Article

‘The Ball of Cooperation Rolls on’: Some Personal Reflections on My Experiences as a Researcher

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Abstract: People with disabilities are increasingly actively involved within research projects. For many of them this is a temporary role, but some work on longer-term projects and even build a career out of it. This is the case for the first author of this paper. He has worked as a researcher for almost six years. He is involved in various projects, all highly diverse in terms of subject, design, scope and collaboration with fellow researchers. In this paper, he looks back on his experiences in recent years. Together with colleagues, he reflects on his contribution to the various projects, his own development as a researcher and the impact of the work on his personal life. He finds that the essence of the motto ‘Nothing about us, without us’ has become increasingly intertwined with his life and identity through his work.

Keywords: inclusive research; participatory research; intellectual disabilities; collaboration; lived experience

1. Introduction

Inclusive research has come more and more to the fore over the last 20 years. This form of research made it possible to switch from research ‘into’ people with disabilities to research ‘with’ people with disabilities. The idea was to involve people in designing as well as conducting research, to better understand their lived experience, and above all to respect their practical knowledge. Much of this research is intended to represent the interests of people with disabilities, and address issues of importance to them. It must be possible to use the research results to help people with disabilities lead better lives.

From the first inclusive studies, lessons were learned and solutions were explored for problems that arose. For example, training programmes were developed in which both co-researchers and professional researchers could participate. These training programmes came in for criticism, as they risked molding the co-researchers too much in the image of an academic researcher (Nind et al. 2016; Sergeant et al. 2020). Within subsequent stages of inclusive research, many co-researchers have become involved in committees set up to evaluate research projects (Bigby et al. 2014; O’Brien et al. 2022). In addition, many were also members of self-advocacy groups that helped ensure that inclusive research was increasingly on the agenda and taken seriously, both locally and internationally (Strnadová and Cumming 2014; Walmsley et al. 2016).

Many lessons have been learned from these initial years of inclusive research, but at the same time, problems sometimes persist. For example, based on their systematic review on the involvement and experiences of co-researchers, Hewitt et al. (2023) emphasize the complexity of inclusive research. This complexity involves, amongst other issues, challenges in organizing appropriate support and training for co-researchers (Bigby et al. 2014; Montgomery et al. 2022) and the experience that funding for inclusive research is not always dependable. In addition, O’Brien et al. (2014) indicate that lack of time often
remains a problem for co-researchers. Guidance from a job coach is not always a given, and many co-researchers only remain involved in specific areas of a research agenda (they conduct interviews, for example, but do not subsequently process them).

This paper presents a unique story, focusing on the position, accumulated expertise and experience of the first author. It details a long, continuous and varied research career, which has taken the first author into various research environments and roles. This paper presents his personal reflections on this experience. The co-authors contributed to the reflections in this regard and offered suggestions at various moments in terms of getting thoughts down on paper.

2. Context

2.1. This Is Me

My name is Mark. I was born prematurely, 48 years ago now. Compared to the people around me, I had a somewhat slower start in life. This had repercussions in the first jobs I worked at through the mediation of an employment agency, where I always realised that I was not a good fit. In 2005, I was diagnosed with PDD-NOS, a form of autism. This led me to the Philadelphia Care Foundation (a care organisation for people with intellectual disabilities in The Netherlands) for support. This opened up opportunities for me, as I could work on my talents in a partially sheltered setting. I was able to develop myself, also because for a long time I served on various client participation councils and even served as chairman of the national council.

My home situation for a long time was living in a residential community where I was supported by professional support workers. I lived with seven other residents and was able to lead my own life. In 2013, my life was enriched when I re-found my faith. I had been raised Christian all my life by my parents, but in 2013 this became a conscious choice. New friendships were forged in the church and my drive to do something for my fellow human beings grew. There were also situations in the church and society where I could help, both practically with my hands and by having something to say. I also began to immerse myself in the church on a spiritual level. In recent years, I have completed studies in the church, at a part-time Bible college. This allowed me to develop even more as a person. Not only in terms of knowledge of the Bible and principles that apply to Christian life, but also in terms of reflecting and describing experiences in personal life. I also met my partner at the church, and we have been married for a few years now, and live together in our own home. I still get support from support workers, but it is different now, being once a week near where I live.

2.2. This Is My Work

Via the participation council of the Philadelphia Care Foundation, I came across a job vacancy for a co-researcher. This seemed like a great opportunity, because it would allow me to observe and advise on policy. Instead of being a hobby, this could become my job. At the end of 2017, I was really a part of Philadelphia. For the first few years, I worked on a large project with one other researcher, the second author in this paper (Miriam Zaagsma). This was her PhD thesis. We wrote a paper together about our experiences in working together on this project (Zaagsma et al. 2022). In this current paper, I discuss the personal experiences I had during the projects that came after that. The first part of its title (‘The ball of cooperation rolls on’) is a reference to our previous paper (the title of which ended with ‘...and then the ball of cooperation started rolling’) and emphasizes the fact that we now focus on my continued work efforts and experiences. Table 1 lists the various projects I have worked on in recent years. You can see that these projects had different subjects and that the composition of the teams varied from project to project.
Table 1. Overview of [Name first author]’s projects.

<table>
<thead>
<tr>
<th>Type</th>
<th>Topic</th>
<th>Organisation</th>
<th>Collaboration</th>
<th>Period</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. Research (PhD)</td>
<td>Digital support service</td>
<td>PCF a</td>
<td>1 researcher</td>
<td>2017–2022</td>
</tr>
<tr>
<td>2. Research</td>
<td>Financial representation services</td>
<td>PCF</td>
<td>2 professionals (not researchers)</td>
<td>2020–2021</td>
</tr>
<tr>
<td>3. Development and research</td>
<td>Serious game on mental resilience</td>
<td>PCF</td>
<td>8–9 professionals (not researchers), multiple disciplines</td>
<td>2021</td>
</tr>
<tr>
<td>4. Development and research</td>
<td>Instrument for screening on health issues</td>
<td>PCF</td>
<td>1 researcher</td>
<td>2021</td>
</tr>
<tr>
<td>5. Research (PhD)</td>
<td>Integrated emotion-oriented care</td>
<td>PCF</td>
<td>1 researcher</td>
<td>2022</td>
</tr>
<tr>
<td>6. Research</td>
<td>Socially assistive robot</td>
<td>PCF</td>
<td>1 researcher</td>
<td>2023–now</td>
</tr>
<tr>
<td>7. Research</td>
<td>Relationships, intimacy and sexuality</td>
<td>DSiN b</td>
<td>1 researcher and a larger project group</td>
<td>2022–2023</td>
</tr>
<tr>
<td>8. Preparation</td>
<td>European research proposal</td>
<td>DSiN</td>
<td>10 researchers (international)</td>
<td>2022–2023</td>
</tr>
<tr>
<td>9. Training</td>
<td>Collaboration in inclusive research teams</td>
<td>DSiN</td>
<td>1 researcher</td>
<td>2022–now</td>
</tr>
<tr>
<td>10. Development and research</td>
<td>Socially assistive robots in families headed by parents with ID/D</td>
<td>DSiN</td>
<td>3 researchers and larger project group (multiple disciplines)</td>
<td>2022–now</td>
</tr>
</tbody>
</table>

a Philadelphia Care Foundation; b Disability Studies in the Netherlands Foundation.

After Miriam’s PhD thesis was completed, a lot of things changed for me. I was still employed by Philadelphia, and I started collaborating on various smaller studies for 20 h a week. I was also working 8 h a week as a project officer in a department that fostered the use of innovation in care and support settings. Since mid-2022, I have been seconded to the Disability Studies in Nederland Foundation (DSiN) for 15 of the 20 h I spend on research. This foundation works to raise awareness of disability in society by means of research and education, and aims to contribute to the empowerment of people with disabilities. The foundation is affiliated with a university: the University of Humanistic Studies in Utrecht, The Netherlands. One of the co-authors of this article (Alice Schippers) is both working for DSiN and as a professor at this university. This means that we are affiliated with both educational institutions and care organisations.

3. Materials and Methods

To write this article, I did not want to reflect on my work on my own. I wanted to involve the people I worked with. I started by approaching six people with whom I had worked closely over the past year and a half. These were five researcher colleagues and my supervisor. I put three questions to them by email: (1) What helped us work well together? (2) How did we make decisions? Did we make decisions together or did I give advice and someone else made the decision? (3) What were the pros and cons of conducting research together?

I received responses from all six of them via email. Based on their responses, I started thinking more about this and writing down my thoughts. I had various conversations with my co-authors (sometimes individually and sometimes all together). Based on these conversations, I started working further with them, drafting this article in several sessions.

4. Reflections

In this section, I describe some of my reflections. I selected those reflections that I think are important to share and will be valuable to other researchers as well. I organised
my reflections into three parts. In the first part (Section 4.1), I describe how the projects in which I am (or have been) involved have complexity as the common feature. Three things stand out in this regard: the subjects on which I conduct research (Section 4.1.1), working (simultaneously) on many different projects (Section 4.1.2) and working in different environments (Section 4.1.3). In the second part (Section 4.2), I go into more detail on the collaborations I have (or have had) with colleagues. I focus on what I consider to be important ingredients to ensure successful collaboration (Section 4.2.1) and what I see as my contribution to the projects as a co-researcher (Section 4.2.2). In the third part (Section 4.3), I analyse the development I have undergone in recent years, both as a researcher (Section 4.3.1) and how my work and my personal life have influenced and interacted with each other (Section 4.3.2).

4.1. Working in a Complex Environment

4.1.1. Complicated Topics

A recent important project looked into the use of robots in families headed by parents with intellectual disabilities. There are various taboos and stigmas associated with this project. It also deals with technology, and involves researchers from different backgrounds, such as researchers from the technological domain. I find this very interesting and enriching, but it also comes with a lot of confusing terminology. The researchers sometimes talk in great detail, and quickly, about technical facets that I am hardly aware of. What also made it complicated for me is that a colleague I worked with a lot did not speak Dutch. My English was better than her Dutch, so we spoke in English. But that did sometimes made communicating and working on the subject complicated.

Another research project also addressed a taboo subject, namely sexuality when living in a care facility. My researcher colleague and I noticed that a number of respondents with mild intellectual disabilities approached us directly to talk about this topic. They told us they wanted to talk directly with us, preferably online, and that they did not want their support workers from the care organisation to know about it. It turned out to be an advantage that I was not affiliated with their care organisation (I worked at a university), since this offered them extra reassurance of confidentiality. Because I had already been involved in several research projects as a co-researcher and hands-on expert, I could also ask more focused questions. I lived in a residential community for over 10 years, together with other clients. At first, I only had my own bedroom, and later my own apartment. I learned a lot during this time, in terms of taking others into consideration and looking for positive sexuality in long-term care settings.

4.1.2. Many Different Projects

In the projects I work on and have worked on, the teams have a highly diverse make-up. In the project on sexuality, I work closely with one colleague, and in another project with three other colleagues. What is more, each of the projects has a structure in which more organisations and people are involved.

I was used to working with just one researcher. In current projects, however, I usually work with several people in a team, or in consortiums. A consortium is a team made up from different organisations, all working together. This complicates things, because not everyone can make the same amount of time available. If you want to optimise the collaboration, it is useful to get to know each other to a certain extent. That way you can show understanding for each other when something becomes a challenge in terms of work and/or time.

Different research methods are used in the various projects, varying from desk research in one project to action- and design-based research in another. I found design-based research a bit more challenging because nothing is fixed in advance and I have to constantly adapt to changes and new plans.

Working on various research projects gives me a lot of freedom. I can arrange the work so that I can give the best of myself. If I am in a positive collaboration with people, in which
everyone’s talents are utilised, I get a lot of energy. At the same time, switching between projects is energy-draining. This makes it important to have good time management. For example, through my job coach I learned to organise my work by using colours in my calendar. For each day, I marked the hours I was going to work on a given project with a specific colour. That way, I could see exactly what I was going to work on, and not spend more time on a project than agreed on. For me, it is a good idea not to switch too much between projects during a day. That way, I keep the balance of work and energy positive.

4.1.3. Different Environments

Within the university, I work with my colleagues from DSiN at the Care Ethics department. We primarily conduct research there. We share knowledge from literature several times a year, and I once contributed to the draft of a research proposal on loneliness.

My colleagues at DSiN mostly work part-time because (like me) they have other work on the side, are still studying, or are trainees. Many of them are ambitious junior researchers. I have found that working on many different projects at the same time is the norm. I have also noticed that people in academia set high goals, especially when they are juniors. Because of their inexperience, they often want to organise meetings at the last minute. There is no guarantee with junior researchers that you will have access to all the information. I noticed, for example, that I was not being put in the cc. of emails. This means that I can get less done, partly because I am less prepared than I would like to be. I have found that if I am included in email exchanges, I can see certain actions coming up, and I can work more efficiently.

There are clearly advantages to working in a small independent team as well, because, as a small organisation, DSiN is affiliated with various educational consortiums and interest groups in care settings, and I have the opportunity to go to various meetings, to follow courses and even to teach myself. This means I can take on board all kinds of additional information, and pick and choose the most interesting for myself, and then continue to share my knowledge again.

I generally experience a lot of mutual commitment. One advantage of working in a small team is that I can be involved in more work. Precisely because I am so eager to learn, this is a nice aspect for me. However, I then need to be flexible in my time, and have the necessary space and time available. It is also important to have colleagues with whom I can work together well and feel a connection with so that everyone can play to their talents. One of my talents is talking. I gave a guest lecture in a seminar at the university in the Disability Studies course. I talked about my research work. I really enjoy teaching; I can introduce students to co-research. This gives me a lot of energy and reminds me that I am in a privileged situation, and that you need to seize the opportunities that come along.

4.2. Working Together with Colleagues

4.2.1. Ingredients for Successful Collaboration

*(Get to) know each other really well.* The collaborations I have been part of were generally pleasant and easy-going. I learned a lot along the way and, more importantly, also gained personal insight. Taking an interest in each other is also important, that you are curious about the other person, also as an individual, outside of work. One of my colleagues agreed, and she wrote to me: “*It helps if you can share some things with each other on a personal level. It doesn’t have to be the case, but to me it makes the collaboration better. When you know each other better, you can know and use each other’s strengths*”. I especially enjoy working with people who, like me, undertake a lot of initiatives and are interested in others. It is important to take the time to get to know each other. Everyone has his or her own way of looking at something. When you know this, there is less chance of having to break down prejudices towards each other. Getting to know each other does not always come naturally. You both have to be willing to be vulnerable and open. When you are getting to know someone and finding common ground, you also need to invest quite a lot of time if you want to get to know each other well. Sometimes, the circumstances make it more difficult to get to
know each other. For example, on one of my projects, we mainly communicated via video calls. Although conversations online are faster, I noticed that it takes longer to get to know each other. When you eventually meet in person, after dozens of online meetings, it does feel familiar.

Equality. I noticed that although some colleagues tried to shape our collaboration in a very equitable way, this was less the case for others. With the colleagues who felt an equal footing was important, I had regular and pleasant contacts. We looked together at what actions needed to be taken, and worked out who would do what based on who was suitable for it and who had time. This was not only a very practical way of collaborating, but also took into account everyone’s talents and abilities. A colleague wrote to me: “In our collaboration, we look at capabilities and talents. For example, some people are good at writing, others at asking questions. I’m sometimes impatient and hasty, but Mark is good at going into detail. We give each other the possibility to do what we are good at. As a result, we work nicely together”. For me personally, time has always been the most important factor in making decisions whether to do things or not. After all, there are a lot of things I like doing. Over the years, I did notice that I can make better and faster choices in what I do and do not do: I say yes or no more consciously. In the collaborations with some colleagues, I noticed that we communicated less with each other. For example, they kept me less informed of developments in their work. They did not involve me in certain decisions they made for themselves. I do not think this was always consciously or on purpose, but it is not pleasant. I noticed that I then had to find out things myself, for example, to ask if an appointment was already planned, if that was necessary for the project. It was more difficult to work like that than being an equal partner in the project/research. And it takes up more communication and energy, which, in my opinion, is a waste of time. For me, the main thing is involving each other and not making decisions on your own. Of course, it is also fine that the other person sometimes makes decisions without me. It is not about ignoring the principle of equality; it is mainly about respecting each other, and involving people where necessary. If we discuss together and agree that the other person makes decisions in a certain period or situation, that is also good. The following quote from my colleague is a good example: “During the ‘train the trainer’ session, I took more of the decisions. We did this by mutual agreement because Mark had a little less time to prepare for it properly”.

Consciously looking at the collaboration together. I think it has been very worthwhile to sit with colleagues and look at our collaboration together, to see what is going well and what could be done better. You can plan a separate meeting for this, or you can do it during the work. In the various projects, this was not always done at the same level of detail. If it did not happen, I always thought it was a pity, and above all a missed opportunity. Sometimes, I felt like I had to take the initiative each time. This was more often the case when I worked with junior researchers. They did not seem to be as interested in reflecting on the collaboration. In contrast, colleagues who (also) had a background in care seemed to consider it more often than colleagues with only a research background.

4.2.2. Not More of the Same, but Something New

Each person has his or her own ideas, and sees the world in their own way. Similarly, I have my own ideas about how the world works. And what makes me extra special compared to my researcher colleagues is that I am more familiar with the experiences of people with intellectual disabilities than they are. That is my strength as a researcher, and I can add this to the knowledge of my colleagues. For example, during interviews, I can ask questions that are more relevant to the lived experience of the interviewee. One of my colleagues said: “A lot depends on conducting research in practice; in our case, how people with intellectual disabilities are represented. Working with Mark brings the practice and experiential knowledge that is so desperately needed. For example, Mark asks different questions during interviews than I might come up with, because he shares that lived experience with many of the respondents”. If you think of a research study as a chessboard, I am a different chess piece than my colleagues. Another colleague put it like this: “Mark can empathise well with the
world of people with disabilities, which gives him a ‘knowledge privilege’ in the field of experiential knowledge”.

In addition, I like to get to the bottom of things, and I think that is a quality as well. Where colleagues often settle for a short answer, I keep asking questions. I may not always be relevant, as I sometimes go off on a tangent with my questions because it may be something in my own interest. And it has also happened that I mix up questions from different studies running at the same time. My persistent questions are not only useful during interviews, but also for colleagues when I keep asking them about the research process.

4.3. My Development and Lessons Learned

4.3.1. I as a Researcher

More nuanced. Being able to process information more deeply and hear opinions and points of view from others means that I have a broader perspective. This provides me with an opinion that is more nuanced than the label I used to give to that information. I have found that looking at things in more detail gives your opinion and conversation more context and meaning. And your opinion becomes more nuanced due to the amount of information. I can also more easily put myself in the shoes of others and show understanding for others. I also feel more easily understood myself.

More philosophical. Continuing to ask questions helps me gain wisdom. As a researcher, I have the opportunity to gather information in many ways, and to ruminate on that information. I have found that I have become more philosophical as a result. I notice this in the way I speak. I think I understand and speak the same language as someone who calls himself a philosopher. On Wikipedia, a philosopher is described as a sage.

More confidence. Even though it is still important for me with colleagues to get to know each other well (see Section 4.2.1), I do notice that this has changed. When I was just starting out as a researcher, it was much more important to feel completely comfortable in a team than it is now. I needed a personal click with a colleague. This is less important now. I think this has to do with my self-confidence as a researcher. I now get my self-confidence more from myself and from experiences at work. I do not need the affirmation of others as much now.

4.3.2. How My Personal Life and My Work Are Intertwined

My private life has changed in recent years, because I got married a few years ago. My living situation, for example, has changed, as mentioned in Section 2.1. Whereas making compromises proved to be a bit of an issue for me before, this is vital when you are married. Because I now find it easier to put myself in others’ shoes in my work, it filters down into my private life. Asking questions, analysing and informing is something that has become interwoven into my life as a whole.

In addition, I have found that my Christian conviction of gratitude influences my work. At Bible college, I reflected on my past and realised that enjoyment has always been an important value in my life. I used to chase it, and now I find it in Biblical values that I embody. For example, the Bible says, “Rejoice always and delight in your faith, be unceasing and persistent in prayer, in every situation [no matter what the circumstances] be thankful”. 5 (Life Church 2024). At work, I find that I do not think in terms of problems, and do not see many hurdles. Having gratitude in my life means that my faith is set free. Gratitude makes big challenges smaller. For me, research is a task where the process is perhaps even more important than the result.

Meditation gives me focus, also in my work. A good example is a research project where I was supposed to collaborate with an English-speaking colleague. I wondered whether I could actually handle it. Meditating and thinking long and hard about it gave me the belief that I could do it, and that my involvement would actually be beneficial for the participating Dutch families. I also believed that it could make me more confident, with the prospect of contributing to a European research proposal. In the end, I did actually become
more confident in terms of the English language. That makes me grateful, to realise I can face a challenge but remain steadfast. Meditation was also valuable in another project. At first, I had reservations when being asked to take part in a research study on sexuality. I consider sexuality and intimacy a private subject that I only talk about with my wife, or possibly very close friends. Meditation made things much less complex, as I realised that I could participate in my role as a researcher rather than as a hands-on expert. As a result, I could commit to that project and I proved to be a complementary asset to my colleague.

The examples above show that my work is strongly interwoven with my personal situation. The Bible says, “Whatever your hand finds to do, do it with all your might” (Life Church 2024). In other words, if you cannot do as you should do, you should do as you can do. So, I do what I can do. And my colleague does what he or she can do. When you understand each other and know what each other wants, and everyone does what they can, there is more space and mutual understanding and you get the best results. Each research study has its own flow, and I have come to the conclusion that any collaboration works best when you ‘go with the flow’. Let me be ‘co(-researcher) with the flow’.

5. Discussion

In this discussion, I go over various issues that have struck me in my various research experiences in recent years.

**Trust.** As a researcher with experiential knowledge, I was able to create trust, which made people (respondents) willing to share sensitive topics with us. I described this in Section 4.1.1. with regard to a specific study on (positive) experiences with sexuality within care and support settings. I think my involvement helped to create trust in several ways. First, the respondents appeared to find it important that they could approach the researchers directly. Contact via supervisors often meant that an interview did not take place. We therefore announced the study via a flyer that was distributed within the researchers’ networks and through social media channels. This meant that people could approach us themselves, directly, and so we got in touch with respondents who were generally motivated to talk about the topic. Second, before and during the interviews, my colleagues and I invested in getting to know each other and creating a safe setting. Specifically, this meant that in all interviews, we took ample time to get acquainted with the respondents and made a conscious decision regarding which topics we would ask about first, and which we were going to come back to later or even omit. Third, I think my own experience of living within a care organisation and wanting to represent people’s interests by standing up for my opinion also made a difference, because it often created recognition and acknowledgement. Reflecting on this with the research team, we noted that trust was created because I am one of them, and can empathise with the ethical dilemma the respondents were in. At the same time, I think it was also nice for the respondents that I had sufficient distance from their day-to-day lives. For example, we also did the interviews online, so there was literally physical distance, while we were talking about physicality. All this created trust.

**Partnerships.** In the research teams, I was given the opportunity to participate as a full partner in research. With my colleagues, we recognised in this the concept of ‘relational autonomy’ (Mackenzie 2014). This concept implies that you are always dependent on each other, or interdependent. That is the case in general, but especially within research teams that divide the work among themselves, and complement each other in terms of skills. For example, I have experiential knowledge that other colleagues do not have, while they have more experience with, for example, writing. This is also how this article came about, by discussing with my co-authors together and sometimes literally handing over the computer while I dictated and a colleague typed. I definitely experienced autonomy. I experienced it precisely because we were equal partners. For me, autonomy is about giving each other space, and respecting each other.

**Interwoven with personal life.** Thanks to my experience with receiving care and support services, and thanks to my role on the participation council, I have seen changes that take
place in care settings over time. One of the most important changes is the shift from people with disabilities as ‘objects’ of research, to people with disabilities as ‘subjects’ in research, and involving them in ambassador roles. Through my more than six years of experience as a researcher, I have increasingly had the opportunity to determine and explore various research themes, topics and questions. I could do this from my (shared) interests and experiences: it is actually my personal life. The common thread was: what do we, people with disabilities, think is important to research? For me personally, this in particular took the form of contributing to a European research proposal on the topic of stigma among people with intellectual disabilities. Through my experiential knowledge, prejudices of colleagues on that subject were visible and recognizable. But it also broadened my own view on the subject. The definition of stigma therefore became clearer to me, namely, that a lack of knowledge is a reason to label something, and that this label can stigmatise. As such, it became clear that not only researchers, but also I myself—and perhaps other people with disabilities—stigmatize.

As a conclusion, it is clear to see in this article that I endeavoured in many ways—together with colleagues—to add real value to research. This was partly by ensuring that my role and tasks as co-researcher were worked out and included in such varied ways as to avoid the risk of stigmatising (in this case: locking someone into a pre-described and unchangeable role of co-researcher). As my colleague (Geert van Hove.) puts it: [Mark] becomes a Houdini figure whenever a role is too rigidly defined. In addition, my involvement in the various studies offered added value because through the process I became more confident and ‘relationally autonomous’, and therefore a veritable partner in the various networks. Finally, the strong connection to my own life also provided additional opportunities to grow, as I experienced it, from ‘object’ (Mark Koning) the co-researcher) to ‘subject’ ([Mark Koning] the colleague).

Author Contributions: Conceptualization, M.K., G.V.H., A.S. and M.Z.; methodology, M.K. and M.Z.; validation, M.K., G.V.H., A.S. and M.Z.; formal analysis, M.K., M.Z. and G.V.H.; investigation, M.K.; resources, M.Z. and G.V.H.; data curation, M.K.; writing—original draft preparation, M.K., M.Z., G.V.H. and A.S.; writing—review and editing, M.K., M.Z., G.V.H. and A.S.; supervision, A.S.; project administration, M.K. and M.Z. All authors have read and agreed to the published version of the manuscript.

Funding: This research received no external funding.

Institutional Review Board Statement: Ethical review and approval were waived for this study due to the authors looking back at past research. This concerned projects for which ethical board reviews were passed: research projects that were conducted in accordance with the Declaration of Helsinki and reviewed by ethical review boards: of the Utrecht University (reference 22-0627, 1 January 2023), University of Humanistic Studies (reference 2022-10, 17 October 2022), VU University Medical Center (reference 2017.507, 1 November 2017; reference 2018.569, 1 November 2018; reference 2019.513, 18 September 2019; reference 2019.721, 17 January 2020) and Tilburg University (reference TSB_RP533, 23 May 2022).

Informed Consent Statement: Informed consent was obtained from all subjects involved.

Data Availability Statement: The data presented in this study are available on request from the corresponding author due to privacy concerns.

Conflicts of Interest: The authors declare no conflict of interest.

Notes

1 A job coach is a professional who helps people (temporarily) to perform their work; for example, helping them with overcoming barriers in the workplace and/or obtaining and keeping an overview of the work.

2 Clients are people who procure care and/or support services from a care organisation (such as the Philadelphia Care Foundation).

3 A participation council is a group of people (in this case clients) who meet regularly to jointly advise and decide on policy in discussion with the care organisation.

4 Disability Studies in Nederland (DSIN) fosters research and education in the field of disability studies. For more information, see https://disabilitystudies.nl/ (accessed on 11 January 2024).
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