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Doing research with children and young people who do not use speech for communication

Abstract

Despite emphasis in policy on participation of disabled children¹, we still know relatively little about how to obtain the views of disabled children with significant communication impairment and their views are often overlooked in planning and service provision. This article describes how the views of children who do not use speech were accessed in research aiming to identify disabled children and young people's priorities regarding outcomes of social care and support services. The main challenge was to develop a method that was reliable, non-threatening, enjoyable and relevant to individual children, as well as enabling children to think beyond their everyday life and express what they aspire to.

Introduction

Research shows that disabled children have been largely excluded from consultations and involvement in decisions, which affect them (Morris, 1999b; Morris, 1999c; Cavet and Sloper, in press). Particular exclusion has been experienced by the children and young people who do not use speech as their

¹ For brevity, the term children is used to cover children and young people up to 18.

first mode of communication and/or are perceived as having significant cognitive impairments (Morris, 1998a; Morris, 2003). Underpinned by medical discourses, children who do not communicate using speech have been and continue to be defined by what they cannot do, rather than what they can. However, there is a growing body of literature, which indicates a whole range of communication strengths and a great willingness and ability on the part of disabled young people to communicate their feelings and experiences and be involved in a process of change (Disabled people using Scope services, 2002; Rabiee and others, 2001; Morris, 1999a; Stalker and others, 2003; Watson and others, 2000; Cavet and Sloper, in press). A report written by disabled people with communication impairments provides many interesting and powerful remarks by disabled people about their communication impairments. While acknowledging that they do have communication difficulties, they believe they have qualities which give them communication strengths such as perseverance, patience, being able to read other people's communication, pointing out things they want and using yes and no in different ways (Disabled people using Scope services, 2002).

Recent policy developments of the 1990s have raised general awareness and placed legal obligations on society in general for improvements in the provision of services for disabled people. Within this larger policy context there is a growing recognition of the need to consult children and involve them in decisions about their lives. The UN Convention on the Rights of the Child emphasises children's rights to receive information and express their views

about matters that affect them and Article 13 directs attention to the need for appropriate means of communication to be provided for children. The Children Act 1989 and Quality Protects (Department of Health, 1998) both stress the importance of ascertaining the wishes and feelings of children, including disabled children, and involving them in decisions about their care and welfare, and the Department of Health (2002) has also issued guidance underlining its commitment to involving children in all aspects of its work. Most recently, the National Service Framework for Children Standard for Hospital Services (Department of Health, 2003a) sets out standards that all hospital services should meet, including

'They [children and young people] should be encouraged to be active partners in decisions about their health and care, and, where possible, be able to exercise choice.

Children, young people and their parents will participate in designing NHS and social care services that are readily accessible, respectful, empowering, follow best practice in obtaining consent and provide effective response to their needs.' (p. 9)

Both Department of Health (1991) guidance and the recent National Service Framework for Children Emerging Findings (2003b) make it clear that provision should be made to involve children with communication difficulties in decision-making.

Despite this emphasis in policy objectives on participation of disabled children/young people, evidence suggests that while in general children are more involved in the process of decision making, disabled children's participation has been more through other agents than being direct (Council for Disabled Children, 2000; Sinclair and Franklin, 2000; Robbin, 2001). Therefore our knowledge of their experiences is still largely second hand knowledge given to us by adults whose views and experiences may differ from those of the children (Beresford, 1997; Mitchell and Sloper, 2001; Thomas and O'Kane, 1998)

The key issue is that we still know very little about how to involve this diverse group of children in areas affecting their lives. Fundamental to achieving the overall aim of participation is therefore to develop communication methods, which can maximise children's communicative potential to express themselves and address the barriers they face. The other key component for effective participation is to recognise the fact that communication is a two way process requiring others to learn and understand how a child expresses her/himself (Triangle/NSPCC, 2001). As a disabled child with communication impairment has put it:

'We are used to people saying we cannot communicate, but of course they are wrong. In fact we have powerful and effective ways of communicating and we usually have many ways to let you know what it is we have in mind. Yes, we have communication difficulties, and some

of those are linked with our impairments. But by far the greater part of our difficulty is caused by 'speaking' people not having the experience, time or commitment to try to understand us or to include us in everyday life' (Disabled people using Scope services, 2002, pp.1-2).

This statement is supported by service providers' own concern about the difficulties they experience in communicating with this group of children (Council for Disabled Children, 2000). For the children who use Alternative and Augmentative Communication (AAC), this would mean adequate training and support not only for children who use the system but also for staff and AAC users' peers (Clark and others, p.108). What is encouraging is that more and more interest is being shown by local authorities in using innovative consultation methods for consulting disabled children and undertaking staff training (Council for Disabled Children, 2000).

In research, there has been increasing recognition of the fact that children's views differ from those of adults and there is now a body of research, which has obtained the views of disabled children. This research has shown that disabled children hold and can express views, given the right environment, and that they value participation (Cavet and Sloper, in press). Therefore, the exclusion of disabled children from research and consultation says more about unsuitability of research and consultation methods and adults not knowing how to relate to them than about the limitations on the part of informants. For example, as Argent and Kerrane (1997) have noted, '...they don't understand', often means

'I can't think how to explain it to them" (p.73). Similarly, Booth and Booth (1996) suggest that '... researchers should attend more to their deficiencies than to the limitations of their informants' (p.67). Unless appropriate tools are found this group of children may remain largely unaffected by all the policy advances made for children.

The project and what it is seeking to do

This paper has arisen out of a four year research and development project funded by the Department of Health to identify the priorities and perceptions of disabled children and young people (0-18 years) and their families regarding outcomes of social care and support services (the research phase), and to develop tools by which these desired outcomes can be assessed or measured (the development phase). The project works with four groups of disabled children who are identified as 'difficult to reach' and causing concern for service providers. This includes children and young people with complex health care needs, communication impairment, autistic spectrum disorders or degenerative conditions. The fieldwork has been carried out in three local authorities and involved interviews with children (if 6 years or over) as well as their parents to identify the outcomes children want for themselves and those that parents want for their children and for themselves.

Previous research involving disabled children has highlighted the importance of identifying their communication needs for participation and adopting a flexible

approach in meeting these (Morris, 1998; Marchant, 1999; Beresford, 1997; Ward, 1998; Watson and Priestley, 2000).

There is a growing body of literature detailing successful approaches to involving children with communication impairments in the process of decision making (e.g. Morris, 1999b). Some of this work aims to improve practice in communicating with this group of children, by offering advice and information to those working with them (Morris, 2002; Triangle/NSPCC, 2001; Warrick, 1998).

There is also some interesting work to support the process of obtaining the views of children and young people with communication impairment, for example a practical 'tool kit' of cards (Kirkbride, 1999), talking mats (Murphy, 1998) and a training video for practitioners (Triangle/NSPCC, 2001).

While these studies have provided useful insights about the life experiences of disabled children, they have mostly explored children's experiences in terms of likes and dislikes specific to certain current situations. The exception to this is a tool called an image vocabulary, developed by Triangle (Triangle/NSPCC, 2002), which aims to enable children to communicate more complex issues, for instance about feelings and safety. Nevertheless, we still know little about how to obtain the views of disabled children with significant communication impairment on more complex issues, such as what they aspire to achieve and experience, for which there may be no appropriate symbols. There is even less progress made in seeking the views of children/young people with

communication impairment who are also perceived as having learning difficulties (Morris, 2003).

This paper explores the method used in this project to access the views of children who do not use speech to communicate about outcomes they want to achieve through services. The most challenging task has been to find out how to deal with the difficulties of understanding what outcome is. By outcome of a service, we mean the impact or effect on the child's life (Nicholas, 2003), rather than just the provision of service. With outcome being an abstract concept, the question was how to break down the concept to make it easier for the children to grasp it, so that we could go beyond what they liked and disliked to explore what really mattered to them and what they aspired to achieve and experience.

The main methodological issue in working with this group of children is giving them the opportunity to participate. To fulfil our research question the method had to be reliable, non-threatening and an enjoyable experience for the child. It also had to be both concrete and relevant to the individual children being interviewed. In keeping with the principle of inclusivity, another key dynamic was the flexibility of approach so that it could be adapted to different ages, needs and abilities of the children involved in the project. While we used visual techniques when working with all children, we had to use different approaches depending on the children's cognitive and communicative condition.

Development of methods

We adopted the ideas of the 'talking mats' (Murphy, 1998), a visual framework using symbols to help people with communication difficulties to communicate, as a basis from which our research tool was developed. To access children's views about outcomes they wanted to achieve through services, the first task was to identify areas of child's life we would need to cover in the work with children who do not use speech as their first mode of communication. To do that we began with interviewing children with complex health care needs who used speech and were able to fully participate in interviews and their parents. The rationale for starting with this group was that while they had some similarities in terms of their health conditions and contacts with services, they were likely to provide the most depth of information. However we were aware that the issues relating to communication were not likely to come up as much in those interviews. To cover that and also to obtain a deeper understanding of the areas important in the lives of these children we then interviewed parents of children who do not use speech. The data generated from all these interviews then informed the content of and approach taken in interviews with children who did not use speech for communication and, in the majority of cases, had more limited understanding.

The interviews with parents centred around their views on the outcomes they desire from social care/support services for their child(ren). Similarly, interviews with children centred on their hopes and aspirations for their lives. We also asked parents and children (wherever possible) about the kind of help and

support they felt was needed in order to achieve those outcomes. To support participation in direct work with children, we obtained background information about the child's abilities and what facilitated their communication by asking parents to fill in a questionnaire. This showed that the majority of these children were familiar with the use of the Boardmaker symbols, which we then used in our work.

Based on these interviews, we identified eight main themes to explore: communication, friends, school, independent skills, mobility, looking after the child when they are away from their parents/carers, activities and social presentation (the way in which child's appearance and impairment is perceived by the outside world). We asked different questions relating to each theme to know what a child aspired to in different areas and how this related to what they were experiencing currently. Having identified the main themes and the areas we wanted to cover, we again used the interview data to generate statements for each area of the child's life, which represented opposing and ambivalent views, using different characters. For example: based on the area of 'How do I want my doctor to talk to me', the statements were: 'John wants his doctor to talk to him in a way he understands', 'Adam doesn't want his doctor to talk to him' and 'Naeem doesn't mind'.

The interviews were facilitated by using A4 laminated cards. The area of the child's life was presented at the top of the card with an accompanying symbol(s). Symbols chosen were as close as possible to the area of life

represented, but what was most important was the meaning we ascribed to a symbol and the words/phrases which we used to name symbols for the purposes of the interview. We used simple symbols and words.

INSERT FIGURES 1 AND 2 ABOUT HERE

The cards were presented in two forms:

- For some areas, the lower half of the card showed three or four characters (faces and names) – each ‘assigned’ to one of the statements (see Figure 1). The characters changed and the order of the statements/options (i.e. positive, negative, and ambivalent) was varied to avoid any response bias. Every card had an Asian character included. Children were asked which character’s statement was most like them and chose only one statement.
- For other areas, the lower half of the card showed different aspects/sub-areas of the overall area/issue. For example, based on the area of ‘My communication aid’ the statements were ‘Sam wants his communication aid to be faster’, ‘Adam wants his communication aid to be able to say more things’, ‘Naeem wants to be able to use his communication aid wherever he is’ and ‘John wants to have a communication system he can use without help’. Here the child could have multiple choices and take as many statements as s/he wanted (see Figure 2).

We used two sets of A4 cards, a male version and a female version and a mat with the child’s name on to make it more personal, on which the child could stick

their chosen statement, building up a picture of how they would want their life to be. The cards were made colourful to make them more interesting. To engage the children more and make it more interactive we made separate labels for the statements and attached them to the cards using Velcro. This gave a chance to the child to get more involved by taking off his/her chosen statement and sticking it on the mat.

For both types of presentations we had some additional questions to further explore the issue. While for some, depending on their cognitive ability and access to communication systems, this was limited to asking a question like 'is that what it is like for you now?' which only required a yes/no response to find out whether what they wanted was different to what they currently experienced, for others we could ask other questions requiring more detailed responses. We carried extra symbols and blank cards on which we could make instant symbols if needed in such cases. In all interviews we were sensitive to the non-verbal behaviour children used such as facial expression, vocalisation, eye pointing and body movement.

Some of the statements were accompanied by a series of sub statements, for example, going out 'on the bus'. While one card asked whether or not the child wants to go out on the bus, the accompanying card asked who s/he wanted to use the bus with. This was only asked if the answer to the first question was positive.

Using the tool

Characteristics of the children

Eleven children with complex health needs (CHN) and seven children who do not use speech to communicate (NS) took part in interviews. Twenty-six parents of CHN children and 24 parents of NS children were interviewed. The tool was used with seven NS children who were between 6 and 18 years of age. While none of the children communicated using speech, the majority had a number of different impairments including cognitive and/or physical impairments. The group did not include children who could speak but, for whatever reason, chose not to speak, and children whose sole impairment was being deaf. To keep the focus on the issues, which were more specific to communication impairments, we excluded from this group children who were included in the other study groups, that is children diagnosed as having autistic spectrum disorders and children who had degenerative conditions.

Similarly to other researchers (for example, Morris, 2003), while seeking to identify potential research participants we were often confronted with negative attitudes from gatekeepers about the child's communication abilities. We were told statements such as 'he/she is not able to participate', 'you will not get anything out of him/her' and 'there is no point in asking him/her any question, I could tell you everything you would want to know'. We were often told that for children classed as having learning difficulties their level of understanding was too limited for taking part in the research project. However, in keeping with the principle of the social model of disability we identified the research sample by

explaining what taking part in the research involved and discussing how the child would be able to cope with that task. Indeed we later found out that had we gone by the label used for the child, the majority of children we included would have been excluded yet again from research.

In terms of communication, some of these children used technological communication aids (computer assisted system) such as Dynavox communicator, a few used sign language and low-tech aids, such as a talking book or communication board. One used a computer at school and signed at home. All of them relied on more than one method to communicate and used facial expression, eye pointing, body movement and vocalisation.

Managing reliability and level of understanding

The data obtained would only be useful if we could ensure that the children understood the questions and their answers were likely to be reliable. To investigate this we started the interviews with three practical questions, based on the background information we had previously acquired from parents. We used very simple questions (for which we had information from parents on whether the child would be able to answer and in some cases what the child's answer would be) using the same mechanisms as for the main research questions. In the first instance, where we wanted to know whether children were able to use the tool and their answers were factually true, we asked the child how s/he went to school. To test the child's ability to answer the question by picking more than one statement/option, we asked what food he/she would

most want to have for dinner, where they could pick more than one option. To test whether they understood the concept of wanting/aspiring (as against currently experiencing something) we asked them what they would most want to do, making sure their favourite activity was there. If at this stage we were not confident that the child understood the questions and that responses were reliable, we would not proceed any further with the interview. This happened with one of the children we approached. The fact that children used a combination of methods to communicate simultaneously was another means by which we double-checked the reliability of their answers throughout the 'interview'.

Children were interviewed on their own unless it was considered useful to have someone who knew the child well to be present to facilitate communication and/or be there as a support for the child. Child's assent was always obtained in those cases. However, on a number of occasions this person left the interview shortly after it had started because there did not seem to be a need for it any longer.

Prioritising the statements for those with limited attention or ability

A number of things had to be done prior to each interview. For example, we had to change some of the questions to make the cards more relevant to children's individual lives. For example, when the child did not have residential respite but went to a club; we changed the area and statements to what was relevant to the child. Some of the questions were not relevant to some children (e.g. missing

school due to treatments) so we would take them out of the pack before the interview. We also prioritised the cards, to help us in situations where the child was not able to go through all the cards for whatever reason.

Where the interviews took place

Individual interviews with parents took place in their home (with the exception of one), but the interviews with children were held at venues recommended as appropriate for the child by the parent/carer. We visited some children within their family setting, some in respite centres and some in schools where the child was said to have a better access to a communication aid and support. Some interviews were held at school because the child was said to be more alert and responsive in the school environment. Some children/young people were interviewed during weekends, some in the evenings and some during school holidays.

Time taken

The interviews with children took between 45 minutes and one hour 15 minutes. In addition, for every interview, we spent at least half an hour with the child, prior to the interview; in whatever environment the interview was taking place, prior to the interview. This not only maximised the child's confidence to express themselves but also our confidence to understand their way of communication better. Where the interview was in school, we used the opportunity of spending time with the child during the break time.

Reflections/conclusion

Key features of this tool are the ease of use of these cards and particularly the fact that its format is non-threatening for children. Young people found it entertaining and fun and appreciated the interactive aspect of being able to control what they chose in response to the questions. Even where children had limited control over their body movement, as is often the case with those having cerebral palsy, they insisted on taking part in doing the activity. In two cases, the person who was present (in one case the child's mother and in another case the school assistant) helped keep the child's arm up in order to enable them to physically pick their chosen option and place it on the mat. Again, the fact that children simultaneously used a combination of methods to communicate helped us check the reliability of their answer in those circumstances and ensure that the response was not prompted by the helper.

While the technique worked for all the children in relation to finding out their choices, with some children, it was possible to further explore some of their underlying reasons for wanting or not wanting certain things. For example, where one child said she does not use public buses but wants to do so, she told us, using signs, that it is climbing and steps that makes it difficult for her.

We were told, on various occasions, that this was quite a new experience for the child involved because very often a disabled child is not used to having choices or expressing their opinion. For example, in one of the interviews with a child where her support assistant was present, the child looked at the assistant

every time she was asked a question. The assistant commented that this was because they were not everyday questions and the child must be wondering why I was asking these questions from her and not the assistant, because the assistant would know the answers anyway. Later on she told me that this happened all the time and one of their aims in the school was 'to teach children not to rely on other people to speak for them'.

Indeed we felt that this was not just a new experience for children. Some parents and teachers were pleasantly surprised to see the child getting so much involved and expressing choices. One mother (whose child was diagnosed as having severe learning difficulties) told us she never thought her son could concentrate for so long. A teacher who was present in another interview was also surprised when she noticed that one of her pupils was taking interest in the work and paying attention to what was going on and responding so eagerly. Despite all our efforts to ease communication, there were times we encountered difficulties. For example, children refusing to respond because they were in the middle of watching a favourite video or they had an argument with someone or they just felt tired. This was largely overcome by either staying a long time with the child, giving them frequent breaks or making repeat visits (within the resource constraints of the project). In many cases, further information from a parent or carer helped to overcome these problems. It was important to learn from every interview and take this learning into account when planning subsequent interviews.

Comment on wider applicability

The method described here has much wider applicability in both research and practice. It could be expanded and adapted for use in different settings (health, social services, education, and private or voluntary sector agencies) where the professionals want to seek the views, and assess the needs, of children and young people who either do not use speech for communication or use speech in a limited way.

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Figure 1: Example of card used in interviews

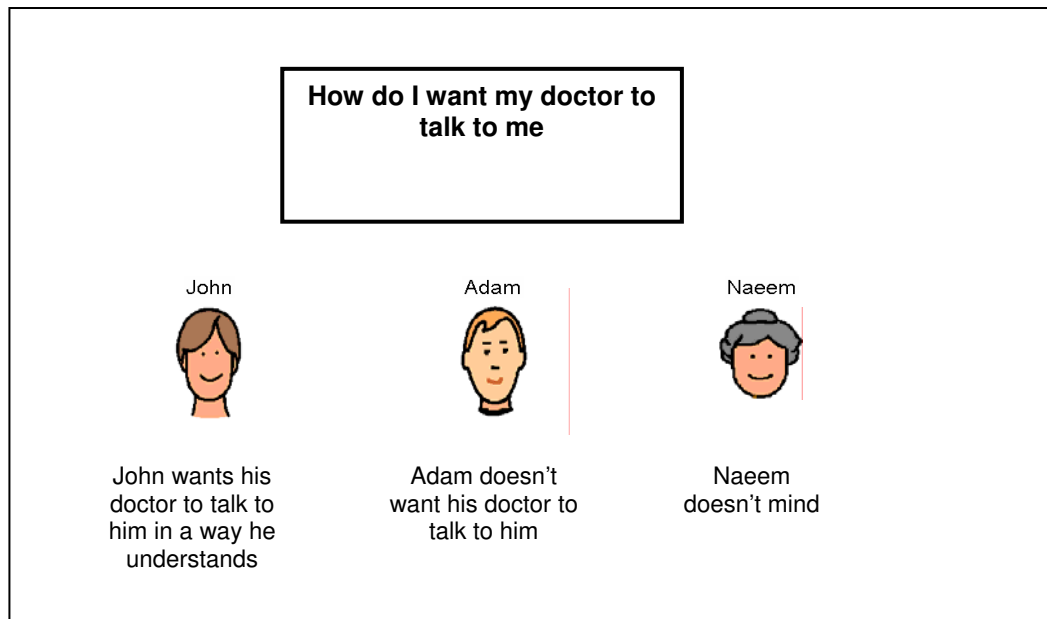


Figure 2: Example of card used in interviews

