

Including all children: finding out about the experiences of disabled children

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In recent years, I have been involved in four projects which sought the views of disabled children and young people, including those with significant communication and/or cognitive impairments: three were research projects (Morris, 1998a and b; Morris, 2001; Abbott et al, 2001) and one was part of a local authority's Best Value review of placements for looked after children (Morris, 1999). Some of the lessons that were learnt about how to include disabled children and young people both as research subjects and as advisors to a research project, were written up in a report published in 1998 (Morris, 1998c). I'm going to draw on the experiences of all four projects to examine the issues around involving disabled children and young people, with particular attention to those with communication and/or cognitive impairments.

Involvement of disabled young people in research Reference Groups

The three research projects each had a Reference Group made up of disabled young people who had similar experiences to the research subjects: of spending most of their childhood away from their families;

of social exclusion; of being at a residential special school. These Reference Groups had an input into the research projects at three key stages (although in each case more than three meetings were held with the Groups): deciding what information was to be gathered, designing the information schedule and advising on how to gather information directly from disabled children and young people; commenting on an initial analysis of the information gathered and identifying the key messages; making suggestions for the dissemination of the research.

Each member of these Reference Groups had their own access needs which had to be met in order for them to fully participate in the process. However, the facilitation process started long before the actual meeting. The young people were unlikely to attend meetings if we had just sent out letters and agendas in the normal way. There may be many different reasons for this, for example:

- A printed letter may not be accessible to the young person
- Letters may be opened by adults (parents, teachers, care staff) who make decisions on behalf the young person
- The young person may not have easy access to the things necessary to communicate with the person organising the meeting (paper, envelopes, stamps, post box, telephone, email)
- The young person may rely on others to organise transport, personal assistance and/or communication facilitation and this may not happen

- Other people may arrange something else to happen on the same day as the meeting, without realising that the young person wanted to come to the meeting
- Other people may decide on behalf of the young person that they cannot come to the meeting: for example, we found that it was quite common for staff in one residential home to decide that a young woman wouldn't be able to come to the meeting because she 'will only just have come back from a weekend home with her family' or 'she's not been very well'.

The following actions made it more likely that people were able to turn up for meetings:

- Making sure when informing people of meeting dates and venues etc. that communication methods are chosen to suit each individual: for example, sending a letter on tape, in large print/Braille, video, using typetalk, text messaging, email, the telephone, plain English, pictures, etc.
- When relying on an adult to help a young person respond, trying to ensure that this adult acts as a channel of communication, rather than gives their own opinion about whether the young person can come to the meeting and what help they will require
- Giving plenty of notice of the date of the meeting but contacting the young person close to the date of the meeting in order to confirm that everything is OK

- Making it clear that any costs incurred in attending the meeting will be reimbursed, including transport, personal assistance, communication facilitation. Making it clear how to claim these expenses and making it easy
- Asking the young person what help they need to come to the meeting and to participate in the meeting. Offering to help organise transport, personal assistance and communication facilitation
- Paying the young people for coming to the meeting and asking each person what is the best way to pay them – in cash, cheque, vouchers etc. Making it easy to claim the fee.

Young disabled people often have little control over their lives and other people make decisions for them: this is even more likely when the person has communication and/or cognitive impairments. The barriers they experience to becoming involved in a Reference Group often concern things which most of us take for granted (having envelopes and stamps and access to a postbox being but one example). We found that attention to detail is the key to enabling young disabled people to come to meetings and participate fully. We also learnt that, just because arrangements worked well on one occasion this does not mean that they will work well on every occasion. One young man, for example, lived in a hospital and staff were very efficient at providing transport and assistance when he attended the first three meetings of the Reference Group. On the fourth occasion, however, the key member of staff who made this possible was on holiday. We had not made contact with the young

man to check that everything was going smoothly and consequently did not pick up the problem and he did not attend the meeting.

Paying attention to detail was also the key to enabling the young people to participate in the meetings. This included the physical environment of the venues, the assistance available and also the way the meetings were run. The experience of the first research project which involved a Reference Group of young disabled people resulted in a Checklist covering both these issues (Morris, 1998c, p.65) but we continued to make mistakes and to learn from them. For example, feedback from young people with communication impairments about the experience of being part of a subsequent Reference Group indicated that we did not adequately meet their access needs. In particular, they suggested we should have spent more time discussing things in pairs or threes as they said this was easier for them than in a larger group of six.

One young man also felt very strongly that it was *they* who should have been doing the research, not us.

Seeking the views of disabled children and young people about their experiences

All four of the projects under discussion aimed to find out about the views of disabled children and young people, including those with significant communication and/or cognitive impairments. None of the projects was able to use the type of ethnographic fieldwork carried

out by, for example, John Davis who spent five months in a special school (Davis et al, 2001). We were limited to visiting the children and young people for short periods of time, at the most spending a day with them, although we often visited more than once. We therefore had to maximise our chances of gaining information directly from the children and young people by ensuring that we were properly prepared.

All of those carrying out interviews or 'visiting with' children and young people took part in training days. Even though most of us had experience of this kind of work (and some had significant experience) we all benefited from exploring together how we could maximise communication with the children and young people we wanted to visit or interview. Three of the projects also held follow-up days to talk about the experiences of doing the work. Looking back over the four projects, there were a number of learning points which have implications for any work of this kind.

The importance of the social model of disability

While most of those carrying out the interviews had a clear understanding of the social model of disability, the training days enabled us to focus on its application to communication. We reminded ourselves of the importance of separating out impairment and disability. To put it in a nutshell, the disabled people's movement in Britain doesn't use the term "disability" to mean impairment but to refer to the disabling barriers of prejudice, discrimination and social

exclusion. *Disabled people* are those people with *impairments* who are disabled by society.

There are significant implications of this approach for how we interpreted and responded to the communication needs of the children and young people whose experiences we wanted to find out about. In particular it enabled us to separate out the child's communication needs relating to their impairment (for sign language interpretation, a piece of equipment, or for people to understand their speech or behaviour, for example) from the disabling barriers created by others (negative attitudes, lack of equipment or relevant expertise, etc).

We found it particularly helpful to be able to separate out impairment and disabling barriers right from the start, when we sought to make contact with potential research subjects. When we negotiated the involvement of children and young people in the research (a crucial part of which was finding out about communication needs), had to deal with adults who were acting as gatekeepers. This role is of course very important in terms of ensuring that we, as unknown adults, did not cause the child or young person any harm. However, gatekeepers could also be disempowering. It was very common, for example, for an interviewer to be told – when first making contact with a child's parent, school, or residential home – 'You won't get anything out of him'; 'He can't communicate so you won't be able to interview him'. These comments do not give us any information about the child's communication needs but they tell us that there are attitudinal

barriers which are getting in the way of both our need for information and also, probably, the child's communication potential. Our recognition of this disabling attitude meant that we did not take the information given at face value. We knew, therefore, that we needed to seek further information, which might have to come from someone else. In these instances, it was the adult's attitude that had to be tackled first, sometimes in order to even get access to the child, and certainly to find out what the child's communication needs were.

We found that there were sometimes significant gate-keeping barriers even when those setting up the visit to the child were social workers carrying out their statutory duty to review a placement (as was the case with the Best Value review). On the other hand, sometimes we were told: 'He uses BSL' or 'She uses a Liberator' or 'He doesn't have speech but he does have ways of indicating yes and no'. These were useful pieces of information about what skills we needed in order to communicate with the child concerned.

Consulting with young disabled people about the information to be gathered

The three research projects each used an Information Schedule, which was developed in consultation with the Reference Group of young disabled people. The piece of work with a London Borough used a questionnaire, which was part of the Best Value review of placements for looked after children. There were a number of ways in which this questionnaire was not suited to the children concerned, for example:

- Asking whether a child feels able to ‘talk’ at their reviews was not an appropriate measure of involvement for children who do not use speech to communicate
- Questions about independence were all about doing things for yourself, and this is an inappropriate measure of independence for children and young people who use personal assistance or equipment for daily living activities.

There were also important issues in terms of disabled children’s welfare, which were not covered in the questionnaire, for example:

- Whether carers understood how the child or young person communicated
- How the child or young person felt about the way carers provided personal assistance.

We therefore had to adapt the questionnaire before visiting the children.

In contrast, the Information Schedules, used by the three research projects, were developed in consultation with young people who had similar experiences to the research subjects. This increased our chances of covering issues that were of importance to the children and young people and also meant that we were more likely to ask the questions in ways that were meaningful to them. For example, the research project on social exclusion wanted to cover experiences of leisure activities amongst young disabled people with high levels of support needs. However, the Reference Group pointed out that this

group of young people was unlikely to be either in employment or, once they reach 19, in full-time education. 'Leisure activities', or 'spare time' – quite apart from being pieces of jargon – are inappropriate phrases they said, and suggested that instead we ask questions such as 'What do you enjoy doing? What would you like to do?'

On the other hand, sometimes children and young people take on the jargon used by those around them: for example, the Reference Group advising the research on disabled children living away from home (correctly) judged that the words 'review' and 'review meeting' would be familiar to our interviewees.

The advice of Black and Asian young disabled people was particularly important when designing the Information Schedule for the research on social exclusion. Our attention was drawn, for example, to the importance of asking questions about involvement in religious organisations when looking at young people's involvement with local communities and politics.

It was also important that the Information Schedules were used in ways that suited the particular child whose experience was being examined and this is discussed later.

Gaining consent

The Reference Groups of young disabled people helped us to understand what kind of information children and young people would

want in order to help them decide whether to participate in the research. For example, the Reference Group advising the research on disabled children and residential schools said that potential interviewees would want to know:

- What questions am I going to be asked?
- Is the information going to be kept confidential. Who is going to see the information?
- Will anything I say get back to staff or my parents?
- What's the point of doing the research? Is it going to change anything? Will it only be a fancy report? What will happen as a result of the research?
- Why have I been picked? How have I been picked?
- What information do you already know about me? Who has given you information about me?
- Are you going to be sensitive to my past experiences?
- What skills/experience have you got?
- Will I have a choice about where the interview happens?
- Will I have a chance to have someone with me, will I be able to choose who this person is. Will I be able to have someone with me to help with communication, to help me understand the questions?
- Can I say I don't want to answer any of the questions, or stop the interview at any time?

The Reference Group also felt that potential interviewees would like to know that young disabled people have been consulted about how the research should be done, and that this consultation included those who use augmentative communication (i.e. who do not use speech as their main method of communication).

Each of the research projects, and the Best Value review, included gathering information about the experiences of children whose level of cognitive impairment meant that a dialogue with them was not an appropriate method of gaining consent. This meant we had to develop other methods of gaining their consent to visit with them. The main way of doing this was to ask someone who knew them well how they indicated that they were happy or unhappy with a situation or person. We were then careful to act on this information when visiting with them. However, it is important to recognise the ethical limits of this kind of situation. These children and young people may have 'consented' to a researcher being with them but this was not consent to the information we gathered about them being used in the research. We had to rely, therefore, on seeking the consent of an adult who firstly, was entitled to give consent on behalf of the child or young person, and secondly, who, we felt, would protect their interests. This was particularly important because, in writing up the experiences of some of the children and young people involved in these projects, it was quite difficult to preserve their anonymity. We needed to take great care in order to do this and consult with a relevant adult in the child's life.

Setting up interviews

When setting up the interviews in each of the projects, we addressed the important issues of privacy, finding a time which would suit the young person, assuring them of confidentiality, and being clear about what we would do if anyone disclosed an experience of abuse (see Morris, 1998c). In terms of addressing communication needs, as already mentioned, we did not need information about diagnosis or impairment but instead about what would assist communication.

We experienced three main barriers to identifying and meeting young people's communication needs:

- Sometimes the person with whom we were negotiating access to the young person did not have enough knowledge of their communication needs: this could sometimes be overcome by making contact with someone who knew the young person better
- Sometimes we were told that there was no point in our trying to include the young person in the research as 'he won't be able to tell you anything' (to quote just one example)
- Sometimes the person with whom we were in contact very much wanted a child or young person to be part of the research. They then underestimated how much assistance would be required to make this possible – often because they assumed we would be happy to just ask questions of a parent or member of staff rather than seek information from the young person themselves.

The key learning points from all of these situations was the importance of asking lots of questions about someone's communication needs, being persistent, and being prepared to find, when we arrived, that the information was wrong or incomplete. An initial visit was often essential to confirm what we had been told over the telephone, and to find out exactly what we needed to do to facilitate communication. Most important was the need to check out what we had been told about their communication with the child or young person concerned.

While interviews were not an appropriate method for gathering information about children and young people who had significant cognitive impairments (see below), we did use this method with a number of children and young people who had significant communication impairments. When interviews went well it was because a number of positive factors were present: the interviewer's confidence with 'total communication'; the respect of the adults involved with the child of their right and ability to choose whether to be involved and to 'speak' for themselves; the time taken to check out preferred methods of communication; the researcher taking the time to check his/her understanding and his/her confidence to say when s/he didn't understand. It was also very important that children did not use only a smile to indicate 'Yes'. Unfortunately, a number of children and young people interviewed in these research projects did not have appropriate ways of indicating 'Yes' if they were communicating about negative experiences.

Apart from taking the time, at the beginning of an interview, to check out issues around communication, we also made sure that the child or young person knew that they could stop the interview at any point. Sometimes we suggested that they practised stopping the interview so that they and we would feel confident that this could be done if they so wished.

The experiences of setting up interviews with children and young people who had communication impairments drove home the importance of paying attention to details such as:

- the venue (whether it was comfortable, quiet, etc);
- the timing of the meeting (allowing more time, ensuring that the time suited the young person);
- identifying any need for a facilitator and allowing enough time to organise this;
- checking that, if the young person used a communication aid, it was available and in working order.

We also found it important not to introduce any new system of communication, such as a package for carrying out reviews or assessments, without checking out first how it might fit in with a child or young person's existing system.

Asking questions

We also learnt a lot about the way the interview should be conducted when a child or young person has a communication impairment. This

included being very careful about the language we used (avoiding figures of speech for example) and how we asked the questions (such as avoiding using double negatives). However, we also learnt a lot about how we should conduct ourselves and the following checklist is part of a longer list included in a guide which was written, in consultation with young disabled people, for social workers, Personal Advisors etc, working with young people with communication impairments.

- don't panic if you feel disempowered by uncertainty or unfamiliarity or your own feelings of inadequacy
- don't react to your feelings of disempowerment by trying to take more control of the situation
- slow down and watch and wait
- don't give in to the temptation to fill every pause in the conversation. The young person may be preparing the next thing to say to you
- look out for other methods of communication, such as facial expressions and gestures – these can tell you when someone has something to say, when they have finished what they have to say, and also important things about how they feel
- if someone is using a piece of equipment or another person to help them communicate, avoid looking at the equipment or other person all the time – make sure you have eye contact with the young person and are picking up on any facial expressions or body language

- if you think it's possible to guess the end of a sentence ask them if it's OK to do this. Sometimes people welcome this because it speeds up conversation, sometimes they have too many experiences of people getting it wrong so they won't want you to do this
- don't rely on your tone of voice to convey meaning if you are interviewing someone with a hearing impairment or autistic spectrum disorder
- don't rely on your body language or facial expression to convey meaning if you are interviewing someone with a visual impairment or autistic spectrum disorder
- don't assume you know what the young person is going to say or what they want to talk about
- don't assume that just because someone does not use speech they do not have a lot to say.
(Morris, 2002).

We found that it can be difficult to always remember the impact of someone's impairment on them. If we do not have a visual impairment, for example, we pick up messages conveyed by facial expression without even thinking about it. While an interviewer may *know* that the young person they are talking to has a visual impairment it is sometimes hard to keep being aware of how this might affect their interaction. It can be easy to underestimate or misinterpret someone's ability to understand or co-operate in these circumstances. We found it was important to keep asking ourselves how someone's impairment may be affecting what they are picking up

or how they are responding – rather than their ability to understand or their wish to co-operate. Again, this demonstrates the importance of the social model of disability – the clear separating out of impairment from disability (disabling barriers) helps to address needs relating to both sets of factors.

Adapting the research tool to suit the children concerned

It is common for children and young people who have significant communication impairments, and particularly children with significant cognitive impairments, to be excluded as subjects of research because it is difficult to gather information from them using traditional research tools such as questionnaires and interviews. This is sometimes the result of an explicit decision. More often, the exclusion is implicit and happens in spite of the researchers' intentions to be inclusive.

We have learnt that, unless there is a specific focus on including children and young people with significant communication and/or cognitive impairments, they will inevitably be excluded. An important part of this focus must be adapting the research tools to suit each child or young person.

Each of the three research project used an Information Schedule which set out questions under a series of headings. We did not assume, however, that the only way to gather the information was to ask each child the relevant questions. Instead, in a number of cases, the questions were used as a way of assessing the child's

experience, using a number of sources of information. For example, one of the questions on the Information Schedule used for the research on social exclusion was: Is there someone who you feel will always listen to you, if you've got something important that you want to talk about? Some of the young people included in the research could not be asked a direct question such as this because of their level of cognitive impairment. On the other hand, we did not want to rely on, say, a parent or keyworker to be a proxy for the young person in answering this question; we wanted to get as close as possible to their actual experience (recognising the constraints of time and resources which we were working with). We also had to recognise that the question itself might be inappropriately worded and to focus instead on the meaning behind the question.

We therefore gathered information from people who were in daily contact with the child or young person – parents, teachers, keyworkers, and sometimes friends and siblings – and also spent time with the young person, usually in more than one setting. We did not rely on any one person to tell us the answer to this question although we paid more attention to the views of anyone who clearly liked/loved and respected the child or young person concerned. Having written up notes of interviews with those who knew them well and notes of time spent with them – we asked ourselves the question: Does this young person have someone in their lives who they could rely on to understand and listen to them, if they had some important experience or feelings they wanted to share? Information gathered under other parts of the Information Schedule was also important in

answering this question, such as how well are their communication needs met, how much privacy do they have, and so on.

'Being with' a child or young person as a method of understanding their experiences

This brings us to what we have called 'being with' as a method of gathering information about children and young people's experiences. Sometimes this took the form of fairly straightforward observation of what was going on in a situation; other times it involved joining in an activity, such as having a meal, accompanying them on an outing and so on. This method was most informative when we were able to experience a range of settings with the young people. For example, 18 year old Mark was visited at boarding school and then a few months later at a day centre which he attended, having left school. On each occasion a day was spent with him: at school, however, there was not much opportunity to do more than observe what was going on, while at the day centre the researcher was much more involved, including joining in on a trip to the local ice rink. The school staff told us that Mark did not communicate at all and that there was no way of knowing what he was feeling. Our observation of him at school seemed to confirm this – he just didn't seem 'there' at all. In contrast, at the day centre there was a high amount of interaction between Mark, the staff and other disabled young people, particularly between Mark and his keyworker. He also expressed his delight at going ice skating. The levels of communication and interaction with others displayed by Mark, once he started attending the day centre, were far higher than his parents had previously experienced. This,

and similar examples involving other young people, led us to conclude that many young people with high levels of support needs are experiencing an extreme form of social exclusion in that their needs and abilities to communicate are not being recognised. 'Being with' them was the appropriate method for gathering information about their experiences rather than the more traditional research methods.

Writing up the experience of sharing the same space and time as a child or young person with significant cognitive impairments was also a way of ensuring that their experiences were part of the research project or Best Value review. One example concerns a 14 year old boy who was at a residential special school. The research report set the scene for the description of what it was like spending time with him:

Howard's school is in the countryside, occupying a large site with a number of hostels, a hospital block, school, staff housing and other large buildings. Each time the researcher visited Howard the grounds seemed deserted and it was difficult to believe that there were over 200 children living there. The researcher described her visit to the hostel where Howard lives. 'It looks like an air-raid shelter from the outside. We go into a dark hall that smells like a hospital. There is a staff office directly in front: all glassed in and lots of filing cabinets and noticeboards. We hang up our wet coats: Howard's in one cupboard and mine is very definitely put into the separate staff cupboard.

'We go into what is apparently the lounge. It is stunningly bare. The furniture is grey plastic sofas and chairs, some in pieces. There is a TV and there are three torn up magazines on the table. One wall is completely covered with rows of small wooden cupboards, which it seems are all empty. There are some framed posters of animals up high on the walls which otherwise are completely bare. There is a plastic wipe container with dusty plastic flowers tied to a pipe up high. There is no-one here, it is silent....I sit on one of the sofas. I notice over my visits that no member of staff sits on the sofas and I begin to feel I have broken a rule but I carry on sitting on the sofas.'

(Morris, 1998, p.7)

Even when a child or young person can participate in an interview, spending time with them when they are engaged in other activities often opens up more opportunities for finding out about their views and experiences. As Ruth Marchant and her colleagues from Triangle found, when finding out about children's views of a residential respite centre:

Some of the best communication took place where the young people did other things at the same time as communicating: for example, eating, drinking, playing, walking, being driven, watching TV, listening to music, playing computer games, drawing' (Marchant et al, 1999a).

Conclusion

Researchers are still learning how to be fully inclusive when examining the experiences of children. It is important that we share the detail of what works and what does not, and that we are brave enough to share our experiences of not getting it right.

If we assume that children and young people are unaffected by physical, sensory or cognitive impairments, research will inevitably always exclude important experiences. None of us wish to do this so it is important to confront the barriers we experience to including disabled children in order that we can at least begin to address them. All four of the projects discussed found that the most important starting point is to assume that *all* children and young people – whatever their communication and/or cognitive impairment – have something to communicate. It is up to us to find ways of understanding their views and experiences.

Abbott, D, Morris, J and Ward, L. 2001. *The Best Place to Be? Policy, practice and the experiences of residential school placements for disabled children*. Joseph Rowntree Foundation/York Publishing Services: York.

Davis, J, Watson, N, Cunningham-Burley, S. (2001). 'Learning the lives of disabled children' in Christensen, P. and James, A, eds. *Research with Children: Perspectives and Practices*. Falmer Press: London.

Marchant, R. Jones, M. Julyan, A. and Giles, A. 1999. *Listening on all channels: consulting with disabled children and young people.*

Triangle: Brighton.

Morris, J. 1998a. *Still Missing? Vol 1. The experiences of disabled children and young people living away from their families,* London:

The Who Cares? Trust: London.

Morris, J. 1998b. *Still Missing? Vol 2. Disabled children and the Children Act.* The Who Cares? Trust: London.

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

Morris, J. 1999. *Space for Us: Finding out what disabled children and young people think about their placements,* London Borough of Newham.

Morris, J. 2001, *That kind of life? Social exclusion and young disabled people with high levels of support needs.* Scope: London.

Morris, J. 2002. *A Lot to Say: A guide for social workers, Personal Advisors, and others working with young people with communication impairments.* Scope: London. (This publication is available free from: Scope, 6 Market Road, London N7 9PW, 020 7619 7100).