Beyond the Common Touch Point: Communication Journeys with Congenitally Deaf-Blind People

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Abstract

This article explores attitudes and approaches that should influence our practice when developing communication and language in partnership with congenitally deaf-blind people. Perhaps there has been a historical overreliance on objects of reference and signifiers simply as instrumental message systems, leading to a subsequent rejection of the communicative strategies that are literally at the fingertips of the deaf-blind person. So this article focuses on the notion that it is always at the meeting place between individuals that solutions to communication breakdowns must be sought. This sets three challenges for communication partners: recognize the potential of the other, think of congenital deaf-blindness as a positive state, and step into relation with deaf-blind people. The article concludes with an exploration of what this means for communication and language development and suggests a number of publications that are worthwhile exploring in more detail.

Keywords: communication and language, tactile, congenital deaf-blindness, partnership

Hope

I sit waiting
For someone to come and take me
For my outing
I know where I want to go
Do they?
How can I tell them
That I want to walk to the top of a hill
To feel the wind
Smell the trees
Touch the bark and the leaves
Not go swimming in a crowded pool.
All week I've worked
Doing what they tell me every minute
I haven't banged my head or made a fuss
But now I might
Sometimes it's the only way
To make them see
That I want to be myself
They're coming!
What will be put in my hand?
My swimming bag again?
Oh Joy! My walking boots.
This time they've understood
My gestures and words
Why don't they always understand
What I tell them?

This poem was written by Sheena Tulloch (1995), the mother of a congenitally deaf-blind man. It suggests a number of attitudes and approaches that should influence practice when developing communication and language in partnership with congenitally deaf-blind people. For example, this mother has faith that deaf-blind people do have thoughts and

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hopes, and these thoughts are independent of language. There might be barriers in sharing these thoughts with another person, but nevertheless sharing them is the goal. It is particularly difficult to share attention to objects, events, people, and places that are not actually present at that time, and in attempting to move away from the here-and-now, perhaps there are hints of a historical overreliance on objects of reference and signifiers simply as instrumental message systems (Hart, 2006; Rødbroe & Souriau, 2000), leading to a subsequent rejection of the communicative strategies that are literally at the fingertips of the deaf-blind person. This may lead to communication breakdowns at the level of the partnership, and indeed frustrations may often boil over into challenges for both people in the relationship. However, the poem also highlights that the world can be rich, exciting, and full of wonder and awe if perceived through the tactile medium. Finally, if gestures and words can be seen as equal to one another, then this points to ways in which effective communication partnerships can be established.

This article explores these attitudes and approaches, with a particular focus on the central importance of partnership between congenitally deaf-blind and non-deaf-blind communication partners. It is always at the meeting place between individuals that solutions to communication breakdowns must be sought (Hart 2008a, 2008b; Nafstad & Rødbroe, 1997, 1999). This sets a number of challenges for communication partners that are explored before a final consideration of what all this means for communication and language development.

Partnership Is Centrally Important

We all learn language in social situations (Rosenthal Rollins, 1999; Trevarthen, 1980, 1998), and this is equally true of deaf-blind people (Hart, 2006; Janssen, 2003; Nafstad & Rødbroe, 1999; Rødbroe & Souriau, 2000). If there have been historical challenges for congenitally deaf-blind people in learning a language, the burden of responsibility should not any longer be placed on the deaf-blind person alone, but practitioners should instead look at the nature of the partnerships that exist. When thinking about communication or language between humans, it makes no sense to simply consider one side of the exchange without reference to the other (Linell, 1998; Markova, 2006, 2008; Reddy, 2008).

The communication partner may already be skilled in at least one language, but the deaf-blind partner is not necessarily so. However, the deaf-blind person is skilled at perceiving the world from a tactile perspective, whereas the communication partner is not necessarily so. It is clear, then, that both partners have something to learn from the other, and this raises questions addressed to both. How can they learn to perceive the world from the other's perspective? How can they learn about the other's communication and language and shape their experiences into communication and language that they both understand? This may even allow them to move toward tactile languages, what some have affectionately and speculatively termed "deaf-blind-ish" (Nafstad & Ask Larssen, 2004). Perhaps these tactile languages will allow congenitally deaf-blind people and their communication partners to draw on one of language's most important functions, that is, being able to make reference to displaced objects and events that are not present at that time (Goldin-Meadow, 2005), what Reddy (2003) describes as "things external in space … (and) events distant in time" (p. 398). In turn, this means that they can journey together, away from the here-and-now to where "new worlds beckon" (Zeedyk, 2006, p. 330).

This is not straightforward, however, and a number of challenges arise for non-deaf-blind communication partners in terms of attitudes and approaches:

- Recognize the potential of the other
- Think of congenital deaf-blindness as a positive state
- "Step into relation" with deaf-blind people

Recognize the Potential of the Other

First of all, it is crucially important simply to recognize the communication and linguistic potential of all congenitally deaf-blind people. Partners must believe that the congenitally deaf-blind person has the potential to become an equal communication partner and can move beyond the here-and-now. Here is an example that has been used many times before (Hart, 2001a, 2001b, 2008a; Hart & Noble, 2002, 2003), but it is used again here because it

helps clarify the way that the author's thinking has developed over the intervening years. During the first meeting between Fiona, a deaf-blind woman, and her communication partner, Paul, in April 2000, there is a communication breakdown. At the start of their interaction, a small lotion bottle is placed onto Fiona's tactile day planner, and it looks as if they have agreed to participate in a massage session. About a minute into the session (with Paul massaging her feet), Fiona takes Paul's hand toward her stomach. Paul briefly touches her stomach but feels uncomfortable about doing this and so withdraws his hand and starts to massage her foot again. On two further occasions, Fiona takes Paul's hand toward her stomach, and both times he pulls his hand back, partly because he is unsure what she is asking for. Instead, he brings the bottle of massage lotion toward her so that she can smell it while at the same time he is touching her foot. He thinks he is offering to continue massaging her feet, but from her perspective she has had her request for a stomach massage turned down, and her immediate response is to curl up on the chair, although she does not push Paul away. This is a breakdown in their negotiation about what type of massage is to take place. Maybe she is thinking of other massages she has had in the past and is trying to alert Paul to what she wishes to happen now. However, Paul is focused entirely on a foot massage. On initial analysis many years ago, this was considered an example of ineffective practice: Paul was clearly not responding to Fiona's request, and he was not able to follow her attention to previous massages she has had.

However, there is more to the interaction than just those early moments. Although it looks as if Fiona is withdrawing from the interaction, it is important to remember that she did not push Paul away, so he does not go away. Instead, he begins a regular slow rhythmic pattern onto her body, tapping first her foot, then her ankle, knee, and lower back and up to her shoulders, all the while returning to her foot. He repeats this pattern many times over the next 10 minutes, and eventually Fiona tentatively wiggles the toes of her foot. She then lifts her foot from under her curled-up body and presents it to Paul. There then follows an excellent 15-minute communicative interaction where she wiggles the toes of one foot, then the other. Often she moves attention from one foot to another, and all the while Paul responds by tickling whichever foot she has moved. In this way, trust is re-established between them.

It is clear that Paul recognized Fiona's action of curling up but not pushing him away as part of the ongoing negotiation between them about what kind of massage should take place. Both of them are still trying to work out what the other is wanting, and their temporary communication breakdown gave them a chance to learn new things about each other (Linell, 1998). It is interesting that it was a foot that Fiona first presented to Paul, and maybe this is an indication that she has learned he is not the kind of partner who feels comfortable massaging stomachs. For his part, Paul learned a way to introduce himself to Fiona, and for many months afterward, every time he met her, he would start with a slow rhythmic pattern, starting with her fingers, then hand, wrist, arm, elbow, and finally shoulder. This became part of a greeting and good-bye ritual between them.

Reconceptualize Deaf-Blindness

Communication partners should conceive of congenital deaf-blindness not as a negative state where there is a lack of vision and hearing but instead as a positive state where touch is someone's principal source of contact with the external world. Sacks (1995) suggests that "when we open our eyes each morning, it is upon a world we have spent a lifetime learning to see" (p. 108). For congenitally deaf-blind people, in contrast, when they stretch out their hands each morning, it is on a world they have spent a lifetime learning to feel. It is touch that keeps congenitally deaf-blind people in contact with the world.

It is easy to slip into the trap of imagining that the world for congenitally deaf-blind people is not so colorful and full of interest and must therefore be a dark and lonely place (Hart, 2008b). However, that is simplistic and possibly inaccurate. Instead, there is an alternative view from an American thinker and teacher, Barbara Miles (2006), who imagines that within a glass "there is an entire landscape for a deaf-blind child." Experienced from the perspective of a tactile "outfeel" (as opposed to outlook) on the world, it is not difficult to realise the possibilities for wonder and awe in such everyday objects (Hart, 2008b).

I recall watching how a 2-year-old (seeing–hearing) toddler showed emotional expressions throughout his entire body. If, for example, he tasted a food that he did not like, then his whole body from the tips of his toes to the top of his head demonstrated his disgust with a highly emotional shaking of his body. If he was particularly excited about something, again the length of his body showed everyone else what he was feeling. Such reactions are seen regularly with deaf-blind people, including deaf-blind adults. For example, as Serge interacts with Anne and Inger in a game of clapping (Daelman, Nafstad, Rødbroe, Visser, & Souriau, 1996), when his excitement grows, he moves the entire upper half of his body, and within a few minutes of this interaction starting, he is jumping up and down in a real outward display of emotion. On the same video, when Thomas gets excited as he feels the plastic tunnel that his teacher is inside, he shakes his entire body, and viewers can see his high level of excitement. Perhaps these capacities still rest within all of us and in communication partnerships with deaf-blind people, we should bring them to the forefront. We know, for example, that at moments of bereavement, an entire dictionary of words could not capture the feeling of loss, devastation, and hurt quite as well as a hug. Or if you have been separated for a long time from a loved one, touch will often come before words and can more easily tell about the love and care that you have for each other—even in cultures as defiantly resistant to touch as Scotland. Miles (1999) provides an excellent account of understanding all that is possible if you use touch as a way of experiencing the world around you, and she provides expert guidance on developing this skill for both communication partners, deaf-blind and non-deaf-blind.

"Stepping into Relation" with Deaf-Blind People

To make the task of understanding the world from the perceptual experience of a congenitally deaf-blind person easier for us as communication partners, instead of understanding *deaf-blindness* as something wholly different from my experience, communication partners must understand the *deaf-blind person* as someone very similar to them. That makes the gap between their experience and the experience of a congenitally deaf-blind person much smaller, and that gap can be crossed by "stepping into relation" with one another, thus contributing to the full revelation of each as a unique person (Buber, 1996). He suggests this leads to "I–You" relationships, which are open, direct, and mutual.

Stepping into relation with others means not seeing the other as an "It"—an object, a client, a service user—but seeing the other as a "You"—a human, a person. Communication partners must bear in mind that if it is through relationships that they get fully revealed, then the flip side is true also. If there are people they struggle to connect with, this must diminish them and prevent them being fully revealed. This has profound implications for all human interactions but especially professional boundaries because it asks practitioners to always treat the other person as an equal, and in my professional experience that does not happen nearly as often as it ought to. This relates to Brown's (2001) idea of teachers as "co-learners," where teachers learn just as much as their pupils do, or, to put it another way, pupils teach just as much the teacher does.

Where Next for Language Development?

So what does all of this mean for the acquisition of language? Traditionally when thinking about communication and language development, we imagine learning the language used by others in the wider cultural community. So, for example, in Scotland we may think about how young children make the journey to being a native English speaker. Or if the child is profoundly deaf and raised in a signing environment, we may think about how they journey toward British Sign Language. Such developmental models are insufficient to describe how congenitally deaf-blind people might journey toward language, especially if we bear in mind that any person learning a language needs the perceptual abilities to perceive the language(s) around him or her and needs to learn from people who already are fluent in the language(s) (Vonen, 2006). This presents a significant challenge for congenitally deaf-blind people. They do not have the perceptual abilities to learn spoken or even visually signed languages because of their hearing and visual impairments. But neither can they find communication partners who are fluent

in tactile communication because none truly exists.[1] So an alternative model is required.

The partnership model considered in this article suggests that both partners should bring their complete selves to communicative exchanges. It is appropriate, then, for communication partners to find creative ways of making sure that their own cultural and linguistic experiences are brought to communicative meeting places with congenitally deaf-blind people. For example, this might mean making tactile adaptations to visual sign language. Miles (1999) and Miles and Riggio (1999) are helpful in this regard. However, if that is all communication partners bring, it is going to be a one-sided affair. They must also rise to the challenge set by Lane (1999) to find ways to reorganize their daily interactions "that are attuned to vision and hearing so that they become attuned instead to touch." People, events, objects, and places should not simply be understood from a seeing–hearing perspective and referred to in the partner's language but should understood and referred to from a tactile and bodily perspective. This means incorporating Bodily Emotional Traces (BETs) used by the congenitally deaf-blind person—movements, actions, and gestures remembered alongside the emotional content of an activity that lay the foundations for negotiated, shared meaning between congenitally deaf-blind people and their partners (Daelman et al., 2002; Gibson, 2005). For example, imagine a deaf-blind is child playing at the water's edge with his mother. He is having fun as he repeatedly splashes his hands in the sea. Later that same day, when back home sitting at the dinner table, he repeats this "splashing" gesture. Is he thinking about his fun time at the beach with his mom? The DVD *Traces* (Vege, Bjartvik, & Nafstad, 2007) shows excellent examples of BETs when Ingerid recalls many gestures from the time she was at the seaside with her teacher and a crab ran up her arm. Such movements, actions, and gestures coming from the deaf-blind person must also be incorporated within communicative meeting places.

[1]It is true that some deaf sign language users who later lose their vision do use very complex and sophisticated tactile sign systems, but these are based primarily on adaptations of their first sign language as opposed to being fully tactile throughout its development.

Recently, colleagues in Europe have produced a series of theoretical and practical booklets (Janssen & Rødbroe, 2007; Rødbroe & Janssen, 2006; Souriau, Rødbroe, & Janssen, 2008, 2009) that outline such a developmental process. This starts with harmonious interactions (Janssen, 2003), first within dyadic interactions before expanding to include objects and events in the external world, then onto tactile gestures emerging from bodily emotional experiences (BETs), and finally onto the challenge of exposure to wider cultural languages within the tactile medium.

In conclusion, if partnerships involving congenitally deaf-blind people are to move away from the here-and-now and they are to develop language, it is insufficient for communication partners simply to lead the deaf-blind person to their language destinations. However, it is insufficient also to imagine that language will emerge only from the movements and gestures brought by the deaf-blind person. Instead, any new tactile languages will have elements of existing linguistic culture (signed and spoken), but they must primarily reflect a tactile perspective on the world. The field of deaf-blind education has reached an exciting point in its history, and around the world such ideas are now being described in practice (Ask Larssen, 2007; Souriau et al., 2009; Vege et al., 2007). It is at the level of partnership that languages will emerge and within these partnerships referential movements, gestures, and signs, brought by either partner, become the starting point for journeys away from the here-and-now.

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