Inclusive Research as a Way of Empowering People with Intellectual Disabilities. Reflections of the Training Participants

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ABSTRACT:

The potential of inclusive research has been indicated in many studies. Yet, it is almost unknown in Poland. A group of researchers from two academic centers invited people with Intellectual Disabilities (ID) to participate in a study. The study aimed to undertake inclusive research projects relevant to persons with ID. Prospective co-researchers with ID were offered training focused on issues related to scientific research and improving social skills necessary for playing various roles, including those of self-advocates. A qualitative, interpretive phenomenological analysis was used to explore the co-researchers’ experiences related to the training. Four main themes emerged: 1) circumstances associated with joining the training, 2) benefits of the training, 3) challenges as a researcher, and 4) training needs. The potential of the training was significant both in terms of expanding the psychosocial skills of co-researchers and integrating the group. The data confirmed the usefulness of the training in terms of preparation for the role of a co-researcher and increasing life skills critical in other areas of social life.

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INTRODUCTION

Over several decades, inclusive research has become an essential platform for the social involvement of the population of people with Intellectual Disabilities (ID). By deriving its epistemological, ontological and methodological roots from the critical and emancipatory paradigm (Mercer, 2004), this study created an opportunity for their active participation in expanding the theoretical and practical knowledge of the essence of intellectual disability, its consequence in various areas of life, but above all, the socio-cultural and political and legal factors affecting the quality of life of people with ID and individuals from their closest environment (e.g. Armstrong et al., 2019; Björnsdóttir & Svensdóttir, 2008; Gratton, 2020; Harris et al., 2022; Heerings et al., 2022; Johnson et al., 2014; Puyalto et al., 2022; Tilley et al., 2021; Walmsley, 2014; Walmsley et al., 2018; Zaagsma et al., 2022).

In inclusive projects, persons with ID are involved as active researchers, “instigators of ideas, research designers, interviewers, data analysts, authors, disseminators, and users” (Strnadová & Walmsley, 2018, p. 133). Diversity in terms of independence and control, the participation of individuals with disabilities in the research can be regarded as a specific continuum whose extreme ends are marked by participation and emancipation (Salmon et al., 2018; Zarb, 1992). Given the wide range of the roles and pro-inclusive actions taken by individuals with ID (Bigby et al., 2014), they are the most correctly treated in the categories of an eclectic and epistemologically diverse collective construct covering “a whole group of approaches reflecting a special turn towards democratization of the research process” (Nind et al., 2017, p. 387).

Inclusive research explores “how people understand the social world in which they live. They allow for creating specific theories about it, verifying their usefulness” (Elden & Levin, in Balcazar et al., 2004, p. 19). Joint development of a theory aimed at the best approach to the experiences of people with disabilities allows one to increase their control over specific aspects of their lives, which Elden and Levin (in Balcazar et al., 2004) refer to as learning for empowerment and democratization. As a complex mental disposition, empowerment denotes a conviction/sense of being a causative individual capable of influencing the environment. As such, it accumulates personality traits such as a sense of control, self-efficacy, and expectations regarding the results (Wehmeyer, 1994). Understood as a mental trait, empowerment is a component of self-determination (Wehmeyer, 2004; Shogren et al., 2016). In the context of analyses performed here, empowerment can be understood as a complex process (gaining experience), during which individuals with intellectual disability regain control over their lives, awareness of their rights and needs as well as the factors that limit their fulfillment (French & Swain, 1997). Factors necessary for empowerment include subjectivity, which denotes the fact that it cannot be transferred from outside, given to someone, or planned for implementation during the education or rehabilitation process (Olivier, 1997; Wehmeyer, 2004).

The negative experiences of socialization of intellectually disabled people, with tendencies to discriminate against and stigmatize, generate an adverse self-image and impart a low social status (Barden et al., 2022; Northway, 2001). Participation in the role of a co-researcher can be a platform for developing awareness of one’s situation and motivating one to change it (Kramer et al., 2011; Nind, 2017); it creates an opportunity for increasing responsibility and control over one’s life, interest in issues important for its quality, motivation for actions aimed at improving it (Northway, 2001), which can be regarded as tangible indicators of the co-researchers’ self-empowerment. Empowerment can also be considered in a group dimension when the inclusive project results, used optimally, contribute to reinforcing social status and improving the quality of life of other members of the disabled population (Armstrong et al., 2019; Doherty et al., 2020; Puyalto et al., 2016; St. John et al., 2018). Taking valued roles, such as one of a researcher, can contribute to a change in the social image of individuals with intellectual disability, including the weakening of deficits and an increase in the importance of the potential at their disposal and their rights in various areas of life (Beighton et al., 2019; Georgiadou et al., 2020; Johnson, 2009).

Referring to the benefits gained from the cooperation by the co-researchers who assume this role, Nind (2016) writes about learning in the personal and social dimensions. The former is indicated by (referred to in the co-researchers’ reflections) a sense of self-fulfilment and adaptation to new roles and difficult situations. Less tangible, the social dimension involves the acquisition of social capital, the type of community experiences in which group cooperation is an opportunity for exchanging ideas, transferring skills and knowledge, and activation (Nind, 2016). The role of social learning and empowerment at the group level is significant for self-advocacy (Armstrong et al., 2019; Doherty, 2020; Embregts et al., 2018; Frawley & Bigby, 2015; Gratton, 2020; Lombardi et al., 2019; Owen et al., 2016; Power et al., 2016).
The experience gained so far shows that preparing for inclusive research is carried out by actions structured to a various extent, including training oriented towards specific goals (Fullana et al., 2016; Gratton, 2020; Rojas-Pernia et al., 2020; Strnadova et al., 2014; Tuffrey-Wijne et al., 2020; Watchman et al., 2020; Wołowicz, 2021). It is essential for a training session to cover not only technical skills but also to lead to building relations, with effective communication (using measures ensuring the participation of individuals with lower competencies), cooperation, the awareness of one’s skills and needs, and mutual influence as the essential components (Embergts et al., 2018; DiLorito et al., 2018). The research team is built during the training (Strnadova et al., 2014; Fullana et al., 2016), the participants’ personalities can be enhanced (increasing self-confidence and self-esteem), and their social image in the life environment can change (Tuffrey-Wijne et al., 2020). It is vital to view research activities not only as a means to achieve competencies but also as an opportunity to understand each other's strengths, weaknesses, preferences, and motivations.

AIM

Inclusive research has been scarce in Polish conditions (Kamecka-Antczak et al., 2020; Wołowicz-Ruszkowska, 2017; Wołowicz, 2018; 2021). It is also not an essential tool for the social activity of self-advocates, unlike in other countries, where the movement has stronger roots and a more comprehensive range.

In the current project, the manuscript’s authors (who work in two academic centers) invited people with ID to participate in the study. The study aimed to undertake inclusive research projects relevant to persons with ID. The training concept was based on an analysis of the literature resources, describing the experience of researchers and co-researchers involved in inclusive projects (e.g., Strnadova et al., 2014). The planned study involving individuals with ID was to be long-term (depending on the individuals’ motivation). Hence, it did not focus on any specific subject or method in the research contents area. When planning the training content, attention was drawn to the importance of disseminating the findings in the living environment, which requires knowledge of their various forms, including those adapted to the needs of individuals with cognitive or sensory limitations. Prospective co-researchers with ID were offered training focused on issues related to scientific research and improving social skills necessary for playing various roles, including those of self-advocates. The role of technical competence, important from the perspective of the co-researchers social adaptation perspective, was also taken into account in conducting the research (cf. Strnadova et al., 2014). The bilateral preparation for inclusive research involved eight meetings totaling 17 hours of training for individuals with ID and fully-abled researchers to build a relationship.

The current research aimed to understand the perceptions of persons with ID on the training for co-researchers in inclusive projects in which they took part and the meaning they found in these experiences. This is a one-sentence paragraph. Maybe combine it with the following one.

The analyses performed for this study included seeking the answers to the following research questions: 1) How do the research participants see the training that prepares them for the role of co-researchers in the context of their experiences and the tasks set before them? and 2) What solutions do people with ID propose that could enrich the training and make it more accessible?

PROCEDURE

Cooperation with individuals with ID was initiated in two groups, part of which members were self-advocates from two Polish cities (Lublin, Ostróda), organized in the movement at the Polish Association for Individuals with Intellectual Disability (PSONI). The training participants were recruited through occupational therapy workshops and vocational activity units subordinate to PSONI. The training was preceded by three preliminary meetings at the PSONI sites, which involved the presentation of the aim, assumptions, and planned preparation. The individuals interested in participating in the project gave written consent and established the principles of mutual communication and the meetings’ frequency, place, and time. The presence of the ID and the declared will to participate in the project were the group selection criteria. The participants included individuals with diagnosed light and moderate ID and with motor disorders. The choice of individuals took into account the fact of preserved self-consciousness, which made it possible for them to decide on participation in the research.

Thirteen adult individuals with ID, including four men, participated in the training. Seven of them were self-advocates. Various methods and measures, based on the visualization of issues and simulation of multiple behaviors and situations, were employed while striving to activate the participants’ potential, stimulating their motivation and the maximum exploitation of their life expe-
Inclusive Research as a Way of Empowering People with Intellectual Disabilities ...

Methods
This research is of qualitative character and uses an interpretative phenomenological framework. Researchers’ interests lie in understanding participants’ inner worlds and how meanings are generated and transformed (Smith, 2017). A focus interview was employed as the data-gathering method (Morgan, 1998). It allows for understanding the study object more deeply and going beyond an ordinary description (Barbour, 2011).

Two focus groups of three and seven participants, facilitated by one or two researchers-moderators, were conducted in June 2022. The study was conducted in comfortable rooms located in the Occupational Therapy Workshops. Each of them lasted approx. 1.5 hours.

During the interview, the participants talked about the training in which they had participated, e.g., how they had found it, what they thought about it, what challenges and benefits from it they saw (for themselves, for other individuals with ID, for the community), what they had learned. Guiding questions and prompts to stimulate discussions included: “What do you think about the training?” and “What could we do better to improve the training?”. Interviews were audio-recorded, and notes were taken by one of the moderators.

The ethical issues were important, which everyone noted at every step of the study. Full ethical approval was granted by one of the universities in Poland [details hidden for peer review] before the project was started. Before the focus interviews, which evaluated the experience of individuals with ID associated with the training, their written consent was obtained, including recording and using their statement for scientific research (the consent, according to Rapley (2010), in easy-to-read text). Participants were also de-identified, and a fictitious name was chosen for each. This name and the number indicating the participant’s name were then used consistently throughout the findings.

Data analysis
The data analysis was performed with the approach of the interpretational phenomenological analysis (IPA) developed by Pietkiewicz and Smith (2012) and the steps recommended by them: (1) repeated reading and making notes, (2) transforming notes into emerging topics, and (3) seeking associations and grouping the subjects, (4) writing a narrative report of the study. An analysis was conducted by three researchers (authors of the manuscript) to enhance reliability and trust.

Findings
Four superior themes were identified during the analysis of the material from both focus interviews: 1) the circumstances of taking part in the training, 2) the benefits from the training, 3) challenges in the role of the researcher, and 4) the needs associated with the training.

Regarding the first superior subject – circumstances of taking part in the training – two specific topics were identified: 1) participation of a significant person, and 2) openness to new experiences. Participation of the individuals under study in the training was associated with the indication by individuals from their environment, such as the site manager, the therapist, or a person supporting the group of self-advocates. It is typical in the statements that one describes oneself as the “chosen one” among the other participants. Being a chosen person is ennobling but can also be associated with an inability to refuse a vital person’s request due to formal and informal subordination. A person with a disability may want not to offend a significant person or betray their trust.

I was chosen by Ms Margaret (PSONI Head – Authors’ note). She asked me if I agreed to take part in the training (Sophia, 38).

A significant person not only proposes/chooses but also persuades and strengthens if concerns appear. Her authority is essential to individuals with ID, accustomed to someone else making decisions for them or helping them to make decisions:

Well, at the beginning, I was afraid. I was embarrassed. But Ms Betty said that it was new to me, that we would be doing things at the workshops and what we do, staying at the workshops (Rosie, 40).
Ms Dorothy came and said that she would very much like me to take part. So I thought, all right. I’ll see (Lara, 28).

She (self-advocate group’s assistant – Authors’ note) acted like a catalyst. Because she recruited me to the training. I didn’t know what it was about (Isabella, 32).

The statements on the circumstances of participation in the training contain parts about cognitive curiosity combined with the will to diversify one’s time and gain new knowledge and experience. One can isolate statements that show that some individuals – despite the absence of any knowledge of what scientific research was and what participation in it would involve – wanted to experience something new owing to them:

Anyway, I came and I was there. I wanted to see what it was. […] For a start, it was that the study... I thought... how to put it... that where the Covid drug was from... things like that. Yeah, that was the association. Yeah. Moreover, if it’s about disability, it’s interesting, too (Henry, 40).

Another superior subject concerns the benefits of the training. The benefits from the interviews, as perceived by the participants, included: 1) enriching their knowledge and satisfying their cognitive curiosity; 2) acquiring or improving their skills (digital competence, conducting interviews); 3) improvement of social competence and increase in the impact on the environment (group work, making decisions).

Acquiring new knowledge – as the study participants see it – concerns the content arising from the subject matter of the training (consent to participation in the study, personal data protection, aim and type of scientific research, developing dispositions for the interview, data analysis and presentation of the results at conferences or in publications) and the study subject matter (conducted as part of the classes), associated with the issues of interest and those important to them.

It stuck in me when I asked a person, a friend, if he agreed to recording, which was about independence, I also asked him. Would be like to live in protected houses? Would be like to have married couples? Would be like to get married? Would be like to have children? Does he go to see the doctor? (Sophia, 38).

It became an important source of satisfaction when people expanded or acquired new skills (e.g., writing text messages, saving sounds on a dictation machine, setting up an email account, and writing notes). The training participants represented varied levels of digital skills, and issues related to this area were challenging. It was also crucial for the training participants to expand their skills, e.g., conducting a conversation during an interview. Exercise could reduce the nervousness related to it.

I most liked the interviews. These and those. When someone asked, I did it. I felt free. Because I was learning when I was at the self-advocates’, I was learning how to talk. I was no longer so nervous. And I felt good. If we went somewhere, I could... (Henry, 40)

I liked it when I learned about various areas. What it’s like to talk on the dictaphone (Rosie, 40).

Another group of perceived benefits from the training involved improving one’s functioning in society and improving the ability to make decisions. It became important for our interviewees to affect the study situation. By participating in selecting the subject matter for the interviews, seeking consensus regarding the questions, and working on the interpretation of the statements, or conducting or co-conducting interviews, they became “the initiated” in the study area unknown so far. This may – on the one hand – improve their social position in the site group and – on the other – give them a sense of success. The interviewees were satisfied with their activity and its effects. They took pride in creating something new. An important element in their statement was that they felt that others heard them and that they felt they could affect their environment.

That we could say what we feel about disability presents our plans for the future, and we don't always have this opportunity (…) That we could influence the subject matter, that we had an opportunity to express our emotions and opinions. That everyone wants to hear it (…) We don't have an opportunity to say it, and not everyone wants to listen… (Isabella, 32).

The interviewees saw the importance of building a sense of community, supporting good relations, helping each other, and sharing duties with other study group members:

Because, generally, we are all very close. We are a group, and we work together a lot (Sophia, 38).

Group work or improvement or initiating (some training group members had not known each other before) contacts was an additional source of satisfaction for some interviewees. Owing to participation in the training, they could meet new people (e.g., fully-abled researchers who conducted the training, also from other cities/research
centers, or co-researchers from another city during the online meetings). Overcoming one’s inner limitations, e.g., nervousness before public appearances, became essential to improving one’s self-esteem and well-being.

When I first came here, I was terribly nervous. So first, before I get persuaded to… I must first overcome my own nervousness. It was eating away at me from the beginning [laughs]. That is, fighting off the stress (Isabella, 32).

These conferences and interviews [are difficult – author's note]. Well, I managed to learn to do it. Now I wouldn’t be as nervous as at the beginning. Because now I know (Henry, 40).

The third major topic was identified during the material analysis concerning the challenges in the researcher’s role. Three specific issues were identified within it: 1) challenges associated with the expected competencies in the researcher’s role; 2) anticipating/perceiving one’s limitations associated with performing the role of a researcher; 3) possibilities of facing challenges. The statements show that challenges associated with being a researcher are recognized. Its role and the assigned tasks are seen as highly responsible, requiring one to master many skills and well-organized tools.

Participants see the researcher’s work as:

Very interesting. In my humble opinion. Certainly, it’s not easy. And you are on the researcher’s side. And you never know where to start. There are so many topics that you don’t know what to do first (…) Gather information, not be late, not evade work (…) Oh yes, … publish, in short: everything at the same time (Isabella, 32).

Responsible. We are responsible for everything. For this research (…) Because they [study participants - Author’s note] don’t have to, but they can. (Henry, 40)

It’s difficult because to know what question to ask so that a person wants to answer, can they refuse to answer? (Sophia, 38)

The study participants anticipated or perceived their limitations in the context of the researcher’s role, such as stress and nervousness during interviews. They talked about the fear they felt of other people’s reaction (including the study participants), of potential uncontrolled disclosure of personal data and so-called “sensitive data”, of coping with a range of tasks or betraying the trust of significant individuals (e.g., members of the research team).

You must be careful how you talk to a person so that there are no leaks. You must be careful how you talk so that the person… so that the person you’re talking to does not threaten you with police, that it’s data theft, something like that (…) And this is why you have to be careful what you say to avoid various unpleasant situations. To avoid any conflict with the law (Rosie, 40).

I was afraid to ask some questions. Because you never know what the answers will be […]. This is because when someone is looking at me, I stutter […] And obviously, we wouldn’t like to disappoint you guys (Isabella, 32).

Some individuals mentioned specific skills, which they learned/practiced during the training, and which—in their opinion—are highly complicated and insufficiently mastered. These include operating equipment (laptop, mobile phone, dictation machine), writing, making notes, coming up with research topics, formulating questions, or appearing at conferences. Importantly, our interviewees can self-evaluate their skills, strengths, difficulties, and skills not mastered sufficiently.

This technical stuff isn’t for me. And neither is writing emails (Thomas, 65).

For me – writing text messages. I can cope with reading (Isabella, 32).

I think that writing. Because I write slowly… (Lara, 28).

It’s the same with me as with Lara. I write slowly, and it takes me a lot of time, and I make mistakes. It’s embarrassing… (Isabella, 32).

The study participants discuss the possibility of meeting the requirements, for example, by sharing resources or tasks, depending on their competencies. They bring up the theme of cooperation within the group:

It’s good either way. Because, well, there are more minds in a team. […] In a group, everyone will suggest saying something together. And it’s more difficult when you’re on your own (Henry, 40).

More minds mean more ideas! (Isabella, 32).

The last of the identified superior topics concerns the needs related to the training preparation for the co-researcher role. Here is a fragment of an interview in which the interviewees suggest that more attention should be paid to contact with other individuals with disabilities:

I’d like to learn more – [Author’s note] somewhere with people with disabilities… how to treat people with disabilities? (Sophia, 38)

It’s very important! (Rosie, 40)

How to approach such people? Does one have good contact with those people or not? How to talk to such people? (Sophia, 38)
Not to offend them. Because, for example, some people are ill with very serious diseases, for instance schizophrenia or Tourette syndrome. (Rosie, 40)

Our interviewees suggested more exercises regarding these activities that they find particularly interesting or which – in their opinion – can be helpful in their other actions (e.g., in performing the role of a self-advocate). These are:

- more practical activities in conducting interviews;
- preparing for public appearances and participation in conferences;
- practicing technical skills (recording, using computer programs and equipment);
- ethical issues (concerns related to losing sensitive data or offending a study participant).

All the study participants agreed to participate in the projects as co-researchers.

Well, we learned it would be worth studying. To see if we can manage. And whether they manage to answer our questions (Henry, 40).

DISCUSSION AND CONCLUSIONS

The interviews for this study aimed to discover the potential of training individuals with ID for co-researcher roles and to identify their difficulties and needs. The material obtained from the focus interviews confirmed the tendencies described in the literature on the subject. Like in other studies presenting co-researchers’ reflections, individuals with ID noticed an opportunity to acquire knowledge and skills vital for conducting research and the skills needed in other areas of life in society. Benefits from participation in the training included an opportunity to strengthen one’s position and acquire tools to express one’s opinion (DiLorito et al., 2018; Nind, 2016; St. John et al., 2018). Individuals with ID pointed to the community aspect of the experience and complementarity of skills. Similar categories appeared in studies of people with ID who evaluated the nature of skills needed for participation in inclusive research (Embregts et al., 2018). Positive experience, indicative of an increase in good personality traits (self-confidence and self-esteem), was also described by Tuffrey-Wijne et al. (2020).

Participation in the training empowered individuals with ID, which was indicated by reinforcing/acquiring a sense of having an influence, of being – as Wehmeyer (1994) writes – a person with causative power. This process has been initiated and will probably continue in research projects. The awareness of the role (of a co-researcher) is developing, of its importance and status, but also of one’s limitations, which arise not out of the disability itself but of low or no competence, which the participants did not have an opportunity to develop earlier. Nind (2016) claimed that the role of a co-researcher, like any new life role, requires permanent learning. The approach to this issue is closely linked to the assumptions at the foundations of inclusive research. Recognizing that each project participant contributes experience and knowledge (Salmon et al., 2018), whose diversity is an asset in this research, is a necessary condition for its democratization (Rojas-Pernia & Haya-Salmon, 2022; Tilley et al., 2021; Vlot-van Anrooij et al., 2022). This provides an opportunity for accepting many models explaining the essence of co-researchers’ preparation, mentioned by Nind and co-authors, including the model of practice, the model of lifelong learning, and the model of inequality (Nind et al., 2016). When starting cooperation with individuals with ID, a fully-abled researcher will perform the role of a mentor and a model of desired skills while at the same time gaining new experience. They will participate in the process of continuous informal learning, whose outcome may include an increase in the skills to work with individuals with ID or a change of attitude (e.g., towards recognizing the co-researchers’ potential) (cf. Puyalto et al., 2016; Strnadova et al., 2014; 2016). This approach to preparation for the co-researcher role reduces the risk of paternalism of fully-abled researchers and underestimates the potential arising from diversity of knowledge and experience.

The role of a co-researcher is performed in the social context, which comprises other co-researchers, fully abled researchers, and research participants with a disability. A kind of experience integration takes place, indicated by participants’ statements on the possibility of coping with the challenges of a demanding role. Categories appear here that refer to the awareness of collaboration and complementarity of competence, which demonstrate that the research process consists, in fact, of the cooperation of many entities. One can refer to what Nind (2016) wrote about the social dimension of learning and the beliefs expressed in the reflections of the inclusive project authors. Each participant contributes experience and knowledge, and their diversity is an asset (Rojas-Pernia & Haya-Salmon, 2022; Salmon et al., 2018; Tilley et al., 2021). It is worth addressing the discussion around the usability and justifiability of training for co-researchers with ID (Nind et al., 2016; Strnadova et al., 2016). Walmsley (after Nind et al., 2016) claims that the life experience itself – in this case, associated with the life experiences of individuals with ID – is an asset for research. It is an asset that cannot be compared to the experience of able-bodied researchers.
Inclusive Research as a Way of Empowering People with Intellectual Disabilities ...  

of a person with intellectual disability – does not make one competent enough to take part in inclusive research. One has to possess knowledge and skills. The training these individuals participated in was an integral element of a wider project aimed at the long-term cooperation of fully-abled and disabled researchers. Reinforced or acquired competence is made use of during joint research1. Owing to acquiring knowledge of the tasks associated with the role of a co-researcher, participation in the training provides an opportunity for making a more thoughtful decision on involvement in a research project. This is especially important because the circumstances of the participation indicate the role of significant persons who make the choice. If one sees the training as an initial step for the co-researchers’ empowerment, one minimizes the risk associated with their preference for training by third parties. This risk may also be associated with the properties of functioning observed more frequently in members of this group of the disabled, such as suggestiveness and a lower ability to evaluate the consequences of certain situations, greater helplessness, and susceptibility to being influenced by others.

Embregts et al. (2018) claim that fully abled researchers traditionally design training syllabuses, indicating the need for greater participation of individuals with ID. It is challenging to accomplish given that these people often have contact with the subject matter of the research for the first time. Undoubtedly, experienced co-researchers may have their contribution in this regard. One can observe that training should cover a broader spectrum of competence because each scientific research (in the social science area) is a process in the social context and, as such, it refers to the life experience of the researchers and the research objects – not only scientific but also wider in the case of the former.

This study confirmed, both in the material gathered in the focus interviews and in the research projects, the reasonability of considering its subject matter in a broader dimension, i.e., both oriented towards universal research skills and those useful in everyday life. Strnadova et al. (2016) address the issue and pose the question: Will people with ID be prepared for the role of researchers or specific projects analyzing the areas (issues) of importance to them? One does not exclude the other, and if one acknowledges that the role of a researcher is not a chance one, limited only to a selected event designated by a significant person, but continued consciously, it is justified to be prepared to implement it. A fully abled researcher is preparing for his role similarly (Strnadova et al., 2014).

STRENGTHS AND LIMITATIONS

Focus groups proved an adequate methodology for exploring an under-researched area of preparing persons with ID for co-researchers’ role in inclusive projects. The phenomenological approach enabled a deeper understanding of these people’s experiences in all its complexity and natural settings. Inclusive projects, preceded by comprehensive training involving co-researchers with ID, are relatively rare, so there were strengths in the uniqueness of their experiences. Nevertheless, this research has some limitations. Some participants with ID did not join the focus interviews, potentially excluding other experience categories. Such findings cannot be statistically generalized. Self-selected participants may have been more willing to share their views than those who did not participate in the interviews. Therefore, including all co-researchers who participated in the training would be valuable.

This research indicated the considerable importance of training for future co-researchers with ID. They not only help to develop research competencies but also to increase the awareness of their strengths and weaknesses, to see the need for cooperation, to build self-confidence, and to reinforce the sense of influence over people with disabilities. It appears that training of this type is essential not only to people with ID but also to fully-abled researchers and to the inclusive research in which these people take part. Future research included in the area under analysis here could concern how the co-researchers with ID, with experience in carrying out inclusive research, perceive their preparation for this type of research and the usability of training. This could allow for the effective designing of training to respond to the needs of people with ID.

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DECLARATION OF INTEREST STATEMENT

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1 When this paper was written, work was completed on the project devoted to self-determination of people with ID (a paper, prepared jointly with the co-researchers, was submitted in an easy-to-read format) and a pilot stage was started within the next project devoted to health of people with ID. I would not use a footnote. Add it to your part under limitations

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