‘We Can and We Want To’: People with Disabilities Intra-acting with Researchers and Technology in Research

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This article aims to offer insights into how people living with intellectual disabilities by intra-acting with researchers and technology, can inform and improve participation in research and the dissemination of it. It draws upon the experiences from adults with intellectual disabilities and researchers participating in the production of audio-visual material. The audio-visual material was initiated and produced by a team in UK with participants living with intellectual disabilities and was based on an earlier article written by the two researchers. This current article highlights the importance of enabling people with disabilities to participate in the research (in various phases, settings, and ways) and as such also make accountable knowledge claims which can bear effects on the life of people with disabilities in their everyday practices and in relation to technology (such as information and communication technology, ICT). The approach, based on a material-semiotic and intra-actional understanding sheds light on the following questions: How can research be guided so that people with intellectual disabilities, the target groups of the research, become involved as actors and participants in the various phases of research concerning them*? Can technology, such as Information and Communication Technologies (ICT), empower people with intellectual disabilities to become involved in research concerning them? And if so, in what ways.*

Keywords: disability, ICT, intra-action, material-semiotic, participation, research

Introduction

There seems to exist a need to conduct studies that focus on methodologies enabling people with disabilities to be collaborators in research concerning their everyday lives (cf. Davis, 2000; Sample, 1996). Additionally, today there also exists a need to take technology, such as

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Information and Communication Technology (ICT), into consideration in this process. As such, the focus of this article is to present ways of how to conduct research, which focuses on people living with disabilities and researchers, and their relations to technology, such as ICT. More specifically, in this article we offer insights into how people living with intellectual disabilities by intra-acting with researchers and technology, can inform and improve participation in research and the dissemination of it. This article links a material-semiotic understanding of disability to empirical material, such as, two researchers' experiences of participating in the production of a video initiated and produced by a team of people with intellectual disabilities and an editor of the journal Disability & Society in United Kingdom (hereafter UK). The video was produced in 2014 and had as its purpose to make journal content more accessible to people who might not be fluent with text materials. The team in UK invited the two of us, Rebecka Näslund and Åsa Gardelli who had written a joint article (Näslund & Gardelli, 2013) that had caught their interest. Our article presented here addresses the following questions: How can research be guided so that people with intellectual disabilities, the target groups of the research, become involved as actors and participants in the various phases of research concerning them? Can technology, such as Information and Communication Technology (ICT), empower people with intellectual disabilities to become involved in research concerning them? And if so, in what ways?

Theoretical framework

Throughout the years disability studies have disentangled disability from various angles. Some of these are: a bio-medical approach, a social approach, and a critical approach of understanding disability (Olaussen, 2010). An alternative way of disentangling disability comes from scholars who are interested in developing an understanding of disability as part of material-semiotic relations (cf. Feely, 2016; Moser, 2003; Näslund, 2017)[i]. This approach enables the researcher to capture the ways lived experience, embodiments, the body, technology, texts and practices are intra-acting (cf. Gardelli, 2004; Moser, 2003, 2005, 2006a, 2006b, 2009; Näslund, 2009, 2017; Näslund & Gardelli, 2013; Olaussen, 2010; Söderström, 2011, 2016).

To explore disability, it is of importance to take into consideration that different naming and

definitions of disability varies between countries. As such we strive to outline the term intellectual disability. In the email communication with one of the team members, also the editor of the journal where our article was published in UK, called the participants in the video and the target group for the video *'people with intellectual disabilities'.* As such we refer to these participants as people with intellectual disabilities. In our ways of referring to the participants, we talk about them as people with intellectual disabilities not from an essentialist view. Instead, the starting point is that bodies, technologies, and practices encounter in the everyday lives of people with dis/abilities and as an effect lead to dis/ability and various ways of participation.

Additionally, as means to understand disability and participation as effects of relationships between technology and the practices/uses of it, we strive to bring together the material-semiotic understanding of disability with the notion of intra-action (Barad, 1998, 2003, 2007)[ii]. By starting out from intra-actions it becomes possible to take the materiality of ICT into consideration simultaneously with the fact that it is re-materialised in intra-actions with various forms of materials and practices (cf. Barad, 1998: 102). Finken and Mörtberg (2014) explore in a study how elderliness and independence intra-act with digital care technologies in the domestic area. They relate their empirical studies from Norway and Sweden to the concepts of intra-action and performativity. For them, the notion of intra-action is of importance when exploring practices as well as designing daily usage of technology since it insists on regarding both subjects [humans, our insertion] and objects [nonhumans, our insertion] as being part of the process of the generating of agency (Finken & Mörtberg, 2014: 308). By drawing upon both the material-semiotic understanding of disability and the concept of intra-action we can trace disability as the lived bodily experience and its relation to technology. This does not imply that disability pre-exists but rather evolves in encounters between bodies, technologies, and practices, etc. (Näslund, 2017).

The article is based on an idea that it is important to encourage people with disabilities to be active participants rather than being passively cared for as part of one's research (Chevalier & Buckles, 2013; Reason & Bradbury, 2008). We regard, like Goodwin et al., (2015: 93), Williams (1999), and Williams et al., (2015), that it is of importance to involve people with disabilities in the research work and in encouraging them to contribute to the research outcomes. Underlying this is the idea that research and action should preferably be done

"with" people with disabilities and not "on" or "for" people with disabilities (cf. Kiernan, 1999: 43). For this article, we frame participation in research within an understanding of it as part of relations and processes of humans (people with/without disabilities, and professionals) and materials (texts, and technologies). This understanding is in line with Perillo (2008) who outlines that participation is not within the human subject but is instead a process, which involves a lot of actors in relation to each other.

Besides exploring participation, we focus on tracing how ICT evolves in encounters with users. More specifically, ICT is an effect of relationships between the material (the hardware, software, video, networks, online applications), and the materiality of bodies, as well as societal practices (cf. Darcy et al., 2016; Näslund, 2017). We consider that it is of importance to explore how ICT involve similar possibilities for participation among people in different settings while at other times the participation might differ (cf. Elovaara & Gustavsson, 2012: 49). Moser (2003, 2005, 2006a, 2006b, 2009) and Söderström (2009a, 2009b, 2009c, 2011, 2013, 2016) articulate from various angles the way technologies intra-act with the lives of people with disabilities. For instance, Söderström (2016) presents how socio-material practices in education (seating in the classroom, teachers' working practices, and application of assistive technologies during the schooldays) bear effects on participation or seclusion among pupils with disabilities. This way of understanding the key concepts and their relations leaves one open to create alternative knowledge of disability, participation and technology.

Methods and Materials

This article is based on the participation of us two researchers in a video initiated and produced by an editor and her colleagues living with intellectual disabilities (two adult women and one adult man) located in the UK. By conducting a meta-analysis of the constructing of the video we became interested to trace how the members of the team in UK, who lived with intellectual disabilities and us two Swedish researchers, in various ways and phases, were involved and participated in the production of the video and in its dissemination. Moreover, we explored in what ways materials (computer hardware and software, videos, textual documents, and bodies) and practices bear effects on the everyday lives of people with disability and their ways to participate in various phases of research.

The underlying article for the video

The article, which the video drew upon, had its empirical base in two empirical studies that we researchers had conducted earlier. One study was presented by Näslund in 2009. The empirical material for it was based on field notes from participant observations and semi-structured interviews with pupils with intellectual disabilities in their everyday school environment (Näslund, 2009; Näslund & Gardelli, 2013). The study strived to gain knowledge of the youth's use and access of ICT. Moreover, in Näslund's (2009) study the pupils drew pictures. Another study by Gardelli and Johansson (2008) was part of the article. It focused on adults with intellectual disabilities at a day center and their activity abilities (Gardelli & Johansson, 2008; Näslund & Gardelli, 2013). The staff documented by various means (template to compare the development of abilities during the start time of the study until its end, own observations collected in diary notes, video-recordings, and photographs) the participants' level of activity (Gardelli & Johansson, 2008; Näslund & Gardelli, 2013). The focus for the article by Näslund and Gardelli (2013) was the relationships between technology, use and access among youths and adults with intellectual disabilities, agency, subjectivity and how the use of ICT influenced their level of activity. It presented disability as relational and the way that ICT bears effects on disability. The article outlined agency as part of its relation to disability, levels of activities, experiences, interests, networking, co-operations, practices of ICT, and inter-actions between human and non-humans. None of the two underlying studies (Gardelli & Johansson, 2008; Näslund, 2009) for the article focused specifically on the concept of intra-action. However, we consider that both studies took the materiality of ICT and its relation to bodies and practices into consideration.

The video

Näslund and Gardelli (2013), had written a joint article, which became published in Disability & Society. In the summer of 2014, we received an email from an editor for the journal and her colleagues who lived with intellectual disabilities, at a research centre in the UK. They invited us to be part of a video about the article we had published in Disability & Society. The editor stated that one of the colleagues had: *"worked on all the articles [in the journal, our insertion] from 2013, to choose one that would be interesting to other people with intellectual disabilities."* (Redweather Production for the Norah Fry Research Centre, 2014). Their choices fell on our article *'I know, I can, I will try': youths and adults with intellectual disabilities in Sweden using information and communication technology in their everyday life* (Näslund &

Gardelli, 2013).

In the summer of 2014, we received a short summary of our article from the team in the UK, which we responded to. At the end of the summer, the team in the UK interviewed one of us as part of the video, *"I know, I can, I will try"* (Redweather Production for the Norah Fry Research Centre, 2014). The video interview took place with the use of an already existing online application. Once the video was recorded, we had the possibility to give comments and to submit extra material for instance, pictures illustrating the topic. The team in UK presented the video at a disability conference while Näslund was present online. The video (Redweather Production for the Norah Fry Research Centre, 2014) also became accessible in Sweden and was presented at the university's home page, Luleå University of Technology, where we researchers worked. Moreover, one of us has additionally presented the video in her student teaching while the other one put it on her page at a social media platform. Thus, all of us: Gardelli, Näslund, the editor, and her colleagues with intellectual disabilities participated in the production and outcome of the video in different ways. However, we wish to stress that the team in UK were the initiators and central key actors throughout the process.

Analysis

In our analysis of the video study the main concepts of disability, participation and ICT emerged in the material (cf. Kvale & Brinkmann, 2014; Miles et al., 2014). More specifically, we watched the video at several occasions and read the email communication. This was done as means to contribute to new alternative methods of how to conduct research, which is inclusive and allows for participants with disabilities to be co-actors in research. The analysis was then brought together to the theoretical and methodological concepts of the material-semiotic understanding of disability (Feely, 2016; Moser, 2003, 2005, 2006a, 2006b, 2009; Olaussen, 2010; Söderström, 2009a, 2009b, 2009c, 2011, 2013, 2016) and intra-action (Barad, 1998, 2003, 2007; Finken & Mörtberg, 2014) The theories and methodologies made it possible to explore the ways disability, participation and ICT are related to each other.

Ethical Considerations

We have taken various ethical considerations in regard to our collection of the material, in the interpretations and writing of the article. The idea for making the video was initiated by the participants with intellectual disabilities in the UK who had read our article and found its

focus on ICT and people with intellectual disabilities of interest. The editor stressed the previous ways the journal had striven to bring in and engage people with disabilities, but to a minor respect had been able to include people with intellectual disabilities. She expressed this as 'over the years, we've tried to include and involve all disabled people, but I'm not sure that we've ever done a really good job with people with intellectual disabilities' (Redweather Production for the Norah Fry Research Centre, 2014). This statement in the video also influenced us and bore effects in the writing of this article. As the participants in the UK were the ones who took the initiative, and who together with us outlined the video, we have for this article striven to include their voices based on their statements in the video. In the later phase of our writing of this article, we communicated with the team via the editor (who also was a member of the team) to give them the possibility to comment on the article. Thus, by having this communication with the team in the UK we attempted to include their views regarding the work we conducted with them in the production of the video, our presentation of the video and their participation. However, due to various reasons it was only the editor who in the end read the article and provided us with her comments. For us, the communication with the team in the UK has been a way to pay attention to ethics and aspects of power. More specifically, ethical clearance was taken into consideration in the outline of this article. By asking the editor (who also was a member of the team) for consent, attention was paid to the aspects of power in the research process. Thus, by having this communication we have attempted to see the team in the UK as important and equal actors not only in the production of the video and the writing of this article but also in the dissemination of the research. We regard that research where people with disabilities are included and involved should strive to focus on them as equal actors in the research rather than passive participants. More specifically we have in our work included the lived experience of disability. This in turn has enabled an understanding that research needs to include various experiences and understandings of disability, participation and ICT.

Results

In this part we strive to present some scenes of the video as a way to outline some processes which took place between the team and one of the researchers, Näslund. It does not present all the scenes in the video nor in a chronological order.

At the outset of the video, the participants from the team in UK introduced themselves. In this scene one of the participants sat in her wheelchair. The editor introduced the reason why our article was chosen and whilst doing so she held a copy of the journal in her hand.

In another scene, three of the team members sat behind a desk, where a computer and a screen were placed. In this scene, one of the team members introduced that they would talk to one of the researchers via an online application. Then the interview started off with one of the team members asking Näslund: *'what started you off on this research? And also where did the title come from?'* (Redweather Production for the Norah Fry Research Centre, 2014) This is followed by a screenshot where Näslund sat with headset on and answered the question.

Following on, there is the voice of one of the team members that outlined the content of the article and at the same time a video of two persons taking photos with a mobile phone close to a beach walk was presented. Then, one of the team members continued and asked questions about the participants who had been part of Näslund and Gardelli's (2013) article. Näslund introduced those participants by giving information about their age and gender. She then continued and asked the team in a sort of introductory question if they would like to know which kinds of disabilities the participants in their earlier studies lived with. The team answered that they would like to know this.

After this, another member of the team asked about the methods used in the research. The screenshot showed Näslund in one part and illustrations like photographs of the methods that had been used, such as, observations, drawings, interviews etc. were presented.

Then came a scene where two of the participants were seated beside each other. One of the women asked Näslund to tell more about the participants and what they did with technology. Another team member looked at her and seemed to assist her by listening to her as a way of confirming that the questions were being correctly introduced.

In another part of the video, there is a scene where one member of the team asked: 'what were the most important things you found out?' (Redweather Production for the Norah Fry Research Centre, 2014). When Näslund gave the following answer: 'I would say that the most important things we found out was that people with intellectual disabilities, they know, they can and they will try to work with information and communication technology' (Redweather Production for the Norah Fry Research Centre, 2014). One of the team members nodded and seemed to agree with the answer given by Näslund.

In another scene the team members outlined what people like to do with technology in UK by introducing their own use. The screen showed two of them outlining with their own answers what they like to do with technology. First person: 'technology is wonderful because you can keep contact with people, especially on Facebook or on Skype' (Redweather Production for the Norah Fry Research Centre, 2014). Second person: 'I use text messages. I use emails on my laptop and the phone. And I use photography, I take pictures with my phone' (Redweather Production for the Norah Fry Research Centre, 2014). The video ends with a part where the team again was in the focus around the desk and one of the participants expressed her feelings about communicating with Näslund in this way: 'To talk to someone somewhere else it's actually been amazing for me' (Redweather Production for the Norah Fry Research Centre, 2014).

Discussion

A challenge facing researchers interested in disability is how research can be undertaken with and disseminated to the people involved. That is to people with disabilities as well as to personnel and dependents that are in their vicinity. In our previous works we have experienced that there exists a need to find ways to both involve and to disseminate research in its various stages to people who are part of the research, or to the target group of one's research. The result from the current study highlighted in different ways how research can be guided so that the persons concerned become actors and participants in the various phases of research. Additionally, the study drew attention to ICT and its part in the process of empowering people with disabilities to become involved in research concerning them.

The processes of the video-production made us as researchers, together with the team in the UK, and the Internet to become co-actors. The video would not have been possible to make

without the initiative by the team and as well as the researchers' intra-actions with various forms of technology. This process was an example of how ICT intra-acts with disability and participation in research. For us, the process of creating a video together with the participants with intellectual disabilities is an example of research, which involved the participants in alternative ways.

More specifically, the forms of participation which evolved in the production, took place in different layers. At one level, there is the article written by Näslund and Gardelli (2013). Another level is the reading of the article by the people with intellectual disabilities. A third level is the team emailing us with an invitation to participate in the video, a tentative manuscript of the video and our email response to them. Additionally, the team's outlining of questions and interviewing Näslund is another level. Moreover, the launching of the video at the disability conference where some of the members with intellectual disabilities and Näslund participated online is another level. The journal together with the team in UK gave the permission for us researchers to publish the video on our homepages at our university. Finally, we emailed the editor about the permission to include the process of the video production in this article.

As the examples from the video show it is also clear that the video was not merely an individual process but a collective process – something the participants do together (cf. Gardelli, 2004). Remember how the team members shifted between them when asking Näslund the questions. Additionally, they also assisted each other by their body language such as when one of the members looks at another team member when she interviews Näslund.

In line with Elovaara and Gustavsson (2012: 49), our study illustrates that ICT is a matter that is an effect and bears effects on its use in various places and contexts. Thus, from the study the participants were part of practices where ICT encountered disability and participation in different places and contexts. During the video we can see that the team members, by using the computer and looking at the screen, are part of creating the interview situation. Furthermore, when the team in the UK worked together with the researchers in Sweden, technology such as online applications had effects in the final product of the video as well as this article. More specifically, the team was by their participation via the Internet enabling the interviews to take place. In the end, this also contributes to our writing and to this article.

Thus ICT, in various forms and in different times and regions, meets with various forms, matters and acts of participation and in the end, contributes to the product, this article.

Our result is in line with Gardelli's (2004) findings that the use of ICT can assist people with disabilities to take control over their lives by making their voices heard, but there are also challenges found in the overall society and in individual bodies that impede or prevent ICT use. In the interview we can see an example of this when two of the team members outline what they like with technology and what the enjoy doing when they use ICT.

Additionally, as Söderström (2016) outlines in her study of socio-material procedures in the classroom, technologies (in her study assistive technologies) form inclusive and exclusive processes during schooldays among pupils with disabilities. Thus, we would like to suggest that the ICT is not the solely actor which contributes to participation. Throughout the study various other forms of materials and practices were of importance. More specifically, different forms of materials (bodies, computer hardware and software, videos, and textual documents) and practices were allowing alternative forms of participation to come through. In the video we can see examples of this when the editor presents the article at the same time as she holds a copy of the journal, which it was published in. It is in intra-action between matters and practices that these take place (cf. Barad, 2007; Finken & Mörtberg, 2014; Moser, 2003). These intra-actions bring life to various forms of participation as well as various forms of effects in relation to disability. The result shows that various forms of materials and practices influence alternative ways of participation.

The study underlying this article made us aware that an understanding of research as intra-actions and a material-semiotic understanding might open up alternative ways of exploring disability and participation. By including ICT in the various phases of the underlying study for this article, we could participate as researchers and participants on equal terms when it comes to both space and well-being. ICT as a matter was intra-acting with other matters (bodies, practices, and previous texts, etc.) and was also part of research practices, and part of our process of being accountable for our research. By drawing upon a material-semiotic understanding, our research enabled us to disseminate it and to be part of intra-action with readers of our article, and the people who were participating in the two studies. Thus, people with individual abilities, technologies, textual resources, and research practices, led to intra-

actions of material-semiotic ways of participating. So, the group in the UK through different forms of technologies, and us as researchers in Sweden, formed a material-semiotic team, which in turn contributed to different forms of participation coming to life. In the video this is visible by the shift in time between the team members, photos and videos for illustrating, and the researcher being interviewed. This meant that sometimes the team were more active while the researcher was less active. The photos and videos as matters also shifted by entering and leaving the scenes. So, from the study it is possible to grasp how relations between bodies, technologies, practices (ways of communication, work, research) have effects on the participants as well as the researchers' ways to participate in their respective contexts (cf. Barad, 2007; Gardelli, 2004; Moser, 2003, 2005, 2006a, 2006b, 2009; Näslund, 2017*;* Olaussen, 2010).

Conclusion

This article has offered insights into how people living with intellectual disabilities by intra-acting with researchers and technology, can inform and improve participation in research and the dissemination of it.

The article has drawn upon a material-semiotic understanding of disability meaning that disability is not solely found in an individual body but rather in intra-actions with other matters such as technologies and practices. Thus, these intra-actions give ways for various forms of participation. By looking at research from this perspective it becomes possible to find alternative ways to guide research so that people with disabilities become involved as active participants in the various phases of research. By allowing for ICT and other material (texts, video recorder, etc.) to intra-act with bodies and practices, people with intellectual disabilities can be empowered to become involved in research concerning them. Finally, by drawing upon the approach and understandings used in the article bodily differences can be taken into consideration and as such also involve people who previously have been missed out in research.

The perspectives outlined in this paper can have an impact on the research community. We consider that the process of including co-creators (people with disabilities, researchers, and technologies) enables a vital process where disability, participation and technology are important matters in research. Furthermore, relying on an intra-actional understanding gives

the opportunity to make the research inclusive, and accessible to the people involved and the audience one wishes to reach. Despite all of this there exists a need to conduct further studies of this to develop more practical methods of how to work with this form of methods.

In conclusion, disability, participation and ICT are matters that matter in research which strives to include people with intellectual disabilities as active actors.

Acknowledgement

We gratefully acknowledge the help of all the people who provided support in various ways and phases of the study.

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Disclosure statement

No potential interest of conflict was reported by the authors.

Notes

A previous version of this article was part of Näslund's (2017) Doctoral thesis. It was later modified and evolved into this current paper.

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[i] Feely's article from (2016) outlines the concept of material-semiotic in relation to disability and is as such recommended in order to gain a more elaborated understanding of its meaning.

[ii] For those interested to gain a deeper insight of the concept of intra-action the article by Barad (2003) is recommended.