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I am submitting herewith a thesis written by Emily Anne King entitled "Communicative Rate, Form,and Function in CHARGE Syndrome." I have examined the final electronic copy of this thesis for form and content and recommend that it be accepted in partial fulfillment of the requirements for the degree of Master of Arts, with a major in Speech Pathology.

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COMMUNICATIVE RATE, FORM, AND FUNCTION IN CHARGE SYNDROME

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Emily Anne King
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ABSTRACT

CHARGE syndrome is a rare and complex disorder that often involves significant expressive communication delays caused by a combination of sensory, cognitive, and physical impairments. For educational purposes, CHARGE is considered to be a deaf-blind syndrome. Little is known about the characteristics of communication in CHARGE syndrome because the assessment of speech and language in this population requires special observational skills and because standard tests and evaluation procedures are typically not appropriate. The purpose of this study was to describe the communication skills of individuals with CHARGE syndrome and to analyze their communication in terms of communicative rate, form, and function. The participants in this study were 21 individuals with CHARGE syndrome who ranged in age from 1:8 to 20:5 and whose communicative abilities ranged from early pre-symbolic communication to conversational language. Analyses of intentional expressive communication were made using 15-minute video-taped communication samples of each participant interacting with a deaf-blind specialist. The rate of intentional communication for each participant was calculated. The communicative form and function of each intentional act was specified on a two-dimensional coding schema for communicative form and function. Expressive communication was specified in terms of (1) communicative forms divided into two groups (pre-symbolic or symbolic) with 22 component forms and (2) communicative functions divided into three groups (behavioral regulation, social interaction, and conversational acts) with 20 component functions. As with studies on other aspects of the disorders that present in CHARGE, the primary value of these analyses was to show the range of abilities that were present and how the schema could be used to differentiate the communicative acts of individuals. In the present study, intentional communication ranged from the lowest level, in which communicative forms were pre-symbolic

and functions were behavioral regulation, to the highest level, in which communicative forms were symbolic and functions were conversational acts. The results provide preliminary evidence that the development of intentional communication in CHARGE syndrome is related to the following factors: development in the use of forms and functions, communicative rate, chronological age, and the ability to walk independently.

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INTRODUCTION

CHARGE syndrome is a rare and complex medical syndrome that occurs approximately 1 in 12,000 births (Campbell, 1999). The acronym CHARGE stands for: Coloboma of the eye, Heart defects, Atresia of the choanae, Retardation of growth and/or development, Genitourinary anomalies, and Ear anomalies. The current criteria for clinically diagnosing CHARGE syndrome includes major and minor features of the syndrome. The major diagnostic features are: colobomas, choanal atresia, cranial nerve anomalies, and characteristic ear anomalies (Blake et al., 1998). The genetic link to CHARGE syndrome has been discovered (Vissers et al., 2004), and the syndrome is now diagnosed both clinically and genetically. It is considered a deaf-blind syndrome for educational purposes, but all of the senses may be affected.

Individuals with CHARGE syndrome have physical, sensory, behavioral, and cognitive anomalies that may affect their ability to develop communication and symbolic language. The consequences of their multiple impairments are multiplicative rather than additive. Additionally, there is some evidence to suggest that all aspects of development may be delayed in CHARGE syndrome. For example, some individuals reach puberty at 20 years of age. Also, parents report their children reaching developmental milestones years beyond expectation.

The communication of individuals with CHARGE syndrome is almost universally delayed. Little is known about communication development in CHARGE syndrome, but from a small sample of individuals with CHARGE, 40% did not use symbolic communication (Thelin & Fussner, 2005). Some individuals with CHARGE syndrome use pre-intentional communication, meaning their behaviors are reflexive, not directed at a specific person, and caregivers must interpret their meaning. This is the lowest form of communication and severely limits the ability

of the individual to make his or her needs and wants known. The communication of a small percentage of individuals with CHARGE syndrome never develops beyond this level.

A larger percentage of individuals with CHARGE syndrome use the lowest level of intentional communication: pre-symbolic communication. Pre-symbolic communication develops before the acquisition of spoken or signed language and is intentional communication through gestures, body movements, eye contact, and non-word vocalizations. Many individuals with CHARGE use pre-symbolic forms as their primary mode of communication for a prolonged period of time. The problem with pre-symbolic communication is that the individual is limited in what he/she can communicate, and in the variety of communicative functions he/she may utilize. For individuals with CHARGE syndrome, the ability of others to recognize attempts to communicate is critical to communication, learning, social, and emotional development. This is especially important when unconventional gestures or other forms of communication are not recognized as communication except by a very small group of caregivers or other individuals. If the individual's attempts to communicate are not perceived as intentional communication, the individual may feel isolated and may resort to disruptive or self-destructive behaviors (Brown, 2005).

Thelin and Fussner (2005) found, in a small sample study, that 60% of their participants with CHARGE used symbolic communication. These individuals use speech, sign language, voice output communication aid (VOCA), or a combination of communication forms. However, because delayed communication development in CHARGE syndrome is nearly universal, the typical individual who has developed symbolic communication uses both spoken and signed language that is well below expectations for age.

At present, there are very few descriptions of expressive communication in individuals with CHARGE syndrome. Most traditional assessment procedures of expressive communication cannot be used with individuals who have multiple disabilities. Standardized tests are inappropriate for this population for two reasons. First, the results of standardized tests typically characterize performance relative to a standard population and do not indicate what communicative forms and functions have been used. Since communication delay is universal in CHARGE syndrome, performance will be poor but not described in such assessments. Second, there are no norms that are appropriate for individuals with deficits in all sensory modalities. A group of investigators recently analyzed expressive communication of three children with CHARGE syndrome who were communicating at the pre-symbolic level (Peltokorpi & Huttunen, 2008). They found that it was difficult to determine communicative form and function due to the individuals' multiple impairments and unconventional ways of communicating. Bashinski (in press) suggests that assessment of individuals with CHARGE syndrome should include the following: ability to use symbolic communication, development of intentional communication, communication rate, characteristics of the individual's natural environments, and level of gesture development.

Purpose of Present Study

In the present study, the goal was to describe the expressive intentional communication for individuals with CHARGE syndrome. This includes pre-symbolic and symbolic intentional communication.

Before a description of communication abilities could be made, it was necessary to define specific procedures both for collecting the communication samples as well as for analyzing the

samples to determine which acts are considered intentional. Communication samples were obtained in video-taped sessions with a deaf-blind specialist who was experienced in communicating with children and young adults at pre-symbolic and symbolic levels using tactile communication, sign language, and spoken language. The abilities of this specialist to gain the attention and cooperation of the participant and to elicit responses from the participant were essential to the acquisition of the communication sample.

After the communication sample was obtained, the investigator and a trained observer made decisions as to which acts were considered to be intentional communicative acts and then judgments as to how the acts were to be described. This required multiple independent and joint viewings of video-taped communication samples and discussion of each participant's communication. Background information was also obtained from parents and from the deaf-blind specialist to assist in the interpretation of the communication samples and in the identification of factors related to communication development.

Paul (2007) has suggested three measures for analyzing pre-symbolic communication: communicative rate, communicative form, and communicative function. In the present study, all three of these measures were incorporated into the analysis used to describe the intentional communication of individuals with CHARGE syndrome. Communicative rate was the number of intentional communicative acts per minute. A coding schema was developed in which each communicative act was described qualitatively in terms of both its form and its function. The term 'communicative form' was used to classify the communicative act as either pre-symbolic or symbolic. Examples of pre-symbolic forms of communication are: tantrums, reaching, showing, giving, pointing, and gestures (e.g. waving hello). Examples of symbolic forms of communication include spoken and signed language. The term 'communicative function' was

used to describe the purpose of the communicative act. There were three major groups of functions: behavioral regulation (e.g. requesting action, protesting), social interaction (e.g. calling, showing off), and conversational acts (e.g. commenting, responding to a request). The description of intentional expressive communication for each participant included a quantitative assessment of communicative rate and a qualitative assessment of communicative form and function. Descriptions were obtained for 21 participants with CHARGE syndrome with a wide range of communication abilities. Individual results were then summarized and grouped to illustrate the general findings among the individual's studied. Grouped results for communication were also related to background information on the participants.

REVIEW OF THE LITERATURE

CHARGE Syndrome

CHARGE syndrome is a rare and complex genetic disorder that is present in one out of ever 12,000 live births (Campbell, 1999). CHARGE stands for: C for coloboma of the eye, H for heart defects, A for atresia of the choanae, R for retardation of growth and/or development, G for genitourinary anomalies, and E for ear anomalies and/or deafness. The acronym for CHARGE was developed in 1981 by Pagon, Graham, Zonana, and Young to describe a series of anomalies seen in several patients (Hefner, 2002). While the acronym is still used by researchers, doctors, professionals, and families, knowledge about the syndrome has expanded and distinctive characteristics are now considered to be different from this original association.

Originally, CHARGE was considered an association, or a collection of related birth defects for which a single cause had not been identified (Pagon et al., 1981), but some investigators used the term CHARGE syndrome because they believed that there was sufficient evidence that the cause had to be genetic (Davenport, Hefner, & Thelin, 1986). In 2004, investigators in the Netherlands discovered mutations in a gene, CHD7, which are associated with the underlying cause of CHARGE syndrome (Vissers et al., 2004). However, because the gene has not been found in all individuals with CHARGE syndrome, the diagnosis is still also made clinically as well as genetically.

The criteria involved in the medical diagnosis of CHARGE are divided into major and minor features. The major features are distinguishing characteristics that occur frequently in CHARGE but rarely in other conditions, and the minor features occur less often or are less specific to the syndrome (Blake & Prasad, 2006). The major diagnostic features are: coloboma

of the eye, choanal atresia, cranial nerve anomalies (I, VII, VIII, IX, and X), and characteristic ear anomalies. Minor features of CHARGE syndrome include: heart defects and anomalies, genital hypoplasia, cleft lip and/or palate, tracheoesophageal fistula, distinctive facial features, growth deficiency, and developmental delay.

Major Diagnostic Factors in CHARGE Syndrome

Coloboma of the Eye

Ocular coloboma occurs in more than 80% of individuals with CHARGE syndrome and can affect the iris, retina, choroid, or optic disc, ranging in its effects from minor to severe (Blake et al., 1998). In the iris, the coloboma can be seen as a "keyhole" in the pupil (Toriello, 1995). According to Blake and Prasad (2006), coloboma of the retina is more common than that of the iris and can affect the optic nerve. Colobomas create holes in one's visual field, limiting the amount of visual input (Campbell, 1999). In addition to lowered visual acuity, individuals with bilateral colobomas of the iris may also have difficulty adjusting to bright light (Lewis & Lowther, 2001). Effects can range from no visual impairment to little or no usable vision. Russell-Eggitt, Blake, Taylor, and Wyse (1990) observed more serious visual impairments in 30 of 50 subjects with CHARGE, such as detached retina, associated with coloboma of the posterior portion of the eye. Colobomas are not associated with complete blindness.

Choanal Atresia

Choanal atresia, or blockage of the breathing passages, is the second major diagnostic feature in CHARGE syndrome and has an occurrence of 50-60% (Blake et al., 1998). This condition presents severe respiratory problems from birth, as the nasal passages are either narrow

or completely blocked (Lewis & Lowther, 2001). Atresia of the choanae can present as either bilateral or unilateral and can be either a membranous or a bony blockage (Blake & Prasad, 2006). Complete blockage of the breathing passages (bilateral posterior choanal atresia) is the most severe manifestation and requires immediate surgery after birth to avoid brain damage or death (Lewis & Lowther, 2001). Lewis and Lowther (2001) also state that even after the condition is surgically addressed, further complications of choanal atresia may manifest themselves as: feeding difficulties, due to lack of coordination between breathing and swallowing, and recurrent ear infections. As a result, about one in 20 individuals with CHARGE require tracheostomies to manage respiratory difficulties, and many need surgeries to treat chronic acid reflux and aspiration (Blake et al., 1998).

Cranial Nerve Dysfunction

In the CHARGE syndrome manual, Hefner & Davenport, (2002) state that cranial nerve dysfunction in CHARGE syndrome can affect cranial nerves I, VII, VIII, IX, and X. They report that abnormalities of the olfactory nerve (I) result in missing or lowered sense of smell, which is present in 90-100% of individuals with CHARGE. More than 40% of individuals with CHARGE have unilateral or bilateral facial palsy, which is caused by a defect to the facial nerve (VII). Blake et al. (1998) explain that facial palsy can have wide-reaching effects besides a lack of facial expression, which include: complicating visual problems, interfering with speech, and aggravating feeding and swallowing difficulties. Incidence of dysfunction of the vestibulocochlear nerve (VIII) is between 70% and 85%. Effects of impairment of cranial nerve VIII include sensorineural hearing loss and vestibular problems. Swallowing problems are

common in CHARGE (70-90%) and result from dysfunction of the glossopharyngeal (IX) and vagus (X) cranial nerves.

Anomalies of cranial nerve VIII affect both hearing and balance. Hearing loss is common in CHARGE syndrome, ranges from mild to profound (Thelin, Mitchell, Hefner, & Davenport, 1986), and is often sensorineural, caused by defects to the vestibulocochlear nerve. Balance problems associated with defects in cranial nerve VIII, including missing or malformed semicircular canals, are also commonly seen in individuals with CHARGE syndrome. Abadie et al. (2000) found vestibular anomalies present in 17 of 17 participants with CHARGE and suggest that these anomalies result in balance problems and contribute to motoric and developmental delays.

Feeding and swallowing problems are common in CHARGE syndrome and often result from cranial nerve anomalies to nerves VII, IX, and X. These problems often cause pooling of liquid in the back of the throat, gagging, and an inability to swallow liquids or solid foods. As a result, many times children with CHARGE are unable to take food by mouth (Blake et al., 1998), and these children are often placed on permanent feeding tubes (e.g. gastrostomy tube) for several years of their childhood and beyond.

Characteristic Ear

Hefner & Davenport (2002) also describe ear anomalies associated with CHARGE syndrome that include a distinctive outer ear, occurring in 90% of cases and an abnormal middle ear, also with a 90% incidence. The external ear anomalies include: short, wide ears with little or no lobe, a snipped off helix, decreased cartilage, and lateral protrusion. Some researchers suggest that because of its distinctive appearance, diagnosis of CHARGE can often be made upon the

basis of the external ear shape alone (Thelin & Swanson, 2006). Middle ear abnormalities often include malformed ossicles and cochlea and result in hearing loss. Thelin, Mitchell, Hefner, and Davenport (1986) suggest that hearing loss is CHARGE is characterized by: conductive loss due to abnormal ossicles, sensorineural loss greatest in high frequencies, conductive loss caused by chronic middle ear effusions, and a potentially progressive hearing loss.

Other Medical Factors Associated with CHARGE Syndrome

Besides the major diagnostic features, there are other medical and physical characteristics commonly present in individuals with CHARGE that are important to its clinical diagnosis and treatment. Congenital heart defects are a minor diagnostic feature of CHARGE but, nevertheless, occur in 75-85% of individuals with CHARGE syndrome (Blake et al., 1998) and often require multiple surgeries. Digestion is affected by renal abnormalities that occur in 40% of individuals with CHARGE (Hefner, 2002). Facial asymmetry, a broad forehead, square face, high nasal bridge, full nasal tip, small mouth, ptosis, arched eyebrows, and laterally protruding ears make up the distinctive facial features in CHARGE (Blake et al., 1998). Other features that are commonly found in CHARGE syndrome: characteristic CHARGE hand(broad palm with "hockey-stick" shaped palmar crease), hypotonia, growth deficiency, brain abnormalities, apnea, seizures, laryngomalacia, nipple anomalies, floppy cartilage, thymic or parathyroid hypoplasia, webbed neck, abdominal wall defects, scoliosis, limb and skeletal anomalies, autistic-like behavior, and behavior problems (Hefner & Davenport, 2002). This large list of potential abnormalities and problems makes CHARGE syndrome one of the most complex medical syndromes and results in unique presentations of the syndrome on an individual basis.

Behavior in CHARGE Syndrome

Recent literature indicates that the challenging behaviors commonly seen in individuals with CHARGE syndrome are an important feature of the disorder. A special edition of the *American Journal of Genetics* (2005) was devoted to the behavioral phenotype with the implication that it is genetic in origin. Bernstein and Denno (2005) describe the behaviors as repetitive and divide them into four categories: self-stimulatory behaviors, maladaptive routines/behaviors, tics, and obsessive compulsive disorder. The behaviors have been frequently described as autistic-like, but Hartshorne, Grialou, and Parker (2005) suggest that these behaviors are unique in children with CHARGE, different from children with only autism or deaf-blindness. The behaviors seen in CHARGE are often adaptations these individuals make to their environment and disabilities (Hartshorne, Hefner, & Davenport, 2005). However, there is also evidence of a behavioral phenotype associated with CHARGE that is more than just a function of their impairments.

Communication in Persons with Multiple Disabilities

While much research has focused on communication skills and development in children with multiple handicaps and deaf-blindness, communication development in CHARGE syndrome has only begun to be described. When investigating communication in CHARGE, it is useful to look at research on communication in children with one or more of the impairments associated with CHARGE syndromes. However, it must be noted that the confounding effects of the multiple abnormalities and deficits associated with CHARGE on communication is still unknown. Thelin and Fussner (2005) suggest that because of the variety in clinical manifestation

of symptoms of CHARGE syndrome, the reasons for not acquiring symbolic language vary as well.

Communication in Persons with Multiple-Handicaps

Communication in children with multiple handicaps is often delayed in its development, as these children use primarily pre-linguistic gestures and vocalizations to communicate well beyond age-expectancy (Brady, Steeples, & Fleming, 2005). These findings suggest that while the use of communicative intentions is often delayed in children with multiple disabilities, children with higher levels of pre-verbal communication, such as pointing, were more likely to initiate requests and comments. Children with autism or other developmental disabilities have difficulty in the development of joint attention and symbol use, as well as a limited repertoire of expressive language functions, using communication mainly to request or reject and communicating through unconventional behavior (i.e., leading, screaming, hitting) (Halle & Meadan, 2007). Communication mode among individuals with severe disabilities often varies, and if spoken or signed symbolic language is not possible, other communication methods, such as picture exchange, gestures, and augmentative and alternative communication (AAC) are employed.

Communication in Persons with Deaf-Blindness

While profiles of individuals with deaf-blindness vary greatly, research reveals that the combination of vision and hearing loss creates a unique and severe communication delay that necessitates the need for unique educational placements (Miles, 2005; Moller, 2003). When vision and hearing loss are accompanied by other severe disabilities, the effects on communication are multiplied, and communication deficits may include: more severe delays in

expressive communication, echolalic speech, disorganized language, restricted topics of conversation, infrequent communication, and poor ability to initiate conversation or communication (Hagood, 1997).

The ability to learn symbolic communication depends on sensory input. Individuals who are deaf-blind receive distorted sensory input. In addition, these individuals may have delays in social or cognitive development and motor impairments, which make learning a conventional or symbolic mode of communication a unique challenge (Hagood, 1997). Symbolic forms of communication must be directly taught to these individuals, and often individuals with deaf-blindness have difficulty understanding that communication has a purpose, and once they do understand this idea, they most often use communication to request or regulate an adult's behavior for their own needs (Hagood, 1997). Joint attention (the ability of the child to attend to the same object/event as the communicative partner) is an important prerequisite for communication, and children who have deaf-blindness have shown lower rates of joint attention (Bruce, 2005). Studies have also shown that children who are deaf-blind may have a unique pattern of development of communicative functions. According to Bruce, Mann, Jones, and Gavin (2007), participants in those studies most often communicated to request objects, request actions, and to protest

Individuals who are deaf-blind use a variety of pre-symbolic and/or symbolic forms to communicate. Studies show that individuals with deaf-blindness commonly use their tactile sense in their primary communication method (Rönnberg, Samuelsson, & Borg, 2002). Morgan, Bixler, and McNamara (2002) suggest that these individuals need assistance in opportunities for more accessible communication in all environments. Commonly used systems of communication for persons who are deaf-blind include: touch cues, gestures, object symbols, sign language,

picture symbols, fingerspelling, signed English, Braille, American Sign Language, lip-reading speech, Tadoma method of speech-reading, Pidgin Signed English, and large print writing and reading (Miles, 2005).

The consensus on communication development in deaf-blindness is that there is much variation. Petroff (2001) found that half of individuals with deaf-blindness do not develop symbolic language and instead use modes such as gesture, facial expressions, and/or behaviors. Brady and Bashinski (2007) suggest that functional communication is a primary goal for children with deaf-blindness and that the use of touch cues, object cues, hand-under-hand strategies, as well as incorporating visual and auditory stimuli appropriate to each child's abilities are augmentative strategies necessary for intervention with these individuals.

Communication in Persons with CHARGE Syndrome

Given the medical complexity of CHARGE syndrome, it is not surprising that delay in developing communication and symbolic language is common in individuals with this syndrome (Thelin & Fussner, 2005). There are many factors that can affect communication development in persons with CHARGE. Lewis and Lowther (2001) suggest that sensory impairment and long periods of hospitalization and illness in infancy in these individuals can result in communication that is limited in both the quality and quantity and delayed in areas such as turn-taking, initiating, and vocabulary. Facial palsy can greatly affect communication because it often results in an inexpressive face, which can lead to incorrect or lowered expectations of others (Brown, 2005). Davenport (2002) discussed the effects on a child's development and understanding of the world in terms of external factors, such as vision, hearing, smell, taste, and touch, and internal factors, such as, swallowing, breathing, mobility, fatigue, and pain (both internal and external).

Furthermore, she presents the idea of a "communication bubble" in children with CHARGE, who, due to their multiple sensory impairments, have certain areas where their vision, hearing, and balance are optimal, and, therefore, communication is best facilitated in those areas. Another challenge to communication development in CHARGE syndrome is the behavioral problems associated with the syndrome. Thelin and Fussner (2005) found that the effect of behavior on communication to be controversial, as many parents believed that behavior problems were a result of limited communication abilities. However, other literature supports that the behaviors are indeed a distinctive feature of the disorder and interfere with social and communication development (Bernstein & Denno, 2005).

Thelin and Fussner (2005) found the development of communication was delayed for nearly all of the individuals with CHARGE syndrome that they studied. They sought to determine relationships among different physical, sensory, behavioral, and intervention factors and the development of symbolic language skills. Their results show three factors that were significantly correlated with the ability to communicate symbolically in children with CHARGE. Most parents believed their child's hearing loss to be the most significant contributor to delayed communication skills. However, results of the study show that use of amplification before age 3, communication therapy before 3 years of age, and the ability to walk independently to be the most significant factors related to acquisition of symbolic language in CHARGE syndrome. Results of a study by King, Swanson, Thelin, and Steele (2007) support those findings, as all of their participants with symbolic language displayed those three factors.

Brown (2005) lists hearing and vision loss, facial palsy, low muscle tone, enlarged tongue, and breathing and swallowing difficulties as obstacles to acquiring speech. Also, low muscle tone, balance problems, and reduced or abnormal tactile and proprioceptive senses, as

well as dyspraxia, are obstacles to utilizing sign language (Brown, 2005). As a result, many different modes of communication, both symbolic and non-symbolic, are commonly used by persons with CHARGE and vary on an individual basis. These modes include: gestures, pictures, touch cues, object cues, sign language, spoken language, and total communication. Swanson, King, Thelin, and Steele (2007) found that 60% of their participants with CHARGE used primarily gestures to communicate, and nearly 40% of participants used a combination of gestures, signs, and vocalizations to convey meaning (see Figure 1). The eight participants are represented on the abscissa, and the number of communicative acts is on the ordinate. The difference in coloring indicates the different modes of communication a participant uses. Every participant used gestures to communicate, but only those at the higher levels of communication used symbolic modes of communication (signs and verbalizations). Participants who used more signs and verbalizations than gestures are at the early stage of developing symbolic language.

Behavior, such as self-injury or aggression, is another mode that some individuals with CHARGE use to communicate. While these maladaptive behaviors may have communicative intentionality, caregivers and teachers may have difficulty interpreting their meaning (Thelin & Swanson, 2006). There are strong feelings among parents and professionals about these challenging behaviors; while some feel they are characteristic of the syndrome, others believe that they develop because of an inability to communicate using conventional forms (Thelin & Fussner, 2005). Because of the unique profile of each child with CHARGE and differences in abilities, there is no preferred mode of communication; instead, it is suggested that any and all modes of communication may be appropriate for individuals with CHARGE (Brown, 2005). Total communication is the combined use of visual plus auditory input (i.e. signed language and spoken English) and has been of value with children with CHARGE syndrome.

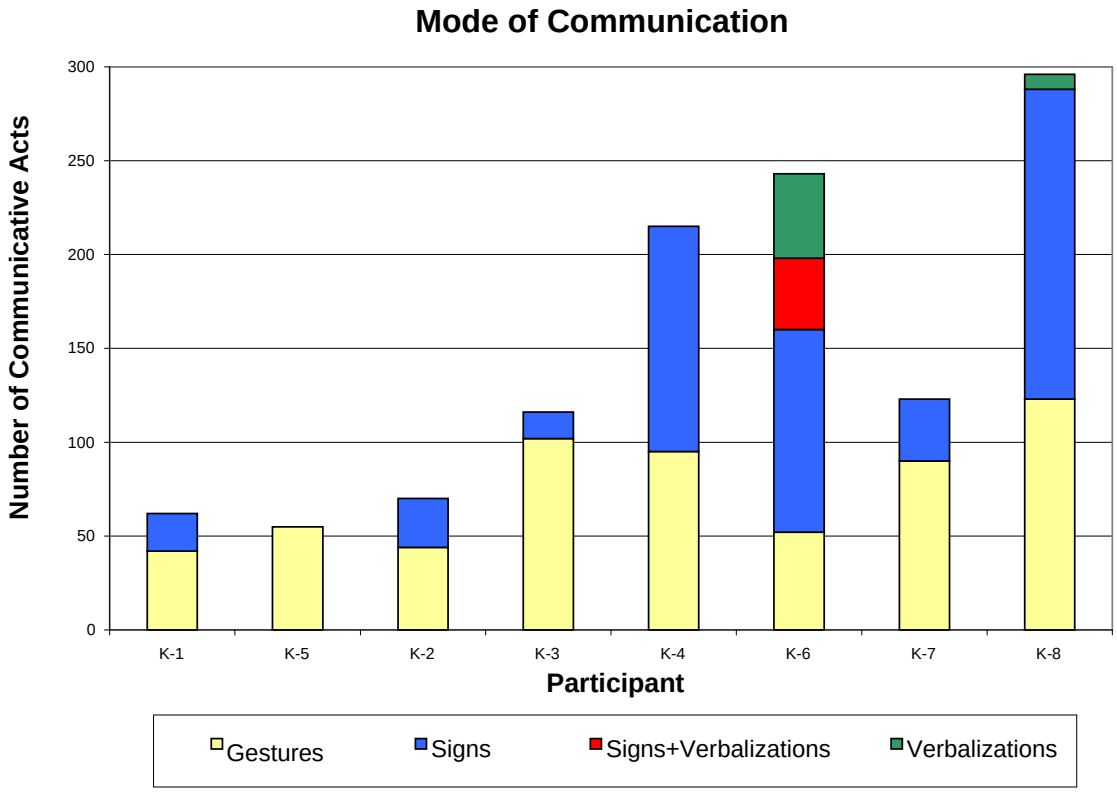


Figure 1. Mode of Communication in Children with CHARGE syndrome (Swanson et al., 2007)

While specifics about communication patterns and development in CHARGE syndrome are unknown, research suggests that about 60% of individuals with CHARGE syndrome develop symbolic language (Thelin & Swanson, 2006). Those who develop symbolic language, either in spoken or manual form, still show a delay in language skills. Thelin and Swanson (2006) suggest that these children are delayed in maintaining a topic and in turn-taking. Those with more advanced forms of language have difficulty in areas such as vocabulary recall, initiation of communication, and abstract forms (Brown, 2005). King et al. (2007) described the language abilities of eight children with CHARGE and found that children with symbolic language communicated more frequently and had a larger repertoire of communicative functions than those who communicated with non-symbolic language. In addition, they found that the youngest two participants (ages 1:8 and 2:0) were the least delayed in their communication development and were both at the stage of emerging symbolic language.

In one of the few published studies on communication in children with CHARGE syndrome, Peltokorpi and Huttunen (2008) analyzed video-taped language samples of three participants with their mothers. Their three participants (ages 1:4, 3:9, and 8:4) were functioning at a pre-symbolic stage of communication. These individuals most often used gestures and vocalizations to communicate. Protesting was the most common communicative function used by the participants. These authors concluded that while children with CHARGE syndrome present with unique clinical profiles, similarities can be found in the early stages of communication development, and communicative function and form were often difficult to determine because of the individuals' multiple impairments and unconventional ways of communicating.

Assessing Communication Skills in Persons with Multiple Disabilities

For individuals with multiple-sensory impairments, like children with CHARGE syndrome, language assessment is a significant challenge because of differences in abilities and levels of performance. Standardized tests are designed to characterize individuals with typical motor and sensory abilities. Assessing children with impairments in these areas may be neither valid nor reliable if performance falls at the extreme low end of the measurement scale. Miles and Riggio (1999) suggest that using a standardized language or articulation test with a child with sensory impairments would be assessing abilities other than speech and language, such as vision, ability to attend, ability to sit upright, hearing acuity, perceptual skills and motor and linguistic ability to respond in words. Sensory impairment greatly affects a child's ability to learn language, and because of their limited sensory input, many of these children develop unconventional ways to communicate (e.g., facial expressions, self-injury, aggression). A typical language assessment would not reveal true communicative capabilities of a child who uses these unconventional methods. Even the earliest tests of expressive and receptive language ability, such as the *Sequenced Inventory of Communication Development—Revised* (SICD-R, Hedrick, Prather, & Tobin, 1995), rely on early vocalizations and pointing to assess communication. Wetherby and Prizant (1991) note the emphasis of assessment of early communication and language on communication form, with a lack of attention to communication function.

Many support the idea of observational assessment for individuals with multiple disabilities (ASHA, 1992; Brady, 2005; Wolf-Schein & Schein, 1998). ASHA (1992) suggests that assessment for individuals with severe disabilities should focus on a descriptive analysis of the individual's awareness of his/her ability to affect the actions of other through intentional communicative acts, the forms of communication that individual uses, and the social functions

the individual uses in communication. According to the ASHA (1992) guidelines, assessment should occur in an environment in which the individual has a need to communication and should reflect every communicative mode the individual uses, including pre-symbolic and maladaptive behaviors and should report the functions, relative to form of each communicative act. Other investigators suggest that assessment should be non-intrusive and should include combination of interviews of parents and teachers, parent questionnaires, and direct observations (Bashinski, in press; Brady 2005; Wolf-Schein & Schein, 1998). Information obtained using these methods are valuable for establishing a baseline for the individual student and for planning treatment (Wolf-Schein & Schein, 1998). *HomeTalk* (Harris et al., 2002) is an example of a parent survey that should be included in the assessment process. It was developed specifically for parents of children who are deaf-blind and gives information on sensory, physical, cognitive, social, and communication development.

In the early stages of communication development, communicative rate, form, and functions can change and increase dramatically in typically developing children (Paul, 2007). Recent research by a number of investigators has suggested that later language outcomes in children with disabilities may be linked to the following factors: the acquisition of higher pre-linguistic forms, rate of communication, and successful use of communicative functions (Halle & Meaden, 2007; McLean, McLean, Brady, & Etter, 1991; Watt, Wetherby, & Shumway, 2006; Yoder, Warren, & McCathren, 1995; Brady, Marquis, Fleming, & Mclean, 2004). Also, in the early stages of language development, frequency of communication, diversity of communicative functions, a diversity of communicative forms are three important measures of communication development that can be useful in planning intervention and assessing the child's language

growth (Paul, 2007). Therefore, analyses of these three dimensions were included in the present study to describe communication abilities in individuals with CHARGE syndrome.

Communicative Rate

Communicative rate is calculated by number of intentional communicative acts per minute in a communication sample. Frequency of communication is an important measure of language abilities, especially in the early stages of communication development. Wetherby, Cain, Yonclas, and Walker (1988) state that communicative rate in early language development is a useful index to measure communicative development, especially in children with language impairments who have few or no words. They also state that rate increases significantly as children move from pre-symbolic to symbolic communication stages. In their study, they investigated rate of communication and found that individuals at a pre-symbolic stage of communication had a rate of about 1 act per minute while those at the one-word stage had a rate of 2 acts per minute, and children at a multi-word stage communicated at about 5 or more acts per minute. Paul (2007) proposed age-related rates for typically-developing children as 2 acts per minute at 18 months, and 5 acts per minute at 24 months, and she suggests that very low rates of communication (less than 10 acts in a 15-minute sample) may be negative indicators for communication development.

Communicative Form

Communicative form refers to the mode or way in which an individual communicates, including: speech, gestures, pointing, reaching, crying, sign language, and so forth. There are two main categories of communicative forms: pre-symbolic forms (vocalizing, reaching, pointing, gestures, etc.) and symbolic forms (signed, spoken, or written language). Many

children with CHARGE continue to use different pre-symbolic forms of communication long past age-expectancy but may still acquire symbolic language. Also, many individual with CHARGE syndrome use unconventional and even maladaptive behaviors or movements to communicate. Paul (2007) states that all forms of intentional communication should be analyzed in order to identify communicative intent of those actions and to give the individuals more appropriate means to communicate.

The consensus of the literature has been that there is a specific order of acquisition of pre-linguistic forms of communication. McLean and Snyder-McLean (1999) propose an order of acquisition of gestures for intentional communication as follows: contact gestures, distal gestures, both contact and distal gestures, and true point and pantomimic gestures. In other words, gestures move from touching an object or person to being distanced from the intended object. Contact gestures are direct physical contact, such as giving and showing, while for distal gestures, no direct physical contact is made. Capone and McGregor (2004) suggest that gesture development is important to assess because it shares underlying symbolic qualities with language development. Brady, Marquis, Fleming, and McLean (2004) found type of gesture to be one of the factors that predicted language ability in pre-symbolic children. Also, Crais, Watson, and Baranek (2009) found analysis of communicative form to be useful in distinguishing between certain disorders in young children.

Communicative Function

Communicative function is the purpose or reason why a person communicates: to request, to comment, to protest, etc. The development of communicative function is closely related to the development of higher communicative forms. Three major categories of

communicative functions are: behavioral regulation, social interaction, and joint attention. Behavioral interaction, which includes the communicative functions of requesting action, requesting objects, and protesting are some of the first communicative functions to develop in the pre-symbolic stage (Crais, Watson, & Baranek, 2009; Wetherby, Cain, Yonclas, & Walker, 1988). Chapman (2000) suggests that these early communicative functions typically occur in children between 8 and 15 months. Requests for information, acknowledgments (imitating or nodding head in agreement), and providing information are more advanced intentions that develop around 18 to 24 months in typically developing children (Paul, 2007). As the individual's language skills increase, these functions increase in variety and in type of function. According to Wetherby, Cain, Yonclas, and Walker (1988), individuals at the pre-symbolic stage use request action and comment most often but should use all three major categories of communicative function. They also suggest that as a child moves to the multi-word stage of communication, behavioral regulation functions should decrease, and their communicative functions should fall within the categories of social interaction and joint attention.

In recent years, research on communication skills of individuals with multiple handicaps, developmental disabilities, intellectual disabilities, and deaf-blindness has included the use of communicative functions. Measurements on function can be used across individuals with different levels of communication because children acquire communicative functions before they acquire symbolic language. Furthermore, research supports that different disabilities impact the acquisition of functions and the number of functions a person uses (Bruce, Godbold, & Naponelli-Gold, 2004). Different codes can be used to analyze communicative functions, depending on level of communication development and type of disability or disabilities.

In their assessment of communicative functions of children with deaf-blindness at pre-symbolic and symbolic levels of communication, Bruce, Godbold, and Naponelli-Gold, (2004) employ a code of 25 intentions, based on work by Coggins and Carpenter (1981). In their study of three children with CHARGE syndrome, Peltokorpi and Huttunen (2008) used the Communication Intention Inventory (Coggins & Carpenter, 1981b), which includes six early developing communicative functions: protesting, acknowledging, request for action, comment on action, comment on object, and answering.

Other researchers who assessed pre-linguistic subjects with developmental disabilities (Brady, Marquis, Fleming, & McLean, 2004) and who were typically developing (Watt, Wetherby, & Shumway, 2006), used methods of assessing communicative function based on the assessment protocol for the *Communicative Temptations Portion of the Communication and Symbolic Behavior Scales (CSBS;* Wetherby & Prizant, 1993). The CSBS codes language samples according to three early developing categories of communicative functions. Ogletree, Wetherby, and Westling (1992) describe the three main categories as: behavior regulation as requesting or rejecting an object or action, social interaction as requsting a social routine, showing off, or greeting, and joint attention as requesting information or commenting. The test has been normed on both typically developing children, ages 8 to 24 months, and on children with developmental disabilities, ages 18 to 30 months (Wetherby & Prizant, 1993).

A well-known method for assessing communicative function in children with symbolic communication and conversational language is the *Proposed System of Coding Conversational Acts for Profiling Children's Levels of Social-Conversational Participation (PSCCA*, Fey, 1986), which divides functions into two main categories: assertive and responsive conversational acts, with 15 sub-categories. This classification scheme is designed to identify children with language

disorders and classify them by their assertiveness and responsiveness. Fey suggests that the child should be equally as responsive as he/she is assertive. If the child is either more assertive, more responsive, or neither assertive nor responsive, he/she is considered delayed in functional conversation skills.

METHOD

Participants

Twenty-one individuals with CHARGE syndrome participated in this study (11 males and 10 females). The participants' chronological ages range from 1:8 to 20:5 (years:months). The mean age was 8:7, and the median was 8:8. The participants have wide range of physical, sensory, cognitive, and motor impairments. Their communication abilities range from early pre-symbolic communication to conversational language. All participants used intentional communicative behaviors.

The participants were recruited from three different family conferences: Kentucky CHARGE Family Weekend (September 2006); 8th International CHARGE Conference in California (July 2007); Tennessee Deaf-blind Weekend (July 2008). Video-taped recordings were made of 28 individuals. A group of 21 individuals met all of the inclusion criteria for the study: (1) a confirmed diagnosis of CHARGE syndrome, (2) completion of a *HomeTalk* (Harris et al., 2002) parent survey, and (3) a video-taped communication sample conducted with deaf-blind specialist of 15 minutes or longer. The participants have a wide range of communication abilities. However, no attempt was made to ensure that the distribution of communication abilities in the experimental group was representative of the population of individuals with CHARGE syndrome.

The *HomeTalk* (Harris et al., 2002) survey was used to obtain background information from parents that would assist in understanding the individuals' communication capabilities. Bashinski (in press) suggests that family interviews and questionnaires, such as *HomeTalk*, are a

valuable part of assessment of individuals with CHARGE syndrome. The survey contributed information about the child's hearing and vision, communication skills, cognitive and physical development, people skills, problem-solving abilities, exploring one's environment, and discovering and learning. This information was used when viewing and analyzing the video-taped communication samples.

Data Collection

Video-taping Procedures

The video-taped communication sample for each participant was 15-40 minutes in length. The length varied depending on the participant's age and attention. A 15-minute segment of each video tape was selected for analysis. In each communication sample, the deaf-blind specialist attempted to elicit expressive communication from the participant using the participant's preferred communication mode. In some of the tapes, the parents were also in the room interacting with their child for one of several reasons: the child's young age, the child's difficulty adjusting to an unfamiliar environment, or the parents' desire to see the interaction. The deaf-blind specialist attempted to elicit any form of intentional communication from each participant, using toys, games, books, and turn-taking rituals (communication temptations, Wetherby & Prizant, 1993). With higher-functioning individuals, the deaf-blind specialist engaged them in interesting activities or initiated conversations on topics of interest.

Data Analyses

Data Transcription

The video-taped communication samples were first transcribed orthographically by research assistants. These transcriptions included all child actions, vocalizations, and words, along with conversation of the deaf-blind specialist and others who were interacting with the participant. The transcriptions for all participants were then entered into *Systematic Analysis of Language Transcripts* (SALT) software program (Miller & Chapman, 2003). This program was used for the tabulation of the number of occurrences for each communication measure used in the present study.

Communicative Rate

The transcripts were first analyzed to determine which of the acts were considered to be intentional communicative acts. Intentional communicative acts were defined from as "words, gestures, and vocalizations that were directed toward the examiner and that seemed intended to affect the examiner's actions, focus of attention, or both" (Brady et al., 2004; McLean et al., 1991; Wetherby & Prizant 1993). An important measure in the present study, communicative rate, was computed by determining the number of intentional communicative acts per minute (acts/min).

Communicative Form

Each intentional communicative act was then classified according to communicative form and communicative function. Communicative form is divided into two major groups: pre-symbolic and symbolic forms. Twenty-two communicative forms were included in the analysis

and are listed from early developing pre-symbolic forms to symbolic forms. The definitions and abbreviations for these forms are shown in Table 1. Pre-symbolic forms include: crying, tantrums, aggression, physical manipulation, gaze shift giving, showing, reaching, contact pointing, distal pointing, head shaking, head nodding, gestures, vocalizations, and picture exchange. Symbolic forms are: one-word sign, one-word verbalization, one-word sign plus verbalization, multi-word signs, multi-word verbalizations, multi-word signs plus verbalizations, and voice output communication aid (VOCA).

Communicative Function

The 20 categories of communicative functions are divided into three main groups and are arranged from early developing to later developing communicative functions. The definitions and abbreviations for these forms are shown in Table 2. The three groups are as follows:

(1) Behavioral regulation—an act in which the individual attempts to affect another person's behavior. Examples of behavioral regulation are requesting an object, requesting action, and protesting. In each of these examples, the goal of the communication is to cause an action and not to interact with the communicative partner.

(2) Social interaction—an attempt by the individual to interact with a communicative partner. Examples of social interaction are requesting a social routine, requesting comfort, calling, greeting, requesting permission, and showing off.

(3) Conversational acts—an act in which the individual and communicative partner exchange information about an action, object, or topic. Examples of conversational acts include commenting, requesting information, providing information, imitating, requesting

Table 1. Communicative Forms: Definitions and Abbreviations

[Adapted from Wetherby & Prizant, 2003 and McLean & Snyder-McLean, 1999]

Pre-Symbolic Forms	Abbreviations	Definitions
Crying	CRY	vocal cry directed towards an adult, either to protest, request an object or action, or gain attention. Reflexive cries, such as when infants are uncomfortable or sick, are not considered intentional.
Tantrums	TANT	kicking, screaming, and/or flapping arms that is communicative but that is not aimed to injure another person or self.
Aggression	AGRES	aggressive behaviors, such as hitting, kicking, pinching, biting, or any other injurious behavior that is directed towards self or another individual and shows communicative intent.
Gaze Shift	GAZE	change in eye movement and/or body position that has communicative intent.
Physical Manipulation	PM	manipulation of another person's hand or other body part in order to communicate a message.
Giving	GIVE	act of giving an object to another person for a communicative purpose.
Showing	SHOW	holding an object in the other person's view in order to communicate something about that object.
Reaching	REACH	extension of the arm/s and hand/s toward an object or person that is out of reach.
Contact Pointing	CP	use of index finger to point to an object or person while touching that object or person.
Distal Pointing	DP	use of the index finger to point towards an object or person that is out of reach.
Head shake	SHAKE	movement of head side to side to indicate a protest.
Head nod	NOD	movement of the head up and down in order to indicate affirmation.
Gesture	GEST	physical movement that is not a formal sign and is not included in the above list of gestures but communicates a message (e.g., waving hello or good-bye).

Table 1. Continued.

Pre-Symbolic Forms	Abbreviations	Definitions
Vocalizations	VOC	vocal productions of vowels and/or consonants that are directed towards an adult and display communicative function.
Picture Exchange	PIC	exchange of visual pictures/symbols with another person in order to communicate.
Symbolic Forms		
One-word signs	s	recognizable one-word manual signs that are accompanied by communicative intent.
One-word verbalizations	v	recognizable spoken one-word utterances that are accompanied by communicative intent.
One-word signs plus verbalization	s+v	combination of a spoken one-word utterance with its corresponding sign.
Multi-word signs	ss	combination of two or more recognizable signs that have communicative intent.
Multi-word verbalizations	vv	combination of two or more word utterances that have communicative intent.
Multi-word signs plus verbalizations	ss+vv	combination of spoken multi-word utterance with its corresponding signs.
One or multi-word VOCA	VOCA	voice output communication aid on a computerized augmentative and alternative communication device that is used to communicate a message (e.g., Dynavox).

Table 2. Communicative Functions: Definitions and Abbreviations

[Adapted from Wetherby & Prizant, 2003, Prizant, 2001, and Fey, 1986]

Functions	Abbreviations	Definitions
BEHAVIORAL REGULATION		communicative acts that attempt to affect another person's behavior.
Request Object	RQOB	request that the communicative partner give the desired object
Request Action	RQAC	request that the communicative partner perform an action.
Protest	PROT	indication of a disagreement with what the communicative partner is doing/not doing.
SOCIAL INTERACTION		communicative acts seeking interaction with a partner.
Requesting social routine	RQSR	request that the communicative partner interact by performing a social routine (i.e., playing peek-a-boo).
Requesting comfort	RQCT	request that the communicative partner provide comfort (i.e., holding the child, providing favorite blanket).
Greeting	GREET	salutations to a communicative partner when he/she enters or exits (i.e. waving or saying hello and goodbye).
Calling	CALL	attempt to gain the attention of a communicative partner with the intent to communicate something.
Requesting permission	RQPM	request that communicative partner give permission to obtain an object or perform an action.
Showing off	SHOF	communication with the intent to perform or show a skill or object so that the communicative partner may praise or comment.

Table 2. Continued.

Functions	Abbreviations	Definitions
CONVERSATIONAL ACTS		communicative acts used to exchange information about an object or event.
Comments	COMT	identification or description of an object or event that is observable (i.e., "We went to the store today," "That's a ball").
Request information	RQIN	communicative acts that seek information or explanations about an object or event (i.e., rising intonation, palms up gestures, wh-questions).
Provide information	PRIN	communicative act that give information requested by the communicative partner.
Imitation	IMI	partial or complete imitation of the communicative partner's previous utterance, gesture, vocalizations, or action.
Requests for Clarification	RQCL	request that the communicative partner provide clarification of a previous utterance either by repeating or rephrasing.
Statements	ASST	opinion, evaluation, or thoughts that are not directly observable (i.e., "I love ice cream," "I'm finished with that").
Performative	PERF	jokes, warnings, or teasing that are often accompanied by laughing and/or an expectant look.
Response to Requests for Action	RSAC	verbal or gestural communicative act that accompanies a requested action from the partner.
Response to Requests for Clarification	RSCL	attempt to repeat and/or clarify a previous utterance after the communicative partner directly or indirectly requests clarification.
Response to Requests for Attention	RSAT	utterances (i.e., "Yes," "What?") that signal to the partner that he/she is attending to the partner after the partner has requested attention.
Response to Assertives and Performatives	RSAS	responses (i.e., "uh-huh," "okay") that add no new information but let the partner know that he/she is paying attention and that the partner can continue the conversation; agreements.

clarification, statement, performative, response to request for action, response to request for clarification, response to request for action, and response to assertive and performatives.

Coding Schema for Communicative Form and Function

A two-dimensional coding schema was developed for representing each intentional communicative act with regard to form and function. The coding schema is shown in Table 3. The 22 communicative forms are displayed across the top of the table, and the 20 communicative functions are displayed vertically on the left-hand side of the table.

The results for communicative rate were calculated as number of intentional communicative acts/min. This number is listed below the coding schema. The results for communicative form and function were recorded on the coding schema by outlining boxes and shading boxes in which communicative acts occurred. Outlined boxes represent a one-time occurrence, and outlined boxes that are shaded represent an act that occurred two or more times in the sample. The number of occurrences for each act is written in the box.

The table for the coding schema has heavy borders that delineate 6 major sections. The beginning levels of pre-symbolic communication are those that fall within the upper left-hand section. The most advanced levels of symbolic communication are those located in the lower right-hand section of the table. Acts that fall in between these two sections are considered to be transitional, between pre-symbolic and symbolic communication.

The example coding schema in Table 3 shows a child with communication at early pre-symbolic levels. This child requested an object one time using a tantrum as a form of communication and also requested action using the following forms: 15 times through aggression, 2 times using physical manipulation, and one time through showing. His acts all fall

Table 3. Coding Schema for Communicative Forms and Functions

		COMMUNICATIVE FORM																	
COMMUNICATIVE								**Pre-Symbolic**									**Symbolic**		
FUNCTION		CRY	TANT	AGRES	PM	GAZE	GIVE	SHOW	REACH	CP	DP	SHAKE	NOD	GEST	VOC	Pic X	1 word	Multi	VOCA
Behavioral	RQOB		1																
Regulation	RQAC			15	2			1											
	PROT																		
Social	RQSR																		
Interaction	RQCT																		
	GREET																		
	CALL																		
	RQPM																		
	SHOF																		
Conversational	COMT																		
Acts	RQIN																		
	PRIN																		
	IMI																		
	RQCL																		
	ASST																		
	PERF																		
	RSAC																		
	RSCL																		
	RSAT																		
	RSAS																		

Communicative Rate=1.3 acts/min (15 min sample)

in the upper left-hand section, indicating early pre-symbolic communication with a low communicative rate (1.3 acts/min).

Inter-Rater Reliability

Observer Training

Inter-rater reliability for the two observers was established using a two-phase process. The first observer was the investigator. The second observer was a retired speech-language pathologist with 35 years experience. The second observer was trained by the investigator to recognize intentional communicative acts using definitions by Brady et al. (2004) and to classify each intentional communicative act with respect to communicative form and function as shown in Tables 1 and 2. Observer training was conducted using data from several participants whose communication skills varied.

In the training process, the two observers made independent judgments before discussion. They found that their assessment of number of intentional communicative acts was in good agreement for most participants. For participants at the lowest communication levels, their agreement was fair. The two observers also found that they could classify communicative form with near perfect agreement on the 22 category continuum for pre-symbolic and symbolic communication forms. As a result, the reliability measure for communicative form was the percentage of times for which there was exact agreement on the 22 point continuum. However, when independent judgments for communicative function were compared using the 20 category continuum, agreement was less than satisfactory (56%). The observers decided that the resolution of 20 categories of function was not necessary for many of the participants in the

present study at the lower levels of communication, so they decided to group the 20 function categories into three function groups, as shown in Table 2. Thus, the reliability measures for communicative function were based on judgments in three groups of function rather than 20 categories of function.

Reliability Judgments for Communicative Rate

In the first phase of the reliability check, each observer independently determined the number of intentional communicative acts in a 15 minute video-taped sample, and the percentage agreement between observers was computed. The measure of reliability for the number of intentional communicative acts was the percentage agreement between these two observers' judgments. This was done for four of the 21 participants selected at random; none of the four participants were used in the training process.

Reliability Judgments for Communicative Form and Communicative Function

In this phase of the reliability check, the observers independently coded each communicative act for communicative form and communicative function according to the coding schema. Coding was done for the acts that the investigator and observer agreed upon as acts of intentional communication. In calculating reliability percentages for these two measures, the denominator was the number of communicative acts that both observers agreed upon as intentional communicative acts for each participant.

Protocol for Data Analysis

The same process used in the reliability check for communicative rate, form, and function was applied to all remaining data. In order to establish greater reliability for the study, observers

viewed all 21 tapes independently and discussed each participant until 100% reliability was reached for all three measures: number of communicative acts, communicative form, and communicative function. Once the number of communicative acts had been agreed upon, the two observers discussed their independent classifications of form and function for each act reached agreement for the classification of the act. The results presented are a result of the concurrence of the two observers as to the classification of the acts that were identified as intentional communication. Many of these participants were either at very low levels of communication or used unconventional methods of communicating so that discussion of two professionals was necessary to better understand the communication of these individuals.

Other investigators have experienced similar difficulty in reaching agreement on the identification of expressive communicative acts for individuals at low levels of communication and with CHARGE syndrome. Peltokorpi and Huttunen (2008) found that communicative function and form were often difficult to determine because of the individuals' multiple impairments and unconventional ways of communicating. However, the use of discussion between two observers in analyzing communication of these individuals was believed to be the most reliable way to assess the expressive communication in this study.

RESULTS

Inter-Rater Reliability of Data Analysis

Identification of Intentional Communicative Acts

Agreement on the number of intentional communicative acts per session is shown for the four participants in Table 4. For three of the four participants, agreement was equal to or better than 83%. For these three participants, communication abilities were in the intermediate to high level range of function for this experimental sample. The fourth participant (Participant I-1), performed at the lowest communication level. One observer credited the subject with more intentional communicative acts than the other. Upon consultation, the observers agreed that the most accurate count was the smaller number of communicative acts.

Communicative Rate

The communicative rate was determined by the number of intentional communicative acts that the investigator and observer agreed had occurred in the each recording session. The agreed upon set of acts were also the set of acts used for the evaluation of communicative form and function. The measure of communicative rate was acts/min.

Communicative Form and Function

The reliability measures for form and function are also shown in Table 4. The judgments of reliability were made using the communicative acts that both the investigator and observer agreed were intentional acts. For communicative form, the investigator and observer considered their judgments to be in agreement only when there was an exact correspondence of

Table 4. Inter-Rater Reliability for Four Participants (Agreement in %)

Reliability Measures	**Participants**			
	III-1	**II-2**	**II-3**	**I-1**
Number of Intentional Communicative Acts/Session	**94%** (102/108)	**83%** (49/59)	**96%** (48/50)	**58%** (19/33)
Communicative Form	**95%** (97/102)	**98%** (46/47)	**69%** (29/42)	**95%** (18/19)
Communicative Function	**84%** (86/102)	**96%** (45/47)	**88%** (37/42)	**100%** (19/19)

judgments using all 22 form response categories. The reliability was equal or greater than 95% for three of the four participants. The reliability for the fourth participant (II-3) was 69%. This participant used several unconventional forms of communication, such as different body movements that were coded differently by each observer. After discussion, a consensus on communicative forms for this participant was met based on the definitions listed in Table 1.

Reliability for communicative function was calculated according to agreement in the three major categories (behavioral regulation, social interaction, and conversational acts). Inter-rater reliability for the three major categories of communicative function was equal to or greater than 84% for all four participants. After all the tapes were independently coded, the two observers discussed each communicative sample and until they came to 100% agreement on each communicative act for form and function. These procedures were used for the analyses of the remainder of the video-taped samples.

Categorization of Participants into Communication Categories

Results for each participant were plotted on the coding schema and are described below along with background information from parent surveys. The results for each participant are presented in a rank-ordered sequence from the lowest level of communication to the highest levels of communication. Participants were grouped into three communication categories based on a combination of the three communication measures: rate, form, and function. Participants in Category I are early pre-symbolic communicators, while those in Category III are symbolic communicators. Category II is an intermediate category, composed of participants who communicate at a transitional level between pre-symbolic and symbolic communication.

Individual Results

Category I—Pre-symbolic Communication

Participants in Category I had an overall low rate of communication and a limited use of symbolic forms and the conversational acts function. Their communicative rate ranged from 0.7 acts/min (11 total communicative acts) to 5.4 acts/min (81 total communicative acts), with a mean of 1.9 acts/min. Individuals in Category I used pre-symbolic forms for equal to or more than 64% of their total communicative acts. For communicative function, their use of behavioral regulation and social interaction was more than 72% of total communicative acts, with few acts falling into the conversational acts category.

Participant I-1: 4:7 Male (Table 5)

Participant I-1 communicates at an early level of pre-symbolic communication. He has a very limited visual field due to severe nearsightedness, cataracts, and bilateral colobomas. He occasionally wears corrective lenses. He has a hearing impairment of severe to profound that is unaided. He has a severe cognitive delay and uses a wheelchair for mobility. His parent reports that he communicates mainly through emotional responses and direct behaviors. He began receiving speech and language services before age 3. In the video-taped communication sample, he interacted with only one object and participants in a social game initiated by the deaf-blind specialist. Many of his movements and vocalizations were difficult to interpret as intentional.

Communicative Rate: Very low rate (1.4 acts/min).

Communicative Form: Early developing pre-symbolic forms.

Communicative Function: Behavioral regulation only.

Table 5. Communication Coding Schema for Participant I-1: 4:7 Male

		COMMUNICATIVE FORM																	
COMMUNICATIVE								**Pre-Symbolic**									**Symbolic**		
FUNCTION		CRY	TANT	AGRES	PM	GAZE	GIVE	SHOW	REACH	CP	DP	SHAKE	NOD	GEST	VOC	Pic X	1 word	Multi	VOCA
Behavioral	RQOB																		
Regulation	RQAC				18	2							1						
	PROT																		
Social	RQSR																		
Interaction	RQCT																		
	GREET																		
	CALL																		
	RQPM																		
	SHOF																		
Conversational	COMT																		
Acts	RQIN																		
	PRIN																		
	IMI																		
	RQCL																		
	ASST																		
	PERF																		
	RSAC																		
	RSCL																		
	RSAT																		
	RSAS																		

Communicative Rate= 1.4 acts/min (15 min sample)

This participant used a very limited variety of communicative forms (only 3) that were often difficult to interpret. He used only one type of communicative function (request for action) in the behavioral regulation category and did not communicate for social interaction or conversational acts. This participant's communication is significantly delayed on each of the three measures used in the present study.

Participant I-2: 9:0 Female (Table 6)

Participant I-2 also communicates at the beginning levels of intentional communication. She has no functional vision in her right eye due to microopthalmia and coloboma and has reduced vision in her left eye due to choroidal coloboma and myopia. She wears corrective lenses. She has a mixed severe to profound bilateral hearing loss that is aided with hearing aids. She has a significant cognitive delay and poor balance. She is unable to walk independently, and uses a wheelchair for mobility. Her parent reports that she communicates through emotional responses, direct behaviors, gestures, vocalizations, single word signs, and object symbols but that her communication has regressed. She began receiving speech and language therapy at age 3 years. In the video-taped sample, she remained in her wheelchair throughout the taping. Many of her vocalizations and communication acts were not intentional and others were difficult to interpret.

Communicative Rate: Very low rate (1.0 act/min).

Communicative Form: Early developing pre-symbolic forms.

Communicative Function: Behavioral regulation and conversational acts.

This participant communicated very few times in the sample and used only four different pre-symbolic forms to communicate. She used three different communicative functions (request

Table 6. Communication Coding Schema for Participant I-2: 9:0 Female

		COMMUNICATIVE FORM																	
COMMUNICATIVE		Pre-Symbolic														Symbolic		
FUNCTION		CRY	TANT	AGRES	PM	GAZE	GIVE	SHOW	REACH	CP	DP	SHAKE	NOD	GEST	VOC	Pic X	1 word	Multi	VOCA
Behavioral	RQOB				7				5										
Regulation	RQAC				1										1				
	PROT																		
Social	RQSR																		
Interaction	RQCT																		
	GREET																		
	CALL																		
	RQPM																		
	SHOF																		
Conversational	COMT																		
Acts	RQIN																		
	PRIN					1													
	IMI																		
	RQCL																		
	ASST																		
	PERF																		
	RSAC																		
	RSCL																		
	RSAT																		
	RSAS																		

Communicative Rate=1.0 act/min (14:30 min sample)

for object, request for action, provide information) from only two categories. She communicated primarily for the purpose of behavioral regulation and did not communicate for social interaction. Her communication is very delayed in rate, form, and function and falls at the level of beginning intentional communication.

Participant I-3: 3:8 Male (Table 7)

Participant I-3 is also at the beginning level of intentional communication. He has visual impairment caused by bilateral colobomas. He also has a severe hearing loss and wears hearing aids. He is unable to walk independently but uses a walker. He began speech therapy at 1 month of age for swallowing purposes only. His parent reports that he communicates through direct behaviors and emotional responses. In the communication sample, he was very mobile and used the deaf-blind specialist to assist him in standing up and looking around the room. The deaf-blind specialist initiated some interactive games that he participated in.

Communicative Rate: Very low rate (1.3 acts/min).

Communicative Form: Early developing pre-symbolic forms.

Communicative Function: Behavioral regulation and social interaction.

His communicative acts were very limited in variety of forms and functions. He used body movements and change in direction of gaze to communicate, which was sometimes subtle. His communicative functions were limited to requests for action and calling for attention.

Participant I-4: 6:7 Male (Table 8)

Participant I-4 communicates at the beginning level of intentional communication. He has very poor vision due to retinal colobomas and right side retinal detachment. He has a mixed bilateral hearing loss that is aided in the left ear. His parent reports a significant cognitive delay.

Table 7. Communication Coding Schema for Participant I-3: 3:8 Male

		COMMUNICATIVE FORM																	
COMMUNICATIVE		Pre-Symbolic															Symbolic		
FUNCTION		CRY	TANT	AGRES	PM	GAZE	GIVE	SHOW	REACH	CP	DP	SHAKE	NOD	GEST	VOC	Pic X	1 word	Multi	VOCA
Behavioral	RQOB																		
Regulation	RQAC				6	10													
	PROT																		
Social	RQSR																		
Interaction	RQCT																		
	GREET																		
	CALL					3													
	RQPM																		
	SHOW																		
Conversational	COMT																		
Acts	RQIN																		
	PRIN																		
	IMI																		
	RQCL																		
	ASST																		
	PERF																		
	RSAC																		
	RSCL																		
	RSAT																		
	RSAS																		

Communicative rate=1.3 acts/min (15 min sample)

Table 8. Communication Coding Schema for Participant I-4: 6:7 Male

		COMMUNICATIVE FORM																	
COMMUNICATIVE								**Pre-Symbolic**									**Symbolic**		
FUNCTION		CRY	TANT	AGRES	PM	GAZE	GIVE	SHOW	REACH	CP	DP	SHAKE	NOD	GEST	VOC	Pic X	1 word	Multi	VOCA
Behavioral	RQOB								1										
Regulation	RQAC																s 1		
	PROT		1	1	1	1									1				
Social	RQSR																		
Interaction	RQCT																		
	GREET				1														
	CALL																		
	RQPM																		
	SHOF																		
Conversational	COMT																		
Acts	RQIN																		
	PRIN																		
	IMI																s 1	ss 2	
	RQCL																		
	ASST																		
	PERF																		
	RSAC																		
	RSCL																		
	RSAT																		
	RSAS																		

Communicative Rate=0.7 acts/min (15 min sample)

He is unable to walk independently but can walk short distances with assistance of a walker. His parent reports that he mainly uses emotional responses, direct behaviors, and some single word signs to communicate. He began receiving language therapy by age 3. In the communication sample, he was in a supine position on the floor the entire time and interacted better with his mother than with the deaf-blind specialist. He used mostly direct behaviors to communicate, and several of these attempts were difficult to interpret as intentional due to his significant visual impairment.

Communicative Rate: Very low rate (0.7 acts/min).

Communicative Form: Early developing pre-symbolic forms and some symbolic imitations.

Communicative Function: Behavioral regulation, social interaction, and conversational acts.

This participant communicated at the lowest rate of all the participants. He used eight different types of communicative forms, but used most only one time each. He did communicate symbolically 3 times with sign language in imitation. He used only five different kinds of communicative functions (request for object, request for action, protest, greet, and imitation). This child is functioning at the level of early pre-symbolic communication. However, this individual's communication was difficult to analyze due to the extremely low rate at which he communicated.

Participant I-5: 4:3 Female (Table 9)

Participant I-5 communicates at an early pre-symbolic level. She has visual impairment secondary to colobomas and has difficulty seeing objects over six feet away. Her hearing impairment is unknown. Her parent reports that she has a significant cognitive delay and that her

Table 9. Communication Coding Schema for Participant I-5: 4:3 Female

		COMMUNICATIVE FORM																	
COMMUNICATIVE								**Pre-Symbolic**									**Symbolic**		
FUNCTION		CRY	TANT	AGRES	PM	GAZE	GIVE	SHOW	REACH	CP	DP	SHAKE	NOD	GEST	VOC	Pic X	1 word	Multi	VOCA
Behavioral	RQOB					1			19										
Regulation	RQAC						2								3				
	PROT				3										2				
Social	RQSR					2													
Interaction	RQCT																		
	GREET																		
	CALL																		
	RQPM																		
	SHOF																		
Conversational	COMT																		
Acts	RQIN																		
	PRIN																		
	IMI																		
	RQCL																		
	ASST																		
	PERF																		
	RSAC																		
	RSCL																		
	RSAT																		
	RSAS																		

Communicative Rate=2.1 acts/min (15 min sample)

mobility is limited due to low muscle tone and vestibular problems. She walks with the assistance of a walker. She communicates mostly with emotional responses and direct behaviors. Communication therapy was initiated by age 3. In the communication sample, she was sitting upright and playing with a bag of cookie cutters. She poured the toys out of the bag and put them back in several times. This participant vocalized several times during the sample, but most were unintentional vocal play.

Communicative Rate: Low rate (2.1 acts/min).

Communicative Form: Early developing pre-symbolic forms.

Communicative Function: Behavioral regulation and social interaction.

This participant communicated with only five different symbolic forms, but was able to vocalize to communicate, which is a higher level communicative form. She used a limited variety of communicative functions (request object, request action, protest, request social routine). The vast majority of her communicative acts were requesting an object through reaching. She did not use communication to show conversational acts. She has a significant delay in all three communication areas.

Participant I-6: 2:0 Female (Table 10)

Participant I-6 communicates at the pre-symbolic stage of communication. She has a limited visual field and sensitivity to light due to colobomas but otherwise has functional vision. Her hearing loss is a mixed moderate bilateral loss, and she wears hearing aids. She has upper body weakness and is unable to walk independently or sit upright without support. Her primary form of communication is gestures. Language therapy has been initiated. In the communication sample, she interacts with the deaf-blind specialist, her aunt, and her father. Her

Table 10. Communication Coding Schema for Participant I-6: 2:0 Female

COMMUNICATIVE FORM																			
COMMUNICATIVE FUNCTION		**Pre-Symbolic**															**Symbolic**		
		CRY	TANT	AGRES	PM	GAZE	GIVE	SHOW	REACH	CP	DP	SHAKE	NOD	GEST	VOC	Pic X	1 word	Multi	VOCA
Behavioral	RQOB								2		1						s 1		
Regulation	RQAC				4				2					2					
	PROT				1	1									1				
Social	RQSR													1					
Interaction	RQCT																		
	GREET																		
	CALL																		
	RQPM																		
	SHOF																		
Conversational	COMT									1									
Acts	RQIN																		
	PRIN																		
	IMI																		
	RQCL																		
	ASST																		
	PERF																		
	RSAC																		
	RSCL																		
	RSAT																		
	RSAS																		

Communicative rate=1.1 acts/min (15 min sample)

family reported that she did not communicate as frequently as she does in her home environment.

Communicative Rate: Very low rate (1.1 acts/min).

Communicative Form: Later developing pre-symbolic forms.

Communicative Function: Behavioral regulation, social interaction, and conversational acts.

This participant did not communicate very often but used some later developing pre-symbolic forms of communication (distal point, gesture, and vocalization). She also used a symbolic form of communication (signed language) on one occasion. She used all three communicative function categories, but mainly used communication for behavioral regulation. She is at the level of developing pre-symbolic communication, and considering her age, her expressive communication is mainly delayed in rate.

Participant I-7: 4:8 Male (Table 11)

Participant I-7 communicates at a pre-symbolic level. His vision is affected by farsightedness and diplopia, and he has a mild high frequency hearing loss that is unaided. He is unable to walk independently and has a trachesotomy. His parent reports a cognitive delay and that he communicates mostly through gestures. He began communication therapy at age 3. In the video-taped sample, he moves around the room frequently and participates with several different toys and games.

Communicative Rate: Low rate (2.1 acts/min).

Communicative Form: Early pre-symbolic forms.

Communicative Function: Behavioral regulation, social interaction, and conversational acts.

This participant uses a limited number of early pre-symbolic forms, but does uses a

Table 11. Communication Coding Schema for Participant I-7: 4:8 Male

COMMUNICATIVE FORM																			
COMMUNICATIVE FUNCTION		Pre-Symbolic															Symbolic		
		CRY	TANT	AGRES	PM	GAZE	GIVE	SHOW	REACH	CP	DP	SHAKE	NOD	GEST	VOC	Pic X	1 word	Multi	VOCA
Behavioral	RQOB																		
Regulation	RQAC				4				1					1					
	PROT		1																
Social	RQSR					6													
Interaction	RQCT																		
	GREET																		
	CALL					1													
	RQPM																		
	SHOF					1								12					
Conversational	COMT																		
Acts	RQIN																		
	PRIN																		
	IMI																		
	RQCL																		
	ASST																		
	PERF																		
	RSAC																		
	RSCL																		
	RSAT					3			1										
	RSAS																		

Communicative Rate=2.1 acts/min (15 min sample)

higher pre-symbolic form (gesture). He uses only six different communicative forms but uses all three categories of communicative function. His most frequent communicative act used for showing off. He is at the pre-symbolic level of communication but shows some positive indicators for communication development with the variety of communicative functions and forms.

Participant I-8: 10:2 Male (Table 12)

Participant I-8 communicates at a pre-symbolic level of communication. He has impaired vision due to colobomas of both retinas and of the left iris but has functional vision with corrective lenses. He has a bilateral sensorineural hearing loss that is 60 decibels in the left ear and profound in the right ear. He is considered cognitively delayed and has balance difficulty but is able to walk independently. His parent reports that he uses mainly direct behaviors to communicate. He began communication therapy by age 3. This participant was laying on the floor for the video-taped sample and was playing with a balloon for the majority of the sample.

Communicative Rate: Medium rate (5.4 acts/min).

Communicative Form: Early pre-symbolic and symbolic form.

Communicative Function: Behavioral regulation and conversational acts.

This participant uses several different pre-symbolic forms, using early developing forms of aggression and physical manipulation the most. He does use sign language, but only uses one to two of the same signs repeatedly. His communicative functions are mostly limited to behavioral regulations. He uses conversational acts only one time to imitate and does not use the function social interaction. This participant communicates more often than the previous

Table 12. Communication Coding Schema for Participant I-8: 10:2 Male

COMMUNICATIVE FORM																			
COMMUNICATIVE FUNCTION		**Pre-Symbolic**															**Symbolic**		
		CRY	TANT	AGRES	PM	GAZE	GIVE	SHOW	REACH	CP	DP	SHAKE	NOD	GEST	VOC	Pic X	1 word	Multi	VOCA
Behavioral	RQOB				1				5										
Regulation	RQAC				36				5					2			s 15		
	PROT	1		6	5	2									2				
Social	RQSR																		
Interaction	RQCT																		
	GREET																		
	CALL																		
	RQPM																		
	SHOF																		
Conversational	COMT																		
Acts	RQIN																		
	PRIN																		
	IMI																s 1		
	RQCL																		
	ASST																		
	PERF																		
	RSAC																		
	RSCL																		
	RSAT																		
	RSAS																		

Communicative Rate=5.4 acts/min (15 min sample)

participants but for a limited number of purposes. More than half of his communicative attempts were requests for the same action (blowing up and letting go of the balloon).

Category II—Transitional Communication

Participants in Category II used both pre-symbolic and symbolic forms of communication. They differed from individuals in Category I in that they had higher rates of communication. Their rate of communication ranged from 1.7 acts/min (25 total communicative acts) to 7.8 acts/min (123 total communicative acts), with a mean of 3.8 acts/min. Participants in this category used a combination of pre-symbolic and symbolic forms, using symbolic forms for equal to or greater than 20% of their total communicative acts. They also showed more variety in their use of communicative functions. They had to have communicative acts in two or more categories of function and use the function conversational acts equal to or greater than 10% of the time. These participants were considered to be at the level of transitional communication, between pre-symbolic and symbolic communication. However, it can not be inferred that these participants will or have reached the level of symbolic communication.

Participant II-1: 6:6 Female (Table 13)

Participant II-1 communicates at the level of emerging symbolic communication. She has depth perception problems and is sensitive to bright light. She has a moderate to severe sensorineural loss in the right ear and a severe to profound loss in the left ear and wears one hearing aid. She is able to walk independently but has some balance problems due to vestibular anomalies. She has a cognitive delay and communicative most often through direct behaviors. This participant began receiving speech and language services at age 3 months. In the

Table 13. Communication Coding Schema for Participant II-1: 6:6 Female

COMMUNICATIVE FORM																			
COMMUNICATIVE								**Pre-Symbolic**									**Symbolic**		
FUNCTION		CRY	TANT	AGRES	PM	GAZE	GIVE	SHOW	REACH	CP	DP	SHAKE	NOD	GEST	VOC	Pic X	1 word	Multi	VOCA
Behavioral	RQOB																		
Regulation	RQAC					2													
	PROT																		
Social	RQSR																		
Interaction	RQCT																		
	GREET																		
	CALL																		
	RQPM																		
	SHOF							1											
Conversational	COMT																		
Acts	RQIN																		
	PRIN					3								2					
	IMI																s 14		
	RQCL																		
	ASST																		
	PERF																		
	RSAC																	ss 2	
	RSCL																		
	RSAT					1													
	RSAS																		

Communicative Rate=1.7 acts/min (15 min sample)

communication sample, this child is sitting upright and participates well with the deaf-blind specialist but does not communicate very often.

Communicative Rate: Very low rate (1.7 acts/min).

Communicative Form: Early developing pre-symbolic forms and symbolic forms

Communicative Function: Behavioral regulation, social interaction, and conversational acts.

This participant communicated with some early developing pre-symbolic forms (gaze, show), gestures, and a symbolic form (sign language). She used six different communicative functions but most often communicated for the purpose of conversational acts. This participant's communication sample was difficult to analyze because she used some later developing communicative forms and functions but communicated at a very low rate.

Participant II-2: 9:1 Male (Table 14)

Participant II-2 communicates between a pre-symbolic and symbolic level of communication. His visual impairments are as follows: significant near-sightedness, poor depth perception, and poor peripheral vision due to colobomas. His hearing loss is unknown. He also has a cognitive delay and is unable to walk independently. He primarily uses direct behaviors beginning to use some manual signs. This participant did not begin receiving communication therapy by age 3. In the video sample, this participant was laying face down on the ground for the entire interaction and had limited movement of his hands and extremeties in this position. The sample mainly consisted of him and deaf-blind specialist playing with a balloon.

Communicative Rate: Low rate (3.4 acts/min).

Communicative Form: Early developing pre-symbolic forms and one symbolic form.

Communicative Function: Behavioral regulation, social interaction, and conversational

Table 14. Communication Coding Schema for Participant II-2: 9:1 Male

COMMUNICATIVE FORM																			
COMMUNICATIVE FUNCTION		**Pre-Symbolic**															**Symbolic**		
		CRY	TANT	AGRES	PM	GAZE	GIVE	SHOW	REACH	CP	DP	SHAKE	NOD	GEST	VOC	Pic X	1 word	Multi	VOCA
Behavioral	RQOB								1								s 3		
Regulation	RQAC				5		6		1								s 23		
	PROT			1											5				
Social	RQSR																		
Interaction	RQCT																		
	GREET																		
	CALL					1													
	RQPM																		
	SHOF																		
Conversational	COMT														1				
Acts	RQIN																		
	PRIN								2										
	IMI								1										
	RQCL																		
	ASST																		
	PERF																		
	RSAC																		
	RSCL																		
	RSAT														1				
	RSAS																		

Communicative Rate=3.4 acts/min (15 min sample)

acts.

This participant uses six different communicative forms, but uses mostly physical manipulation to communicate. He does use a symbolic form (signed language) to request but uses the same word repeatedly. This child uses all three types of communicative functions, but behavioral regulation accounts for the highest percentage of his communicative acts.

Participant II-3: 9:2 Female (Table 15)

Participant II-3 communicates at a pre-symbolic level. She has limited vision due to bilateral colobomas and a right retinal detachment. Her hearing loss is severe to profound, and she wears a cochlear implant. She is unable to walk independently and typically uses a wheelchair. Her cognitive delay is unknown. She communicates mainly through direct behaviors and emotional responses. This participant began receiving speech and language services around 3 months of age. Much of the communication sample consists of the deaf-blind specialist feeding the participant.

Communicative Rate: Low rate (3.3 acts/min).

Communicative Form: Early developing and later developing pre-symbolic forms and one symbolic form.

Communicative Function: Behavioral regulation, social interaction, and conversational acts.

This participant uses a wide variety of pre-symbolic forms to communicate. She uses a few later developing pre-symbolic forms (distal point, head nod, gesture, vocalization) and a symbolic form (sign language). While she does use all three categories of communicative function, the majority of her communicative acts are for behavioral regulation.

Table 15. Communication Coding Schema for Participant II-3: 9:2 Female

		COMMUNICATIVE FORM																
COMMUNICATIVE		Pre-Symbolic														Symbolic		
FUNCTION		CRY	TANT	AGRES	PM	GAZE	GIVE	SHOW	REACH	CP	DP	SHAKE	NOD	GEST	VOC	Pic X	1 word	Multi	VOCA
Behavioral	RQOB								1		1								
Regulation	RQAC				8	2	2		10		1						s 1		
	PROT		4												4				
Social	RQSR																		
Interaction	RQCT																		
	GREET																		
	CALL									1									
	RQPM																		
	SHOF					1							1	1					
Conversational	COMT																		
Acts	RQIN																		
	PRIN								1				1						
	IMI																s 9		
	RQCL																		
	ASST																		
	PERF																		
	RSAC																		
	RSCL																		
	RSAT																		
	RSAS																		

Communicative Rate=3.3 acts/min (15 min sample)

Participant II-4: 1:8 Male (Table 16)

Participant II-4 communicates at the level of emerging symbolic communication. He has bilateral colobomas, but vision is reported to be a functional strength for him. He has a profound mixed hearing loss in the right ear and a severe loss in the left ear. He wears a hearing aid in the left ear. He has no known cognitive delay. He is unable to walk independently due to vestibular anomalies. His parent reports that he mainly communicates through gestures and one-word signs. This participant has begun receiving speech and language services. In the communication sample, he interacts with the deaf-blind specialist and his mom. He participates in several social routines that his mother initiates.

Communicative Rate: Low rate (2.6 acts/min).

Communicative Form: Pre-symbolic and one symbolic form.

Communicative Function: Behavioral regulation, social interaction, and conversational acts.

This participant communicates with four different pre-symbolic forms. He uses gestures, which is a later developing pre-symbolic form and uses a symbolic form (sign language) several times throughout the sample. He mainly uses communication for behavioral regulation, but uses communication for social interaction and conversational acts several times throughout the sample.

Participant II-5: 3:5 Male (Table 17)

Participant II-5 is at the emerging stage of symbolic language development. This child is not considered deaf-blind but has visual impairment due to far-sightedness. He cannot walk independently and uses a walker. His parents report signs of a cognitive delay and tactile defensiveness. His parents report that he uses a combination of emotional responses, direct

Table 16. Communication Coding Schema Participant II-4: 1:8 Male

COMMUNICATIVE FORM																			
COMMUNICATIVE								**Pre-Symbolic**									**Symbolic**		
FUNCTION		CRY	TANT	AGRES	PM	GAZE	GIVE	SHOW	REACH	CP	DP	SHAKE	NOD	GEST	VOC	Pic X	1 word	Multi	VOCA
Behavioral	RQOB								2								s 8		
Regulation	RQAC						5			1				1			s 1		
	PROT													2					
Social	RQSR													1					
Interaction	RQCT																		
	GREET																		
	CALL								5										
	RQPM																		
	SHOF																		
Conversational	COMT																		
Acts	RQIN																		
	PRIN																s 2		
	IMI								1	7							s 3		
	RQCL																		
	ASST																		
	PERF																		
	RSAC																		
	RSCL																		
	RSAT																		
	RSAS																		

Communicative Rate=2.6 acts/min (15 min sample)

Table 17. Communication Coding Schema for Participant II-5: 3:5 Male

		COMMUNICATIVE FORM																	
COMMUNICATIVE		Pre-Symbolic														Symbolic		
FUNCTION		CRY	TANT	AGRES	PM	GAZE	GIVE	SHOW	REACH	CP	DP	SHAKE	NOD	GEST	VOC	Pic X	1 word	Multi	VOCA
Behavioral	RQOB								2		2								
Regulation	RQAC					1	1		2								s 2		
	PROT																		
Social	RQSR																		
Interaction	RQCT																		
	GREET													1					
	CALL					1													
	RQPM																		
	SHOF					1								1					
Conversational	COMT													1					
Acts	RQIN										1								
	PRIN								1	7				6			s 2		
	IMI									1				2			s 16		
	RQCL																		
	ASST																		
	PERF																		
	RSAC						1												
	RSCL													2					
	RSAT																		
	RSAS																		

Communicative Rate=3.6 acts/min (15 min sample)

behaviors, gestures, sounds, and single-word signs to communicate. He began language therapy at the age of 1:5. In this sample, the child interacts well with the deaf-blind specialist while sitting on the floor and playing with mainly one toy.

Communicative Rate: Low rate (3.6 acts/min).

Communicative Form: Early and later developing pre-symbolic and symbolic forms.

Communicative Function: Behavioral regulation, social interaction, and conversational acts.

While this participate had a low rate of communication, he used several different communicative forms, including later-developing pre-symbolic forms (distal point, gestures) and a one-word symbolic form (sign language). He used a variety of communicative functions, with conversational acts being the most common. He had a high rate of symbolic imitative acts.

Participant II-6: 8:8 Male (Table 18)

Participant II-6 communicates at the level of pre-symbolic communication. He has a limited visual field secondary to bilateral colobomas. His hearing loss is mixed moderate in the right ear and moderate to severe in the left ear. He wears hearing aids bilaterally. He is able to walk independently but is unstable. He does have a cognitive delay. His parent reports that he communicates most often by using gestures. This participant began receiving speech and language services around 1 year of age. In the video-taped sample, this participant is anxious and upset because he has difficulty transitioning from one environment to another. The deaf-blind specialist, however, is able to get him to interact in some turn-taking activities.

Communicative Rate: High rate (7.8 acts/min).

Communicative Form: Pre-symbolic and symbolic forms.

Communicative Function: Behavioral regulation and joint attention.

Table 18. Communication Coding Schema for Participant II-6: 8:8 Male

COMMUNICATIVE FORM																			
COMMUNICATIVE FUNCTION		**Pre-Symbolic**															**Symbolic**		
		CRY	TANT	AGRES	PM	GAZE	GIVE	SHOW	REACH	CP	DP	SHAKE	NOD	GEST	VOC	Pic X	1 word	Multi	VOCA
Behavioral	RQOB																		
Regulation	RQAC	1	1		3		1			3				3	12		s 1		
	PROT	5	4	14										1	2				
Social	RQSR																		
Interaction	RQCT																		
	GREET																		
	CALL																		
	RQPM																		
	SHOF																		
Conversational	COMT																		
Acts	RQIN																		
	PRIN													1			s 1		
	IMI									1			1	2	16		s 30	ss 14	
	RQCL																		
	ASST																		
	PERF																		
	RSAC																		
	RSCL																		
	RSAT																		
	RSAS																		

Communicative Rate=7.8 acts/min (15 min sample)

This participant communicates with a variety of early-developing and later-developing pre-symbolic and symbolic forms. He uses sign language in one-word and two-word combinations, mostly in imitation. He uses behavioral regulation frequently for requesting and protesting. Imitation was the communicative function he used most frequently. His rate of communication is appropriate for his communication level, but his variety of communicative forms and functions is significantly reduced.

Participant II-7: 13:1 Male (Table 19)

Participant II-7 communicates at an emerging symbolic level. His parent reports that his vision is stable, and he wears glasses. He has severe to profound hearing loss in his left ear and mild to moderate hearing loss in his right ear; both ears are aided. He is able to walk independently, with some balance problems. His trachesotomy prevents him from vocalizing. His parent reports that he has a cognitive delay and that he uses signs, gestures, and emotional responses to communicate. Communication therapy was initiated by age 3. The interaction in the communication sample consisted of the deaf-blind specialist and participant playing a board game, with the deaf-blind specialist asking many questions.

Communicative Rate: Medium rate (4.1 acts/min).

Communicative Form: Later-developing pre-symbolic and symbolic forms.

Communicative Function: Behavioral regulation, social interaction, and conversational acts.

This participant used higher level pre-symbolic forms and one-word and two-word symbolic forms (sign language). He mainly used the communicative function conversational acts most frequently, which is a later-developing function. Several of his communicative acts were symbolic, but nearly all were at the 1-word stage. This participant used a good variety of

Table 19. Communication Coding Schema for Participant II-7: 13:1 Male

		COMMUNICATIVE FORM																	
COMMUNICATIVE		Pre-Symbolic															Symbolic		
FUNCTION		CRY	TANT	AGRES	PM	GAZE	GIVE	SHOW	REACH	CP	DP	SHAKE	NOD	GEST	VOC	Pic X	1 word	Multi	VOCA
Behavioral	RQOB																		
Regulation	RQAC																s 1		
	PROT																		
Social	RQSR																		
Interaction	RQCT																		
	GREET																		
	CALL																		
	RQPM					1		1											
	SHOF																		
Conversational	COMT									2							s 4		
Acts	RQIN																	ss 1	
	PRIN									8			13				s 9	ss 1	
	IMI									1				1			s 1		
	RQCL																		
	ASST																		
	PERF							3		1									
	RSAC					1				2									
	RSCL																	ss 1	
	RSAT																		
	RSAS												9						

Communicative Rate-4.1 acts/min (15 min sample)

communicative forms and later-developing functions.

Category III—Symbolic Communicators

Participants in Category III all utilized symbolic communication as their primary mode of communication. They also communicated at higher rates than those in Categories I or II. Their rate of communication ranged from 6.5 acts/min (97 total communicative acts) to 12.5 acts/min (187 total communicative acts) with a mean of 8.6 acts/min. These individuals communicated mainly through symbolic forms, and more than 60% of all communicative acts were symbolic. These participants used the highest level of communicative function (conversational acts) for more than 60% of their total number of communicative acts.

Participant III-1: 20:5 Male (Table 20)

This participant uses symbolic communication. He has bilateral retinal colobomas and left retinal detachment, resulting in limited vision in his right eye. He wears corrective lenses. He has a moderate to severe mixed hearing that is aided bilaterally. He is able to walk independently. Parents describe him as having a severe cognitive delay with tantrums and autistic-like outbursts. He communicates most often through direct behaviors and signs. He began receiving speech and language therapy at age 8 months. This video-taped sample consisted mostly of the participant asking for or trying to pop a balloon. He also showed obsessive compulsive tendencies for opening or popping objects or toys.

Communicative Rate: High rate (7.0 acts/min).

Communicative Form: Pre-symbolic and symbolic forms.

Communicative Function: Behavioral regulation, social interaction, and conversational acts.

This participant uses several different pre-symbolic forms along with several symbolic

Table 20. Communication Coding Schema for Participant III-1: 20:5 Male

COMMUNICATIVE FORM																			
COMMUNICATIVE FUNCTION		Pre-Symbolic															Symbolic		
		CRY	TANT	AGRES	PM	GAZE	GIVE	SHOW	REACH	CP	DP	SHAKE	NOD	GEST	VOC	Pic X	1 word	Multi	VOCA
Behavioral	RQOB																v 1		
Regulation	RQAC				13		5				1						v, s+v 8	vv 2	5
	PROT				1										1		v 2		
Social	RQSR																		
Interaction	RQCT																		
	GREET																		
	CALL				1														
	RQPM										2								
	SHOW																		
Joint	COMT																v 17	vv 8	1
Attention	RQIN																		
	PRIN				1												v 4		
	IMI													1			s, v 10	ss,vv 4	
	RQCL																		
	ASST																		
	PERF																v 1		
	RSAC				1									1			v 1		1
	RSCL																v 5	vv 1	
	RSAT																		
	RSAS																v 8		

Communicative Rate=7.0 acts/min (15 min sample)

forms to communicate. He communicated with signs, verbalizations, and also uses a voice output communication aid (VOCA), where he spells several words and communicates a message through a digital voice output. He used all three categories of communicative function, but continues to utilized behavioral regulation frequently even though he can use higher-level communicative functions, such as response to request for clarification. He uses symbolic communication but for limited topics.

Participant III-2: 6:9 Female (Table 21)

Participant III-2 communicates at the beginning level of symbolic communication. She has significant visual impairment due to a left retinal detachment and bilateral colobomas of the retina and optic nerves. She wears corrective lenses and also has a tracheostomy. Her hearing loss is level sensorineural and aided. She has no known cognitive delay and is able to walk, run, and jump independently. This child communicates primarily through American Sign Language. She began receiving communication therapy by age 3. Half of the interaction consists of the deaf-blind specialist asking the participant to label several objects in a vocabulary book. She vocalized frequently in the sample, but many of her vocalizations were faint and very difficult to understand.

Communicative Rate: High rate (8.6 acts/min).

Communicative Form: Pre-symbolic and symbolic forms.

Communicative Function: Behavioral regulation, social interaction, and conversational acts.

This participant uses a wide variety of early developing and later developing pre-symbolic and symbolic forms to communicate. Her symbolic forms of communication include several one-word signs or verbalizations, signs plus verbalizations, and one two-word sign. She

Table 21. Communication Coding Schema for Participant III-2: 6:9 Female

COMMUNICATIVE FORM																			
COMMUNICATIVE		**Pre-Symbolic**														**Symbolic**		
FUNCTION		CRY	TANT	AGRES	PM	GAZE	GIVE	SHOW	REACH	CP	DP	SHAKE	NOD	GEST	VOC	Pic X	1 word	Multi	VOCA
Behavioral	RQOB													1					
Regulation	RQAC						2		4						1				
	PROT				2		1		2			2		2	1		v 3		
Social	RQSR																		
Interaction	RQCT																		
	GREET																		
	CALL																		
	RQPM														1				
	SHOF													2	3		s+v 5		
Conversational	COMT							1		4							s,s+v,v 4		
Acts	RQIN									3							s 2		
	PRIN									3			7	2			s,s+v,v 47		
	IMI																s,s+v,v 8	ss 1	
	RQCL																		
	ASST																s 2		
	PERF																v 2		
	RSAC																		
	RSCL												2				s, v 3		
	RSAT																		
	RSAS												3				s+v, v 2		

Communicative Rate=8.6 acts/min (15 min sample)

uses thirteen different communicative functions, including several later-developing functions, like statement and response to assertives and performatives. The majority of her acts fell into provide information, which was influenced by the deaf-blind specialist asking her to label pictures.

Participant III-3: 19:7 Female (Table 22)

Participant III-3 is an adult at the conversational level of language development. She has low visual acuity due to optic nerve pits, colobomas, severe myopia, nystagmus, and left exotropia. She wears corrective lenses. She has a mixed severe to profound bilateral hearing loss and wears hearing aids. Her mobility is impaired by her poor vestibular functioning, but she is able to walk independently. Her primary mode of communication is speech. She first began speech language therapy at age 7 months. In the video-taped sample, she mostly uses speech to communicate. Her utterances were sometimes difficult to interpret due to her lowered speech intelligibility and difficulty maintaining topic of conversation.

Communicative Rate: High rate (9.3 acts/min).

Communicative Form: Later-developing pre-symbolic and symbolic forms.

Communicative Function: Social interaction and conversational acts.

This participant uses mostly multi-word verbalizations to communicate. Most of her communicative functions fall under conversational acts, and she uses nine different communicative functions. She uses a wide variety of communicative functions but has difficulty maintaining conversational topics.

Participant III-4: 9:6 Female (Table 23)

Participant III-4 communicates at a conversational level. She has vision impairment due to colobomas, nystagmas, 7th nerve paresis, and several other visual problems, but her vision is

Table 22. Communication Coding Schema for Participant III-3: 19:7 Female

		COMMUNICATIVE FORM																	
COMMUNICATIVE								**Pre-Symbolic**									**Symbolic**		
FUNCTION		CRY	TANT	AGRES	PM	GAZE	GIVE	SHOW	REACH	CP	DP	SHAKE	NOD	GEST	VOC	Pic X	1 word	Multi	VOCA
Behavioral	RQOB																		
Regulation	RQAC																		
	PROT																		
Social	RQSR																		
Interaction	RQCT																		
	GREET																		
	CALL																		
	RQPM																		
	SHOF													3					
Conversational	COMT																	vv 37	
Acts	RQIN																	vv 1	
	PRIN												4				v 24	vv 31	
	IMI																	vv 1	
	RQCL																		
	ASST																	vv 17	
	PERF																v 1		
	RSAC																		
	RSCL												1				v 10	vv 2	
	RSAT																		
	RSAS											1	3				v 3		

Communicative Rate=9.3 acts/min (15 min sample)

Table 23. Communication Coding Schema for Participant III-4: 9:6 Female

COMMUNICATIVE FORM																			
COMMUNICATIVE		Pre-Symbolic															Symbolic		
FUNCTION		CRY	TANT	AGRES	PM	GAZE	GIVE	SHOW	REACH	CP	DP	SHAKE	NOD	GEST	VOC	Pic X	1 word	Multi	VOCA
Behavioral	RQOB																		
Regulation	RQAC													1				vv 4	
	PROT														1		v 1		
Social	RQSR																		
Interaction	RQCT																		
	GREET																		
	CALL																	vv 1	
	RQPM																		
	SHOF																		
Conversational	COMT																	vv 4	
Acts	RQIN							1									v 1	vv 14	
	PRIN																v 38	vv 10	
	IMI																		
	RQCL																		
	ASST																v 1	vv 2	
	PERF																		
	RSAC																		
	RSCL													1			v 8	vv 5	
	RSAT																		
	RSAS																v 3	vv 1	

Communicative Rate=6.5 acts/min (15 min sample)

functional with corrective lenses. She has a severe to profound mixed hearing loss bilaterally that is aided with a BAHA Divino Implant. She is able to walk independently. Her primary mode of communication is speech. She began receiving communication therapy at 12 months of age. Throughout the sample, her speech was quiet and often difficult to understand, but she responded well to requests for clarification.

Communicative Rate: High rate (6.5 acts/min).

Communicative Form: Symbolic and some pre-symbolic forms.

Communicative Function: Behavioral regulation, social interaction, and conversational acts.

This participant uses symbolic language in one-word and multi-word phrases. She uses communicative functions in all three categories, but mainly uses conversational acts functions. She uses nine different communicative functions, with the provide information function being used most often. She showed a wide variety of communicative functions and an ability to maintain topics.

Participant III-5: 9:1 Female (Table 24)

Participant III-5 communicates at a conversational level. Her vision is nearly perfect in her left eye but very poor in her right eye due to colobomas. She wears corrective lenses. She has a moderate to severe hearing loss that is aided with hearing aids. She is able to walk independently and can run and jump. It is not known whether or not she has a cognitive delay, but she is able to participate in a regular classroom at school. She communicates through speech. She began receiving communication therapy between ages 3 to 6 months. This communication sample consists of the deaf-blind specialist interviewing the participant. This child is very talkative but a few of her verbalizations unintelligible related to an un-repaired palatal fistula.

Table 24. Communication Coding Schema for Participant III-5: 9:1 Female

		COMMUNICATIVE FORM																	
COMMUNICATIVE		Pre-Symbolic															Symbolic		
FUNCTION		CRY	TANT	AGRES	PM	GAZE	GIVE	SHOW	REACH	CP	DP	SHAKE	NOD	GEST	VOC	Pic X	1 word	Multi	VOCA
Behavioral	RQOB																		
Regulation	RQAC																	vv 2	
	PROT																v 1	vv 1	
Social	RQSR																		
Interaction	RQCT																		
	GREET																		
	CALL																		
	RQPM																		
	SHOF																		
Conversational	COMT																	vv 29	
Acts	RQIN																	vv 6	
	PRIN																v 6	vv 32	
	IMI																		
	RQCL																		
	ASST																	vv 15	
	PERF																	vv 3	
	RSAC																		
	RSCL																v 6	vv 5	
	RSAT																		
	RSAS																v 5	vv 1	

Communicative Rate=7.5 acts/min (15 min sample)

Communicative Rate: High rate (7.5 acts/min).

Communicative Form: Symbolic forms.

Communicative Function: Behavioral regulation and conversational acts.

This participant uses only symbolic forms of communication, one-word and multi-word spoken utterances. The majority of her communicative acts were conversational acts. She uses nine different communicative functions. She showed a wide variety of functions and a high rate of communication, with an ability to maintain topics of conversation. This participant communicates at a near-age appropriate level of symbolic language with some deficits in intelligibility of spoken language.

Participant III-6: 17:11 Female (Table 25)

Participant III-6 communicates at a conversational level with spoken language. She has very limited vision due to colobomas and wears glasses. Her hearing loss is a mixed moderate to severe loss that is aided with conventional hearing aids. She is able to walk independently but walks with a wide base step. She communicates through spoken language and began receiving communication therapy at age 3 months. The video-taped communication sample consists of the deaf-blind specialist interviewing the participant.

Communicative Rate: High rate (12.5 acts/min).

Communicative Form: Symbolic forms.

Communicative Function: Behavioral regulation and conversational acts.

This participant communicates with one-word and multi-word spoken utterances. The vast majority of her acts involved conversational acts. She used ten different communicative functions and was the only participant to request for clarification. Her communication was at the highest level of all the participants.

Table 25. Communication Coding Schema for Participant III-6: 17:11 Female

		COMMUNICATIVE FORM																	
COMMUNICATIVE								**Pre-Symbolic**									**Symbolic**		
FUNCTION		CRY	TANT	AGRES	PM	GAZE	GIVE	SHOW	REACH	CP	DP	SHAKE	NOD	GEST	VOC	Pic X	1 word	Multi	VOCA
Behavioral	RQOB																		
Regulation	RQAC																	vv 1	
	PROT																		
Social	RQSR																		
Interaction	RQCT																		
	GREET																		
	CALL																		
	RQPM																		
	SHOF																		
Conversational	COMT																	vv 37	
Acts	RQIN																v 2	vv 3	
	PRIN																v 5	vv 52	
	IMI																		
	RQCL																	vv 2	
	ASST																	vv 32	
	PERF																		
	RSAC																v 2		
	RSCL																v 2	vv 5	
	RSAT																v 1		
	RSAS																v 34	vv 8	

Communicative Rate=12.5 acts/min (15 min sample)

Group Results

The results are shown in Table 26 for the three participant communication categories: Category I (pre-symbolic), Category II (transitional), and Category III (symbolic). The large block on the left side of the table shows the results for the three communication measures (form, function, and rate). On the right-hand side of the table, selected background information is summarized for each category of participants.

Communication Measures

In Table 26, the results for communicative form (pre-symbolic and symbolic) are shown. The measure is the average percent usage of symbolic communication in each of the three communication categories. In Category I, the mean usage of symbolic communication was 8% of the total number of intentional communication acts. For Category II, the mean increased to 40%, and in Category III, to 87%.

In the middle part of the Communication Measures section, results for communicative function are summarized according to the three categories of function (behavioral regulation, social interaction, and conversational acts). For participants in Category I, it can be seen that the vast majority of communicative acts (80%) were for purpose of behavioral regulation, a smaller percentage of acts were used for social interaction (13%), and the fewest number of acts involved conversational acts (7%). At the other extreme, in Category III, only a small percentage of the acts were associated with behavioral regulation (11%) and social interaction (2%). The vast majority of communicative acts for these participants involved conversational acts (87%). The results in Category II fell between the results for Categories I and III.

Table 26. Group Data Compared Across Communication Measures and Categories of Background Information as a Function of Communication Category

Communication Categories	Communication Measures					Background Information			
	Form	Function			Mean Rate (acts/ min)	Mean Age [Range] (years: months)	Gender	Language Therapy By Age 3 Years	Walks Indepen-dently
	(Average % of total intentional communicative acts)								
	Symbolic Acts	Behavioral Regulation	Social Interaction	Conversational acts					
Category I Pre-symbolic (N=8)	**8%**	**80%**	**13%**	**7%**	**1.9**	**5:9 [2:0-10:2]**	**5M:3F**	**7/8**	**1/8**
Category II Transitional (N=7)	**40%**	**40%**	**5%**	**55%**	**3.8**	**7:4 [1:8-13:1]**	**5M:2F**	**6/7**	**3/7**
Category III Symbolic (N=6)	**87%**	**11%**	**2%**	**87%**	**8.6**	**13:10 [6:9-20:5]**	**1M:5F**	**6/6**	**6/6**

For rate of communication, the measure was the mean rate in acts per minute for a 15-minute communication sample. For Categories I to II to III, the mean rate of communication increased from 1.9 to 3.8 to 8.6 acts/min.

Background Information

On the right-hand side of the table, selected background information for the three groups has been summarized for the following factors: gender, age, language therapy initiated by age three, and the ability to walk independently.

Gender

There are more males than females in Category I (5:3) and Category II (5:2). For Category III, there are many more females than males (1:5).

Age

The mean age for Category I is 5:9 (range = 2:0 to 10:2); for Category II, 7:4 (range = 1:8 to13:1); Category III, 13:10 (range = 6:9 to 20:5).

Language Therapy Initiated by 3 Years of Age

In the present study, language therapy was initiated by age 3 for the majority of participants in each of the three categories. In Category I, 7 of the 8 participants had language therapy by age 3, 6 of 7 participants in Category II, and 6 of 6 participants in Category III.

Ability to Walk Independently

The percentage of participants with the ability to walk independently increased systematically as a function of communication category: Category I = 1/8, Category II = 3/7, Category III = 6/6.

DISCUSSION

One purpose of the present study was to describe individual communicative performance in those who have CHARGE syndrome. This was accomplished using a coding schema that included form and function as well as a measure of communicative rate for each individual. The analyses from the coding schemas provided a means for characterizing each individual's communication in terms of specific abilities. The individual characterizations revealed communication patterns that allowed for a categorization of individuals on the basis of communication ability. These characterizations were then used to create communication categories and to differentiate among groups in the experimental sample.

Communication Factors Related to Communication Development

Participants in Category I communicated at a low rate (1.9 acts/min), using forms that were predominantly pre-symbolic (92%) and functions that were primarily for behavioral regulation (80%). These participants will be referred to as "pre-symbolic communicators." The participants in Category III will be referred to as "symbolic communicators." They communicated at a high rate (8.6 acts/min) using forms that were primarily symbolic (87%) and functions that were mainly conversational acts (87%). Participants in Category II, "transitional communicators," fell in between the other two categories. The results indicate that the development of communication from pre-symbolic to symbolic is related to increases in three dimensions: rate of communication, use of symbolic forms, and use of conversational acts.

The communicative function of "social interaction" deserves special attention. This was the least utilized function. It was used infrequently by pre-symbolic communicators (13%) and rarely by transitional communicators (5%) and symbolic communicators (2%). The behavioral

regulation function is used solely to obtain an object or action, without regard for the communication partner. The social interaction function is used to gain the attention of the communication partner rather than just seeking an action or object. The conversational act function goes beyond social interaction in that it involves reciprocal interaction of communication partners regarding an object or event. Pre-symbolic communicators in this study used the social interaction function to a limited degree. Transitional and symbolic communicators rarely used this function. Among the symbolic communicators in the present study, it is apparent that there is a primary reliance on the higher level conversational acts than on the lower level social interactions. One interpretation of the findings for the transitional group may be that the development from regulatory behaviors to conversational acts occurs quickly with little utilization of social interactions. Another explanation may be that the methods for acquiring the communication samples in the present study may have limited the opportunities to use social interactions.

Background Factors Related to Communication Development

The relationships between communication development and four background factors were examined. The background factors included in the analyses were: gender, age, initiation of language therapy by age 3, and the ability to walk independently.

Gender Distribution

There was a nearly equal number of males and females (11:10) in the present study. However, the gender distributions differed in the three communication categories: pre-symbolic (5M:3F), transitional (5M:2F), and symbolic (1M:5F). Thus, there were more males in the lower communication categories and more females in the highest communication category. With this

small sample, it is unclear whether this finding is characteristic of the CHARGE population as a whole or whether it is due to sampling artifact.

Age

As expected, age systematically increased with the increase in use of symbolic communication. However, what is striking is the wide range of ages within the categories and overlap between categories (see Table 26). The oldest child in the pre-symbolic category (10:2) was older than the youngest child in the symbolic category (6:9). These differences represent the wide range of communication abilities in CHARGE syndrome and reveal the very significant delays in some individuals.

Language Therapy Initiated by 3 Years of Age

Thelin and Fussner (2005) found the development of symbolic communication in individuals with CHARGE was related to the following factors: (1) the ability to walk independently, (2) the initiation of language therapy by age 3, and (3) successful audiologic management. In the present study, it was not possible to determine if the initiation of language therapy was a significant factor because nearly all participants had participated in language therapy by 3 years of age.

Ability to Walk Independently

In the present study, there was a significant increase in the percentage of participants who could walk independently as communication ability increased: pre-symbolic (1/8), transitional (3/7), and symbolic (6/6). These results are in agreement with the findings of Thelin and Fussner (2005).

Audiologic Management

The relationship between successful audiologic management and communication ability could not be evaluated in the present study because of insufficient information provided by parents.

CONCLUSIONS

The motivation for this study was to describe communication abilities of individuals with CHARGE syndrome, many of whom were at the beginning levels of intentional communication and for whom standardized tests were not appropriate. In the present study, communication abilities were described for individuals using three communication measures developed by previous investigators to describe emerging language. The measures were communicative rate, form, and function.

Communicative form and function were arranged on a two-dimensional coding schema. There were 22 communicative forms that were arranged in approximate order of emergence and then grouped into two categories: pre-symbolic and symbolic forms. There were 20 communicative functions that were also arranged in approximate order of emergence and then grouped into three categories: behavioral regulation, social interaction, and conversational acts. With this method, any communicative act could be categorized as having one of two forms and one of three functions. The results indicate that this system was useful in predicting the development of communication in CHARGE and its relation to other factors, such as age and ability to walk. As a result, the system developed in the present was useful for providing an initial description of communication abilities and for understanding communication development in this population.

The system developed in the present study may be useful to parents, professionals who provide services, and others who need to communicate with the individual. Use of this communication analysis may be of value in understanding the communication attempts of individuals with CHARGE syndrome. This method of analysis is tedious and time-consuming, but this may be necessary to develop an understanding of the individual's communication

abilities that may lead to the recognition of previously unrecognized communication attempts. The successful recognition and understanding of the individual's attempts to communicate may lead to increases in the individual's level and sophistication of communication, which will significantly impact the individual's well-being and overall development.

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