Searching for good practices in collaborative research.
A qualitative responsive study about partnerships in teams of researchers with and without intellectual disabilities.

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Abstract

This article focuses on the practice of partnership working in collaborative research teams consisting of people with and without intellectual disabilities and how to manage and navigate the responsibilities that come with these types of research partnerships.
To answer the questions 'How do researchers with and without intellectual disability experience working together?', What is necessary to develop and take care of partnerships in collaborative research?', and 'How could these practices be further developed?', we designed a qualitative responsive study. Five experienced researchers were interviewed, and engaged in several post-analysis dialogues about the findings. In this study we aim to explore the daily practice of collaborative research partnerships, particularly the concept of responsibility towards each other, by drawing on our own collaborative research experience and analysing the joint problems, concerns, conditions and learnings. Findings indicate that the involvement of researchers with intellectual disabilities can depend on the motivations for, and the perceived value of collaboration by the researchers without intellectual disabilities. Good practice is defined as finding ways to foster safe, personal partnerships, and deal with responsibilities like power imbalances on a daily basis. Further development of collaborative research practice requires space to think openly, trust, and an academic environment where vulnerability is accepted. Then research teams can learn more about how to deal with responsibilities, power imbalance, solutions to discrimination and labeling, and about safe partnerships. In that way the benefits drawn from collaborative research can be wider-reaching; benefiting more areas of society than just those being studied in social science research projects.

Introduction

It is well established that people with intellectual disabilities experience inequalities in areas such as health (Department of Health 2008; Emerson, et al. 2012; Heslop et al. 2013; Mencap 2007; 2012). These inequalities are not related to health conditions directly associated with having an intellectual disability but rather due to society's inability to make the adjustments needed to ensure equitable access and outcomes for this group.

Achieving social justice in society requires adjustments to be made that enable all citizens to participate (UNESCO 2012), otherwise, disparities in health and well-being will be fostered, without

working in partnership with those whose lives are the subject of the research its uncertain if the areas studied are pertinent to the need (Schippers; Bakker and Peters 2018).

In social science research, many challenges concerning these mechanisms are still left. For example, research has shown that in the Netherlands one in three people are still excluded from social science research because of learning difficulties, socially vulnerable backgrounds, or a lack of academic or technological skills. Researchers with academic backgrounds exclude consciously or unconsciously by using criteria for participation that leave these people behind (Pharos 2020).

Recently, more academic researchers are collaborating in research projects with people with intellectual disabilities (ID) (Brooks et al 2013; O'Brien et al 2014; Stevenson 2014; Puyalto et al 2016). This type of research is known as participatory research, inclusive research or collaborative research. We have chosen to use the term 'collaborative research' to emphasise that we want to work together using research practices based on equality, in all stages of research projects, from beginning to end. As opposed to letting someone participate with the rest of the team, or be included -meaning they are fitting into something that already exists (Wooster 2009).
This cooperative effort in all aspects of the research design, process, dissemination and impact defines collaborative research in recent literature (Banks and Brydon-Miller 2019; van Asselt-Goverts et al. 2017; Frankena et al. 2015; Nind 2014; Schippers; Bakker and Peters 2018). Therefore collaborative research is often characterised by the self-advocacy principle of 'nothing about us without us' (Chapman and McNulty 2004).

Collaborative research has proven itself to be beneficial for both people with and without ID. First, it enriches the quality of research (Nind, 2014). Recent studies indicate that research participants with ID are more open to researchers who also have intellectual disabilities (Frankena et al. 2015 ; van Asselt-Goverts et al. 2017). Secondly, the likelihood of sustainable use of an intervention increases when stakeholders are involved in the development process during the study (Frauenberger 2011; van 't Veer et al. 2020). Thirdly, literature indicates an enlargement of communication- and research skills of all participants (Frankena et al. 2015), an increase in creativity, flexibility and clarity (Sergeant 2019), and increased empowerment of all participants (van Asselt-Goverts et al. 2017). Literature underlines that this kind of research can make a big difference to the lives of people by giving explicit attention to all voices (Banks and Brydon-Miller 2019).

We believe that equal collaboration in research demonstrates respect for the fact that society consists of different individuals with different abilities as described by Wooster (2009). To us that means that collaboration in research teams requires what the United Nations (2006) described as validation of human diversity, with respect and acceptance as guiding principles.

However, in the practice of collaboration in teams and partnerships of researchers with and without ID, distinctive issues of responsibility, power sharing, the changing roles of researchers, and the partnerships themselves, raise many questions (Banks and Brydon-Miller 2019). Drawing on our own experience we agree with Groot and Abma (2019), who are both experienced collaborative researchers, that the practice of doing research together, and especially the experience of responsibility towards each other has to be made explicit.

The practice of collaborative research partnerships in literature

The literature suggests that one of the most important conditions for successful collaboration practice in research is having a lot of time (Embregts et al. 2015; Schippers; Bakker and Peters 2018). Especially time to get to know each other, to connect into equal power positions, to have open

dialogues about expectations and needs, and to build up safe partnerships with mutual support and shared vulnerability (van Asselt-Goverts et al. 2017). This requires that partnerships in collaborative research teams should be given specific attention before, during, and after the research process. The literature also shows that particular skills and attitudes for collaborative partnerships are considered important (Embregts et al. 2015). These skills and attributes include honesty, respect, asking for and receiving feedback, clear communication, and explaining and asking questions. Frankena et al. (2015) concluded after their extensive review of 28 studies that the anticipation of skills, capabilities, and the preferences of all stakeholders involved is helpful.

Banks and Brydon-Miller (2019) have developed a framework for -what they call- the "ethical practice" in collaborative research. They have listed several guiding principles like mutual respect, ensuring time for active learning, creating positive change, and personal integrity as being essential for building safe relationships. Such a theoretical framework can be a useful guideline to help construct and manage successful collaborative partnerships; but we think that more is likely needed to make partnerships a 'safe haven' in which all involved can practice, experiment, make mistakes and celebrate successes. Like Schippers, Bakker and Peter (2018) we think that therefore, continuous reflection is needed on how to develop and manage partnerships in research for and by all participants as the challenges that arise through the collaboration of people with and without ID are not yet clear enough.

After viewing the literature in the collaborative research field, we decided to design a research study to get a better understanding of the practice of working together, and learn from each other's experiences and perspectives. With this article we aim to contribute to the literature on the exploration of the practice of collaborative research partnerships between people with and without intellectual disabilities, by drawing on our own collaborative research experience in this area and analysing the joint problems, concerns, conditions and learnings.

In the findings, firstly we focus on experiences of partnerships in collaborative research teams, on how researchers work together, and we focus on the degree of involvement of researchers from different backgrounds and experience.
Secondly, we report in our findings on what is necessary to build up and support partnerships in collaborative research, and on how to cope with reciprocal responsibility.
Thirdly, we look at possible future developments.
From there, in the discussion section we elaborate on what counts as good practice in collaborative research: the discussion is based on post-analysis dialogues and literature exploration. Conclusions are drawn on how to anticipate problems in collaborative research teams and respond to them in early stages.

Method

To answer the question of what counts as good practice in collaborative research we drew on our own experiences and stories that we shared of good and bad practice. In this qualitative study about partnerships between researchers with and without ID, we were our own critical respondents. With this we embrace a radical way of learning and working together and drawing conclusions of good practice for other collaborative research teams.

We designed a qualitative and responsive study (Abma; Nierse and Widdershoven 2009). Firstly, the first author, who just started working as a collaborative researcher, interviewed the other authors who are researchers with different knowledge and experience backgrounds. By focusing on degrees of involvement of researchers in collaborative research teams, the emphasis lies on the different experiences of partnerships rather than on the difference between academic or experiential background. Secondly, we engaged in several post-analysis dialogue sessions with each other. During the sessions we acted as partners and shared decision-making power. By engaging in the dialogue sessions we constructed the meaning of findings, as mutual learning processes by sharing our thoughts, feelings, and hopes for the future.

We are researchers with different knowledge and experience backgrounds, with and without ID, some with a lot of experience of collaborative research, and others with limited experience. We are involved in projects on using ID experiential knowledge, social justice and inclusion for people with intellectual disabilities, and in developing training and coaching for collaborative research teams.

Between May and July 2020 five semi-structured qualitative interviews were undertaken with the use of an interview guide lasting for 60 minutes. The interviews were audiotaped with the participant's consent and transcribed literally.

1. The interview focused first on the respondent's experiences as a researcher in collaborative research. How do they work together in the research team? How do they experience this partnership? How do they describe the different ways of involvement from different backgrounds et cetera.
2. What is necessary to develop and take care of partnerships in collaborative research? How to cope with responsibility?
3. Finally, we asked about current problems in collaborative research practice, and posed the so-called 'desires question': suppose you could look five years ahead, what would be the best practice version of partnerships in collaborative research? And, how could these developments be fostered?

The first author analysed the content of data by open and axial coding (Verhoeven 2020). In two rounds we member checked the analysis and categorisation. In this process, the data was divided into manageable units for purposes of data reduction. Characteristic statements of the interviews were highlighted and the specific wording and phrasing of significance assigned a code. Some of the codes included in later analyses were generated based on interview questions (i.e. selective-deductive) while other codes were generated based on the data itself (i.e. open-inductive).
After the first findings based on the interviews were presented, we critically discussed the findings in three post-analysis dialogue sessions. In different combinations of our research group members we discussed what they may mean in the practice of doing collaborative research to gain a rich, multi-layered understanding, and to discuss our own paradigms. We chose that approach to learn from each other and to take the discussion a step further than the interviews would allow us to. Memos of the post-analysis dialogue sessions were kept by the first author and included in the writing of findings and discussion.

In Table 1 the main categories and the associated codes of the interviews are presented.

MAIN CATEGORIES	CODES

Part 1 Experiences of partnership in collaborative research	1.1 Degree of involvement in collaborative teams differs 1.2 Unsolved problems: power imbalance
Part 2 Developing and taking care of partnerships	2.1 Search for and investment in mutual connection 2.2 New responsibilities
Part 3 Future developments	3.1 Today's problems 3.2 Views on developments

Table 1: Main categories and codes

Procedure and reliability

We performed our content analysis as a mutual learning process based on a general inductive approach. The aim to discover experiences and building up partnerships was guided by methodological notions of being a responsive and mixed research team (Abma; Nierse and Widdershoven 2009).

Though, to ensure sufficient reliability we took the following steps:

1. Establishment of an interview protocol as each other's 'critical peers' and discussed how personal ideas and assumptions could influence the interpretation of data (objectivity).

2. A pilot interview was conducted before the interviews.

3. A final interview guide was drawn up based on the feedback.

In addition, coding consistency checks were conducted by independent parallel coding, by checking of the clarity of categories and by iterative member checking.
Subsequently, in three analysis sessions, we discussed findings together: codes and categories were jointly determined. Three of the authors were each other's 'critical peers' when analysing the data. The results were fed back in dialogue sessions and critical views on the findings were asked (internal validity) (Van der Donk and van Lanen 2015). The integration of the post-analysis dialogues was member checked again.

Findings

In this section, we present the original coding and categories of the interviews. A qualitative summary of the results is presented alongside what the respondents judged to be the most important per code.
In Part 1, the experiences of partnerships in collaborative research are presented. First the degree of involvement of researchers with experiential knowledge in collaborative research teams (1.1); and second experiences about unsolved problems of power imbalances in the coalition (1.2).

In Part 2, how respondents build up and take care of safe partnerships in their collaborative research projects. This category contains two codes: search for and investment in mutual connection (2.1) and new responsibilities (2.2).

In Part 3, we focus on what respondents' views on the current problems (3.1) and potential developments for the future (3.1).

Part 1, How do researchers with and without intellectual disability experience work together?

Experiences of partnership in collaborative research

1.1 Degree of involvement in collaborative teams differs

The study indicates differences in the degrees of involvement of researchers with intellectual disabilities in projects that were considered collaborative by the respondents. In two projects that we heard about, the researchers with intellectual disabilities were involved in all steps of the project's development because of their knowledge of the research subject. Those with intellectual disabilities, and those without worked together in partnership, sharing power and responsibility for the work. In the third project, researchers with intellectual disabilities were, especially in the beginning, only involved as a representative of people with intellectual disabilities; participating in small parts of a project as a kind of bystander to the research team. Their participation made a subsidy for the project possible. For example, a project about people with severe intellectual disabilities and their families, where a researcher with a mild intellectual disability was included in the team to satisfy the requirements of the organisation that was funding the research project. The respondent said that in the beginning her team "*did not look at what his talents were. We just came up with 'well that will be your role'*." The researcher with ID addressed that she and her colleagues with disability experience are often still "*kept too short*" by their colleagues without intellectual disabilities. Too often people with intellectual disabilities are only seen as an advisor from the outside instead of being a full member of the team.

A desire to ensure the full involvement of all was reported in the interviews. In the project with the researcher with a mild intellectual disability who was not actively involved, the perspectives he brought into the focus group interview were valued afterward. The respondent said that at first, the team thought that

> *he disturbs the process [of data collection]. [But] ultimately, when I listened to the audiotapes of the focus group interview, there was also a kind of twist in the conversation, which gave me new perspectives.*

This respondent said that she will continue doing collaborative research in the future because of that experience, but that she had learned that the involvement of all needed to be invested in from the beginning.

According to the researcher with ID, achieving a higher degree of involvement requires training and coaching for all members of research team, as old patterns and habits need to be addressed and new ways of working together need to be learned. She emphasised that the process towards full involvement means a process of not only working together but also learning together, how to work together.

1.2 An unsolved problem: power imbalance

The study demonstrates that balancing power in partnerships was of central concern for all researchers when they were asked about the 'good practice' of working together. Respondents mentioned the term *power* and related terms such as *equality*, *equity*, *sharing instead of hierarchy*, *acting together*, *feeling equal*, and *learning together to do it 'right'*.

Respondents described power imbalance in the partnerships as a problem that is not easily solved. They gave examples, like that they *"had to manage an always existing sort of imbalanced power by nature of people's intellectual disabilities"*. Even experienced collaborative researchers have problems finding ways to balance power cooperation. Researchers reported that their colleagues with intellectual disabilities are sometimes still seen from the perspective of *"being someone with intellectual disabilities instead of being someone with a different kind of knowledge and talents"* by different stakeholders in the field of social science.

Some respondents indicated that power imbalances can also exist for researchers with intellectual disabilities, by internalised prejudice of not being able to do things. For example, a respondent said that, *"all of her life others told her what she can or cannot do, and that she had to learn in a difficult and painful process to take agency and responsibility in the research process"*. Many examples were given in the interviews by researchers without intellectual disabilities about their colleagues with ID asking 'permission' of them to do things, that they themselves would do without question. Examples included: *"asking permission to order a beer in the pub after a conference"*, *"asking if it is possible to order a steak in a restaurant during a team dinner"*, and to *"get permission to offer a tea bag for a cup of tea"*.

According to the respondents they deal with power imbalance in different ways. In projects where there is a high degree of involvement from everybody, the researchers without intellectual disabilities, firstly *"encourage"* their researcher colleagues with intellectual disabilities *"to take resolute"*, they *"confront them with behavioral patterns"* to help them reflect on them, they *"verbalise mutual responsibilities and needs"* to gain more equal power positions, they *"take care of working conditions of their colleagues"* to help them gain an equal financial position. Secondly, they reflect on their own behavior, like for example the respondent who said that she keeps reflecting on *"am I doing the right thing to balance power between us?"*. The interviews indicate, thirdly, that researchers ask questions about a fair share of tasks, roles, and responsibilities. Questions are for example: *"do we have to do the same work?"* And, *"do we have the same responsibilities?"*. One respondent said for example that her research team

> *wanted to keep it as equal as possible. Some of the team members thought equality means that everyone does the same thing. For example, we have already done something in the Atlas.ti program. But I said, "I think Atlas is quite a complicated program, which does nothing but highlight text." Why would I teach [the researcher with intellectual disabilities] the program completely? Is this of much use to us? And then everyone in the team said 'if he has to put it on paper, then we will do it too'. And then I said, "Oh, are we?". I don't feel that we have equality then if everyone does the same thing. (. . .). I think you should talk about and agree in advance: What do you consider collaborative? And what does equality mean?*

Another aspect that emerged from the data is that the researchers with intellectual disabilities can tend to act submissive at the beginning of a career as a researcher; but learn to take up more power

during the working process. As a respondent said that *"it was by working as a researcher that I learned for the first time in my life to take initiatives, to verbalise needs and wishes, and to dare to take up space"*.

The study shows that the experienced collaborative researchers define good practice as a continuous process of finding ways to foster personal connection and equal research partnerships. Researchers with ID reported that learning to know each other well from a personal side helps to develop safe connections, and opens up space to deal with issues of mutual responsibilities, fears, habits, imbalances of tasks, risks and power. Another researcher added that

> *we are not yet used to work together in all steps of research and because of that, we have to learn to cooperate, we must take risks by letting go of power control, and we have to share responsibility. To do so, all of these issues have to be discussed many times, and protection -like emotional protection- to all must be provided. Is it easy to share power? No, it is not. Continuous reflection is needed on how to develop and manage partnerships on an equal basis.*

The interviews and post interview discussions show that a lot of time and courage is needed to adopt open communication about the collaboration itself, and for each individual to voice what they need from each other. According to respondents, these moments can be hard as old patterns get frequently addressed.

One of the respondents summarised her perspective on power imbalance by saying that *"you cannot solve this problem, you can only deal with it on a daily basis by reflecting, taking care of each other, and communicating about the collaboration"*.

To summarise Part 1, how researchers with different experiential backgrounds work together in collaborative research, we found that there are different degrees of involvement for participants, ranging from an advisory role of someone with ID to full involvement of all in all steps of the research process, alongside a recognition of the different fields of knowledge. The degrees of involvement of researchers with intellectual disabilities can depend on the motivations for, and the perceived value of collaboration by the researchers without intellectual disabilities. The perception of the reasons for, and the value of collaborating can make a difference in how partners work together. There is a tendency of increased motivations for-, and valuation of full involvement in collaborative research.

Power imbalance appears to be biggest challenge of working together. This imbalance is a problem that is not easily solved, but is dealt with in different ways on a daily basis. Researchers without intellectual disabilities encourage their colleagues with intellectual disabilities to reflect on their behaviour. Researchers with ID learn to take up more space and power during the working process. Therefore, sharing power in collaborative research is a process of dealing, daily, with issues of collaboration and personal relationships by developing and taking care of research partnerships.

Part 2 What is necessary to develop and take care of partnerships in collaborative research?

Developing and taking care of partnerships

This second category contains two codes: search for and investment in mutual connection (2.1) and new responsibilities (2.2).

2.1 *Search for and investment in mutual connection*

According to the respondents in this project, building up and taking care of partnerships between researchers with and without intellectual disabilities can be considered an "*intense process of growth that needs a lot of time, patience, and attention*".

Several topics were found about the fundamentals of developing and taking care of 'good' partnership practices. Firstly, the respondents highlighted 'safety'. Respondents said that feeling safe in the mutual connection is crucial. For example, a respondent said

> *to let the cooperation run smoothly, there has to be safety to build a good partnership with each other. And then all those other things will come naturally, because that's where it starts, with safety. Feel the security to be able to indicate your limits. If you feel comfortable and safe, you can also take the space to bear responsibility.*

There was limited data about how safety can be developed in the beginning to foster mutual connection, but some of the interviews indicated that researchers got to know each other very well, learning a lot of personal information about each other's lives and history. In most cases a lot of time was spent learning about each other's talents, strengths, and difficulties.

A researcher with intellectual disabilities highlights that it helps to know each other's history, for example, education and work history. She said that *"it helps to know what qualities can be pinpointed in that history, and where the partners feel vulnerable in collaborations"*.

Secondly, the interviews indicate that developing and sustaining partnerships requires a willingness to make mistakes and learn from this. One respondent said *"you know that things will go wrong. (. . .). Because you need to give up old patterns of thinking and doing. And you don't know how to act in the new ways of doing research together".* Learning to work together and to engage in long term collaborative partnership can, according to the respondents, be an "*intense and harsh process*".

Thirdly, open communication about the division of tasks, the roles in projects, mutual expectations, and how colleagues work together is needed. One of the respondents said:

> *What goes well in our collaboration is that my colleague who experiences intellectual disability, and I can complete each other very well and that we can make good agreements with each other. We tell each other what we like and what we don't like, indicate our limits about what we can or cannot do. (. . .).*
> *In every phase of the research, every time, we look at how we are going to do things.*

The study shows that although well developed, safe collaboration partnerships of researchers with and without ID can be an *"intense and harsh process"*, researchers are willing to learn and invest in the necessary personal, mutual, caring connections to make the collaboration successful. According to a researcher with ID, good partnership connections increase over time as *"partners learn more about each other and build up a history together"*.

2.2 *New responsibilities*

The study shows first that collaboration between researchers with and without intellectual disabilities can bring new perceived responsibilities about the wellbeing of colleagues, because of the longitude and personal connections in the partnership. Team members without intellectual disabilities may want to protect their colleagues with intellectual disabilities. They reported for example, that they "*protect their colleagues from disappointments*", help "*to find new jobs after the research project*" and "*make sure that colleagues didn't lose their benefits because of seasonal*

payments for the research project". Colleagues with intellectual disabilities report they want this support and care to work in both directions within the partnership because (collaborative) research can be tough, unpredictable and pressure in academia can get harsh.

These new responsibilities in research teams create additional challenges that need to be faced. One respondent said that she feels responsible to her colleague with ID in a more profound way than she feels for other colleagues. She said

> *I feel concern for my colleague [with an intellectual disability]. We worked well together and at one point she said, "I hope there won't be a time when we have to say goodbye". That sentence touched me deeply. And then I started to investigate my responsibility in this. And what's at stake for her. She wants to move forward with research work. Then I thought that I can make additional project requests so that she can stay in our project even longer. (. . .). However, I wonder if I have behaved too much as a counselor rather than a colleague by taking care of her in that way.*

This shows how the researcher tried to help her colleague to a better position in work and life but by doing so, she then considered if this had the potential to disrupt the power balance in their partnership. The sense of responsibility for her colleague coupled with the awareness of the potential for an unequal balance of power in the working partnership creating conflicting and competing dilemmas.

At the same time researchers without ID also shared that sometimes they too need support from colleagues. Researchers with intellectual disabilities report on the importance of reciprocity of support.

Secondly, the respondents reported new perceived responsibilities relating to openness and readiness in the research team for researchers with intellectual disabilities. For example, responsibilities relating to the preparation of the collaboration, how to welcome new team members, and the conditions that can make a collaborative project successful:

> *Two researchers with intellectual disability experience work in our team. I think that we have not paid enough attention to what it means to us in the beginning.*
> *(...). Some colleagues have said: I wish I had an instruction manual from [x], then it would have been much easier for me. I find it very strange when you say that. We don't have manuals from another, do we? But I understand what she meant. It is assumed that [x] will be one of your colleagues with full participation. But we did not discuss the preconditions of participation at all. I think you should talk about the conditions to let [x] be and feel welcome in our team.*

However, while the above response suggests a sense of responsibility to include people and make the project accessible it does not foster a sense of inclusion, rather a team attitude of 'them and us'.

From the perspective of the researchers with intellectual disabilities, this can mean they experience a profound responsibility toward themselves. One respondent gave an example:

> *I have to think about how I can ensure that I can survive in that research world. How can I develop so that I can also progress and participate in more things? That is why I also take an English course. I want to attend conferences without the need of someone who constantly translates. So developing that responsibility of yourself is up to you. And to take the responsibility that I also*

have, to take initiative for what I can do, that everything does not end up with someone else [the work has to be done by someone else]. ... I must unlearn the old pattern of behavior.

This shows that this researcher feels responsible to adapt to the existing research environment to achieve collaboration. This suggests a contradictory parallel where researchers without intellectual disabilities perceive that they belong in the research environment and strive to include those with intellectual disabilities, rather than adapt and reinvent ways of working to accommodate shared ownership of the work and work environment.

To summarise part 2, we found that to develop and take care of partnerships in collaborative research requires an investment in personal connections and to developing and taking care of safe partnerships. Willingness to learn together and building up a history, and intense working processes with open communication is important.
In the partnerships all team members have to face their perceived responsibilities towards each other's wellbeing that can, create dilemmas about power balances or create an attitude of 'them and us'. To invent ways of creating balanced power in partnerships in collaborative research, alongside dealing with perceived responsibilities appears to be the biggest challenge faced.

Part 3 How could these practices be further developed?

Future developments

In Part 3 we focused on the respondents' views on the current problems in collaborative research (3.1) and desired developments (3.2).

3.1 Today's problems

Before talking about the problems and desired developments in the practice of collaborative research, the respondents talked about how proud and happy they were about what had been achieved so far. They reported that they had learned to explore and gain new, rich perspectives and new, unusual insights on the subject of research projects, and what it means to work together. They reported that they were confronted with insights they never thought of, or that only become apparent later in the research process.
The enthusiasm of respondents about collaborative research was evident. According to respondents, collaborative research is "*bloody awesome*", and provides "*totally new insights*".
Even in projects where the partnership was not easy in the beginning, respondents report that they "*found it interesting to be able to do it together. And [that] it did yield a lot as it does provide a lot of new insights*". And, "*during interviews, my colleague who experiences intellectual disability feels the atmosphere and what is going on very intensely, because of [his/her] disability experience. Afterward, we talk about that: "how was that situation for you?", "What did you notice?". "And that is so useful to us".*

The biggest problem reported by the respondents is that researchers with ID are too often still seen as a member of a category: a person living with intellectual disabilities and not as a researcher with different characteristics, knowledge, and experience that can complement a team. An example given by a respondent was:

We had to involve someone with an intellectual disability [because of financing demands] and we just did that, but in fact, we never really thought carefully if that has a valuable influence on the subject. (. . .) However, our research is about people with severe intellectual disability experience and we now doubt whether we have done well to involve someone with mild intellectual disability experience. Because the person has no idea what a severe intellectual disability experience means, too. Afterwards, we thought, perhaps we would have been better off involving a family member in our team. Who then perhaps has a little more insight into someone living with a serious intellectual disability.

This example again highlights that involvement of researchers with ID can sometime be tokenistic, to meet the study criteria and that they are regarded as a representative of a category/group only. This can lead to situations where the talents and abilities of that particular person are not seen and deployed. The researcher with an intellectual disability highlighted that she and her colleagues with intellectual disabilities are still "*kept too short*" by their colleagues without intellectual disabilities. She said that too often they are only seen as an advisor from the outside, and suggested that training and coaching about collaboration is needed for the whole team before and during research projects to address power balance and drive equal involvement forward.

Another issue that was raised by different respondents, both with and without intellectual disabilities was the reaction of people outside of the research team that can make them feel insecure about their work. For example, one researcher with an intellectual disability reported that a lady being interviewed by her kept asking when the 'real researcher' would show up. Many examples of negative attitudes were given. One respondent without intellectual disabilities shared the following story:

Some people frame me as 'the researcher who works with people with disabilities'. This feels like a 'label'. Moreover, I engage in creative research approaches to make research more inclusive. This sometimes is perceived as 'less quality research' in the academic world.
When I am with my colleagues with experiential knowledge, I sometimes feel that other researchers don't approach us. Is that because of the uneasiness this evokes in them? I wonder…

The examples show that internally and externally there are problems of labeling and discrimination against researchers with ID and those without who work in partnership with researchers with ID that need to be addressed.

The respondents agreed that further development of collaborative research practice of researchers with and without ID is needed. Firstly, to be able to anticipate problems in their own partnerships and teams, and secondly, to consciously take up more space in the social science academic world.

3.2 Views on developments

The study addresses that the respondents' views on future developments of partnerships are related to the context in which they operate. The researchers long for "*more credibility of collaborative research in the academic world as a complementary way of doing science"*. They need more space to think openly, trust, and an academic environment where vulnerability is accepted. Within the available space, there is still much learning for researchers to improve collaborative practice. An experienced researcher said that *"we are not yet used enough to work together in all*

steps of research and because of that, we have to learn to cooperate, to take risks, share responsibility and balance power."

According to the post-analysis discussions, "*Investing*" and "*learning*" seem to be the two most important aspects of the development of collaborative research partnerships. In the context of this study, investing means that *"more long term partnerships should be created in which researchers can work and learn together by collaborative reflection"*, and by an investment in collaborative research skills development. Learning adds to the investment in the continuous exploration of a failure free, safe environment where all partners can practice , express and share expectations, insecurities, needs, hopes, feelings, boundaries, and ambitions without losing face.

Key learning indicated in this study is that collaborative reflection on the partnership, and research skills make it possible to find new ways of including an even richer spectrum of researchers with intellectual disabilities in research teams. One respondent said about her hope for future improvement:

> *In five years, I hope that new ways of conducting research have been found, which make it possible to expand the collaborations into partnerships with researchers who experience intellectual disability who are excluded until now. Like people who cannot speak. (. . .) and that the academic context in which the partnerships function becomes more human and caring to be able to be open to and vulnerable in the new ways of working together.*

To summarise, we found that researchers highlight the problem of labeling and the discrimination of researchers doing collaborative research. This problem can occur both inside and outside of research partnerships. To develop collaborative research practices the researchers need space to think openly, trust, and an academic environment where vulnerability is accepted. So they can learn more about how to deal with responsibilities, power imbalance, solutions to discrimination and labeling, and about safe partnerships. Key to developments are investment in collaborative research skills in teams, and continuous reflection on how to develop and manage partnerships in research for and by all participants.

The learning and investment could contribute towards insights about how to anticipate problems in collaborative research teams and how respond to them earlier in the process.

In conclusion

Currently, researchers with and without intellectual disabilities work together in the relatively young field of collaborative research with different degrees of involvement. Involvement of researchers with intellectual disabilities in all aspects of the research design, as described in the literature (Banks and Brydon-Miller 2019; van Asselt-Goverts et al. 2017; Frankena et al. 2015; Nind 2014; Schippers; Bakker and Peters 2018) is not guaranteed in practice. Equal involvement can depend on the reasons for, and the perceived value of collaborating by the researchers without intellectual disabilities. The principle of 'nothing about us without us' (Chapman and McNulty 2004) is not always characterised in collaborative research projects.

Sharing power and responsibility on an equal base seems to be the shared ambition but also the main challenge to achieving 'good practice' as defined in this paper. Issues of power balances are not easily solved but are dealt with in different ways. Researchers without intellectual disabilities often encourage their colleagues with intellectual disabilities to take up power and be decisive, as

well as continually reflecting on their behaviour. Researchers with intellectual disabilities learn to take up more power during the working process through the encouragement of their colleagues without intellectual disabilities and their own reflections. As identified by Banks and Brydon-Miller (2019), this study also demonstrates that collaborative research projects can make a difference to the lives of people who previously have not had access to the world of social science.

To foster good partnerships, most researchers invest as described in the literature by van Asselt-Goverts et al. (2017) in close personal connections with each other and open themselves up to an intense learning and working process. This practice brings about new perceived responsibilities to the team members. These responsibilities can create new dilemmas in the power balance between colleagues, and can even foster an unwanted attitude of 'them and us'. Researchers are challenged to address these responsibilities and to keep inventing ways to maintain safe and power balanced partnerships.
 'Good practice' in collaborative research could be defined as the process of finding ways to foster an equal power balance through safe partnerships, whilst dealing with the new responsibilities these partnerships bring. This remains a challenge in the current culture within academia and requires research teams to create a space for these issues and to invest in training to learn the skills for new ways of working together and collaborating. Predicting problems that may arise in the practice of collaborative research is not an easy task, but one that requires on going attention.

Discussion

Our study indicates that levels of involvement in collaborative research differ despite the premise that collaboration with researchers with intellectual disabilities in social science is not to allow people to 'join in as well as they can', but to respect the fact that society consists of different individuals with different abilities (Wooster 2009). The partnerships in the study that demonstrated equal partnership working rather than 'allowing someone to join in' were characterised by reflection and open communication about how to change working practices, rather than just making adaptations to the existing ones.

The motivation for engaging in collaborative research can impact on the nature of the partnerships. When the reason for collaboration is driven by funding/ money rather than an acknowledgment and acceptance of what somebody with an intellectual disability can contribute to the team, this appears to then be reflected in the level of involvement and responsibility given to them and can result in inequality and exclusion. In contrast, valuing the differences in knowledge areas and the intention to find new ways of cooperation can lead to strong partnerships based on equality with the shared responsibility of tasks in research projects. Perhaps starting from a standpoint of involvement contributes to the problem. It has been said before that a change in thinking that incorporates partnership working rather than inclusion is needed if people with intellectual disabilities are to become equal partners (Richards et al. 2018). The results from this study demonstrate the pitfalls of starting from a point of inclusion and how this differs from partnership working.
On the other hand, we have seen that a study that initially started as a collaborative project for the wrong reason can be a starting point to make researchers conscientiously think about the partnerships. That, too, is part of learning to do it together and can thus strengthen collaborative research in the future. In one of the projects described the partnership was in the beginning not quite as collaborative as you would like it to be, but the researchers are now much more open to

work together as a team in future projects. Benefits have been recognized and people feel more able to deal with the challenges associated with collaborative research.

The study also shows that researchers with and without intellectual disabilities both foster responsibilities when involved in collaborative research. However, in the process of developing and sustaining these partnerships, there are differences in the responsibilities that are taken by researchers with different experience and knowledge backgrounds. Research team members with intellectual disability experience in the study expressed a sense of responsibility to adapt to the existing research environment, perhaps suggesting attempts to camouflaging their support needs associated with their disability. This raises questions around how collaborative research under these conditions can be, and how a safe, supportive partnership can be developed if there is a reluctance to show vulnerability.

The theme of the academic context featured in "future developments". It could be considered a factor that adds to the responsibilities taken by both the researchers with and to those without intellectual disabilities. If the space to learn together opens up more, responsibilities in partnerships would change. For example, the risk we feel regarding academic community views' on the credibility of our research projects can foster pitfalls to do research tasks in the usual exclusive way by leaving colleagues with ID experience behind. This factor can only continue to be a risk while we keep anxious about our place in academia.

The perception of researchers with intellectual disabilities as not being an equal partner in a valued role. For example, when interviewees asking "when the real researcher" will show up. This has been noted by researchers before (Flynn et al. 2018). This then raises questions about the readiness of society to engage in connecting with people with intellectual disabilities, overcoming the 'uneasiness', and to valorise collaborative research. In many aspects, this study raises more questions than answers.

The responsibilities towards each other and balance of power in partnerships in collaborative research is an area of concern for respondents representing an unresolved dilemma. Respondents without intellectual disability experience acknowledged the potential for differences in power in their partnerships and expressed concern about this. None of the respondents had found a solution for this. This leads to our conclusion that this issue cannot be 'solved' but can only be managed by bringing it in, in the joint dialogue. Discomfort with the difference in power dynamics clearly were more apparent in the discourse of the respondents without intellectual disability experience; those who are ID experienced initially seemed to accept this as the norm. From our research we suggest funding organisations to consider how stipulations for the involvement of people with ID experience in research may be carried out in practice and how the impact of these stipulations may have paradoxical effects and undermine the ethos of collaboration. It is only by acknowledging and addressing these issues that safe partnerships, based on mutual support and shared vulnerability can then develop. There are many challenges left unresolved in this area, while a framework for practice may be helpful, our study suggests that the nuances associated with responsibilities are not so easily defined.

Interestingly, we all saw the value of collaborative research and the different perspectives it brings when we had directly experienced this way of working. While Banks and Brydon-Miller's framework (2019) consider the skills and attributes needed as guiding principles for working collaboratively, the findings of this study raise questions about the experience of those involved in collaborative

research. Do researchers without ID need to have experiential knowledge and experience of working with researchers with ID experience before they can begin to foster the attitudes and skills required for safe and effective collaborative research? This also emphasises the importance of reflection in collaborative research, again suggesting that there is no direct path or defined outcome for successfully undertaking this type of research, rather a continuous process of learning, reflection, and growth for both researchers with and researchers without ID experiential knowledge.

Power imbalances in the academic environment are not exclusive to collaborative research teams. But, changes that are needed to ensure equality in the academic workplace for all people could also be applied to the academic environment in general. Meaning that changes in attitudes and practices derived from creating environments that are conducive to collaborative research could act as a catalyst for more democratic relationships within academia.

This again demonstrates how the benefits drawn from collaborative research can be wider-reaching; benefiting more than just those being studied in this project.

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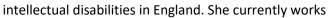E-mail address: Anja.Zimmermann@HAN.nl

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Citation

Zimmermann, Anja; Hermsen, Maaike; Richards, Leisa; Santvoort, Henriette; Simons, Rianne & Sergeant, Sofie (2021). Searching for good practices in collaborative research. A qualitative responsive study about partnerships in teams of researchers with and without intellectual disabilities. *HAN.nl*