Ask us too! Doing participatory research with disabled children in the global south

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What is This?
Ask us too! Doing participatory research with disabled children in the global south

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Abstract
This article considers how disabled children and young people living in the global south can be included actively in research that explores their lives. While acknowledging the complex, theoretical dilemmas in the overlapping arenas of childhood, disability and international development, the focus here is on methodology. Many researchers argue that children in diverse contexts can be active participants in research and this is increasingly occurring globally. However, this trend towards consulting children themselves is rarely extended to those with disabilities. Arguably, they are accidentally forgotten, assumed to have nothing to say or perceived to be methodologically difficult to include. Thus, disabled children and young people's perspectives are overlooked, particularly in the global south. We describe two participatory research projects with disabled children and young people in India and Sri Lanka, and focus particularly on practical issues that arose including recruitment, information and consent processes and data collection methods. We argue that considering these issues and making the necessary adaptations to enable children with a variety of impairments to participate meaningfully contributes to enacting both the relevant United Nations conventions, the 1989 United Nations Convention on the Rights of the Child and the 2006 United Nations Convention on the Rights of Persons with Disabilities. Advocating their participation without making appropriate provisions is potentially tokenistic and unethical. It is necessary and possible to include them both in ‘mainstream’ child-focussed research, and specific disability-orientated projects. Involving disabled children in research has dual purposes: inclusion of their perspectives alongside those of other children and highlighting their disability-specific views where relevant. What they say may be surprising to some and challenge assumptions about them. Importantly, this will contribute to reducing their marginalisation from mainstream society.

Keywords
Disabled children, inclusion, participatory research, qualitative methods, South Asia

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Introduction

This article explores how disabled children and young people living in the global south can be active participants in research that explores their lives. There are some complex, theoretical issues in the overlapping arenas of childhood, disability and international development. However, the focus here is on practical methodological issues which need consideration to ensure disabled children’s successful participation in research and for their perspectives to be heard alongside their peers’. We use the dichotomising terms ‘disabled’ and ‘nondisabled’, and global ‘north’ and ‘south’ as less than satisfactory short-hands, while recognising them as potentially problematic and reductionist.

Research with children

Childhood researchers argue that children and young people in diverse contexts can and should be involved in research both as active competent participants and perhaps additionally as researchers themselves, rather than merely as subjects of adult gaze (Alderson and Morrow, 2004; James et al., 1998). Kellett (2010) reminds us that Article 12 of the United Nations (UN) Convention on the Rights of the Child (UN, 1989) assures children the right to express their views on matters affecting them. Others have emphasised the importance of respectful child-centred research approaches in giving young people a sense of involvement in decision-making, both about individuals’ lives as well as in policy-making and service provision planning (Ben-Arie, 2005). This kind of research is increasing globally, gradually reflecting the diverse life worlds in which children live, and there has been active debate about methodological aspects of working with children (Mishna et al., 2004; Punch, 2002).

However, in the context of sometimes hegemonic promotion of children’s rights and seemingly universal emphasis on participation, Gallacher and Gallagher (2008) caution against suggestions that participatory research with children is necessarily ‘empowering’. Others are wary of the essentialising of ‘children’s voices’ (James, 2007; Spyrou, 2011). Clearly, then, researchers should be cautious in claiming the power or essential ‘goodness’ of participation per se and wary in interpreting and representing what children say and in claiming its authenticity or potential to empower. Like data from adults, those from children often reveal diverse and multidimensional lives which may be contradictory, ambiguous and therefore ‘messy’ (Elden, 2012). Nevertheless, increasingly research with rather than about children recognises that given appropriate opportunities, they have and can express their own views, and these are often different from those of proxies such as parents or professionals who might previously have answered for them.

Disability research

Like the movement towards participatory research with children, a parallel shift has taken place within disability research, underpinned by theories from Disability Studies. The Social Model of disability, which sees societies’ attitudes as the main problem for
people with impairments, promotes participatory and emancipatory research (Priestley, 1998). Hence, disability research has also taken an inclusive and reflexive turn in the last two decades. Ideally, disabled people lead the research agendas, rather than being passive subjects or objects of investigation. There has been increasing interest in the socio-political processes which create disability and in disabled people’s views about how these impact on them and can be challenging. Activists argue for the power, legitimacy and authenticity of research by or at least with disabled people themselves (Mercer, 2002). Garland-Thompson (2006) argues that research that explores the real lives of disabled people is ‘humanizing’ and thus challenges stereotypes about them.

The main drivers of the theoretical shift towards social models of disability have been in the global north, originated and promoted, at least initially principally in academia. These ideas are also prominent in the global south although not clearly located in universities, but through activism promoted by disabled people’s organisations (DPOs) advocating disabled people’s empowerment (Disabled People International http://www.dpi.org). Often human rights discourses and latterly the UN Convention on the Rights of Persons with Disabilities (UNCRPD; UN, 2006) are invoked to argue for equity and the removal of barriers to inclusion in all aspects of disabled people’s lives.

However, research about disability in the global south is recognisedly lacking (Singal, 2010; World Health Organization [WHO], 2011). Historically, it has tended towards quantitative approaches focusing on identification of impairments or evaluation of services usually with a health focus (WHO, 2011). Recently, there has been increased interest in qualitative studies of structural aspects such as relationships between disability and poverty and/or gender (Ghai, 2002; Grech, 2011). Critically engaged work is increasing, focusing on socio-political and experiential aspects, exploring policy and/or the lives of disabled adults with them directly (Disability Rights Promotion International [DRPI], 2010). However, with some exceptions, there is still a dearth of research by scholars from the global south or disabled researchers (Chappell and Johannsmeier, 2009; Singh and Ghai, 2009). Meekosha (2011) argues powerfully the need to problematise the domination of ‘northern’ models of disability, research, funding and publishing biases. Additionally, most of the research so far has asked about the lives of disabled adults rather than children.

**International development research and disability**

International development practitioners have a longstanding tradition of using participatory methods to explore the concerns of people at community level (Chambers, 1997) and disability is now coming onto development agendas (Groce and Trani, 2009). However, the exact meaning of participation and its relationship with empowerment is being problematised (Stoecklin, 2013; Tisdall, 2013). Crivello et al. (2009) highlight that incorporating children’s participation into the research agenda will contribute to breaking down the barriers imposed by power differentials based on age and material differences. Hart (2008) argues importantly that participation by children (and we emphasise in research) is not only a right in itself but also a vital means to the realisation of children’s other rights. He notes that
Children’s participation has become an important element of development efforts. (p. 408)

Likewise, Camfield et al. (2009) emphasise that

there is a strong pragmatic, ethical and human rights imperative for understanding and monitoring the outcomes of poverty and other adversities on children’s well-being … (p. 74)

**Research with disabled children**

This shift towards consulting children is only gradually extending to disabled children. They are usually implicitly or explicitly excluded from ‘mainstream’ child-focussed development projects (Feldman et al., 2013). There are some participatory studies involving disabled children in the global north (National Children’s Bureau, 2012). Here there is also some more nuanced discussion about the particular exclusion of children with learning, communication and social-emotional impairments and on methodologies (Morris, 2003; Nind, 2008). However, many of the studies focus on specific impairment or disability aspects, such as service provision, or individual problem-solving related to impairment, rather than exploring broader aspects of disabled children’s lives. Thus, they are rarely asked about general life experiences such as friendships, consumption, the environment, the media or future aspirations as other children are. Exceptions are Davis et al. (2003), Cocks (2008) and Wickenden (2011a, 2011b), who set out to explore disabled children’s broader perspectives. In the latter study, participants emphasised their irritation that their disabled identities were the ones that were privileged by most people around them. They saw themselves firstly and more importantly as ordinary teenagers.

The inclusion of disabled children and young people themselves in research has yet to emerge strongly in the global south, where they are arguably more excluded and disadvantaged than their northern counterparts (WHO, 2011). The recent UN International Emergency Children’s Fund’s (UNICEF, 2013) *State of the World’s Children 2013* report, focusing particularly on disabled children, states that

Research on child disability is woefully inadequate, especially in low and middle-income countries. The resulting lack of evidence hinders good policymaking and service delivery for children who are among the most vulnerable. (p. 8)

Lansdown (2012a, 2012b), in arguing for the potential of the two relevant UN conventions (UN Convention on the Rights of the Child [UNCRC], 1989; UN Convention on the Rights of Persons with Disabilities [UNCRPD], 2006), in combination, to improve the lives of disabled children, also highlights their increased vulnerability. Although some would dispute this label (Groce et al., 2011), it is recognised that in the global south they are often particularly disadvantaged as evidenced by higher levels of mortality, malnutrition, poverty and abuse and lower access to healthcare, school attendance and literacy (UNICEF, 2013; WHO, 2011). There is clearly a need to learn directly from them about their lives.

Disabled children’s exclusion from research may be explained in various ways. Possibly they are simply forgotten as potential participants, which suggests that they are
not seen as agentive citizens (Goodley and Runswick-Cole, 2011). They may be invisible in communities because of their absence from school and community activities, and thus hard to recruit. Additionally, adult gatekeepers may assume they have nothing to say or are incapable of having or expressing views. In this case, they are being judged on the basis of what they can (or cannot do) rather than on who they are (Thomas, 2004). Finally, researchers may judge that including them is methodologically difficult and expensive.

Research undertaken in the global south looking at disabled children’s lives usually does so from adult perspectives (Singal et al., 2010). Kembhavi and Wirz (2009), Singh and Ghai (2009) and Singal (2010) are rare exceptions. In the United Kingdom, Rabiee et al. (2005) propose and we would extend this globally, that

the exclusion of disabled children from research and consultation says more about unsuitability of research and consultation methods and adults not knowing how to relate to them than about the limitations on the part of informants. (p. 8)

Two studies with disabled children

We describe briefly two research projects, carried out in South India and North India/Sri Lanka, respectively, which used participatory methods with groups of disabled children and youth. Both explored aspects of inclusion, participation and well-being, though the findings are not discussed here and are published elsewhere (Kembhavi and Wirz, 2009). The focus is on methodological aspects, illustrating the practical considerations needed to ensure the genuine rather than tokenistic participation of disabled children and young people in research.

Researchers’ positionality

The authors are social researchers, originally with clinical backgrounds working with disabled children (speech/language therapy and physiotherapy). We have many years of experience of working with children who have a variety of skills and difficulties, in their schools, homes and health settings in the United Kingdom, India, Sri Lanka and Canada. Our doctoral and postdoctoral work explores the lives of disabled children from broad sociological and anthropological perspectives. We are particularly interested in developing participatory methods of working with disabled children that remove barriers to their perspectives being heard and which facilitate their inclusion alongside their nondisabled peers. We are, however, wary of generalising either about what happens in particular contexts (i.e. parts of ‘the global south’) or about supposed categories of children (i.e. ‘disabled’ or ‘nondisabled’) or childhoods.

Study 1. Exploring participation with disabled adolescents in South India

Gayatri Kembhavi-Tam (G.K.T.) undertook this exploratory qualitative research study in Bangalore, India, with a group of adolescents with physical disabilities, in collaboration with local schools and nongovernmental organisations (NGOs).
The primary research question was, ‘What are the perceptions of participation and inclusion of disabled adolescents in south India?’

The study took place in three settings: a special school for children with cerebral palsy, two urban slums and a vocational skills training programme at a local NGO. The disabled adolescents were recruited by an occupational therapist (special school) or community health workers from two NGOs (urban slum setting) and by the vocational training programme director. A total of 37 participants were divided into groups based on age (11–15, 16–18 years) and the older age group was further separated by gender, as suggested by NGO staff. Adolescents were invited if they had a physical impairment leading to mobility limitations or had multiple physical and sensory impairments (vision or hearing). Those with severe learning disabilities were excluded (discussed below). Focus groups, individual interviews and group activities carried out over 10 months sought the participants’ perceptions and experiences.

Photography was used as a key visual method to foster discussion among participants during focus groups. Participants were given disposable cameras, instructed on their use and asked to take pictures of things that (1) made them happy, (2) made them sad, (3) made them angry and (4) that they would like to change. A week later, the cameras were returned for development of the images. During the groups, the photographs were returned to each participant, and discussion was facilitated about issues relating to participation and inclusion. The suggested foci of the photographs were deliberately chosen to elicit feelings rather than documentation of their environment. The pictures taken varied widely in content and they enhanced and illustrated the points during discussions, leading to heated debates about a range of issues, some unanticipated by the researcher.

Given the possible barriers imposed by culture, language and power relations between the researcher and the participants, the photographs were a highly successful way to facilitate disabled young people to talk about important issues without having to answer direct questions. Even initially quiet and reluctant participants were excited to share their pictures. For many, this was the first time they had used a camera or seen photographs of their families. Several participants who experienced physical challenges with using the cameras asked relatives for assistance, reporting that they instructed them what to photograph.

The NGO staff and community health workers who were effectively gatekeepers to the teenagers’ participation were initially unsure that they would be able to complete the tasks. They anticipated that the adolescents would not be able to use the cameras, and would be irresponsible with the equipment. Contrary to these expectations, the young people took immense pride in being given this responsibility.

The local partners were surprised and pleased with the success of the study and discussed using similar methods in the future. They were also surprised at the depth and openness of the discussion. These teenagers had not previously been involved in such consultations or in decision-making. While the NGOs had several different outreach programmes for disabled children and young people, only their parents were involved in community groups and weekly consultation sessions. The success of these adolescent-focused discussions demonstrated to the local partners the potential of including children and young people directly in their future work. The study is described in depth elsewhere (Kembhavi and Wirz, 2009).
Study 2. A pilot study exploring disabled children and young people’s views of inclusion and well-being in rural and urban India and Sri Lanka

Mary Wickenden (M.W.) undertook this pilot study for a larger study in four sites in India and Sri Lanka. The aim was to investigate the feasibility of and methodological issues in exploring disabled children’s perceptions of their lives, through participatory meetings. The larger study aims to explore issues of inclusion and exclusion, well-being and poverty, working with disabled children over a period of 9–12 months, as well as collecting data from their parents and comparator families.

The pilot study was undertaken in partnership with local universities and NGOs in four settings, one rural and one urban in each country, India and Sri Lanka. The researcher had previous relationships with the local partners, working on a number of training and research activities related to disabled children and their families.

Two children’s meetings were held in each of the four settings, with younger (8–11) and older (12–18) groups of children. Participants were recruited in collaboration with the local partners who provided organisational support and research assistance. Each group had 3 to 6 participants with a variety of types and severities of impairment, including some children with communication and cognitive difficulties. Information and written consent procedures were undertaken with their parents and we tried a variety of consent/assent processes with the children. These included written consent for some (appropriately worded), individual and group, picture, symbol and signed versions. All parents and children who were invited agreed to join in.

The meetings lasted 1½ hours and were held in familiar settings (house, temple hall, school, NGO room). Most parents accompanied their children to the meeting, but all except one left their child and returned later. One mother stayed as her son was quite anxious. In all meetings, there was at least one research assistant who knew the participants well, in addition to M.W.

We piloted broadly the same four activities in all meetings, as described below, but made adaptations to match the participants’ ages and skills. In the older groups, there was more written material and less picture/sign support, as most were literate, and there was more verbal discussion. In the younger groups, the research activities were supported by pictures and symbols/signs and alternated with games. All the meetings ended with snacks and small gifts.

The main activities were designed to be very flexible in relation to topic and degree and type of participation expected. Particularly, we did not want to start discussions about complex or potentially sensitive topics during this pilot phase as we did not know the participants well or whether and when we would be able to run subsequent meetings.

1. ‘My important people’. Circles of closeness. All children’s names were written in the middle of a set of concentric circles on a joint flipchart. Each child had different coloured stickers on which to write, draw or have written, names of people to place on the circles to show who was important to them. A tactile version was made for a blind child and symbols to represent different people provided for a
boy who had no speech. Children were encouraged to talk about the people they had named and why they were important.

2. ‘Things I like and don’t like’. A large grid with a pictorial emoticon scale in column headings (like, don’t mind, don’t like, don’t know). Initially the researchers suggested things that children might like or dislike and they then placed stickers, thumb prints or their initials to rate their feelings in the relevant rows and columns. Initially, ‘easy’ and obvious items were suggested so that everyone understood the task (e.g. food, going out, being with family, festivals, being on your own) and then the children contributed their own items (e.g. positive: bathing in the sea, eating out, playing with my brother, my dog; negative: adults fighting, schoolwork, wanting a job).

3. Vignettes. A problematic story supported by a series of pictures (about a disabled boy who wanted to play cricket but who was excluded) was told. This was supported by pictures and signing of the key events and then followed by a group discussion about what solutions there might be. The older groups had a second story about a deaf girl and friendships.

4. Review of the meeting. There was a discussion about what the participants thought of the meeting, supported by visual emoticons. They considered some possibilities (represented pictorially) for the content of future meetings, as well as contributing their own ideas for topics and how future meetings could run.

The meetings were successful both in the sense of being enjoyed and rated positively by the participants and in generating rich and interesting data. In all meetings and activities, there was enthusiastic discussion and comparison of ideas between participants and tolerant attitudes towards other group members who needed help or extra time to respond. All groups said they would like further similar events. However, we should treat such views with some scepticism, as there was likely to be a degree of courtesy bias, especially in the context of poverty and because of a noticeable lack of community resources or activities for disabled children in all these settings, as reported by their parents.

Discussion

We discuss key aspects of the research process which arose as needing further reflection in one or both studies and in planning for further studies.

Selection and recruitment of disabled children

Selection and recruitment of disabled children in research is a thorny subject, and the issues are different depending on whether a ‘mainstream’ or specific disability-focussed study is planned. As noted earlier, in mainstream childhood research, they are often simply excluded at the design and sampling stages. The number of disabled children within a general population is statistically likely to be small (5%–10% UNICEF, 2013), but they should be present.

When forming focus groups, researchers typically aim for homogeneity of members. For example, nondisabled children might be matched on gender, age, skills, interests
and/or life situations depending on the research question. There is a general assumption that they will be similar enough to work together, given sensitive handling of variations in skills, experience, personality or confidence. If the focus is a generic topic that affects all children (e.g. nutrition, safety, transport), disabled children should be included alongside their nondisabled peers, matched on these same criteria. Ideally, their types and severities of impairment should, if they are being treated equitably, not be criteria for selection. Their impairment would only be noted in order to plan for appropriate support and access provision.

In contrast, if as in our two examples, the research is disability-specific (e.g. disabled children’s access to health, education, sport), and therefore having an impairment is a selection criterion, then strategies for recruitment might be quite different. The researchers need to decide whether it is appropriate to stratify the sample by impairment group. It may sometimes be appropriate to run separate groups or activities for children with different types of difficulties. For example in G.K.T.’s study above there was a specific focus on children with physical impairments, and this is a common choice made by researchers who perhaps perceive this as the ‘easiest’ disabled group to work with. Although this may seem to conflict with a wholly inclusive approach, it can perhaps be justified on the grounds both of maintaining homogeneity of the group and also because the types of activities and the adaptations needed might be similar for all recruits.

In contrast Study 2 deliberately set out not to select children on the basis of type of impairment, and the recruitment information to adult gatekeepers actively encouraged them to facilitate children with any kind of support needs being invited. This was an attempt to subvert the usual ‘hierarchy of impairment’, whereby those with more stigmatised impairments are more excluded. This required considerable reassurance that the meetings would be suitable for children with any impairment and that the activities would be appropriately adapted for them.

Reticence about suggesting the inclusion of children with communication, learning and behavioural difficulties (the most stigmatised difficulties) was particularly noticeable from some teachers, community workers and parents. The concepts of ‘competence’ and ‘evolving capacity’ are pertinent, as disabled children are still often regarded as incompetent, whatever their individual abilities, and thus their views are not expected to be sought (Lansdown, 2004). Jans (2004) questions whether disabled children are regarded as citizens in the way that other children are, or indeed at all and these pathologising views were somewhat in evidence in both our studies during recruitment. Work with nondisabled children shows clearly that they are highly sensitive to judgements about their perceived ages and competencies (James et al., 1998), and this is exaggerated for disabled children. Historically, disabled children have been infantilized (Shakespeare, 1993) and similarly in our studies the participants complained about being patronised. They were very pleased to be invited to participate and be consulted, as this was a novel experience. Another issue about which both authors were wary was the potential reifying of particular identities that inviting children to a ‘disability focused’ group might imply. Careful use of language was therefore important (Holt, 2010).

In Study 2, the researchers felt that including children with a mix of impairments worked well as a pilot. However, we sensed that to explore some issues in more depth, it
might be useful to group them more specifically according to their skills and support needs. In the main study, we are considering forming three types of groups:

1. Children with visual impairment and/or physical impairments who need physical and tactile support
2. Children with communication difficulties (including deaf and alternative/augmentative communication users) needing sign and picture support
3. Children with cognitive impairments who need visual support, a slower pace and simpler language.

This will make planning activities and adaptations more straightforward and cut down on waiting times for everyone during the activities. Group membership choices will be flexible and guided partly by the participants’ preferences. Participants will also be invited to bring a friend or sibling to assist them if they choose. Our preference is for another child to support them rather than parents so that discussions are as child-led as possible. However, parents whose children want them to be present will be welcome.

**Ethics processes: information and consent processes**

The ways in which nondisabled children can or should consent to participate in research is still much debated (Christensen and James, 2000). Many of the options apply automatically to disabled children too, although there are some particular considerations. Our approach echoes Ebrahim’s (2010) proposed adoption of ‘situated ethics’ and we espouse a ‘process’ approach which is ongoing and responsive throughout the research.

In our studies, the usual practice of gaining parents’ consent before any kind of parallel process with children was followed. However, there was initial reluctance and ambivalence about consenting from some parents for several understandable reasons:

First, given the recognised higher rates of abuse of disabled children worldwide, there may be well-founded concerns about their safety in a new situation (National Society for the Prevention of Cruelty to Children [NSPCC], 2002).
Second, privacy and confidentiality are of particular concern for disabled children, their rights to these often being overlooked (UNICEF, 2013).
Third, parents needed reassurance that the activities would be sufficiently adapted for their children to be able to join in easily. They are used to their children being excluded and so assume that positive, inclusive attitudes and suitable methods and materials will once again be unavailable.

The parents’ questions during our information-giving sessions suggested these concerns. However, all consented and were pleased and intrigued by our interest in their children’s views.
Children’s consent

For disabled children with a range of skills and difficulties, a wider menu of types of consent/assent methods is needed than for other children of similar ages. Materials need to be produced using adapted language and formats to match the children’s cognitive, physical sensory and communication competencies.

In Study 1, all the children had good understanding, were literate and could talk. They received written information and signed consent forms. In Study 2, a range of methods were piloted. These included using sign language and/or symbols and picture versions, as well as ‘easy read’ written formats, alongside verbal explanations. We experimented with giving the information the day before the group meetings or on the day, to individuals and to small groups of children. Even so, it was difficult to know whether some children had understood what was going to happen. For children with cognitive, communication and behavioural impairments, whose levels of understanding and responses may not be clear, their cooperation with tasks may, with caution, be seen as assent. This was the case for four children in the younger groups and one teenager. A child who opted out of an activity was considered to have withdrawn assent. For example, one boy who left the meeting, but then under no pressure from the researchers, returned. Children may refuse to participate in one particular activity or choose to leave the whole project. We interpreted such behaviours as children making choices and did not overrule them, although some of our research assistants were keen to do so! As disabled children are often cast in disempowered positions, and have a tendency to acquiesce and be easily coerced, issues around consent need particularly careful consideration (Rabiee et al., 2005; Stalker, 1998).

Child protection issues are also particularly important with disabled children. Given positive relationships with ‘outsider’ researchers with time to listen and use of appropriate communication support, a disabled child may disclose sensitive information about their situation which they have not revealed before. In both studies discussions were held prospectively, about how to deal with such difficult issues and who the key people to refer to would be. The identified person was often a community-based rehabilitation (CBR) worker who would know the child, family and community well.

Data collection methods: An inclusive approach

Children’s skills vary greatly and disabled children’s do so even more because of the effects of their impairments and sometimes because of consequent lack of experience. However, they are very alert to being underestimated, commonly complaining that they are not treated in the same way as others (Wickenden, 2011a). Additionally, professionals and researchers often ask parents and teachers to act as proxies for disabled children, rather than asking them directly. The result of both these tendencies is that disabled children are regularly spoken about, rather than to, and so when they are asked, they habitually defer all questions to their parents or others. This apparent passivity or ‘learned helplessness’ (Basil, 1992; Davis et al., 2003) can pose a challenge, as researchers may be faced with disabled children unused to speaking for themselves. Our experience in these two studies underlined the importance of using methods which are both matched
and adapted to individual children’s skills and most crucially provide extra time and encouragement for them to respond for themselves.

**Visual and tactile support – Pictures, symbols and signing.** Cognitive psychological research shows that information is understood much more easily visually than through hearing. Therefore, activities that are supported by visual information are more easily accessible for everyone. Pictures are often used in activities with young children, but visual support is also useful for many older children (and adults). In both our studies, there is a deliberate predominance of visual material (photos, pictures, charts, symbols) and this clearly contributed to the success of the sessions.

In M.W.’s study, every activity had a visual aspect. For older participants, this provided a joint focus rather than necessarily being needed to aid understanding. In the younger groups and for children with cognitive and communication difficulties, pictures (e.g. to support vignettes), mind maps, visual timetables and ‘talking mats’ were essential to enable them to contribute (Cameron and Murphy, 2002). In parallel, for visually impaired children, objects and tactile versions of charts were important.

**Drawing.** Both studies avoided choosing drawing as major data collection method for similar reasons. Drawing has been used by a number of researchers undertaking ‘mainstream’ childhoods studies globally (Guillemin, 2004; Punch, 2002); however, there is critical discussion about its use (Elden, 2012; Robinson and Gillies, 2012).

There is often a mistaken assumption that all children both have experience of and enjoy drawing. For some disabled children, the barriers posed by their impairments (e.g. those with visual, mobility or severe cognitive impairments) mean that it is not an activity they would choose. It can lead to feelings of failure, embarrassment or frustration and so an unwillingness to participate. We provided alternatives such as readymade images, stickers and photography. In high-income settings, computer-based drawing can work well if an adapted mouse, high-visibility screen and large images are available. For disabled children who do like drawing, it is important to provide suitable adaptations such as high-contrast materials for visually impaired children, supportive seating providing stability (substantially improving children’s manual skills), large grip pencils and nonslip surfaces.

**Photos and videos.** Other popular visual research techniques are photography and videography. ‘Photovoice’ is now an established method of participatory research and has been used in various child and youth projects (Boyden and Ennew, 1997; Wang and Burris, 1997). An important and novel aspect may be the element of choice and control the camera imparts, as well as the objectivity and distance from what the children are describing. For those with cognitive or physical impairments, the demands are much less than drawing, although some may need physical assistance or an adapted camera.

Similarly videography has become increasingly popular as a method (Rich et al., 2006). The international NGO Leonard Cheshire Disability, in one of the few disability-related projects in the global south, have made a series of videos with disabled young people in 22 different countries (http://youngvoices.lcdisability.org). In M.W.’s study the older children in Colombo spontaneously suggested making videos as something they would like to do in future meetings.
Other participatory methods. Other participatory methods commonly used with adults in international development research (Chambers, 1997), such as ranking, listing and rating, and stories and drama, can also work well, even with young or disabled children. For older children and those without cognitive difficulties, complex choice-making, reasoning and discussion, including reflection about the processes themselves, are popular and generate animated discussion and rich data illuminating their worldviews. In all these cases, adaptations to the materials may be needed to avoid the children’s impairments being barriers to their participation.

School experience

We sought to make our research activities different from those typically done in school. However, a large number of disabled children in the global south do not anyway go to school (WHO, 2011). Nevertheless, individual biographical facts about children are important to consider when planning data collection approaches. Although we are wary of being overly normative about children’s development, participants’ interests, ages, capacities and skills do affect the nature of the study methods. Children not attending school may not have learnt some basic skills, which might otherwise be taken for granted. They may have lower levels of numeracy, literacy and visual literacy (familiarity with pictures, symbols, tables, graphs). Doing structured individual or group activities may also be new to them. Some types of tasks may be strange, difficult or embarrassing. This is not to suggest that they do not have other life skills and capabilities which they can bring to the research process. Our strategy as exemplified in our descriptions above was to provide information in a number of formats and be prepared for, encourage and accept a variety of types of responses and styles of participation.

Styles of interaction

Cultural factors in particular contexts may inform what disabled children expect or conversely are allowed to do or discuss. Being invited to choose, criticise or to offer opinions may be unfamiliar to many. The power differential between adults and children, which may be particularly marked in some cultural contexts, may be exaggerated for disabled children whose agency is not recognised. In M.W.’s study, a teacher who knew some of the potential participants opined beforehand that they would not be able to do the activities we were planning. In the event, she was quite surprised by their contributions! We noticed that initially some children responded in an acquiescing ‘school like’ way, for instance, asking what the right answer was or putting their hand up to answer. A local researcher commented that she thought some children were saying what they thought a ‘good Sri Lankan child should say’. However, after encouragement and modelling of more informal and flexible styles of interaction most were relaxed and responsive.

Other impairment-related factors

Some disabled children have challenges related to their impairments which require attention and accommodation such as dealing with pain, needing assistance with mobility,
manual tasks or self-care, needing medications or rest breaks, short attention span and distractibility, anxiety or sensory sensitivities. These need to be considered and anticipated and often require extra support from adults and ideally small group sizes. If children need a slower pace because they require more time to think or to communicate using alternative communication systems, then planning fewer activities in a session may be realistic. Indeed various authors have commented on the tyranny of time constraints for many disabled people, which detrimentally affect their relationships. Extra time is needed to gain meaningful data with some disabled participants (Paterson and Hughes, 1999; Wickenden, 2011b).

**Researcher skills and attitudes**

As researchers with pre-existing skills and experience in working with disabled children, we would actively encourage ‘nonspecialists’ to include disabled children in their studies. Highly technical skills are not needed, but awareness of and willingness to provide the necessary adaptations are. Perhaps the most important ingredients are flexibility, optimism and an inclusive, respectful approach which recognises disabled children as having things to say. Disabled children are quick to detect being patronised and are sensitive and indignant about being left out of activities which routinely include their nondisabled peers. They say clearly that they expect adults to give them enough help to enable them to join in, but not so much that they feel ‘mollycoddled’ (Wickenden, 2011b). Researchers need to achieve this fine balance between encouraging autonomy and providing appropriate nonpatronising support.

**Conclusion**

Disabled children can and should actively participate in both mainstream childhoods research and in specific disability-focussed studies. This requires carefully planned adaptations, extra time and some specific resources if they are to be included in genuinely equitable ways. We have shown that there are a number of practical and attitudinal issues to be considered. If this is done well, the children’s identities as disabled are not privileged over their views of themselves as interesting and ordinary young people. It is relatively easy to provide the physical adaptations needed for children with mobility restrictions, but takes more imagination and effort to accommodate to children with a broader range of impairments. Including only those who require minimal adaptations risks perpetuating an existing hierarchy of exclusion, whereby those perceived as having more challenging difficulties (learning, communication, behavioural and multiple impairments) are always left out. It is imperative that research funding proposals cost in extra adult time, specialist support (e.g. sign language interpreters), adapted environments and materials (e.g. easyread/picture/symbol/Braille versions) as appropriate (see UNICEF, 2013: 18). Unless these resources are budgeted for, lack of availability of these essential adaptations will be a recurring reason for exclusion of disabled children from research and other activities. Adaptations that are a necessity for some children often benefit other children too, so that an inclusive rather than ‘special’ approach can be the best way to argue for the resources needed and to maximize everyone’s participation.
There are thorny theoretical arguments about the nature of participation, inclusion and empowerment and culturally diverse understandings about childhood and disability. However, the human rights perspective underlines disabled children’s right to be included and consulted. Consideration of practical adaptations to facilitate this is required. We argue that without this, rhetoric about inclusion of disabled children in research is likely to be at best tokenistic and at worst ethically untenable as it may exacerbate their excluded position. Inviting them to join in but not providing the adaptations to methods that they need to do so equitably will just marginalise them further.

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