Abstract

This article examines the role of the “differently-abled” researcher in facilitating inclusive research with adults (age 16 and older) with intellectual disabilities living in Sami areas of Norway. Topics discussed include challenges that may arise while conducting such research due to the nature of the project (externally-funded pre-existing project), methods applied (quantitative) and people involved (some being of Sami background and some with intellectual disabilities). In this study, for example, the research sponsors had pre-determined both the topic of investigation (i.e. living conditions) and the method (i.e. by questionnaire), without first consulting people of indigenous background. I argue that, although such stipulations and the double-minority status of research participants may pose additional challenges in fully accommodating the ideals of inclusive research, it is possible and sometimes advantageous to use inclusive research designs to conduct studies involving people with intellectual disabilities. In performing such research, an important question is whether people who have experienced discrimination and stigmatisation should be forced to take on identities they are not comfortable with in order to be involved in research about themselves. The article additionally illustrates how to apply an inclusive design in quantitative research while working with pre-existing research projects.

Keywords: Inclusive research, intellectual disability, indigenous people, researcher role

Résumé

Cet article vise à examiner le rôle de la chercheuse sans déficience intellectuelle en facilitant la recherche inclusive avec des personnes ayant une déficience intellectuelle et vivant dans des régions laponnes en Norvège. Je vais discuter les défis de type différent qui peuvent se présenter lors d'une telle recherche, dû au caractère du projet de la recherche, des méthodes appliquées et des personnes impliquées. Dans cette étude, par exemple, les sponsors de la recherche, qui comprennent des personnes ayant un statut de double minorité (à savoir, ayant une déficience intellectuelle et étant d'origine indigène), ont décidé a priori l'objet de la recherche (les conditions de vie) et la méthode appliquée (un questionnaire). Je soutiens l'idée que malgré les défis additionnels qui peuvent se présenter face aux idéaux de la recherche inclusive, avec de telles stipulations et avec l'inclusion des personnes au statut de double minorité, il est possible et parfois avantageux d'employer les modèles de la recherche inclusive afin de mener des études qui impliquent les personnes à déficience intellectuelle. Dans une telle recherche, on cherche aussi à savoir dans quelle mesure les personnes qui ont eu l'expérience de discrimination et de stigmatisation doivent être contraintes à adopter des identités avec lesquelles ils ne sont pas confortables, pour leur inclusion d'une recherche qui porte sur eux-mêmes.

Mots clés: Recherche inclusive, déficience intellectuelle, indigène, le rôle de la chercheuse.

Introduction

In June 2016, at the request of the Norwegian Directorate for Children, Youth and Family Affairs (Bufdir) and the Nordic Centre for Welfare and Social Issues (NVC), a team of researchers from the Arctic Centre of Welfare and Disability Studies at the Arctic University of Norway joined me in agreeing to conduct a study on the living conditions of adult persons with intellectual disabilities (age 16 and older) of all backgrounds, living in Sami areas of Norway. The Sami are the indigenous people of Sápmi, a territory encompassing parts of Arctic Norway, Finland, Sweden and Russia (Bjerregaard & Young, 2008). In Norway, both the indigenous Sami people (H. Minde, 2005) and people with disabilities have a history of experiencing oppression (Owren, 2008). Although research has been conducted on people with disabilities (Swain & French, 2004) and people of Sami background (Norges Forskningsråd, 2001), studies have not traditionally both addressed *and* involved those populations in their research processes. In response, and in line with Article 19 of the United Nations Convention on the Rights of Persons with Disabilities (United Nations, 2006), we sought to uphold the right of people with intellectual disabilities to participate in all aspects of society, including disability research, developing a study with an inclusive design to investigate the living conditions of persons with intellectual disabilities living in Sami areas of Norway.

Despite literature describing how inclusive research may actively include and sometimes be driven by people with intellectual disabilities (Bigby, Frawley, & Ramcharan, 2014; Williams, Simons, & Team, 2005), my colleagues and I anticipated that we would struggle to fully accommodate some of the ideals of inclusive research (Walmsley & Johnson, 2003), such as having a high degree of participant involvement throughout the entire research process. We also recognised that most inclusive research is qualitative and that quantitative inclusive research would pose additional challenges (Nind & Vinha, 2013); e.g., participation in the data collection and analysis process. At the same time, as Bjørnsdottir and Svensdottir (2008) have indicated, there is a risk of excluding some people from participation if the criteria of inclusive research are viewed too literally. Nevertheless, given Nind and Vinha's (2013) observation that inclusive research can follow various approaches, none of which is more correct than another, and following the shift from conducting research *on* people to conducting research *with* people, we developed a quantitative inclusive research study to examine the living conditions of persons with intellectual disabilities living in Sami areas of Norway.

In performing research on people with intellectual disabilities, part of the shift towards using more inclusive research methods stems from an increasing recognition that people with intellectual disabilities are the best authorities on their own lives, feelings, experiences and views (Stalker, 1998)[1]. Even so, as Walmsley (2004b) has highlighted and other authors have discussed (Kramer, Kramer, Garcia-Iriarte & Hammel, 2010; Tuffrey-Wijne & Butlert, 2009), intellectual impairments influence the degree to which people can participate in certain activities involving a high degree of abstract reasoning, including the analytical processes of research. At the same time, in accordance with the relational model of disability (Tøssebro & Wendelborg, 2014), we recognise the disabling effects of both social structures/processes and cognitive impairment. Consequently, in certain research contexts, researchers need to accommodate differences in the individual capacities of people involved (Bigby & Frawley, 2010; Shakespeare, 2006) and adjust necessary tasks in order to enable their participation. As a result, as Walmsley (2004a) has claimed, people with intellectual disabilities, when given appropriate support and accommodating conditions, can perform the cognitive and practical tasks involved in research participation. Bigby, Frawley, and Ramcharan (2014) have termed such facilitation of tasks in research

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[1] However, in the Norwegian research context this understanding has not been adopted until recently (Gjertsen, Melbøe, Fedreheim, & Fylling, 2017).

processes as *scaffolding for inclusion*. To provide such scaffolding, we sought to engage persons with intellectual disabilities living in Sami areas of Norway when generating new knowledge about their living conditions.

Although inclusive research has been widely conducted, especially in the United Kingdom, the level of detail describing this sort of inclusion scaffolding varies. Early on, Walmsley (2004a) warned against mystifying the inclusive research process and downplaying the skills of researchers. On the contrary, she stressed the importance of clarifying the research process and the role of the researchers involved, in addition to presenting thorough descriptions of the process and methods during the inclusive research process. Although many researchers have followed that advice in describing qualitative inclusive research (for example, Beail & Williams, 2014; Bigby et al., 2014; Nind, 2017; Nind & Vinha, 2012), there are few explicit descriptions of how to quantitatively perform inclusive research (e.g., Boland, Daly, & Staines, 2008; Emerson, Malam, Davies, & Spencer, 2005; Turk et al., 2012). In Norway, inclusive research remains in its infancy, and studies that are performed using inclusive designs are still quite rare (Haugenes et al., 2017).

The university members of our research group faced numerous challenges in facilitating the participation of co-researchers with intellectual disabilities and/or Sami background in our study. Although some of the challenges we experienced were similar to those previously described in literature addressing inclusive research (Bigby et al., 2014; Turk et al., 2012), others were unique or hardly discussed in the literature we reviewed, if at all; most likely because the researcher’s role in inclusive research can vary greatly depending on the people involved and the nature of the study (2004a). As a case in point, some challenges we experienced derived from the stipulations of the study sponsors regarding the focus of our investigation (i.e. the living conditions of persons with intellectual disabilities residing in Sami areas of Norway) and the method (i.e. quantitative via questionnaire). From another angle, our study partially involved people of double-minority status – i.e., both with intellectual disabilities and of Sami background. Moreover, although self-advocacy groups often partner academics in conducting inclusive research studies (Tuffrey-Wijne & Butlert, 2009), Norway currently has no self-advocacy movement, which makes the recruitment of co-researchers different from that of the UK. Thus, the focus of this article is to reflect upon the role of the "differently-abled" researcher, particularly in terms of challenges faced and solutions applied when facilitating inclusive research involving persons with intellectual disabilities living in Sami areas of Norway.

The Sami

The Sami are the only recognised indigenous people in Europe (Hansen, Minton, Friborg, & Sørlie, 2016), a majority (40,000) of them living in Norway (Dagsvold, Møllersen, & Stordahl, 2016). The Sami have their own culture and language, as well as having initially practised their own religion (Hansen, Melhus, Høgmo, & Lund, 2008). Historically, the traditional Sami way of life was based on reindeer herding and primary trades such as small-scale farming and fishing (Lund et al., 2007). Today, however, most Sami have adopted western lifestyles, including modern professions and dietary habits (Sjölander, 2011), and have gradually migrated from traditional Sami municipalities to more urban cities and towns in Norway (Sørlie & Broderstad, 2011). From approximately 1850 to 1980, the Sami people in Norway experienced an extensive assimilation process. During this period, the Norwegian state sought to force the Sami into abandoning their own language and traditional identity in favour of the Norwegian language and culture (Minde, 2003). The assimilation process so stigmatised Sami identity that many Sami came to conceal their traditional identity (Bjørklund, 1994). During the last four decades, however, Sami society has experienced a cultural and ethnic revitalisation involving increased cultural awareness and use of the Sami language, as well as the establishment of Sami institutions such as the Sami Parliament of Norway and Sami upper secondary schools (Pedersen & Høgmo, 2012).

The Research Project

This article recounts experiences from a study on the living conditions of persons with intellectual disabilities living in Sami areas of Norway, which was funded by Bufdir and the NVC. The survey examined whether there are differences in the living conditions of persons with intellectual disabilities, both of Sami and other backgrounds, residing in Sami areas, in addition to having compared their living conditions with those of other intellectually disabled persons living in Norway and with those of the general Norwegian population. Our focus was on the following dimensions of living conditions and quality of life: education, daily activities, housing, social relationships, health, help required, leisure activities, democratic participation, life satisfaction, self-determination and bullying. The questionnaire was the first in Norway to examine the living conditions of people with intellectual disabilities *and* Sami background. While previous questionnaires we found on the living conditions of persons with intellectual disabilities had been filled out by service providers or next of kin, our study was the first in Norway for which persons with intellectual disabilities had the opportunity to answer the questionnaire themselves. Moreover, it was the first quantitative study conducted in Norway in which persons with intellectual disabilities actively participated in researching their own living conditions (Gjertsen, Melbøe, Fedreheim, & Fylling, 2017).

A total of 93 persons, all of whom were at least 16 years old, responded to the questionnaire during interview sessions. Most respondents had a mild or moderate intellectual disability, whereas few had a severe or profound intellectual disability. A third of respondents reported being of Sami descent. To collect each respondent's replies to the questionnaire items during the interviews, we read the items aloud and recorded the respondents' answers live on a computer. Most respondents (88%) answered the questionnaire themselves, while 25% opted to be joined by an assistant while answering the questionnaire, and 12% had a guardian or next of kin answer the questionnaire on their behalf because the guardian or kin considered them unable to answer themselves. On average, each interview lasted approximately an hour. Respondents could choose whether to be interviewed in Sami or Norwegian; all preferred Norwegian. Data from the questionnaires were analysed using the Statistical Package for the Social Sciences (SPSS, version 24) to facilitate frequency distributions and bivariate correlation analysis.

We performed the study in accordance with the guidelines of the National Ethical Committee for the Social Sciences, and the study was approved by the Norwegian Social Science Data Service. We recruited five co-researchers: two women of Sami background from Sami organisations, as well as one man and two women with intellectual disabilities, all of whom were service users we had met through professional networks[2]. They were of varied ages, from adolescent to senior. The co-researchers received oral and written information about the inclusive research study, including an easy-to-read overview. They all consented to participate in the study as co-researchers and to be interviewed about their participation in the project. Furthermore, they agreed to the use of observations and interview data to examine their experiences as participants in inclusive research on the living conditions of people with intellectual disabilities in Sami areas of Norway. Those data, as well as data regarding the work experiences of the research group during the study, were used to illuminate the roles of (non-

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[2] The co-researchers were invited to participate due to their lived experiences as Sami and/ or as having an intellectual disability, thus having "insider cultural knowledge" (Walmsley, Strnadova, & Johnson, 2017). However, we find all people to be different and, as such, none more qualified than others to express the voice of "their people".

disabled) researchers; challenges and solutions of inclusive research with people with intellectual disabilities in Sami areas of Norway. As described in this article, we tried to achieve as equal participation as possible in the research process. However, we acknowledge that the asymmetry, due to the general history of discrimination experienced by Sami and disabled people, has probably affected the co-researchers' position during the research process, thus constituting a potential bias. In this paper, the co-researchers are perceived as agents who interpret their own role in inclusive research; i.e., during research group discussions, they themselves stressed that they were not our colleagues but were involved in cooperating to improve the situation of disabled people.

Results and Discussion: Challenges and Solutions in the Research Process

Choice of research approach

Although the university research team members agreed to follow an inclusive design for the study, inclusive research has no fixed formula, as pointed out by Ollerton (2012). Thus, our first challenge was to determine which inclusive research approach would be possible and applicable within the framework agreed upon with the research sponsors. According to the stipulations imposed by Bufdir and the NVC, we were obliged to examine the living conditions of persons with intellectual disabilities in Sami areas of Norway, by administering a questionnaire, and were expected to complete the project within budget by September 2017.

A useful starting point in determining our inclusive research approach was Bigby et al.'s (2014) description of three major approaches to conducting inclusive research with persons who have intellectual disabilities. According to these approaches people with intellectual disabilities may either: a) lead and control the research, b) give advice about what to do in the research or c) collaborate with people without intellectual disabilities as part of a team whose members perform different jobs according to their skills and interests. Because the quantitative design of our study would require formal skills that persons with intellectual disabilities generally lack, and the rigid study schedule could not realistically allow for people with intellectual disabilities to lead and control it, we dismissed the first approach. We also rejected the second approach, which provided intellectually disabled persons with merely a passive, advisory role. Such an approach would have contradicted our goal of assigning the co-researchers with intellectual disabilities more active roles in generating knowledge about themselves. Furthermore, the schedule, albeit rigid, allowed time for more than simple advisory involvement. Thus, we selected the third approach: collaboration among university researchers and co-researchers with intellectual disabilities, who would contribute their experience living with intellectual impairment, and people of Sami background, who would contribute their experience with Sami culture and lifestyle. Consequently, the research group that was established consisted of three persons with intellectual disabilities - one of whom was also of Sami background - two persons of Sami background and seven persons with formal academic training who worked at the university. One of the university researchers assumed leadership of the project.

To ensure that the research group realised important aspects of the collaborative research approach, such as equality of member contribution, emphasis was placed on trusting relationships and dispersal of power (Bigby, 2014) when organising the group’s work. For example, all co-researchers were paid for their work on the project and all group members had a say in group meeting agendas, questionnaire design and the selection of venues for the dissemination of findings. Nevertheless, the research approach and its execution also posed several challenges during the study period, some of which are discussed in the following section.

Ownership of the research problem

Ideally in inclusive research, persons with intellectual disabilities should identify and initiate the research problem to be studied and, at minimum, they should own the research problem (Walmsley & Johnson, 2003). However, in our study, the research sponsors identified the research problem to be examined; i.e., what are the living conditions of people with intellectual disabilities living in Sami areas of Norway? Consequently, our challenge was to enable the co-researchers to develop ownership of that research problem. To that end, we followed Nind and Vinha’s (2013) recommendation to use people’s own lives as the starting point of the inclusive research. Thus, after establishing the research group and getting acquainted with each other, we discussed what aspects of life the co-researchers found most important in their own lives. As a result of that discussion, the co-researchers became aware of what “living conditions” refer to and pinpointed certain ones as being more significant than others, thus identifying the research topic and making it their own. In the process, they also suggested indicators of living conditions to be examined in the study; some of which differed from indicators stipulated by the research sponsors and/or typically excluded from studies on living conditions. For example, the co-researchers with intellectual disabilities highlighted the importance of accessible transport and relationships with neighbours; they had experienced inaccessible transport as a significant barrier to their participation in leisure activities and other aspects of everyday life, and had taken offense when their neighbours had protested the establishment of group homes. As a contrast, the Sami co-researchers particularly wanted to examine access to Sami culture, the Sami language and the use of traditional medicine. In this way, the various co-researchers provided links to different cultural knowledge, which Nind and Vinha (2012) have underscored as an advantage of inclusive research.

Designing the questionnaire: Contradictory communication needs

Selecting topics to include in the questionnaire went according to the stipulations of the research sponsors and the indicators of living conditions that had been suggested by the co-researchers. The university members of the research team drafted a questionnaire of those topics by referring to available instruments such as national surveys on living conditions among the general Norwegian population (e.g., Fylling, Bliksvær, Gjertsen, & Lundhaug, 2014) and among people with intellectual disabilities (e.g., Söderström & Tøssebro, 2011; Tøssebro & Wendelborg, 2009). All co-researchers received the drafted questionnaire by mail well in advance of the subsequent group meeting, which afforded them the opportunity to review the document and attempt to complete it themselves. Consequently, at the meeting, the co-researchers suggested several changes to make the questionnaire more accessible. For example, the co-researchers with intellectual disabilities suggested that questionnaire items should be worded in simpler language to make them easier to understand. In Tuffrey-Wijne and Butler's (2009) words, the co-researchers thus helped the research group 'ask the right questions in the right way' (p. 175). In particular, some co-researchers objected to the wording of the question, 'Are you healthy?', which they associated with taunting questions commonly asked by adolescents, such as 'Are you dumb?' and 'Are you insane?'. Therefore, as suggested by co-researchers, the item was re-worded as 'Do you have any illnesses?'

Due to the expressed contradictory wishes of the co-researchers with intellectual disabilities and those of Sami background, it was particularly challenging to design a questionnaire that was accessible to both subgroups when it came to effective communication. On one hand, to ensure that questionnaire items were brief and simply worded for people with intellectual disabilities, the questionnaire design should contain items worded primarily as direct questions. On the other hand, members of the Sami community have traditionally preferred a more indirect style of communication (Norwegian Official Report 1995:6) that uses metaphors and involves speaking in a roundabout way. In fact, Sami persons with disabilities have characterised the highly straightforward Norwegian welfare service style of communication as being generally unpleasant (Melbøe, Johnsen, Fedreheim, & Hansen, 2016). Although using a directly-worded questionnaire design risked offending Sami respondents, perhaps thereby reducing their willingness to reply, due to the fact that Sami participants were also expected to have intellectual disabilities, the research group ultimately prioritised wording that would enable all participants to understand the items.

At the same time, the breadth and quantity of questionnaire items became problematic, as with Turk et al.'s study (2012). To address the questionnaire topics stipulated by the research sponsors and those suggested by all of our co-researchers, the research group initially produced a questionnaire with too many items. Following some discussion, the group was able to omit numerous items and ultimately developed a questionnaire that, according to Bigby (2014), neither the university researchers nor the co-researchers could have constructed alone; and that likely constituted a more accessible, relevant questionnaire for respondents with intellectual disabilities and those of Sami background than would have otherwise been the case.

Choice of terminology: Identity, recruitment and publishing

Worldwide, different terms are used in reference to persons with intellectual disabilities, some of which have negative implications including stigmatisation (Williams, 2011). In Norway, *intellectual disability* is the commonly used term and was therefore used in the agreement signed with Bufdir and the NVC. Nevertheless, use of the label *intellectual disability* faced criticism several times throughout the research process. First, while Norway currently lacks a self-advocacy movement for persons with intellectual disabilities, we were not able to recruit co-researchers from self-advocacy groups. We therefore contacted work acquaintances at the Department of Social Education at the Arctic University of Norway. Of the three who expressed interest, one expressed early on that she preferred to be described as having an impairment rather than an intellectual disability. Second, to gain access to possible questionnaire respondents, we contacted gatekeepers (such as service providers at sheltered workshops), who reported that they sometimes did not know which workers to invite to participate; i.e., because workshop employees do not register their diagnoses, the providers did not always know who had an intellectual disability and who did not. The gatekeepers also described how several persons invited to participate declined because they did not identify themselves as having intellectual disabilities or, despite a diagnosis to the contrary, did not want to be labelled as such. Third, while finalising the report of the study, a co-researcher suggested using *persons with impairments* instead of *persons with intellectual disabilities*. Thus, both co-researchers and respondents had expressed discomfort with the latter term. Such discomfort presumably stems from the fact that persons with intellectual disabilities do not identify themselves as such (Gillman, Heyman, & Swain, 2000) and that, as several Norwegian studies have found, persons with intellectual disabilities reject such a categorical identity (Johnsen & Kittelsaa, 2014; Kittelsaa, 2008). Among the first to address this identity challenge was Edgerton (1967). He described the rejection of the label, “intellectual disability”, as a way to manage the accompanying stigma and pass as an ordinary person. His suggested solution to avoiding the stigma was to change the concept; however, as described above, this linguistic change has not resolved the challenge.

Both during the process of recruiting co-researchers and questionnaire respondents and in writing the report, the research group discussed whether to use a term other than *intellectual disability*. Although the group agreed that it would have been better to use another term, we decided to maintain the application of the concept of intellectual disability for two reasons. First, despite the suggested use of *general learning disabilities* or *general learning difficulties* in educational settings, Norway has no official alternative terms referring specifically to intellectual impairment. Moreover, as Williams (2011) has stressed, the term *learning difficulties*, when used as a stand-on for intellectual disability, often causes confusion given its use in referring to conditions such as dyslexia. Second, according to the stipulations of the research sponsors, we were obliged to publish our findings in a final report on the living conditions of people *with intellectual disabilities*. Finding it ethically unacceptable to use one term when recruiting participants and another term in the report, our university team members overruled objections by the co-researchers and gatekeepers, albeit with considerable reservations about not 'respecting the right of people to choose how they wish to name themselves' (Ollerton, 2012, p. 4).

Bogdan and Taylor (1982) argue that the way in which society and the service system are structured is what stigmatises people with differences. They recommend abandoning the practise of labelling people and, instead, shifting attention to the societal and service deficiencies that hinder the participation of some citizens. One way of doing this is to design research projects in line with inclusive research principles (Walmsley & Johnson, 2003) to increase the opportunity for people with intellectual disabilities to take part in research. According to Gustavsson, Nyberg and Westin (2016) the self-identity of people with intellectual disabilities is made up of experientially-based identity positions. Consequently, the position of co-researcher may provide them with valued social roles and the opportunity to develop "valued" skills (Walmsley et al., 2017). However, it is then important that the collaboration agreement with those funding the research, through the phraseology and project requirements, does not stipulate the label, *person with an intellectual disability,* as a master position, but rather gives co-researchers the opportunity to acquire positions that they themselves view as positive.

Recruitment of participants of Sami background

The university research team members also encountered difficulties in recruiting participants of Sami background who had an intellectual disability as well. Recruiting Sami individuals to participate in research studies is notoriously complicated (Minde, 2010) for several reasons. First, Norway does not maintain any exclusive public register of Sami citizens. Second, due to the previously mentioned assimilation process, through which the Norwegian state tried to force Sami individuals to abandon their own language and identity, being of Sami background continues to be associated with shame (Minde, 2005). Consequently, many Sami people remain sceptical to authorities such as researchers (Norwegian Official Report 1995:6). Third, Sami individuals are quite defensive when it comes to participating in research on Sami-related topics (Bull, 2002), given negative experiences with past studies, some of which were extremely degrading; e.g. those involving skull measurements (Bryn, 1925; Skorgen, 2002). Out of respect for those experiences, and to improve the likelihood of recruitment, we petitioned the Sami Parliament of Norway for what Myrvoll (2002) has called *collective consent* to conduct our study. We thereby sought to include the Sami community and receive Sami approval for the study on a collective rather than individual basis in order to afford the group influence over research that would be conducted on them as an indigenous group. Moreover, involving the Sami Parliament mitigated possible challenges related to the representativeness of the co-researchers, as Beighton et al. (2017), Bigby et al. (2014) and Heath et al. (2009) have explained. To obtain collective consent, we visited the Sami Parliament, presented the study to the representatives and ultimately received approval.

Despite having obtained collective Sami consent, involved Sami co-researchers, provided information and consent forms in Sami and Norwegian, in addition to offering the opportunity to answer the questionnaire in Sami or Norwegian, recruiting participants of Sami background nonetheless remained difficult. Several participants who reported speaking Sami or having Sami parents did not openly identify themselves as Sami. One such participant stated that his mother had forbidden him to admit that he was Sami. Consequently, in order to recruit enough respondents to generate representative findings on the living conditions of people with intellectual disabilities, both of Sami and other backgrounds, our university team members merged questionnaire respondents who had reported being Sami with those who had reported being of Sami background into one group labelled "of Sami background" but not necessarily Sami. Because that solution affected how we would code questionnaire variables, and required reflection based on training in quantitative research methods, that particular decision was made by the university researchers in the research group. Much like Bigby et al. (2014), we thus let the research method develop around the skills of the research group and adjusted the process to best accommodate the strengths and limitations of its members.

Data collection

Because none of the co-researchers participated in data collection, this was the least inclusive part of the research process and presented a different set of challenges. Above all, because the study was set up to be conducted in Sami communities of northern Norway, scattered over an area of 112,951 km^2, meaning that none of the interviews would be conducted in our university's municipality, data collection would be both time consuming and expensive due to the travel involved. Another challenge of data collection was the extent of the 76-item questionnaire, which meant that conducting the interviews and assisting participants in completing the questionnaire would be rather demanding for co-researchers with intellectual disabilities to manage on their own. For these reasons, the leader of the research group decided that the university researchers would be responsible for data collection. Although one co-researcher with intellectual disabilities had wanted to participate in conducting a couple of the interviews, he ended up having to withdraw from those arrangements due to health difficulties. Although inclusive research has been described as doing some things together and some things apart (Bigby et al., 2014), the university research team members admit that, despite the funding and time constraints, we could have involved the co-researchers in data collection to a greater degree.

Data analysis

Another challenge was related to involving the co-researchers in analysing quantitative data collected from the questionnaires. Researchers have questioned the participation of people with intellectual disabilities in data analysis (Tuffrey-Wijne & Butlert, 2009) and, until recently, methods of applying inclusive strategies in data analysis have scarcely been documented in literature (Kramer et al., 2010).

Despite wanting to involve all of our co-researchers in data analysis, the university team members realised that doing so would be difficult to accomplish throughout the analytical process. Although we wanted to afford participants the opportunity to conduct research that upheld the idea of ‘nothing about us without us’, part of the data analysis had to incorporate a ‘non-accessible room’. Using SPSS to perform frequency distributions and bivariate correlation analysis on data collected from questionnaires requires academic skills beyond what the co-researchers could be expected to learn. After using SPSS, however, the university team members translated the data into formats that were accessible to the co-researchers to enable their participation in the next phase of analysis. Following the recommendations of Dowse (2009), we presented the co-researchers with summaries of the data that were written in plain English and avoided academic jargon. Furthermore, we created visual representations of numerical data in pie charts, depicting rating category frequency with pictures representing the proportions of how many respondents had answered different questionnaire items and in what ways—e.g., how many respondents owned their homes versus how many rented. The co-researchers with intellectual disabilities suggested that, although such visualisations made the data easier to understand than if they had they been presented in tables with numbers, using bar graphs would have made the data even more comprehensible. According to them, it would have been easier to understand variations in bar height, rather than a pie chart, in distinguishing which responses had been selected more or less. The university research team members could have undoubtedly adopted a more inclusive strategy had we presented different types of graphs to the co-researchers and asked their preferences; a strategy we later learned had been recommended by Kramer et al. (2014).

Ultimately, contributions from the research group members complemented each other during the analytical process. Sami co-researchers discussed ways of understanding the findings within the framework of traditional Sami knowledge and culture. For example, the reason why Sami participants with intellectual disabilities were more dissatisfied with their place of residence could be that sheltered homes were often located outside Sami communities. For their part, co-researchers with intellectual disabilities debated how to understand findings in light of their friends' and their own experiences—for example, how the organisation of housing, leisure, education and work services limited their ability to participate in society as they would have liked.

Finishing the project

The final challenge was bringing the project to an end. As Nicholls (2003) has observed, co-researchers with intellectual disabilities sometimes face difficulties in concluding their relationships at the end of a study. Nind and Vinha (2013) have added that, while university researchers perceive the completion of research as the end of a process, researchers with intellectual disabilities often experience the completion of a study as a new beginning, in which they can more justifiably hope for change because people may pay attention to the findings. That tendency became clear at the end of our study, when two of the co-researchers with intellectual disabilities expressed that participating in the research group had made them feel useful, that they enjoyed contributing to improving the situations of others with disabilities and that they would like to continue promoting their rights. At the end of research involving co-researchers from self-advocacy groups, as is common in the United Kingdom, co-researchers retain an arena for advocating for their rights and changes based on study findings. By contrast, co-researchers in our study were recruited from professional networks, due to Norway's lack of a self-advocacy movement, and thus had no group or network outside the university through which they could continue their involvement after the study ended.

After dissemination of the study findings and the exhaustion of its funding, my university colleagues and I began to pursue new projects. Nevertheless, to provide a visible completion of the study, we arranged a seminar with the research sponsors and external participants in addition to a closing meeting with the research group members only to celebrate the group's achievements. Furthermore, the university team members talked with two co-researchers with intellectual disabilities, who wished to continue advocating the rights of people with such disabilities, about what self-advocacy groups are and how they work. The co-researchers decided to establish such a self-advocacy group, and the university researchers agreed to support them in that process. Those co-researchers also began teaching master-level students in the Disability and Participation programme about inclusive research. Nonetheless, after the study had ended, my university colleagues and I ultimately determined that the roles of co-researchers in future inclusive research need to be more thoroughly planned from the beginning.

Conclusion

This article has identified numerous challenges and possible solutions in facilitating inclusive quantitative research with people with double-minority status. The most challenging aspect of the role of non-disabled researcher was how to reconcile the ideals of inclusive research with the stipulations placed upon the study by the research sponsors – i.e., what should be investigated and how. Furthermore, constraints such as rigid deadlines, limited funding, and data collection to be performed over quite a large geographic area, reduced opportunities to involve co-researchers in data collection. At the same time, the quantitative design prompted methodological challenges, including how to involve co-researchers in analysis that demanded the use of abstract statistical programmes and how to visualise findings in a way that makes them accessible to co-researchers with intellectual disabilities. Additionally, the double-minority status of co-researchers and respondents complicated the process of designing the questionnaire. Co-researchers with intellectual disabilities and those of Sami background expressed contradictory communication needs in preferring direct versus far more indirect wordings of questionnaire items.

However, the study's major challenge in terms of inclusive research with persons who have double-minority status involved identity. Both persons with intellectual disabilities and Sami people, having experienced discrimination and stigmatisation, did not necessarily want to identify themselves as having either status. Thus, an important question is whether it is acceptable for Sami people with intellectual disabilities to be forced into assuming such identities for the purposes of being involved in inclusive research. If not, should they be excluded from participating in the process of generating new knowledge about themselves? Alternatively, participation in inclusive research could be a way of providing them socially valued positions (cf.

Gustavsson et.al. 2016), whereby they themselves may influence what terminology should be used and how it should be presented.

In our project, the criterion of having an intellectual disability posed challenges for the recruitment of co-researchers and participants as well as for the dissemination of findings. Involving persons with intellectual disabilities, who are not affiliated with self-advocacy groups, in research proved to be an ethical challenge. Although participation in the research initiated an empowerment process, co-researchers with intellectual disabilities did not have an arena in which to continue that process once the research ended. As mentioned, we have tried to mitigate this drawback by offering to assist in the establishment of a local self-advocacy group. Despite the described challenges and an evaluation focusing on how the study could have been more inclusive, the research group members ultimately agreed that the inclusive design contributed to a more accessible, relevant and accurate study.

A main self-critique of our project is how our retroactive attempts to integrate inclusive design elements into a pre-existing research project limited the co-researchers degree of involvement, particularly during parts of the research process. An implication for future externally-funded inclusive research is the importance of involving persons with intellectual disabilities from the very beginning of the research process, while working on the application as well as the negotiation with sponsors to reach an agreement. This is important to ensure a collaboration agreement that permits a design that is as inclusive as possible. While there is an increasing demand to obtain external research funding, researchers and co-researchers cannot always decide the topic and other central aspects of their research projects. Hence, there is a need for more research exploring how to involve people with intellectual disabilities in externally-funded projects with requirements that may not necessarily make it possible to meet all the criteria of inclusive research. This is critical in making sure that people with intellectual disabilities are not excluded from participating in this sort of research. Second, there is also a need for more research on how to conduct quantitative inclusive research, including the need for a discussion on what type of training co-researchers, who are involved in such research, should be provided. Third, involving indigenous people, such as the Sami, in inclusive research on living conditions also raises some challenges concerning paradigmatic differences that are not addressed in this article. Examples of such challenges are how to handle the paradigmatic differences between the scientific western and traditional Sami understandings of illness (Nergård, 2012) and concepts of knowledge (Guttorm, 2011). More knowledge on how to deal with such paradigmatic differences has relevance beyond the Sami population, as these differences are common to many indigenous people (Kovach, 2009).

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