



## Listening to young disabled children

Mary Dickins

### Why do we listen to children?

We listen to children because:

- it acknowledges their right to be listened to and for their views and experiences to be taken seriously about matters that affect them
- of the difference listening can make to our understanding of children's priorities, interests and concerns
- of the difference it can make to how children feel about themselves
- listening is a vital part of establishing respectful relationships with the children we work with.

### *Who benefits from listening?*

Listening is important for the children who are being listened to, but also for the adults who are listening, whether at home or in an early years setting, at school, at local authority level or in national government.

### Why listen to young disabled children?

The reasons for listening to young disabled children are the same as the reasons for listening to all children.

Although we often take it for granted, making effective choices and being able to engage in and contribute to

### YOUNG CHILDREN'S VOICES NETWORK (YCVN)

Young Children's Voices Network is a national project promoting listening within the early years. The network supports local authorities in developing good practice in listening to young children, so that young children's views may inform policy and improve early childhood services. Local authorities across the country have established local networks that focus on developing a listening culture. These networks support practitioners by offering opportunities to share effective practice, providing training and undertaking projects.

### LISTENING

In this leaflet, listening is defined as:

- an active process of receiving (hearing and observing), interpreting and responding to communication. It includes all the senses and emotions and is not limited to the spoken word
- a necessary stage in ensuring the participation of all young children, as well as parents and staff, in matters that affect them
- an ongoing part of tuning in to all young children as individuals in their everyday lives
- sometimes part of a specific consultation about a particular entitlement, choice, event or opportunity.

Understanding listening in this way is key to providing an environment in which all young children feel confident, safe and powerful, ensuring they have the time and space to express themselves in whatever form suits them.

sensible decision-making processes demand specific skills and reasoning, and these processes require facilitation and support. Such opportunities and experiences are crucial for all children but there are issues for disabled children that make listening particularly important.

For example, disabled children:

- are subject to a much higher degree of adult intervention and their scope for making day-to-day choices and decisions is often severely limited
- have many things done to, and for, them and they are significantly more vulnerable to abuse than non-disabled children (NSPCC 2003)
- are more likely to be subject to a number of medical interventions and treatments
- are more likely to be subject to various kinds of assessment procedures and less likely to be involved in the process
- are more likely to be excluded from consultation processes because these are often based on written and spoken language
- are supported by parents and staff who are more likely to see their roles as advocates rather than listeners
- are more likely than other children to have contact with multiple carers who lack the skills to understand their communication system.

Historically acquired attitudes and prejudice among individuals and institutions such as the 'medical model' of disability (see opposite) have encouraged us to be prescriptive in our attitudes towards disabled people and to limit opportunities for their preferences and opinions to be expressed and acted upon.

It is important to remember that disabled children from black and minority ethnic groups face additional cultural and linguistic barriers (Chamba and others 1999). One final reason to include disabled children is that doing so will improve practice with all children. 'For many young children speech and language are not the best routes of communication, especially about wishes and feelings. Creating listening environments that are inclusive will benefit all children' (Marchant and Jones 2003). Throughout history, society has sought to explain disability to itself. The following two models illustrate our current thinking.

### *The medical model of disability*

This is the view that because disability is caused by 'impairment(s)' professionals must cure or alleviate it in order to be seen as successful. It is a medical 'problem' that we must 'treat'. The impairment thus becomes the primary focus of attention. In this model the child is seen as

'faulty'. However, in effective listening, it is important that the child is seen as the expert on his or her life.

### *The social model of disability*

The social model of disability *demand*s that we listen to disabled children and adults and take their views on board. This model takes the view that dis(ability) is socially constructed. It is the social and physical barriers that society creates that are seen as the disabling factors and not the individual's impairment(s). This model enables us to accept and value difference.

Viewed from the perspective of the social model 'many of the problems faced by disabled adults and children are not caused by their conditions or impairments, but by societal values, service structures, or adult behaviour' (Marchant and Jones 1999). Although, in recent years, considerable attention has been directed at seeking the views of children generally, younger disabled children in particular have remained a neglected group. For these children, the fundamental human right (the right to be consulted) has often been ignored, particularly where there are high support needs and/or communication difficulties (Ward 1997). An example of this is an assessment form completed by a social worker, which said: 'He has no speech and therefore his view is unavailable' (NSPCC/Triangle 2001).

Under disability discrimination legislation (the DDA 1995 and SENDA 2001) all early years providers have a duty not to discriminate against disabled pupils in education and social care or other services made within their provision. And in particular, 'not to treat disabled children "less favourably" for a reason related to their disability, without justification'. Failure to include disabled children in consultations and planning along with their peers might well fall into this category as case law is gradually established.

### **How can we listen to young disabled children?**

Communication difficulties are most often cited as the reason why disabled children, especially younger ones, are not consulted. Adults often fear that they require specific expertise to listen to disabled children. But if we explore this assumption in more detail it becomes obvious that spoken language is only one of a range of methods that we employ in order to communicate our thoughts, feelings, information and ideas. Body language, humming, laughing, kissing, hugging, blinking and crying are just some of the ways in which we naturally express ourselves. So although some new resources and skills may be needed, attitudes and approaches are very important.

Listening to disabled children can be loosely divided into three categories:

- focused listening to individual children – perhaps as part of a specific consultation or assessment procedure
- inclusive strategies that include the 'voice' of the disabled child as a fully fledged and participating member of a group
- everyday listening and consultation as a vital element of good early years practice.

Listening to young disabled children effectively, particularly if their needs are complex, may sometimes involve learning new communication techniques, but more often than not it is a question of acknowledging and 'fine tuning' the skills that effective practitioners already use every day, including *sensitivity*, *creativity* and *intuition*. (See later section 'Ethical issues in consulting young disabled children')

### *Listening to individual children*

It is very important to collect as much information as you can from parents, professionals and other carers about how the individual child already communicates. Other children, siblings and friends may also have important knowledge and observations to contribute. Observation of the individual child and how they interact and communicate is an essential part of this process. Observing children is as important as listening to what they say – much of what young children say would not make sense without observation. Children communicate, for example, through their behaviour, art, gestures and sounds, and also by their inaction, what they choose not to do or say. It is important, where possible, to establish the child's means of communicating 'yes' and 'no' and to incorporate, where possible, a range of familiar objects of reference (toys, photographs, etc.). Where it is not possible to establish a reliable 'yes' and 'no' it might be helpful to think in terms of distress or happiness, consent or refusal. Interpretation requires careful and sensitive assessment. Smiling, for example, does not automatically mean 'yes'.

The Communication guide (on p. 4) is an example of a child-centred approach to communicating. Listening to individual children also involves becoming a more effective listener.

The following guidelines for effective listening were developed as part of the Save the Children CHOOSE project which used equality training and awareness raising in order to develop 'whole setting' inclusive approaches and strategies for consulting disabled children and their non-disabled peers in two London nurseries. (Taken from Dickens, Emerson and Gordon-Smith 2003, p. 13.)

- Show interest in everything the child has to say, using your judgement later on to draw out the information you actually need for future planning.
- Give children time and try not to interrupt or finish sentences.

- Don't attempt to fill every silence.
- When the child has finished talking, sum up what he or she has said and reflect it back, for example, 'It sounds like you felt very angry when Tommy took your ball away.'
- Don't feel that you have to have an answer or a solution for everything.
- Acknowledge the feelings that are being expressed and give them validity.
- Avoid closed questions that leave you open to a yes/no answer (e.g. 'Are there things you like at nursery?'); use open-ended questions instead (e.g. 'Tell me some of the things you like about nursery?').
- Make eye contact and get down to the child's level (but bear in mind that some autistic children find eye contact very difficult).
- Remember that 'why?' questions can sound like an accusation.
- Talk respectfully to children; they know when they are being patronised.
- Be honest if you don't know something.
- If you make a mistake, apologise.

When collecting information about how an individual child communicates, keep an open mind and remember that all children use a combination of communication methods.

### *Communication techniques*

There are a number of communication techniques and methods and a list of these can be found in Marchant and Gordon (2001) *Two-Way Street* (an NSPCC handbook and video available from [www.triangle-services.co.uk](http://www.triangle-services.co.uk)).

### *Inclusive strategies for listening to children in groups*

An effective practitioner may consult children every day about their choices, likes and dislikes without giving it much thought. Consultation does not have to be a formal process. A typical circle time, for example, will usually involve information-sharing and listening skills.

Consultation in groups can be an extremely useful way of involving children in planning outings, buying equipment and contributing to child-led activities and learning. It is vital that disabled children are not excluded from these processes. The CHOOSE project found that even young

## Communication guide

When I do this:	People think I mean	You should do
Smile	I am saying 'yes' I am happy I like what I am doing	Give me time to smile and act according to my answer of 'yes'
Lift up my left hand and bang the tray (I am just learning to do this)	I am trying to say 'no'	Ask me the question again and act according to my answer of 'no'
Close my eyes and moan	I am uncomfortable I am sad I am bored I don't like what I'm doing	<ol style="list-style-type: none"> <li>1. Ask me if I am uncomfortable, if I smile, move my position; for example, if I am in my wheelchair, take me out and let me stretch out on a mat. If I'm on the mat, sit me back into my chair. See my practical support plans to help you to this properly</li> <li>2. If I don't smile, just talk to me and see if you can cheer me up</li> <li>3. If I don't smile, see if I would like to do something else; offer me a choice</li> </ol>
Keep letting my head fall forwards	I am tired	Let me rest, stretched out on the mat, or on my side lying board
Stick my tongue out	I am thirsty	Give me a little warm drink of water from my special mug. See my practical support plans to help you do this properly
Cry but there are no tears	I am cross	<ol style="list-style-type: none"> <li>1. Check to see if I need anything, change my activity or include me in an activity</li> <li>2. Move me from sitting next to someone who may be upsetting me</li> </ol>
Screw up my hands	I feel very unsafe	Give me more support and help
Screw my nose up and twist my head	I have a tummy ache	<ol style="list-style-type: none"> <li>1. Help me change my position</li> <li>2. Give me sips of warm water to drink</li> </ol>

children with complex and multiple difficulties can participate effectively so long as practitioners establish the right way of listening for the individual child. The case study 'Outdoor choice at Anansi' (see p. 5) demonstrates how an inventive and committed staff team can devise ways of involving all children in their planning. Some of the disabled children involved demonstrated their preferences by smiling, blinking or even sneezing.

### *Everyday listening and consultation*

Once established, listening and consultation become part of the everyday fabric of good practice. Consultation for all young children needs to be carefully planned and supported and no child should take part in a consultation

if they really do not want to do so. The best participatory methods are those that are enjoyable, creative, flexible and open to negotiation with the individual child or group of children. Remember that the more opportunity children have to influence and control the agenda, the better the outcome is likely to be. When we plan to consult children, it is crucial that we consider how we will process and use the information they give us. If the children's views, suggestions, likes and dislikes, etc., have been established and recorded, the children then need to know that these have been taken seriously. One way to do this is to present their views respectfully in ways that are accessible to them – for example, using their own words, signs, symbols and art. Feedback on how their views have influenced decisions and whether their ideas and suggestions have been taken up, and why, is a crucial part of the process.

## Ethical issues in consulting young disabled children

*The biggest ethical challenge for researchers working with children is the disparities in power and status between adults and children.*

(Morrow and Richards 1996, p.98)

For disabled children there are additional power issues as they face the double challenge of being young and disabled. Listening to, and consulting, young disabled children, especially where children are communicating without speech, may involve a high level of interpretation on behalf of the listener. This raises ethical issues that need to be taken into account as part of the process of listening and consultation.

Such issues include the following:

### *Conflicting agendas*

As adults we may be inclined to 'hear' what we want to hear. It is important to allow for the emergence of differences of perspective and opinion, to be honest about them and be willing to negotiate. Children may also have

conflicting agendas; for example, where choices are indicated in a group consultation it may well be impossible for everyone to get their own way. When this happens it is important to explain, as far as possible, the reasons why a particular choice has been made.

### *Informed consent*

It is important to make every effort to ensure that the individual child is aware of what they are being asked to do, its purpose, and that they have the right to say 'no' to anything. All young children need careful guidance to enable them to express their views: find out what they need to know in order to make an informed decision and provide the relevant information. Also ensure that parents are kept informed and have an opportunity to contribute information about how the individual child communicates. Consent should be ongoing and it is important that we are aware of and respond to any body language or gesture that may indicate that a child does not want to continue or hasn't finished and has more to say.

## Case study: All Join In

*All Join In* is a unique video, made with a diverse group of three-to seven-year-olds, about playing and getting on together. The video has been heavily influenced by young children – disabled and non-disabled – from start to finish. The children who appear in the video were involved in planning, filming and editing; this includes children communicating through sign, gesture, communication books and other visual resources. Children are encouraged to wonder about other children and about differences in a positive way. Different communication methods and strategies are introduced, including sign language around feelings and getting along, and skills for observing and understanding each

other's feelings. The video is almost adult free, interactive, lively and fun (NSPCC/Triangle 2004).

*Two-Way Street* is another video made with disabled children and young people, aiming to improve practice in communicating with children and young people who have communication impairments. Children in the video communicate through behaviour, sign, symbols, body language, eye pointing, facial expression, gesture, play, use of art, objects of reference, speech, vocalisation and physical movement.

(Marchant and Gordon 2001)

## Case study: Outdoor choice at Anansi

Staff at Anansi Nursery received basic training in communication skills and inclusive strategies as part of the Save the Children CHOOSE project. They worked over a period of time with the children to identify their preferred outdoor play activities, plan the physical layout of the outdoor provision and provide the very best outdoor environment for all the children. The consultation involved several techniques, such as offering different practical and natural resources (bamboo, gravel, long grass, a mini-beast area) to find out which the children enjoyed most, and asking them to point to areas on a map of the garden to see which they liked best. Anansi has two gardens; one in front and one

at the back. The children were invited to say which garden they preferred and offered very clear views, both positive and negative. One child said, 'I like the pre-school garden better because there are no boys'. Another said 'We must not shout because it hurts the old people's ears' (in a building next door). One child repeatedly signed 'tree' in Makaton and located the flash card with a picture of the tree, indicating her desire to be taken to the back garden. Staff helped her to climb the tree, where she stayed for half an hour.

(Case study taken from Dickens, Emerson and Gordon-Smith 2003, p 5)

## Young disabled children can!

One of the findings of the Save the Children CHOOSE project was that young children, even those with complex and multiple disabilities, *can* participate effectively and have a right to do so. The 'Ask Us' project (led by the Children's Society) and 'Two-Way Street' (led by Triangle and NSPCC) both found that disabled children and young people had strong views about the society they live in, how they are treated, the services they receive, their education, health and leisure. Moreover, they found that disabled children wanted to be respected and to have a say in things that affect them. Early years services and settings can do much to help children in the process of developing decision-making skills and forming a positive sense of identity. Taking disabled children and their views seriously and listening to what they have to communicate is an empowering process that can help to ensure their sense of belonging and membership of a group as well as enabling them to achieve their full potential as individuals.

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## Useful websites

### [www.ncb.org.uk/ycvn](http://www.ncb.org.uk/ycvn)

Young Children's Voices Network (YCVN) is a national project promoting listening within the early years. The network supports local authorities in developing good practice in listening to young children, so that young children's views may inform policy and improve early childhood services. Practice development, consultancy, networking opportunities and resources are available.

### [www.ncb.org.uk/ecu](http://www.ncb.org.uk/ecu)

The Early Childhood Unit (ECU) is based at NCB and provides information on specific topics within early years care and education. It also includes networks and projects which aim to improve early years services and support workforce development.

### [www.ncb.org.uk](http://www.ncb.org.uk)

NCB promotes the interests and well-being of all children and young people across every aspect of their lives. NCB advocates the participation of children and young people in all matters affecting them and challenges disadvantage in childhood.

### [www.cafamily.org.uk](http://www.cafamily.org.uk)

Contact a Family brings together families who have a disabled child. It has information on rare and unusual conditions, and the groups associated with them. It runs a national helpline for parents.

### [www.thechildrenstrust.org.uk](http://www.thechildrenstrust.org.uk)

The Children's Trust is a national charity working with children who have multiple disabilities and complex health needs.

### [www.direct.gov.uk](http://www.direct.gov.uk) and search on 'early support'

Early Support helps coordinate, and can improve, the services your child and family receives. It helps parents and carers to be more actively involved in decisions about their child.

### [www.crae.org.uk](http://www.crae.org.uk)

Children's Rights Alliance for England (CRAE) protects the human rights of children by lobbying and raising awareness. CRAE also publishes an annual review of the state of children's rights in England.

### [www.coram.org.uk](http://www.coram.org.uk)

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

### [www.ncb.org.uk/cdc](http://www.ncb.org.uk/cdc)

The Council for Disabled Children (CDC) is the umbrella body for the disabled children's sector in England.

### [www.ican.org.uk](http://www.ican.org.uk)

I CAN is the charity that helps children with speech and language difficulties across the UK. The charity works to create a society in which their special needs are recognised, understood and met, so that they have the same opportunities in life as other children.

### [www.participationworks.org.uk](http://www.participationworks.org.uk)

Participation Works is a partnership of six national children and young people's agencies. It enables organisations to effectively involve children and young people in the development, delivery and evaluation of services that affect their lives. The site contains an Early Years Room with specific information on listening to young children, developed by the Early Childhood Unit at NCB.

## Listening as a way of life

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This leaflet is one of six leaflets from the government funded project 'Listening as a way of life'. The series provides guidance to practitioners in designing creative and individual ways of listening to children and to each other.

Others in the series include:

Why and how we listen to young children

Listening to babies

Are equalities an issue? Finding out what young children think

Supporting parents and carers to listen – A guide for practitioners

Listening to young children's views on food

There is a second series of leaflets also available:

Developing a listening culture

Leadership for listening

For copies contact the Early Childhood Unit by email on [ecu@ncb.org.uk](mailto:ecu@ncb.org.uk), or call the switchboard on 020 7843 6000 and ask for the Early Childhood Unit.

## STATUTORY GUIDANCE

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The requirement under section 3 of the Childcare Act 2006 states that LAs must have regard to any information about the views of young children which is available and relevant to those duties. For services to be successful the voices of young children need to be listened to and actively taken into account. Children need to be recognised as 'partners' in the planning and commissioning of services. By regularly listening to young children, local partnerships can respond to children's needs, identify barriers to learning and development, and ultimately work towards improving services for children and supporting children to achieve their potential.

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