

This is a repository copy of *'Making Choices in my Life': Listening to the ideas and experiences of young people in the UK who communicate non-verbally*.

White Rose Research Online URL for this paper:

<https://eprints.whiterose.ac.uk/11170/>

Article:

Mitchell, Wendy orcid.org/0000-0002-1608-2368 and Sloper, Patricia (2010) 'Making Choices in my Life': Listening to the ideas and experiences of young people in the UK who communicate non-verbally. *Children and Youth Services Review*. ISSN 0190-7409

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.

‘Making Choices in my Life’: Listening to the ideas and experiences of young people in the UK who communicate non-verbally

Wendy Mitchell and Patricia Sloper

Social Policy Research Unit

University of York

Available online 2 June 2010

Mitchell, W. and Sloper, P. (in press) Making choices in my life: listening to the ideas and experiences of young people in the UK who communicate non-verbally, *Children and Youth Services Review*, (Available online from 2 June 2010).

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 publisher’s online version:

<http://dx.doi.org/10.1016/j.chilyouth.2010.05.016>

DOI: [10.1016/j.chilyouth.2010.05.016](https://doi.org/10.1016/j.chilyouth.2010.05.016)

Abstract

Service user participation and making choices are frequently advocated, however, they are complex concepts and how they are translated and/or experienced in everyday life can vary amongst different groups of service users. Recognising the importance of participation in current international guidance and UK government policy this paper seeks to explore how research can include a frequently marginalised group of disabled young people, in particular young people with learning disabilities and/or who communicate non-verbally. The paper discusses the use of non-traditional research methods, especially symbols based interviews developed in an ongoing English longitudinal study exploring choices and decision-making processes for young people with life limiting conditions. The paper then presents some research findings and concludes by discussing their implications. In particular, the use of symbols based interviews for informing policy makers about how these young people can be included in research and how listening to them can inform our understanding of decision-making processes.

Key Words

Disabled children, Participation, Choice/decision making, Communication methods, Non-traditional research methods, Learning disabilities

Author Details

Dr Wendy Mitchell (Lead Author)

Social Policy Research Unit

Department of Social Policy and Social Work

University of York

York

YO10 5DD

UK

Telephone number: +44 1904 321950

Fax number: +44 1904 321953

E-mail: wam1@york.ac.uk

Professor Patricia Sloper

Social Policy Research Unit

Department of Social Policy and Social Work

University of York

York

YO10 5DD

UK

1. Introduction

Current UK government policy advocates young people's participation in policy and service development thus aiming to involve children in decisions about their lives, listening to all children, including those with learning and communication impairments. This move towards prioritising and increasing children's participation has arisen from a number of sources including the wider UK focus on social inclusion and a corresponding concern that some citizens, including children, are socially excluded. The importance of service choice and decision-making is also a UK government priority and similarly associated with increased participation and social inclusion for disabled people, including disabled children. However, disabled children are frequently included less than their non-disabled peers. This paper seeks to begin to redress this gap by exploring how disabled young people, especially those with learning and/or communication impairments, can be listened to using non-traditional research methods. It draws on research experiences from an ongoing English longitudinal project (called '*Choice and Change*') exploring the choices that young people with life limiting conditions make.

1.1 Social Exclusion and Participation

In the UK and Europe, addressing 'social exclusion' is part of government policy and debate (UK Social Exclusion Task Force) but the concept remains ambiguous due to the complexity surrounding definitions.

Different theorists focus on different aspects of social exclusion.

Bradshaw and Bennett (2007) focus on poverty whereas MacDonald and Marsh (2005) highlight specific group characteristics such as age, gender or ethnicity. Children are an ongoing focus of concern (see UK Every Child Matters, Department for Education and Skills (DfES, 2004) and Children's Plan, Department for Children, Schools and Families (DCSF, 2007) but some groups (e.g. teenage parents) have received more government attention compared to others such as disabled children. However, disabled children's exclusion is complex and multi-dimensional as they face material barriers and also poor service provision and co-ordination (Clarke, 2006).

Participation of disabled children in service planning and participation is thus important, especially as disabled children are often likely to face more assessment, supervision and medical interventions than other children (Franklin and Sloper, 2006a) and disabled children themselves have indicated that they value opportunities to participate (Mitchell and Sloper, 2001).

The move towards greater participation has evolved from a number of sources, including UK based legislation and policies advocating greater

rights for children, such as the Every Child Matters programme (DfES, 2004), the English National Service Framework for Children, Young People and Maternity Services (NSF) (Department of Health (DH) and DfES, 2004); Healthy Lives, Brighter Futures (DH, 2009); Children Act (2004); and internationally, United Nations Convention on the Rights of the Child (1989). Theoretical developments presenting children as competent and knowing social agents (Mayall, 2006; Hill et al., 2004) have also given their participation credence.

1.2 Participation

Controversy surrounds the concept of participation with numerous models advocated with different levels and/or types of participation. A frequently used typology (e.g. Arnstein's, 1996) is based on a continuum with progressive participation from consultation through to collaboration and finally, user control. However, hierarchical models are frequently based on adult participation and not always appropriate for children. Other theorists (Hart, 1997) have developed child based hierarchies. Alternatively, non-hierarchical models have also been advocated (Kirby et al., 2003 and Treseder, 1997) based on the idea that the highest level of participation is not always the best or most appropriate for all children and young people. Not all children want or are able to be the main decider. Children may need or value adults' involvement (Franklin and Sloper, 2006b).

Past UK based literature has demonstrated that children 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 (Franklin and Sloper, 2006a). A participation charter (2007) has been developed by children. Innovative practice clearly exists, (see www.participationworks.org.uk¹) but there are still gaps between theoretical developments and policy guidance and everyday practice (Carnegie UK Trust, 2008). Some projects focus on consultation with children but their active involvement is limited. The need to move beyond 'consultation' has been highlighted (Hill et al., 2004). How children experience participation is also important, past literature has highlighted that participation can be viewed as tokenistic and even negative if children are not kept informed after their views have been sought. Reporting back to participants is important (Cavet and Sloper, 2004).

There are also complex and much debated tensions surrounding children's' right to participate versus associated responsibilities, and for adults, especially practitioners with a 'duty to care', there are potential tensions reconciling children's right to participate with their right to protection (Cousins and Milner, 2007).

¹ Participation Works – consortium of six UK voluntary and statutory organisations.

As Franklin and Sloper (2006a) note, English government policy may advocate that all children should be included as far as possible in assessment and decision-making processes, including those who rely on electronic aids to assist communication or who use non-verbal modes of communication, but disabled children's participation has been less than their non-disabled peers. The children most likely to participate are older children and those more vocal and socially confident (Franklin and Sloper, 2009, 2006b). The exclusion of disabled children has arisen as Franklin and Sloper (2009) 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. For those with communication impairments, there are also additional problems of patchy speech and language services and support provision, and inexperienced and untrained practitioners (Berkow Report, 2008), factors recently acknowledged by the UK DCSF's Better Communication plan (2008). Some positive developments have emerged, especially for those seeking to include young people with communication impairments (see Participation Works, 2008, Every Disabled Child Matters campaign²). It is important to redress the marginalisation of disabled young people as their views are frequently lost, disabled children's experiences can differ from their non-disabled peers, and disabled

² Every Matters (ECM): national government framework developing joined-up children's services across different departments. Every Disabled Child Matters (EDCM): English based campaign to develop ECM prioritising disabled children.

children themselves are a heterogeneous group (Franklin and Sloper, 2006a).

1.3 Choice and Decision-making

The concept of choice is currently a key component of the UK Government's modernisation agenda, frequently associated with issues of consumer rights and increased independence and control for individuals. In *Valuing People Now* (DH, 2009) 'choice' is a key principle advocated in planning improved services for people with learning disabilities. Although targeted at adults, disabled children were recognised as a group requiring specific support and consideration. This focus on choice has also been highlighted in the government's personalisation agenda focusing on adult individual budgets (DH, 2007). Individual budgets are now being piloted for disabled children and their families (Her Majesty's Treasury/DfES, 2007).

The concept of choice is complex and much contested, reviewing the literature is clearly beyond the scope of this paper but it is important to acknowledge that there is a large literature spanning many disciplines (psychological, social, economic). Drawing the psychologically based choice literature together, Beresford and Sloper (2008) note the importance of having at least two alternatives and for both to be viewed as real alternatives with positive values. Choices and the decision-making processes that people engage in are frequently multi-dimensional with many potential factors taken into consideration. Cognitive ability is

often discussed, especially, capacity or competence to make a choice (Beresford and Sloper, 2008). This is an important issue for the young people in the *Choice and Change* study.

Cognitive ability clearly needs to be taken into account but should not exclude people with cognitive impairments from choice/decision-making. Beresford and Sloper's (2008) review found an absence of literature specifically exploring children with cognitive impairments and their families' decision-making processes. Most studies indicated that adults with cognitive impairments can make choices or express preferences but this depends on the level of impairment and the degree of choice complexity (Connella et al., 2005). Research also indicates the importance of environment in facilitating children's participation in decision-making, for example, access to communication aids, support and the knowledge and skills of others (Ware, 2004).

2. The Choice and Change Project

The *Choice and Change* project explores 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) over a three year period (2007 to 2010). This paper focuses on the sample of young people with life limiting conditions recruited from two children's hospices. The overall sample of 27 young people varies in terms of gender, age (13-21 years), ethnicity and disability type (www.york.ac.uk/inst/spru/research/summs/DHPpanel.html)

Choice and Change aims to develop project wide research methods and tools in order to compare the different groups. However, it was apparent that this was not always possible for the young people. Traditional semi-structured interviews and research materials based on a written format were inappropriate for some of the young people (subsample of 12³) who had learning and/or communication impairments. For these young people non-traditional methods were developed and used.

³ Longitudinally, the number of young people interviewed with the aid of Talking Mats™ varies slightly. In round one (spring/summer 2007) 12 young people were interviewed and in round two (autumn/winter 2008/09) 11 young people were interviewed.

2.1 Adapting research materials and facilitating young people's involvement

Using the study's adult based consent and information sheets as a template, separate written consent and information sheets were developed for the young people using simpler and more focused language. Symbols based information and consent forms were also developed for those young people with learning and/or communication impairments using two diverse but general symbol systems - Widgit™ and Boardmaker™.

The *Choice and Change* project used short questionnaires to collect socio-demographic information from adult participants. For the young people, this information was collected via a cartoon based booklet called 'All About Me'. The researcher (WM) and young people with learning and/or communication impairments completed this booklet before each interview. The booklet, as Kelly (2007) has noted in her research, was a positive experience and acted as an important 'ice-breaker'. The researcher (WM) was always careful to end the booklet on a positive note with things that the young person could do and enjoyed doing. This boosted confidence and demonstrated to them (and their parents) that they 'could' answer research questions. After the interview, each young person enjoyed receiving a completed copy. The 'All About Me' booklet provided the researcher with important background information and enabled a quick assessment of each child's preferred mode of communication and their level of understanding in an unobtrusive manner.

2.2 Using Talking Mats™

The 15 verbal young people from the overall sample of 27 were interviewed first via semi-structured interviews. Using their responses and identifying some key themes, 16 simply worded questions were developed and a range of appropriate symbols identified as potential responses. These questions were used as the basis for a series of Talking Mats™. Each question was printed on A3 laminated card and underneath a range of symbols (using the Boardmaker™ symbol system) was attached with Velcro. Participants were asked questions and invited to choose the symbol(s) that matched their ideas and/or feelings. In each interview the young person created their own symbols board (the Talking Mat™) with the researcher (WM).

[Insert Figure1 here]

Talking Mats™ were first used in the UK with adults by Murphy (1998) and have subsequently been developed for use with other groups, including older and younger disabled people (Whitehurst, 2006; Rabiee et al., 2005; Cameron et al., 2004). Other non-verbal methods (e.g. drawing and puppets) have been used with varying degrees of success with young children and disabled young people (see Participation Works, 2008) but these were felt to be largely inappropriate for the young people in this study due to levels of understanding, age appropriateness and/or their restricted physical movement. Talking Mats™ were chosen because of

their flexibility and ability to be used in conjunction with other communication systems, they aid rather than dictate participant's communication preferences.

Twelve young people in round one and 11 young people in round two were interviewed with the aid of Talking Mats™. All the young people appeared to recognise the symbols (to varying degrees in line with their level of understanding), liked their colourfulness and enjoyed creating their own board. The Talking Mats™ flexibility was particularly useful as the young people had different learning disabilities and/or preferred communication modes. For example, some chose from up to 12 different board-based symbols whereas others focused on two or three. Their choice of symbols was made through a range of preferred communication modes, including verbalising, eye-pointing, signing, and moving an arm/hand or facial expressions. The researcher (WM) was able to personalise each interview with the aid of the 'All about Me' booklet and the background information it provided.

2.3 Issues arising

2.3.1 The role of 'others'

As noted above, past literature has discussed how research involving young people frequently involves negotiating access via adult gatekeepers (Kelly, 2007; Ware, 2004). Issues of confidentiality and the need for parental consent (for minors) also arise; this is further complicated by the

social and legal ambiguity surrounding adult status (Morrow and Richards, 1996). For young people with learning and/or communication impairments there is the additional issue of competence, especially assumptions of competence and ability to make informed decisions (Cousins and Milner, 2007).

Some parents felt that their son/daughter would be unable to participate as they were either non-verbal or had severe learning disabilities. The researcher (WM) carefully explained the project and the use of symbols based research tools to try and allay parental concerns. This resulted in some parents reconsidering their initial refusal.

Some parents continued to be anxious that their son/daughter would not provide 'appropriate' data for the researcher and the experience may be negative for both parties. This fear and negativity illustrates wider issues and social presumptions; for example, parents had rarely experienced professionals seeking to involve and listen to their child using non-verbal methods. It also highlighted that parents can have fixed ideas about data types and what is required and/or valued by researchers as 'knowledge'. Making time to talk to parents, reassuring them and validating the information that their child could provide was important in the research negotiating process.

Providing opportunities for parents or formal carers to be present during the researcher and young people's meetings was welcomed by both the young people and parents/formal carers. Two young people were interviewed with a formal carer present (in both rounds); the remaining young people were all interviewed with a parent(s) present.

Parents/carers provided important background information and had invaluable interpretative skills, especially when participants used personalised and/or indistinct modes of communication, such as eye-pointing or thumb movements. Parents/carers presence also re-assured the young people. However, it is acknowledged that the presence of others, especially parents/carers, can influence the context and dynamics of interviews (Ware, 2004). Open and honest recognition of the potential role of others is helpful (Mitchell, forthcoming; Mitchell et al., 2009 also discuss the role of others).

2.3.2 Being flexible

Developing specific and relevant materials and research tools was a gradual process of cumulative learning for the researchers. Learning from the young people participating in research is an important part of this process. Having different research tools available at each interview, such as the young people's verbal topic guide, the Talking Mats™ and the 'All About Me' booklet enabled a flexible and more personalised approach with participants (as far as possible) choosing the research tools they preferred. Parents/carers were sometimes also asked which they felt

would be most appropriate. Young people could and did change their minds, for example, one young person felt the Talking Mats™ would be 'babyish' but on seeing them changed his mind.

The project's longitudinal nature also helped to facilitate a flexible approach as the researcher had time to develop appropriate research tools and utilise and reflect on ongoing learning experiences. For example, taking a photo of each young person's personal mat and sending them a copy was not done in the first round but was in the second interview.

3. Findings

The paper now reports some findings from the young people with learning and/or communication impairments who communicated their ideas and feelings with the aid of the Talking Mats™. These are drawn from the first (spring/summer 2007) and second (autumn/winter 2008/09) rounds of interviews.

3.1 Choice areas discussed

In the first interview, all young people were asked to identify decisions they wanted to discuss and felt were important. Decisions could potentially occur in a wide range of areas; however, only four choice areas were noted: education, leisure, social care and respite services. Within this, 10

out of 12 young people focused on education (five) and leisure (five). Areas such as equipment, health care and housing were not discussed.

3.2 Making choices – general feelings and other people helping

In round one, all the young people (12) indicated that they liked and wanted to make choices, it made them 'happy'.⁴ When they could not make choices, three specifically highlighted that they felt 'sad'. However, making decisions was not always easy, seven young people felt it could be both 'easy' and 'hard'. When asked 'what made it easy?' only five young people could answer this, but all five felt 'people talking to me' helped and three also valued being given and/or having information.

Decision making is often not a solitary activity or process, the role of other people is important to consider, especially for children with cognitive impairments. The significance of others helping was clear in both rounds one and two. In round one, all the young people indicated that they generally make choices with other people, usually a family member or a key formal carer. However, three young people were more emphatic that they made decisions by themselves and liked this but when probed, they also acknowledged the role of others and that they liked to talk to other people about choices. None of the young people expressed a desire not to involve others in decision making.

⁴ Inverted commas (e.g. 'happy') indicate the exact word/phrase accompanying a symbol on the Talking Mats™.

In round one, participants talked about who generally helped them make decisions, parents were noted by eight young people and within this, 'Mum' predominated (six). When talking about a specific choice area, young people were then more likely to note the help of other people in addition to parents, for example, in leisure activities, the role of outreach workers, youth club leaders, formal carers and friends were noted

When asked how other people helped them, almost all (11) the young people valued being talked to and within this, five noted the importance of 'people explaining things to me' and 'taking me to visit' (i.e. see college or activity and meet staff and/or other young people). For two young people with severe learning disabilities being shown choice options by formal carers was also important.

In round two interviews (n=11), the role of others helping young people to make choices was explored further. Seven young people answered questions in this section.⁵ The second interview asked young people to concentrate on who helped them with a specific choice. For all but one this was a different choice from that discussed in their first interview, however, the areas within which choices were being made were generally the same as in round one, i.e. education (five) and leisure (two). The young people tended to talk about help received from others in general terms, i.e. people who usually helped them. Here, as in round one,

parents predominated (six), only one young person did not mention his parents and focused on the help his older brothers had given him when choosing a college, as both his brothers were at or had been to this specific college. For the two young people focusing on leisure choices, the help of formal carers and friends was noted alongside their parents, especially 'Mum'.

As in round one, the help that participants noted was 'people talking to me', 'explaining things to me' and 'taking me to visit' (especially different colleges or leisure activities). These were all noted equally and most (six) of the young people felt that the help they had received was 'just right'. Three out of five felt that they had asked other people to help, one had not asked and one could not remember if they had asked or not. However, all seven were clear why other people had helped them: five felt it was because 'they understand' and 'I trust them', two felt 'they know about the choice' and 'they make my choices'. 'I can't make choices' and 'I need help' was only noted by one participant. More positively, all seven young people felt they would ask the people who had helped to help them again. Similarly, most were very clear that they would need help in the future from other people; only two were less sure.

⁵ Second round interviews were split into four sections: old/new choices, the role of others, information and independence, due to variations in concentration span and level of understanding not all sections were answered by all participants

3.3 Being listened to

In round one, almost all (11) of the 12 young people felt that the person(s) helping them to make a decision listened to them, only one young person felt that she was not listened to at school and unsurprisingly, her teachers and formal carers did not feature during the interview as key people.

When young people were listened to, they expressed a range of emotions with all feeling 'happy', in addition, feeling 'clever' was noted by four, 'proud' by two and 'safe' by one. Conversely, for the seven young people who also discussed people not listening, negative emotions were expressed, the overriding one being sadness (six). In addition, feelings of anger and loneliness were noted (three), confusion and not being 'grown-up' (two) and disappointment by one.

Seven young people were able to explain how they knew that people were listening, and for them the importance of interaction was clear with six choosing 'they look at me' and 'talk to me' symbols. Two young people also valued active indicators: 'they write down what I say' and 'they do what I ask'.

3.4 Independence, being 'grown-up' and the future

Second interviews explored the role and importance of independence within choices and decision-making with all participants (n=11). In the interviews this was described in concrete terms as 'being grown-up'. All the young people responded positively to the question of feeling grown-up

when making choices, indeed, seven emphatically demonstrated this, either verbally or physically.

When asked 'what makes you feel grown-up?', the most frequently noted indicators (each by five participants) were: 'people listening to me', 'people asking me what I want', 'people explaining things to me' and 'choosing what I want to do during the day'; 'being with my friends' was also highlighted by three participants. Everyone felt that 'being grown-up' was important to them; eight indicated it was 'very' important. Conversely, when asked 'what makes you feel like a child/baby?' the opposite was clear: six noted, 'people not asking what I want', five, 'people not listening' or 'people not explaining things to me' and four, 'not being with friends'. In addition, the role of parents and home was highlighted: 'people talking to Mum and Dad and not me' (three), 'being with Mum and Dad' (one) and living at home (one). Unsurprisingly, this raised negative emotions with sadness and anger expressed by five, frustration and feeling stupid by four and loneliness by two young people.

However, parents could also actively facilitate being 'grown-up', this was recognised by nearly all the young people (ten) and also welcomed with expressions of happiness when people did help; indeed, four participants felt 'proud' when others helped them to be 'grown-up'. In addition to parents, especially 'Mum', a range of other people were noted; four different participants noted key formal carers or their siblings or friends,

two highlighted the help of teachers, but social workers and physiotherapists were each only noted by one young person. As before, the help that was valued stemmed from being listened to (nine) and being asked what they want (five), in addition, the importance of privacy was noted by two young people.

Continuing to make choices in the future was also important, when asked, 'when I'm older, I'd like to make choices about ...', the four most popular choices were: choosing what I do during the day (seven), making new friends (six), choosing who helps me with my personal care (four) and choosing where I live (four), one young person noted making choices about their health care. As in round one, health care decisions were not discussed by the young people.

4. Discussion and Concluding Comments

This paper has illustrated the value of using Talking Mats™ to facilitate communication with young people with learning and/or communication impairments. Recording young people's views does not automatically lead to service changes or policy developments. There is still limited evidence that children's participation leads to real change (Carnegie UK Trust, 2008) but this should not detract researchers, professionals and policy makers from seeking to begin to involve young people with communication impairments.

The *Choice and Change* project demonstrated that young people enjoyed using the Talking Mats™, second interviews showed that they remembered the Talking Mats™ and felt comfortable using them. This familiarity boosted confidence and level of engagement. The benefits of a longitudinal study and continuity of methods are apparent. In terms of participation, Talking Mats™ enabled young people with learning and/or communication impairments to participate in the project and provide real insights into the choices/decisions that they make and want to make, how they make them and how they feel about decision making processes. This is important as children's participation is, as noted earlier, a key English government policy (NSF/DH, 2004) but as past UK research has demonstrated (Franklin and Sloper, 2009) participation for disabled children, especially those with learning and/or communication impairments, is underdeveloped. The data gleaned here helps to broaden our understanding of choice and decision making, another important UK policy (DH, 2009).

However, it is important to acknowledge the limitations of the *Choice and Change* study. This paper is based on a very specific project with a precise group, i.e. young people with life-limiting conditions, 13 to 21 years old and within this, a sub-sample of young people with learning and/or communication impairments. Numbers are small and generalisations cannot be made for disabled young people or even those with learning and/or communication impairments. The Talking Mats™ were largely

context specific, focusing on pre-defined symbols and interviews were conducted in the presence and with the help of other people. These influences on the young people's responses must be acknowledged but cannot be easily assessed. Longitudinal research, as demonstrated in this project, can help to begin to address some of these issues, for example, exploring in more depth areas highlighted in first interviews within second interviews. Ongoing concern surrounds the reliability of answers people with learning disabilities give during interviews (Sigelman et al., 1981). As a longitudinal study the *Choice and Change* project was able to non-obtrusively check first interview responses and ambiguities during second interviews and demonstrated that second round data frequently reinforced first interview results.

4.1 Young people's choice/decision-making experiences and what they value

The data demonstrate that generally young people like and want to be involved in making decisions about their lives. The decisions young people chose focused on education and leisure, other areas, especially health did not really feature. This could be for a number of reasons, such as participants' lack of interest or the fact that they are not included in health decisions. However, it is important to note this absence as UK government policy advocates disabled young people participating in both health and social care decisions (DCSF/DH, 2009; HM Treasury/DfES, 2007).

Interviews demonstrated that these young people do make choices/decisions, however, level of understanding is important, as noted in past literature (see Ware, 2004). Participants do not make choices alone, other people are involved and this is generally valued as the young people found it helpful and reassuring. Most young people wanted shared decision-making, emphasising the importance of being asked what they want and being listened to by others. The people most frequently highlighted as helping them are family, formal carers and friends; the role of parents, especially 'Mum' was apparent and ongoing. Conversely, professionals such as social workers and health care practitioners were infrequently mentioned. This could be partly a result of the choice areas and decisions discussed by the young people in this study; especially, the notable absence of medical decisions. It must also be acknowledged that 'Mum' or formal carers were present during the interviews and so may have influenced the young people's responses.

When making decisions, the importance of people talking directly to the young people was clear. Parents played an important role informing young people, often acting as intermediaries for their child. The importance of 'trust' also comes to the fore as the young people needed to be happy and comfortable with those helping them. Parents and key formal carers were frequently trusted as the young people felt these people knew and understood them and the choices they faced. The

young people's responses also demonstrate the importance of concrete information presented simply and clearly.

Independence is important for these young people as many are approaching adulthood. Participants all viewed being 'grown-up' positively and aspired to it, making choices was part of this process. This reiterates the importance of current UK government policy prioritising independence and choice for people with learning disabilities (DH, 2009). For these young people being grown-up was linked to how they were treated by others, once again being consulted and listened to and also who they spent time with, especially friends, was also valued. However, it is important to note that parents had an ongoing role in helping young people to feel grown-up as they got older, the young people did not expect or want their parents to be excluded. Shared decision-making is still important.

4.2 Facilitating participation – thinking more broadly

Lessons learnt from adapting the *Choice and Change* research approach and tools to meet the specific needs of young people with learning and/or communication impairments are now discussed, especially wider implications for practitioners and policy makers working with disabled children.

The research has demonstrated the importance of challenging traditional ideas of what participation is and the type of data collected and valued as knowledge. In doing so, it has highlighted the need for policy makers to think broadly about participation if they are really going to work towards improved outcomes for all children, including disabled children.

As noted above, some writers (Kirby et al., 2003; Treseder, 1997) have argued that hierarchical models of participation are not always appropriate for, or wanted by, young people. This is clearly demonstrated as the researcher sought to be flexible and sensitive to the needs and wishes of the young people participating. The *Choice and Change* project has also illustrated, in line with previous research (Franklin and Sloper, 2009), that involving disabled young people, especially those with learning and/or communication impairments, is not easy, quick or unproblematic. One approach does not fit all groups of young people. Having different research tools to draw on aided the researcher's communication with a diverse group of disabled young people.

4.3 Implications for practice: training and development

To help practitioners begin to think more about disabled children's participation, especially those with learning and/or communication impairments, issues of skills, training and confidence need consideration.

A lack of professional awareness of and skills to meet the needs of children with communication impairments is highlighted by the UK's

Berkow Report (2008) and its corresponding government response (DCSF, 2008). This is a positive development. Past social work research (Lefevre et al., 2008) has also noted that the absence of curriculum uniformity can lead to students receiving very different types and levels of training. To help practitioners develop skills and confidence when working with disabled children, communicating with disabled children needs to be placed clearly on the curriculum (see Mitchell et al., 2009 for further discussion). For qualified professionals, there is also a need for more specific ongoing training. Although a number of resources have been developed providing guidance on communicating with disabled young people (see Participation Works, 2008), past research with social workers (Mitchell and Sloper, 2008) has highlighted that knowledge of these resources is patchy. Raising awareness is clearly a priority area.

4.4 Implications for practice: time and working with young people

Facilitating participation takes time (Cavet and Sloper, 2004). The longitudinal nature of this project aided researcher rapport, however, time is a luxury many professionals do not have, as UK based research with social workers has demonstrated (Mitchell and Sloper, 2008). Recognition of the extra time needed to work with disabled young people is often not allocated by employers or acknowledged in government targets/outcomes. For practitioners to begin to build young people's participation into their everyday practice, support is required from all levels within organisations.

The complexity of participation and need for professional skills and flexibility were brought to the fore in *Choice and Change* by the young people's ideas around independence and shared decision-making. As they progressed towards adulthood and being more 'grown-up', the young people still valued and expected their parents to be involved in decision-making. The importance of professionals taking a holistic approach is apparent, listening and working with parents as well as young people, but this can be a difficult balance to negotiation. Professionals need to avoid an either/or approach, such as focusing predominately on parents as it is easier and quicker to ask them rather than consulting young people with learning and/or communication impairments, or conversely, seeing the young person as an 'adult' and thus independent of their parents, resulting in parents being sidelined, a situation young people do not want. Negotiating a balance with each young person and their family clearly takes time but it is an important part of these young peoples' participation and choice making.

Acknowledgements

The authors would like to thank the young people and their families who participated in the study and also the practitioners who assisted the researcher. The authors would also like to thank all members of the *Choice and Change* project team: Hilary Arksey, Kate Baxter, Janet Heaton, Caroline Glendinning and Parvaneh Rabiee. Special thanks to Parvaneh Rabiee for her initial advice on using Talking Mats™ and our conversation during the *Choice and Change* project when developing the young people's Talking Mats™. The *Choice and Change* research project is funded by the UK Department of Health Policy Research Programme. The views expressed here are those of the authors and not necessarily those of the funder.

References

Arnstein, S. (1969). A ladder of citizen participation in the USA. *Journal of the American Institute of Planners*, 35, 4, 216-224.

Beresford, B. & Sloper, P. (2008). *Understanding the dynamics of decision-making and choice: a scoping study of key psychological theories to inform the design and analysis of the Panel Study*. York: SPRU, University of York.

Berkow Report (2008). *A review of services for children and young people (0-19) with speech, language and communication needs*. London: DCSF.

Bradshaw, J. & Bennett, F. (2007). *UK: tackling child poverty and promoting the social inclusion of children: a study of national policies*, European Commission (DG Employment, Social Affairs and Equal Opportunities) (web publication only) http://www.peer-review-social-inclusion.net/policy-assessment-activities/reports/first-semester-2007/first-semester-reports-2007/united-kingdom_1_07

Cameron, L., Watson, J. & Murphy, J. (2004). Talking Mats: a focus group tool for people with learning disability. *Communication Matters*, 18, 1, 33-35.

Carnegie UK Trust (2008). *Empowering young people: the final report of the Carnegie Young People Initiative*. Fife: Carnegie UK Trust, Fife, Scotland.

Cavet, J. & 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.

Clarke, H. (2006). *Preventing social exclusion of disabled children and their families, literature review paper produced for the National Evaluation of the Children's Fund*. Research Report No.782, Birmingham: University of Birmingham.

Connella, H., O'Reilly, M. and Lancioni, G. (2005). Choice and preference assessment research with people with severe to profound developmental disabilities: a review of the literature. *Research in Developmental Disabilities*, 26, 1-15.

Cousins, W. & Milner, S. (2007). Small voices: children's rights and representation in social work research. *Social Work Education*, 26, 5, 447-457.

Department for Children, Schools and Families (2007). *The children's plan: building brighter futures*. Cm7280, London: DCSF.

Department for Children, Schools and Families (2008). *Better communication: an action plan to improve services for children and young people with speech, language and communication needs*. London: DCSF.

Department of Health (2004). *The Children Act 2004*. London: DoH.

Department of Health (2007). *Putting people first: a shared vision and commitment to the transformation of adult social care*. London: DoH.

Department of Health (2009). *Valuing people now: a new three-year strategy for people with learning disabilities*. London: DoH.

Department of Health/Department for Children, Schools and Families (2009). *Healthy lives, brighter futures: the strategy for children and young people's health*. London: DoH.

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: DoH.

Every Child Matters (2004) <http://www.ecm.gov.uk> (accessed 14/07/08).

Every Disabled Child Matters Campaign (2008).

<http://www.edcm.org.uk/Page.asp> (accessed 14/07/08).

Franklin, A. & Sloper, P. (2006a). *Participation of disabled children and young people in decision-making relating to social care*, York. SPRU, University of York.

Franklin, A. & Sloper, P. (2006b). 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.

Franklin, A. & Sloper, P. (2009). Supporting the participation of disabled children and young people in decision-making. *Children and Society*, 23, 1, 3-15.

Hart, R. (1997). *Children's participation: from tokenism to citizenship*. Florence: UNICEF.

HM Treasury/Department for Education and Skills (2007). *Aiming high for disabled children: better support for families*. London: HM Treasury.

Hill, M., Davis, J., Prout, A. & Tisdall, K. (2004). Moving the participation agenda forward. *Children and Society*, 18, 2, 77-96.

Kelly, B. (2007). Methodological issues for qualitative research with learning disabled children. *International Journal of Social Research Methodology*, 10, 1, 21-35.

Kirby, P., Lanyon, C., Cronin, K. & Sinclair, R. (2003). *Building a culture of participation: involving children and young people in policy, service planning, delivery and evaluation - Research Report*, London: Department for Education and Skills.

Lefevre, M., Tanner, K. & Luckock, B. (2008). Developing social work students' communication skills with children and young people: a model for the qualifying level curriculum. *Child and Family Social Work*, 13, 2, 166-176.

MacDonald, R. & Marsh, J. (2005). *Disconnected youth?* New York: Palgrave MacMillan.

Mayall, B. (2006). Child-adult relations in social space. In E.K. Tisdall, J. Davis, M. Hill & A. Prout (Eds.), *Children, young people and social inclusion: participation for what?* Bristol: Policy Press.

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

Mitchell, W. & Sloper, P. (2001). Quality in services for disabled children and their families: what can theory, policy and research on children's and parent's views tell us? *Children and Society*, 15, 4, 237-252.

Mitchell, W. & Sloper, P. (2008). The Integrated Children's System and disabled children, *Research Works*, 2008-1. York: SPRU, University of York.

Mitchell, W., Franklin, A., Greco, V. & Bell, M. (2009). Working with children with learning disabilities and/or who communicate non-verbally: research experiences and their implications for social work education, increased participation and social inclusion. *Social Work Education*, 28, 3, 309-324.

Morrow, V. & Richards, M. (1996). The ethics of social research with children: an overview. *Children and Society*, 10, 2, 90-105.

Murphy, J. (1998). Talking Mats: speech and language research in practice. *Speech and Language Therapy in Practice*, Autumn, 11-14.

Participation Works (2008). *How to involve children and young people with communication impairments in decision-making*. London: National Children's Bureau, Council for Disabled Children, Participation Works.

Participation Works (2007). *The Participation Charter*. London: Participation Works.

Rabiee, P., Sloper, P. & Beresford, B. (2005). Desired outcomes for children and young people with complex health care needs, and children who do not use speech for communication. *Health and Social Care in the Community*, 13, 5, 478 - 487.

Sigelman, C.K., Budd, E.C., Spanhel, C.L. & 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.

Social Exclusion Task Force (2007). *Reaching out: progress on social exclusion*. London: Social Exclusion Task Force, Cabinet Office.

Treseder, P. (1997). *Empowering children and young people*. London: Children's Rights Office/Save the Children.

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.

Figure

Figure 1 Example of Talking Mat™ used in the *Choice and Change* study

