Tilburg University

Reasons for collaborating in inclusive research projects

van den Bogaard, K.H.J.M.; Frielink, N.; Giesbers, S.A.H.; Schippers, A.; Embregts, P.J.C.M.

[Link to publication in Tilburg University Research Portal](#)

Reasons for collaborating in inclusive research projects: The perspectives of researchers with experiential knowledge, academic researchers and principal investigators

5 authors, including:

Noud Frielink
Tilburg University
63 PUBLICATIONS   **690** CITATIONS

Sanne Giesbers
Tilburg University
25 PUBLICATIONS   **460** CITATIONS

Alice Schippers
Amsterdam University Medical Center
50 PUBLICATIONS   **606** CITATIONS

P. J. C. M. Embregts
Tilburg University
297 PUBLICATIONS   **3,472** CITATIONS

ORIGINAL ARTICLE

Reasons for collaborating in inclusive research projects: The perspectives of researchers with experiential knowledge, academic researchers and principal investigators

Kim H. J. M. van den Bogaard[1] | Noud Frielink[1] | Sanne A. H. Giesbers[1] | Alice Schippers[2] | Petri J. C. M. Embregts[1]

[1]Tranzo, Tilburg School of Social and Behavioral Sciences, Tilburg University, Tilburg, The Netherlands

[2]Disability Studies, University of Humanistic Studies, Utrecht, The Netherlands

Correspondence
Noud Frielink, PO Box 90153, 5000 LE Tilburg, The Netherlands.
Email: n.frielink@tilburguniversity.edu

Abstract

Inclusive research—in which people with an intellectual disability both collaborate with researchers and work as researchers themselves—has gained increased attention over the last three decades. Although the foundational principles of conducting inclusive research are well-established at this point, there is a relative dearth of insights concerning the underlying reasons for collaborating as part of inclusive research projects. Therefore, this study sought to identify the reasons why researchers with experiential knowledge ($n = 9$), academic researchers ($n = 8$) and principal investigators ($n = 10$) collaborate within inclusive research projects. All 27 participants were interviewed individually, in order to explore their reasons for collaborating within one of the six inclusive research projects, which encompassed a range of research avenues within the field of intellectual disability research. A thematic analysis was conducted to gain insight into these reasons. For the three groups of participants, several themes emerged, such as experiencing full participation (researchers with experiential knowledge), making research (processes) better suited to the needs of participants with an intellectual disability (academic researchers) and striving for equivalence (principal investigators). Understanding why people collaborate within inclusive research projects is important for facilitating collaborative partnerships, which are a precondition for inclusive research projects.

KEYWORDS

collaboration, inclusive research projects, intellectual disability, practice, reasons

INTRODUCTION

Over the last 30 years, inclusive research—in which people with an intellectual disability both collaborate with and work as researchers themselves—has gained increased attention (Garratt et al., 2022; Strnadová & Walmsley, 2018). Building on their previous widely-cited definition of inclusive research ('research which includes or involves people with learning disabilities as more than just subjects of research'; Johnson & Walmsley, 2003, p. 61), Walmsley et al. (2018) proposed a revised definition, based on their review of 52 peer-reviewed journal articles, which posits that research is inclusive when it: (1) aims to both contribute towards social change and improve the quality of life of people with intellectual disabilities; (2) is focused on issues that are of significance to a wider group; (3) aims to acknowledge, foster and share the contributions that can be made by people with intellectual disabilities; (4) provides information that can be used to campaign for change on the behalf of others by people with intellectual disabilities; and (5) ensures that those involved in such campaigns are 'standing with' those whose issues are the subject of study.

In accordance with this revised definition, we position collaborative researchers in research projects as researchers, whereby some researchers have experiential knowledge as a result of living with an intellectual disability themselves, while others are trained as academic researchers. Specific training for inclusive research teams is recommended, in order to build the capacity of all the stakeholders involved (Nind et al., 2016; O'Brien et al., 2022; Sergeant et al., 2021). Regarding the context, in this paper we alternate between the terms researchers with experiential knowledge (i.e., those researchers having an [intellectual] disability) and academic researchers. Additionally, when referring to both researchers with experiential knowledge and academically trained researchers, we use the term researchers in general.

The revised definition of inclusive research is reflective of the second generation of inclusive research (O'Brien et al., 2022), which strives to bring about social change, namely a greater sense of belonging, within both the field of disability itself and among the wider community. This sense of belonging is engendered by shared learning and reciprocity (Riches et al., 2020), which one researcher with experiential knowledge described as 'giving me more confidence' (O'Brien et al., 2022, p. 8). Based on their structured literature review, Walmsley et al. (2018) showed that the most preferred and inclusive approach for achieving positive outcomes for all individuals involved in research is through collaboration as researchers. Being part of an inclusive research project may help to encourage the participation and social inclusion of researchers, and, in turn, lead to positive feelings as a result of being able to help others (Flood et al., 2013), in addition to feeling valued (Bell & Mortimer, 2013; Nind & Vinha, 2014) and experiencing increased self-confidence and self-esteem (Flood et al., 2013; García Iriarte et al., 2014).

To achieve these positive outcomes, establishing collaborative relationships between researchers with experiential knowledge and academic researchers in inclusive research teams is vital and requires commitment from all parties involved (Embregts et al., 2018; Nind & Vinha, 2014; Sergeant et al., 2021). For example, Nind and Vinha (2014) posited that having good knowledge of each other, having fun and spending time together were key indicators of establishing a collaborative relationship. Embregts et al. (2018) stressed the importance of communication with each other, which includes listening and providing adequate feedback, being cognisant of each other's skills and developmental needs, and developing a collaboration in which everyone involved feels they can contribute. The ability to form collaborative relationships between the researchers is also dependent on the context (e.g., the type of research and the setting), the available resources (e.g., the additional resources required to support researchers with experiential knowledge), not to mention the extent to which the ideology is embedded in the research institution and the underlying purpose and reasons for the individual team members to collaborate in the research (Frankena et al., 2016; O'Brien et al., 2022).

A limited number of studies have explored the reasons why researchers collaborate in inclusive research projects (e.g., Frankena, van Schrojenstein Lantman–de Valk, et al., 2019). Frankena, van Schrojenstein Lantman–de Valk, et al. (2019) explored the personal experiences and preferences of researchers with experiential knowledge and their supporters (i.e., professional caregivers) and academic researchers within four inclusive health research projects. The broadly shared reasons for conducting inclusive health research were: (1) gaining and expanding upon their experience with conducting inclusive health research, (2) increasing the quality and impact of health research (e.g., improved data interpretation), (3) exercising the basic human rights of people with an intellectual disability, (4) intrinsic reasons, which varied from practical reasons (e.g., having a stable job and salary) to personal reasons (e.g., personal growth, making friends, having a partner and enjoying the process) and (5) gaining an insider perspective. Although Frankena, van Schrojenstein Lantman–de Valk, et al.'s (2019) study is deeply relevant, the reasons why the different stakeholders (i.e., academic researchers and researchers with experiential knowledge) were collaborating in an

inclusive health research project in the first place were not reported separately. Given that they may have all had different reasons for collaborating (Frankena, Naaldenberg, et al., 2019), it is important to consider and compare and contrast the reasons why all researchers and principal investigators collaborate within inclusive research projects. In the context of this research, it is essential to clarify the roles: principal investigators, senior researchers without having an intellectual disability, assume leadership responsibilities that encompass project inception, execution, funding acquisition, team management, protocol adherence, and also include guiding the academically trained researcher in the execution, analysis, and documentation of the research. Meanwhile, academically trained researchers actively engage in various project aspects, including data collection, analysis and interpretation. Gaining insight into the various reasons for collaborating in inclusive research projects allows for the development of further collaborative partnerships in inclusive research projects, which, in turn, would allow the unique skills of all persons involved to be used (Nielsen, 2003; Plasch et al., 2021). With this in mind, this paper identified the reasons why researchers with experiential knowledge, academic researchers and principal investigators collaborate within inclusive research projects.

METHODS

Setting and participants

The Netherlands Organisation for Health Research and Development (ZonMw) funded seven research projects in the first round of a grant call within the national program for people with disabilities (in Dutch called 'Gewoon Bijzonder'), with the proviso that people with an intellectual disability or acquired brain injury (hereafter referred to as people with disabilities) would be involved as researchers. Six of these research projects were included in this study; the present paper forms part of the seventh project in which the collaboration between researchers with experiential knowledge, academic researchers and principal investigators in the other six research projects was examined. The six research projects that are central to this study focused on various themes, including stimulus processing, healthy lifestyles, social relations and technology, self-determination, living in an ethnically diverse city and participation. Each project was initiated for a 4-year period, and began somewhere between the period October 2016 to January 2017. The projects sought to develop, share and apply knowledge for the purpose of

improving both the quality of life and quality of support for people with intellectual disabilities.

In each research project, which encompassed several sub-projects, researchers with experiential knowledge and academic researchers formed close collaborations within at least one of these sub-projects. Our study included a minimum of one researcher with experiential knowledge, one academic researcher, and the principal investigator from each of the six research projects. While the full research teams ranged from approximately 4–10 members, researchers with experiential knowledge and academic researchers frequently worked in pairs within specific sub-projects, maintaining regular communication with the principal investigator. So despite the larger team sizes, most researchers with experiential knowledge and academic researchers operated in dyads with substantial interaction with the principal investigator. The researchers with experiential knowledge actively contributed to data collection preparation, providing invaluable insights to enhance the accessibility and comprehensibility of questions posed to participants engaged in the six inclusive research projects.

In our study, the research team comprised three academic researchers (KvdB, NF and SG) and two principal investigators (AS and PE). KvdB and PE initiated and designed the study, with KvdB conducting data collection. Interviews were coded by SG and KvdB, while the analysis involved SG, NF and PE, with all authors contributing to results interpretation. NF and PE led the manuscript writing, while all authors offered critical feedback to shape the research, analysis and manuscript. Additionally, to enhance result interpretation, we engaged in collaborative discussions with a researcher in our team possessing experiential knowledge in the subject matter, aiming to provide additional insights and perspectives.

A total of 27 participants took part in this study, including 10 principal investigators (9 females) with a mean age of 47.1 (SD = 7.6; range 32–54), eight academic researchers (7 females) with a mean age of 30.8 (SD = 6.2; range 26–43) and nine researchers with experiential knowledge (3 females) with a mean age of 40.6 years (SD = 12.9, range 23–63). All demographic information was obtained through a concise questionnaire administered as part of the interview process. While our interview inquiries were centred on understanding participants' engagement in their research project, it is plausible that the reasons shared by participants for engaging in inclusive research collaborations could be influenced by their prior experiences. Though we did not explicitly collect data on participants' past experiences, we acknowledge the potential impact of previous involvements on their current motivations.

Procedure

After obtaining ethical approval from the Ethics Review Board of Tilburg University (EC-2017.68), the first author contacted the principal investigators from each project to arrange an initial introductory meeting with two additional researchers, who were part of the overall project but not directly involved in the present study. During these introductory meetings, the principal investigators were invited to explain the goal and research design of their research, while the first author explicated the aim and research design of the present study. Following these introductory meetings, all principal investigators received an information letter providing them with additional details about the data collection within this research. Next, the principal investigators received an email from the first author in which they were invited to participate in this study; all accepted this invitation and a meeting was subsequently scheduled with each of the principal investigators—at a time and place of their preference—to discuss the involvement of the researchers (and other principal investigators if applicable) in the project and how they could best be contacted by the authors. The potential participants in each project were then contacted by email by the first author to, first, inform them about this project by means of an information letter, and second, to invite them to participate in this research. With the exception of one academic researcher who declined the invitation due to a high workload, everyone else accepted the invitation. The participants were then contacted by the first author to arrange in-person appointments—at a time and place of their preference—for conducting the individual interviews. A total of 27 interviews were conducted, with each participant having one interview. All interviews were conducted in-person by the first author, with most of the interviews taking place at the participants' workplaces. In a few cases, participants chose a public setting, such as a café at a central railway station. The interviews were audio-recorded and transcribed verbatim with the assistance of a professional transcription service. They took place between December 2017 and July 2018, at which point the research projects had been running for around one to one and a half years. Given the higher risk of traceability of the participants in the current study, we decided not to include pseudonyms when describing the results and presenting extracts from their accounts.

Prior to their interview, all the participants provided written informed consent. For the researchers with experiential knowledge, the interviewer read the consent form to the participant and explained information related to the ethical aspects of the study (e.g., confidentiality) in accessible language until an understanding was reached. No incentives were provided to any of the participants, as

their involvement in the study was considered an integral part of their roles as principal investigators, academic researchers, or researchers with experiential knowledge within the six participating research projects.

All interviews were conducted in Dutch, and the analysis of the interview transcripts was carried out in Dutch as well. However, the findings were subsequently translated into English by the authors themselves, with the translation later reviewed by a native English speaker. Quotations, on the other hand, were translated independently by a native English speaker who was not directly involved in the study.

Interview guide

To identify the reasons for collaborating in inclusive research projects, a semi-structured interview guide was developed. The interview guide focused on reasons for working together in an inclusive research project during the year prior to both the collaboration forming (i.e., the participants did not know each other prior to their research project) and the preparation for data-collection taking place. The interview guide consisted of open-ended questions, such as 'What was your main reason for applying for this project'? and 'What was your main reason for wanting to be part of an inclusive research project?', which were designed to elicit non-biased responses from the participants. The interview guide for academic researchers and principal investigators remained consistent, featuring identical questions. However, for researchers with experiential knowledge, the questions in their interview guide were streamlined, though the overall topics covered were unchanged. This approach enabled us to investigate potential differences in responses rooted in individual backgrounds, thereby enriching our study's insights and providing a more comprehensive understanding of the research phenomenon from diverse perspectives. In the development of this interview guide, a researcher with experiential knowledge played an active role by providing valuable input, suggesting modifications and offering concrete word and phrase suggestions whenever she identified questions that could be challenging for participants. The interview guide was piloted with two academic researchers and two experts-by-experience living with an intellectual disability and based on their feedback some minor adjustments were made to the interview guide.

Analysis

The thematic analysis approach used to analyse the interviews consisted of six distinguishable steps (Terry et al., 2017). First, two authors carefully read the

transcripts to familiarise themselves with the data. Second, independently, two researchers assigned codes to phrases within the transcripts that held clear importance for the study. Specifically, within each transcript, codes were assigned to capture the reasons for collaboration among researchers with experiential knowledge, academic researchers and principal investigators. Next, two researchers compared and discussed their coding, seeking resolution through consultation with two additional researchers in case of disagreement. Third, the coding for each participant group (i.e., researchers with experiential knowledge, academic researchers and principal investigators) was separately discussed by the two researchers who coded the interviews, and any disagreements were discussed with the other authors. Codes were then grouped together based on their similarities. In the fourth step, a collaborative review of the themes was conducted by all researchers to assess both internal homogeneity (i.e., the extent to which the codes within each theme formed a coherent and meaningful pattern) and external homogeneity (i.e., the extent to which the codes across different themes were distinct and easily distinguishable). Fifth, the emerging themes were defined and named by all authors, with accompanying descriptions for each theme. To further interpret the results, both the themes and the accompanying description were thoroughly discussed with a researcher possessing experiential knowledge in the subject matter. This collaborative discussion aimed to provide additional insights and perspectives. During the final step, a scholarly report was collaboratively produced by the authors. The report was supplemented with vivid and compelling quotations from the participants, which helped to enrich the manuscript and provide illustrative examples.

RESULTS

The results with respect to the subsequent participant groups are described below, distinguishing between various themes and, in some cases, sub-themes. An overview of these themes and subthemes is presented in Table 1.

Researchers with experiential knowledge

For the researchers with experiential knowledge, the analysis identified four themes, two of which were divided into several subthemes.

Theme 1: Experiencing full participation

Being able to experience full participation (1) within the inclusive research team and (2) in the work itself was an important reason for the researchers with experiential knowledge to work within inclusive research projects.

Subtheme 1.1: Feeling valued and belonging to a team

The researchers with experiential knowledge talked about how they were willing to collaborate in inclusive research projects, because they felt respected, were taken seriously, heard and valued by other team members. As one participant formulated:

> The feeling that they really, not really the feeling because it does actually happen, that my opinion really counts for something. I think that's going very well. Letting me know and showing me that they're doing something with what I say.

Moreover, they described how they enjoyed engaging in conversations with other members of the inclusive research team, insofar as it allowed them to share and discuss each other's stories, experiences, emotions and feelings. They appreciated being able to work together in a team towards an end goal, not to mention being able to rely and fall back on each other if needed. As such, the researchers with experiential knowledge appeared to experience a sense of belonging within the inclusive research team.

Subtheme 1.2: Participation in work

Being able to fully participate in work was also a reason for the researchers with experiential knowledge to work within inclusive research projects. The researchers with experiential knowledge felt that they, and other people with intellectual disabilities, have the right to participate in work, just like everyone else does. Working within an inclusive research project hence fulfilled their wish to participate in work. However, some of the researchers with experiential knowledge also expressed that they felt their work position was not wholly equal to those of their academic researchers and principal investigators, namely with respect to appropriate payment arrangements, which primarily concerned the fact that appropriate payment would have been incompatible with their disability pension. This resulted in some researchers with experiential knowledge being paid in gift cards.

Theme 2: Being able to develop yourself in a job that suits your competencies

Feeling that they were suitably equipped for the job encouraged the researchers with experiential knowledge to start working in inclusive research projects. It was

TABLE 1 An overview of the themes and subthemes for each participant group.

Participant group	Theme	Subtheme
Researchers with experiential knowledge	Experiencing full participation	Feeling valued and belonging to a team
	Being able to develop yourself in a job that suits your competencies	Participation in work
		(Enhancing) equal participation in society
	Utilising their unique knowledge and learning from each other's expertise	Empowering people with intellectual disabilities in research
	Helping other people with intellectual disabilities	Adapting tools and methods to the needs of people with intellectual disabilities
Academic researchers	Making research (processes) better suited to the needs of participants with an intellectual disability	
	Experiencing increased value of research outcomes for clinical practice	
	Striving for inclusive knowledge production	
	Learning from the experiential knowledge of researchers	
Principal investigators	Striving for equivalence	
	Academic researchers learn from the experiential knowledge of researchers	
	Experiencing increased value of research outcomes for clinical practice	
	Forging stronger connections with the research population	

important for them to do something they felt they were good at, for example their capacity to empathise, their decisiveness, their research abilities, and being able to travel independently.

> Also because I had or did a lot of the skills already. I don't think the step was that big at that moment. I was often told that I was a good listener. I also built some experience helping them figure things out and traveling by myself was not such a problem either.

Moreover, the researchers with experiential knowledge appreciated the fact that their job was challenging, and described performing research activities as fun, varied and stimulating. They also talked about the opportunities afforded by their job to both develop new skills and grow, not only as a researcher but also as a person, by, for example, overcoming their fears (e.g., fear of talking over the phone or talking to other people), gaining self-insight, or learning how to handle their emotions when talking about sensitive topics.

Theme 3: Utilising their unique knowledge and learning from each other's expertise

The researchers with experiential knowledge also placed importance on the fact that they could utilise their unique experiential knowledge within the inclusive research project. The researchers with experiential knowledge stated that while academic researchers possess scientific and theoretical knowledge, this knowledge can never encompass the experiences and feelings of someone with an intellectual disability. Therefore, they felt that their experiential knowledge was of great value for the academic researcher, and, consequently, for the research project as a whole.

> We know what we're talking about. After all, we're the ones with autism and a mild intellectual disability. Why isn't science asking us anything? Of course they have a lot of knowledge in their heads and I'm not saying that's nonsense. But I think our part can be just as valuable. I think they as scientists they can, if they pay attention, a good scientist can get a lot of knowledge there.

The researchers with experiential knowledge not only felt that sharing their experiential knowledge could help the academic researcher and strengthen the research project, but, at the same time, they themselves could learn from the expertise of the academic researcher. In this respect, they believed that researchers with experiential knowledge and academic researchers can reinforce each other's competencies.

Theme 4: Helping other people with an intellectual disability

Being able to help other people with intellectual disabilities was also cited as a reason for researchers with

experiential knowledge to collaborate within inclusive research projects. More specifically, they felt they could play a significant role for other people with intellectual disabilities in different ways and across different domains, namely by (1) enhancing their participation in society, (2) empowering them in research and (3) contributing towards the development of tools and methods that aim to improve support.

Subtheme 4.1: (Enhancing) equal participation in society

An important reason for researchers with experiential knowledge to work within inclusive research projects was to contribute to the equal participation of people with an intellectual disability in society. That is to say, they felt that working as a researcher with experiential knowledge could help people with intellectual disabilities to be valued and recognised by people in society at large as well as raising awareness about the barriers they face.

> To share that from my experience, I have autism [as well as an intellectual disability], to share that uhm, from my experience people are struggling a lot with this in society. I see lots of people, different ones, that have different kinds of autism, that they're misunderstood. And that there's not that much demand, not that much publicity, that really something should, something should be done.

Subtheme 4.2: Empowering people with an intellectual disability in research

For researchers with experiential knowledge, supporting other people with an intellectual disability to participate in research as research subjects, and thereby empowering them to communicate and share their needs and views with researchers, was an important reason for working in inclusive research projects. For example, they explained how they were able to clarify information to them, comfort them, ask them the right interview questions (because of their capacity to empathise), and help them when they were struggling with words. According to the researchers with experiential knowledge, this resulted in people with an intellectual disability being more confident about expressing their needs and views and answering the interview questions.

> I think it has an added value in doing interviews, because clients are more unsure if they are telling it right and if they're using the right words and if you're also there then they feel... then they like recognise things.

Subtheme 4.3: Adapting tools and methods to the needs of people with an intellectual disability

The development of a tool or method to improve the quality of support provided to people with intellectual disabilities formed part of some of the research projects included in this study. For the researchers with experiential knowledge working in these projects, the development of this tool or method was an important reason for participating in the inclusive research project. Specifically, they felt that their contribution resulted in a product that was more fun and attractive, and better adapted to the needs and wishes of people with intellectual disabilities.

> Because I think it's important, like it's difficult to teach things to some people with a certain handicap, but if you put it in a game they can visualise it and I think that makes it easier to learn something. I think for me that's a big reason why I got involved in this (...) I play lots of videogames myself so I know what's appealing and what isn't and I try to look at the game from that angle to keep it fun and appealing.

Academic researchers

The analysis of the academic researchers' accounts revealed four themes.

Theme 1: Making research (processes) better suited to the needs of participants with an intellectual disability

One of the reasons stated by the academic researchers for working within inclusive research projects was their belief that researchers with experiential knowledge were better equipped to empathise and understand the perspective of potential research participants with an intellectual disability. Therefore, according to the academic researchers, the research design and execution thus became better suited to the needs of people with an intellectual disability. For example, the academic researchers stated that inclusive research projects could lead to both better (interview) questions for participants, including the tools needed to facilitate the participants' communication and understanding (e.g., visual tools), and research procedures that were not overly demanding for participants with an intellectual disability.

According to the academic researchers, working together with researchers with experiential knowledge

also contributed towards a better operationalisation of the research concepts: by discussing the concepts with their researchers with experiential knowledge, the meaning became clearer to them and, as such, was easier to interpret. Moreover, the academic researchers felt better able to interpret and give meaning to the results of their research when working together.

> And because they are used to being around people that, I suppose, speak a simple language and for example don't always finish their sentences, they help me interpret as in don't you think they mean that and that way they help the process too.

Theme 2: Experiencing increased value of research outcomes for clinical practice

The academic researchers experienced that when working together with researchers with experiential knowledge, there was a greater likelihood that the research findings would make their way into clinical practice, by virtue of discussing how to translate the research findings in ways that are accessible for and applicable to both people with intellectual disabilities and those who support them. In addition, the academic researchers believed that working together with researchers with experiential knowledge would result in a better practical tool (developed based on the research findings) through which to improve the quality of support for people with intellectual disabilities.

> And because we want to develop such a concrete methodology and it has to be right for users so then it's also best to start with the users, those are the people, what do they want? I think the end result will be best then.

Theme 3: Striving for inclusive knowledge production

The academic researchers also stated that they wanted to work inclusively because they were striving for inclusive knowledge production. It was felt that knowledge production requires working together (clinical practice—science) on a shared research question. In this respect, the academic researchers stressed that they believed that it is not only academically educated people who have valuable knowledge, but that people from various sociocultural backgrounds, including people with intellectual disabilities, have expedient and valuable knowledge.

> I know lots of people in my own network that didn't go to school, that don't have diplomas, but that have a huge amount of knowledge and are incredibly rich simply in all kinds of insights and information which quite often makes me think like yes, if only they could do research. You know? Then we would have so much more knowledge in the world, but because they don't have the right diplomas they can't get there.

Theme 4: Learning from the experiential knowledge of researchers

The academic researchers felt that by working in inclusive teams, they could learn a lot about the research population (i.e., people with intellectual disabilities). Moreover, they explained that it made them more cognisant of what living with an intellectual disability actually entails, in addition to what barriers they face within society. They stated that this awareness strengthened their work motivation and perseverance, insofar as it underscored the urgency of their work.

> Her life story as well, which sometimes moves me and which makes me think, like, don't quote me on this but ***[expletive masked], it's important. This is. And it helps me stay with the research, sometimes that's, you know, when you're having tough days, but then she reminds me, like, we know why we're doing it.

Moreover, the academic researchers described that the researchers with experiential knowledge and academic researchers themselves each contributed to the project via their respective knowledge, views and experiences. This ensures that they adopt a broad perspective in the research process (i.e., staying open to other views and ideas) as well as learning from the views and experiential knowledge of their researchers. They felt that the input of both academic researchers and researchers with experiential knowledge complements each other in the research process.

Principal investigators

For the principal investigators, the analysis also yielded four themes.

Theme 1: Striving for equivalence

It was evident to all the principal investigators that research about people with intellectual disabilities should

include the views and experiences of people with experiential knowledge themselves. Some principal investigators stressed that they believed that experiential knowledge is equivalent to scientific knowledge, and, as such, that they complement each other. According to them, researchers with experiential knowledge should have an equivalent place within inclusive research projects.

> I think that if you say: people are equal and deserve an equal place in this society. Then you should also… and you're getting information from those people, then you should also acknowledge that, that those people also get a place in the projects. Otherwise you're just milking them and, yeah, that I think is not respectful and equal so… if we're working together, they also deserve a place in those projects.

For those principal investigators, an equivalent place within inclusive research projects meant that researchers with experiential knowledge should be taken seriously, feel that they belong to the research team, and feel encouraged and supported to truly utilise their experiential knowledge and other strengths. It was important to them that researchers with experiential knowledge were not merely involved for the purpose of making the research look inclusive to the outside world.

> Because you can't just involve them in everything. As in: 'we have another co-researcher with experiential knowledge'. And that's also something we're very sensitive about. It shouldn't just look good. It should add something meaningful.

Some of the principal investigators strived to build long-term collaborations with researchers with experiential knowledge in which they can build on a trustful and equal relationship, which they believed to be a prerequisite for true equality within inclusive research projects. However, some of the principal investigators believed that it was not necessary to include people with intellectual disabilities within inclusive research projects in order to incorporate their views and experiences within the research process. Despite stating that they did not consider people with intellectual disabilities to be researchers, they nevertheless stressed that their views and experiences are still of tremendous value and, as such, they should be included either as research subjects or by asking them for feedback upon request. It is important to note that while these particular principal

investigators held this viewpoint, it does not reflect the perspective of all principal investigators or the general consensus within the field.

Theme 2: Academic researchers are learning from experiential knowledge

Similar to what the academic researchers themselves indicated; the principal investigators also believed that working together with researchers with experiential knowledge was important in terms of the personal development of principal investigators and academic researchers. That is to say, the principal investigators also felt that, generally speaking, principal investigators and academic researchers would be more able to understand what it entails to live with an intellectual disability. Because the academic researchers were moved by the personal stories of the researchers with experiential knowledge, the principal investigators felt that by working together, academic researchers would constantly experience the value and urgency of their work for the lives of people with intellectual disabilities, which, in turn, may increase their internal work motivation.

> That all the time, more often than when you're not working with people with a disability, that you're sort of all the time being reminded of, aware of, the fact why you're doing this work.

In addition, according to the principal investigators, all the researchers have their own views and knowledge, and when these are brought together, they can all learn from each other. The researchers with experiential knowledge can provide important information that, at least initially, academic researchers are simply not cognisant of. For example, academic researchers could receive valuable feedback on their research (ideas), which, in turn, would stimulate the development of the (academic) research(ers).

> That it simply results in very important information, which as a professional or researcher you're not always aware of or had thought about. It's just important to me.

Theme 3: Experiencing increased value of research outcomes for clinical practice

Similar to the academic researchers, the principal investigators also talked about the importance of conducting

research that ultimately benefits clinical practice. They felt that by working together with researchers with experiential knowledge, they could develop materials that better fit the needs and wishes of the end users (i.e., people with intellectual disabilities).

> If you're developing a methodology for a certain target group, or target groups in this case, you have to optimally involve those target groups from the start when you start thinking about 'where do we want to go'. So that's the big added value. That you're not coming up with something without those target groups. And then find out it's not a good fit for them after all.

Theme 4: Forging stronger connections with the research population

The principal investigators also talked about how researchers with experiential knowledge can help to forge stronger connections with the research population. For the principal investigators, it was important that, by working together, principal investigators and academic researchers could learn the right kind of language and disposition to attract and retain people with intellectual disabilities as research subjects. In other words, researchers with experiential knowledge could be asked whether the questions the academic researchers want to ask people with intellectual disabilities are correct and understandable, in addition to giving feedback on the academic researchers' attitudes towards them. For instance, if academic researchers approach people with intellectual disabilities straight away, then there is a chance that they will not attune to their needs well enough, which, in turn, increases the risk that they either refuse to participate or withdraw from the research at a later date.

> What I think the added value can be is that such a researcher can also test themselves a bit before they really talk to a client we have in the study, because if you go wrong there, you're kind of ruining your own chances. That the client doesn't want to be involved for a long time. And if you can first test this with your researchers with experiential knowledge if you want to ask this, or want to use this, and they already shoot it down, then you get feedback. Then you can do something with it. Then you can do a better job in the talk.

DISCUSSION

In this study, the reasons why researchers with experiential knowledge, academic researchers and principal investigators collaborate in inclusive research projects were explored. The participants were all related to one of the six inclusive research projects that were funded by the Netherlands Organisation for Health Research and Development (ZonMw), with the proviso that people with intellectual disabilities would be involved as researchers with experiential knowledge. Each project focused on a variety of themes, including stimulus processing, healthy lifestyles, social relations and technology, self-determination, living in an ethnically diverse city, and participation.

The participants reported several overlapping reasons for collaborating in inclusive research projects. More specifically, all three participant groups indicated that one of the main reasons for collaborating in inclusive research projects is the increased value of inclusive research projects with respect to both (clinical) practice and learning from each other's expertise. Moreover, the researchers with experiential knowledge indicated that experiencing full participation in work and feeling valued and experiencing a sense of belonging with a team was an important reason for collaborating in inclusive research projects. This reason was also shared by the academic researchers and principal investigators, insofar as they reported that they wished to strive for equivalence between all team members in inclusive projects. These overlapping reasons for collaborating are consistent with several assumptions of inclusive research (Walmsley et al., 2018), which state that inclusive research aims to improve the quality of the lives of people with intellectual disabilities (e.g., experiencing full participation), and to acknowledge, foster and share the contributions that can be made by people with intellectual disabilities based on their experiential knowledge. These overlapping reasons are imperative, insofar as they may create a shared sense that everyone is working towards a mutual end goal, which, in turn, can engender feelings of connectedness and a sense of belonging (Sergeant et al., 2021), and reduce the disparities between academic researchers and researchers with experiential knowledge (Kidd et al., 2018). Moreover, reciprocal learning contributes towards changing views on knowledge production and epistemic justice, where experiential knowledge is seen as equivalent to academic knowledge (Knevel et al., 2022). One particularly noteworthy finding is that although working within an inclusive research project fulfilled their wish to participate in work, some of the researchers with experiential knowledge indicated that their work position was not wholly equal to the academic

researchers and principal investigators in terms of appropriate payment arrangements. These reasons, especially the part about monetary gain, were also reported in previous research (Frankena, van Schrojenstein Lantman–de Valk, et al., 2019; O'Brien et al., 2022). Payment is thus an important factor to take into account also—or perhaps especially—in the case of inclusive research teams, as earning money is of crucial importance for the social representation of work for people with intellectual disabilities (Gaymard, 2014), and in terms of increasing their autonomy (Jahoda et al., 2009) and providing a means through which to legitimise their self-worth (Lysaght et al., 2009). Hence, as inclusive research aims to contribute towards social change (Walmsley et al., 2018), we concur with O'Brien et al. (2022) that it is important to address issues of appropriate funding and payment arrangements when setting up new inclusive research projects.

In addition to the similarities in the reasons for collaborating in inclusive research projects, there were also differences between the participant groups. For researchers with experiential knowledge, for example, being able to develop themselves in a job that suits their competencies and allows them to help other people with intellectual disabilities were key reasons for working in inclusive research projects. Interestingly, experiencing competence and helping other people—which are constitutive components of self-determination theory, a macro theory that has identified three basic psychological needs (i.e., autonomy, competence and relatedness)—have been shown to play an important role with respect to well-being, life satisfaction and work satisfaction (Ryan & Deci, 2017). Hence, despite this not being the framework for the study, the researchers with experiential knowledge nevertheless indicated the importance of these psychological needs, which is likely associated with their job satisfaction while working in inclusive research projects. In addition, the feeling of being able to help other people may enhance feelings of self-worth and self-esteem (Forrester-Jones & Barnes, 2008), and may challenge feelings of dependence (Milner & Kelly, 2009), thereby positively contributing to individuals' mental health (Fyrand, 2010; Thomas, 2010).

A distinctive reason why the academic researchers collaborated in inclusive research projects was that they helped to make research (processes) better suited to the needs of participants with intellectual disabilities, a reason that was also identified in previous research (Frankena, van Schrojenstein Lantman–de Valk, et al., 2019). For principal investigators, in addition to the aforementioned overlapping reasons, forging stronger connections with the research population was a distinct reason. Given that principal investigators are responsible for the entire research project, it seems somewhat obvious that their main reasons for collaborating in inclusive

research projects were related to academic research and the outcomes of the research process. Due to their position, in most cases, principal investigators fulfil a supportive role in the collaboration between the researchers involved (Frankena, Naaldenberg, et al., 2019). They also play a role in terms of initialising this collaboration at the beginning of a research project, even before the actual collaboration begins. It would be interesting for future inclusive research projects to explore and discuss everyone's reasons for collaborating in the research project at the onset of the project. Given that individuals have different types of reasons with respect to both their work and collaborating in inclusive research teams, considering the different reasons of the individuals that are working together is critically important, in light of the fact that, compared to more extrinsically driven reasons, intrinsically—or autonomously—driven reasons are likely to enhance various favourable outcomes, such as increased well-being and performance (Ryan & Deci, 2017).

Both identifying and discussing the reasons of all partners involved is important for facilitating collaborative partnerships (Plasch et al., 2021). Contextual factors, including the values and characteristics of all team members, are foundational for collaborating in inclusive research projects. Collaboration within inclusive research projects is maintained, in part, by the perceived personal and social benefits (Schwartz et al., 2020) deriving from the shared reasons for collaborating. In the present study, some principal investigators did not acknowledge the benefits of working together with the researchers with experiential knowledge in inclusive research projects, and, instead, viewed their role as mainly the subjects of research. This could have impacted upon both the research process and the collaboration between the researchers within these projects. Therefore, developing an awareness of and mitigating the inherent power relations in research is crucial for establishing fruitful collaborative relations in inclusive research projects (Knevel et al., 2022; Nind & Vinha, 2014). Moreover, since the results indicate that researchers with experiential knowledge learn on the job, a fact which is also recognised by García Iriarte et al. (2023), examining the role of the principal investigator within an inclusive research project as well as the impact that they have on the collaboration is imperative for future research.

However, the results of this study should be interpreted in light of some limitations. First, working together with researchers with experiential knowledge within an inclusive research project was a prerequisite of the funder of the six projects. This proviso may have prevented the academic researchers and principal investigators from sharing all their thoughts about their collaboration within inclusive research projects, such as

feelings that they were forced to work together. To mitigate this potential bias, the researchers explicitly took time during the interview to put the participants at ease and reassure them that all information was confidential and that their names and projects would not be linked to particular statements. Second, this study did not include a researcher with experiential knowledge from the outset, although a researcher with experiential knowledge was involved at various aspects of the study. Specifically, the researcher with experiential knowledge was involved in the preparation of the data collection (i.e., the researcher with experiential knowledge provided valuable advice with respect to both the accessibility and comprehensibility of the questions the academic researcher wanted to pose to the researchers with experiential knowledge involved in the six inclusive research projects) and in terms of interpreting the results. Third, the timing of our interviews was influenced by the need to capture participants' initial reasons for collaboration in inclusive research projects before potential shifts occurred during the collaborative process. However, a limitation of our study was that we were reliant on coordination with the six other projects, resulting in interviews being completed before the data collection phase began. This timing may have influenced participants' responses and perceptions, and future research could explore how reasons and experiences evolve over time to gain a more comprehensive understanding of the dynamics involved. Fourth, future research may consider collecting and analysing demographic data, including gender, age and ethnic backgrounds, to enhance understanding and account for potential associations. Incorporating these demographic factors will contribute to a more inclusive and representative study, improving the generalizability of findings and promoting equity in research. Additionally, future research should investigate whether the varying viewpoints of principal investigators regarding the value of including people with intellectual disabilities in inclusive research projects are associated with different project requirements, individual approaches, and past experiences of working with individuals with intellectual disabilities, both within and outside of inclusive research settings. This exploration would shed light on the potential factors influencing these perspectives. Finally, it is crucial to highlight that our research approach adheres to traditional research structures, where the principal investigator assumed a leadership role within the project. None of the projects examined in this study featured a researcher with experiential knowledge and intellectual disabilities in a leadership capacity. As argued by Jones et al. (2020), they assert the significance of researchers with experiential knowledge taking on leadership roles, suggesting that further research in this area is warranted.

Despite these limitations, the present study was able to identify the reasons why researchers with experiential knowledge, academic researchers and principal investigators collaborate in inclusive research projects. Knowing these reasons for collaborating within inclusive research projects is important for facilitating collaborative partnerships, which are a precondition of inclusive research projects. Moreover, gaining insight into the reasons for collaboration create a solid base from which to build sustainable collaborations in research projects, where the voices of people with intellectual disabilities are heard.

CONFLICT OF INTEREST STATEMENT
The authors declare no conflicts of interest.

ETHICS STATEMENT
Ethical approval was obtained from the Ethics Review Board of Tilburg University.

ORCID
Noud Frielink https://orcid.org/0000-0001-8489-8409
Sanne A. H. Giesbers https://orcid.org/0000-0001-8358-5806
Alice Schippers https://orcid.org/0000-0002-6376-1718

REFERENCES
Bell, P., & Mortimer, A. (2013). Involving service users in an inclusive research project. *Learning Disability Practice*, *16*(4), 28–30.

Embregts, P. J., Taminiau, E. F., Heerkens, L., Schippers, A. P., & Van Hove, G. (2018). Collaboration in inclusive research: Competencies considered important for people with and without intellectual disabilities. *Journal of Policy and Practice in Intellectual Disabilities*, *15*, 193–201.

Flood, S., Bennett, D., Melsome, M., & Northway, R. (2013). Becoming a researcher. *British Journal of Learning Disabilities*, *41*, 288–295.

Forrester-Jones, R., & Barnes, A. (2008). On being a girlfriend not a patient: The quest for an acceptable identity amongst people diagnosed with a severe mental illness. *Journal of Mental Health*, *17*, 153–172.

Frankena, T. K., Naaldenberg, J., Cardol, M., Meijering, J. V., Leusink, G., & van Schrojenstein Lantman-de Valk, H. M. J. (2016). Exploring academics' views on designs, methods, characteristics and outcomes of inclusive health research with people with intellectual disabilities: A modified Delphi study. *BMJ Open*, *6*, e011861.

Frankena, T. K., Naaldenberg, J., Tobi, H., van der Cruijsen, A., Jansen, H., van Schrojenstein Lantman-de Valk, H., Leusink, G., & Cardol, M. (2019). A membership categorization analysis of roles, activities and relationships in inclusive research conducted by co-researchers with intellectual disabilities. *Journal of Applied Research in Intellectual Disabilities*, *32*, 719–729.

Frankena, T. K., van Schrojenstein Lantman–de Valk, H., Cardol, M., van der Cruijsen, A., Jansen, H., Leusink, G., & Naaldenberg, J. (2019). Contributing to inclusive research policy and practice: A synthesis of four inclusive (health) research projects. *Journal of Policy and Practice in Intellectual Disabilities*, *16*, 352–360.

Fyrand, L. (2010). Reciprocity: A predictor of mental health and continuity in elderly people's relationships? A review. *Current Gerontology and Geriatrics Research*, *2010*, 340161.

García Iriarte, E., Díaz Garolera, G., Salmon, N., Donohoe, B., Singleton, G., Murray, L., Dillon, M., Burke, C., Leddin, N., Sullivan, M., & Spelman, M. (2023). How we work: Reflecting on ten years of inclusive research. *Disability & Society*, *38*, 205–227.

García Iriarte, E., O'Brien, P., & Chadwick, D. (2014). Involving people with intellectual disabilities within research teams: Lessons learned from an I rish experience. *Journal of Policy and Practice in Intellectual Disabilities*, *11*, 149–157.

Garratt, D., Johnson, K., Millear, A., Picken, S., Slattery, J., & Walmsley, J. (2022). Celebrating thirty years of inclusive research. *Social Sciences*, *11*, 385.

Gaymard, S. (2014). Social representation of work by women and girls with intellectual disabilities. *Life Span and Disability*, *17*, 145–173.

Jahoda, A., Banks, P., Dagnan, D., Kemp, J., Kerr, W., & Williams, V. (2009). Starting a new job: The social and emotional experience of people with intellectual disabilities. *Journal of Applied Research in Intellectual Disabilities*, *22*, 421–425.

Johnson, K., & Walmsley, J. (2003). *Inclusive research with people with learning disabilities: Past, present and futures*. Jessica Kingsley Publishers.

Jones, K. E., Ben-David, S., & Hole, R. (2020). Are individuals with intellectual and developmental disabilities included in research? A review of the literature. *Research and Practice in Intellectual and Developmental Disabilities*, *7*, 99–119.

Kidd, S., Davidson, L., Frederick, T., & Kral, M. J. (2018). Reflecting on participatory, action-oriented research methods in community psychology: Progress, problems, and paths forward. *American Journal of Community Psychology*, *61*, 76–87.

Knevel, J., Wilken, J. P., & Schippers, A. (2022). Experiences of inclusive action and social design research with social workers and people with intellectual disabilities. *Social Sciences*, *11*(3), 121.

Lysaght, R., Ouellette-Kuntz, H., & Morrison, C. (2009). Meaning and value of productivity to adults with intellectual disabilities. *Intellectual and Developmental Disabilities*, *47*, 413–424.

Milner, P., & Kelly, B. (2009). Community participation and inclusion: People with disabilities defining their place. *Disability & Society*, *24*, 47–62.

Nielsen, B. B. (2003). An empirical investigation of the drivers of international strategic alliance formation. *European Management Journal*, *21*, 301–322.

Nind, M., Chapman, R., Seale, J., & Tilley, L. (2016). The conundrum of training and capacity building for people with learning disabilities doing research. *Journal of Applied Research in Intellectual Disabilities*, *29*(6), 542–551.

Nind, M., & Vinha, H. (2014). Doing research inclusively: Bridges to multiple possibilities in inclusive research. *British Journal of Learning Disabilities*, *42*, 102–109.

O'Brien, P., Garcia Iriarte, E., Mc Conkey, R., Butler, S., & O'Brien, B. (2022). Inclusive research and intellectual disabilities: Moving forward on a road less well-travelled. *Social Sciences*, *11*, 483.

Plasch, M., Pfoser, S., Gerschberger, M., Gattringer, R., & Schauer, O. (2021). Why collaborate in a physical internet network?—Motives and success factors. *Journal of Business Logistics*, *42*, 120–143.

Riches, T. N., O'Brien, P. M., & Network, T. C. I. R. (2020). Can we publish inclusive research inclusively? Researchers with intellectual disabilities interview authors of inclusive studies. *British Journal of Learning Disabilities*, *48*(4), 272–280.

Ryan, R. M., & Deci, E. L. (2017). *Self-determination theory: Basic psychological needs in motivation, development, and wellness*. Guilford Publications.

Schwartz, A. E., Kramer, J. M., Cohn, E. S., & McDonald, K. E. (2020). "That felt like real engagement": Fostering and maintaining inclusive research collaborations with individuals with intellectual disability. *Qualitative Health Research*, *30*, 236–249.

Sergeant, S., Schippers, A. P., Sandvoort, H., Duijf, S., Mostert, R., Embregts, P. J. C. M., & Van Hove, G. (2021). Co-designing the Cabriotraining: A training for transdisciplinary teams. *British Journal for Learning Disbilities*, *49*, 230–246.

Strnadová, I., & Walmsley, J. (2018). Peer-reviewed articles on inclusive research: Do co-researchers with intellectual disabilities have a voice? *Journal of Applied Research in Intellectual Disabilities*, *31*, 132–141.

Terry, G., Hayfield, N., Clarke, V., & Braun, V. (2017). Thematic analysis. In C. Willig & W. Stainton-Rogers (Eds.), *The sage handbook of qualitative research in psychology* (pp. 17–37). Sage.

Thomas, P. A. (2010). Is it better to give or to receive? Social support and the well-being of older adults. *Journal of Gerontology: Social Sciences*, *65B*, 351–357.

Walmsley, J., Strnadová, I., & Johnson, K. (2018). The added value of inclusive research. *Journal of Applied Research in Intellectual Disabilities*, *31*, 751–759.