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## REVIEW

# A systematic review of photovoice research methods with people with intellectual disabilities

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## Abstract

**Background:** Photovoice is an arts-based participatory action research methodology that is growing in popularity. Our aim was to systematically review photovoice research with people with intellectual disabilities to describe the current 'state of the art' and identify areas for further methodological consideration.

**Methods:** We searched five databases using search terms relating to photovoice and intellectual disabilities. Thirty one studies met inclusion criteria. We used thematic analysis to identify common themes.

**Findings:** The themes identified—adaptations to the photovoice method, collaboration, participation and power, impact and outcomes—explored how far the 'voice' and agency of participants with intellectual disabilities taking part in photovoice research were supported and whether photovoice lived up to its promise as 'action' research.

**Conclusion:** Photovoice creates opportunities for self-representation of people with intellectual disabilities through photography. Participants could be further supported to engage with researchers in critical reflection on findings and collaborate on tangible outcomes.

## KEYWORDS

arts-based research, intellectual disabilities, participatory action research, photovoice, systematic review

## 1 | INTRODUCTION

### 1.1 | Photovoice

Photovoice is a qualitative research method that originated in the work of Caroline Wang and colleagues in the 1990s with rural women in China with the following aims: to record and reflect a community's concerns, promote critical dialogue through discussion of photographs and reach policy makers (Wang & Burris, 1997). Unlike usual qualitative research where the researcher approaches participants with a list of questions and a recording device, in photovoice projects the community member selects how aspects of their environments and experiences are identified and represented as 'data' by capturing them in a photographic image. Photovoice is a participatory action research (PAR) method,

which means that community members not only decide how their lives are represented, they also determine how meaning and new knowledge is created through taking and discussing photographs, and how community strengths and assets are foregrounded in ways that allow community members to bring about the changes they want to see.

Wang and Burris (1997) assert that photovoice has many advantages over other research methods. It positions community members (rather than researchers) as experts in understanding their experiences and needs. It provides an accessible way for people from marginalised groups to represent aspects of their everyday lives not accessible to researchers through visual images, representing aspects of lived experience beyond what can easily be put into words. Community members use an approach that is an enjoyable and motivating and builds skills, pride and relationships. In addition, it allows community members to

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bring in the narratives and perspectives of others who become part of the photo-taking process. The 'action' aspect of PAR is built into the photovoice method, providing a platform to 'reach, inform and organize other community members' (Wang & Burris, 1997, p. 373) in the service of ameliorating individual and community experiences.

Photovoice also has the advantage of having a well-described methodology with a clearly articulated theoretical basis. Wang (1999) sets out the key stages in photovoice and these have been commonly referenced in subsequent studies: (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 using the SHOWeD method, and (ix) planning how to share this information with the target audience. The SHOWeD method encompasses five questions to stimulate discussion of experiences related to each image, connecting them to wider structural inequalities: *What do you See here? What is really Happening here? How does this relate to Our lives? Why does this concern, situation, or strength Exist? And what can we Do about it?*

Since the 1990s photovoice has gained enormously in popularity. One driver has been the increasing importance given by researchers in putting community members' 'voice', priorities and experience-based expertise at the centre of research and development of new interventions in health and social care. Another has been the dominance of the visual in contemporary culture alongside the digital revolution which has facilitated everyday practices of taking and sharing visual images using mobile phones and social network platforms such as Facebook, Instagram and WhatsApp (Rose, 2016). From being a relatively expensive and exclusive hobby, photography has become an everyday practice for millions and we are increasingly skilled and comfortable in framing, selecting and sharing images of ourselves and our contexts as a way of curating social identities and fostering social networks (Peters & Allan, 2018).

## 1.2 | Photovoice and people with intellectual disabilities

It is not hard to appreciate the benefits of this approach for people with intellectual disabilities. Photovoice offers opportunities for self-representation of people who often need support with verbal communication (Booth & Booth, 2003; Boxall & Ralph, 2009) allowing them to concretize their lived experience and translate concepts, feelings and issues into tangible representations (Wass & Safari, 2020). These images provide a way of preserving their perspective for reflection and discussion making fewer demands on memory. As a participatory research method, photovoice is consistent with the aims and principles of inclusive research (Strnadová & Cumming, 2014) whereby research is done *with* rather than *on* people with intellectual disabilities and academic researcher share power and responsibility with people with intellectual disabilities to identify research questions, collect data, derive meaning and learning from the data and share the findings.

Furthermore photovoice research holds out possibilities for the inclusion and empowerment of people with intellectual disabilities, including those with profound and multiple intellectual disabilities who have traditionally been excluded in the research process (Cluley, 2017). Wang and Burris emphasise the potential of photovoice for marginalised groups, and people with intellectual disabilities are among the most marginalised in society and face considerable barriers in making sure their unique perspectives contribute to public debate. Photovoice creates opportunities for participants to develop a collective voice through group discussion which can inform those who design, fund and run services about how people with intellectual disabilities want to live their lives.

Photovoice research with people with intellectual disabilities has been gathering momentum over the last twenty years, since the publication of Booth & Booth's landmark photovoice study of mothers with intellectual disabilities in 2003. As yet there has been limited effort to consolidate and distil the learning from using this approach with people with intellectual disabilities. The purpose of this review therefore was to gain a perspective on the 'state of the art' of photovoice research with people with intellectual disabilities. We aimed to answer the following research questions: (1) What adaptations to photovoice have been used for people with intellectual disabilities? (2) How has photovoice been used as an inclusive and participatory research method with this group? (3) What have been the outcomes and impacts of photovoice research with people with intellectual disabilities?

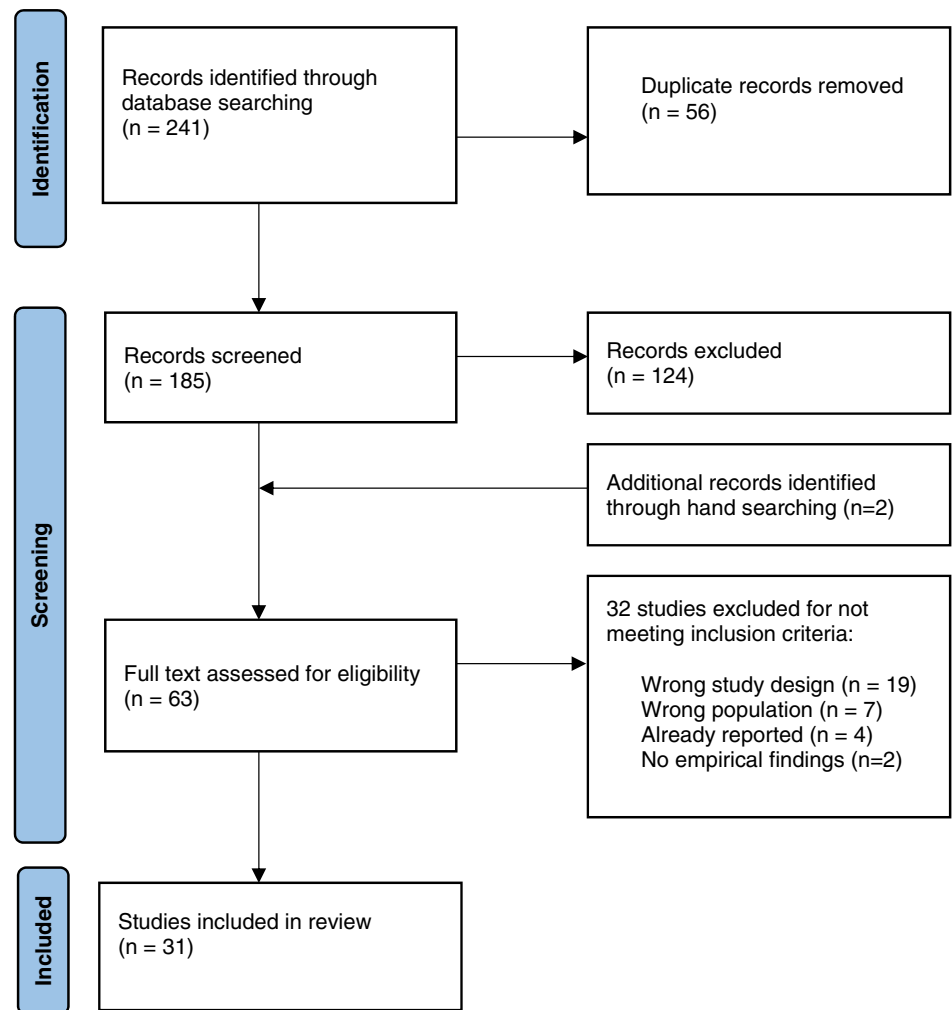
## 2 | METHOD

We undertook the review following PRISMA guidelines for completing systematic reviews of research literature (Page et al., 2021) and registered the review with Prospero (Ref: CRD42022320005).

### 2.1 | Inclusion and exclusion criteria

We included peer-reviewed articles in English from 1994 when the first photovoice study was published (Wang & Burris, 1994) up until the date when the search was conducted in May 2022. We included research sites anywhere in the world, with participants of any age who had been identified as having an intellectual disability. We defined 'intellectual disability' as the presence of significant limitations in intellectual functioning and adaptive behaviour that manifests before the age of 18 (Schalock et al., 2010). We excluded research with people with acquired brain injury, dementia or with specific learning difficulties such as dyslexia, and people with autism if more global cognitive impairments were not present. Research where photovoice as a methodology was explicitly mentioned was included, or where the methodology was recognisably similar to this, specifically where participants took their own photographs and discussed/reflected on these with the researchers. We excluded studies that used other visual methodologies (drawing, collaging, participatory film and video research).

**FIGURE 1** PRISMA 2020 flow diagram (from Page et al., 2021)



## 2.2 | Search strategy

We searched databases that included research conducted in health services, social care and education, namely MEDLINE, PsycINFO, Applied Social Science Index and Abstracts (ASSIA), Social Policy and Practice and ERIC. The search terms used related to 'photovoice' ('photovoice,' 'photo elicitation' and 'visual methods'), and 'intellectual disabilities' ('intellectual disabilities', 'mental retardation', 'mental deficiency', 'learning disabilities', 'learning difficulties' and developmental disabilities'). We also conducted hand searching through articles' reference and citation lists.

## 2.3 | Study selection

The initial search generated 241 articles. Covidence software was used to manage selection and review of articles. Fifty six duplicate article were removed and 185 were included in the initial screening. The initial assessment of the articles involved the authors reading through the titles and the abstracts to assess the eligibility of the articles, and those that did not meet the criteria were excluded.

Two studies were included following hand searching. The remaining articles were read in full and we resolved any uncertainties through further discussion. At this stage we also excluded articles by the same groups of authors which provided little additional information about methods or findings (see Figure 1).

## 2.4 | Data extraction and data analysis

We created a bespoke data extraction form to input study details regarding country where the study was conducted, the setting (e.g., health care, social care, employment and workplace, etc.), how photovoice elements were conducted (training and ethics, group or individual interviews, data analysis and dissemination). We then conducted a more detailed thematic analysis of included studies (Braun & Clarke, 2006) involving line by line inductive coding and generation of descriptive and interpretive themes supported by NVivo data analysis software. An initial coding frame was developed from reading a selection of articles, which was then discussed between reviewers and refined. Development of themes took place in further discussion between the researchers until consensus was reached.

TABLE 1 Summary of included studies

Authors (date), country	Research focus	Participants	Procedures and data collection
Booth and Booth (2003), UK	Experiences of motherhood	Sixteen mothers taking part in support group for mothers with intellectual disabilities. 13 took photos.	Participants took photos over 6 month period, discussed these with researchers and in a group meeting.
Aldridge (2007), UK	Experiences of social inclusion/exclusion	Nineteen members of social and therapeutic horticulture (STH) groups, 15 men and 4 women	Participants given 1 month to take photos at STH sites followed by individual interviews about photos
Jurkowski and Paul-Ward (2007), USA	Disparities in health promotion	Four members of larger focus group study with Latinos with intellectual disabilities ( $n = 13$ ), aged 32–68, 2 women and 4 men	Individual briefing and photo-taking over 3 month period.
O'Brien et al. (2009), Ireland	Experiences of third level education	Nineteen students attending inclusive university course, aged 19–48, 13 women and 6 men	Focus groups; photographs were collected annually as part of a <i>day in the life</i> Photovoice exercise and discussed in groups, individual student diaries
Ollerton and Horsfall (2013), Australia	Experiences of and barriers to self-determination	Five people aged 18–23 with 'mild' to 'moderate' intellectual disabilities	Photos taken by 'co-researchers' (participants) discussed individually with researcher and in group.
Ottmann and Crosbie (2013), Australia	1. Comparison of research methods 2. Views on issues that affect the lives of people with intellectual disabilities	Eleven people with 'mild' to 'moderate' intellectual disabilities aged 15–30, 5 women and 6 men, 11 family or paid carers	Different data collection methods: Questionnaire Semi-structured interview Ethnographic observation Photo taking over 7–10 days Individual interviews to discuss photos
Schleien et al. (2013), USA	Community inclusion	Seven members of self-advocacy organisation, aged 21–48, 1 women and 6 men	Group orientation, two photo taking periods of 2 weeks, group discussions.
Akkerman et al. (2014), Netherlands	Employment and job satisfaction	Nine individuals working in sheltered or integrated employment, aged 21–56, 6 women and 3 men, 'mild' to 'moderate' intellectual disabilities	Individual training, photo-taking over unrestricted period between 6 and 25 days, individual interviews to discuss photos
Povee et al. (2014), Australia	Identities and social roles	Eighteen members of self-advocacy organisation aged 20–45 years, 7 women and 11 men	Group briefing, photo taking over 3 month period. Interviews to discuss photos took place individually, in pairs and small groups
Dorozenko et al. (2015), Australia	Identities and life experiences	Eight members of self-advocacy organisation, aged 20–45, 7 women and 1 man	Group briefing, photo taking and individual interviews with participants about the photos.
Dorozenko et al. (2016), Australia	Identities and life experiences	See Dorozenko et al. (2015)	See Dorozenko et al. (2015)
Pallisera et al. (2016), Spain	Transition to adulthood	Eight young people aged 17–23 taking part in transition training course at supported employment project. 13 family members	i. Individual interviews with young people ii. Two focus groups with young people, second one with discussion of photos taken by participants over 1 week period iii. Individual interviews with young people and focus group with family members
van Heumen and Schippers (2016), Netherlands	Perspectives on transition to adulthood	Four young men with Down Syndrome aged 26–28 living in own flats. Interviews with 2 other people with intellectual disabilities and 8 family members	i. Interviews and focus group with family members ii. Interviews with all participants with intellectual disabilities iii. Focus group with photovoice participants iv. Photo taking—10 week period v. Group meeting to discuss and choose photos

TABLE 1 (Continued)

Authors (date), country	Research focus	Participants	Procedures and data collection
Cluley, 2017, UK	Meaning of intellectual disabilities 'in the real world'	Sixteen adults attending social groups, 6 with 'mild' intellectual disabilities, 4 with 'moderate' and 6 with 'profound and multiple' intellectual disabilities	Photos taken over 1 week period with assistance of carers as needed. Individual discussion of photos with researcher.
Weiss et al. (2017), Canada	Experiences of Special Olympics	Five Special Olympics athletes, 4 women and 1 man, aged 13–33 with 'mild' or 'moderate' intellectual disabilities	One 2 h group training session, photo taking for 1 month, individual interviews about photographs.
Tajuria et al. (2017), UK	Experiences of bereavement	Ten self-advocates with 'mild to moderate' intellectual disabilities who had experienced loss/bereavement within last 5 years	Group training workshop, photo-taking over 2 week period, individual interviews to discuss photos
Heffron et al. (2018), USA	Community participation—barriers and supports	One hundred and forty-six people with ID living in group homes or with family, 84 men and 61 women	Training in photo-taking. Photographs taken either individually or in groups. Group discussion of photos using SHOWeD
Overmars-Marx et al. (2018), Netherlands	Neighbourhood social inclusion	Eighteen people aged 24–65, living in group homes (13) or independently with support (5), 8 women and 10 men.	'Guided photovoice method'—individual briefing, photo taking during photovoice walk with researcher, individual interviews to discuss photos.
Williamson et al. (2020), USA	Ideas of health and wellness among Native American adults	Dyads of 4 men with ID aged 19–24 and 4 family caregivers	Group orientation followed by individual photo-taking over 1 month and semi-structured interviews. Final group meeting to discuss presentation of photos.
Garrels and Sigstad (2019), Norway	Motivation for employment	Seven employees, aged 21–58, 4 women and 3 men, with 'mild' intellectual disabilities. seven employers	Participants given instructions on using cameras, given 1 week to take photos. Individual interviews to discuss photos and interviews with employers.
Spassiani et al. (2019), USA	Community-based health and participation initiatives for people ageing with intellectual disabilities	Thirty-five residents in 6 group homes, aged 26–98, 18 women, 17 men. 19 residential staff	Interviews with residential staff. Residents given cameras for 5 day period to take photos. Group discussion of photos with residents in each home.
Kim et al. (2021), Korea	The life experiences of middle-aged adults	Six adults with ID aged 40–52 (3 men & 3 women) living with family members with range of support needs ('severe' to 'mild' ID) attending day centres	Six weekly Photovoice group sessions including instruction and group discussion using SHOWeD questions. Individual interviews between group meetings
Wass and Safari (2020), Norway	Design of assistive technology to support independent travel	Nine people attending sheltered workplaces with 'mild' to 'moderate' intellectual disabilities, 5 men and 2 women	Individual instruction on photo-taking and individual interviews.
Watchman et al. (2020), UK	Perceptions of dementia	Four 'co-researchers' with ID with prior experience with dementia in their peer group	Group photovoice training and dementia information workshops, photo-taking and individual interviews over 10 month period.
Patka et al. (2020), Pakistan	Life experiences and views of Special Olympics athletes	Five Special Olympics athletes aged 19–30 and 5 guardians	Group meeting with athletes and guardians followed by 2 days of taking photos. Two further group discussions with athletes and guardians. One additional group meeting with guardians only.

(Continues)

TABLE 1 (Continued)

Authors (date), country	Research focus	Participants	Procedures and data collection
St. John et al. (2021), USA	Health disparities	Ten people aged 22–52, 4 women and 6 men, all in full-time or part-time employment	Individual briefing and orientation interviews, photo taking over 2–4 sessions, individual interviews to discuss photos, group discussion of photos.
Benoot et al. (2021), Belgium	Experience of residential care and support	Ten people with ID, aged 29–69, six men and four women, with range of support needs receiving support from Flemish care organisation	Individual instruction, photo-taking over 2–3 week period and individual interviews about photos
Krisson et al. (2021), UK	Expression of identity	Three people with diagnosis of intellectual disabilities and autism with little or no verbal communication attending college, family members and carers.	Photos taken by participants over 2 week period, discussed during 'dyadic interview' with family member/carer
Rinaldi (2021), Canada	Experiences of institutional care	Seven co-researchers with intellectual disabilities who had lived in an institution (Huron), 3 men and 4 women 'approaching or entered into old age', all white, all currently living independently. Fourteen others in research team including artists, students, community members	Photo-taking during weekend visit to institution. Discussions in monthly meetings over 12 month period in research dyads and with whole group. Used other artistic techniques as well as photovoice – collage, dance, performance, poetry.
Cluley et al. (2021), UK	Meaning of intellectual disabilities 'in the real world'	Sixteen adults with intellectual disabilities (see Cluley, 2017), 12 focus groups with 42 people—social care providers, local authority councillors, personal assistants, parent carers, teachers, healthcare professionals, student journalists and social workers, and social scientists.	Photovoice procedure described in Cluley (2017). Further discussion of photos and reflections of participants with intellectual disabilities carers and others in focus groups.
Wos and Baczała (2021), Poland	Experiences of motherhood	Seven mothers aged 22–43, 'mild' to 'moderate' intellectual disabilities	Individual instruction in photovoice, photo taking over 'a few days' followed by individual interviews to discuss photos

## 2.5 | Quality evaluation

The quality evaluation of the studies was conducted using the Critical Appraisal Skill Programme (CASP) checklist for qualitative research (Critical Appraisal Skill Programme, 2022). It is a tool that prompts allows consideration of the quality of research with reference to clarity of the research question, appropriateness of the research design, and comprehensive reporting of all aspects of the research. The main quality issues identified related to small participant samples, lack of consideration of issues pertinent to researcher-participant relationships (including strategies to ensure researcher reflexivity) and evidence of local impact of research undertaken. These quality dimensions are discussed further below.

## 3 | FINDINGS

Thirty one articles were included in the review. Seven articles described research conducted in the UK, six in the USA, five in

Australia, three in The Netherlands, two in Norway and in Canada, and one each in Ireland, Spain, Belgium, Poland, Korea, and Pakistan (Table 1).

Photovoice research with people with intellectual disabilities has clearly been growing in popularity with 5 articles published between 2003 and 2012 compared to 14 studies published between 2020 and 2021 (Figure 2). Numbers of participants with intellectual disabilities ranged from 3 to 146, though most studies had 10 or fewer participants with intellectual disabilities (mean = 15, median = 9). Age of participants ranged from 13 to 98.

Thematic analysis generated three themes: adaptations to the photovoice method, collaboration, participation and power, and impact and outcomes.

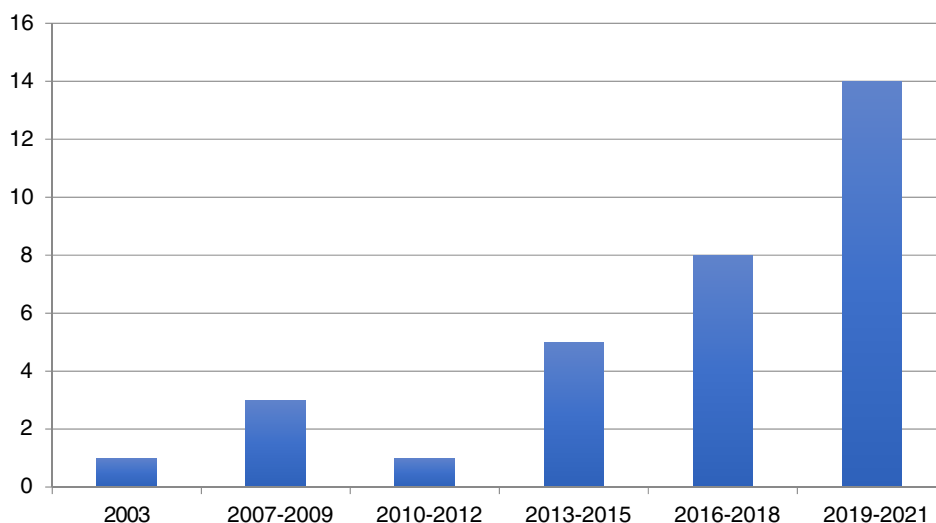
### 3.1 | Adaptations to the photovoice method

A range of adaptations to the original photovoice method were used by researchers in order to involve people who present with diverse



FIGURE 2 Date of publication

## Publications by Date



support needs associated with their intellectual disability, including difficulties with memory and attention, communication and physical dexterity, as well as restricted life experiences and limited opportunities to learn skills.

Some researchers could rely on participants' existing ownership of and familiarity with smart phone cameras (Kim et al., 2021; Patka et al., 2020; Wass & Safari, 2020) which they used for the photovoice project. However, Watchman et al. (2020) advocated for handing out a straightforward point-and-shoot digital camera as a more accessible and easy to use option, especially as smartphone ownership is far from universal among people with intellectual disabilities (Johansson et al., 2021) particularly among older people (Anrijs et al., 2022). Digital cameras also have further advantages; they allow unlimited numbers of photographs to be taken and they have large screens on the back so that participants can view their photographs instantly and photographs are easy to share digitally and print out (Heffron et al., 2018). Schleien et al. (2013) and Tajuria et al. (2017) provided most detail about how they helped participants take photographs, including sharing an accessible information sheet or slide show about the camera, and putting coloured stickers on the camera to highlight the control buttons.

The photovoice process incorporates training on practicalities and ethical aspects of taking photos. In most studies this was completed in a group setting, though Overmars et al. (2018) recommended individual training sessions to build rapport with researchers. Group training was supplemented with opportunities for participants to practice taking photos in group sessions (Schleien et al., 2013; St. John et al., 2018; Tajuria et al., 2017; Weiss et al., 2017), emphasising the importance of experiential learning for people with intellectual disabilities. Watchman et al. (2020) recommended use of mini printers so participants can view and handle tangible copies of their photographs.

In several articles more pervasive adaptations were made to the photovoice process. Most researchers gave participants time to take photographs on their own, after giving brief instructions about what

to focus on. Overmars et al. (Overmars-Marx et al., 2018) describe a different method for taking photographs during a 'walking interview' during which the researcher accompanied the participant on a walk in their neighbourhood. During the walk either the participant could take the photos or direct the researcher to do so. Cluley (2017)'s participants were people with profound and multiple intellectual disabilities who were not able to take photographs themselves. Instead they asked the individual's residential support workers to take the photographs from the vantage point of the person and at their eye level. Brief mention of help in taking photos given by carers was made by Ottmann and Crosbie (2013) and Benoot et al. (2021).

More commonly researchers added opportunities for individual interviews about the photographs taken in combination with group discussions (Booth & Booth, 2003; Kim et al., 2021; Ollerton & Horsfall, 2013; Pallisera et al., 2016; Povee et al., 2014; Rinaldi, 2021; St. John et al., 2018; Watchman et al., 2020; Williamson et al., 2020) or substituted individual interviews for the group discussions usually employed in photovoice projects (Akkerman et al., 2014; Aldridge, 2007; Benoot et al., 2021; Dorozenko et al., 2015; Garrels & Sigstad, 2019; Jurkowski & Paul-Ward, 2007; Krisson et al., 2021; Ottmann & Crosbie, 2013; Overmars-Marx et al., 2018; Tajuria et al., 2017; Wass & Safari, 2020; Watchman et al., 2020; Weiss et al., 2017; Wos & Baczała, 2021). Frequently used questions were 'what is in this photograph?'; 'why did you take it?'; 'how does this photograph make you feel?'. Researchers justified this departure from the usual photovoice method by asserting that individual interviews allowed more sensitive issues to be discussed that might cause discomfort or embarrassment in group situations (Kim et al., 2021; Wos & Baczała, 2021), to explore personal issues and individual stories in more depth (Booth & Booth, 2003; Jurkowski & Paul-Ward, 2007), facilitate reflection (Weiss et al., 2017) and minimise the influence of peers (Overmars-Marx et al., 2018). Scheduling more than one interview can be helpful to ensure familiarity with the interviewer and build trust (Overmars-Marx et al., 2018; Rinaldi, 2021).



Interviewing participants about their photographs therefore can enrich our understanding of the individual meanings of the images. However, even when adaptations are made and supportive and empathic interview methods are used, researchers commonly argue that individuals with intellectual disabilities, particularly those with greater communication support needs may find it difficult or impossible to provide verbal commentary and explanation of their photos (Aldridge, 2007; Overmars-Marx et al., 2018). Researchers have therefore used other methods to learn about the participants' experiences represented in their photos. Krisson et al. (2021), Ottmann and Crosbie (2013) and Benoot et al., 2021 adopted ethnographic methods involving naturalistic observations of their participants' lives through repeated encounters, and Overmars-Marx et al. (2018) made detailed fieldnotes during their walking interviews. Cluley (2017) elicited contextual information about the photos of individuals with little or no verbal language from their carers and supporters and Krisson et al. (2021)'s interviews were conducted as dyadic interviews with participants and their carers looking at their photographs together. In this study carers were invited to 'step into the participant's shoes' and answer questions about the participant's photographs in the first person (Head et al., 2021) to capture the participants' perspective.

### 3.2 | Collaboration, participation and power

As Strnadová and Cumming (2014) argue, there is no single definition or set of practices that define inclusive and participatory research with people with intellectual disabilities. Indeed they mention that the two terms can denote different research approaches, or be used interchangeably. Bigby et al. (2014) propose a typology of participation for people with intellectual disabilities in inclusive research—advisory, leading and controlling and collaborative. In its original form photovoice conforms most closely to a collaborative form of inclusive research with participants working alongside researchers. In this section we consider how photovoice research with people with intellectual disabilities includes them as collaborators in determining the focus of research questions, in taking photographs and engaging in photovoice discussion groups and in meaning making and analysis of findings.

In photovoice projects instructions to participants about what to photograph tend to be broad, so that participants can themselves identify key features in their lives. In a number of the studies reviewed here this approach was followed and participants were given only very general instructions to take photographs to show what was important to them (Booth & Booth, 2003; Ottmann & Crosbie, 2013; Schleien et al., 2013; van Heumen & Schippers, 2016), what helped them have 'a good life' (Benoot et al., 2021) or what typical day looked like (O'Brien et al., 2009). Participants themselves went on to choose a weekly theme for photo taking in two studies (Kim et al., 2021; Patka et al., 2020).

In several studies an overall topic of health and wellness (Jurkowski & Paul-Ward, 2007; St. John et al., 2018; Williamson et al., 2020), identity (Dorozenko et al., 2015; Povee et al., 2014),

parenting (Wos & Baczała, 2021) or dementia (Watchman et al., 2020) was introduced by the researchers at the outset of the study and elaborated for participants in group discussions before participants started taking photos. Aldridge (2007) steered participants towards taking photographs of more positive aspects of their experience by asking them to take photographs of things they liked about their day projects, though others encouraged participants to look at both positive and negative aspects of their experience (Akkerman et al., 2014; Heffron et al., 2018; Jurkowski & Paul-Ward, 2007; Overmars-Marx et al., 2018; St. John et al., 2018). Garrels and Sigstad (2019) used more focused prompts, providing each participant with a 'pocket file' labelled with different topics relating to employment for participants to put their photographs in. In Weiss et al. (2017) participants were asked to focus on facilitators and barriers to environmental access in their homes or in the community.

Many people with intellectual disabilities who take part in photovoice projects, especially those with higher support needs, will rely on input of supporters, chiefly paid support staff or family members to facilitate their participation. The involvement of supporters raises the question of how far these other parties, who have a stake in how their care and the services they work for is represented might guide and shape the contribution of participants who are in more or less dependent relationships with those providing support.

These issues are confronted head on by Cluley (2017) and Krisson et al. (2021), who argued for the inevitable necessity of including carers as mediators and key informants for people with no or little verbal language. In other articles the role of supporters was less transparent, with only a brief mention of carers assisting in photo-taking in the studies by Ottmann and Crosbie (2013) and Benoot et al. (2021). In some studies this assistance was formalised with each participant with intellectual disabilities being allocated a supporter, either a student or junior researcher at the researchers' university (Rinaldi, 2021; St. John et al., 2021; van Heumen & Schippers, 2016) or someone from the participants' work (Akkerman et al., 2014), family or social network (Schleien et al., 2013; Tajuria et al., 2017; Williamson et al., 2020). In Heffron et al., 2018, 'peer mentors' with intellectual disabilities also gave assistance. Schleien et al. (2013), Akkerman et al. (2014) and St. John et al. (2021) explicitly instructed supporters to assist only with technical aspects of using the camera and refrain from making suggestions about what photographs to take. Researchers found in some cases supporters/carers found it hard to resist taking a more active and directive role in taking photos (Jurkowski & Paul-Ward, 2007).

A key part of photovoice methodology is collective meaning-making through group discussion which allows participants to compare and contrast experiences, validate feelings and opinions and decide on common courses of action. As mentioned above, faced with challenges in engaging participants in group reflections on their photographs in several studies group discussions were replaced by individual interviews. Booth and Booth (2003) noted that only a minority of their participants came along to the group discussion session, though all were enthusiastic about talking about their photographs individually. Kim et al. (2021) described the gradual process of gaining

confidence and elaborating narratives and emotional expression for members of their photovoice group. They adopted the strategy of setting and reiterating group 'groundrules' and encouraging the group to select a group leader to manage the discussion. Both Heffron et al. (2018) and Kim et al. (2021) used the SHOWeD approach to structure group discussion and encouraged participants to write captions for their photographs to clarify meanings and contexts.

In two studies (Patka et al., 2020; Williamson et al., 2020) group discussions involved not only participants with intellectual disabilities, but also family members and carers/guardians. This facilitated access to wider discourses around culture, religion and disability, but ran the risk of subsuming the perspectives of the participants with intellectual disabilities (Patka et al., 2020).

In Wang and colleagues' own photovoice projects little detail is given on how analysis of data might take place using processes commonly used to analysis qualitative data—codifying data and identifying key themes. In the studies reviewed here these processes were undertaken primarily by the academic researchers, using accepted qualitative data analysis methods including content analysis, causal layered analysis, grounded theory and (most frequently) thematic analysis. With a few exceptions (Ollerton & Horsfall, 2013; Rinaldi, 2021; Schleien et al., 2013) participants with intellectual disabilities were generally not involved in analytic processes of coding and generating themes, perhaps because of unstated assumptions that including people with intellectual disabilities in these activities is a 'step too far' (Nind, 2011) even when using a nominally 'participatory' research method. Use of the participants' photos in the analysis varied. For many of the researchers, participants' photos were used only as stimulus materials for individual or group discussions, rather than as a source of data requiring analysis in its own right. Participants' photos were reproduced in the findings of only a third of the published articles.

On the other hand, there were many examples of engaging photovoice participants in 'member checking', opportunities to verify and validate themes proposed by the academic researchers with participants (Garrels & Sigstad, 2019; Jurkowski & Paul-Ward, 2007; Overmars-Marx et al., 2018; Patka et al., 2020; van Heumen & Schippers, 2016; Watchman et al., 2020) or other stakeholders (Weiss et al., 2017). Unfortunately details are lacking about how this activity was enacted, whether there were disagreements between participants and academic researchers (McClimens, 2008) or how these were resolved.

A more critically informed strategy for addressing validity and rigour of qualitative research is the integration of researcher reflexivity into the analytic process, providing occasions for identification of assumptions, personal biases and the workings of structural inequalities in the research process. Dorozenko et al. (2015), Krisson et al. (2021) and Povee et al. (2014) used reflexive research journals which helped researchers document and challenge how ableist assumptions about incapacities of people with intellectual disabilities impacted on their own processes and sense-making within their photovoice projects. Cluley et al. (2021) adopted a methodology drawn from critical visual analysis (Drew & Guillemin, 2014) engaging in separate layers analysis starting with participants' own meanings attributed to their photos, and then integrating these with interpretations from researchers and

contextualisations of findings drawn from focus groups with a range of audiences, including practitioners and academics.

These discussions of power and influence relate to important ethical issues in research with people with intellectual disabilities. Ethical issues in photovoice research with people with intellectual disabilities were documented with varying degrees of robustness and detail. Researchers tended to focus on procedural issues of gaining informed consent through distributing accessible information about the project (e.g., Williamson et al., 2020). There was an acknowledgment that consent with this population should be seen as an ongoing, rather than one-off process and that providing study information in accessible formats was an important aspect of acquiring informed consent. There was widespread reporting of discussions with participants of photovoice ethics (Wang & Redwood-Jones, 2001), particularly asking permission from others who might be included in a photograph. However, other ethical issues associated with visual research methods received less consideration. Few researchers described negotiating ownership of photographs, photo-release permissions, legal definitions of privacy and defamation, rights to disseminate photographs with participants, or even risks of negative attention that photographing their local community might present for participants (Power & Bartlett, 2018). Provision of emotional support and aftercare for participants dealing with potentially upsetting and traumatic material was mentioned in Kim et al. (2021) and Rinaldi (2021) but otherwise given little consideration.

### 3.3 | Impact and outcomes

The research reviewed tended not to foreground the 'action' element of PAR. Overmars-Marx et al. (2018) were upfront about this when they stated that they were not attempting to promote empowerment of people with intellectual disabilities or bring about change through their project. Their aim was 'providing people with intellectual disabilities a voice and using this voice to answer research questions'. In most studies the main outcome was knowledge production and new learning about a variety of topics that affect people with intellectual disabilities from the perspective of members of this community themselves. Presumably the main audiences for this learning are other academic researchers and practitioners who might read the published research findings or attend conferences where research teams and the participants themselves were able to present their findings, with no clear trajectory to the political sphere of policy makers and change agents. This does raise the question how far this learning is likely to travel outside the walls of the academy.

There were a few examples of findings being shared more broadly with overt political intent in a few of the reviewed articles. Co-researchers with intellectual disabilities in Ollerton and Horsfall's (2013) study shared their concerns about inaccessible public transport with local transport authorities and government ministers and contributed to public reviews and reports.

Public gatherings were employed in some of the studies to share findings. Kim et al. (2021) invited participant support providers' and

family members to a feedback event. Jurkowski and Paul-Ward (2007) convened a 'town hall' meeting to which service providers, family carers, people with intellectual disabilities, community leaders and members of the academic community were invited to hear about the research and listen to a presentation by one of the photovoice participants, who also shared his photographs. A town hall meeting with local stakeholders was also convened by van Heumen and Schippers (2016) at a local theatre, where the photovoice photographs were also displayed to the general public. Schleien et al. (2013) held a similar exhibition with invited guests at their city's Chamber of Commerce while Patka et al. (2020) exhibited participants' photographs within a local university. Povee et al. (2014) and Dorozenko et al. (2016) described organising a public exhibition of participants' photographs in local shopping centre; an accessible venue where participants could interact with and answer the questions of the general public.

It was suggested by researchers that the experience of viewing the photovoice project photographs and reading accompanying captions will raise awareness of the social barriers experienced by people with intellectual disabilities (Aldridge, 2007; Ollerton & Horsfall, 2013; Schleien et al., 2013) and challenge stereotyped views of group as dependent and incapable. Povee et al. (2014) reported one audience member expressing surprise at the holidays and hobbies of participants represented in their photographs. Only Schleien et al. (2013) described any more formal evaluation of the exhibition of participants' work, distributing a short questionnaire to the audience (mainly family and friends) who attended. Responses attested to finding the exhibition to be a powerful learning experience that provided an insight into the accomplishments of people with intellectual disabilities as well as the social exclusions that they face.

There is little information in the selected studies on whether photovoice projects undertaken led to tangible improvements in the lives of people with intellectual disabilities. We generally do not learn what steps were taken by members of the public, service providers and policy makers who attended the town hall events to address the issues raised by project participants. Watchman et al. (2020) is the exception in this regard; the learning from the findings was used to co-design training on dementia, which was delivered by participants themselves to other people with intellectual disabilities. The participants also facilitated a conference on dementia aimed at peers with intellectual disabilities.

The most obvious benefits were those experienced by the participants themselves. Taking part in the photovoice project engendered a sense of pride and achievement (Akkerman et al., 2014; Jurkowski & Paul-Ward, 2007), and opened opportunities for self-knowledge and recovery of personal histories (Rinaldi, 2021). Other participants experienced the photovoice project as enjoyable and fun (Wass & Safari, 2020). Participants also reported increased confidence and knowledge about the topic they were investigating, as well as enhanced motivation for individual and group advocacy and political action (Ollerton & Horsfall, 2013; Rinaldi, 2021; Watchman et al., 2020). Participants developed skill in taking photographs, in exercising leadership and in mentoring and supporting others (Dorozenko et al., 2016). For two of Overmars-Marx et al. (2018)'s participants the guided photovoice walk led them to renew acquaintance with local people they met during the walk.

## 4 | DISCUSSION

This review has demonstrated that photovoice is an increasingly popular research method that has the potential to identify important areas of interest for people with intellectual disabilities. We have also identified several creative strategies that photovoice researchers have employed in order to meet the access needs of people with intellectual disabilities. In this section we consider how far photovoice research conducted with this group has succeeded in meeting the aims of the method as initially outlined by Wang and Burris (1997), namely to record and reflect a community's concerns; promote critical dialogue through discussion of photographs and reach policy makers.

### 4.1 | Record and reflect community concerns

The first aim relates to the frequently cited assertion made in many of the studies reviewed here, that photovoice privileges the 'voice' and perspective of people with intellectual disabilities in representing their lives. Promoting participant 'voice' is frequently claimed as a means to disrupt power relations and remove the researcher from the site of data production. We might ask first, who exactly is being given the opportunity to self-represent in the studies discussed here and how?

Although Cluley (2017) and Krisson et al. (2021) deliberately set out to involve people with limited or no verbal language, photovoice projects with people with intellectual disabilities have still tended to include more independent individuals with fewer support needs. Engagement in a photo-taking does imply a range of capabilities; understanding the researchers' explanation of the purpose of the project, being able to use a camera, or the ability to learn how to do so and being able to 'read' a photographic image and understand its relation to its subject. In some of the reviewed studies, participants with intellectual disabilities were able to take photos alone, but in the majority support from others was enlisted. Photovoice often involves the researcher being absent at the site of data production, though as Mannay (2015) points out, this space can be filled by the 'intrusive presence' of significant others, and this intrusive presence was made explicit in one of the research studies reviewed (Patka et al., 2020), though perhaps overlooked and under-theorised in others.

Within the reviewed studies few details were offered that illustrated the photography process in terms of the actual practices engaged in by participants with intellectual disabilities and supporters. This can perpetuate a romanticised view of photovoice (Prins, 2010) as 'voice-giving', and a binary between 'silencing' and 'giving voice' for people who lives are enmeshed in support relationships. It may be more realistic therefore to acknowledge that photo taking is a process of co-creation of images in many cases between people with intellectual disabilities and others in their support networks.

The tendency to represent participants' photographs as unmediated representations of their lived reality also sidesteps a more critically informed approach to understanding visual images (Cluley et al., 2021; Rose, 2016). Few researchers explicitly identified the epistemological assumptions underpinning their approach, implicitly

adopting a postpositivist paradigm, seeing reality as stable and 'discoverable' by academic researchers (Evans-Agnew et al., 2022), instead of appreciating the inherently indeterminate nature of the visual, which resists being reduced to a verbal description. Moreover, like other image creators, people with intellectual disabilities' photography practices will be influenced by social norms and artistic conventions (Brooks et al., 2020). With reference to this point, Finney and Rishbeth (2006) noted that participants in their participatory photography project tended to orientate to common cultural conventions of what constituted a 'good' photo, featuring friends, panoramic views and presentation of self in prestigious and valued roles and settings.

Evans-Agnew and Rosemberg (2016) argue that issues of participant 'voice' extend to how photographs are analysed and disseminated. Our review found that stages of analysis of photovoice data such as coding and synthesis was largely seen as the province of academic researchers. Involving people with intellectual disabilities in data analysis can be seen as a 'step too far' in inclusive research with people with intellectual disabilities (Nind, 2011), though more recently researchers have been developing and refining methods for addressing this (Tilley et al., 2021). More commonly researchers in the reviewed studies engaged in 'member checking' of the themes generated by researchers from photovoice data. However, member checking has been critiqued for claiming to improve the trustworthiness and validity of qualitative research whilst sidestepping issues of power differentials between academic researchers and research participants (Birt et al., 2016) that are particularly salient here with marginalised individuals such as people with intellectual disabilities.

Only a minority of researchers endeavoured to raise awareness of the participants' concerns within their wider community through exhibitions of their photos. Mounting an exhibition requires money, time, as well as skills in curation beyond the usual skill set of academic researchers as well as consideration of ethical issues involved in showing 'research data' in public fora (Seitz & Orsini, 2022). Nevertheless, exhibitions provide opportunities for participants' voice to engage in dialogue with wider audiences (Latz & Mulvihill, 2017). Holding an exhibition also foregrounds an important and often overlooked aspect of photovoice—namely that photographers are engaging in an arts practice requiring skill and emotional investment (Cluley et al., 2021; Golden, 2020). The photovoice participants' photographs are art works in their own right, which can stand alone, or be integrated with other forms of artistic expression, such as collage, drawing, poetry and dance (Rinaldi, 2021). Exhibitions of participants' work can therefore afford them the respect and status of arts practitioners rather than just 'research participants'.

## 4.2 | Promoting critical dialogue through discussion of photographs

A second aim of photovoice is to promote critical dialogue through group discussion of photographs. This aspect of photovoice is linked to its theoretical alignment the work of Paulo Freire (Freire, 1970) and his concept of 'conscientização'. This concept refers to the generation

of critical consciousness about social conditions that goes beyond individual experience to provide the impetus for community social action against structural inequalities. Group discussion allows for collective meaning-making and identification of common experiences of disadvantage, and allows for the pooling of knowledge of community strengths and resources. However, in the majority of the studies reviewed here group discussions was replaced by individual interviews with participants about their photos, an adaptation that has been widely adopted in photovoice research with a range of participants (Seitz & Orsini, 2022).

People with intellectual disabilities to varying degrees experience limitations with memory, attention, comprehension and expressive language and group discussions may make demands on all these capabilities. Other factors linked to exclusion and structural disadvantage, rather than intrinsic impairments, militate against their confident engagement with critical consciousness-raising as imagined in photovoice ideals. This group can also face low expectations regarding their capacity for self-determination and are excluded from life experiences that build a sense of self-efficacy and are commonly socialised into positions of dependence, with the default expectation if they face dilemmas or difficulties they should 'ask the staff' (Redley & Weinberg, 2007) rather than take action themselves.

Creating opportunities for the emergence of critical consciousness through group discussion is therefore likely to take time and require relations of trust and openness between participants and researchers (Booth & Booth, 2003). Time is often at a premium in funded research projects, where funders and research ethics boards may look askance at requests for extended periods of relationship building before the 'actual research' takes place (Gustafson & Brunger, 2014). Moreover this process requires critical reflexivity on the part of researchers who have the role of facilitating discussion (Evans-Agnew & Rosemberg, 2016) to examine how personal and institutional assumptions and agendas may shape what is talked about and how. Researcher reflexivity is a complex topic in its own right and a key aspect of qualitative research (Pillow, 2003), yet received little consideration in much of the research in this review.

## 4.3 | Reaching policy makers

The third aim of photovoice—to reach policy makers and effect change—was not widely reflected in the research reviewed. This limitation is by no means exclusive to photovoice research with people with intellectual disabilities. There is a recognised tension between photovoice as a tool for social change and as a social research method of phenomenological inquiry (Tsang, 2020) and other reviews of photovoice literature have noted that projects frequently 'under-deliver their action potential' (Sanon et al., 2014). There was very little detail provided in the studies reviewed here regarding what further tangible change was brought about as a result of the project or any attempts to evaluate this in any systematic way. Again, photovoice research with other groups has drawn the same criticism; that evidence of concrete changes in social policy resulting from photovoice

research is sparse (Seitz & Orsini, 2022) and researchers rarely describe evaluating the impact of their projects (Catalani & Minkler, 2010). Wang and Burris (1997) talk about involving policy makers in the set-up of a photovoice project, and feeding the results directly back to them. However, researchers seldom have a direct line to policy makers as agents of sociopolitical power (Golden, 2020). Moreover the timescale for effecting substantive policy or community change cannot be underestimated, and as noted above, researchers are under pressure to complete projects and publish findings before any intended policy changes have time to be achieved (Seitz & Orsini, 2022).

Assertions in the reviewed research that photovoice with people with intellectual disabilities leads to participant 'empowerment' also requires more thorough interrogation. We might contrast Booth and Booth's (2003, p. 432) conclusion that simply giving participants cameras automatically empowers participants with Wang & Burris (1994, p. 18) formulation of empowerment as requiring 'at least four kinds of access: access to knowledge, access to decisions, access to networks and access to resources'. The assumption that participants are 'empowered' through the research process risks framing the participants as intrinsically powerless and lacking capacity for communication through other means. This can imply a deficit orientation to people with intellectual disabilities, characterising photovoice as salvific, rather than facilitative (Golden, 2020).

## 5 | CONCLUSIONS

Given the increased rate of publication of photovoice research with people with intellectual disabilities over the last few years it is likely that this method will continue to gain in popularity. We would like to flag up some gaps evident from our review that might suggest topics for future research. We noted that the majority of studies involved working aged adults, whilst the experiences of children and young people under 18 and those in older age was under-represented. There was little research with people with intellectual disabilities specifically from racially minoritized groups, apart from Williamson et al. (2020), or with individuals experiencing additional challenges because of physical or mental health conditions, or additional sensory impairments.

This review has shown how photovoice has created opportunities for people with intellectual disabilities to be engaged in knowledge production. We acknowledge that the review has its own limitations in being restricted only to articles published in English. Moreover, our search strategy led us to studies that explicitly referred to Wang and Burris' (1994, 1997) photovoice framework or those that had been cited by existing studies, meaning that other studies that used a similar inclusive photography methodology (e.g., Power & Bartlett, 2018) were not included.

Many of our critiques of studies reviewed here have been cited in other reviews of photovoice research with different populations (Catalani & Minkler, 2010; Evans-Agnew & Rosemberg, 2016; Sanon et al., 2014; Seitz & Orsini, 2022), so our recommendation would be that intellectual disabilities engage with the debates that are

circulating in the wider literature. Although the tensions described here between photovoice as a method of gathering qualitative research data and as a tool for social justice and addressing structural disadvantage are perhaps inevitable, methods for working with people with intellectual disabilities in inclusive participatory action research are advancing all the time in response to the 'participatory turn' in qualitative research (Henwood et al., 2019). We hope therefore that the potential of photovoice to bring about the sorts of changes that people with intellectual disabilities want to see in their lives is further realised in future research.

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Research data are not shared.

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