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Communication Programming for Learners With CHARGE Syndrome: Augmenting Comprehension and Expression

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Abstract

"Communication, communication, communication," Hartshorne, Hefner, Davenport, and Thelin's groundbreaking book, CHARGE Syndrome (2011), opens with these words and continues, "For 25 years, this has been our mantra when asked what it is that children with CHARGE syndrome need […] The biggest barrier to ultimate success for individuals with CHARGE is communication" (p. xi).

Introduction to CHARGE Syndrome

CHARGE syndrome is an exceptionally complex, genetic condition attributable, in a majority of cases, to mutation in the *CHD7* gene. CHARGE affects males and females with approximately the same frequency and occurs across multiple ethnicities. CHARGE syndrome is generally estimated to occur in 1 per 10,000–15,000 births (Deuce, Howard, Rose, & Fuggle, 2012; Issekutz, Graham, Prasad, Smith, & Blake, 2005; Lewis & Lowther, 2001; Salem-Hartshorne & Jacob, 2004; Thelin & Swanson, 2006; Wachtel, Hartshorne, & Dailor, 2007). Individuals who experience CHARGE syndrome manifest a wide variety of medical (i.e., anatomic and physiologic), sensory, developmental, and psychological diagnostic characteristics. Elements of the "CHARGE" acronym refer to: Coloboma of the eye; Heart defects; Atresia of the choanae; Retardation of growth and development; Genital and/or urinary abnormalities; and Ear anomalies (outer, middle, and/or inner), both in structure (i.e., malformation—cochlea and pinna) and in function (i.e., severe/profound hearing loss). "CHARGE may be the only disorder that presents with deficits of all of the senses" (Hartshorne, Hefner, Davenport, & Thelin, 2011, p. xiii).

It is critical to note that CHARGE syndrome is manifested clinically in highly variable ways (Hartshorne et al., 2011). No two individuals with CHARGE are alike—a "typical child with CHARGE" does not exist; if an individual has met one child with CHARGE she has met one child with CHARGE—though, as a group, these individuals do share some similar strengths and areas of need.

This article provides the reader with a basic understanding of the myriad complexities of CHARGE syndrome that have implication for the development of communication and language skills. It addresses communication comprehension and expression for learners with CHARGE syndrome and includes practical ideas for addressing these in the development and implementation of an AAC system for a learner who experiences CHARGE.

General CHARGE Characteristics With Implications for Communication/Language Development

At birth, children with CHARGE are medically fragile. Typically, a child with CHARGE will undergo at least 10 surgeries prior to her third birthday (Hartshorne et al., 2011; Thelin & Swanson, 2006). This reality is significant because the critical focus on the child's health, and even survival, can preclude a rich pattern of early language stimulation and typical experience of interacting with the environment. Very limited experiential opportunity early in life, due to medical and motor problems, significantly impacts communication development. Families of children with CHARGE do encourage new parents to try their best to focus on providing their infant/toddler with language stimulation, even though this might prove challenging (Lauger, Cornelius, & Keedy, 2005).

Multiple anatomical and physiological congenital anomalies often affect chewing, swallowing, or the ability to make typical facial movements. These limitations affect not only a child's ability to communicate nonverbally through facial expressions; they impact the child's oral-motor ability to produce vocalizations and, ultimately, speech (Hartshorne et al., 2011; Smith, Smith, & Blake, 2010; Thelin & Swanson, 2006).

"Approximately 30% of children with CHARGE have tracheostomies" (Swanson, 2011, p. 256)—some for as long as 15 years. While a child's tracheostomy is in place, it remains a barrier to oral communication development; until the trach is eventually removed, the child is in need of communication augmentation. Neurogenic problems often result in frequent respiratory / middle ear infections and impact swallowing and breathing—all medical issues related to the development of spoken language (Brown, 2005; Hartshorne, Hefner, & Davenport, 2005; Thelin & Swanson, 2006).

Due to vestibular system and balance problems, as well as low muscle tone (Brown, 2005), many children with CHARGE experience delay in the achievement of motor milestones. Age of independent walking is frequently cited for its negative correlation with adaptive behavior achievements (Dammeyer, 2012; Salem-Hartshorne & Jacob, 2004). Questionnaire data collected from parents of children with CHARGE indicated a significant relationship between independent ambulation and the acquisition of symbolic language (Davenport & Hefner, 2011; Thelin & Fussner, 2005). As such, promoting a child's independent walking should be a priority for facilitating communication development (Swanson, 2011).

As is the case with physiologic characteristics of CHARGE syndrome, cognitive skills present across a wide range—from significantly impaired to above-average intelligence. Though early studies tended to indicate all/nearly all individuals with CHARGE experienced cognitive disability (Hartshorne, 2011; Smith et al., 2010; Wulffaert, 2010), current research has corrected this misrepresentation. The behavioral phenotype proposed by Hartshorne (2011) suggests a trend toward "low normal cognitive functioning" (p. 319). Dammeyer (2012) and Salem-Hartshorne (2011) report that approximately 50% of individuals with CHARGE have "good" intellectual outcomes, 25% "moderate," and 25% "very poor" intellectual outcomes. Due to young children's typically under-developed communication systems, estimates of cognitive development early in the life of a child with CHARGE tend to significantly underestimate her or his potential. The adaptive behavior delays preschool and school-aged children exhibit most frequently result secondarily from the interaction of cognitive function and sensory impairments, illnesses, and limited communication (Dammeyer, 2012; Smith et al., 2010).

Vision/Hearing Characteristics with Implications for Communication/Language Development

In the United States, CHARGE syndrome is the principal genetic cause of congenital deafblindness (Thelin & Swanson, 2006); it is estimated that as many as 80–90% of individuals with CHARGE experience concurrent vision and hearing losses (Abou-Elhamd, ElToukhy, & Al-Wadaani, 2014; Hartshorne et al., 2005).

Given the impact the two primary distance senses, vision and hearing, have on an individual's understanding of environmental events, it is no surprise deafblindness significantly affects the development of communication skills. Sensory impairment is consistently identified as a primary obstacle to the development of communication skills for children with CHARGE

(Hartshorne et al., 2005; Lewis & Lowther, 2001; Souriau et al., 2005; Swanson, 2011). In light of the numerous life-threatening conditions which present in a child's early years, it is not surprising the prescription of glasses or hearing aids is often "put on hold." Nonetheless, this postponement is detrimental to the establishment of solid communication foundation (Hartshorne et al., 2005; Thelin & Fussner, 2005).

Visual loss impacts the ability of a child with CHARGE to communicate and learn, as much because of limited experience as anything else. Acuity loss limits a child's environmental awareness; reliance on touch/tactual input for information significantly shrinks a child's experience of the world. Visual field restrictions, most commonly upper field loss due to retinal coloboma (Brown, 2005; Hartshorne et al., 2011), also severely limit a child's access to visual stimuli. Estimates suggest that at least 80% of individuals with CHARGE experience some type of vision loss (Hartshorne et al., 2011; Smith et al., 2010); some researchers set this number as high as 91% (Deuce et al., 2012).

Hearing impairment in CHARGE may include conductive or mixed loss, but in nearly all cases is at least partially attributable to sensorineural impairment. Any part of the auditory structures and pathway may be affected (Hartshorne et al., 2011; Southwell, Bird, & Murray, 2010; Thelin & Swanson, 2006). Conservative estimates suggest that at least 90% of individuals with CHARGE experience hearing loss of a sufficient degree to affect the typical development of speech and language (Deuce et al., 2012; Smith et al., 2010; Southwell et al., 2010). Even learners who have similar hearing losses might process/understand speech differently, depending on a number of other factors (i.e., cognitive ability, visual impairment). It is critical that educational teams remember the optimal window of opportunity for audiologic intervention occurs very early (Edwards, Kileny, & Van Riper, 2002; Thelin & Fussner, 2005).

An increasing number of young children with CHARGE are receiving cochlear implants (CI) though the literature is divided in regard to reasonable outcome expectations. Ahn and Lee (2013) report "steadily improving auditory benefits following CI regardless of (the child's) intellectual ability" (p. 1151) for children with CHARGE, along with speech improvements in 5 of 6 participants; Southwell et al. (2010) report results in the conversational speech range for 2 of 3 participants with CHARGE. Better sound awareness and connection to environmental stimuli are reported as a generally more reasonable expectation for some children (Cardoso, de Meneses, de Castro Silva, & Alves, 2013; Lanson, Green, Roland, Lalwani, & Waltzman, 2007; Lina-Granade, Porot, Vesson, & Truy, 2010). Todd (2011) takes a stronger stance, stating "if the expected outcome is normal hearing and speech all involved are likely to be disappointed" (p. 88). Given the multiplicity of sensory challenges faced by learners with CHARGE, improvements in audition not considered meaningful for children without CHARGE might be viewed as quite significant for some individual children.

General Features of Communication of Learners With CHARGE

Learners who have CHARGE syndrome demonstrate a wide range of communication skills that range from idiosyncratic, nonsymbolic, nonintentional signals to conventional, abstract symbolic, intentional forms (Bashinski, 2011; Peltokorpi & Huttunen, 2008; Smith et al., 2010; Swanson, 2011; Thelin & Swanson, 2006). Although learners' communication profiles vary tremendously from one to another, due to their incredibly diverse patterns of CHARGE characteristics (Miller, Swanson, Steele, Thelin, & Thelin, 2011), "it generally is accepted that development of both receptive and expressive communication abilities is delayed, in at least some areas, in all persons who experience CHARGE syndrome" (Bashinski, 2011, p. 275). According to Sheri Stanger, Director of Outreach for the CHARGE Syndrome Foundation, "one of the most pressing concerns for our population is communication" (personal communication, 7/14/14).

Individuals who raise and work with children with CHARGE syndrome recognize that "all behavior is communicative." Parents frequently report noncompliant behavior as communication

(Miller et al., 2011). It is essential, however, for families and professionals to work to establish a more conventional, formal system for communicating with a child with CHARGE.

Little research specific to the description of communication abilities of learners with CHARGE Syndrome has been published (Miller et al., 2011; Peltokorpi & Huttunen, 2008; Smith et al., 2010), though it is hypothesized that approximately 60% of learners with CHARGE do eventually develop symbolic language skills (Miller et al., 2011; Swanson, 2011). In the vast majority of cases, learners with CHARGE continue to acquire communication skills beyond the critical growth periods for typical language learners. Even if/when symbolic communication is achieved, it is not atypical for a learner with CHARGE to require extended time to process language (Bruce & Bashinski, 2015).

Though communication development is generally delayed in children with CHARGE, their language style is not typically characterized by scripted phrases, particular errors, or echolalia (Graham, Rosner, Dykens, & Visootsak, 2005), though many learners with CHARGE do engage in ritualistic or repetitive talk (Bruce & Bashinski, 2015.). The greater the variety of communication forms and functions an individual learner utilizes, the more positive is the prediction for later language outcomes (Miller et al., 2011).

Case Example: Robert, a Teen Who Experiences CHARGE Syndrome

Robert is a 13-year-old who exhibits all major features of CHARGE syndrome. He experiences visual field and acuity losses. It is hypothesized Robert sees clearly, with his corrective lenses, within a distance of approximately 6 inches; he is, however, considered to be legally blind. Robert's sensorineural hearing loss is categorized in the profound range bilaterally; He is not believed to experience either auditory neuropathy or central auditory processing disorder. His sensory losses significantly impacted Robert's ability to gain information from the environment during his first few years of life. Robert has one cochlear implant; during the surgery in which Robert was to receive the cochlear implant, the surgeon paused at midpoint in the procedure to speak with his parents. After all prep work was completed, the surgeon explained to Robert's parents that he "could not insert all the electrodes [i.e., 25], but only 12 of them," because of the presence of Mondini malformation and "the cochlea is soft." Following surgery, Robert's prognosis for the development of auditory/oral communication was "poor." His parents did not expect him to develop speech; they had one post-surgery goal for him—"to hear emergency sounds, for safety purposes." The most major change Robert experienced attributable to his cochlear implant was in relation to his motor skills—"he began walking independently" (Bashinski, Thomas, & Reagle, 2015).

Initial assessments indicated Robert experienced severe cognitive disability. At the age of 5 years, Robert began participation in a research study that targeted the facilitation of communication gestures. During the baseline phase, Robert used only three communication forms (i.e., push object away, drop item, cry), to fulfill two functions (i.e., protest, reject; Brady & Bashinski, 2008); he demonstrated significantly delayed development in comparison to the "16 gestures by 16 months" communication milestone (Wetherby, 2014). Robert's baseline rate of communication initiations was 0.27/minute.

In this study of adapted prelinguistic milieu teaching (A-PMT), Robert participated in instructional activities that provided him with multi-modal communication input (e.g., gestures, iconic signs, vocalizations/speech, object cues, touch cues) and targeted his development of multi-modal communication expressions (e.g., natural gestures, vocalizations, body movements, actions on objects, actions on persons). Following this multi-modal communication instruction, Robert demonstrated nine communication forms (i.e., three baseline forms plus six new forms), eight communication functions (i.e., two baseline functions plus six new functions), and initiated communication at the rate of 1.66 communication acts/minute. As Robert's communication and language skills began to emerge, it became evident his initial diagnosis of severe cognitive disability was incorrect—rather, this appeared to be an artifact of his extremely limited communication skills.

Following his first 2 years of elementary schooling, Robert attended his neighborhood school, where he continued to show great strides in gaining communication skills, through augmentation. Certainly, his mastery of several communication gestures seemed to bridge his communication skills to a more symbolic level (Caselli, Rinaldi, Stefanini, & Volterra, 2012).

Currently Robert greets staff, upon arrival at school, with manual sign (i.e., “morning”); produces a variety of expressions via visual symbols (e.g., requesting to take a break from academics; asking for teacher’s assistance); and uses a speech-generating device (SGD) independently to spontaneously say “Hello” in his school environment.

With his family, at home and in the community, Robert communicates primarily via manual sign language and gestures. His mother and sisters sign *to* Robert; his comprehension of manual signs is very good. Robert seldom uses manual sign expressively, but will sign a few common phrases; he initiates production of a variety of communicative gestures.

At school, Robert demonstrates very functional, self-initiated communication with the support of a multi-modal AAC system. Robert utilizes a few manual signs and gestures, but primarily relies on visual symbols (i.e., Picture Communication Symbols™, line drawings, photographs) and a light tech SGD for expressive purposes. He relies primarily on manual sign for receptive communication.

Robert’s case study illustrates both the criticality of gesture development for predicting language outcomes (Bashinski, 2011; Brady & Bashinski, 2008; Brady, Marquis, Fleming, & McLean, 2004; Peltokorpi & Huttunen, 2008; Watt, Wetherby, & Shumway, 2006) and the effectiveness of a multi-modal AAC system for developing symbolic language forms. Most importantly, the case study exemplifies the not uncommon need of learners with CHARGE to utilize different communication modes for expressive and receptive purposes, as well as the criticality that both receptive and expressive elements of a learner’s communication system be multi-modal in nature.

Special Considerations regarding Key Decision Points in the Development of an Augmentative Communication System

An augmentative communication program for a learner with CHARGE must be individualized and accommodate the learner’s degrees and types of sensory loss, his or her communication level, and also the learner’s preferred mode of communication. As illustrated in the Robert case study, communication programming for a learner with CHARGE must be multi-modal (Bashinski, 2015; Brown, 2005; Miller et al., 2011; Smith et al., 2010; Souriau et al., 2005; Swanson, 2011). Wulffaert (2010) links the need for AAC to quality of life for learners with CHARGE syndrome.

When working with learners with CHARGE syndrome, practitioners need to consistently present communication forms and content within the “communication bubble”—“the area in which the child’s vision and hearing are optimal for communicating” (Swanson, 2011, p. 259).

Multisensory input needs to be provided for all learners with CHARGE, (i.e., nonsymbolic, pre-intentional, transitional, concrete/abstract symbolic), including those learners with the most limited communication abilities (Bashinski, 2015). Nonsymbolic, preintentional communicators should be provided with touch/textural/movement/object cues, gesture, and vocalizations. Communication partners need to be sensitive to potentially communicative expressive signals. Symbolic communicators might need tactual sign or braille/refreshable braille for participation in academics.

Organization of an AAC display must consider visual field restrictions, which often necessitate the reliance on poor peripheral vision (Brown, 2005). A learner’s AAC supports must be visually accessible from a variety of body positions (Smith et al., 2010). Portability of an AAC system is key, since the majority of learners with CHARGE do develop independent mobility (Hartshorne et al., 2011).

The representations utilized in a learner's AAC system must correspond to her or his level of symbolization ability, as well as take into account her or his visual and auditory skills. Because many learners with CHARGE have limited visual acuity, manual sign might need to occur close to the face; tactile-enhanced representations might be required (Swanson, 2011). Even though many learners will utilize gestures, line drawings, print, manual/tactual sign, the integration of verbalizations should not be forgotten, since some learners with CHARGE have only mild hearing loss—or have improved auditory function, due to amplification or a cochlear implant.

Vocabulary choices for a learner's AAC system also must correspond with his or her level of symbolization ability and cognitive function. It is not uncommon for learners with CHARGE, even those who demonstrate conversational communication, to experience delays in vocabulary recall and abstract forms (Brown, 2005). Planning multi-modal supports to address this need would be helpful. In addition, interprofessional teams would be well-advised to consider vocabulary for an AAC system to help a learner deal with pain, more conventionally express feeling upset, and deal with sensory overload (Bruce and Bashinski, 2015.)

Augmented means of expression, both aided and unaided, need to be explored for all learners with CHARGE; for example, a learner might need her or his AAC system to generate some sort of permanent product, particularly for academic participation. All communication modes available to an individual child should be embraced in her or his AAC system. The increased use of gestures and improved rate of communication appear to be correlated with improved communication outcomes for children with disabilities (Brady et al., 2004).

Even for the 40% of learners with CHARGE who do use speech as a primary communication mode (Thelin & Fussner, 2005), augmentation with an SGD or visual forms is often necessary for supplementation, due to a learner' poor speech intelligibility (Brown, 2005). As noted previously, numerous characteristics of CHARGE (e.g., craniofacial anomalies, odontology, clefts, respiratory problems) make precise articulation challenging (Hartshorne et al., 2011; Thelin & Swanson, 2006).

Some practitioners unnecessarily steer away from including visual elements in a learner's AAC system; the majority of learners with CHARGE do retain sufficient visual function to process stimuli presented at close range (Swanson, 2011). Visual symbols are recommended for nearly all learners, since these symbols are more concrete and less complex than manual sign—as well as non-time transient.

Another worthwhile AAC application often not given sufficient consideration is the appropriateness of learners with CHARGE using an SGD (Swanson, 2011)—Because the learner, herself, is likely to not be able to hear its digitized expressions. Potential communication partners could, however, process the auditory messages. A learner with CHARGE might be able to meaningfully utilize an SGD to more fully participate in general classroom activities and academics. Interprofessional teams are encouraged to consider the incorporation of an SGD as one element in a learner's multi-modal AAC system.

The learner's educational team needs to integrate a variety of sensory inputs/representations to facilitate the learner's comprehension (i.e., receptive communication) and more than one representation/sensory mode to support the learner's formulation of output (i.e., expressive communication). It is critical the team remembers that the way in which a learner with CHARGE syndrome receives information is highly likely to be different from the way she expresses information.

Summary

Learners who experience CHARGE syndrome, "who receive rich input (i.e., real life experiences, multisensory input, language presented in a variety of modes) from early on tend to have higher language comprehension skills" (Swanson, 2011, p. 264). Children with CHARGE need their families and educational service providers to provide them with authentic language stimulation from an early age, utilizing augmented input and enabling augmented expression. Provided with such opportunities, the majority of learners who experience CHARGE syndrome should develop to be very functional, effective communicators.

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