

# Adapting photovoice to explore identity expression amongst people with intellectual disabilities who have limited or no verbal communication

Emma Krisson<sup>1</sup>  | Maria Qureshi<sup>2</sup> | Annabel Head<sup>3</sup>

<sup>1</sup>University of Hertfordshire, Hatfield, UK

<sup>2</sup>University College London, London, UK

<sup>3</sup>South London and Maudsley NHS Foundation Trust, London, UK

## Correspondence

Emma Krisson, University of Hertfordshire, Hatfield, UK.

Email: emma.krisson@outlook.com

## Accessible Summary

- People with intellectual disabilities who have limited, or no verbal communication can be involved in research.
- Ethnographic observations and interview techniques can work together with photovoice.
- More research needs to be completed directly involving people with intellectual disabilities.

## Abstract

**Background:** Inclusive research requires adapting methodologies to meet the needs of people with all degrees of intellectual disabilities. However, it must also balance this with the requirements of academic research. Building from previous research a study was completed to illustrate how photovoice could not only be adapted to meet the needs of people with intellectual disabilities who have limited or no verbal communication but to also explore how they express their identity.

**Methods:** A qualitative multiple case study method was used to explore identity expression amongst three participants with intellectual disabilities and limited or no verbal communication. The methodology integrated ethnographic observations, photovoice and interview techniques.

**Findings:** Integrating the ethnographic observations, photovoice and interview techniques offered families and carers the opportunity to become curious about participants' identities, and this methodology was considered valuable in getting to know more about the person.

**Conclusions:** It is hoped that through conducting research that directly involves people with intellectual disabilities, more creative and inclusive methods can be explored, verified and applied across various research contexts.

## KEYWORDS

clinical psychology, intellectual disabilities, profound and complex learning disabilities

This is an open access article under the terms of the Creative Commons Attribution License, which permits use, distribution and reproduction in any medium, provided the original work is properly cited.

© 2021 The Authors. *British Journal of Learning Disabilities* published by John Wiley & Sons Ltd.

## 1 | INTRODUCTION

People with intellectual disabilities who are nonverbal are often left out of academic research, but new creative research methods, such as inviting participants to take photographs (a method known as photovoice), have gone some way to re-address this in recent years. However, there are challenges to balancing creative methodological approaches to what is considered reliable and valid research. In the past, this has led to the exclusion of people with more severe forms of intellectual disabilities (Cluley, 2016; Mietola et al., 2017). This paper will describe how a recent study, built from previous research (Baxter & Jack, 2008; Cluley, 2016; Povee, 2014; Booth and Booth, 2003; Thompson, 2018; Yin, 2004), to develop an inclusive methodology to involve people with intellectual disabilities who have limited or no verbal communication. The paper will focus on the reasons why this research is important, how visual methodologies have been applied in inclusive research and how an adapted methodology was created and utilised to explore identity expression. Attention will specifically be paid to the development and implementation of the adapted methodology rather than reporting on the research findings from the study.

Throughout this paper, the terms 'people with intellectual disabilities' and 'people with severe and profound intellectual disabilities' will be used to reflect people's level of need and functioning. The Diagnostic Statistical Manual (DSM-V; American Psychiatric Association 2013) identifies severity codes that reflect the clinician's impression of the severity of adaptive functioning; 'profound', 'severe', 'moderate' or 'mild'. These categories are not rigid, nor are there clear dividing lines between the different groups (Mietola et al., 2017). In the United Kingdom, these terms are determined by society and we use them to make distinctions between levels of need (Povee, 2014; British Institute of Learning Disabilities 2019). For example, people described as having more severe and profound intellectual disabilities are likely to experience cognitive difficulties, to use nonverbal forms of communication and to be unable to attend to their own basic needs (World Health Organization 1992).

### 1.1 | Identity expression

The word 'identity' is often used in everyday discourse, yet it is difficult to provide a succinct summary that captures the range of its meanings (Beart et al., 2005; Fearon, 1999; Vignoles, 2017). Whilst the dictionary may define it as "who a person is, or the qualities of a person or group that make them different from others" (Cambridge Dictionary, 2019), this does not fully capture the meaning(s) of 'identity' (Fearon, 1999). Much of the work exploring identity amongst people with intellectual disabilities has considered identity as a fluid concept, developed within the contexts of ongoing relational experiences with others and not something that relies solely on the internal world of a person. These ideas adopt a social constructionist view, that is, our understandings of the world are socially derived and "what we take to be knowledge of the world, and self, finds its

origins in human relationships" (Gergen, 2011, p. 109). This perspective argues that a person cannot be separated from their social context but instead, they derive their identities from social interactions (Beart et al., 2005). Therefore, we can learn about a person's identity through their communication and interactions with others and their environment.

Intellectual disability is "commonly conceptualised as a stigmatising identity" (Dorozenko et al., 2015, p. 1,345) and a "master status that overrides all other identities and social roles a person may have" (Povee, 2014, p. 232). For people with intellectual disabilities, the embodiment of these labels has resulted in a broad range of biases and social assumptions being made about a person's competence, abilities and access to opportunities (Beart et al., 2005; Davies & Jenkins, 1997; Povee, 2014). However, taking a fluid and relational perspective can open new ways of understanding identity and hopefully impact the way intellectual disabilities are viewed within society. To do this, we need to consider the methods we adopt within academia and research to ensure they are inclusive and not exclusive of the needs of people with severe and profound intellectual disabilities.

### 1.2 | Involving people with intellectual disabilities in research

Prior to 1980, it was "unusual for people with intellectual disabilities" to be included in research (Box all & Ralph, 2010, p. 174), and if they were, the approach was "very much research on rather than research with" (Kiernan, 1999, p. 44). Furthermore, much of the research involved people who were connected to the person with intellectual disabilities, rather than the person themselves. Over subsequent decades, there has been more interest and investment in involving people with varying degrees of intellectual disabilities in research. 'Inclusive research', an umbrella term for emancipatory and participatory research, has grown in practice and is underpinned by social model theorists. Walmsley (2004) argued that people with intellectual disabilities must be actively involved in research rather than passive recipients and that research should be pursued in the best interests of the research subjects.

Described as "probably the most marginal group of disabled people in both society and in research" (Mietola et al., 2017, p. 264), people with severe and profound intellectual disabilities continue to be excluded from theoretical, methodological and empirical discussions, regardless of the efforts of inclusive research (Box all & Ralph, 2010; Cluley, 2016; Mietola et al., 2017). Cluley (2016) argues that the epistemological parameters of traditional research methods are not inclusive of people who have severe and profound intellectual disabilities. In other words, through using interviews and focus groups (methods typically used within inclusive research), there is an implicit expectation that participants have certain cognitive and communicative capacities that are less accessible for people with severe and profound intellectual disabilities (Kiernan, 1999; Mietola et al., 2017). There have also been questions raised about

whether it is possible for people with severe and profound intellectual disabilities to have views on complex issues, such as identity, but also whether researchers can accurately capture these (Boxall & Ralph, 2010; Cluley, 2016; Ware, 2004). Therefore, it is important that researchers be aware of the communication abilities of their participants, acknowledge the degree to which inferences are being made, and the limits of what can be achieved (Porter et al., 2001; Ware, 2004).

Boxall and Ralph (2009) argue that these uncertainties and concerns about capturing the views of people with severe and profound intellectual disabilities are exacerbated by developments in research governance and ethical review processes in the UK. They question whether the tightening of ethical approval measures will extend towards limits being placed on the application of novel methodologies that are required to involve people with severe and profound intellectual disabilities in research, for example visual methodologies. There is of course, an important role for governance and ethical review processes within disability research. Yet, as Boxall and Ralph (2009) note it is important this does not prevent or prohibit studies being completed with people with intellectual disabilities, but supports and facilitates them instead. To support researchers applying to ethical committees, guidance has been developed in relation to conducting research with people with severe and profound intellectual disabilities (BPS, British Psychological Society 2008). These have centred on how to conduct research with people who have intellectual disabilities (British Psychological Society 2008), the role of the nondisabled researcher (Walmsley, 2004) and the challenges of capacity and consent (Cameron & Murphy, 2007).

### 1.3 | Visual research methodologies

Over the last decade, several studies have set out to explore how to directly involve people with severe and profound intellectual disabilities in research (Boxall & Ralph, 2010; Brewster, 2004; Cluley, 2016; Robinson & Eagle, 2018; Rojas & Sanahuja, 2011). Utilising visual methodologies (such as taking photographs, videos or making drawings), these studies have actively involved participants in research and offered the “opportunity to voice their worlds visually” (Cluley, 2016, p. 42). Visual methods offer a “medium to explore, know and understand” (Rojas & Sanahuja, 2011, p.36) more about participants and are considered invaluable by many researchers in the field for engaging and empowering participants who are typically excluded from research (Robinson & Eagle, 2018).

### 1.4 | Photovoice

One form of visual methodology which has a growing literature base is photovoice (Booth & Booth, 2003; Cluley, 2016; Povee et al., 2014; Shumba & Moodley, 2018). Conceptualised by Caroline Wang and Mary Ann Burris in the early 1990s, it was originally

**TABLE 1** The process of implementing photovoice (Cluley, 2016; Wang, 1999)

Process of photovoice	
<b>Step 1</b>	<b>Select and recruit target audience</b>
Step 2	Recruit participants
Step 3	Introduce photovoice methodology
Step 4	Obtain informed consent
Step 5	Identify an initial theme
Step 6	Distribute cameras
Step 7	Provide time to take pictures
Step 8	Meet to discuss photographs
Step 9	Plan a format to share photographs and stories with policymakers or community leaders.

termed Photo Novella, meaning ‘picture stories’. Developed as a participatory action research tool, it centres participants in the study and offers “greater decision-making agency than traditional researcher-directed studies” (Sutton-Brown, 2014, p. 171). Over time it was redefined by Wang and Burris (1997), to ‘photovoice’ and described as “a process by which people can identify, represent and enhance their community through a specific photographic technique” (Wang, 1999, p. 185). This meets the aims of inclusive research and researching *with* people who have intellectual disabilities rather than researching *on* people with intellectual disabilities (Cluley, 2016; Ellis, 2014).

Photovoice involves a series of nine procedural steps; see Table 1. Whilst there is a prescriptive element to these steps, Wang and Burris (1997) emphasise that there are many ways in which photovoice can be applied across different contexts with different groups and communities and for different purposes. This adaptability within the photovoice methodology has led to variation in both its delivery and application within a wide range of contexts to meet the needs of its participants (see Overmars-Marx et al. (2018); Sutton-Brown, 2014).

Of the research completed with people who have intellectual disabilities, a limited number of these have included participants with more severe cognitive disabilities. Photovoice as a method “emphasises action over cognition” (Booth & Booth, 2003, p. 432) therefore making it accessible to participants who have limited linguistic ability. However, some have argued that photovoice is not suitable for participants who are unable to communicate verbally (Jurkowski, 2008; Overmars-Marx et al., 2018). This has mainly been due to the challenges faced in gaining participants’ reflections on their photographs during the interview stage of the process (Overmars-Marx et al., 2018). Of the studies included in Overmars-Marx et al.’s (2018) review, two included participants with limited or no verbal communication abilities (Aldridge, 2007; Povee et al., 2014). Participants were supported to point at the pictures, use gestures and facial expressions to convey their answers during the interview stage (see Overmars-Marx et al., 2018).

In another study, Cluley (2016) outlines how photovoice can be successfully used to include people with severe and profound intellectual disabilities in research. Cluley (2016) emphasised the importance of a flexible approach to inclusive research that accommodates a range of abilities to avoid unwarranted claims, generalisations or further marginalisation of people with intellectual disabilities. Cluley (2016) also stresses the importance of being realistic about the type of research questions asked, and acceptance that the structure and outcomes will be different from research involving those that do not have an intellectual disability. Cluley (2016, p. 44) advocates for the involvement of carers as co-researchers or 'allies' and emphasises the "plurality of voices is a necessary condition" when including people with severe and profound intellectual disabilities in research. If applied, Cluley (2016) concludes that it would be possible to conduct inclusive research that is accessible to people of all cognitive abilities and focuses on limitations of methodology rather than individual limits.

As noted above, there have been criticisms in relation to involving participants in research who are unable to provide their own account or validate accounts made by those around them (Ware, 2004); the interpretative nature of such visual approaches runs the risk of "putting words into their mouths" (Brewster, 2004, p. 166). Whilst inviting family members to participate allows the opportunity to draw on wider experiences, their accounts must not be considered 'absolute' (Cluley, 2016). Rather the process of ascertaining views should be considered an ongoing process (Brewster, 2004), one that utilises multiple sources of data and adopts methods to explore response from carers and family members (Cluley, 2016). Ultimately, it is important that not only do researchers take responsibility for conducting mediated approaches, but ethical bodies and academics accept that "facilitating voices are sometimes necessary" (Cluley, 2016, p.45) to avoid the exclusion of people with intellectual disabilities in research.

In summary, there has been a growing interest in the application of visual methodologies as a way of directly involving participants with intellectual disabilities in research. This participation can support people with intellectual disabilities to tell their own stories and change the way in which they are not only supported day to day, but viewed within society. At present, there is limited research involving people with more severe and profound intellectual disabilities. Arguably, it is people with severe and profound intellectual disabilities, whose identities are more likely to be misrepresented, due to the inability for them to confirm or deny the narratives that surround them. Therefore, identifying creative ways of involving participants with severe and profound intellectual disabilities in research, through giving them a visual voice, could help encourage people to re-evaluate how they perceive people with such needs and challenge the idea of being seen as 'less than human' (Kamlager, 2013).

## 2 | DEVELOPING A METHODOLOGY

The project outlined in this paper set out to research whether photovoice could explore identity expression amongst people with a diagnosis of intellectual disabilities and limited or no verbal language.

Of the three research questions explored in the project, this paper will focus on the following:

- Can photovoice be used as a research methodology to engage people with intellectual disabilities in research?
- Can we learn more about the person's identity through integrating ethnographic ideas, photovoice and dyadic interview components?

Three participants, their families and carers were invited to participate in the project. Each participant had a diagnosis of intellectual disabilities, autism and had limited or no verbal communication. All participants were recruited from a single educational setting following ethical approval provided by Health, Science, Engineering & Technology Ethics Committee with Delegated Authority (ECDA) at Hertfordshire University. The consent procedure for this project followed recommendations outlined by Head (2017), Cameron and Murphy (2007) the British Psychological Society (2008).

### 2.1 | Adapting photovoice to be inclusive of people with intellectual disabilities and limited or no verbal communication

It was important to identify a qualitative methodology, which supported creative and flexible methods of data collection, whilst remaining academically rigorous. Therefore, drawing on previous research (Baxter & Jack, 2008; Ellis, 2014; Gustafsson, 2017; Llewellyn 1995; McDonald et al., 2012; Thompson, 2018), a multiple case study approach was adopted. Defined by Baxter and Jack (2008, p.544) as "research that facilitates exploration of a phenomenon within its context using a variety of data sources...this ensures the issue is not explored through one lens, but rather a variety of lenses." Collecting data from multiple sources supports a flexible research methodology that is responsive to the needs of participants and appreciates the complexity of exploring identities (Ellis, 2014). The different layers of data collection methods incorporated into this project's design are outlined below and adopt a similar method to that of Thompson (2018; see Figure 1).

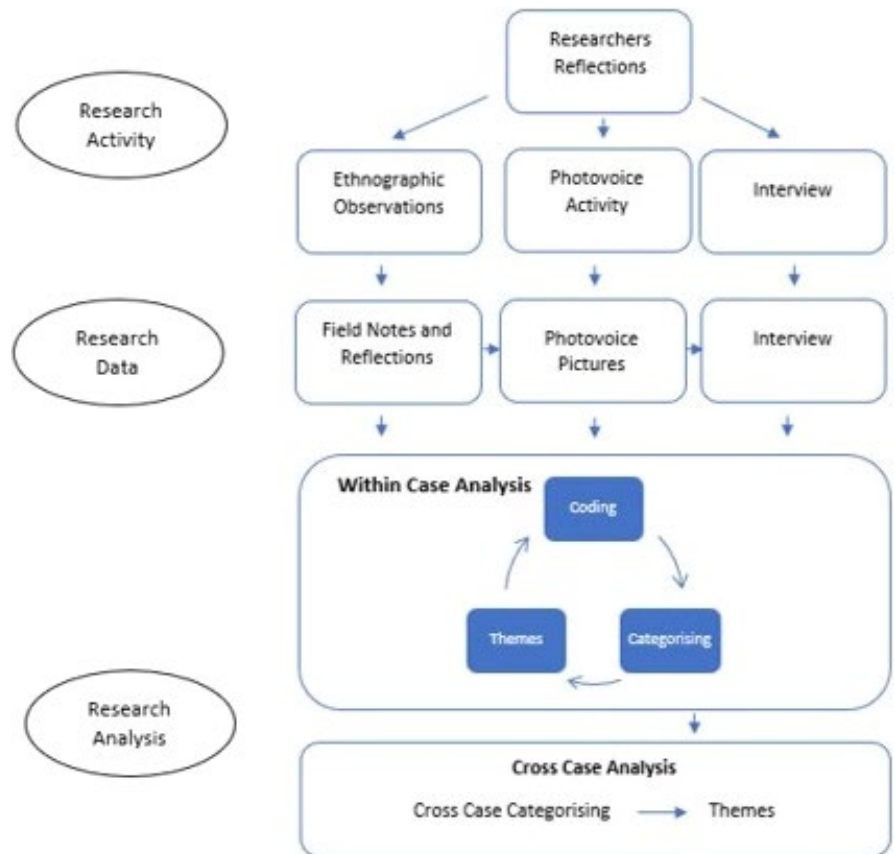
### 2.2 | A layered approach

A combination of data collection strategies made up the different stages of this project's methodology including ethnographic field notes, photovoice, transcribed interviews and the researcher's reflections (see Figure 2).

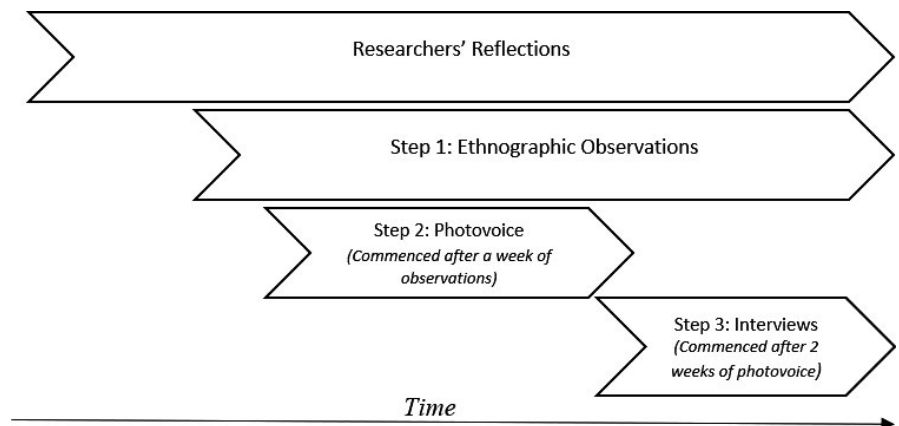
#### 2.2.1 | Stage 1: Ethnography

The project adopted an ethnographic approach to collecting data (Finlay et al., 2007; Ellis, 2014; Hubert & Hollins, 2010). Ethnography

**FIGURE 1** A diagram illustrating the different methods of data collection and process of analysis (Adapted from Thompson, 2018)



**FIGURE 2** A diagram illustrating the stages of data collection



"is the study of people in naturally occurring settings or 'fields' by methods of data collection which capture their social meanings and ordinary activities" (Brewer, 2000, p. 6). It is the researcher's aim to immerse themselves within the group, observing and interpreting everyday behaviour (Holloway et al., 2010; Fusch et al. 2017). Whilst traditional ethnographic research is longitudinal, the project adopted a mini-ethnographic approach, only lasting several months (Ellis, 2014; Fusch et al., 2017). This approach particularly suited the aims of the project since it allowed for naturalistic observation of how individuals with intellectual disabilities expressed their identities in their own contexts, allowing for the opportunity to gather richer data.

The ethnographic aspect of the project mainly involved observing participants at college, with one participant also visited at their residential address. These visits occurred several times a week over the course of a month. Each participant was observed on different days, times and contexts (e.g. in college or on trips out in the community) to allow for a variation in data collection and opportunity to see the participant in different contexts. During each visit, field notes were taken describing the events that occurred throughout the observation period including how the young person presented themselves (e.g. clothes), their interactions with others, gestures and involvement in activities (see Ellis, 2014; Fusch et al., 2017). In addition to this, conversations and statements made by those supporting the individual were also noted.

### 2.2.2 | Stage 2: Photovoice

Each young person was asked to take photographs over a period of two weeks. Participants were provided with a visual information sheet. In line with photovoice guidelines, limited instruction was given to participants around what they take pictures of. The only direction parents and carers received was to support the participant to take pictures of things that were meaningful to them. Two of the participants were provided with a camera, the third utilised their own iPad. Those provided with a camera were shown how to use it. After the two weeks, the cameras were collected and photographs printed. For the participant using the iPad photographs were shared electronically. Family members and carers were asked to keep notes on how the participant engaged in the activity and any challenges that were faced.

### 2.2.3 | Stage 3: Interviews

Typically, participants who participate in photovoice are invited to reflect on their pictures and tell their story. The participants invited to take part in this project were unable to provide verbal descriptions of their photographs. With the aim of keeping participants central, the project incorporated ideas of dyadic interviewing and the systemic technique of interviewing called the 'internalised other' (Tomm, 1999 cited in Mudry et al. 2016), as suggested by Head (2017).

Dyadic interviewing involves interviewing people in pairs rather than individually and emphasises interdependence, recognising "the value of interconnected relationships" (Caldwell, 2013, p.492). Structured as an activity, participants were observed looking through their printed pictures, with family members and carers present. Observations were made in relation to behaviours, gestures and any use of speech. Some open and closed questions were used, such as '*what can you see?*' and '*does [participant] have a favourite picture?*'. Due to the global outbreak of coronavirus, it was not possible to complete two of these interviews as intended. Therefore, alternative methods were used, one via Skype and another by telephone.

Family members were further invited to 'step into the participant's shoes' and answer questions in the first person, that is from the participant's perspective (Head, 2017; Head, Ellis-Caird, Rhodes & Mengoni, in press). The interview involved exploring parents' and carers' conceptualisations of 'identity' in general, as well as what their thoughts were in relation to the participants' photographs, and whether they captured the participants' identities. Due to the nature of the participants' needs, they were unable to confirm or deny whether the carers' interpretations aligned with their own views. Therefore, in line with Cluley (2016), this study adopted Boxall's (2010) approach to critically reviewing the carers' responses to the pictures, by asking questions such as '*what makes you think that?*' to help get a better understanding of the carer's response and where it came from.

### 2.2.4 | Reflexive journal

In line with the positioning of the researcher in this project, an important aspect of the design is the researcher's reflexivity. As defined by Ellis (2014, p. 64) reflexivity is used to study the interactions between researcher and participants at a deeper level by moving the observational lens from "The aim was to encourage conscious awareness of the researcher's values and make visible the 'constructed nature of research outcomes'" (Ortlipp, 2008, p. 695). A reflexive journal was kept throughout the duration of the project. Written through the researcher's lens, the journal contained "thoughts, opinions, musings, discussions, and reflections on the process and the participants" (Fusch et al., 2017, p. 930).

## 3 | A PROCESS OF TRIANGULATION AND ANALYSIS

One of the benefits of utilising multiple methods of data collection is that the data can be triangulated to identify converging lines of evidence. Triangulation can be described as combining research methods to answer particular research question(s). It is a systematic process that involves the researcher identifying patterns, across and between data, to validate the analytic process (Mays & Pope, 2000). Through combining methods, it can help avoid biases that may arise out of a singular method, help explore and explain complex issues, and increase credibility and validity of research findings (Noble & Heale, 2019; Yin, 2004). It has also been identified as a useful method when conducting research with people with intellectual disabilities (Llewellyn, 1995), as it offers flexibility and allows for participants' preferences to be met through different methods of data collection.

### 3.1 | Analysis procedure

The analysis procedure followed recommendations from Yin (2004) and Baxter and Jack (2008). The process of analysis involved triangulating the data (field notes and interview transcripts), initially within each case and then across the three cases (Yin, 2004) using reflexive thematic analysis (TA; Braun & Clarke, 2006, 2012, 2018, 2019). Braun and Clarke define TA as "a method for systematically identifying, organising, and offering insight into patterns of meaning (themes) across a data set" (2012, p.57). Data were coded line by line using phrases and sentences. Both inductive and deductive coding processes were adopted. It is important to note the photographs themselves were not analysed but incorporated into the interviews to prompt discussion. The process of presenting the within-case data was guided by previous papers, some of which included vignettes as a way of introducing the reader to the case and illustrating themes within each case pertinent to the research questions (see Hubert & Hollins, 2010; Johnson, 1998; Thompson, 2018). A summary of the analysis process is illustrated in Figure 3.

## 4 | FINDINGS

Utilising all three components (ethnographic observations, photovoice and interview) contributed to understanding aspects of a person's perceived identity. The ethnographic observations often reinforced what was discussed with families and carers during the interview. For example, one participant was described as 'mischievous' and 'fun loving', by their family, and this was observed during interactions with them at college and captured in particular pictures taken by the participant. These pictures were further brought to life through the accompanying stories of their family. See Table 2 for an illustration of this. These findings suggest that all three components were important to building a rich understanding of a person's identity.

## 5 | DISCUSSION

The interview questions encouraged families and carers to reflect on their knowledge of the person, to step into their shoes and provide narratives in relation to the photographs. Like previous research (Cluley, 2016; Overmars-Marx et al., 2018), the pictures were therefore brought to life in the narratives provided by family and carers. Looking through the pictures in isolation limited what could be understood about the person's identities. This demonstrates the importance of accompanying the pictures with narratives rather than them standing alone (Cluley, 2016; Overmars-Marx et al., 2018).

Additionally, families and carers also spoke of the opportunities photovoice offered for interacting with participants and being curious about their existing perceived identities. For example, one family member spoke about how their child's interactions with the pictures revealed more about the strength of their relationship with another family member.

"...it's strange isn't it because that's not what I would have thought from looking at the pictures, I thought he'd definitely go for his sister...but it was definitely his cousin so yeah that was interesting."

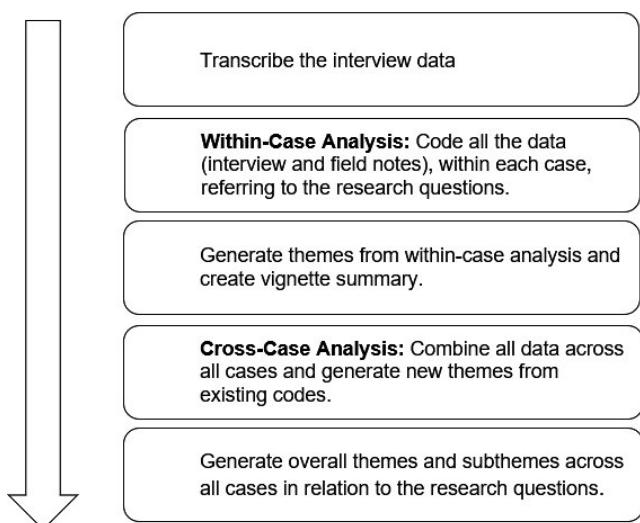
Similarly, another parent spoke about the pictures possibly revealing more about the participant's love of colour;

"...maybe [participant] likes really bold colours. It could be and I told you he likes, well reds and pinks [pause] and see even with this one where he chose mommy, mommy has got like a 'reddie' colour top on."

Viewing identity as something that is co-constructed between people and their environment and expressed through interaction can account for how we might understand a person who is less able to express themselves through language. Therefore, these findings suggest that whilst photovoice may reinforce what is already perceived of a person's identity, it can also introduce new areas to become curious about in relation to what may be important to that person. However, these additional and alternative perspectives about someone's identity rely on important facilitating factors including providing opportunities for inclusion, having knowledge of the person, a positive attitude and a safe relationship. Through implementing these facilitating factors, participants are more likely to be given opportunities to express themselves and challenge the stigma and stereotypes that may narrow perceptions of their identity.

This approach emphasises the importance of directly involving people with severe and profound intellectual disabilities in research, as well as those closest to them. Inviting others to act as co-researchers, as part of photovoice, was something explored by Cluley (2016). Cluley (2016, p. 43) emphasised that the narratives offered by families and carers added "an extra layer of meaning" that could not be gathered from the photographs themselves. Cluley (2016) highlighted that this view differs from that of Pink (2007), who suggests pictures can stand alone and provide insight into peoples' lives. The results of this study support Cluley's (2016) findings and illustrate the importance of involving people around the participant as a way of getting to know them. It was the combination of Box all's (2010) questions, as utilised by Cluley (2016), and those influenced by Karl Tomm's (1999 cited in Mudry et al. 2016) internalised other, that provided a richer understanding of participants, and invited families and carers into those storytelling roles.

Despite this, some may still question whether the photographs taken by participants provide an accurate representation of their identities. Alone, photovoice may not be enough to explore identity expression amongst people with severe and profound intellectual disabilities. Yet, as discussed above, using multiple methods of data collection that are triangulated to explore corresponding and opposing themes can help validate what is illustrated in the photographs themselves. In addition to this, inviting carers and family members into the positions of people with severe and profound intellectual disabilities can offer insight into that person's life. Of course, more



**FIGURE 3** A description of the process of triangulation and analysis

**TABLE 2** The overlap of themes across different methods of data collection

Photographs taken by participants	Family interview data	Field note observations
Muddy walks in the countryside	Family members described this as “things like mud I mean, she is just like one of those youngsters, who likes, you know, if there is a dry bit of the path and a muddy bit of the path, you know where [she] will be!”	Observations included noticing the participants love for the outdoors and choosing to go outside no matter the weather.
Selfies	Family members talked about the participants' love of photographs and them being “a way of him expressing himself...I like seeing him laugh when he takes a picture of himself.” The participant was often described as “cheeky” and “funny.”	During interactions with the participant “I noticed his big eyes and cheeky grin.” I also witnessed his cheeky behaviour during a cooking session when he placed the “whole pot of gravy granules in the saucepan” when prompted to put more in.
Pictures of family members and peers	During the interview, the participants' mother spoke of the importance of relationships “it's very important to [participant] that he has people he likes.” She described how he would “ask permission for everything he does, by making eye contact with those supporting him.”	During my interactions with the participant, I noticed he would make direct eye contact with those supporting him and engaged in intensive interaction with them. In conversations with the participants' care worker she informed me that intensive interaction was his main method of communication and something that was important to him.

needs to be done to validate the methodology and work towards answering the question of whether photovoice can give voice, yet for this to be done, people with severe and profound intellectual disabilities need to continue to be involved in research.

Additionally, whilst photovoice may offer an inclusive method for some people with severe and profound intellectual disabilities, it may not be so accessible for people with physical or visual impairments. In Cluley's (2016) research, they accommodated participants' physical and visual impairments by carers taking photographs from the viewpoint of participants. Whilst this enabled most participants to participate in the study that explored what is important to participants' day-to-day lives, it would be harder to answer questions on whether the photographs captures are a representation of someone's identity. Therefore, more needs to be done to consider exploring identity expression amongst people with severe and profound intellectual disabilities who have physical or visual impairments.

In summary, photovoice can offer an interactive and inclusive activity that invites people into positions of curiosity. Additionally, people familiar with the person play a central role in providing accompanying narratives that help bring the photographs to life. Through including people with intellectual disabilities in research, we can begin to understand more about their identities and work towards challenging the stigmatising views that exist within society. When partnered with additional observations and interview techniques photovoice provides a means by which people with severe

and profound intellectual disabilities can be included in research and given a voice. However, in line with previous recommendations (see Boxall & Ralph, 2010; Cluley, 2016; Mietola et al., 2017), it requires the facilitation of people around the person and acceptance from ethics committees and research governance for this type of research to continue.

## 5.1 | Avenues for future research

The main aim of this study was to trial an innovative methodology and process of analysis to include and capture the views of people with severe and profound intellectual disabilities. Building on the study's findings, two future avenues for research are of particular interest. The first concerns how to evaluate research using this type of methodology. The second considers the use of videography as an alternative to photography.

As noted by Noble and Smith (2015, p. 34), “qualitative research is frequently criticised for lacking scientific rigour with poor justification of the methods adopted” and it is therefore important to identify a process for formally assessing the quality of the method itself. This may include using several researchers so that the analysis process could be cross-validated, or family members and carers could be offered the opportunity to comment on the vignettes produced. Alternatively, researchers could collect pre/post-statements



from family and carers to explore similarities and differences in the data collected following ethnographic observations and application of photovoice.

Photographs are just one method of involving participants with severe and profound intellectual disabilities in research. However, the photographs themselves are limited by only capturing a fixed moment and it can be difficult for families and carers to remember exactly what was going on beyond this picture when providing narrative accounts. One way of building on this method would be to utilise videography. There are some studies that have started to involve participants with intellectual disabilities in video ethnographic studies (see Kaley et al., 2019). Although, like other studies, they have mainly involved participants with less severe forms of intellectual disabilities since they have been able to participate in interviews whilst watching the videos. Depending on the approach taken, videography may offer the opportunity to walk in the shoes of participants and would not rely on them having to learn to use a camera. Despite this, the challenges remain when it comes to eliciting participants views and perspectives since they cannot provide the narratives themselves (Kaley et al., 2019). Additionally, individuals with physical and visual impairments would also continue to struggle to engage in this type of activity. Whilst it may not solve all the challenges of including people with severe and profound intellectual disabilities in research, it may offer another medium of inclusive research.

## 6 | CONCLUSIONS

This research provides further evidence that people with all degrees of severe intellectual disabilities can and should be directly involved in research. It is evident from this study that directly involving people with intellectual disabilities can also influence relationships and quality of life. Attempting to give a visual voice to people with intellectual disabilities and using research to create the opportunity for these voices to be heard can challenge stigmatising assumptions and biases that so often overshadow the lives of people with intellectual disabilities. The methodology used in this project provides one-way researchers can directly involve people with severe and profound intellectual disabilities in research and challenge the idea they are 'less than human'. Moving forward, it is important that researchers continue to develop ways of directly involving people with all degrees of intellectual disabilities in research and develop ways of validating creative methodologies.

## ACKNOWLEDGEMENTS

A special thank you to all those who contributed to this project, namely Dr Helen Ellis-Caird, Academic Manager at the University of Hertfordshire; Dr Louisa Rhodes, Clinical Psychologist at Hertfordshire Partnership University NHS Foundation Trust; Dr Hilary Harris, Visiting Fellow, Cranfield University; and to all the participants with intellectual disabilities, their families and staff at the education centre.

## DATA AVAILABILITY STATEMENT

Data are not available.

## ORCID

Emma Krisson  <https://orcid.org/0000-0001-6562-0655>

## REFERENCES

- Aldridge, J. (2007). Picture this: The use of participatory photographic research methods with people with learning disabilities. *Disability and Society*, 22(1), 1–17. <https://doi.org/10.1080/09687590601056006>
- American Psychiatric Association (2013). *Diagnostic and statistical manual of mental disorders*, 5th ed. Author.
- Baxter, P., & Jack, S. (2008). Qualitative case study methodology: Study design and implementation for novice researchers. *The Qualitative Report*, 13(4), 544–559.
- Beart, S., Hardy, G., & Buchan, L. (2005). How people with intellectual disabilities view their social identity: A review of the literature. *Journal of Applied Research in Intellectual Disabilities*, 18(1), 47–56. <https://doi.org/10.1111/j.1468-3148.2004.00218.x>
- Booth, T., & Booth, W. (2003). In the frame: Photovoice and mothers with learning difficulties. *Disability & Society*, 18(4), 431–442. <https://doi.org/10.1080/0968759032000080986>
- Boxall, K. (2010). Involving people with profound and multiple learning difficulties in research: barriers and possibilities. In *Disability Studies Conference*. Retrieved 08.06.2019 from [https://www.lancaster.ac.uk/fass/events/disabilityconference\\_archive/2010/Papers/Boxall2010.pdf](https://www.lancaster.ac.uk/fass/events/disabilityconference_archive/2010/Papers/Boxall2010.pdf)
- Boxall, K., & Ralph, S. (2009). Research ethics and the use of visual images in research with people with intellectual disability. *Journal of Intellectual and Developmental Disability*, 34(1), 45–54. <https://doi.org/10.1080/13668250802688306>
- Boxall, K., & Ralph, S. (2010). Research ethics committees and the benefits of involving people with profound and multiple learning disabilities in research. *British Journal of Learning Disabilities*, 39(3), 173–180. <https://doi.org/10.1111/j.1468-3156.2010.00645.x>
- Braun, V., & Clarke, V. (2006). Using thematic analysis in psychology. *Qualitative Research in Psychology*, 3(2), 77–101. <https://doi.org/10.1191/1478088706qp0630a>
- Braun, V., & Clarke, V. (2012). Thematic analysis. In H. Cooper, P. M. Camic, D. L. Long, A. T. Panter, D. Rindskopf, & K. J. Sher (Eds.), *APA handbook of research methods in psychology*, Vol. 2. Research designs: Quantitative, qualitative, neuropsychological, and biological (p. 57–71). American Psychological Association.
- Braun, V., & Clarke, V. (2018). Thematic analysis – an introduction. [Video file]. Retrieved from <https://www.youtube.com/watch?v=5zFcC10vOVY>
- Braun, V., & Clarke, V. (2019). Reflecting on reflexive thematic analysis. *Qualitative Research in Sport, Exercise and Health*, 11(4), 589–597.
- Brewer, J. D. (2000). *Ethnography*. Open University Press.
- Brewster, S. J. (2004). Putting words into their mouths? Interviewing people with learning disabilities and little/no speech. *British Journal of Learning Disabilities*, 32, 166–169.
- British Institute of Learning Disabilities (2019). *Information about learning disabilities*. Retrieved from <http://www.bild.org.uk/resources/faqs/#What-is-the-difference-between-the-terms-learning-disabilities-learning-difficulties-and-intellectual-disabilities>
- British Psychological Society. (2008). *Conducting research with people not having the capacity to consent to their participation: A practical guide for researchers*. Leicester: BPS. Retrieved 11.12.2019 from [https://www.ed.ac.uk/files/atoms/files/bps\\_guidelines\\_for\\_conducting\\_research\\_with\\_people\\_not\\_having\\_capacity\\_to\\_consent.pdf](https://www.ed.ac.uk/files/atoms/files/bps_guidelines_for_conducting_research_with_people_not_having_capacity_to_consent.pdf)
- Caldwell, K. (2013). Dyadic interviewing: A technique valuing interdependence in interviews with individuals with intellectual disabilities. *Qualitative Research*, 14(4), 488–507.

- Cambridge Dictionary (2019). Identity. Retrieved from <https://dictionary.cambridge.org/dictionary/english/identity>
- Cameron, L., & Murphy, J. (2007). Obtaining consent to participate in research: The issues involved in including people with a range of learning and communication disabilities. *British Journal of Learning Disabilities*, 35(2), 113–120.
- Cluley, V. (2016). Using photovoice to include people with profound and multiple learning disabilities in inclusive research. *British Journal of Learning Disabilities*, 45(1), 39–46.
- Davies, C. A., & Jenkins, R. (1997). 'She has different fits to me': How people with learning difficulties see themselves. *Disability and Society*, 12, 95–109.
- Dorozenko, K. P., Roberts, L. D., & Bishop, B. (2015). The identities and social roles of people with an intellectual disability: Challenging dominant cultural worldviews, values and mythologies. *Disability & Society*, 30(9), 1345–1364.
- Ellis, S. J. (2014). Perspectives of the autistic 'voice': An ethnography examining information education learning experiences. (Doctoral dissertation). Sheffield Hallam University, UK.
- Fearon, J. (1999). What is identity (As we now use the word)? Retrieved from <https://web.stanford.edu/group/fearon-research/cgi-bin/wordpress/wp-content/uploads/2013/10/What-is-Identity-as-we-now-use-the-word.pdf>
- Finlay, W. M. L., Antaki, C., & Walton, C. (2007). On not being noticed: Intellectual disabilities and the non-vocal register. *Intellectual and Developmental Disabilities*, 45(4), 227–245.
- Fusch, P. I., Fusch, G. E., & Lawrence, R. N. (2017). How to conduct a mini-ethnographic case study: A guide for novice researchers. *The Qualitative Report*, 22(3), 923–941.
- Gergen, K. J. (2011). The self as social construction. *Psychological Studies*, 56(1), 108–116.
- Gustafsson, J. (2017). Single case studies vs. multiple case studies: a comparative study. Retrieved 01.05.2020 from <https://www.semanticscholar.org/paper/Single-case-studies-vs.-multiple-case-studies%3A-A-Gustafsson/ae1f06652379a8cd56654096815dae801a59cba3>
- Head, A. (2017). *How people with intellectual disabilities experience transition through the transforming care programme: A grounded theory study*. (Unpublished doctoral dissertation). University of Hertfordshire, Hatfield, United Kingdom.
- Head, A., Ellis-Caird, H., Rhodes, L., & Mengoni, S. (in press). "It was really good, she sort of took some words what happened, like what I would say": Adapting dyadic interview techniques to capture the stories of marginalised voices in research. *Qualitative Methods in Psychology Bulletin*, Manuscript Submitted.
- Holloway, I., Brown, L., & Shipway, R. (2010). Meaning not measurement: Using ethnography to bring a deeper understanding to the participant experience of festivals and events. *International Journal of Event and Festival Management*, 1(1), 74–85. <https://doi.org/10.1108/17852951011029315>
- Hubert, J., & Hollins, S. (2010). A study of post-institutionalised men with severe intellectual disabilities and challenging behaviour. *Journal of Policy and Practice*, 7(3), 189–195.
- Johnson, K. (1998). Deinstitutionalisation: The management of rights. *Disability and Society*, 13(3), 375–387. <https://doi.org/10.1080/09687599826696>
- Jurkowski, J. M. (2008). Photovoice as participatory action research tool for engaging people with intellectual disabilities in research and program development. *Intellectual and Developmental Disabilities*, 46(1), 1–11.
- Kaley, A., Hatton, C., & Milligan, C. (2019). More than words: The use of video in ethnographic research with people with intellectual disabilities. *Qualitative Health Research*, 29(7), 931–943. <https://doi.org/10.1177/1049732318811704>
- Kamlager, C. (2013). Identity Making Process of Individuals with Mild Intellectual Disabilities. (Unpublished dissertation). University of Kentucky, Kentucky, USA.
- Kiernan, C. (1999). Participation in research by people with learning disability: Origins and issues. *British Journal of Learning Disabilities*, 27(2), 43–47. <https://doi.org/10.1111/j.1468-3156.1999.tb00084.x>
- Llewellyn, G. (1995). Qualitative research with people with intellectual disability. *Occupational Therapy International*, 2, 108–127. <https://doi.org/10.1002/oti.6150020206>
- Mays, N., & Pope, C. (2000). Qualitative research in health care: Assessing quality in qualitative research. *British Medical Journal*, 320, 50–52. <https://doi.org/10.1136/bmj.320.7226.50>
- McDonald, K., Kidney, C., & Patka, M. (2012). 'You need to let your voice be heard': Research participants views on research. *Journal of Intellectual Disability Research*, 57(3), <https://doi.org/10.1111/j.1365-2788.2011.01527.x>
- Mietola, R., Miettinen, S., & Vehmas, S. (2017). Voiceless subjects? Research ethics and persons with profound intellectual disabilities. *International Journal of Social Research Methodology*, 20(3), 263–274. <https://doi.org/10.1080/13645579.2017.1287872>
- Mudry, T. E., Strong, T., Sametband, I., Rogers-de Jong, M., Gaete, J., Merritt, S., Doyle, E. M., & Ross, K. H. (2016). Internalized other interviewing in relational therapy: Three discursive approaches to understanding its use and outcomes. *Journal of Marital and Family Therapy*, 42(1), 168. <https://doi.org/10.1111/jmft.12110>
- Noble, H., & Heale, R. (2019). Triangulation in research, with examples. *Evidence Based Nursing*, 22(3), 67–68. <https://doi.org/10.1136/ebnurs-2019-103145>
- Noble, H., & Smith, J. (2015). Issues of validity and reliability in qualitative research. *Evidence-Based Nursing*, 18(2), 34–35. <https://doi.org/10.1136/eb-2015-102054>
- Ortlipp, M. (2008). Keeping and using reflective journals in qualitative research process. *The Qualitative Report*, 13(4), 695–705.
- Overmars-Marx, T., Thomése, F., & Moonen, X. (2018). Photovoice in research involving people with intellectual disabilities: A guided photovoice approach as an alternative. *Journal of Applied Research in Intellectual Disabilities*, 31(1), 92–104. <https://doi.org/10.1111/jar.12329>
- Pink, S. (2007). *Doing visual ethnography: Images, media and representation in research*. SAGE Publications Ltd.
- Porter, J., Ouvry, C., Morgan, M., & Downs, C. (2001). Interpreting the communication of people with profound and multiple learning difficulties. *British Journal of Learning Disabilities*, 29(1), 12–16. <https://doi.org/10.1046/j.1468-3156.2001.00083.x>
- Povee, K. (2014). The identities and social roles of people with intellectual disabilities: Challenging dominant cultural worldviews, values and mythologies. (Unpublished doctoral dissertation). Curtin University, Perth, Australia.
- Povee, K., Bishop, B. J., & Roberts, L. D. (2014). The use of photovoice with people with intellectual disabilities: Reflections, challenges and opportunities. *Disability & Society*, 29(6), 893–907. <https://doi.org/10.1080/09687599.2013.874331>
- Robinson, J., & Eagle, S. (2018). An exploration of drawing as a method for understanding identity in adults with a learning disability. (Unpublished masters dissertation). University of Bristol, United Kingdom.
- Rojas, S., & Sanahuja, J. M. (2011). The image as a relate: Video as a resource for listening to and giving voice to persons with learning disabilities. *British Journal of Learning Disabilities*, 40, 31–36.
- Shumba, T. W., & Moodley, I. (2018). Part 1: A review of using photovoice as a disability research method: Implications for eliciting the experiences of persons with disabilities on the Community Based Rehabilitation programme in Namibia. *African Journal of Disability*, 7, 1–11. <https://doi.org/10.4102/ajod.v7i0.418>
- Sutton-Brown, C. A. (2014). Photovoice: A methodological guide. *Photography and Culture*, 7(2), 169–185. <https://doi.org/10.2752/175145214X13999922103165>
- Thompson, T. G. (2018). Thriving with Down Syndrome: A Qualitative Multiple Case Study. (Unpublished doctoral dissertation). University of Denver, Canada.

- Vignoles, V. L. (2017). Identity: Personal AND Social Identity. In K. Deaux, & M. Snyder (Eds.), *The Oxford Handbook of Personality and Social Psychology* (pp. 289–309). Oxford University Press.
- Walmsley, J. (2004). Inclusive learning disability research: The (non-disabled) researcher's role. *British Journal of Learning Disabilities*, 32(2), 65–71. <https://doi.org/10.1111/j.1468-3156.2004.00281.x>
- Wang, C. (1999). Photovoice: A participatory action research strategy applied to women's health. *Journal of Women's Health*, 8(2), 185–192. <https://doi.org/10.1089/jwh.1999.8.185>
- Wang, C., & Burris, M. A. (1997). Photovoice: Concept, methodology, and use for participatory needs assessment. *Health Education & Behaviour*, 24(3), 369–387. <https://doi.org/10.1177/109019819702400309>
- Ware, J. (2004). Ascertaining the views of people with profound and multiple learning disabilities. *British Journal of Learning Disabilities*, 32(4), 175–179. <https://doi.org/10.1111/j.1468-3156.2004.00316.x>
- World Health Organization (1992). The ICD-10 classification of mental and behavioural disorders: clinical descriptions and diagnostic guidelines. World Health Organization. <https://apps.who.int/iris/handle/10665/37958>.
- Yin, R. K. (2004). Case study methods. Retrieved 20.04.2020 from <https://www.scribd.com/doc/37102046/Robert-Yin-Case-Study-Research>

**How to cite this article:** Krisson E, Qureshi M, Head A. Adapting photovoice to explore identity expression amongst people with intellectual disabilities who have limited or no verbal communication. *Br J Learn Disabil*. 2021;00:1–11. <https://doi.org/10.1111/bld.12373>