Communicating with disabled children

Kirsten Stalker and Clare Connors discuss the methods used in a study seeking disabled children’s accounts of their everyday lives. The research is set in the context of policy and practice initiatives promoting communication with disabled children and other recent research, which suggests that not all practitioners and policy makers are meeting their responsibilities in this area. In this study of 26 disabled children’s lives, different interview schedules were used with younger and older children, along with a number of visual aids and activities. The design and effectiveness of these is discussed in detail. Various methods were used to obtain the views of children with communication impairments. The authors conclude that communicating with most disabled children is little different from communicating with any child. Some basic skills are not hard to learn, and attitudes are all important. The methods described here could well be adapted and expanded for use in the field of adoption and fostering.

Introduction
In recent years there has been an upsurge of interest in ‘listening to children’, ‘hearing children’s voices’, ‘letting the child speak’, and so on. The phrases almost trip off the tongue but in reality our practice may be more halting, less flowing, especially where disabled children are concerned. This paper begins by looking briefly at policy initiatives promoting communication with disabled children and what research tells us about the extent to which this is happening. We then discuss in some detail how we went about communicating with disabled children in a recent study looking at their everyday lives, reflecting on what worked well and what was less effective. Finally, we draw out lessons for future practice in communication with disabled children. The literature on adoption and fostering includes very few studies about disabled children (Phillips, 1998). It is hoped that lessons from this study will be useful to those working and researching in this field.

Policy and practice
Article 12 of the United Nations Convention on the Rights of the Child (1989) stipulates that children have a right to express their views about matters relating to them and that these views should be taken into account in any decisions made about them. Article 23 states that disabled children have the right to a full and decent life, to dignity and independence and to active participation in the community. For much of the 20th Century, disabled children have been excluded from mainstream childcare legislation (Shearer, 1980), but the Children Act 1989 and the Children (Scotland) Act 1995 both place a duty on authorities to have ‘due regard’ for the wishes and feelings of every child when making decisions affecting him or her.

However, research in England has found that some local authorities are not listening to disabled children, despite their statutory obligation to do so. Morris (1998) spoke to 30 children and young people in residential homes and schools. She found they had not been consulted about short-term care arrangements, were distressed about being separated from their parents and were sometimes treated disrespectfully by staff. Some social workers reported they had not attempted to obtain a child’s view because the child was ‘too young’ or ‘too disabled’ to express it. Morris concludes that where children had very limited or no use of verbal language, or were seen as having a high level of impairment, little effort had been made to find alternative methods of communication.

Similar findings were made in a report by the Social Services Inspectorate (1998) after an inspection of services to disabled children provided by eight local authorities. Despite the fact that each
authority had local policies and guidelines emphasising the importance of talking to children and recording their views in care plans and reports, in only a few cases was there evidence of this having taken place. A number of social workers felt they did not have the necessary skills to communicate with some children, and this kind of training was not prioritised by managers. However, attitudes are also a crucial factor: if adults expect to get little or nothing from communicating with children, that is probably exactly what they will get.

As Phillips (1998) points out, adoption is a difficult concept for any child to understand: information given should be tailored to the individual’s intellectual ability and emotional maturity. A number of techniques have been developed to help children cope with the experience of being adopted or fostered, such as life story work, videos, cassettes, diaries, exercises, games and computers (Phillips, 1998). The extent to which these are used with disabled children is less clear. Phillips cites a number of commentators who have indicated that some social workers may perceive disabled children as unable to understand what is happening to them, may feel uncomfortable working with children with learning difficulties, want to ‘spare’ them painful information or, again, lack communication skills. On the other hand, she quotes Atwell’s example of a boy with visual impairment whose life story book included buttons from a favourite person’s jacket, a shell from a seaside outing, dried flowers from the garden . . . a handkerchief perfumed with the mother’s favourite perfume (Atwell, 1993, p 58).

Research about disabled children has usually relied on data collected from parents and professionals, with few studies trying to explore the children’s own views. Baldwin and Carlisle (1994) drew attention to the fact that we know very little, from disabled children’s point of view, about their everyday lives, their likes and dislikes, their experiences of pain and discomfort, nor their opinions of professionals and services. Beresford (1997) argues that we need to know these things ‘at first hand’ if we are to help children enjoy the best possible quality of life, exercise choice and control over their own lives and prevent abuse. A number of documents have been published recently setting out ways to improve communication with disabled children and young people, including those with communication impairments (Ward, 1997; Moore, Beazley and Maelzer, 1998; Morris, 1998; Murphy, 1998; Robinson, 1998; Children in Scotland, 2000; The Children’s Society, 2001; Potter and Whittaker, 2001).

However, it should be emphasised that talking to disabled children is often no different from talking to any child: many have neither learning difficulties nor communication impairments. The most important ‘rule’ is probably to see the child as a child first and disabled second. One of the authors (Stalker), who designed the study described below and carried out two sets of interviews, had some, but not extensive, experience in communicating with disabled children and no special skills. The other (Connors), who carried out most of the fieldwork, had many years of experience in communicating with disabled children, and is fluent in British Sign Language (BSL) and Makaton. Makaton is a signing system derived from BSL but adapted for people with learning difficulties. It makes use of facial expression and sometimes symbols, and is accompanied by speech. Experience in these methods of communication was crucial to including some children who would otherwise have been excluded from the study.

One of us is disabled: Connors has a speech impairment. Although none of the children referred to this, we wonder what impact, if any, it may have had on how they perceived her. Was it easier for the children to identify and thus communicate with a disabled researcher? Did they feel that she understood their experiences better than a non-disabled person could? The answer partly depends on the young people’s awareness of themselves as impaired, and to what extent children with one type of impairment identify with people with a different impairment. Using a social model approach, it also depends how far children viewed themselves as
disabled, that is, were aware of the social and material barriers affecting all disabled people, irrespective of impairment.

Our study: children’s experiences of disability
The study was carried out as part of a research programme ‘core funded’ by the Scottish Executive at the Social Work Research Centre at Stirling University. The main aim of the study, which drew on insights from the social model of disability and the sociology of childhood, was to explore the effects of disability on children from their own point of view. Specifically, we were interested in how disabled children perceived and understood disability and their experiences of its impact on their day-to-day lives. Other aims were to examine the children’s perceptions of professionals and their views and experiences of service provision, to explore their future aspirations, and to examine siblings’ perceptions of the effects on them of having a disabled brother or sister. This article concentrates on the communication methods used. A full account of the findings will be available in Connors and Stalker (2003).

Twenty-six disabled children were recruited to the study through schools and voluntary organisations. Due to some difficulties recruiting, we cannot claim that the sample was representative of the wider population of disabled children, but it did have the range of characteristics we were looking for in terms of age, gender, location and type of school attended. There were 15 boys and 11 girls, aged between seven and 15. Thirteen had learning difficulties, five had sensory impairments and six physical impairments. A number had dual impairments and two had very high support needs. One child was of mixed race; the others were white British, reflecting the low proportion of people from minority ethnic communities within the Scottish population (1.3 per cent). We also interviewed 24 siblings and 38 parents; however, the focus of this paper is on the disabled children.

Gaining informed consent
We identified potential participants through schools and voluntary organisations. On our behalf, they sent parents information about the study and a consent form. Once parents had agreed to participate, we sent a leaflet and an ‘agreement form’ to the children. There were four versions of these leaflets – one for disabled children aged seven to ten, one for disabled children aged 11 to 15, and two for siblings, divided into the same age groups. The leaflets included a photograph of the relevant researcher, coloured illustrations, with positive images of young disabled people, and information expressed in what we hoped was a straightforward way about the study. We explained what participation would involve and stressed that it should be fun. However, we were also careful to emphasise that children did not have to take part and could change their mind at any point. We also explained that the children would receive in return a booklet about the study findings, and stressed confidentiality.

Once children had agreed to take part in the study, an initial visit was made to the family home to discuss the project in more detail. This was generally the first occasion that the researcher met the family and it was mainly an opportunity to begin to get to know each other, rather than collect ‘data’ for the research. The aim of this meeting was to establish some ground rules for future visits, to check that each person understood what was involved and give them a chance to ask any questions. Another important function of the first meeting was to identify the disabled child’s communication method and thus decide what approach and materials should be used when talking to him or her on return visits. It was gently pointed out to families that we would prefer to talk to parents and disabled children separately and in most cases this was readily accepted. One teenage boy opted to have his mother present during subsequent visits but she did not answer questions for him. At the end of the first meeting, the researcher asked the child (if aged up to ten) if she would like to write a story, draw a picture...
or record an audiotape to share with the researcher on the next visit. We took along felt-tip pens, note pads and tapes to leave with the child for this purpose. For some children, this proved a useful ‘way in’ and helped ‘kick start’ the conversation the next time we met.

We met with most children on two occasions after the first visit. One teenager felt she spent the third session going over ground she had already covered in the previous visit while two children were visited on four occasions in all, reflecting the pace at which they were able to respond to the questions. This included a six-year-old who had some speech but found it difficult to sit still for any length of time and engage in discussion. His attention was eventually engaged through a personalised life story book, designed by Connors, with the little boy as the main character.

Semi-structured interview schedules were used in our conversations with children aged seven to ten and a more open-ended topic guide, covering the same questions, with those aged 11 and over. We drew on ideas from a number of previous studies and documents (most of which were not aimed at disabled children) when designing the materials (Macaskill, 1985; Alderson, 1995; Cavet, 1995; Mauthner, 1997; Ward, 1997; Hurley, 1998; Morrow, 1998; Punch, 1998). We also benefited from the advice of two disabled children who acted as advisers to the study. They looked through the draft materials and made several very useful suggestions for improving them.

The interview schedules for younger children
The interview schedules for children aged eight to ten were also used for those of any age who had learning difficulties. While we believe it important to treat every child in an age-appropriate manner as far as possible, and would not endorse treating those with learning difficulties in a ‘childish’ way, we felt the more simple and structured format of this questionnaire would be more accessible to them than that designed for older children. This view was confirmed when we piloted the schedules. We began by reminding the child that she could stop the interview at any time, pass on any particular question, that there were no ‘right’ or ‘wrong’ answers and that nothing she said would be passed on. We asked for the child’s permission to tape-record the interview. If the child had prepared a story, tape or drawing, we then talked about that. At this point, particularly if the child was diffident, we sometimes asked if she would like to hear some of the tape we had just recorded. This was then played back to the child, or she was asked to play it back, thus giving her ‘control’ of the tape-recorder.

The schedules included various questions in conventional format. For example, children were asked what they did on a typical school day and at the weekend. While this was enough to launch some on a blow-by-blow account of everything they had done the previous day, other children needed the task broken down into more specific questions: ‘What time do you usually get up?’; ‘What do you have for breakfast?’; ‘How do you get to school?’; and so on. Other questions were accompanied by visual aids or presented as activities or games. These served several purposes. The key to talking to younger children is often to do something else at the same time. Thus the materials acted as a distraction, allowing the children to chat freely while working on the exercises. This seemed to help some children volunteer more information than had been requested, or to express their feelings about the information, for example, grief about losing a grandparent. At the same time, the materials helped sustain the children’s interest by injecting some ‘fun’ into the discussion. They also facilitated communication where this might be obstructed by cognitive, hearing or communication impairment.

Activities and visual aids
We developed a ‘spidergram’ which was a colour drawing of a spider, on a sheet of A4 paper, with a box at the end of each of its eight legs. We used spidergrams to ask the child about significant people in her life, inviting her to write in each box the name of someone who was important to...
her. If the child was unable to see or to
write, then the researcher filled in the
boxes for her. It was stressed that she did
not have to fill in all the boxes (a few
children did not have many important
people in their lives). Equally, children
could add further boxes. The child was
asked to say a little about each person –
how she knew them, where they lived,
what they did together and why they were
important. This exercise served as a
useful means of gaining a picture of the
child’s social world and the key characters
in it. It was interesting that two children
did not identify their parents as important
people. A less successful aspect, however,
was that some children were frightened of
spiders and did not like the picture, despite
its smiling face! In our latest study, we
have replaced the spider and its hairy legs
with a sun and its yellow rays. A spider-
gram was also used, in the third visit, to
explore any worries or problems the child
had. This time the problem itself was
written in the main body of the spider and
causes of the problem in the top four
boxes, while the bottom four were for
‘How does it make you feel?’ Overall, this
was probably less successful, perhaps
because some children could not think of
any problems – or did not mention them –
while others found it difficult to identify
causes, which was perhaps too abstract or
complex a question for some.

In another question, about ‘favourite
things you like doing’, pictures were used
as prompts. These were images down-
loaded from a computer graphics pro-
gramme and pasted on to A5-sized cards.
They showed children, including wheel-
chair users, engaged in a number of
pursuits such as using computers, playing
football, dancing, reading and painting.
Picture cards have potential advantages
and drawbacks. They may broaden the
range of responses, by prompting people
to consider areas they might not other-
wise have thought of: they may also limit
the range of responses if they are pre-
sentated as exhaustive, or the only items the
researcher is interested in. Therefore we
generally held back from showing the
child these cards until after they had
answered the question themselves, so as
to avoid ‘leading’ their responses. In
some cases where children were unable to
think of favourite activities, or could only
think of one or two, the cards were pro-
duced earlier and proved a useful means
of identifying a range of liked, if not
favourite, activities, as well as those that
were disliked. This again sometimes
sparked off further discussion.

The cards were probably less useful in
helping children think about services and
professionals. We wanted to explore their
experiences of any services they might
have used, and their perceptions of
teachers, general practitioners, nurses and
social workers. A lot of young children do
not identify professionals by their job
titles: they may know them by name or
recognise a description of what the indi-
vidual does or where they work. Simi-
larly, children would not always know
what was meant by a ‘short-breaks facility’
or ‘playscheme’ and are more likely to
call these by name or respond to a
description of what goes on there. We did
not always have detailed knowledge about
the child’s contact with services and so
used picture cards, for example of a
doctor carrying a medical case, children
playing at a youth club, or a nurse stand-
ing beside a child in bed, to help children
identify the services they used. However,
it was difficult to convey some questions
in this way – for example, how do you
represent a social worker pictorially? Or
how useful is it to show a picture of a
short-breaks unit, if it looks nothing like
the one they go to? Interestingly (although
they were exceptions), we did not gain a
lot of data from children about services
and professionals. Parents had much more
to say about these. Perhaps this was
because most professionals did not count
as important people in children’s estima-
tion. It may also be that professionals
tended to communicate more with parents
than children, although this was not
always so. It is worth considering whether,
had a more effective way been found
to communicate with children on this
subject, they would have had more to say
about it. Clearly the cards were no help to
children with very little vision. However,
they were produced with matt rather than
gloss surfaces, thus enabling children
with reduced vision to see them better.
Another exercise involved a ‘word choice’ whereby children were presented with a brightly coloured A4 sheet showing four rows of three words each. Children were asked to circle all the words which described what they were like at school, for example, ‘happy’, ‘fed up’, ‘friendly’, ‘lazy’ and ‘sad’. Most children seemed to enjoy this exercise. Again, where children had a visual impairment, could not read or might not understand every word, the researcher read out, explained and/or circled the words for them. A fascinating finding from this exercise (reflected in much of the data) was the strongly positive image which most children had of themselves. This flies in the face of much previous research, mostly based on parents’ or professionals’ accounts.

Children were asked to complete a ‘lifeline’, a long line drawn down the middle of an A4 sheet, with ‘life very good’ written at one end, ‘life very bad’ written at the other and ‘life OK’ in the middle. Children were asked to write in different events that had occurred in their lives, placing these at a point on the line depending on how ‘good’ or ‘bad’ they were. This technique was not very effective. Younger children tended to find the exercise too hard. While it worked better with the older ones, overall it produced little new data.

Illustrated A4 cards were devised to seek children’s views about their brothers and sisters. These had cartoons of children at the top, and then listed a number of points, such as ‘name’, ‘age’, ‘best things about her’, ‘worst things about him’, ‘we have fun when . . .’, ‘she annoys me when . . .’. Children could fill in the blanks or just talk through their answers. The same cards were used in the interviews with siblings: they proved a good way of comparing how disabled children viewed their brothers and sisters, and were in turn viewed by them.

The extent to which children made choices about their lives was explored through a ‘choices chart’. This was really just a table set out on a coloured sheet of A4 paper, listing a number of daily activities, such as ‘what time I get up’, ‘what I wear’, ‘what I do after school’, ‘what I do at weekends’, and so on. The aim was to establish who made decisions in these domains. Different possibilities were listed at the top of each column (eg ‘me’, ‘mum’, ‘dad’, ‘someone else’) and children were asked to tick the appropriate response.

The ‘neighbourhood map’ was a different type of aid. The idea here was to explore themes of independence and inclusion by examining children’s familiarity with their local community, and the extent to which they made use of mainstream amenities. The map consisted of a metal board with magnetic pictorial counters depicting various landmarks with which children might be familiar, such as ‘my house’, ‘school’, ‘shops’, ‘park’, ‘church’, ‘swimming pool’ and ‘library’. Children were asked to place these counters on the board in order to construct a map of their neighbourhood, and to talk about when and why they would, or would not, go to various places. Again, this revealed a good deal, not just about their knowledge of the local area but also about how far they were able, or enabled, to lead ‘ordinary lives’. A number of factors emerged including physical barriers to access, parental concerns about safety, the inhibiting effect of other people’s behaviour, such as name calling or staring, and the implications of specific impairments for children’s independence.

We seldom asked children directly about their impairment. We did not wish to make it a bigger issue in their lives than it perhaps was. Rather, we wanted them to describe and delineate its impact. We included a number of questions which gave children an opportunity to talk about impairment if they wished. For example, we used sentence completion to introduce some ‘serious’ issues interspersed with some lighter ones. The child was asked to complete a series of sentences, starting with ‘My favourite TV programme is . . .’, ‘My most valuable possession is . . .’, ‘I feel happy when . . .’. Later sentences included ‘I feel sad when . . .’, ‘Something I find difficult is . . .’. We also asked the children if they had a magic wand, what they would wish for and why. If, after a second wish, they had not
mentioned their impairment (and most had not), we then specifically asked, for example, ‘What about being in a wheelchair: would you change anything about that?’ Similarly, after the spidergram exercise focusing on worries (in which few referred to impairment), we asked ‘Do you ever worry about your disability?’ The final questions were about the children’s aspirations. Here, after asking what they wanted to do when grown up, where they would live and so on, we asked if they thought their impairment, e.g. ‘not being able to see’, would affect their ability to work, and if they would need any help to achieve their goals. (See also Watson et al., 2000 for discussion of children’s responses to being categorised as disabled.)

**Topic guide for older children**
The pilot study, in which we met with five families and tried out more and less structured schedules, indicated that a less structured topic guide was more appropriate for young people aged 11 and over. This covered the same areas as the schedule for younger children but some of the questions were worded differently and, for the most part, the older children were not asked to do exercises. They did have a ‘choices chart’, which included items such as ‘choosing what school I attend’ and ‘where I live’. Occasionally other exercises were offered, to break up the conversation or if the young person seemed stuck on a topic. This group was not asked the magic wand question, although they were asked if there was anything they might want to change in their lives.

**Children with communication impairments**
Some children had particular speech and language impairments, and in these cases parents were asked to advise on ways of adapting the materials, and about appropriate language to use. Four young people communicated in BSL or Makaton. As mentioned above, one of the researchers is fluent in BSL: she conducted, video-recorded and transcribed these interviews. A deaf adult checked the transcriptions. In the following section we describe how we went about exploring the views and experiences of one child who had an unusual way of communicating.

**Case example**
This boy, aged ten, whom we will call Angus, was one of several in the study with a diagnosis of autism. Angus was a very restless child who liked to run around the house, in and out of rooms, jumping up and down on chairs. He had virtually no speech, but his mother had been using Facilitated Communication with him for some time. This method is more widely used in the USA than in Britain and remains controversial (Mostert, 2001). It involves a board with written letters and a few basic words such as ‘yes’ and ‘no’; the facilitator takes the other’s hand and allows the latter to guide him to different letters, thus making up words and perhaps sentences. Critics allege that it is impossible to tell whether the disabled person is in fact guiding the facilitator, or the other way round. Angus’s mother faced both scepticism and disbelief from the professionals working with him about the validity and reliability of this method.

Through his mother, Angus agreed to take part in the study. She offered to work on the questions with him as and when suitable opportunities arose. She wrote down the answers and passed them on to the researcher. They did not get through all the questions and Angus apparently declined to answer some. However, when asked what he did at school, he communicated, ‘I just do nothing’, and in the playground, ‘walk around’. Asked if he had ever been bullied, he replied, ‘Yes, a boy – Duncan’. Asked ‘What happened?’, Angus replied, ‘He hit me.’ He communicated various worries for the spidergram, including ‘feeling mean towards others’, ‘my education’, ‘overpowering feelings – emotional anger, frustration’, ‘What will happen to me when I am older?’ and ‘wanting to be able to speak’.

How did we judge the authenticity of these data? After careful consideration, we decided not to judge. We presented Angus’s responses alongside the others, but prefaced any quotations by alerting the reader to the fact that these were
obtained through Facilitated Communication. Readers could then make up their own minds. We would argue for an ‘if in doubt, take it seriously’ approach, since the alternative is to discount and thus exclude. Where more time is available, it may be possible for a researcher or practitioner to attempt Facilitated Communication with a child who already uses it, or observe him doing so.

Children with high cognitive impairment
Two other children had complex support needs to the extent that parents advised they would not be able to understand nor respond to the interview questions. Both used non-verbal communication, such as eye gaze and head turning to indicate needs or interests. However, the issue here was not so much about communication as cognitive ability. It would be very wrong to suggest that these children were unable to feel joy and sadness, to express preferences or to make meaningful relationships with others – all important aspects of children’s lives covered in our research. However, to explore these dimensions from their perspective it would have been necessary to spend prolonged periods of time with each child, to become familiar with their ways of communicating and be able to distinguish, for example, what crying meant on one occasion from what it meant on another. While this might well be possible in an ethnographic study using participant observation over many months, we simply did not have that amount of time available. Therefore in these two cases, it was agreed to interview the parents instead: they were asked to give their views on the various topics covered in the schedules, but not to speak on behalf of the child. We feel it is important to be honest about the fact that some children have a level of intellectual impairment such that meaningful communication cannot be established in a short space of time. Indeed it would be disrespectful of them, their parents and those working with them to suggest otherwise.

Conclusions
Researchers and practitioners may be put off attempting to communicate with disabled children because they think it will be too time-consuming and too difficult, because they think some children will not understand what is happening to them nor have a particular view about it, or because they see themselves as lacking the necessary skills or confidence. On most of these counts, they will probably be wrong. Communicating with disabled children is often little different from communicating with any child: it needs to be done in an age-appropriate manner, combining fun with a more serious aspect, as appropriate, so as to engage but not patronise the child. Careful consideration needs to be given to ethical issues such as confidentiality, dealing with sensitive issues and responding to information about potential harm and risk, as with all children.

Where a child has learning difficulties – although that umbrella term covers a very wide range of conditions and abilities – it is important to present information and pose questions in a way that avoids being childish, but is tailored to the individual’s pace and ability. This calls for flexibility and, until one knows the child well, a certain amount of ‘playing it by ear’. Wherever possible, it is important to use the child’s accustomed method of communication rather than try to introduce new ones. Thus the onus is on the adult to learn to communicate in the way with which the child feels most comfortable. This may mean becoming familiar with some form of electronic communication aid, such as Bliss or Alphatalkers. These do not require special skills or prior knowledge, but simply some time to get used to. In other cases, it may be necessary to use an experienced sign language interpreter although it is better, where possible, to employ researchers or practitioners who can sign. Introductory courses in Makaton are often run by local Speech and Language Therapy departments. It does not take long to pick up a few basic signs which will help the child feel at ease and increase the practitioner’s confidence.

Another argument in favour of
communicating with disabled children (were it needed) and not treating their parents as proxies, is that the two sometimes see things differently. We found that parents and children had different views about a number of topics, including what caused the young people distress, how they behaved at school and what the future held for them. It was therefore worrying that some professionals tended to rely on parents for information rather than talking directly to the child.

We do not claim that the activities and exercises used in the research reported here were particularly new or original. What was perhaps innovative was using them with children who had a range of impairments. The study showed that this could be done successfully, and there is no reason to think these approaches could not be adapted and expanded in other fields, including fostering and adoption. Argent and Kerrane (1997) suggest a number of aids for informing and preparing disabled children entering substitute care, such as drawings, puppets, a doll’s house, games and meeting other disabled children with similar experiences. Reassuring them about their anxieties and giving them some control over the process is as important as for any child. The authors make the point that no child entering substitute care is ‘too disabled’ to be informed about what is going to happen in some way she can understand.

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