

ARTICLE

Potential for Communication in Individuals Who Are Congenitally Deafblind: It's in the Eye of the Beholder

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Introduction

The cognitive system predominantly uses two senses in order to take in information from the environment: vision and hearing. These distance senses allow the mind to access information about the world without making direct contact with objects within the environment and play an important role in communication and the acquisition of language. Auditory access to speech sounds (phonemes) is key to early language comprehension and production. Vision also supports language processing and communication. We use visual cues such as facial expressions, facial movements and gestures to make sense of much language (e.g., Harris, 1992). Infants rely on vision for access to social precursors to language. For example, visual cues may allow shared attention between parent and baby, signal turn-taking or confirm mutual understanding. These visual cues support communication long before language itself is acquired and much communication is guided via the visual and auditory processes. The availability of visual and auditory stimuli is therefore assumed, to a great degree, in early adult-child and child-child interactions.

The child with significant visual and auditory deficits, as associated with congenital deafblindness, faces immediate and lasting disadvantages that affect the potential for language. From the very beginning, there

is a "mismatch between the immediate behaviour repertory of the congenitally deafblind child and the reactive behaviours of the adult partner" (Nafstad & Rødbroe, 1997), and this mismatch is arguably more significant than the sensory deficit itself in the attempt to acquire language (see Hart, 2008). Overcoming this mismatch is a key objective of communication strategies for deafblind people. As Hart (2006) reminds us, "All congenitally deafblind people are potential communication partners. The key question ... is how to help them achieve that potential" (p. 264).

The current paper argues that the potential for communication is in the eye of the beholder. The recognition of non-typical communicative attempts for their communicative potential is crucial if we are to repair the mismatch of expectations noted by Nafstad and Rødbroe (1997) and appreciate the meaning of behaviours for the deafblind person. In the absence of a formal or agreed system, communication needs to be established on the terms of the deafblind person. This is problematic in and of itself as, without an agreed meaning, behaviour is open to interpretation. The meaning of a social action (including sign or speech) is "systematically related to some agreed-on definition of what is going on between participants in a social scene" (Ninio, 1991,

p.3). Such meanings are quickly established for those acquiring speech within a verbal community, informed by a large and well-established social network. While there is a need for negotiation of the meaning of early utterances based on context (requiring a so-called "rich interpretation" of a child's speech; see Bloom, 1970), agreed upon meanings are quickly conveyed via speech and visual cues, so that the sighted and hearing child's behavioural repertoire matches their parents' expectations. The deafblind child resides in a much "smaller culture". As Ask Larsen (2007) notes: "While natural languages are imbedded in large cultural networks providing a large vocabulary and a stable grammatical structure, the languages of [congenitally deafblind] children are only imbedded in very small cultures" (p. 10).

The Social Basis of Language

All language initially emerges from social interaction between infant and caregiver (e.g., Bruner, 1975a, 1975b) and knowledge about words and how they are used derives from early social experience (Bruner, 1983; Halliday, 1975; Harris, 1992). Much of the early communicative attempts of infants are non-conventional (Bruner, 1983; Halliday, 1975), with the child gradually adopting the conventions of the parents. In pre-lingual children, early gestures tend to be idiosyncratic (Marschark, 1994) and they represent actions; therefore, embodiment is key to their form. Early gestures of typically developing children have been shown to represent objects based on experiences of actions performed with objects (e.g., Acredolo, Goodwyn, Horobin, & Emmons, 1999), while later gestures come to be based on perceptual qualities of objects (Marschark, 1994).

In early interactions, routines between adult and child establish expectations that will support the adoption of a conventional form. Such routines are initially non-verbal, but they establish patterns of turn-taking, shared attention (and inter-subjectivity) and imitation

that will later support verbal communication. Such behaviours lay the foundations for language and the *expectation* that this will follow plays an important part in development. Snow's (1977) "conversational hypothesis" of early mother-child interactions, based on her longitudinal study of two children from infancy, recognises the role of expectations around language. She noted that mothers used the type of simplified speech referred to as child-directed speech (or, at that time, "motherese") long before the child was capable of understanding it or responding appropriately. She suggested that the mother's *expectations* regarding the child's ability to communicate influenced the language directed to the child so as to promote communication.

Behaviour is adjusted for the child with a sensory impairment. Cross, Johnson-Morris and Nienhuys (1980) noted more simplified speech in mothers' interactions with children with a hearing impairment, while Harris (1992) found that deaf mothers were more likely to sign when their deaf child was making eye contact. Research showing advantages for deaf children of deaf parents over deaf children of hearing parents supports this role of parental expectations about communication (e.g., Kampfe & Turecheck, 1987). Infants, too, have expectations about parental responses, and adjust their behaviour accordingly. For example, an infant's behaviour changes when a parent looks away (e.g., Trevarthen, 1975). Interactions with a congenitally deafblind child must be carefully negotiated if the expectations of the child and the caregiver are to be matched.

What is Deafblindness?

Deafblindness involves substantial impairment of both vision and hearing and is sometimes referred to as dual-sensory or multi-sensory impairment. The degree to which each of the senses is impaired differs from person to person; the term covers a range of combinations of varying degrees of vision and hearing loss. At one end of the continuum is a total loss of vision and hearing, while at the other end residual vision or hearing, or some residual facility in both senses, is possible. In all cases, the hearing and visual impairments occur to a degree that precludes compensation for the weaker by the stronger sense. In other words, the person cannot function as someone who is deaf or as someone who is blind. Some people who are congenitally deafblind will be able to use their residual sight or residual hearing to support communication. Residual sight allows someone to use picture cues and visual signing, while those with residual hearing may benefit from audio language augmentation devices and may be able to hear and use some vocalizations. The communication strategy employed must therefore be tailored to the individual according to their particular abilities and indeed their communication preferences.

The pattern of visual and hearing deficit varies further with aetiology and some causes bring additional physical or neurological complications. The resulting heterogeneity has limited research in this area (Ronnberg & Borg, 2001). Deafblindness can be acquired or congenital in origin. The implications in terms of prospects for language, social development and functioning differ in these groups, as do the

associated needs. Some common causes of congenital deafblindness include premature birth, pre- and post-natal trauma, and viral infections such as rubella. Acquired deafblindness occurs when a person becomes hearing and visually impaired during childhood or in adulthood. By contrast, individuals who are congenitally deafblind are hearing and visually impaired from birth or early childhood. The opportunities for acquiring communication skills are severely limited for this pre-lingual group. Early attempts at communication may be idiosyncratic and may be discontinued if they do not predictably lead to responses. The passivity often associated with deafblindness brings further challenges (e.g., Marks, 1998). Pre-symbolic gestures and body movements, which may be an attempt at communication, might not be readily interpreted as such. Not leading predictably to a response, these behaviours will not survive to evolve into more abstract forms. Where use of symbolic forms (e.g., Braille or sign language) occurs, it is generally limited. Without early intervention and stimulation, the isolation experienced in the early years may have a lasting negative impact on the potential for language and communication. This presents unique challenges for the deafblind person, for their families and for professionals providing educational and support services.

Strategies for Communication: Some Case Examples

Although specific challenges face each deafblind person in his or her efforts to acquire language, educational strategies have been developed to facilitate

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communication and language. Hart (2006) provides a useful historical overview of the progression of thinking around deafblind education. Until the 1950s, emphasis was placed on the role of the teacher in conveying knowledge about the world to the deafblind child. From the 1950s to the late 1980s, efforts to support communication came to be increasingly based on emotional bonding and related interactive routines. During this time, a focus on the acquisition of a symbolic language system came to the fore. As Hart (2006) notes, the methods used at this time aimed to bring the deafblind person's communication methods into line with the expectations of the seeing and hearing world. The use of tactile calendars, for example, appeared at this stage, and was found to be useful in communicating a basic schedule. However, declarative communication – that is, communicating one's own experience to another person – was rarely observed (Hart, 2006).

In the 1990s the focus returned to the strategies for communication that might be favoured by the deafblind individual, with attention turning to co-activity, imitation and response contingency (Hart, 2006). Educational strategies for promoting communication support an individualised approach (Chen & Downing, 2006; McInnes & Treffrey, 1982; Nafstad & Rødbroe, 1999; Van Dijk, 1986). There is a need to be amenable to the use of many different methods of communication, such as gestures, sign language and tactile signs, tangible "objects of references", or even speech, as suits the individual, and to take an open-minded approach to the atypical ways in which signs and symbols might be employed.

Formal sign language systems such as Irish Sign Language for the Deaf (ISL) provide some signs that can be adapted for use by deafblind individuals. The Language Augmentation for the Mentally Handicapped (LAMH) with communication difficulties system adapts signs for simplified representation of an activity or object using simple hand shapes and gestures. If the deafblind person has

or had residual sight, he or she may sign for vision. In tactile signing, or hand-over-hand signing, the person who is signing holds their hands under the hands of the person they are communicating with, so that the signs can be perceived. Signing can also occur co-actively, that is when sign language is assisted by a communicative partner. This is often used to teach a new sign, for example. Turn-taking can be established in a number of ways, such as by hand holding, using a resting position or tapping the non-dominant hand of the signer (Frankel, 2002) and turn-taking signals will vary across individuals. Back-channelling signals (or response tokens) also vary. In spoken language, back-channelling occurs in a number of ways, signalling interest and providing feedback to speakers. For example, we might nod the head to signal understanding or say "yes", "right" or use non-lexical utterances such as "yeah" or "uh-huh" (Ward & Tsukahara, 2006). These tokens occur at predictable junctures in a conversation as prompted by a speaker's prosody or by other cues.

A deafblind person may use a number of methods to convey and receive such feedback. For example, repetition of a sign or maintaining the hold of a sign may be a request for back-channelling (Frankel, 2002). Colin, a deafblind man with whom the first author has worked over several years uses a "hand-contact" method to ensure that the person is still attending. Colin signs with one hand while maintaining contact with the other person with the hand that is closer to that person. He often therefore signs what ought to be two-handed signs using just one hand, so as to maintain contact with the other hand. He may be using this contact in a similar way to the sighted person using eye contact. By contrast, a deafblind girl whom we have worked with, Amy, uses repetition and imitation within a signed routine to aid turn-taking. Amy has some residual hearing, such that, with hearing aids, she can benefit from vocalised feedback. She had acquired some early signs when, several years ago (at about the age of 12 years), Amy's parents

and teachers noted her use of a short routine-like sequence of signs, which appeared not to be relevant to the current context. For example, she would sign on greeting someone, or on coming home from school. The sequence of signs translated to: TEA-BISCUIT-TEA-BREAD-SWIMMING-OK. At one stage Amy was producing this sequence 30 to 40 times a day, across a range of contexts, and at school as well as at home. As use of the routine continued, Amy began to use verbal feedback from her communication partner (e.g., parent, teacher) as she signed, waiting for someone to say the sign before she continued (her residual hearing allows her to make use of verbal responses to these signs). In this way, the communication partner imitated (or repeated) verbally what Amy had just signed.

Over a 12-month period in a research project funded by the National Council for Special Education, we conducted regular visits to Amy's home and school in order to document the development of this sign routine by video-recording and analysing Amy's use of it in a variety of contexts. Initially, the short core routine of six signs was produced, but it was already apparent that the imitation provided by another person repeating back the sign (verbally) was key to the interaction for Amy. Particularly when using the routine with her mother, Amy seemed to be using it as a ritual to introduce an imitative interaction. She would begin by signing the sequence until she got her mother's attention. She would then wait on her mother's imitative response to each sign before continuing with the sequence. On one occasion, her mother mistranslated one of the signs. Amy re-signed it until her mother imitated/"translated" it correctly, and it was only after she had that response that she continued with her routine.

This repetition of the sign until it is understood suggests intentionality as well as flexibility to adjust responses within the routine. Amy's persistence until her mother imitates her appropriately shows that she is acting with the intention of eliciting an appropriate response (Bruce, 2005a). She wants

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to be understood even if at this stage the sequence of signs is not in and of itself particularly meaningful. The rapport and the responsiveness of her communication partner are salient to her. Amy's mother shows sensitivity to Amy's behaviour, and she produces a timely, contingent and predictable response. These three factors form the basis for successful interactions identified by Siegel-Causey and colleagues in research on communication between mothers and their deafblind babies (e.g., Siegel-Causey & Guess, 1989). Over time, Amy's routine grew to include new signs and even showed some early grammar, with some pivot-open sequences embedded in the routine. This example also illustrates the role of imitative sequences and routines in stimulating further communication. Imitation has been identified as a key developmental milestone that supports development of the abstract representation that underpins language (Bruce, 2005a). Hart (2006) notes the role of imitation in teaching turn-taking, attracting attention and providing a "powerful mechanism for obtaining, sustaining and even regaining interpersonal togetherness" (Hart, 2006, p. 268). Imitation supports a joint dyadic space (Rødbroe & Souriau, 2000), which in turn will re-align the mismatched expectancies of adult and child that constrain early communication with a deafblind child.

Non-formal signs can also be adopted into an agreed vocabulary and may be easier to use than formal signs. A type of "home-sign" that we refer to as "adaptive signs" are signs that are agreed upon by family members or individuals who work with the deafblind person, as opposed to items from a formal system. These signs emerge through use and differ from agency to agency, or

from family to family. They can undergo modification with use and may involve transformation of a formal sign, altered so as to be easier for the deafblind individual to understand. They are often selected because they are closely connected to an activity and might be easily associated with that activity. These signs usually involve a motor re-enactment of the activity. For example, a "music class" might be communicated via the use of a drum, or by the action of banging the palm of one hand with the index finger of the other. Adaptive signs are not unique to one individual but are based on an interpretation of what individuals (teachers, care staff or family – not necessarily the deafblind person) perceive the activity to be. These adaptive signs follow close observation of the deafblind person when engaging in an activity and successful use will depend on their salience for that person. The cues that might be selected by someone with sight and vision might not be those that would be selected by the deafblind person (Bruce, 2005b, on the role such cues play in distancing).

Natural gestures are specific to an individual and re-enact an experience with the body (Robbins, 1983). A natural gesture comes from the deafblind individual's own activity and becomes a gesture through use. It is important to remember that someone who is deafblind may not represent the same aspects of an event a sighted hearing person would. Perceptions are based on direct contact with or impressions on the body (Nafstad & Rødbroe, 1999). Any of a number of salient features of bodily experience might become representative. For example, the adaptive sign for "music class" could be similar to the activity of banging a drum, but the natural gesture could involve raising the foot (because vibrations are felt

through the feet when banging the drum), or making a fist with the hand (because that was the way the drumstick was held to hit the drum). These gestures vary among individuals who are deafblind and interpretation of their meaning requires situation-specific and individual-specific knowledge and experience (Robbins, 1983; Goode, 1994). One type of spontaneous gesture referred to as *bodily emotional traces* (BETs; e.g., Daelman et al., 2004) emphasises the emotional impact of a movement-based experience. Appropriate reaction to BETs by a communication partner may lead to further meaningful exchanges. The potential for meaning in apparently content-limited communication has to be recognised, as often it is the sharing of a moment in time with a responsive communication partner that will lead to a breakthrough in communication and not the sudden understanding of a shared formal system that expectations may bias towards.

Another case example from our research with Amy illustrates the role of expectations in perceiving an attempt at communication via gesture. Amy uses some formal signs and has a vocabulary of about 25 signs. Recently, we have noted that Amy has started to make up her own signs from the way she perceives an activity. One such sign initially appeared similar to a stereotypical behaviour; Amy would pull her finger repeatedly with an up and down motion. Amy's mother, knowing that Amy could use some signs, was open to the possibility that this motion was representative and/or communicative, and was able to interpret this gesture appropriately: Amy was making a reference to a toy thimble that she liked to play with (whether she was initially communicating a request or just recalling the activity is debatable). In this case, Amy's use of a "bodily perceived gesture" representing the action of putting the thimble on her finger led to a contingent and appropriate response: she was given her toy thimble. Amy continued to use this sign when she wanted her thimble. She has added to her communicative repertoire because the gesture was effective. However, the action of pulling her finger

could have been misinterpreted as non-communicative by someone else and ignored; thus potential for interaction would have been missed. We have noted how Amy began to exhibit more of this kind of gesture as she became aware of the fact that such gestures can be referential. Through consistent application, these bodily perceived gestures have become part of Amy's repertoire of signs along with her use of formal sign language.

Conclusion

We have aimed in this short paper to give a flavour of the breadth of behaviours that may be effectively utilised in communication with deafblind persons, and in doing so we emphasise the need to recognise the potential for communication in such behaviours. The role of expectation is clear: the potential for communication is, to a large extent, in the eye of the beholder. Behaviours that may initially appear meaningless have an important role to play in communication and to ignore them, or to try to substitute more conventional behaviours early on, would be to miss an opportunity to connect with the deafblind person on his or her terms. It would be, to paraphrase Hart (2006), to miss an invitation because it does not come in the expected form. In doing so, we reduce the likelihood that a return invitation will be issued.

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Endnotes

¹ We use the term "imitation" here in a broad sense to mean a response which follows from a person's behaviour, and which is broadly imitative in representing the form or content of that behaviour. This is consistent with the treatment of the term in the deafblindness literature, which can be conceived of as "learning the language" of our partner" and "responding to whatever it is that has meaning for them" (Caldwell, 2006, p. 277).
