Research Report

Sign Language, Speech, and Communication Repair Abilities by Children with Congenital Deafblindness

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Children with congenital deafblindness face serious challenges as they develop early communication skills and the use of symbols (Bruce, 2005). These children have fewer opportunities to practice communication and they lack access to naturally occurring social cues, the actions of others, and information about context (Bruce, Godbold, & Naponelli-Gold, 2004; White, Barrett, Kearns, & Grisham-Brown., 2004). These challenges are compounded when children have preintentional, presymbolic, or idiosyncratic behaviors that may not be easily interpreted by their communication partners and thus are not reinforced within socially contingent reciprocal activities (Schweigert, 2012).

There are many reports that identify the communication of persons with deafblindness. These reports are descriptive in nature, highlighting comprehension, gesture development, communication actions (that is, forms) and purposes (that is, functions), and the collection of verbal skills. Although varied in content, two trends emerge.

One trend is that the majority of children with deafblindness utilize prelinguistic communication, since they rely on vocalizations, body language, and gestures to convey protest, physical cooperation, calling, and answering (Bruce, 2003; Bruce et al., 2004; Hammeyer, 2014; Vervloed, vanDijk, Knoors, & vanDijk, 2006). Prelinguistic skills were also reported by Murray-Branch, Udavari-Solner, and Bailey (1991), who described a 23-year-old student with skills that were estimated to be at the 12-month level. Although most children with deafblindness have prelinguistic skills, not all children function at such lower levels. For example, Bruce, Randall, and Birge (2008) described a child, Colby, who spoke in multiword utterances and sentences.

Colby's abilities suggest there is communication skill diversity among children with deafblindness, a second trend in the literature (Bruce et al., 2008). This diversity occurs when contrasting Colby to prelinguistic communicators, and also within prelinguistic communication itself. Children with deafblindness, for example, use sign language, gestures, idiosyncratic actions, referential objects and drawings, communication boards, body language, and some speech (Brady & Bashinski, 2008; Bruce et al., 2003; Heller, Allgood, Ware, Arnold, & Castelle, 1996; Janssen, Riksen-Walraven, & vanDijk, 2002; Murray-Branch et al., 1991; Vervloed et al., 2006). The case for a diversity of skills was further supported in a microanalysis that found these children used 44 different gestures (Bruce, Mann, Jones, & Gavin, 2007).

This report extends the literature with an in-depth descriptive analysis of sign language, spoken words (that is, speech), communication repair strategies, and Communication Matrix levels. As already noted, sign language and speech are typically included in other research reports, but few consider Communication Matrix levels or repair skills despite the importance and relevance of both.

The Communication Matrix is a widely available nonstandardized assessment that is useful for identifying prelinguistic actions and intentionality (Rowland, 2011). The protocol has seven levels that range from preintentional behavior (level I) to language (level VII) (see https://www.communicationmatrix.org for additional information). In contrast, *communication repair* skills enable a person to take corrective actions when a communication partner misunderstands the person's initial message. This skill shows that a person values and persists in communication, a functional life skill, and suggests emerging or definite intentionality (Brady, McLean, McLean, & Johnston, 1995).

The research presented here also explores whether particular medical, physical, and cognitive characteristics inhibit or contribute to communication abilities, a frequently asked clinical practice question (Shipley & McAfee, 2009). For example, joint attention has been shown to support early language development (Morales et al., 2000). Similarly, independent ambulation is an important milestone in children's cognitive and communication development (Clearfield, 2011). Two questions were addressed by the present study:

1. What are the sign language skills, speech patterns, communication repair abilities, and Communication Matrix scores of children with congenital deafblindness?
2. Is there a relationship between children's communication and their age, gender, medical status (for instance, prematurity; CHARGE syndrome), ambulation status, and joint attention skills?

Methods

Participants

This paper is an extension and reanalysis of the seven participants earlier reported by Bruce et al. (2007), and Table 1 identifies their demographic characteristics.

Data collection and analysis

As reported in Bruce et al. (2007), the seven participants were videotaped for six hours during naturally occurring school activities between the participants and their teachers, peers, and related staff members. The second author analyzed the video recordings and developed comprehensive written profiles (see Bruce, 2010). The current data were extracted from those profiles.

Cumulative data are reported for the seven participants (research question 1). For research question 2, participants were grouped to examine trends based upon age, gender, joint attention (partial vs. full), independent or assisted ambulation, and history of prematurity or CHARGE syndrome. *Independent ambulation* was defined as walking, with or without assistive equipment, but not with assistance from a person. *Joint attention* was defined as reciprocal and mutual focus with someone towards an object, person, or event. Since this study had only seven participants, only descriptive trends are reported.

There were four dependent variables: the number of sign-language signs, the content of speech, Communication Matrix levels, and communication repair skills. Repair definitions were adapted from Brady et al. (1995, p. 1340) as follows: *repetition*, "the same gestures/vocalizations for both the original and repair communication acts"; *addition*, "the same gesture/vocalization that was observed in the original communication act, plus additional gesture(s) or vocalizations(s)"; and *recast*, "not . . . the same gestures or vocalizations that were observed in the original communication act" (that is, a change in the message's conveyance, but not the message itself). For this study, speech and sign language were included as additional ways of communicating.

Results

Sign language

All 7 participants used sign language (see Table 1); one participant had 14 signs, another had 7 signs, and a third participant had 4 signs. The remaining participants used 2 to 3 signs each. Three participants used 2-sign combinations. Cumulatively, the participants used 20 different signs, including: *more* (n = 6), *finished/all done* (n = 6), *eat/drink* (n = 4), *basket* (n = 2) and n = 1 each for *tickle*, *swing*, *helicopter*, *giraffe*, *help*, *school*, *ketchup*, *car*, *me*, *book*, *broken*, *paint*, *paper*,

Table 1
Demographics and communication skills of the participants.

	Amy	Colin	Dean	Mason	Sidney	Sierra	Tyler
Age, Gender	8–9, Female	4–3, Male	6–7, Male	7–8, Male	4–9, Female	8–1, Female	6–0, Male
Vision	None ANO	None ROP-5	20/260	MON, VFL, ES	20/1000	CVI, VFL, OA, STR	20/260 VFL, NYS
Hearing loss	Bilateral severe	Bilateral moderate-profound	Bilateral severe-profound	Bilateral severe	Right mild	Left: severe, right: mild-moderate	Bilateral severe
Prematurity	Yes	Yes	No	No	No	Yes	No
Independent ambulation	Yes	Yes	Yes	Yes	Assisted	Assisted	Assisted
Joint attention	Partial	Full	Full	Full	Full	Partial	Full
CHARGE syndrome	No	No	No	Yes	No	No	Yes
Speech	(n = 2)	(n = 5)	(n = 0)	(n = 0)	(n = 1)	(n = 1)	(n = 7)
	Mama, no	*Hi, bye, bumpy, mama, eat, all done*			*Hi*	*Hi*	*Truck, bye, basket, circle, more book, more work*
Sign language	(n = 3)	(n = 3)	(n = 4)	(n = 14)	(n = 2)	(n = 3)	(n = 7)
	Eat, finished, more	*Tickle, all done*	*Finished, swing, more eat*	*Basket, drink, help, school, giraffe, car, ketchup, paint, paper, helicopter, finished, more waffle, more chips*	*More, eat*	*Finished, me, more*	*More, book, finished, broken, light, want basket*
Repair skills	Repetition addition	Repetition addition	Repetition recast	Repetition recast	Repetition	None	Repetition
Matrix level range	IV: IV to VI	V: V to VI	IV: IV to VI	IV: IV to VI	V	III: III to IV	III: III to V

ANO = anopthalmia; R0P = retinopathy of prematurity, stage 5; MON = monocular; VFL = visual field loss; ES = esotropia; CVI = cortical visual impairment; OA = optic atrophy; STR = strabismus; NYS = nystagmus.

waffle, *chips*, and *light*. The signs for *more* and *help* were requests, but it was difficult to identify if other signs acted as labels or requests. The two youngest participants (both 4-year-old children) had the fewest signs, and the 2 participants with CHARGE syndrome had the most signs. Signing did not appear related to ambulation, joint attention, gender, prematurity, speech, repair skills, or Communication Matrix levels.

Speech

Five participants said or approximated real words; one said seven words, one said six words, and the remaining three said one or two words. One participant had two-word combinations. Spoken words included: *hi* ($n = 3$), *mama* ($n = 2$), *bye* ($n = 2$), and $n = 1$ each for *no*, *truck*, *more*, *book*, *basket*, *circle*, *work*, *bumpy*, *eat*, and *all done*. Spoken words were used to greet and convey farewell (*hi* and *bye*), to protest (*no*), and to request (*more*). It was difficult to identify if other words were labels or requests. The analysis indicated no trends for age, gender, prematurity, ambulation status, joint attention, CHARGE syndrome, repair skills, or Communication Matrix scores.

Communication repair strategies

Six participants demonstrated repair skills: repetition ($n = 2$); repetition and addition ($n = 2$), and repetition and recast ($n = 2$). The four participants with independent ambulation used addition and recast, the more advanced repair skills. Repair strategies did not appear related to age, gender, prematurity, joint attention, CHARGE syndrome, or Communication Matrix level.

Communication Matrix scores

Participants were at level III, unconventional communication ($n = 2$); level IV, conventional communication ($n = 3$); and level V, concrete symbols ($n = 2$). Participants had skills scattered across two levels ($n = 2$) and three levels ($n = 4$), and these levels did not seem related to age, gender, prematurity, ambulation, joint attention, or CHARGE syndrome.

Discussion

The results indicate that these 7 participants had sign language skills ($n = 7$), speech ($n = 5$), communication repair abilities ($n = 6$) and Communication Matrix scores at or nearly at levels V and VI (concrete to abstract symbols) ($n = 6$). Cumulatively, these participants used 20 different signs (range 2 to 14 signs per participant), 13 spoken words (range 0 to 7 words per child), and 3 different communication repair strategies. Three children used 2-word combinations, either in signing or speech. The youngest participants had the fewest signs, and children with CHARGE syndrome used the most sign language. Participants used more sign language than speech, but they had more communication functions with speech. Interestingly, sign language and speech did not seem related; that is, children who used more or less sign language were not the same children who used more or less speech. In addition, independent ambulation was associated with the more advanced recast and addition communication repair skills.

These results confirm the presence and diversity of prelinguistic and early communication abilities among persons with congenital deafblindness. These results also extend the literature by showing the presence of communication repair strategies that are similar to other individuals with severe disabilities who are not deafblind (Brady et al., 1995). Communication repair skills may be related to independent ambulation, a child-directed exploration skill that may enable more opportunities for the child to experience typical discourse patterns. Similarly, our research group has reported that independent ambulation was salient in the learning of tangible object symbols by children with vision impairments (Trief, Cascella, & Bruce, 2013).

These results also indicate that scores on the Communication Matrix were not fixed at specific levels, since most of the children had skills scattered across two to three levels of the scale. This suggests, perhaps, that the scale is sensitive to identifying emerging communication skills. Finally, speech abilities were not related to the other communication skills or demographic characteristics. It is difficult to infer information from this result except to suggest there was no predictive evidence about potential speech outcomes.

Summary and implications

These results imply that parents and educators might expect a wide range of skills as children who are deafblind develop speech and sign language abilities, specifically, and communication skills more generally. It is difficult, however, to know why particular children develop more skills than others. These data imply that ambulation and age could be factors that contribute to communication skills, but without the ability to study larger groups of children, predictions about communication outcomes will remain tenuous. To address this gap, future research needs to consider which intrinsic and environmental factors influence the acquisition of communication skills so that parents and professionals (that is, special education teachers, developmental pediatricians, educational psychologists, or speech-language pathologists) can consider evidence-based prognostic elements during educational assessment activities.

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