I want to Choose too

A resource for teachers and others for including primary school age children with little or no speech in decision–making

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in association with Bristol City Council and the SW Regional Partnership

Acknowledgements

Booklet

Messages from the PIE project are summarised in a short booklet which can be found in the front pocket of this pack. It includes messages from:

- Primary school age children with little or no verbal communication.

- Parents and carers

- Teachers

- Teaching Assistants

- Speech and language therapists

- Head Teachers and Deputy Head Teachers

- Other professionals

CD Rom

This resource pack is also available on a CD Rom, which is inserted in a pocket on the back cover.

Contents

Part
1

How we compiled this resource – who helped us – how to use it

> It doesn't matter whether a child can use a switch or joystick or whether they don't understand much, if any child can join in and enjoy anything in school, as far as I'm concerned that's all that matters... I think there's always going to be something that the child can make a decision about, it might only seem so small to some people but it gives children a feeling of independence and it makes them feel quite special. My child always seems happiest when we give him decisions.

Quote from a parent involved in the PIE research project.

This resource was compiled as the result of a research project 'Participation in Education' (PIE). The project has been carried out by researchers at the University of Bristol, with members of The Listening Partnership, a group of young disabled people in Bristol supported by the City of Bristol Council and the West of England Centre for Inclusive Living. The project has been advised by a group of professionals, academics and parents and was funded from 2005-2007 by the Esmée Fairbairn Foundation. The resource is designed to be complementary to the 'R U Listening' self-evaluation framework for organisations eliciting the views of young people with special needs. The framework was developed by the South West Regional Partnership and can be downloaded from:

http://sw-special.co.uk/documents/students/docs/RUListeningSelevaluationframeworkfolder.pdf

We take an interactionist approach, as described by Groves in Jones and Hodson (2006). This approach asserts that there are three principal dimensions of effective inclusion: what the child brings, the skills and attitudes of those who interact with the child, and the context within which the child functions. This approach recognises the complex situation that the child finds his or her self in. This situation cannot adequately be explained by either the medical or the social model of disability; the one focusing on the child's impairments, and the other on the social environment which they are in. Recognising the complexity makes it possible to make inroads into enabling children with little or no speech to be involved in decisions and choices that affect them.

The PIE project initially carried out a postal survey of schools in England to determine the current level of involvement of children with little or no speech in their education. This report can be accessed online at:

www.bris.ac.uk/norahfry/download/questionnairereport.pdf

The project team then worked with two special schools in the south west, one primarily for children with physical impairments, and one for children with severe learning difficulties. We determined from the survey and from previous knowledge that both of these schools were carrying out innovative work with this group of children.

Within these two schools, we worked closely with 11 children with little or no speech, observing them in the classroom, and talking to their families, classroom assistants, teachers, head teachers, school nurses, deputy heads, and speech and language therapists. We also carried out some group work in one of the schools, with the help of two members of the Listening Partnership. In addition, we have drawn on the work of several schools that we discovered are known to have 'good practice' in this area and on the relevant literature and related research.

A **booklet**, found in the front pocket, includes messages from groups of people that we have consulted in the research project. These messages have been written as a result of thematic analysis of the interview transcripts or from the notes taken at observation and group sessions with the children. The messages have generally evolved from the voices of several participants, but where a particularly strong message was given, but only one person said it, this has also been included. The key messages are also, where appropriate, interspersed throughout Part 2 of the pack.

Part 2 includes ideas and resources for involving children with little or no speech in peer relationships, in the classroom, in the whole school and in the community. Quotes are inserted from the research to illustrate points where appropriate. We have chosen examples of resources on the basis of their usefulness and ease of implementation. We are not asserting that all examples are necessarily the best or only way of doing things!

Part 3 lists useful resources, literature and contacts in themes covering: guides and resource packs, signing and symbols, views of young disabled people, classroom environment, Augmentative and Alternative Communication (AAC), total communication, Individual Education Plans (IEPs), objects of reference, parents and families, inclusion, wider community and services and useful websites.

Our aim was to make this resource as accessible and 'user friendly' as possible, therefore we frequently use a 'signposting' technique to draw attention to relevant and useful materials rather than aim to include everything in one, cumbersome document. At the same time, we want to include all the really important messages that we have heard throughout the course of the project, so in the booklet we have devoted at least a page to each of the groups that we have consulted. We hope that you find this a useful and inspiring resource and that it doesn't collect dust on a shelf! Our inspiration has been the desire that young people have to communicate, however difficult that is for them, and the joy they find in being heard.

Key message from the PIE research:

There needs to be better sharing of good practice, both within and between schools.

An exercise to imagine how it feels to be without speech from Somerset Total Communication

A full version of this exercise is included in Appendix A, page 50

For most of us, communicating does not present too many difficulties. However, for the children that are the focus of this resource pack, communication can be very challenging and frustrating. To help us to imagine what this must feel like, we have included an exercise that could be used in training.

> You could say…
> One person in each pair is person A and the other person is person B
>
> I would like person A to begin by communicating their message to person B.
> But whilst doing this activity person A must not speak at all.
> Person B however can do anything they feel they need to do to try to receive the message from person A. You have about two minutes to do this. Then you may swap over and then person B should try to get their message across to person A again without speaking and without moving from their chair.
>
> You are requested not to use any charade conventions.

NB Before starting this activity it is important to check if there are any participants who can already sign. If there are, then ask them not to use the signs they know.

Reflecting upon Communication breakdown

- Ask participants to feed back how they felt first when they were giving the message to their partner and then ask for feed back about how it felt to receive or get the message

- You may choose to use 'feelings' symbols when you take the feed back

- Or you may divide a flip chart/whiteboard into two sections and take feed back from the group and record their comments first on one side headed "giving the message" and then on the other side "receiving the message"

> You could say…
> You were able to talk about your feelings and in doing so were able to off load those feelings. For a child who finds it difficult to express themselves it could mean that those feelings build up and the the way they get expressed might be through unacceptable behaviour.

Part
2

Resources and Ideas

In this section we have divided the resources and ideas into four areas:

1 **Peer support and friendships**

2 **The classroom: visual timetables, choice-making, objects of reference, evaluation and assessment, reading, group work, target setting**

3 **Whole school strategies: meetings, auditing, recording, training, school councils, signposting, assemblies, policies and guidance**

4 **The wider community:**
Total Communication, legislation, advocacy

Peer support and friendships (1)

Message from the children involved in the PIE project:

> 66 We hardly ever communicate with children our own age. We might like to spend more time with our peers without adults being around all the time. 99

Peer interaction between children with little or no verbal communication and their peers was found to be a very rare occurrence in the research that we have carried out (Watson et al 2006). Parents told us that their children needed role models and the chance to learn skills in this area. In addition, when taking a holistic approach, children with communication impairments and others (for example children who did not speak English as a first language) would benefit greatly from all the children around them having a basic knowledge of 'low tech' ways of communicating such as the use of symbols and signing. It is clear that children with little or no verbal communication experience few chances to interact without substantial adult intervention.

Idea!
What about arranging a school reunion and inviting younger children along to see how the older children are getting on?

Idea!
Check the Map (sponsored by Inclusive Technology Ltd. and BILD) has a great website that takes you directly to fun activities for young people that are designed to be used with a click of the mouse, touch screens, switches or interactive whiteboards. Go to:

http://www.checkthemap.org/links/fun_sites

Widgit SOFTWARE

Widgit software runs a free monthly magazine called 'elive' for young people with communication difficulties – go to:

http://www.symbolworld.org/index.htm

Could be fun to look at with a friend!

SymbolWorld.org

'Symbolworld also has features on learning, stories and 'My World' where young people can write stories about themselves in symbols. Free downloads for parents include some fun games that could be used in break times.

Idea!

If you type in 'games' in the search box on the ICAN website: http://www.ican.org.uk/sitecore/content/home/GlobalPages/Search. aspx?q=games&group=_disabled&id=&page=2 it comes up with lots of ideas about games suitable for classes that include children with communication difficulties

1 Voice – Communicating Together

1 Voice takes a family and social perspective on communication and recognises the great need for adult role models to inspire children and families alike. Their website offers opportunities for young people using AAC to contact each other.

1 Voice is run by a committee of parents, adults who use AAC , and professionals. Volunteers are responsible for organising and running events, as well as for all administration, policy making, fundraising, publicity and all other duties. As 1 Voice grows, they hope to appoint paid workers to cover the anticipated workload.

Contact details: 1 Voice – Communicating Together, PO Box 559, Halifax, HX1 2XT
Website: **http://www.1voice.info/**   Tel: **08453307862**

In the PIE research project we did find rare instances of friendships between children with little verbal communication. As one mother told us:

66 There's a little boy in her class that she's got such a good relationship with – they laugh, they giggle, they touch one another like that on their hands and it's like "get off", and she will chase him in the wheelchair and, you know things like that so, they really are good friends and I've never, and some of the teachers have said they've never, seen any children that have got such a good relationship like that. 99

Idea!

A school in Sussex has installed all-weather white boards in their playground to help non-verbal children to tell others how they are feeling. Pictures and words are printed on magnetic tiles that the children have previously been made familiar with.

Ways that other schools have encouraged peer support and provided role models:

Joint assemblies with mainstream peers, inclusion in mainstream classes, use of puppets, peer support in classroom tasks, being voted on to School Councils by peers, making classroom rules together and through the use of advocates.

A Speech and Language Therapist responding to our questionnaire says it is vital that there is the:

❝ expectation from the adults in their lives that they have the ability to make and express choices and have chances to practice this throughout life. ❞

Further reading

Clarke, M. (2003) Patterns of interaction between children with physical disabilities using augmentative and alternative communication systems and their peers. *Child Language Teaching and Therapy*, Vol. 19, No. 2, 135-151

Claxton, K. and Crothers, T. (2007) Role models: Who needs 'em? *Communication Matters* Vol 21, 1 pp 2-4

1Voice (2004) Role model involvement project July 2004. 1Voice/Communication Matters
http://www.1voice.info/

2 The classroom

Children with little or no speech can be involved in all aspects of the classroom with careful planning and creativity. The section that follows draws on the ideas that we have come across in our research that seem to show evidence of 'good practice'. We start with a general introduction and then go on to give examples of work around visual timetables, choice making , objects of reference, evaluation and assessment, reading skills, group work and target setting.

Message from the teachers involved in our research:

66 We start out by interpreting all behaviour as communicative. 99

A very helpful resource for use in the classroom is 'Listening to Children with Communication Support Needs' by Stuart Aitkin and Sally Millar (2002). This pack is produced by the Call Centre in Scotland and Sense Scotland. They have also written a definitive guide to producing **communication passports** (Millar, S. with Aitken, S. (2003) Personal Communication Passports. Call Centre: University of Scotland). There is also an online guide to producing communication passports using Powerpoint at:

http://callcentre.education.ed.ac.uk/downloads/quickguides/passports/ passports_in_powerpoint.pdf

In addition, **Ispeek** provides free downloads of templates for communication passports and symbolised 'feelings' sheets. These can be found at: **http://ispeek.co.uk/index. asp?page=freebies.asp**

Somerset Total Communication have produced many resources for use in the classroom (see next section for more details about their 'total' approach). A list of available resources and further information can be found at: **http://somerset.gov.uk/somerset/ socialservices/pi/stc/**

Widgit software are one of the leading companies providing software and resources to support inclusion. Visit **http://www.widgit.com/** for information about what they can offer and some free downloads.

www.easyinfo.org.uk contains downloadable guidance on all aspects of accessible information, including the use of pictures, symbols and information for people with high individual communication needs.

Visual timetables

Many schools use visual strategies to support their work. Timetables are an important part of this. Widgit software provides some guidance about producing a simple visual timetable at:

http://www.widgit.com/SIP/resources/classroom/timetables/index.htm

Some schools have developed this idea further. For example, St. Rose's School in Stroud has developed a tactile, interactive timetable for use in the classroom.

Objects are removed as the day goes on, so that the children can get an idea of what is coming next!

Idea!

An easy way to make audio files from easy to read information using your computer (with Windows XP, cd burning capability and Clicker5) is explained in a straightforward document that can be found at:

http://www.totalcommunication.co.uk/library/audio_handout.pdf

Choice making

> I think that one of the priorities through the curriculum is that children are given choices, in their day-to-day life about what they want to eat and what they want to drink, and to some extent about what they want to do during their free-time.

Quote from a Headteacher

Choice and decision-making in the classroom is a complex and multi-layered activity. Activities range from giving simple choices between two items, such as holding up hands to signify, for example, blackcurrant or orange juice, to use of sophisticated communication aids. In our research, we found that children with little or no verbal communication had many opportunities for making choices but that teachers were keen to discover new ways of extending this.

As a communication co-ordinator said:

> They need the means to respond and you have to have a means prepared for them, if you're asking the child to make a decision about, I don't know, what sandwiches shall we take on a picnic, they've got to be able to say all the options from chocolate spread to ham to cheese, you know, there have to be all those options there ready for them, either in symbol form or on voice output switches or photos or whatever methods you're using, you have to think beforehand to actually offer them that diverse choice, otherwise you're simply saying, ham or cheese and okay, they're making a decision but not really.

In this section, we do not intend to list all the ways in which choices can be given, as each teacher will be finding ways that are relevant for the children in their care, but we will provide links to useful resources that are available. A teacher told us that what might appear to be small steps in choice making were extremely rewarding:

> This year he's learnt to choose by picking up his apple as opposed to just eye pointing. Having that kind of success I feel is quite fantastic!

Crick software, who produce the Clicker software commonly used in special schools, have some free downloads on their website and examples of the ways in which their software can be used to support children with choice making. Find the link to the free download website, Learning Grids at:

http://www.cricksoft.com/uk/

This site also contains a 'case study' area where examples of Clicker software have been successfully used to support children with communication difficulties, particularly in mainstream schools.
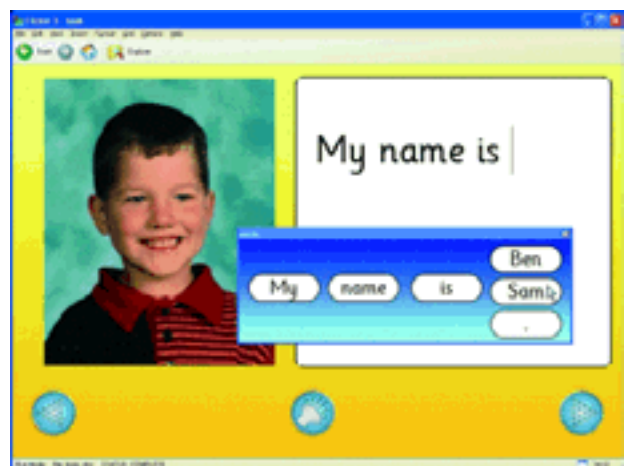
Reproduced by kind permission of Crick Software

Alderman Jackson School in Norfolk have devised simple symbolised sheets for making choices. For example, the sheet below shows how a child made choices about activities and food choices for a party.

The child was asked to put a mark on the paper by his or choices.

Talking Mats are increasingly being used in schools to support children to express an opinion. The child's own way of communicating can be used and some schools have adapted or simplified the idea to suit their own needs.

Talking Mats Information Sheet

Joan Murphy devised the framework called Talking Mats (literally mats with pictures attached) during a research project in 1998. Talking Mats was originally developed to help people with communication difficulties to think about the issues discussed with them and to express their opinions. Since then Talking Mats has been used with many people with and without communication difficulties both in the UK and abroad. People who have used Talking Mats have found it enjoyable and easy to use. It is not an assessment, but rather a tool for helping people to express themselves. Recent research has proved it improves the quality and quantity of information gained.

Talking Mats is an interactive resource that uses 3 sets of picture symbols –topics, options and visual scale.

- topics: whatever you want to talk about (e.g. pictures symbolising what do you want to do during the day, where you want to live, who do you want to spend time with, ...

- options: relating specifically to each topic. For example, whether you want to go to college, attend a day centre, stay at home, ….

- visual scale: in order to allow participants to indicate their general feelings about each topic and option. For example, whether they are happy, unsure, unhappy.

Once the topic is chosen e.g. 'what do you want to do during the day?' the participant is given the options one at a time and asked to think about what s/he feels about it. S/he can then place the symbol under the appropriate emotion to indicate what s/he feels. It allows topics to be explored at different levels. The use of both video and digital camera are used, the former to ensure non verbal communication is taken account of and the latter to give a permanent record of the mat.

You can go to **www.talkingmats.com** for more information.

> **"** He gets quite a lot of choice, and if he wasn't given that amount of choice you would get behaviour problems. **"**

Teacher talking about a pupil on the autistic spectrum

A parent involved in the research sounded a note of caution:

> **"** They've got to feel safe in what they do and feel that they're achieving something within their smaller boundaries to start off with. You give them too much choice and they're going to get, you know, a bit lost in it I think. You need to build their confidence up in sort of increasing circles, if you know what I mean? **"**

Key message from the PIE research:

Children can be included in all aspects of decision-making at some level, given the right support and the motivation.

Objects of reference

It has been shown that using objects of reference supports learning in a number of ways; as a 'bridge' to more complex forms of communication such as signs and symbols, to develop an awareness and understanding of the environment and as an aid to memory (Park 2003). This approach is useful not only with children with little or no speech but can also be of great advantage to children for whom English is not their first language. The Call Centre in Edinburgh has produced a 'Quick Guide' to objects of reference. This, along with other useful guides, can be found at:

http://callcentre.education.ed.ac.uk/About_CALL/Publications_CAA/Quick_Guides_CAB/AAC_CAC/aac_cac.html

Further reading

Brower, F. and Barber, M. (2005) When words are not enough. *Special!* Autumn 2005 pp 10 -12

Park, K. (2003) A voice and a choice. *Special Children* Issue 153, Feb/March
www.education-quest.com

Evaluation and Assessment

Alderman Jackson School in Norfolk have devised a sheet for a pupil to be able to give feedback about a lesson:

The Surrey Speech Language and Communication Profile is an informal assessment which is used to collate information about a child's speech, receptive and expressive language and communication skills. It is presented in a simple visual format and is designed to be used by speech and language therapists in conjunction with professionals and parents, with a contribution by the child where appropriate. A copy of the form can be found at:

www.surreycc.gov.uk/.../780923e823f7e29780256cab00556789/

The Welsh Assembly has produced a 'Routes for Learning' pack which provides assessment materials for learners with profound learning difficulties and additional disabilities. The materials aim to support schools in assessing early communication and cognitive skills. Copies can be ordered by ringing **0870 242 3207**.

Reading

Teaching reading skills to children with little or no speech has been identified by the teachers and parents in our study as a major area of difficulty. ISAAC (the International Society for Augmentative and Alternative Communication) has listed some websites that provide support in this area. Find it at:

http://www.isaac-online.org/ie/articles/123/1/Literacy-websites

Inclusive Technology Ltd. has produced the 'Read it!' series of interactive, animated storybooks which can be used on an interactive whiteboard or on a touch monitor/standard computer. Details at:

www.inclusive.co.uk/catalogue/acatalog/the_readit_series.html

Idea!

Some parents support their children to learn to read through the use of sign by working with the school and putting together a file of signs for all the words their children are reading.

Idea!

Story telling is a great way to get enthusiastic about books. Go to http://www.storytracks.com/ to find out more about resources, training and workshops.

Bettridge School works with 'Language through Colour' to support understanding of text, symbols and photos and in formulating sentences. The aims of this are; to help children get maximum information from wirtten presentations and visual displays, aid interpretation of questions and improve the quality of their responses and improve the information content and/or the word order in spoken or written language.
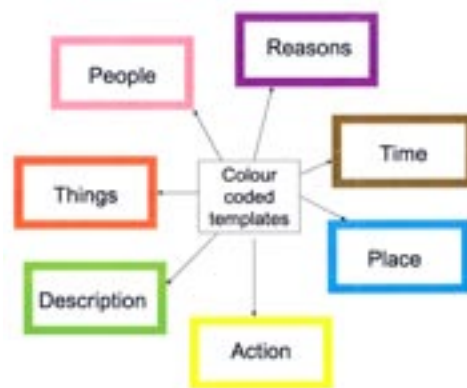
Further reading

A useful article on the use of AAC and literacy is by Hetzroni, O. (2004) AAC and Literacy *Disability and Rehabilitation* Vol. 26, no 21-22/ 4-18 November, pp 1305-1312

For information about using symbols to support literacy, read Detheridge, T. and M. (2002) *Literacy through Symbols*. London: David Fulton

I CAN, the charity that helps children to communicate has produced a paper about the link between communication difficulties and literacy. Included in this paper are many useful references to sources of help. It can be found at:

http://www.ican.org.uk/upload/i%20can%20talk%20-%20communication%20disability%20and%20%20literacy%20difficulties.pdf

Group work

One of the major areas of difficulty for teachers working with children with little or no verbal communication was identified in our research as being group work situations. In 'Speaking, Listening and Learning' suggestions are made to encourage discussion with this group of children:

http://www.standards.dfes.gov.uk/primary/publications/inclusion/sll_sen/

- Make sure other children make space for and listen to the child, however basic or fleeting the participation.

- Comment on what the child does or says, and encourage others to do the same, for example, *you smiled then, Jayesh so I guess you liked the music*.

- Provide picture or object clues to the topic and represent choices in a visual way through pictures or symbols.

- Teach the child phrases for joining in I want to say something, good idea, not sure.

- Have cards for the child to use to indicate if they want something repeated or said or signed more slowly and simply.

- Translate the objectives of the discussion into a meaningful choice for the child, for example, in a debate *Should animals be kept in zoos*, a child might select three animals to be the focus of discussion.

- Give children roles they can fulfill, for example, starting the timer for a timed discussion; passing the talking stick to children who put their hand up; recording decisions by making marks on a chart; recalling who said what, counting votes.

- Help children to understand the purpose of discussion by summarizing the point of the debate and recalling who said and felt what at the end.

- Be sensitive to children's contributions and incorporate anything relevant that they offer.

- Be aware that many children will tend to go along with a dominant view rather than disagree; help them to express disagreement by role-playing some outrageous opinions, and look at appropriate ways of disagreeing.

- Play games which dramatise the views and perspectives of others, for example, taking photographs of a model landscape from different standpoints, asking children to say or sign or draw what they can see; acting out characters in drama, or guessing what is in a closed box.

Target setting

We know from previous research that teachers are increasingly involving children with little or no speech in setting their own targets. In our research, we found that this has been done in a number of ways:

> **Target setting – ideas in practice**
> - **Symbol sheet/targets written as symbols in child's book**
> - **Give child a choice of targets**
> - **Child evaluates own performance /self review exercise**
> - **Use child friendly language**
> - **Reward system with tactile and visual components to illustrate progress and encourage active participation**
> - **Particular emphasis on behaviour and social skills that child can understand**
> - **Document child's views on IEP paperwork**
> - **Work with children so they come up with their own targets**
> - **Targets are written up in home/school diary, and displayed in the classroom**
> - **Involve parents in target setting with the child**
> - **Use a symbolised questionnaire**
> - **Pupil has a self-evaluation file and level of self-advocacy is recorded/ achievement portfolio**
> - **Look at the child holistically and experiment with the child's reaction to a target**
> - **Targets set in Annual Review, and then broken down into very small steps**
> - **Reinforce displayed targets and constantly remind child when working**

In this example from Bettridge School, symbols are chosen that are personal motivators for the child. They are then moved along a velcro band at the bottom until the target is reached.

One teacher involved in our research is just developing this area:

> 66 I decided really what their target was, then they were involved in how they think they could achieve that target, and because it was the first time that we had done it it was Ok but obviously it needed a bit more work on my part, but I think it is something that can work because they've actually then made the choice of what they are going to do to achieve that target. 99

This is a developing area in schools, and there are not many available resources for tackling it in relation to children with little or no speech. A common approach is to use symbols or to support the child to choose between two targets that the teacher has set.

Further reading

Aitken, S. and Millar, S. (2002) *Listening to children with communication support needs*. Call Centre/Sense Scotland: University of Edinburgh

Aitken, S. and Millar, S. (2004) *Listening to children 2004*. Call Centre/Sense Scotland: University of Edinburgh

DfES (2005) *Speaking, Listening and Learning: working with children who have SEN*. DfES1187-2005 and DfES1231-2005 to DfES1235-2005 **http://www.standards.dfes. gov.uk/primary/publications/inclusion/sll_sen/**

Shotton, G. (2003) *Pupil Friendly IEPs: Individual Education Plans for primary school children age 6 to 11*. London: Paul Chapman Educational Publishing

Whole school strategies

The literature tells us that the most successful way of including all children in their education is to have clear, whole school approaches in place (DfES, 2005). This provides consistency throughout the school and enables children to move between classes with the minimum of disruption and confusion. One school we visited is working out a strategy for this:

66 I think one of the things particularly is looking at continuity from class to class, as children actually move through the school, not that they'll necessarily need the same things, because hopefully they will mature and develop new skills. But certainly when they first make transition through classes, that will actually be supported in the same way. It's just trying to change the emphasis that it's actually our responsibility to facilitate their communication, not that they have to learn to communicate to us but we have to learn to understand their communication. 99

This school has recently appointed a member of staff whose responsibility is for disseminating total communication and information and who will be developing communication across the school. They are hoping in this way to give communication a higher profile in the coming years.

This section of the resource pack will provide information about good practice in meetings, auditing, recording, training, school councils, assemblies, signposting and guidance.

Key message from the PIE research:

An increase in whole school and whole Local Authority approaches to communication is needed to ensure continuity.

Meetings

A parent that took part in our research project told us:

> She came to her review this year and it's the first one she's been to. She didn't have a great deal of involvement and she obviously didn't understand a lot anyway really of what was going on, but [teacher] brought in her two work folders from school and [child] actually showed me all the pictures and she went through it with me and she was all beams and smiles – this is mine I've done this and I'm showing you, and that was really really nice. I think it's important because it's their school, it's their learning and it could be a chance for them to communicate if there's something they're not happy with. With a parent there they might have the confidence to say 'I don't like that!

A teacher told us about another child's review:

> It was all very positive and it would have been good for the child to have been able to hear all that. I think it would be nice if they were able to contribute something even if it was only on their VOCA and they wanted to say how they felt they'd done over the past year or whether they were enjoying school, or putting together a bit of video evidence but again it's the time to do that with the child although if they have a key worker there's no reason why the key worker shouldn't be able to do that. I think it would be nice to involve them in some way.

We found examples of the children contributing in a number of ways:

Meetings

- **Photographic contribution**
- **Use of video**
- **They are supported by an advocate in the meeting**
- **Symbols/symbol questionnaire, using happy/sad faces**
- **Symbol supported discussion**
- **Completion of 'views sheet' / 'pupil's views/report' before the meeting or another type of written contribution from the child**
- **Make sure that the child is aware that the review is happening**
- **The children represent their successes and achievements of the past year in a written and/or pictorial form**
- **Interpretation of child's contribution by an adult/ Scribed report**
- **Use Alternative and Augmentative Communication (AAC), either pre-prepared or in response to questions**
- **Powerpoint presentation**
- **Child is invited to bring examples of work he/she is proud of**
- **Review report read to child, child makes mark on front to indicate this has been done**
- **Report is written in rough while working with the child**
- **Child is asked set of questions and responds with 'happy/sad' faces**
- **Completion of a response form**

Manor Park School in Worcester have produced guidelines for including pupil's views in their annual review (abridged to show level 1 only):

ANNUAL REVIEW – PUPIL VIEWS
Guidelines

These Pupil Views Forms have been produced in response to the changing policy environment on consulting children. Professionals are being encouraged to offer children more choice in their personal management and education.

The three levels correspond to a pupil's cognitive development.
The adult will have to select the level that is appropriate to the individual pupil.
The pupil is offered choices to gauge his or her views about school.
Please make certain that the pupil works with three familiar adults to ensure a confirmed view.

The adult uses objects, photographs, symbols, signing and speech to enable the pupil to communicate.
Using OBJECTS
• Write down the pupil's choice in the appropriate space or take a photograph of the pupil with the object
• Complete the sheet
• Photocopy the sheet/sheets to form part of the Annual Review paperwork
Using PHOTOGRAPHS or SYMBOLS
• Stick the pupil's choice in the appropriate space
• Complete the sheet
• Photocopy the sheet/sheets to form part of the Annual Review paperwork
Using SPEECH
• Write down the pupil's choice in the appropriate space
• Pupil could copy/trace/write own choice
• Photocopy the sheet/sheets to form part of the Annual Review paperwork

Your intimate knowledge of the pupil and the range of activities that he or she undertakes throughout the school year will guide and determine the choices you present and the method/methods used.

LEVEL 1

SECTIONS
Please cross the method/methods used to complete the form
Please sign your name

"I like …. I am good at …"
• Offer 2 choices at a time
• If pupil is unable to express a choice, the familiar/known adult needs to interpret the pupil's behaviour/ reactions to identify activities
• Record choice or take photograph

"I need help with …."
• Offer 2 choices at a time – one is something that the pupil dislikes or finds hard to do
• If pupil is unable to express a choice, the familiar/known adult needs to interpret the pupil's behaviour/ reactions to identify activities
• Record choice or take photograph

"My friends are …."
• If pupil is unable to express a preference include photographs of familiar pupils and/or adults

"My favourite piece of work …."
• If pupil is unable to express a preference include a sample and/or photograph of work

P2 – P3 (approx)

RESOURCES
Objects
Photographs
Symbols
Signing
Speech

"I like …. I am good at …"
• Range of objects/photographs that pupil likes and dislikes/finds hard to do

"I need help with …."
• Range of objects/photographs that the pupil is moderately interested in and actively dislikes/finds hard to do

"My friends are …."
• Photographs

"My favourite piece of work …."
• Samples or photographs of work

ANNUAL REVIEW - PUPIL VIEWS

Name: **Date:**

- **O** I used objects to make my choice
- **O** I used photos to make my choice
- **O** I used symbols to make my choice
- **O** I used signing to make my choice   enabled me to make my
- **O** I used speech to make my choice   choice

I like:
I am good at:

I need help with:

My friends are:

My favourite piece of work is:

These pictures are from an Annual Review meeting at St. Rose's School in Stroud (with thanks to the family for giving permission for these pictures to be used). This shows how a contribution can be relatively easily put together with the use of a digital camera and a computer.

Annual Review - December 2006

These are some of the things I enjoy doing at school.

Listening to music and playing musical instruments.

Relaxing in my comfy Chair or getting out onto the bed.

Taking part in cookery lessons.

Making choices.

Listening to stories.

Key message from the PIE research:

Children with little or no speech are increasingly successfully involved with their reviews, school councils and target setting.

Further reading

Barnardo's/Yorkshire and Humberside SEN Regional Partnership (2006) *Involving children and young people in meetings and reviews*.

http://thepartnership-yh-involvingchildren.org.uk/pdfs.asp

Hayes, J. (2004) Visual Annual Reviews: how to include pupils with learning difficulties in their educational reviews. *Support for Learning* 19, 4. pp 175-180.

Kids Consultation Project (2003) *Thank you all*. KIDS: South Gloucestershire. Includes top tips for including disabled children in meetings, written in consultation with disabled young people. **www.sw-special.co.uk/parents/students/docs/KIDSConsultationprojectCCreamer.doc**

Whole school auditing on communication and inclusion

'R U Listening' is a self-evaluation framework for schools and other organisations to assess how well they are eliciting the views of young people with special needs. It was developed by the South West Regional Partnership and can be downloaded from:

http://sw-special.co.uk/documents/students/docs/RUListeningSelevaluationframeworkfolder.pdf

The Centre for Studies on Inclusive Education has developed the 'Index for Inclusion' which is a set of materials to guide schools through the process of inclusive school development. The Index for Inclusion: developing learning and participation in schools is published by the Centre for Studies on Inclusive Education. Price £24.50 (incl p+p) UK only. Details can be found at:

http://inclusion.uwe.ac.uk/csie/indexlaunch.htm

In addition, ICAN has information about "Speaking Out: Speech and Language Audit Tool and Framework". Details can be found at: www.ican.org.uk

Accessible recording of meetings and feedback

Our research project found that very few (10%) schools were recording the outcomes of meetings in a way that the children could understand.

However, some schools were doing this, for example Alderman Jackson School produce the minutes from their school council meeting in an accessible way:

One teacher involved in the research described what she does to help children with little or no speech give feedback about the day's lessons:

66 We have switches programmed with a verbal choice and you would have a symbol on there, so at the end of the day I might ask them what they enjoyed doing most – was it library work or PE? There would be a picture of the library and a picture of PE then if they choose a switch and hit it, it will say I really enjoyed being in the library. 99

Training

It was significant that within our research project we found a pressing need for training that was specific to children with little or no verbal communication, particularly training for Teaching Assistants, but teachers and families also expressed concerns in this area. One teacher summed up the value of a cross -county approach which also includes parents and carers:

" Certainly I think that is a good practice thing to have something that is county wide like that and train people who're working with children who are communicating in different ways. Basically I mean that's the bottom line, and the county has trained parents as well in this which is really good so there is consistency, cross communication. "

The following section relates to resources that are available in this area.

I CAN Training
I CAN have developed a workforce development programme to meet the needs of practitioners who work with children. They use the experience of their staff, many of whom work in direct service delivery, and their associates who are experts in the field. The programme covers early years, school aged children and young people aged 14-19. Training relates to the National Qualifications Framework and supports the Children's Workforce Strategy. It links to the delivery of the Early Years Foundation Stage, the Primary and Secondary National Strategies and targets for further education. For more information, contact the I CAN training team on 0845 225 4073 or 0207 677 2781or email training@ican.org.uk.

The CALL Centre in Scotland works to support pupils with Additional Support Needs, especially those with speech, communication and/or reading and writing difficulties, and the staff who work with them. The Centre is based in the University of Edinburgh's Moray House School of Education. They provide training on making Communication Passports and other areas: **http://callcentre.education.ed.ac.uk/About_CALL/Services_CAA/Training_ CAB/training_cab.html**

CALL Centre Paterson's Land Holyrood Road Edinburgh EH8 8AQ
E-mail: **info@callcentrescotland.org.uk** Telephone: **0131 651 6075/6236**

The Paediatric Communication Aids Service (PCAS) provides training throughout the South West, either at their base at Claremont School, Henleaze, or in local schools. PCAS has a library of VOCAs and switches to lend out. **http://www.pcas.claremont.bristol.sch.uk/**

Frenchay Communication Aids Centre also provides training to school-age children. **http://www.cacfrenchay.nhs.uk/**

The ACE Centre Advisory Trust (South) provides a focus for the use of technology with the communication and educational needs of young people with physical and communication difficulties. Based in Oxford, they offer a wide variety of services including in-depth individual assessments, information, R&D, and specialist training for parents and professionals: **http://www.ace-centre.org.uk/**

ACE Centre (North) is a charitable company that is independent of all manufacturers and suppliers in the services they provide. They offer a wide range of services to support communication and learning through the use of Assistive Technology (AT) and Alternative & Augmentative Communication (AAC) systems and resources for children and adults with physical and communication difficulties. The ACE Centre North offers a range of training and professional development opportunities: **http://ace-north.org.uk/index.asp**

Cornwall AAC Team have produced an excellent CD for the Communication Aids Project entitled 'Finding a Voice: Using AAC, an interactive information and training package for all those supporting learners with complex communication difficulties'. It contains a modular training package covering:

- Mod 1 Introduction
- Mod 2 Disability Awareness
- Mod 3 Communication Strategies
- Mod 4 Positioning and Access
- Mod 5 Issues for Schools
- Mod 6 Effective Interaction
- Mod 7 IT and High Tech Solutions

The CD is available from Mick Thomas at Becta: **becta@becta.org.uk**

Triangle (**www.triangle-services.co.uk**) is an independent organisation working with children and young people and providing training and consultancy throughout the UK. They work directly with children and families, teach and advise parents and professionals, and provide consultation to individuals, teams and organisations. Most of their work is around disabled children's rights, child protection, consultation, communication and inclusion. They are advised by three inclusive consultative groups of children and young people (aged 3-24), and a number of disabled people work within Triangle. Triangle/NSPCC (2001) Two Way Street – training video and handbook on communicating with children who do not use speech or language. Leicester: NSPCC.

The DfES and the Disability Rights Commission have produced a training resource about 'Implementing the Disability Discrimination Act in schools and early years settings'. It is published by the Stationery Office and costs £15+ VAT per pack. Email: **customer.services@tso.co.uk**

The Speech and Language Therapy Department at St. Rose's School has produced a document about Alternative and Augmentative Communication (AAC) strategies for use in the induction of new staff:

Speech and Language Therapy Department
Induction for New Staff

AAC Strategies

The majority of pupils at St. Roses School experience some degree of difficulty with communication. The cause of these difficulties may be physical, cognitive, sensory or emotional or most commonly a combination of any of these. We are committed to supporting all pupils to communicate to the best of their ability. If the pupil is, or may become, an "intentional communicator" we encourage them to use a range of methods referred to as:

"Alternative and Augmentative Communication Strategies"
(any method of communication other than speaking and writing).

Some pupils learn to use "low tech" AAC strategies naturally, supported by their families. Others require a high level of staff support to acquire communication skills which are consistent with their development.

Gesture, Body Language and Facial Expression
These are natural, powerful methods of communicating. They are rarely directly taught in school. Some pupils have difficulty interpreting these aspects of communication.

Formal Signals
Pupils use a variety of methods to indicate "yes" and "no". Examples of currently used signals are:
- "yes" – vocalisation, extend upwards in chair, look up, make direct eye contact, smile, look at symbol on left wristband
- "no" – look down, frown, look away, look at symbol on right wristband

Makaton
This is a formal manual signing system. Key concepts are signed
- for expressive communication if a person has inadequate natural speech
- to support a pupil's understanding of spoken language
- to gain and hold a pupil's attention during communication.

Take and Show, Pointing
The pupil takes the other person somewhere, or points, to show what is wanted.

Eye Gaze
The pupil looks at something which attracts their interest. This "prolonged looking" is interpreted as signifying desire for the object or activity. If the eye-gaze is appropriately reinforced, the pupil may learn to develop more intentional eye-pointing.

Eye Pointing
The pupil establishes eye contact with another then looks deliberately at their desired item or location. At a simple level this powerful strategy can be used to convey choices of object or activity. It can also be used to access communication charts.

Communication Charts and Books
Books and charts are devised to provide an appropriate vocabulary to be used by pupils who do not have adequate natural speech. Words and phrases are represented by photographs, symbols and text. The pupil is taught to indicate single words by using their fingers, hand or eyes to point. Sophisticated coding systems are sometimes used. If the pupil is cognitively able, functional phrases can be constructed from single words and sometimes by spelling out with an alphabet chart.

PECS
Some pupils benefit from the specific approach of the "Picture Exchange Communication System". Symbols and photographs are displayed on individual cards and used to exchange for the item or experience represented. This is a carefully structured system of teaching the principle of communicative exchange.

Simple VOCA's
Simple electronic "Voice Output Communication Aids" are used to provide one or several pre recorded messages that the pupil can speak out, by pressing directly or accessing with a switch. Examples of these devices are: BigMack, 4 Talk 4, and the Mini MessageMate.

Sophisticated VOCA's
A variety of "high tech" (and high cost) communication aids are used to provide synthetic speech. Extensive vocabularies and sometimes word processing features are programmed into the devices. The pupils control them by direct access (touch) or switch access. The pupils must learn complex skills to access these devices, and require a very high level of support from experienced staff. Examples of these devices are: Dynavox Cameleon, Tellus, LightWriter, and MessageMate.

Susan Blandford   Speech and Language Therapist, St. Roses School

Coram Family run a training course on 'Listening to Young Children'. Contact Penny Lancaster at penny@coram.org.uk or phone 0207 520 0357.

The Children's Society run accredited training on 'Communicating with Disabled Children and Young People'. Contact the project on 01904 639056 or go to:

http://www.childrenssociety.org.uk/what+we+do/Training+and+consultancy/ Pact+Training+and+Consultancy.htm

Key message from the PIE research:

More training and support with communication is needed, for professionals, for families and Teaching Assistants in particular as they play a vital role.

School Councils

66 School Council? Oh! He'd love that!.... If they had more voice, it might result in them getting more out of school. 99

This was a quote from a parent of a child with no verbal communication. Her child's school was just setting up a council and she felt strongly that children like hers should be involved and that he would gain a huge amount from it. Other parents were a bit more sceptical, but agreed that their child could make a positive contribution. We found that schools were keen to develop this area:

66 We are developing a school council – we want the children to be able to have more influence over things like the outside area; we want to develop play equipment, and what do they want to do when they're out there, what do they need to be out there to make it accessible... 99

Quote from a Head Teacher

Some counties are developing networks to share experiences about school councils. This increases good practice and supports schools who are unsure as to how to start the process.

The Children's Society writes about School Councils in a submission to the recent Select Committee on Education and Skills:

❝ School councils have an important role to play in the life of schools and young people's experiences of democratic processes and practices. Where they are effective they can meet some of the active requirements of the National Curriculum for citizenship and at the same time promote inclusive cultures, policies and practices. We know from our experience of developing school councils in both mainstream and special schools, disabled pupils can work alongside their non–disabled peers in influencing change in the school environment and develop a sense of empowerment and ownership from their involvement. However to be fully inclusive, flourish and succeed in achieving their goals school councils must be embedded in whole school policies and practices which foster respect for the views of students and staff. ❞

http://www.publications.parliament.uk/pa/cm200607/cmselect/cmeduski/147/147we26.htm

Bettridge School has been running a school council for a while now and they say:

❝ We found we had to train our pupils in aspects of social use of language and notions such as expressing their views and that it is OK to have an opinion that differs from others, etc. As well as giving pupils a voice we need to train them on how to use it and give them the skills and confidence to use it effectively. ❞

Further reading

The School Councils UK website provide details of a book entitled 'School Councils for all' which gives detailed guidance about including disabled children:

http://www.schoolcouncils.org/resources/resources-for-sale/all-primary-resources/school-councils-for-all/?searchterm=school%20councils%20for%20all*

Signposting

For children to feel fully included in their environment and able to participate in their education, it is important that the physical surroundings are accessible to them. Claremont school in Bristol has commissioned a signposting system all through the school that provides a pathway for the children and also allows them access to rooms.

Bettridge school in Cheltenham labels each classroom with photographs of all the children in that class and their teachers and teaching assistants.

They also have a board, informing the children of the day's lunch menu.

Idea!

Photos of the children and their teacher and T.A.s could be put up outside the classroom. Pictures could be laminated with Velcro on the back, so changes can be made when needed. This promotes a sense of belonging to a classroom

Further reading

On the Teachernet website: **www.teachernet.gov.uk/_doc/2220/Access_Guide_.doc**

There is a useful document about monitoring the accessibility of your school called 'Accessible Schools: Planning to increase access to schools for disabled pupils'.

Assemblies

Teachers have told us that it's really important to include all the children in an assembly. If a child feels excluded this can have repercussions all through the day. We were unable to find any relevant information about including children with little or no speech in assemblies. This could be an area for further investigation!

School policies and guidance

There are a number of resources which have been produced to support the involvement of disabled children which are suitable for use with children with little or no speech. For example:

'Listening to Children with Communication Support Needs' by Stuart Aitkin and Sally Millar (2002). This pack is produced by the Call Centre in Scotland and Sense Scotland.

Children's Society (2003) **Ask Us 2**. This is a follow up to the Ask Us CD Rom. It is aimed at key people in local authorities who are tasked with taking forward the *Quality Protects* programme for transforming children's services. Available from the Children's Society: **http://host2.clickandbuild. com/cnb/shop/tcs?productID= 54&op=catalogue-product_info-null&prodCategoryID=14**

Idea!

A school in the South of England has written a simple document on 'Augmentative Communication: an easy guide to using visual and technical communication to support speech'. This contains ideas about using alternative methods of communication and the use of pictorial symbols, covering the purpose of communication, AAC, signing, objects of reference, photos and symbols, Picture Exchange Communication Systems (PECS), support and training. They have also written a document on the use of Voice Output Communication Aids (VOCAs).

Children's Society (2005) **How to ask us**: *Using multi-media methods to consult with disabled children and young people*.
How to Ask Us learning Pack is the third CD-rom in the Ask Us series - a multi-media compilation of messages from disabled children and young people. A resource for involving disabled children and young people in decisions that affect their lives or consulting with them about the development of facilities and services that affect them. Details from: **http://host2.clickandbuild.com/cnb/shop/tcs?op=catalogue-products-null&prodCategoryID=14**

Mencap (2004) **Listen Up**
Listen Up is a toolkit of multi media resources to help children and young people with a learning disability complain about the services they use. www.mencap.org.uk

Scope **Supporting communication through AAC**. A downloadable package containing 12 modules that aim to help parents, teachers and professionals support individuals in their use of AAC. It can be found at: **www.scope.org.uk/education/aac.shtml**

Further reading

Chan, S. (2005) Implementing AAC in Schools: Part 2. *Bulletin* (RCSLT) February pp16-17

4 Including children in the wider community

Our research has shown that children with little or no verbal communication have few opportunities to fully participate in the community, or even fully take part in family life. This quote from a parent was fairly typical:

66 She doesn't really communicate with anybody when she's out. She'll smile and if people talk to her she'll laugh and she'll smile back at them, if they wave she'll wave back, but she won't initiate any conversations when she's out. **99**

This lack of communication can be for a number of reasons, partly because there may be practical difficulties such as mountings for their communication aids, but also because we live in a largely inaccessible environment. As one parent told us:

66 It's [communication aid] quite big, it's bulky yes. I mean in the house, I can't get her through the doors with it on, I have to take it off and if she wants it in her bedroom I've got to collapse it all and set it upstairs, because it won't go in her lift because it's too wide. **99**

Other parents told us about the difficulties that they had with insurance of VOCAs and the lack of resources that are available to schools. However, a Speech and Language Therapist talked of what is possible, given the right equipment:

66 We are building a life skills room, which will include environmental controls. Our children will be able to open doors, operate blinds, phone their mum or friends, turn on the TV/DVD – all independently, without the need for anyone else being there. All of these can be controlled via their VOCAs. A number of our children are using their communication aids to operate TVs at home, stereos, DVDs, and it's great, it's giving them that power. **99**

For families, this sort of equipment can make a huge difference. As one parent told us:

66 But since she's had the mighty–mo (VOCA) it's helped a lot because rather than, for breakfast having to nod at the cupboard or the fridge, she can now actually tell you by using the machine and we've programmed it so that when her dad phones her she say certain things on the phone, she can talk to her brother and sister. Her sister comes home from school and she'll say hi what have you done at school today, so it's got lots of questions on there as well. She loves it, absolutely loves it. **99**

> ### Key message from the PIE research:
>
> **The funding and insurance of communication aids is an issue that needs to be addressed.**

The Total Communication Network (**http://www.totalcommunication.co.uk**) are aiming to tackle the general lack of involvement of people with communication difficulties by encouraging people to share their ideas, find out about what else is being done in the area, and campaign for the communication rights of people with learning disabilities. The Council for Disabled Children and Triangle have produced a document for the Department of Health which lists resources that may be useful in the community, such as information for social workers, short break services, etc. It can be found at:

http://www.everychildmatters.gov.uk/socialcare/integratedchildrenssystem/ resources/

Legislation and Policy

Without the backing of legislation and policy, it is harder to make these changes happen. The following pieces of legislation and policy are particularly relevant to the needs of young people with little or no speech:

● **UN Convention on the Rights of the Child (1989)**

This was an early piece of legislation and was the primary source for developing child-focused policies and services. Article 12 is the most relevant part as it states the right of a child to express an opinion and to have that opinion taken into account in any matter or procedure that affects him or her.

● **Children Act (1989)**

The 1989 Children Act aimed to bring Britain closer to the objectives in the UN Convention on the Rights of the Child. It highlighted the need to take children's views into account and came into force on 14 October 1991. The Act was welcomed by many although the Government has been criticised by some who claim that the resources for implementing it are not sufficient. Others have said that it gives too much influence to young people. The Act is important for a number of reasons but particularly because it emphasises the importance of putting the child first.

● **Disability Discrimination Act 1995**

This is relevant in that it ensures that reasonable steps are taken to avoid discrimination on the grounds of disability. The Act was amended and extended in 2004 and 2005 and from 1 October 2004, Part 3 of the DDA 1995 has required businesses and other organisations to take reasonable steps to tackle physical features that act as a barrier to disabled people who want to access their services.

● **SEN Code of Practice (2001)**

The code of practice encourages pupil involvement in decision-making and having a voice This was important because it stated that all children should be involved in making decisions where possible right from the start of their education – including in their IEPs.

● Every Child Matters (2003)

A main theme of this policy document is about involving children in finding out what works for them and acting on it. The Government's vision is to create a joined-up system of health, family support, childcare and education services so that all children get the best start possible so that all children, and especially those from vulnerable groups, have the support they need to:

- Be healthy
- Stay safe
- Enjoy and achieve
- Make a positive contribution
- Achieve economic well-being

A recent development of 'Every Child Matters' is the 'Every Disabled Child Matters' campaign. This has the aim of all disabled children and their families having the right to the services and support they need to live ordinary lives. It is a campaign led by four leading organisations working with disabled children and their families – Contact a Family, Council for Disabled Children, Mencap and the Special Educational Consortium. Details can be found at: **http://www.edcm.org.uk/Page.asp?originx_157qn_74514704196194n42n_2006911575g**

● DfES Removing Barriers to Achievement (2004)

This developed from 'Every Child Matters' and focuses on early intervention and support. It proposes personalised learning for all pupils and improving teachers' skills to meet the diverse range of educational needs. More children would be taught in mainstream schools under the plans. Special schools would become centres of excellence - working closely with mainstream schools to share expertise.

● National Service Framework for Children (2004)

This framework stresses the importance of seeking and taking into account children's views in health and social services settings. Standard 3 of the framework states that services should be co-ordinated and take account of children's individual views.

● UN Disability Convention (2006)

A recent addition in Article 24 gives the right to inclusive education to all disabled learners. Furthermore, it states that:

'In order to help ensure the realization of this right, States Parties shall take appropriate measures to employ teachers, including those with disabilities, who are qualified in sign language and Braille, and to train professionals and staff who work at all levels of education. Such training shall incorporate disability awareness and the use of appropriate augmentative and alternative modes, means and formats of communication, educational techniques and materials to support persons with disabilities.'

http://www.un.org/esa/socdev/enable/rights/ahc8adart.htm#art24

- **Implementing the Disability Discrimination Act in schools and early years settings. DfES 2006**

This publication provides a guide to the duties in the DDA (Disability Discrimination Act). This includes an account of how the DDA duties fit with the SEN duties and the planning duties and it provides more detail on the definition of disability used in the DDA.

http://publications.teachernet.gov.uk/default.aspx?PageFunction=productdetails &PageMode=publications&ProductId=DfES+0160+2006

- **Disability Equality Duty (DED)**

The Disability Equality Duty requires schools to take a more proactive approach to promoting disability equality and eliminating discrimination. Guidance can be found at: **http://www.teachernet.gov.uk/wholeschool/sen/disabilityandthedda/guidancedi sabilityequalityinschools/**

Advocates

We found in our research that there were some examples of the use of advocates with children and young people with communication difficulties. The Children's Society has produced an explanation of advocacy with children and is currently campaigning for it's use (**www.childrenssociety.org.uk**). Communication Matters has produced a pack about advocacy and communication difficulties which gives details of how to develop an advocacy plan with individuals. Details can be found at: **http://www.communicationmatters.org. uk/Publications/Books/Books_Speaking_Up_Speaking_Out/books_speaking_up_ speaking_out.html** .

The Thomas Coram Research Unit have also carried out a lot of work in this area. A report can be found at **http://www.ioe.ac.uk/tcru/Advocacy%20BP.pdf** .

Parental support

The parents that were involved in our research project were largely very happy with the schools that their children attended in terms of the way that their children were involved in decisions. They did, however, have a few suggestions about what they would like to happen in the future:

- More positive role models so that their children could learn skills around friendships.
- More involvement in reviews and target setting.
- A support/training group for parents whose children use AAC and particularly VOCAs.
- More information about topics and events that are coming up at school, so they don't have to do so much 'guessing'!
- More training around signing and which could involve fathers as well as mothers.

- More consistency between classes.

- More help with insuring VOCAs and advice about the hardware and software involved.

- A better changeover of teachers and TAs as some parents felt that their child had the same adults around for too long.

- Would like to hear from parents of older children with little or no speech to see how they have coped as their child has grown up.

- More input from Speech and Language Therapists.

> **"** It would be nice for speech and language therapists to work with the parents as well, either in school or at home and preferably at home for the likes of my husband because of timing and things, but it would be good to say right, well, this is the way we're doing it, how can we get you to do as close to the same thing at home so there's a continuity. **"**
>
> Parent

Further reading

Holmes, E. and Logue, J. (2003) *Fighting hard: Parents' experience of accessing communication support for their child*. London: Scope. **www.scope.org.uk/downloads/ earlyyears/fighting_hard.pdf**

Lewis, A., Davison, I., Ellins, J., Parsons, S and Robertson, C. (2006). *Survey of parents and carers of disabled children and young people in Britain. Research report to Disability Rights Commission, June 2006*. Birmingham: University of Birmingham, School of Education. Full report on DRC website

http://www.drc.org.uk/library/research/education/survey_of_parents_and_ carers.aspx

Talking Point – part of the I CAN website that provides information and support for parents of children with communication difficulties **www.talkingpoint.org.uk** The 'Chatter Matters' campaign has produced a free DVD for families.

PLUS is an organisation in Scotland that opens doors to better social opportunities for disabled children. Ideas and details at: **www.plus-stirling.org.uk**

Part
3

In this section we will firstly list all the major guides and resource packs that are suitable for use with children with little or no speech. Following on, we will list some further reading and then list some useful websites.

1. Guides and resource packs

Aitkin, S. and Millar, S. (2002) *Listening to Children with Communication Support Needs*. Call Centre in Scotland and Sense Scotland.

Children's Society (2003) *Ask Us 2*. This is a follow up to the award-winning Ask Us CD Rom. It is aimed at key people in local authorities who are tasked with taking forward the *Quality Protects* programme for transforming children's services. Available from the Children's Society: **http://host2.clickandbuild.com/cnb/shop/tcs?productID=54&op =catalogue-product_info-null&prodCategoryID=14**

Children's Society (2005) *How to ask us: Using multi-media methods to consult with disabled children and young people*.

Gordon R., Marchant M. NSPCC (2001) *Two-Way Street: Communicating with Disabled Children*. A training video and handbook about communicating with disabled children and young people. Contact: Triangle: 01273 241015 info@triangle-services.co.uk or NSPCC: 0116 234 7223 sferrar@nspcc.org.uk

How to Ask Us learning Pack is the third CD-rom in the Ask Us series - a multi-media compilation of messages from disabled children and young people. A resource for involving disabled children and young people in decisions that affect their lives or consulting with them about the development of facilities and services that affect them. Details from: **http://host2.clickandbuild.com/cnb/shop/tcs?op=catalogue-products-null&prodCategoryID=14**

Council for Disabled Children (2005) *Including Me: Managing complex health needs in schools and early years settings*. This is a practical handbook which will help local authorities, schools, early years settings and health providers develop policies and procedures to ensure that children with complex health needs can access education and childcare. Available to download from: **http://www.ncb.org.uk/Page. asp?originx2964rs_77640241276965p56v30647296**

Mencap (2004) *Listen Up.* Listen Up is a toolkit of multi media resources to help children and young people with a learning disability complain about the services they use. **www. mencap.org.uk**

Morris, J. (2002) *A lot to say: A guide for social workers, personal advisors and others working with disabled children and young people with communication impairments*. Scope: London. Available to download from: **www.scope.org.uk**

Scope (undated) *Supporting communication through AAC*. A downloadable package containing 12 modules that aim to help parents, teachers and professionals support individuals in their use of AAC. It can be found at:
http://www.scope.org.uk/education/aac.php (accessed April 2007)

2. Further reading

Signing and symbols

Abbott, C. and Lucey, H. Symbol communication in special schools in England: the current position and some key issues *British Journal of Special Education* Vol 32, 4 pp196-201

Harding, C. (2002) Signs of the times *RCSLT Bulletin* June pp 4-5

Widgit software
http://www.symbolworld.org/index.htm

Peer interaction

Clarke, M. (2003) Patterns of interaction between children with physical disabilities using augmentative and alternative communication systems and their peers. *Child Language Teaching and Therapy*, Vol. 19, No. 2, 135-151

Claxton, K. and Crothers. T. (2007) Role models: Who needs 'em *Communication Matters* Vol 21, 1 pp 2-4

Views of young disabled people

Franklin, A. and Sloper, P. (2004) *Participation of Disabled Children and Young People in Decision-Making within Social Services Departments in England Findings*. Social Policy Research Unit, University of York **www.york.ac.uk/inst/spru/**

Lewis, A., Parsons, S., and Robertson, C. (2007) *My school, my family, my life: Telling it like it is. A study drawing on the experiences of disabled children, young people and their families in Great Britain in 2006*. London: Disability Rights Commission/Birmingham: University of Birmingham, School of Education.
http://www.drc.org.uk/library/research/education/my_school_my_family_ my_life.aspx

Lewis, A., Robertson, C., and Parsons, S. (2005) *Experiences of Disabled Students and their Families. Phase 1.* Research report to Disability Rights Commission, June 2005. Birmingham: University of Birmingham, School of Education. Full report on DRC website http://www.drc.org.uk/library/research/education/experiences_of_disabled.aspx

Jade, R. and Wilson, C. with 'Young and Powerful' (undated) **www.leeds.ac.uk/ disability-studies/archiveuk/wilson,%20christine/whose%voice%20is%20it% 20anyway.pdf** (accessed April 2007)

Marchant, R. and Jones, M. (2003) *Getting it right: Involving disabled children in assessment, planning and review processes*. Hove: Triangle

Morris, J. (1998) *Don't Leave Us Out:Involving disabled children and young people with communication impairments*. Joseph Rowntree Foundation/York Publishing Services: York

Morris, J. (2003) Including all children: finding out about the experiences of children with communication and/or cognitive impairments *Children and Society* Vol 17 pp 337-348

Murray, P. (2002) *Hello! Are You Listening? Disabled teenagers' experience of access to inclusive leisure.* Available from **www.ibkinitiatives.com**

Triangle (2002) *This is my school: views of young people in Wokingham. Report of a consultation with young people in Specialist Educational Settings*. Hove: Triangle

Triangle/NSPCC (2001) *Two Way Street – training video and handbook on communicating with children who do not use speech or language*. Leicester: NSPCC

Turner, C. Barnardos Cymru & NCH Cymru (2003) *Are you listening? What are disabled children and young people in Wales telling us about the services they use?*
Download from: **www.childrenfirst.wales.gov.uk/content/framework/**

Ward, L. (1997) **Seen and Heard: involving disabled children and young people in research and development projects**. Joseph Rowntree Foundation/York Publishing Services: York

Watson, D., Abbott, D. and Townsley, R. (2006) Listen to me, too! Lessons from involving children with complex healthcare needs in research about multi-agency services. *Child Care, Health and Development* Vol 33, 1 pp 90-95

Classroom environment

Aitken, S. and Millar, S. (2002) *Listening to children with communication support needs*. Call Centre/Sense Scotland: University of Edinburgh

Aitken, S. and Millar, S. (2004) *Listening to children 2004*. Call Centre/Sense Scotland: University of Edinburgh

DfES (2005) *Speaking, Listening and Learning: working with children who have SEN*. DfES1187-2005 and DfES1231-2005 to DfES1235-2005 http://www.standards.dfes.gov.uk/primary/publications/inclusion/sll_sen/

Detheridge, T. and M. (2002) *Literacy through Symbols*. London: David Fulton

Haigh, c. and Catterick, A. (2003) Collaborative classroom action RCSLT Bulletin December pp 14-15

Hetzroni, O. (2004) AAC and Literacy *Disability and Rehabilitation* Vol. 26, no 21-22/4-18 November, pp 1305-1312

Jones D. and Hodson, P. (2006) *Unlocking speaking and listening.* London:David Fulton Pub.

Millar, S. with Aitken, S. (2003) *Personal Communication Passports*. Call Centre: University of Edinburgh

AAC

Chan, S. (2005) Implementing AAC in Schools: Part 2. *Bulletin (RCSLT)* February pp16-17 Gloucestershire Advisory Teaching Service have produced guidelines on AAC with particular reference to communication aids. **www.gloucestershire.gov.uk**

Integrating Community Equipment Services (ICES). A Department of Health funded initiative across health and social care to develop community equipment services in England. Have a downloadable report on communication aids. **www.icesdoh.org.uk**

Young.J. and Storer, J. (2002) Speaking the same language. RCSLT Bulletin July pp13-14

Wright, J., Newton, C., Clarke, M., Donlan, C., Lister, C. and Cherguit, J. (2006) Communication aids in the classroom: the views of education staff and speech and language therapists involved with the Communication Aids Project *British Journal of Special Education* Vol 33,1 pp 25-32

Total communication

Bradshaw, J. (2000) A total communication approach towards meeting the communication needs of people with learning disabilities. *Tizard Learning Disability Review* Vol 5, 1. pp 27-30

Brown, L. (2002) Communication Education *RCSLT Bulletin* September pp 12-13

Jones, J. (2000) A total communication approach towards meeting the needs of people with learning difficulties *Tizard Learning Disability Review* Vol 5, 1. pp. 20-26

IEPs

Frankl, C. (2005) Managing Individual Education Plans: reducing the load of the special educational needs coordinator *Support for Learning* Vol 20, 2. pp 77-82

Shotton, G. (2003) *Pupil Friendly IEPs: Individual Education Plans for primary school children age 6 to 11*. London: Paul Chapman Educational Publishing

Meetings

Barnardo's/Yorkshire and Humberside SEN Regional Partnership (2006) *Involving children and young people in meetings and reviews*.
http://thepartnership-yh-involvingchildren.org.uk/pdfs.asp

Hayes, J. (2004) Visual Annual Reviews: how to include pupils with learning difficulties in their educational reviews. *Support for Learning* 19, 4. pp 175-180.

Kids Consultation Project (2003) *Thank you all*. KIDS: South Gloucestershire.
www.sw-special.co.uk/parents/students/docs/KIDSConsultationprojectCCreamer.doc

Objects of reference

Brower, F. and Barber, M. (2005) When words are not enough. *Special!* Autumn 2005 pp 10-12

Jones, F., Pring, T. and Grove, N. (2002) developing communication in adults with profound and multiple learning difficulties using objects of reference. *International Journal of Language and Communication Disorders* Vol 37,2. pp173-184

Park, K. (2003) A voice and a choice. *Special Children Issue 153*, Feb/March www.education-quest.com

Parents

Holmes, E. and Logue, J. (2003) *Fighting hard: Parents' experience of accessing communication support for their child*. London: Scope. **www.scope.org.uk/downloads/earlyyears/fighting_hard.pdf**

Lewis, A., Davison, I., Ellins, J., Parsons, S and Robertson, C. (2006). *Survey of parents and carers of disabled children and young people in Great Britain*. Research report to Disability Rights Commission, June 2006. Birmingham: University of Birmingham, School of Education. Full report on DRC website
http://www.drc.org.uk/library/research/education/survey_of_parents_and_carers.aspx

Talking Point – part of the I CAN website that provides information and support for parents of children with communication difficulties **www.talkingpoint.org.uk**

Inclusion – general

Booth, T. and Ainscow, M. (2006) *Index for Inclusion: developing learning and participation in schools* Centre for Studies on Inclusive Education **http://inclusion.uwe.ac.uk/csie/indexlaunch.htm accessed April 2007**

DfES and the Disability Rights Commission (2006) *Implementing the Disability Discrimination Act in schools and early years settings*. Stationery Office: London

Douch, P. (2005) *The Buskers Guide to Inclusion*. Eastleigh: Common Threads

Lewis, A. and Norwich B. (2001) A Critical Review of Systematic Evidence concerning Distinctive Pedagogies with Pupils with Difficulties in Learning. *Journal of Research in Special Educational Needs*, 1(1) Online at http://www.nasen.org.uk. Tamworth: National Association for Special Educational Needs.

South West Regional Partnership (2006) *R U Listening.A self-evaluation framework for schools and other organisations*.
http://sw-special.co.uk/documents/students/docs/RULListeningSelevaluationframeworkfolder.pdf

Watson, D., Tarleton, B. and Feiler, A. (2006) *Participation in Education: Full report from research on the involvement of children with little or no verbal communication*. Bristol: University of Bristol. **www.bris.ac.uk/norahfry/download/questionnairereport.pdf**

Wider Community and services

Franklin, A. and Sloper, P. (2004) *Participation of disabled children and young people in decision-making within Social Services departments in England Research Works* York: SPRU

Rabiee, P., Sloper, P. and Beresford, B. (2005) Desired outcomes for children and young people with complex health care needs, and children who do not use speech for communication *Health and Social Care in the Community* Vol 13, 5. pp 478-487

Evaluation and assessment

The Surrey Speech Language and Communication Profile is an informal assessment which is used to collate information about a child's speech, receptive and expressive language and communication skills. A copy of the form can be found at: **www.surreycc.gov.uk/.../780923e823f7e29780256cab00556789/**

Welsh Assembly (2006) *Routes for learning: assessment materials for learners with profound learning difficulties and other disabilities*. Cardiff: Welsh Assembly Government. Tel 0870 242 3207 ref: AC/GM/0612

3. More Websites

1voice is run by parents, adults who use AAC and professionals and provides a forum for communication.
www.1voice.info

ACE Centre. The ACE Centre Advisory Trust provides a focus for the use of technology with the communication and educational needs of young people with physical and communication difficulties. Based in Oxford, we offer a wide variety of services including in-depth individual assessments, information, R&D, and specialist training for parents and professionals.
www.ace-centre.org.uk

ACE Centre North. This is the sister centre to the ACE Centre situated in Oldham. They carry out assessments and deliver training on communication and writing aids for school and further/higher education.
www.ace-north.org.uk

Call Centre (Communication Aids for Language and Learning) provides specialist expertise in technology for children who have speech, communication and/or writing difficulties, in schools across Scotland.
www.callcentrescotland.org.uk

Check the map. This site has been set up to make it easy for everyone to find out what services there are for people with Learning Disabilities/Difficulties (LD) in their local area, or any area, just by clicking the map or typing in a postcode.
http://www.checkthemap.org.uk

Children's Society
www.childrenssociety.org.uk

Communications Forum Network. This site is designed to promote awareness and knowledge of communication impairment, and to be the UK's national information resource for people with communication impairment, their carers and service providers.
http://www.communicationsforum.org.uk/cslt.html

Communication Matters is a UK national charitable organisation of members concerned with the augmentative and alternative communication (AAC) needs of people with complex communication needs. Communication Matters is also known as ISAAC (UK) - the UK Chapter of the International Society for Augmentative and Alternative Communication (ISAAC) - and is a core member of the Communications Forum
www.communicationmatters.org.uk

Coram Family is a leading children's charity that aims to develop and promote best practice in the care of vulnerable children and their families.
www.coram.org.uk

Council for Disabled Children (CDC) provides a national forum for the discussion and development of a wide range of policy and practice issues relating to service provision and support for disabled children and young people and those with special educational needs.
www.ncb.org.uk/cdc/

Crick software produce the Clicker software commonly used in special schools. They have some free downloads on their website and examples of the ways in which their software can be used to support children with choice making.
http://www.cricksoft.com/uk/

Easyinfo contains downloadable guidance on all aspects of accessible information, including the use of pictures, symbols and information for people with high individual communication needs.
www.easyinfo.org.uk

Every Child Matters is the Government agenda which focuses on bringing together services to support children and families.
www.everychildmatters.gov.uk

Find a Voice supports children and adults with communication difficulties. They provide on-line information to everyone in the UK and personal support to individuals, their carers and professionals who live in Kent and Medway.
http://www.findavoice.org.uk

Foundation for Assistive Technology (FAST) works with the AT community to support innovation in product development and good practice in service provision.
http://www.fastuk.org/home.php

Gloucestershire Total Communication Project has a website and they provide training for parents, staff in education, health and social services and the community in Gloucestershire. **www.totalcommunication.org.uk**

I CAN is a charity concerned with children's communication. The website has many useful links and details of their campaign 'Make chatter matter' which aims to ensure that children's communication skills are at the core of policy development.
www.ican.org.uk

Inclusive Technology Ltd provides special educational needs software, switches and computer access devices, simple communication aids and assistive technology for learners with a physical disability, sensory impairment or learning difficulty.
www.inclusive.co.uk

Integrating Community Equipment Services (ICES). A Department of Health funded initiative across health and social care to develop community equipment services in England. Have a downloadable report on communication aids.
www.icesdoh.org.uk

ISAAC supports and encourages the best possible communication methods for people who find communication difficult. It has groups of members in 14 countries. These groups are called Chapters. It also has members in 50 other countries. All these people have a "vision" that everyone in the world who could communicate more easily by using Augmentative and Alternative Communication (AAC), will be able to do so.
www.isaac-online.org

Ispeek provides symbols that are particularly suited for use for people on the autistic spectrum. Many downloadable resources can be found on the website.
www.ispeek.co.uk

Participation Works is an online gateway to the world of children and young people's participation. It enables you to share resources, learn about children's rights, search the knowledge hub or find out about innovative practice and new ideas.
www.participationworks.org.uk

Royal College of Speech and Language Therapists. This site has links to many useful organisations and research.
www.rcslt.org.uk

School Councils UK has been helping schools to develop into caring, inclusive communities, working with teachers and pupils in infant, primary, secondary and special schools for more than ten years.
www.schoolcouncils.org.uk

Sensory Support Service. Provides support for children with hearing and vision needs throughout their time at school. Covers the four authorities in the Bristol area and provides access to free documents.
www.sensorysupportservice.org.uk

Signalong is a sign-supporting system based on British Sign Language.
http://www.signalong.org.uk/

Somerset Total Communication (STC) is a multi agency partnership led by Somerset County Council and Somerset Health Community to ensure a consistent "cradle to grave" strategy. Total Communication is a nationally recognized process of using speaking with body language, facial expression, multi-sensory channels, objects , representational objects, photographs , pictures, symbols, writing, videos, computers as appropriate for individual understanding and expression of needs, wants, choices, independence.
http://somerset.gov.uk/somerset/socialservices/pi/stc/

Storytracks is an organisation which helps people of all abilities and ages to listen to stories and to start telling and sharing their own stories. Storytrack workshops are designed for children and adults with severe communication difficulties.
www.storytracks.com

Talking Mats was originally developed to help people with communication difficulties to think about the issues discussed with them and to express their opinions. Since then Talking Mats has been used with many people with and without communication difficulties both in the UK and abroad.
www.talkingmats.com

Teachernet is an education site for teachers and managers and has a wealth of useful information and links.
www.teachernet.gov.uk

Thomas Coram Research Unit is a multidisciplinary research unit within the Institute of Education and is a designated research unit of the Department of Health. The focus of its research is children and young people both within and outside their families. This includes care, education, health and social service settings.
www.ioe.ac.uk/tcru

Total Communication Network is about people working towards one aim: that every person with a learning disability in the South West is able to communicate in the way that is right for them. The TC Network is a place for people to share their ideas, find out about what else is being done in the area, and campaign for the communication rights of people with learning disabilities.
www.totalcommunication.co.uk

Triangle is an independent organisation working with children and young people and providing training and consultancy throughout the UK.
www.triangle-services.co.uk

Widgit software is a company providing software to support inclusion.
http://www.widgit.com/

Appendix A: Communication breakdown exercise

- Ask participants to pair up with someone they know least well
  (or don't know at all)
- Give each participant a sentence strip from the communication breakdown sentences.
- Ask each person to read, but not show the sentence to anyone else.

Explain the activity.

You could say…
One person in each pair is person A and the other person is person B
I would like person A to begin by communicating their message to person B.
But whilst doing this activity I don't want person A to speak at all.
Person B however can do anything they feel they need to do to try to receive the message from person A. I will give you about two minutes to do this. When I tell you, you may swap over and then person B should try to get their message across to person A again without speaking and without moving from their chair.

You are requested not to use any charade conventions.

NB Before starting this activity it is important to check if there are any participants who can already sign. If there are, then ask them not to use the signs they know.

Reflecting upon Communication breakdown

- Ask participants to feed back how they felt first when they were giving the message to their partner and then ask for feed back about how it felt to receive or get the message
- You may choose to use 'feelings' symbols when you take the feed back
- Or you may divide the flip chart/whiteboard into two sections and take feed back from the group and record their comments first on one side headed "giving the message" and then on the other side "receiving the message"
- The flip chart may look like this

Giving the message	Receiving the message
•	•
•	•
•	•

- Words people might use to describe how they felt about the exercise
  Frustrated, angry, silly, embarrassed, awkward, shy, tired, exhausted, anxious, nervous, fed up, flustered, confused, pressurised, impatient.

  Give out handout "Problems when there is no communication system"(1.3)

You could say…
You were able to talk about your feelings and in doing so were able to off load those feelings. For a child who finds it difficult to express themselves it could mean that those feelings build up and then usually the only way they get expressed is through unacceptable behaviour.

Show the participants the emotions symbols.

You could say…
If a child was able to understand the meaning of these symbols then they could point to one and this would be an acceptable way for them to off load their feelings. However you all know what these symbols represent because you can read. The child would have to be taught. How would you do that?

Some participants might say…
Whenever a child looked unhappy I would show them the sad symbol and gradually over time they would learn to associate that feeling with the symbol. You would gradually add new symbols as the child showed that they had an understanding of them.

You could ask...
What was the overriding feeling in this exercise?

Other things people might say
It took ages/time consuming
I had to concentrate very hard
It was very difficult
Couldn't be bothered
I didn't know where to begin
I felt like giving up
I was relieved when they finally got the message

You could talk about…
- Emphasise that this happens 24 hours a day for those with no speech
- Communication break down can lead to a cycle of frustration/withdrawal
- Need for a common language
- Need for different ways of communicating to support different learning and communication styles
- It is the right of the individual to communicate in a way that they prefer about issues which concern them
- Understand that communication is a 2 way process