny committees to engage more with the SEN parents. Working with this recommendation, the Hounslow pathfinder has operated like a scrutiny review and had parents at the heart of the project from the outset; parents sat on a steering group and have helped to shape the project all the way through. It is important to note however that the success of the Hounslow pathfinder approach at engaging and working with parents is drawing on five to six years of the work of the borough's scrutiny unit to build relationships and gain the trust of SEN parents. Hounslow has a mature scrutiny function and this has enabled the success of the project, as parents already have confidence in the function and feel able to approach the team if necessary. It is believed that the reason why the parents have consistently trusted them is because scrutiny is viewed as being independent from service departments within the local authority.

### How the project engages with parents

Hounslow have done all the usual engagement activity, such as focus groups with parents. One of the more original elements of the project is that they have encouraged and supported parents to do their own research. In addition there is a sub-project to train a group of parents to train other parents on how to be more involved in the annual review process and the development of their child's statement, how to focus more on outcomes, and how to engage with staff, and schools.

In the parental research element of the project the pathfinder is supporting a group of three parents, just as elected councillors would be in a normal scrutiny review. Meetings were set up for them in eight local primary schools in order for the parents to understand the schools' perspective, with the central questions being 'how do you approach an annual review?' and 'what are your processes?' This system has been very effective, and has helped to increase the parents' understanding of the school perspective. It has refined questions in their minds and given them the background information to become much more equal partners in discussions with schools. The pathfinder also considers the parents have appreciated the trust that the statutory partners have shown in encouraging them to carry out this work.

The 'train the trainer' element of the project is about equipping parents with the knowledge to be more equal partners in the process of the annual review of their child's statement. It is intended to carry out a pilot with approximately five parents in the autumn term 2010.

### Key learning:

Take parents on a journey: It is very important to take everyone, including parents, on a journey, in order to shift the focus from outputs on to outcomes. For example, it is not just about the number of hours the teaching assistant is 'Velcroed' to their child's arm; but more about what their child needs to achieve as a result of any support they receive.

There is nothing necessarily wrong with listening to those who shout the loudest: It is unhelpful to have the belief that it is only the articulate parents who get their voices heard, therefore somehow skewing the 'voice of the local parents'. Whilst this is sometimes the case it is important for commissioners not to be afraid to use those parents who put themselves forward. In the majority of cases, they do actually think about other parents and are keen to ensure they are represented fairly. For example, in Hounslow there was a case of a proposed cut to the local authority grant to a local parent advocacy group. Part of the rationale given for the cut was that the money was going to 'pushy white parents'. However when scrutinised the figures showed that the parents supported by the advocacy group matched almost exactly to the ethnic make-up of the borough. It is the articulate ones from this group who attend meetings but they fully understood their role to act as representatives of their 'constituency'. In reality you need to have parents that have got the time, the inclination, and the ability to speak for those who do not. Do not be afraid to work with and use those articulate parents!

## Experiences from the Hounslow Pathfinder (continued)

**Links to the parent videos are now available to view on Hounslow's website:**

www.hounslow.gov.uk/speech_language_videos **(they can be downloaded from here too)**

 **The videos are also available on youtube:**

**Importance of Speech and Language:** www.youtube.com/user/LBHounslow#p/u/4/8wfpfLkEy-Y

**Importance of Play:** www.youtube.com/user/LBHounslow#p/u/0/h_-1O_rBLPU

**Top tips for parents:** www.youtube.com/user/LBHounslow#p/u/2/ZHUR2d9wi0o

**Top tips for early years practitioners:** www.youtube.com/user/LBHounslow#p/u/1/0F-AMPiXeQU

**Building Blocks of Communication:** www.youtube.com/user/LBHounslow#p/u/3/5Z0rvMbLP2o

**Hounslow have also designed posters, postcards and credit cards with the top tips for parents and early years practitioners. Electronic versions are downloadable from this page:** www.hounslow.gov.uk/speech_language_videos.

# User involvement at different stages in the commissioning cycle

The following section presents some ideas on what types of involvement activities to use at the various stages of the commissioning process, for different levels in the participation ladder.

**Table 2: User involvement at different stages in the commissioning cycle**

| Activity in the commissioning cycle | User involvement activity | | | |
|---|---|---|---|---|
| | **Providing information** | **Consulting/involving** | **Seeking agreement** | **Co-production** |
| Understanding the needs of the local population and the resources available to meet those needs, setting priorities and agreeing outcomes | Presentations, reports or summaries of findings from research, population needs analysis or national guidance made available in appropriate formats for service users or carers<br><br>Work with theatre groups to illustrate the issues facing service users, the impact of current arrangements and future needs | Feedback from practitioners in seminars or questionnaires about unmet needs identified by service users<br><br>Questionnaires to service users and carers asking for comments on needs or services<br><br>Workshops or 'sounding boards' with selected groups of service users to explore the extent to which services meet their needs, advocacy support to facilitate feedback from individuals<br><br>Reviews of complaints or suggestions schemes<br><br>Discussions with existing pupil or youth forums to explore their views about service needs<br><br>Reviews of national and international research on the views of service users, potential service users and carers to their needs | Service users on steering groups/other governing bodies to agree analyses and help identify desired outcomes and commissioning priorities<br><br>Care pathways reviews of cases with service users to explore their experience of services, and to agree what kind of improvements are needed in the future | Working groups including service users to design research projects<br><br>Advisory groups with service users to undertake joint analysis of research<br><br>Service users, families and carers undertaking projects to gather information through interviews, information gathering or direct observation, to feed in to a final analysis |

| Activity in the commissioning cycle | User involvement activity | | | |
|---|---|---|---|---|
| | **Providing information** | **Consulting/involving** | **Seeking agreement** | **Co-production** |
| Mapping and planning sustainable and diverse services to deliver outcomes | Commissioning plans and strategies made available in appropriate formats in reports, presentations or other formats to service users and carers<br><br>Opportunities to observe council meetings or Board meetings where plans are discussed | Service user focus groups to comment on proposals for service development and change<br><br>Questionnaires to obtain feed back from service users and potential service users on service design proposals<br><br>Reviews of the contents of suggestion boxes prior to design and planning exercises | Children and young people panels to test and agree proposals<br><br>Service users as members of project steering groups to agree proposals and plans<br><br>School and youth councils with a role in analysing and agreeing to service design proposals | Service design teams including service users and potential service users to analyse potential service developments and make recommendations for change<br><br>Service users to be members of agency led decision-making bodies<br><br>Service users and commissioners jointly running consultation exercises with the public or other service user groups<br><br>Scenario analysis workshops where proposed arrangements are tested, and changes are agreed with workshop members |
| Procuring and developing services based on the plan | Information in appropriate formats about service development plans<br><br>Open contracting – service contract information made available to service users and the public | Service users and carers feed back on the effectiveness of services in meeting the aims of individual contracts<br><br>Service users and potential service users offer input into the desired outcomes to be specified for a service in an outcome-based contract<br><br>A service user and carer advisory panel to feed into decision-making about the awarding of contracts | Advocates representing the views of children in decisions about the award of contracts<br><br>Children's panels with responsibility for making decisions about the distribution of resources, e.g. 'Community Chest' | Service users working together with commissioners as part of a decision-making panel about the awarding of contracts or SLAs |

| Activity in the commissioning cycle | User involvement activity | | | |
|---|---|---|---|---|
| | **Providing information** | **Consulting/involving** | **Seeking agreement** | **Co-production** |
| Monitoring and evaluating service delivery of outcomes and taking remedial action if necessary | Reviews of commissioned services, gaps and emerging needs made available to service users and carers in appropriately formatted reports or presentations for information | Service user panels to feedback views on the effectiveness of services as part of ongoing monitoring and review of service quality<br><br>Regular questionnaires and focus group meetings to review service user and carer views about the effectiveness of services<br><br>Regular monitoring of complaints, complements and suggestions from service users | Service users as regular members of review panels responsible for interpreting evaluations and drawing out the implications for service improvement | Mystery shopper exercises using service users and potential service users<br><br>Service users undertaking regular focus group meetings with other service users on behalf of commissioners<br><br>Monitoring and review teams including stakeholders, meeting regularly to draw together information about progress of strategy<br><br>Service users designing performance indicators and performance monitoring arrangements |

# Important considerations

All involvement activity should be mindful of the following considerations.

## Skilled facilitation

Involving children and young people with speech, language and communication needs can require skilled and experienced facilitation. For certain groups of children, specialist knowledge of consultation and engagement techniques with children with speech, language and communication needs is vital for the engagement process to be meaningful and safe for participants.

## Informed consent

Everyone should have the right to contribute as much or as little as they choose. Participants need to be clearly informed about the purpose of the activity, and how their views will be used. Make sure you have the permission of the children and young people, but also think who else you need to ask. It may be parents and carers, a teacher or youth worker. If you are planning to take photos, take particular care to have the right permissions, which may need to be in writing.

## Protection

What are the risks of involving children and young people and how can these be reduced? Have you done a risk assessment? Are workers checked by police? Have you the right insurance? Do you have a clear child protection policy and do all those involved know it? Is the venue safe? Has transport to and from the venue been arranged? Do any of the children and young people need to be accompanied, because, for example, of age or disability? If using the web, does access need to be supervised or is the site secure?

## Access

Who is likely to be affected by the work you do and do those you want to involve reflect this wider group? Who is likely to get overlooked and what steps can you take to reduce this risk? Do members of your target group have special communication needs? Have you considered age, ethnicity, gender, sexuality, ability and geography? Have you considered whether parents may themselves have communication issues? Access is about buildings, but also time, place, style of meetings, language, interpreters and access to computers.

## Rewards and feedback

How are children and young people being thanked and rewarded for their involvement? How will they know their participation has led to influence, action and change? Who is going to tell them, when and how? What ways are there to reward their contribution? Certificates and letters of thanks, payment, remuneration, gifts and accreditation all have their place.

## What to do with the information collected from users

Any user involvement process needs a mechanism for implementing changes that arise from a user involvement activity. Otherwise, user involvement will be tokenistic and lack respect for the users. This is crucial in the process of establishing an integrated system of user involvement and will become part of the ongoing change and development of a service. Considering how the information will be used should be an integral part of your user involvement plan, built-in from the start. You will also need to provide feedback to users on the outcome of their involvement.

# 6. Useful resources

## Participation organisations

- Participation Works: a consortium of six national children and young people's agencies that enables organisations to effectively involve children and young people in the development, delivery and evaluation of services that affect their lives. They publish a range of guides on different aspects of involving children and young people, including How to involve children and young people in commissioning. They also run events and training courses. www. participationworks.org.uk

- Involve: Involve are public participation specialists bringing institutions, communities and citizens together to accelerate innovation, understanding discussion and change. www.involve.org.uk

## Research reports

- Building a culture of participation: *Involving children and young people in policy, service planning, delivery and evaluation*. Research report by NCB & PK Research Consultancy (2003) published by DCSF. The paper can be found at: http://publications.education. gov.uk/eOrderingDownload/DfES-0827-2003.pdf.pdf

- *Consulting with Disabled Children and Young People*. Report by the Joseph Rowntree Foundation (2001) which highlights the innovative approaches of two projects aimed at supporting disabled young people to express their views and providing communication training for practitioners. The report can be found at: www.jrf.org.uk/publications/consulting-with-disabled-children-and-young-people

- *Engaging children and young people in research and consultation: A review of principles, policy and practice*. Research report by OPM for the General Teaching Council (2010) on good practice in engaging young people in research and consultation. The report contains a number of useful case studies and can be found at: www.gtce.org.uk/research/commissioned_research/accountability/engaging_cyp1010/

- *Hear by right*, from the National Youth Agency (NYA) is standards framework for organisations in the statutory and voluntary sector to enable them to assess and improve practice and policy on the active involvement of children and young people. www.nya.org.uk

- *Creative Influence: Research Led by Young People*. Written by OPM (2010) this publication provides a practical guide to involving children in research to enable them to influence decision making. It can be downloaded from: www.opm.co.uk

## Guidance, resource packs and CD ROMs

- *I'll Go First*. The Children's Society (2006) A CD ROM on using computer technology to enable disabled children and young people to make their views known in a fun and creative way. Contains new story boards and the option for disabled children and young people to record their views online. Available from www.childrenssociety.org.uk

- *Listening to Children with Communication Support Needs*. Developed by Stuart Aitken and Sally Millar, and published by Call Centre and funded by the Scottish Executive Education Department, this resource pack consists of three books that cover a range of topics relating to engaging with people with communication support needs. It can be found at: http://callcentre.education.ed.ac.uk/About_CALL/Publications_CAA/Books_CAB/Listening_CAC/listening_cac.html

- *Speaking with someone who uses AAC*. Developed by Communication Matters, this guide is useful when consulting those who use augmentative and alternative communication. It can be found at: www.communicationmatters.org.uk/sites/default/files/downloads/focuson/Speaking_with_someone_who_uses_AAC_A4.pdf

- Buckinghamshire Children and Young People's Trust, *Involving Children and Young People in Commissioning: Guidance Document*, www.buckinghamshirepartnership.gov.uk/partnership/CYPT/joint_commissioning.page?

- Sinclair R and Franklin A (2000) *A Quality Protects Research Briefing: Young People's Participation*. Department of Health, Research in Practice and Making Research Count: London. Making Research Count is a network of ten universities and their health agency and social care partners. The Network was commissioned, along with Research in Practice, to produce a series of research briefings. Originally known as Quality Protects Research Briefings, and produced for the Department of Health from 2000 onwards, they subsequently became Every Child Matters Research and Practice Briefings: children and families and were published by DfES, now the DfE.

- Action for Children and New Economics Foundation (2009) *A guide to co-producing children's services*. This guide is a supplement to a larger report, *Backing the Future: why investing in children is good for us all*, which is the culmination of a programme of research carried out by NEF and Action for Children.

- *How to involve children and young people with communication impairments in decision-making.* This guide produced by the National Children's Bureau provides information and ideas about how you can enable children and young people with communication impairments to be involved in decision-making. The guide can be found at the National Children's Bureau, www.ncb.org.uk/cdc/home.aspx

- *I Want To Choose Too.* University of Bristol (2007). A resource aimed at teachers and others who support primary age children with little or no speech in decision-making, containing a range of practical, easy to use resources and ideas. The resource can be found at: http://rose.bris.ac.uk/dspace/bitstream/1983/1188/1/I%20want%20to%20choose%20too.pdf

- *Listening to Young Children: The Mosaic Approach.* National Children's Bureau in association with Joseph Rowntree Foundation (2001). The Mosaic Approach is a multi-method approach in which children's own photographs, tours and maps can be combined with talking and observing to gain deeper understanding of children's perspectives on the places in their early childhood. This resource can be purchased from JRF at: www.jrf.org.uk/publications/listening-young-children-mosaic-approach

- The Children's Society (2007) *My Life, My Decisions, My Choice.* Disabled young people have assisted The Children's Society in developing a set of resources to aid and facilitate decision-making. The resources are aimed at both disabled young people and the professionals who work with them. The resources can be downloaded from: sites.childrenssociety.org.uk/disabilitytoolkit/about/resources.aspx

- Shephard C (2002) *Participation Spice it Up!: Practical Tools for Engaging Children and Young People in Planning and Consultations.* This tool can be purchased from Save the Children: www.savethechildren.org.uk/en/54_2346.htm

- CALL Centre (2003) *Personal Communication Passports.* This is a resource outlining the key principles of making and using communication passports as a way of documenting and presenting information about disabled children and young people who cannot easily speak for themselves. It can be purchased at: www.callcentre.education.ed.ac.uk

- Council for Disabled Children and Participation Works (2008) *Top Tips For Participation: what disabled young people want.* A poster, highlighting in disabled young people's own words, their top tips for participation. Available from: www.ncb.org.uk/cdc_moh

- DCSF (2008) *Working Together: Listening to the Voices of Children and Young People*, . This guidance promotes the participation of children and young people in decision-making in school, local authority and related settings and provides advice on the principles and practice that support such involvement. The resource can be found at: http://publications.education.gov.uk/eOrderingDownload/DCSF-00410-2008.pdf

- Stone E (2001) *Consulting with Disabled Children and Young People*, Joseph Rowntree Foundation. Survey results demonstrated that disabled children are being involved in a range of decision-making areas. However, the findings suggest that participation is not yet sufficiently embedded or sustained across all social services departments, and a lack of involvement in disabled children at strategic level persists.

- Holliday E, Harrison L J and McLeod S (2009). 'Listening to children with communication impairment talking through their drawings'. *Journal of Early Childhood Research.* 7(3),. 244-263. This article suggests how drawing may be an appropriate method for 'listening' to the ideas of children with SLCN.

- McCormack J, McLeod S, McAllister L and Harrison L J (2010) 'My speech problem, your listening problem, and my frustration: The experience of living with childhood speech impairment', *Language, Speech, and Hearing Services in Schools.* Published online Jun 25, 2010 at http://lshss.asha.org/cgi/content/abstract/41/4/379 [doi:10.1044/0161-1461(2009/08-0129)]. This article explores the experience of speech impairment in everyday life, described by children with speech impairment and those they communicate with.

- Together for Disabled Children, *How to Produce Clear and Accessible Information* www.togetherfdc.org/SupportDocuments/How%20to%20Guide%20PP%20Sec%202.pdf This guide is aimed at anybody producing information for parents.

- Together for Disabled Children, *Securing the Future of Parent Forums* www.togetherfdc.org/SupportDocuments/How%20to%20Guide%20PP%20sec%206a.pdf This guide may be particularly relevant for people seeking to establish or sustain parent forums.

- OPM (2006) *Making Consultation Real. A toolkit for health and social care*. NHS Wales. www.wales.nhs.uk/sites3/Documents/420/Makingconsultationreal.pdf. This toolkit has been designed as a resource to help those involved in user and public consultation in health and social care in Wales. Its aim is to set out principles and good practice to guide statutory organisations undertaking consultation, together with examples of how these principles might be put into practice. It has also been designed as a resource for those being consulted.

# Appendix: Specific tools used to support children and young people with SLCN

The Bercow Review carried out various consultations with children, young people and parents as part of its fieldwork. The following provides examples of some tools that were used.

Illustrations used in the Bercow Review were produced by Jess Bradley These illustrations are available individually for downloading, with notes on how each might be used. They can be found at: http://picasaweb.google.com/RosalindMerrick/JessBradleyIllustrations#

**Materials for children to choose from, look at and talk about during interview.**
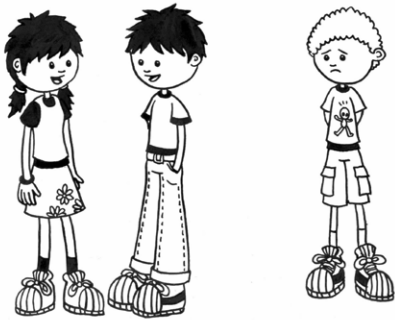


**Children selecting this drawing talked about friendships and playmates.**
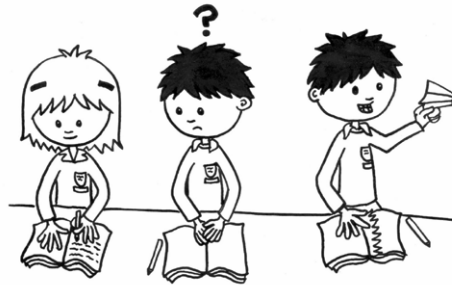


**Children identified with various figures in this drawing and talked about their experience of schoolwork.**



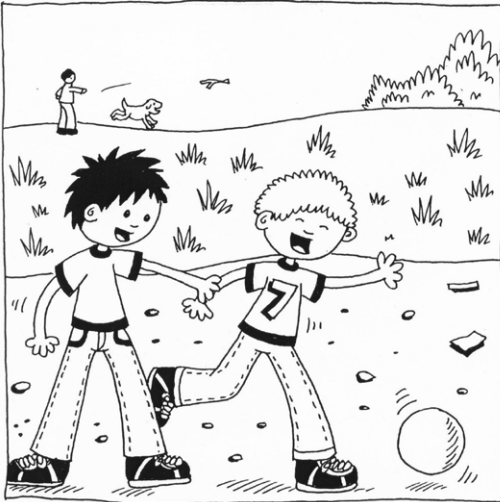**Children selecting this drawing talked about friendships and playmates.**
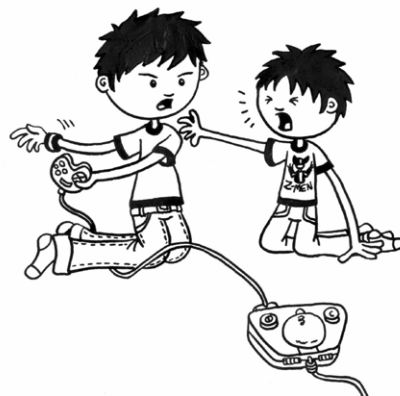


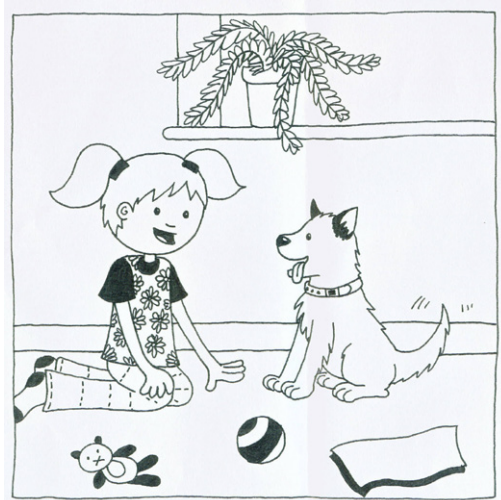**Children shared their experiences of conflict with friends and siblings.**
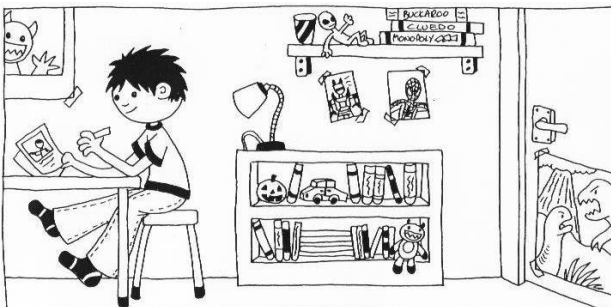


**Children choosing this drawing talked about quiet time, homework and activities at home.**
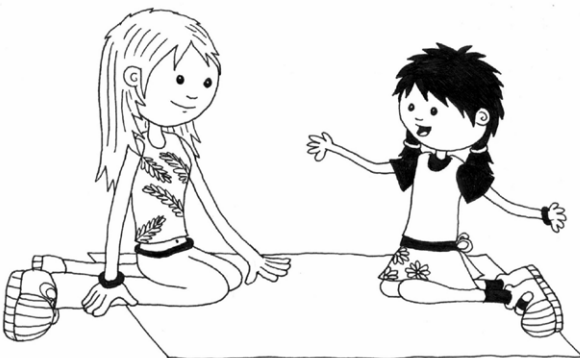


**Children identified with various figures in this drawing and talked about bullying.**

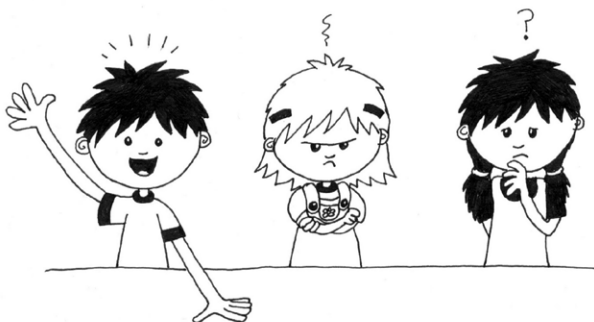Some children selected this drawing as a conversation starter.



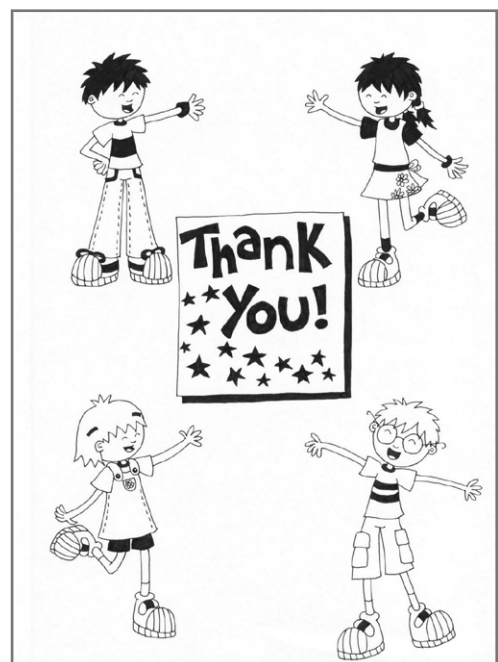Some children selected this drawing as a conversation starter.



Drawing used for the children's information sheet about the research.



Drawing used for the information sheet.



Drawing for the information sheet to illustrate the consent process, with the captions 'Yes', 'No' and 'I'll try it'.



Cover of a thank you card posted to participants after the interviews.

# Example topic guide for children and young people – as used in the Bercow Review[7]

| Topic guide | Activity |
|---|---|
| Checking consent | Introducing the session, checking informed consent |
| What are good talking times? What makes them good?<br><br>Which talking times are bad?<br><br>What makes them bad?<br><br>What would make them better? | Talking about talking pictures<br><br>– Pictures are placed on the table for the YP to look at. Flip chart sheets/card with X and ✓ or smiley/frown faces. Or alternatively stick smiley/frown faces onto the pictures themselves<br><br>– YP asked to put the pictures into the place they feel most appropriate and asked to comment/explain their choice |
| Who helps you with your talking?<br><br>What do they do that is helpful?<br><br>Who is not helpful?<br><br>Why?<br><br>What do they do that you don't like?<br><br>What could do they differently that would be better? | Circles of friendship<br><br>– Demonstration by leaders first (brief outline of how this might work)<br><br>– We're going to talk about who helps us with our talking, who is helpful and who is not very helpful. This is me (stick picture in middle of circles). My science teacher used to be really helpful, cos he always explained what words meant to me (put face of science teacher close to me in the middle). I had a friend called Tom who wasn't very helpful cos he used to interrupt me all the time and take the micky (put Tom's face at the outside of the circle).<br><br>– Ask them to put their own picture or name in the middle of their picture. It may be easier to get YP to think about a particular context: people at school/college; when I go the shops; when I go to the hospital/clinic.<br><br>– Choose stickers (4-6) to represent some people who are helpful or not helpful. Ask the young people about their stickers – who and why |
| What sort of talking goes on in their day?<br><br>What do they regard as good or bad?<br><br>What makes some talking good or bad? – things that other people do, things that they do, other factors – noisy environment, tiredness<br><br>With bad situations, what would make it better?<br><br>What do they remember about learning to talk and talking when they were younger?<br><br>Did anyone ever help them with their talking?<br><br>What do they remember about it?<br><br>Did they like it or not?<br><br>What would have made it better? | Typical day<br><br>– Leader sketches out a day in own life showing the ups and downs of that day. Tells the events and interactions that cause the ups and downs.<br><br>– 'I'm going to talk about one of the days I had over the Christmas holidays and all the talking I did on that day. That day had some nice things and some nasty things (drawing up for nice and down for nasty); there were some good things and some bad things. For example, I had a chat with my best friend (drawing or sticking a picture to represent this on one of the high points) – I like doing that cos we talk about shopping and she listens to me; I also talked to the man at the bank (low spot) and I couldn't understand what he said. There was so much noise in the bank that I couldn't hear him properly.'<br><br>– YP asked to make their own typical day, using A4 sheets and pictures to stick on.<br><br>– Discussion whilst they construct their typical day<br><br>This activity could be turned into a life-span picture for some children e.g.<br><br>'When I was little I remember someone teasing me at school because I couldn't talk (drawing a down path) and when I went to school I had to have help for my talking cos I wanted to be in the school play but just got too flustered; I was in the school play and it was horrid because I forgot all my lines. When I was in the senior school I was in the guides and we used to do lots of singing and I used to love that and I used to help at cubs too, teaching the cubs how to tie knots.' |

7    Roulstone S, Evidence from parents and children to the Bercow Review (2007)

| | |
|---|---|
| What are good talking times/places/people?<br><br>What makes them good?<br><br>Which talking times are bad?<br><br>What makes them bad?<br><br>What would make them better? | Collage of communication contexts<br><br>– Start off with a large sheet of paper on the table so that it covers the table and everyone has part of the blank sheet in front of them with some basic details to create some initial sense of what the picture will be about (e.g. if it is to be a school, mark the middle section as the playground).<br><br>– 'We're going to make a big picture of your town/school/college (whichever is most appropriate to the group) Where are all the places you talk? (playground, diner/café, classroom, gym – draw and label places as they talk – encourage them to draw and stick pictures onto the collage) Who do you talk to? What do you talk about?'<br><br>– 'Sometimes when it's a big group of people, its hard to talk and I get left out (add relevant picture)'<br><br>– 'Sometimes I like just talking to my friend when its nice and quiet'<br><br>– 'When I was at school, there was a boy who used to laugh at me and tease me when I talked.'<br><br>– They may like to create their own school or classroom in the space in front of them |
| What different people do they work with?<br><br>Where do they see them?<br><br>What sorts of activities happen?<br><br>Which things/people/places do they like?<br><br>What do they like about them?<br><br>What would make them better? | Choices<br><br>– Discussion of how speech and language therapy and other 'support' sessions are conducted and how that works for the YP.<br><br>– How many of you see a<br><br>   – doctor<br><br>   – dentist<br><br>   – teacher (who are their different teachers?)<br><br>   – someone who does extra work with your reading or maths<br><br>   – speech and language therapist<br><br>   – anyone else that you go to see<br><br>(stick up pictures/names as they mention different people)<br><br>– Where do you see them? (talk about the possibilities illustrated) Get them to put stickers on those contexts that have happened to them<br><br>– What do you do when you're with them? (try to illustrate these – maybe with words, diagrams, drawing, pictures etc)<br><br>– Which things do you like best? Why? |

# Topic guide used for parent consultation groups during the Bercow Review[8]

Can I start by asking everyone to introduce themselves?

- Say your first name
- Why you came to the meeting
- And your favourite colour


Thinking back about when you first knew there was a problem with communicating

- How did it come up?
- What happened then?

Did you get help?

- What help did you get?
- Who helped you?
  - –type of professional
  - –type of organisation
  - –location

What it was like being helped?

- Types of activity, context, group/individual
- Expectation of child/young person
- Expectation of parent/carer
- How did you feel?

Could it be done differently?

- Type of service
- Availability
  - –Access
  - –Information
- Level of provision
  - –School funding (School Action/Action Plus)
- Identification of problem

Has the help you got made a difference?

- Learning
- Daily life
- Social life
- Family life

How are things for you now?

8 Roulstone S, Evidence from parents and children to the Bercow Review (2007)