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Analysis of Variables Related to Social Interactionsin Children with Agenesis of the Corpus Callosum

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ANALYSIS OF VARIABLES RELATED TO SOCIAL INTERACTIONS IN CHILDREN WITH AGENESIS OF THE CORPUS CALLOSUM

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An Abstract of the Thesis Presented
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The purpose of this study was to analyze and describe the common communication, social, and behavioral attributes of individuals with agenesis of the corpus callosum (ACC), a rare congenital brain anomaly, as they relate to social interaction. This study analyzed data collected from over seven hundred families and made available through The ACC Network. The researcher utilized descriptive statistics to analyze the total sample and ANOVA to determine if differences occurred due to primary callosal diagnosis or age. An additional analysis examined features of individuals with higher level communication abilities.

This sample represented a broad range of ability and disability, from individuals with multiple congenital disabilities which included ACC, to individuals diagnosed with ACC only. Common features included a happy, social, and cooperative nature with rare aggressive or antisocial tendencies. Yet, consistent with previous research, these

individuals experience difficulties in their interactions with peers. Many experience language delay, deficits, or anomalies which affect successful social interaction. Attention to social conventions, responsiveness to social partners, and emotional awareness are areas of concern, but much more research is needed to further explore these issues. Mood was less positive with increasing age, but this matter also deserves further investigation.

Limitations of this study include the subjectivity which can occur with use of caregivers as informants, and the lack of a comparison group.

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CHAPTER 1

LITERATURE REVIEW

Children's Social Interactions

Peer relationships play an important role in the normal social, emotional, and cognitive growth of children. Although during the first year of life an infant's social relationships are predominantly egocentric and occur with their primary caregivers, sometime during the second year most children become aware of their peers as potential social partners as well (Brownell & Brown, 1992). Most children begin to show an increased interest in reaching out to other children and practicing social behaviors. Through trial, error, and guidance, they learn the rules and norms of social interaction with their peers, moving from parallel play, or play alongside their peers, to cooperative play, a more mature type of play which involves engaging in frequent interactions with others and shared goals (Berger, 2000; Trawick-Smith, 2000).

Throughout childhood, children often make special connections or friendships with particular peers along the way. These early relationships are important in developing empathy and a healthy self-concept and in sharing knowledge and skills. Friendships can become a source of enjoyment, strength, and support throughout a lifetime (Erdley, Nangle, Newman, & Carpenter, 2001; Rizzo, 1989; Staub, 1998; Stocking, Arezzo, & Leavitt, 1980; Trawick-Smith, 2000). Children who have difficulty developing positive peer relationships and friendships in childhood are more likely to lead isolated lives and experience more mental health disorders as adults (Erdley et al., 2001; Farmer, Pearl & Van Acker, 1996; Field, Roopnarine & Segal, 1984).

Social Competence. Social interaction forms the basis for all interpersonal relationships. Effective interactions involve the exchange of words, gestures, or objects between two or more people who are responsive to one another (Odom & Brown, 1993). Social competence, or the ability to interact with others effectively, is an important aspect in gaining entry into groups and acceptance from others (Trawick-Smith, 2000). Rubin and Rose-Krasnor (1992) describe social competence as "the ability to achieve personal goals in social interaction while simultaneously maintaining positive relationships with others over time and across situations" (p. 285). Children who are frequently unsuccessful in their social interactions are often rejected by others. This can lead to negative self perceptions or to the development of negative behaviors such as aggression or withdrawal (Rubin & Rose-Krasnor, 1992; Trawick-Smith, 2000).

Specific skills and behavioral attributes are necessary for children to become socially competent with others and in developing positive peer relationships. The ability to communicate, whether through verbal or nonverbal means, is a prerequisite for all social interactions (Owens, 1998). Being able to perform prosocial behaviors is important and having a clear understanding of which behaviors are acceptable within the social context and when and how to use them is also necessary. Prosocial behaviors include greeting others appropriately, smiling, making eye contact, taking turns and sharing. The ability to use physical space appropriately, tell the truth, and initiate, maintain, and end interactions is also necessary (Berger, 2000; Campbell & Siperstein, 1994; King & Kirschenbaum, 1992; Trawick-Smith, 2000) .

Social knowledge, or social cognition, is also critical to successful social interactions for children. It requires an understanding of the social and emotional world,

as well as the coordination of complex thinking, perspective taking, and adaptation (Gallagher, 1991). The ability to use social behaviors appropriately requires perceiving the situation accurately, selecting an age appropriate response (through problem solving), carrying out that action, monitoring the result, and making the necessary adjustments to behavior. Successful social interactions also involves a clear knowledge and understanding of the social rules for the culture and being able to take the viewpoint of social partners. For most children, social cognition improves over the childhood years (Campbell & Siperstein, 1994; King & Kirschenbaum, 1992).

Communicative Competence. Communicative competence, or being able to communicate effectively, is an important factor in the development of social competence and creates the foundation for all social interactions. Communication, or the exchange of ideas and information between people, includes not only the words that are spoken and understood by individuals (language) but nonverbal communications as well (Owens, 1998). Nonverbal communication consists of the gestures, facial expressions, and body positions one uses as well as the intonations and pauses in one's speech. Nonverbal communication conveys additional information and cues about the emotion and meaning of the verbal content (Owens, 1998). Successful use of language depends on both receptive and expressive abilities of each partner as well. Each person must be able to listen and understand the message which is being sent (receptive skills) as well as being capable of using language to convey meaning to others (expressive skills). Language can be oral, as in speech, or other modes may be used, such as American Sign Language, but both partners must be competent in the chosen mode to be effective (Lerner, Lowenthal, & Egan, 1998).

Communicative competence also depends on a child's ability to understand the social perspective of others and the social context of the communication (Dimitracopoulou, 1990). This includes being able to understand linguistic conventions, such as humor and metaphors, make inferences about the emotions and behaviors of others, and acquire knowledge and understanding of social conventions. While young children may be essentially egocentric in their communication abilities, this skill typically improves over the childhood years and by school age most children become more adept at detecting these nuances of communication (Dimitracopoulou, 1990).

Many factors affect the ability to use language and communicate effectively and competently. Sensory impairments (such as hearing loss or visual impairments), cognitive delay or deficits (such as mental retardation), emotional disturbances (such as depression), or motor dysfunction (such as cerebral palsy), all can interrupt typical speech or communication acquisition or abilities (Lerner, et al., 1998). Some children may develop speech abilities, yet have difficulty with the pragmatics of language, or how to effectively use language in their everyday lives (Lerner, et al., 1998; McCormick & Schiefelbusch, 1990). Pragmatic skills include maintaining socially acceptable eye contact, conversational turn taking, making relevant and appropriate statements, establishing, maintaining, and ending conversations, and using the cultural conventions for politeness (Wiig & Secord, 1998; Owens, 1998).

For some children, the complex problem solving and cognition required for effective communication can be an overwhelming task. They may be unable to interpret multiple word meanings and figurative expressions, as well as the various perspectives and affects of others. In addition, this complex thinking must occur while they also plan

and make decisions about appropriate responses. This type of problem usually becomes apparent during preadolescence and adolescence, and can put these children at increased risk of being rejected by their peer group, less resistant to peer pressure, or for developing other social adjustment problems (Wiig & Secord, 1998). Communicative competence is a complex skill that requires the integration of multiple skills and abilities in both receptive and expressive communication, yet it is essential to successful and fulfilling social interactions with others.

Development of Social Competence

As children grow and develop, the skills necessary to engage in successful peer interactions change. Infants as young as two months old show heightened states of visual interest in other babies. Later in the first year, smiles, touches, and vocalizations directed at other children are often observed, yet actual time spent engaging in these behaviors with peers at this age remains quite low (Berger, 2000; Brownell & Brown, 1992; Seifert & Hoffnung, 1994). Communication generally improves and becomes more complex over the first year as well. Initially, a newborn's communication is reflexive and nonpurposeful, but older infants quickly learn purposeful communication through the use of eye gaze, cries, and reaching behaviors to express their intentions (Berger, 2000; Lerner, et al., 1998; Owens, 1998).

Social behavior continues to emerge and change over the early years. During the second year of life, toddlers show increased interest in engaging with and playing with their peers, yet need frequent environmental support from caretakers as they negotiate peer interactions. Affectionate behaviors, imitation, turn taking, and verbal exchanges are seen and indicate a growing interest and motivation to engage with peers (Brownell &

Brown, 1992). Coordinated play between children emerges early in the third year as most children begin to spend more time together and their interaction skills improve (Hartup, 1992). During these preschool years, most children become less egocentric and show early empathic behaviors such as sharing toys and showing concern for a peer in distress (Berger, 2000; Trawick-Smith, 2000). Aggressive behaviors, such as grabbing toys, pushing, hitting, or biting may also occur but may not necessarily indicate an intention to hurt others. At this age, some children can become frustrated with their inability to negotiate social conflicts or problems and resort to forceful behaviors (Berger, 2000; Seifert & Hoffnung, 1994). Adult supervision and intervention continues to be important to the growth and development of acceptable social behavior at this age.

Many individual differences exist between children in affect, social skills, and motivation for peer interaction (Brownell & Brown, 1992). Individual temperament plays an important role in social interactions, with differences in activity level, adaptability to new and different situations, attention span, and mood all playing a role in an individual's behavior and their acceptance by others (Lerner et al., 1998). For young children, learning to share toys and to play together successfully is an important developmental task. Being able to gain entry to a group, cope within a play area, acquire desired toys, and handle conflicts with peers requires the integration of multiple emerging skills and behaviors of toddlers and preschoolers (Berger, 2000; Guralnick, 1990; Stocking et al., 1980; Trawick-Smith, 2000).

The ability to regulate emotions is important to social interactions throughout life and begins in the early years. During the preschool years children typically progress in their ability to regulate their emotions, both positive and negative (Berger, 2000).

Successful peer interactions includes the ability to enhance, inhibit, and regulate one's own emotional state. This entails both the development and maturation of the frontal cortex of the brain and social learning. A child who experiences prenatal brain damage or stunted brain growth in the early years "may be intellectually intact in most ways but unable to regulate his or her emotions" (Berger, 2000, p. 309). Difficulty with emotional regulation can lead to other difficulties in social interactions such as impulsive behavior or inappropriate friendliness toward strangers. Both of these attributes can place a child or adolescent at increased safety risk both with their peers and within the community.

The ability to communicate is also important to the development of social behaviors of toddlers and preschoolers. By twelve months of age, most infants begin to use their first words in purposeful ways to influence others. During the preschool years, children are typically using sentences to express their intentions, although individual skill and ability varies widely. Most preschoolers have also learned how to modify their language by using stress or emphasis to clarify their messages (Lerner, et al., 1998; Owens, 1998). Overall, communicative competence plays an important role in their social interactions with others.

Researchers who assess children's social acceptance by their peers have identified common attributes among children who experience more positive peer interactions and are more accepted by their peers (Trawick-Smith, 2000). Peers more often nominate children who have an effective use of language, use prosocial behaviors, and are competent in interpreting others' actions and emotions, as "popular" or well liked. On the other hand, peers frequently reject children who are aggressive or act in an antisocial manner. Rejection is the act of deliberately avoiding another child. Hitting, biting,

yelling, ignoring others, or hyperactivity are examples of behaviors which can lead to rejection by peers. Aggressive or inappropriate behavior may be intentional or the result of misreading a peer's intentions. Children who have difficulty reading the social cues of other children or taking their viewpoints may be at increased risk for rejection by peers for this reason. Another group of children identified by researchers are usually considered shy and are frequently observed in isolated play. These children often lack the prosocial skills necessary to enter or maintain peer play. These children are rarely named as a friend by other children or as someone with whom they would play. These children are sometimes referred to as "neglected" (Guralnick, 1990; Parkhurst & Asher, 1992; Roberts & Zubrick, 1992; Staub, 1998; Trawick-Smith, 2000).

Social reputation can play a role in whether a child is accepted or rejected by a peer group as well. Once children get to know one another, they develop schema or expectations which are based on previous behavior and interactions. A child who has a reputation for being shy, aggressive, destructive, or just "acts weird," may be treated differently than a child who has a reputation for being kind or funny. These expectations are often long lasting and can bias the actions and attitudes of others indefinitely (Hartup, 1992).

As children become older, play normally becomes more complex, requiring higher cognitive and language skills. School-age children are most concerned with loyalty, intimacy, disclosure, and acceptance from their peers (Berger, 2000; Parker & Asher, 1993). They must be able to cooperate and compromise with their peers, while showing a sense of empathy and altruism. Shared interests and mutual support can enhance the development of important friendship relationships as well (Erdley, et al.,

2001). By school-age most children are using language effectively to convey their thoughts and information as well as adapting their language to express mood, humor, or sarcasm. Most are also capable of adjusting their message to meet the needs and perspective of the listener (Lerner, et al., 1998; Owens, 1998). During the school years, peer relationships provide practice in acquiring relationship skills and knowledge as well as a creating a sense of belonging and companionship (Seifert & Hoffnung, 1994).

During adolescence, peer relationships become increasingly important and a more common source of companionship and support than parents or other adults (Erdley, et al., 2001). The ability to share feelings, beliefs, ideas, and opinions while understanding and accepting others' perspectives becomes essential. Mutual support, respect, and loyalty are vital to the development of the more intimate relationships of teens (Seifert & Hoffnung, 1994). Communicative competence becomes central to overall social interactions as these less tangible skills become more crucial to sustaining social interactions (Dimitracopoulou, 1990).

Peer Interactions in Children with Disabilities

Children born with disabilities or those who acquire them soon after birth may face particular challenges in developing the necessary skills for positive social interactions and peer relationships. They may have physical, cognitive, communication or behavioral attributes which make typical interactions with others more difficult. Although each child is unique and may confront specific challenges, some generalizations can be made regarding peer interactions for this population.

Challenges for Children with Disabilities. Children with disabilities may experience a variety of individual barriers in acquiring the social competence necessary

to achieve positive interactions and develop friendships with their peers (Lerner, et al., 1998; Schloss, 1984; Sigman & Ruskin, 1999; Staub, 1998; Trawick-Smith, 2000). Some disabilities, such as autism, deafness, or blindness can reduce a child's ability to respond to other children. Other children may have difficulty perceiving, processing, or interpreting social cues, such as the moods, emotion, voice inflections, or gestures of others (Lerner, et al., 1998; Schloss, 1984; Sigman & Ruskin, 1999; Staub, 1998; Trawick-Smith, 2000). Given the fast pace of social interactions, these children may be unable to keep up with others. Children with atypical means of communication or severe physical disabilities may confront other unique challenges that preclude the usual modes of social interaction and play (Field, et al., 1984; Odom & Brown, 1993; Schloss, 1984).

Some behavioral or interaction difficulties are more common with specific diagnoses. Children with attention deficit disorder (ADD) or attention deficit hyperactivity disorder (ADHD) often have difficulty with social and emotional behavior due to problems with attending skills and impulsive or hyperactive behavior. Children with pervasive developmental delay (PDD) or autism often face challenges with peer interactions due to stereotypic behaviors or compulsive interests or activities. Aggressive behaviors sometimes observed in these populations may be directed at self (self-abusive behaviors such as scratching, biting, or hair pulling) or directed at others; both can create challenges to interactions. Aggressive behaviors may be a learned response, a reaction to frustration, or a response to peer group behavior (Lerner, et al., 1998).

Children with visible disabilities, such as cerebral palsy or paralysis, are less frequently rejected by their peers since other children can see and more easily understand the disability (Trawick-Smith, 2000). Children with less visible or invisible disabilities

(such as autism or cognitive delays) are more likely to be rejected by their peers due to the difficulty in understanding unusual behaviors or perceptual or cognitive difficulties which are not immediately apparent. In addition, children who look "less beautiful" are more likely to be rejected by their peers as well (King & Kirschenbaum, 1992).

Observational Data. Observational data reveal several differences in the social interactions of children with and without disabilities. Several studies have shown that children with disabilities tend to engage in solitary play more frequently and are often involved in less complex play than other children (File, 1994; Guralnick & Groom, 1985, 1987). These children are also often unable to gain the attention of their peers or maintain successful play outcomes (Guralnick & Groom, 1985, 1987). Some studies suggest that students with disabilities receive more social initiations than they initiate themselves. The social initiations from other children were most frequently in the form of some assistance. Yet, play, talk, and physical affection were noted as well (Evans, Salisbury, Palombaro, Berryman, & Hollywood, 1992; Hall, 1994). Evans, et al. found the frequency of social initiations and interactions decreased over the school year, particularly with children who were less verbal. They noted that this reduced the amount of assistive or affectionate behaviors observed, suggesting this was a "normalizing" effect. Unfortunately, this also reduced the opportunities for the children with disabilities to practice their communication and social skills and be a part of the social environment of the classroom. "The risk is that children with strong skills will succeed in establishing mutual peer relations, leaving the children with weaker skills increasingly isolated from peer circles" (File, 1994, p. 237).

Agenesis of the Corpus Callosum

Although children with various disabilities may share some similarities in their challenges with peer social interactions, uncovering the attributes common to a specific condition can be useful. For example, Sigman and Ruskin (1999) have published an extensive report on their research study of the social competence of children with Down Syndrome and of children with autism. An understanding of the unique strengths and challenges faced by children with a shared diagnosis may help foster understanding and tolerance, as well as provide insight into designing specific interventions.

Children born with agenesis of the corpus callosum (ACC), a rare congenital brain anomaly, may be at risk for difficulties with peer interactions and friendship formation. Currently, the general population has little knowledge or awareness of ACC. Additionally, a widespread lack of understanding of the social and behavioral consequences exists among educators and service providers. This may place these children at increased risk for misunderstanding or rejection by peers and others. It may also increase the possibility of ineligibility for services or a mismatch of services. This has made it difficult for many families to cope with the implications of raising a child with ACC. (Schilmoeller & Schilmoeller, 2000). The focus of this study is the psychosocial, behavioral, and communication characteristics of children with ACC which can affect peer interactions and relationships.

Description. The corpus callosum is a major anatomical structure of the human brain that connects the two cerebral hemispheres. Made up of approximately 200 million nerve fibers, it is a broad band of white brain matter which provides the main route for the transfer of information between the two hemispheres of the brain (Shonkoff &

Marshall, 2000; Windhorst, 1996). Studies of brain lateralization suggest each hemisphere of the brain performs specialized functions, and the corpus callosum provides the means for integrating the information from each hemisphere in order to perceive, comprehend, and act fully upon sensory input. Although there are other smaller commissures in the brain that may provide for information transfer and integration, absence of the corpus callosum is considered a major brain anomaly (Mercer, 1998; Shonkoff & Marshal, 2000; Windhorst, 1996).

Prenatal Development. Normally, the corpus callosum begins to develop early in prenatal life, sometime around the tenth or eleventh week of gestation, when nerve fibers begin to cross the midline to connect the cerebral hemispheres. These connections begin in the anterior areas of the brain and proceed toward posterior areas. Although most callosal fibers have completed the crossing by 18 to 20 weeks prenatally, maturation and myelination of these fibers continues through adolescence (Shonkoff & Marshall, 2000; Windhorst, 1996; Wisniewski & Jeret, 1994).

Failure of the corpus callosum to develop during the prenatal period is known as agenesis of the corpus callosum (ACC). The failure may be partial or complete, depending on the timing and cause of the prenatal insult. Early disruptions to brain development can lead to a complete ACC, while later insults can cause a partial agenesis of the corpus callosum (P-ACC). While the precise etiology of ACC is often unknown, suspected factors can be intrinsic, such as genetic factors or chromosomal errors, or extrinsic, such as maternal infections, toxins, or asphyxia incurred early in a pregnancy (Shonkoff & Marshall, 2000; Wisniewski & Jeret, 1994).

Incidence. ACC is estimated to occur in up to seven births per 1,000 in the general population and more frequently, as many as 2 or 3 per 100 births, in the developmentally disabled population (Smith & Rourke, 1995; Wisniewski & Jeret, 1994). Smith and Rourke (1995) suggest the incidence of ACC in the general population may actually be higher than this estimate as individuals with isolated ACC and normal intelligence may not be assessed and diagnosed. With the advent of more routine and sensitive prenatal ultrasonography, these incidence rates may be modified.

Diagnosis. Historically, ACC was discovered only during postmortem autopsy. Today, diagnosis can be established through the use of computerized tomography (CT), magnetic resonance imaging (MRI), and ultrasonography, including prenatal ultrasound (Schilmoeller & Schilmoeller, 2000; Smith & Rourke, 1995; Wisniewski & Jeret, 1994). Magnetic resonance imaging (MRI) is considered the most accurate and beneficial method of imaging the midline structures of the brain, yet can be used after birth only. Newer, more sensitive ultrasonography has become useful for a more accurate prenatal diagnosis as well (Smith & Rourke, 1995). Some parents of children with ACC report the use of MRI in the prenatal period (K. Schilmoeller, personal communication, November 5, 2002), yet this has not yet been reported in the literature. Although ACC or P-ACC may be identified as early as the prenatal period, it is often discovered as part of a postnatal neurological work-up due to other visible birth anomalies, such as suspected hydrocephalus, or due to seizure activity. It may also be discovered later in childhood or adolescence as part of a work-up for developmental delays, neuropsychological issues, or an unrelated trauma incident (Chiarello, 1980; Schilmoeller & Schilmoeller, 2000; Sorensen, 1997).

Other brain anomalies are frequently associated with ACC and may aid in diagnosis. Most commonly occurring are Probst bundles (longitudinal fiber tracts along the medial cerebral hemispheres), abnormally shaped lateral ventricles, and "a radial pattern of sulci" also found along the medial cerebral hemisphere (Chiarello, 1980; Smith & Rourke, 1995).

Co-occurrence of Congenital Anomalies and Other Conditions. ACC may be an isolated congenital anomaly, or it may be associated with other birth defects (Shonkoff & Marshall, 2000; Wisniewski & Jeret, 1994). Some syndromes of birth anomalies which affect the nervous system and organ systems, particularly Aicardi, Andermann, Shapiro, and Acrocallosal Syndromes and Menkes Disease, frequently include ACC (for additional information on these syndromes, see Lassonde & Jeeves, 1994). Individual impairments can range from mild to severe, including mental retardation, seizure disorders, motor impairments and ocular abnormalities. Some children with ACC have a normal IQ, despite the anomalies (Wisniewski & Jeret, 1994). Schilmoeller & Schilmoeller (2000) report significant developmental and language delays in their large-scale survey of children with ACC.

Social, Communication, and Behavioral Characteristics. Although there are no known studies which specifically target peer social interactions of children with ACC, several studies do report communication, behavioral, and social attributes which may influence these interactions (Brown & Paul, 2000; O'Brien, 1994; Ritter, 1981; Sauerwein, Nolin & Lassonde, 1994; Schilmoeller & Schilmoeller, 2000; Sorensen, 1997). In addition, parental reports and surveys can also be useful in describing the strengths and challenges their children with ACC face in real social situations with their

peers, which are not always apparent during formal testing (Brown & Paul, 2000; O'Brien, 1994; Schilmoeller & Schilmoeller, 2000). Together, these studies can inform current inquiry and lay a foundation for future study.

Considerable controversy exists among researchers as to whether the brain can compensate for the congenital absence of the corpus callosum. Some researchers caution that functional problems may largely be the result of concomitant anomalies and state there are cases of individuals who are "asymptomatic" and function normally throughout their lives (Sauerwein, et al., 1994; Wisniewski & Jeret, 1994). Yet, there is emerging evidence of important communication, social, and behavioral functioning deficits which impact social interactions and the personal relationships of children with ACC, including those with normal intelligence (Brown & Paul, 2000; O'Brien, 1994; Schilmoeller & Schilmoeller, 2000; Smith & Rourke, 1995; Sorensen, 1997; Stickles, Schilmoeller, & Schilmoeller, 2002). Attention to these more subtle, yet important details of social interaction skills which impact peer relationships will be reviewed.

The ability to communicate and respond to social partners is an important aspect of peer interactions. Communication difficulties in children with ACC can range from mild to severe; some children are unable to communicate verbally and may use a form of alternative communication while others may have few noticeable functional deficits (Stickles, 2001a). Although there is a wide range of communication abilities among children with ACC, many experience early language delays and deficits, particularly in their ability to express themselves (McCardle & Wilson, 1993; O'Brien, 1994; Ritter, 1981; Sauerwein, et al., 1994; Schilmoeller & Schilmoeller, 1997, 2000, 2001; Sorensen, 1997, Stickles, 2001a, Stickles, Schilmoeller, & Schilmoeller, 2002). Repetitive,

meaningless, or out of place verbalizations are also reported (O'Brien, 1994; Schilmoeller & Schilmoeller, 2001) and can make conversation difficult to understand or be accepted by others. Both researchers and parents commonly note pragmatic deficits in children with normal IQs as well as others (Brown & Paul, 2000; McCardle & Wilson, 1993; Sorensen, 1997; Stickles, 2001a, 2001b; Stickles, Schilmoeller, & Schilmoeller, 2002). These deficits can include difficulty with maintaining proper eye contact, staying on topic, interrupting others, attempting to control the conversation, and maintaining acceptable physical distance from social partners. Errors in recognizing and responding to the nonverbal communication of their social partner, as well as misinterpreting the subtle meanings of stories or jokes are also reported (Brown & Paul, 2000; Stickles, Schilmoeller, & Schilmoeller, 2002). Pragmatic deficits are difficult to overcome and may persist despite speech intervention in children with ACC (Stickles, 2001a).

Deficits in pragmatic skills may be apparent in the early childhood years or become increasingly noticeable as children reach adolescence. This is when social interactions typically become more complex and the ability to read subtle cues, nonverbal communication, and emotional context becomes more critical (Stickles, 2001b). Adolescents with ACC have particular difficulty understanding the slang and sarcasm which is common among this age group and may interject inappropriate comments or make unclear or unrelated statements within a social situation (Stickles, 2001a). Additionally, Brown and Paul (2000) and O'Brien (1994) reported the participants in their studies were unable to communicate their own emotions to others, which can also be an important aspect of adolescent communication and interaction. As the communication

and interaction expectations become more complex, it may become more difficult for teenagers with ACC to meet the social demands.

Although the underlying causes for the emotional and communication deficits which are reported in individuals with ACC are unclear, studies of brain lateralization may provide some insight. Brain studies indicate each hemisphere of the cerebral cortex produces, processes, and experiences language and emotions in different ways, yet must function cooperatively in order to correctly interpret, appreciate and respond to incoming information (Mercer, 1998; Windhorst, 1996). The corpus callosum is typically the main route for transfer and integration of this information, although smaller subcortical brain structures may also play a role (Windhorst, 1996). Children who have difficulty integrating the complete message may have difficulty in social interactions and relationships (Mercer, 1998). Whether children without a corpus callosum are able to compensate for the absence of this main information transfer route is the subject of debate among researchers.

Behavioral characteristics of children with ACC are reported by parents and described in several research studies. Anecdotal parental reports and parent surveys often describe the behavior of their children with ACC as generally happy, social, and cooperative (Schilmoeller & Schilmoeller, 1997, 2001). There is also some indication though, that children with ACC have more difficulties interacting with their same age peers and prefer to interact with younger children (Sorensen, 1997; Schilmoeller & Schilmoeller, 2001).

A survey conducted by O'Brien (1994) compared the behavior patterns of 47 children with ACC, P-ACC and Aicardi Syndrome (ACC with specific additional

disabilities) to investigate whether children with ACC are more likely to have challenging behaviors. O'Brien reported aggressive or antisocial behavior, as well irritability, hyperactivity, and self-injurious behaviors were uncommon in the children with ACC or P- ACC. Autistic-like behaviors, such as disinterest in others, repetitive bodily movements and "obsession for sameness" were also uncommon in these children. Conversely, he noted a higher incidence of lethargy or "the unwillingness to initiate or engage in activity to an extent not accountable by the level of physical and intellectual disability" (O'Brien, 1994, p. 244). He also reported a common concern voiced by the parents surveyed was a sense of frequently not knowing what their children were feeling emotionally. Overall, the relative lack of antisocial behaviors in children with ACC can be advantageous, yet this study suggests there are challenges to be overcome in their interactions with their same age peers.

Brown and Paul (2000) explored the social and psychological functioning of two adolescent males with ACC and normal intelligence. The parents of both individuals expressed concern regarding their sons' peer relationships and their poor social judgment skills. Brown and Paul conducted extensive cognitive and psychological testing and made behavioral observations of the participants, and compared the results with published norms. The participants were friendly and cooperative throughout the testing, however, their behavior was described as immature. No unusual behaviors or psychopathology were noted by observation, parental survey, or self-report. Discrepancies were apparent, though, in the area of social problems, as the two adolescents seemed unaware of the interaction difficulties expressed by their parents. The authors suggest this may be related to the adolescents' poor self-awareness and social understanding, as well as their naiveté.

Test results concluded both subjects lacked insight into the complex nature of social behavior, had tendencies to miss or misinterpret emotional information, and had difficulty interpreting ambiguous information. Brown and Paul concluded these deficits in social cognition seem to be related to " reduced ability for reasoning, concept formation and problem solving, and deficits in complex psychosocial perception, understanding, and age-appropriate social behavior" (p. 154). They attributed these deficits to the less efficient transfer of information between the two hemispheres of the brain. Given the often fast pace, novel circumstances, and complexity of social interactions, this type of deficit is likely to create challenges for individuals with ACC.

A long-term case review of the communication development of a male individual, "G.," with ACC and a normal IQ provides further insight into some of the social and behavioral strengths and challenges for children with ACC. Stickles, Schilmoeller, and Schilmoeller (2002) describe the individual through the use of careful observations and a variety of formal assessments gathered over 23 years of his life. Since "G." also has dysgenesis of his frontal lobes it is impossible to confirm that his difficulties are solely due to ACC. Future research may help separate out the more specific issues for individuals such as "G." who possess concurrent brain anomalies.

Throughout childhood and his teen years, G. was described as enthusiastic, social, and cooperative by his parents, educators, and service providers. With the exception of some difficulty sharing toys and minor aggressive behavior as a preschooler, there is no mention of aggressive or self-abusive behaviors. G. seemed to enjoy peer interactions and activities throughout his childhood and teen years. With the consistent support and advocacy of his parents, he was able to participate in sports, youth groups, and other

extra-curricular activities. Although he participated in peer interactions and activities, his parents state he did not experience close friendships. Psychological evaluations done over the years reveal persistent difficulties with social cognition that would likely affect social judgment and functioning. Indeed, G.'s parents expressed concern about him as an adult due to his impulsive behavior, poor social judgment, and tendency to confabulate. They believed this left him vulnerable to others who might take advantage of this disability. Although G. overcame his early mild language delay, persistent difficulties with fluent speech and pragmatic skills were reported into adulthood despite intervention. The inability to perceive and utilize social cues and conventions, maintain topics, and take the perspective of the social partner were frequently mentioned as concerns. These social, communication, and behavioral attributes contributed to G.'s difficulty in obtaining and retaining successful employment as well (Stickles, Schilmoeller, and Schilmoeller, 2002).

Together these case studies, surveys, and parental reports can provide insight into the strengths and challenges of children with ACC in their interactions with peers. A wide range of social, behavioral, and communication abilities exist within this population, yet even those individuals with a normal IQ appear to experience difficulties in their social lives. Building on these early studies with large-scale studies may provide useful data which can be helpful in generalizing to the larger population of children with ACC.

Nonverbal Learning Disabilities. Some researchers have identified ACC as one of several neurological entities which can be manifested by nonverbal learning disabilities, with resulting ramifications for social and emotional development (Rourke, 1995; Smith & Rourke, 1995; Rourke & Tsatsanis, 1996). A nonverbal learning disability (NLD) is

believed to be the result of neurological brain disease, disorder, or trauma which primarily affects the white matter (the long myelinated fibers of neurons) of the brain. Smith and Rourke (1995) believe it is the absence of these nerve fibers of the corpus callosum in individuals with ACC that leads to the manifestations of NLD. Although NLD is manifested in ways which affect social, personal, and academic achievements, those which are important to social interactions include "significant deficits in social perception, social judgment, and social interaction skills" (Rourke & Tsatsanis, 1996, p. 32), particularly when in novel or complex situations. Emotional perception and the expression and understanding of nonverbal communication are particularly challenging for children with NLD (Harnadek & Rourke, 1994; Matte & Balaski, 1998; Rourke, 1995; Rourke & Tsatsanis, 1996; Smith & Rourke, 1995). Panos, Porter, Panos, Gaines, & Erdberg (2001) studied an eleven-year-old child with ACC to compare Rourke's NLD model with the full range of neuropsychological performance of their participant. These researchers concluded the NLD model did not account for the full range and severity of this child's deficits. Whether children with ACC manifest NLD in its entirety or whether there is a commonality of some, but not all manifestations, awaits further, large-scale studies. Until then, cautious use of the intervention recommendations for individuals with NLD may prove helpful to persons with ACC (Rourke, 1995).

Purpose of This Study

The purpose of this study is to analyze and describe the predominant communication, social, and behavioral patterns that may influence peer interactions in children with ACC. Although case studies, parent surveys, and anecdotal reports are useful in identifying attributes and characteristics that create challenges to social

interaction, the small number of subjects utilized in published studies preclude generalizations. Using previously collected data from a survey conducted by The ACC Network and collected from over seven hundred families, I intend to assess patterns of psychosocial behavior and communication which are common to a larger sample. The larger sample available may also prove useful in considering confounding variables such as coexisting anomalies or syndromes.

Constructing a picture of the development of language and social behavior of children with ACC may also be beneficial. For example, do children with ACC face the same challenges in their social interactions with their peers in preschool as they do in middle school or adolescence? As growing children increase their reliance on language, abstract thought, and nonverbal forms of communication, can children with ACC meet that challenge? Are children with ACC at risk when faced with forming relationships based on intimacy and the sharing of emotions, which becomes more important in their teen years?

Developing a sound picture of the specific challenges and strengths that children with ACC bring to a peer relationship may be helpful to promoting these important relationships. Attention to these issues has led to the construction of the following research questions for this study.

Research Question 1.

What are the social, behavioral, or communication attributes, or patterns, of children with ACC that may influence their ability to interact with their peers?

Research Question 2.

Are there differences in the social, behavioral, and communication attributes based on diagnosis of ACC, P-ACC, and thin corpus callosum?

Research Question 3.

Is there a developmental picture of children with ACC which illustrates changes in attributes important to peer interactions over the childhood years?

CHAPTER 2

METHOD

Participants

Twenty- one hundred surveys were mailed internationally to families who have been in contact with The ACC Network, an organization founded to identify and provide resources and support to families who have a family member with ACC (Schilmoeller & Schilmoeller, 2001). Surveys were mailed beginning in March of 2000 and continuing until January of 2002. Seven hundred and thirty-three (35%) surveys were returned. The mean age of individuals with ACC for whom a survey was returned was 7.6 years with a range of 4 months to 45 years old. The majority of persons with ACC represented in this sample were white (91.1%), but Hispanic (3.7%), Asian (1.8%) and "other" race or ethnicities (3.4%) were also represented.

Informants were overwhelmingly birth mothers (88.5%), but adoptive mothers (2.7%) and birth fathers (5.1%), also responded. The remaining respondents (3.7%) were related or unrelated caretakers. The age range for mothers was 19 to 68 years, with 78.0% in the 25-45 year range. Fathers were 20-75 years with 75.4% in the 25-45 year range. Years of school completed by the respondents ranged from 9 years to 18 years with 97.4% completing 12^{th} grade or more. Spouses had completed 6 to 18 years of schooling, with 94.8% completing 12^{th} grade or more. See Table 1 for a descriptive analysis of the individuals with ACC.

Procedure

After approval from the University of Maine Human Subjects Research Committee, the original survey was mailed, beginning in March of 2000, to families with

Table 1

Descriptive Analysis of the Total Sample*

	Frequency	Percentage
Gender (n = 729)		
Male	423	58.0%
Female	306	42.0%
Race/Ethnicity (n = 721)		
White	657	91.1%
Hispanic/Latino/Spanish	27	3.7%
Asian	13	1.8%
Other	24	3.4%
Diagnosis (n =705)		
ACC	465	66.0%
P-ACC	154	21.8%
Thin/underdeveloped CC	86	12.2%
Age of Diagnosis (n = 722)		
Before birth	76	10.5%
Between birth and one month	195	27.0%
Between 1 and 24 months	313	43.4%
2 years or older	135	18.7%
Don't know/unsure	3	.4%
Siblings (n = 733)		
None	144	19.7%
One or more	589	80.3%
Blood Relative with ACC (n = 721)		
Yes	27	3.7%
No	694	96.3%

*Since not all informants responded to each survey question, n is provided for each question

a member with ACC who had been in contact with The ACC Network. Additional surveys were mailed to new families who contacted the network over the time span described above. The surveys were coded to maintain confidentiality, and personal identities were known to the primary researchers only. Data analyzed for the current research project were unidentified to this researcher. The data were analyzed using Statistical Package for Social Sciences (SPSS).

Instrument

According to Schilmoeller and Schilmoeller (2001), survey questions were constructed based on a literature review of previous studies of children with ACC and their experience and knowledge based on their work with families as coordinators of The ACC Network. The first section of the ACC survey included demographic questions regarding both the individual with ACC and his/her family. The remainder of the survey was comprised of extensive categories of questions about the individual with ACC, including diagnostic information, physical, social, communication, and behavioral characteristics. Also included were questions regarding learning style, educational experiences, and adjunct therapies (see Appendix A for a complete copy of original survey).

Answer categories were diverse. Several questions allowed informants to report the presence or absence of specific characteristics such as attention deficit disorder, cerebral palsy, seizure activity, developmental delay, and sensory deficits. Other questions allowed informants to utilize Likert scales to grade the level or frequency of specific abilities (such as communication or motor skills), behaviors (such as activity level, social behavior, and unusual body movements), and specific experiences (such as

early intervention services). Open-ended questions allowed for additional comments as desired.

The current research project utilized data from this data set. For the purpose of this study, data which are relevant to social interaction (based on the literature review) have been identified to be analyzed. This included questions related to communication, social, and behavioral characteristics of children with ACC that may affect their peer relationships. Demographics, such as age and primary diagnosis, were utilized to examine whether diagnostic and chronological age factors may influence social interaction. These factors were important in addressing research questions two and three.

Data Analysis

Research Question 1. What are the social, behavioral, and communication attributes, or patterns, of children with ACC that may influence their peer interactions?

The ability to communicate is considered the foundation for all social interactions and was analyzed using several survey questions. Communication was analyzed using descriptive statistics to describe the form of communication used by the individuals with ACC (for example facial expressions, touch, sign language, spoken language) and their level of communication ability (for example, understands very little, understands two-word combinations, understands most messages at person's age level). Expressive and receptive forms of communication and level of ability were scored and analyzed separately. The presence of several specific communication anomalies, such as vocalizing meaningless conversation, and shouting or screaming unexpectedly, have been identified for analysis as well.

Specific social, physical, and behavioral attributes which may affect social interactions were also identified and analyzed using descriptive statistics. These included diagnosis of behavioral or neurological disorders such as autism or ADD, activity level, muscle tone, tendencies to perseverate, unusual sensitivity to touch, and the ability to attend. Attention was drawn to the presence or absence of attributes which enhance successful peer interactions as well as attributes which can make peer interactions more challenging for children with ACC.

To synthesize the vast amount of data related to social and behavioral characteristics available from this survey, several scales were developed as indicators. For example, a social interaction scale devised from several variables related to social interactions (such as enjoyment of interactions with familiar people, with siblings, and with peers, as well as displaying physical affection or enjoying physical contact). Other scales devised and utilized were scales for socially difficult behaviors, aggressive behaviors, autistic characteristics, mood, and motor skills. Each scale was developed based on the literature review. A Cronbach alpha of each scale was calculated to determine inter-item reliability and each scale measured a Cronbach alpha of .80 or better. The range and interpretation of scores varied from scale to scale and will be described in the results chapter. For a complete listing of items utilized in developing the scales, see Appendix B.

Research Question 2. Are there differences in social, behavioral, and communication attributes between children with a diagnosis of P-ACC, complete ACC, and a thin corpus callosum?

The same variables which were identified in Research Question 1 were analyzed using a one-way analysis of variance (ANOVA) to determine if there were any significant differences in communication, social, and behavioral attributes due to diagnosis of P-ACC, complete ACC, and thin corpus callosum.

Research Question 3. Is there a developmental picture of children with ACC which illustrates changes in attributes important to peer interaction over the childhood years?

Age groups were developed utilizing traditional and theoretical age groupings most often described and utilized in the literature. Child development texts frequently construct their chapters by approximate age groups of 0 to 2 years; 2 or 3 years to 5 or 6 years; 6 to 12 years; and 12 to adulthood (e.g., Berger, 2000; Seifert & Hoffnung, 1994; Trawick-Smith, 2000). Erikson's Psychosocial stages describe "approximate" ages for development as 0-18 months; 18months – 3.5 years; 3.5 years to 6 years; 6 years to 12 years; and 12 years to adulthood. Piagetian theory also used "approximate" ages to describe cognitive development, these stages are 0-18 months; 18 months to 6 or 7 years; 8- 12 years; and 12 to adult (Trawick-Smith, 2000). Applying these constructs and other research on the social development of children (e.g., Brownell & Brown, 1992; Erdley, et al., 2001; Hartup, 1992; Lerner, et al., 1998; Owen, 1998: Parker & Asher, 1993; Van Hasselt & Hersen, 1992) led to the construction of age groupings to utilize for analysis. Five age groups were developed; 0-18 months (infants and toddlers); 19 months to 5 years, 11 months (preschool age); 6 years to 11 years, 11 months (childhood); 12 years to 21years (adolescence); and over 21 years (adulthood). ANOVA was used to identify differences across age groupings.

CHAPTER 3

RESULTS

The purpose of this study was to analyze and describe the strengths and challenges of children with ACC in their peer interactions. A descriptive analysis of variables related to social interaction includes attributes related to communication, individual behavior, and social behavior as well as characteristics which may impede or support positive peer interactions. Descriptive statistics were used to analyze and describe attributes of the sample and attend to differences based on diagnosis and chronological age.

Research Question 1: What are the social, behavioral, and communication attributes, or patterns, of children with ACC that may influence their peer interactions?

Communication was analyzed as to the form of communication used and the level of ability, and differentiated as receptive and expressive communication. As shown in Table 2, in regard to the receptive form of communication only 15.1% are unable to understand most forms of communication, while 73.4% are able to understand the highest level indicated in the survey, spoken language. Many (54.1%) understand facial expressions as well. As to form of expressive communication utilized by these individuals, 11.3% do not indicate their needs using any form of communication, and 53.7% use spoken language. The use of facial expression (40.4%) and touch (37.8%) were also common.

The best level of communication ability was also distinguished as expressive or receptive. As shown in Table 3, 18.0% of the individuals in this study show very little understanding of communicative messages. Conversely, 40.7% understand most age level

Table 2

Form of Communication (N=733)

	Frequency	Percentage
Form		
Receptive (n = 714)*		
Understands very little	108	15.1%
Understands facial expressions	386	54.1%
Understands through touch/gesture	284	39.8%
Understands sign/symbol system	92	12.9%
Understands with electronic device	88	12.3%
Understands sign and spoken language	106	14.8%
Understands spoken language	523	73.4%
Other forms	70	9.8%
Expressive (n = 711)*		
Does not indicate needs	80	11.3%
Uses facial expression	287	40.4%
Uses touch/gestures	269	37.8%
Uses sign/symbol system	86	12.1%
Uses electronic device	53	7.5%
Uses sign and spoken language	56	7.9%
Uses spoken language	381	53.7%
Other	134	18.9%

*n is number of informants who answered this question. Since informants were allowed to mark all answers that applied, totals were greater than 100%

Table 3

Best Level of Communication (N= 733)

	Frequency	Percentage
Ability Level		
Receptive (n = 567)*		
Shows little understanding	102	18.0%
Understands single words	54	9.5%
Matches names to objects	11	2.0%
Understands two words linked	28	4.9%
Understands two word sentences	24	4.3%
Understands most long sentences	117	20.6%
Understands most age level messages	231	40.7%
Expressive (n = 618)*		
None	206	33.3%
Gives name only	1	.3%
Indicates several objects	88	14.2%
Two word sentence	42	6.8%
Two word with linking words	23	3.7%
Makes long sentence	52	8.4%
Able to engage in conversation	206	33.3%

*n represents the number of informants who answered this question

Note. Informants were asked to choose the one answer that best characterized the individual with ACC

messages, with an additional 20.6% who understand most long sentences. Regarding the ability to express themselves using any form of communication, 33.3% are unable to express themselves in any way and 33.3% are able to engage in conversations. An additional 8.4% can make some long sentences, a skill which precedes conversation.

Language anomalies which would negatively impact communication success were also analyzed. For those who completed this question, 22.9% "occasionally" engage in meaningless conversation and 15.6% do so "very frequently." Conversation which is "out of place" (context) was also noted in this sample, occurring "occasionally" in 31.2% and "very frequently" in 14.4%. Shouting or screaming unexpectedly occurred "occasionally" in 26.0% and "very frequently" in 13.8%. Repeating words or phrases without understanding them also occurred "occasionally" in 19.4% and "very frequently" in 10.9%.

Factors which may effect the development of communication were considered. In this sample, 0.8% of children with ACC had cleft lip, and 4.2% had a cleft palate. Another indicator of current or past communication issues is shown in the results for speech therapy; 64.1% attend speech therapy frequently, while others attend infrequently (8.0%) or in the past (13.5%). Thus, 87.6% are involved in speech therapy at some time.

Professional diagnosis of behavioral or neurological disorders which may influence communication, social behavior, and interaction were analyzed for frequency within the sample. As shown in Table 4, some behavioral disorders were represented in this sample but at relatively low frequencies. Learning disabilities were more common though, representing 32.6% of this sample. A large number of the participants were

Table 4

Professional Diagnosis of Behavioral or Neurological Disorders (n = 730)

	Frequency	Percentage
Attention Deficit Disorder (ADD) w/o hyperactivity	49	6.7%
Attention Deficit Hyperactivity Disorder (ADHD)	48	6.6%
Hyperactivity Disorder w/o ADD	5	0.7%
Autism or Autistic behavior	69	9.5%
Obsessive Compulsive Disorder	50	6.8%
Schizophrenia	6	0.8%
Depression/Mood Disorder	32	4.4%
Cerebral Palsy	112	15.3%
Developmental Delay	563	77.2%
Learning Disability	237	32.6%
Mental Retardation	187	25.8%
Seizure Disorder	212	29.1%

considered developmentally delayed (77.2%); others were diagnosed with mental retardation (25.8%), seizure disorder (29.1%), CP (15.3%), and autism (9.5%).

Although some informants reported a professional diagnosis of hyperactivity (see Table 4), many informants reported slightly underactive (27.8%) or very underactive (23.4%) activity levels. A normal activity level was reported in 32.6%. Characteristics of activity which may cause concern for social interactions were also reported and shown in Table 5. "Frequently leaving tasks unfinished" (36.8%), "if left alone tends to do little or nothing" (30.5%) and "frequently squirmy or fidgety" (27.4%) were reported in many of the participants. Physical characteristics which could impact social interactions with others include poor muscle tone ("slightly floppy" in 34.9%, and "very floppy" in 17.8%); and being more sensitive (29.8%) or much more sensitive (10.2%) to being touched by others. Average sensitivity was reported in 48.5%. Perseveration in an inappropriate activity was sometimes (27.7%), often (25.3%) or almost always (16.8%) an issue for these participants. On the other hand, self-injurious behavior was reported as rare/not true (68.4%).

Several scales were designed to allow multiple items to be used as social indicators (See Appendix B for specific items). Mean, standard deviation (SD), and range for these scales are shown in Table 6. The social interaction and social difficulty scales (range 1-5) were designed to allow a score of 3 to be described as about the same as other individuals their age, a higher score would be indicative of increasing levels of those characteristics, while lower scores indicates decreasing levels. The mood scale (range 1-4) was designed to indicate a higher score as indicative of a more positive mood and a

Table 5

Frequent Characteristics of Activity (n = 725)

	Frequency	Percentage
If left alone tends to do little or nothing	221	30.5%
Frequently squirmy or fidgety	199	27.4%
Requires longer than usual to settle down for enjoyable activity	99	13.8%
Frequently leaves tasks unfinished	267	36.8%
Creates chaos aimlessly	94	13.0%

Table 6

Social and Behavior Scales

	n	Mean	SD	range
Social Interaction Scale	711	3.0	.71	(1-5)
Social Difficulty Scale	677	2.9	.77	(1-5)
Autistic-like Behavior Scale	698	1.5	.45	(1-3)
Mood Scale	713	3.3	.52	(1-4)
Aggressive Behavior Scale	666	1.4	.43	(1-3)

lower score as indicative of a less desirable mood. High scores on the autism and aggression scales (range 1-3) indicate frequent/common occurrences of these behaviors while a low score indicates these behaviors are rare or not present.

Results suggest individuals in this study are similar to individuals their own age on the social interaction and social difficulty scales. Autistic and aggressive behavior scores indicate low levels of these behaviors in this sample. The mean score for the mood scale was high (3.3), suggesting the individuals in this sample were frequently or almost always cheerful, content, and relaxed, and rarely angry or anxious.

Several social and behavioral attributes contained within the scales were identified for further descriptive analysis in order to address characteristics identified in the ACC literature. Attributes which are commonly associated with prosocial behavior or activities are identified in Table 7. Children with ACC tend to be described as almost always happy/cheerful (57.3%), and enjoying social interaction with others slightly or much more than others their age (44.3%). Yet, when asked specifically about peer interactions, only 21.7% report enjoying interactions with peers slightly or much more than others their age. Also, 42.4% of respondents reported peers enjoy interactions slightly or much less with the child with ACC (see Table 8 for attributes related to social difficulties).

More common attributes which may lead to difficult social interactions for children with ACC were less responsiveness to others (58.3% were slightly/much less responsive to instructions/requests), difficulty reading the child's emotions (36.1%), and difficulty using physical space appropriately (40.3%). Stubbornness (60.1%), temper

Table 7

Prosocial Attributes

	n	About the same (%)	Slightly/much more (%)
Enjoys social contact with others	702	42.0	44.3
Friendly with strangers	694	26.7	42.7
Seeks/enjoys physical contact	687	36.5	38.4
Enjoys interactions with siblings	590	45.3	30.3
Enjoys interactions with peers	658	37.4	21.7
Reserved/Shy	589	33.3	19.1

	n	Often (%)	Almost always (%)
Happy/cheerful	701	33.2	57.3
Content	699	39.6	46.9
Relaxed	692	41.8	31.1

Table 8

Attributes Associated with Social Difficulties

	n	About the same (%)	Slightly/much less (%)
Independent	650	23.7	66.1
Siblings enjoy interactions	557	49.2	30.9
Peers enjoy interactions	615	45.0	42.4
Responds to instruction /requests	618	31.6	58.3
Difficult for others to read emotions	623	44.6	36.1*
Difficulty using appropriate physical space	561	43.0	40.3*

*(slightly/much more)

	n	Occasional (%)	Common/ very frequent (%)
Extraordinary attachment to objects	634	18.8	20.3
Unusual fears	629	25.8	19.6
Compulsive behaviors	633	22.3	22.1
Obsessive thoughts	587	16.9	19.3
Easily upset with changes	646	32.4	32.8
Unusual reaction to sounds	655	27.3	26.9
Stubborn	654	40.2	20.9
Temper tantrums	650	40.6	12.0

tantrums (52.6%), and difficulty with change (65.2%) were also reported as occasional or frequent behaviors.

Research Question 2: Are there differences in social, behavioral, and communication attributes between children with a diagnosis of P-ACC, complete ACC, and a thin corpus callosum?

The ability to understand communication and express themselves verbally was compared between groups using ANOVA. Statistically significant differences were noted across groups for both receptive, $F(2, 545) = 6.298$, $p < .01$, and expressive, $F(2, 593) = 5.320$, $p < .01$, communicative functioning. A Post-Hoc Tukey HSD determined differences between the individuals with a thin corpus callosum and the other two groups. Those with a thin corpus callosum are reported to possess lower levels of communication abilities. The levels for each group are shown in Table 9.

Analysis of variance was performed to determine if there were differences across groups for the social interaction, social difficulty, aggression, autistic behavior, and mood scales. Results of this analysis are found in Table 10. There were no significant differences found across these groups.

Research Question 3: Is there a developmental picture of children with ACC that illustrates changes in attributes important to peer interaction over the childhood years?

Five age groupings were designed to allow for analysis of developmental change over time in the identified attributes (see methods chapter for a description of age group development). For ease of discussion, Group 1 (0-18months) will be referred to as infant/toddler, Group 2 (19 months to 4 years 11 months) will be referred to as preschool, Group 3 (5 years to 11 years, 11 months) will be called school-age, Group 4 (12 years to

Table 9

Communication Ability Level by Primary Diagnosis

	n	Mean	SD	F	Sig.
Receptive Understanding					
Full ACC	358	4.94	2.4		
Partial ACC	124	5.27	2.2	6.298**	.002
Thin CC	66	4.00	2.5		
Expressive Communication					
Full ACC	394	4.08	2.5		
Partial ACC	131	4.44	2.5	5.320**	.005
Thin CC	71	3.23	2.6		

Note. For levels of communication ability/ receptive, 1 = shows little understanding, 2 = understands single words, 3 = matches names to objects, 4 = understands two words linked, 5 = understands two word sentences, 6 = understands most long sentences, 7 = understands most age level messages. For levels of communication ability/ expressive, 1 = none, 2 = gives name only, 3 = indicates several objects, 4 = two word sentences, 5 = two words with linking words, 6 = makes long sentences, 7 = able to engage in conversation.

**$p < .01$

Table 10

ANOVA for Social and Behavioral Scales by Primary Diagnosis

	n	Mean	SD	F	Sig.
Social Interaction Scale (range 1-5)					
Full ACC	451	3.0	.73		
Partial ACC	149	3.0	.65	.253	.776
Thin CC	83	2.9	.69		
Social Difficulty Scale (range 1-5)					
Full ACC	428	2.8	.75		
Partial ACC	144	2.9	.80	1.09	.334
Thin CC	80	2.9	.77		
Autism Scale (range 1-3)					
Full ACC	441	1.5	.45		
Partial ACC	147	1.6	.42	1.25	.287
Thin CC	83	1.6	.45		
Aggressive Behavior Scale (range 1-3)					
Full ACC	421	1.3	.43		
Partial ACC	141	1.4	.40	2.11	.122
Thin CC	77	1.4	.43		
Mood Scale (range 1-4)					
Full ACC	450	3.3	.50		
Partial ACC	149	3.2	.53	.983	.375
Thin CC	86	3.3	.5		

Social Interaction and Social Difficulty Scales
3 = about the same as same age individuals
Higher score = more of this characteristic
Lower score = less of this characteristic

Mood Scale - High scores indicative of a more positive mood, low scores are indicative of less desirable mood

Autistic Behavior and Aggression Scales – High scores indicate a high frequency of these behaviors, low scores indicate they are rare

21 years) will be called adolescent, and Group 5 (over 21 years) will be referred to as adult.

For the individuals with ACC in this study, the ability to understand the communication of others and respond verbally improved over the childhood years, as is typical (see Table 11). The receptive communication ability of the adults in this sample was lower than the adolescents. Mean scores for the adult group may be attenuated due to the low number of participants in this sample (25) and may not represent the full range of ability in adults with ACC that a larger sample may indicate. With the exception of the adults with ACC, mean scores for receptive ability was higher than expressive ability, with a larger discrepancy noted in the younger years.

The five social and behavioral scales were analyzed using ANOVA (see Table 12). Statistically significant differences were noted across groups for each scale, so a Post-Hoc Tukey HSD was performed for each. For the Social Interaction Scale, $F(4, 699) = 8.029$, $p < .05$, significant difference in the adult group with each of the other age groups was found. This indicates that attributes associated with positive social interactions with others were less common in the adults sampled.

Significant differences on the Social Difficulty Scale, $F(4, 665) = 2.970$, $p < .05$, were also found. Except for during infancy, the trend for mean scores increased with age. A Post-Hoc Tukey HSD revealed the only significant difference was between the preschool group and the school-age group, with the older children displaying more social difficulties.

Table 11

Communication Ability by Age Group

	Receptive			Expressive		
	n	M	SD	n	M	SD
Infant/Toddler	40	2.9	2.6	37	1.4	1.2
Preschool	170	4.1	2.6	197	2.7	2.1
School-age	198	5.4	2.1	226	4.7	2.4
Adolescent	129	5.8	1.8	125	5.5	2.1
Adult	25	5.4	2.0	26	5.5	2.2

Note. For levels of communication ability/ receptive, 1 = shows little understanding, 2 = understands single words, 3 = matches names to objects, 4 = understands two words linked, 5 = understands two word sentences, 6 = understands most long sentences, 7 = understands most age level messages. For levels of communication ability/ expressive, 1 = none, 2 = gives name only, 3 = indicates several objects, 4 = two word sentences, 5 = two words with linking words, 6 = makes long sentences, 7 = able to engage in conversation.

Table 12

ANOVA for Social and Behavioral Scales by Age Group

	n	Mean	SD	F	Sig.
Social Interaction Scale (range 1-5)					
Infant/Toddler	66	3.2	.760		
Preschoolers	215	3.0	.653		
School-age	248	3.1	.709	8.029*	.000
Adolescents	143	2.9	.693		
Adults	32	2.3	.819		
Social Difficulties Scale (range 1-5)					
Infants/Toddler	46	2.8	.951		
Preschoolers	207	2.7	.780		
School-age	244	2.9	.735	2.97*	.019
Adolescents	142	2.9	.732		
Adults	31	3.0	.674		
Autistic-like Behavior Scale (range 1-3)					
Infants/Toddler	53	1.3	.510		
Preschoolers	214	1.5	.458		
School-age	247	1.6	.420	6.754*	.000
Adolescents	144	1.6	.397		
Adults	33	1.6	.487		

Table 12 (con't)

ANOVA for Social and Behavioral Scales by Age Group

	n	Mean	SD	F	Sig.
Aggressive Behavior Scale (range 1-3)					
Infants/Toddler	44	1.1	.243		
Preschoolers	202	1.3	.337		
School-age	241	1.5	.477	10.155*	.000
Adolescents	141	1.4	.454		
Adult	31	1.5	.448		
Mood Scale (range 1-4)					
Infants/Toddler	70	3.4	.566		
Preschoolers	216	3.4	.441		
School-age	244	3.3	.471	20.026*	.000
Adolescents	143	3.2	.517		
Adult	33	2.6	.747		

Social Interaction and Social Difficulty Scales
3 = about the same as same age individuals
Higher score = more of this characteristic
Lower score = less of this characteristic
Mood Scale - High scores indicative of a more positive mood, Low scores indicative of less desirable mood
Autistic Behavior and Aggressive Behavior Scales – High scores indicate a high frequency of these behaviors, low scores indicate they are rare

*$p < .05$

In addition, significant differences were found with the Autistic-like Behavior Scale, $F(4, 689) = 6.754$, $p < .05$. Group differences occurred in the scores of the infant/toddler group with school-age and adolescents, and the preschooler group with school-age and adolescents. Autistic-like behavior scores were higher in the older children, suggesting autistic-like behaviors increase with age as well.

The Post-Hoc Tukey HSD also revealed significant differences in the Aggression Scale, $F(4, 654) = 10.155$, $p < .05$. Aggressive behavior scores increased over the childhood years, being most problematic during the school-age and adult years. Differences were found between the infant/toddler group with school-age, adolescent, and adult groups, as well as between preschoolers with school-age and adolescents.

The Mood Scale, $F(4, 701) = 20.026$, $p < .05$, revealed significant differences in scores between the Infant/Toddler group and adults, preschoolers with the three older groups and school-age with adults, and adolescents with adults. Mean scores decreased over the years, indicating a less desirable mood with increasing age.

To determine whether developmental changes were inadequately assessed due to the structure of the age groupings, a Pearson correlation was performed utilizing the age of the participant and the score from each of the five social behavioral scales. Statistically significant ($p< .01$) positive correlations were found for autistic characteristics (.106) and aggressive behaviors (.124), while statistically significant negative correlations were found for mood (-.286) and social interaction (-.163), suggesting attributes associated with positive social interactions become more problematic with age.

Several individual attributes of interest to social success which have been identified in the ACC literature have been identified for descriptive analysis, in order to

determine if there were developmental trends. These are shown in Table 13. Mean scores for a "happy or cheerful" mood decreases over time, as does the variable "peers enjoy social interactions"; mean score for "difficult for others to read their emotions" increased in adulthood.

Higher Functioning Group

An additional finding which emerged during data analysis is of interest. Another group of children with ACC, described by Brown and Paul (2000), Stickles, Schilmoeller, & Schilmoeller (2002), and K. Schilmoeller (personal communication, August, 2001), concerns those who are considered higher functioning individuals with ACC. These individuals possess a normal IQ, yet may continue to have difficulty with social functioning. For the purpose of this study, (IQ scores were not available), this group was identified using the criteria described by Schilmoeller, Moes, Schilmoeller, & Nowak (2002). A sub-sample of individuals (n = 231) who were reported to have the highest level of communication ability (as indicated in the survey) was drawn for additional analysis and comparison with the total sample. This method would also likely exclude individuals with more severe neurological disorders which may confound the data. The mean age of individuals of this sub-sample is nine years old.

An examination of the frequency of behavioral or neurological disorders showed the professional diagnosis of seizures (19.6%), ADD (9.6%), ADHD (8.7%), and OCD (8.3%) in this sub-sample. Other diagnoses were noted less frequently although relatively high frequencies of learning disabilities and developmental delays were reported (see Table 14). A comparison of frequencies of these disorders with the total sample revealed

Table 13

Group Means of Individual Social Attributes

	Infant/ Toddler	Preschool	School-age	Adolescent	Adult
Happy/cheerful mood*	3.5	3.6	3.5	3.3	2.7
Peers enjoy interactions**	3.0	2.7	2.7	2.3	2.1
Difficult to read emotions**	3.2	3.2	3.3	3.2	3.6

*Range for this item is 1- 4, low numbers indicate less of this attribute

**Range for this item is 1- 5, 3 is similar to typical peers, low number is less of this attribute, high number is more of this attribute

Table 14

Professional Diagnosis of Behavioral or Neurological Disorders in Higher Functioning Individuals

	Total Sample (n = 730)	Higher Functioning (n = 231)
ADD w/o hyperactivity	6.7%	9.6%
ADHD	6.6%	8.7%
Hyperactivity Disorder w/o ADD	0.7%	0.0%
Autism or Autistic behavior	9.5%	4.3%
Obsessive Compulsive Disorder	6.8%	8.3%
Schizophrenia	0.8%	0.9%
Depression/Mood Disorder	4.4%	5.7%
Developmental Delay	77.2%	65.7%
Learning Disability	32.6%	32.2%
Mental Retardation	25.8%	12.2%
Seizure Disorder	29.1%	19.6%

some differences. As would be expected with the sampling criteria, the frequencies of MR and seizure disorders were lower with the higher functioning sample. Frequencies for autistic behavior and developmental delay were reported less frequently in the higher functioning group as well. On the other hand, the higher functioning group did report a higher frequency of diagnosis of ADD, ADHD, OCD, and depression/mood disorders.

Scores on the social and behavioral scales for the higher functioning individuals were examined and compared to the total group. Comparison of the group means for the social and behavior scales revealed similar overall scores. The means for the mood scale and aggressive behavior scale were the same for the total sample and the sub-sample (3.3 and 1.4, respectively). The higher functioning sub-sample scored slightly higher on the social interaction scale (3.1 for high functioning, 3.0 for total group) and the social difficulty scale (3.0 for high functioning, 2.9 for total group), and slightly lower on the autistic behavior scale (1.4 for higher functioning, 1.5 for total group). These results report the social behavior of the higher functioning individuals with ACC as similar to same age peers, with low incidence of aggressive or autistic behavior, and a generally positive mood.

A more in-depth data analysis of specific social behaviors was performed in order to determine whether behaviors reported in the total group also were present in the higher functioning group. The frequencies for prosocial attributes are reported in Table 15. The results again suggest these individuals possess a happy, cheerful demeanor and seem to enjoy interacting with siblings and peers. Yet, as found in the total sample, the number of participants who enjoy interactions with others (which includes adults, peers, and

Table 15

Prosocial Attributes in Higher Functioning Individuals

	n	About the same (%)	Slightly/much more (%)
Enjoys social contact with others	225	49.3	42.3
Friendly with strangers	227	33.0	42.3
Seeks/enjoys physical contact	227	46.7	35.2
Enjoys interactions with siblings	185	52.4	31.9
Enjoys interactions with peers	223	46.2	18.4
Reserved/Shy	207	38.2	26.6

	n	Often (%)	Almost always (%)
Happy/cheerful	229	34.5	54.6
Content	228	39.0	43.0
Relaxed	227	41.4	31.3

siblings), is noticeably higher than those who enjoy interactions with peers or siblings specifically.

Attributes associated with social difficulties are reported in Table 16. Informants report the higher functioning individuals in this sample have multiple characteristics of concern to social interaction. Less responsiveness to the instruction/requests of others (35.7%), stubbornness (24.5%), lack of independence (53.6%), difficulty using physical space appropriately (38.5%), and being easily upset by change (31.6%), are particularly prominent. Being able to read the emotions of these individuals is also reported (24.7%) as more difficult. The informants indicate peers enjoy interactions less (38.9%) with these individuals than with other peers.

To determine whether there was a correlation between the current age of the higher functioning individual with ACC and the social and behavioral scales, a Pearson correlation was performed. As with the total group, several statistically significant correlations were found (see Table 17). In addition, the correlations for this group were stronger than the total group, suggesting the higher functioning group experiences more difficulties than the total sample in social functioning as they get older. Mood became less positive, social interactions were less enjoyable and more problematic, and autistic-like behaviors were higher in the older individuals. There was no statistically significant correlation between age and aggressive behavior.

Table 16

Attributes Associated with Social Difficulties in Higher Functioning Individuals

	n	About the same (%)	Slightly/much less (%)
Independent	222	32.4	53.6
Siblings enjoy interactions	181	53.0	28.2
Peers enjoy interactions	216	51.9	38.9
Responds to instruction /requests	218	49.5	35.7
Difficult for others to read emotions	210	61.0	24.7*
Difficulty using appropriate physical space	208	51.4	38.5*

*(slightly/much more)

	n	Occasional (%)	Common/ very frequent (%)
Extraordinary attachment to objects	218	19.3	15.1
Unusual fears	221	29.4	14.5
Compulsive behaviors	217	22.6	15.7
Obsessive thoughts	210	22.9	21.0
Easily upset with changes	228	33.8	31.6
Unusual reaction to sounds	226	27.0	19.5
Stubborn	220	44.1	24.5
Temper tantrums	218	43.6	11.9

Table 17

Comparison of Pearson Correlations for Total Sample and Higher Functioning Individuals

	Total Sample	H.F. Sub-sample
Social Interaction/Age	-.163**	-.281**
Social Difficulty/Age	.068	.149*
Autistic Behavior/Age	.106**	.217**
Aggressive Behavior/Age	.124**	.097
Mood/Age	-.286**	-.430**

* $p < .05$

** $p < .01$

CHAPTER 4

DISCUSSION

Agenesis of the corpus callosum is a rare congenital brain anomaly for which a dearth of information is available to families, researchers, and service providers. While much can be learned about individuals with this rare disorder, attributes related to social interaction are the focus of this study. The purpose of this study is to contribute to the emerging body of research by providing a descriptive analysis of the communication, social, and behavioral attributes of a large sample of individuals with ACC. Group comparisons were made to analyze differences due to primary callosal diagnosis and chronological age. An additional analysis, that of a sub-sample of higher functioning individuals with ACC, will also be discussed in an effort to control for the confounding variables of severe neurological disorders. The limitations of this study and implications for further research will also be examined.

Discussion of Results

Research question one examined communication, social, and behavioral attributes of individuals with ACC for whom data were available. The persons with ACC in this study ranged from those with multiple physical and neurological deficits which include ACC to those diagnosed with ACC only. While it is of interest to determine what attributes may be associated specifically with ACC (which will be addressed in an adjunct research question), it is also important to understand the wide range of ability and disability among the entire sample.

Although some individuals with ACC face challenges in their interactions with others due to neurological or cognitive deficits, behavioral disorders were rarely reported

in this study. More than three-quarters of those surveyed reported developmental delay and a quarter to one third reported other disorders, such as LD, MR, and seizures. On the other hand, behavioral diagnoses such as ADD, OCD, hyperactivity, and autistic behaviors were reported at relatively low incidences. This supports the findings of O'Brien (1997), who reported behavioral disturbances were rare in his study of 47 children with ACC, as well as several case studies (Brown & Paul, 2000; Ritter, 1981; Stickles, Schilmoeller, & Schilmoeller, 2002) and parental reports (Schilmoeller & Schilmoeller, 1997, 2001). The relatively low incidence of behavioral disorders (which often leads to poor social outcomes) should be considered a strength for children with ACC.

The ability to communicate is the foundation for social interaction and individuals with ACC vary widely in their ability to do so successfully. Clearly, many individuals in this study experience early language delay, deficits, or anomalies; most receive some form of speech/language therapy at some time in their life. A small number of the individuals with ACC in this study do not understand the communication of others or express themselves in any way. This may likely be the individuals with the most severe and multiple disabilities. Others use a variety of methods to communicate, such as facial expressions, augmentative communication devices, sign language, or a combination of means. Noting that only half of the persons in this study use spoken language to express themselves and even fewer are capable of engaging in conversation, the ability to communicate in a way that is understood by others appears to be a common challenge for individuals with ACC. Some of the children in this study may be too young to communicate at higher levels. Yet the mean age of participants was 7.6 years, typically

old enough to engage with others in this way. Because the ability to use language competently becomes increasingly important to social success as children enter schools and engage in social activities outside the home (Dimitracopoulou, 1990; Lerner, et al. 1998; Owens, 1998), this may become a growing challenge for children with ACC. These findings of communication difficulties are consistent with previous research which addressed communicative competence in children with ACC (McCardle & Wilson, 1993; O'Brien, 1994; Ritter, 1981; Sauerwein, et al., 1994; Schilmoeller & Schilmoeller, 1997, 2000, 2001; Stickles, 2001a; Stickles, Schilmoeller, & Schilmoeller, 2002).

The ability to utilize spoken language is not indicative of communicative competence for this group of individuals, though. In fact, language anomalies are prevalent among those who are able to acquire a higher level of language ability. Remembering that only slightly more than half of those surveyed have acquired spoken language, the individuals who engage in meaningless conversation (38.5%) or out of context conversation (45.6%) are likely to be the same individuals. This means many of those with speech capability converse in this way at least occasionally.

Pragmatic ability is also an aspect of communicative competence and, although not specifically measured by this survey, some characteristics were contained within the social difficulty scale and can be examined. Difficulty using physical space appropriately and responding to others requests or instructions are reported as areas of concern. While language anomalies or pragmatic difficulties may be accepted in a young child, or overlooked by a knowledgeable adult, older peers may be less accepting of this characteristic in their same age peers. This may create more problems for children as they grow older and expectations increase (Dimitracopoulou, 1990; Owens, 1998). These

findings of difficulties with communicative competence support previous research and family reports of speech anomalies (O'Brien, 1994; Schilmoeller & Schilmoeller, 2001; Stickles, 2001a, 2001b) and pragmatic deficits (Brown & Paul, 2000; McCardle & Wilson, 1993; Sorensen, 1997; Stickles, 2001a, 2001b; Stickles, Schilmoeller & Schilmoeller, 2002). More in-depth study of the communication patterns in individuals with ACC during normal daily activities could shed additional light on this important aspect of social discourse.

Another area of interest to social interaction concerns attributes of physical activity. Although there were few reports of hyperactive behavior, a common cause of peer rejection, other characteristics of personal activity may be a cause for concern. Several variables which were measured may be indicative of a reluctance or inability to initiate, participate, or continue in typical childhood play. Many individuals were described as under-active (results in text, p. 36), frequently leaving tasks unfinished, or virtually sedentary when left alone (seen in table 5). This supports O'Brien's (1994) report of an "unwillingness to initiate or engage in activity" (p. 244) by the children in his study. Perseveration in an inappropriate activity (results in text, p. 36) and squirmy or fidgety behavior (seen in Table 5) were also noted in many participants. Research in childhood peer relationships suggests these attributes often contribute to difficulties in peer play and may be a cause for peer rejection (Berger, 2000; Campbell & Siperstein, 1994; Guralnick, 1990; Guralnick & Groom, 1985, 1987; King & Kirschenbaum, 1992; Roberts & Zubrick, 1992; Staub, 1998; Trawick-Smith, 2000).

Mean scores for the Social Interaction and Social Difficulty scales indicated the individuals in this study were described as similar to persons of the same age in these

social attributes. Yet, a much richer depiction was obtained when individual variables were identified for descriptive analysis. Most caregivers report the individuals with ACC are most often happy, cheerful, and content persons who enjoy social contact with others. The scores of the Mood Scale were quite high as well, indicating they were almost always in a pleasant mood with rare instances of disagreeable temperament. This was consistent with previous research findings (Brown & Paul, 2000; Schilmoeller & Schilmoeller, 1997, 2001; Stickles, Schilmoeller, & Schilmoeller, 2002). It was interesting to note, though, that these individuals with ACC enjoy interactions with siblings, and peers in particular, noticeably less than they did with "others" (which would include adults and older or younger unrelated children). Informants also indicated that a large percentage of siblings and peers do not enjoy social interactions with these individuals with ACC, despite their seemingly outgoing personalities (seen in Table 8). This is also consistent with the findings of Schilmoeller & Schilmoeller (2001), Sorensen (1997), and Stickles, Schilmoeller, & Schilmoeller (2002), who report individuals with ACC tend to get along better with adults or younger children than same age peers.

The disparity between the desire to be socially involved with others and the apparent lack of success in their interactions may be related to several attributes which emerged from the data. Although aggressive behavior and autistic behaviors are rare (as reported on each of these scales), several variables within the scales could be problematic for personal interactions and relationships (as seen in Table 8). Many caregivers indicated the individual with ACC was occasionally or frequently stubborn, easily upset by changes, possessed some obsessive thoughts or compulsive behaviors, and have some unusual fears or unusual reactions to sounds. Interpersonal behaviors which emerged as

prevalent involve lack of attention to social conventions and cues such as maintaining appropriate physical distance from social partners and a lack of responsiveness to others' instructions or requests. In addition, many reported it was difficult to read the emotional state of individuals with ACC, a finding which supports previous research that suggests they experience difficulty with emotional awareness and processing (Brown & Paul, 2000; O'Brien, 1994). It may be that although the rudiments of social behavior, such as friendliness and cheerfulness, are common and the desire to be social is present, the requirements for sustained reciprocal relationships, such as attention to the social cues and conventions, empathy, and emotional regulation, remain elusive. Further study of this aspect of behavior and social cognition in individuals with ACC would be worthwhile.

One finding which emerged from this study bears special attention. Many informants indicated the person with ACC displayed exceptional friendliness toward strangers, and although this can be conceived as outgoing behavior, it can also be a safety concern. Previous research indicates that children with prenatal brain damage or stunted brain growth often have difficulty with emotional regulation which can be exhibited as impulsive behavior or inappropriate friendliness toward strangers (Berger, 2000). Children, such as those in this study, may be at increased risk for being taken advantage of by unfriendly or dangerous individuals. In fact, this concern has been voiced by parents of children with ACC (K. Schilmoeller, personal communication, July, 2001; Stickles, Schilmoeller, & Schilmoeller, 2002). Caregivers and others should be aware of this potential and take appropriate measures to safeguard them.

Research question two asked whether there were differences in attributes of social interaction related to the degree of agenesis of the corpus callosum. Although this

question was not explored in depth, several broad findings can be noted. Individuals who are diagnosed with a thin corpus callosum are reported to achieve lower levels of both receptive and expressive communication abilities than those with P-ACC or complete ACC. Perhaps the communication differences could be accounted for by neurological anomalies, age differences, or the low number of participants within that group, but this awaits further analysis. Although Schilmoeller, Moes, Schilmoeller, & Nowak (2002) report more behavioral and social deficits in children with P-ACC than complete ACC (utilizing the same data set as this researcher), the ANOVA performed on the Social and Behavioral Scales found no significant differences across groups. It is possible an in-depth study of individual variables would confirm their findings. Caution should be taken in interpreting the results of this question, though, as the diagnoses were reported by informants only and not verified with diagnostic reports.

Research question three addressed differences in attributes related to social interaction as they change over the childhood years. Clearly, there is much to be revealed about developmental changes in social success for children with ACC. While it would be beneficial to analyze individual variables of communication and social behavior, as performed in research question one, this is also beyond the scope of this paper. Instead, the analyses performed for this project may provide some insight into the developmental issues faced over the childhood years.

Overall, the results of the analyses suggest social interactions are less enjoyable and grow more difficult as individuals with ACC grow older, particularly in adulthood. Mood tends to become less positive as well. The characteristic happy, cheerful, and relaxed mood of the younger participants is less frequently reported among older teens

and adults. Aggressive and autistic-like behaviors also increased slightly as children moved into the school years and beyond. Although it is impossible to determine the cause of these changes from the data, some hypotheses can be made. As children grow older, communication and social demands become more complex, requiring higher levels of both verbal and nonverbal communication abilities, social cognition, responsiveness to others, and perspective taking, all areas of concern for these individuals. Emotional information plays an increasing role in mature relationships based on companionship and intimacy (Berger, 2000; Odom & Brown, 1993; Trawick-Smith, 2000). Since the corpus callosum is normally the main route for information transfer (Mercer, 1998; Windhorst, 1996), efficiently processing and integrating the incoming sensory and emotional information to respond appropriately may be an overwhelming task for an individual with ACC. Younger children are typically not expected to meet those demands, and for a time, children with ACC may have some difficulty, yet still be accepted despite their misjudgments. As children become school- age, and increasingly as they become adolescents and adults, complex social cognition and responsiveness to the others plays a growing role in successful mature relationships (Berger, 2000; Odom & Brown, 1993; Trawick-Smith, 2000). Additionally, in typical children, the corpus callosum continues to develop during this time and contributes to meeting the increasing social demands. For individuals who do not have a corpus callosum, the discrepancy between expectations and their own limitations may increase over development.

Mood changes, as well as the slight increase in negative behaviors, of older individuals with ACC could be related to frustration, recognition of their own social difficulties, or even loneliness or unhappiness. Yet, Brown & Paul (2000) reported the

adolescents in their study were friendly and cooperative during testing and seemed unaware of the social interaction problems described by their parents. Stickles, Schilmoeller, & Schilmoeller (2002) reported the young adult in their case study also frequently displayed a happy disposition and had actively participated in youth activities throughout his childhood. Yet this individual did not develop close relationships with peers in his youth and continues to experience social difficulties as an adult. Whether adolescents and adults with ACC are aware of their own deficits is unclear. More in-depth analysis of these data, as well as continued research is necessary to uncover the implications for individuals as they grow older. Studying these individuals as they interact within the everyday life situations may also reveal issues which cannot be measured by the usual methods. It is clear that the challenges for social interactions change and evolve as children with ACC grow older. However, building on their strengths while recognizing the challenges and intervening in meaningful ways may transform outcomes.

Analysis of data for higher functioning individuals with ACC also merits discussion. Although a more extensive analysis is likely to reveal important additional information, the limited analyses performed for this study suggests that even individuals who are least likely to be noticeably disabled face challenges in their social lives. Research in childhood disability indicates that individuals with less visible disabilities are more often rejected by peers because the reason for their unusual behaviors, perceptions, or faulty cognition is less apparent (Trawick-Smith, 2000). Higher functioning individuals with ACC are likely to be the ones most involved with typical peers and thus expectations for their behavior may be higher than for those who possess more severe

neurological disorders. Consequently, they may be at higher risk for peer interaction difficulties and social repercussions.

Like the total sample, the social and behavioral scales suggest that higher functioning individuals are friendly and enjoy social interactions with others. These individuals often exhibit a positive mood, and possess rare aggressive or autistic tendencies. Results for the Pearson correlations were more revealing though, indicating that social interactions get less enjoyable as higher functioning individuals with ACC get older. Mood was also less positive in the older individuals than the younger. Although this was also found in the total sample, most correlations were stronger for this sub-sample. The negative correlation for mood was particularly strong and should be a cause for concern.

While the higher functioning individuals with ACC in this sample may function in day-to-day life with whatever supports are necessary or available, it is clear their social lives and mental health are a continuous and possibly a growing challenge. These findings support previous research which suggests that adolescents with ACC and normal IQ scores continue to experience social and relational difficulties (Brown & Paul, 2000; Stickles, Schilmoeller, & Schilmoeller, 2002). Research on peer relationships indicate that individuals who lack healthy peer relationships frequently lead more isolated lives and suffer more mental health disorders (Erdley et al., 2001; Farmer, et al., 1996; Field et al., 1984). Although this was not specifically measured in this study, findings suggest that the potential for such outcomes do exist. Much more research is necessary to learn more about the unique strengths and challenges of this sub-sample.

Unlike many developmental disabilities, the diagnosis of ACC does not require a series of tests, assessments, or observations. Instead, individuals with ACC are increasingly being diagnosed by CT scan, MRI, or ultrasound, early in life, some even prior to birth (Schilmoeller & Schilmoeller, 2001). Yet, determining and understanding the behavioral and psychosocial implications remains somewhat of a mystery. While this large scale study has its limitations, it does provide some clues to unlocking that enigma. Despite a wide range of ability and disability in this sample, most were described as happy, social individuals. Aggressive or antisocial behaviors were very rare. However, social cognition, particularly an awareness of their social partners, and attention to and comprehension of the emotional content of interactions, appeared to challenge their interpersonal lives. There were indications that successful social interactions become more challenging with age. Uncovering the scope of the unique nature of individuals with ACC will take much more extensive research.

Limitations of This Study

While this study may be considered valuable due to the limited availability of research regarding individuals with ACC and the large number of participants, several limitations must be discussed. Although the unusually large sample is advantageous, it is a self-selected sample of families who were known to The ACC Network. Demographic information indicated many were highly educated, and the informants were actively seeking information regarding ACC. While the response rate was good for this type of study it is unknown how those who chose not to participate or those who were not surveyed would differ from this sample. Utilizing caregivers as informants increases the probability of subjectivity, as well. Still, they may also be more aware of important, yet

subtle characteristics that may be missed during formal testing. Any generalizations to the population of individuals with ACC must be done with caution.

It is possible that the individuals surveyed for this study are the more severely affected individuals with ACC and may not represent the full range of potential (O'Brien, 1997). While this may have been an issue in the past when those with higher functionality may be diagnosed only after a brain scan for other reasons (such as a head injury), many in this sample were diagnosed early in life, even prenatally, due to more common use of diagnostic tools. This may have provided a much broader cross section of individuals in this sample than in past studies.

The data utilized for this study were taken from a preexisting data set designed for another purpose. While many variables were pertinent to this study, not all questions could be answered completely and some inferences had to be made with caution. Surveys which specifically address a broader range of social interaction skills, standardized assessment tools, and direct observation within typical environments could yield additional and important data. A control group study would provide the comparison group necessary to support findings as well.

Another issue of concern relates to the question of individuals with ACC who are considered higher functioning. The criteria utilized to identify the sub-sample in this study are problematic since individuals with MR were drawn (see Table 14). It is possible the criteria may have been insensitive to other factors as well; therefore, caution must be used in interpreting the results reported on these individuals. Future studies of higher functioning persons with ACC may require IQ scores as a more valid indicator.

Finally, the scales which were developed to economize the social and behavioral data were less informative than expected, in particular on the social interaction and social difficulty scales. The wide range of ability and disability within the sample, as well as the age span of participants, may have attenuated the mean scores. It may also be that composite measures are less sensitive to the characteristics of ACC. Much more could be learned by analysis of individual variables contained within the scales, as performed in research question one, across development and for high functioning individuals. New tools may need to be developed as more is learned about the unique nature of this congenital anomaly.

Implications for Future Research

Although this study yielded important information about the implications for individuals with a little known and little researched brain anomaly, it is just a beginning. Replication and control group studies, as well as new studies, are needed to support these and previous research findings. More in-depth analysis of these preliminary findings could yield a much richer and more helpful description of the strengths and challenges faced by individuals with ACC across the range of degree of agenesis and across development. Several possibilities for further research will be discussed.

Research which examines developmental changes for children with ACC more closely would be beneficial. The age spans of the groups developed for this study were quite large and possibly missed the evolution of some characteristics of ACC. Shorter time spans, particularly in the early years, may have yielded more information as to how characteristics evolved over time. This may be especially important to communication and emotional issues. Do those who receive early and appropriate service interventions

have different outcomes than those who are diagnosed later in life or do not receive appropriate services? It would also be interesting to investigate more closely the mood changes which seem to become characteristic of the older individuals. Is this characteristic of the brain anomaly or is it a result of environmental experiences?

Using caregivers as informants can be useful in determining the unique and often subtle characteristics of a little known entity. Yet, these attributes must be confirmed by objective means as well. As more is discovered about ACC, better tools and measures need to be developed to objectively study these individuals over time and in typical environments, as well as in the laboratory setting. It is obvious there is a need for much more research in the area of ACC. As more children are diagnosed early in life, the demand for knowledge and intervention strategies will continue to grow.

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Appendix A

ACC Network Survey

Thank you for your participation in The ACC Network Survey. The results of this survey will help researchers and families like yours better understand agenesis of the corpus callosum and other conditions involving the corpus callosum (i.e., hypoplasia and dysgenesis of the corpus callosum).

The code printed in the top right corner of this form is there to maintain your privacy, while at the same time allowing us to contact you. **The code, along with your name and address, is known only to the coordinators of The ACC Network.** None of the information you provide will be associated publicly with your name. The code will be used only in the following circumstances: 1) We will use the code to confirm the return of your survey (reducing the cost of a second mailing); 2) We will use the code to return any requested information; and 3) We might contact you for follow-up information based on what we learn from this survey.

NOTE: Unless stated differently for a specific question, all questions are concerned with the person in your family who has agenesis of the corpus callosum (ACC), dysgenesis (malformation) or hypoplasia (incomplete development) of the corpus callosum, or some other condition related to the corpus callosum.

Directions: Please mark the item (with a check mark or X) that best describes your situation. You may leave questions blank if you do not wish to answer or you feel you cannot answer. If possible, **please review and consult any medical records, medical professionals, and personal diaries or journals** which give the most accurate information. **NOTE:** Answer only those items that you understand completely and for which you can provide accurate medical information. Provide estimates to items ONLY when asked to supply your "best estimate." Please do not suggest your own diagnosis or your own interpretations unless you are confident that a qualified health care professional could confirm your answer.

Parents may collaborate in answering the following questions concerning their child.

Family Information

Background about Yourself - For the person filling out the survey.

1. What is your first language? ☐ English ☐ Other (please specify):_____

List other languages you speak fluently:

_____

List other languages spoken fluently by other family members:

_____

2. Your relationship to the person with ACC (or related condition) is...
☐ self ☐ birth mother ☐ birth father ☐ sibling
☐ adopted mother ☐ adopted father
If adopted, year of adoption: _____

☐ other _____

How many years of school have YOU (person filling out form) completed? (Circle your answer)

Elementary through high school *College*

Grade K 1 2 3 4 5 6 7 8 9 10 11 12 13 14 15 16 17 18+

How many years of school has your spouse/partner completed - if this applies? (Circle your answer)

Elementary through high school *College*

Grade K 1 2 3 4 5 6 7 8 9 10 11 12 13 14 15 16 17 18+

NOTE: If you attended schools that do not follow this United States model, please indicate the number of years of school that you have completed:

Years of Education Completed: _____

Background about Family

4. Indicate age and gender of siblings of person with ACC or related condition:
☐ None (**Go to question #5**)

Age:	Gender:	
_____	☐ Male	☐ Female
_____	☐ Male	☐ Female
_____	☐ Male	☐ Female

Additional siblings: (please list age and gender):

_____

5. Any blood relatives who have been diagnosed with ACC or other condition involving the corpus callosum?

☐ yes ☐ no
If yes, please list relationship and condition:
_____

6. Mother's current age: _____ (years) [**NOTE**: Answer for adoptive mother if person with ACC is adopted]

7. Father's current age: _____ (years) [**NOTE**: Answer for adoptive father if person with ACC is adopted]

General and Diagnostic Information about Person with ACC (or Related Condition)

8. Gender: ☐ Male ☐ Female
Date of birth: Month _____ Day _____ Year _____
Birthweight: _____ (pounds and ounces) **or** _____ (grams)
(Estimate if you are not certain.)

Race or Ethnicity:
☐ White
☐ African-American, Black, Negro
☐ Hispanic/Latino/Spanish
☐ Native American or Alaska Native
☐ Asian
☐ Pacific Islander
☐ Other _____

9. Which diagnosis has been given?
☐ agenesis of the corpus callosum (total absence of corpus callosum)
☐ partial agenesis, with this part of the corpus callosum remaining: (Mark all that apply)
☐ front ☐ middle ☐ back ☐ don't know/unsure
☐ corpus callosum is thin or underdeveloped (Indicate which.)
☐ dysgenesis ☐ hypoplasia ☐ don't know/unsure
☐ other _____

10. Age at time of diagnosis:
☐ before birth at _____ (gestation weeks, if known)
☐ between birth and 1 month
☐ between 1 and 24 months: Please specify _____ (months)
☐ 2 years of age or older: Please specify _____ (years)
☐ don't know/unsure

11. *If you have a brain scan report (MRI, CT scans) or other medical records*, do the medical records describe the presence of the following? (Mark all that apply). [If you are uncertain, please consult with medical professionals to help you answer this item.]

☐ anterior commissure (small bundle of nerve fibers in front of the corpus callosum)
☐ Probst bundle (bundle of nerve fibers along the walls of the ventricles)
☐ enlarged ventricles
☐ cysts; describe: _____
☐ thinned cortex
☐ diminished white matter
☐ optic nerve/tract abnormalities
☐ left hemisphere abnormalities
☐ right hemisphere abnormalities
☐ frontal lobe abnormalities
☐ parietal lobe abnormalities
☐ occipital lobe abnormalities
☐ temporal lobe abnormalities
☐ cerebellum abnormalities
☐ spinal cord abnormalities
☐ other _____

☐ I don't know or am unsure about the terms listed above

Please describe medical records or other sources you checked to determine the information checked above:

_____
_____

Comments/Additional information:

_____
_____
_____

12. What test was performed to make the diagnosis? (Mark all that apply)
☐ MRI (Magnetic Resonance Imaging)
☐ CAT scan (Computer Axial Tomography)
☐ other _____
☐ ultrasound or sonogram
☐ EEG
☐ don't know/unsure

13. At what age (in years) did you first notice differences in appearance or behavior compared to other children who do not have ACC or related condition?
☐ have not yet noticed any differences
☐ before birth
☐ between birth and 1 month

☐ between 1 and 24 months; Please specify _____ (months)
☐ 2 years of age or older; Please specify _____ (years)
☐ don't know/unsure

What differences did you observe?

_____

_____

_____

_____

14. Additional *current* diagnostic terms or descriptions of behavior - based ONLY on professional evaluations or records. [If you are uncertain, please consult with the professionals who conducted the evaluations to help you answer this item.]
(Mark all that apply):
Note: See later questions for more detailed issues related to behavior, movement or appearance.

☐ ADD (attention deficit disorder without hyperactivity)
☐ ADHD (attention deficit / (without/hyperactivity disorder) deficit)
☐ Aicardi syndrome
☐ Andermann syndrome
☐ Arnold Chiari syndrome
☐ Asperger syndrome
☐ autism (or autistic-like behaviors)
☐ cerebral palsy
☐ chorioretinal anomalies or lacunae
☐ depression (or similar mood disorder)
☐ developmental delay
☐ fetal alcohol syndrome
☐ hydrocephalus
☐ hyperactivity disorder attention
☐ learning disability
☐ mental retardation
☐ microcephaly
☐ obsessive-compulsive disorder
☐ schizophrenia or psychosis
☐ seizure disorder (permanent condition OR treated for this within the past year)
☐ spina bifida
☐ I don't know or am unsure about the terms listed above
☐ other; please describe any and all significant physical/behavioral diagnosis or descriptors:

_____

_____

_____

_____

If any of these diagnoses were different at various stages of development, please explain:

_____

Please describe medical records or other sources you checked to determine the information checked above:

_____

_____

_____

Comments/Additional information:

_____

_____

_____

15. Has the person with ACC or related condition used medication for any of the conditions listed in #14:

☐ yes ☐ no ☐ don't know/unsure

If "yes," please list:

Condition: _____ Medication: _____ ☐ currently used ☐ used in past

Effectiveness: ☐ very effective ☐ somewhat effective ☐ not effective ☐ dont know/unsure

Condition: _____ Medication: _____ ☐ currently used ☐ used in past

Effectiveness: ☐ very effective ☐ somewhat effective ☐ not effective ☐ dont know/unsure

Condition: _____ Medication: _____ ☐ currently used ☐ used in past

Effectiveness: ☐ very effective ☐ somewhat effective ☐ not effective ☐ dont know/unsure

Condition: _____ Medication: _____ ☐ currently used ☐ used in past

Effectiveness: ☐ very effective ☐ somewhat effective ☐ not effective ☐ dont know/unsure

Please describe medical records or other sources you checked to determine the information checked above:

_____

_____

Comments/Additional information:

_____

_____

_____

Physical Features

16. Describe **current** body size compared to persons of the same age and gender:

☐ small
☐ slightly smaller than average
☐ average
☐ slightly larger than average
☐ large

If relative body size was different at various stages of development, please explain:

_____

_____

17. Describe **current** head size compared to persons of the same age and gender:

☐ small
☐ slightly smaller than average
☐ average
☐ slightly larger than average
☐ large

If relative head size was different at various stages of development, please explain:

_____

_____

18. Head or facial features: (Mark all that apply)

☐ cleft lip ☐ cleft palate ☐ eyes set wide apart ☐ slanted eyes ☐ low-set ears

☐ unusual head shape; describe:

_____

☐ other (describe):

_____

Prenatal Information

19. Was there anything abnormal about the pregnancy (example: blood loss, lack of movement, etc.)?

☐ yes ☐ no ☐ don't know/unsure

If "yes," please explain:

_____

_____

_____

_____

20. Was the person with ACC born:

☐ Within one week before or after the due date?
☐ More than one week before the due date? How many weeks early? _____ (best estimate)
☐ More than one week after the due date? How many weeks late? _____ (best estimate)
☐ don't know/unsure

21. Form of birth? ☐ vaginal ☐ Cesarean ☐ don't know/unsure

22. Any problems during delivery? ☐ yes ☐ no ☐ don't know/unsure
If "yes," please explain:

_____

23. Any additional problems immediately after delivery?
☐ yes ☐ no ☐ don't know/unsure
If "yes," please explain:

_____
_____
_____
_____

24. Length of infant's hospital stay after the birth? (in days)

_____

25. Was a special unit (example: neonatal intensive care) required after birth?
☐ yes ☐ no ☐ don't know/unsure
If "yes," please give the type of unit:

_____

Reason for needing special unit:

_____

Comments/Additional information:

_____
_____
_____

Neurological Status

26. Have seizures occurred at any time? **(If "no" go to #32)** ☐ yes ☐ no
☐ don't /know/unsure

27. Total number of seizures from birth to now: (Mark best estimate of all seizures up to the present)
☐ 1-2 ☐ 3-10 ☐ 11-50 ☐ 51-100 ☐ more than 100

☐ don't know/unsure

28. At what age did the seizures start?
☐ at birth
☐ between birth and 1 month
☐ between 1 and 24 months; Please specify _____ (months)
☐ 2 years of age or older; Please specify _____ (years)
☐ don't know/unsure

29. Describe severity, type and frequency of seizures:
_____
_____
_____

30. Currently on any medication for the seizures/epilepsy?

☐ yes ☐ no ☐ don't know/unsure
If "yes," please list:
_____
_____

If "yes," is the medication effective at reducing or controlling seizures?
☐ yes, very ☐ yes, somewhat ☐ no ☐ don't know/unsure

31. Have the seizures stopped? ☐ yes ☐ no ☐ don't know/unsure
If "yes," at what age? _____

Vision, Hearing, Touch and Pain Status

32. Mark any that currently apply:
☐ no difficulties with vision or hearing of any kind -- now or in the past **(Go to question #34)**
☐ currently has or previously had some vision difficulties
☐ currently has or previously had some hearing difficulties

33. Vision or hearing problems now or in the past: (Mark all that apply)
☐ difficulty with binocular (two eye) vision (strabismus)
☐ involuntary eye movement or vibration (nystagmus)
☐ dimness of sight (amblyopia)

- ☐ difficulty seeing in low light
- ☐ blind spots in visual field
- ☐ blurred vision
- ☐ drooping eyelids (ptosis)
- ☐ eye muscle control difficulties
- ☐ no peripheral vision (either side or both sides)
- ☐ nearsighted - difficulty seeing distant objects (myopia)
- ☐ farsighted - difficulty seeing close objects
- ☐ wears corrective lenses
- ☐ blind in one eye
- ☐ totally blind
- ☐ legally blind - but limited sight remains
- ☐ difficulty with depth perception
- ☐ deaf in one ear only
- ☐ total deafness
- ☐ frequent ear infections causing hearing loss
- ☐ wears electronic hearing aids
- ☐ other _____
- ☐ other _____

34. Pain perception: (Mark only one item)
- ☐ little or no pain perception (high pain tolerance)
- ☐ less pain perception than average
- ☐ average or typical pain perception
- ☐ more pain perception than average
- ☐ much more pain perception than average (low pain tolerance)

35. Touch: (Mark only one item)
- ☐ little or no sensitivity to being touched by others
- ☐ less sensitivity than average to being touched by others
- ☐ average sensitivity to being touched by others
- ☐ more sensitivity than average to being touched by others
- ☐ much more sensitivity than average to being touched by others

36. Sensitivity to cold: (Mark only one item)
- ☐ little or no sensitivity to cold
- ☐ less sensitivity to cold than average
- ☐ average sensitivity to cold
- ☐ more sensitivity to cold than average
- ☐ much more sensitivity to cold than average

37. List any visual, hearing, or touch problem that has diminished or disappeared. Also indicate the age of the change:

_____

_____

Comments/Additional information:

_____

_____

_____

_____

Mobility/Physical Development

38. Describe muscles (predominant type):

☐ very stiff or tight (hypertonic)
☐ somewhat stiff or tight
☐ slightly floppy or with poor muscle tone
☐ very floppy or with poor muscle tone (hypotonic)
☐ average or typical for age

Comments (e.g., did this change over time? If so explain.)/Additional information:

_____

_____

39. Hand usage; which hand is <u>most frequently used</u> for each task?
Note: You may need to observe actual situations to respond to some items.

	Does not do	Left hand	Right hand	Both about the same	Don't know /unsure
writing	☐	☐	☐	☐	☐
drawing/coloring	☐	☐	☐	☐	☐
using a spoon	☐	☐	☐	☐	☐
using a toothbrush	☐	☐	☐	☐	☐
using scissors	☐	☐	☐	☐	☐
using an eraser	☐	☐	☐	☐	☐
throwing a ball	☐	☐	☐	☐	☐
swinging a bat (or something similar such as a tennis racquet, fly swatter, etc.)	☐	☐	☐	☐	☐
using a hammer (toy or real)	☐	☐	☐	☐	☐

40. For each of the developmental "milestones," **give the age in months - if known -** that the person with ACC developed these skills. **If exact age in months is not known, please indicate child's age in years.**

Very Early	Slightly Early	Typical/ Average	Slightly Late	Very Late	Has not yet Developed		Age (months):
☐	☐	☐	☐	☐	☐	Lifted head (lying on stomach)	_____
☐	☐	☐	☐	☐	☐	Rolled over	_____
☐	☐	☐	☐	☐	☐	Sat without support	_____
☐	☐	☐	☐	☐	☐	Stood holding on	_____
☐	☐	☐	☐	☐	☐	Crawled	_____
☐	☐	☐	☐	☐	☐	Stood alone	_____
☐	☐	☐	☐	☐	☐	Walked alone	_____
☐	☐	☐	☐	☐	☐	Walked up stairs	_____
☐	☐	☐	☐	☐	☐	Talked (single words)	_____
☐	☐	☐	☐	☐	☐	Toilet trained	_____
☐	☐	☐	☐	☐	☐	Learned to ride bike [2 wheeled bike - without "training wheels"]	_____

List any other behaviors that were delayed and age acquired:

_____
_____
_____
_____

41. Any special difficulty with behaviors that require a person to coordinate the left and right limbs (hands, arms, legs or feet)? ☐ yes ☐ no

If yes, difficulties with particular type of behaviors (past or present):

_____
_____
_____
_____
_____

42. Current levels of other activities. Mark level of ability for each item - relative to age group.

Not at All	Minimal	Fairly Well	Very Well	**Person with ACC or related condition is able to..**
☐	☐	☐	☐	use hands to motion/gesture
☐	☐	☐	☐	squeeze objects
☐	☐	☐	☐	use a pencil
☐	☐	☐	☐	catch a ball
☐	☐	☐	☐	throw a ball
☐	☐	☐	☐	run
☐	☐	☐	☐	go down stairs
☐	☐	☐	☐	go up stairs
☐	☐	☐	☐	hop/jump
☐	☐	☐	☐	skip
☐	☐	☐	☐	balance when standing or walking
☐	☐	☐	☐	feed self with fingers
☐	☐	☐	☐	use a spoon
☐	☐	☐	☐	drink from a cup/glass
☐	☐	☐	☐	cut food with knife and fork
☐	☐	☐	☐	dress self
☐	☐	☐	☐	button clothing
☐	☐	☐	☐	close a zipper

Not at All	Minimal	Fairly Well	Very Well	**Person with ACC or related condition is able to..**
☐	☐	☐	☐	cut with a scissors
☐	☐	☐	☐	brush own teeth
☐	☐	☐	☐	bathe self
☐	☐	☐	☐	tie a shoe (with little or no assistance)
☐	☐	☐	☐	play video/computer games
☐	☐	☐	☐	swim

Comments/Additional information:

_____

_____

_____

_____

Feeding Issues

43. Miscellaneous feeding issues:

Displayed adequate sucking reflex at birth? ☐ yes ☐ no ☐ don't know/unsure

If "no," describe type of difficulty

_____

_____

_____

Currently has or previously had a (gastric) feeding tube?

☐ yes ☐ no ☐ don't know/unsure

Has difficulty swallowing?

☐ never or rarely ☐ occasionally ☐ often ☐ only in past ☐ don't know/unsure

Experiences (or experienced) reflux (food coming back up)?

☐ never or rarely ☐ occasionally ☐ often ☐ only in past ☐ don't know/unsure

Does not know when he/she has had enough food or fluid?

☐ never or rarely ☐ occasionally ☐ often ☐ only in past ☐ don't know/unsure

Unusually picky and will only eat certain foods?

☐ never or rarely ☐ occasionally ☐ often ☐ only in past ☐ don't know/unsure

Tries to eat things other than food? (examples: frozen foods, coal, wood, cardboard)

☐ never or rarely ☐ occasionally ☐ often ☐ only in past ☐ don't know/unsure

Chewing difficulties?

☐ never or rarely ☐ occasionally ☐ often ☐ only in past ☐ don't know/unsure

44. Amount of food eaten generally?

☐ much less than average ☐ more than average
☐ less than average ☐ much more than average
☐ typical/average for age

45. Typical fluid intake?

☐ much less than average ☐ more than average
☐ less than average ☐ much more than average
☐ typical/average for age

Comments/Additional information:

_____
_____
_____
_____

Bladder/bowel Control

46. Any difficulty with bladder control? [Skip if child is younger than 3 years of age]
☐ never or rarely ☐ occasionally ☐ often ☐ only in past ☐ don't know/unsure

If yes describe type of difficulty:

_____

47. Experiences constipation?
☐ never or rarely ☐ occasionally ☐ often ☐ only in past ☐ don't know/unsure

48. Experiences diarrhea?
☐ never or rarely ☐ occasionally ☐ often ☐ only in past ☐ don't know/unsure

Comments (e.g., did this change over time? If so explain.)/Additional information:

_____
_____
_____
_____

Communication Issues

49. Ability to ***understand*** others? (Mark <u>all</u> that apply)
- ☐ appears to understand very little from any type of communication
- ☐ understands facial expressions
- ☐ understands through touch (or other informal gesture system)
- ☐ understands formal sign language (or similar symbol system)
- ☐ understands using electronic device (touch board, computer, etc.)
- ☐ understands sign AND spoken language
- ☐ understands spoken language
- ☐ other_____

50. Ability to ***express thoughts to*** others? (Mark <u>all</u> that apply)
- ☐ does not indicate needs
- ☐ uses facial expressions to communicate needs
- ☐ uses touch (or other informal gesture system)
- ☐ uses formal sign language (or similar symbol system)
- ☐ uses electronic device (touch board, computer, etc.)
- ☐ uses sign AND spoken language
- ☐ uses spoken language

☐ other_____

51. How much does person with ACC ***understand*** from communications (using any form - signed, written, spoken, etc.)? (Mark the *one* item that is *closest* to your situation)
- ☐ shows very little understanding
- ☐ understands single words
- ☐ can match names to objects
- ☐ can understand more than two words combined with linking words
- ☐ can understand sentences with two words
- ☐ can understand most long sentences
- ☐ understands most messages that are at the person's age level

52. How much is the person with ACC able to ***express to*** others (using any form - signed, written, spoken, etc.)? (Mark *one* item that is *closest* to your situation):
- ☐ none
- ☐ only gives own name
- ☐ can indicate several objects
- ☐ can make sentences with two words
- ☐ can combine more than two words and use linking words (example: and, but, or, etc.)
- ☐ can make some long sentences
- ☐ able to engage in conversations

53. Other Language Difficulties: (Mark all that apply)

Very Rare /Never	Occasional	Very Frequent	
☐	☐	☐	conversation is meaningless
☐	☐	☐	shouts or screams unexpectedly
☐	☐	☐	conversation is "out of place"
☐	☐	☐	repeats words or phrases in a parrot fashion without understanding their meaning?

Describe any additional problems with language or speech that you would like to tell us about:

_____

_____

_____

_____

_____

_____

Sleep

54. ☐ Most often shows a regular pattern of sleep with very few difficulties **(go to question #55).**

Compared to persons of similar age, what is the frequency of sleep difficulties? (Mark all that apply)

Very Rare /Never	Occasional	Very Frequent	
☐	☐	☐	wakes up during the night
☐	☐	☐	has difficulties settling to sleep
☐	☐	☐	has disturbing behaviors during sleep (sleep walking, talking, etc.)
☐	☐	☐	has night terrors or bad dreams
☐	☐	☐	enuresis (bed wetting)

Comments (e.g., did this change over time? If so explain.)/Additional information:

_____

_____

_____

_____

Social and General Behavior

55. Describe activity level, compared with a person of the same age:

☐ very underactive
☐ slightly underactive
☐ normally active
☐ slightly overactive
☐ very overactive

Comments (e.g., did this change over time? If so explain.)/Additional information: ____

_____

_____

56. Other FREQUENT characteristics of activity level (Mark all that apply):

☐ if left alone tends to do little or nothing
☐ frequently squirmy or fidgety
☐ requires longer than usual to settle down to do something enjoyable
☐ frequently leaves tasks unfinished
☐ creates chaos aimlessly
☐ other _____

Comments (e.g., did this change over time? If so explain.)/Additional information: _____

_____

_____

57. Mark the level of each characteristic - compared to other individuals of the same age:

Much Less	Slightly Less	About Same	Slightly More	Much More	
☐	☐	☐	☐	☐	Enjoys social contact/interaction with familiar people
☐	☐	☐	☐	☐	Friendly with strangers
☐	☐	☐	☐	☐	Displays physical affection
☐	☐	☐	☐	☐	Seeks/enjoys physical contact
☐	☐	☐	☐	☐	Reserved or shy
☐	☐	☐	☐	☐	Independent
☐	☐	☐	☐	☐	Enjoys interactions (play, spending time) with siblings
☐	☐	☐	☐	☐	Enjoys interactions (play, spending time) with peer group
☐	☐	☐	☐	☐	Siblings enjoy interactions
☐	☐	☐	☐	☐	Peers enjoy interactions
☐	☐	☐	☐	☐	Enjoys music
☐	☐	☐	☐	☐	Enjoys water
☐	☐	☐	☐	☐	Enjoys animals
☐	☐	☐	☐	☐	Uses loud speech
☐	☐	☐	☐	☐	Dominates conversations
☐	☐	☐	☐	☐	Responds to instruction or requests (compliant)
☐	☐	☐	☐	☐	Shows unusual eye contact (Example: rarely direct or overly direct)
☐	☐	☐	☐	☐	Shows unusual facial expressions
☐	☐	☐	☐	☐	Makes unusual gestures
☐	☐	☐	☐	☐	Difficult for others to read his/her emotional state
☐	☐	☐	☐	☐	Sexual interests
☐	☐	☐	☐	☐	Has difficulty using appropriate personal space (too close or too far)
☐	☐	☐	☐	☐	Shows "hard-to-manage behavior" when shopping
☐	☐	☐	☐	☐	Is physically capable of most personal hygiene or dressing, but is unwilling or unable for other reasons (specify or describe): _____

Comments (e.g., did this change over time? If so explain.)/Additional information: ____

_____

_____

_____

58. Unusual movements or interests. Mark level for each item:

Very Rare or Not True	Occasional	Very Frequent or Common	
☐	☐	☐	pacing
☐	☐	☐	rocking
☐	☐	☐	spinning self
☐	☐	☐	hand flapping
☐	☐	☐	extraordinary attachments to objects
☐	☐	☐	unusual social or emotional interest
☐	☐	☐	unusual fears of specific objects or situations
☐	☐	☐	shows compulsive behaviors (tries to repeat actions over and over)
☐	☐	☐	has obsessive thoughts (cannot stop thinking about certain things)
☐	☐	☐	easily upset with changes in routine
☐	☐	☐	unusual reactions to sounds
☐	☐	☐	unusual reactions to lights
☐	☐	☐	unusual reactions to smells
☐	☐	☐	other

_____

____

Comments (e.g., did this change over time? If so explain.)/Additional information: ____

_____

_____

Self-Injurious Behavior and Aggression

59. Mark appropriate level for each:

Very Rare or Not True	Occasional	Very Frequent or Common	
☐	☐	☐	exhibits self-injurious behavior (biting, head banging, scratching, etc.)
☐	☐	☐	physically attacks other people/children
☐	☐	☐	suddenly lashes out or hits for no apparent reason
☐	☐	☐	deliberately destroys things
☐	☐	☐	so violent that others need assistance to restrain
☐	☐	☐	verbally abusive
☐	☐	☐	stubborn
☐	☐	☐	temper tantrums
☐	☐	☐	other

_____

Comments (e.g. did this change over time? If so, explain)/Additional information:

_____

_____

_____

Mood

60. Mark how often each trait occurs - compared to individuals of similar age.

Never/ Rare	Some-times	Often	Almost Always	
☐	☐	☐	☐	happy/cheerful
☐	☐	☐	☐	content
☐	☐	☐	☐	relaxed
☐	☐	☐	☐	sad/unhappy
☐	☐	☐	☐	angry
☐	☐	☐	☐	fearful/anxious
☐	☐	☐	☐	shows quickly changing moods
☐	☐	☐	☐	mood is out of place (example: happy at sad occasions)
☐	☐	☐	☐	shows very little emotion of any kind
☐	☐	☐	☐	other

_____

Comments/Additional information:

_____

Learning and Memory

61. Most recent IQ score for person with ACC or related conditions - IF known:

What IQ test was used: _____Age when administered: _____

IQ (Full Scale Score): _____If known: Verbal Score: _____Performance Score: _____

62. Mark level and type of learning - compared to individuals of similar age.

Not True /Rare	Some-times	Often	Almost Always	
☐	☐	☐	☐	Learns by repetition
☐	☐	☐	☐	Learns by imitation
☐	☐	☐	☐	Good memory
☐	☐	☐	☐	Difficulty with abstract reasoning
☐	☐	☐	☐	Perseverates (difficulty in stopping incorrect behavior)
☐	☐	☐	☐	Learns from video/computer games
☐	☐	☐	☐	Enjoys learning/working with computer
☐	☐	☐	☐	Difficulty staying on task when learning

63. Form(s) of educational programming - past or present: (Mark all that apply)

☐ play group
☐ preschool/nursery
☐ self-contained special education classroom
☐ regular education classroom
☐ regular resource room attendance (or "pull-out" program)
☐ other special education program; describe _____
☐ Headstart program
☐ home schooling
☐ Other _____
☐ Other _____
☐ too young to begin any form of schooling **(Go to question #65)**
☐ no formal schooling ever **(Go to question #65)**

Describe any changes in educational programs:

_____
_____
_____
_____

64. Current or highest educational level completed by person with ACC or other related condition.

☐ non-graded/non-traditional system (**Go to item #65**)

Circle your answer:

Elementary through high school *College*

Grade K 1 2 3 4 5 6 7 8 9 10 11 12 13 14 15 16 17 18+

NOTE: If the person with ACC or related condition attended schools that do not follow this United States model, please indicate the number of years of school completed:

Years of Education Completed: _____

Therapies Received

65. Mark frequency that applies:

Never	Only in the past	Infrequently	Frequently	
☐	☐	☐	☐	Speech Therapy
☐	☐	☐	☐	Occupational Therapy
☐	☐	☐	☐	Physical Therapy
☐	☐	☐	☐	Early intervention
☐	☐	☐	☐	Sensori-motor integration
☐	☐	☐	☐	Vision Therapy
☐	☐	☐	☐	Academic tutoring
☐	☐	☐	☐	

Other_____

Miscellaneous

66. List any skills the person with ACC or related condition is unusually good at? (Examples: memory, mental arithmetic, puzzles, art, video games, etc.)

_____

_____

_____

_____

_____

_____

67. What activities, therapies and/or techniques do you feel have been helpful in remediating the effects of ACC or related condition?

68. What types of information about ACC or related conditions would be most helpful to you?

69. Do you (or have you) participate(d) in the ACC electronic listserve (ACC-L)?
☐ yes ☐ no

70. Do you have any other comments you would like to share?

Thank you very much for completing this survey! Your efforts will help to expand our collective knowledge of ACC and related conditions.

A summary of the findings will appear in The Callosal Connection newsletter.

Appendix B

Social and Behavioral Scales

Social Interaction Behavior Scale

Much Less (1)	Slightly Less (2)	About same (3)	Slightly more (4)	Much more (5)	
____	____	____	____	____	Enjoys social contact /interactions with familiar people
____	____	____	____	____	Friendly with strangers
____	____	____	____	____	Displays physical affection
____	____	____	____	____	Seeks/enjoys physical contact
____	____	____	____	____	Reserved or shy*
____	____	____	____	____	Independent
____	____	____	____	____	Enjoys interactions with siblings
____	____	____	____	____	Enjoys interactions with peer group
____	____	____	____	____	Siblings enjoy interactions
____	____	____	____	____	Peers enjoy interactions

*This item was recoded so high number is considered very social and low is considered less social

(Cronbach Alpha = .80)

Socially Difficult Behaviors Scale

Much Less (1)	Slightly Less (2)	About same (3)	Slightly more (4)	Much more (5)	
____	____	____	____	____	Uses loud speech
____	____	____	____	____	Dominates conversations
____	____	____	____	____	Shows unusual eye contact
____	____	____	____	____	Shows unusual facial expressions
____	____	____	____	____	Makes unusual gestures
____	____	____	____	____	Difficult for others to read their emotional state
____	____	____	____	____	Sexual interests
____	____	____	____	____	Difficulty using appropriate physical space
____	____	____	____	____	Shows "hard to manage behavior" when shopping
____	____	____	____	____	Is physically capable of most personal hygiene or dressing, but is unwilling or unable for other reasons

(Cronbach Alpha = .80)

Aggressive Behavior Scale

Very Rare Or Not True (1)	Occasional (2)	Very Frequent or Common (3)	
_____	_____	_____	Physically attacks others
_____	_____	_____	suddenly lashes out or hits for no apparent reason
_____	_____	_____	deliberately destroys things
_____	_____	_____	so violent that others need assistance to restrain
_____	_____	_____	verbally abusive
_____	_____	_____	stubborn
_____	_____	_____	temper tantrums

(Cronbach Alpha = .82)

Mood Scale

Never/Rare (1)	Sometimes (2)	Often (3)	Almost always (4)	
____	____	____	____	Happy/Cheerful
____	____	____	____	Content
____	____	____	____	Relaxed
____	____	____	____	Sad/Unhappy*
____	____	____	____	Angry*
____	____	____	____	Fearful/Anxious*
____	____	____	____	Shows quickly changing moods*
____	____	____	____	Mood is out of place*
____	____	____	____	Shows little emotion of any kind*

*These items were recoded so high number is considered optimum and low is considered least desired

(Cronbach Alpha = .81)

Autistic-like Behavior Scale

Rare/Never	Occasional	Very Frequent	
____	____	____	Conversation is meaningless
____	____	____	Shouts/Screams unexpectedly
____	____	____	Conversation is "out or place"
____	____	____	Repeats words/phrases in a parrot fashion without understanding their meaning
____	____	____	Pacing
____	____	____	Rocking
____	____	____	Spinning self
____	____	____	Hand flapping
____	____	____	Extraordinary attachments to objects
____	____	____	Unusual social or emotional interests
____	____	____	Unusual fears of specific objects or situations
____	____	____	Shows compulsive behavior
____	____	____	Has obsessive thoughts
____	____	____	Easily upset with changes in routine
____	____	____	Unusual reactions to sounds
____	____	____	Unusual reactions to lights
____	____	____	Unusual reactions to smells

(Cronbach Alpha = .86)

BIOGRAPHY OF THE AUTHOR

Donna Ross Doherty was born in Manchester, New Hampshire December 7, 1959. She attended grade school and high school in Manchester, and graduated from the Concord Hospital School of Nursing in 1981. After working in community health and pediatric nursing in New Hampshire for a number of years, she relocated with her husband and children to Orland, Maine in 1989. In 1998, Donna completed her Bachelor of Science in Nursing at The University of Maine in Orono.

After working in childhood disability services for two years, Donna enrolled in the graduate degree program in Human Development at The University of Maine, in September, 2000. While enrolled, she worked as a teaching assistant for Dr. Gary Schilmoeller. Donna is a candidate for the Master of Science degree in Human Development from The University of Maine in December, 2002.