



ORIGINAL ARTICLE

# Using photovoice to include people with profound and multiple learning disabilities in inclusive research

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## Accessible summary

- Many researches now include people with learning disabilities, which is really positive, but people with profound and multiple learning disabilities are often left out.
- It is important to include people with profound and multiple learning disabilities in research to make sure all voices are represented.
- This article talks about how a research method called photovoice can be used to include people with profound and multiple learning disabilities.

## Abstract

**Background:** It is now expected that projects addressing the lives of people with learning disabilities include people with learning disabilities in the research process. In the past, such research often excluded people with learning disabilities, favouring the opinions of family members, carers and professionals. The inclusion of the voices of people with learning disabilities is a welcome and much needed change. While there has been many valuable inclusive researches carried out in the past 10–15 years, much of this research has included people with mild and/or moderate learning disabilities. Far less published research has included people with profound and multiple learning disabilities.

**Materials and Methods:** This research article outlines how the visual method ‘photovoice’ can be successfully used to include people with profound and multiple learning disabilities in the research process.

**Results and discussion:** It is argued that inclusive research is often limited by the choice of research methods, which result in the exclusion of people with profound and multiple learning disabilities from the research process. The article advocates a mediated and flexible approach to inclusive research that embraces and supports the needs of all involved. A practical example of photovoice research with people with learning disabilities demonstrates how this can be achieved.

**Conclusion:** When planning inclusive research, researchers should be mindful of both the variety of needs that people with learning disabilities can bring to the research process and the need to tailor methods to these needs. Such action requires a flexible approach to the inclusive research process.

**Keywords** *Inclusive research, photovoice, profound and multiple learning disability*

## Background

Following disability studies' call to produce emancipatory research (Oliver, 1992), it is now expected that projects about people with disabilities include people with disabilities in the research process. Within learning disability research specifically, the use of inclusive methods is increasingly regarded as best practice (Nind & Vinha, 2013). Indeed, there are now many positive examples of this (See *British Journal of Learning Disabilities* Vol. 40, No. 2 for example). Such work must be celebrated as a welcome move away from the previously dominant perception that people with learning disabilities are unreliable research subjects, likely to say yes to anything (Sigelman *et al.*, 1981). The term 'learning disability' refers to a continuum of ability that includes mild, moderate, severe and profound and multiple learning disabilities (Hardie & Tilly, 2012). In contrast to this, much of the published inclusive research includes people with mild and/or moderate learning disabilities only. Indeed, research involving people with profound and multiple learning disability is relatively scarce (for example, see Boxall & Ralph, 2012; and Ware, 2004). Consequently, inclusive research can be seen to reflect a consistent and sometimes problematic pattern: inclusion is often limited to those that are most cognitively able. In order for research to benefit the lives of people with learning disabilities, though, it is important that all voices are heard.

It is argued here that the relative exclusion of people with more profound learning disabilities from the inclusive research process is often a consequence of the epistemological parameters of the research method used. The epistemological requirements of the more traditional qualitative research methods such as interviews and focus groups that are often used in inclusive research implicitly favour cognitive ability (Klotz, 2014). To address this issue, the article urges researchers conducting inclusive research to do two things: first, to be mindful of the significantly different life worlds and cognitive abilities found among people with learning disabilities and, second, to choose an appropriate research method that can embrace and support such heterogeneity. To highlight how these two suggestions can be put into practice, the article draws on recent practical experience of including people with a range of abilities in a research project using photovoice. To set the context, a brief overview of the epistemological barriers found within inclusive research is provided. This is followed by a discussion of photovoice that addresses its background, how the method can be used to include people with profound and multiple learning disabilities and the benefits and challenges this presents.

## Review of literature: inclusive learning disability research

Many research projects addressing learning disability are now framed as 'inclusive' (Blunt *et al.*, 2012) and seek to include people with learning disabilities as coresearchers in an attempt to equalise power relations and avoid the criticism of speaking *for* people with learning disabilities (Walmsley, 2001). Such projects have used a wide variety of research methods. While traditional methods such as interviews (Fitzgerald & Withers, 2013; Salmon, 2012; Scior, 2003) and focus groups (Chapman *et al.*, 2012; Gates & Waight, 2007) are most commonly used, a smaller number of researchers have used oral histories, life histories and autobiographies (Atkinson & Walmsley, 1999; Barron, 1996) and an increasing number of studies have applied art-based methods (Welsby & Horsfall, 2011) and visual methods (Povee *et al.*, 2014). As such, there are now many excellent examples of inclusive research. Haigh *et al.*, (2013), for example, conducted a fully inclusive research project where people with learning disabilities were included in research design, interview delivery, analysis of findings, writing the research paper and dissemination of the findings.

Common to many of the studies presented, however, is the involvement of people with a particular level of cognitive ability. People who can verbalise life histories, discuss issues in focus groups, respond to interview questions, engage in art workshops and participate in the analysis and write up are generally representative of people with relatively high levels of cognitive ability. Interviews, focus groups, oral histories and questionnaires, moreover, can be problematic research methods when including people with learning disabilities (Booth & Booth, 1996), particularly those with more profound learning disabilities. Traditional research methods hold particular epistemological 'rules' that implicitly discriminate against people with learning disabilities (Aldridge 2007).

The use of focus groups clearly illustrates this argument. As Kaene & O'Connell (2010 p. 138) state, focus group participants 'need to have the ability to: (i) reflect on their own and other participants' views, (ii) engage communicatively with each other, and (iii) explore a given issue with minimal guidance from the moderator'. The characteristics of some people with a learning disability, that is lack of verbal communication, pre-intentional communication, inability to process abstract questions/concepts and limited social interaction, therefore, challenge the use of focus groups methodologically. Consequently, inclusive research that employs such methods can serve to further the marginalisation of certain people with learning disabilities based on their abilities. Only the most able can participate.

In addition to this, research that only includes specific groups of people with learning disabilities risks making

unwarranted claims if presented as representative of learning disability as a whole. One such example can be found in Welsby & Horsfall's (2011) study. While presenting a good example of inclusive research with people with mild/moderate learning disabilities, it did not include people with profound and multiple learning disabilities. Yet the authors claimed that they 'believe there will be resonances for other women who have an intellectual disability in the western world' (Welsby & Horsfall, 2011 p. 796). While this may well be true for other women with similar abilities to the women involved in their study, people with profound and multiple learning disabilities are unlikely to find resonances with the employment and relationship management issues discussed by Welsby and Horsfall's participants.

Research with people with profound and multiple learning disabilities, although relatively scarce, has been conducted, and there are a number of good examples of inclusive research in this area. Boxall & Ralph (2009), for example, used photography with people with profound and multiple learning disabilities living in hostel accommodation. The project successfully involved staff and the people they cared for in the research process and resulted in better communication between the two groups. Whitehurst (2007) also used an art-based approach to explore the perspectives of children with profound learning disabilities. Over a 2-year period, Whitehurst worked with children with and without profound learning disabilities to produce and evaluate a drama production. When evaluating this project, Whitehurst (2007) successfully used a combination of tools to support the inclusion of children with profound needs in the process. Such tools included talking mats and carer support. Such research, however, is often conducted with this group alone owing to their specific needs. Consequently, there is a need to reframe research with people with profound and multiple learning disabilities from a focus on their individual limits to limits of the research method chosen (Boxhall, 2010) and also the abilities of all involved.

### **Reframing research to include people of all cognitive abilities**

As Walmsley (2001 p. 198) tells us, 'most people with learning disabilities need allies to do research'. For some people with learning disabilities, this support will be more intensive than is required for others. In some cases, people with profound and multiple learning disabilities, for example, it may be necessary to speak on behalf of people with learning disabilities. While this statement might appear to be an anathema to the inclusive research agenda, it should not be seen as a backward step but rather as a move towards the inclusion of all people with learning disabilities in the research process. As Ware (2004) argues, researchers need to

be realistic about the abilities of people with more profound learning disabilities. People with profound and multiple learning disabilities generally cannot express nor cognitively process abstract concepts/questions for themselves, nor can they perform everyday tasks in the same way that people without profound and multiple learning disabilities can (Mansell, 2010). Indeed, as Klotz (2014 p. 98) tells us, 'the aspirations, concerns, behaviours and expressions of people with profound and severe intellectual disabilities are often very different, idiosyncratic, opaque and challenging to engage with'. Consequently, people with profound and multiple learning disabilities lead mediated lives. In many cases, their life would not be possible without support.

A mediated approach to involving people with a profound and multiple learning disabilities in research, therefore, should not be shied away from. This should not be seen as a limitation or an encroachment on liberty but rather should be treated as a necessary condition of the research. It is also essential that, as researchers, we are realistic about the type of research that can be conducted with people with more profound and multiple learning disabilities and that the research questions that we ask reflect this (Ware, 2004).

When conducting inclusive research, an appropriate method that can be tailored to the abilities of all involved must be prioritised. People with profound and multiple learning disabilities can be included in inclusive research as more than research subjects as long as an appropriate method that can embrace and support their individual abilities is used. While traditional research methods are less flexible in application, researchers have the choice of a wide range of innovative and participatory research methods that can be adapted to suit the needs of those included in the research process. To show that this is possible, the article now draws on the experience of a recent empirical study that included people with a range of learning disabilities in the research process.

### **What does learning disability mean in the real world? A photovoice study to include all people of all learning abilities**

What does learning disability mean in the real world? Was a research project conducted over the course of 3 years. It sought to explore how different groups, including people with and without learning disabilities, understand the term 'learning disability'. The project began from a specific philosophical starting point: that people's views, perceptions and understandings are meaningful reflections of social reality and that people with learning disabilities represent a diverse population group. Such a position allowed a flexible approach to research that is conducive to including all levels of cognitive ability. Among other research questions, the project asked how is learning disability understood by both people with and without

learning disabilities? To answer this question, the project used a combination of research methods to reflect the needs of those involved. Focus groups were used with people without learning disabilities, and photovoice was used with people with learning disabilities. It is the practical application of photovoice that is focused on here.

### Method: photovoice

Photovoice is a visual method that focuses on participant-led photography. It was originally developed by Wang & Burris (1997) as an action research tool to be used within health promotion research. Wang (1999) outlined nine prescriptive steps for delivery: (i) selecting a target audience, (ii) recruiting participants, (iii) educating participants about the photovoice method, (iv) gaining informed consent, (v) brainstorming the project focus with participants, (vi) distributing cameras, (vii) providing time for participants to take photographs, (viii) meeting with participants to talk about their pictures, and (ix) planning how to share this information with the target audience. While retaining its general structure, Catalani and Minkler (2010 p. 448) tell us that over time Wang's nine steps have been adapted by other researchers to meet the needs of their projects and participants such that photovoice can now be described as 'a flexible tool. ...It can be altered to fit diverse partnerships, community contexts, participant characteristics and research or intervention interests'.

While photovoice etymologically implies visual and verbal communication, the method allows participants the opportunity to voice their worlds visually, opening up the method to people who may not be able to articulate themselves verbally as is the case for many people with learning disabilities (see Booth & Booth 2003; Jurkowski & Paul-Ward, 2007; Povee *et al.*, 2014 for example). Booth and Booth (2003 p. 433), for example, tell us 'photography as an activity emphasises action over cognition (we 'take' photos after all): it provides a means of concretising issues and concerns in a way that corresponds more closely to the thinking of people with learning difficulties than other more abstract modes of expression'. In sum, photovoice provides an accessible method that allows an insight into the lives of people who often cannot communicate their experiences via more traditional research methods. Most importantly, for those conducting learning disability research, photovoice is an accessible method for all people with learning disabilities regardless of difference in cognitive ability.

### Results and discussion: the practical application of photovoice

The photovoice sessions were carried out with four pre-existing learning disability support groups. Across the four

groups, 16 adults took part. Of these 16 adults, six had been categorised as having mild learning disabilities, four with moderate and six with profound and multiple learning disabilities. The research participants were unknown to the researcher, and ethical approval was granted by the University of Nottingham. This article focuses on the use of the photovoice method with the six people with profound and multiple learning disabilities.

The six adults with profound and multiple learning disabilities all attended the same social group where the research was carried out and all lived in one of two group homes in the nearby area. All of the participants relied on the use of an electric wheelchair. Only one person was able to operate his wheelchair, while the others relied on their carers. The participants required the use of a hoist to access and exit their wheelchairs. Only one participant could communicate verbally, and this was restricted to 'yes' and 'no'. Most of the participants moved and communicated pre-intentionally, although all were able to express emotions such as pleasure, happiness, frustration and sadness in some way. Consequently, all attended the group with a personal carer employed by the group home in which they live. The carers knew the people with profound and multiple learning disabilities well and assisted them with everyday living on a day-to-day basis. For these reasons, the carers were also included as coresearchers, as necessary and integral allies for the people with learning disabilities. The photovoice sessions were conducted over the course of three consecutive group meetings. Wang's (1999) nine-step framework was used as a flexible guide. However, the method was tailored to meet the needs of the participants as advocated by Catalani & Minkler (2010). In line with the requirements of the Mental Capacity Act (Her Majesty's Stationary Office (HMSO), 2005) and also Mencap's (2011) guide to including people with profound and multiple learning disabilities, *Involve me*, a combination of proxy/best interest consent and participation as consent was used in replacement of traditional written consent. This was not possible due to the participants' cognitive ability. Consent was given to use all talk and images publicly. In addition to this, in line with other photovoice projects with people with learning disabilities (Povee *et al.*, 2014), consent was treated as a continuous process. I was mindful throughout the photovoice process of nonverbal signals that might indicate a desire to stop as recommended by Cameron & Murphy (2006).

All of the participants and their carers were given a digital camera, battery, charger and set of instructions for use. In line with the photovoice method, the brief for photographers was unrestricted, and participants were asked to take photographs of anything that showed their everyday life and were given a week to do this. As a group, we discussed how the participants with profound and multiple learning disabilities could be involved in the

process as much as possible. The carers suggested taking the photographs from the vantage point of the person with profound and multiple learning disabilities as seated in their wheelchair to achieve images at their eye level. In addition to this, the carers agreed to only take photographs when the participant showed signs that this was ok.

A week later, the cameras were returned. All of the participants had been successfully supported to take photographs of their everyday life. The photographs taken were varied and included images of the participants involved in a range of activities; their bedrooms; their shared living spaces; their mobility aids; and objects that were meaningful to them such as a fish tank, bedroom wallpaper and Christmas decorations. The participants enjoyed viewing the images of themselves and the things and people familiar to them. When talking about the content of the photographs, the care workers as coresearchers facilitated the people with profound and multiple learning disabilities' communication and added extra detail to the visual images that the people with profound and multiple learning disabilities could not.

In the final session, the participants were given a copy of their photographs to keep and were asked to pick two favourite images with the help of the support workers. These photographs were then discussed in detail. While Pink (2007) tells us that images can stand alone and provide an insight into the lives of other people in a way that traditional research methods could not achieve, talking about why the images were taken provided an extra layer of meaning. This is information that could not have been gained from looking at the image alone. For example, when discussing the image of the bank (Fig. 1), the participant's carer added detail to the image by talking about how the participant had enjoyed the sound of a high-heel shoes against the wooden floor as a member of staff at the bank walked around. The carer was also able to provide detail about how the image was produced, telling me that the

photograph had been taken from the vantage point of his wheelchair, specifically at ear level to reflect the person with learning disabilities aural experience. The detail provided by the carer transformed the image of a scene in a bank into a sensory journey.

Similarly, when talking about Fig. 2, the photographer's carer revealed that one of his favourite activities is to 'wreck his room'. She also told me that the mats on his bedroom floor, shown in the image, had been put there by the group home staff because the participant had been getting carpet burns on his face because he enjoyed the warmth from the underfloor heating. A simple image of a man in a bedroom, therefore, was transformed into an image with a complex range of meanings.

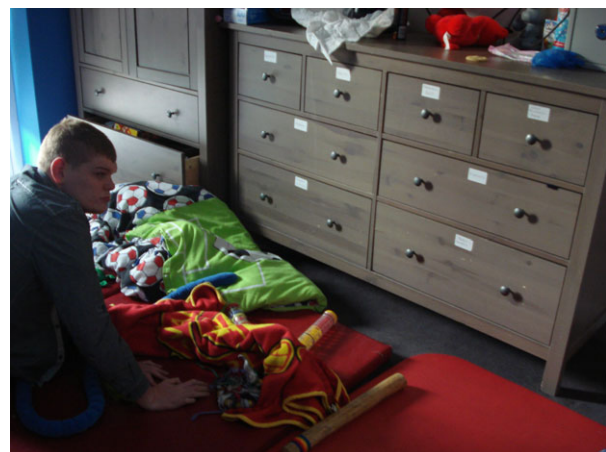
As these examples show, the photovoice method, combined with a flexible approach to the inclusive research process that allowed for the inclusion of additional voices, such as care workers, not only allowed for the inclusion of people with learning disabilities across the continuum of ability but also facilitated the production of rich research findings that revealed much about the lives of people with learning disabilities.

## Challenges

While the photovoice method brought many benefits to the research project, such as epistemological flexibility and an alternative yet in-depth method of presenting complex lives, the application of the method also involved challenges. When asking any research question that seeks to explore personal understandings, some form of communication is necessary. Although the photovoice method allowed for an emphasis on visual communication, as seen verbal communication can add extra layers of meaning to what the images show. While speaking for people with learning disabilities has been heavily



**Figure 1** Photograph taken in Natwest bank by the participant's carer. [Colour figure can be viewed at [wileyonlinelibrary.com](http://wileyonlinelibrary.com)]



**Figure 2** Photograph taken in participant's bedroom by participant's carer. [Colour figure can be viewed at [wileyonlinelibrary.com](http://wileyonlinelibrary.com)]

critiqued, it is also important to be realistic about what individuals with learning disabilities can do (Ware, 2004). It is for this reason that the project adopted a mediated approach to research that included the voices of paid carers as coresearchers in their own right. The carers' voices were not taken as an absolute representation of the views and perceptions of the people with learning disabilities but rather were considered necessary to gain further detail and therefore were treated as coresearchers in the same way that the people with learning disabilities were.

Importantly, a mediated approach to the inclusive research process allows for the reality of some people with learning disabilities to be accommodated and accepted. As Ware (2004) urges, it is necessary to ask whether people with more profound learning disabilities can have thoughts on abstract concepts at all. As research generally addresses such concepts, it is necessary to be mindful of this and to have realistic expectations about the outcomes a project including this group can generate. It is unrealistic to think that people with profound and multiple learning disabilities can conduct focus groups or that they can respond to abstract verbal questioning in the same way that people with mild or moderate learning disabilities might be able to. Nor is research with people with more profound learning disabilities going to generate long, detail-rich transcripts. This is not to say that the research findings cannot be useful. They will, however, require mediated facilitation and also an acceptance that a plurality of voices is a necessary condition of including people with profound and multiple learning disabilities in research.

While it is argued here that carer involvement plays an integral role in the inclusion people with profound and multiple learning disabilities in research, researchers must be mindful of the challenges that this presents. Carer voices should always be viewed with caution. Their interpretations of the thought processes of the person they care for are presumptions based on their relationship with and knowledge of the person they care for. When talking about Fig. 1, for example, the carer's interpretation of enjoyment regarding the noise of high heels on the bank's wooden floor is a presumption. Due to having profound and multiple learning disabilities, the participant cannot be asked if this presumption is correct. The carer interpreted his behaviour, described as 'laughing' and 'loving it' when the bank staff member crossed the floor, as evidence of his enjoyment. With this in mind, Boxhall's approach to including carer voices (2010) was followed to critically probe the carer's responses. When the carers added detail to the images, for instance, they were always asked questions such as 'is that what you think or is that what you think [participant] might think?' And 'how do you know they might think this?' To realistically accept the abilities of people with profound and multiple learning

disabilities also requires the acceptance that the research will be structured differently. Not only will the research findings take an alternative form to those that might result from a project conducted with people without learning disabilities, the research project must necessarily begin differently in that certain research questions will be ruled out. The initial research questions asked must reflect the abilities of those involved in the project. In the case of the project detailed in this article, the same research question was asked for people with and without learning disabilities. However, the project began from the assumption that people with learning disabilities are a heterogeneous group with varying levels of cognitive ability and that this will affect what the research produced looks like. This starting point allowed for the use of a flexible methodological approach to answering the question whereby the understanding of learning disability sought could be portrayed in a number of different ways.

## Conclusion

As Klotz (2014 p. 99) urges, 'a radically different approach' to research, in particular inclusive research, is required if all people with learning disabilities are to be afforded access to the research process. One such radical change proposed here is the inclusion of additional voices in the research process. The example provided above demonstrates a high level of carer involvement in the support and facilitation of people with profound and multiple learning disabilities in the research process. The role of the carers in the photovoice project was not only essential, as it would be to all research methods when involving people with profound and multiple learning disabilities, but it also added an extra layer of meaning to the images taken. While speaking for people with learning disabilities is something that has been heavily critiqued for good reason, facilitating voices are sometimes necessary. It is not the case that 'there are no subjects that people with learning disabilities cannot talk about' (Butler *et al.*, 2012 p. 140). The reality is that some people with learning disabilities require alternative approaches to research to facilitate their inclusion and to hear their voice/see their world. Without a mediated approach to research, there is a risk of excluding some people with learning disabilities from the research process.

In applying this approach, it is possible to achieve research that is both accessible to people of all cognitive abilities and generates valuable findings. In the case of the research project discussed here, for instance, photovoice allowed the research question 'how is learning disability understood by both people with and without learning disabilities?' to be explored and answered in a depth that could not have been achieved using traditional methods. The photovoice findings highlighted that the learning disabled body plays a significant role within social

interaction and the social construction of learning disability – something that is often overlooked by other research projects. In this way, research with people with learning disabilities can be reframed to include a focus on ability and also limitation of research design rather than a focus on individual limitations. Such an approach is of direct consequence and importance to the lives of people with learning disabilities. It allows for all voices to be heard rather than some.

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