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**The Role of Culture and Cultural Differences when Communicating with People with
 Congenital Deafblindness**

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Abstract

This study investigated to what extent cultural differences affected and influenced the communication between individuals with congenital deafblindness (CDB) and their communication partners. It was hypothesized that because cultural differences has an effect on people who are not deafblind that a similar thing would be present for deafblind people. Six professionals in the field of deafblindness were recruited to participate in two online focus group discussion sessions where they shared their experiences and opinions on the subject matter. Based on the results of these two sessions, partial support for the hypothesized effect was found. Most of the participants of this study agreed on the idea that being deafblind is a culture itself, and the culture where the CDB individual was raised in did not play a significant part. Several challenges in communication due to differences in culture with the CDB individuals were highlighted during the sessions. For example, the CDB individual needed to learn multiple sign languages and the need to find alternative ways of communication. Given the results of the study and the lack of other studies done in this topic, more research is needed to fully understand the effects cultural differences have on the communication between individuals with CDB and their communication partners.

Keywords: deafblindness, congenital deafblindness, culture, language, communication

Introduction

Deafblindness is a term used to describe the condition of impaired or loss of vision and hearing in an individual (Wittich et al., 2016; Roy et al., 2021). There are three subgroups of deafblindness based on the age of onset: (1) at birth or before language development (congenital deafblindness, CDB), (2) after language development, (3) and at elderly age (Damen et al., 2020). The focus in this thesis is on individuals with CDB, which affects approximately one in 27,000 newborn children (Dammeyer, 2012).

Studies on language development in children who are deaf or hard of hearing have

shown that they can develop in the same ways as hearing children can, provided they are given a language that is consistent and easy for them to understand (Preisler, 2005). Gestures and hand motions are already a source of information for children who are not deaf or hard of hearing (Alibali et al., 1997; Gather et al., 1998). For deafblind children, if they were given a tool for communication they could communicate with another individual and that they have the ability and desire to communicate with their environments (Preisler, 2005). One of these tools is gestures, which the deaf and hard of hearing children use to communicate in a manner that is structured like a language (Goldin-Meadow, 2003).

Another tool for communication is tactile sign language, which is something that the child with CDB can learn “through bodily experiences leading to gestures from the child with CDB himself, or bodily experienced tactile signing introduced by the communication partner” (Brede & Souriau, 2016, p. 5). In practice, the child with CDB will need to learn and understand the handshape, movement, and locations for their signs (Forsgren et al., 2018).

Interestingly, cultures and countries may differ in the use of nonverbal communication that includes gestures, signs, and physical contact. Culture is therefore a tricky concept to define due to its use to describe different phenomena. However, culture has some key characteristics. For example, culture is tied to a specific group, learned from other individuals within that group, consists of several interconnected and related components, and can gradually change over time (Spencer-Oatey & Franklin, 2012; Oyserman, 2017). Culture “provides the foundation for schemata used to process memories, form personality expression, and determine appropriate reactions to environmental stimuli” (Seibert et al., 2002). Culture was also described by researchers in the field of deafblindness as “a medium, and not an independent variable” (Hart & Rødbroe, 2010, p. 2). This would indicate that culture should play a significant role in the individual’s development and help determine who they are.

As cultures are tied to a specific group, different groups will have different values.

These values help determine what a person finds more important and helps the person decide between right and wrong, and these differences in values can lead to misunderstandings in communication (Ennels, n.d.) or stress to adjust to the differences between the two cultures even for individuals who are not deafblind (Firmin et al., 2013). An example provided by Ennels (n.d.) is how education was handled for disabled children, including deafblind children. When visiting a school in Israel, a large focus was placed on the children doing activities together and to interact with other children. This was contrasted by Ennels' experience with schools in the UK and USA where the focus was more on individualized curriculums that were focused on the child's individual needs.

Similarly to how different groups have different values, they will also have different ways to communicate with others in the community. For example, deafblind individuals in Japan might be quick to adopt finger Braille as a communication method whereas this method is less common in European countries (Hersch, 2013). Another example is that interactions involving deafblind children in Uganda, Kenya, and Tanzania indicated a noticeable difference in communication styles compared to European countries (Hart & Rødbroe, 2010). The hotter climates of these African countries promoted wearing less clothes. This allowed more contact with the skin and allowed physical touch to be more socially acceptable in the community.

There are many theoretical models about how and why cultural differences occur, and perhaps one of the most popular and widely used models was developed by Hofstede in 1980 (Dabić et al., 2015). This theory, the cultural dimensions, can be used to identify how much two cultures differ from one another. It uses six categories to do so: (1) power distance index, (2) individualism vs collectivism, (3) masculinity vs femininity, (4) uncertainty avoidance index, (5) long term vs short term normative orientation, and (6) indulgence vs restraint (Nickerson, 2022). The cultural dimensions theory can be used to provide understanding of how things work in certain cultures relative to other cultures. This, in turn, will help when

interacting with individuals from other cultures. If two cultures share many similarities in these categories it will be much easier for individuals to communicate with each other compared to if the two cultures do not share many similarities in these categories (Hofstede, 2011).

The Developmental Model of Intercultural Sensitivity (DIMS) codes observations of interactions from people interacting with other cultures (Bennett, 2017). In the DIMS, communicative competence was defined as “the ability to understand and generate appropriate utterances in context” (Bennett, 2017, p. 2). The move from communicative competence within the individual’s own culture and communicative competence in another’s culture was a key concept from the DIMS (Bennett, 2017). Within the DIMS itself there are six stages to describe the progress of an individual in their communicative competence: (1) denial of differences, (2) defense against differences, (3) minimization of differences, (4) acceptance of differences, (5) adaptation to differences, and (6) integration (Rasmussen, 2012). The first three stages were also grouped together as the ethnocentric stages whereas the last three stages were grouped together as the ethnorelative stages (Bennett, 2017; Rasmussen, 2012).

Individuals who are at the first stage of the DIMS, denial of differences, will be unable to perceive or recognize a culture other than their own, or they will choose to ignore the other cultures. At the second stage, defense against differences, individuals think in a ‘we’ and ‘them’ mentality where other cultures are recognized but in highly stereotyped ways. The third stage, minimization of differences, minimizes the differences between the two cultures and focuses heavily on the similarities whilst thinking that things familiar to their culture are familiar in other cultures as well. At the fourth stage, acceptance of difference, individuals can accept that other cultures have different norms and values, but these recognized differences might still be recognized as a negative by the individual. At the fifth stage, adaptation to difference, is when individuals take the steps to learn and bridge the gap between the two cultures. At the sixth and final stage, integration, individuals have applied the differences between the cultures to

themselves and can freely shift between different frames of references (Bennett, 2017; Rasmussen, 2012).

Differences in culture can be viewed as a negative, viewing others as being distant and not part of the same group. However, it can also be viewed as a positive, to try and connect with more groups and provide a new learning opportunity by interacting and involving with others (Hart, 2015). The focus of the study was culture and the effects that cultural differences may have in terms of communication involving individuals with CDB. Cultural differences has been known to affect people who are not deafblind so it was hypothesized that a similar phenomenon is present for people who are deafblind.

Research Purpose and Questions

The purpose of this research was to identify both advantages and challenges that communication partners might find when interacting with individuals with CDB from different cultures. This could ideally be used to alleviate some challenges communication partners face when communicating with an individual with CDB from a different culture. It will also serve as useful examples on the benefits provided by the cultural differences during communication between communication partners and congenitally deafblind individuals from different cultures.

The main research question of this study was as follows: “to what extent does cultural difference affect and influence the communication individuals with CDB and their communication partners?”. In order to answer the research question, six subquestions were formulated to help guide the collection of data. The process of how these questions were formulated can be seen under the *Instruments* section of the methods. The six subquestions were as follows:

1. What challenges did the communications partners face when trying to communicate with individuals with CDB from other cultures?

2. How much can these challenges be attributed to the differences in culture between the individuals with CDB and their communicating partners?
3. How did the communication partner feel when they noticed these challenges?
4. What methods did the communication partner use to overcome them?
5. What advantages did the communication partners identify when trying to communicate with individuals with CDB from other cultures?
6. In what ways can these advantages benefit the communication partner and/or the individuals with CDB?

Methods

The method used in this exploratory study was focus group discussions. The method was adapted from the methodology described by Ochieng et al (2018). As such, this method would allow participation of more participants in a shorter period and the discussions between the participants were also used as a source of data in this study.

Procedure

An invitation poster (see Appendix A) was posted on the Alumni Facebook group of the Deafblindness Master's program at the Rijksuniversiteit in Groningen, the Netherlands. This post had the contact details of the researcher written on it, so participants interested in the study could contact him. The participants were sent an information document detailing the structure of the sessions and an informed consent document (see Appendix B) that they had to sign. They were also sent a Background Information document (see Appendix C) that they were asked to fill in. Both of these documents had to be returned to the researcher before the start of the focus group discussion session so he could send the invitation links to the participants. The sessions lasted no more than sixty minutes and were held online due to the ongoing COVID-19 pandemic at the time. The platform used was Google Meet as it had an integrated recording function, removing the need to download and install a third-party software

to record the session.

The sessions started with the researcher welcoming and thanking the participants for their participation in this study. He would then introduce and describe the study to the participants before initiating a round of introductions. The researcher would introduce himself to the participants after which the participants introduced themselves to each other, including their names, the country they worked in, and their work experiences with individuals with CDB. The researcher, using the research questions listed above to help guide the discussions, did not engage unless the participants strayed off-topic or there was a dip in activity amongst the group. Without the researcher's active involvement in the discussion, the participants discussed their experiences interacting and communicating with individuals with CDB from different cultures. The discussion then shifted to what the participants perceived were positive and negative effects that stemmed from the cultural difference between them and the individuals with CDB. It would then be concluded by the participants discussing what effect it had on them and what methods they used to try and adjust for the cultural differences.

Participants

Participants were recruited through the Alumni Facebook group of the Deafblindness Master's program at the Rijksuniversiteit in Groningen, the Netherlands. Each session aimed to have six participants. To stimulate more discussion about cultural differences and its effect on communication with individuals with CDB, priority was given to participants of different cultures to enable more diversity of culture within each session. Therefore, each session had a maximum of two people from the same nationality.

Instruments

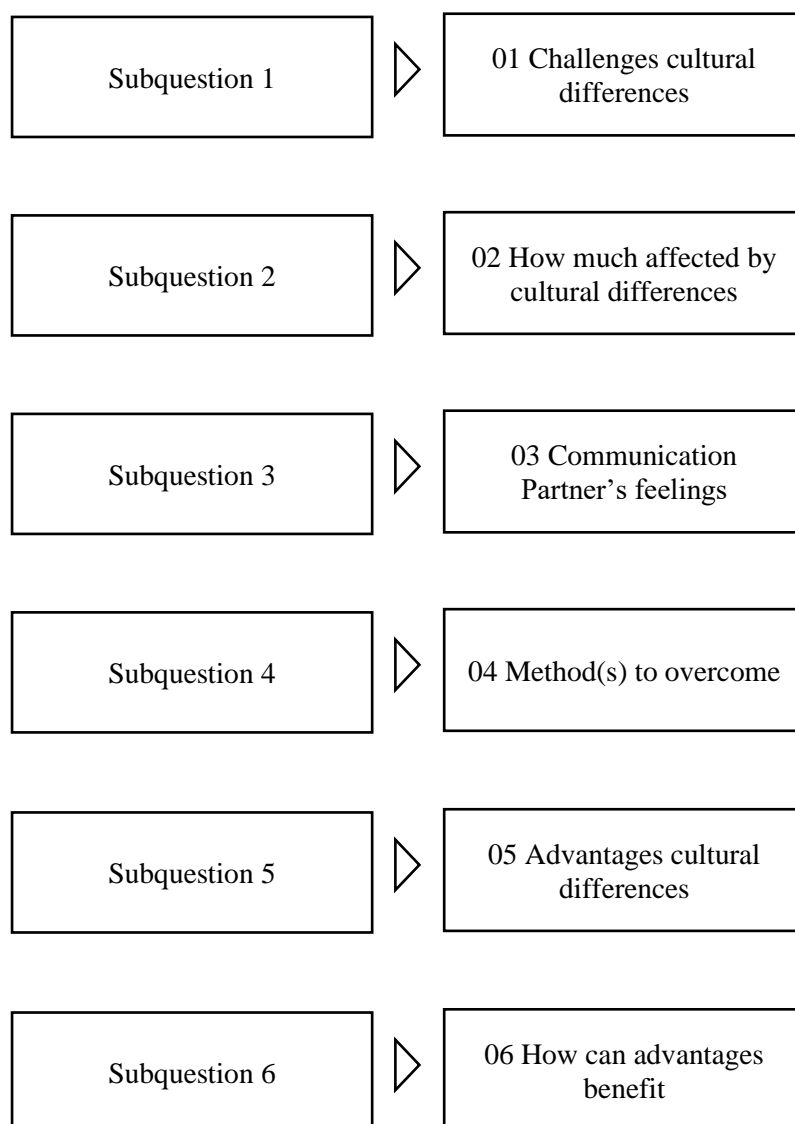
As the author had learned in the two sessions about Developing Intercultural Awareness (Carrascal, 2021a; Carrascal 2021b), there were a myriad of potential differences between any two cultures that can influence the communication between two individuals from different

cultures. It was also specified that cultural differences are not always a negative presence as it can also enhance or benefit certain situations.

The six subquestions were therefore designed with the idea that a similar idea would be applicable for communication partners trying to communicate with individuals with CDB from different cultures. The main research question was divided into challenges (negative effects that cultural differences had on communication) and benefits (positive effects that cultural differences had on communication). To reduce the risk that any challenges were due to a different cause, a sub question was formulated to determine whether these challenges that the communication partner faced were due to the cultural differences. It was then decided that it was important to find out how these effects affected the communication with the individuals with CDB from the perspective of the communication partner so a subquestion dedicated to this was formulated. Finally, it was also important to understand the participant's feelings upon learning of these challenges, if any.

Analysis

After the sessions were completed, a written transcript was made of the session with every personal identifiable information anonymized and given a number (1-6) for privacy reasons. Thus, the names of the participants, where they were from, where they worked, and for which organizations they worked were all anonymized. This anonymized transcript was then sent to the participants of the session to ask for their feedback and input. During this process, participants could fill in gaps resulting from inaudible audio in the transcript or request words, phrases, or even sentences to be removed or phrased in a different way.

Figure 1*Coding creation process*

Deductive coding was used during the analysis process. As can be seen in figure 1 above, six codes were created prior to the analysis process based on the six subquestions. Segments of the transcript designated the first code were parts of the transcripts where the participants described the challenges they faced when communicating with individuals with CDB from different cultures (subquestion one). The second code was tied to the second subquestion, so segments of the transcript marked with the second code were the points where the participants discussed to what extent the challenges could be attributed to the difference in

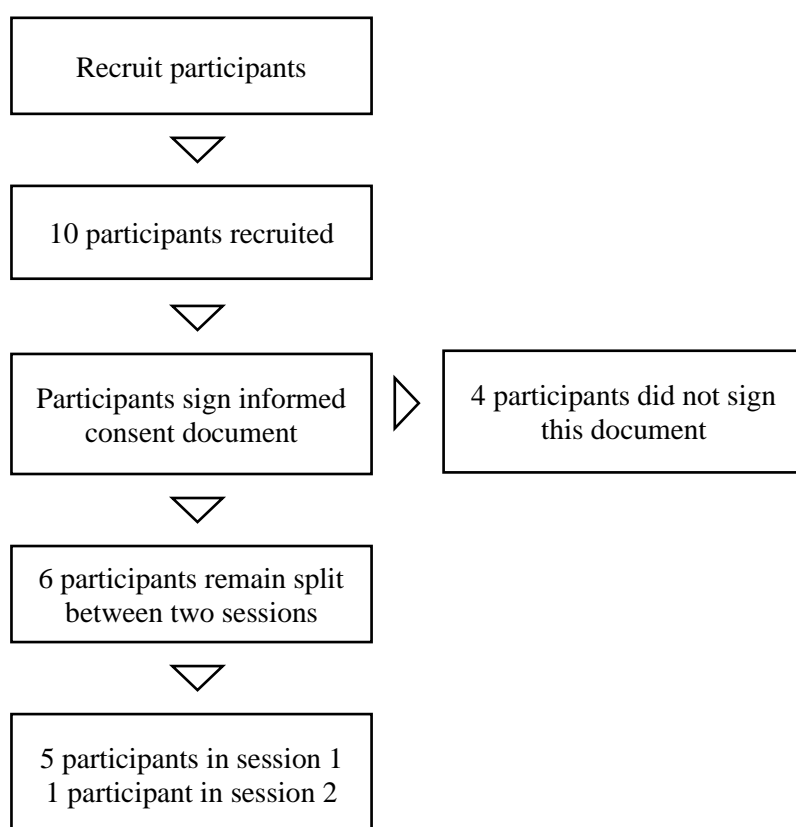
culture. This connection between the code number, the subquestion number, and the sections divided by these codes remained the same for subquestions three up to and including subquestion four. The connections and differences between these segments of the transcript were then evaluated using the Atlas.ti 22 software for Windows.

Results

Participant recruitment

Figure 2

Recruitment process of participants



As can be seen in figure 2 above that details the recruitment process resulted in ten participants through the Alumni Facebook group for the study. Of the ten participants recruited, 60% (n=6) returned a signed informed consent document before the start of the session they had registered for. Of these six participants, 83% (n=5) were women and all of them resided in

a European country at the time of the focus group discussion session. The remaining participant was a man residing in an African country. This resulted in two sessions: session one of five European women and session two of one African man. When the transcripts were sent to the participants for feedback, 33% (n=2) participants responded to the email. One of these participants said that no changes were needed. The other participant filled in the gaps of an inaudible section from the recording and requested a word she used to be replaced by another.

The age of the six participants ranged from thirty-five to sixty years old. There was a wide range when it came to their years of experience communicating with individuals with CDB, ranging from five to forty years.

Code one – challenges faced by the participants during interactions with individuals with CDB from different cultures

In session one, there were several instances shared where the participants had experienced communicating with individuals with CDB from different cultures. One of the participants, participant four, told a story recalling her experience accompanying a deafblind child to an international deafblind event where communication between the attendees was different. The event had families from many different countries and therefore every family would use a different sign language from each other. Another participant, participant two, described her experience where a religious family asked the participant not to touch the congenitally deafblind child “*too much*” in the parents’ perspective for religious reasons. Participant two did not go into further detail to describe what “*too much*” physical contact entailed in the parents’ perspective.

However, the discussion revolving around experiencing difficulties in communication due to cultural differences shifted almost immediately when one participant, participant five, voiced her thoughts on the matter. Participant five said that she “*can’t particularly think of any huge sort of cultural differences in the way [she] supported anyone*”. She would then say that

this is because *“for me you know being deafblind is a culture in itself”*. She finished this statement by explaining that *“people can be you know from different countries”*, recognizing that the country they are from can be *“part of their identity”* but considers being *“deafblindness is a big part of their cultural identity”*. The other four participants in the session were quick to show their agreement with this statement.

Despite agreeing with what participant five said about how being deafblind itself is a culture, there were several things that participant three could list that she felt could be a source of different experience for the individual with CDB. Among these differences were things like textures of the clothes worn by the participant, how much and where the participant could touch during communication, the movement speed and intensity of the signs, movement of the door and whether this opens inwards or outwards vibrations in the place the individual with CDB sat due to the music playing and different cultures having play different songs leading to different vibrations.

The participant of the second session, from here on referred to as participant six, faced difficulties due to cultural differences in the form of interacting with individuals with CDB who used a different sign language than he is using. The participant mentioned that the individuals with CDB *“use another [sign] language which is not commonly used in the other areas where they live”*.

Code two – how much are these challenges related to cultural differences

The participants of session one who had explained their experiences as outlined in code one specified that the challenges they described were a result of cultural differences between them and their clients. Participant four explained in her retelling of her experience that *“throughout the week [CDB child from European country A] met this wee chap from similar age from [European country B], and they had no shared language of course”*. This quote indicated that there was a language barrier between the two children with CDB and another

method of communication between the two had to be found. This method would be marked under code four as will be identified below.

Participant two described her experience where “[*participant two*]’s first [CDB] pupil who came to [*participant two*]’s country of birth in Europe] to [city name] from [Asian country]” together with his parents “because his parents hoped to find more support in [*participant two*]’s country of birth] than in their country”. During this segment, participant two would also specify that “[*the parents of the child with CDB*] religious traditions of the family changed the way of my work with him, of my communication with him”. She then explained this statement by saying that “I couldn’t use touch as much as I would like” with the specific example of “sometimes he wanted to sit on my lap. But his parents were against [*sitting on participant two*]’s lap] and shouldn’t let him to do this so I had to change my way because usually I let children to do this if they want if it is more comfortable for them to feel physical support like this”.

Participant six mentioned that “They are [at] school, learners are to school, they [are] using a different language in a specific culture, and then when they go home they also meet another situation whereby when using the communication signs they are different they don’t mean the same in all the two cultures where they mean [something] different”. This quote indicated that the participant identified the different culture between the home and the school of the deafblind child as being a source of challenges. This challenge stems from the fact that the child will need to learn one sign language in one place and another sign language in another place whilst understanding both signs.

Code three – participant’s feelings facing these challenges

There was no recorded segment from the first session that detailed the feelings of the participants when facing the challenges highlighted using the first code. There was, however, a segment of session one detailing participants’ feelings in general. When the discussion shifted

to the different sign languages used in the participants' respective countries there was a response from two participants. Participants five and one voiced how they did not understand why there were schools in the country that utilized a sign language that was different from the sign language typically used in their respective country of residence. As they shared this, participants five and one were laughing. This laughter wasn't joyful or happy but rather a deflated and exhausted laugh.

There was also no recorded segment from the second session that detailed the feelings of the participant when facing the challenges highlighted using the first code because it was not spoken about during the session.

Code four – methods used by the participants to overcome these challenges

In the first session, all five participants described how they would naturally adjust their methods to best suit the individuals with CDB and, as a result, none of them felt that the cultural differences were a challenge or a noticeable obstacle in their communication. Participant four explained that she would look for another way to form a connection, listing *“facial expressions, big gestures, objects of reference, touch, feel”* as possible sources to do so.

Participant four would later go on to say that a shared interest or hobby can put aside any potential issues in communication *“if you got a shared interest like music or something like that”*. Participant one would share this sentiment and share a story of how two clients with CDB at her organization with a fifteen-year age gap and a little bit of vision who share a similar hobby and would use this hobby to have an informal form of conversation between them, agreeing with the comment made by participant four that *“if you do have a shared interest or shared activity, you don't always need a huge amount of formal communication to communicate”*.

Participant six had a method to overcome these challenges that occurred because of cultural differences. This method involved him going to one of the places the individual with

CDB went to so he could learn the language used in that location. He would then go to a different place and learn what the equivalent signs were in that place. This is described in the following quote: *“what I did actually was to communicate with those who are at school and learning how to use the language that they use at school. And then when I went home, when I saw that there was a different language that they use, I came back to school again and I show them what is happening at the home and they said yeah, this is also what we call this sign”*.

Code five – advantages observed by the participants during interactions with individuals with CDB from different cultures

The participants of the first session discussed how the differences can be used as a basis to learn new things. These things were highlighted in more detail under the sixth and final code below.

Participant six believed that a possible advantage of cultural differences between him and individuals with CDB was more knowledge. During this segment, he specified that the benefit included bringing words from different languages together and sharing this knowledge with each other.

Code six – how these advantages can benefit the participant and/or individuals with CDB

The participants of the first session who spoke of the advantages and how these might benefit either party of the communication all spoke of a common idea: learning new things from another person. Participant one described her experience traveling to an overseas organization that had a specialized and individualized system to help support the clients with CDB. The participant spoke of the time *“when [participant one] was going all around the residential houses”* she noticed that *“the level of individual communication was just so high that every single person had a different communication system, and it was very obvious and very accessible to that person”*. The participant was clearly impressed by what she saw in those residential houses and this was not something that she was used to in her workplace. She had

learned something new during this encounter of a different culture and this was then followed by the participant saying that the systems that she saw This was then followed by the participant saying that the systems The participant was *“was something that [participant one] tried to bring back to my service because I think that we always kind of we always kind of struggled a little bit with maintaining communicating systems with particular people you know we might have a really good key worker and that key worker leaves and you know someone takes over and yeah maybe they are brand new to the service or they haven’t been trained in deafblind communication or things like that, so it tends to fall by the wayside sometimes”*.

Participant three explained how there was a deafblind center established by several countries, and at this place the members would collaborate on *“producing books and teaching methods”*, highlighting the exchange and flow of information between members of different countries.

Participant six said that the variety of signs can be applied to communicate the same thing in a different way to or by the individual with CDB. It should be noted, however, that the participant also foresaw a risk in this in the form of *“confusing this child with deafblindness”*, because *“you are giving him two things [signs in two different sign languages], maybe which meant the same thing, so it can also cause some sort of problem would not understand easily”*.

Results summary

The two focus group discussion sessions lasted approximately ten minutes for every participant in the session, meaning that session one was approximately fifty minutes while session two was about ten minutes long. Based on these sessions, it can be concluded that overall the participants did not experience significant challenges due to cultural differences and if they did they were able to overcome these challenges without much difficulty. Several minutes of these sessions had to be removed from the transcript as they were small talk and not relevant for this study. It was attempted to include a balanced amount of quotes and statements

from each participant. This proved unsuccessful as participant six's experiences and opinions would be talked about in five of the six codes as he was the only participant in the session he participated in. For the participants of the other session, this would be unsuccessful as well as some participants would talk more than other participants in the session.

Discussion

Interpreting the results

The original research question had six subquestions developed with the idea that there are both positive and negative effects that cultural differences may have in terms of communicating with individuals with CDB. Based on the results of the two sessions, partial support for the hypothesized effect was found. Most of the participants of this study agreed on the idea voiced by participant five in that being deafblind is a culture, and the culture of the country or region where the individual with CDB was raised in did not play a significant part in communication. These participants voiced that they did not experience any negative effects that the differences in culture would have. Instead, the discussion revolved around discussing positive and interesting interactions the participants had and the benefits that the cultural differences had in giving them new information and knowledge. Examined from a theoretical perspective, this would indicate that the participants were already in the fifth stage of the DIMS, adaptation to difference, as they were sharing their experiences and showing that they were learning from these differences (Bennett, 2017; Rasmussen, 2012). Hart (2015) also described how differences in culture can be seen as a positive to try and connect with more groups and provide a new learning opportunity by interacting and involving with others

In contrast to the participants of the first session, the only participant from the second session provided an almost opposite insight. When discussing the challenges and benefits while communicating with individuals with CDB from different cultures, a disproportionate amount of time was spent highlighting the challenges he faced. While he had also described benefits

that might happen due to the cultural differences, the emphasis put on the challenges indicated that he believed there were more challenges than benefits when it comes to cultural differences between individuals with CDB.

It is also of note that none of the participants voiced how they felt when it comes to cultural differences and communicating with individuals with CDB from different cultures. Participants one and five were laughing as they talked about how they did not understand why different schools in their country used different sign languages, but it was not a joyful or happy laugh. The two participants sounded tired which could indicate that they were exasperated and annoyed by this fact. The lack of an obvious emotional response during the sessions, whether positive or negative, could be an indication that the participants were so comfortable with dealing with challenges that arose from communicating with individuals with CDB from different cultures as a result of their experience in the field that this no longer evoked any feelings from the participants.

Answering the research question

It can be concluded that based on the focus groups, most participants agreed that it made little difference when communicating with an individual with CDB from a different culture to their own culture. One explanation rising from the focus group suggests that this is because being deafblind can be considered a culture and most participants were able to adapt their approach and avoid running into any challenges in communication. There were still some challenges voiced by one participant associated with cultural differences, however. This means that communication partners need to understand that these differences and challenges exist and are confident in adjusting their approach when trying to communicate with individuals with CDB from different cultures.

Differences in data between session one and session two

The two sessions provided different data and insights as in session one all participants

agreed that there were no significant challenges in communication with individuals with CDB from a different culture than their own culture. This contrasts with session two where the participant voiced multiple problems faced in the same situation.

There are several reasons to explain the differences between the two sessions. First of these is that there were more participants in the first session than those who attended the second session, a single participant. This meant that the format of the second session shifted to become an interview-based session rather than a focus group discussion. It also meant that because session two did not involve a group, the participant lacked the possibility to hear what other participants would have had to say and the opportunity to share experiences with others. There were several instances in the first session where one or more participants responded to and elaborated on what another participant had said.

The second possible reason could stem from different levels of experience in deafblind communication as well as the number of cultures the participant had been involved in between the participant of session two and the participants of session one. Participant six had five years of experience working as a communication partner for individuals with CDB. Meanwhile, all the participants of the first session had a minimum of fifteen years of experience working with individuals with CDB. The different number of years could influence opportunities to interact with individuals with CDB from different cultures compared to the participants of session one. These extra years might also have given the participants of session one the knowledge and practice necessary to be less hindered by any potential challenges that might have arisen from cultural differences.

Limitations of the study

The biggest limitation of this study is the scope of the study. Due to the time constraints of a master's thesis, only a limited number of participants could be recruited for the study. After several weeks of recruitment efforts, six participants could be recruited for and participate

in the study. Due to the limited availability of the participants, five of the participants could be scheduled in one focus group discussion session while the other session only had a single participant. This resulted in the second session having more of an interview format than a focus group discussion. This was a clear procedural weakness and resulted in loss of information that could potentially have been obtained through interactions and discussions between participants.

Another limitation of the study was the distribution of cultures of the participants of the sessions. Five of the participants were from European countries while the sixth was from an African country. This restrictive scope also could have resulted in lack of insight on how communication partners from different continents might have experienced cultural differences during their time working with individuals with CDB.

Author's position

The author was a beginning researcher at the time this study was conducted, with minimal experience in qualitative studies and no background in the field of deafblindness prior to this master's program. The focus group discussion sessions were also moderated and led by only the author, who had no prior experience in moderating or leading a focus group discussion. This lack of prior knowledge and experience could have impacted the focus group discussion sessions and the overall data collection process as the author's lack of experience might have made him unaware of certain techniques or procedures useful in focus group discussion sessions.

The author is a third-culture individual, meaning that the author has experienced cultural differences throughout his life. These experiences inspired him to learn if a similar phenomenon occurs for individuals with CDB and their communicating partners. This was the primary foundation for the author to conduct this study.

This study was a big learning experience for the author. He got to learn from the

experiences of six professionals in the field of deafblindness thanks to the six participants of the focus group discussion sessions. Prior to the data collection he was also assuming that his experiences with cultural differences in his personal life could be used as an indication that something similar happens with deafblind individuals. Now that the study has been completed, the author understands that for deafblind individuals being deafblind has a larger influence on who they are than the culture of the area they grew up in. The author also never moderated and led a focus group discussion session so being put in that role has provided him with the experience and more understanding in how to moderate and lead a focus group discussion.

A suggestion for the procedure of future similar studies is to broaden and expand the scope of data collection. If a participant brings up what sounds like a constructive point, try to stimulate the participant to share more about it during the session. In this study, participant two of the first session was sharing her experiences where she supported a deafblind child, and the parents of the deafblind child asked the participant to not touch the child too much in the perspective of the parents due to religious reasons. This was a point made by the participant that showed there was a story behind these parents' motive to voice the request. The discussion shifted focus soon after participant two finished talking and no extra information on the story or background could be gathered. In hindsight, as the focus group facilitator I could have guided the discussion to further elaborate the topic.

Another suggestion for the procedure of future studies that involve focus group discussions is to set aside a section of the session to go over some of the responses provided by the participants already during the session. It is very possible that throughout the session the participants share their thoughts and opinions on the topic. As the other participants in the session listen to what the speaker is saying, they might be reminded of experiences that they did not think of before. Having a section of the session to go over the responses again can provide a second opportunity to possibly remind the participants of experiences or answers that

they did not think of before and give more data for the researcher to work with.

Suggestions for future studies

Based on the process and results of this study, several research ideas for future studies in this field can be suggested. Firstly, most of the participants in this study were Europeans whose experience were mainly with European individuals with CDB. It could be interesting to see what experiences and opinions communication partners from other regions or continents have in terms of communicating with individuals with CDB from different cultures. If focus group discussions involving participants from different regions were to be conducted it could also be interesting to see how much overlap the results of those studies have in comparison to the results of this one.

During this study, several statements and experiences were shared during the focus group discussion sessions that could be used for a new study. Participant five of the first session shared her opinion how *“I guess for me you know being deafblind is a culture in itself”*. This can also be seen by what is said by Granda and Nuccio (n.d.), discussing protactile communication which was developed by a group of deafblind people from the United States for other deafblind people. After sharing this with the other participants of the session, the remaining four participants all nodded to show they agreed with this opinion or voiced this after participant five finished talking. Based on this study alone, it is unclear how common of an opinion this is amongst professionals in the field of deafblindness. It could be interesting for future studies to see if this is a stance that more people in this field share. If it is shared among other professionals as well, future studies can be conducted to investigate how the idea that deafblindness is a culture of its own can be used to help communication between professionals and individuals with CDB from different cultures.

It could also be interesting to see future studies with slightly adjusted focus compared to this study which focused on culture, cultural differences, and the effects, if any, this had on

communication between individuals with CDB and their communication partners. Suggestions for other studies include focusing on specific aspects of cultures like religion and family habits. A focus group discussion session involving the individuals with CDB would also be very interesting as well to learn if the individuals with CDB shares similar experiences as the communication partners.

The final suggestion for future studies is to focus on bilingualism in deafblind children. Interpreters and communication partners are already known to be bilingual and require understanding of the language understood by the deafblind individual and the language used by the deafblind individual's surroundings (Subak, 2014; Subak, 2016). Participant six's comment on how the deafblind individuals he worked with needed to learn one sign language at home and another at school might indicate that there are deafblind individuals who are bilingual. Learning how language develops for these individuals and what effects this bilingualism has on the deafblind individual's communication with others.

Conclusion

This study aimed to identify both advantages and challenges that communication partners might find when interacting with individuals with CDB from different cultures. The main research question of this study was "to what extent does cultural difference affect and influence the communication individuals with CDB and their communication partners?". Two focus group discussions were held with a total of six participants with each session being recorded and transcribed. After this the transcription was anonymized and then checked by the participants for any feedback or suggestions. Six codes were created based on the six subquestions of the study. The connections and differences between these segments of the transcript were then evaluated using the Atlas.ti 22 software for Windows.

Based on the results of this small-scale study, there was little to no significant effect on the communication when communication partners communicated with individuals with CDB

from different cultures. This was due to deafblindness being considered a culture in itself, so the individual with CDB being from a different country with a different culture did not affect communication much. The benefits of cultural differences was identified as more knowledge and the ability to share this knowledge with other people. The main challenge with cultural differences was the language barrier and the need to learn and adjust their methods of communication to accommodate the different values.

For future studies in this field, several suggested topics can be formulated based on this study. Firstly, broadening the scope of participants in the sessions could provide interesting insights. The majority of the participants in this study were European, so learning if participants from other countries share similar opinions can be used to see if the results of this study can be shared by other countries and cultures. During this study, several interesting insights were shared by the participants which could also be used as the basis of a future study. These topics include focusing on specific aspects of cultures like religion and family habits as well as studies focusing on bilingualism in deafblind children and the effects that may have on communication. Finally, because this study was done with only the communication partners, it could be very interesting to have a focus group discussion session where all the participants are individuals with CDB to see if they share similar experiences as their communication partners.

References

- Alibali, M. W., Flevaris, L. M. & Goldin-Meadow, S. (1997). Assessing knowledge conveyed in gesture: Do teachers have the upper hand? *Journal of Educational Psychology*, 89, 183-193
- Bennett, M. J. (2017). A developmental model of intercultural sensitivity. *The International Encyclopedia of Intercultural Communication*, 1(10).
<https://doi.org/10.1002/97811118783665.ieicc0182>
- Brede, K. S. & Souriau, J. (2016). Let me join your tactile attention: a sign language perspective on the communicative togetherness with a child who is congenitally deafblind. *Journal of Deafblind Studies on Communication*, 2, 4-21.
<https://jdbsc.rug.nl/article/view/25418>
- Carrascal, M. A. S. (2021a, November 3). *Developing Intercultural Awareness Session 1* [online lecture]. Deafblindness Master Program at Rijksuniversiteit Groningen, Groningen, the Netherlands.
- Carrascal, M. A. S. (2021b, December 15). *Developing Intercultural Awareness Session 1* [online lecture]. Deafblindness Master Program at Rijksuniversiteit Groningen, Groningen, the Netherlands.
- Dabić, M., Tipurić, D. & Podrug, N. (2015). Cultural differences affecting decision-making style: a comparative study between four countries. *Journal of Business Economics and Management*, 16(2), 275-289
- Damen, S., Gibson, J., & Nicholas, J. (2020). Perspectives on assessment of individuals with congenital deafblindness. In Damen, S., Costain, K., Hart, P., Nicholas, J., Creutz, M. & Lindström, C. (Eds.), *Revealing hidden potentials - Assessing cognition in individuals with congenital deafblindness* (pp. 10-21). Nordic Welfare Center.
- Dammeyer, J. (2012). Identification of congenital deafblindness. *The British Journal of*

- Visual Impairment*, 30(2), 101-107. <https://doi.org/10.1177/0264619612443882>
- Ennals, P. (n.d.). *Values and value changes in society impacting on deafblind individuals*. Royal National Institute for the Blind. <http://www.deafblind.com/valuesdb.html#Values%20and%20Value%20Changes%20in%20Society%20impacting%20on>
- Firmin, M. W., Holmes, H. J., Firmin, R. L. & Mercial, K. L. (2013). Personal and cultural adjustments involved with an Oxford study abroad experience. *Procedia-Social and Behavioral Sciences*, 89, 555-558. <https://doi.org/10.1016/j.sbspro.2013.08.893>
- Forsgren, G. A. G. C., Daelman, M. & Hart, P. (2018). Sign construction based on heightened tactile perception by persons with congenital deafblindness. *Journal of Deafblind Studies on Communication*, 4, 4-23. <https://doi.org/10.21827/jdbsc.4.31373>
- Gather, P., Alibali, M. W., & Goldin-Meadow, S. (1998). Knowledge conveyed in gesture is not tied to the hands. *Child Development*, 69, 75-84
- Goldin-Meadow, S. (2003). *The resilience of language: What gesture creation in deaf children can tell us about how all children learn language*. Psychology Press. <https://doi.org/10.4324/9780203943267>
- Granda, A. & Nuccio, J. (n.d.). *Protactile Principles*. Tactile Communications. <https://tactilecommunications.org/Documents/PTPrinciplesMoviesFinal.pdf>
- Hart, P., & Rødbroe, I. (2010, June 22). *Dialogicality in culture. Response from the perspective of congenital deafblindness* [Conference Presentation]. Paris, France.
- Hart, P. (2015). Pursuing happiness through trust, relationships and communication. *DbI Review*, 21-24
- Hersch, M. (2013). Deafblind people, communication, independence, and isolation. *Journal of Deaf Studies and Deaf Education*, 18(4), 446-463
- Hofstede, G. (2011). Dimensionalizing cultures: The Hofstede model in context. *Online*

- Readings in Psychology and Culture*, 2, <https://doi.org/10.9707/2307-0919.1014>
- Nickerson, C. (2022, May 4). *Hofstede's Cultural Dimensions Theory*. SimplyPsychology. <https://www.simplypsychology.org/hofstedes-cultural-dimensions-theory.html>
- Ochieng, N. T., Wilson, K., Derrick, C. J., & Mukherjee, N. (2018). The use of focus group discussion methodology: Insights from two decades of application in conservation. *Methods in Ecology and Evolution*, 9, 20–32. <https://doi.org/10.1111/2041-210x.12860>
- Oyserman, D. (2017). Culture three ways: Culture and subculture within countries. *Annual Review of Psychology*, 68, 435-463
- Preisler, G. (2005). Development of Communication in Deafblind Children. *Scandinavian Journal of Disability Research*, 7, pp. 41-62. <http://doi.org/10.1080/15017410510032145>
- Rasmussen, A. S. (2012). *Assessing interpreter intercultural sensitivity* (Doctoral dissertation, Union Institute and University). <https://www.proquest.com/openview/e31b67f525b02042c7240bc401272bf5/1?pq-origsite=gscholar&cbl=18750>
- Roy, A., McVilly, K. R. & Crisp, B. R. (2021). Working with deafblind people to develop a good practice approach. *Journal of Social Work*, 21, 69-87. <https://doi.org/10.1177/1468017319860216>
- Seibert, P. S., Stridh-Igo, P. & Zimmerman, C. G. (2002). A checklist to facilitate cultural awareness and sensitivity. *Journal of Medical Ethics*, 28(3), 143-146. <http://dx.doi.org/10.1136/jme.28.3.143>
- Spencer-Oatey, H., & Franklin, P. (2012). What is culture. *A compilation of quotations*. *GlobalPAD Core Concepts*, 1-22.
- Subak, L. L. (2014). *Becoming hearing: a qualitative study of expert interpreter deaf-world*

cultural competence [Doctoral dissertation, Kent State University].

[https://etd.ohiolink.edu/apexprod/rws_etd/send_file/send?accession=kent1417610717
&disposition=inline](https://etd.ohiolink.edu/apexprod/rws_etd/send_file/send?accession=kent1417610717&disposition=inline)

Subak, L. (2016). Becoming hearing: describing co-construction of expert ASL/English interpreter deaf-world culture competence. *International Journal of Interpreter Education*, 8(2), Article 3. <https://tigerprints.clemson.edu/ijie/vol8/iss2/3/>

Wittich, W., Jarry, J., Groul, G., Southall, K. & Gagné, J. P. (2016). Rehabilitation and research priorities in deafblindness for the next decade. *Journal of Visual Impairment & Blindness*, 110(4), 219-231.

Appendices

Appendix A

Invitation Poster

Figure A1 – Invitation poster sent to prospective participants of the focus group discussion sessions

WANTED!

Participants for study!

Are you **curious** about how **culture** impacts **communication partnerships**?

Communication partners of individuals with **congenital deafblindness** from different **cultures**

Looking for **participants** to take part in the **focus group discussions**

All participants have access to the final report

Sessions will be **one hour** and are on these days:

March 2022						
Mo	Tu	We	Th	Fr	Sa	Su
28	1	2	3	4	5	6
7	8	9	10	11	12	13
14	15	16	17	18	19	20
21	22	23	24	25	26	27
28	29	30	31	1	2	3
4	5	6	7	8	9	10

9 March 2022 15:00 (UTC + 01:00) *

11 March 2022 10:00 (UTC + 01:00) *

14 March 2022 19:00 (UTC + 01:00) *

* The times listed are flexible and can be adjusted to the needs of the participants if needed

Supervised by Dr. Marja H. Cantell and Dr. Paul Hart

For more information, please contact fard.ivan.aditya.julianto@student.rug.nl

Appendix B

Information + Informed Consent form



Informed Consent Form

[The role of culture and cultural difference when communicating with people with congenital deafblindness]

➤ **Why do I receive this information?**

You are invited to take part in a research study which seeks to identify effects and influences cultural differences may have in the communication between individuals who are congenital deafblind (CDB) and their communication partners. You are currently working with and/or have worked in the field of CDB and come across individuals from different cultures, so that is why you are being invited to participate in this study.

The research is carried out by Farid Julianto, a Master student of the Deafblindness programme at the Rijksuniversiteit, Groningen, the Netherlands and supervised by Dr. Marja H. Cantell and Dr. Paul Hart.

The start of the research will be 01-03-2022 and the research will end on 31-08-2022.

➤ **Do I have to participate in this research?**

Participation in the research is voluntary. However, we are requesting your written consent. Therefore, please read this information carefully and ask all the questions you might have so that you make an informed decision of your participation. If you decide not to participate, you do not need to explain why, and there will be no negative consequences for you. You have this right at all times, including after you have consented to participate in the research.

➤ **Why this research?**

The focus of the study is how culture influences communication with individuals with CDB. Therefore, the purpose of this research is to identify both advantages and challenges that communication partners might find when interacting with individuals with CDB from different cultures. This research may provide new information that can be applied in training and daily practice of communication partners in the field of deafblindness.

➤ **What do we ask of you during this research?**

Prior to the start of the study, the participant will be given the opportunity to ask any question that the participant may have about the research study. After being fully informed, the participant is also asked for consent to participate with a separate consent document which needs to be signed and returned to the researcher prior to the start of the study.

The method in which this research project will be carried out is through focus group discussions using Google Meet. The researcher will have a list of questions that can be asked to help guide the group discussion. Every participant is encouraged to participate in the discussion and share their thoughts and experiences relating to these questions.

A written transcript of the sessions will be made immediately after the focus group sessions. Once completed, this transcript will be sent to the participants of the session to check for participant validation and allow the participants to review the transcript. The transcript will then be divided into themes and connections and the differences will be evaluated using the Atlas.ti program.

➤ **What are the consequences of participation?**

You will not directly benefit from participating in this study.

➤ **How will we treat your data?**

Data processing is taking place for the strict use of the educational purpose of writing a Master Thesis. All data will be stored on a password-protected device that only the researcher has access to.

The transcripts of all the focus group sessions will be kept until the end of the study, after which they will be destroyed. Any identifiable features that could link the participant to this

study will be removed and the participant's name will be substituted with a letter that is not linked to the participant's initials in the transcript.

In the event of any publication or presentation resulting from the research, no video or personally identifiable information will be shared.

➤ **What else do you need to know?**

You may always ask questions about the research: now, during the research, and after the end of the research. The contact information is below.

Do you have questions/concerns about your rights as a research participant or about the conduct of the research? You may also contact the Ethics Committee of the Pedagogical and Educational Sciences of the University of Groningen: ecpedon@rug.nl

Do you have questions or concerns regarding the handling of your personal data? You may also contact the University of Groningen Data Protection Officer: privacy@rug.nl.

Your participation in the research is really important and I would like to thank you in advance for your time. In case you are interested in taking part, please confirm by signing that you accept all of the above.

Contact Information

- MA-student Farid Irvan Aditya Julianto

Email address: farid.irvan.aditya.julianto@student.rug.nl

Telephone number: +31612214093

- Dr. Marja Cantell

Email address: m.h.cantell@rug.nl

- Dr. Paul Hart

Email address: phart@sensescotland.org.uk

Informed Consent for Participation in Research

I volunteer to participate in the research conducted by Farid Irvan Aditya Julianto.

- I have read the information about the research. I have had enough opportunity to ask questions about it.
- I understand what the research is about, what is being asked of me, which consequences participation can have, how my data will be handled, and what my rights as a participant are.
- I understand that participation in the research is voluntary. I myself choose to participate. I can stop participating at any moment. If I stop, I do not need to explain why. Stopping will have no negative consequences for me.
- Below I indicate what I am consenting to.

Consent to participate in the research:

Yes, I consent to participate; this consent is valid until 31-08-2022

No, I do not consent to participate

Consent to make audio / video recordings during the research:

Yes, I consent to make audio / video recordings of me as a participant in the research.

No, I do not consent to make audio / video recordings of me.

Consent to processing my personal data:

Yes, I consent to the processing of my personal data as mentioned in the research information. I know that until 31-08-2022 I can ask to have my data withdrawn and erased. I can also ask for this if I decide to stop participating in the research.

No, I do not consent to the processing of my personal data.

Participant's full name:	Participant's signature:	Date:

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Thank you for filling out the informed consent form.

Full name of researcher present:	Researcher's signature:	Date:

The researcher declares that the participant has received extensive information about the research.

You have the right to a copy of this consent form.

Appendix C

Background information form



university of
 groningen

faculty of behavioural
 and social sciences

Background Information Form

**[The role of culture and cultural difference when communicating with people
with congenital deafblindness]**

Name:

Age range: 18-25 | 25-30 | 30-35 | 35-40 | 40-45 | 45-50 | 50-55 | 55-60 | 60-65 | 65+

Gender: Male | Female | Others | Prefer not to say

Educational background:

Year when last education was completed:

Country of birth:

Nationality/Nationalities:

Current country of residence:

Nationality/Nationalities of deafblind people you have worked with and/or currently
work with:

Years working as a communication partner:

Thank you for filling out the background information form!

Appendix D

Anonymized transcript session one

Date and Time: Friday, 11 March 2022 10:00

Researcher: [thanks everybody for joining the session while setting up the recording]

Researcher: Let's start with some introductions so everyone can get to know each other a little bit better. Me, personally, I'm—my name is [Researcher's name], I'm a student at the Rijksuniversiteit in Groningen, the Netherlands, studying deafblindness. And I am doing a Master's Thesis on how culture affects our communication with individuals with congenital deafblindness. I think it would be nice if we could go down the list and everyone introduce each other—introduce themselves to each other real quick. [short pause] who wants to begin?

Participant One: I'll start. I'm [Participant One's name], I work in [City name], in [European Country's name], I work for the [Organization name]. So we support adults mainly in our residential service and our day service but I also work in [other Organization name]. We work with the whole spectrum really the whole age range, so I work with children and adults as well. I carry out assessments and training with other professionals.

Researcher: Thank you. Next person, or do we want to just go down the list of the participants in the participant list. [Participant Four], I think that's you now. [Short pause]

Participant Two: Hello? If it's okay with my sound? (nodding from other participants) hello because I have many problems with microphone and I have to use my phone instead of computer, I'm sorry for that. My name is [Participant Two's name] and I'm from [European Country's name] and though my practical experiences is linked with [European Country's name] deafblind children and children with multiple disabilities. Now I stay in [different European Country's name] but I continue working online with and I help parents with little children with deafblindness and multiple disabilities to play and work with [European

Country's name] families.

Researcher: Thank you! [Participant Three]? Either of [the remaining two participants]? (short pause) Who wants to go first?

Participant Three: Okay! [soft laughs as [Participant Four] was also about to start as well] I can start, so hi, I'm [Participant Three's name] [makes the sign for [Participant Three's name]] and I live here in [European Country's name] and also in [different European Country's name]. And I've been working with deafblind—acquired deafblind and congenitally deafblind last [number] years. My [spouse] is also deafblind and I'm doing my continuing research work uh at [research topics] so I did my PhD work [year] and now I am in the research group and I supervise people's theses and their haptics dictionaries now in Europe and in Australia. And I'm interesting about this issue and I didn't know if I'm the right place but [Researcher's Supervisor's name] said that it would be good because I am teaching about how we can haptically to observe about people's participation in different cultural aspects. Are they odd or... like a music, paintings, movements, and so on. So I thought that it would be lovely to come here and just to listen and if you say that I'm the wrong place just say that it's okay [laughs] but I hope that I'm the right place hehe

Researcher: It's lovely to have you here as well, don't worry

Participant Three: Okay, yup

Researcher: So thank you for being here.

Participant Three: Yeah, okay [thumbs up]

Participant Four: Shall I go, [Participant Five]?

Participant Five: Yeah, you go

Participant Four: Good morning, I'm [Participant Four's name] and I'm [role] with [organization]. [Organization] works with people with a *range* of support needs but particularly with people with congenital deafblindness and my role is very much first contact with

[organization], support to families, support to named to access most appropriate support services whether that's [organization] or alternative. And I've been involved in assessments over the years and supporting people to hear their voice and create their own support and I have a diploma in deafblind studies.

Participant Three and Four: [asking each other if they have met each other in the past]

Participant Five: Okay, so... my name is [Participant Five's name], which is confusing—it's always confusing when me and [Participant Four] are in meetings together. We have the same name, and we work for the same organization, so I work for [organization] as well. I'm a [role] and my role is all about inclusive communication, but it's about, again, like [Participant Four] was saying, it's about getting the voice of the person that we support to come through. My background is working in housing support services so twenty-four hour support services for people who are congenitally deafblind and I still do it but at the minute at the weekends kinda have to put two hats on at the minute and [grins] [talks about how Five has met Three and Three's spouse in Three's city while Participant Three nods vigorously with a smile]

Participant Three: It's lovely to be in a group where I know someone [Participants Three and Five laugh]

Researcher: Yes, so we already talked a little bit of our experiences. Let's jump off of that. What have your experiences been like communicating with the deafblind from different nationalities from different cultures than your own? Can anyone start with sharing their experiences with that regard?

Participant Four: My initial thoughts is going back many years—going back to [year]. I was across in [European country A] for a week, and it was an international conference for families, so I had traveled over there our art tutor had come with us as well. Our primary role was to support the family that I had nominated to attend the conference. So it was a little awkward, for the children it was activity days, and for the parents carers it was conferencing that was

happening. So I was involved in supporting a young a young boy who lives in [Four's country of residence] very rural, lived very rurally in [Four's country of residence], has a very rare medical condition which resulted in him being deafblind. But at that time his mum wasn't there, she just didn't, you know, hadn't processed that her boy was deafblind. She had been looking at the other medical issues, I suppose, for her at the time. So at the time when we invited her and her son and the sister to come along, she was a bit "hm, what do I get out of this?". So we went for the week, and I was aware that he was educated very rurally as well, very small school, and mum also said he had very little connections very little normal friendships really because of his unique way of communication I suppose as well, it was it was difficult for his peers at school. Anyway, throughout the week he met he met he met this wee chap from similar age from [European country B], and they had no shared language of course, but they had a vehicle and the vehicle was a go-kart. And it was it really was just this wee chap this wee boy from [European country B] was just [motions arms in circular motion like the coupling rods of a steam train] going so fast and he was deafblind and he was going so fast on this [motions with arms in pedaling motion] pedaled go-kart. And I just remember the wee chap I was supporting *desperate* to be *desperate* to be involved in the activity. And throughout this week they formed this friendship the two moms were very very different; the mom from [European country B] she was *really* chilled, she was you know he was racing ahead and obstacles in his way and really she was quite chilled about it. Whereas the [Four's country of residence] mom was just so *so* anxious and she was always trying to intervene and slow him down and trying to find the language she had language between the two just words you know slow or sign or whatever. So my job really was I think to support the [Four's country of residence] mom to take a step back, let them play, and by the end of the week they were firm friends, they were sitting together, they were communicating together, they were *dining* together, and it was just wonderful and then the [Four's country of residence] mom by the end of the week was in tears and she was

saying “my son is deafblind”, so for her the journey of recognition and also “he has a friend”. Now I still see I’ve been with [organization name] like [Participant Five] a long time, [number] years, so I’ve seen him grown up as well, so [number] years on he still talks about his friend in [European Country B] and it was his (raises index finger) first friend. So I don’t know if that’s that’s yeah. That’s kind of my first story that comes to mind.

Researcher: It’s going to be really hard to distinguish between [Participant Four] and [Participant Five]. [Participant Five], did you have something to say?

Participant Five: I think for me I don’t have a lovely story like [Participant Four] does [Participants Four and Five laughs] but I think for me when supporting anyone you know whatever culture or country or [inaudible] it’s just about for me it’s just about finding the person within it and I can’t particularly think of any huge sort of cultural differences in the way I’ve supported anyone I mean I’ve I guess for me you know being deafblind is a culture in itself [everyone nods in agreement] that’s more you know what’s obviously people can be you know from different countries and but I think it’s the culture, the country they are from is just part of their identity and deafblindness is a big part of their cultural identity.

Researcher: Yeah, [Participant One], do you have any stories you want to share in this regard?

Participant One: Yeah nothing particularly springs to mind but I haven’t worked a huge amount outside of [Participant One’s country of residence], actually. I’ve been at my organization for [number] years, so a lot of my experiences have been just at that one organization, really, but I did go over to [American Country name] a couple of years ago, we did an exchange with [organization name]. And what I noticed when I was going all around the residential houses the *level* of individual communication was just it was just so high that every single person had a different communication system and it was very very obvious and it was very very accessible to that particular person. And that was something that I tried to bring back to my service because I think that we always kind of we always kind of struggled a little bit with maintaining

communicating systems with particular people you know we might have a really good key worker and that key worker leaves and you know someone takes over and yeah maybe they are brand new to the service or they don't they haven't been trained in deafblind communication or things like that, so it tends to fall by the wayside sometimes. And I just thought it was really nice what they did in [American Country name] was just they really put a huge amount of focus whether the person used pictures or objects it was just really so lovely and well-maintained that I thought it was something I wanted to bring back to our place as well as sort of stay with me a little bit like it was just so individualized and I think that is. Well, communication is for a lot of deafblind people very unique for each person so yeah I suppose that's enough of an observation on my part from just going to a different just going to a different organization can be very eye-opening and it sounds really simple like communication system but it's I think where you're working in an organization sometimes all the other stuff gets you're involved with all the other stuffs so maybe communication doesn't always get the priority or the attention that it deserves.

Researcher: Yeah, thank you! [Participant Two], do you have any stories?

Participant Two: No, I have maybe one story which I could tell but I want first to make a remark about what [Participant Five] said that yes the identity of deafblind and it is also how you say very strong grouping factor and but maybe it reduces as a cultural differences when people are in communication all together. My experiences are more linked with children and the differences in communication they come not from children but mostly from the family and in my life it was my first client [phone buzzing] my first pupil who came to [Participant Two's country of birth] to [city name] from [Asian country] because his parents hoped to find more support in [Participant Two's country of birth] than in their country. And he came to school where I worked as [occupation]. And he had a lot of how to say different specifics in his behavior and in his development, teachers didn't know what to do and most of his time he spent

with me [chuckles]. Because I was ready to play with him and to try to build the communication. And yes his for me he was just a child with some behavioral specific behavior problems with challenging behavior with deafblindness but for example their religious tradition of Muslim religious tradition of his family it changed the way of my work with him, of my communication with him. For example, I couldn't use touch as much as I would like. And it is not very strict, for example when I visited [school name] in [American Country] I saw that there are some children who their teachers can't touch without gloves because of the family is against and of course we have to respect. In my case it was not like this, of course I could touch him and for example he was little, he was five when I met him, and sometimes he wanted to sit on my lap. But his parents were against and shouldn't let him to do this, so I had to change my way because usually I let children [chuckles] to do this if they want if it is more comfortable for them to feel physical support like this. It is one side of the story, and another side of the story when he is this boy grow up—now he is twenty-five I think, I still am in contact with his family, but I don't work with them but just good relationship and yes, and I sometimes have contact with his parents. And there is also another problem then this thing called [inaudible] development of children because the parents the family they have strict tradition how to be and for example the child he didn't have right to masturbate and parents didn't let him to do this. There were behavioral problems as they grew up and finally now he is married. I don't know how [chuckles] it happens but I think it should be not very easy to organize all this for his parents but it's like this. But then to understand this is a child with intellectual disability, deafblindness, and challenging behavior very aggressive behavior and he didn't change during he didn't change a lot during this time and yes so... it is a little bit difficult should be for his family to organize his family life, I think so. So it's my story, one of, but the most of stories in my experience they are linked with between difference in religious confessions. Thank you.

Researcher: Thank you. [Participant Three], I know that you have only worked with

[Participant Three's country of residence] clients

Participant Three: [points at self] Me?

Researcher: Yeah, you

Participant Three: Yes, okay, yeah. I work in two countries, I work in [European Country] and also here in [Participant Three's country of residence], and we travel a lot with my [spouse] for the last [number] years. And I was just talking your theme last three days and we've been thinking about the culture like if I'm observing a congenitally deafblind work—the parents and the workers and one would say the language aspect and I was thinking that when the child is on your lap and you hold that my way of talking [Participant Three's country of residence] is toning and the way how the language works is totally different comparing to like for English. So [spouse's name] always says that when he touch a person's like a back and so on so the spoken language information even if you don't hear the word is totally different. Then we were thinking about the country's own way of for like building making houses and buildings and how you have the furniture's. So in [Participant Three's country of residence] those people who move to [Participant Three's country of residence] the structure is totally different. We do different kinds of height, we do different kinds of textures that perhaps the congenitally deafblind has used to do in their own country and now when they come here so even the space where they are is totally different. My clothes. I wear totally different kind of textures than perhaps the deafblind person's own family are using, so when they are then going to kindergarten or some kind of special groups everything is different. Even the smell is different than your own home what they use there [Participants Five and Two nod] and then when you are going to another area. The behavior is how we if we go to outside even the traffic is different. So it's for you to going outside to the car should remember which country he is because that is totally different so your *movements* when you are learning to go to the car or out is totally different perhaps than the country that you have been before. So I was thinking

that this is like the holistic experience for the congenitally deafblind, it's not just like learning about the communication it's more also the cultural aspect. And we were talking about the vibrations because my husband is teaching about how to use vibrations with congenitally deafblind and the original elements was to feel perhaps on your bed or your chair what kind of music is around you is different when you are at your home or then when you are going to the school. Because perhaps the songs and everything what they used was mostly [Participant Three's country of residence] culture, sometimes they of course take some songs, but it is totally different kind of sensory experience when you go to the school. And we were just looking about the pictures! The pictures, if you have little bit of vision left, for your own home country has been based different way than here in [Participant Three's country of residence]. So how we draw something is different how they draw things [chuckles] so... I think it's what you are doing is very important and it's actually a bigger issue than actually what we can think about it if you look about different how you define the word 'culture'. I don't know, do you pick up on what I'm trying to say? [everyone nods] [Participant Four] is like nodding, okay, yeah. Of course then the religion is one aspect and I agree with that touch thing so some countries where we teach need to have more specific agreements on the paper who can touch, where you can touch, and so on, comparing like in [Participant Three's country of residence] because we already have kind of law that we teachers [Participant Two starts nodding until the end of the sentence] or assistants have to obey and so and so it is already based on that. Of course, we tell the parents and we do profiles but it's total different kind of way of perhaps working with the [Participant Five nods] congenitally deafblind when they move to [Participant Three's country of residence] or if we are going to another country. And the movements what we do are different how do I explain it? From [city name] when people are coming here to south the interpreters' way of moving so it's more peaceful they are more... how do I explain? They are not so busy-bodied. In [different city] area, they seem to be very active, we always

look and we their body is almost like [air quotes] hurry [air quotes] if you know what I mean because the space there is different so they walk even differently [laughs as Participant Five smiles]. So this kind of observation I remember talking about culture that how does it show you if you are deafblind and you have somebody coming from different part so how do you receive that information? [pauses to think for a split second] Does it make any sense? [everyone nods, Participant Three laughs again]

Participant Four: You reminded me [Participant Three] [Participant Three smiles and nods along] you reminded me when I was in [city in Participant Three's country of residence] I was supporting a young man in his... late-twenties... yeah very late twenties and we were there for a week went up in [city in Participant Three's country of residence] we we landed in [different city in Participant Three's country of residence] but we traveled up to [city in Participant Three's country of residence] and he's deafblind and sauna [Participant Three laughs] I remember sauna being such a thing that he could not... you know, my challenge was to explain that it was a *cultural* thing of no clothes in the sauna as opposed to a *sexual* thing because he been brought you *cover up* and your dignity and you know when you go swimming in [Participant Four's country of residence] there is a changing room and there is a curtain and oh what a journey we had however by the end of the week it was one of his highlights he was so proud of himself that he understood he got it and he'd experienced the sauna, you know.

Participant Three: Yes, yes. Yeah, that is sauna experience I remember [number] years ago when I took my [spouse] first time and I said 'it's a very hot place you can burn yourself' and then we go out and then we have a little home in a lake and then we go to swim there. And first part about that heat coming out and then going out and you... you need to put your socks on because he was so cold and he was so funny going naked there to go swimming and just having your socks on [Participants One, Three, Five laughs] so it is a little difficult for us he wanted to almost like cover inside me because he has learned that but there was nobody else just us.

And then we were going in and I said ‘okay now we have these uh these birch branches and-and-and now we hit each other’ [laughs] it was totally [trails off as laughter continues, Participants Four and Five laugh as well] new experience but that was smell that was heat that was everything so bodily experience but because if you’re not used to that it could be [laughs] bit shock

Participant Two: And can I make one a little remark, it’s not from my own practice but I think that some cultures cultural differences should be determined by linguistic things and it is not really between now only people from other countries and different cultures basic cultures. Even inside one country I think that tactile sign language is developing mostly in groups of deafblind who communicate with each other and I think that for example there some specifics maybe not problems but specifics of communication between different groups even in one country but who communicate together. I don’t know in different about all but for example [European Country] it is *big* and even sign language for deaf [Participant One starts nodding] is very different [Participants Three and Four start nodding as well] in different parts [Participant Five starts nodding] of [European Country] and sometimes first time from west and the east yes they can’t find immediately understanding even deaf people yes they can’t understand but anyway they should agree what they will use which signs and so on. And I think that in groups of deafblind adults who use tactile sign language the differences also should play their role. And it also language like part big part of culture it should also determine some communicational differences. Thank you

Participant Five: I think actually that is a really good point, even in [Participant Five’s country of residence] which is a really small country [Participant Four nods] it depends what school you went to [Participant One nods] so how you the methods that you learn for communication there was one school for people who are deafblind [Participant Two nods] in [Participant Five’s country of residence] based in near [city] and very many years people that went there learned

American finger spelling, American one-handed finger spelling [everyone nods] in a tactile modality and the decision for that isn't really clear to me why that was [laughs] why that would happen. Because there wasn't really anyone else in [Participant Five's country of residence] who would communicate using American one-handed finger spelling so... the culture there in that school was completely different to maybe if you been to a school in [city]. And it just deafblind community [Participant One nods] seem so small to have that split [Participant Four nods] seems quite strange to me.

Participant One: We have something similar, [Participant Five], actually in [Participant One's country of residence]. A lot of deaf schools were separated by girls school for deaf and boys school for deaf [Participant Five, while muted, reacts with an "ohh"] and they actually have different signs [lets out a laugh] really, so [Participant Four nods] the signs were different depending if you went to the boys school or if you went to the girls school. And then there was also like old sign language so we actually have a resident client and she came to us about [number] years ago we got her a sort of tutor to you know maintain her communication and her education and things like that and the tutor was saying 'she uses really old sign language' [laughs] I just thought that was so strange because I was I don't know why it changed or when they decided to use a different sign or if they just sort of you know got rid of the girls signs and [every other participant nods] focused on the the men's signs I don't really know the sort of how it developed but I just thought it was yeah. You know, [Participant One's country of residence] is a fairly small [Participants Four and Five nods] country as well, we have about [number] people, I'm not sure how many people use [national sign language of Participant One's country of residence], there's not like a *huge* massive amount compared to some other places, but the differences and a lot of the deaf schools are in [city], so a lot of people would have to traveled up and boarded in [city], so it's very centered in the [descriptor of city], there's no other—well, traditionally there's no other sort of deaf schools yeah so outside of [city], so...

interesting [laughs] how it-so many differences within such a small population.

Researcher: Yeah, those were some very interesting insights. Yeah going on to the next topic we've all discussed-you've all brought up things that were different in different regions, in different areas, and such, how do you feel that this has impacted your communication with the individuals from different groups, from different areas? Does it hinder you at all or does it give you a new a new pathway to better communicate that you didn't consider before?

Participant Three: I'm not sure if I [Participant Two unmuted to say something as well but stops to let Participant Three finish] understand what you mean [Participant Two nods to indicate that similar concerns were had]. Can you explain it a little bit more, please?

Researcher: Yeah, so, everyone said something about the differences between the regions, differences that there were different groups, different schools, different areas even within the same country where there were different uh techniques different sign languages and that communicating between one group and the other would be very difficult because it was essentially a different language, so there was a language barrier in that regard. That is obviously a hindrance in communication, but are there any potential benefits that you can see in the different methods in the different areas? I think [Participant One] mentioned something about that [American Country] had a very – what was it? [looks at notes] – a very direct communication [Participant One nods] very individualized that you tried to bring back to your home. So something similar to that for everyone else?

Participant Two: I'm sorry, you mean inside one country or inside or between countries all?

Researcher: Inside country, between countries, [Participant Two: okay okay] anything really.

Participant Two: Okay okay, thank you yes

Participant Four: I think for me I don't know if this is relevant, I think when there's such differences I'm starting to look for probably kind of common if you like-no, it might be supposed we talking total communication approach where you know I would be facial

expressions, big gestures, objects of reference, touch, feel, you know because whatever country, whatever language things can still feel the same uh I suppose. So maybe that's kind of like a safety net for me as a practitioner that no matter who I'm talking to, where they've been brought up, what culture, there are commonalities, I suppose. And at least it gives you a starting point [Participants Three and Five nod] of then moving towards the preferred communication, I suppose.

Participant Three: Hm if I'm thinking about communication methods in [region of Europe] countries, so we have a very strict [region of Europe] deafblind center [Participant Four nods] so that is now in [European country] in [city]. And we countries [counts on fingers as the country names are listed] [lists European countries] belong to that group so I do remember when I started to work on this field in [year] so we all go to that center and we produce materials together so we are producing books and teaching methods and so and so we have a very common way to teach so if I go to [European country] start to talk about communication because we have the same terms so like you [Participant Four] said that we talk about total communication and everyone knows what we're talking about because we have so close contact because we all are very small countries so we have and also the rehab is quite similar perhaps but how they have organized it is different. So I don't see any differences there, it's only like okay, if you want to teach sign language, do you teach hands under or do you teach over, so that's kind of little [inaudible] but everybody is teaching about their own national sign language. In [Participant Three's country of residence] we have two sign languages, we have [name of sign language one] and we have then [name of sign language two], because the [European country] people would usually have a very good contact to [European country] so it's more similar to the [sign language name of that European country mentioned earlier] but it's so nearby so we can quite easily understand it. But yes, we have also two sign languages and depends on the family their background which one they choose. And even if we have a

congenitally deafblind they have cochlear implants, it seemed to be that they are still learning also signs, supports signs, or how do you call you make easier the sign perhaps if it's difficult to produce. So but they still have that kind of connection to the sign language even if they have their auditory equipment, if they don't know how they are going to function if their own expressing language is different than their receiving language. Finished.

Participant One: One comment, or question, I always get from new staff starting is 'is [sign language of Participant One's country of residence] similar to [sign language from a different European country]?', and it's completely different [laughs]. So the [sign language of Participant One's country of residence] alphabet uses one hand the yeah the alphabet letters and I know [sign language from a different European country] uses two, but in [region of country of Participant One's country of residence] a lot of people use [sign language from a different European country] and then end up dropping it. Majority of people use [sign language of Participant One's country of residence] so we have gone to [region of country of Participant One's country of residence] to put the time to teach [sign language of Participant One's country of residence] and you can see communication is completely different fingerspelling is completely different and it is, again, a small island, but you know [region of country of Participant One's country of residence] is also under a different jurisdiction and things like that. So yeah there are cultural differences very next to each other but like yeah completely different. It's a comment we always get or I always get asked you know 'why isn't the sign language the same?' [laughs] across all the countries and things like that, so made me aware this piece that there needs to be done about this or origins of each of the sign language I don't know. Just interesting the things that do come up.

Participant Two: I can maybe say also only about [Participant Two's country of birth] experience here [Participant Two's country of birth] is big and we should know that first problem is very different access to education of deafblind children and to special services for

deafblind adults in different regions. So close to [capital city of Participant Two's country of birth] and in big cities isn't big as [inaudible] some big cities. There are special services for children and the adults but the farther [laughs] from the center the worse the situation is and the it means also lack of knowledge of professionals [everyone nods] for example about the alternative communication, for bodily-tactile communication, for basic communication tools and their work with children is how to say more [air quotes] traditional [air quotes] in educational systems and we still can meet enough children who have no access to professional help and who live only in family I don't know nine-ten years old who yes of course their families communicate but they don't have some special knowledge and of course them how to say the set of communication tools is [laughs] much smaller than in big cities and this differences we can meet everywhere, so the access to communication of children is very different inside the country this is a problem. The research center where I work it works for all the country, that's why I can and children from different regions [starts playing with hair while continuing to talk] come to us and we managed some courses some teaching for professionals in for different regions, I don't know how it will be continue now according to world events, but I see the difference and we try to solve this problem but... yes, anyway, it is still there [laughs] it's still here, is this [short pause] difficulties. Thank you.

Researcher: Thank you

Participant Four: I was just going to mention shared interests can [pause] can put the language can put the communication aside if you got a shared interest like music or something like that. Sometimes it doesn't-it just doesn't matter what your language is because [Participant One nods] that music brings you together, it makes you dance, makes you sing, makes you move, makes you touch, you know? Obviously there is different, you know, traditional music for different, you know, countries, but the rhythm, the beat it's a great yeah it's a great connector, I think. Music or shared interests whatever that might be.

Researcher: Yeah, thank you. Any other thoughts or ideas that you want to share in this topic?

Participant One: Actually, yeah, I just what [Participant Four] was saying that was really interesting because we have two services in our center and they actually both use picture communication, but they wouldn't really communicate with each other. Sort of use signs with each other, but they actually like the same thing, they like doing the same thing together, and they both have a little bit of vision, so I think they can kind of read the facial expressions a little bit of each other there is a little bit of an age gap I think there's probably fifteen years between them, so one's sort of in her late twenties and the other one in her early forties. They both have [inaudible] syndrome, but yeah we were actually talking about this the other day that they did-wouldn't necessarily they might wave at each other or reach for each other's hands but they wouldn't necessarily have formal communication just between each other, you know, when they when they achieve the activity on their iPad or choice board and they achieve what they would like to do separately, but when they get together they seem to have this yeah sort of informal language or informal sort of connection almost which is really lovely to see, you don't we don't often see that in our place [inaudible] sometimes very difficult for our services to have friends and find things in common. Yeah, that was actually really interesting if you do have a shared interest or shared activity, you don't always need a huge amount of formal communication to communicate yeah.

Researcher: Thank you for that. I think those were all the question I had prepared for this focus group session. Is there anything that anyone has noticed interesting from the other participants that they want to bring up again, that they thought was interesting or eye-opening or anything?

Participant Four: I thought it was real interesting, [Participant Three], how you were saying about textures, different countries textures, prints, that is really interesting. I mean, I felt it as a visitor when I was in [European Country] and particularly [European Country], actually, [inaudible] and there was just a difference [Participant Three: yes] and you can feel and smell

I thought that was really interesting, and I'm desperate to ask you this does your [spouse] play the accordion?

Participant Three: No he's playing guitar and piano nowadays [Participant Four: uh-huh] now [spouse's name] is if when you met perhaps [spouse's name] was like have little bit ten degrees vision field and then normally [inaudible] he was more deafened and now he has two cochlear implants but now he is blind. So communication has changed the last now every [range of numbers] years and it has been very interesting to observe and he is doing this research in the university about the [research topic] as to deafblind person if you're interested to go to see the website it is [website] [spelling out the website more slowly]. So we have a website there and it's interesting to even I have been working in this field now [number] years and I everyday I learn something new stuff because he is analyzing that and when we were part of this [organization] and they picked up my PhD [PhD topic] this touch messages and the grammar so that's how this new textile and this smart clothes can actually also to be helping like congenitally deafblind to if somebody is coming so they have their own kind of vibrations, what you can actually feel about you-they can smell you but it can give you the distance information because most of with congenitally deafblind we have this close information [everyone nods] what we are giving and that has been like eye-opening for me to try to understand this feel that when you perhaps moving that how similar kind of messages we can give to the body these haptics because the directional info is always what is in front of me is also in front of the congenitally what is behind and side and so on and what is up and down. So the gravity aspect is also there and how we move our hands and legs so that has been fascinating me for last years (laughs) and when I'm going to the family, I try to observe how they do things. For example when we open in [Participant Three's country of residence] the doorways coming like towards us, but in [different European country] it is just like vice versa. So all this hand movements and how we make even coffee or how we do potatoes or whatever

it's two totally different kind of things, so if the mother is looking us or how we do it then they observe that okay and then I teach the deafblind and then at home they do it in different way different directions, but if we as educators or instructors don't know that, so what I was thinking that when I was teaching the professionals I teach them as they are deafblind so I always give the information to their body. They need to start to learn to evaluate that info that they get because that is the key factor that they can then do the similar messages because if you have five six different professionals during the day. And they all give different information. It *looks* the same visually, but haptically it's totally different.

[short pause as everyone is waiting for someone to say something to break the silence]

Researcher: Okay so I think if nobody else has anything else left to say then I think we can – [notices that Participant Two has unmuted] – [Participant Two]?

Participant Two: Ah yes I just want to say that I am very happy to see everybody [laughs] and I would like to ask you, [Researcher], if it would be possible to see your results because it very interesting and I would like to read and to see which conclusions you will make and if it is possible to share after?

Researcher: Yeah, I will [multiple smiles and nods and thumb-ups | Participant Two: thank you] okay, so thank you everyone for coming and participating in today's session and yeah I wish everyone a wonderful rest of their day and a happy weekend in advance

Everyone all together: Thank you! Bye! [waves]

Appendix E

Anonymized transcript session two

Date and Time: Monday, 14 March 2022 19:00

Researcher and Participant: [Introduces themselves to each other]

Researcher: [Setting up the recording]

Researcher: So it is just you and me I think we can just go into the main topic of the discussion [Participant: yes yes yes] can you tell me about your experiences with communicating with deafblind people?

Participant: Yup communicating with deafblindness has been a very difficult task because if you try to use the signs they don't they can't see and they sometimes they don't understand what you want to communicate. But still if you are used to do them frequently they catch up with time. I've been communicating with them not so long because I teach at the I teach at the higher school but communicating with learners with deafblindness I do that at the primary school where I also did my experience when I was doing my Masters, so I have been communicating with deafblind for [number] year and I always also go there to communicate with them always say challenge but to those people who have the signs and the if the learners are also have signs they are linked to this signs. Using tactile is a little bit easy for them but there are also some challenges that are there, there was the parents of the learners don't have experience of the signs more specifically the sign language they don't know the sign language that can be turned into tactile so we have also a problem in that area. So I've been with them yeah for the last part of my experience with them in terms of communication. Sometimes we also tactile by using some materials also, we can also use some materials so we can communicate, or even the calena the thing that I also experienced during my touch with the deafblindness. Yeah.

Researcher: Mhm, okay thank you. So you started to talk about difficulties in communicating

let's yeah let's start continue on-off that [Participant: yes] do you have any difficulties with communicating with specific individuals or from specific regions or specific groups or are they all the same for everyone?

Participant: Hm no they are not the same for everyone because when I was doing my studies I studied I looked at linus in different areas where they come from and the others they do use another language which is not commonly used in the other areas where they live. They are school, learners are to school, they using an a different language in a specific culture, and then when they go home they also meet a another situation whereby when using the communication signs they are different they don't mean the same in all the two cultures where they mean different yeah. So when they go at home they experiencing something that is not in school where they learn. I went to this street where they live and the communication with their parents their learners they deafblindness it was also something else was little bit confuse the learners who have also learn another cultural—who was who have been you know cultural situation at school. Yeah. [short pause] So the problem is where their [static] is, the meaning of what they use.

Researcher: So there is a different meaning in the signs at home and at school.

Participant: Exactly.

Researcher: Yeah yeah okay [taking notes]

Participant: Yeah

Researcher: So... how were you able to overcome that obstacle because I—because it can because I can understand it is going to be really difficult for the individual that they need to learn two different languages to communicate at home and at school. [Participant: Yes...] How do you overcome that? How do you yeah avoid that—those issues?

Participant: Yeah what I did actually was to communicate with those who are at school and learning how to use the language that they use at school. And then when I went to home, when

I saw that there was a different language that they use, I came back to school again and I show them what is happening at the home and they said yeah, this is also what we call this sign. So which means bringing them together solved the problem. Bringing the parent, the situation at home, and the situation at the school at another [inaudible] bringing them together using the people that they—that used the language. Then we came to a success, like this like miss this one. ‘Cause how I overcome that problem I was able to know what we go meant the same thing, but first that didn’t know.

Researcher: Yeah yeah yeah [Participant: Yeah] thank you. So we’ve talking about the problems, but do you also think there were any benefits or advantages to the different languages used in the school and the home or do you only see that as an obstacle?

Participant: Yeah you can say they are benefits if you bringing them together you [inaudible]. But as we use English we can use English [inaudible] way but meaning the same thing. So this then you can use different and meaning the same thing, **but** it also has a problem with learners with deafblindness some sort of confusion confusing this child with deafblindness. You are giving him two things, maybe which meant the same thing, so it can also cause some sort of problem would not understand easily. That’s what I saw but maybe the benefits is will be having variety [inaudible] so many things to use when using language maybe. But to me I wouldn’t say that’s good what was it confusingly child with learning difficulties with deafblindness. [short pause] Yeah.

Researcher: Yeah, thank you. [Closing statements apologizing that other participants were recruited for this session but did not return the signed informed consent document and therefore could not participate in this study and thanking the participant for taking the time to participate in this session].

Researcher and Participant: [Saying goodbye]