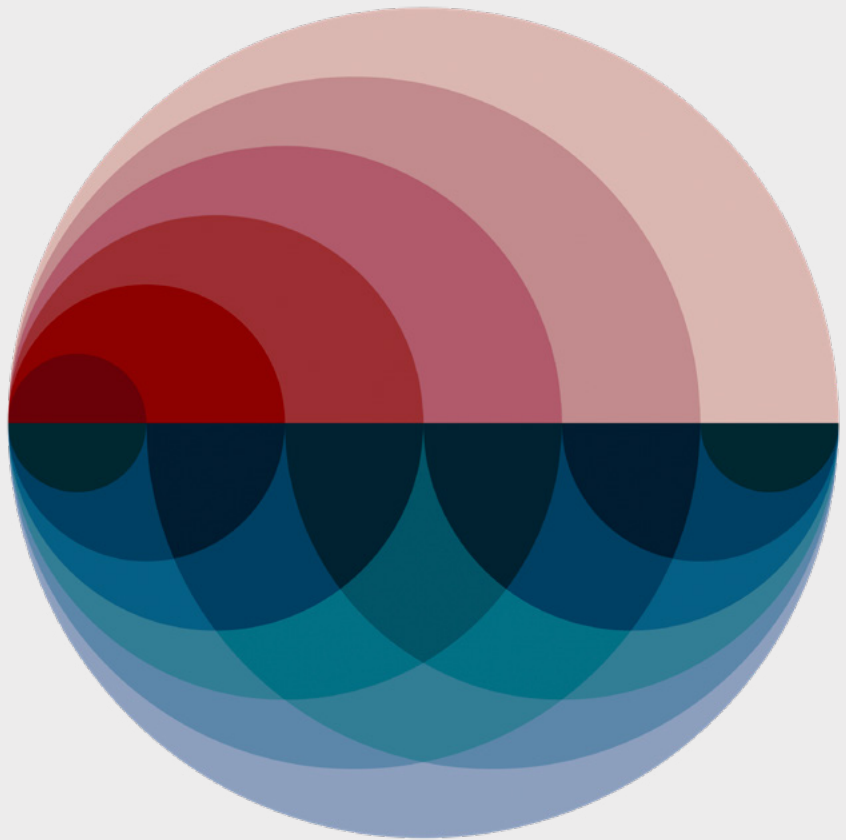


Tactile Transition

→ A report from focus group
interviews in Sweden



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Background

In order to live an active life and feel included when you have deafblindness, you need to have access to as many sensory impressions as possible in different situations. The brain does not care how it happens, it processes all impressions to understand what is happening in a certain situation and how we should react to it.

In the European project *Tactile Transition*, people with acquired deafblindness have participated in focus group interviews, where they together have evaluated and discusses how they have become aware of their bodies, how they use their tactile senses, and what strategies they use to engage in physical activities in everyday life. The project was initiated by Femke Krijger from the Netherlands. With her own experience of living with deafblindness, she has been reflecting over these things for several years.

In addition to Sweden, the Netherlands, Norway, and England have also contributed with resources for this project. The Nordic Welfare Centre (NVC) supports the project and are also represented in the reference group put together for the project.

The *Tactile Transition* project is about raising awareness of how people with acquired deafblindness use their tactile sense when vision and hearing are no longer sufficient, with the aim of using this knowledge as an important part of the rehabilitation process for people with acquired deafblindness.

This progress report describes the results of the focus group interviews conducted in Sweden during the spring of 2019.

Briefly about deafblindness

Vision and hearing are the senses that play the greatest role when it comes to communicating, absorbing information, living independently and being able to develop and maintain relationships with others. When one sense does not work, we compensate with the other. Compensating is difficult or, for some, impossible if both senses are impaired. Therefore, deafblindness is considered a distinct disability.

Deafblindness does not always mean that you have no sight and hearing at all, some people with deafblindness have both residual vision and hearing. Factors such as the degree of visual and hearing impairment, which sense is affected first, and when in life deafblindness occurs, have different consequences for the individual. Night blindness, binocular vision and sensitivity to glare are common, as well as hearing and/or sight

gradually deteriorating over time. Sometimes there are also additional disabilities.

Living with deafblindness means lifelong strategic work. Current research shows that it also has consequences healthwise, both for the physical and mental health (Ehn, 2020; Wahlqvist, 2015). It takes strength to keep stress, anxiety, and insecurity at bay, and also to recurringly adapt to changing conditions. Many people with deafblindness describe the energy loss as “the third disability” (Gullacksen et al., 2011).

Deafblindness increases the need to compensate with, above all, the sense of touch, the tactile sense, for example by using a white cane when moving, reading Braille and, for example, using social haptic signals or tactile sign language to communicate with others. Deafblind-specific support therefore needs to be largely based on methods focused on the tactile sense.

The tactile sense compensates

Deafblindness implies that new strategies need to be developed to obtain information about what the environment looks like, and what is happening or being said. Things that vision and hearing usually take care of. Specific aids as well as other technology are also needed to compensate for impaired vision and hearing function, but the technology is not always sufficient to fully compensate.

Nerves from our senses; sight, hearing, smell, taste and touch, lead impulses from the sense organs to the central nervous system, which handles the interpretation of this information. What happens outside the body is not as accessible when our most important distance senses, sight, and hearing, have impaired function. Instead, touch, balance, and joint and muscle sense may take a larger role to compensate to varying degrees, but also the sense of smell and taste. In deafblindness, the touch, the tactile sense, is of great importance in many different situations. It can be when communicating with other people in a tactile way or getting a sighted guide. The tactile sense also plays an important role in exploring the environment and in movement. New research has shown that people who gain tactile experiences and tactile information also develop a better working memory (Cohen et al., 2011; Heled et al., 2021).

The tactile sensory impressions can be divided into three groups. With *the receptors of the sense of touch*, we feel touch, pressure, pain, cold, heat, and vibration. The collected information gives a picture of what the

body comes into contact with. The number and sensitivity of the touch receptors vary in different places on the body. The fingertips and mouth, for example, are more sensitive to impressions than the back, where the receptors are placed relatively far apart. The first group distinguishes touch, pressure, and vibration. In addition, the skin reacts to slow and light touch which is closely linked to the feeling of something being pleasant. Pleasant touch releases hormones and contributes to the physical regulation of stress and feelings of well-being. The second group perceives temperature and pain. The third group is about *proprioception*, what is called *the joint and muscle sense* or the *kinesthetic sense*. It helps us, for example, to perceive the position of the body, where we are in the room, or what muscle power is needed to lift something. All this interacts and is integrated with the tactile sense.

You could say that the tactile sense is a multisensory sense because there are several different bodily functions that interact when we perceive tactile signals. What we henceforth in this report refer to as the tactile sense is thus not only the impressions that are captured by the skin, but by the whole complex system described above and which encompasses the body as a whole. Therefore, it is increasingly referred to in literature as *the bodily-tactile sense*. Figure 1 below illustrates the tactile sense with circles. In the circle in the middle, it says: "Multiple types of sensation received from the surface or inside the body. Around that circle there are other small circles where it says, vibration, proprioception, pain, temperature, pleasant touch, pressure and light touch." (Nicholas et al., 2019).

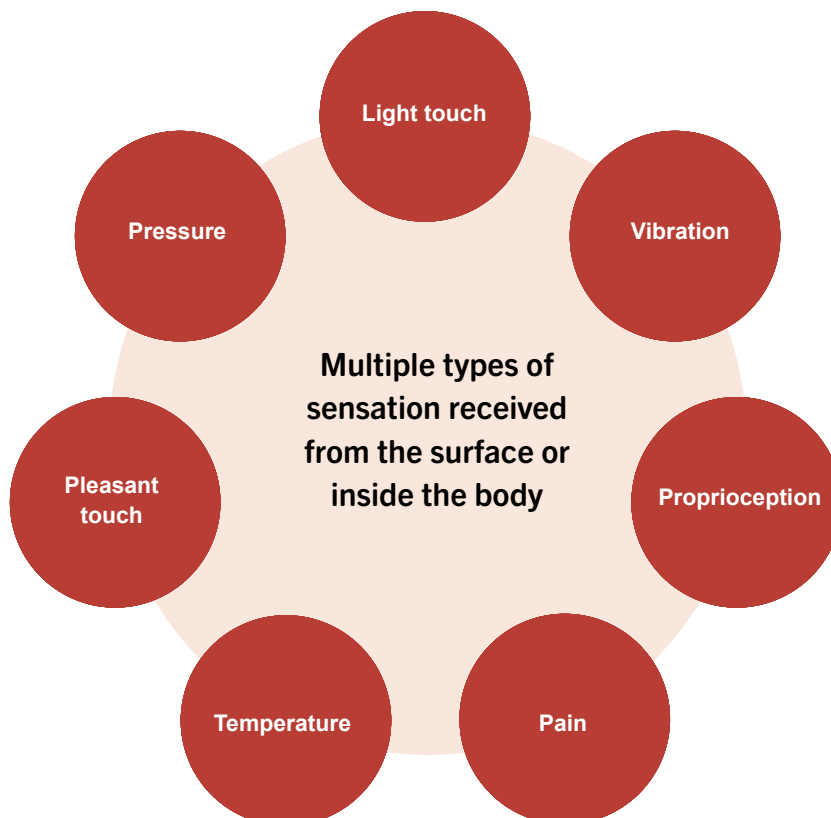


Figure 1. Sensory impressions that can be perceived on the outside or in the body.

Purpose and aim

The purpose of the Tactile Transition project was to find out how the process of transition to tactile strategies for people with acquired deafblindness can look like when sight and hearing can no longer compensate for each other. The project wanted to find out and describe tactile strategies that are used and experienced as facilitating in everyday life for people with deafblindness, but also which factors in the environment prevent and which factors facilitate the use of tactile strategies. The aim of the project group was also to gain a deeper understanding of the compensatory strategies of the sensory system and the potential of the tactile sense for people with acquired deafblindness.

The aim of the project was to increase awareness of how people with acquired deafblindness use the tactile sense when sight and hearing are no longer sufficient, to be able to use this knowledge as an important part of the rehabilitation process for people with acquired deafblindness in the next step.

Project questions

To gain more knowledge and increased understanding of how people with acquired deafblindness use their bodies and tactile strategies, the following questions were formulated in the project group:

- How do people with deafblindness become aware of their bodies?
- How do people with deafblindness experience their bodies and body parts?
- How do people with deafblindness describe the adjustment process, increasingly using the tactile sense and the body as a whole, when sight and hearing are no longer sufficient?
- Which tactile strategies do people with deafblindness describe that they use?
- Which factors in the environment prevent or facilitate people with deafblindness to use tactile strategies?

Method

Design

The project group jointly came up with the design for data collection. To collect data focus groups have been used in the project. The appropriate number of participants for focus group interviews is three to eight (Wibeck, 2010), and the project sought to include five to six people in each country's focus group interviews.

The focus group as a method and form encourages participants to share their experiences and reflect on them from their different perspectives. The method is well adapted for questions where knowledge is lacking or sparse regarding a phenomenon or a tendency. There is a great lack of knowledge about how people with acquired deafblindness use their tactile sense and what the transition looks like from being able to use sight and hearing to switching to gradually more tactile strategies.

Interview guide

Based on the purpose and the questions formulated, the project group produced an interview guide with common areas with related questions. The areas identified were: tactile and bodily awareness, tactile and bodily strategies, as well as support functions in society that can enable the adjustment process to make greater use of the body and tactile sense when sight and hearing are no longer sufficient. In addition to the common question areas, the Swedish working group added the topic of community support.

Selection

To identify possible participants, the selection applied was non-random, for convenience, i.e., a list of participants was compiled based on personal knowledge that existed in the Swedish working group. However, there were some criteria for inclusion to capture different experiences of the participants in the focus group:

- different modes of communication (spoken language, visual sign language, and tactile sign language)
- varying ages and gender
- experience of using the tactile sense

The Head of operations at the National Resource Center for Deafblindness (NKCDB) sent out a first request by e-mail where the project was briefly described. After both positive and negative responses, some additional inquiries were made. One month before the first meet-

ing was to take place, further information was sent out, where the purpose of the project, how the study would be conducted, and how data would be handled, was described. A consent to participate in the focus group interviews as well as a program for the days with times for the focus group interviews and workshops were also attached in the e-mail.

Participants

Five people participated in the focus group interviews. The different characteristics of the participants will not be described in detail to avoid possible identification of individuals. The group included both women and men, aged 28–69, with different ways of communicating (spoken language, visual sign language and tactile sign language). Several of them use a combination of these ways to communicate with others. The participants have different causes for their deafblindness, but in common they have a progressive deterioration of vision and/or hearing function.

Project execution

A location suitable for the purpose was booked. Accessibility aspects, such as sound and light conditions, distance to public transport, accommodation, coffee, and food, were taken into account as much as possible. The room was adapted for the planned activities. Chairs were placed in a circle for the interview itself. Camera equipment was placed and tested. When the participants arrived, placements as well as sound and light conditions were discussed, and some adjustments were made for the participants to see and hear each other as well as possible. The interpreters were seated according to the participants' needs. Hearing loops were used during the interviews.

The data collection in the focus groups was divided between two occasions. Before the interviews started, there was an introduction round by all participants and others present, who also stated their different roles. The background of the project was presented, and the participants were given the opportunity to ask questions. Programs and practical information were presented. After a short introduction to focus group interviews as a method, the interview could begin. The interview leader presented the first topic about tactile and bodily awareness and then left it to the participants to discuss it further. The second occasion began in the same way.

The interview leader checked if the participants had any questions or reflections from the first occasion and then went through the program for the day.

The first gathering was a two-day meeting, where the first day included interviews divided into several parts with breaks for a workshop. The workshop was conducted with the aim of increasing awareness of one's own body. Femke Krijger, project manager for the project as a whole, led the workshop. She is a trained shiatsu therapist and yoga instructor and has deafblindness herself. The workshop was held in English and another person was involved as a communication support to the project manager so that she could participate. In the evening, there was a dinner for all. Day two began with a short summary from the previous day's interviews and there was time allocated for questions and reflections. After that, the discussions in the focus group continued. The second gathering was held as a one-day activity with a lunch. As an assignment between the first and second occasion, the participants had to reflect on situations where they use tactile strategies.

The interviews were led by a person from the working group, who also introduced the various topics and helped with taking turns and follow-up questions when needed. Another person from the working group participated as an observer and supported the interviewer by taking notes, asking questions, and asking for clarification when needed.

To document the discussions in the focus groups, it was all recorded with both sound and video. Two film cameras were placed in the room so that all participants were part of the film. Sound was recorded directly to a computer.

Deafblind interpretation

Several of the participants used deafblind interpretation during the interviews as well as during the other activities. The interpretation methods that were represented were, visual sign language, tactile sign language, speech-to-text interpretation, and amplified speech. Social haptic signals were used as a complement to both spoken and sign language. Social haptic signals mean pre-agreed signals that are given on the person's

body, usually on the back or upper part of the arm, in order for the person to receive information about what is happening in the room, emotional expressions, etc. The interpreters had received information in advance about the project and how the interviews would be conducted.

Ethical considerations

Information about the project and the processing of data was sent out together with a consent form before the first interview. The signed consents were handed in at the first gathering. The films and audio recordings from the interviews were transferred to a secure server. All material was destroyed after the transcription was completed.

Transcription

Transcription of the material was carried out by the person who was the moderator during the interviews. The interviews were transcribed word by word, and initially it was stated which participant said what. After the transcript was checked against the recordings and corrected where necessary, the material was de-identified.

Analysis

In analyzing the transcribed interviews, three theoretical models have been applied. Based on the models, a number of markers have been identified. A marker consists of a smaller unit in each model, for example tactile sensations, mental effort, or norms and values of others. The choice of theoretical models and markers has been developed jointly in the project group. The models are briefly described below.

In the analysis work, the transcribed interviews were read several times, after which text sections describing a marker have been highlighted, something that has been repeated for each model. Any ambiguities have been discussed in the working group, and thereafter all text sections under each marker have been compiled. There is a certain overlap between the different models, and the analysis has also been about identifying these overlaps, thus confirming the respective model.

Theoretical background

The three different models that have been used in the analysis of the focus group interviews are described below. Models 1 and 2 emphasize the awareness of the bodily and tactile impressions, and the cognitive processes involved in that work. They also highlight that new or non-routine physical and tactile activities, or situations of high stress, can be mentally demanding. This in turn can lead to frustration, overload, and exhaustion. Model 3, on the other hand, describes the individual in relation to the outside world, how the individual interacts with the surrounding society in different ways and at different levels.

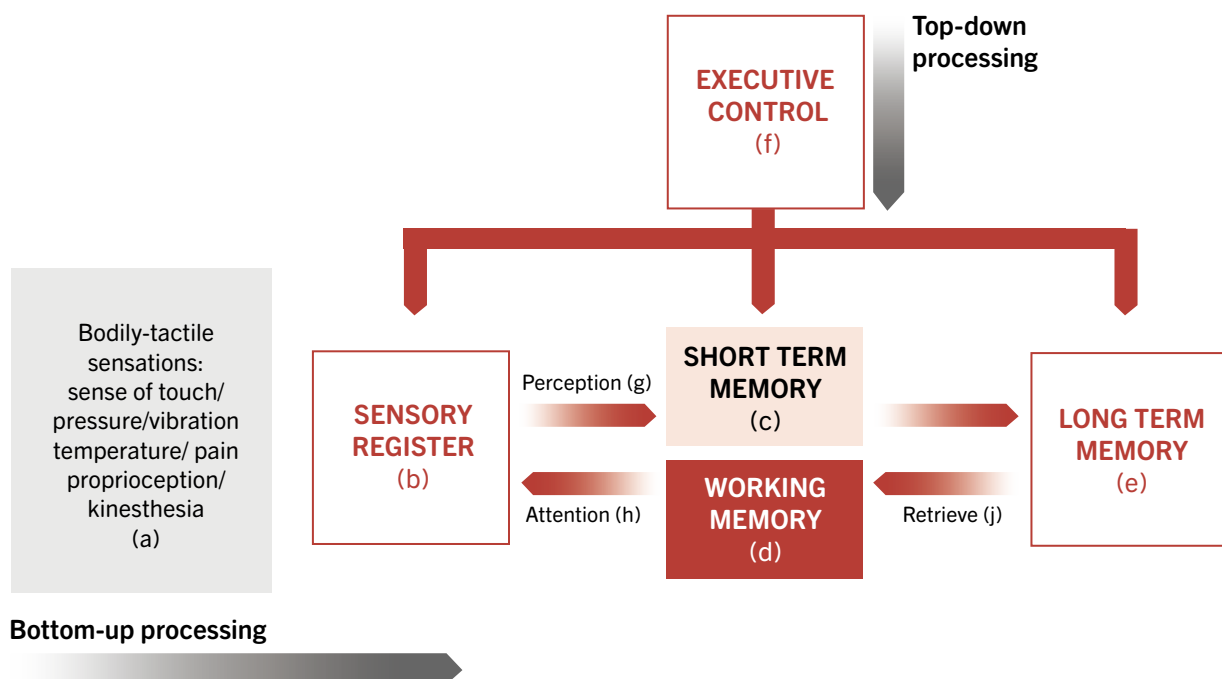
Model 1. The somatosensory system

The first model is about the somatosensory system and how the bodily tactile sensory impressions are processed and how these are made conscious (Nicholas et al., 2019).

Soma is the Greek word for “body” and the somatosensory model describes what happens when humans receive tactile information through bodily impressions. When the information reaches the brain, a sorting takes place so that we can interpret whether it is a light

and pleasant touch, pressure, vibration, temperature, or pain. The somatosensory system is furthermore about becoming aware of where you have your body parts and where you are in the room (proprioception) as well as the signals you get from joints and muscles.

The sensory impressions that come to us are sorted and categorized, which allows us to recognize objects, locate things and places. Some sensory impressions disappear before they are noticed by the short-term memory, or working memory, as it is also called. The working memory can be described as a temporary storage place for information that we receive. The process also goes in the other direction from the long-term memory to the working memory. Long-term memory consists of memories that have been processed and stored to be able to remember what was important on a specific occasion. The whole process is monitored by the executive control system in the brain’s frontal lobe, which has the task of ensuring that we can keep our attention aimed in a certain direction and that we can plan, implement, and achieve the goals or tasks we are faced with. Information from tactile and bodily impressions is closely integrated with the brain’s motor system, so that we can act on and manage our surroundings in an efficient way.



Model 1: The somatosensory processing system: how received bodily-tactile sensations can be processed in the loop of several processing units through which they pass. The processing units (a, b, c, d, e, f) and the chain of information processing (g, h, i, j) are illustrated in the figure. The two arrows (black and gray) that symbolize bottom-up processing and top-down processing are also illustrated (Nicholas et al., 2019).

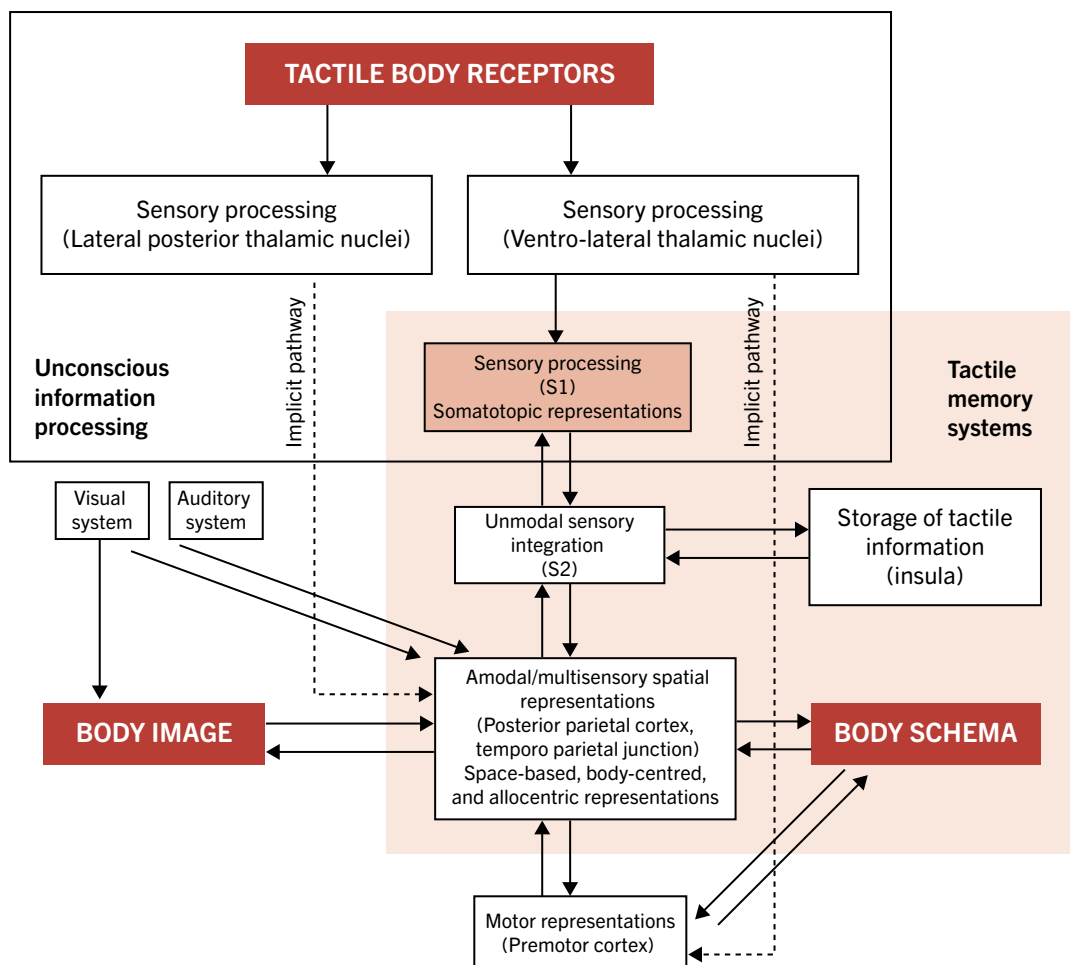
Model 2. Body representation and body awareness

The second model deals just like model 1 with how sensory impressions are processed through the sensory receptors (tactile body receptors) and on to different cognitive functions in the brain (Gallace & Spence, 2010). But unlike model 1, model 2 also addresses how the body is perceived in the brain based on the information that the brain has access to. This is called body representation.

The model by Gallace and Spence (2010) describes two types of body representations through a neuro-cognitive perspective. One concept is “body image” (body perception), which is about the perception of one’s own body and which includes attitudes and perceptions about one’s own body. For example, it can be how to perceive size and weight. The second concept is “body schema”, which is about the awareness of one’s own body and its body parts, and how they behave in the space we move in.

In other words, “body image” has more to do with the view of one’s own body based on how one perceives it, which is mainly done by seeing it, but also by feeling it. While “body schema” is about where you have your body and your body parts in relation to the room, and has more to do with proprioception, the feeling together with muscles and joints. Proprioception is, for example, involved in the awareness of how to move (“I am moving forward”) and of where different body parts are in relation to each other (“my foot is placed in front of the rest of my body”).

Together with “body image” and “body schema”, the body is strongly related to our experiences and feelings about ourselves. It includes the feeling that our body parts are our own and that we can have control over our body.

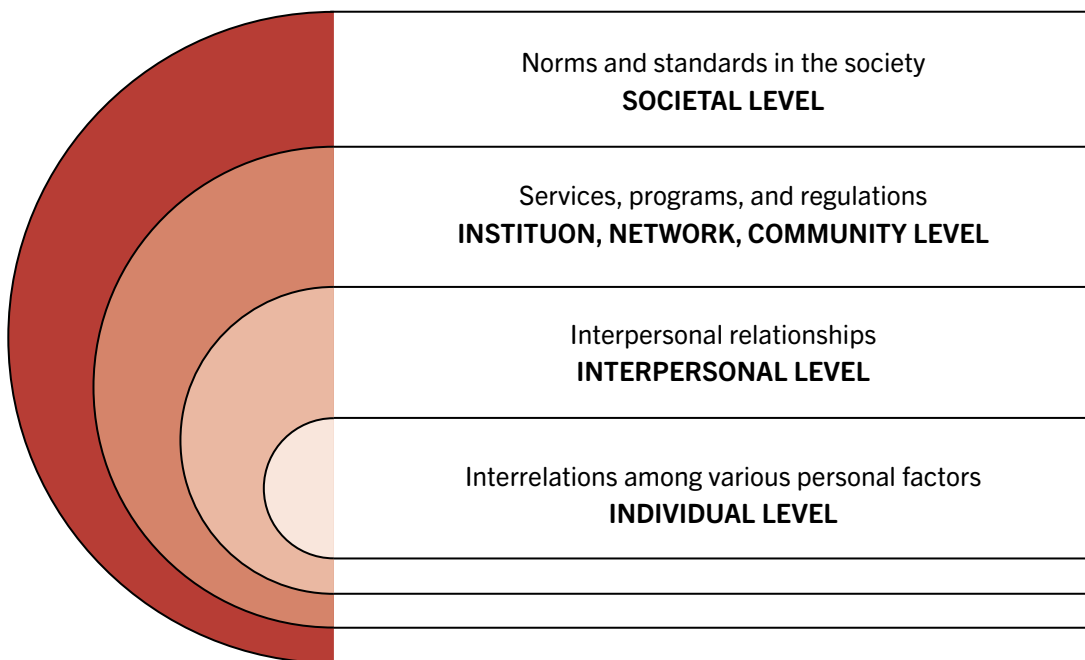


Modell 2. A neuro-cognitive model explaining the processing of body schema and body image (Gallace & Spence, 2010).

Model 3. Ecological system model

The third and final model describes the individual in relation to the outside world, how the individual interacts with the surrounding society in different ways and at different levels (Bronfenbrenner, 1994). The model is dynamic, and the different parts interact with each other in a constantly ongoing process. Relationship refers not only to the ties that exist to other people but also to institutions, networks of various kinds, and to society as a whole. Relationship also refers to culture, norms, and values in the society in which the individual lives.

A human should, in this model, be understood as a psychological being who is first and foremost surrounded by its own body, in the shape of a biological organism which is in constant interaction with its various environments, and which adapts, but also has the opportunity to affect these environments. The image below illustrates these different environments and systems within and around us humans.



Model 3. Ecological system model, a model that shows the different systems (context levels) that surround the individual and how these relate to the individual (Bronfenbrenner, 1994).

Results

The three models described above have been used as a starting point in the analysis of the focus group interviews. With the help of the models, the questions of the project, and the markers that were identified in the project group and which have been used in the analysis work, the result describes the focus group participants' experiences and understanding of impressions they get from the body and the tactile sense. It also describes how factors in the environment affect the use of tactile strategies such as relationships with family and friends, and norms and values of the society.

Model 1. The somatosensory system

The participants describe how they become aware of bodily tactile impressions in different ways. They reflect together based on concrete situations that they have encountered and have experience of. Initially, it was the hands and feet that were mainly described as a source of tactile information, but in the discussions, it became clear that they also use other parts of the body to get information. They describe how, with the help of the body and the tactile sense, they can distinguish and identify things, people, and places, but also how important the tactile information is when moving between different places.

Receiving information through the body and the tactile sense

The participants say that they use their whole body to get tactile information. Many express that hands and feet are extra important. They say that wearing gloves, socks, and shoes inhibits the experience of sensory impressions.

“At home, I use my feet: I never wear slippers when I’m on my own. It feels completely wrong, like an extra layer of skin.”

As they reflect and share their experiences with each other, they become increasingly aware of the importance of the whole body in activities in everyday life and to get information about what is happening around them. In the discussion, the participants express that the impressions they get from the body make a difference and help in everyday activities. Words that the participants use to describe what they experience with their body and their tactile sense are, for example, “to feel”, “the touch”, “feel and touch”, “the bodily”, “my muscles” and “the tactile feeling”. Furthermore, the participants describe that it can be difficult to know whether a touch is active or passive when something they perceive is happening simultaneously.

“In motion, for example when you walk in the city, you feel with your body if there are unevenness on the ground... at the same time I can feel a movement or vibration when someone walks past me.”

With the body and the tactile sense, you can mainly perceive things up close, but the participants also describe experiencing impressions coming from a certain distance. It can be vibrations, the beat of music, draft, or heat, and cold.

“... I can feel a type of vibration or that it is blowing, somehow I feel the vibrations ...”

Some of the participants describe how they feel the structure of fabric to determine if the fabric is a material they like to wear. They pick up and feel fruits and vegetables to know if they are ripe or overripe. Touching others is a good way of creating an image of the person you meet. By, for example, shaking hands with another person, you get different types of information, such as how the hand feels, the strength of the shake, heat, cold, size, etc.

“When you go around and touch everyone by shaking hands ... You get a picture of them and feel more involved.”

The interview participants describe how the awareness, and how they use the body and different tactile strategies, has increased as their vision and/or hearing has deteriorated.

“... When my vision gets worse, my senses, my other senses, the feeling, the tactile feeling must take over more and more in different situations.”

One reflection that the participants make is that there is a difference between what you perceive with sight and hearing compared to what you perceive with the tactile sense and body. The participants describe that the sense of smell fulfills an important function for them and is a sense that they rely on. The sense of smell is used both to identify things and people in the environment, and the experience is that the sense of smell has become a stronger sense as vision and/or hearing has deteriorated. But this is not always perceived as positive – some scents, for example strong scents, can rather be experienced as a strain and as something disturbing.

“If my eye-sight had been normal, I guess that scent wouldn't have bothered me, because sight would have been the primary thing.”

All but one participant say that they use their sense of smell to locate themselves and to understand where they are. They also use the sense of smell to identify a flower or to find a café by smelling the coffee or freshly baked bread. Some restaurants can also be recognized by their aroma, such as pizza and kebab places. With

the sense of smell, the participants can get information about someone entering the room, and if it is someone they already know. Being able to identify a person with the help of a person's scent was as important to one of the participants as getting a name or a personal sign.

“Talking about names and personal signs ... I had scent signs of those nearby or who were in the room before.”

The participants describe how they can identify things and places with the help of touch. It can be finding your way from how the surface feels, for example if it is cobblestone, gravel, asphalt, or grass. One of the participants describes how it is possible to decide which side of the house they are on, depending on what direction the planks on the terrace are placed in:

“On the west side of the house, you walk along the length of the floor planks. If you walk around the corner, the planks are placed across ...”

By touching another person, it is possible to determine who it is. The participants also describe how, by feeling something, they get the information they need to choose, for example, a clothes item.

“I like to go and run my hands over the clothes, to get some understanding of the material. By feeling it, I get a lot of information that makes me find the item I'm looking for.”

When traveling by public transport, it can be difficult to determine whether someone is nearby or not. To find out, one participant describes how she discreetly tries to check.

“If I'm on the bus or the train, I don't know if anyone is sitting beside me. Then I put out my hand carefully, where the leg should be ...”

Small signals have significance

The interviewees describe that they are sensitive to signals they can perceive with the body, for example when riding, dancing with a someone, or when using a guide dog. Small signals are often sufficient to change body position, for example during exercise. The participants have experience of using socially haptic signals, but also say that practice is required to be able to perceive and read tactile signals that are transmitted on the body.

“If I do circular training, it’s enough for someone to press their finger against my back. Then I know I have to adapt and straighten my back.”

One of the participants, who has a guide dog, describes how the dog’s reactions provide information about what is going on.

“Someone comes towards us, the dog pulls a little, and I feel the tail wagging. Through the harness, I get the information.”

The body remembers

Even though the interview participants already use tactile strategies in everyday life, they describe that the conversations in the focus group have made them more aware of the way in which they use their bodies in different situations. They describe how they in familiar environments, for example in their own apartment, with the body memorize how to move best between the rooms, where different things are located, and where they put something.

“When I sit at my desk, I can’t see where I put my mug, but I know anyway, since it’s where it should be ... I can just take it.”

Another example is how to memorize your home environment so that you can move around freely without using sight and hearing.

“Next to the carpet I have a dresser. From there I find my way to the other rooms. This happens automatically. If I go into my living room, I go in the direction of 11 o’clock and I come to the carpet around the sofa and there is the coffee table, and then I know exactly where I am.”

During activities in their free time or to get between different places, the participants experience that they benefit from the tactile sense, and they rely on the body to remember.

“I want the place next to one of the pillars, so I know exactly where I am. Then I can pick weights and other things without any problems. But I have to get there early before anyone else takes the spot.”

Being aware of your body memory is important, but the most important thing is daring to trust it. When you can no longer rely on your sight or hearing, the need to trust what your body remembers increases. One participant describes that it gets stored in the body after one time, or when someone has described it.

“It’s with the tactile sense I find my way around, it’s kind of stored in my head, and my body.”

That the body remembers also plays a great role in being able to feel safe and secure, for example when being outdoors.

“I know where to go and where to put my feet to not take a wrong turn, or where I need to be extra careful, so a bike doesn’t hit me. I know where the bus stops are and all that ...”

Orientation and moving around

Difficulties with spatial orientation and being able to move safely and securely are one of the consequences of deafblindness. Knowing where you are in your apartment or at work is important. Not being able to see that the cabinet doors or the dishwasher are open are just a few everyday examples of difficulties described in the focus group. The participants convey how they have come up with tactile strategies to facilitate their everyday life. Carpets are described as important landmarks for indoor orientation.

“Then I placed the carpet so it was exactly right in front of it, and then I’m completely sure. I walk the length of the carpet, and then I need to turn. That’s how you do it.”

One of the participants folds the edge of the carpet to indicate that the dishwasher door is open, to not trip over it. Other benchmarks that the participants describe are tables, cabinets, or radiators.

When changes occur in the known environment, it affects the ability to orientate and move around. Newly fallen snow on the ground can make it more difficult to orientate oneself in surroundings that are otherwise known. Having to get off at a different bus stop than the usual one, due to road or construction work, is another example. Not being able to use the usual strategies when locating your position and moving around is described by the participants as very straining and something that can lead to uncertainty and exhaustion.

“If I miss my bus, I don’t know how to find the train station. How will I manage? Well, then I need to call a taxi. But first I need to find out where I am, by checking the GPS on my phone. It takes so much energy.”

Getting to new unknown places and being able to orientate oneself in an unknown environment is an extra challenge when one’s sight and hearing cannot be relied on.

“I moved to a city where I can’t find my way anywhere. Where am I? Where to go? I do not feel safe. I feel very unsettled. I guess I have to start getting to know the city ...”

The participants describe how they count steps, use the sun or the wind to confirm the direction, or use various tactile landmarks in their surroundings. Someone describes how they walk with one foot on the asphalt and the other on the grass not to lose their direction.

“I like to know the compass directions and how the wind is blowing if I have to go out by myself. I can use the wind direction. You use what is available.”

Being interrupted when trying to orientate yourself can disrupt concentration, and then you have to start over with your strategy, for example counting steps.

“It can, for example, be in a store, and I walk straight into the bread shelf! And I just thought to myself, I got it covered and know exactly where I am. Then something interrupts me, and I suddenly turn in the wrong direction, even though I think I’m in the same spot. And then I walk straight into the shelf.”

Another way of losing orientation can be when you meet someone and you stand talking for a while, perhaps you turn your body a little in another direction. In those cases, it can be difficult to know in which direction you were heading. One strategy described is to keep one foot firmly in the intended direction while talking.

Model 2. Body representation and body awareness

The perception of one’s own body, how it moves, how it looks, or how it can compensate for deafblindness, differs between the participants and is described in different ways. Some experience that awareness of the body has changed in step with increasing deterioration of sight; for example, that certain parts have more or less disappeared from their consciousness. They also describe how physical exercise such as weight training, swimming, stretching, or dancing, but also touching through massage, has helped to increase awareness of the body and its various parts. In this way, they have been able to regain awareness of the body. Touching others is described as safe and something that gives awareness of both one’s own body and that of others, but in some situations touch from others can be experienced as something stressful and energy draining.

Energy loss is a topic that recurs in the conversations in the focus group. To always plan and have one or more backup plans, in case something unforeseen happens, is described as mentally stressful and something that leads to frustration and exhaustion. It also drains you of energy to have to explain to the environment in different situations what deafblindness implies.

Awareness of the own body

The participants share how they perceive their bodies and that it is something that changes over time. Due to the visual impairment, no longer being able to see their bodies in the mirror affects the perception of the own body.

They give a lot of examples of how they actively use the body in various activities and how much that means to the body awareness. Both when it comes to how the body functions in different situations, and how they perceive its different parts. It is clear, that awareness of the body, and how it is used to compensate for deafblindness, is a process that takes place over time.

“This part about using the body as a tool ... I can’t think of when, but I know that somehow I’ve noticed that I use the body more and more and in different ways. When moving around, for example in the city, you feel unevenness on the ground with your body and you feel with the cane ... that feeling ... the tactile feeling as a tool has increased over time.”

One participant also described that it has become increasingly difficult to know if you are doing a movement in the right way, for example during training or stretching

“I can’t see myself in the mirror at the gym, so I really have to feel this with body movements ... try to find the muscles and the right position.”

Several of the participants also describe that their balance is affected, and in order to keep their balance, they use different tactile strategies.

“I don’t trust my balance, and I am very aware of how safe you are in the tactile, how to relax. You feel with your feet and with the white cane ... What trust you put in the tactile!”

They describe that the body sometimes cannot sufficiently compensate for the deafblindness, which can be experienced as an insecurity or tension in the body.

“I’m worried about getting down a slope or that there will be a hole and I will end up spraining my ankle. These are the things you get anxious about. But I feel that I’m well on my way to finding my whole body.”

The participants discuss how they can regain the perception of their bodies. They share examples such as swimming, horseback riding, and dancing. One of the participants talked about previously experiencing the body not as a whole but as consisting solely of a head and feet. Through tactile massage, the other parts of the body gradually were activated in the consciousness.

“What happened was that I suddenly discovered my body. I feel where it begins and ends. Before it was only my head and then came my feet. I had no sense of what was in between. The process I went through then taught me to find my body.”

Acceptance of touch

Participants describe how and where on the body they want to be touched, and when it feels uncomfortable or annoying. Some of the participants appreciate when a touch is distinct, while others want a lighter touch. Someone prefers to be touched with the whole hand instead of just the fingers, and someone else wants to establish contact by being tapped on the shoulder. The participants also describe that there are parts of the

body where they do not want to be touched, for example on the belly. It is also not a positive experience when someone touches you unexpectedly.

“I find it unpleasant if you only touch with your fingers, you should use the whole hand. The touch should not be too light.”

The strategic work takes energy

The focus group gives many examples of how they need to put energy into planning and organizing their everyday lives. It can be anything, from choosing which way is best when you go to work, or how to find what you need in the grocery store in the simplest possible way. It is also about what to do when carefully learned strategies need to be changed, for example because the transportation service car did not show up, or because you did not get an interpreter for a planned activity.

The participants describe how they use different strategies to compensate for the visual and hearing impairment. Some of the strategies used are tactile, and the tactile sense has become more important for the participants, in order to use their energy as wisely as possible. But using tactile strategies is not enough to find the energy you need. Sometimes a different type of recovery or rest is needed.

“It’s perfect, finding tactile strategies that save energy. I’ve been reflecting a lot on this lately. But I have a hard time finding my way through that transition, so to speak, learning to take a break and understanding what kind of break gives me energy.”

They explain that misunderstandings easily occur when they are tired, because they feel that the tactile sense cannot compensate in the same way as when they are rested. It could be a signal that is not perceived correctly, or that you forget where you placed something.

“I’m thinking of when you’re very tired. I said it before ... that the tactile feeling helps a lot. But when you’re extremely tired, then it can instead get worse, and you can misunderstand ... It’s very stressful.”

The participants reflect on events and situations that they previously did not react to, but which nowadays become a stress factor when they occur in everyday life. To counteract stress, they explain about the different plans they have if something goes wrong. They also find

it difficult to explain the constant planning and logistics of everyday life so that others can understand it. They describe this constant planning as very tiring and something they did not have to put much energy into before.

“Having deafblindness is a project in itself, and you are the project manager in your own life. You have to have different strategies and plans A, B, C, D, and E ...”

The participants agree that all the strategic work of constantly finding new strategies that work in different situations takes energy and courage. Living with a number of uncertainties in everyday life, and always having to have several strategies to resort to when something does not go as planned, takes energy. This is described in different ways in several examples.

“If you’re very, very tired, you have no use for the strategies you have learned. Then it feels even worse, if you get what I mean ...”

The participants express that it is difficult for others to understand what it is like to live with deafblindness.

“... well, I don’t know about strategies ... I close my eyes and ears and focus only on pedaling that bike. Because I don’t get tired from it ... It wasn’t my intention to dump this on you, but it’s tiring to have deafblindness. Not having it yourself ... but the fact that others don’t have it ...”

The energy it requires, merely planning to participate in various physical activities, is discussed in the group. Everyone wants to be physically active, but when it takes too much energy only getting to an activity, that might just make you decide not to do it at all. You may also have to give up because something unforeseen happens, even if you have planned for several different scenarios in advance.

“I just want to add, that what prevents us from participating in activities is not only that we have poor vision and hearing. But it’s also this planning before and trying to predict what to do if this or that happens ...”

The fact that deafblindness, as a disability, is not as visible as, for example, a mobility impairment is something the participants keep coming back to. In everyday life and in various activities together with others, the participants need to tell everyone that their vision and hear-

ing is impaired, and what that implies. Often, it is not enough to say this only once, it needs to be repeated. Sometimes it takes so much energy that the participants choose to refrain from even going. Not being met with understanding, even though you have explained, becomes yet another strain.

“I get annoyed and exhausted when colleagues don’t listen when I tell them things that can help me out.”

Not being able anymore to see what you could see before causes a vulnerability that can create great stress. One participant describes how differently one and the same situation can be experienced.

“... but then something happens that makes me walk into a doorpost. Some days I feel like “it wasn’t the whole world”. But on other days, I can feel it thumping in my head, tears welling up, and I feel really bad about it.”

The participants describe strategies to compensate and reduce energy consumption. It can be standing or sitting in a special place to perceive the instructor when training. It can also be standing near a pillar or other known object to be able to orientate oneself. But for these strategies to work, you might need to be in place well in advance to be sure that no one else takes that spot. All participants describe how they opted out of activities because it takes too much energy to manage all aspects of it. But they also describe how they try to find other activities to participate in when vision and hearing deteriorate.

“Workouts where you stand in the same place the whole time work better now. Then I know where to be. Sometimes, perhaps you need to do something in a different way, use a barbell and things like that, and it’s difficult when I’m expected to get stuff. It’s easier to stand in one place, that’s what makes spinning so good.”

No longer being able to do something spontaneously, or not being as flexible as before, is described by the participants as difficult to accept. It takes new strategies, and courage, to dare to try and dare to fail. This is something that the participants describe as a huge change they need to work on a lot.

Model 3. Ecological system model

The ecological system model is about interrelationships between individuals, interpersonal relationships, the service available in society, and the norms and values that affect us as individuals. What emerges in the focus group interviews is largely about the participants' experiences of the lack of knowledge and the misunderstandings from the outside world. There is also an awareness among the participants that they themselves often break unwritten rules and social norms in their meetings with others, both in relation with their close ones, and with society at large. For example, having to stand close to be able to perceive what is being said, exploring something by touching it, or having body contact when socializing with others. The balance between being independent, but at the same time needing support in different situations, is a recurring theme that the interviewees believe affects their self-esteem and increases vulnerability. The right support needs to be available when you need it, and you are ready to receive it.

Handling the lack of understanding and knowledge of your environment

The lack of understanding of the consequences of deafblindness among family members and relatives is often perceived as more sensitive and problematic than in regard to other people in the environment. The participants believe that this is due to the dependence that exists in relation to the family and relatives, also in adult life.

“My way of communicating has changed, which is no surprise. But it's been tough for my family, how they should handle it. There are misunderstandings and frustration, I feel my patience's running low ...”

Getting help from family members and relatives is sometimes necessary to be active and involved, even if you would prefer to be independent. That can make it harder to speak up or talk about what is perceived as difficult in a family member's or relative's behavior or actions. You do not want to show that you get annoyed, and instead you try to pretend that all is fine.

“When I'm out walking with my partner, someone might walk towards me with a baby stroller ... And instead of telling me in a nice way, he pinches me and pulls me aside. What's happening? Then my whole head gets chaotic.”

Sometimes family members and relatives need to take on a professional role, which can be problematic. The participants believe that relatives should be allowed to be, for example, parents and not assistants, interpreters, or guides. Sometimes family members and relatives can be perceived as overprotective, in all their good intentions.

“You don't want to lose your independence, and you don't want your family and relatives to boss you around.”

Having to repeatedly explain what deafblindness is, and what the double disability means, is perceived as tiring. The consequences are largely invisible, and the environment shows greater understanding if they see the white cane, or if you use visual or tactile sign language, according to the participants. However, the cane is not possible to bring in all situations, and it is mainly interpreted as having a visual impairment, even if you have the red markings on the cane that show that the person also has a hearing impairment. One person describes the opposite, a meeting with a person who knew exactly what Usher's syndrome means, and what to think about.

“It turned out she worked with deafblind people in London ... knew how to do with simple means. I've never had such good contact with a human being before, because she knew!”

The participants describe how they have told people in their environment, it can be family members or colleagues, what they should think about that can help people with deafblindness. It can be how to make contact, or how to use an aid. It usually works for a short time, but then people tend to forget the tips they were given. The participants agree that it is not possible to keep repeating the same tips over and over. Instead, it is easier to not give any advice or tips, and rather use a strategy where you avoid situations perceived as difficult.

Being met with understanding or lack of understanding from the environment is also discussed on the basis that the visual and/or hearing impairment changes over time. It can be difficult, both for the person with the impairment and for others in the environment, to describe and understand the consequences of the change, since it often happens gradually and slowly. Getting to know each other at a stage in life when sight and/or hearing is at a certain level, then meeting again after several years, can affect the understanding and behavior, the participants describe. You do not always remember to

say something about it yourself, and it can also be that you do not have the energy to tell people. For family members and relatives, it can be difficult to accept that a functional decline actually has taken place. Sometimes the participants experience that they maintain a facade in front of family and friends, so they do not get worried.

“You must be allowed to be sad and need some space, it must be ok to look tired. People have this idea that you should be alert and happy and so on. When that is not the case, the fully seeing and hearing around you get a little anxious.”

Someone describes that it can be easier for friends you have gotten to know later in life to understand how deafblindness affects you, than for friends you have had a relationship with since childhood.

“People I got to know recently are easier for me to spend time with on my own terms, I can more easily ask them for help. But if I meet childhood friends, they hand out with me in the way we have always done ... They can’t meet and treat me in the same way now ... the conditions have changed.”

Everyone wants to be treated based on who they are, and not be seen as a person with deafblindness. However, the limited ability from the surrounding people to understand what deafblindness means and what consequences it has, becomes a strain, according to the participants.

Norms and values regarding touch

When the participants talk about the importance of touch and the need to compensate with the tactile sense, this is something natural and not perceived as strange or sensitive. On the other hand, when they use tactile strategies in meetings with people who do not have deafblindness, they might feel that they are breaking a norm. The participants reflect on the MeToo movement and that touching can be misunderstood. They also have experience of others laughing and commenting when they touch or feel things to get information.

We are governed by the norms and attitudes of society and culture; and being physically close and touching each other is not a given for people with deafblindness either. Several participants say that they thought it felt strange at first, but after their sight and hearing deteriorated, they had to disregard both their own attitudes and

perceptions, as well as the attitudes and perceptions of those around them.

“I remembered the first time I entered into the deafblind world, then I thought there was a lot of touching going on. I remember that reflection, but I understood quite quickly that there was a reason for it.”

They believe that it is all about uncertainty and ignorance, and that the most important thing is trying and wanting to understand and learn. The participants agree that knowledge about deafblindness should not only be about the consequences of impaired vision and hearing, but also about the need to break norms around body contact and physical touch.

“It is quite important that you dare to have physical contact for it to work. If people don’t really dare to touch me, then it is difficult to communicate, and there will easily be misunderstanding. But it’s interesting how cultures clash when we behave in different ways.”

The participants draw a parallel to how it works for people who are deaf. The deaf culture is based on being visual and reading sign language with sight, but they are also more physical in contact with each other than what hearing and seeing people normally are, as the participants express it. For one of the participants, it is challenging to become increasingly dependent on physical contact during communication. One experience was when the participant’s vision deteriorated, and it became more difficult to perceive when someone tried to draw or call attention with their hands to make contact.

“In step with my sight deteriorating, I’ve become increasingly dependent on my friends coming up to me tapping me on the shoulder to get my attention.”

One of the participants says that touch can sometimes be experienced as a burden, which can be difficult to cope with and calls it “tactile noise”.

“Sometimes it gets too much. I worked at a camp, and a lot of people sought me out to make contact and ask things. It got too much with the contact-seeking and people coming up to me, touching me. I usually call it “tactile noise.”

An increased dependence on others affect self-esteem

The participants describe that they gradually became increasingly dependent on the support of people around them, when sight and hearing can no longer compensate for each other as before. They can no longer independently do things they have previously been able to do, such as traveling or getting to various activities. Nor can they perform the same activities as they did before, such as running or taking a dance class. They describe how it affects the ability of being independent, but also how an increased dependence on others negatively affects their self-esteem. Being independent is considered important by everyone in the group, and they try to find different activities they can participate in, but do not require full sight and hearing. Comments and questions from the environment have led the participants to start thinking about which bodily strategies they actually use. Most come automatically, without having to think about it. The participants also say that they sometimes get attention and confirmation from people saying that what they are doing is unbelievable, considering that they cannot see and hear, and that such feedback strengthens their self-esteem.

“Only when the postman came up the stairs and asked what I was doing with the heavy window sill in my hands and my behind against the wall, did I realize what I was doing. It was fun to be caught in the act. I want to feel that I managed, then my independence is preserved as well.”

Being active in a world where great focus lies on sight and hearing is not uncomplicated for the participants. Sometimes they experience feelings of inadequacy which affects their self-esteem.

“You feel inadequate, not worth as much as others. You really want to be seen for the individual you are and what you stand for. You don’t want to show the tired, exhausted, resigned part of yourself.”

It is not just the feeling of inadequacy that the participants put into words. They also describe a great deal of frustration at not being able to be active and participate in society on equal terms with others.

“I broke down because it will never end. I’ll continue to fight, demand, whine and tell people that I need things to be like this and that for it to work for me, but it will never end.”

Being able to reconsider and finding their way back to the positive aspects in life, is described by the participants as important after periods of negative emotions and frustrations.

“Accepting doesn’t mean you like it, but that you have realized that this is how it is. This is me, this is what I need to do. I also have to let go of all that negative stuff, otherwise I will never find my positive self again.”

All the participants testify how important it is to be as independent and autonomous as possible, but also what a high price they have to pay, both physically and mentally. They also describe the balancing act they constantly go through in order, on the one hand, to be able to live independently and, on the other hand, receive support when needed. The following quote describes the price they have to pay.

“I was burnt out this summer and was on sick leave for three months ... I didn’t work, had no feelings, I was very, very tired. I just shut down, couldn’t manage anything. I couldn’t take it anymore, and I was angry at myself because, just like you said, you need to be a good girl.”

Need for support and services

The participants believe that many of the resources and services available for people with deafblindness are not always working optimally today. They want to feel sure that there is access to an interpreter when they need one, that it is possible to get transportation service for a trip or guidance from someone you can communicate with, and to get working aids and technology as needed. They keep coming back to the importance of being able to feel safe, not only with people who work with these services, but also with the people who make decisions about different services and resources.

“There must be support, and there must be a multitude of services so you can choose what suits you and your current needs. And the deaf-blind teams should collaborate with the vision team, and the audiology team.”

The participants agree that physical activity is important to feel good. They believe that the rehabilitation offered also needs to be focused on how to feel safe and to be active. A physical activity you enjoy, and can participate in, contributes to you functioning better in your everyday life.

“It is incredibly important that we get services so we can feel safe when we participate in different activities. If you don’t get that support, you don’t dare to take the steps you need to be able to participate.”

Even if knowledge is perceived as very central, all participants agree that the most important key is the attitude and mindset of the professionals. Openness, patience and understanding of the need to develop tactile strategies are highly valued.

When it comes to development in the field of technology, the participants wish that there was a greater focus on solutions based on the tactile sense. They are convinced that it would benefit other groups in society than merely people with deafblindness. Experiences from people with deafblindness of technical solutions based on the tactile sense should be seen as a resource, the participants agree.

One participant shared a tactile tip from a low-vision therapist, a strategy for feeling one’s way. The discussion in the group was about the need to learn many more tactile strategies in rehabilitation.

“She told me to hold my arm out and have my palm inwards, not outwards. You should be careful with the inside of your hand, so if you bump into something, you should do it with the outside of your hand instead.”

The participants also talked about the vulnerability it entails when only a few professionals have the specific knowledge and understanding of deafblindness. This means that in the event of illness or leave, for example, it can be difficult to get good quality services and help. And services, such as getting a new hearing aid when the old one stops working, cannot wait but must be handled quickly when the vision cannot compensate. In the meeting with professionals, it is also necessary to set aside enough time, according to the participants. For example, it takes longer to learn how to use an aid when you lack sight and hearing, and you might also need to communicate via a third person, such as a deafblind interpreter.

“I was meeting this technician because I needed alerting devices for my new apartment. I had an interpreter as well as an interpreter student with me, and then two technicians came. I didn’t know who was who, and one of them was in a great hurry and spoke very quickly. And so I didn’t get a chance to see what they did. It was very frustrating, and I had to say “wait, please

slow down ... I’m trying to see what you’re doing, and it is not possible to talk at the same time”. I got angry afterwards! But then I decided that this person perhaps had a bad day.”

The participants experience that the support system can sometimes be difficult to navigate, and that there are many different parties to relate to. They describe a support system that they experience as fragmentary, and which does not always meet their needs. The participants believe that the uncertainty leads to you having to become your own expert. They also agree that there is room for improvement in different parts of the support system, when it comes to collaborating and aligning with each other, to make it possible to get the right help and services, from the right person, at the right time.

“It’s hard to define special support that revolves around tactility, there is so much and it’s really all about collaboration and the professional approach.”

Family members and relatives, as well as professionals, all need more knowledge about the tactile sense, how it works and can be used to compensate for the visual and hearing impairment. The participants reflect on the fact that there are specialists in both vision and hearing, and that the focus is usually on compensating for the visual and hearing impairment as much as possible, and often with the help of various aids. But no professionals have told them how they could use the tactile sense to compensate in different situations.

“The norm in society is to hear and see well. But we forget to talk about the tactile sense. Many professionals don’t think about how important the tactile sense is for us who have deafblindness. It’s easily overlooked. We have to break that norm.”

The group believes that professionals need to have knowledge of the tactile sense, both to be able to understand deafblindness on a deeper level, and to be able to support people with deafblindness to start using tactile strategies.

“They look at your hearing and how to improve it. The look at your vision and how to improve it. But the tactile then? Nobody talks about that. We want to stress that the knowledge exists. There are audiologist and visual therapists, but the tactile therapists ... where are they?”

Summarizing reflections

The purpose of the Tactile Transition project was to find out what the transition process to tactile strategies for people with acquired deafblindness can look like, when sight and hearing can no longer compensate for each other. The project wanted to find out and describe tactile strategies that are used and perceived as facilitating in everyday life, but also which factors in the environment hinder and facilitate the use of tactile strategies. All with the aim of increasing awareness of how people with acquired deafblindness use the tactile sense when sight and hearing are no longer sufficient, in order to use this knowledge as an important part of the rehabilitation process.

The results from the focus group interviews have been interpreted with the three models described in the report; the somatosensory system (Nicholas et al., 2019), body representation and body awareness (Galace & Spence, 2010), and the ecological system model (Bronfenbrenner, 1994). Together, these models include how the bodily tactile impressions are processed, and how one becomes aware of different sensory impressions, recognizes objects, and can locate things and places. They also include how one perceives one's own body and an awareness of how one's own body and its parts relate to the surrounding environment. The

third model describes the individual's constant interaction with the environment, from the close relationships to society's various systems. but also values, attitudes, and norms.

The results correspond well to the project's goals and objectives, but also to the three models. The participants have generously shared their experiences and they describe examples of how they have developed, and how they use tactile strategies of different kinds and in different situations. They also share the experience that sometimes this is both energy-draining and frustrating, and that it can lead to feelings of exhaustion and insecurity. The discussions in the group are also put in relation to the environment, both to the close relationships and to society at large. The participants describe how they experience that they are met by a lack of knowledge and understanding.

There is no doubt that tactile strategies are important for people with acquired deafblindness and that there is still a lot to do in deafblind-specific rehabilitation to improve the transition to tactile strategies when sight and hearing are not enough – "Tactile Transition".

The following quote from the project manager Femke Krijger (2019) will conclude this report.

**“ I hear, I see what you can't see
that is the difference between you and me
but it's not the limitations that are essential,
let us focus on the potential!**

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