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Collaboration in Inclusive Research: Competencies Considered Important for People With and Without Intellectual Disabilities

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Abstract

With inclusive research being an emerging field of interest, there is growing recognition that establishing collaborative relationships between researchers with and without ID entails specific demands. However, since studies on collaboration in inclusive research merely provide individual reports on experiences and challenges in one particular research project, building a shared knowledge base of concrete competencies considered important for those involved merits attention. This study contributes to a shared knowledge base in asking people with and without ID with (experiential) knowledge of inclusive research for competencies they consider important in collaborating in inclusive research in general, that is, without reference to a specific research project they participated in. Researchers with and without ID, coaches, policy makers, and teachers involved in the education of people with ID participated in this study. Data were collected from a focus group, individual interviews, and expert meetings. Qualitative analysis was carried out immediately after each moment of data collection, providing the use of increasing insights in each consecutive phase of data collection. Participants describe that establishing collaborative relationships between researchers with and without ID in inclusive research requires the commitment of both parties. They mentioned concrete competencies they consider important for people with and without ID to collaborate in inclusive research in the categories: building a mutual relationship, communicating, achieving a collaboration in which everyone involved can contribute, being aware of skills and developmental needs, and being aware of impact. Clearly, describing competencies for people with and without ID is not intended to exclude anyone who does not possess these competencies from collaboration in inclusive research. However to avoid "tokenism," this study might contribute to effective participation of people with ID in inclusive research in providing concrete competencies considered important in collaboration.

Keywords: collaboration, inclusive research, intellectual disabilities, participation, qualitative research

Introduction

Despite great advances in participation and social inclusion of people with intellectual disabilities (ID), barriers hindering societal equality, and equal opportunity continue to exist (Association of University Centers on Disabilities & American Association on Intellectual and Developmental Disabilities, 2015). People with ID experience lower levels of participation in society compared to nondisabled people (Verdonschot, de Witte, Reichrath, Buntinx, & Curfs, 2009). To promote more equality, the United Nations Convention on the Rights of Persons with Disabilities aims for the "full and effective participation and inclusion in society" of people with disabilities (United Nations [UN], 2006). One way to ensure people with ID have their views and experiences represented in policy, implementation, and research projects is conducting inclusive research, in which knowledge is developed and shared by people with and without ID (Walmsley & Johnson, 2003). In inclusive research, people are actively involved as participants in research rather than subjects of research. As indicated by Walmsley and Johnson (2003), the term inclusive research includes "research approaches that traditionally have been termed 'participatory', 'action' or 'emancipatory' (Freire, 1970; Reason, 1998)."

In including people with ID as coworkers in research, they will experience feelings of being able to help others (Flood, Bennett, & Melsome, 2012), being valued (Bell & Mortimer, 2013; Nind & Vinha, 2014), and feelings of confidence and increased self-esteem (Flood et al., 2012; García Iriarte, O'Brien, & Chadwick, 2014), all of which stimulate equal and full participation. Moreover, participation of people with ID in inclusive research might also enrich the research process and its outcomes

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by including and reflecting on their experiential knowledge and insights (Puyalto, Pallisera, Fullana, & Vilà, 2016; Woelders, Abma, Visser, & Schipper, 2015). In a review on the active involvement of people with ID in health research, researchers showed that their study was of higher quality, had greater validity and had more benefits for stakeholders when the study was conducted in collaboration with people with ID (Frankena, Naaldenberg, Cardol, Linehan, & van Schrojenstein Lantman-De Valk, 2015).

The extent to which people with ID participate in inclusive research projects may vary from an advisory approach via an initiating and leading approach through to a controlling and collaborative group approach (Bigby, Frawley, & Ramcharan, 2014a). Regardless of the approach chosen, the main focus of inclusive research is collaboration between people with and without ID (Nierse & Abma, 2011). There is growing recognition that establishing collaborative relationships between researchers with and without ID entails specific demands such as awareness of power dynamics (Nind & Vinha, 2014), clarity regarding roles and expectations (Turk et al., 2012), building a trusting relationship (Bigby et al., 2014a; O'Brien, McConkey, & García-Iriarte, 2014; Strnadová, Cumming, Knox, Parmenter, & Welcome to Our Class Research Group, 2014; Walmsley, 2004), and taking into account the risk of overburdening people with ID (Nierse & Abma, 2011; Turk et al., 2012). The (time-consuming) role of preparing and supporting people with ID in inclusive research is addressed as well (Bigby & Frawley, 2010; Richardson, 2000). For example, Turk et al. (2012) provide information on how their research design was explained by using simplified terms and pictures, Bigby et al. (2014b), and Kramer, Kramer, García-Iriarte, and Hammel (2010) describe methods of involving researchers with ID in data analysis and O'Brien et al. (2014) mention the use of free communication software in overcoming travel problems. However, previously mentioned studies on collaboration in inclusive research adopted the focus of providing individual (or project group) reports describing experiences and challenges in one particular research project. Although these studies generated valuable information, building a "shared knowledge base" (Frankena et al., 2015) on how to achieve full and effective participation of people with ID in inclusive research in general merits attention. One such attempt to add shared knowledge to the individual reports and reflections is a study reported on by Nind and Vinha (2014), in which people with and without ID discussed the challenges and possibilities of inclusive research. Based on their outcomes, Nind and Vinha proposed a model with formalized ways of working together at one end of a continuum and improvised ways at the other end, both taking place via support, negotiation, or interdependency. Related features of an inclusive research practice are at times described as competencies, such as "making things accessible" and "being honest." Other features are described less concretely, for example "the importance of talk in research collaborations." Further development of Nind and Vinha's valuable framework on doing research inclusively, might therefore focus on making more explicit which competencies this collaboration requires from which party involved. First, people without ID need competencies to support people with ID to participate meaningfully in inclusive research (Tuffrey-Wijne & Butler, 2009). Being able to provide this support asks for a broad range of competencies possessed by people without ID, addressing observable, measurable and quantifiable skills, knowledge, and attitude (Kaslow et al., 2009). Second, as argued by Walmsley and Johnson (2003) it is also important to identify what skills people with (intellectual) disabilities have, and not to expect them "just to be able to carry out work for which other researchers have had extensive training" (Tuffrey-Wijne & Butler, 2009, p. 177). To avoid tokenism in the emerging field of inclusive research, it is essential to gain insight into the specific competencies that are important for people both with and without ID to adequately collaborate in inclusive research. Therefore, the aim of this qualitative study was to ask people with and without ID with (experiential) knowledge of inclusive research to identify the competencies they consider important in collaborating in inclusive research in general (i.e., without reference to a specific research project they participated in), and thereby contributing to a shared knowledge base (Frankena et al., 2015).

Method

Participants

Since our aim was to gain more insight into the "how" of working together in inclusive research projects, we adopted a qualitative research design (Green & Thorogood, 2014). Data were collected by means of a focus group, individual interviews, and expert meetings (see Table 1). First, we organized a focus group for researchers without ID experienced in collaborating with people with ID in inclusive research. In interviewing them in a group environment in which they were encouraged to share their experiences and ideas, we expected to gain rich output on competencies they considered of importance (Roller & Lavrakas, 2015). We recruited participants by asking senior researchers in the field of ID and the advocacy group for people with ID in (The Netherlands) to indicate name(s) of researchers without ID experienced in collaborating with people with ID in inclusive research. This resulted in the names of 11 researchers who were then invited by e-mail to attend the focus group. Six researchers affiliated to six different universities and research centres, in the academic discipline of social or health sciences agreed to participate. Second, given the importance of tuning to the participants with ID in gaining insight into their experiences and opinions, we conducted individual interviews with them (Roller & Lavrakas, 2015). In recruiting participants, we asked all researchers invited

TABLE 1
Participants

	Focus group	Interviews	Expert meeting I	Expert meeting II
People with ID		6	4	5
Researchers	6			5
Coaches			3	6
Teachers			2	1
Policy makers			2	3
Project leader				1

to the focus group whether they could inform the co-workers with ID they had worked with about this study and to ask whether we could contact them by mail or telephone for participation in an individual interview. Four researchers indicated that they had informed their co-workers, and one of them consented to participate in an individual interview. In addition, we recruited two persons with ID experienced in participating in inclusive research via the (Dutch) advocacy group for people with ID and three participants via personal contacts. We thus conducted individual interviews with six participants with ID with experience in inclusive research. Third, we organized two expert meetings for which we (by mail) invited the researchers who participated in the focus group and the co-researchers who participated in the individual interviews. In addition, we invited policy makers, teachers involved in an experts-by-experience education program (i.e., in which people with ID are educated to deploy their expert knowledge in the support of others), researchers in the field of ID, co-researchers and their coaches via the advocacy group for people with ID, and the senior researchers. In the first expert meeting ($N = 11$), four persons with ID, three coaches, two policy makers, and two teachers participated. Five persons with ID, six coaches, three policy makers, one project leader, one teacher, and five researchers attended the second expert meeting ($N = 21$). Eight participants out of the total of 21 had also participated in the first expert meeting (see Table 1). The only requirement to participate was having (experiential) knowledge about collaboration between people with and without ID. This requirement was set to obtain "lived" experience with this collaboration and consequently reliable input regarding the competencies considered important.

Procedure

Data were collected from a focus group, individual interviews, and expert meetings with only people involved in data collection and participants being present (see Figure 1). Prior to data collection, the study was approved by the Psychological Ethics Committee of Tilburg University (EC-2015.26). All participants signed an informed consent form, stating the aim of the research and funding body. Data were collected by a senior researcher, a co-researcher, and a facilitator.[1] Prior to data collection, the researchers and participants were (at most) familiar with each other based on the joint working area of ID. However, no relationship was established between them.

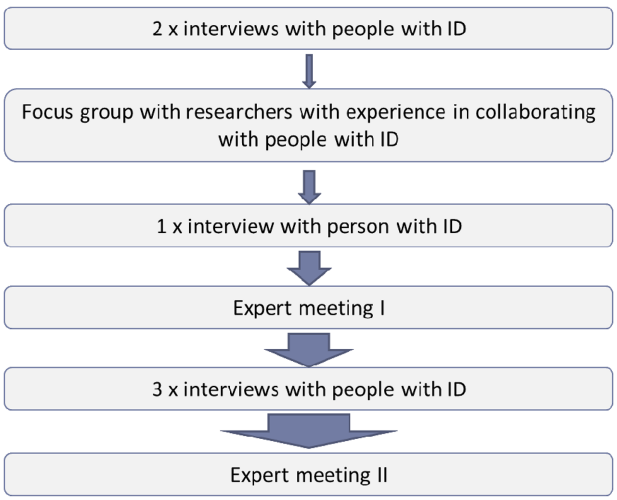

FIGURE 1
Graphical presentation of iterative data collection.

The meeting of the focus group was organized at Tilburg University. In the focus group, the participants brainstormed in smaller subgroups facilitated by (ET and LH) about the competencies that they considered to be important for people both with and without ID to adequately work together in inclusive research. These competencies were written down by them and subsequently discussed with all participants.

In the individual interviews, the participants were asked which competencies they felt were important for people both with and without ID to adequately work together in inclusive research. The interview questions were formulated by the researcher and co-researcher involved in this study (ET, HS). This interview consisted of questions like "What is important to you in working as a researcher?" and "What did you like in the collaboration with the other researcher?" The researcher with ID collaborated in conducting two out of the six individual interviews. In the interviews, participants were asked for examples of positive experiences in collaborating in inclusive research and examples of what they felt could be improved. The interviews took place at a location that was most convenient for the participants, either at home or at the site of a self-advocacy group for people with ID. All interviews were audio-recorded and subsequently transcribed verbatim.

The joint expert meetings for participants with and without ID were organized at a self-advocacy group for people with ID. The focus of the first expert meeting was on the competencies that were considered important for people without ID to adequately work together with people with ID in inclusive research. The participants were divided into three groups, each group consisting of someone with ID, a coach and a policy maker or a teacher. In each group, participants discussed competencies that emerged from the previous methods of data collection (focus groups and interviews with people with ID). They subsequently wrote down a summary of their discussion and were also asked to write down any competencies that they felt were missing. In the second expert meeting, the focus was on the competencies that were considered important for people with ID to adequately work together with people without ID in inclusive research. Data collection was, to a large extent, the same as the data collection in the first expert meeting. However, due to the number of participants, five heterogeneous groups were formed instead of three with the subgroup discussions also being audio-recorded and transcribed verbatim. This verbatim transcription was sent to two participants who asked for it, they did not provide comments and/or corrections to the transcription.

Analysis

Qualitative content analysis (Roller & Lavrakas, 2015) was carried out immediately after each moment of data collection, providing the use of increasing insights in each consecutive

phase of data collection (see Figure 1). Because the researcher with ID indicated that she preferred not to take part in the initial data analysis due to a lack of time available to her, the researcher without ID (ET) started initial data analysis by categorizing the information regarding competencies resulting from the focus group. Next, she analyzed the first three interviews both deductively, according to the categorization resulting from the focus group and inductively, by actively seeking competencies not captured by this categorization. These latter competencies were subsequently added to the categorization scheme based on the focus group. Next, the data from the first expert meeting were first analyzed deductively using the categorization scheme based on the preceding focus group and the interviews with persons with ID. Second, the data were analyzed inductively with additional competencies added to the categorization scheme. Next, the three individual interviews were analyzed both deductively and inductively. Again, additional competencies were added to the categorization scheme. In analyzing the data from the second expert meeting, the audio-records were transcribed verbatim and subsequently analyzed deductively using the categorization scheme. Inductive analysis did not result in any additions to this categorization, indicating data saturation. All analyses carried out were discussed with the the co-researcher (HS), the facilitator (LH), and the supervising professor (PE) throughout the period of data analysis. Participant checking was not included however. Analysis was conducted supported by the software package for qualitative data analysis ATLAS.ti (Muhr, 2005).

Results

Participants mention a variety of competencies they consider important for people with and/or without ID when collaborating in inclusive research. In Table 2, results are presented in five categories, that is, building a mutual relationship, communication, achieving a collaboration in which everyone involved can contribute, being aware of skills and developmental needs, and being aware of impact. These categories include competencies, which hold for people both with and without ID (I). Next, there are competencies considered important solely for people without ID (II) or people with ID (III). In part, the subcategories in the latter two columns are identical, the competencies considered important differ however. For example, the subcategory transferring information is presented as important for people without ID (II) and people with ID (III) but contains the competency "making information accessible by partitioning and repeating information" for people without ID, while containing the competency to "pose questions and request for information" for people with ID. Interestingly, people both with and without ID mentioned the same competencies as important in working together in inclusive research. In presenting the results, we will thus refer to participants instead of differentiating between participants with and without ID. We will include this information only in illustrating our findings with quotations from participants.

Building a Mutual Relationship

Participants describe the importance of building a trusting relationship consisting of reciprocity between coworkers with and without ID. To obtain such a relationship, participants pointed at the ability to take time to get acquainted and to create a safe atmosphere. As a researcher with ID said, "*Professors and researchers need to know me, and know what they can and can't ask someone with ID*" [participant 11]. A researcher without ID described the reciprocity related to getting acquainted: "*To get to know each other first and build a relationship, and that this is perceived as a mutual process*" [participant 2]. Participants mention aspects referring to a basic attitude as fundamental in building a mutual relationship, that is, being respectful, honest, reliable, responsible, motivated, interested, enthusiastic, open, and realistic. A researcher with ID described the importance of being honest as follows: "*If I'm not up for it, I need to be honest and say so to you. You know, I'm not up for it today*" [participant 15].

Communication

Competencies relating to communication skills are considered important for people with and without ID, such as listening and the ability to transfer information. The latter ability is described in more detail for people without ID as consisting of the ability to meet the level of functioning and/or communication of the person with ID, to make information accessible by partitioning and repeating information and the ability to speak in verbal and nonverbal language. As a researcher with ID said, "*Don't automatically think someone gets what you mean, for example by using very short words. Sometimes they use three words and abbreviations and you are completely blank*" [participant 12]. Vice versa, participants mention the ability to pose questions and request for information as important competencies for people with ID. A researcher with ID described, "*If I don't get something, I need to ask to have it explained to me in a different way*" [participant 13]. For people with ID the ability to transfer information is illustrated by a researcher without ID who said "*[they] need to make sure the content of what they want to say comes across, and whether you write something with a 'd' or with a 't' isn't that important*" [participant 29].

Being able to give, ask for and receive feedback are also mentioned as important communication skills for coworkers with and without ID. For example, a researcher with ID said that it was important for people without ID to be able to give feedback: "*A lot of people who work with someone with ID will think that it is hurtful to give feedback. They feel like they are saying there's something wrong with that person. But that's part of learning too*" [participant 11]. Giving feedback is also considered important for people with ID as illustrated by a researcher without ID: "*In my experience it is very important that the person with ID has the courage to indicate what he likes or dislikes, to give feedback about working together*" [participant 1].

Achieving a Collaboration in Which Everyone Involved Can Contribute

Participants mention the importance of achieving a collaboration in which all parties involved are able to contribute.

TABLE 2
Competencies considered important for people with and without ID in collaborating in inclusive research

	I. People with and without ID	II. People without ID	III. People with ID
Building a mutual relationship	- Taking time to get acquainted - Creating a safe atmosphere - Having a basic attitude consisting of being respectful, honest, reliable, responsible, motivated, interested, enthusiastic, open, and realistic		
Communicating	- Listening - Giving, asking for and receiving feedback	- Transferring information: a) Meeting the level of functioning of the person with ID b) Making information accessible by partitioning and repeating information c) Speaking in verbal and non-verbal language	- Transferring information: a) Pose questions and request for information
Achieving a collaboration in which everyone involved can contribute	- Adapting oneself - Contributing to finding solutions, being creative and flexible	- Practising: a) Being aware of allowing people with ID enough time to prepare - Sharing and adjusting: a) Sharing tasks and responsibilities b) Not taking over the lead c) Adjusting the working pace - Structuring a project: a) Structuring information b) Holding and offering an overview c) Planning and setting priorities d) Making clear agreements about goals, roles and expectations - Facilitating collaboration on a practical level: a) Taking into account transport; adequate working space, attainability and accessibility; and resources to provide a salary	- Practising: a) Taking time to prepare

TABLE 2
Continued

	I. People with and without ID	II. People without ID	III. People with ID
Being aware of skills and developmental needs		- Ability to recognize the skills of the person(s) with ID - Ability to assess the developmental needs of the person(s) with ID - Ability to contribute to the fulfilment of the developmental needs of the person(s) with ID	- Willingness to learn and develop themselves - Becoming an expert-by-experience: a) Having insight into one's own competencies and limitations b) The ability to reflect c) The ability to deploy experiential knowledge
Being aware of impact		- Being aware of the role of the network of the person with ID: a) Making contact and collaborating with the network members of the person(s) with ID - Being aware of the project's impact: a) Taking into account the possible intimidating effect of a new (working) environment b) Taking into account the possible impact of the project's subject	- Being aware of the role of the network of the person with ID: a) Preparing and debriefing with a network (such as a coach and/or other support)

According to them, relevant competencies for people without ID include sharing tasks and responsibilities, not taking over the lead and adjusting his/her working pace. The latter category was illustrated by a researcher with ID saying, "*Sometimes she wants to work faster, but I can't go faster. She needs to adjust to me a little*" [participant 13]. In addition, participants describe competencies related to structuring a project as important for people without ID. These competencies include structuring information, holding and offering an overview, planning and setting priorities and making clear agreements about goals, roles, and expectations. According to a researcher with ID "*The study is very big, but every week we discuss what we will do that day. So I don't feel I have to know everything in detail immediately*" [participant 3]. During the focus group, a researcher without ID said, "*I need to be able to divide the process into smaller parts.*"

Next, preparing oneself by practising is considered important for people with and without ID. For people without ID, participants consider that being aware of allowing people with ID enough time to prepare themselves is important. As a researcher with ID said, "*I need to have the chance to read things properly*" [participant 11]. At the same time, participants considered not only getting but also actively taking time to prepare themselves as important for people with ID, as illustrated by a researcher with ID "*Taking time to practise. That makes you more self-confident, you know what to expect before you do it for real*" [participant 10].

Participants mention the ability to adapt oneself, contribute to finding solutions, and being creative as important competencies for people with and without ID during the process of collaboration. A coach described it as "*. . .a process, during a project they'll [people with ID] find out what works and what doesn't work. They need to be able to adapt to that*" [participant 20]. In the focus group, a researcher without ID illustrated the importance of being flexible oneself as follows: "*To be able to take on different roles: coach, researcher, process manager, facilitator, trainer and translator.*"

On a practical level, participants mention facilitating transport and adequate working space, attainability and accessibility, and allocating resources to provide a salary as important abilities for people without ID. As one researcher without ID said, "*If you work as a co-researcher, you are a colleague so you need to be paid for that*" [participant 1].

Being Aware of Skills and Developmental Needs

Participants describe the importance of the person without ID being able to recognize peoples' skills on the one hand, to assess the developmental needs of the person with ID and to contribute to the fulfilment of these needs. In the focus group, a researcher without ID said, "*Ask, what is it that you want to learn? What is important to you?*" On the other hand, participants said that they find it important that people with ID are willing to learn and develop themselves. A researcher with ID said, "*For me it was important to learn not to stick at that one question, but to dare to ask more. That is a skill you need to learn*" [participant 11]. In addition, participants mention competencies captured by the category of becoming an expert by experience as important for people with ID, consisting of having insight into one's own competencies and limitations as well as the ability to reflect and to deploy experiential knowledge. A participant without ID gave the following description: "*That you are capable of saying, this is what I have to offer and this is what I find difficult*" [participant 28].

Being Aware of Impact

Participants considered it important that people without ID take into account the possible intimidating effect of a new environment (e.g., university, location where interviews take place) and the possible impact of the project's subject. As a researcher with ID related, "*You can encounter things that make you feel less happy, things you need to process rapidly. I feel people need to pay attention to that*" [participant 11]. For people with ID the availability of a network (such as a coach and/or other support) to prepare and debrief was also felt to be important. The ability to make contact and collaborate with the network members of the person with ID (such as a coach) was therefore considered important for people without ID. As mentioned by a researcher without ID in the focus goup, "*Collaborating with the social network is a prerequisite.*"

Discussion

In presenting concrete competencies considered important for people both with and without ID in collaboration in inclusive research, we build on the model of Nind and Vinha (2014) "as a [researcher's] tool of thinking with." In our study, participants considered a variety of competencies important in establishing collaborative relationships between people with and without ID in inclusive research projects. First, these competencies reflect concrete competencies to meet the demands of inclusive research as presented in earlier studies. For example, the competencies of structuring information, holding and offering an overview of a project, and planning and setting priorities reflect concrete skills to meet the demand of preventing the risk of overburdening people with ID as described by Nierse and Abma (2011). Second, this study also adds competencies related to the existing body of literature. On the one hand, these add to competencies for people both with and without ID already described, for example, in addition to giving feedback (O'Brien et al., 2014), the competencies asking for and receiving feedback are also considered important for both parties according to the participants in our study. On the other hand, the participants mentioned new competencies, for example, in describing the importance of the person without ID being able to assess the developmental needs of the person with ID and subsequently contribute to the fulfilment of these needs. The importance of the latter finding is underlined by Walmsley (2004) in stating that many researchers are unsuccessful in both identifying the skills of people with ID and assessing the additional skills needed for them to be "effective researchers" (Frankena et al., 2015).

In addition to gaining practical knowledge about inclusive research, Grant and Ramcharan (2007) urge for research on the forms of partnership that make inclusive research effective. In this respect, it is relevant that participants in our study mention being reliable, motivated, and interested as important competencies for both people with and without ID in working together in inclusive research. Participants in our study stated that adequate collaboration between people with and without ID requires the

commitment of both parties. Participants indicated the importance of people with ID to take responsibility and contribute in line with their ability to achieve an equal (working) relationship, for example by saying that building a trusting relationship and seeking solutions are not only important competencies for people without ID but also for people with ID. Describing competencies for people with and without ID is by no means intended to exclude anyone who does not possess these competencies from collaboration in inclusive research. Moreover, it is crucial to stipulate that the competencies that are considered important by the participants are desirable but not always necessary. As indicated by Bigby et al. (2014a) several degrees of participation in inclusive research projects exist, each of them placing varying weight on relevant competencies. Rather, in providing a description of concrete competencies, this study might contribute to providing people both with and without ID the opportunity to develop these competencies in order for people with ID to collaborate fully and effectively. Training and coaching is helpful in developing these competencies. Although knowledge and skills can be trained and tested in a relatively straightforward way, more and more studies are illustrating that attitude can be trained and measured (Hermsen & Embregts, 2015; Vanlaere, Coucke, & Gastmans, 2010), for example, for professionals to develop a stimulating attitude (Van Oorsouw, Embregts, Bosman, & Jahoda, 2014; Zijlmans, Embregts, Gerits, Bosman, & Derksen, 2011) and for people with ID to become an expert-by-experience (Verbrugge & Embregts, 2013). Clearly, the exact content of such training and coaching is dependent on factors such as experience of the (co-)researchers in inclusive research and the degree of participation in the research project. Training and coaching consisting of different modules would optimally contribute to meeting individual experiences, qualities, and interests. However, as in all collaborations, it takes time for coworkers to get to know each other, build a trusting relationship and develop knowledge, skills and attitude relevant for a particular research project. It is, therefore, recommended that people with and without ID take part in a training and coaching programme together. In various papers, experiences with a training programme as part of inclusive research projects are described for example, Strnadová, Cumming, Knox, and Parmenter (2014); O'Brien et al. (2014); Fullana, Pallisera, Català, and Puyalto (2017). However, these training programmes were primarily focused on developing knowledge on how to conduct research and developing research skills, and were designed solely by people without ID (Fullana et al. 2017; Strnadová et al., 2014) or only attended by people with ID (Fullana et al., 2017; O'Brien et al., 2014). Our recommendations extend this to co-workers with and without ID designing and attending a training programme together, as effective inclusive research is also reflected in interpersonal processes and reciprocal relations. This is in line with the results of Fullana et al. (2017) who stated, "group building and teamwork has not been sufficiently taken into account" in their research-training programme for people with ID.

As stated in the introduction, inclusive research is an emerging field of interest. Valuable inclusive research is conducted, in which, in most cases, people with mild or moderate ID are involved as participants (Cluley, 2016). This is reflected in the competencies considered important for people with and without ID in collaborating in inclusive research as presented in this study as well. In furthering the field of inclusive research, it is important to also include people with profound and multiple ID in inclusive research however. The competencies presented here do offer insights in collaborating with people with lower levels of functioning, for example the competencies related to building a mutual relationship, and achieving a collaboration in which everyone involved can contribute will hold for all people with ID. In this respect, using photovoice or arts-based methods to collect data are illustrative for the presented competency "contributing to finding solutions, being creative and flexible." The fact that we did not purposively sample for people with profound or multiple ID as participants in this study ourselves, is a limitation of this study. In addition, results are based on a convenience sample instead of a random selection of participants. We cannot exclude the possibility that a random sample of participants would yield other or additional competencies considered important. Next, we did not include participant checking in our data analysis procedure, that is, permitting participants to provide feedback on the findings (Tong, Sainsbury, & Craig, 2007).

To conclude, to avoid "tokenism" and make progress in the field of inclusive research we need to take into account the individual capacities and interests of people with ID as well as to create circumstances to allow participation in inclusive research to be a realistic option (capability) for people with ID (Pelleboer-Gunnink, van Weeghel, & Embregts, 2014). This study contributes to this approach in describing competencies considered important for people both with and without ID to collaborate in inclusive research.

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Note

[1]The COREQ 32-item checklist (Tong, Sainsbury, & Craig, 2007) is used for an explicit report of this study. Regarding the domain research team and reflexivity, we state that one researcher (ET) has a PhD in Medicine. She was trained in qualitative research methodology at Utrecht University, the Netherlands, and the Dutch platform of qualitative research. She is currently employed at Tilburg University, the Netherlands, as senior researcher in the field of ID. The co-researcher (HS) is educated in an experts-by-experience education program, and experienced in collaborating in inclusive research. She is currently employed at the Dutch advocacy group of people with ID. The facilitator (LH) is experienced in the care of people with ID and is currently employed at Tilburg University as knowledge manager. Both ET and LH work at the Academic Collaborative Center Living with an ID (under supervision of professor P.J.C.M. Embregts) The COREQ-domains study design and analysis and findings are integrated in the body of this paper.

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