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ORIGINAL ARTICLE

Building Relationships in Inclusive Research in Diverse Contexts

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This article explores relationships between academics and people with intellectual disabilities collaborating in inclusive research. The authors present and reflect upon narrative accounts from Norway and England from both sides of the relationship. Each relationship is examined, including how it was initiated, established, developed and sustained, what worked well, what the obstacles were and how any conflicts were approached. The concept of being an 'alongsider', working alongside each other (and alongside participants with intellectual disabilities) is used. The paper shows variety in how alongsider relationships are initiated and fostered over time. Mostly, partnerships were initiated informally, based on pre-existing relationships as friends or through support worker-client relationship or earlier research cooperation, although one was initiated through a formal selection process. The paper concludes that when building relationships over time, the personal dimension is important, including sharing an interest, mutual respect and liking each other, while funding and tight timelines can interfere.

Accessible Summary

- Academics and researchers with intellectual disabilities from England and Norway wrote this article together.
- Academics thought up the idea and wrote the background and discussion; people with intellectual disabilities wrote about their experiences.
- The paper tells how we got to know each other and how we kept in touch over time.
- We wanted to do this because academic researchers in Norway want to do more research with people with intellectual disabilities, and need to know how to get started and keep it going.
- We learnt that it takes time spent alongside each other to build good research relationships, and it depends on having fun together as well as working.
- We learnt that the academic researcher needs to provide some support, even when there is someone else with that job.
- We learnt that sometimes funding and deadlines can get in the way of building strong research relationships.

Purpose

In this paper we explore relationships between academics and people with intellectual disabilities who do research together. The idea came out of a discussion between Norwegian and UK researchers about experiences of doing inclusive research. We approach this exploration by reflecting on the narrative accounts of some of the authors, with and without intellectual disabilities, across the two countries, drawing out themes, and making connections with other work on this topic. The academics authored the parts of the paper beyond the core narratives, though our aims and the core themes were shared and discussed amongst us all.

In England, self-advocacy and inclusive research are relatively well established compared with other countries. Although under threat from cuts, self-advocacy organisations have helped build people's capacity to communicate their own interests, desires, needs and rights. Organised self-advocacy groups have helped academics to find people with intellectual disabilities interested in research, and they can lead to research initiated by disabled people (e.g. Armstrong et al. 2019). In England (and Australia), there have been repeated accounts of researching with the same self-advocates with whom strong relationships build over time (e.g. Herron, Priest & Read 2015; Strnadova et al. 2019). In Norway, by contrast, organised self-advocacy is largely undeveloped; the country lacks the kind of self-advocacy organisations with experience in doing research and supporting researchers that have emerged in England. Other routes for disabled people and academics finding each other for collaborations are needed. Moreover, without the support afforded by self-advocacy organisations or similar, the work of supporting a disabled person to be a researcher is potentially more firmly placed on the shoulders of academic researchers. Given these different national and structural contexts, we explore how the dissimilarities can make a difference to how academics and people with intellectual disabilities collectively relate with one another. In this paper we draw on our own experiences, and reflect on how research relationships are, and can be, established. The contexts span funded and unfunded research in both countries on a range of topics. Our purpose is to reflect upon ways to foster relationships which support inclusive research, where academics work alongside researchers with intellectual disabilities, and to ask what supports such relationships.

We begin the paper with some background context about the rise of inclusive research and then discuss attention to relationships within the literature about it to set the scene. In a traditional format, the methods and ethics surrounding the generation of data—narratives of relationships in inclusive research—are then presented ahead of the narrative accounts (findings) and finally discussion of what they add to the field.

Background

Inclusive research emerged in England and Australia in the late twentieth century, alongside deinstitutionalisation, the emergence of self-advocacy and a discourse of human rights—Nothing About Us Without Us (Walmsley & Johnson 2003). It is defined as research where people with intellectual disabilities work with and as researchers, no longer objects of research, but active in the process (Walmsley & Johnson 2003; Nind 2014; Bigby et al. 2014). Inclusive research requires an ethic of respect for the lives, views and experiences of people with intellectual disabilities, and for the knowledge they hold and can add to the research process. There is now a wealth of material upon which researchers can draw for guidance if they want to work inclusively. This includes in Norway, Østby and Haugenes' (2019) handbook, which includes Norwegian examples from early inclusive research work in the country.

Some of the literature on inclusive research includes discussion of roles and responsibilities, and ventures into the nature of the relationships between researchers (e.g. Walmsley 2004; Butler et al. 2012; Frankena 2019). This is not surprising given that the inclusive turn is very much about a radical change in how research relationships are configured. A goal has been to disrupt these relationships so they become more democratic, actively including the people whom the research is about in decision-making, and encouraging them to take on roles as researchers (Nind 2014). Some papers focus on relationships between individuals and organisations (e.g. Armstrong et al. 2019). The majority of the literature, though, focuses on how power dynamics are managed within a particular project or partnership. For example, Bigby, Frawley and Ramcharan (2014: 56) describe in some detail how 'trusting relationships and dispersed power' is a core component of their collaborative group model for doing inclusive research. They relay how members of one group got to know each other, building trust and camaraderie through regular contact which included banter, mutual respect, doing what they promised, and being collegial in their decision-making. Such relationship building, they argue, takes skill, care and time. However, Frankena et al. (2019: 720) observe that the structured study of roles and relationships in inclusive research has 'received little attention' and 'focussed mainly on short-term projects'.

Literature on teamwork and team-building in inclusive research projects (e.g. Bjornsdottir & Svensdottir 2008; Butler et al. 2012; Strnadova et al. 2014) indicates the value of people with different skills and backgrounds spending time together, enabling people to find what they have in common. Team building for inclusive researchers might mean being friendly, or even being friends; spending non-work time together; being committed to each other in deep ways (e.g. The Learning Difficulties Research Team; Townson et al. 2004; Chapman and McNulty 2004). Partnerships, though, can begin by being open to people who need to 'learn on the job … reflecting, and adjusting to experiences along the way' (Woelders et al. 2015: 532).

Occasionally, there has been interest in bringing the difficult aspects of inclusive research into the open for debate (Walmsley & Johnson 2003). McClimens (2008: 273) echoes concerns that 'some of the grittier and messier aspects of collaboration [get] … glossed over or perhaps ignored'. Woelders et al. (2015) argue that expectations arising from an idealised vision of inclusive research can interfere with building good relationships and research practices. Ellis (2018) discusses the minutiae of working together to make decisions and shows that relationships with support workers can be a complication when seeking collaboration. After wide engagement with people

with intellectual disabilities and academics doing research inclusively, Nind and Vinha (2014) identified factors that were important to relationship building: talking things over, sharing skills and knowledge in working things out, sharing a purpose, spending enjoyable time together and opening new opportunities for each other. Differences in power and experience were handled through providing support, lengthy negotiation or recognising interdependence.

In this paper the focus is on how academics and people with intellectual disabilities have initiated and sustained research relationships. Utilising a convenience sample—those research relationships of which the Anglo Norwegian authors have direct experience—we include reflective accounts from both sides of the relationship, those with intellectual disabilities and those with academic roles. This is less about researcher positionality (as insiders or outsiders) as about our relationships as 'alongsiders', a concept developed by Carroll (2009) in the context of video-ethnography and video-reflexivity in hospital research. The concept reflects her feminist research concern with being an agent of change, of wanting to support active participation of research participants, being honest and reflexive. This is captured in the idea of 'feeling alongside' and 'looking alongside' (rather than at) participants. In inclusive research, researchers with different skills and life experiences explore alongside each other and alongside participants; they align themselves to each other and a shared purpose. This paper discusses what kind of relationship-building supports this stance.

The Narrative Method

We include narrative accounts of five inclusive research relationships here; the first three from Norway, and fourth and fifth from England. There is a long tradition of using narrative approaches in intellectual disability research. Narratives have been collated and examined to present alternative histories (Atkinson et al. 1997; Walmsley & Jarrett, 2019), to explore identity (Atkinson et al. 2000) and to destabilise intellectual disability grand narratives of deficit and deviance (Goodley 2001). Narratives give voice to lived knowledge and offer the potential for new hybrid discourses to emerge (Roets et al. 2007). As Andrews (2007: 10) has pointed out, narrative research is also 'broad and flexible' enough to accommodate multi-disciplinary endeavours such as this paper, which brings together experiences across the social sciences and humanities.

All but one of our narratives comprises reflections from both the academic researcher and the disabled researcher. We have used pseudonyms because regulations to protect vulnerable people in Norway necessitate anonymity, including concealing place and project names. This illustrates the tensions between protection and empowerment which haunt inclusive research. While there were no such requirements in England, as part of the ethics protocol required and approved by the Norwegian Centre for Research Data, the authors with intellectual disabilities consented 'to help to write an article together about working with the researcher', 'to answer questions about my work with the researcher', 'that the researcher can write about her work with me in the article', 'that my name is on the list of authors', and how personal data would be used. The academics wrote their own narrative accounts, while the narrative accounts of the people with intellectual disabilities were generated through a supportive process. This involved a researcher other than the person they do research with asking specific questions to generate an account that the person could reflect on and check. In advance, the academic authors agreed on the questions to address, including about how the relationship was initiated, established, developed and sustained, the potential obstacles or conflicts and how they were resolved. We created an accessible interview guide to support the process. The authors reflected on a relationship that stood out as the first such research relationship, or one that lasted a long time or developed from friendship, because it was challenging or creative, or sometimes a combination of these factors.

Analysis of the narratives was conducted by the academic researchers and followed a set of questions linked to the interview guide. We were looking at what the stories emphasised, what qualities in the person or relationship were valued, how the relationships were sustained and how conflicts were resolved. The analytical process and its readings were inspired by the work of Fjetland (2015, 2019) with an emphasis on description of results and interpretation. The iterative analytic process is summarised in **Table 1**.

Table 1: Analytic process.

First round: open, naive, intuitive reading	Second round: thematic reading	Third round: discursive reading	Fourth round: interpretative reading
What characterizes the research relationship?	How are the relationships initiated?	What conflicts are described and how are they resolved?	What are the qualities of the alongsider research relationships?
(General characteristics of research –relationship)	How are the relationships developed and sustained?	Any other challenges?	What challenges are depicted in the narrative accounts?
	(General characteristics of research relationship)	(Responsibility, fear of harm, power imbalance, equality, end of relationship?)	

Narrative Accounts of Relationship Building in Inclusive Research
1. Norway: Shared perspectives from Brittany and Anna
This part is written together by the academic, Brittany, and the co-researcher, Anna, based on extracts from a book they wrote together.

We have known each other since we grew up in the same neighbourhood. Brittany knew that Anna had many friends, was good at telling stories and was a good team player. The conversations we had about friendship became a good start for us to write a book. It was important for us to decide together how the book would be. Neither could write the book alone. Anna's job was to decide what stories the book should contain. Brittany's job was to encourage Anna to gather her experiences and feelings into words.

Initially, we sound-recorded our conversations. The idea was that Brittany should write what Anna said and read it back. Brittany wrote about what Anna said, but we realised that we wanted the book to be Anna's words and not what Brittany wrote about her. We came on track when Brittany started writing while Anna spoke about her experiences. Anna corrected and edited the text. Anna had a printed manuscript, but she wanted us to read the text together, as that made it easier to understand and to change. Every time we met to write, we re-read what we wrote last time. This gave Anna ideas for new stories.

Often, it was easier to work with the book and make important contributions when we were together for several days. The cooperation gave us the opportunity to experience something good together. When we did things we liked, it was easier to work on the book.

The staff in Anna's home were helpful when we planned writing trips. Anna advised them when we were going to travel and where, and the staff helped her with packing and getting on the train. However, if Anna came home after ten o'clock in the evening, her father had to collect her from the station as there was only one person at work.

During the writing process there were new experiences that Anna felt insecure about. However, when she chose pictures for the book, she was quite sure which pictures she wanted. People who know her say that she became more confident after the writing started.

Sometimes, it was difficult for Anna to find words. When she was completely stuck, Brittany made suggestions, but Anna always found her own way of saying it. When we read large sections of the book together, we often found more changes we had to make. Anna would say, 'It was not quite the way it was' and Brittany would ask, 'What do you want me to write instead?'

Brittany had once been Anna's service provider, but it was important that Brittany was not Anna's staff when we wrote the book; it made it easier to be honest. Because we know each other well, it was hard to find the boundary for what was right to share with everyone. We asked for other people's opinions in such situations. At the beginning, Anna decided where the different stories should be in the book, but in the end, Brittany did the last rounds of editing and text placement. She never changed the content without Anna's agreement. Anna read and approved each word in the book.

Anna was the driver behind getting the book done. We are a good team. Our respect and love for each other increased in line with each new page we wrote together. We still work together with research and presentations, and we are still very good friends. We talk almost every week. Anna is an important discussion partner in many things Brittany is doing as a teacher and researcher.

1. Norway: Co-researcher Anna
A trusted staff member conducted this interview with Anna. The interview was transcribed verbatim and translated to English.

What made you say 'yes' to work together with Brittany this time? She asked me. I wanted to continue the collaboration and try something new.

Is there anything you want to say about Brittany that you think is important for others to know about? I think we enjoy working together. We travel together. We have good time together. We are active together. We call each other. She is nice to talk with. It is easy to keep in touch with her. It is always exciting when we are together. I experience many new things together with Brittany. I enjoy being together with her. We work in a café. I like that.

What do you think the collaboration has been like? Very good. We know each other very well. We have close contact.

Is anything boring or difficult about the collaboration? No. We both come up with suggestions. I have good ideas and she has good ideas. We cooperate. I am interested in the same things as her. We exchange and take up matters. I'm happy with that. We never disagree. We solve things together. I'm not afraid to say either. We have the same values. She is important to me.

2. Norway: Academic researcher Yvonne
I met Oliver a few years ago, while working at a supported living facility for people with intellectual disabilities. We discovered we had a lot in common and enjoyed spending time together. I got to know Oliver's wishes for the future, and I started to think about doing research together with people with intellectual disabilities to explore everyday life topics together.

Conversations with Oliver and his curiosity to explore some topics inspired a research project application. This emphasised inclusive research and exploration of the issues of relevance for the everyday lives of people with intellectual disabilities, initiated by them.

In the project, I worked with two groups, and Oliver was a member of one of them. I did not approach him directly but through staff, because I did not want to influence his decision. This was due to ethical considerations but could be perceived as paternalistic. In both groups, we worked within the framework of participatory action research, with emphasis on cooperation and co-production. We talked about our lives, mundane activities throughout the day, leisure activities etc., before we discussed the topics we in the group wanted to explore together. Oliver was an active contributor and mentioned some of the same issues we were talking about when we first met a few years ago.

I hoped that researching together might bring different perspectives on the topics and give some answers to the co-researcher as well. Even though I knew Oliver well, I could not be sure if this way of working together would fit us or if it would put our relationship at risk. Nevertheless, it was important to try. Knowing each other before the start of the project could be both a plus and a minus. It was important to reflect on this before and during the project. I discussed the pros and cons, ethics, moral actions and vulnerability in colleague supervision.

My relationship with Oliver changed and probably grew stronger during the project. We are now both colleagues and friends. We went from email communication, including one or two staff, to direct email communication between just the two of us. I was anxious initially, but I am now sure that it was right to include Oliver, as he is now participating in new projects and still enjoys research very much. I did not want to put our relationship at risk and did not want to cause Oliver any trouble or harm. There were many layers of both risks and gains, responsibility, power imbalance, having faith in the co-researcher and willingness to change our relationship. His 'I'm already looking forward to the next meeting' was reassuring.

The research group developed and grew into a version of a self-advocacy group. In addition to researching, we discussed other issues brought up by members, such as how to tell support staff what they do not like or how to approach a specific problem. Researchers' relationships have many functions, not only as researchers and colleagues but also as supporting staff and friends. When it comes to my relationship with Oliver, the original project has ended. He is now taking part in two new projects and thriving in the role of researcher.

2. Norway: Co-researcher Oliver
Yvonne's colleague conducted the interview on which this is based. The interview was recorded and transcribed verbatim. This is taken from the transcript.

I got to know Yvonne when she started to work where I live. She worked there for a while. She is nice and kind. I do not remember when it was, but it has been a while. Yvonne is very kind, nice, listens to people, likes to help people, and respects people, very helpful and good, you can trust her and feel safe. During the time Yvonne worked at my supported living facilities, we spent time together during the day and sometimes in the afternoon after 3 pm. We did different things together mostly everyday life stuff.

When it came to the project, Yvonne asked my contact people, then they asked me if I wanted to participate and I said yes. I have not regretted. No, it went very well. It was not easy all the time, but it went very well. We talked about how it is to live in places, how we are on a daily basis, how we feel, and different stuff. I think it was very good; it was positive and pleasant to meet other people. I was very nervous the first time and afraid. Nothing was difficult. Everything went well. It was nice. We asked questions and wrote down how things were. Everybody got to say what they meant, how they felt, what they thought. There was nothing I thought of as difficult. Everything went well. When it comes to how we decided the topics, Yvonne came up with some ideas at first then we had ideas about what we wanted to say. It was both Yvonne and us. I do not remember everything I said but I said quite a few things during the research project. I do not think we could have spoken about other topics; I do not know what it could be. We always agreed. I like to be with Yvonne; it feels like you can be yourself and it feels as if you can trust Yvonne and feel safe so you think you can be open and be yourself, I really enjoy being with the researcher. I trust Yvonne, so it is very nice.

3. Norway: Academic researcher June
I met Mike when I was interviewing persons with intellectual disabilities about self-determination. His level of reflection interested me; he discussed different views of the situations in filmed vignettes and related these to his own life, both the similarities and differences.

In a new project, I had to recruit a co-researcher and Mike was the first to come to mind. Mike was very interested. He said yes and we became a team. We travelled together to meetings, staying at hotels. Sometimes we also met other participants in the evenings, but on several occasions it was only Mike and me. This brought us quite close, getting to know each other well. During dinners, we discussed politics, football, news and how we liked to live our lives. We talked a lot. Since we did not bring an assistant, I helped Mike in matters like medical assistance and booking tickets.

At the time when we got funding for a second project, I moved to another part of the country. Nevertheless, I continued as the project manager, and met Mike quite often. We also talked by phone. It was sad to split the team, but we were both pleased to meet in project meetings. The last year of the second project we were invited into a third project about assistive technology.

Mike and I have worked together since 2011, in three different projects, also lecturing together and collaborating in translating official documents into an easy read. He is remunerated for his work.

Although I assisted Mike when travelling, we agreed that I would not be like his assistant, but a colleague. We talked about colleagues helping each other. This has worked both ways. Once I ordered a wrong ticket for the plane, luckily Mike discovered that and told me. Sometimes we quarrel and bicker, but we also talk a lot and laugh a lot; we are partners.

When we worked on two parallel and quite similar projects, I think it sometimes was too much for Mike. But now that the third project is ending, he thinks it is too little. He says that as long as he can work with me, he will.

This is a long-lasting relationship that has given both of us insight into each other's lives, and we have found good ways for collaborating. We learn from each other, and we know each other's difficulties and priorities. It is also about a person's experiences of being empowered by participation in research and being a teacher. As Mike answered when he was asked about his participation: 'It feels good to be a part of society'.

3. Norway: Co-researcher Mike
June's colleague interviewed Mike, writing down his answers. June went through the transcript with Mike. He also read June's narrative and asked her to change one part.

We got to know each other in 2011. I was interviewed about a film and if I thought that the person in the film was self-determined or not. Later I was asked to participate in a research project. I thought, why not? And I said yes because it is nice to get out of day-care centres and try another kind of work. I think it was June that asked me, because she thought of me.

The first two projects, co-researchers participated because they knew how it was to receive help at home. The last project I had to think a lot about. It was about not being able to talk, and having assistive technology. Because they were without spoken language, it was not quite me. Then I thought about a friend of mine, who I have known for some years. He has lost some of his language, and sometimes uses a wheelchair. That experience made me say yes.

I think June is a cracking good research manager and mentor. She is very smiley, nice, and easy to get to know.

We collaborated about analyses in the projects. And we have planned travels, hotels and budgets. I need some help with my budget and travels for our meetings and conferences. I think our collaboration is nice. We take everything with a smile and make things work.

I cannot really come up with anything that is boring or difficult. It can be cumbersome after June moved to another part of the country. Because, then I do not travel together with her, and we have to find other ways. Sometimes it is hard to participate, difficult or boring if I do not manage. It might be analysing. Or talking about the same things over again.

She is the researcher and decides what we should do, and then I have to answer if I agree, and then we start. It might be that she starts, and then I get going and then I also decide. You know, that is her motto: Self-determination!

[Are you interested in continuing cooperation with June?] Yes, yes, yes, absolutely.

Everyone has the right to have different opinions. Neither of us wants to start a conflict if we disagree. Maybe she finds another way to explain, to make me reconsider. She helps me to formulate my thoughts in another way, to think more carefully about things. First I disagree, than she says something, and I think 'that is ok'. If she disagrees with me, she says things that make it easier for me to reformulate. But that's not the same way with others. With another one I can be stuck more than necessary. June is cracking good in helping me to think more about things. I need a couple of conversations to think more about things. How to say things, if something is wrong, how to do that.

[Why it is important for you to cooperate with her?] To manage to function in all projects, and whatever we do, to make me function. How we work together. It is extra, extra important to work together with her after she moved. To maintain our contact so it does not fade. I do not want to lose our contact.

4. England: Academic researcher Danny
In 2012–2013, I undertook a study with another researcher to explore what welcoming communities look like for adults with intellectual disabilities. We began working with a local advocacy organisation and a core group of four adults with intellectual disabilities to record their experiences over a year. We conducted repeat focus groups which enabled us to build relationships with each participant. We also gave everyone disposable cameras to photograph the places where they liked spending time. One of the participants, Mason, shared his experiences of going to football games, saying he felt he 'fitted in' as a fan. At the final meetings we co-produced the analysis, and an exhibition of the photographs and findings. Mason was actively involved, suggesting ways to generate publicity, and ideas for the venue.

We undertook a second project in 2015, where we sought to employ two adults with intellectual disabilities as co-researchers. I invited Mason to become one of them. The research was about the experiences of middle to older age adults with intellectual disabilities. Mason helped shape the interview questions and interviewed other local adults.

On completion of the project, I was keen to stay in touch with Mason as he had shown a strong passion for making a positive difference, and had similar interests to me in gadgets and football. I successfully applied for a small impact grant to co-establish a disability platform to maintain linkages with Mason and other local disabled people and their representative organisations. This enabled us to fund workshops and seminars with people we had met in previous projects, including Mason.

The members helped to co-produce the activities of the platform. Mason co-presented findings from our previous project at the launch. The grant also enabled us to build international connections with the colleagues in Norway with whom we are writing this paper.

Payment for members became an issue as the University refused to pay for vouchers over the long-term, and monetary payment provided obstacles to some members' disability benefits. I bought Mason an iPad as payment in lieu. Funding cuts began to put constraints on the advocate-facilitators, who often missed meetings due to other urgent commitments, reminding us that inclusive research relationships are a precarious resource to manage. Despite this, in 2017, the platform helped inform a successful national research council grant proposal. Mason continues to advise on the design of this project and the platform supports the local relationships involved.

4. England: Co-researcher Mason
A colleague of Danny and Mason interviewed Mason, audio-recording his answers and translating them into a narrative account. She sent this to him to check and double checked again when they met whether he wanted any changes.

I first got to know Danny through the advocacy organisation when he came to a meeting to talk about the research. A lot of us volunteered. It was about places and towns and what you did. We ended up presenting the research at the town hall together. I think we've worked together since 2012.

I thought I could work with Danny because of his enthusiasm for research. He's got an approachable nature. Thinking back to the beginning he made it interesting. We had pocket cameras to take pictures of things that meant something to us. When he came back with another project idea I thought, yeah, go for it. We've got to know each other—he builds bonds with people. He allows you to speak and put your ideas—your frustration at what's going wrong.

It's good now to work with people from the University, that's really interesting and meeting people from People First, it's not all rosy for them, but they have big social events. For me now, money's really tight so I don't get out so much. The research work has been paid through vouchers which has helped me get some electricals and Danny's putting money towards a device. Danny is good in that way. Trips over to the University mean I get to see what's going on. The topics that Danny has come up with have been very interesting and important. If someone new asked me to do research I would be interested. If you think about it, before 2012 I'd never met Danny.

5. England: Academic researcher Lucy
Lucy narrated her experience, but co-researcher Emily opted not to contribute her account.

Our three-year project was focused on researching the co-production of an inclusive archive of intellectual disability history. We secured funding to build a research team that included academics, two post-doctoral researchers and an intellectually disabled researcher.

This was the first time a UK University had research council funding to employ an intellectually disabled researcher on the same terms and conditions as a post-doctoral researcher. The aim was both political and ethical. We wanted to demonstrate the value of lived experience and set a precedent for intellectually disabled people to be remunerated fairly for their contributions in academic research. It was to signal equality in employment rights, but also equality in research relationships. The project also had funds to pay a personal assistant for the disabled researcher.

Things got off to a shaky start. The University required persuading that the project should advertise specifically for a researcher with intellectual disabilities, and that its standard recruitment materials and processes needed adaptation to make them accessible; this delayed the project start date by months.

Eventually we pulled together the core team and hired Emily, our intellectually disabled researcher. Although Emily did not have much research or self-advocacy experience, she was passionate about history and making information accessible. While we were in the process of recruiting Emily's personal assistant, support was provided by Anne, one of the post-doctoral researchers. They worked very closely, undertaking an inclusive literature review, designing workshops and promoting the project at conferences. Much of this was new to Emily, who required a lot of support, including emotional support. She was quite anxious in these first few months. They developed a close rapport, prompting innovative work as the project progressed.

My own relationship with Emily developed more slowly. Much of my time on the project involved administrative, financial or management issues. Delays to the project start date and early team meetings that Emily did not find accessible created tensions which I felt a responsibility to resolve. The three researchers (along with Emily's assistant once she was in place) developed strong working relationships and became 'a team within a team'. They spent time together and communicated regularly by Skype. My perception was that challenges in managing the work between them were dealt with sensitively, kindly and with good humour. Emily and Anne both had a strong interest in involving people with profound and multiple intellectual disabilities in the archive and led this strand of work.

When Emily's personal assistant left a few weeks before the end of the project, Anne and I agreed with Emily to cover the support role between us. By that stage Emily was confident in the job. We worked together productively, analysing data, co-writing an article and organising/archiving the project material. We ate lunch together and talked about our lives, our families and our holiday plans. Emily still referred to me as 'the boss' (a nickname she coined in the first few weeks), but our relationship changed. I experienced that with calmness and time, co-researching can be a

hugely stimulating, creative and enjoyable process. I reflected that much of my time on the project had been focused on schedules and outputs, and this had influenced my interactions with Emily. I'm pleased that we had the opportunity to redress this towards the end; I only wished we'd had the chance to do it earlier.

Discussion

The five research partnerships that form our narrative data sit on a spectrum—from a friendship which blossomed into a writing partnership (#1) through to a full blown salaried research post and boss-employee relationship (#5). In between was one collaboration which started as a service provider-client relationship and migrated into a friendly research relationship (#2) and two where academic researchers talent spotted people who had previously been involved in self-advocacy or research (#3 and #4). Four of the five relationships are medium to long term, spanning several different projects. Only the fifth, where the researcher was salaried, was confined to one three-year project, ending thereafter.

Our purpose in gathering and analysing the narratives was to reflect upon ways to foster relationships which support inclusive, alongsider research, where academics work alongside researchers with intellectual disabilities in conducting research, and to ask what supports such relationships. It was prompted by the absence of self-advocacy or user-led organisations in Norway to partner academics seeking to do inclusive research. The narratives indicate a range of ways to initiate alongsider research relationships. Other than in #5, no formal interview, scrutiny of skills or qualifications is mentioned. Pre-existing relationships were sufficient for the academic to ask an intellectually disabled person to work alongside them. These pre-existing relationships came from friend-friend, staff-client or researcher-researched beginnings and therefore they had to evolve and transform to become alongside in nature. Only in #4 did the co-researcher come from an established advocacy organisation, and even there it was based on a personal relationship. While self-advocacy groups could not be the route to growing intellectually disabled researchers in Norway, in one of the Norwegian examples (#2) the opposite was true and research involvement grew a kind of self-advocacy group.

In four of the five examples, relationships grew organically. The relative informality of the projects made this possible and there are lessons for others in this. The difference from #5 is striking. Emily was appointed through a formal selection process to a salaried post. Timescales meant that the relationship could not evolve organically in the same way and the sense of feeling alongside each other was quite different.

The five accounts show that building alongsider research relationships is a slow burn, something also commented upon by many practitioners of inclusive research including, most recently, Frankena et al. (2019). The personal dimension is central to this slow development. The academic researcher is described, variously, as 'kind', 'gentle', 'nice', frequently but not always providing friendship as well as a professional relationship. Reciprocity is stressed, as are common interests. They enjoy one another's company, share time out together. Shared interests and fun, positive experiences help to consolidate the relationships. There is also an element of caring through small acts, which helps sustain affection and trust. These elements help sustain the relationships in the absence of funding. In #5, this is less clear because we do not hear from Emily, who declined to contribute, having moved on since her employment as a researcher had ended.

The external context plays an important part. Often relationships started off informally, but in the English examples particularly, finances for continued research played a part in sustaining the relationship. However, it is Danny's personal qualities and commitment, not money, that encouraged Mason to think he would like to do more research. The relationship in #5 survived as long as Emily was employed as a researcher. Beyond the end of the project Emily was happy to be friendly, have a coffee or a chat, but not to put in unpaid work writing for this paper. One might describe this as a more instrumental relationship.

Working alongside each other, the need for support always needs to be tailored to the situation. In the Norwegian examples practical support is provided by the academic researchers, perhaps influenced by their previous support roles prior to the research. In the English examples, practical support is ostensibly paid for separately from the academic research role. Nevertheless, in both, academic researchers played a critical role in creating and sustaining the relationships. Whatever form inclusive research takes, with or without the support of an advocacy organisation or other staff, support is inherent to the relationships; it cannot be fully outsourced to personal assistants or others.

Other than in #5, the research experience began with the researcher with intellectual disabilities reflecting on his or her own life. In #2, #3 and #4 they gradually migrated to considering other aspects of the lives of people with intellectual disabilities, sometimes on matters of which they had no direct experience; #5 was again different. Emily was appointed because she showed a passionate interest in history at her interview, and she was highly motivated to explore issues of consent because she could see how they impacted on people she knew well.

In returning to Carroll's (2009) concept of the alongsider, we observe that in the literature on the process of doing research inclusively, authors have mostly focussed on the dynamics of working alongside each other as researchers and, for more activist research, standing alongside each other in solidarity. This reflects the much-rehearsed questions about who the research is with, by and for. The narratives in this paper, though, more illustrate Carroll's dimension of *feeling* alongside being enjoyed by the people on both sides of the relationship. This came through the longevity of many of the relationships and appeared to grow as the relationship grew. Moreover, this supported the transition into new research projects. We suggest that the alongsider concept merits further attention in work developing and examining the added value of inclusive research.

External factors, along with the way the research is conceived and funded, emerge as crucial in determining how the relationships develop. Where the work was informal, unfunded, mutually determined, there was the luxury of time, to get to know one another, to get things just right. Where there is funding and a timetable, the relationship building has to be managed differently. These accounts do not discuss the difference in education level between researchers with intellectual disabilities and academic researchers, differences which may lead to asymmetrical relationships. None of the narratives directly addresses the question of power, which has been such a point of debate in the literature on inclusive research (see e.g. McClimens 2008; Ellis 2018). Whether negotiating power dynamics was an issue in the research itself, it appears not to have been a factor in the long-term relationship building which features here. The reasons for this are unclear. It may be that alongsider relationships were achieved, including relationships built on equal employment in the case of #5-or built on genuine affection and mutuality as in the other cases-thereby helping to ward off disagreement or conflict over research processes, methods and findings. It is also possible that the relationship is so valuable to both sides that no one wants to risk dissent. Being regarded as more than a 'service user' matters a lot, as does being a researcher who is inclusive.

Contextual influences may also constitute a form of power, including the facilities for carrying out the research, the opportunities the co-researcher is given and the beliefs (theories and values) of other people. The properties possessed by the social and cultural forms, such as the academic research environment, administrative systems at the University, work tasks and everyday life situations, may be very different for co-researchers than from those possessed by the academics. The academics have to negotiate these in order to be able to work productively with intellectually disabled researchers, whether this is adapting employment practices (#5), finding ways to pay the co-researcher (#4), or simply negotiating with ethical committees (Wikgren 2005). The academic must organise the "institutional response" which makes it possible for the co-researcher to exercise any power (Payne 1997). Further reflection is needed to explore how alongsider research by people in close, long-lasting working relationships permits or inhibits disagreement and difference, possibly through inviting an observer to research meetings and conference presenting, with a view to commenting on the way power is used.

Finally, the implications for these findings for researchers who may not have such alongsider relationships already need to be considered, given the pressures in some countries to co-produce. Our findings suggest that investing time in building such relationships incrementally ahead of attempting large scale research projects is important for researchers doing research inclusively with people with intellectual disabilities.

Conclusion

This paper moves the discussion on research relationships in inclusive research beyond who holds the power, deliberately echoing the way Carroll (2009) positions power in the Foucauldian sense as shifting and uncertain. Instead of making the research participants or the co-researcher relationships the objects of academic scrutiny, we have tried to bring narratives about those relationships alongside each other and into dialogue. Reflecting on the five examples alongside the academic authors' broader experience in inclusive research, we propose that to build insightful, alongsider perspectives—where researchers from different standpoints investigate and reflect upon aspects of their own lives, and those of others—there needs to be a sustained relationship based on mutual respect, even liking each other. Developing this involves making the communication effective so that people can express themselves and understand each other. It involves building feelings of equality and trust, which enable all the parties to use their best resources. This is a positive, informed handling of the power issues. Money and resources help, but the relationship depends on more than material recompense. Time is needed to relax into relationships that are allowed to build slowly and organically. Sharing an interest or a purpose also plays a role. External constraints, such as timetables, funding and research topics, can get in the way.

Competing Interests

The authors have no competing interests to declare.

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