

**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**

Wendy Mitchell, Anita Franklin, Veronica Greco and Margaret Bell

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Abstract

Social exclusion, although much debated in the UK, frequently focuses on children as a key 'at risk' group. However, some groups, such as disabled children, receive less consideration. Similarly, despite both UK and international policy and guidance encouraging the involvement of disabled children and their right to participate in decision-making arenas, they are frequently denied this right. UK based evidence suggests that disabled children's participation lags behind that of their non-disabled peers, often due to social work practitioners' lack of skills, expertise and knowledge on how to facilitate participation. The exclusion of disabled children from decision-making in social care processes echoes their exclusion from participation in society.

This paper seeks to begin to address this situation, and to provide some examples of tools that social work educators can introduce into pre- and post-qualifying training programmes, as well as in-service training. The paper draws on the experiences of researchers using non-traditional qualitative research methods, especially non-verbal methods, and describes two research projects; focusing on the methods employed to communicate with and involve disabled children, the barriers encountered and lessons learnt. Some of the ways in which these methods of communication can inform social work education are explored alongside wider issues of how and if increased communication can facilitate greater social inclusion.

Keywords: Disabled children; social exclusion; participation; research methods; user-involvement; communication methods; social work education; learning disabilities; non-verbal communication; deaf children

Introduction

Despite both UK and international policy and guidance encouraging increased social inclusion and the involvement of disabled children and young people and their right to participate in decision-making arenas, they are frequently denied this right. UK based evidence suggests that disabled children's participation lags behind their non-disabled peers, often due to a lack of skill and knowledge on how to facilitate participation, especially with children who communicate using non-verbal methods. There is also limited evidence of good practice in communicating with disabled children, despite training materials available, such as those published by Triangle¹ (2001), and the video material provided to accompany the *Framework for the Assessment of Children in Need and their Families*² (2000). A Department of Health (2006a) review suggests these are not widely used by trainers at qualifying level.

Social exclusion

In this paper we focus on the participation of children with learning disabilities and/or who communicate non-verbally. This is grounded in the wider theoretical context of social exclusion, as participation is interwoven within the UK social exclusion agenda. Although social inclusion and participation are interlinked, they are distinct concepts. Social inclusion frequently involves being enabled by others to take part whereas participation suggests a more active role, individuals choosing to participate.

The term 'social exclusion' has become part of UK [Social Exclusion Task Force (SETF)] and European policy (e.g. Lisbon Summit, 2000), with the UK at the

forefront of academic debates. International research is less developed. While Tony Blair's government popularised social exclusion, it remains an ambiguous term due to complexity surrounding definitions, decisions as to who are the socially excluded and the processes of exclusion they face. As Hill *et al.* (2004) note, some theorists focus on poverty (Bradshaw, 2007), whereas others focus on certain group characteristics, such as gender or age (MacDonald and Marsh, 2005). There are also competing discourses. Levitas (2006) notes three: social inclusion (predominately poverty and labour market based), moral underclass (prioritising individual or community deficits), and radical income redistribution (underpinned by wider socio-economic structural inequalities). Despite its contested nature, UK government policy does recognise social exclusion's multi-dimensional nature; economic, social and political [Social Exclusion Task Force (SETF), 2007].

Currently, children and young people are a key policy concern, especially groups such as young offenders and teenage parents. However, other groups of children who face multiple social exclusion, in particular children with disabilities, are less frequently considered. Clarke's (2006) literature review for the English Children's Fund³ highlights six areas of potential exclusion, all of which comprise materially based barriers, such as a dearth of available appropriate and safe housing (Beresford and Rhodes, 2008) and a lack of co-ordinated and integrated services (Morris, 2001). While inclusive education is high on the government agenda, poor resources and attitudinal barriers remain (Rix *et al.*, 2005). Similarly, in play and leisure services, environmental and attitudinal barriers persist (Petrie *et al.*, 2007).

Clarke's review highlights that disabled children are children first and that they also have specific needs which should be addressed. This complexity is reinforced by the

ongoing debate about specialist and mainstream services, especially in leisure and education. Barnes *et al.*'s. (2006) evaluation of two case studies (within the aforementioned Children's Fund) highlights that disabled children wanted time both to mix with disabled peers and to interact with non-disabled children and services need to be effectively co-ordinated across agencies.

Participation and why it is important

It is for these reasons that the participation of children with disabilities in their own service provision and in agency planning is particularly important. Dickens (2004) adds that, in fact, they have a greater need to be consulted because they are subject to more assessments and medical interventions than other children. Additionally, many are subject to increased surveillance in their lives, leading to increased adult control and disempowerment. The children themselves continually highlight the importance of participation as Beresford (2002) and others (Morris, 1999; Mitchell and Sloper, 2001) have found.

Definitions

The term participation covers a broad continuum of involvement in decisions involving many different processes (Kirby *et al.*, 2003; Sinclair, 2004). Interpretations of the term include taking part, being present, being involved or consulted. It can also denote a transfer of power when participants' views influence decisions. Although the second definition is our primary concern here, the first is equally important. The case for children's participation is well documented and is often grouped into legal, political and social reasons. Discussions revolve around upholding children's rights,

improving services and decision-making, promoting protection and enhancing democratic processes (McNeish and Newman, 2002; Willow, 2002).

Policy context

Since the late 1990s, the UK government has demonstrated a commitment to increasing the involvement of children in decision-making processes. Children's rights to participate are enshrined in the Children Acts (1989, 2004), the United Nations Convention on the Rights of the Child (CRC) (1989), the Human Rights Act (1998) and the Convention on the Rights of Persons with Disabilities (2006). The National Service Framework for Children, Young People and Maternity Services in England (NSF) (2004) stresses the need to consult and involve children, including those who rely on communication equipment or who use non-verbal communication such as sign language. The NSF states that facilities, equipment and skilled workers should be available to enable these children to participate in assessment and decision-making processes.

Evidence of disabled children's participation

However, despite the above, evidence suggests that disabled children in the UK, especially those with complex needs or who communicate non-verbally, are much less likely than their peers to be engaged in decisions about their own lives (Cavet and Sloper, 2004; Department of Health/Department for Education and Skills, 2004; Franklin and Sloper, 2009). One limitation is the lack of availability of communication aids (Hodge, 2007). Other problems are raised by linguistic and cultural barriers for disabled children from ethnic minority groups (Marchant and Jones, 2003). Despite recent endeavours towards participation of deaf adults (McLaughlin *et al.*, 2007),

much needs to be done in consulting with deaf children. This exclusion from decision-making processes reflects and adds to disabled children's exclusion and disempowerment by rendering their views and experiences invisible.

There is a small, but growing body of evidence providing examples of disabled children expressing their views about services (see for example, Mitchell and Sloper, 2001; Knight *et al.*, 2006). These studies and the rest of this paper illustrate that disabled children have much to contribute and that their exclusion from participation often results from the lack of skills, training and knowledge of the adults who hold the power to facilitate or withhold their involvement. Sharing good practice continues to be important, and the use of websites and forums such as www.participationworks.org.uk and www.childrenssociety.org.uk/disabilitytoolkit⁴ facilitate this process.

Social work training

Turning to social work training, whilst the curriculum must now include communication skills with children (Department of Health, 2002) there is no certainty as to what, exactly, should be taught at qualifying level. One of the main contributory factors is the management of specialist skills within a generic curriculum. While teaching may include methods of direct work with children, such as non-directive play therapy (Wilson and Ryan, 2005), it does not always nor necessarily include the specific skills and tools used for work with disabled children. The same is true at post-qualifying level. Currently, social work students' experiences of working and communicating with children are *ad hoc*, much depending on the nature of the agency in which they undertake their practice learning and the particular interests and expertise of their teachers. Lefevre *et al.* (2008) argue for introducing a

standardised and planned element of communicating with children onto the curriculum for social work students, specifying the inclusion of the skills needed to communicate with disabled children.

One aspect of facilitating communication with children in social care is to ensure they have the necessary information. So preparing a child for and facilitating their appropriate involvement involves explaining the process and exploring the choices and boundaries of decision-making as well as enabling them to decide what, for them, is the best means of participating, be it being present in a meeting, in writing or through the use of an advocate (Bell, 2002). Some children will need help in devising symbolic means of communicating their wishes. For some, computers will provide a further avenue (Mitchell and Sloper, 2008). Good practice would also require that feedback and explanation as to the reasons for the decisions made, is accessible and properly understood.

Social work practitioners should involve service users in assessment, planning, intervention and review (Department of Health, 2006b). However, the 26 Integrated Children's System⁵ (ICS) electronic exemplars used for this purpose have not been designed with the needs of disabled children in mind, and research suggests that practitioners are having difficulties in using them with disabled children (Mitchell and Sloper, 2008).

Working with children with learning disabilities and/or who communicate non-verbally: methods and Approaches

To provide some examples of how disabled children can be better involved in social work processes this paper describes two research studies involving children with learning difficulties and/or who communicated non-verbally.

The first of these is on-going, the *Choice and Change* project. It explores choices made by young people with progressive medical conditions and their families about their support and other related services over a three year period (2007-2010). This paper focuses on interviews conducted with a sample of 27 young people with a life limiting condition recruited from two children's hospices. The sample varies re gender, age (13-21 years), ethnicity (white and Pakistani) and type of disability (www.york.ac.uk/inst/spru/research/summs/DHPpanel.html). For the 12 who had learning disabilities and/or communicated non-verbally, semi-structured interviews were inappropriate so non-traditional methods were developed and used.

The second study, the *Deaf Services* project (2005 and 2007), aimed to explore the views of 25 young people, aged from seven to 18, who were using specialist mental health services for deaf children and their families. They were interviewed twice, at a six to nine month interval.

Deaf children use a variety of ways of communicating including British Sign Language (BSL), Sign Supported English (SSE) and/or oral methods of communication (speech, lip-reading, and the use of residual hearing). A child may use more than one method of communication and their BSL or SSE may be idiosyncratic. Furthermore, English is a second language for many deaf children and

much of the written material commonly used in both assessment and treatment may be inaccessible to many (Beresford *et al.*, 2008).

Therefore, in both projects it was recognised that more 'traditional' research materials, based exclusively on the English language, were inappropriate, and separate research materials were developed, for example a range of 'visual' research materials for deaf children (see also Kelly, 2007).

Adapting materials - information leaflets

For both projects, separate consent sheet and information sheets were developed, based on the written word and in simple, focused language. Symbols-based information and consent forms were also developed in the *Choice and Change* project. Because different young people use different symbols, two diverse symbol systems (Widgit™ and Boardmaker™) were chosen based on hospice staff advice and the researcher's previous experience.

In the *Deaf Services* project, three deaf researchers and other both hearing and deaf professionals who work with deaf children were consulted. Simply worded information leaflets were provided and explained by staff working in the specialist services and when necessary, in sign language (Beresford *et al.*, 2008).

Facilitating involvement - data collection materials

In both projects, researchers initially showed the children a red card ('stop') and yellow card ('no thanks'), encouraging them to use these cards at any time if they

wanted to interrupt the research process (red) or move onto the next question (yellow).

In the *Choice and Change* project, socio-demographic information was collected from the young people via a cartoon based 'All About Me' booklet and a booklet was made before each interview. This was a positive experience, boosted confidence by demonstrating to the young people that they could answer research questions, and provided an important 'ice-breaker'. It brought an element of fun to the meeting and each young person enjoyed receiving a completed copy.

An 'ice-breaker' was also used in the *Deaf Services* project. Here children drew a 'map' of everyone who helps them when they are feeling upset, including professionals, family and friends. Background information about the child's use of the specialist mental health service was collected via a brightly coloured sheet of paper with five geometric shapes, each containing a question about their clinician, such as 'How do we communicate?'. Photographs of the clinic and staff were used to aid recall. Both projects' ice-breakers provided important background information in a relaxed manner, while enabling a quick assessment of each child's preferred mode of communication and level of understanding. For the child, it focused attention on their everyday lives, things that we thought that they would be able to and enjoy doing.

The Choice and Change project -Talking Mats™

Turning to the non-verbal methods utilised in the two projects, 16 very 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. Talking Mats™ are primarily a series of question based 'mats' with symbols attached. Participants are asked questions, invited to choose the symbol(s) that matches their ideas and/or emotions and each created their own symbols board (see, for example, Figures 1 and 2).



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

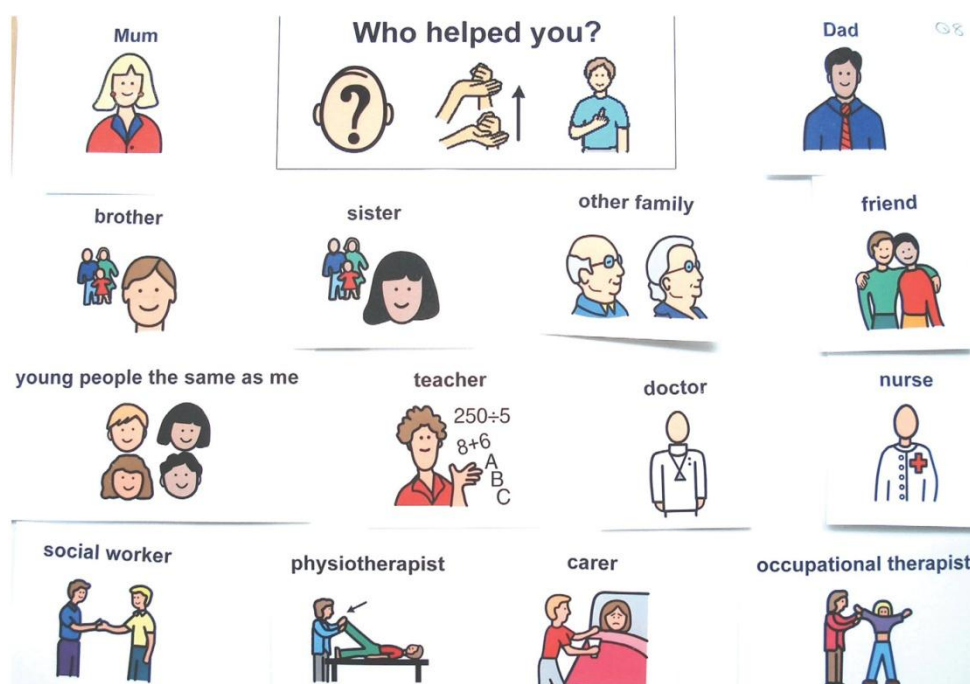


Figure 2. Example of Talking Mat™ used in the Choice and Change study.

Talking Mats™ were initially used with adults and have been subsequently developed for use with other groups, including older and younger people (Cameron *et al.*, 2004; Murphy, 2004). Others, e.g. Whitehurst (2006), have used them with disabled children. Talking Mats™ were chosen because of their flexibility. They can be used in conjunction with other communication systems as they aid rather than dictate a participant's communication preferences.

Twelve young people with different learning disabilities and/or preferred communication modes were interviewed with the aid of Talking Mats™.

They all engaged with the symbols, liking their colourfulness and enjoying creating their own board. Their flexibility enabled them to choose different symbols, some focussing on 12 and others on two or three. The choice was made through a range of preferred communication modes, including verbalising, eye-pointing, signing, and

moving an arm/hand or facial expressions. The researcher personalised the interview by using background information, such as relevant people or places, from the 'All about Me' booklet.

The Deaf Services project - use of 'visual' materials

In the *Deaf Services* project, a number of 'visual' research materials were developed with the help of deaf researchers who ensured the words used were meaningful and consistent (between BSL and English) and that the materials were appropriately pitched. Children were given a task to choose, from nine illustrated cards, those that represented their desired personal outcomes for specialist support. Each card contained a short sentence with a colourful picture illustrating its meaning, and including some feeling statements. Children were also given some blank cards on which to write anything they wanted. The researcher placed these cards in a booklet, 'How I am feeling now', under each of which was a scale from one to 10 ('worse' to 'better'). Six to nine months later each child indicated where they now placed themselves, thus providing a starting point for the researcher to discuss if services had helped each child reach their desired outcomes. Similarly, for a discussion about their clinician, the children were shown a photograph of their clinician and asked to mark them out of 10.

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, 2007). Difficulties include issues of confidentiality and

parental consent (for minors). For young people with learning disabilities and/or non-verbal communication, there is the additional issue of competence, perceptions of their competence and ability to make informed decisions surrounding consent (Cousins and Milner, 2007).

In the *Choice and Change* study, the sample was gained by working closely with hospice staff. Although some parents felt that their child could not participate because of their disability, following careful explanation of the project and the use of symbols, a number reconsidered and agreed for the researcher to meet their child. The initial, and in some cases continuing fear and negativity displayed by the parents highlights wider issues and social presumptions; for example, that parents had rarely experienced practitioners seeking to listen to their child using non-verbal methods. Franklin and Sloper (2009) noted this in relation to young people's participation in review meetings. Spending time talking to and reassuring parents that their child could provide information was an important part of the negotiating process in this project.

Providing opportunities for parents and/or carers to be present when the researcher met the young people was also welcomed in this project, where 10 out of 12 young people were interviewed with a parent(s) present and the remaining two with a carer. This was invaluable in helping with interpretative skills, especially when participants used personalised and/or indistinct modes of communication, such as facial expressions or thumb movements. It was also re-assuring. However, it is recognised that the presence of others, especially parents/carers, can influence the context and dynamics of interviews (see Cameron and Murphy, 2006). Open and honest recognition of the potential role of others is clearly helpful.

In the *Deaf Services* project, many children were accustomed to parents and carers acting as intermediaries in the communication process between them and other people (such as professionals working with the family). So the researcher asked parents to ask their child which method of communication they preferred and whether they preferred a deaf or hearing researcher. Researchers felt that children's preferred method of communication may not always coincide with what their parents choose for them. For example, it is possible that the parents might choose British Sign Language or spoken English, and that their choice of researcher may depend on their perception of their child's identity as 'deaf' or 'hearing'. Where they viewed their child as part of the 'hearing' world they may prefer a hearing researcher and use English. Others, who favour their child meeting deaf adults and establishing a deaf identity, may want their child to meet a deaf researcher and use sign language. Conversations with parents revealed that their views did not necessarily coincide with their child's, thus highlighting the importance of listening to the preferences of parents and deaf children separately. The researchers endeavoured to mediate an agreed plan but ultimately, prioritised the child's preference.

Importance of Flexibility

In both projects, developing different research tools, such as a simple verbal topic guide, the Talking Mats™, or tasks using picture-cards enabled the researchers to develop a flexible and more personalised approach and allowed each participant to choose the method they preferred. For example, one young person in the *Choice and Change* project initially felt the Talking Mats™ would be 'babyish', but when he saw the symbols and the fun nature of the boards, changed his mind. Similarly, the range of options available gave the researcher flexibility to be more inclusive. In this

project, although two young people on the telephone seemed to be verbally competent, in person their level of understanding and verbal communication was less. The verbal topic guide was inappropriate and the Talking Mats™ were more relevant.

The longitudinal nature of this project also enabled the researcher to be flexible and to develop appropriate research tools. For example, a photo of each personal mat could be sent to the child for development in the next round of interviews. Working with young people with learning disabilities and/or non-verbal communication takes time (Franklin and Sloper, 2009): it is not a 'one off' encounter.

The *Deaf Services* project also demonstrated the importance of researchers being flexible and responsive to participants' changing communication preferences. For example, some deaf children began their interview in English but then used increasingly and, in some cases exclusively, sign language. The project highlighted that communication amongst deaf children is extremely varied. Deaf children may have cochlear implants, hearing aids, or neither and amongst those with an implant or hearing aid, their ability to hear may be very limited and sign language preferred. Others with an implant may hear and speak very well and some children who use sign language may be fluent, whilst others may have very limited signing skills. In other words, deaf children are heterogeneous and do not fit into one or two neat categories. Researchers and practitioners need to be sensitive to this diversity and responsive to communication preferences if or when they change. Having some signing skills is clearly an important asset to professionals working with deaf children.

Discussion and concluding comments

Researcher lessons learnt

Working with young people with learning disabilities and/or non-verbal communication has thrown up a number of important practical and theoretical issues. The lessons learned have wider applicability and raise considerations for the development of social work education and training. However, it is important to acknowledge that these considerations are based on two specific projects which focused on precise groups of children: the *Choice and Change* project on young people 13-21 years with life limiting and progressive conditions; and the *Deaf Services* project on deaf children, 7-18 years old. Different groups of disabled children may raise different issues and lead to other suggestions for social work education. Here, three issues appear particularly relevant.

A range of communication tools

These projects echo messages from others (Whitehurst, 2006; Franklin and Sloper, 2006, 2009) of the importance of developing a range of tools for listening to disabled young people. One standard does not fit all. The development of skills and tools in the *Choice and Change* and *Deaf Services* projects was a gradual, cumulative process, involving close listening to participants. Talking Mats™ were particularly useful, providing a flexible and adaptable mode of communication. This method could be used with disabled young people more generally to discuss important issues, such as in planning and reviewing services. As already mentioned, this method has been successfully used to discuss transition (Cameron and Murphy, 2002) and desired outcomes from services (Rabiee *et al.*, 2005).

Spending time and learning how to communicate with participants

The importance of time is also key in involving disabled children. As demonstrated here, this is particularly important when working with young people with learning disabilities and/or non-verbal communication. Developing rapport with them and talking to them is a slow process. The need for researchers and practitioners to develop confidence, knowledge and skills is also emphasised (Council for Disabled Children, 2000). This highlights the importance of teaching a range of communication skills, as well as ensuring students appreciate the importance of developing relationships over time.

Different types of knowledge and levels of data

In these projects working with a diverse range of young people, both verbal and non-verbal, produced a range of data. The Talking Mats™ and the card-based tasks and BSL communication provided data that differed from that produced by more traditional verbal semi-structured interviews. Reflecting on that difference, while the BSL based data were as rich as data produced by the spoken word, the symbol based data provided invaluable insights about the lives and priorities of two previously marginalised groups. These research experiences demonstrate the need to move beyond and challenge traditional ideas of what is deemed 'appropriate' and acceptable knowledge (see also Aldridge, 2007; Nolan *et al.*, 2007).

Implications for social work education and some suggestions for future developments

The experiences from these projects highlight the need to incorporate communicating with people with learning disabilities and non-verbal communication

as specific areas of learning for all social work students, with provision as a coherent and uniform aspect of the curriculum. Current provision is, as Lefevre *et al.* (2008) have demonstrated, *ad hoc* and poorly monitored. Students need opportunities, in class and on placement, to develop appropriate communication skills, techniques and aids and to gain experience in a supported learning environment. Hands-on practice takes time to nurture and the provision of specific disability relevant communication information is necessary. Basic deaf awareness training and sign language skills for social workers preparing to work with deaf children are clearly needed as is knowledge of how to access specialist services and support.

In addition, opportunities should be provided for students to listen to and learn from service users who are learning disabled and who communicate non-verbally. The involvement of service users is increasing apace in qualifying training, and learning from participants' personal experiences of what works/does not work was important here for the researchers as it is to social work students. Including research participants and social work clients in curriculum development and student workshops is one way forward.

Practical ideas and experiential learning are part of a wider process which should encourage social work students to think creatively. While many social workers do recognise the importance of listening to these children, many are handicapped because of inadequate resources and the need to meet government targets. For example, the time limits set for assessment may militate against practitioners having the time necessary to build up relationships, or to use non-verbal communication (see Mitchell and Sloper, 2008). In addition, as Ware (2004) notes, many young people lack participatory experience and do not know how to express their views.

Talking to verbal participants or family members is often quicker and easier for time limited practitioners. While social work educators may not be able to remove such practice and policy conflicts, they should alert students to these tensions and think creatively together about how they can be addressed in practice.

Increased communication and social exclusion

A wider question is also posed: does improved communication increase participation and address some of the exclusionary barriers that disabled children face? Within this article, the authors have sought to demonstrate, through their work as researchers, that children with learning disabilities and/or non-verbal communication have important things to say and can participate if appropriate methods are used. Involving this particular group of disabled children is important in itself because of their experience of marginalisation. It also demonstrates clearly that disabled children are heterogeneous both in their support needs and their service preferences.

Enabling social work students to use alternative modes of communication in their work has the potential to address some social exclusionary barriers, in particular those relating to inter-agency working and to decisions about specialist or mainstream services. Disabled children and their families frequently want both but at different times and in different contexts, and they need to be helped to articulate their views and make considered choices. At the same time, social workers can take a lead role in educating or facilitating practitioners from health, education and housing to work with these children. This could facilitate greater inter-agency co-operation and provide more co-ordinated integrated services to address the multi-dimensional nature of social exclusionary barriers.

Despite this, it is important to acknowledge that merely recording children's views does not automatically lead to service or policies development. There is still limited evidence that children's participation leads to real change (Kirby and Bryson, 2002; Badham, 2004). In addition, since we know that social exclusion occurs on many different levels, better communication may have little impact on the wider socio-economic barriers identified at the beginning of this article, such as poverty and housing. While such issues require policy changes beyond social workers' and children's control, the views of marginalised children must contribute to the decision-making process. Change takes time and does not occur in a vacuum.

This article has demonstrated important links between research and social work education and practice. We hope it will begin to inform policy makers of the importance of hearing and acting on the views of children with learning disabilities and/or non-verbal communication, as well as providing some helpful and concrete suggestions and guidance to social work educators.

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Notes

1. Triangle—an independent UK based organisation providing training and consultancy for families and professionals around issues, such as children's rights, child protection, communication and participation. Triangle frequently advises on working with disabled children.

2. Assessment Framework—government based framework (England and Wales) to guide practitioners in their assessment of children and their families advocating evidence-based information and interagency working.

3. The Children's Fund (2000-2008)—an English initiative to facilitate greater inter-agency co-operation and develop preventative services for families in local authorities. The Fund focuses on five groups 'at risk' of social exclusion; disabled children (5-13 years) are one of these groups. A national evaluation of the Fund took place between 2000 and 2006.

4. Participation Works—consortium of six UK voluntary and statutory organisations; Disability Tool Kit—interactive website developed by the UK based Children's Society for practitioners, academics and lay people to share ideas and good practice.

5. Integrated Children's System (ICS)—single approach to assessment/review for all 'children in need' (including disabled children) in England and Wales based on electronic recording and information sharing.

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