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Examining People's Experiences of Working in Collaborative Relationships While Conducting Inclusive Research Involving Persons with Intellectual Disabilities

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Abstract: This study examined the experiences of working in collaborative relationships while conducting inclusive research involving persons with intellectual disabilities. More specifically, the study explored work relationships, social relationships, and factors that influence collaboration within inclusive research teams. Interviews were conducted with nine researchers with intellectual disabilities, eight academic researchers, and nine principal investigators who were all involved in six inclusive research projects together. The analysis of the interviews produced four themes: (1) the diverse nature of the involvement of researchers with intellectual disabilities; (2) the significance of involving researchers with intellectual disabilities within academic research; (3) shaping equity in research projects; and (4) stereotyping hindering collaborations with researchers with intellectual disabilities. These findings have implications for research and practice, both in terms of promoting inclusive research and facilitating the meaningful participation of persons with intellectual disabilities within various aspects of society, including education, employment, healthcare, and social activities.

Keywords: intellectual disabilities; collaborative relationships; inclusive research; intergroup contact theory



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1. Introduction

The importance of full participation and social inclusion for people with intellectual disabilities is widely acknowledged and anchored in the United Nations Convention on the Rights of Persons with Disabilities (United Nations 2006). Alongside this, inclusive research, which involves people with intellectual disabilities being empowered to actively collaborate as co-researchers rather than merely serving as the subjects of research, has emerged as an effective strategy through which to ensure that the perspectives of people with intellectual disabilities are represented within policy, implementation, and research (Walmsley et al. 2018; O'Brien et al. 2014; O'Brien 2022; Strnadová and Walmsley 2018). Aligned with Walmsley et al.'s (2018) updated definition of inclusive research, we position collaborative researchers in research projects as researchers, whereby some researchers bring experiential knowledge from living with an intellectual disability, while others have received formal training as academic researchers.

Inclusive approaches foster an environment of equitable knowledge production and sharing between academic researchers and researchers with lived experience (Bigby et al. 2014; Milner and Frawley 2019; Nind and Vinha 2014). Built upon participatory and emancipatory research methodologies derived from the constructivist research paradigm, inclusive research is a specific branch of participatory and emancipatory research within the realm of intellectual disabilities. This approach advocates for the comprehensive involvement of persons with intellectual disabilities throughout all phases of the research process, adhering to the principle of "Nothing about us, without us". Inclusive research, a

concept that gained prominence in the 1990s, aligns itself with broader inclusion-focused developments, such as Social Role Valorization (Wolfensberger 2000). In 2003, Walsmley introduced a foundational strand of inclusive research specific to the field of intellectual disabilities, contributing significantly to the evolution of inclusive research methodologies in this domain.

The focus on reciprocal relationships within collaborative teams is crucial for understanding the shared benefits of collaborating within inclusive research for both academic researchers and persons with intellectual disabilities (Embregts and Frielink 2023). Reciprocal relationships, which are characterized by trust, respect, and mutuality, form the foundation of successful collaboration (Embregts et al. 2018; Sergeant et al. 2022). As such, persons with intellectual disabilities gain increased self-confidence, self-esteem, and a sense of control through actively participating, which, in turn, yields opportunities for skill development and capacity building within the context of inclusive research (Bigby and Frawley 2010; High and Robinson 2021; Sergeant et al. 2022). Researchers with intellectual disabilities have underscored the significance of experiencing full participation, which extends far beyond carrying out core research tasks to instead encompassing the collaborative dynamics of a research team, thus fostering a sense of value and belonging that is constitutive of social inclusion (Fulton et al. 2021). While the competencies and skills that facilitate optimal collaboration have been outlined previously (Embregts et al. 2018), a deeper exploration is required in order to understand both the nuanced experiences of academic researchers and persons with intellectual disabilities and how they navigate such collaborative relationships within real-world research contexts (Chalachanová et al. 2020; Hewitt et al. 2023). This shift in focus emphasizes the pivotal role of reciprocal relationships in driving successful collaboration within inclusive research.

Inclusive research brings together academic researchers and researchers with intellectual disabilities to cooperatively work toward the common goal of conducting research on issues relevant to enhancing quality of life (Walsmley et al. 2018). Within these collaborations, inclusive institutional support from principal investigators, funders, and the broader research community affirms valuing and equally recognizing the diverse contributions of both academic researchers and researchers with intellectual disabilities. Moreover, consciously incorporating and maximizing the key conditions that underpin this approach—frequent and extended contact, equality, cooperation, and institutional support—may serve to further enrich the collaborative relationships and degree of mutual understanding within inclusive research teams (Novak et al. 2011). With this in mind, the present study explores the first-hand experiences of academic researchers, researchers with intellectual disabilities, and principal investigators engaged in collaborative partnerships.

2. Method

2.1. Setting and Participants

The “Gewoon Bijzonder” national program for persons with disabilities in the Netherlands secured funding from the Netherlands Organization for Health Research and Development (ZonMw) for an initial grant call, which would support six research projects. A key requirement of this funding was the active engagement of people with intellectual disabilities as co-researchers. The present study forms part of the seventh research project funded by the “Gewoon Bijzonder” national program, exploring the collaborative relationships between researchers with intellectual disabilities, academic researchers, and principal investigators who worked together on the other six projects. The focal areas of these six research projects encompassed topics such as social relations and technology, living in an ethnically diverse city, healthy lifestyles, self-determination, and participation. These projects took place over a four-year period, commencing sometime between October 2016 and January 2017, and they all had the common objective of generating, disseminating, and applying knowledge that would enhance the quality of life and support for persons with intellectual disabilities. Within each research project, which encompassed multiple studies,

researchers with intellectual disabilities and academic researchers collaborated closely on at least one of these studies.

The present study involved the active participation of at least one researcher with an intellectual disability, one academic researcher, and the principal investigator from each of the six research projects. Given that most of the research projects comprised multiple academic researchers, researchers with intellectual disabilities, and/or principal investigators, a total of 26 participants took part in the present study. Specifically, nine researchers with intellectual disabilities participated (three females; six males) with an average age of 40.6 years ($SD = 12.9$, range 23–63), eight academic researchers (seven females; one male) with an average age of 30.8 ($SD = 6.2$; range 26–43), and nine principal investigators (eight females; one male) with a mean age of 47.8 ($SD = 7.8$; range 32–54). Demographic information was collected through a concise questionnaire that was administered during the interview process.

2.2. Procedure

Subsequent to receiving approval from the Ethics Review Board of [name of university removed for blind peer review purposes] (EC-2017.68), the first author initiated contact with the principal investigators on each project to set up an introductory meeting. This meeting was also attended by two additional researchers who were part of this seventh overall project but not directly involved in the present study. During the meeting, each of the principal investigators explained the objectives and research designs of their respective projects, while the first author clarified the purpose and design of the present study. Following these meetings, all principal investigators received a detailed informational letter describing the data collection process. The first author also sent an email inviting them to participate, which they all accepted. The meetings were then scheduled at their earliest convenience in order to discuss the involvement of their academic researchers and researchers with intellectual disabilities, including the best way to approach them. The potential participants (i.e., the researcher with intellectual disabilities and the academic researcher working together on a project) were then informed about the project and invited to participate, but only one of the academic researchers declined due to their workload. Those participants who were willing to participate were then scheduled for interviews at a time that was convenient for them, which led to a total of 26 interviews being held at either the participants' workplaces or homes.

These interviews, which were transcribed verbatim by a professional service, were conducted between December 2017 and July 2018, approximately one to one and a half years after the start of the research projects. To protect participants' identities, no names were used in the results. All the participants provided their written consent prior to the interview, with the consent form being explained to the researchers with intellectual disabilities using accessible language. No incentives were offered as participation was seen as forming part of their roles in the six included research projects.

All interviews were conducted and analyzed in Dutch, with the findings subsequently being translated into English by the authors and reviewed by a native English speaker. An independent translation of the quotations was performed by a native English speaker who was not involved in the study.

2.3. Interview Guide

A semi-structured interview guide was developed to explore the first-hand experiences of academic researchers, researchers with intellectual disabilities, and the principal investigators engaged in collaborative partnerships. The guide drew upon an existing study by [Novak et al. 2011](#), which was translated into Dutch and adapted to fit the specific circumstances of this study, that is, inclusive research collaborations. Notably, customized versions of the guide were created for each of the three key participant groups: researchers with intellectual disabilities, academic researchers, and principal investigators. This allowed the interview questions to be tailored to the respective roles and experiences of each

type of research partner. The guides primarily focused on illuminating the relationships between researchers with intellectual disabilities and academic researchers, as it is these two groups who most frequently interact in day-to-day collaborative work.

The semi-structured interview guides contained open-ended questions designed to elicit detailed, descriptive responses without introducing bias. The questions probed for various details pertaining to the participants' research relationships and experiences of the collaboration, such as, for example, "How many other colleagues work in the direct environment of the researcher with a disability?" and "Where and with whom does the researcher with a disability have their lunch break?". By adapting a previously validated interview protocol for exploring intergroup contact within the workplace to fit the context of inclusive research, the guide developed here was able to provide a relevant framework through which to explore the on-the-ground experiences of collaborative dynamics and social inclusion from the perspectives of the different research partners. The open-ended question format allowed the respondents to share their perspectives in their own words, thus yielding richer qualitative insights that can help inform the future optimization of inclusive research practices.

2.4. Analysis

A six-step thematic analysis approach (Terry et al. 2017) was used to analyze the interviews. First, two members of the research team thoroughly read through all the transcripts to familiarize themselves comprehensively with the data. In the second step, the first author coded salient phrases within the transcripts to identify key concepts emerging from the data, a process that was subsequently reviewed by a second researcher. Any disagreements over coding were resolved through in-depth discussion and consultation with two additional team members. In the third analytic phase, the coded data fragments were systematically grouped based on their shared similarities in order to begin forming overarching themes. Fourth, the coherence and consistency of these themes were evaluated both internally (within each theme) and externally (between different themes) by all members of the research team. This process, in turn, allowed for the refinement of the thematic structure so as to ensure that the themes were distinct, robust, and grounded in the dataset. Fifth, the emerging themes were defined, named, and discussed with a researcher with intellectual disabilities to gain additional insights. Finally, a comprehensive report was prepared by the authors, including the selection of evocative quotations from the participants to enrich the manuscript.

2.5. Rigor of the Methodology

The methodology of our study incorporates multiple measures to enhance trustworthiness and credibility. First, comprehensive discussions on codes and proposed (sub)themes were conducted among the authors and three additional researchers. This collaborative process aimed to ensure the richness of emerging themes, taking into account a diverse range of perspectives. Furthermore, to validate the consistency and clarity of our coding, a second coder performed coding checks. Triangulation, a key aspect of our approach, was achieved by interviewing various stakeholder groups, researchers with intellectual disabilities, academic researchers, and principal investigators. This methodological strategy not only strengthens the reliability of our findings but also ensures a holistic understanding by considering multiple viewpoints within the studied context.

3. Results

After analyzing the interviews, four themes were identified as follows: (1) the diverse nature of the involvement of researchers with intellectual disabilities; (2) the significance of involving researchers with intellectual disabilities within academic research; (3) shaping equity within research projects; and (4) stereotyping hindering collaborations with researchers with intellectual disabilities.

3.1. Theme 1: The Diverse Nature of the Involvement of Researchers with Intellectual Disabilities

The diverse nature of the involvement of researchers with intellectual disabilities was evident across the various collaborative research projects. While some researchers with intellectual disabilities spent an average of only two hours per week working on projects, others contributed a much more significant amount of time, sometimes dedicating, on average, two to three full days each week. This was in contrast to academic researchers, who typically worked four to five days per week on related research projects. In addition, researchers with intellectual disabilities often did not have a designated workplace or consistent work location within their organization. Next, researchers with intellectual disabilities carried out a wide range of activities and tasks, which were tailored to each project's specific research requirements. For instance, one researcher with intellectual disabilities indicated that they contributed to developing suitable interview questions, while others described participating in data collection through interviews, focus groups, or workshops, along with actively contributing to the writing process and playing a role in shaping the project during the design phase, offering valuable insights and perspectives that enhanced the overall research framework.

On days when the researcher with intellectual disabilities was working, the academic researcher and the researcher with intellectual disabilities most commonly had lunch together. Other colleagues frequently joined them, which, according to researchers with intellectual disabilities, helped to strengthen their sense of belonging with the team of researchers. The mealtimes also provided opportunities for the academic researcher and researcher with intellectual disabilities to casually connect, updating each other on the project as well as their personal lives outside of work. They believed that engaging in discussions about both work and personal matters positively contributed to a greater sense of belonging.

"I bring my own lunch, but I always have lunch with the researcher. But sometimes I have lunch with other people, I don't mind, but I always have lunch with others, which is nice. It adds to a sense of belonging for me. It is also a way to have a pleasant moment, filled with humor. We do that on days I work. We don't see each other outside work."

Besides frequent face-to-face meetings, the researchers with intellectual disabilities stayed connected through regular phone calls, emails, and text messages in order to both communicate about the project and schedule upcoming tasks. However, outside of work hours, the academic researchers and researchers with intellectual disabilities rarely interacted socially.

While some principal investigators tended to remain distant from the day-to-day collaboration, others made an effort to actively engage with the researchers with intellectual disabilities. For instance, one principal investigator scheduled frequent meetings with a researcher with intellectual disabilities to discuss progress, challenges, and goals, both with respect to the project and their own personal development. However, other principal investigators openly admitted to having very minimal interaction with and knowledge about the co-researcher's specific work schedule and contributions. Hence, although not all principal investigators had frequent direct contact with the researchers with intellectual disabilities they worked with, they nevertheless played a crucial role in promoting collaboration and equal treatment within the research project. For instance, according to all parties, most principal investigators actively facilitated the involvement of researchers with intellectual disabilities within both formal and informal team activities and social gatherings, which, in turn, fostered an inclusive team environment. One principal investigator explained it in the following way:

"In an effort to include researchers with intellectual disabilities in daily work activities, I took steps like consulting with academic researchers when we received invitations to give presentations at events. I proposed, 'Hey, I think it would be beneficial for us to participate in this. I believe X [name of researcher with intellectual disabilities] should be involved as well. They are our researchers with intellectual disabilities, so I would

appreciate their participation.' I would bring attention to it by suggesting that they bring along the researchers with intellectual disabilities, without being coercive, but rather by asking."

Within several projects, researchers with intellectual disabilities underscored the pivotal role played by the principal investigator's commitment to ensuring the project's success. They valued the principal investigator's genuine concern for and involvement with all of the team members. Moreover, these researchers saw the principal investigators and academic researchers they worked with not as their superiors but rather as their direct colleagues. In addition, according to the academic researchers, the principal investigators they worked with played a crucial role in terms of both ensuring that they started out from a position of equality and enabling joint decision-making. For example, several principal investigators actively facilitated the cultivation of egalitarian partnerships by taking measures such as translating complex texts into more understandable language, fully incorporating input from researchers with intellectual disabilities, and investing time in relationship-building activities that promoted a sense of belonging between all the collaborators. However, it may not always be flawless, as one academic researcher asserted: *"I believe we approach the collaboration and relationship-building activities with utmost seriousness, and there's a strong commitment from each of us. We are dedicated to it, and we acknowledge that, yes, mistakes happen. Learning is a continuous process for all of us."*

3.2. Theme 2: The Significance of Involving Researchers with Intellectual Disabilities within Academic Research

Overall, principal investigators, academic researchers, and researchers with intellectual disabilities broadly recognized the significance of involving researchers with intellectual disabilities within academic research projects. Specifically, as noted by several principal investigators and academic researchers, they offer a unique viewpoint that can enhance the research process. One academic researcher explained in what ways their perspective was valuable.

"You especially learn how the perspective can also be different. What the average other person's perspective is, you just don't know. You can't assume that if you've learned how it works with one person with an intellectual disability, then it works like this for everyone. Utilising that experiential knowledge in your project expands, as it were, multiplies that experiential knowledge amongst researchers who do not have an intellectual disability."

In addition, both academic researchers and principal investigators greatly acknowledged and appreciated the active engagement of researchers with intellectual disabilities within their respective research projects. This active engagement was observed to significantly enhance the level of collaboration within the team. Several principal investigators recognized the value of involving researchers with intellectual disabilities within research and, moreover, demonstrated their support for the collaboration by dedicating time to engaging in in-depth discussions about project developments with researchers with intellectual disabilities. As one principal investigator stressed:

"What I find most annoying is when I get the feeling of 'oh, are we doing this for the content or just for appearances?'. You simply don't want that. You really want them [researchers with intellectual disabilities] to have a substantive contribution, and I do feel that we have followed that. It gives you a good feeling. People really put a lot of effort into it. Everyone does. Not only the researchers with intellectual disabilities, but also the academic researchers."

Furthermore, both principal investigators and academic researchers underscored the importance of the input from researchers with intellectual disabilities, who were able to directly draw upon their lived experiences, particularly during the foundational phases of research projects, including the design and implementation stages. For example, academic researchers argued that the process of collaborating with a researcher with intellectual disabilities added an extra dimension of diversity and creativity to the research approach and

outcomes, explaining how the partnership allowed for the combining of complementary strengths and perspectives. Several principal investigators emphasized that the contribution of researchers with intellectual disabilities led to research that was more inclusive, pragmatic, and reflective of the priorities of the target population.

Moreover, the principal investigators recognized the potential for researchers with intellectual disabilities to play an important role in the wider dissemination and distribution of research findings to key audiences. Academic researchers highly valued the unique perspectives and experiential insights that were shared by the researchers with intellectual disabilities, deeming them to be profoundly informative contributions that significantly enhanced the practical implications of their study results. Researchers with intellectual disabilities also asserted that they could serve as a direct link to practice, insofar as they are easily able to connect with the target group. However, it is worth noting that some researchers with intellectual disabilities did not feel responsible for the project as a whole; rather, this responsibility was seen as laying with the academic researcher. Indeed, they even went so far as to state that they felt the project could be completed without their involvement.

“Well look, X [name academic researchers] is the academic researcher, and I am the co-researcher. She handles the broad contacts with the projects, something I’m not involved in. Nevertheless, I do receive emails from her, keeping me updated on the projects and what is expected. I collaborate on vlogs, create reports, read, and contribute to trainings. Our tasks are different and not equally important. The academic researcher has the final responsibility for the entire research, as she oversees everything. She does a lot of writing, and although I’ll also co-author an article with her, if I’m not there, the article will probably still be written.”

3.3. Theme 3: Shaping Equity within Research Projects

Both academic researchers and researchers with intellectual disabilities shared the goal of promoting equity in their collaborative relationships within research projects. As part of the pursuit of equity within research projects, they underscored the critical importance of building robust relationships, facilitating open dialogue that encompasses both work-related and personal information, fostering a profound sense of belonging, and demonstrating unwavering commitment. The principal investigators, who were leading the research initiatives, also recognized the importance of promoting equal and harmonious team dynamics. However, according to insights from both academic researchers and researchers with intellectual disabilities, the specific ways in which equity sometimes manifested in practice differed across the teams. For instance, some academic researchers place great importance on establishing an equal foundation right from the outset of a project. For them, equity was rooted in co-ownership over the research and collective responsibility being shared between all team members. Several researchers with intellectual disabilities shared this perspective and felt collectively responsible for the project as well. As one researcher with intellectual disabilities stated:

Yes, . . . Just to be clear, I’m referring to my fellow researcher, I’m not talking about the secretary or anything, but you all think about how you will carry out all phases of the research, that the involvement will be the same.

Academic researchers and researchers with intellectual disabilities understood equity within the context of inclusive research projects as referring to appropriately recognizing persons’ inherent strengths and talents, which then naturally leads to a division of tasks based on complementary areas of expertise. The academic researchers emphasized that researchers with intellectual disabilities were deliberately included within the present research teams, specifically because of the unique personal experiences and perspectives they contributed. According to this view, it is important to actively create conditions that allow researchers with intellectual disabilities to provide input equitably based on their knowledge and capabilities. For example, one academic researcher referred to topics like

advanced statistical analyses, in which they made the decisions, and then subsequently informed the researcher with intellectual disabilities about this afterwards.

“When it comes to complex statistical analysis, connecting it to theory, and engaging in higher-level academic reflection, those tasks are a bit beyond the co-researcher’s expertise. Thus, I do handle different responsibilities in those areas. However, I always make sure to inform the co-researcher afterward and explain our actions to ensure a clear understanding of the work. This communication is crucial.”

Some researchers with intellectual disabilities also acknowledged that there were clear distinctions between the roles of academic researchers and researchers with intellectual disabilities, viewing academic researchers, for example, as being responsible for the foundational study design while positioning themselves primarily as serving in an advisory capacity based on their experiential knowledge. Both parties openly acknowledged and valued these different skills and abilities within their collaboration, which was also reflected in the number of hours dedicated to the project. In the words of an academic researcher:

“Well, in that regard, I think that... yes, we [academic researchers] contribute much more to the project, just realistically speaking, but it’s also logical. For my PhD trajectory, including writing articles, I work four days a week, and we estimate an average of half a day to one full day for the project. And that doesn’t just include preparing for meetings but also writing documents and, yes, everything else that is involved.”

3.4. Theme 4: Stereotyping Hindering Collaboration with Researchers with Intellectual Disabilities

Academic researchers, researchers with intellectual disabilities, and principal investigators all underscored the significance of discarding stereotypical thinking when collaborating within inclusive research. One principal investigator emphasized the significance of involving researchers with intellectual disabilities, insofar as it served as a catalyst for profound self-reflection regarding their own preconceptions of collaborative engagement within inclusive research initiatives. Similarly, some principal investigators and academic researchers indicated that other researchers may sometimes hold unfounded stereotypes toward researchers with intellectual disabilities, including, among other things, assumptions regarding their hesitancy to seek assistance and the misunderstanding that they lack the ability to conduct research, which, for example, is attributed to a perceived difficulty in understanding complex statistical analyses.

According to several academic researchers, holding onto such stereotypes can create a work environment that hinders inclusive collaboration. Researchers with intellectual disabilities themselves shared varying experiences related to stereotyping in the workplace. While some experienced being approached in a childish way, others felt that the academic researchers did not view them through the lens of their disability. Furthermore, they underscored that it was important for both researchers and the broader research community to be mindful that well-intentioned attempts to make persons feel comfortable can potentially be perceived as patronizing, thereby undermining their independence and capabilities.

“Most people in the research world, especially scientists, find it difficult to be honest with people with disabilities. So, they just act all nice and friendly because they think that’s what those people prefer. They do it to avoid hurting them, but in doing so, they don’t take me seriously as a researcher. I wish they would just be honest, even though it’s hard. Not everything is feasible, and it’s okay to say that. When they do that, trust is built, and the atmosphere between me, my colleagues, and the researchers I work with becomes very positive. Being honest, open, and trustworthy makes a big difference.”

4. Discussion

This study explored the first-hand experiences of researchers with intellectual disabilities, academic researchers, and principal investigators who were actively engaged in collaborative partnerships. These insights, derived from participants involved in six inclusive research projects funded by ZonMw, which involved people with intellectual

disabilities actively contributing as researchers with experiential knowledge, may serve to contribute to the continued optimization of inclusive research practices. Conducting a thematic analysis of the interview data generated four overarching themes: (1) the diverse nature of the involvement of researchers with intellectual disabilities; (2) the significance of involving researchers with intellectual disabilities within academic research; (3) shaping equity within research projects; and (4) stereotyping hindering collaboration with researchers with intellectual disabilities. These themes encompass several important findings that will be discussed in turn below.

First of all, the present study underscores the diverse nature of the involvement of researchers with intellectual disabilities within collaborative research projects, encompassing varied time commitments and a broad spectrum of tailored activities. Notably, while researchers with intellectual disabilities were involved in the project design phase in some cases, in the majority of cases, they were not, which is in line with findings from previous studies by [Nind \(2014\)](#) and [Walmsley et al. \(2018\)](#). Drawing on their findings, [Nind \(2014\)](#) and [Walmsley et al. \(2018\)](#) noted that this lack of involvement in agenda setting hinders a comprehensive understanding of their potential contributions. Thus, these authors stress the importance of incorporating researchers with intellectual disabilities into all research phases, including the project design phase. Additionally, it is crucial to recognize the distinct challenges, namely in terms of both time and energy dynamics, that researchers with intellectual disabilities face compared to their “typical” researcher counterparts ([Molina Roldán et al. 2021](#)). Addressing these challenges, as highlighted by [Sergeant et al. \(2022\)](#) and [Molina Roldán et al. \(2021\)](#), is essential for both optimizing their contributions and fostering a supportive and inclusive research environment that values diverse capacities and needs.

Secondly, according to the participants within the present study, inclusive research projects benefit from the involvement of the unique perspectives and experiential knowledge of researchers with intellectual disabilities, insofar as they enhance the research process and findings. Prior research has demonstrated numerous benefits associated with collaborating with persons with intellectual disabilities within their capacity as experts by experience, whether in a researcher role or other positions, such as being an advisor ([Bigby et al. 2014](#); [Embregts and Frielink 2023](#)). Specifically, according to earlier research ([Bell and Mortimer 2013](#); [Nind and Vinha 2014](#); [van den Bogaard et al. 2023](#)), experts with experience with intellectual disabilities reported an enhanced sense of value and empowerment. Similarly, people with intellectual disabilities working as experts by experience in non-research roles, such as trainers, also reported experiencing increased self-esteem, confidence, a greater sense of belonging, and enhanced reciprocity ([Den Boer et al. 2024](#); [Embregts and Frielink 2023](#); [Flood et al. 2013](#); [García Iriarte et al. 2014](#)). These insights are in accordance with the comprehensive synthesis conducted by [Walmsley et al. \(2018\)](#), who analyzed 52 articles focusing on inclusive research projects. Their findings identify three primary areas in which inclusive research generates added value compared to conventional research-led endeavors. First, they drew attention to the distinct contributions made by co-researchers with intellectual disabilities as a result of their insider perspective. Second, their comprehensive synthesis explicitly recognizes these contributions through published accounts. Lastly, inclusive research was shown to enhance the lives of a broader population by addressing their specific needs and challenges. In light of these areas of added value, [Walmsley et al. \(2018\)](#) underscore the significance of inclusive approaches that actively involve researchers with intellectual disabilities throughout the entire research process. Such approaches ensure the accessibility and real-world applicability of research outcomes, with the amount of time allocated to the project being of secondary importance to the depth of their active participation, which, in turn, significantly enriches the authenticity and effectiveness of the research.

Thirdly, the goal of equity within research collaborations is shared by academic researchers and researchers with intellectual disabilities, with an emphasis on co-ownership, shared responsibility, and equitable decision-making from the very inception of projects.

According to our participants, building robust relationships, engaging in open dialogue related to both work-related and personal matters, and fostering a profound sense of belonging and commitment all have a pivotal role to play in terms of establishing an equitable starting point within research teams. To cultivate successful collaborative relationships between researchers with intellectual disabilities and academic researchers within inclusive research teams, Embregts et al. (2018) also found that the unwavering commitment of all stakeholders is of paramount importance. In addition, effective communication, honesty, and respect are shown to be essential for establishing trust, fostering a positive atmosphere among researchers, minimizing patronizing behavior, and cultivating an environment of trust and professionalism (Embregts et al. 2018; Sergeant et al. 2022). Moreover, both the development and maintenance of collaborative relationships are contingent upon a variety of factors, including, among other things, the contextual setting, resource availability, the extent to which the inclusive ideology is integrated within the research institution, and the underlying motivations driving the research collaboration between team members (Frankena et al. 2016; O'Brien et al. 2022).

Finally, the academic researchers and researchers with intellectual disabilities involved in this study emphasize the pivotal role of principal investigators in both championing collaboration and cultivating an inclusive team environment that places significant value on everyone's contributions. Consequently, they play a pivotal role in shaping and sustaining positive contact and interactions within research teams. In this context, the application of Allport's intergroup contact theory (Allport et al. 1954) offers a highly pertinent framework through which to make sense of the interactions within inclusive research teams. The theory postulates that positive contact and interactions among members of different groups, whether majority or minority groups, privileged or marginalized, can mitigate prejudice and enhance intergroup attitudes. However, the realization of these benefits necessitates several optimal conditions: firstly, frequent and extended interpersonal contact to facilitate the development of meaningful relationships; secondly, the establishment of equal status relations amongst group members; thirdly, cooperative efforts toward shared goals that foster interdependency; and finally, explicit endorsement of collaboration and equity by authorities and institutions (Pettigrew and Tropp 1998). The significant role of the principal investigator with respect to the latter is evident. Decades of extensive research have consistently provided robust evidence for the validity of intergroup contact theory across a wide array of social groups and real-world contexts (Davies et al. 2011; Pettigrew and Tropp 2006; Zhou et al. 2019). Given this substantial evidence base, employing the intergroup contact theory as a theoretical framework for future research on inclusive research projects holds considerable promise, insofar as it may help to elucidate the dynamics of inclusive interactions and prejudice reduction.

However, the results of this study should be interpreted in light of some limitations. Firstly, the fact that the funder required collaboration with researchers with intellectual disabilities within inclusive research projects may have discouraged academic researchers and principal investigators from openly sharing their thoughts, such as, for example, feeling compelled to collaborate. In an effort to address this bias, researchers ensured the confidentiality of the interviewees by decoupling participant identities and project affiliations. Secondly, across the six research projects, variations existed in the levels of interaction that the principal investigators had with the researchers with intellectual disabilities. While researchers with intellectual disabilities and academic researchers affirmed the significant role of even those principal investigators with limited interaction in promoting collaboration and equal treatment, a potential study limitation lies in the limited scrutiny of persons' roles within the projects and the extent to which these roles were equitable and rooted in inclusion. We encourage future research to systematically evaluate and address this aspect to enhance our understanding of the dynamics of inclusion in research settings. Thirdly, the present study did not include a researcher with intellectual disabilities from the outset, although one was involved at various stages to aid data collection preparation and result interpretation. Fourthly, this research adheres to traditional structures in that the

principal investigator was in a leadership role. As such, it is important that future research engage with Jones et al.'s (2020) call for researchers with intellectual disabilities to assume leadership positions within inclusive research. Hence, we underscore the importance of future research exploring more inclusive role boundaries, wherein researchers with intellectual disabilities actively lead rather than primarily supporting projects led by researchers without intellectual disabilities.

For research to genuinely embrace inclusion for people with intellectual disabilities, approaches such as conducting inaccessible statistical analyses or engaging in exclusionary everyday research tasks may not be suitable. Therefore, a critical call to action is for principal investigators and academic researchers to engage in closer collaboration with researchers with intellectual disabilities, aiming to entirely reshape the research process and integrate inclusion at every level. To further this aim, in a sister project of this study, training for inclusive research teams was developed (Sergeant et al. 2021). Furthermore, it is crucial to investigate the specific phases of a project in which persons with intellectual disabilities can provide valuable contributions, especially when addressing questions that may require handling larger datasets. For these situations, the Academic Collaborative Center [name removed for blind peer review purposes] has designed a training course titled "Experts by experience in research". This course introduces persons with intellectual disabilities to the process of conducting scientific research. Beyond direct involvement as researchers, another common avenue for contributions from persons with intellectual disabilities is through advisory roles (Bigby et al. 2014). In alignment with this advisory approach, the Academic Collaborative Center has established a scientific research advisory board comprising individuals with intellectual disabilities. Selected for their experiential expertise, these board members provide guidance on research design, recruitment strategies, and data collection methods (Embregts and Beenhakker 2023).

5. Conclusions

In conclusion, despite the acknowledged limitations of the study, our findings nevertheless indicate a clear imperative for targeted initiatives within inclusive research. This emphasizes the critical need for sustained efforts that are specifically aimed at fostering inclusivity and ensuring the meaningful involvement of persons with intellectual disabilities within the field of academic research. By addressing these challenges within the research context, we strive to contribute toward the realization of a more equitable and inclusive research agenda that values the invaluable contributions and overall well-being of all parties involved in the process.

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