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Photovoice in research involving people with intellectual disabilities: A guided photovoice approach as an alternative

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Background: In studies involving people with intellectual disabilities, photovoice is increasingly used to include the voice of participants. Analysing existing literature, the present authors found that photovoice was used in various forms with different outcomes. These studies describe both obstructing and facilitating factors. The present authors designed a more standardized approach of photovoice and developed an alternative strategy: "guided photovoice."

Method: The "guided photovoice" approach was tested on fourteen participants with intellectual disabilities. The outcomes of the approach were evaluated.

Results: The effectiveness of the approach varied with the participants' capabilities and needs. Some participants were talked more while taking photographs, others told their story easily during the interviews. The use of follow-up questions was helpful to deepen the interview.

Conclusions: A more standardized, guided photovoice approach is a helpful addition to the various options for using photovoice; it is important to decide which approach best fits the needs and capabilities of the participants.

KEYWORDS
photovoice, guided photovoice, walking interview, people with intellectual disabilities

1 | INTRODUCTION

In an increasing number of studies, photovoice is used to involve people with intellectual disabilities in research (Akkerman, Janssen, Kef, & Meininger, 2014; Booth & Booth, 2003; Jurkowski & Paul-Ward, 2007) . In a typically photovoice procedure, participants take photographs which are later used to facilitate reflection on their feelings, ideas and experiences (Mitchell, 2011).

Photovoice was first developed and applied by Wang and Burris (1994, 1997). They used photovoice to gain insight in the perspectives of rural women in China on their health. According to Wang and Burris (1997), photovoice offers several advantages compared with other research tools; it enables participants to address their needs and it offers researchers insight into the perspectives of participants. The method is explicitly useful in vulnerable populations because it does not presume the ability to read or write. Booth and Booth (2003) emphasize its suitability for people with intellectual disabilities. It helps

to include people in research who, for example, have difficulties with direct communication or are hampered on a cognitive and conceptual level (Finlay & Lyons, 2002; Jurkowski, 2008; Sigstad, 2014).

One of the main goals of photovoice is to enable participants to record and reflect on their lives (Wang & Burris, 1997). This provides participants with a voice, which can empower them to advocate for changes in their living environment, (Wang & Burris, 1997). Our study did not focus on the empowerment of the participants in our research project and their opportunities for effectuating changes. The present authors concentrated on the third research goal: providing people with intellectual disabilities a voice and using this voice to answer research questions. In the studies in which photovoice was used in research involving people with intellectual disabilities, there was variation in how photovoice was applied. This variation concerned the practice of qualitative research in general (e.g., the recruitment of participants) as well as specific aspects of photovoice (e.g., the number of photographs taken or the type of camera used) or the level of intellectual disabilities

of the people involved in the research (e.g., the level of assistance needed). Although some studies critically reflect on photovoice (e.g., Jurkowski & Paul-Ward, 2007), it is unknown how this variation affects the outcomes of research. The aim of our study was to develop a more standardized approach to photovoice, built on clear methodological choices, to optimize the effectiveness of photovoice.

First, the present authors analysed existing research to identify the obstructing and facilitating factors of photovoice to help the voice of people with intellectual disabilities be heard. During the next step, the present authors discussed our methodological considerations and choices based on the obstructing and facilitating factors found in step one. These considerations and choices led to a more standardized approach. In step three, the approach was tested in a small-scale study with fourteen participants with intellectual disabilities, analysed and discussed.

2 | LITERATURE SEARCH

A literature search was conducted to identify studies in which photovoice was used to interview people with intellectual disabilities. A search was conducted in CINAHL, ERIC, Web of Science, PubMed and PsycINFO, combining one of the keywords "photovoice," "photo elicitation," "photo elicitated interview" or "photographic research" with the keywords "intellectual disabilities," "learning disabilities," "mental retardation," or "development disabilities." The present authors identified eleven relevant titles. In three publications—Jurkowski (2008), Jurkowski and Paul-Ward (2007) and Jurkowski, Rivera, and Hammel (2009)—the same data set was used. The present authors included the article by Jurkowski and Paul-Ward (2007), because it is in this article the use of photovoice is described in detail. Nine publications were included in our comparative analysis. Table 1 shows an overview of the included studies and the way photovoice was applied in the stages that the present authors will describe below in more detail.

In our comparative analysis, the present authors distinguished different stages in the photovoice research process:

Stage 1: preparation
Stage 2: taking the photographs
Stage 3: the interview
Stage 4: post-interview

After describing each stage, the present authors examined what the obstructing and facilitating factors were. The obstructing and facilitating factors the present authors identified were of theoretical, practical, ethical and methodological nature.

2.1 | Stage 1: Preparation

The stage of preparation involved the recruitment and selection procedures, the consent procedure and providing information to participants and training them. The first step, the recruitment and selection of participants, is relevant in all qualitative research. However, the recruitment and selection procedure of people with intellectual disabilities is of a special nature, as the recruitment is not done directly by the researchers themselves but via care organizations, schools or other agencies involved in the research project or with the people with intellectual disabilities (eight of nine studies). The studies of Aldridge (2007) and Povee, Bishop, and Roberts (2014) included non-verbal participants.

Because of the vulnerability of the target group, people with intellectual disabilities, a proper consent procedure is essential. This procedure was described clearly in six of nine studies. There was a focus on confidentiality and anonymity. For example, if photographs were presented, the photographer should remain anonymous. In three of these six studies, the consent forms were adjusted to the cognitive level of the participants, for example by adding photographs. In the study of Povee et al. (2014), the consent procedure was an ongoing process during the entire research project. Prior to each meeting, participants were asked whether they would like to continue being involved in the project.

Training the participants is an important aspect of photovoice. In the studies examined, participants were informed and trained in different ways, either individually or collectively. Participants were informed collectively, for example, during a focus group or an information meeting (Jurkowski & Paul-Ward, 2007; O'Brien et al., 2009; Ollerton & Horsfall, 2013; Povee et al., 2014; Schleien, Brake, Miller, & Walton, 2013). Participants were trained, individually or collectively, in the ethical aspects of photographing (e.g., asking written consent when photographing another person) and instructed how to operate a camera.

2.1.1 | Obstructing and facilitating factors during the stage of preparation

The studies described some ethical and methodological obstructing and facilitating factors during the preparation stage.

An important methodological question is to formulate the criteria on which a participant should be included or excluded in the study. A photographic intervention does not work for everyone. An important consideration is whether or not to include non-verbal participants. Jurkowski (2008) describes photovoice as useful for engaging those who cannot read or who have low literacy levels. On the other hand, the method is difficult to use with people who are non-verbal. They may be able to participate in the photography component of the project but it would be difficult for them to engage in reflecting on their photographs taken and relating themes to their daily lives. Ottmann and Crosbie (2013) state in their study that the combination of using photographic images and an interview seemed to be an effective mix to represent the views of people with intellectual disabilities. As Aldridge (2007) emphasizes, it is not appropriate to analyse photographs without having heard the story of the photographer, because without it, a researcher cannot interpret the significance of what is depicted in the photograph.

Aldridge (2007) also addresses the challenge the consent and confidentiality procedures pose. In cases where participants were not able to provide consent because they could not understand the consequences of their participation, consent was sought from parents or guardians.

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TABLE 1 Overview of studies in which photovoice was used in research with people with intellectual disabilities

Reference & country	Number of participants	Research aim	The stages of photovoice
Akkerman et al. (2014) The Netherlands	9	Photovoice was used to identify themes related to job satisfaction.	Stage 1: Recruitment through a care organization. Participants were first informed and after providing their consent trained individually. Stage 2: Participants used a digital camera to take photographs individually and were assisted in practical aspects if necessary. Stage 3: Participants were interviewed individually and the interviewer focused on open questions. Stage 4: Interviews were transcribed verbatim and analysed with ATLAS.ti.
Aldridge (2007) United Kingdom	19	The study explored photographic participation and elicitation techniques as a way of including vulnerable respondents more effectively in social research studies	Stage 1: Participants of specific projects were recruited. After the informed consent, participants were instructed about their assignment. Stage 2: Participants used a disposal camera to take photographs and general guidance was provided if necessary. Stage 3: All participants were asked individually to choose five favourite photographs and, where possible, to explain their reasons for their choices. Stage 4: Photographs were content analysed, as well as the explanations of the participants.
Booth and Booth (2003) United Kingdom	16	The mothers' photograph albums provided insights into discriminatory views of the women as deviant mums.	Stage 1: The participants were part of project and volunteered to participate. Participants were instructed about their assignment. Stage 2: Participants used a disposable camera. No guidance was provided. Stage 3: The albums were discussed individually and afterwards a group session took place to share concerns and common threads that characterized their lives. Stage 4: The content of the photograph albums was analysed in the context of personals stories.
O'Brien et al. (2009) Ireland	19	Photovoice was part of a mixed-method approach to investigate the experiences of students with intellectual disabilities in gaining access to university.	Stage 1: Photovoice was part of data triangulation. Students were invited to participate. Stage 2: Participants took photographs across a typical day in their student life. Stage 3: The photographs were discussed during a group meeting. Stage 4: Open, axial and selective forms of coding were used to synthesize the material.
Jurkowski and Paul-Ward (2007) USA	4	The study had three goals: (a) to raise awareness of health disparities, (b) to describe the strategy of using photovoice, and (c) to encourage the use of photovoice.	Stage 1: Participants were recruited from focus groups. Participants signed an adapted informed consent. Participants and staff members were trained individually. Stage 2: Participants used a disposable camera. Participants were provided with examples during a peer group session. Staff members encouraged participants and the researcher was frequently available if participants had any questions. Stage 3: Participants were interviewed individually in a private setting at the community agency during their day programme Stage 4: Interviews were transcribed verbatim and analysed together with the outcomes of the focus groups. Afterwards, participants were brought together in a member check focus group. The researcher created scrapbooks of photographs.
Ollerton and Horsfall (2013) Australia	5	Photovoice was used to show that people labelled with learning difficulties can do research, leading to positive social change.	Stage 1: Participants self-referred to an information session and voluntary joined the project. Participants were trained individually. Stage 2: Participants had the choice to use a disposable camera, digital camera or mobile phone to photograph barriers to their self-determination. Stage 3: The resulting photographs were printed and used as the basis for research team discussions. Stage 4: Photographs were categorized and coded by the participants. Afterwards, discussions took place about each theme. Having identified disability rights concerns, the participants devised actions to assert their rights and to tell others.

TABLE 1 (Continued)

Reference & country	Number of participants	Research aim	The stages of photovoice
Ottmann and Crosbie (2013) Australia	11	The study compared the results of a suite of qualitative methods, including photovoice, and identified the advantages and disadvantages of each method.	Stage 1: Participants were recruited through their case manager or teacher. All participants and, where appropriate, their guardians signed an informed consent form. Stage 2: Participants used a digital camera or a mobile phone to photograph the most important aspects in their lives. Some participants drew on carer assistance to take the photographs, due to physical or vision impairments. Stage 3: Semistructured interviews and focus groups were part of the approach but it is not described how the photographs were discussed. Stage 4: Data were thematically coded, and the results were entered into a spread sheet for comparison.
Povee et al. (2014) Australia	18	The aim of the study was to explore the process, opportunities and challenges associated with the use of photovoice with people with intellectual disabilities. They used the "This is me" project to explore photovoice.	Stage 1: All members of an advocacy agency were invited to participate. Participants were provided with an adapted consent. Information and training were provided during a group meeting. Stage 2: Participants used a digital camera. The researcher provided assistance if necessary. Stage 3: Members were interviewed individually, in pairs or in small groups at their home. Some participants requested that their parent or guardian was present. Stage 4: Interview transcripts were analysed using causal layered analysis. Participants selected their own photographs which were displayed at a public photograph exhibition.
Schleien et al. (2013) USA	7	Photovoice was used to give seven individuals with intellectual disabilities or developmental disabilities the opportunity to document their lives through the use of photography and discuss their interests, hopes and dreams.	Stage 1: The participants were recruited through an organization and responded to an invitational letter. Participants were informed and trained during a group meeting. All participants signed an informed consent. Stage 2: Participants used a digital camera. Assistants provided support in the technical aspects, in prompting to complete photography assignments, and in transporting to and from programme meetings or photography locations. Stage 3: An individual interview took place between the instructor, participant and his/her assistant. Stage 4: Programme staff discussed the content of photographs and transcripts using the constant comparative approach. Individual transcripts were coded and discussed again. The identified themes were presented to the participants' group discussion as a member check. Afterwards, two community exhibitions took place.

In the studies of Povee et al. (2014) and Schleien et al. (2013), participants were informed and trained collectively. Povee et al. (2014) mentions the collectivity of the training as a facilitating aspect, because participants were able to encourage and help each other.

2.2 | Stage 2: Taking the photographs

During the second stage, taking the photographs, decisions have to be made on instruction, assistance provided, restrictions in time or number of photographs taken, and on type of camera used. All these decisions concern aspects of photovoice or conducting research with people with intellectual disabilities. In the studies, an open instruction procedure was used, allowing participants to take any photographs they wanted. The instructions varied from "take photographs of people, places and things that are important to you" to "take photographs showing a typical day in your student life" (see Table 2). In one study, examples were provided by peers (Jurkowski & Paul-Ward, 2007).

In six of nine studies, some level of assistance was given to the participants with intellectual disabilities. There was great variety in the form of assistance provided: assistance was given by either a staff member or a family member and it stretched from mere technical support to helping the person to remember the purpose of taking the photographs. The studies also varied in the level of restrictions. Seven of nine studies did not mention any restrictions on the number of photographs taken. Six of nine studies did mention a restriction on the total amount of time permitted to take the photographs. The time available varied from seven days to three months. In four of nine studies, participants used a digital camera; in three studies, a disposable camera was used. In one study, both types of cameras were used.

2.2.1 | Obstructing and facilitating factors during the stage of taking the photographs

In the photograph-taking stage, theoretical, practical, ethical and methodological obstructing and facilitating factors were distinguished.

TABLE 2 Questions related to the instruction and questions during the interview

Reference & country	Questions related to the instruction	Questions during the interview
Akkerman et al. (2014) The Netherlands	Participants were instructed to take photographs of "things at work which make you feel good" and of "things at work which do not make you feel good."	What is on the picture? Why did you take the picture? Is it something that makes you feel good or something that doesn't make you feel good?
Aldridge (2007) United Kingdom	Participants were asked to take photographs on site about projects over a period of time (approximately one month). They were asked to take photographs of aspects of their participation in projects that they particularly enjoyed or liked.	The participants commented on the significance or importance of the photographs they had taken and to choose five of their "favourites." Participants were asked to explain the reasons for their choices.
Booth and Booth (2003) United Kingdom	All participants were asked to photograph people, places and things that "are important to you."	No questions were specified. The albums were discussed in order to listen to the stories behind the photographs, to learn why these particular snaps had been taken and to understand the significance they had for her.
O'Brien et al. (2009) Ireland	Participants were invited to take photographs showing a typical day in their student life.	No questions were specified. Participants took photographs of a typical day in their life.
Jurkowski and Paul-Ward (2007) USA	Participants were asked to take photographs of "what they felt made them healthy or sick." They were provided with the examples given by their peers during focus groups. The researcher walked around with them when they took their first few photographs.	No questions were specified. Participants discussed how the images represented their experiences and how those experiences related to their health. General questions were asked. However, most of the discussion was free flowing.
Ollerton and Horsfall (2013) Australia	Participants photographed barriers to their self-determination. It is not specified which instructions (questions asked) the researchers gave.	A group discussion took place on the following questions: why was the photograph taken and what was happening in the photograph
Ottmann and Crosbie (2013) Australia	The following question was asked: "In your opinion, what are the most important issues that affect your life?" If needed, the question was rephrased.	No questions were specified.
Povee et al. (2014) Australia	During a group meeting, participants were reminded of the purpose of the research and encouraged to think about and discuss the following questions; "Who am I?," "What makes me me?" and "What is important to me?" They were given no directions as to what to photograph.	What made you take this photograph; and what is happening in this photograph?
Schleien et al. (2013) USA	In the first assignment, participants were asked to take photographs of people, places and activities that were important to them.	Why did you take this photograph? What are the people, places and activities in this photograph? What do you like about these people, places and activities? What bothers you about these people, places and activities?

Booth and Booth (2003) face both practical and ethical problems in the use of cameras. One participant said her camera was broken, but did not want to be further involved in the project when she was offered a new camera. Another participant decided to print the photographs but did not want to share these photographs. Some participants involved in the study found it difficult to develop their films quickly and put aside the camera. This meant the project took much longer than planned. This was also the case in the study of Jurkowski and Paul-Ward (2007): participants took more time in returning the cameras than foreseen. One participant in the study of Jurkowski and Paul-Ward (2007) had trouble handling the camera and some photographs were unclear. He was given another camera but never returned it. The study of Akkerman et al. (2014) faced methodological difficulties because there was no limitation on the number of photographs taken,

which therefore varied widely between the participants. This meant it sometimes took a long time to discuss all the photographs and some interviews were less complete because of the limited amount of photographs.

The role of staff in taking photographs can be both facilitating and obstructing. Staff can encourage participants and support them in the technical and practical aspects of taking photographs, such as reminding the participants to take the photographs (Akkerman et al., 2014; Schleien et al., 2013). On the other hand, staff can have an unwanted influence on the content of the photographs.

Akkerman et al. (2014) mention another theoretical obstructing factor. Participants in their study were asked to take photographs of their workspace. The participants were inclined to photograph the most prominent aspects of the workplace, which may have led to the

omission of more neutral aspects. Discussing the photographs alone could have resulted in an under-representation of the more neutral aspects. Another concern, according to Akkerman et al. (2014), is that some participants may have difficulty photographing negative matters. Finally, Akkerman et al. (2014) warn that some concepts may be hard to take a photograph of, for example abstract concepts (e.g., vacation) or things, which are absent during the time the study is taking place, such as Christmas decorations in summer. Apart from this, Akkerman et al. (2014) mention ethical difficulties in photographing other people. Asking permission caused a barrier for participants to photograph other people. To overcome these limitations, participants were asked whether there were any other aspects which they did not photograph but which were important to them to talk about in the interview. However, certain themes may still have been under-represented or absent.

2.3 | Stage 3: The interview

In all studies, the stage of taking the photographs was followed by an interview with the participant. At this stage, several methodological issues concerning the context of the interview need to be addressed: opting for an individual or a collective interview approach, deciding on the presence of an assistant and what kind of interview questions to use. In eight of nine studies, an individual interview was conducted. In four studies, the individual interview was combined with a group session. The individual interview was, for example, followed by a group meeting in which participants were asked to explain their photographs to the entire group (Schleien et al., 2013). The group meeting was also used as a member check. In two studies, participants were interviewed in the presence of an assistant (Povee et al., 2014; Schleien et al., 2013). In one study, input from the assistant was directly checked with the participant for validation. This is relevant, as the presence of an assistant during the interview might influence the type of responses the participant might give. Four of nine studies reported the use of printed photographs and in three of nine studies participants were asked to select photographs. In all studies, open-ended questions were used, offering participants maximum opportunity to tell their story about the photographs they took. Table 2 lists the questions researchers asked during the interviews.

In two studies, photographs of non-verbal participants were included (Aldridge, 2007: Povee et al., 2014). In the study of Povee et al. (2014), the non-verbal participants pointed at photographs and used gestures and facial expressions to convey their story.

2.3.1 | Obstructing and facilitating factors during the interview stage

Also in the interview stage, methodological and practical obstructing factors were encountered. The studies which used a combination of an individual interview with a group meeting (Booth & Booth, 2003; Ollerton & Horsfall, 2013; Povee et al., 2014; Schleien et al., 2013) point to the added value of a group meeting in sharing concerns, opening a critical discussion and/or identifying themes together. Staff and peers were able to encourage participants in their reflection process.

However, Schleien et al. (2013) mention a methodological limitation: the potentially negative influence of assistants and staff members. They tried to mitigate this negative influence by clearly delineating the role of assistants. However, it should be noted that individuals with intellectual disabilities can be easily influenced, as they often desire to please others. Therefore, comments made by assistants or staff members may have had an impact on participants' answers. Akkerman et al. (2014) state that an individual unassisted interview gives participants the opportunity to express their views without undue influence from others.

In their study in which they compared different methods to represent the views of people with intellectual disabilities, Ottmann and Crosbie (2013) found another methodological limitation. The photographic images predominantly generated concrete issues and missed out on abstract themes, such as living independently in the community. But when the images were combined in a semistructured interview, these themes did emerge. Reflecting on their own study, Ottmann and Crosbie (2013) point out that it also might have been useful to ask participants if there was anything else they would have liked to have photographed, if they had had the opportunity. This recommendation was also made by Akkerman et al. (2014).

Participants in the study of Aldridge (2007) had difficulty expressing the meaningfulness or significance of their photographs. They tended to simply describe the photograph. For example, "That's my friend Diane."

2.4 | Stage 4: Post-interview

Each study approached the last stage differently (see Table 1). Decisions had to be made on how to analyse the data and what type of data analysis to use, performing a member check procedure and other actions to process the results. The decisions made concerning the data analysis are relevant to qualitative research in general and are not discussed in this article.

The only aspect of data analysis which specifically concerns the use of photovoice is the question whether a researcher should or should not analyse the photographs that are taken (outside the context of the interview). In one study (Aldridge, 2007), the photographs were interpreted by conducting a content analysis.

In two studies, a member check was mentioned (Jurkowski & Paul-Ward, 2007; Schleien et al., 2013). This member check consisted of discussing the themes that were identified during a group meeting (see also the interview stage).

In the studies, the actions taken on the basis of results varied. This also depended on the aim of the research project: whether it was just a matter of hearing the voice of participants and using this information to answer research questions or whether the topic of the study also had an aspect of trying to generate change and of empowering participants. Four of nine studies (Jurkowski & Paul-Ward, 2007; Ollerton & Horsfall, 2013; Povee et al., 2014; Schleien et al., 2013) payed specific attention to the dissemination of the results to a wider public, for example by organizing a presentation or an exhibition. Besides their regular report, Jurkowski and Paul-Ward (2007) also reported their results in a format for people with a low literacy.

2.4.1 | Obstructing and facilitating factors of the post-interview stage

There was only one obstructing factor mentioned by Aldridge (2007) concerning the post-interview stage. This was a theoretical obstructing factor having to do with being careful in interpreting the content of the photographs taken, because not all participants were able to expand verbally on the meaning of their photographs. If photographs are analysed without the comments of the participant involved, this may lead to false conclusions.

During the member check procedure, or other actions undertaken after the interview stage, no specific obstructing and facilitating factors of photovoice as a research tool were mentioned. Studies, which also focused on photovoice as an empowerment tool, point out that, for example, organizing an exhibition or proving photograph books could be seen as facilitating empowerment.

3 | METHOD

3.1 | Towards a more standardized (guided) photovoice approach

Based on the obstructing and facilitating factors mentioned above, the present authors decided to design a more standardized approach to use photovoice. Also, the present authors decided to develop an alternative option within the approach the present authors called guided photovoice. In our analysis of the literature, the present authors presented the most commonly used aspects of photovoice. Below, the present authors will discuss our more standardized (guided) photovoice approach.

3.2 | Stage 1: Preparation

It is evident from the obstructing and facilitating factors mentioned above, clear selection criteria should be used in photovoice projects which can be used by the caregivers involved:

- Participants should be able to understand the consent procedure, the instructions and the content of the assignment;
- Participants should be able to demonstrate they understand the consent procedure;
- Participants should be able to demonstrate they understand all aspects of the process of taking photographs;
- Participants should be able to reflect verbally on the photographs they have taken.

The present authors recommend to ask staff members to invite all residents who meet the formulated selection criteria of an upcoming research project to cooperate in the research. All potential participants should receive a personal invitation and if they are interested in participating they should have the opportunity to contact the researcher individually. The purpose of the invitation is to explain the research project and what is expected from the participants, written in plain language,

supported by photographs. Staff members and potential participants should be able to ask the researcher questions about the project and the researcher should visit the homes of the participants to provide information about the research project and introduce him or herself as a neutral party. This could reduce unwanted influence of staff members on the (outcomes of) the research process. A neutral party can reduce "gratitude participant responses" and take away any fear of repercussions of critical answers (D'Eath, 2005; Tassé, Schalock, Thompson, & Wehmeyer, 2005). Although in earlier studies the collective process of informing and training was said to facilitate enthusiasm and support, the present authors recommend an individual meeting to inform and train participants, for two reasons. The first reason is to create trust and familiarity between the researcher and the participant during this individual meeting. During this individual meeting, participants will also be informed about the consent procedure. The consent procedure should include the aim and the content of the project, the photovoice process itself, information about anonymity and confidentiality and information about how the photographs and related stories will be used in the project and beyond. A second reason for an individualized approach lies in the fact that participants should not influence each other by talking about which photographs should be taken or about their hesitations to take a certain photograph (Slump, Moonen, Hoekman, & Jongmans, 2010).

3.3 | Stage 2: Taking the photographs

To include people with intellectual disabilities who would otherwise not choose to enter a photovoice project without the involvement of a staff member, the present authors have developed the "guided photovoice" option. The present authors define "guided photovoice" as follows:

> Participants take photos together with the researcher. The researcher is guided by the participant during a walk, but does not interfere with the content of the photos.

The guided elements make it more informal and easier for people with intellectual disabilities to take the photographs (Garcia, Eisenberg, Frerich, Lechner, & Lust, 2012; Kusenbach, 2003). During the guided photovoice procedure, participants have the option to take their own photographs or to instruct the researcher to take the photographs for them. This could also prevent problems such as not being able to handle the camera, being unwilling to return the camera or taking too many photographs. The present authors advocate that there is always an alternative option of taking the photographs without the presence of the researcher. Guided photovoice could also offer a solution to other obstructing factors, such as not being able to photograph abstract aspects or not being able to photograph persons who are not willing to cooperate. Because participant and researcher work (and walk) together, participants may be more inclined to tell about all aspects or persons of concern.

In ethnographic research, detailed field notes or other observations can be advantageous for deepening the understanding of the participants' process (Carpiano, 2009; Emerson, Fretz, & Shaw, 1995). This is why the present authors also recommend to take field notes.

They can be useful for subsequent analysis and in the guided photo-voice procedure, these observations can provide useful information for the following interview.

Furthermore, the present authors recommend the use of a digital camera (or tablet or smartphone), to be able to save the photographs which are taken in a computer file. However, a shift from film to a digital camera also poses some challenges. Using a digital camera with many options might be difficult for a person with intellectual disabilities. The present authors would therefore recommend providing an "easy-to-use" digital camera together with a clear instruction. In general, there should be no restrictions on the number of photographs taken.

3.4 | Stage 3: The interview

Before the interview starts, the present authors would recommend the researcher to print the photographs. This avoids problems such as delays due to participants not having photographs developed in time. Researchers can also consider the possibility of using a digital display screen, for example tablet. Kagohara et al. (2015) show the possibility of using Ipods and Ipads in teaching programmes. Using a tablet is not explored in our study. If necessary, only a selection of the photographs, chosen by the participant, can be discussed during the interview. A person who is well known to the person with intellectual disabilities is probably the best interviewer, as a greater level of communications and trust may already exist between them (D'Eath, 2005). For this reason, the present authors do not recommend a single interview, without an introductory meeting and spending time taking the photographs together. By the time the interview starts, the interviewer should be able to create an atmosphere of trust in which the participant is encouraged to share accurate information on the topic under discussion (D'Eath, 2005).

It is best to discuss the photographs during an individual interview, to limit the unwanted influence of bystanders, peers, assistants or staff members. The interviewer has to formulate open questions and participants should have the opportunity to tell their story without being limited by response categories or structured questions. Participants will typically be asked what is on the photograph and why the photograph was taken. If necessary, participants will be encouraged by follow-up questions. The present authors recommend these two sentences: "Could you tell me more?" and "'Can you give an (other) example? Finally, participants should be specifically asked about photographs they have not taken, following the approach of Akkerman et al. (2014). In this way, limitations mentioned above, such as not being able to photograph abstract concepts or not being able to photograph people who are not willing to cooperate, can be overcome.
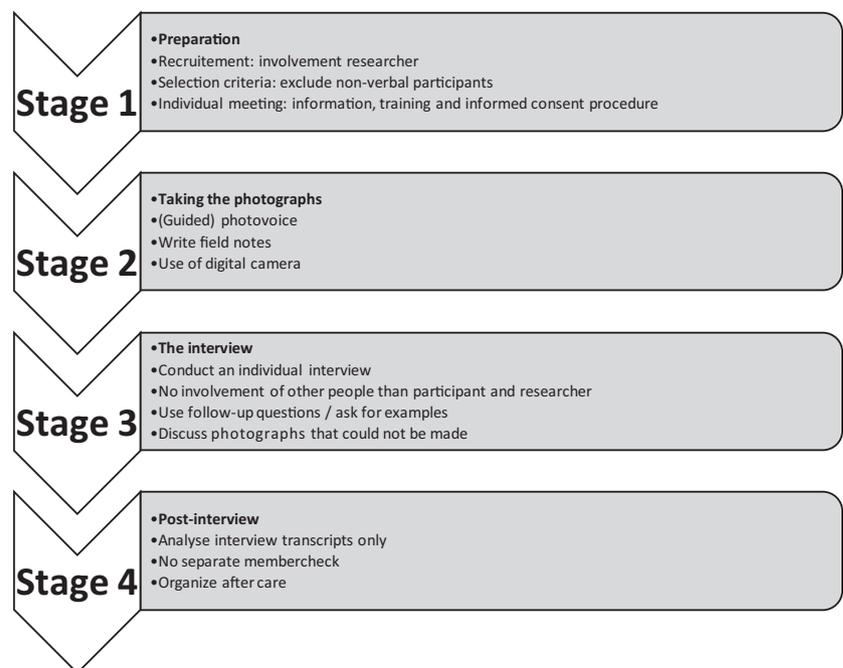
3.5 | Stage 4: Post-interview

Based on the results of earlier studies, the present authors recommend not to analyse the photographs outside the interview context. Photographs cannot be interpreted without the explanation of participants. Photographs can be inserted in the interview transcripts to connect stories to the photographs.

Because researchers are already involved from the beginning (introduction meeting, (guided) photovoice procedure and interview), a separate member check is not needed.

Necessary precautions should be taken for participants for whom the photovoice process can be disturbing because of the sensitivity of the topics touched upon (Slump et al., 2010). Therefore, aftercare should be provided when necessary.

Figure 1 shows the methodological decisions to be considered for our more standardized (guided) photovoice approach.

Stage 1
- Preparation
- Recruitement: involvement researcher
- Selection criteria: exclude non-verbal participants
- Individual meeting: information, training and informed consent procedure

Stage 2
- Taking the photographs
- (Guided) photovoice
- Write field notes
- Use of digital camera

Stage 3
- The interview
- Conduct an individual interview
- No involvement of other people than participant and researcher
- Use follow-up questions / ask for examples
- Discuss photographs that could not be made

Stage 4
- Post-interview
- Analyse interview transcripts only
- No separate membercheck
- Organize after care

FIGURE 1 Methodological decisions during the (guided) photovoice approach

3.6 | The (guided) photovoice approach applied in a study about the social inclusion of people with intellectual disabilities in their neighbourhood

To obtain more knowledge about the perspectives of people with intellectual disabilities on their social inclusion in the neighbourhood, the present authors used the (guided) photovoice approach described above. Together with the participants, the present authors walked around in their neighbourhood. Participants were able to photograph places and people in their neighbourhood together with the researcher. After the photographing stage, the photographs were discussed during an individual interview. The next sections provides an overview of the participants, the process of data analysis and the results and a reflection on how the methodological decisions in the various stages of the (guided) photovoice approach worked out in this study. Finally, the present authors reflect on the general outcomes and provide recommendations for future research.

3.7 | Participants

The present authors included fourteen participants in our study with a mild to moderate intellectual disability, to test our (guided) photovoice approach. Table 3 shows the characteristics of the fourteen participants in our study and the steps within the photovoice process followed by each participant.

3.8 | Plan for the analysis of the approach used in this research project

To analyse the effectiveness of our approach in revealing the voice of people with intellectual disabilities, each step of our approach was planned thoroughly for each participant. This evaluation concerned the observations and interpretations of the researchers (who were involved in each stage for each individual participant).

The present authors started with the preparation stage, in which the present authors evaluated the (dis)advantages of extra involvement of the researcher. First the present authors explored whether our formulated selection criteria were helpful in selecting the most appropriate participants for the project. This particularly meant evaluating the participants' understanding of the process. Next, the present authors evaluated the individual meeting in which information was given on the purpose of the research and the training procedures and the consent procedure. Because there was no involvement of peers and staff, the present authors were particularly curious how participants would respond.

Then, the present authors related the information provided by the participants during the guided photovoice and the written field notes to the interview transcripts. The present authors particularly wanted to evaluate the decision not to involve staff but instead introduce an independent researcher who was guided by the participant during the process of taking the photographs. The present authors focused on the field notes. How did the present authors use these field notes in preparing our interviews and was there an added value in doing so? Finally, the present authors wanted to evaluate the use of a digital camera.

All interviews were recorded and transcribed. ATLAS.ti was used to code the interview transcripts. The present authors searched for text fragments in the interview data that showed how participants related to other residents and staff members, in order to obtain information about our decisions to conduct an individual interview instead of a group interview and for staff members to be absent. To evaluate the intervention of asking about photographs not taken, and using the specific follow-up questions mentioned above, the present authors used the technique of process coding, followed by an evaluative analysis (Saldaña 2013). The present authors focused on the interaction process between the interviewer and the participant. To explore the significance of the techniques, the present authors coded the responses to the follow-up question "photographs not taken" and the "example" questions and to "active listening" which was aimed at encouraging the participant to tell his or her story.

In the post-interview stage, the present authors compared the content of the photographs with the stories of the participants. This comparison provided information about the (im)possibility of interpreting photographs without a story. Next, the present authors compared the evaluation of the guided photovoice with the analysis of the interview transcripts, to see if this could replace a member check procedure. Lastly, the present authors evaluated the need for aftercare by coding our transcripts based on two questions: Did our participants need aftercare and what kind of care was provided?

4 | RESULTS

4.1 | Stage 1: Preparation

In the recruitment procedure, the present authors encountered some difficulties because staff members wanted to decide for us whether or not their residents with intellectual disabilities were able or willing to participate in our project. They tended to think that their residents were too occupied, or incapable of understanding the procedure. For this reasons, the first author paid extra visits to some group homes to discuss the selection criteria with the staff members. Providing this extra information to staff members created enthusiasm and a better understanding of the research project. This enthusiasm helped with the recruitment of their residents. In one group home, the first author visited a group meeting and provided information to potential participants. This direct contact made it easier to recruit participants because the people with intellectual disabilities and their staff gained more understanding about the research project. Eventually, fourteen participants from four care organizations were involved in our research project (for their characteristics, see Table 1). During the recruitment procedure, two participants dropped out of our study. The reason for this was related to the subject of the research project. These two participants experienced difficulties participating in the neighbourhood and did not feel safe enough to walk around and take photographs.

All participants were informed and trained individually. The consent procedure was discussed with each participant. In some cases, the interviewer left the form with the participants, so, they could talk it over with family or a staff member if they wished to do so. All

participants signed the consent form and provided information in such a way that it was clear that they understood the procedure. In two cases, a participant explicitly asked to participate in the project together with another person living in the same group home. However, the present authors insisted that they would participate individually because the present authors wanted to avoid mutual influencing.

4.2 | Stage 2: Taking the photographs

Table 3 shows how the photovoice procedure was conducted with each participant. Eleven of twelve participants were guided by the interviewer during the photographing stage. Two of the participants took their own photographs and during nine guided walks the interviewer took the photographs. During the guided walk, participants were encouraged to point out people and locations in their neighbourhood that were important to them. One participant hesitated to participate but finally went for a walk with the researcher. After taking one photograph, he got really enthusiastic and showed a

lot more spots he considered important for him in his neighbourhood. Two other participants were quite silent during the walk but guided the interviewer to people who were important to them and who lived in their neighbourhood. In meeting these people, the participants opened up and told more about their relationships in the neighbourhood. One participant took her own photographs with her mobile phone and sent the photographs by WhatsApp. Because it was difficult to plan a meeting with her to take the photographs, this approach worked well in her case. Another participant took his own photographs during the walk, but lost his camera. The photographs were not printed and no interview took place. Only in this case, the recording of the guided photovoice walk was used. On average, almost thirteen photographs were taken per participant, ranging from 4 to 24 photographs. The amount of photographs with people depicted was limited (see Table 3), but the stories behind other photographs often involved people.

Directly after every guided photovoice walk, field notes were taken. These field notes were used as input for every interview. The

TABLE 3 Participants in the study about social inclusion of people with intellectual disabilities in their neighbourhood

	Gender	Age	Photovoice process	Number of photographs	Number of photographs showing people
A	Male	65	Guided photovoice: participant took photographs together with the researcher. Photographs were discussed during an interview.	24	0
B	Female	48	No guided photovoice. Participant took photographs without involvement of the researcher. Photographs were discussed during an interview.	12	0
C	Male	38	Guided photovoice: participant took photographs together with the researcher. After this stage he lost his camera. No interview took place. The guided photovoice transcript was analysed.	Unknown	Unknown
D	Male	53	Guided photovoice: researcher took photographs. Photographs were discussed during an interview.	6	2
E	Male	48	Guided photovoice: researcher took photographs. Photographs were discussed during an interview.	10	2
F	Female	54	Guided photovoice: researcher took photographs. Photographs were discussed during an interview.	11	0
G	Female	64	Guided photovoice: researcher took photographs. Photographs were discussed during an interview.	12	0
H	Male	61	Guided photovoice: researcher took photographs. Photographs were discussed during an interview.	12	0
I	Female	48	Guided photovoice: researcher took photographs. Photographs were discussed during an interview.	14	1
J	Male	42	Guided photovoice: researcher took photographs. Photographs were discussed during an interview.	15	0
K	Female	30	Guided photovoice: researcher took photographs. Photographs were discussed during an interview.	20	3
L	Male	51	Guided photovoice: researcher took photographs. Photographs were discussed during an interview.	12	1
M	Female	47	Guided photovoice: researcher took photographs. Photographs were discussed during an interview.	4	0
N	Female	42	Guided photovoice: researcher took photographs. Photographs were discussed during an interview.	6	0

interviewer made a small summary of the experiences during the guided photovoice walk and wrote down what was observed and where this was located, for example, whether participants were recognized by a lot of people in the neighbourhood, whether participants smiled when they saw a neighbour, showed signs of "happiness" walking around the marketplace or whether participants showed signals of anger when talking about some residents. These field notes were used as a member check and were in some cases helpful in formulating follow-up questions during the interview.

In all cases a digital camera was used. All participants who took the photographs themselves were able to operate the camera.

4.3 | Stage 3: The interview

An individual interview was conducted with thirteen participants. In every interview, the relationships with staff members and other residents of the group home was topic of discussion. In three interviews, a difficult relationship with one or more staff members was mentioned; it was stressed that this information was not to be shared with their professional caregivers. According to five participants in our study, the relationships with other residents were also troublesome (e.g., when someone's privacy is constantly invaded). Two participants were interviewed in a joint room and when another resident walked in, they felt uncomfortable and stopped telling their story.

In twelve interviews, follow-up questions were used frequently (more than five times during the interview). Participants were asked to tell more about the site or the person depicted. These follow-up questions were often combined with an active listening style, encouraging participants to tell more. Aspects of active listening were, for example, saying uhuh or yes. Part of the follow-up questions was asking for examples about activities they had undertaken at a certain spot or with a person in the photograph. The responses to the questions differed for each participant. Eight participants told extensive stories and provided detailed information, whereas four participants had difficulty answering these questions. They remained quiet, kept saying yes or no or were not able to provide more in-depth information. These participants had said more during the guided photovoice walk. This information was used for follow-up questions during the interview.

At the end of each interview, participants were asked about photographs not taken or important places and persons they had missed during the guided photovoice walk. Seven participants provided extra information and five participants answered with "no" or "don't know" (one participant was not interviewed). This extra information was about concrete spots, like a shop but, also about abstract themes, like loneliness. The question about the photographs not taken and the last question "is there anything else you would like to tell" provided extra information and were therefore valuable. At the end of each interview, the photographs were handed over to the participant.

During the interviews, the field notes taken after the guided photovoice walks were used as a member check which the present authors needed in the post-interview stage.

4.4 | Stage 4: Post-interview

During the coding process—after the interview—it became clear that photographs were often used as a catalyst to tell a story about a topic or about relationships with friends and family. These stories related to the picture but in a lot of cases the pictures could not be interpreted by themselves. For example, a picture showing a building which was experienced as an unsafe place or a picture of a bar which led to a story about relationships with family members. In some cases, a participant had more stories to tell about one picture, for example because there was more than one interesting spot visible in the photograph.

It is most common to conduct a separate member check after the interview, but the present authors recommended in our approach to do the member check within interview stage. During eight interviews, the interviewer explicitly referred to the guided photovoice walk. In all interviews, the walk was implicitly referred to, for example when the interviewer recalled information heard during the guided photovoice walk and this information was repeated during the interview. All eight participants confirmed this information after it was referred to. Combining the guided photovoice process with the interview was useful as a member check.

Four participants indicated problems that needed after care. The interviewer stressed that they could discuss these issues with staff members and they confirmed they would do so or had already done so. In one case, the interviewer discussed the issue—on the participant's request—with a staff member.

5 | DISCUSSION

The aim of this article is to investigate how the photovoice process could be most useful in enabling participants with intellectual disabilities to express their opinions in research studies. The present authors analysed the existing literature, introduced a more standardized (guided) photovoice approach and conducted a research project to test important methodological decisions. The present authors will reflect on all of this along the stages of the research process.

5.1 | Stage 1: Preparation

In the research project on neighbourhood involvement, the personal involvement of the researcher in the preparation stage, which the present authors recommended, created among the participants and staff more understanding and enthusiasm about the research aim and the recruitment procedures. It became a joint process, in which more participants were involved in the research project. During this stage, a researcher should be aware of his or her own role and should be as objective as possible, maintain a neutral presence and apply no pressure.

In the photovoice approach, it is essential to be able to reflect on the photographs. Our study showed that even verbal participants had difficulties answering questions during the interview. This supports our recommendation to exclude non-verbal participants. Excluding

non-verbal participants does not mean the present authors do not consider it important to involve these people in research, but that photovoice may not be the ideal method to give them a voice.

During the recruitment procedure, the present authors noticed that some residents influenced each other's decisions on whether or not to participate in the study and this stresses the importance of an individual approach.

5.2 | Stage 2: Taking the photographs

In the photographing stage, the present authors added a new option to our approach: guided photovoice. Participants could take pictures of their neighbourhood together with the researcher. This mode made photovoice more accessible for participants who had difficulties in, for example, operating a camera or walking around in the neighbourhood. Sometimes, the guided photovoice procedure helped participants to overcome psychological barriers.

The results of our project support our recommendation to use a digital camera.

5.3 | Stage 3: The interview

In accordance with our recommendations, it turned out that the field notes were useful as input for the interview stage. These field notes were valuable for confirming information provided during the interview and for formulating follow-up questions. The recommendation to conduct interviews individually and unassisted led to unexpected information about how participants perceived their relationships with staff members and other residents.

As expected, using follow-up questions, asking for examples and active listening all resulted in in-depth information about how participants felt in their neighbourhood and in what way facilities, activities and people contributed to this feeling. Walking around provided participants with an opportunity to tell their story in a well-known context and when meeting friends and family in the neighbourhood they were encouraged to tell more. The recommendation to exclude non-verbal participants from involvement in photovoice projects was supported by the outcome in our project that six of our participants faced difficulties in answering questions during their interviews. In some cases, this prompted unwanted interviewer assistance and showed that there are indeed limitations to the involvement of people with limited verbal capacities in a (guided) photovoice research project. An extensive guided photovoice walk (and talk) could perhaps serve as an alternative to the interview.

The results of our neighbourhood research project show that the question about the photographs not taken and the final question on whether or not there are more issues to be addressed are important to complete the stories of the participants.

5.4 | Stage 4: Post-interview

As expected, the present authors found that the stories which were revealed during the interviews often could not be deduced from the photographs alone. This underpins the recommendation not to interpret the photographs separate from the interview transcripts.

The more standardized (guided) photovoice procedure makes the special member check redundant. It is replaced by the recommended interview procedure. During the stages before the interview, a lot of information is exchanged that can be used as a member check.

Aftercare proved necessary and should always be considered when conduction a photovoice project.

5.5 | Reflecting on the strategies of the guided photovoice

There seems to be a paradox in the use of photovoice. Photovoice is often used to include people who have difficulties with direct communication and are disadvantaged on a cognitive and conceptual level (Jurkowski, 2008). But during the interview, the participants often have difficulty reflecting on the photographs they have taken. How realistic is this interviewing? And do these interviews reveal the information the present authors are looking for? Our study showed that some participants benefit from a guided photovoice walk and talk, but that the subsequent interview did not provide us with extra information. In these cases, the face-to-face interview could be excluded from the research process. Literature focusing on walking interviews confirms our findings that respondents find it easier to verbalize attitudes and feelings when "in place." This way of gathering information produces richer data (Aldridge, 2007; Evans & Jones, 2011; Garcia et al., 2012). Kusenbach (2003) states that the walking interview is primarily relevant in research that focuses on environmental perceptions, special practices, biographies, social architecture and social realms. Sensitive topics might be more difficult to address; participants could feel uncomfortable by the presence of a researcher in their natural habitat. This uncomfortable feeling might also occur when walking with certain people with intellectual disabilities, depending on the research topic and the needs of the participants. The present authors would recommend further research on "guided photovoice" in research involving people with intellectual disabilities.

For two people involved in our research project, the guided photovoice walk led to renewed contacts in their neighbourhood. These participants took the initiative to visit people they met during the guided photovoice walk. This "by-catch" of guided photovoice relates to the other aim of photovoice projects, that is empowering people and changing their current situation. In our study, this may lead to social inclusion in the neighbourhood. The present authors would recommend care organizations to consider using guided photovoice walks as a method for empowering their residents and providing them with opportunities for change.

5.6 | Digital tools and photovoice

One participant in our study took her own photographs and provided them via WhatsApp. She was perfectly able to explain the photographs she took. For participants who have a limited amount of time and who have the ability to take their own photographs, it would

be recommendable to further explore the use of WhatsApp. Using WhatsApp prevents from difficulties as losing a camera or lacking the development of photographs by participants. If participants are clearly guided in this procedure, it can offer opportunities in applying a relative fast and cheap photovoice procedure.

Looking ahead, more new and existing digital techniques are becoming available to support photovoice interviews. For example, geolocation could be added to the interview material to include a spatial analysis. By linking the locations of pictures taken by different participants, themes and shared concerns relating to specific locations could be identified (Jones & Evans, 2012; Paulus, Lester, & Dempster, 2014). The present authors also mentioned the use of tablets for displaying the pictures. In the near future, a review of such techniques and their use in photovoice interviews would be useful to the research and support people with intellectual disabilities living in the community.

Our study shows that clear methodological decisions during the photovoice process helped to design a method that elicits rich stories of participants. Within this approach, it is important to cater to the needs and capabilities of each participant.

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