

## RESEARCH

# People with Intellectual Disabilities Can Speak for themselves! A Methodological Discussion of Using People with Mild and Moderate Intellectual Disabilities as Participants in Living Conditions Studies

Hege Gjertsen

UiT The Arctic University of Norway, NO

[hege.gjertsen@uit.no](mailto:hege.gjertsen@uit.no)

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In 2016–2017, a living conditions survey was conducted among people with intellectual disabilities in Sami areas in Norway. The aim of this article is to discuss methodological aspects of carrying out living conditions studies where people with mild and moderate intellectual disabilities answer the questions themselves. What kinds of methodological challenges related to the reliability and validity of the study arise? How do we cope with these challenges? How can they affect the quality of the study? The challenge, among other things, is whether we measure what we want to measure. We argue it is possible to let people with intellectual disabilities answer surveys if we carefully consider methodological and research ethical issues throughout the entire research process. To let people with intellectual disabilities answer for themselves will strengthen the quality of the research. At the same time, we must recognise the limitations.

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**Keywords:** living conditions studies; intellectual disabilities; research method; gatekeepers

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## Introduction

If someone asks questions about your life situation and intends to report your answers to others, would you prefer that someone else answered on your behalf? Of course not. So why should it be different when it comes to people with intellectual disabilities? This question was our point of departure when the Norwegian Directorate for Children, Youth, and Family Affairs (Bufdir) asked if we, The Arctic University of Norway, could conduct a survey of the living conditions of people with intellectual disabilities in Sami areas in Norway (Gjertsen et al. 2017). We underlined the importance of letting people with intellectual disabilities have a voice of their own and insisted that this was a nonnegotiable demand if we were to carry out the survey. The funders agreed. Their agreement was not a given, because previous living conditions surveys in Norway have consistently been answered by service providers or relatives. Our study is the first quantitative living conditions study answered mainly by people with intellectual disabilities in Norway. People with intellectual disabilities were also involved in the project as co-researchers (Gjertsen et al. 2017).

This article aims to discuss methodological aspects of doing living conditions surveys where people with intellectual disabilities are the respondents, and we use the study described above as an example: what kinds of methodological challenges arose, how did we cope with these challenges, and how did they affect the quality of the study? The discussion in this article is mainly about participants with mild and moderate intellectual disability. Making the voices of those with severe and profound intellectual disability heard involves major challenges that we do not discuss. As we will elaborate later, we did not delimit the study to include those with mild or moderate intellectual disability, but as a consequence of our recruitment strategy, we ended up primarily with participants with mild or moderate intellectual disability.

After describing the background for the article and briefly presenting the survey, we will discuss methodological challenges related to the reliability and validity of the study and its methods. Reliability is the extent to which data collection techniques and analysis procedures will give consistent findings (Saunders, Lewis & Thornhill 2007); validity refers to the extent to which the research findings give a correct picture of the living conditions of this group (Ringdal 2001). We focus mostly on how the questionnaire was designed, how the participants were recruited, and how data were collected. In the conclusion, we present some final reflections about how to conduct living conditions surveys among people with mild and moderate intellectual disabilities.

Intellectual disability is a common term for different diagnoses and health states that cause reduced cognitive capacity and adaptive behaviour. Intellectual disabilities often involve reduced capacity to manage everyday life situations and may require some level of support for daily functioning. The group in question is highly heterogeneous, however, and those with mild intellectual disabilities are often not diagnosed. People with intellectual disabilities make up approximately 1–3% of the population (White paper no. 45, 2012–2013). WHO (2019) use a medical definition.

Intellectual disability means a significantly reduced ability to understand new or complex information and to learn and apply new skills. This results in a reduced ability to cope independently (impaired social functioning), and begins before adulthood, with a lasting effect on development.

However, the UNs Convention on the Rights of Persons with Disabilities (CRPD), ratified by Norway in 2013, is based on a social-relational understanding of disability, which emphasizes that disability is a result of the gap between demands made by the society and the individual's preconditions (UN 2006).

The Sami are an indigenous people living in Northern Scandinavia and Russia, an area named as Sápmi. They have their own culture and traditional way of living, though most Sami people in Norway today are also part of mainstream Norwegian culture. Although they have their own languages, only about one-third of the Sami in Norway speak a Sami language. The Sami population in Norway today is estimated to be approximately 60,000 (Sjölander 2011). In this article, specific challenges related to doing research among Sami people are not emphasised. Briefly, this concerns being accepted in the Sami community, despite the fact that the assimilation process for several decades, until the 1980s, encouraged the Sami people to reject their language and culture, resulting in a dismissive attitude towards researchers (Bull 2002; Melbøe 2017). We tried to meet these challenges by including researchers and co-researchers with a Sami background and by presenting the project at the Sami parliament to get acceptance in advance. We also translated the questionnaire into Sami and offered interpreters during the interviews.

In Norway, the first living conditions survey was conducted in 1973 (NOU 1976: 28). It examined respondents' resources in different areas, including at school, in work life, and with regard to health (Barstad 2014). The systematic examination of people's living conditions was motivated by a need for knowledge that could be used to evaluate whether political decisions and measures worked as intended and reached the groups they were meant to reach. An important aim of the living conditions surveys is to be able to compare different groups, to compare groups over time, to find out whether some groups have poorer living conditions than others, and to find out if the differences are increasing. Since the 1970s, there has been a growing focus on including a subjective dimension to the objective living conditions questions. This is about how satisfied we are with our life situation and is often referred to as a quality of life-study (Allardt 1975; Næss 2001). Since 1995, Statistics Norway (the central bureau of statistics) has conducted yearly, ordinary, national living conditions surveys of the general population. These are based on structured self-reporting, where the respondent answers questions about him- or herself. Statistics Norway's living conditions surveys today include questions about how satisfied the respondents are with their lives, in addition to questions intended to measure more objective living condition indicators. Nevertheless, because people with an intellectual disability have not answered living conditions surveys themselves, this dimension was not captured in surveys about living conditions of this group. This stresses the need for people with an intellectual disability to answer living conditions surveys themselves.

In the early 1990s, Norway closed all institutions for people with intellectual disabilities as a result of the Responsibility Reform Act for persons with intellectual disabilities, which was implemented in January 1991 (White paper no. 47, 1989–1990). The responsibility for providing accommodation and services to the approximately 20,000 individuals diagnosed with intellectual disabilities was transferred to the municipalities. Several surveys of living conditions for this group have been conducted since then, focusing on how services changed during the reform and how they have evolved through today. One survey was conducted in 1989, before the institutions were closed; one at the end of the reform period (1994/95); one ten years after the reform, in 2001; and one twenty years after the reform, in 2010. The results were reported in Tøssebro (1992, 1996), Tøssebro and Lundebj (2002), and Söderström and Tøssebro (2010). These studies used an administrative definition of intellectual disability, according to which people with intellectual disabilities are those categorised by the welfare state as being in need of, or eligible for, certain support systems (Grönvik 2007). None of these surveys were answered by persons with intellectual disabilities; they were conducted by structured telephone interviews with service providers and questionnaires were sent by mail to relatives. The mentioned studies could therefore not include questions about the target group's own assessments.

## Background

It has been commonly thought that people with intellectual disabilities could and should not participate in research. Over the last few years, there has been an increasing focus on involving this group in research, both as participants and as co-researchers, but mostly in qualitative research (Nind & Vinha 2013). Nevertheless, we are witnessing an awakening when it comes to letting people with intellectual disabilities participate as co-researchers and as informants in different kinds of research (Chappell 2000; Nind & Vinha 2013). Our attempt can hopefully be considered a step in this direction.

As mentioned, previous living conditions surveys among people with intellectual disabilities in Norway have consistently been answered by service providers or relatives (Kittelsaa, Wik & Tøssebro 2015; Söderström & Tøssebro 2011; Tøssebro 1992, 1996). Söderström & Tøssebro (2011) argue that as a substitute for self-reporting they interviewed

so-called proxy persons who knew the person with disability and his or her life situation well. The reasons for the choice were related to methodological as well as research ethical considerations. These considerations were important for us to take into account when doing something previously considered to be a bad idea. To provide a context for this article, we will describe the arguments used against the idea of letting people with an intellectual disability answer the questions.

Firstly, several researchers have claimed that letting people with intellectual disabilities answer the questions will weaken the validity of the study (Tossebro 1996). Arguments used for this claim are linked to the group's difficulties when it comes to understanding and expressing their assessments, due to reduced cognitive capacity. Tossebro (1996) says that most of the people with intellectual disabilities will not be able to answer the questions asked in traditional living conditions surveys. Another set of arguments are linked to doubts regarding whether people with intellectual disabilities are reliable, presuming a higher risk of yes-saying and idealisation. According to Tossebro (1989), idealisation means that the respondents are trying to make the situation look more positive than it is. This may be a result of not wanting to criticise their helper, on whom they are dependent, either where they live or at a day activity. Tossebro also stresses that persons with intellectual disabilities have a tendency to answer yes or to agree regardless of the question, which can result in conflicting or contradictory responses. Secondly, there has been a prevalent assumption that vulnerable groups, including people with intellectual disabilities, must be protected and should therefore not participate in research because of the potential harmful effects such participation may have (Collings, Grace & Llewellyn 2016; Mallander 1999).

We argue that excluding people from participating in research can instead weaken the research. People with intellectual disabilities have reduced cognitive capacities and can have trouble understanding and expressing themselves verbally or in writing; nevertheless, many can answer if the questions are easy to understand. Moreover, while participating in a research project can sometimes be stressful, such ethical considerations must not be an obstacle to having the opportunity to participate in research. Strandbu and Thornblad (2010) point to the need for clear guidelines that can facilitate participation, instead of excluding vulnerable groups from participating. Today, research guidelines determine the conditions for designing and conducting research. The National Research Ethics Committee (NESH) emphasise that 'researchers have a special responsibility to respect the interests of vulnerable groups throughout the entire research process' (2016: 24). Research participation must be perceived as voluntary and must be carried out in accordance with these ethical guidelines. It is important to stress that the NESHs guidelines for research ethics also point out that 'protecting a vulnerable group is occasionally counter-productive' (2016: 25).

Letting people with intellectual disabilities answer the living conditions studies themselves has been done in England. Emerson et al. (2005) conducted the first national survey among adults with intellectual disabilities in 2003/2004. Almost 3,000 persons 16 years or older were interviewed. In 1 of 4 interviews (24%) they talked just to the person with an intellectual disability. In the rest of the interviews, a support person was present. When doing our study, we looked at what Emerson et al. (2005) emphasised during the research process and how they coped with the methodological challenges.

### Presentation of the Living Conditions Survey

The living conditions study was conducted in 2016–2017 in the 10 Sami administrative municipalities and 19 other municipalities with a Sami population in Northern Norway. This survey is the first to examine the significance of a Sami background for living conditions among people with intellectual disabilities. Inclusion criteria were age (over 16 years of age) and intellectual disability, in addition to living in one of the selected municipalities. Both persons with and without a Sami background were included, because the aim was to compare the living conditions among people with intellectual disabilities with and without a Sami background. It was also important to include people of both genders. When recruiting participants, we did not focus on diagnoses or IQ score; we relied on our contact persons' assessment of whether a person had an intellectual disability. We stressed a subjective definition of intellectual disability: whether people perceived themselves as intellectually disabled, irrespective of the basis for such perceptions (Grönvik 2007).

A total of 93 persons between 16 and 76 years of age answered the questionnaire: 29% were in the age group 16–30 years, 44% were in the age group 31–50 years, and 27% were in the age group 51–76 years. The proportion of men was slightly higher at 57%. One-third (33%) of the sample had a Sami background. In the analysis, the group of people with a Sami background includes those self-reporting having a Sami background (speaking or understanding a Sami language) and/or identifying as Sami. Level of intellectual disability was not registered. Nevertheless, because most of the participants answered for themselves, we can assume that people with mild to moderate intellectual disabilities are overrepresented. **Table 1** provides an overview of the participants and who answered the survey in what way.

We used a structured questionnaire with mainly fixed response categories, including some open-answer questions where the participants or the researchers could write text. The information letter and the questionnaire were designed in an easy-to-read language. We emphasised shorter sentences, understandable words, and less text. There were also fewer answer alternatives than in standard living conditions surveys conducted by Statistics Norway. The survey focused on the following dimensions of living conditions: education, daytime activities, housing, social relations, health, help needed, leisure activities, democratic participation, life satisfaction, income, self-determination, and bullying.

**Table 1:** Description of the respondents (N = 93).

Gender	Age	Background	Who answered the survey
Male 57%	16–30 year 29%	Sami 33%	People with i.d. 88%
Female 43%	31–50 year 44%	Non-Sami 67%	Parents or service provider 12%
	51–76 year 27%		
100%	100%	100%	100%

The data were collected mainly through structured interviews using an Internet-based questionnaire (Questback). The researchers sat beside the participants during the interviews, read the questions aloud, and filled out the replies on the computer as the participants answered. People with intellectual disabilities answered the questions themselves in 88% of the cases. They could ask someone to be with them as support during the interview, such as a teacher at the high school. This happened in 25% of the cases. They could also fill out the Internet-based questionnaire at home or via a paper version that could be returned by mail. If they were not able to answer themselves, a parent or a service provider could answer instead. This happened in 12% of the cases. Each interview lasted approximately one hour. The interviews were conducted at sheltered workshops (58%), at home (25%), or other places (18%), such as high schools, day centres, or group homes.

In the analysis, we examined whether there were differences in living conditions among people with intellectual disabilities with and without a Sami background. We also compared the participants' living conditions with the living conditions of people with intellectual disabilities in Norway in general, as well as with the living conditions of the Norwegian and Sami populations in general. Descriptive statistics were conducted according to three background variables: ethnicity, age, and gender. The statistical analyses were done using simple descriptive analysis techniques: frequency distributions and bivariate analysis. Bivariate analysis was done to determine correlation between variables (Bohrnstedt & Knoke 1988). SPSS version 23 was the software package used for the statistical analysis.

Because people with intellectual disabilities can be seen as a vulnerable group, we emphasised ethical considerations throughout the entire research process. The study was approved by the Norwegian Centre for Research Data (NSD) (approval number). The participants received information about the purpose of the study and what they were going to be asked about, and they were told that participation was voluntary. All participants were also informed orally and in written information letters (in Norwegian and Northern Sami) about their right to withdraw from the study without stating a reason, and they were assured that confidentiality would be maintained. We obtained written informed consent from all participants.

The study has some limitations as well as strengths. It aimed to say something about the living conditions of people with intellectual disabilities in Sami areas in general, but answers were obtained mainly from people with mild to moderate intellectual disabilities. The reason for this was partly that many of the participants were recruited from sheltered workshops—working there requires some level of cognitive capacity—and partly the fact that we focused primarily on recruiting participants with mild to moderate intellectual disability, those with the prerequisites for understanding and answering our questions. This skewed the sample, making it difficult to generalise the findings to persons with intellectual disabilities in general. Still, parents or service providers could answer on behalf of a person if he or she couldn't answer by filling out the questionnaire on the Internet or using a paper version. We are unable to say anything precise about the response rate, although we can assume that it was low. The study, therefore, has limitations when it comes to statistical generalisations. Another obstacle may be that there were too many questions, making the participants tired and wanting to finish. There were 76 questions in total, but not everyone had to answer all of them. Nevertheless, the fact that people with intellectual disabilities answered the questions about their living conditions themselves strengthens the validity of the study. Another strength is the contribution from the co-researchers. They improved the questionnaire with regard to which questions to ask and how. It is also a strength that the survey includes people with intellectual disabilities' own assessments of different areas and not only focuses on the objective living conditions dimensions. Furthermore, the way the study was conducted strengthened the validity because we got the opportunity to explain questions and words.

## Results and Discussion

### *Designing the questionnaire*

Designing a questionnaire for a living conditions survey to be answered by people with an intellectual disability involves some specific challenges. Research validity in surveys concerns the extent to which the survey measures what it is intended to measure (Ringstad 2001). In general, when doing quantitative surveys, the questions and answer alternatives must be well processed before publishing the questionnaire, because they cannot be changed afterwards. In other words, a well-prepared questionnaire is important to the validity of living conditions surveys. It is perhaps even more critical when designing a survey that people with intellectual disabilities are going to answer. People with reduced cognitive skills often have difficulty understanding concepts and may have difficulty expressing themselves orally or in writing. Some of the main challenges in our study were designing a questionnaire that captured the selected living conditions areas

(measuring what it intended to measure), that was easy enough to understand for people with intellectual disabilities, and that made it possible to compare our findings with previous studies. Meeting these challenges involved several considerations: what questions do we ask to measure the living conditions, how do we phrase the questions and answer alternatives to ensure that people with intellectual disabilities can understand and answer them, and how do we make them precise enough to make comparisons possible? We recommend letting co-researchers with intellectual disabilities participate in the process of designing the questionnaires. Furthermore, it is important to use an easy language and short sentences, to operationalise theoretical concepts, and to pre-test the questionnaire.

To make comparisons possible, the institutions funding the study wanted us to include the living conditions variables that are usually used in living conditions surveys in Norway. In addition, we had to include areas that are especially relevant for people with intellectual disabilities and that have previously been used in living conditions studies among this group, such as self-determination and bullying. This was the point of departure for our approach to designing the questionnaire. We also wanted to capture the significance of having a Sami background. Moreover, we wanted to include some open-answer questions about the participants' own assessments of different aspects of their life situations, because this was the first time the group had the opportunity to express their own opinions in a living conditions survey.

In the beginning of the research process, we involved three persons with intellectual disabilities (two of them with mild and one with moderate intellectual disability) and two Sami people representing Sami organisations as co-researchers in a research group, and we worked with them when designing the questionnaire. At the first meeting, we discussed factors important to having a good life. The co-researchers underlined several areas as particularly important, including self-determination and good relations with neighbours. Subsequently, we made a first draft of a questionnaire based on questions used in previous living conditions surveys and input from the co-researchers. We then sent the draft to the co-researchers and asked them to consider whether some questions were missing or some questions should be removed or reformulated. At the next meeting, we continued working with the questionnaire. Based on the feedback from the co-researchers, we subsequently changed the formulation of several questions and answer alternatives, added some new questions, and reduced the number of response categories. For some questions, we chose to only have 'yes' or 'no' as answer alternatives. The co-researchers contributed extra questions, ideas on how to phrase the questions, and ideas on how to phrase the answer alternatives (Gjertsen et al. 2017). One of the extra questions was: 'Do you think of those you live together with in the group home as your friends?' Emerson et al. (2005) also received help from people with intellectual disabilities when deciding which questions to ask and how to ask them. As Emerson et al. (2005) and Turk et al. (2012) experienced, we found the co-researchers' contributions made the questionnaire easier to understand for people with intellectual disabilities and helped ensure that we measured the living conditions of this group. After revising the draft of the questionnaire, we asked two persons with intellectual disabilities (not the co-researchers) to pre-test the survey. We sat together with them, read the questions aloud, and filled out the questionnaire, exactly as we intended to do when conducting the survey. The pre-testing resulted in some extra changes to the questionnaire.

When designing the survey, we had to operationalise theoretical concepts to ensure the validity of the study. Do we succeed in making multifaceted concepts concrete and able to measure what we intend them to measure? For instance, we cannot ask people directly whether they experience their living conditions as good or not, because it may vary from one person to the next what he or she defines as 'good living conditions'. We therefore have to use indicators to measure living conditions, such as health, social network. These indicators can give a picture of the living conditions. Similarly, we cannot ask people whether they have a good social network. Indicators for social network consists of detailed questions about numbers of close friends, how often they meet their friends, and so forth, which, taken together, can say something about a person's social network. The operationalisation of concepts was part of our work with the questionnaire.

Finally, when designing questions that were easy to understand, we emphasised using words that are easy to understand and using short sentences. The questionnaire also included explanations of the questions. When it comes to answer alternatives, some of the questions could be answered 'yes' or 'no', while others contained a few answer alternatives, often with three options. The questionnaire and the various answer options are available by using this link: [xxx](#). Phrasing the questions and answer alternatives in a way that made them easier to understand for the participants contributes to ensuring the validity of the study. Although we changed the formulation of some questions compared to those asked in previous living conditions studies, the original meaning was considered retained. This was important due to one of the aims of the study being comparisons between the living conditions of people with intellectual disabilities in Sami areas with the living conditions of people with intellectual disabilities in Norway in general, as well as with the general population.

### ***Recruiting participants***

Recruiting participants in a way that makes statistical generalisations and comparisons possible is challenging. In living conditions studies, it is important that the response rate is high and that the respondents represent the population. This will make statistical generalisations and comparisons possible (Ringdal 2001). While in general living conditions surveys a sample is drawn from the entire population, surveys among people with a specific disability often use other recruitment strategies, such as letting the entire population participate (Kittelsaa, Wik & Tøssebro 2015). Challenges

recruiting participants are common in most research within the disability field (Kittelsaa et al. 2015). In our study, we wanted all persons with intellectual disabilities in the chosen municipalities to participate, regardless of Sami background, insofar as the total number of persons with an intellectual disability in these municipalities was limited. We also knew that it was likely that only a part of the group would participate.

The recruiting process proved to be challenging. There is no complete register in Norway of persons who have an intellectual disability, only a register of those diagnosed as intellectually disabled and receiving help from the municipality. Neither is there a common understanding of who counts as intellectually disabled (Grönvik 2007). Many of those with a mild intellectual disability are not diagnosed, are unaware of having an intellectual disability, or do not consider themselves as having an intellectual disability. As such, it was not easy to determine who should be included, or how to get in touch with potential participants. As a result, we had to depend on help from gatekeepers in the selected municipalities to recruit participants. The term gatekeepers has been used to describe other adults mediating the relationship between researchers and informants (Collings, Grace & Llewellyn 2016). Gatekeeping may occur when researchers must depend on other persons to recruit participants.

We contacted managers and service providers at sheltered workshops, day centres, group homes, services for people with intellectual disabilities, and high schools and asked if they could help us recruit participants. To avoid being rejected, we first sent an e-mail asking for help to recruit participants. In the e-mail, we presented the project, stressed the importance of letting this group finally speak for themselves, and emphasised that it would not involve any extra work for them. After that, we called and asked again. Although we provided written and oral information, the recruiting process still turned out to be challenging. It is both ethically and methodologically problematic if gatekeepers prevent persons with intellectual disabilities from participating in research. The gatekeeping encountered in our study highlights the need for addressing recruitment barriers that can prevent the voices of people with intellectual disabilities from being heard in research concerning their lives.

Potential participants received an easy-to-read information letter in Norwegian and Sami about the project and their right to withdraw from the study without stating a reason, and they were assured that confidentiality would be maintained. They also verbally received information about the study. Finally, as mentioned, we obtained written informed consent from all participants. The concept of informed consent presumes an individual freely capable of making an intentional decision to engage in research (Collings, Grace & Llewellyn 2016). When it came to the participants between 16 and 18 years old, we also obtained consent from their parents. This means that we had to pass two gatekeepers to reach the youngest participants: first, our contact person at the school, and then the parents. Some of the parents said no. It is not known whether a negative answer was based on their assessments of their son's or daughter's ability to participate or whether they wanted to spare their child from participating in something challenging. They also got the opportunity to answer on behalf of their son or daughter.

When we must depend on gatekeepers to recruit participants, these persons will influence decisions about whom to include. Not everyone was helpful in the process, probably for several reasons. This is problematic, because it has the unintended consequence of undermining the opportunities for persons with intellectual disabilities to decide for themselves whether they want to participate in research. As pointed out above, people with intellectual disabilities have rarely been asked in research about conditions related to their life situations. There was much variation in how important gatekeepers thought it was to let this group participate in research and in their beliefs about the ability of people with intellectual disabilities to answer questions, as well as their opinions concerning whether this group should be 'bothered' with participating in research. On the one hand, some gatekeepers were helpful and stressed the importance of letting people with intellectual disabilities participate in research. On the other hand, some gatekeepers asserted this group could not or would not participate without even having asked them. One example of the latter was a leader at a large day centre who said that no one was interested in participating. Unfortunately, they probably never got the chance to decide for themselves whether to participate. In other cases, the gatekeepers assumed that participating in the survey would involve extra work, and they unfortunately had to say no to help us recruit participants. We had to negotiate with gatekeepers to convince them of the importance of helping us recruit participants.

The Norwegian expression for intellectual disability also created challenges in the recruiting process, insofar as it is viewed as stigmatising. Not everyone having an intellectual disability is comfortable with the expression, neither do they necessarily identify as intellectually disabled. Our contact persons in the municipalities had to take this factor into account and, therefore, could not ask everyone they knew with an intellectual disability to participate in the study. Another related challenge was that in sheltered workshops they do not focus on the workers' diagnoses; as such, the gatekeepers do not know precisely whether a worker has an intellectual disability; accordingly, they do not know precisely whom to ask. Nevertheless, we had to rely on the gatekeepers' assessments of whether a person has an intellectual disability.

### ***Collecting data***

How the living conditions survey is conducted affects both the reliability and the validity of the survey. We faced several challenges when collecting the data. It was important that the participants understood the questions and received help and explanations if something was difficult to understand. It was also important that the answers were registered in a

correct way. Moreover, it was important to avoid yes-saying and idealisation in the interview setting. Below, we describe how we conducted the study.

Before data collection, the five researchers participating in the data collection practised doing interviews to ensure validity and reliability. The extent of experience the researchers had in interviewing people with intellectual disability varied. We ensured in advance how we should conduct the data collection and that we had a common understanding of the questions and concepts. We discussed what we had to remember during the interviews: giving the participants enough time, being aware of the risk of yes-saying, explaining questions or words that some may find difficult, and establishing a relationship of trust.

When we met with the participants, we explained the purpose of the study and what the interview would be like, and we assured them of the confidentiality of their answers. We also stressed their right to choose which questions to answer. During the interviews, several participants said they did not want to answer some of the questions, which indicates that they understood they had the opportunity to choose whether to answer. Finally, we asked whether they would like to have a support person present during the interview. When a support person participated, we stressed that he or she was solely there to help and should not dominate the interview.

At the beginning of the interviews, we spent some time getting to know the person. We tried to establish a friendly atmosphere. It was also possible to take a coffee break during the interview. During the interviews, we stressed the importance of letting the participants have enough time to think the questions over carefully before answering. The reason for conducting the survey sitting beside the participants was the opportunity it gave us to explain and clarify questions during the conversation. Despite our efforts towards designing an easy-to-read questionnaire, some participants did not understand some of the questions. For example, what does 'different' mean in questions like 'do you want anything to be different at your workplace'? Difficulties understanding the questions must be seen in light of this groups' reduced cognitive capacity, and our ambition to let everyone participate meant that we might have included people without sufficient mental capacity to respond appropriately to some questions.

Based on our experiences, it is not a good idea to distribute the questionnaire by Internet or by mail, because people with intellectual disabilities may need support to understand the questions and fill out the form. This implies a risk for different understandings that can weaken the validity of the study. The questionnaire must at least be accompanied by specific and easy-to-understand explanations. As described, we were sitting beside the participants, reading the questions out loud and filling out the form after receiving the answers. This made us able to explain and elaborate on difficult questions. Doing so requires the researchers conducting the study to have established in advance a common understanding of the questions and concepts used. In addition, it is important to ensure in the interview setting that one has enough time, clarifies questions, and establishes a friendly atmosphere.

As mentioned above, several researchers have focused on the risk of people with intellectual disabilities wanting to give answers they assume are right or wanting to portray their life situation in a positive light (Kittelsaa 2010; Tøssebro 1989). They may be afraid of answering wrongly or admitting that they do not understand the questions. We were especially aware of the risk of yes-saying during the interviews, which made us reflect even more on our own position as researchers and strive to prevent the respondents from answering just what they thought we wanted to hear. This required we did not ask questions in a leading manner. Nevertheless, our experiences are divided. In some cases, we experienced respondents tried to answer 'the right way', but the overall picture was the opposite: most of the participants spent time reflecting before answering. They gave a clear impression they truly meant what they answered. During the interviews, the participants often pointed to the answer alternatives on the computer that they wanted us to check. The risk of yes-saying is probably less extensive among those with mild intellectual disabilities. It is, however, a challenge in all living conditions surveys, regardless of who the participants are.

## Conclusion

We started this article wondering about advantages and disadvantages regarding the quality of the research when we let people with intellectual disabilities answer questions concerning themselves in living conditions surveys. Based on our experiences discussed in this article, we argue, although it is challenging and imposes certain limitations, having those with first-hand knowledge of their own life situation answering the questions will improve the quality of the study and also makes it possible to include questions about subjective assessments. Nevertheless, there are several methodological challenges related to conducting surveys among people with intellectual disabilities, which can be summarised in terms of three main issues: how the questionnaire is designed, how the participants are recruited, and how the study is conducted. However, the challenges are issues researchers are responsible for solving; they are not arguments for excluding this group from participating in research.

When conducting living conditions surveys where people with intellectual disabilities are the respondents, it may be necessary to delimit the group, insofar as not everyone can answer for themselves. One may, for example, recruit persons receiving disability benefits from the Norwegian labour and welfare services and who are diagnosed as having an intellectual disability. This was done by Söderstöm and Tøssebro (2011), who used registers of service receivers obtained from the municipalities. One may also use people living in a group home and defined by social services as intellectually disabled or persons working in the permanent adopted work measure in a sheltered workshop. The

most challenging issue may be to delimit the group of people having a mild intellectual disability. The main point, however, is that it is difficult to design a survey representing the entire heterogeneous group of people with intellectual disabilities, ranging from mild to profound. Designing a survey may not be methodologically challenging as long as it is made clear who we are talking about, however, and as long as one is not pretending to say anything about all people with intellectual disabilities. To monitor the living conditions of these groups over time, the surveys must be repeated regularly.

Kittelsaa, Wik, and Tøssebro (2015) find it problematic that people with intellectual disabilities are excluded from the ordinary living conditions studies in Norway. There is no system for mapping the living conditions for this group, although they are among the people at greatest risk for experiencing poor living conditions. Previous living conditions studies among people with intellectual disabilities, answered by service providers, have been initiated by research institutes and conducted at random intervals. Kittelsaa, Wik, and Tøssebro (2015) stress there is a need to find a way to study their living conditions, working like a parallel track to the ordinary system for documentation. We agree there is a need for unique living conditions surveys for those having a mild or moderate intellectual disability. It is difficult to see how this group could answer ordinary living conditions surveys conducted by Statistics Norway. At the same time, people with profound and severe intellectual disabilities cannot answer for themselves insofar as they do not possess the cognitive capacity to do so; parents or service providers will still have to answer on their behalf. Highly specialised alternatives, such as Talking Mats-type approaches, can also enable people with more severe intellectual disability to participate. However, we did not use this. The challenges of making the voices of those with severe and profound intellectual disability heard remains to be solved. At the same time, Balboni et al. (2013: 1) stress report of others assessments are sometimes necessary and 'estimation of the client's point of view may be a valid and reliable substitute of self-report when clients are not able to answer'.

By taking into account methodological considerations, it is possible for people with mild to moderate intellectual disabilities to answer living conditions surveys themselves. Doing so presents challenges to the researchers and is time consuming, but it increases the quality of the study. Furthermore, doing so requires the research guidelines set by the NEHS (2016) be followed during the entire research process. Finally, it is important to remember when having this discussion that according to the CRPD (UN 2006), people with intellectual disabilities have a right to participate in research.

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### Competing Interests

The author has no competing interests to declare.

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