

The importance of the bodily-tactile modality for students with congenital deafblindness who use Augmentative and Alternative Communication (AAC)

Kirsten Costain Schou¹, Torill Gullvik² and Gøran Forsgren³

The study of the bodily tactile contribution to language development in students with congenital deafblindness (CDB) is an emerging field (Dammeyer & Nielsen, 2013). In work with these students, the bodily-tactile modality is essential for the development of understanding, conceptual learning and cognitive abilities. For individuals with CDB, shared touch and motion with their communication partners are the primary means for attachment building, joint attention and communication (Nafstad & Rødbroe, 2008, 2015; Ask Larsen, 2013). This modality involves much more than a simplistic notion of tactility as limited to basic touch focused on the hands alone (though “touch” is in itself a vast and highly complex topic, and tactile communication involves far more than mere “hand-over-hand” signing; Buelund Selling, 2013). Rather, the bodily-tactile modality involves an eclectic, bodily approach to the whole child as a physical individual in a physical world. The physical approach also includes the residual senses (vision/hearing) and the entire body. Use of tactual signs/sign support based on elements from Norwegian Sign Language as well as haptic communication are part of, but not the full extent of this modality. Maintaining contact between the child and the physical world is essential for development of both language use and cognition. The increasing number of children with congenital deafblindness who also have additional (multiple) disabilities makes this even more of a challenge, and no less important for the adults who support and work with them.

¹ Senior Advisor, Department of dual visual and hearing loss and deafblindness, Statped Southeast, Oslo, Norway

² Statped School for the Congenitally Deafblind, Skådalen, Oslo, Norway.

³ Advisor, Statped Southeast, Department of dual visual and hearing loss and deafblindness, Oslo, Norway



School students with congenital deafblindness and AAC

Children with congenital deafblindness have, in common with other children, youth and adults who completely or partially lack functional formal language, the need for alternative and/or supplementary forms of communication in order to make themselves understood. Persons with congenital deafblindness generally have little or no understanding of what others say when communication is based solely on vocally expressed language. These people belong to the group of AAC users with differing forms of sensory loss in that they have a combined visual and hearing loss of varying degrees of severity. Although all the students have the functional description known as congenital deafblindness, there can be great variation among individuals with regard to education and training in and with AAC. Many students have motor difficulties that lead to reduced mobility and compromised movement, which in turn lead to the need for help in moving about in the world from place to place, in making use of helping aids and/or in performing motor actions and functions. At the School⁴, teaching is performed in the most appropriate communication form(s) available, adapted to the child's limitations, and with a basis in the creation of opportunities to develop functional communication and linguistic development.

⁴ Statped School for the Congenitally Deafblind, Skådalen, Oslo, Norway
(www.statped.no/spraksider/in-english)



At the School, the teachers facilitate the construction of individual and adapted solutions to these challenges with a central focus on the tactile modality, including the use of tactile reference symbols and the tactilization of signs. The spontaneous expressions in communication (viewed as possessing linguistic qualities) of the students, their way-of-being and bodily expressions in general are accorded a communicative intention by the teacher. An attempt is made to interpret these with reference to the here-and-now as well as to knowledge of the student's experiences in other arenas and in the past.

Tetzchner and Martinsen (2002) divide people with need of AAC into three main functional groups. This division is based on the function AAC is intended to have for the individual, whether in terms of a means of expression, a support language or an alternative language. Persons with congenital deafblindness will primarily belong to the *group with need of an alternative language*. Many people with combined sensory loss have residual vision and/or hearing. Those with residual hearing can develop more or less understandable vocal speech, and/or can understand the speech of others if it is supported by tactile symbols, tactile signs or pictures. It is thus possible to locate these students in the *expression support group*, or the *linguistic support group*.

In order for the students to gain access to an appropriate or most effective form of communication, the work is on two levels at the same time:

- Investigation of how the individual student can gain the opportunity to express themselves in the best possible way, and

- Facilitation and construction of an environment/arena in which all students can have the opportunity to understand and be understood.

As mentioned above, use is made of tactile signs and gestures, tactile symbols, photographs, graphic signs, objects, data-technical aids such as the Sarepta program⁵ and various iPad⁶ programs. Much time is used at the School to create communication systems and learning aids adapted to the needs of the students, as there is little ready-made material available.

In the teaching, teachers are concerned with maintaining a focus on dialogue and access to competent communication partners. These are the foundational elements in everything they do together with the students.

The bodily-tactile modality in supporting children with congenital deafblindness

Blind children with CDB are especially dependent on their partner's ability to interpret the world for them by sewing together contexts to which they otherwise do not have access, through haptic and mobility-based (among other sources) forms of information. Access to context is nevertheless a main challenge for all children and adults with congenital deafblindness. Bodily-tactile experiences with the physical world are an important part of giving them this access, and thereby helping them build up the contents of their conceptual apparatus, which can otherwise remain extremely abstract and impoverished. Through experiences with interaction between the child's physical self and the rest of the world (including the teacher/other), certain mental schema are constituted over time. These can be called *gestalts*⁷. A *gestalt* is "an organized unified whole within our experience and understanding that manifests a repeatable pattern or structure (...) experiential *gestalts* have internal structure that connects up aspects of our experience and leads to inferences in our conceptual system" (Johnson, 1987, p. 44). The manner of this constitution and inference-making for the individual is through repeated experience and embodied action on, in and from the world of physical, emotional, social and cultural experience. By bringing the physical world to the child through interpretation (based on touch and bodily

⁵ www.icevi-europe.org/dublin2009/ICEVI2009_Paper_121.doc

⁶ www.apple.com/ca/ipad/

⁷ www.thefreedictionary.com/

engagement), and information (through tactile communication forms, contexts and actions) become clarified for the child, along with the presence and roles in these contexts of other people. Tactile and bodily-tactile information can prevent the kinds of breaks or 'breaches' in action sequences and contexts that can otherwise create chaotic and haphazard experiences for persons with congenital deafblindness.



Increased bodily-tactile information increases understanding of the physical environments in which the child lives, and this understanding in turn facilitates a greater feeling of belonging within the physical-cultural context. The bodily-tactile *inclusion* (also, beyond the mere use of tactilized signs) of the person in interactional contexts can reduce feelings of isolation as well as support the agency of the person (Nafstad, 2015). Bodily-tactile inclusion means that the person is in physical contact with the context and the (co-produced) actions occurring in it in a participative bodily manner adapted to their needs and prerequisites for such participation.

Being able to understand how actions lead to results in the course of the many practical actions and tasks that comprise much of everyday life is difficult for persons with congenital deafblindness. Their inclusion in a bodily-tactile manner in such tasks and activities (instead of only or primarily being acted-upon or around by helpers) creates opportunities for the person with CDB to experience their own ability to act on the world. Agency, or the understanding that one's actions have consequences, that one can influence one's surroundings (Goldbart, 2015) is one of the most important conditions for learning. This understanding increases in accordance with the understanding of how things (interactions, actions and activities) arise and are connected in each context before they disappear again and something new is begun.

Being able to gain insight into this process through inclusion in the physical world of objects, actions and relationships in a way that is felt by the body is to *know* that one is included, rather than merely being told that one is. A crucial aspect of access to context is thus also access to participation in cultural contexts (Nafstad & Rødbroe, 2008, 2015; Ask Larsen, 2013) that are also, always, physical. This participation, then, needs to be bodily-tactile (that is, physical in the extended sense of focus on whole-body presence), genuine (the person actually *is* physically participative in the cultural activity), and engaged (part of the bodily-tactile modality is the emotions and their bodily expression).

The hands (and the body) are always there

Children with need of support systems for expression and communication often use several forms of such support. There have been great developments in the field of AAC, both in terms of access to and opportunities for choice of technical communication aids. It appears however that there are still many challenges remaining with regard to access to such aids and adequate follow-up to ensure that their use has good and lasting effect (Mirenda, 2014).

One example of such a challenge is maintenance of regular use of communication tools and systems when a child becomes an adult and moves into a residential setting. Hamm and Mirenda (2006) point out that lack of follow up of use of technical communication tools after schooling is completed is a well-known problem in the AAC field with roots in both practical and policy barriers. Several studies within the field confirm that good quality of life is equivalent to good quality of communication (Hamm & Mirenda, 2006; Lund, 2001; Slesaransky-Poe, 1997). It is also clear that even though technology can be wonderful, it cannot solve every problem (Lund, 2001, p. 108 cited in Hamm & Mirenda, 2006). Technical tools require supervision, instruction, follow-up and maintenance, and these are not always as available outside of the educational setting.

When we look at tactile communication as one of the alternatives to vocal speech, we see several clear advantages. Tactilized signs and haptic communication of information are always-available means by which to communicate, and tactile communication forms make it easier to communicate continuously and to maintain a

communicative focus in all the situations of daily life. Tactile communication is also much more than use of the hands to communicate, and includes basic touch, and the kinesthetic (movement) and proprioceptive (muscular-sensory) modalities (Buelund Selling, 2013). The tactile modality in general is also part of strengthening the person's relationships with other, more technical forms of alternative and augmentative communication. Establishing and maintaining good and consistent use of communication systems based on picture cards and other symbols for example, is dependent on the motivation of the communication partners, and follow-up is thus extremely vulnerable and individual-dependent. The hands and body are always present however, and communication accordingly is always important, regardless of absent technical support there-and-then. Communicative relations have to do mainly with communicating with persons, not systems; a bodily-tactile approach can provide physical proof of the truth of this focus, that the person with congenital deafblindness is the primary focus, and not the communication system in itself. This combination between tactile modality and other communication tools can provide an optimal solution.



Maintaining the flow in communication is based in large part on being able quickly to perceive and understand, answer and engage oneself as a communication or support partner in communication with other people, and this is even more important in communication with people who have little or no formal language. A bodily-tactile approach provides many opportunities for quick response and confirmation of the person as a communicative being. Body language that has meaning for

communication partners, both those with and those without congenital deafblindness, can include everything from eye-blinking to positioning of the whole body, pointing with different parts of the body including the hands, and all forms of movement and acceptable bodily contact between the parties. A rich register of possibilities for interpretation and communicative contact with the person with congenital deafblindness can be revealed if the partner takes a diverse and varied approach to communication and understanding based in the bodily-tactile modality.

Face-to-face communication is always vulnerable and must be borne through the frequent difficulties and breaches, lack of understanding, misunderstandings and other challenges that are common for all communicators but especially challenging in the case of congenital deafblindness. It is the intention of the communication partner expressing towards the person with CDB, to communicate, understand and most importantly, to see the person as a worthy subject, that keeps communication moving. This intention, when expressed well, makes the partner appear to be one who listens and tries to follow the person's expressions rather than one who is primarily a decoder (Nafstad, 2015). Through listening and following expressions also in a bodily-tactile manner, even without understanding them, the partner provides acknowledgement that the bodily and bodily-symbolic expressivity of the person with CDB *is* the person's own voice (Nafstad, 2015). One who experiences themselves as seen and treated as a worthy and communicative subject can more easily tolerate difficulties and setbacks in communicative situations, and can more easily stand in the tension between being self-directed and being directed toward the other, even when the distance between these different perspectives is great (Nafstad, 2015).



Not one or another, but all means of communicative practice

For the communication partner of a person with complex communication needs, it can be very easy to worry over not being faithful to or disciplined enough with regard to the use of one or several main communication tools or systems, such as pictures, graphic symbols, tactile reference objects, voice synthesis and so forth. It can also be the case that the goal that supportive others have for the child, of acquisition of a formal cultural language, locks communication with the person to a more or less exclusive focus on, for example, formal cultural tactilized signs. It is in any case clear that people with CDB have need of several information channels as the distal senses are lacking or severely limited, and that the tactile sense in the broadest sense is the most primary of all the sensory channels (Nafstad & Rødbroe, 2015). Studies of language acquisition have begun to focus to an increasing extent on multi-modality in language-in-use: that is to say, away from a one-sided focus on (so-called) verbal language, and toward a focus on the multiplicity of linguistic *practice*, in which also body use and prosodic (rhythmic, sound) elements are involved (Dufva, Aro & Suni, 2014). Language is not so much acquired as lived in and through and as such is part of our embodied being in the world. The bodily-tactile perspective must not be viewed as in any way incompatible with the use of augmentative and alternative communication systems, but rather as part of the rich repertoire of linguistic-communicative practice in which such systems participate.

The bodily-tactile modality is a bridge-builder between several communication forms and channels. In addition, it creates a continuity in the experience of the person with

CDB of the presence of partners, and of being an integrated part of a physical and social context. Thus, a basis in a bodily-tactile approach along with a meta-perspective about what communication is, liberates partners to respond in a fluent way with touch and movement in a communicative dance with the person with CDB. Bunning (2009) states that “communication concerns two or more persons working together and coordinating their actions in a continued attempt to respond *to one another and to the context.*” (p. 48). Further, it can “(...) be intentional or unintentional, involve conventional or non-conventional signals, take linguistic or non-linguistic forms and occur through spoken or other modalities.” (p. 48). This broader perspective on communication can support the partner in maintaining a general bodily-tactile way of being with people with CDB. Making use of haptic and tactual signs in a playful manner, for example, when singing a well-known song or rhyme is a good way to build on and make a routine activity more interesting, and is something that can have significant impact on language development. Use of tactile sign support in addition to visually perceived sign language and vocally expressed language (when these are part of the flow of communication) does not need to distract from or undermine the other modalities. When distal sensory channels are weakened to the extent they are in CDB, any addition channel is likely to have a strengthening effect on understanding in communication rather than being a distraction. A more spontaneous use of bodily-tactile modes of communication and remaining in touch in the course of communication and participation can support other modes during their use.

Lastly, but no less importantly, supporting through the body-tactile modality should never be confused with creating dependency, or depriving the person with CDB of the opportunity to move out into the physical-social and cultural environment on their own. Through taking a bodily-tactile approach to, for example, mobility training, the person can be introduced to the physical environment and the task of moving herself around in it through application of techniques, and gradually move toward greater independence and spontaneity in this movement. In addition to enlivening the teaching of mobility, a bodily-tactile approach to this teaching combines learning the *techniques* involved in this skill with the kind of embodied phenomenological accompaniment of the person by the partner that underscores the primacy of the *learner* herself in the learning. Part of both learning and motivation for learning is

being able to understand the reason for learning something. The bodily tactile modality can be used to show the function of skills enactively as the partner provides a bodily-tactile scaffold for learning which demonstrates their purpose at the same time as modelling the skills in an immediately relatable way to the learner with CDB. Ultimately, the central reason for learning skills and developing competencies is access to opportunities for a richer experience, and a richer quality of life.



Conclusion

With the condition that there are sound intentions and respect for the person's own boundaries, a rule of thumb for the partner is that it is not possible to make mistakes in the attempt to make contact and come into a communicative position with a person with congenital deafblindness.

Having a playful and open relationship to the bodily-tactile approach is part of supporting communicative competencies under development, and contributes to keeping the focus on the communicative project. It provides emotional and moral support (through showing and being a concrete experience of inclusion) as well as the experience of confirmation of oneself as a communicative *subject*, a person with communicative intentions and aims. This experience is fundamental to the maintenance of the motivation to learn, and to use language. The bodily-tactile modality is a foundation for relations with persons with CDB and is part of the unification of the often fragmentary or dissolving and, sometimes, chaotic experiences such persons have in meetings with a primarily seeing and hearing

world. As such, it is of great importance for communication and continuity, both for persons with CDB and for their seeing and hearing partners.



References

Ask Larsen, F. (2013). Acquisition of a bodily-tactile language as first language. In J. Dammeyer and A. Nielsen (Eds.), *Kropslig og taktil sprogudvikling*, Aalborg: Materialcentret, pp. 91-119.

Buelund Selling, H. (2013). Tactile communication is more than visual sign-language hand-over-hand. In J. Dammeyer and A. Nielsen (Eds.), *Kropslig og taktil sprogudvikling*, Aalborg: Materialcentret, pp. 177-188.

Bunning, K. (2009). Making sense of communication. I J. Palwyn og S. Carnaby (Red.), *Profound multiple intellectual disabilities: nursing complex needs*. London: Blackwell.

Dammeyer, J. & Nielsen, A. (Eds.) (2013). *Kropslig og taktil sprogudvikling (Bodily-tactile language development)*. Aalborg: Materialcentret.

Dufva, H., Aro, M. & Suni, M. (2014). Language learning as appropriation: how linguistic resources are recycled and regenerated. Lintunen, P., S. Peltola & M.-L. Varila (Eds.) 2014, *AFinLA-e Soveltavan kielitieteen tutkimuksia 2014/n:o 6*, 20-31.

Goldbart, J. (2015). Forelesning: Pre-intentional and early intentional communication intervention. ISAAC Norge, 12. nasjonale konferanse 13 – 15 april.

Hamm, B. & Miranda, P. (2006). Post-school quality of life for individuals with developmental disabilities who use AAC. *Augmentative and Alternative Communication*, 22:2, 134-147.

Johnson, M. (1987). *The body in the mind: the bodily basis of meaning, imagination, and reason*. Chicago: The University of Chicago Press.

Lund, S. K. (2001). Fifteen years later: Long-term outcomes for individuals who use augmentative and alternative communication. *Dissertations Abstracts International* (UMI No. 3036075).

Mirenda, P. (2014). Revisiting the mosaic of supports required for including people with severe intellectual or developmental disabilities in their communities. *Augmentative and Alternative Communication*, 30:1, 19-27.

Nafstad, A. V. (2015). Communication as cure: communicative agency in persons with congenital deafblindness. *Journal of Deafblindness Studies on Communication*, 1, 23-39.

Nafstad, A. V. & Rødbroe, I. B. (2015). *Communicative relations: interventions that create communication with persons with congenital deafblindness*. Aalborg: Materialcentret.

Nafstad, A. V. & Rødbroe, I. (2008). Kommunikative relasjoner: Innsatser der skaber kommunikation med mennesker med medfødt døvblindhed. Aalborg: Materialcentret.
Slesaransky-Poe, G. L. (1996). *Consumer Survey on Communicative Effectiveness*. Unpublished manuscript, Temple University, Philadelphia, PA.

Tetzchner, S.V. og Martinsen, H. (2002). *Alternativ og supplerende kommunikasjon: en innføring i tegnspråksopplæring og bruk av kommunikasjonshjelpemidler for mennesker med språk- og kommunikasjonsvansker*. Oslo : Gyldendal akademisk.

For more information, contact Kirsten Costain Schou (kirsten.schou@statped.no)