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Crippling Collaboration: Science Fiction and the Access to Disability Worlds

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ABSTRACT

Inclusive participatory approaches strive to make participants with mild intellectual disabilities (MID) co-researchers. However, academic standards of knowledge production and the need for cognitive skills can complicate collaboration. I argue that collaboration with people with disabilities is not about efforts of inclusion, but instead, it is our methodologies that need to be “crippled.” This means moving away from the ideal of inclusion, toward a more interdependent and relational understanding of access and collaboration. This multimodal article shows how my “research subject” Olof and I explored this way of working together by describing the coproduction of the science-fiction film “O.”

DUTCH ABSTRACT

Onderzoekers streven naar de inclusie en participatie van mensen met licht verstandelijke beperkingen (LVB) in onderzoeksactiviteiten, vaak door ze mede-onderzoeker te maken. Tegelijkertijd maken academische normen en de cognitieve eisen van het onderzoekswerk de samenwerking met mensen met een LVB in wetenschappelijke praktijken moeilijk. In dit artikel beargumenteer ik dat samenwerking met mensen met een handicap geen kwestie is van inclusie in een set van normen die niet bij ze passen. In plaats daarvan moeten onze methodologieën “gecrippled” worden. Dat betekent dat we op zoek moeten naar een meer relationeel begrip van samenwerking, waarin ieders sterke punten en beperkingen ruimte kunnen krijgen. Met dit multimodale artikel laat ik zien hoe mijn “onderzoekssubject” Olof en ik hiermee aan de slag zijn gegaan door samen te werken aan de science-fiction film “O.”

KEYWORDS

Collaboration; crip theory; ethnography; intellectual disability; science fiction; visual anthropology



KEYWORDS

Crip-theorie; etnografie; licht verstandelijke beperking; participatie; science-fiction; visuele antropologie

Before you proceed

This story is not only told through text. The sections of this multimodal article are supported by film clips. The camera on your smartphone can read the QR codes in the text. A link to the video will pop up on your screen!

PS: If you do not have access to this technology, you can find a list of hyperLinks to the videos in the appendix of this article.

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Media Teaser: Taking collaboration with people with disabilities seriously means not imposing “ablist” forms of research, but making space for what people like and are good at.

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Please, watch the trailer of O the movie:



SCAN ME



O [the script]

[AMSTERDAM – EARLY MORNING]

A man dressed in a brown canvas bodywarmer and a shirt as blue as his eyes slowly cycles his way to work. On his head of gray hair he wears a flapless cap with the words: Sail 05. His name is Olof.

He exits the city through a landscape of meadows next to a busy highway. The summer morning sun shines in a cloudy sky. He cycles up a hill. When he goes down, we hear the sound of the loose strap of his bicycle bag ticking against the spokes of his wheel [tiktiktik].

Then, suddenly, an Unidentified Flying Object appears from the clouds and lands in the meadow right next to Olof and his bike! Olof looks up, stops, gets off his bike and in total amazement watches the enormous silvery saucer land [dramatic music playing in the background].

The door of the UFO slowly opens. Two aliens, gray with googly black eyes, come out of the ship and make contact with Olof. The aliens explain that they are on a mission to offer their Super Advanced Technology to humankind as a gift and a friendly invitation to planetary collaboration. As they do not know the workings of the human world, the aliens ask Olof to be their human guide in this process. Naturally, he says yes.

With Olof as their new captain, the crew flies off to visit the United Nations (UN), the European Union (EU), and the National Aeronautics and Space Administration (NASA) to negotiate contact and possible collaboration between aliens and humans. Unfortunately, these human institutions refuse to work together with captain Olof and the aliens for different reasons.

At the UN, people are too busy to even notice alien visitors. At the EU, people get scared of the aliens and run away screaming. At NASA, the organization is enthusiastic about a meeting with the aliens at first – but then refuse Olof as a guest because he is considered to be “too under-educated” to attend a gathering of such great importance. As their beloved captain is rejected, the aliens refuse to come to the NASA meeting as an act of protest. “If our captain can’t go, we don’t want to go!” they say. Finally, the group has had it with all the human institutions and decide to go on a world trip together instead.

The end

~

This is the storyline of “O” the film. While this story has been re-told and re-written many times, it is situated at the heart of the collaboration between me and Olof ten Have.

I met Olof in 2019 through my volunteer work at a social care organization for people with mild intellectual disabilities (MID¹) in Amsterdam.² At first, I got to know Olof as the man sitting by himself in the corner. But one day, Olof took a camera with him to the table of our neighborhood dinner, and it connected us. Curious about his passion for filmmaking, I joined Olof to a film club for people with disabilities. That day, I learned that we shared a passion for creating visual imagery, and a love for science fiction. And, that he had a fantastic idea for a film.

I was fascinated with Olof’s story. It is not just a story about aliens and UFOs, but also about disability and facing institutional rejection because of it. I see it as a story about exclusion and failure, but also as a story about friendship, solidarity, and protest. As Olof is rejected by the NASA meeting officials, the aliens remain loyal to their captain and refuse to collaborate with the institutions that ignore or reject him. In the end, excluding Olof ensures that the human institutions (and humanity more broadly) miss out on the great gift of alien technology.

Doing research on access to care for people with MID, the metaphors I saw in Olof’s story resonated with the themes I wanted to explore in my project. With his idea for this science fiction film, Olof not only offered me a new way to approach my research in the quiet and inaccessible times of COVID-19, but also a way out of my struggles with the question of collaboration within the field of disability studies.

A recurring problem in collaborative disability research is that academics doing research with people with MID want to enter collaborative partnerships, and include them in research activities. At the same time, traditional research practices are often the opposite of what people with intellectual disabilities want, like and are good at (Brueggeman 1996, in Price and Kerschbaum 2016: 23). Academic practices require very specific cognitive, intellectual, and linguistic skills. As people with MID are usually excluded from educational trajectories precisely because they do not possess these skills, this paradox continues to obstruct collaborations between academics and people with MID (Atkinson 1997).

So how to go about collaboration when the demands of academia do not match the needs and talents of people with MID? Many contemporary writings are focused on how to overcome the barriers to collaboration, and *still* include people with MID in research practices. But throughout this field of research, it is the researcher’s perspective and the nature of academic practices that continue to frame the terms of collaboration. In other words, studies on collaboration have to date focused on how *they* (people with MID) can join *us* (scientists) in *our* modes of knowledge production.

This paper revolves around the question of how to do collaboration otherwise. How can researchers build collaborative relationships in a way that attunes to the needs and talents of people with MID and is open to mutual learning? Answering this question, I aim to show how the notion of “cripping” is a much more fruitful methodological concept than that of inclusion when it comes to collaborating with people with MID. As inclusive collaborative strategies tend to presuppose that people need to adjust to norms and practices that are outside their life worlds, skillsets, and comfort zones, in this article I argue for radically reimagining collaborative methodologies: for “cripping” collaboration.

Before expanding on the arguments and interventions that I make in this article, let me first take some time to explain my research problem. Or, better said: my problem with inclusion.

The paradox of inclusive research

Since the 1990s, collaborative approaches have become increasingly emphasized within disability studies. The slogan “nothing about us without us” (Charlton 1998) came to represent the view that informants with disabilities should be considered as more than mere subjects of study, but are to be

seen as active collaborators joining in the process of knowledge production (Gilbert 2014; Johnson & Walmsley 2003). This brought about new participatory or inclusive approaches that strived to involve people with disabilities as co-researchers – who participate in the design of the study, co-formulating research questions, conducting interviews, and analyzing data (see for example: Bigby et al. 2014; Embregts et al. 2018; Nind 2017; Sergeant et al. 2022; Johnson & Walmsley 2003).

Since this collaborative turn, lots has been written about engaging people with MID in research practices. While striving to involve and give control to people with MID in every stage of the research process (Sergeant et al. 2022: 185), studies on collaboration point to significant challenges³ that need to be faced when working together with co-researchers with MID. These challenges include: difficulties in communication, a lack of institutional infrastructures to facilitate the inclusion of research partners, the risk of reproducing unequal power relations, problems of ownership over the research, the risk of overburdening co-researchers with MID, and – last but certainly not least – the ever-present risk of tokenism (Bigby et al. 2014; Embregts et al. 2018; Nind 2017; Nind and Vinha 2014; Sergeant et al. 2022; Tregaskis and Goodley 2005).

At the heart of the obstacles to collaboration lies an issue that often remains undiscussed in inclusive research: traditional academic practices are often not at all accessible for people with MID. The practice of (social) science traditionally demands specific verbal, linguistic and intellectual skills such as interviewing, analytic thinking and writing. These demands of competence make possibilities of collaboration with people with intellectual disabilities difficult and the terms on which to collaborate unequal (Atkinson 1997; Bjornsdottir and Svendsdóttir 2008).

My problem with strategies of inclusion, which is a problem for many crip and critical disability scholars, is that these strategies implicitly understand collaboration as a matter of assimilation. Assuming that collaboration is about people with disabilities accessing a particular space, a practice or a particular social group, these scholars implicitly impose the assimilation of disability into practices, environments and relations in which the norms are already set, and which people with intellectual disabilities had no part in creating. In this way, the notion of inclusion always implies an adaptation to able-bodied, middle-class, white, productive, neurotypical, (hetero)normative, academic relations and environments (Hamraie and Fritsch 2019: 10). In other words, inclusion assumes that all is good when people with disabilities join able-bodied folks in the things they do. But the problem is, people with disabilities often cannot, or do not want to do this. What if it is us who need to change, not them?

Crippling collaboration

This article is, first of all, a plea against co-researcher constructions and a call for “cripping” collaboration. Building on the work of feminist, crip, and neurodiverse scholars,⁴ I argue that collaboration with people with MID should not be about efforts of inclusion. Instead, it is our methodologies that need a radical reimagining that is not just in tune, but arises from, the lives of our research partners. It is our methods that need to be crippled⁵ (Price and Kerschbaum 2016: 24).

To crip methods means to radically reconsider the methodologies we draw upon (Price and Kerschbaum 2016: 21, 24), which tend to derive from the traditions of our discipline rather than from the field of study. Crip methodology instead aims to center the work of disabled people as knowers and makers, and to take seriously the question of how to make epistemological space for “crip knowing-making forms” (Hamraie and Fritsch 2019: 7).

Considering the inaccessibility of scientific practices for Olof, who cannot read or write text, it did not make sense to ask him to join me in doing academic research. Besides, Olof had a much better idea of what we could do together. Instead of doing the co-researcher thing, I wanted to join him in realizing his fantastic idea of making this science fiction film. Taking on Olof’s project instead of involving him in mine, I wanted to see what would happen if we made something different together. Something that would be centered around Olof’s interests and talents. Something that would be out of my professional comfort zone as a researcher.⁶

Parting from the idea that Olof had to join me in making science, making fiction together became my method to learn about his lifeworld (Jackson 2012) and his position in society. But the decision to go ahead and make our film was only the beginning. As we started to engage in new and unfamiliar practices, we still needed to learn how we could collaborate. The question is thus not only why to crip collaboration, but also *how* we criped collaboration in practice.

A note on neurodiversity

While I focus in this article on the “hows” of criping collaboration, this is not intended as a one-size-fits-all guide to collaboration. This is the particular story of two neurodivergent collaborative partners moving sideways in the attempt to make a low-budget science-fiction film.

In telling our story, I join critical disability scholars in viewing disability as a relational and interactive process of becoming (see Kafer 2013; Kasnitz 2020). Instead of fixing disability as a solid fact, it is about recognizing when and how impairments come to surface as problematic (Kasnitz 2020: 18). In this article, I shall explore when and how our labels came to matter – and how we dealt with our differences in practice.

For Olof the most present label in his life is that of Mild Intellectual Disability (MID), and for me it is Attention Deficit Hyperactivity Disorder (ADHD). While these labels are only labels, our neurodiversity mattered in our collaboration. In writing this article, though, I mainly focus on how and when the category and experience of MID became an issue. Not only because it was my goal as a researcher to learn about this, but also because Olof’s impairments came to the foreground as problematic much more often than mine.

Reflecting on our creative process, I have found that “staying with the trouble” (Haraway 2016) is a better strategy than trying to overcome or solve “the problem” of disability (Kafer 2013: 4). Discussing the troubles of our filmmaking process, I will elaborate on how we “stayed” with them, and learned from them. With this, I want to argue that the point of crip collaboration is not about including people with disabilities in academic practices, but about trying to create collaborative relationships in which we can truly learn, do, and make something together.

Moving sideways: collective access and the practice of filmmaking





Taking on Olof's project instead of including him in mine was the first step in crippling our collaboration. The medium of film enabled us to form a collaborative relation in which I, the researcher, was not automatically the expert. Using film as a mode of engagement allowed us to move away from a text-centered approach, and to engage with a more visual kind of literacy. Creating fiction thus helped to level the grounds in our collaboration, but it was certainly not the answer to all our collaborative questions. Because making a film requires many skills and capabilities too.

As neither of us had any experience in making fiction films, the first part of our filmmaking journey was characterized by struggle and failure. The first part of the video (Noobs⁷) captures some of the troubles we encountered in this period. Many times, we cycled to the meadow that Olof had in mind as the stage for our film. But once we arrived, we did not really know what to do. During that time, we shot hours of unusable material and did many things that did not make sense in terms of filmmaking. But being bad filmmakers was still productive – because we built our collaborative partnership by trying. Through our collective struggles, we learned about each other's ways of living, working, talking, and doing.

But still, we had no clue how we could translate Olof's story into a film. How are we going to land a UFO in this meadow? Where do we find aliens to star in our film? How are we depicting those big and inaccessible institutions? We had so many questions that we did not have the answer to. After our failed attempt to learn 3D animation, we processed our defeat in a bar next to Olof's house. "How are we going to do this, Olof?," I remember asking him desperately. We finally agreed that we could not do it all by ourselves. We needed people with experience in filmmaking. We needed someone to tell us what to do.

The challenge and vulnerability of asking for help is something that Olof was more used to than I was – but did not particularly like. Being a person that does not read text, Olof often has to ask for help when he wants to do something or go somewhere. But asking for help is difficult when the right people, institutions, or resources are not easily at your disposal. Observing interactions between Olof and people who were assigned to help him, I learned that Olof often prefers not to be helped. He once told me that as a disabled person, you are always assumed not to be able to do things on your own – and this is exactly why he always wanted to prove them wrong. Even when his house was a mess, Olof preferred being the boss of his own mess instead of being helped by others in sorting it out.

Olof's reluctance to ask for help turned out to be a big challenge in our collaboration. Often, Olof did not communicate his needs and boundaries, and did not ask for help when he needed it. But for me, it was also not easy to ask for help. Just like Olof, I prefer taking on projects on my own instead of accepting help from others. I guess both I and Olof are affected by what living in a neoliberal society does to you. It makes you believe that independence is a goal that needs to and can actually be achieved. While asking for help was not a pleasant thing to do, needs must. We did not know how to make a film and we could not do it by ourselves. We *had* to reach out for allies.

Fortunately, I had many creative friends⁸ who could help us out. As a first and very important step, we asked my friend Sjuul Joosen⁹ to be our co-director. In the second part of the video (Help), you could see Sjuul helping us design and build the UFO for our film. Being a talented artist and a true DIY science-fiction filmmaking expert, we were very lucky that Sjuul agreed to join our team. Without his incredible work in the roles of co-director, camera operator, prop designer, special effects manager, and editor we could never have made our film.

Realizing you cannot do it by yourself is central within understandings of access within crip theory. Instead of reducing access to an individual problem “that arises from the bodies incapable of gaining access” (Fritsch 2016: 31–32), Crip scholars prefer a more collective and interdependent understanding of access. Rather than a mode of solving individualized problems, collective access is about seeing access as a social and interdependent matter. Collective access is about committing to “moving together as crips and comrades, [it is about] achieving things together, [but even more] about being limited together” (Mingus 2010). The notion of interdependency, here, is seen as a central political technology for “weaving relational circuits between bodies, environments, and tools to create non-innocent, frictional access” (Hamraie and Fritsch 2019: 12). Reaching out to our team of experts, we learnt that interdependency was a key ingredient to our filmmaking journey – and to our collaboration.

Learning through mistakes, working with difference



In this second video, we see Olof and I arriving for the very first time at the meadow where the story of the film takes place. Trying to give Olof the lead in our creative process, you hear me asking him open, pragmatic and repetitive questions: “What should we do?” “How can we film this?” But Olof makes clear that he does not know either.

At the time, I thought giving Olof the lead was the right and enabling thing to do. I wanted to make space for Olof’s ideas, his agency, for his say in the project. Playing back this video, I realized that asking someone to take control is not a universal good. It confronted me with my own assumptions about (divisions of) agency and autonomy. What is good for me is not necessarily good for Olof. And in this case that meant that taking the lead is actually a burden instead of a blessing.

Watching this video together provided a means for us to talk about how I could do better in the future. This proved to be a very productive way of improving our collaboration. Olof suggested that instead of asking too many questions, I could give him one clear assignment that he could figure out later – on his own. We took up this idea of giving ourselves individual assignments for the next time we would meet. This helped to structure our project for the both of us.

Working with difference

In the beginning of our collaboration, I was set on relating to Olof as an equal. The video shows how my idea of, and need for, equality lead to Olof's disablement. By asking him to take the lead, I actually painfully confronted him with a role he could not fulfill. Gradually, I learned that striving for a horizontal partnership did not mean that we had to be or do the same. It meant thinking carefully about how to work *with* difference.

In inclusive research, there is often the aim to give people with MID as much power and control as possible within the research process (Sergeant et al. 2022: 8–9). But despite the efforts of inclusive researchers to create the best conditions for involvement, they are more than often the ones that maintain the most power (Woelders et al. 2015: 530). While departing from the co-researcher construction relieved some of the power dynamics between myself and Olof, I was often confronted with the asymmetries in our relationship.

I often realized I had many skills and resources that Olof did not have. Like the ability to write, or an extensive social network. These things unavoidably create a power imbalance in our relationship. Despite my efforts in recalibrating, many asymmetries in our relationship were there to stay. So how to work with difference in practice? Throughout our collaboration, I continuously realized that the question is not how to overcome asymmetry, but how to work *with* it.

When I talked with Olof about this he said: “We are equal . . . But you are the manager . . . and that makes sense because if it was the other way around and *you* had an intellectual disability . . . then I would have been the manager . . . Simple as that . . .” “But on the other hand, nobody has a fantasy like you,” I respond. “I mean without your imagination there would be nothing to manage.”

We agreed that we are equals, but we are not the same. We have different talents, capabilities and resources and we divided the tasks and responsibilities in our project accordingly. Being the main actor, scenarist and creative director, Olof had the most important roles in the production of our film. He was the one that dreamed up the story of the film, and was always having visions of new scenes, plots and twists we could add. As the production manager, I would listen to Olof's creative ideas and see how we could practically execute them. I also had to disappoint him at times, because Olof's dreams were sometimes too fantastic for our limited budget. Other roles that I took in the production of our film were that of co-director, script writer, co-editor, and actress. Olof further fulfilled the roles of production assistant, equipment supervisor, camera operator, and drone operator.

Throughout our film project, we learned how we could divide tasks in a way that was attuned to our own skills and capabilities, but also to the resources available to us for the project. The latter was also a very important asymmetry between us that needed consideration. As Olof did not have access to the funds to make a film, I invested a part of my research budget to fund the production of this film. We further funded the post-production of this project through a crowdfunding set up by both of us.¹⁰ I feel it is important to mention this because the asymmetry in resources available to the both of us mattered in our collaboration.

Struggling with scripts

One of the situations in which we had to figure out how to navigate our differences was when we had to act together in our film. According to the story, there had to be a dialogue between Olof and the human-alien translator clone played by me. But how do you work with dialogue when one of the starring actors cannot read, and the other one cannot act?

Our co-director Sjuul had advised us to write a script for our film. But as learning lines by heart was not possible for Olof, I decided that improvising our dialogue would probably be best. So, we rehearsed the gist of our conversation without using text to guide us. While this acting strategy worked for Olof, it did not work for me at all. On the first shooting day of the film, it turned out that I had completely underestimated the art of acting. It was impossible for me to do it without a script. Unlike Olof, I was unable to handle the openness that comes with improvisation. After my acting fiasco, the crew suggested that I needed to learn my lines by heart. Finally, we found a middle way in which I learned my lines by heart while still giving space to Olof to improvise. In preparation for our second day of filming, we rehearsed our dialogue many times and recorded these sessions to support Olof to remember the essence of what he would say.

While I initially thought that Olof's inability to read would be our biggest problem in acting together, the fact that I did not know how to act was a problem I had not considered seriously when trying to meet Olof's needs. Just like Olof I had my needs in this project, not only as a person with ADHD, but also in my roles as a filmmaker and actor. I needed a script, I needed Olof's creativity, I needed guidance in the filmmaking process from more experienced people like Sjuul, I needed Olof to take care of the equipment because I would lose or break things.

It is important to realize that recognizing difference and communicating needs is hard. This relates to an inherent paradox in the recognition of impairment, where the fear of labeling someone (or yourself) as disabled is in the way of making a practice more accessible, and of communicating needs. Olof has a hard time telling me he needs me to take the lead, and I have a hard time realizing that I need a script. We are both conditioned by ableism in different ways. The medium of film helped us to recognize, talk about this – and attune our collaboration to *both* our needs.

Attuning to crip time





The video you just saw tries to illustrate how attuning to crip time is essential in crippling collaboration, but also a characteristic of Olof's filmmaking practice. Before reflecting on the videos, let me start by explaining the concept of crip time.

Crip time is a concept arising from disabled experience that addresses the ways that disabled, chronically ill and neurodivergent people experience time (and space) differently than able-bodied folk. (Samuels 2017: 1, my emphasis)

In her essay on crip time, Ellen Samuels explains how people with disabilities travel differently through time than others (Samuels 2017: 2). She explains that crip time means not only that people with disabilities might need more time to get things done, it also means that “disability and illness have the power to extract us from linear, progressive time with its normative life stages and cast us into a wormhole of backward and forward acceleration [. . .]” (Samuels 2017: 2). For those who occupy the bodies of crip time, age is not an indicator for what your body can do, how people treat you, or what kind of life events await (ibid).¹¹ In this way, crip time is time experienced as “out of sync” with normative temporal orders of everyday life.

Having time

The concept of crip time is not only about limitations. The two parts of the video also show how crip time is not only about being slow or late, but also about breaking open the rigid socio-economic structures of normalized time (Samuels and Freeman 2021: 249). The first part of the video (Wait) shows the desynchronization between me and Olof. The movement of the camera shows my impatient nature, moving back and forth to see if Olof needs any help. But the fact that Olof takes a long time to start up the drone does not mean he cannot do it. It takes a bit more time, but eventually the drone takes off.

The second part of the video (See) focuses on the liberating aspects of crip time. We follow Olof and his camera through the city of Amsterdam, observing the world and the beings around him. This video shows that Olof does need more time, but also that he is able to take that time – because compared to “able-bodied folk,” he has much more of it. As Olof says himself when for the umpteenth time an annoyed cyclist catches up with us in Amsterdam traffic: “I’m not in a hurry like those busy people . . . I can take it easy, they never do”

Time was a resource which Olof had plenty of, while I did not. The fact that Olof had lots of time was of great benefit to our collaboration. I almost never had to worry that Olof was too busy to meet with me. The fact that Olof has and takes more time for things shows in his filmed material. As a filmmaker, he dares to take the time to look at things and fully appreciate them, no matter who is watching. Filming together with Olof, I found that taking this time to stand still and just film is one of the most challenging aspects of filmmaking. In this way, crip time is not only about being out of sync with others, but also about “how disabled bodyminds move within, meet, resist, and create unique temporalities” (Bailey 2021: 170).

Conflicting temporalities: struggles with crip time

Understanding and attuning to crip time was essential in the collaboration between me and Olof. But sometimes, we simply did not have access to the kind of time that Olof needs. It is interesting when Olof's temporal needs come into conflict with other, faster, timeframes. The following notes of a transcribed online meeting give a good example of this:

“She’s busy!”

Olof and I have an important Zoom meeting today with Y, the manager of a care organization, about the possible sponsoring of our film project. I know Y has little time to meet with us. She squeezed us in between two meetings and sacrificed her lunch break to make the video-call. As a result, there simply was not enough time for Olof to say something, or at least not enough time to finish his stories. At one point, Y compliments Olof on the message we want to get across with the film. In response, Olof starts a long story about his experiences of exclusion in the labor market. He talks slowly and often needs time to find the right words. It's not easy to follow and not very relevant in terms of what we need to discuss. I see the manager wriggling in her chair, obviously too polite to interrupt Olof. She needs to go soon and wants to get on with the things we still need to discuss. I need to cut Olof's long story off. “Maybe we can talk about this when she has more time? She needs to go to her other meeting soon!,” I say. “Oh yes, yes, yes, Sorry!,” Olof responds. There is just not enough time.

The example above shows how conflicts between crip temporalities and other, more normalized temporalities often lead to disablement. When collaborating with people outside of crip time, like managers or academics, we often ran into the problem of not having enough time for Olof. These situations show how, despite good intentions, the rhythms and temporal demands in and of society excluded Olof from participating with those without disabilities.

The issue of not having enough time was a recurring challenge in our collaboration. While I learned how to better attune to Olof's temporal needs, it is hard to keep up the good work when pressured by other kinds of temporality. In my rhythm of work, things need to go faster because my PhD trajectory demands it. But I had to be careful not to project this temporal pressure on Olof.

I remember one day when we were working on the film at the studio of our co-director Sjuul Joosen. That day, we needed to do lots of things. We were recording a video for our crowdfunding, and we edited it at the same time. As Sjuul and I really wanted to finish the video, we took little breaks and quickly moved from one activity to the other. But suddenly, Olof felt physically unwell, and we had to stop what we were doing. Taking a walk outside after this incident, Olof explained that it was all “just a bit much” and that he needed more breaks. This experience showed me how our need for speed made Olof's disability a reality (Bailey 2021: 287). It confronted me with how regimes of productivity drive the pace of my own life – and with the ethical necessity of slowing it down to meet Olof's temporal needs.

While it was not always possible, the need to attune to crip time required us to find slower ways of moving through our project. For instance, I learned to always check in with Olof before, during and in between activities. “Are you tired?,” “Do you need a break?,” I learned how to be less ambitious in our planning, I learned to increase the number of breaks, I learned when it was time to call it a day and I learned how to do things (like cycling, filming, walking, talking, and editing) more slowly. These lessons did not come easily, since my diagnosis of ADHD also comes with its own, hyperactive, version of crip time. But Olof helped me in learning how to slow down.

Getting involved: interdependency, care and solidarity

This video captures a moment in the beginning of our collaboration in which I realized that our relationship would be more than a professional partnership. Working on this film project together for over three years, Olof and I became more than just partners in science fiction. We became friends.

Being one of Olof's few friends, I got involved in his life beyond our collaborative project. I became a point of reference for his individual counselor – who sometimes calls me to discuss things she wants to arrange for Olof and discuss which tasks she could delegate to me. This reliance on volunteers like me is needed because care organizations are heavily understaffed these days.¹²

Living independently in his own apartment like many people with MID, there were many issues that remained behind closed doors. Visiting Olof on a regular basis taught me about the things that his counselor did not know about or did not consider as care tasks, but still formed obstacles in Olof's everyday life. Like the boxes full of closed envelopes I found at Olof's house, or the health issues of his cats, or his problems in getting a working washing machine. Being a frequent guest in Olof's home, I often found myself helping him with things he did not want to bother his social worker with. Like connecting his PlayStation to the internet, or helping him order a new chair online, or helping to carry the new washing machine up the stairs.

Becoming friends through our film project, I not only learned about what care and access mean in the practice of Olof's life – I also got actively involved in making those happen. Especially in the beginning of our collaboration, this was sometimes more about my needs than about Olof's. This was particularly the case when I got involved in arranging home cleaning services for Olof. Olof did not consider the state of hygiene in his house as a problem, but I needed a certain level of hygiene in my work environment. As we always worked on our film from Olof's home, I convinced Olof to register with the home cleaning services.

Being involved in Olof's life like this taught me that asking for help from a friend is easier than asking for help from a care giver. What I find important here is that the question of collaboration with people with MID also brings in questions of care and accountability. As a researcher, I did not anticipate the impact I would have on Olof's life and the role I got to play in it in terms of care.¹³ When a researcher decides to enter an intensive, crippled, collaboration with someone with MID – they need to realize they might make up the biggest part of someone's social network. Loneliness is a big problem in disabled communities and many people with MID often have very small networks. Where other people can divide their care needs among several friends and family members, people with MID often do not have this luxury.

I here want to draw on Donna Haraway, who says that “staying with the trouble means making odd kin: that is that we require each other in unexpected collaborations and combinations, in hot compost piles” (Haraway 2016: 4). The need for the kind of kin that are not blood relatives,” is very much present in disabled communities. Researchers aspiring to crippled collaborations should realize this need for “crip kin” (Kafer 2019) also brings a need for commitment and solidarity. I think where a crippled collaboration radically differs from co-researcher constructions, is that it requires the researcher to get involved beyond the walls of the academy. Working together is a way of living together, and living together forms unpredictable kinds of relations that go beyond the realm of the professional. This requires us to learn how we can be an ally to our disabled research partners, and to assess critically if we are able to do so.

Nearing the finish of the post-production of our film, Olof and I keep the conversation open about how our relationship will change after my PhD trajectory. While new hometowns, new jobs and new family members will impact our professional partnership, we agreed that we will do everything in our power to sustain the quality of our friendship.

Conclusion: how to crip collaboration?

In inclusive research, collaboration often unintentionally becomes a normalization project. Implicitly understanding collaboration and accessibility as assimilation into the normative relations and environments of the academy, inclusive methods understand collaboration as people with disabilities joining academic researchers in *their* projects and worlds. In this way, collaboration always remains a home match for the researcher, and participation the challenge for the research partner.

This article has followed crip scholars in rejecting collaboration as self-evidently good, and to “push beyond liberal and assimilation-based approaches to accessibility, which emphasize inclusion in mainstream society” (Hamraie and Fritsch 2019: 10). Since assimilation with academics is often not what people with disabilities want or can do, I have sought to answer the question of how researchers can build collaborative relationships in a way that takes difference seriously, and in which they can learn by attuning to the needs and talents of people with MID. In other words, how to crip collaboration.

In this article, I have shown *one* way to do this by describing the lessons we learned through making our science fiction film together. Even though crippling collaboration can take many forms, there are some core principles that researchers can follow when aspiring to move from an individualized, assimilation-based approach toward a more collective and interdependent understanding of collaboration. Let me summarize them here.

Crippling is about centering disabled voices and stories

As the demands of academia do not meet the needs and talents of people with MID, they are unlikely to be the true producers of academically-valid knowledge. Crippling collaboration is about being aware of the politics of marginalized knowledges, and about finding new ways to appreciate them. It is about creating a form of knowledge production that centers the skills and ways of knowing of people with disabilities. Making a low-budget DIY science-fiction film became our way to make something that we both had true ownership over, and both equally participated in. For us it was not important that Olof

could enter scientific practices, but to produce the socio-material conditions that allowed his skills and talents to thrive.

Crippling is collective

Accessing the practice of filmmaking together, we learned that crippling collaboration is not an individual effort, but a collective one. And this collective does not have to be limited to the collaborative partners themselves. Struggle and failure were an important part of this realization. Expanding our collective in desperate need of people who knew what to do, we learned that crippling collaboration is about resisting the myth of independence. It is about embracing interdependency as a political technology (Hamraie and Fritsch 2019: 12) and to create new networks and constellations in which movement becomes possible.

Crippling is about attuning to, and working with, difference

Crippling collaboration is not a singular act, it is a continuous process. Throughout the process of making our film, we continuously needed to reinvent how we could work and live together in practice. Finding our way as we went, we learned how to navigate and work *with* our differences instead of overcoming or doing away with them. Ableism can be in the way of this, as the myths of neoliberalism unconsciously make it difficult to recognize needs and talk about them.

Crippling is about taking, and making time

Attuning to crip time is essential in crippling collaboration. This is not only about slowing down and taking time, but also about breaking open the rigid structures of normalized time. Time is an important resource in crippled collaborations, and it is important to take and make enough of it. Being claimed by fast-paced environments, academics are often the ones who have a permanent shortage of time as a resource. When aiming to crip collaboration, it is important to be aware of these conflicts between crip and more normalized, more fast-paced temporalities.

To crip means to care

Moving from an individualized, assimilation-based approach to access toward a more collective, interdependent and crippled understanding of collaboration also means getting involved beyond the walls of the academy. Becoming friends through this project, I not only learned what care and access meant in the practice of Olof's life, I also got actively involved in making it happen. It is important for researchers who aspire to a crippled collaboration approach to realize that crip relationships last longer than research projects, and bring a different kind of accountability for the researcher. They need to realize that crippling collaboration can form unpredictable kinds of relations that go beyond the realm of the professional. This requires us to learn how we can be an ally to our disabled research partners, and to assess critically if we are able to do so.

What we have tried to do with this project, is to make space for Olof's ways of knowing. For Olof's stories. For Olof's imagination. For me, this is the great gift that human institutions, like the university, have been missing out on. In the same way, inclusion models often unintentionally miss out on the talents, skills, and gifts of research partners with MID. As the realm of the verbal and the possibilities of academia are often too constraining for people with MID, creating a different way of hanging out, doing something other than research together, gives us the opportunity to learn from our research partners with MID in new ways.

Throughout writing this article, I was continuously surprised how the elements of Olof's story continued to form the basis of the lessons that this article has tried to convey. A story about living and working together across different abilities. A story about finding allies, who do not care about labels – but who respond to your needs as they come about. A story about embarking on a mission, but being misunderstood, restrained and rejected by institutions. A story about activism and collectivity, as comrades of a disabled captain refuse to go somewhere if he cannot get access. A story about finding alternatives, when institutionally paved ways seem to remain shut.

With this project, we hope to have made an intervention in collaborative disability studies by showing how science fiction became our means to access each other's lifeworld, and our way to create a different kind of collaboration. Living and working together beyond the demands of academia has opened up new ways to learn about and from each other, and to realize a collaborative film that does justice to Olof's world and ways of knowing.

Notes

1. I join critical disability scholars in understanding disability as a relational and political category (Kafer 2013). This also brings a critique on pathologizing labels, and a need for clarification on the use of them. Throughout this article, I refer to "MID" as a name for an experience, and "people with MID" as a name for a perceived demographic category (following Kasnitz 2020: 18).
2. Many people with MID in Amsterdam live independently in their own apartments. This is why social care organizations focusing on people with MID are often community-based organizations that operate on a "street-level." As a volunteer, I am involved in organizing public events for people with disabilities, such as communal dinners, sport events, or cultural activities.
3. Trying to overcome these barriers, inclusive strategies have come up with research designs that invest in training researchers with MID in scientific practices such as writing, interviewing, presenting and communicating with other researchers (see: Embregts et al. 2018; Sergeant et al. 2021). But other inclusive researchers have questioned if participation in every stage of research is possible, or even desirable (Walmsley and Johnson 2003, Bigby et al. 2014; Gilbert 2014: 33).
4. such as Alison Kafer, Margaret Price, Stephany Kerschbaum, Aimi Hamraie, Kelly Fritsch, and Mia Mingus.
5. As a noun, *crip* refers to an identity term that represents the activist reclamation of the word *cripple* (McRuer 2018: 18–19). As a verb, "to *crip*" refers to a process that unsettles normative understandings of disability and radically reimagines "conceptual boundaries, relationships, communities, cultural representations and power structures" (Hutcheon and Wolbring 2013: 1). Closely related to the verb *queering*, to *crip* something means to spin around "mainstream representations or practices to reveal able-[body-minded] assumptions and exclusionary effects" (Sandahl 2003: 37).
6. This is also why Olof does not feature as the coauthor of this text. The whole point of this project was to do something other than text together. Therefore, I did not want to expire in symbolic attributions that do not relate to the reality of our collaboration. Writing academic articles about the lessons we learned from making our film is my job, not Olof's.
7. <https://www.urbandictionary.com/define.php?term=Noob>.
8. Next to Sjuul, this project could not have been realized without the help of my friends Annemarije Rus, Paul de Jong, Pieter van Vliet and Anouk van Klaveren. Visit their websites here: <https://www.annemarijerus.nl/>; <https://www.jongdepaul.nl/>; <https://debescheidenheid.nl/>; <https://cargocollective.com/anoukvanklaveren>.
9. Sjuul Joosen is an artist based in the Hague His artwork is characterized by an authentic do-it-yourself mentality and a fascination for the hidden aspects of natural phenomena. Moreover, Sjuul has been working on his own independent science fiction film "Tijdjager" (Timechaser, workingtitle) since 2016. In this ongoing project, Sjuul fulfills almost all the roles necessary to produce a film: screenwriter, camera operator, editing, special effect making, and animator (www.sjuuljoosen.nl).
10. For more information about this crowdfunding check out our project page here: <https://www.voordekunst.nl/projecten/12765-o-de-post-productie-1>.
11. In research and care for people with MID, we see this extraction happening through use of the term "developmental age." This term refers to a kind of age that corresponds with people's IQs and social-emotional development. According to development psychology, this conception of age reflects that people with MID function at a level lower than expected considering their calendar age. They say: while this person is 64 years old, their disability makes them function at the level of a 6- to a 12-year-old child (emotionally, socially or cognitively). While the concept of developmental age was meant to help practitioners to attune to the needs of people with MID there has been lots of critique on the use of this term within critical disability studies.
12. <https://open.overheid.nl/repository/ronl-a7e6f4b4-de5d-4dff-9815-6696fa895d48/1/pdf/kamerbrief-over-nieuwe-prognose-verwachte-personeelstekort.pdf>.
13. Of course care is not always good as strivings for the good can have good and bad effects (see Pols 2015).

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Appendix

Links to the videos

1. Introduction: Trailer O
https://www.youtube.com/watch?v=iXwxiwtBxOY&ab_channel=LeonieDronkert
2. Moving sideways
https://www.youtube.com/watch?v=avq_bRYPMkE&ab_channel=LeonieDronkert
3. Learning with mistakes
https://www.youtube.com/watch?v=Gsmoq05bFfU&ab_channel=LeonieDronkert
4. Crip time
https://www.youtube.com/watch?v=AJl-6e3CTRQ&ab_channel=LeonieDronkert
5. Care
https://www.youtube.com/watch?v=kHREgvDrcmE&ab_channel=LeonieDronkert