

This is a repository copy of *'I know how I feel': listening to young people with life-limiting conditions who have learning and communication impairments*.

White Rose Research Online URL for this paper:
<http://eprints.whiterose.ac.uk/11153/>

Article:

Mitchell, W orcid.org/0000-0002-1608-2368 (2010) 'I know how I feel': listening to young people with life-limiting conditions who have learning and communication impairments. *Qualitative Social Work*. pp. 185-203. ISSN 1741-3117

<https://doi.org/10.1177/1473325009346460>

Reuse

Items deposited in White Rose Research Online are protected by copyright, with all rights reserved unless indicated otherwise. They may be downloaded and/or printed for private study, or other acts as permitted by national copyright laws. The publisher or other rights holders may allow further reproduction and re-use of the full text version. This is indicated by the licence information on the White Rose Research Online record for the item.

Takedown

If you consider content in White Rose Research Online to be in breach of UK law, please notify us by emailing eprints@whiterose.ac.uk including the URL of the record and the reason for the withdrawal request.

‘I Know How I Feel’. Listening to Young People with Life-limiting Conditions who Have Learning and Communication Impairments

Wendy Mitchell

Qualitative Social Work 2010, 9: 185 - originally published online 1 October 2009

Mitchell, W. (2010) 'I know how I feel': listening to young people with life-limiting conditions who have learning and communication impairments, *Qualitative Social Work*, 9, 2, 185-203.

This is an author produced version of the article published. This paper has been peer-reviewed but does not include the journal pagination.

Link to the online version: <http://qsw.sagepub.com/content/9/2/185>

DOI: 10.1177/1473325009346460

Abstract

UK government policy advocates involving children in decisions about their lives. However, disabled children are often marginalized and not consulted, especially those with learning and communication impairments. Drawing on an ongoing English Government funded longitudinal study exploring different groups of service users' choices, this article demonstrates the important contribution that qualitative research methods, especially non-traditional methods, can procure when working with young people who are nonverbal or have limited speech. Working with young people with life-limiting conditions raises some specific challenges for researchers. Here, adapting project wide materials and research methods in order to gain some thematic continuity across different service user groups. Some of these considerations and challenges will be discussed, especially the development of non-verbal forms of communication (talking matsTM). Practical experiences, both positive and negative will be examined. The article concludes by considering some wider implications of using symbols based methods for future research and how these methods can be used across disciplines and by practitioners in their everyday work.

Keywords

Young people with learning and communication impairments, non-verbal research methods, participation, longitudinal research, talking matsTM

Introduction

Listening to young people, including those with learning and communication impairments is part of wider theoretical and policy developments surrounding the concept of ‘participation’ and the general aim to involve children in decisions about their lives. The move towards greater participation has come from a range of developments. These include, UK based legalisation and policies advocating greater rights for children and setting targets for governments to meet, such as the English National Service Framework for Children, Young People and Maternity Services (NSF) (2004) and Children Act (1989 and 2004) and internationally, the United Nations Convention on the Rights of the Child (1989, especially Article 12). There have also been theoretical developments surrounding childhood within which children are viewed more positively, as competent and knowing social agents rather than passive and incompetent dependents of adults (Hill et al., 2004; Mayall, 2006; Sinclair, 2004; Swallow et al., 2007). In addition, there has also been a wider general trend and policy focus towards prioritising experience, especially consumer based knowledge when planning services (Nolan et al., 2007; Sinclair, 2004). Facilitating participation is viewed positively as leading to a number of potential benefits for both children and wider society, for example, personal self-development and confidence building, consumer gains with more relevant services, political ideas of citizenship and increased social inclusion and finally, epistemological developments, especially, understanding children and childhood (Cavet and Sloper, 2004; Sinclair, 2004).

However, the concept of participation remains controversial with numerous models advocated and within this many different levels and/or types of participation discussed. The most frequently used typology is based on a continuum with progressive participation from

consultation through to collaboration and finally, user control. One of the earliest models is Arnstein's (1969) 'ladder of participation'. However, hierarchical models such as Arnstein's 'ladder' are based on adult participation and thus not always appropriate for children. Other theorists, such as Hart (1997) have developed child based hierarchies. More recently a children's 'Participation Charter' (2007) has been developed by a range of UK based children's statutory and voluntary organizations.

Participation in practice

Past UK based literature has demonstrated that children and young people have increasingly been involved and consulted by policy makers and researchers in a range of areas and over different issues in their lives, such as leisure facilities and health and social care services (Cavet and Sloper, 2004). Some innovative practice clearly exists, however, it is apparent that gaps have frequently emerged between theoretical developments and policy guidance and everyday practice (Hill et al., 2004; Swallow et al., 2007). This can occur in a number of different ways, for example, in the degree to which children participate. Many projects focus on consultation with limited collaboration or progression to user involvement. A number of theorists argue there is a need to move beyond this, from 'representative' to 'participatory' democracy (Cairns, 2006; Hill et al., 2004; Tisdall and Davis, 2004). However, one must avoid, as Nolan et al. (2007) and Sinclair (2004) suggest, the presumption that 'top level' participation (i.e. user control) is always the best or most appropriate option. In some situations, young people may prefer a more gradual approach or may not want to participate. How children experience participation is also important, past literature has highlighted that participation can be viewed as tokenistic and even potentially negative if children are not kept informed, especially after their views have been sought. Reporting back to participants any

action taken or outcomes achieved demonstrates the value attached to their participation (i.e. adults have taken them seriously) (Prout and Tisdall, 2006; Cavet and Sloper, 2004; Sinclair, 2004).

Gaps between participatory ideals and practice are often accentuated by the legal ambiguity and confusion surrounding issues such as adult status (when does adulthood begin?), competence (to participate and/or make decisions) and providing consent (informed consent). Different pieces of UK legislation provide different or unclear guidance, which can, at times conflict (see Mental Capacity Act 2005; NSF 2004; Children Act 1989). In addition, there are complex and much debated tensions surrounding children's' right to participate versus associated responsibilities, and for adults, there are potential tensions reconciling children's' right to participate with their right to protection. This is particularly pronounced for practitioners with a 'duty of care' (Cousins and Milner, 2008; Murray, 2005). Within these tensions, there are also issues of power, not only general child versus adult inequalities but also how power is perceived. If power is viewed as 'zero sum' and either/or, this may hamper participation with adults fearing increased participation for children as a potential challenge to and reduction of their own power (Davis and Hill, 2006; Hill et al., 2004; Prout and Tisdall, 2006).

Such complexity and potential controversy surrounding children's' participation has led to certain types of children in the UK being involved more than others, particularly older, more vocal and socially confident young people who are most likely to be viewed as competent. Other groups, such as younger children, children from black and minority ethnic families and

disabled children have received less attention (Cavet and Sloper, 2004; Franklin and Sloper, 2006, 2008; Hill et al., 2004). The exclusion of these groups, especially disabled children has arisen as Franklin and Sloper (2008) note, from a range of practical problems and considerations. For example, a 'standard' approach and/or tools are frequently inappropriate, listening to disabled children can take time and negotiating access may involve a range of adults, not only parents/carers but also professionals. Issues of additional time, resources and knowledge often underpin these problems and will be discussed further in the article.

The need to redress this marginalization of some children, especially disabled young people, is important as their views are frequently lost. Children and young people are a heterogeneous group. Disabled children may face different life experiences and may have different needs, wishes and expectations compared to their able bodied peers (see Every Disabled Child Matters campaign¹). This article seeks to begin to redress this gap by exploring how young people with learning and communication impairments can be listened to using a range of verbal and non-verbal methods. Drawing on research experiences from an ongoing project in England, the paper initially explores how a range of appropriate tools were developed and then discusses some of the issues that arose during the process of listening to participants and how these were addressed. The article concludes with some lessons learnt and considers the implications of these for practitioners, in particular, how Talking MatsTM can be used in everyday practice when working with young people with learning and communication impairments.

The Choice and Change Project

Research with young people with learning and communication impairments was conducted as part of a wider ongoing longitudinal study (Choice and Change project). The study examines the choices made by three groups of people (adults and older people with fluctuating or sudden onset conditions, and young people with progressive medical conditions and their families) about their support and other related services over a three-year period (2007 to 2010). The study explores similarities and differences across the three groups in their experiences of choice making and, as the study is longitudinal, some of the consequences of these choices for participants and their families. This article focuses on the first round of interviews conducted with a sample of 27 young people with a life-limiting condition recruited from two children's hospices. The overall sample of 27 young people (communicating verbally and non-verbally) varies in terms of gender, age (13–21 years), ethnicity (white British and British Pakistani) and type of disability (<http://www.york.ac.uk/inst/spru/research/summs/DHPpanel.html>). For some (sub-sample of 12) who had learning disabilities and/or communicated non-verbally, semi-structured interviews were inappropriate, non-traditional methods were developed and used with these young people.

Adapting Materials

To facilitate group comparisons, project wide materials were produced; information sheets, consent forms and a core semi-structured topic guide. For the young people these materials were generally inappropriate and a separate consent sheet and two information sheets were developed based on the written word (the value of developing different materials for children is also noted by Kelly, 2007; Stalker and Connors, 2003). These were generally shorter, more

focused and used simple, direct language. The first information sheet was for older young people and the second being even shorter was more appropriate for younger members of the sample and for those with some learning impairment. To make the information accessible to as many young people as possible, symbols based information and consent forms were also developed. Recognizing that different young people use different symbols, two diverse symbol systems (WidgitTM and BoardmakerTM) were chosen following consultation with hospice staff and the researcher's previous experience of what young people find easy to understand, colourful and age appropriate. Separate information packs were sent to young people and parents, hospice staff sent out symbols based information when relevant.

Short questionnaires were used to collect socio-demographic information from each participant. For the young people, a cartoon based 'All About Me' booklet was developed. The researcher and young people with learning disabilities and/or those who communicated non-verbally completed this booklet before each interview. The booklet, as Kelly (2007) has noted in her research, was a positive experience and provided an important 'ice-breaker'. It brought an element of fun to the first meeting and each young person enjoyed receiving a completed copy. More importantly, it boosted confidence demonstrating to the young people (and their parents) that they 'could' answer my questions. For the researcher, it provided important background information and enabled a quick assessment of each young person's preferred mode of communication and their level of understanding in an unobtrusive and relaxed manner.

The standard adult topic guide was also adapted for young people to a shorter version with more focused and direct questions but generally followed the same overall sequencing of

choice topics and areas within the wider study. Verbal young people were interviewed first. After interviewing a couple, it was apparent that the general young people's topic guide was too long and complicated for the younger members of the sample (13–16 years) and those with some learning impairment. A simpler verbal version was developed focusing on key questions identified from the older verbal young people's interviews.

Talking Mats™

Drawing on experiences from interviewing the verbal young people, 16 specific and simply worded questions were developed and a range of appropriate symbols identified as potential responses. These questions were used as the foundation for a series of Talking Mats™ based on the Boardmaker™ symbol system. Participants were asked questions and invited to choose the symbol(s) that matches their ideas and/or emotions. Each participant created their own symbols board. Talking Mats™ were initially developed in the UK by Murphy (Murphy, 1998) and have subsequently been used for both adults and young people with learning and communication impairments (Cameron and Murphy, 2002; Murphy et al., 2005). Whitehurst (2006) and Rabiee et al. (2005) have also used them with disabled children.

A range of non-verbal methods, such as drawing, sentence writing, time lines/charts, photographs, working with puppets and role play (Kelly, 2007; Participation Works, 2008) have all been used with varying degrees of success by researchers and practitioners working with children, especially children under seven years and disabled young people. However, Talking Mats™ were felt to be the most appropriate method for this study. Practically, colleagues (Rabiee et al., 2005) had successfully used them with children with

communication impairments, and important lessons had been learnt and shared (such as the pacing and sequencing of questions). Other methods, such as drawing and sentence completion were considered inappropriate for the young people in the sample due to levels of understanding and/or restricted physical movement that made drawing difficult. It was also important to avoid childish and patronising methods as many participants were young adults, Talking Mats™ and the symbols chosen were all age-appropriate (see also Cameron and Murphy, 2002). In addition, Murphy (1998), Whitehurst (2006) and Rabiee et al. (2005) have demonstrated Talking Mats™ flexibility and ability to be used in conjunction with other communication systems; they aid rather than dictate the communication preferences of participants.

Practical issues (time delays and a limited pool of young people) prevented piloting with young people from hospices and so the Talking Mats™ were piloted with six four-year old children whose level of comprehension and concentration was similar to many of the young people with pronounced learning impairments in the study sample. Twelve young people were interviewed with the aid of Talking Mats™ and all engaged with the symbols. They liked their colourfulness and, appeared to enjoy choosing them and creating their own board. The flexibility of Talking Mats™ was particularly useful as the young people had very different learning and communication impairments. For example, some young people were able to choose from up to 12 symbols whereas, others focused on 2 or 3. The choice was made through a range of preferred communication modes, including verbalizing, eye-pointing, signing, and moving an arm/hand or facial expressions. Each interview was personalized with the aid of the ‘All about Me’ booklet and the background information it

provided. For example, the researcher used the name of relevant people, places or things, this clearly aided understanding amongst the young people.

Issues arising

Working with and acknowledging the role of ‘others’

Past literature has discussed how research involving young people frequently involves negotiating access via adult gatekeepers, such as professionals and parents (Cousins and Milner, 2008; Kelly, 2007; Ware, 2004). This is a complex area due to issues of confidentiality and the need for parental consent (for minors) and is further complicated by the social and legal ambiguity that surrounds adult status in the UK (for a general discussion, see Morrow and Richards, 1996; Mayall, 1994). For young people with learning and communication impairments there is the additional issue of competence; perceptions of their competence or lack of competence and ability to make informed decisions surrounding consent (Alderson, 1995; Cousins and Milner, 2008).

Gaining a sample of young people involved working closely with hospice staff in order to avoid insensitive invitations, to respect family privacy and protect confidentiality. Some parents felt that their son/daughter would not be able to participate as they were either non-verbal or had a pronounced learning impairment. To try and allay parental fears, the researcher carefully explained the project and the use of symbols based research tools, with the result that a number of parents reconsidered and agreed for the researcher to meet their son/daughter. Some parents were anxious that their son/daughter would not provide ‘appropriate’ data for the researcher fearing it would therefore be a negative experience for

both parties. This fear highlights a number of wider issues and social presumptions. For example, these parents had infrequently experienced practitioners seeking to involve and listen to their son/daughter using nonverbal methods. It also demonstrated that parents can have set ideas about what type of data is required by researchers and valued as ‘knowledge’, largely premised on academic, scientific ideals (for a wider discussion, see Aldridge, 2007; Nolan et al., 2007; Ware, 2004). Spending time talking to parents, allaying fears and validating the knowledge that their son/daughter could provide was an important part of the negotiating process.

Providing opportunities for parents and/or carers to be present when the researcher met the young people was also welcomed by both parents/carers and young people. Ten out of 12 young people were interviewed with a parent(s) present and the remaining two with a carer. This was advantageous for the researcher as parents/carers provided both background information and had invaluable interpretative skills, especially when participants used personalized and/or indistinct modes of communication, such as facial expressions or thumb movements. Parents/carers presence also reassured many of the young people. However, it is recognized that the presence of others, especially parents/carers can influence the context and dynamics of interviews. In this instance, factors influencing included how the young people responded, the type of questions the researcher felt able to probe, particularly questions about parents’ roles in choice making and young people’s feelings about this, and parents/carers directly contributing by ‘chipping in’ or suggesting responses for the young person. However, during the fieldwork process it was apparent that actively involving parents whilst using the Talking MatsTM could help to diffuse the situation. When parents were asked to hold-up the mats, they were less vocal but still present and thus able to provide support for their

son/daughter and also the researcher. Parents/carers were thus ‘steered’ to a more active role whenever possible. Similar ‘presence’ problems have been discussed by Cameron and Murphy (2006) and Ware (2004) and will continue to remain debated issues. Open and honest recognition of the potential role of others is required.

It is also important to acknowledge different types of data and their limitations. The symbols based Talking Mats™ data is very different in both depth and scope to that gleaned from the more traditional semi-structured interviews conducted with the verbal young people (and also adults and parents in the wider study). For example, it must be acknowledged that the young people chose from a set of symbols the researcher had previously identified. This was necessary due to level of understanding amongst the young people. Although the researcher strove to develop a comprehensive set of symbols based on the experiences of the verbal young people in the project, this approach clearly has its limitations, as the symbols may not necessarily reflect the diverse life experiences, situations and feelings that a group of young people can experience. Recognizing this, the researcher is faced with an ongoing dilemma, how to balance the need for concrete examples and guidance when working with young people with learning impairments, while also trying to be sensitive to individual life situations and experiences. Once again, the personal background data provided by their ‘All About Me’ booklet was helpful and enabled the researcher to focus on certain groups of symbols. In addition, the researcher encouraged young people, whenever possible, to suggest other symbols if they felt they were important and/or relevant. Although very few young people actually did this, if alternative ideas were suggested these were captured as data even if they did not appear on the mat as the researcher was providing a running commentary of the interview (which was being audio recorded). Having a recorded account of each interview thus provided additional information for the researcher, especially when listening to the interviews at a later date.

The potential for biased and confusing data has been frequently noted when working with people with learning impairments (Sigelman et al., 1981), for example, in terms of inconsistent responses, a tendency for participants to choose positive options and acquiescence, most notably choosing what is thought to be the ‘right’ answer. However, problems with ‘the right’ answer are endemic in any research, irrespective of the type of participants. Acknowledging the potential for inconsistency and confusion, the researcher sought to continually clarify each respondent’s reply and if responses remained contradictory, these data were treated with caution (see also Rabiee et al., 2005). The researcher strove not to place her own interpretation onto the data. Recognizing these issues does not devalue the importance and validity of the symbol based data but it does highlight the need, when reporting the data, for researchers to make it very clear what type of data is being provided and presented to the reader, a point also made by Ware (2004). Acknowledging this difference and diversity among the data gleaned was particularly important in this study as it sought to compare the ideas and experiences of not only young people with life-limiting illnesses but also groups of people with very different ages, disabilities and life experiences.

Importance of flexibility

As noted earlier, developing specific and relevant materials for chronically ill young people, especially those with learning and communication impairments, within a wider verbally based study was a cumulative learning process for the researcher. The researcher drew on both past and current research experiences of working with disabled young people and listening to the verbal young people participating in the current study was also an important part of the process.

Developing a range of different research tools that could be used with or without symbols, enabled the researcher to develop a flexible approach and a more personalized, choice oriented interview context for the young people. Each participant could choose the method they preferred or felt most appropriate to meet their needs and/or preferences. For example, one young person felt the Talking MatsTM would be 'babyish' on the telephone but when he saw the symbols and the fun nature of the boards, changed his mind. Similarly, having a range of options available gave the researcher flexibility to be more inclusive. Speaking to two young people on the telephone, both appeared verbally competent, however, on meeting the young people it was apparent that their level of understanding and verbal communication was less than initially presumed, the verbal topic guide was inappropriate and the talking matsTM were more relevant.

The importance of flexibility has also been noted by Kelly (2007), Ware (2004) and Whitehurst (2006). Here, the Talking MatsTM were particularly useful when young people had a limited concentration span as they allowed the researcher to pause an interview as and when necessary, for example, for personal care breaks or when a young person wanted to do something else, such as listening to their music or showing the researcher favourite pictures or photos (see also Cameron and Murphy, 2002). As each young person developed their own mat, the researcher had a visual record of their meeting and so the board could be put down and then picked up again with relative ease, recapping was easy as the symbols provided an accessible summary. Identification of priority questions was also useful when the researcher felt a young person's concentration span was limited and a clear focus was required.

The longitudinal nature of the study similarly aids a flexible approach as the researcher has time to develop appropriate research tools and utilize ongoing learning opportunities in future meetings. For example, taking a photograph of each personal mat and sending a copy of this to each participant could be developed in the next round of interviews. This reiterates the importance of time, working with young people with learning and communication impairments takes time; it is ideally not a 'one off' encounter (see also Cameron and Murphy, 2006; Franklin and Sloper, 2008; Kelly, 2007).

Recognizing power inequalities

The issue of power within qualitative research between participants and researchers has been much discussed, especially within feminist research (Oakley, 1981; Stanley and Wise, 1993). Power is frequently present in any research encounter with the researcher in a relatively more powerful and controlling (or viewed as more powerful by participants) position. This is further complicated by wider socio-legal perceptions of 'competence' and who is viewed as 'competent'. Disabled young people, especially those with learning and communication impairments are frequently viewed as 'incompetent' or 'unknowing' and this can have a negative effect on their inclusion and perceived ability to participate in research. Associated to this, issues of 'informed consent' are much discussed (Cameron and Murphy, 2006; Cousins and Milner, 2008) and it may, as Whitehurst (2006) notes, be more realistic to talk in terms of young people with learning impairments 'assent' rather than 'informed consent'. Information may be provided in accessible formats, but how much and how far participants feel informed or appreciate the implications of participation frequently remains unknown, especially when working with young people with learning and communication impairments.

The researcher was also very aware of power inequalities and realistically, the limited opportunities to create an equitable relationship and interview context, especially, as the parameters of the research were set within a wider project. However, steps were sought to provide opportunities for participants to take a more dynamic role. For example, young people were given red and yellow cards to hold up if they wanted to take a break (yellow) or stop (red) the interview at any time. These are small steps but it is important to recognize that young people are not passive and could exert some control through the very act of non-participation. Some young people initially chose not to participate and two young people decided not to participate on the day the researcher met them. This was communicated in two very different ways, one young person asked his parents to inform the researcher of his decision and the other, adopted uncommunicative body language, ignoring the researcher when she arrived at his house. These acts are viewed as positive developments (see also Cameron and Murphy, 2006) as both young people felt able to say 'no'. They also demonstrate the importance of providing opportunities for participants to say 'no' verbally and also the need for researchers to be sensitive and receptive to body language. The researcher felt that this presented 'power' in a more positive, productive and shared manner compared to the more traditional view of power noted above as 'zero sum' (Davis and Hill, 2006; Hill et al., 2004; Prout and Tisdall, 2006). The researcher made a point of positively reinforcing the young people's choice not to participate.

Discussion and concluding comments

As noted in the introduction, current policy both international and UK advocates young people's participation. Listening to young people's ideas and experiences is viewed as both ethically important and practically advantageous in terms of informing policy and practice.

However, the concept of participation is complex and controversial; unanswered questions remain as rights bring responsibilities for both young people and adults, the boundaries of which are often unclear regarding how to, and how far to involve young people in practice (Franklin and Sloper, 2008; Hill et al., 2004; Sinclair, 2004). In addition, although policy makers and practitioners in the UK have sought to involve and consult young people it is clear that this participation has focused on certain types of young people and excluded others. Disabled young people, especially young people with learning and communication impairments are one of these groups. Past UK based literature has indicated that this exclusion results from a number of factors, including a lack of practitioners' confidence, knowledge, time and resources (Cavet and Sloper, 2004; Franklin and Sloper, 2006, 2008; Hill et al., 2004). It is often easier and quicker to consult young people without learning and communication impairments. However, this article has demonstrated that young people with learning and communication impairments can express their ideas and feelings with the aid of non-verbal communication techniques.

Researcher Lessons Learnt

Working with young people with learning and communication impairments has identified a number of important practical and theoretical issues. The lessons learnt, as discussed below, appear to have a wider applicability and raise some interesting considerations for the future direction of research, particularly with young people with learning and communication impairments. However, it is important to acknowledge that these conclusions are based on a specific longitudinal project and the ideas and experiences of one researcher. The method discussed (the development and use of Talking MatsTM) is only one of many potential non-verbal methods. As noted earlier, other non-verbal methods have been used successfully by

different researchers and with different groups of disabled children. Indeed, one particular approach, the 'Mosaic Approach' has gained much credence (Clark and Moss, 2001; Clark and Statham, 2005). The Choice and Change project clearly focused on a very precise group of young people 13 to 21 years with life-limiting and progressive conditions. A different group of disabled and/or chronically ill children may have raised different issues for the researcher; the importance of context and the potential heterogeneity of disability is acknowledged.

Despite this, three issues appear particularly relevant when seeking to listen to young people with learning and communication impairments:

A range of research tools

The importance of developing a range of research tools for those seeking to listen to young people with learning and communication impairments to draw on, as and when appropriate. Moving beyond, as previous literature has similarly noted (Clark and Statham, 2005; Cocks, 2008; Franklin and Sloper, 2006, 2008; Kelly, 2007; Stalker and Connors, 2003), the idea that 'one standard fits all'. Here, development was a cumulative process with the researcher learning from ongoing research experiences and listening to participants, for young people with learning and communication impairments this includes non-verbal communication, especially body language. Within this tool kit, Talking MatsTM were particularly useful, providing a flexible and adaptable mode of communication for both the researcher and participants; they could be used with or alongside the simple topic guide or as a standalone

tool. They also enabled participants to communicate in their preferred manner (Murphy et al., 2005).

Spending time with participants

Issues of time (especially a lack of time) are important and often problematic in any research. Time is frequently a luxury that researchers, particularly contract researchers do not have. Juggling the demands of funders and their priorities/ requirements (especially financial) with a desire to produce 'good' quality research which meets the needs of participants can be challenging. Working with disabled young people brings this to the fore. The importance of time has been previously noted when seeking to involve disabled children (Franklin and Sloper, 2006, 2008; Kelly, 2007) and this article has demonstrated that this is particularly important when working with young people with learning and communication impairments, listening to and beginning to develop a rapport takes time. However, in this study, the benefits of longitudinal research are also apparent. As this study is ongoing the researcher will be able to reflect on previous interviews, refine communication skills and rapport over an extended period. Issues that were unclear, needed confirmation or verification can be pursued in later interviews. Longitudinal research has enabled the researcher to begin to identify areas of interest and themes to develop and, conversely, to identify potential gaps or areas not previously considered that can be followed up in subsequent meetings. The importance of researchers developing their own confidence and knowledge has been similarly noted by the Council for Disabled Children in the UK (CDC, 2000).

Different types of knowledge and levels of data

Working with a diverse range of young people, both verbal, and non-verbal led to data varying in presentation and depth. The Talking Mats™ provided very different data to the more traditional semi-structured interviews conducted with the verbal young people and also adults, parents and older people in the wider study. Recognizing and being clear that the data provided by diverse groups can differ is important. The verbal young people's topic guide data was analysed alongside the data gleaned from the adults in the wider study by a qualitative computer-assisted package (MAXqda) and then compared. This was not appropriate for the young people's symbols based data. The symbols based data was analysed more simply and presented separately. Comparisons were made where possible but the data's limited depth and scope was noted by the researcher. Despite this difference, the symbols data provided important insights into the lives and prioritisations of a previously marginalised group. The symbols based data may not have provided as much detail as verbally based data but this should not detract from its value. Indeed, when project results are written up, data from both verbal and non-verbal participants will be included, albeit presented differently. Dissemination to participants will also include a summary sheet using Boardmaker™ and Widget™ symbols presenting the ideas of the young people with learning and/or communication impairments.

Recognizing this difference in data types and depth is important and demonstrates the need to move beyond and also challenge traditional scientific ideas of knowledge and what is deemed 'appropriate' and 'acceptable' knowledge (see also Aldridge, 2007; Cocks, 2008; Nolan et al., 2007; Ware, 2004). Presumptions clearly persist, as parents' initial concerns surrounding

some young people with learning and communication impairments ability to participate and provide 'adequate' research data demonstrated.

Some implications for practitioners and future considerations

Talking Mats™ have potential advantages for health and social care practitioners in their everyday work with young people with learning and communication impairments seeking to work in a multidisciplinary context. Although the focus of this article has been on working with young people, Talking Mats™ have a wider applicability and as noted earlier, they have been successfully used with adults with communication impairments (Murphy et al., 2005). Indeed, within the Choice and Change project, a series of Talking Mats™ (based on those prepared for the young people) were developed by a colleague to aid communication with adults and older people who had a range of communication impairments resulting from strokes and brain injury. The ability of Talking Mats™ to meet the communication needs of a diverse range of people from different sectors of the population could be particularly useful for practitioners working with both adults and children. Talking Mats™ can also be used in a variety of settings from participants' homes and community spaces to more formal contexts such as meetings and schools. They are easy to set up and transport (see also Murphy et al., 2005). In addition, they are also relatively cheap and easy to develop; symbols and boards can be created by practitioners. More complex computer based versions can be developed utilising the ever expanding range of information technology (IT), such as computer based touch screens. However, it is recognized that resources are frequently limited for health and social care practitioners and levels of IT skill and confidence vary amongst practitioners. Despite this, important lessons could be learnt from teachers' use of computer based

whiteboards in schools, where their interactive use with pupils has become a common phenomenon.

Past literature (Cavet and Sloper, 2004; Franklin and Sloper, 2006, 2008) has highlighted a lack of multidisciplinary working and practitioner training as ongoing barriers to involving disabled children in decision making processes. Talking Mats™ could aid cooperation and communication between health and social care practitioners, especially social workers and speech and language therapists, with the latter providing training and advice for colleagues in social work. This is particularly pertinent as current English health and social care policy advocates the development of shared information and assessment processes such as the Common Assessment Framework² (CAF) and Integrated Children's System³ (ICS). Talking Mats™ provide an easy to use tool for health and social care practitioners. After meeting a young person, practitioners can capture and summarise young people's ideas in a photograph of their personal board. This photograph not only records the young person's ideas in an accessible manner for them, it also provides an additional information tool for practitioners to share. Video recording Talking Mats™ interviews is another option, as Murphy et al. (2005) note, this enables observation of non-verbal cues. Talking Mats™ also provide a quick way to recap on prior meetings with young people, for example, recreating previous boards or if recorded, watching the meeting. For the young person, this provides a visual and concrete reminder of the past meeting and for the practitioner, a useful starting point and source of comparison for current discussions.

Talking Mats™ are thus part of a wider process that seeks to encourage thinking beyond traditional social presumptions, for example, the idea that one standard approach to

communication or output (i.e. verbally produced interview data) is frequently the best or most appropriate. Many health and social care practitioners in the UK clearly recognize the importance of listening to clients with learning and communication impairments. However, they may feel thwarted in practice by conflicting prioritizations and the need to meet official targets. As noted above, listening to young people with learning and communication impairments takes time but assessment processes are often time limited and do not take account of the extra time needed to work with young people with learning and communication impairments, a factor recently noted by social workers piloting the ICS in England and Wales with disabled children and their families (Mitchell and Sloper, 2008). In addition, as Ware (2004) notes, many young people lack participatory experience, not knowing how to express their views. Social workers may have to spend time teaching them. Talking to verbal participants or family members is often quicker and easier for time limited practitioners seeking to meet the demands and non-disabled expectations of 'official' targets.

A number of UK based charities working with disabled children have produced resources packages and advice on how to communicate with children with learning and communication impairments (for example, CDC, n.d.; Participation Works⁴, 2008). Indeed, Talking MatsTM have their own website (<http://www.talkingmats.com>); however, practitioners' knowledge of these resources is often patchy. Within the ICS evaluation, very few social workers working with families with disabled children knew of these resources or how to access them (Mitchell and Sloper, 2008). Raising awareness remains an area requiring further development.

There is also issue of power (Davis and Hill, 2006; Hill et al., 2004; Prout and Tisdall, 2006). If power is viewed as either/or, practitioners may be reticent to give young people more

power, equating this to a reduction in their own power or control. Talking Mats™ may help to demonstrate to practitioners that sharing power with young people (especially young people with learning and communication impairments) and their families does not necessarily need to challenge their status as practitioners or adults. The creation of personal boards for young people can be a positive experience for both parties, sharing responsibility and the end product, i.e. an informative board. However, it is important to remember that the development and everyday use of non-verbal techniques by practitioners does not occur in a vacuum.

Policy makers and health and social care managers need to help facilitate a context within which practitioners feel confident and able to spend time listening to young people with learning and communication impairments and that the data that they collect from these young people although it may be very different to that gained from verbal young people is still valued. These are clearly complex practical and theoretical developments that require shared knowledge and goals in order for change to occur on all levels: policy, management, practice and research. Indeed, although practitioners and researchers may frequently view their roles very differently, this paper has demonstrated that they both face the potential problem of ‘dualism’ when working with young people with learning and/or communication impairments, i.e. trying to facilitate opportunities for these young people to express their ideas and for others to hear them but facing ongoing problems and barriers. Hence, despite the best efforts of the researcher in this study, it is acknowledged that the young people’s input remains partial and their voices mediated through the researcher and often their parents/carers. Questions can be raised concerning the depth, privacy and accuracy of the data gleaned, especially by policy makers requiring ‘hard’ or large-scale data. However, this

article has also sought to highlight the potential of longitudinal research with young people with learning and/or communication impairments. Longitudinal research does not overcome the problem of ‘dualism’ but it does provide an opportunity for researchers to sensitize and accommodate themselves to the aforementioned problems and thus begin to seek ways to address them. Despite this potential, longitudinal research remains underutilized, often due to practical problems of funding and the investment of time it requires, especially with disabled young people. However, the value of involving young people with learning and communication impairments within research, especially longitudinally may be more clearly recognized as the profile of disabled children continues to be raised by the ongoing English Every Disabled Child Matters Campaign.

Notes

1 Every Disabled Child Matters – English based campaign to develop current Government policy (Every Child Matters – ECM) prioritising disabled children. ECM is a national framework developing joined-up children’s services across different departments.

2 CAF – a standardized assessment process enabling different groups of practitioners to assess children using a shared assessment form.

3 ICS – single approach to assessment/review for all ‘children in need’ (including disabled children) based on electronic recording and information sharing among different groups of practitioners.

4 Participation Works – a consortium of six UK voluntary and statutory organizations.

Acknowledgements

This article is based on a presentation given at the Logic and Methodology in Sociology conference, International Sociological Association in Naples, 1–5 September 2008. The author would like to thank all the young people and their parents participating in the study, without their time and patience this paper would not have been possible and also Professor Tricia Sloper for her advice and helpful comments. The author would also like to thank the Choice and Change research team: Hilary Arksey, Kate Baxter, Caroline Glendinning, Janet Heaton and Parvaneh Rabiee. The research is funded by the English Department of Health; however, the views expressed here are those of the author and not necessarily those of the funders.

References

- Alderson P. (1995) *Listening to Children: Children, Ethics and Social Research*, London: Barnardo's.
- Aldridge J. (2007) 'Picture This: The Use of Participatory Photographic Research Methods with People with Learning Disabilities', *Disability and Society* 22: 1-17.

Arnstein S. (1969) 'A Ladder of Citizen Participation in the USA', *Journal of the American Institute of Planners* 35(4): 216-224.

Cairns L. (2006) 'Participation with Purpose' in E.K. Tisdall, J. Davis, M. Hill and A Prout (eds), *Children, Young People and Social Inclusion: Participation for What?* Bristol: Policy Press.

Cameron L. and Murphy J. (2006) 'Obtaining Consent to Participate in Research: the Issues Involved in Including People with a Range of Learning and Communication Disabilities', *British Journal of Learning Disabilities* 35(2): 113-120.

Cameron L. and Murphy J. (2002) 'Enabling Young People with a Learning Disability to Make Choices at a Time of Transition', *British Journal of Learning Disabilities* 30(2): 105-112.

Cavet J. and Sloper P. (2004) 'The Participation of Children and Young People in Decisions about UK Service Development', *Child: Care, Health and Development* 30(6): 613-621.

Clark A. and Statham J. (2005) 'Listening to Young Children: Experts in Their Own Lives', *Adoption and Fostering* 29(1): 45-56.

Clark A. and Moss P. (2001) *Listening to Young Children: The Mosaic Approach*, London: National Children's Bureau.

Cocks A. (2008) 'Researching the Lives of Disabled Children: The Process of Participant Observation in Seeking Inclusivity', *Qualitative Social Work* 7(2): 163-180.

Common Assessment Framework <http://www.everychildmatters.gov.uk/deliveringservices/caf/> (website accessed on 15/05/08).

Council for Disabled Children (2000) *Quality Protects: Second Analysis of Management Action Plans with Reference to Disabled Children and Families*, London: Department of Health.

Council for Disabled Children <http://www.ncb.org.uk/Page.asp?sve=785> (website accessed on 15/05/08).

Cousins W. and Milner S. (2008) 'Small Voices: Children's Rights and Representation in Social Work Research', *Social Work Education* 26(5): 447-457.

Davis J. and Hill M. (2006) Introduction, in K. Tisdall, J. Davis, M. Hill and A. Prout A (eds) *Children, Young People and Social Inclusion: Participation for What?* Bristol: Policy Press.

Department for Constitutional Affairs (2007) *Mental Capacity Act 2005*, London: The Stationery Office.

Department of Health (1991) *The Children Act 1989 Guidance and Regulations: Volume 6 children with Disabilities*, London: Department of Health.

Department of Health/Department for Education and Skills (2004) *National Service Framework for Children, Young People and Maternity Services: Disabled Children and Young People and Those with Complex Health Needs*, London: Department of Health.

Every Disabled Child Matters (2007) *Disabled Children and Child Poverty – Briefing Paper*, Contact a Family, Council for Disabled Children, Mencap, Special Educational Consortium, London.

Franklin A. and Sloper P. (forthcoming) 'Supporting the Participation of Disabled Children and Young People in Decision-making', *Children and Society*.

Franklin A. and Sloper P. (2006) 'Participation of Disabled Children and Young People in Decision Making Within Social Services Departments: A Survey of Current and Recent Activities in England', *British Journal of Social Work* 36(5): 723-741.

Hart R. (1997) *Children's Participation: The Theory and Practice of Involving Young Citizens in Community Development and Environmental Care*, New York: Unicef.

Hill M., Davis J., Prout A. and Tisdall K. (2004) 'Moving the Participation Agenda Forward', *Children and Society* 18(2): 77-96.

Integrated Children's System <http://www.everychildmatters.gov.uk/socialcare/integratedchildrenssystem/about/> (website accessed on 15/05/08).

Kelly B. (2007) 'Methodological Issues for Qualitative Research with Learning Disabled Children', *International Journal of Social Research Methodology* 10(1): 21-35.

Mayall B. (2006) 'Child-adult Relations in Social Space', in E.K. Tisdall, J. Davis, M. Hill and A. Prout (eds) *Children, Young People and Social Inclusion: Participation for What?* Bristol: Policy Press.

Mayall B. (Ed) (1994) *Children's Childhoods. Observed and Experienced*, London: Falmer Press.

Mitchell W. and Sloper P. (2008) *The Integrated Children's System and Disabled Children*, Research Works, 2008-1, Social Policy Research Unit, University of York.

Morrow V. and Richards M. (1996) 'The Ethics of Social Research with Children: An Overview', *Children and Society* 10(2): 90-105.

Murphy J. Tester S., Hubbard G., Downs M. and MacDonald C. (2005) 'Enabling Frail Older People with a Communication Difficulty to Express Their Views: The Use of Talking Mats as an Interview Tool', *Health and Social Care in the Community* 13(2): 95-107.

Murphy J. (1998) 'Talking Mats: Speech and Language Research in Practice', *Speech and Language Therapy in Practice* Autumn: 11-14.

Murray C. (2005) 'Children and Young People's Participation and Non-participation in Research', *Adoption and Fostering* 29(1): 57-66.

Nolan M., Hanson E., Grant G., Keady J. and Magnusson L. (2007) 'Introduction: What Counts as Knowledge, Whose Knowledge Counts? Towards Authentic Participatory Enquiry', in M. Nolan, E. Hanson, G. Grant and K. Keady (eds) *User Participation in Health and Social Care Research* pp1-13, Berkshire: Open University Press.

Oakley A. (1981) 'Interviewing Women: A Contradiction in Terms', in Roberts H. (ed) *Doing Feminist Research* pp30-61, London: Routledge.

Participation Charter (2006) http://www.ncb.org.uk/dotpdf/open%20access%20-%20phase%201%20only/partposter_participation052006.pdf (website accessed on 15/05/08).

Participation Works (2008) *How to Involve Children and Young People with Communication Impairments in Decision-Making*, National Children's Bureau, Council for Disabled Children, Participation Works, London.

Prout A. and Tisdall E. K. (2006) 'Conclusion: Social Inclusion, the Welfare State and Understanding Children's Participation', in E.K. Tisdall, J. Davis, M. Hill and A. Prout (eds) *Children, Young People and Social Inclusion: Participation for What?* Bristol: Policy Press.

Rabiee P., Sloper P. and Beresford B. (2005) 'Doing Research with Children and Young People who do not use Speech for Communication', *Children and Society* 19(5): 385-396.

Sigelman C.K., Budd E.C., Spanhel, C.L. and Schoenrock C.J. (1981) 'Asking Questions of Retarded Persons: A Comparison of Yes/No and Either/Or Formats', *Applied Research in Mental Retardation* 2: 347-357.

Sinclair R. (2004) 'Participation in Practice: Making it Meaningful, Effective and Sustainable', *Children and Society* 18(2): 106-118.

Stalker K. and Connors C. (2003) 'Communicating with Disabled Children', *Adoption and Fostering* 27(1): 26-34.

Stanley L. and Wise S. (1993) *Breaking Out Again – Feminist Ontology and Epistemology*, London: Routledge.

Swallow V., Coad J. and Macfadyen A. (2007) 'Involving Children, Young People and Parents in Knowledge Generation in Health and Social Care Research', in M. Nolan, E. Hanson, G. Grant and J. Keady (eds) *User Participation in Health and Social Care Research* pp151-165, Berkshire: Open University Press.

Tisdall E.K and Davis J. (2004) 'Making a Difference? Bringing Children's and Young People's Views into Policy-making', *Children and Society* 18(2): 131-142.

United Nations High Commissioner for Human Rights (1989) *Convention on the Rights of the Child*, Geneva, Switzerland: Office of the United Nations High Commissioner for Human Rights.

Ware J. (2004) 'Ascertaining the Views of People with Profound and Multiple Learning Disabilities', *British Journal of Learning Disabilities* 32(3): 175-179.

Whitehurst T. (2006) 'Liberating Silent Voices – Perspectives of Children with Profound and Complex Learning Needs on Inclusion', *British Journal of Learning Disabilities* 35(1): 55-61.