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# Doing and Talking: People with Intellectual Disabilities' Handling of Challenges of Remote Communication

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**ABSTRACT**

This article is about the challenge of communication via smartphones and tablets by people with intellectual disabilities (ID). We will give special attention to persons that struggle with verbal communication. One of our co-researchers, the fourth author, has a severe ID. She cannot read, write or use voice assisted technology in any functional manner. As a result of many years of collaboration, and the need for solutions in connection with the challenges with COVID-19, she and her family have developed ways of remote communication that can be mastered both by the person with an ID and the majority (those without similar disabilities). We call it *doing and talking*. Successful remote communication not only depends on technology and how to use it, but also on communication strategies that both work for the person with an ID and the majority. It is often the case that people with ID are expected to learn the skills necessary to adapt to the majority. We will show that success is just as much a question of the majority learning new skills and strategies that can make real inclusion and collaboration possible.

## Introduction

Talking over the phone or just texting are simple everyday ways of communicating with each other. We send messages to say we are late or call to say that we are stuck in traffic. Most of us do this multiple times a day. During COVID-19, communication at a distance has become even more valuable. Keeping a distance and simultaneously being social has for most people become an essential way of handling and enduring the situation.

For many people with intellectual disabilities (ID) this has been a time of even more exclusion and loneliness than usual (Courtenay & Perera, 2020). People with ID have experienced that even family and friends have been asked to keep social distance therefore limiting direct interaction and physical contact. Variations of restrictions have been tough on the majority, but they have mostly found alternative social strategies. Applications (apps) like Facebook, Instagram, Messenger and Snapchat have become

even more important social arenas (Buchholz, Ferm, & Holmgren, 2018). For the majority, talking with friends and family on the phone, with or without video, has at least been an option for maintaining some sort of social life.

But what if you could not read or write and even struggled with saying what you wanted to say? This is the case for many people with severe ID (Boardman, Bernal, & Hollins, 2014). People with ID are in different ways often cut off from remote communication (Buchholz et al., 2018). This can be due to problems with access and handling the technology, but also handling the communication itself. In this article we want to share a positive example of how a group of people have developed ways of addressing this challenge. We have found that it is not only a question of learning new skills on the part of the person having an ID, but it is also a question of developing new strategies for the rest of the participants involved in the communication. The equipment we have used are generic smartphones and tablets with generic apps.

We will focus on how to handle the difficult activity of remote communication. We will show that the fourth author is a key factor in the development of alternative strategies. This way of communicating still contains an element of *talking*, but the success is to a large degree due to how *talking* has been closely connected to *doing*.

## Researcher-Participants

Our research is based on the collaboration between the first and the fourth author. They have worked together as parent and daughter co-researchers for many years (Kversøy & Kversøy, 2018). The fourth author has a severe ID. She does not read or write in any functional way. She also struggles to express herself verbally and cannot use voice assisted technology. Despite her challenges, she has been using touchscreen devices since 2011. To our research team she is considered as a co-researcher and a participant. She has to a large degree developed the strategies and solutions. The rest of the research team has in different ways been engaged in facilitating her exploration process and understanding and analysing her solutions. Buchholz, Ferm, and Holmgren (2020) claim that in order to gather new knowledge on how to enable remote communication for persons with communicative and cognitive difficulties, the persons themselves must be involved in the research. Østby, Bakken, Oterhals, and Ellingsen (2021) claim that co-researchers with ID can see phenomena from their perspective that may be missed or overlooked by researchers without ID. Their collaboration has also led to writing articles in as accessible language as possible.

The Norwegian National Research Ethics Committees (The Norwegian National Research Ethics Committees (NENT), 2016) encourage active citizenship and research that has a focus on inclusion. The Research Council of Norway (NSD) and the research policies of the European Union also recommend more inclusion, collaboration and active citizenship in research (Kostakopoulou, 2013). The authors have had corresponded with the NSD about our special case. They have made it clear that people with ID have the same right to be acknowledged for their contributions to research as anyone else (Nind & Strnadová, 2020). The fourth author has for the same reason been recognised as co-author and co-researcher in articles published in 2018 (Kversøy & Kversøy) and in (Kversøy, Alhassan, Kversøy, & Kversøy, 2019) (Kversøy et al., 2019). Since the fourth author is 15 years old, it is recommended by the NSD that the use of the data is overseen by one of the parents. Sandoval (2018) states that the primary ethical consideration between researcher-participants is respect. In this case it has been both

a question of acknowledging all the researcher's contributions and making ethical considerations about vulnerability. Through our correspondence with NSD, and our internal dialogue in the research team, hiding the fourth author was never a fair option.

## Persons with ID Participating in a Digitalised Society

Our current experiences with COVID-19 has reconfirmed the relevance of technology in our everyday life. Proponents of technological determinism have long claimed that societies are influenced and shaped by new technologies. They have claimed that there is a need to adjust and adapt (Haure, 2017). People with ID are a part of society and are therefore also in need of adjusting and adapting to the changes happening. Hartley writes (Hartley, 2011, p. 279): 'Technological determinism is the doctrine that social change is determined by technological invention'. Our ways of everyday communication and social interaction are constantly changing. COVID-19 has not ignited this change but has accelerated it.

Most face-to-face meetings from friendly contact, to meetings, in person lectures and teaching, have suddenly shifted to be carried out through applications like Messenger, Facetime, Skype, Zoom and Whatsapp. Video calls have become a taken-for-granted activity. Video calls help us get a glimpse of family members, keep contact with friends and allow us to continue work with co-workers and students. The proponents of technological determinism have warned that society will change in ways like this. From this position, we claim that persons with ID are challenged to keep up with the change.

Sadly, the necessary technology has often been inaccessible for those unable to write and read (Chadwick, Wesson, & Fullwood, 2013; Hegarty & Aspinall, 2006; Williams & Shekhar, 2019). An example can be any technology dependent on a keyboard. Hoppestad (2013, p. 190), who has a special focus on people with severe ID, writes: 'Persons with developmental disabilities, particularly adults, are often overlooked and are not thought to be capable of using a personal computer'. Our experience suggests that the introduction of touchscreen devices similar to the iPad® in 2010 has changed the accessibility even for people with severe ID (Kagohara et al., 2013; Kversøy et al., 2019; Kversøy, Kellems, Alhassan, Bussey, & Kversøy, 2020).

## Communication as Talking and Doing

As noted in the introduction, the crux of this article is about the concept of *doing and talking*, involving both persons with and without ID. We claim this is also a pedagogical challenge. Alexander (2008) proposed that pedagogy is not only a matter of teaching technique, but it is also 'a purposive cultural intervention in individual development' (p. 92). *Talk* is a mediating power between cognitive and cultural spaces and other aspects of human development. We can facilitate talk through developing strategies 'to create interactive opportunities and encounters that directly and appropriately engineer such mediations' (Alexander, 2008, p. 92). He argues that effective talk that engages children and scaffolds their understanding, is unfortunately less common as it should be.

We propose that *talking* is not just about communicating with each other verbally. It goes beyond this. Human relations are often defined by inter*acting* together through doing together. Eide and Eide (2017) have contributed to widen our understanding of the term *communication* and in this way made the term *talk* more applicable to our case. Eide

and Eide (2017) write that the Latin term *communicare* includes *doing together, making common ground, including another, having interaction with* and *having connection with*. In this article we have chosen to understand both *doing* and *talking* as parts of *communicating*.

Through our collaboration we have become even more aware of the value of creating knowledge together. Kurt Lewin (1948) claims that development work and action research can be understood as social experiments to create knowledge through practical positive change for those involved. Kurt Aagaard Nielsen (2004) writes that Kurt Lewin makes us aware of how to understand and judge the value of the knowledge created. This often involves a change in the participants. Through their collaboration they become more capable of handling the situation they are in and the social relations they interact with.

### Developing Through a Network of People and Technology

The fourth author has had access to touchscreen devices such as tablets and smartphones since 2011. She has extensive experience with these devices and has developed her own ways of using them. In earlier articles we have shared how the fourth author uses YouTube as a search engine (Kversøy et al., 2019). In this article, we want to share how the interaction over many years between the fourth author, her parents and her grandmother has paved the way for developing alternative distance communication strategies. The strategy now also includes an extended network. We call it the concept of *doing and talking*.

Since Norway went into lockdown on March 13th, 2020, the fourth author has communicated through video phone app solutions with family and friends 1–3 hours a day. In this period, we have found the video phone option on Messenger as the most accessible tool for this task. The reason for choosing Messenger is simply because most people in Norway have and frequently use Facebook and Messenger on their smartphones and tablets. As far as we can see most any mainstream video phone application will do the job.

The parents have for many years had an ambition that the fourth author should develop ways of remote communication but have struggled getting it to become a natural part of her everyday communication. The early seeds of success were sown in collaboration with Grandma. We have videos of the fourth author sitting on the floor playing with toys. At the same time, she had Grandma on a live video feed playing along. The smartphone was simply leaned up against one of the toys in a way that made it possible for the fourth author and Grandma to have a clear view of each other during play. This was exciting to see, but it did not result in the fourth author taking the initiative to contact Grandma in this way or wanting to talk with other friends and family through video phone.

### Methodology and Data Collection

Given that this study involves complex and detailed social interactions among the researchers and the participants, a single qualitative case study design has been used. Several of the researchers, the first, the second and the fourth author, have also been participants some or all the time. The third and the fifth author create a reflective distance. Our intention is to develop 'an in-depth understanding' (Creswell, 2013, p. 97) of employing digital devices for remote

communication with people with ID. We describe this case study as a single 'intrinsic case study' (Stake as cited in Creswell, 2013, p. 100), since it involves one group of individuals' events and focuses on bounded cases that present a unique situation – remote communication between a person with ID and her network of family and friends using digital devices. Our 'angle of vision' (Mannheim, 1949, p. 245) is on the fourth author, the close family members and the remote communication strategies during COVID-19. We see this as a window of opportunity for further learning communication strategies that have the potency to support persons with ID, close family members, friends and others involved in the daily lives of persons with ID.

We even see the potential for making it possible for persons with ID to extend their network by suggesting new ways of interaction in a broader sense. One example is how the staff at the local church has started sending short 15–30 second video messages to the fourth author. In this way the fourth author is for the first time in her life included in the flow of information that is a part of most people's lives (Kversøy et al., 2020). People with ID are often excluded from the public information flow as it is mostly done in writing. Kellems, Rickard, Okray, Sauer-Sagiv, and Washburn (2017) claim that tablets, through video prompting, also have potential for learning independent living skills. There seems to be a cluster of potential for inclusion and independence in making touchscreen devices and videos a part of the daily routine for persons with ID.

Through the case study design, we argue that with efficient use of digital devices and appropriate apps, in addition to clearly understood strategies by all participants in the communication situations, persons with ID can benefit from remote communication in a way that makes them more able to participate in a modern digital society (Kversøy et al., 2020). This could also have the potential to become an important element in establishing a life of more independence. Social interaction through video phones is not only relevant during COVID-19 but makes it possible for more frequent social everyday interaction when physical interaction is not always practical or possible. To systematically untangle the processes and strategies that have emerged we find Erving Goffman's (1961, p. 7) quote relevant:

> ... any group of persons - prisoners, primitives, or patients - develop a life of their own that becomes meaningful, reasonable, and normal once you get close to it, and that a good way to learn about any of these worlds is to submit oneself in the company of the members to them daily round of pretty contingencies to which they are subject.

This suggests that persons with severe ID, as we are prepared to argue in this case study, perform meaningful and reasonable activities in their everyday lives. However, those meaningful activities are often not recognised as meaningful and reasonable by the majority simply because they are either not willing to get close to them or they choose to ignore them. Often it is not a lack of willingness, but a lack of strategies. Several of the participants in the extended network have found remote communication with the fourth author awkward and stressful. They care about the fourth author, but earlier they did not have a strategy for communication they mastered.

One reason could be that we most often automatically do as we are used to doing things. Habit is a powerful determinator. It creates confusion when our habitual ways of doing things no longer seem to work. Change requires us to stop and reflect and ask ourselves if our

strategy actually works (Dewey, 1916). It can be important to be aware that unsettling habits often awakens resistance (Dewey, 1927). This must not be confused with negativity. It can be hard to accept that the habitual way of communication is no longer working. Unsettling habits unsettles control. Both the majority and the person with ID need patience and recognition when habits are challenged (Alhassan, 2013; Kversøy & Hartviksen, 2018).

In any variation of qualitative case study designs, multiple sources of data collection methods could be applied (Creswell, 2013). In this intrinsic case study design, we have collected data mainly through video. Also, our systematic discussions about the communication events that have happened are parts of what we consider as data.

We experience an emergence of methodology as we go. We see the need for methodology on many levels. Our data collection strategies are just one of several central parts of our methodology. The second is our methodology of enhancing the possibilities of development through interpreting needs, interests and solutions suggested and shown by the fourth author (Kversøy, 2018). Thirdly we think of methodology in how we analyse our data (Charmaz, 2006; Creswell, 2013). In this last instance it has been important to include researchers that have not been part of the interaction directly. As stated earlier, the third and fifth authors are a critical part of our research team to maintain distance. In addition, methodology is concerned with how the parents facilitate pedagogical and developmental ideas.

Like many parents of people with ID, the first author, together with the fourth author's mother, have through the years been presenting an array of options of things and activities for the fourth author. Often these suggestions have not amounted to anything significant or have just awakened brief interests that disintegrate in a short time. The first important steps of our pedagogical and developmental methodology have been to offer options and be aware of interests. The latter can both be registering and encouraging interests that emerge from options presented, but also an awareness of interests that the fourth author discovers and develops herself (Johnson, 1974). Often it is this last point that has been the source of successful development.

The parents have been inspired by pedagogical and developmental thinkers like Dewey (1916), Johnson (1974) and (Freire, 2018). The parents aim has been to facilitate the development of the fourth authors self-determination – i.e. the ability to act with intent to freely chosen goals (Garrels & Palmer, 2019; Wehmeyer & Shogren, 2017). Firstly, the fourth author's decisions are taken very seriously (Johnson, 1974). This is a planned and intentional strategy. When the fourth author says a *no* or a *yes*, these decisions are respected to as much degree as possible. The parents claim that this facilitates the building of the power of autonomy. Secondly, any initiative is, as far as possible, supported. If the fourth author suggests something, the parents always do their best to make it happen. They also do their best to make it happen as soon as possible. The parents claim that the fourth author has in this way developed a confidence that she has the power to make things happen. This strategy is supported by psychological research. Wehmeyer and Schwartz (1998) claim there is a clear correlation between self-determination and the quality of life for people with ID. They recommend systematic work with self-determination. 'Self-determination is an aspect of participation. It is the ability and freedom to make one's own choices and is essential for optimal functioning and wellbeing (Buchholz et al., 2018).'

Collaboration and development work require active citizenship (Kostakopoulou, 2013). We claim that this becomes possible when the participants experience that their will is respected and their will happens (Freire, 2018). This might look like a recipe for creating young spoilt dictators, but the opposite strategy might easily create powerlessness. The emergence of personal willpower is not dependent on getting every want satisfied, but is about being taken seriously (Johnson, 1974). Willpower and self-determination are closely connected. It can be tempting to train people with ID to do as they are told and act in ways that are likeable to the majority. Often the upbringing of people with ID has been just this. Unfortunately, this strategy has the potential of increasing vulnerability and powerlessness. A person with an ID that cannot set clear boundaries for herself and lacks self-determination becomes more vulnerable than necessary. Being able to initiate remote communication can be one important element to contribute to empowerment. The aim is that the fourth author is able to take initiative to call friends, family and assistance when she feels the need to. The aim is also that she can operate the technology independently and has the locomotion necessary to make it happen.

## Descriptions of the Case and the Development Process

Even though the fourth author struggles verbally, she does understand most of what is being said. The challenge is more that she is not able to answer with longer sentences or groups of sentences. She answers in single words or short sentences. As she also lacks words, she often has to generalise by pointing and using words like 'thing' and 'there'.

Even the simplest questions can be impossible to answer. People might ask: 'How are you?' 'How old are you?' 'What do you like to do?' 'What have you done at school today?' These are normal questions people ask each other when they meet. The fourth author is unable to answer them. In most cases the reaction is a sad face and the words: 'No, no, no.' People feel awkward when they experience this reaction (Kversøy et al., 2020). The fourth author gets embarrassed and answers the only way she can. The majority often have no idea of how to proceed. The result is that the moment of potential communication is lost. We claim the challenge is not the skills or abilities of the fourth author, but the lack of strategies for alternative communication on the part of the majority.

The first seed of creating curiosity and interest for remote communication was planted by the fourth author herself. It is important to note that in the beginning, this initiative was not comfortable. The initiative could easily have been stopped by the parents. It felt awkward. Some might even see it as something a spoilt and demanding child would do to control the Grown-ups by commanding them to do things at her will.

It all started when the fourth author asked Grandma to walk around the house with her smartphone in video mode. The fourth author wanted to see the sofa, the bed, the bathroom in and so on. The fourth author would say: 'I see . . . ' (can I see . . . ?). She would ask questions like this every time she spoke to Grandma. The questions would go on and on, and Grandma would patiently be walking around the house showing rooms and items at the fourth author's request. Grandma is very patient. Even though Mom and Dad would express their feelings of unease, Grandma would say it was fine and that she was able to set her own boundaries. Other friends and family members found the fourth author's strategy more demanding in the beginning.

The fourth author most often prefers to socialise and speak with Grown-ups. This is not uncommon for a person with severe ID. Grown-up family members, friends and professional helpers are often better at understanding what is going on than what might be referred to as peers. It can be challenging to be in social interaction and building a relationship with a person with severe ID. It can be even more challenging for a person with severe ID to build a functioning relationship with another person with ID. The idea of 'birds of a feather flock together' is often just a myth when it comes to people with ID. The idea of 'them', as a group of people with a special ability to connect because of their perceived likeness might seem sweet and be with good intent, but is of consequence often a form of social segregation that can even be described as a form of ableism (Grue, 2016; Hehir, 2005). We are not saying that people with ID cannot have good social relationships with each other. Many people with ID have great relationships with other people with ID. We are just pointing out that these relationships can be very challenging for the participants.

The fourth author does have friends with ID. The people with ID she does have a relationship with are her school friends. These relationships are valuable and wanted. For the fourth author, the social interaction with these friends comes with a high cost of energy. Social interaction with people like family members, friends and teachers, who are able to handle the interactions more on the fourth author's terms, most often comes with a lower cost of energy. Experiencing that others understand what you are saying and are willing to do as they are asked to do, is empowering.

## Remote Communication During COVID-19

The possibilities for social interaction changed with COVID-19. On March 13th, 2020, the fourth author and her immediate family were cut off from direct physical contact with others. Schools were closed and people in Norway were asked to have as little direct contact with others as possible. The fourth author, who was 14 years-old (now 15), found herself stuck at home with Mom and Dad.

Luckily the fourth author is a daily user of touchscreen devices. Also, a few weeks earlier in 2020, the first author had purchased a tripod for taking closeup pictures. The fourth author found the tripod very interesting to play with it. The first author saw an opportunity. The new tripod became the first trigger to call Grandma. The fourth author wanted to test the tripod and show it to Grandma.

The first author has also supplied Grandma with an iPad®. This means that Grandma is a competent user. The fourth author has been a teacher and a great motivation for Grandma. A few days after the first lockdown we started having daily video communication with Grandma. Grandma asked the fourth author if she wanted to take part in things like preparing meals, looking around Grandma's house or washing clothes. The fourth author would take initiative to show Grandma around her own house, invite Grandma to play with dolls, do arts and crafts and look at her new tripod. The communication rapidly evolved. Talking to Grandma, other family and friends was a welcome break from the monotony.

Soon the fourth author experienced increasing creativity. As an example, the first author filmed a situation where the fourth author is teaching Grandma and Uncle how to wash dishes. The fourth author set the tripod correctly in place so that Grandma and Uncle could

participate. It was great fun. Just putting the tripod in place required a great deal of experimenting.

The fourth author is usually not very interested in washing up. In addition, the family has a dishwasher. Boredom, a good sense of humour, being left alone to fool around and a patient audience consisting of Grandma and Uncle, ignited a bundle of energy. The first author filmed a long sequence of this situation and showed it to the fourth author the following day. This was maybe even more fun. The fourth author could see herself in the role of teaching Grandma and Uncle. She could also see closeups of their faces. It was a wonderful example of *doing and talking*. The doing, in combination with the comments from the participants, made it very interesting and fun for all those involved.

The daily video meetings soon became the best part of the day. The fourth author would talk to Grandma, Uncle, Aunt and family friends from one and up to three hours a day. To one of the family friends we suggested using a timer. This greatly improved the structure and made it easier to stop when she got tired. The fourth author talks to this family friend nearly every day in this way. First there is fifteen minutes of doing and talking and then a routine discussion that mostly results in an agreement that the call was too short. The fourth author routinely suggests an additional five minutes. The suggestion is nearly always accepted. The fourth author understands 'five minutes' as 'a little longer', but the routine seems to be stimulating a little more understanding of numbers and time.

The first author has filmed many shorter sequences of these conversations. The external co-researchers have in this way been able to observe many of the same situations as the internal researcher-participants. It would be near to impossible for any outsider researcher to get this sort of privileged access. The parent/daughter researcher-participant configuration has been paramount both for the research and the development process.

The videos are also part of the fourth author's entertainment, reflections and inspiration. People with ID get fewer opportunities to reflect over their own actions and interaction. The fourth author does this daily. The comments, laughter and initiative that emerges from watching the videos indicate an ongoing reflection process. The videos are not watched randomly. The fourth author will search for the particular videos she is interested in at that moment. She has a video library of more than 1000 short videos of herself and her network accessible from her iPad®.

In the beginning most of the participants struggled with interacting and socialising with the fourth author on video phone. We introduced the concept of *doing and talking* and explained that they could do whatever practical shores they needed to do while talking with her. We even encouraged them to plan to do something practical. This strategy helped the participants master the social situation better. This might be the most important discovery of this development work.

When one of the participants struggles with verbal communication, the verbal options are limited. The communication easily becomes boring, embarrassing and awkward. The fourth author found the solution. She started taking initiative to do something she found interesting. Doing something interesting ignited creativity and confidence. Boredom can be a great source of creativity.

## Discussion

What are the success factors? Our group of researchers have watched some or all of the video footage. Either we are insider participating researchers or outsider researchers we see common elements. All the equipment you need is a smartphone or tablet and a video phone application. Attaching the touchscreen device to a tripod gives you free hands. In the case of the fourth author the iPhone® and the iPad® seems to have a more intuitive interface than other touchscreen devices. This is only important when the fourth author is making the video phone call herself.

The fourth author master's touchscreen devices and can use them independently. She is used to taking initiative and being respected for her choices. She is used to being respected for her initiatives and solutions. It is through playing along with her suggestions we have found a functioning strategy. It requires very little language to participate in *doing and talking*. It is built up by simple elements:

I do my thing and you do your thing.

I show you what I am doing, and you show me what you are doing.

I comment on what you are doing, and you comment on what I am doing.

I ask you to do something or show me something and you ask me to do something or show you something.

We let ourselves engage by what the other person is doing. Simple comments fuel the interaction: 'How interesting' 'Show me more' 'What is in there?' 'What is that?

Lots of laughter

We have shared our experiences and many people tell us they experience recognition. Many people have been making video phone calls in this way during COVID-19. I recently talked to a former colleague who is 75. She has a boyfriend in another country. He is 81. They met just before the lockdown last year and have only been able to meet physically a few times because of the restrictions. She tells me how they have coped. They eat their meals together on FaceTime. She eats with her iPhone® in front of her and he does the same. Every Friday they put on their best clothes and share a special video meal. They do things together and do not need to talk all the time. It is not always easy to have something to talk about if you meet often. Just being together and doing things together over video phone is very satisfying. My former colleagues' distance relationship works very well.

Our discovery opens an array of social possibilities. The lack of reading and writing skills is not a problem. Even if you struggle with verbal communication it does not exclude you from this form of social interaction. What we found was that the biggest obstacle was often the majorities' lacking alternative strategies to master the communication. It seemed not to be a lack of willingness, but more a confusion connected with not being able to communicate the way they were used to. Habits seemed to get in the way. The fourth author had solutions, but they could be hard to understand if you were not paying attention. Reflecting together and making the strategies of communication explicit has been a key factor in helping the majority master the communication.

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No potential conflict of interest was reported by the author(s).

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