

Listening to children

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Title Slide Overview

We will describe two projects we were involved in to find out the views of children and young people with a range of communication support needs. The projects were undertaken jointly between Sense Scotland and Sally Millar based at the CALL Centre, University of Edinburgh.

Slide 2 Introduction

The need to take account of children's views is enshrined in the UN Convention on the Rights of the Child so we will first consider briefly what the Convention says. We will then describe a few of the things that Scotland has done to implement the Convention, and a few of the changes taking place in classrooms and elsewhere. While we're doing that, each of you might like to think about how your own country's laws and policies reflect the principles of the Convention.

We will then discuss the main theme of our presentation. How do you seek and take account of the views of children and young people who have communication support needs which are often quite complex? We will describe some of the work we have been doing in this area. We will emphasise that it is not enough simply to identify the right communication techniques for a particular child, it's also important to know what it is you are consulting about, what the context is, what procedures are in place and how they might need to change.

A note on terminology

We will use the term communication support needs or complex communication support needs. We use these terms rather than the more traditional "multi-sensory impairment" or "complex learning difficulties", for example, for three reasons.

First, the term "communication support needs" focuses on the needs arising from a child's difficulties in communicating rather than on the impairments that give rise to these difficulties.

Second, the term 'support needs' places the onus on us to find ways to communicate with, listen to and find out the preferences of the child rather than passing responsibility for communicating to the child alone.

And finally, there may be as much, if not more, variation among children and young people assigned to one of these 'groups', as there is variation between groups.

Slide 3 Examples of consulting situations

- A primary school is inviting its pupils to say what they think of the school. Teachers in the learning base want to ask children the same questions. The pupils cannot read, speak, write, sign or use symbols to express their views.
- Isla has some speech but very few people understand what she says. She

council.

Slide 4 More examples

- Julie is blind and has some difficulties learning and communicating. Her teacher has worked with Julie for several weeks to help her present her views at a forthcoming assessment of her future needs.

International background

In many countries a huge shift in thinking has taken place on involving children and young people. Participation of children and young people was once a minority interest, it is now a central issue for us all. The rise of young people as consumers, increased power brought by pressure groups, media scandals involving child abuse both by individuals, corporate business and institutions, and an increased emphasis on citizenship have all contributed to increased participation of young people. But it was the UN Convention on the Rights of the Child that provided a framework through which increased participation has been and is being encouraged. It has required us to take seriously children's and young people's rights to have a say about what happens to them.

Slide 5 UN Convention on Rights of the Child (UNCRC)

The Convention is a landmark in human rights. It outlines the rights that all children around the world (defined as eighteen years and younger) are entitled to, regardless of their status, religion or race. It places their rights at the centre above parents or other adults. Signatory States have a responsibility to protect these rights and to act in the best interests of the child. The Convention is the most widely ratified human rights instrument in the world. Every nation state in the world – except for the United States and Somalia – has ratified the Convention. Once States sign up to a convention they are legally obliged to do what it says. National laws must reflect its provisions. The Convention is a primary concern of the United Nations and it monitors how well a State has responded to the Convention in its laws and policies. A child cannot use the courts to claim Convention rights but the provisions can be referred to in court and other proceedings. The UK ratified the Convention in January 1992. Slovakia ratified it in January 1993. For a full list of countries that have ratified the convention see:

[\[http://www.freethechildren.org/youthinaction/children's_rights_who_has_ratified.htm\]](http://www.freethechildren.org/youthinaction/children's_rights_who_has_ratified.htm)

How do children and organisations find out about children's rights? One way is to download documents and read them. But that's not possible for everyone, in particular it won't help those who cannot read, the very people whose rights may be most compromised. Realising this difficulty, UNICEF set up a project called Cartoons for Children's Rights. The cartoons offer a simple, visual means of informing people around the world about children's rights. So far, 70 animation studios in 32 countries have developed 30-second non-verbal public service announcements (PSAs). UNICEF then distributes the PSAs to broadcasters for the cost of the tape. They have been broadcast on over 2,000 television stations globally. You can see some of these cartoons on their website [\[http://www.unicef.org/crcartoons/\]](http://www.unicef.org/crcartoons/). The website versions use Macromedia Flash which may make accessibility more difficult for some.

society about its obligations, all over the world. Through Cartoons for Children's Rights, broadcasters can use their influence to help make the Convention relevant and important to the life of every child. Their first tape was distributed in 1998 and has been shown in over 160 countries to an audience of around one billion people.

Slide 6 Laws and policy in Scotland

When the United Nations adopted the Convention and opened it for signature in 1989, public policy in Scotland and many other countries was already beginning to change.

There has been a clear trend over the last ten years to base legislation on core principles, require the involvement of children in matters that affect them, taking account of their views, and the provision of supporters or advocates to help articulate their views. This is a welcome trend.

Scotland's progress with Convention responsibilities is reported to the United Nations along with the rest of the UK. When the UK produced its second report in 1999, the UN's response was very much along the lines of 'could do better'¹. As a result we saw a number of changes in Scotland – but would the UN consider they have gone far enough?

Slide 7 Laws and policies contd

Consent and capacity

The Age of Legal Capacity (Scotland) Act 1991 defines the age of majority as sixteen but a child is still considered someone under the age of eighteen. This is pretty consistent with other countries. Note though that a child over twelve but under sixteen can do a number of things including appointing a solicitor, making a will and consenting to medical treatment. Even younger children may do this if the child is considered to have sufficient understanding of what's involved.

Seeking the child's views and taking them into account

Four years later, a new piece of child welfare law in Scotland noted the need to take account of the views of the children in matters which affect them: the Children (Scotland) Act 1995. It took a bit longer for education legislation to do this: the Standards in Scotland's Schools Act 2000 and most recently the Education (Additional Support for Learning)(Scotland) Act 2004. The latter law is clear that a child's views need not be sought if the child is considered incapable of expressing a view, presenting challenges for children with complex communication support needs but is consistent with the Convention.

Right to education

Education must now be directed to the development of each child's personality, talents and physical and mental abilities to help them reach their full potential (Standards in Scotland's Schools Act 2000).

¹ United Nations Committee on the Rights of the Child, Concluding observations, 9 October 2000

Slide 8 Laws and policies contd

Avoiding discrimination

Disabled children must not be discriminated against on the basis of disability. This applies to the provision of goods and services (the Disability Discrimination Act 1995) and in the provision of education (Special Educational Needs and Disability Act 2001). There are two key duties for education establishments:

1. Not to treat disabled children less favourably.
2. To make reasonable adjustments to avoid putting disabled learners at a substantial disadvantage.

The Education (Disabilities Strategies etc)(Scotland) Act 2002 aims for an improvement in the physical environment of schools and other learning settings, access to the curriculum and communication of information to disabled learners.

Slide 9 Laws and policies contd

Inhuman or degrading treatment

Children with mental health problems were still being treated routinely in psychiatric wards for adults until the Mental Health (Care and Treatment)(Scotland) Act 2003 outlawed it.

Corporal punishment

It is now against the law to hit a child in any service, including childminding. But parents may still use physical punishment with their own children, so long as they do not shake the child, hit on the head or use an implement.

Protection

A range of measures have been introduced to protect children who are vulnerable, for example because of disability, including:

- qualifications requirements for staff and criminal background checking of staff and volunteers in children's services (the Regulation of Care (Scotland) Act 2001)
- list of adults unsuitable to work with children (the Child Protection (Scotland) Act 2003)
- special provisions for witnesses in court including different ways of taking evidence (Vulnerable Witnesses (Scotland) Act 2004)

Children's Commissioner

A Children's Commissioner was appointed in 2004 to scrutinise legislation, policy and practice in relation to the Convention requirements.

Across the spectrum of education, social work services, health and leisure, the views of children and young people are increasingly important in deciding what services there should be and how they should be delivered.

Slide 10 Schools and services

So we come to the point where the policy framework affecting all aspects of legislation requires us to seek and take account of children's views.

But it's one thing to set out principles, it's quite another to answer:

- how will we do this?
- who with?
- how will it work with other services?
- how will we know it's been done?
- what staff development issues arise?
- what materials can be put in place?

For example we often hear of demands for stakeholder consultation to include those who will be most affected: children who use the services.

There can be difficulties, of course. One young person was fully involved in her education reviews but was ignored when she asked to go to a different school because of bullying. There is also the story of the young man who simply answered "yes" to all the questions he was asked even though he was able to tell his relative later that he didn't know what they meant. The public body was able to say that he was consulted.

A huge amount of effort has gone into encouraging children to participate and for their views to be heard. Examples include:

- school council representation: children share views of classmates and peers
- supporting young people who are 'looked after' to represent themselves at planning meetings
- self-evaluation: *How good is my school?* questionnaire
- "circle time" where children talk about things that are important to them in a supportive environment
- integrated within communication curriculum

Slide 11 Children with communication support needs

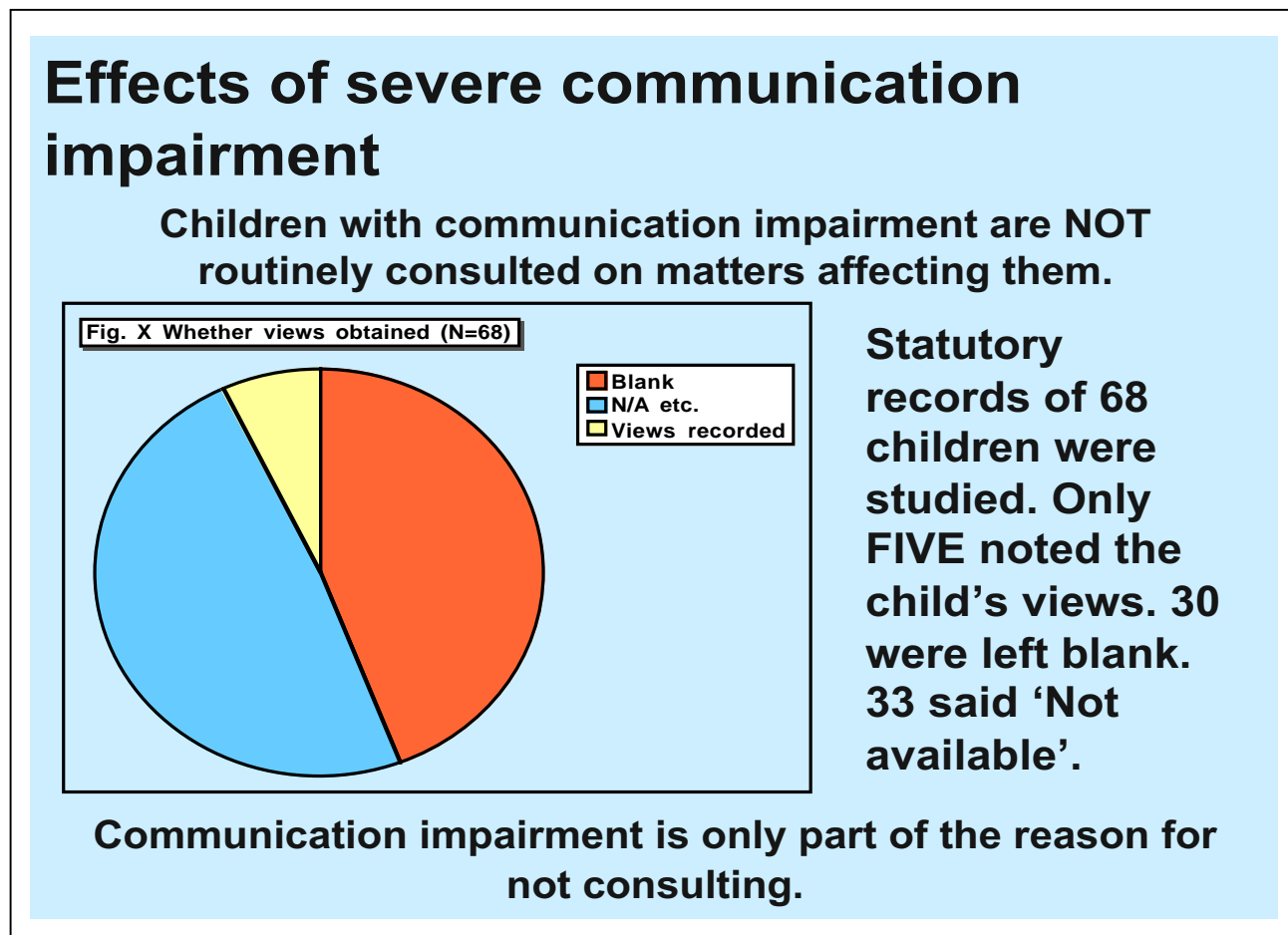
What about children and young people with communication support needs? Are they asked for their views? There is a great deal of good work here. For example, in the UK the Triangle Consultancy team has undertaken a number of important exercises. In the book *Tomorrow I Go* they report on finding out from a group of children with learning disabilities what they thought about the respite care service they used (Triangle, 1999). Triangle facilitated the young people to communicate their likes, dislikes, preferences and views through speech, sign, symbols, body language or through other means that suited the child. [find out about services and publications from <http://www.triangle-services.co.uk/>]

Slide 12 Are their views sought routinely?

Early in our first investigation we looked at whether the views of children with

the things we did was to look at what the statutory record keeping said about each of 68 individual children from eight different local authorities using Sense Scotland services. The children came from eight different local authorities. We looked at what the formal records asked about the child's views and what responses were given. The graph below summarises our findings.

Figure 1. Analysis of 68 records on whether children's views were noted.



Of the records analysed, seven per cent noted the child's views. The full results were:

- 30 were returned blank with no information about the child's views
- 33 noted 'not applicable', 'views not sought'
- 5 forms reported that views were recorded

Together with other results not reported here but which are available in Aitken & Millar (2002) we established that there was a need for practical tools to support people to seek the views of children with communication support needs. Key requirements of these tools were to:

Slide 13 What was needed:

- cover all children, including those with the most complex communication support needs

- be useful to different professional groups, avoiding jargon and assumptions about skills of those who would use the tools
- incorporate (but not entirely rely on) the knowledge of those who know the child well
- raise awareness of non-verbal communication behaviours and AAC (augmentative and alternative communication), while not assuming specialist knowledge
- provide examples and case stories, and practical examples and tools
- suggest basic communication good practice guidelines, e.g. how to ask questions, how to present choices, interpret responses reliably

Slide 14 Communication Profile

When trying to consult children for their views it is important to do so in a way that matches their level of communication, or their capacity to understand the subject matter. Otherwise, results will be misleading and possibly distressing to the child.

To help target approaches to the child's communication we produced a short 2-page profile. The Communication Profile is not an assessment nor is it intended to label the child. Instead it is a general guide to help find approximately the right approach to use when trying to listen to the views and feelings of children with communication impairment and to evaluate appropriate approaches. The Communication Profile is structured around three groups: group one, group two and group three.

Slide 15 Groups and approaches

As a guide, each of the three groups is associated with approaches to finding out the child's views. We'll describe briefly a few of the approaches to demonstrate the range of materials contained on the CD accompanying *Listening to Children 2004* (Aitken S & Millar S, 2004).

Observation and recording

The books and CD in the Listening to Children series contain a huge amount of information on making best use of observation and recording. We are not going to look at any of it today but we do have some books with us for purchase!

Slide 16 Table of Activities

The activity table is especially useful for staff new to post, or staff working with a child for brief sessions who have very little time to record observations on paper. We have used this approach in several settings. For example, with rotating staff teams when a member of staff worked with Child A on Day 1, wasn't on shift on Day 2, and worked with Child B on Day 3. This approach helps bring together multiple sessions of observations made by different people.

It uses old technology: carbon paper. Quick notes can be taken of activities the child takes part in, together with the time spent on the activity and whether it was liked, disliked or just OK. A Comments box allows notes or observations to be recorded. By using a sheet of carbon paper between two copies, the child can take the top copy home to show the family what he or she has been up to that day. Staff can use

for the same child and have a cumulative record to plan activities at future sessions. You can print a master copy from the CD or a template which you can use to suit each circumstance.

Slide 17 Basic rating scales: smiley and sad faces

Smiley and sad faces are remarkably useful. And if you'd like a ready source in different versions, you'll find them on the CD. Here we'll take a quick look at a couple.

Slide 18 Personal Communication Passports

Personal Communication Passports provide a practical and child-centred approach, a tool developed by Sally Millar, at the CALL Centre, University of Edinburgh (Millar S & Aitken S, 2003). They've been widely used since 1993 across the UK and in other countries. Practical guidance on using Passports is provided in this key publication. Passports aim to support children with complex communication difficulties who cannot easily speak for themselves, by:

- presenting them positively as individuals, not as a set of 'problems' or disabilities
- drawing together information from past and present, and from different contexts
- describing the child's most effective means of communication
- presenting information in an attractive easy to understand way

Passport booklets (or cards, folding pockets, wall charts etc) present information about the child in an accessible way that assumes no prior knowledge and is simple, clear, direct, honest, specific and detailed (and - hopefully - attractive & fun).

Passports are a special way of sorting information. They don't contain ALL the information about a child only KEY information about day-to-day things. A Passport is not a list but a synthesis of information to help other people to help the child to 'be the best he or she can be'.

Passports are especially important at times of transition, when new people come into the child's life. They are also helpful when new or temporary staff or volunteers meet the child, helping them quickly to acquire key information. Passports can show the details of how to use a child's communication system, as opposed to simply "Jan uses a communication book."

Slide 19 Passport information about a young person's vision

Rather than having lots of information about visual acuity scores, visual field and contrast scores, documented in report which staff often do not understand, Passport information records what you need to know to work with the child.

- I need lots of time to work out what my eyes are seeing – one thing at a time works best.
- I see objects but I can't make sense of pictures, photos or symbols.
- You need to think very carefully about where I sit. I am easily distracted by lots of things, especially by people's faces or by strong visual stimuli such as the bright light from the window.

uncluttered and contrasts well.

- I see best in the mid to upper fields of vision so use my easel or hold things up. Be warned – if I'm standing and have to look down, I may topple over!

Passports as a tool for consulting

Passports can be very useful when seeking the views of a child with complex communication support needs. They also help by giving guidance to others about, for example, the best way of asking questions in the right way; or giving information to help others understand how the child feels – whether happy or not. A template for a Consulting Passport is one of the resources to be found on the Listening to Children 2004 CD (Aitken S & Millar S, 2004).

Slide 20 Talking Mats™

Talking Mats™ is a simple and practical pictorial approach developed by Joan Murphy, at the University of Stirling (Murphy, 2002). It was designed as an interviewing tool to help people with communication support needs to think about things in a different way and to make their views and choices known. The approach was originally designed for use with adults and young people, but can be useful with children as well.

Slide 21 Talking Mats™ (contd)

Talking Mats™ provides a framework for discussion. Based around a specific topic, the child is presented with a series of pictures, one by one. He or she is encouraged to indicate feelings about each thing, place, person or activity associated with the picture. A three point scale is used, the child signals feelings by putting each picture either to the left side of the mat (under the smiley *Yes, I like it* picture heading); to the middle (the *Not really bothered either way* picture heading); or to the right side (the *No, I don't like it* picture header).

When would we use the Talking Mats™ approach?

Talking Mats has been proved useful in, for example:

- evaluating service users views of short break care services
- consulting and supporting young people over key transitions eg leaving school

Talking Mats™ sessions can help to illuminate how the person feels about various things, as well as sorting out what they prefer. They can also help to identify further issues and factors to be considered in future discussions. A Talking Mats™ session can be relatively quick, though I have been surprised at how well some children have concentrated.

Who is it suitable for?

- children who can see and recognise pictures
- children who use their visual skills more effectively than auditory/language comprehension skills
- children who can indicate YES and NO more or less reliably by any method
- children who can point somehow, even if only vaguely, by finger, hand, eye or whatever

cards, but who have good cognitive ability, good language comprehension and good auditory memory skills, might just be able to benefit from a modified form of this approach, carried out orally, like a multiple choice quiz. For example:

- I'm going to shout out one of the things you can do at summer school/. You have to tell me straightaway *I like it!*; *I'm not bothered* (or whatever wording seems appropriate); or *I don't like it*

With a few children, it may be possible to achieve the sorting of objects or objects of reference instead of pictures, but it is generally not effective to simply 'translate' the approach into tactile materials. Great care needs to be taken if using with children who have significant visual difficulties.

Slide 22 Talking Mats™ example

Slide 23 Permissions and protocols

When we embarked on our project, we made sure that parents and where possible, children and young people, consented to participation and to the use of their images and materials for publications and training. Without their participation, this project would have been nothing and we thank them for sharing it with us.

We also had to establish protocols for taking still photographs and video film which outlined when we would not take photographs or video film. These included when a child was:

- eating a meal
- in a state of undress
- upset or distressed

These were taken as pointers from the child to the researchers that they were not willing to participate in the project at that point and that the researchers should withdraw.

Conclusion

Participation leads to better outcomes for children, it leads to better services. To do it well means adopting a radically different way of thinking – in which we address several different levels from policy through to direct practice.

Increasing participation in any meaningful way means seeing it as part of a culture change in planning, running and monitoring services. Participation requires a different way of thinking.

Slide 24 Example

As a final point, let us return to the beginning of our presentation. We didn't finish Julie's story. Remember that Julie was blind and had some difficulties learning and communicating. Julie's teacher worked with her for several weeks to help her present her views at a review meeting. What happened at that meeting?

The meeting took place. Julie managed to present her views about what she wanted to do after leaving school ... but nobody listened.

A

Section 2: Additional Materials

LtC2004 Resources

Addition Materials, each information sheet has a simple table to indicate how relevant the material on the page might be to children with different types of communication support needs.

Below is a summary of the tables for all the parts of Section 2. For chapters marked *, consult the book for more detailed information.

| This material is relevant for Children in: | Group 1 | Group 2 | Group 3 |
|---|----------------|----------------|----------------|
| Observation and Recording | ✓ | ✓ | ✓ |
| Table of Activities | ✓ | ✓ | ✓ |
| Basic Rating using Smiley faces / Sad faces | * | ✗ | ✓ |
| Personal Communication Passports | * | ✓ | ✓ |
| Using Social Stories™ | * | ✗ | ✓ |
| Combining Approaches in a Consulting Exercise | ✗ | ✓ | ✓ |
| Talking Mats™ | ✗ | ✓ | ✓ |
| Using Computers | ✗ | ✓ | ✓ |
| Listening and Discussion | * | ✓ | ✓ |
| Key Steps to make it Happen | ✓ | ✓ | ✓ |
| Permission Form for Record Keeping | ✓ | ✓ | ✓ |
| Permission Form for Photos and Video Material | ✓ | ✓ | ✓ |
| Creating a Supportive Visual Environment | ✓ | ✓ | ✓ |
| Developing Community Resources | ✗ | ✓ | ✓ |
| Evaluating Services | * | ✓ | ✓ |

[\[Introduction\]](#) [\[What is on the CD?\]](#) [\[Accessing Resources\]](#) [\[Using this CD\]](#) [\[Trying stuff out\]](#) [\[Searching for text\]](#)
[\[Printing Materials\]](#) [\[Saving Materials\]](#) [\[Adapting Materials\]](#) [\[Consulting\]](#) [\[Supporting Staff\]](#) [\[LtC2004 Resources\]](#)
[\[Legal & Copyright\]](#)

Activity Table: Sample completed for one session (2 hour)

Name: Charlie

Date:

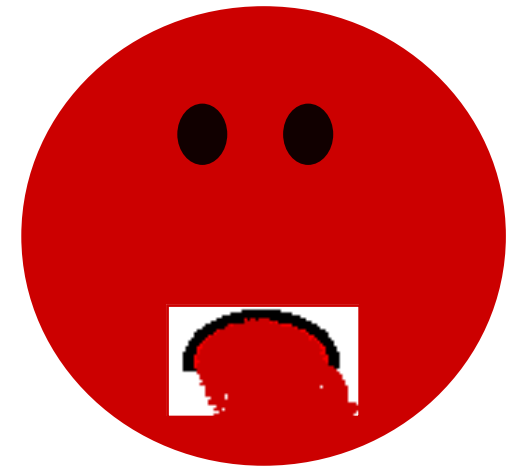
10/2/04

Completed by: Liz C

Today I Did

| Activity or Event | Really enjoyed /long time) | OK | Fleeting | Didn't like | Comments |
|-------------------|----------------------------|----|----------|-------------|--|
| Badminton | | | | | |
| Books | | | | | |
| Bubbles | √√ | | | | <i>walked round blowing, kept going to</i> |
| Cars & Trucks | | | | | |
| Catch | | | | | |
| Chute / slide | | | | | |
| Crayons | | | | | |
| Drink | | | | | |
| Football | | | | | |
| Gym Ball | | | | | |
| Jigsaw | | | | | |
| Karaoke | | | | √ | <i>Seemed too noisy</i> |
| Letters & numbers | | | | | |
| Lunch | | | | | |
| Music | √ | | | | <i>Played each instrument in turn</i> |
| Painting | √√ | | | | <i>Ages on it, seemed to really like</i> |
| Picture Pairs | | | | | |
| Shape sorting | | | | | |
| Shops | | | | | |
| Snack | | | | | |
| Sound Story | | | | | |
| Swing Ball | | | | | |
| Swings (indoor) | | | | | |
| Table Football | | | | | |
| Taking Photos | | | | | |
| Tent | | | | | |
| Toys | | | | | |
| Tunnel | | | | | |
| Watering can | √ | | | | <i>Plants, grass, much more</i> |

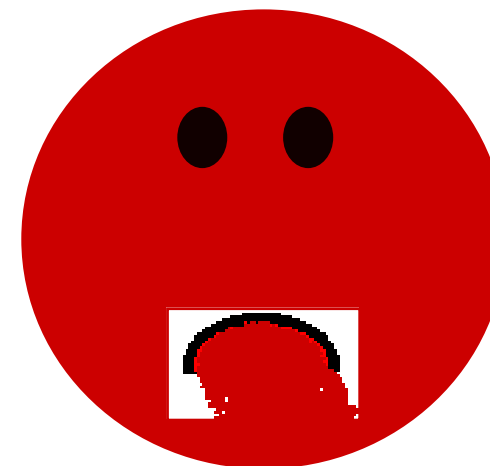
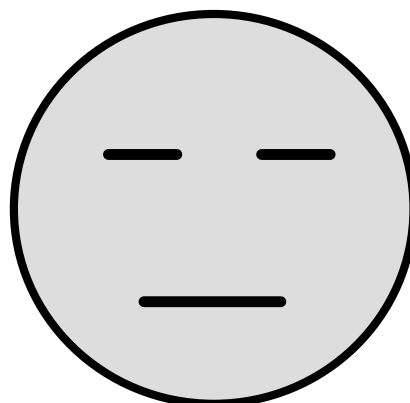
| | | |
|---------------|--------------------|--------------------------------|
| Name of Child | Date | Staff |
| Activity | 1:1 or in a group? | How long for (approx)? minutes |






Ratings to express preferences

N.B. Colours used in practice (Yellow = Happy/like; Red = Sad/not liked; Grey = Neither)

| | | |
|---|--------------------|--------------------------------|
| Name | Date | Time |
| Activity | 1:1 or in a group? | How long for (approx)? minutes |
| Child's mood before activity started? (eg relaxed, agitated etc.) | | |



| | | | | | |
|--|---|--|---|--|---|
| Child responded by him/ herself, above. Adult adds view here (circle Y/N as approp) | Child understood rating task Yes NO | Child's behaviour seemed to match their rating Yes No | Was there something within the activity the child seemed to particularly like or dislike? (note here) | | |
| Child could not respond him/ herself. Adult answers here from their knowledge/ observation of child (✓ or X above) | Not sure whether child liked activity (or not)? | Child seemed to enjoy the activity  <input type="checkbox"/> | Child seemed <u>not to enjoy</u> activity  <input type="checkbox"/> | Child apparently not bothered either way  <input type="checkbox"/> | What clues did child give to make you think this? (note child's behaviour here) |

References

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Murphy J (2002) Let your Mats do the talking. In Speech and Language Therapy in Practice, Spring. Pp18-20. AAC Unit, Dept. of Psychology, University of Stirling.
<http://www.psychology.stir.ac.uk/old/AAC/> or go direct to <http://www.talkingmats.com/>

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