Biographical Study of a Woman with Agenesis of the Corpus Callosum: A Story of Hope and Inspiration

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A BIOGRAPHICAL STUDY OF A WOMAN WITH AGENESIS OF THE CORPUS CALLOSUM: A STORY OF HOPE AND INSPIRATION

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Submitted in Partial Fulfillment of the Requirements of the Degree of Doctor of Psychology

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DEPARTMENT OF PSYCHOLOGY

Dissertation Approval

This is to certify that the thesis presented to us by Robin Comerford on the 50th day of May, 2009, in partial fulfillment of the requirements for the degree of Doctor of Psychology, has been examined and is acceptable in both scholarship and literary quality.

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Abstract

School psychologists must be knowledgeable about brain development to help students in their care. The human brain has the capability to determine a person's happiness, effectiveness, and positive relationships with others. This biographical study examined how a young woman diagnosed with Agenesis of the Corpus Callosum (ACC) and agenesis of the cerebellum came to live a productive, happy life. ACC is a low incidence form of brain damage marked by inconsistent behavioral and emotional manifestations throughout the lifespan. Personal life artifacts, school documents, and medical records were used to help organize her life experiences in the form of a narrative biography. Through listening to her stories and that of her mother, life stages identified with key events were analyzed to help others gain insight into how she experienced her brain damage. The key events, known as epiphanies, that emerged through her life span focused upon: 1) feelings of frustration, and anger when dealing with the medical and school systems, 2) establishing secure attachment through mother and daughter connection, 3) desire for positive connections through supportive relationships to heal, 4) issues regarding educational values of competency, perseverance, and a focus on strengths, 5) issues involving advocacy for the underdog. Relational-cultural theory and resiliency research was used to analyze her stories and create a Model of Relational Resilience in Mother-Daughter Connection. Strategies and new insights into resiliency can be gleaned from this research to help school psychologists, educators, and parents be better equipped to deal with the brain injured.
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Chapter One: Statement of the Problem

The more frequent use of neuroimaging techniques has brought about a vast amount of research on brain injury, yet there is much to be learned about the brain’s amazing ability to recover from insult. A vast majority of literature on the brain focuses on adult brain functioning, not children’s. Parts of the brain may have the ability to compensate for damage to other areas of the brain by changing structure and function. School psychologists will continue to be required to help implement effective intervention strategies with more diverse group of learners and will need to sort through recent discoveries about the brain.

Statement of the Problem

Survey research indicates that a majority of teachers have worked with students with chronic illness, such as brain injury, and did not receive adequate training (Brown, 2002). Little research has been done on the capacity of the educational system to accommodate the needs of children with chronic illness. Over the past four decades, a developmental approach of examining brain-behavior relationships, which relies on the study of the development of the brain with the study of behavior development, has been used to explain certain types of learning disabilities. It is vital for school psychologists to recognize the developmental stages in children when discussing brain function.

There is a great need for school psychologists to be involved with developmental, educational, social, and family issues of their clients. There are few studies about these systems and the influence they have on children and adolescents with chronic illness. As more information about the brain’s chemistry and functioning is gathered, school
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psychologists need to be able to sort through all the data and make informed decisions to help students in their care. School psychologists must be knowledgeable about brain behavior in order to develop evidence based strategies to help students with neurological conditions.

A mysterious, low-incidence, form of brain injury little known to school psychologists is known as Agenesis of the Corpus Callosum (ACC). This condition is marked by inconsistent behavioral and emotional manifestations that may be confused with other neurological injuries. Experimental situations have been used to study those with ACC though it appears essential that these individuals need to be studied in more naturalistic settings as some deficits go unnoticed by standard neurological examinations. Thus, the study of individuals diagnosed with ACC who have succeeded in living to their fullest potential can give great insight to school psychologists and educators.

New insights learned from individuals diagnosed with ACC can be incorporated into training programs for school psychologists and educators responsible for their care. They may have the advantage of understanding how an individual with ACC experiences their brain injury through the lifespan. Exploring the life experiences of a woman in college with ACC through hearing her story and the perspectives of her mother will help provide an understanding of how one can achieve their fullest potential. Since this research will investigate the lifespan of a single individual, it is anticipated that the outcomes of this study will provide a foundation to build upon for future research. There is also the need to track the development of a specific brain injury and parental
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involvement through the lifespan. Further research is needed to identify how relationships with adults promote psychological health and well-being in youth.

Purpose of the Study

The purpose of this narrative biographical study is to understand what it is like to experience ACC through stories and key events known as epiphanies. These lived experiences will be placed in chronological order to display how ACC is lived, experienced, articulated, and felt through the lifespan. The experiences that occurred throughout this young woman’s various life stages will be explored. These epiphanies will be analyzed according to developmental theories, relational-cultural theory, and resiliency research.

The rationale for this investigation is that by using in-depth interviews to extrapolate critical periods in the life of a woman with ACC, an increased awareness of how she achieved to her fullest potential can give hope to others with brain injury. The goal of this investigation was to chronical the life history of a woman with ACC in detail from childhood to young adulthood. An analytic abstraction of her life story was written using adolescent developmental theory, relational-cultural theory, and resiliency theory to give voice to a population seldom written about to seek to understand how her relationship with others has contributed to her life success (Denzin, 1989).

Overview of Literature Review

The Development of the Corpus Callosum

The corpus callosum, the largest commisure in the human brain, is made up of many millions of nerve fibers in a thick bundle that contain myelinated and
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unmyelinated axons in the cerebral cortex. Clusters of axons, known as tracts, connect different areas of the brain known as commissures. The corpus callosum is composed of white matter (myelinated axons) that connect the left and the right hemispheres of the brain. The myelinated axons are responsible for the transfer of information through the brain. The corpus callosum serves as the communication pathway allowing information to transfer back and forth between the left and right hemispheres. Myelin, the substance that helps speed the transmission of nerve impulses, is essential for the callosal fibers to be operational.

Fetal cell migration occurs and the neural tube develops during the first trimester of pregnancy. A normal corpus callosum develops between seven to twelve weeks of gestation. It develops sequentially and is generally formed by twenty weeks as it continues to develop in post-natal life (Barkovich, 1991; Barkovich, 1994; Bennett, 1996). The corpus callosum develops from anterior to posterior (Brown, Jeeves, Dietrich, & Burnison, 1999). The corpus callosum is made up of the genu, which forms first, followed by the body, then the splenium, and the rostrum is formed last (Barkovich and Norman, 1988). The corpus callosum undergoes a burst of development during the first four years of life, continues growth until adulthood, and becomes part of the highest order of brain structures (Taylor & David, 1998; Scheafer, Sheth, and Bodensteiner, 1994). The corpus callosum continues myelinating until the end of the first decade of life contributing to the speed and efficiency of interhemispheric communication (Giedd, Castellanos, Casey, Kozuch, King, and Hamburger, 1994; Brown, Symington, VanLancker-Sidtis, Dietrich, and Paul, 2005). The functional consequence of this
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communication pathway, which is the last to develop in the brain, is not entirely known (DeBoard, Kilian, Naramor, & Brown, 2003).

**Diagnosis, Possible Causes, and Incidence of Agenesis of the Corpus Callosum**

Agenesis, meaning absence, occurs when the cells of the corpus callosum fail to develop as the cerebral cortex develops sometime between 8 and 20 weeks of gestation (Marszak, Jamroz, Pilch, & Kluczemska, 2000; Gupta, 1995). The cause of ACC may be due to vascular or inflammatory lesions that develop prior to 12 weeks of gestation (Bennett, 1996). During the process of cell migration, infection, neurological malformations, or metabolic error may occur and interrupt the process of the development of the corpus callosum (Scheafer et al, 1994). Others believe that the corpus callosum fails to develop because the axons of callosal neurons develop in parallel to the interhemispheric fissure instead of completely connecting the left and right hemispheres of the brain (Barkovich, 1994; Huber-Okrainec, Blaser, and Dennis, 2005). Defects of the corpus callosum occur as the result of a failure of fibers to develop or cross the midline during development, but instead form Probst bundles that are believed to be made up of intersecting fibers that may have grown in the wrong direction (Sztriha, 2005; Gupta, 1995). The absence of the corpus callosum is not essential for life functions. Dysgenesis is the term used to describe partial agenesis of the corpus callosum where parts of the rostral portion of the corpus callosum are present and a portion of the posterior callosum is absent (Brown et al., 1999).

Once thought to be a rare birth defect, ACC has been diagnosed with increasing frequency due to advances in Magnetic Resonance Imaging (MRI), Computer Axiel
Tomography (CAT), and ultrasonography neuroimaging techniques (Goodyear, Bannister, Russell, and Rimmer, 2001). The incidence of ACC varies widely depending on the diagnostic techniques and the cohort of children studied with estimates ranging from .0005% to 0.7% for children in the general population (Marszak, Jamroz, Pilech, Kluczeewskia, Jablecka-Deja, & Krawczyk, 2000; Taylor & David, 1998; Bennett, 1996; Doherty, Schilmoeller, and Schilmoeller, 2005). The incidence of ACC in the developmentally disabled population has been reported as 2 to 3 per 100 (Sztriha, 2005; Bennett, 1996). Some feel that the incidence of ACC in the general population is an underestimate because individuals with ACC may have normal intelligence and may not go for medical assessment. A study conducted in the United Kingdom of fifty six cases of those diagnosed with complete or partial ACC found that fourteen percent had an identifiable developmental syndrome with no significant relation between the degree of ACC and the presence of a developmental disorder (Taylor & David, 1998).

Prognosis for Those with Agenesis of the Corpus Callosum

Prognosis for those with complete or partial ACC is uncertain, but generally ACC is associated with normal developmental outcomes such as average IQ with some neurological findings, and cognitive deficits (Bennett, 1996; Gupta, 1995). A study conducted in the United Kingdom of adult cases of those with ACC found that fifty one percent had some degree of an intellectual impairment (Taylor & David, 1998). Prenatal diagnosis made in the late second or third trimester using fetal karotyping may reveal a chance of other concurrent medical and neurological conditions along with ACC with poor prognosis (Bennett, 1996; Gupta, 1995; Shevell, 2002). Twenty- two patients with
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callosal abnormalities were studied using karotyping and it was found that clinical outcome and development correlated with the severity of associated abnormalities (Bennett, 1996).

Chromosomal syndromes and brain malformations that often occur with ACC are known as acrocallosal, Aicardi, Andermann, Shapiro, (Marszak et al., 2000; Gupta, 1995). In patients with Spina Bifida Meningomyelocele (SBM), ACC is evidenced as there is a profound disturbance of brain development including abnormalities of the white matter, midbrain, cerebellum, and corpus callosum (Fletcher, Dennis, and Northrup: 2000). Anomalies of the corpus callosum can also occur with inborn errors of metabolism (Marszak et al., 2000). ACC is also being liked to various neuropsychiatric disorders including Attention Deficit Disorder, and schizophrenia with serious emotional consequences (Taylor & David, 1998; Rourke, 1995; Cleaver & Whitman, 1998; Dughartey, 2000; Thompson, 1998; Nopoulos, Berg, Castellenos, Delgado, Andreasen, & Rapoport, 2000).

Other health and behavioral outcomes associated with ACC include seizures, dysmorphic features, intellectual disability, psychomotor retardation, language deficits, psychosocial deficits, as well as visual and hearing impairments (Sztriha, 2005; Marszak et al., 2000; Doherty et al., 2005). A longitudinal study of forty children with partial agenesis of the corpus callosum found that those diagnosed in infancy had developed seizures and older patients had a more favorable outcome as they were less likely to develop epilepsy (Lacky, 1985). Information on other health issues was obtained from a survey of a large group of individuals with ACC in contact with an international support
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Group. Results from this survey indicate that individuals with ACC were more likely to have difficulty getting to sleep, be less active, and have significantly lower pain perception, difficulty chewing and swallowing, display quickly changing moods, stubbornness, and temper tantrums as compared to their siblings (Doherty et al., 2005).

The first symptoms of ACC are usually seizures followed by feeding problems, difficulties with walking, standing, and in holding the head erect. Diagnosis is usually made by neuroimaging observations typically administered because a parent reports that their child experienced language delays, visual impairments, seizures, and/or low muscle tone (Schilmoeller, 1995; Marszak et al., 2000; Shevell, 2002). A study conducted in the United Kingdom looking at adults with ACC found that fifty seven percent of the patients had some form of seizures (Taylor & David, 1998). Studies have shown that very few neuropsychological deficits are observed in patients with ACC when other brain impairments are present; therefore most conditions related to ACC are not discovered until a child is experiencing difficulties in school because of learning and behavioral problems (Panos, P., Porter, Panos, A., Gaines, & Erdberg, 2001). Children with ACC may be misdiagnosed as emotionally disturbed or behaviorally disordered because of their misinterpreted conduct which is a neurological, not a deliberate action (Plomin, Price, Eley, Dale, & Stevenson, 2002; Thompson, 1996).

Effects of this disorder range from a mild to a severe developmental delay (Shevell, 2002). Some individuals with ACC appear to be asymptomatic. Other students may need speech
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therapy, physical therapy, and occupational therapy. Split-brain operations reveal that the corpus callosum itself is not necessary for a productive intellectual life. The research indicates that those with ACC experience a wide range of intellectual, motoric, and language abilities. Children born without a corpus callosum may be able to utilize alternative commissural pathways and develop alternative routes of interhemispheric communication.

Interhemispheric Communication and Split Brain Studies

Surgical disconnection of the cerebral hemispheres, by severing the corpus callosum, helps scientists study interhemispheric communication and the organization of sensory motor systems. Split brain research demonstrates that the corpus callosum is possibly responsible for the exchange of information between the two hemispheres of the brain and the specialization of function that each hemisphere controls. Originally, these split brain operations were performed on patients to control epileptic seizures on humans in the 1940's with little improvement in the frequency of seizure activity (Springer and Deutsch, 1998). As long as forty years ago, Norman Geschwind was interested in the complexities of the human mind and studied disconnection syndrome in split brain patients. Animal studies were conducted later where the entire corpus callosum was severed along with the optic chiasm resulting in poor transfer of visual information suggesting that the corpus callosum provided the interhemispheric pathway for visual information. Longitudinal research following patients with commissurotomies gives great insight as to the function of the corpus callosum. Two major populations have been followed in split brain operations from California in 1965 and Dartmouth Medical School.
Agenesis of the Corpus Callosum in 1977 (Gazzaniga, 2000). Medical advances with commissurotomy patients have gone from the use of tachistoscopes to computer driven presentation systems to assess sensory pathways.

Many decades of split brain research demonstrates the specialized functions of the two hemispheres of the human brain. It is thought that the left hemisphere is responsible for speech, problem solving, making inferences, generating hypotheses, and language capacities. The right hemisphere is responsible for facial recognition, attentional monitoring, processing emotions, and making perceptual distinctions. Studies of split brain patients further indicate that the left hemisphere has marked limitation in perceptual function, and the right hemisphere has even more limitations in cognitive function (Gazzaniga, 2000).

Interhemispheric transfer which involves the integration of information from the left to the right hemispheres of the brain has been studied for over fifty years on adults and children with ACC similar to the “disconnection syndrome” seen in commissurotomized patients who display deficits on sensory motor and tactile functioning (Sperry, 1974; Karneth, Schumacher, and Wallesch, 1991; Paul, Van Lancker-Sidtis, Schieffer, Dietrich, and Brown, 2003). Even though the brains of split brain patients differ from those with ACC, it is known that they share the absence of the linking of the right and left hemisphere because of the absence of the corpus callosum. It is demonstrated that individuals with ACC are different than the split brain patients in that they are able to use interhemispheric integration for simple visual information but not for complex visual tasks.
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Visual Information and Interhemispheric Integration

One of the believed functions of the corpus callosum is to transfer all types of sensory information and coordinating the processing between the right and left hemispheres. It is demonstrated through split brain research using tachistoscopes that visual information remains lateralized to one hemisphere. Visual information presented to the right visual field projects exclusively to the left hemisphere and visual information presented to the left visual field projects exclusively to the right hemisphere. The role of the corpus callosum in bilateral integration of visual information was studied by Brown (1999) who observed four individuals with complete ACC, two individuals with partial ACC, one commissurotomy patient, and normal controls as they tried to match unilateral and bilateral (one to each visual field) visual field letters and patterns (Brown, et al. 1999). It is demonstrated that the commissurotomy patients and those with ACC show deficits in complex spatial patterns as they are unable to recognize a pattern of five dots, but are able to recognize a single letter (Brown et al., 1999; Paul, VanLancker-Sidtis, Schieffer, Dietrich, & Brown, 2003). It appears that those with ACC may have difficulty transferring bilaterally presented visual stimulus information from one hemisphere of the brain to the other which involves the complexity of callosal transfer (Hannay, 2000; Brown et al., 1999).

Split brain patients studies also demonstrate that some people with commissurotomies are unable to cross integrate visual information between their two half visual fields. It was found that when the visual information is lateralized to the disconnected left hemisphere or disconnected right hemisphere, the unstimulated
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hemisphere is not able to use the information for perceptual analysis (Gazzaniga, 2000). It was also found that split brain patients are not able to use visual information for perceptual analysis when visual information is lateralized to either the left or right disconnected hemispheres. These patients are unable to cross integrate visual information and show no measurable interaction between the two hemispheres during processing of perceptual information. Each hemisphere is able to perceive simple visual patterns separately, but is unable to perceive complex visual information by combining the visual patterns together with each half of the brain. The role of the corpus callosum in the reorienting of selective visuospatial attention between visual fields was tested in ten individuals to matched controls. Results indicate that those with ACC have significantly greater difficulty reorienting attention to an invalidly cued target stimulus occurring in the opposite visual field (Hincs, Paul, & Brown, 2002).

Sensory Motor, Tactile Functioning and Interhemispheric Integration

Studies of split brain patients and those with ACC help us study the nature of the neural pathways that coordinate the hands and arms of humans. It is believed that bimanual coordination in children is similar to that of split brain patients and those with ACC as the corpus callosum is not fully developed until the end of the first decade of life. A study focusing on bimanual coordination in normally developing children indicates that interhemispheric interaction plays a significant role in bimanually coordinated motor activity (DeBoard et al., 2003). Patients with ACC were studied to see if they show a “disconnection syndrome” like those of split brain patients who display deficits on the transfer of more complex information involving sensory motor and tactile functioning.
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(Karneth, Schumacher, and Wallesch, 1991; Paul, Van Lancker-Sidtis, Schieffer, Dietrich, and Brown, 2003). During these studies, form boards were used while the subject was blindfolded and had to feel blocks and place them in appropriate locations on the board with their dominant and nondominant hand. These studies were looking at intermanual transfer of spatial information in those with ACC. Different forms of the block patterns were used increasing in number from six to twelve blocks and it was demonstrated that those with ACC displayed increasingly significant deficits as the complexity of the form boards increased and when the subjects had to use their nondominant hand (Sauerwein, & Lassonde, 1994; Brown et al., 1999; Brown, & Paul, 2000).

The corpus callosum allows for the transfer of sensory and motor information between the brain’s hemispheres and coordinates motor planning and control. Jeeves studied interhemispheric communication of those with ACC and normal controls on a task involving reaction time to light stimuli and hand movements and found that those with ACC responded at a slower pace to the stimuli than the normal controls (Brown, Jeeves, Dietrich, & Burnison, 1999; Berlucchi, Aglioti, Marz, and Tassinar, 1995; Paul et al., 2003). However, they found that if responses were made unilaterally, as in visual patterns, there was no difference in reaction time between those with ACC and controls. Lassonde looked at somatosensory systems as he studied reaction times using a pointing response to a visual target on partially callosomatised patients, normal controls, and those with ACC. It was demonstrated that ACC patients were impaired on all tasks involving
transfer of motor and visual-spatial skills as they displayed slow response times and increased error rates (Lassonde, Sauerwein, and Lepore, 1995; Lassonde, 1995).

Another study investigated the role of the maturation of the corpus callosum in interhemispheric transfer of unilateral visual motor learning. Pre and post tests were conducted on those with callosal agenesis to controls on a unilateral aiming task (Chicoine, Proteau, & Lassonde, 2000). It was demonstrated that those with ACC were able to complete the unilateral aiming task with the trained hemisphere, but failed to transfer the acquired skill to the untrained hemisphere (Chicoine et al., 2000). Split brain patients are not able to initiate ipsilateral (same side of the body) hand movements with accuracy. In other words, having a split brain impairs the left hemisphere’s ability to control the left hand, and the right hemisphere’s ability to control the right hand (Gazzaniga, 2000). Chiarello (1980) found that finger localization was the only area in which patients with ACC performed poorly as compared to controls.

Patients with ACC may display deficits in complex visuospatial construction and complex visuospatial memory. The Rey Osterrieth Figure was used to assess this in patients with ACC and it was found that they demonstrated problems with delayed recall of the design (Temple, & Ilsey, 1994).

Language Development and Interhemispheric Communication

Early studies of language development based on those with brain lesions demonstrate that language processing may be dominant in the left hemisphere of the brain with little attention paid to the right hemisphere. Recent studies of right hemisphere brain damaged individuals through the use of improved neuroimaging techniques suggest
that the right hemisphere may be important for comprehending emotional prosody, making inferences, processing context, word knowledge, pragmatic, and figurative language (Bryan, & Hale, 2001; Huber-Okrainec, et al., 2005; George, Parekh, Rosinsky, Ketter, Kimbrell, Heilman, Herscovitch, & Post, 1996). Interhemispheric communication may be a contributing factor in language competence as the right hemisphere may no longer be ignored (Van Lanker, 1997; Bryan, and Hale, 2001). The corpus callosum is important for the transfer of cognitive functions and language functions possibly because of this interhemispheric communication (Gazzinga, Kutas, VanPetten, and Fendrich, 1989; Huber-Okrainec, et al., 2005). When the corpus callosum is severed, language processing is not as proficient and comprehension is weaker when words are presented to one half visual field (Mohr, Pulvermuller, and Zaidel, 1994; Huber-Okrainec, et al., 2005).

The brain bases of figurative language disorders have been studied and may provide insight into the processing of specific language functions. Figurative language impairments are reported in those with ACC as it is suspected that interhemispheric communication is required for successful idiom comprehension (Huber-Okrainec, et al., 2005; Brown, Symington, VanLanker, Dietrich, and Paul, 2005). Neural networks may be important for figurative language processing, instead of a single brain region (Huber-Okrainec et al., 2005). Idioms are a part of figurative language that are defined as nonliteral phrases (e.g. *kick the bucket*) whose meaning cannot be determined by the literal meaning of each individual word in the phrase. A study looking at idiom comprehension tasks of 76 children with spina bifida meningomyelocele (SBM), and
various levels of abnormal development of the corpus callosum compared to a control
group, found that impaired idiom comprehension occurred in those with SBM and the
level of idiom comprehension was due to the extent of the corpus callosum damage
(Huber-Okrainec, et al., 2005). It is speculated that those with callosal damage may be
slower than their peers to accept the interpretation of idioms because idiom
comprehension requires the rejection of the literal meaning and accepting the figurative
meaning of the phrase. Figurative language comprehension may be disrupted because of
interhemispheric communication deficits related to ACC (Huber-Okranec et al., 2005).

Other research has revealed impaired processing of affective prosody and
nonliteral interpretation of words in adults with normal intelligence that are diagnosed
with ACC. Prosody involves the right hemisphere of the brain and is demonstrated in the
rhythm, rate, and intensity of speech. This is demonstrated in marked difficulties with
social communication skills even though there appears to be no difficulties with basic
language skills. Other aspects of language skills possibly governed by the right
hemisphere are known as pragmatics which deals with the function of language in
relation to the environment.

Paralinguistic skills (nonverbal communication) involve social and pragmatic
aspects of language. It is believed that individuals with ACC are likely to misunderstand
and to be insensitive to nonverbal communication. A study of young adult males
diagnosed with ACC with average intelligence as measured by the Wechsler Intelligence
Scales-Third Edition (WISC-III) were compared to normal controls to assess
paralinguistic skills. The Formulaic and Novel Language Comprehension Test (FANL-C)
Agenesis of the Corpus Callosum requires no verbal ability in the response, LA Prosody Test, and Gorham Proverbs Test which requires verbal interpretation and multiple choice options, was utilized to assess these skills. It was found that those with ACC exhibited impairment with nonliteral language (idioms and proverbs) and emotional-prosodic meanings of words with no significant difference than controls in comprehension of literal items (Paul, et al., 2003; Van Lancker & Kempler, 1987). It was also demonstrated that those with ACC had deficits in self-generated interpretation of proverbs but did not have difficulty on the multiple choice items suggesting that more complicated tasks require more interhemispheric communication (Paul, et al., 2003).

It appears that having ACC may reduce the brain’s capacity to integrate complex material from each of the hemispheres. In the case of ACC, the left hemisphere has limited information processing from the right hemisphere and the individual is unable gain interhemispheric integration. The processing of speech that involves social communication is a significant deficit for those with ACC. Parents of children with ACC report that their children interpret speech very literally, misinterpret nonliteral language, and engage in meaningless conversation (O’Brien, 1994; Stickles, Schilmoeller & Schilmoeller, 2002). Anecdotal reports from parents indicate that their children with ACC display deficits in the comprehension of jokes, miss the point in subtle stories, and display difficulties with problem solving in novel situations (Brown, Paul, & Symington, 2005; Brown & Paul, 2000). It was found in a small study of those diagnosed with complete ACC and average IQ scores that they performed worse than controls on the narrative joke subtest (Brown et al., 2005).
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Another study examined the complexity of processing nonliteral language in brain damaged individuals compared to controls by having patients identify idiomatic expressions in a reaction time task. It was found that both the right hemisphere and left hemisphere of brain damaged groups performed poorly as compared to controls on tasks involving idiom definitions (Tompkins, Boada, & McGarry, 1992). It is presumed that idiom comprehension requires multiple mental operations and the capacity for understanding second-order meanings.

It is believed that the right hemisphere is responsible for processing emotions, understanding affective prosody, and emotional tone of speech (Ross, Thompson, & Yenkosky, 1997; George et al., 1996; Paul et al., 2003). Effective communication uses words and nonverbal body language such as facial expressions, posture, gestures, and gaze that must match the social context. Studies using Positron Emission Tomography (PET) and Electroencephalogram (EEG) found that right hemisphere regions are activated during recognition of emotional prosody in non-brain damaged individuals (George et al., 1996; Paul et al., 2003). Interhemispheric pathways may be necessary for interhemispheric communication of emotional prosody as patients with left and right hemisphere brain damage were tested in their ability to repeat and comprehend affective prosody (Ross et al., 1997; Paul et al., 2003).

Agenesis of the Corpus Callosum and Psychosocial Functioning

There are a few reported case studies of deficits in psychosocial coping and personal awareness in those with ACC. Psychosocial deficits reported in those with ACC include appreciation and recognition of social dynamics, overlooking complex socio-
emotional material, misinterpreting meaning to emotional stimuli, lack of social
guidment, and lack of self awareness (Paul & Brown, 2000). Individual case studies of
those with right hemisphere lesions have demonstrated a wide variety of neuropsychiatric
disorders such as depression, anxiety, mania, psychosis, personality changes, dissociative
states, and altered sexual behavior (Cummings, 1997). A large study of patients in an
inpatient psychiatric hospital found that those with right hemisphere damage, white
matter damage, and arithmetic disabilities were at a greater risk for depression than
patients who do not show this pattern of learning disabilities (Cleaver & Whitman, 1998).
Another study of patients with right hemisphere lesions found that they required
psychiatric care because of emotional and interpersonal problems (Gross-Tsur, Shalev,
Manor, & Amir, 1995). These patients were considered to be odd or even bizarre as they
displayed withdrawn, excessively shy behavior, and avoidance of eye contact (Gross-
Tsur et al., 1995).

Survey research on a large data base given to families of those with ACC who
have siblings was analyzed to determine health-related factors in those with ACC.
Results from this survey indicated that people with callosal disorders were more likely
than their siblings to be diagnosed with Autism and Obsessive-Compulsive Disorder, but
not Attention Deficit Hyperactivity Disorder (Doherty et al., 2006). Small studies with
considerable limitations conducted in the United Kingdom to see if ACC is associated
with a psychiatric disorder utilized a psychiatric history of adult patients with ACC and
found that thirty-five percent had a psychiatric disorder (Taylor & David, 1998). The
exact nature of any psychopathology in those with ACC has yet to be explored in depth
or identified. Those with partial ACC, complete ACC, and Aicardi Syndrome were studied and it was found that a lack of emotional communication was a common trait with all three groups (O’Brien, 1994). Case studies of two older males of average IQ with ACC were studied to see if there was significant psychopathology. It was demonstrated that there was a lack of self awareness, social understanding, and understanding of the complexities of social dynamics (Brown & Paul, 2000).

Other studies using neuroimaging techniques have been conducted to see if there is any link between ADHD and damage to the corpus callosum. The corpus callosum is easily visualized on MRI scans and the fibers from the somatosensory regions can be mapped using silver staining techniques to trace the pathway of interhemispheric connections (Giedd, Castellanos, Casey, Kozuch, King, Hamburger, & Rapoport, 1994). A small study looked at structural brain abnormalities of ADHD patients and a normal comparison group and found that the rostrom and the rostral body of the corpus callosum were significantly smaller in the ADHD group when measured from MRI images (Nopoulos et al., 2000; Giedd et al., 1994). Other small MRI studies indicated that those with ADHD had smaller corpus callosums than controls in the genu and splenium region (Hynd, Semrude-Clikeman, Lorys, Novey, Eliopoulos, & Lyytinen, 1991).

Agenesis of the Corpus Callosum and Nonverbal Learning Disabilities (NLD)

Byron Rourke (1989) has researched types of learning disabilities and has focused upon nonverbal learning disabilities (NLD) which he describes as a syndrome that develops from central processing difficulties and white matter dysfunction (Rourke, 1995). Rourke has looked at neuropsychological profiles of those with ACC and has tried
to demonstrate that individuals with ACC have NLD. Rourke suggests that those with NLD have deficits in visual discrimination, tactile perception, psychomotor coordination, and problem solving with novel stimuli (Rourke, 1989; Rourke, 1995; Panos, Porter, Panos, Gaines, & Erdberg, 2001). Rourke contends that these deficits lead to other difficulties with social competence, emotionality, visual attention, and responding to novel situations (Rourke, 1989; Rourke, 1995; Panos, Porter, Panos, Gaines, & Erdberg, 2001).

*Brain-Behavior Relationships*

Gaining more access to understanding how our brain functions has been made available by the use of new imaging techniques, such as the PET and the functional MRI. These imaging devices have helped scientists discover where activity is coming from in the brain. During infancy and childhood brain development is dramatic and sequential. Research has found that early stimulation during critical periods of brain development may occur during the first four years of life when synaptic refinement occurs at a rapid pace (Eliot, 1999). Once the refinement stage has passed for a given brain region, its critical period has ended and the opportunity for rewiring is significantly limited. There is much debate about the brain’s ability to grow and recover following brain injury and evidence has shown that a child’s brain has priceless neural plasticity where limited function occurs (Eliot, 1999). Critical periods can extend across childhood and adolescence and remain open for improvement, but others may close while parents may not even be aware of the vulnerability of their child’s brain development (Eliot, 1999). It is essential to discover how a person can create new neural pathways after suffering from
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a brain injury to live to the fullest potential promoting a sense of psychological well-being.

Family Systems and the Social-ecological Perspective

Families play a substantial role in promoting well-being and managing chronic conditions like ACC. Support, communication skills, and problem solving ability are vital to a quality of life for individuals with chronic conditions. Interventions involving family members are vital in disease management. A member of a family with chronic illness has an effect on all other members. The adaptation to the chronic illness of the family unit has a profound influence on the child and adolescent (Brown, 2002). Bronfenbrenner (1979) focused upon the social ecology of human development as he studied the relationships between people and the settings and contexts of their life situations (Kazak, 1989). The microsystems involved with children and adolescents with chronic illness are made up of family members, school contacts, health care workers, peers, and cultural influences (Brown, 2002). These microsystems are little researched and have a reciprocal relationship in the life of the family member with chronic illness. This social ecological theory has been proposed as a useful framework for pediatric psychologists as they try to predict illness management across the lifespan (Brown, 2002). A broad view is needed to understand the adjustment in the family when the stress of raising a chronically ill child pervades the many systems in which the child and family are embedded.

Studies tracking the development of a disease and the parental involvement over time are also needed. Evidence suggests that adolescents with chronic illness do not follow medical regimens as well as they did during childhood even though they are more
able to solve problems and consider future consequences of risky behaviors (Thomas, Peterson, & Goldstein, 1997). Excessive parental control was linked with lower levels of autonomy associated with higher levels of problem behavior (Holmbeck, 2002). Increases in cognitive development during adolescence are likely to be associated with the child’s ability to handle their own illness (Brown, 2002). Support from peers rather than isolation is a critical component of adaptation to chronic illness management (Brown, 2002). Parental restrictiveness and over protectiveness restricts the opportunity for peer interactions.

_Erikson’s Developmental Phases_

To understand how a person develops over the lifespan and how the brain develops, it is important to be aware of the theories in developmental psychology. Major longitudinal studies helped create a shift in thinking for developmental psychologists. Erik Erikson (1950) offered a process model of human development where a person moves through major psychosocial challenges in eight different life stages. Each stage is resolved by the attainment of new knowledge and development of the personality. Failure to move through each stage blocks healthy development. People move through these stages as they achieve a sense of mastery over central issues experienced during these time periods. Erikson’s developmental stages place emphasis on autonomy and independence; a separate sense of self.

The central issue in Stage 1 involves conflict between the attitudes of trust versus mistrust. This stage involves infants achieving a sense of trust as they explore their environment using their mouths. Positive experiences bring about feelings of comfort and
security, while unsatisfactory experiences create mistrust (Lefrancois, 1976). Through the relationship with loving parents, infants resolve the crisis, learning to appreciate connectedness through feelings and learning to trust. Neglected infants may never learn to trust anyone which can interfere with later stages of development. This stage is relevant to this study as we will examine the ways in which the mother of the woman with ACC comforted her child.

In early childhood, Stage 2 involves a child’s need for a sense of autonomy versus a sense of shame and doubt. This occurs after the child achieves basic trust and discovers that they can control their own actions as they move through the environment (Lefrancois, 1976). With proper guidance, the child experiences free choice, self-control, and learns to solve the crisis by learning importance of rules and self control. This stage is relevant to this study as we will examine the ways in which the mother of the woman with ACC promotes independence in her child.

Stage 3 involves initiative versus guilt as children gain mastery and autonomy over their actions and are developing a sense of initiative during play (Lefrancois, 1976). This conflict is resolved when a child develops a sense of purpose.

As a child enters school up until age ten, Stage 4 occurs which involves industry versus inferiority where children have the increasing need to be accepted by their peers. He or she learns during this stage to connect to their same-sexed peers and of their importance, not inferiority to others (Lefrancois, 1976). Successful resolution of this stage involves a feeling of competency.
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Stage 5 involves identity versus role diffusion during adolescence where the central theme forms around accepting, discovering, or choosing a sense of identity (Lefrancois, 1976). Conflict occurs when there is doubt about identity choices. The period of adolescence provides time for them to develop a clear and positive sense of self. The woman with ACC seems to have an identity that she is very capable and will graduate from college proving the doctors wrong.

Stage 6 occurs in early adulthood and involves intimacy versus isolation. Love is the successful resolution of this stage. Erikson’s later stages involve caring for others, and developing a sense of integrity.

Relationships with Caring Adults and Psychological Well-being

Recent research has demonstrated a strong link between the psychological health and wellness of children and caring or confiding relationships with adults (Holahan, Valentiner, & Moos, 1995; Spencer, Jordan, & Sazama, 2002; Spencer et al., 2002). This research is relevant to the study in that we will examine the success story of a young woman with ACC and the relationship she has established with her mother. The work of the Jean Baker Miller Training Institute at the Stone Center, Wellesley College, has played a pivotal role in defining how relationships help psychological well-being (Spencer et al., 2002; Nakash, Williams, & Jordan, 2004; Miller, 1976; Walker, & Rosen, 2004; Jordan, Kaplan, Miller, Stiver, & Surrey, 1991; Jordan, Walker, & Hartling, 2004). Scholars at the Stone Center have developed relational-cultural theory as an alternative model to developmental psychologists who view women as isolated beings with the ultimate goal of separation-individuation. Relational-cultural theory developed from the
close study of women and the belief that previous approaches to psychotherapy predominantly developed by men were insufficient and harmful to women. Relational-cultural theorists believe in the importance of relationships and social supports to the well-being of women. They feel that a woman’s sense of self is refined and enhanced through mutual relationships and affective connection.

Multicultural focus groups from different socio-economic backgrounds described their desire for relationships with adults and barriers that get in the way to researchers at the Stone Center (Spencer, Jordan, & Sazama, 2002). Themes from transcripts of interviews were analyzed and it was found that mutuality and authenticity were important to growth fostering relationships (Spencer et al., 2002). Mutuality occurs when there is commitment, contribution, and responsiveness to the relationship. Authenticity occurs when a person is genuine and present in the relationship. Other themes were related to having fun with adults and those who really cared about them for who they were (Spencer et al., 2002). Mutual respect was another theme defined as the adult’s willingness to allow the child to have a direct impact on him/her (Spencer et al., 2002).

Further research is needed to identify how relationships with adults promote psychological health and well-being in youth and the relational-cultural model provides a framework for studying such relationships.

**Key Features to Relational Connection**

Three key features to building relational connection in the relational-cultural model include mutuality, authenticity, and empowerment/zest when a person is personally strengthened and inspired to take action (Jordan et al., 1991; Jordan et al.,
2004; Walker, & Rosen, 2004). It is through these relationships that women can become empowered even when they do not have sufficient skill, energy, confidence or time (Jordan et al., 1991). Relational-cultural theorists have organized and defined self-in-relation as a core self structure that occurs through committed involvement with others, mutual understanding, and emotional support. Mutual empathy is a term used by relational-cultural theorists that is defined as a deeper, more resilient connection when women take in cognitive/affective aspect of the other’s experience (Walker, & Rosen, 2004). This empathetic skill has a healing aspect as a person moves out of isolation and begins to feel that she is worthy of respect and connection with others.

Female Development and Relational-Cultural Theory

Relational-cultural theorists believe that a women’s sense of self and well-being is organized around relationship building and is defined by the ability to take care of others. Power is defined as having strength to give to and care for others as this is displayed in the relationship between mother and daughter. Each party experiences empowerment which is defined as power in connection, not power over another. Growth occurs in this emotional connection as the mother carefully attunes to the affective state of her infant daughter and the infant moves toward relatedness (Jordan et al., 1991). This mother-daughter relationship is mutual as well as reciprocal as the infant initiates contact with the mother and the mother responds. The infant begins to influence the relationship as she moves toward relatedness which is the opposite of separation. The infant grasps an early sense of herself through this connectedness as she has the ability to understand and to be understood by the mother’s ability to listen, respond, and empathize (Miller, 1976).
Empathy is at the heart of the mother-daughter relationship and is defined as the capacity to understand and attune to the affective experiences of another. The female infant begins to influence the relationship and sees the mother as an active caretaker in tuning into her affective states. This core self structure known as self-in-relation occurs through this mutually affirmative relationship full of understanding and emotional support by both mother and daughter (Miller, 1976; Jordan et al., 1991). The experience of self is developed and organized in the context of this important mother-daughter relationship. The infant moves towards relatedness as she discovers that she is part of a larger unit as she grows from the mother responding to her (Jordan et al., 2004).

Girls grow up to believe in the power of serving others and that the needs of others can be fulfilled (Miller, 1976; Jordan et al., 1991). Females are motivated to attend to the affect in others as they learn to understand their emotions and reactions. Empathetic communication, a key feature to building relational connection, is developed in girls as they learn to understand the perspective of another. The mother-daughter relationship is significant in developing the adult women’s capacity for emotional closeness, relatedness (connectedness through feeling states), and boundary flexibility (Miller, 1976). Girls learn about themselves through emotions and reactions of others as they have a more “open sense of self” (Jordan et al., 1991). The self continues to be refined, enhanced, and strengthened through connections.

Relational-Cultural Theory and Adolescence

As girls move through adolescence, they try to remain connected to their mothers as they develop their own values and views about life (Jordan et al., 1991; Jordan et al.,
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2004). Growth does not occur in a discrete series of stages with independence and separation as the final goal. Instead, self esteem and self affirmation occurs through empathetically sharing and maintaining the well being of relationships. Mutually empathic interactions help girls develop feelings of relational competence as they learn that they can build relationships. During adolescence, girls may begin to feel disconnected from their own experiences as they try to work out conflict with key relationships. Their goal is to remain connected with their mothers while they are developing their own values and beliefs. An adolescent wants to take care of her relationship which is a large part of her self worth. A majority of college woman interviewed at Wellesley College for a project on women's development stated that their mothers are the most important people in their lives (Kaplan et al., 1985). It is essential that there is flexibility in the mother-adolescent daughter-relationship to confront differences for connections to grow. Healthy development occurs through conflict which is a necessary part of relationships so that each person in the relationship can change and grow (Miller, 1976). The goal is to remain in connection with the other and establish a mutuality of concern even if it is expressed in conflicting ways. An internal dialogue of the parent's beliefs and values is present even if they are different than their own (Jordan et al., 1991).

Adolescence is a time when girls focus energies on the well being of men as they are taught in western culture to uphold man's superior importance (Jordan, et al., 1991). The girl's sense of self becomes deeply affected which devalues the importance of the mother-daughter relationship. It is also a period of time when girls are very interested in
relationships, particularly with other girls their age. The developmental aim during the high school years comes from empowerment in the ability of the female to create relational ties. Parental approval of her accomplishments can create a sense of mutual affirmation contributing to a healthy self-image.

This is also a time when girls begin to become passive and submissive and feel that parts of themselves are shameful or wrong (Gilligan, 1982). Sexuality does not become an acceptable aspect of her sense of self and does not bring this into relationships. This is the time when girls feel pressure to defer to the desires and needs of others. Recent studies are exploring the relationship with one’s body and having authentic relationships with others (Nakash, Williams, & Jordan, 2004).

*Relational-Cultural Theory and the College Setting*

From studies of college age women interviewed at the Stone Center, women’s development in late adolescence is viewed differently than developmental theories that equate this time period with autonomy, separation, and independence. Through interviews, relational-cultural theorists are finding that these young women want to keep relational ties with their mothers even if there is conflict and disagreement (Kaplan, & Klein, 1985). Conflict is a necessary part of relationships as it is confronted within the relationship moving towards connection, not disconnection. The desire to take care of relationships is strong, which can promote gains in self-esteem and competence (Miller, 1976). Adolescence can be a difficult time for girls as they can shut down during this time period feeling that they have to ignore their sexuality feeling that parts of themselves are shameful and wrong (Miller, 1976; Jordan et al., 1991). Adolescent girls are not
encouraged to use their power as they feel pressure to defer to the needs of others. A source for self esteem and self affirmation comes from the ability of the adolescent to maintain the well-being of relationships and sharing with another.

Structured interviews of college age women at Wellesley College found that the majority of the women selected their mothers as the most important person in their lives (Kaplan et al., 1985). The relational process between the mother and daughter is an integral part of the daughter’s sense of self as a competent and able being.

The academic setting in college with an emphasis on competition, and grades, instead of relational connections may disrupt feelings of trust and support in females. Isolation from others may occur which may contribute to depression and low self esteem.

Culture and Female Development

The relational-cultural model places strong emphasis on the effect culture and society has on the development of women. We live in a multi-cultural society where the dominant culture is patriarchal and has the power to define one group as better than the other leading to disconnection, or separation. This kind of disconnection leads to conflict as one tries to hold on to a sense of well-being or safety by shaming the other or oneself (Jordan et al., 2004). Authenticity is compromised in relationships of unequal power, where the less powerful person is expected to conform to the expectations of the more powerful person. The dominant group defines the role of the subordinate group which affects their ability towards self understanding (Miller, 1976). These painful feelings of shame contribute to an inauthentic representation of experience which interferes with growth fostering relationships (Nakash et al., 2004; Jordan et al., 2004).
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Essential to human life is cooperation and creativity where women come up with new roles different than the dominant culture (Jordan et al., 1991; Miller, 1976). Past and present experiences are reflected upon as the adolescent develops her personal vision. Relational-cultural theory proposes that the dominant culture distorts images of self, placing strong emphasis on physical appearance. Personal creativity is established as the adolescent has a changing vision of herself and the world.

Resiliency

Another area relevant to the research involves looking at protective factors that may have contributed to the success of the young woman with ACC. Protective factors are believed to contribute to the development of resilience in children under aversive conditions. Although it cannot be readily measured, resilience occurs when an individual adapts well in the face of adversity, such as serious health consequences, which is a remarkable stressor. Social support systems are protective factors that can help with stressful life problems promoting resiliency (Beardslee, & Podorefsky, 1988).

More than forty years of data has been gathered from studying the development of children in Kauai, Hawaii. Researchers identified children that were at high risk because of various stressors and found that nearly one third of the children functioned well despite these risk factors (Werner, 1993). 698 children of Hawaiian, Filipino, and Japanese decent were followed. It was found that the coping mechanisms used to deal with stressors related to dispositional attributes, affectional family ties, and external support systems that rewarded competencies (Werner, 1987).
Early researchers wanted to know about single risk factors interfering with psychological, educational, and developmental difficulties and soon discovered that most children have several risk factors for health development. Risk factors reduce the individual’s ability to cope with stress, trauma, or a perceived threat (Masten, 1997). Other researchers have identified that familial characteristics play a part in protective factors. These familial characteristics are qualities of the family environment that reflect the interpersonal relationships within the home (Barron-McKeagney, 2002). Strong expectations, structure, emotional support, and connection with extended family members are some of the protective factors promoting resiliency (Brooks, 1994; Cowen, & Work, 1998; Werner, 1997).

Other protective factors may come from the community, school, or social support systems (Benard, 2004). Positive school experiences, involvement in after school activities, and connections with significant adults such as tutors or teachers, may contribute positively to the well-being of an individual. Prevention outcome studies were analyzed by Durlak (1998) who found that risk factors within the family affected eight major developmental outcomes for children: drug use, AIDS, school failure, pregnancy, physical injury, poor physical health, physical abuse, school failure and behavior problems (Durlak, 1998). Resilience may be able to be developed, taught, and nourished (Little, 2002). The development of children can be supported by resiliency-based interventions designed to create more protective environments for children at risk (Durlak, 1998).
Chapter 2: Method

Participants

The participants of the biographical study are a young woman who has been diagnosed with Agenesis of the Corpus Callosum (ACC) and her mother. She selected the pseudo name, Paige, to be used for research purposes. Her mother will use the pseudo name, Mrs. Clarke. Paige has been academically and socially successful as she is about to graduate from college. She was purposefully selected by the research investigator based upon outcomes of this low incidence brain disorder and findings in relational-cultural research in three areas. First, the literature suggests that relationships help psychological well-being (Spencer, Jordan, & Sazama, 2002; Nakash, Williams, & Jordan, 2004; Miller, 1976; Walker, & Rosen, 2004; Jordan, Kaplan, Miller, Stiver, & Surrey, 1991; Jordan, Walker, & Hartling, 2004). Second, a woman’s sense of self becomes organized around the making and maintaining relationships (Miller, 1976). Third, mutuality, authenticity, and mutual respect are found to be important to growth fostering relationships (Spencer et al., 2002; Holahan et al., 1995). These findings with regard to relationships, and Paige’s self confidence helped to determine the researcher’s choice of this young woman. None of the studies in the review of the literature qualitatively examined influences of relationships on those with brain damage. Paige’s story and the experience of raising her from her mother’s point of view will contribute to understanding how relationships have contributed to her life success.
Participant Invitation

The participant and her mother volunteered to participate in this research through face to face conversations with the responsible investigator to help others understand the challenges of living with a brain injury. Paige is known to the responsible investigator as she went to the same district where she is employed as a school psychologist. The participant and her mother shared their experiences of living with ACC. The participants were initially contacted by phone to participate in this study. All procedures were reviewed and an appointment was set to obtain informed consent. They received a gift certificate in the amount of $25 to Target at the end of the interviewing process.

Participants consented in writing to all conditions of the research as dictated by the Institutional Review Board of the Philadelphia College of Osteopathic Medicine. They were provided a summary of results of the study upon written request. Pseudonyms were used to protect anonymity.

Additionally, archival information was gathered, reviewed, and stored in a locked file cabinet for organized retrieval of documents. This information consisted of medical and school records, researcher field notes, and personal-family-social artifacts. A filing method for the archival information and field notes was employed using a master list of types of information gathered. The name of the participant was masked in all of the data gathered.

Research Design Overview

Narrative research is an approach in qualitative inquiry. A biographical study is a form of a narrative study where another person’s life experiences are the subject matter.
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The responsible investigator was reflective and present in the study. Narrative research originated from the disciplines of social sciences and humanities. Biographical writing comes from feminist and cultural thinking and is found throughout psychological, sociological, anthropological, and historical disciplines. The basic foundation of biographical research is rooted in capturing sharable understandings of the life experiences of a single individual (Denzin, 1989).

Narrative research in the form of a biography is selected when the responsible investigator wants to capture the detailed stories or life experiences of an individual that can illuminate a specific issue. Problematic life experiences which are significant events in the life of an individual were recorded by the responsible investigator. This individual was a young adult college woman name Paige who was diagnosed with ACC and agenesis of the cerebellum. The types of stories collected revolved around life stages, childhood memories, lived experiences, and were put in chronological order. A chronology of experiences descriptive in nature that accounted for the human experience of living with brain injury was written by the responsible investigator.

Narrative research also relies on the use and collection of personal life documents, memos or official correspondence about the individual, and other personal-family-social artifacts. Medical records, school documents, and personal family-social-artifacts were obtained to help the responsible investigator record Paige’s experiences. The life course stages and experiences came from the key events, known as epiphanies, which are the focus for the responsible investigator (Denzin, 1989; Creswell, 2007).
The reconstruction of Paige’s life experiences and contexts of her personal stories will be situated within her home, culture, and historical context by the responsible investigator. Restorying occurred as the stories are reorganized by the responsible investigator into a chronological framework and were rewritten because individuals do not present their stories in chronological order (Creswell, 2007). The responsible investigator will present Paige’s life experiences in stages according to her age at that time of her life. Epiphanies that may be positive or negative, may emerge from her stories to provide further detail to qualitative data analysis.

The responsible investigator recognized that she was present in the text as the unfolding story is an interpretation of the author as well as the woman with ACC. The narrative expressions of the Paige’s and Mrs. Clarke’s life experiences were written with a double perspective in mind. Validation checks occurred as the responsible investigator went through a series of interviews with the parties for clarification. Reciprocity between the responsible investigator, Paige, and Mrs. Clarke involved intense sharing, trust, and mutuality. The responsible investigator was aware of her psychological and emotional states before, during, and after the research investigation.

Measures

Two sets of interview questions (one to Paige, one Mrs. Clarke) were developed based on the literature related to ACC and relational-cultural theory. One set of questions was used for Paige and the second set of questions was designed for her mother. The questions were open-ended research questions in an effort to listen to the voices of both participants and to understand their experiences. The specific research questions focused
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upon life experiences during different stages of development. Additionally, the responsible investigator asked the participants to provide explanations for different epiphanies in their lives. New questions occurred after information was gathered after hearing the participant’s stories and clarification was needed.

In depth interviews to understand fully what it is like to live with ACC occurred at the responsible investigator’s home. It was explained to the participants that the open-ended questions were about their lives and their recall of Paige’s lived experiences to help and give hope to others living with this brain injury.

Multiple interviews were scheduled at the participant’s convenience. The interviews were completed at the home of the responsible investigator at the request of Paige and Mrs. Clarke so there would be no interruptions during the interview. The interviews were audio taped, and transcribed by the responsible investigator. Each interview lasted approximately 2 hours in length or where there was a natural break in the story telling. Interviews were conducted and transcribed interviews were analyzed until their stories were fully shared. Participants had the opportunity to withdrawal from the study at any time and were informed of their right to do so. If at any time either of the participants appeared to be in need of therapeutic support, a list of counselors was provided.

Semi-Structured Interviews:

The responsible investigator provided the following instructions to Paige at the beginning of the interview. As you already know, over the next two hours, I’m going to ask you a few open-ended questions about your remarkable experience of living with
ACC when you were in elementary school, high school, and college. These questions will allow for your complete story to be told. The questions will allow you to talk about your own personal experience of living with ACC and hearing your true feelings about it. I will ask you about your relationships with your mother, roommate, and case managers to help me understand your relationship with them. It is my hope that information learned throughout this process will give a voice to others with brain injury. Your participation in this interview may help others never lose sight that their relationships and positive connections to those with brain injury aid in their development. Please feel free to answer as fully as you are able to do so. Following these questions, I will ask you several more specific questions related to experiences and relationships you have had during your life stages. These specific questions will help me to clarify and understand your story of living with ACC.

You may, of course decline to answer any question, for any reason. At the end of my questions, please feel free to add any additional information that may be helpful in helping others know what it is like to live with ACC. I will be audio taping the interviews so I can write it out at a later date. At this time, do you have any questions that I can answer for you? Okay, let us begin!

General Overview Questions

1. Briefly tell me about yourself and what you are doing at this time in your life.

2. In your own words tell me the definition of ACC.

3. What are your strengths?

4. What have been the challenges of living with ACC?
Open-Ended Questions

1. Tell me about yourself as an elementary school student.
   a. Can you remember a specific instance when you were frustrated in school and how you dealt with that frustration?
   b. Tell me about any joyous or happy times and what they were like for you.
   c. Tell me about your teachers. (How may they have helped you? How they were not helpful?)

2. Tell me about yourself as a middle school student.
   a. Can you remember a specific instance when you were frustrated in school and how you dealt with that frustration?
   b. Tell me about any joyous or happy times and what they were like for you.
   c. Tell me about your teachers. (How may they have helped you? How they were not helpful?)

3. Tell me about yourself as a high school student.
   a. Can you remember a specific instance when you were frustrated in school and how you dealt with that frustration?
   b. Tell me about any joyous or happy times and what they were like for you.
   c. Tell me about your case managers in high school. (How may they have helped you? How they were not helpful)

4. Tell me about yourself as a college student.
   a. Can you remember a specific instance when you were frustrated in school and how you dealt with that frustration?
so I can write it out at a later date. At this time, do you have any questions that I can answer for you? Okay, let us begin!”

General Overview Questions

1. Briefly tell me about yourself and what you are doing at this time in your life.

2. What are your strengths?

3. What have been some of the major challenges you have faced in your life?

4. In your own words tell me the definition of ACC.

5. Briefly tell me about your daughter.

6. What are her strengths and challenges?

Open-Ended Questions

1. Tell me about her preschool, elementary school, middle school, high school, and college years.

2. Looking back, can you remember any specific instance when you were frustrated with her school experiences?

3. Tell me about your relationship with her. (infant, preschooler, school aged, middle school, high school, currently?)

4. Tell me about support systems that you had as a parent of a child with a brain injury?

5. What suggestions do you have to help others understand the challenges of living with ACC? (school, home, social, etc.)

6. Do you think there is anything else that I need to know about you or your daughter?
Procedures

Informed consent forms were obtained in a face to face meeting with the participants. The responsible investigator explained the purpose of the research along with procedures, benefits, and potential liabilities inherent in participating in the audio taped interview. All questions of the participants were answered in detail. The interviews were scheduled upon receipt of the informed consent. The interviews were conducted in the home of the responsible investigator at the request of the participants.

The interview process began with an explanation of the purpose for the study. The responsible investigator told the subjects that she would be taking notes throughout the interview and gave a pen and notepad to the interviewees. The tape recorder was placed at a nearby table and the responsible investigator explained that the audiotape and note taking process was used to accurately record everything that was shared.

Paige and Mrs. Clarke engaged in two semi-structured interviews with the responsible investigator. The final set of interviews involved further clarification of stories and epiphanies gleaned from the first interview. The first semi-structured interview process began with brief overview questions geared towards defining ACC and how it is experienced. The second group of questions was open ended intending to evoke their own perspectives and descriptions of their experiences and relationships through childhood, adolescence, and adulthood. The responsible investigator wrote down notes during the interview for clarification or elaboration of the story. Additionally, field notes were written immediately after each interviews to elicit the responsible investigator's own thoughts and feelings from interviewing. A journal containing a chronology of life
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course stages was created from the stories of the participants. An objective set of experiences was placed in chronological order and was used for analysis of epiphanies.

The participants' identities were kept confidential by providing each participant with a pseudo-name and identifying information altered. All data including tapes, field notes, journals, evaluations, school records, medical records, personal artifacts, and transcribed interviews of the subject were stored in a locked drawer when not in use. Participants were informed that the dissertation committee and validation team would have access to the data, the names that would be provided upon request. The participants were offered a summary of the results after completion of the biographical study.

Data Analysis

The responsible investigator started the biographical analysis by identifying an objective set of experiences in the participant's life (Denzin, 1989). A chronology of Paige's life was created by the responsible investigator focusing on her life course stages. This was accomplished by reviewing the interview transcriptions and all collected documents in a chronology. Each transcript was read several times by the responsible investigator for the purposes of identifying life course stages, epiphanies, and creating a sketch of Paige's life. Three professionals, known as peer auditors, with at least at a Master's degree in education or psychology were a part of the validation team. The events of Paige's and Mrs. Clarke's recount of her life were "triangulated" as events were sorted out by source and point of view to stabilize contradictions, irregularities, and discontinuities (Denzin, 1989). Triangulation strengthened the validity of the
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investigation addressing possible bias as the validation team members interpreted the larger meaning of Paige’s story and general features of her life.

An analytic abstraction of the participant’s life was written to highlight (a) the processes in the participant’s life, (b) the different theories that relate to the life experiences, and (c) the unique and general features of the participant’s life (Creswell, 2007).

Limitations of the Study

The narrative biography has the central focus of telling the story of a single individual with ACC and cannot be generalized to all people with ACC. It is a measure that allows for the articulation of how a subject deals with human dignity, hopes, and dreams. Meaning and interpretation is best given by the person that experiences them. The quality of a biography is determined by the responsible investigator’s ability to utilize thick, descriptive language to illustrate the life of the individual being studied. The participants in the study reviewed the accounts of the responsible investigator to judge the accuracy and credibility of Paige’s experiences. Life stories are open ended, interpretive accounts which can be biased and come in multiple versions.
Chapter 3: Results

Database Sources and Collection

The database utilized throughout this investigation was cultivated over a period of four months. During this period, the responsible investigator contacted Paige and Mrs. Clarke and obtained informed consent. Paige gathered her medical records, school documents, and family personal-social artifacts that she wanted shared with the responsible investigator. This data is used in qualitative research for analytic integration to reconstruct her life in chronological order. A filing method was created and names were removed from the medical records, school documents, and family personal-social artifacts which were stored in a locked file cabinet in the home of the responsible investigator. The interviews were completed at the home of the responsible investigator at the request of Paige and Mrs. Clarke so there would be no interruptions during the interview. A total of 6 hours of audio-taped interviews was created. Throughout the investigation, the responsible investigator consistently maintained research field notes, which is often a widely accepted practice in conducting qualitative research.

Data Analysis and Interpretation

The data analysis and interpretation occurred consistently throughout the entire investigation. This process was instituted by the responsible investigator after informed consent was obtained. Medical records, school documents, and family personal-social artifacts were obtained and were filed in chronological order. Paige’s name and those of her family members were removed or covered up. A master list of types of information gathered to analyze her life story was created by the responsible investigator and placed
in chronological order. After the first interview of Paige was completed and transcribed, the responsible investigator reviewed the life stories to determine if further clarification was needed. The responsible investigator was aware that she was present in the text as she reviewed the narrative accounting of the participants’ life experiences. Content analysis commenced with several examinations of the transcript to identify childhood memories, lived experiences, and a chronology of life stages. This process allowed the responsible investigator to capture the life’s journey of Paige and Mrs. Clarke. Validation checks requiring an additional interview of each participant was conducted by the responsible investigator to clarify life experiences and unique features of living with ACC. Ultimately, a validation team consisting of one school psychologist at the doctoral level, two New Jersey certified school psychologists, and one member of the research committee met to triangulate the data gathered. The purpose of this process was to compare and contrast themes taken from life stories of the woman with ACC and her mother. The validation committee communicated through electronic mail, telephone conversations, and one extensive meeting held in the home of the responsible investigator, which discussed and determined the most significant areas of discussion within the findings.

**Discussion of Findings**

The research findings integrated a combination of interviews from Paige and her mother along with medical documents, school records, and family personal-social artifacts. Demographic findings include a description of ACC from the perspective of Paige and Mrs. Clarke through her life stages of development. Another section included
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descriptive findings including a chronology of Paige’s life experiences explained through relational connection of important people in her life. These life events were integrated with medical records and school records and were divided into the following five life stages: Infancy/Early Intervention, Early Elementary School (grades K-5), Upper Elementary School (grades 6-8), High School, and College. Each life stage of the participant provides a description and detailed analysis of the (a) processes in the life of a woman with ACC and her mother, (b) different theories that relate to her life experiences, (c) the unique and general features of living with ACC. Research findings resulted in a model of relational resiliency taken from their secure mother-daughter connection.

Demographic Findings

The investigation participants consisted of a twenty-three year old woman named Paige who is diagnosed as having brain injuries and a coordination disorder. Paige will be graduating from a four year college this year and holds a job at a video store. The other participant is her mother, Mrs. Clarke, who has been a teacher for over twenty years and is very involved with her local community as president, running a food bank, and a member of the International Lions. They are willing participants known to the responsible investigator. Paige attended the school district in which the responsible investigator was employed as a school psychologist.

Paige was diagnosed with complete agenesis of the corpus callosum (ACC) and of the left cerebellar hemisphere according to a radiology report from a CT of the brain in November of 1986 when she was two years old. A later diagnosis from an MRI of the
brain completed in March of 1997 when she was thirteen, confirmed a Coordination Disorder. The corpus callosum serves as the communication pathway allowing information to transfer back and forth between the left and right hemispheres. The cerebellum is a part of the brain believed to be responsible for assisting with posture and body position, sensory-motor integration for locomotion, and fine motor movement initiation, maintenance, and sequencing (Hale & Fiorello, 2004). It is described as the air traffic controller of the central nervous system made up of about half of the entire brain’s neurons (Eliot, 1999). Paige’s neurologist reports in a letter to her family physician, 1997, that she has congenital anomalies of the brain, dysarthria, and dysmetria that affect her fine motor and coordinative abilities, as well as balance. Her doctor further reports that despite these considerable deficits, she has done quite well developmentally and in learning. Paige describes what it is like to have ACC describes by stating,

My brain looks like a meatball. It is all smushed into one. I don’t have the line in my brain. Because that’s what my brain looks like. I don’t have the lines that separate my hemispheres in my brain. So that’s how I tell people. Your brain is separated into two parts. You have two meatballs that have separated. I have one. I don’t have the line that separates it. It’s a pile. It’s like mush. It’s all conformed into one. I do not elaborate if there are simple yes or no questions. I have trouble remembering. The doctor didn’t know what to say because it was rare when I was diagnosed. My parents told me that the doctors told them they were lucky that I was cute and I wasn’t expected to advance to high school. Those people were
idiots! I can do anything I want to. I might have to work a little bit harder at what I want to do, but I can still do anything I want to.

Mrs. Clarke has had twenty three years to reflect on living her daughter diagnosed with ACC. It was difficult for her to describe ACC because the news was so devastating. She talks of Paige’s brain injury in this manner,

I used to call her corpus crispy, so I don’t think I’m going to be too helpful in the medical terms...It’s hard for me to describe it because when they told us this, our news was so devastating and so different than what I’ve seen. It’s hard for me to even say what it is. I mean, there are things I see in her, but is that just her or is that the disability? You know, how do you tell what is innately the child and what’s the cause of the disability? What’s a personality trait? I don’t think I can really answer that. The news was devastating because it had taken us so long to at least get a diagnosis. In one way at least I knew this is what she has...It was so hard to wait for tests and doctors and specialists! So from one point of view it was relief, from the other point it was pretty devastating.

Mrs. Clarke and her husband tried for many years to get pregnant and she recalls the pain of finding out that her daughter had a brain injury,

Then we went through the whole not being able to get pregnant. And then we had a baby. I was pissed off at God, the world, Mother Nature. My husband and I took a while to get married, we never lived together, we had apartments, we had friends, and we traveled. We got married to have kids. We both wanted kids. My sister had four (kids). He comes from a family of four. Then we went through
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the whole not being able to get pregnant. I mean to a lot of people, this sounds awful, I would say, “Why did I have to get the factory reject? Why me? What in God’s name did I do that I can’t have a normal kid?” I was angry. There were times I was resentful.

She speaks of the difficulty that her daughter has with motor planning that is a characteristic of ACC as well as agenesis of the cerebellum. Some individuals with ACC appear to be asymptomatic, but others may need speech therapy, physical therapy, and occupational therapy as in Paige’s case. Split-brain operations revealed that the corpus callosum itself is not necessary for a productive intellectual life. The research indicates that those with ACC experience a wide range of intellectual, motoric, and language abilities. Mrs. Clarke involved her in many activities to develop her motor skills. She says,

With any kind of brain injury, the whole motor planning is so difficult. I was fortunate. Karate for her was a very positive experience. They worked with her so patiently. That really helped her self-esteem. I think it helped her patterning… to get them involved in something where they’re going to get applause from in athletics. I think that’s one thing that I’m really happy that I did because we couldn’t play the sports…I think anything where you’re working on some kind of motor planning and hand-eye coordination. If you can nurture that at a young age I think that’s good. Plus, it gives them a feeling of accomplishment that they’re out there. If you could just sit back and watch to see how difficult it is for them to plan the simplest task.
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Difficulty tying a shoe or riding a bike are two of the most significant hallmarks through the literature on ACC as well as nonverbal learning disabilities. Mrs. Clarke talks about this,

It took her forever to learn how to tie a shoe. She still ties her shoes very slowly. So I think that's one thing to try to let them experiment and find their own way to do a lot of tasks. You know, even with cooking or anything. I know with cooking because her left hand, she would try to stir a bowl and her left hand would be up in the air. She has a way that she (moves her left hand).

Mrs. Clarke talks about her left side that is affected because of ACC and how she notices her left hand when Paige is stressed,

I can tell when she's stressed. She kind of holds her hand (moves her left hand). Oh! I don't know how to describe that. She moves her left hand up and away from the activity. I have to kind of just remind her to bring that hand into the activity. And I notice now, especially when she's under stress, the left hand. She holds the hand in that same position.

The following is a timeline of Paige's medical history (Table 3.1):
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### Medical History Table 3.1

<table>
<thead>
<tr>
<th>Year</th>
<th>Details</th>
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| 1984 | Born 7 weeks premature by cesarean section.  
      | Spends 2 weeks in intensive care, apnea monitor (18 mo.).  
      | Could not lift head at 3 months. |
| 1985 | Early intervention (6 mo.) Scalp hemangioma removed.  
      | Tubes in ears, orthopedic evaluation-hypomobil joints. |
| 1986 | Neurological consultation-left motor paresis, moderate hypotonia, slight head tilt to right.  
      | Cannot sit without assistance; 3 word speech.  
      | CAT scan-Agenesis of the Corpus Callosum with hypoplasia of left cerebellar hemisphere  
      | Diagnosis-stroke in utero. |
| 1987 | McCarthy Scales-1.5 SD below mean-gross motor.  
      | Toilet trained—does not have physical strength to control bladder at night. |
| 1988 | Occupational therapy-left sided weakness. |
| 1989 | Occupational therapy-mild left hemiparesis. |
| 1990 | Physical therapy-deficits in sensorimotor processing, left sided weakness.  
      | Anxiety going downstairs. |
| 1991 | Physical therapy-deficits in motor planning, muscle power, bilateral coordination, sensorimotor processing.  
      | Occupational therapy-difficulty with bilateral coordination, fine manipulation with isolated fingers, toileting & dressing need extra time. |
| 1992 | Physical therapy-deficits in vestibular processing, motor planning, left leg strength. |
| 1993 | Neurological evaluation done because of dizzy spells, headaches.  
      | MRI EEG showed that there was a slight interhemispheric asymmetry, white matter thinning in periventricular regions bilaterally.  
      | Coordination disorder. |
Infancy/Early Intervention

Paige was born seven weeks early because of spontaneous rupture of membranes as reported in a neurological consultation in October of 1986. Mrs. Clarke delivered in a strange hospital that she did not plan on and had to leave her baby in intensive care.

Paige’s mother reflects on this time period stating,

I actually was very anxious during my pregnancy and I don't know why. She didn't move around...I never really felt her kick at all and my doctors did start to get concerned. She was almost seven weeks early right before I actually delivered because she really was not moving around very much. I ended up quitting my job because I wasn't feeling well and about a week after I quit I had her... So I was literally sitting in my gynecologist’s office on a towel hysterical because they could not find a place that would take myself and let me deliver there. So finally he called an infertility doctor that I had gone to ... in another state and they took me even though I was really not their patient because we had kind of given that up...It was just a blur of doctors, tests, monitors and training. I don't even have a baby picture of her in the hospital...I wasn't feeling well...and I was running a fever. I barely got to see my daughter because they were worried about me running a fever...Interestingly enough, because I couldn't see her, they had a Polaroid camera and the nurses would actually take a Polaroid. That's the first shot I ever saw of my daughter...I thought, “At least I had something.” So actually my husband and my mother-in-law helped my daughter before I did.
Paige was placed on an apnea monitor for eighteen months. She was supposed to be off the monitor by her original due date. Mrs. Clarke reflects on the first nights at home with her daughter and how scary it was. She recalls specific incidents of fear saying,

When she first came home, I got to the point that I brought her in the bathroom with me because I was afraid I'm going to be sitting on the toilet and then the monitor's going to go off and I'm going to be zooming down the hallway...I went through a lot of anxiety then...I would have nightmares that I would get up in the morning to go see her and she would be dead in the crib, but the monitor was working...I went through that for a long time. Then you kind of get to the point where you know it kind of settles down. I did have great parental support.

Mrs. Clarke was very concerned during that time period feeling isolated and alone. She thought that her daughter was not progressing as she should have. Diagnosis of ACC is usually made by neuroimaging observations typically administered because a parent reports that their child experienced language delays, visual impairments, seizures, and/or low muscle tone (Schilmoeller, 1995 Marszak et al., 2000; Shevell, 2002). She recalls this time period saying,

My concerns started because she came home from the hospital on an apnea monitor...By her due date, her numbers were no better than when she was born. This is when the real concerns started. She could not even lift her head off my shoulder. My sister had twins that were premature. My four pound nephew, when I held him for the first time snuggled him up to me, could actually turn his head
and lift his head off my shoulder. My daughter at, I'm going to say, two months, probably still could not do that. I started having concerns...I was starting to get a lot of anxiety about the things that she couldn't do and the things that she should have been able to do at birth.

She talked about the confusing visits with her pediatrician who seemed to not understand how she was feeling as a new mother. At three months, Paige could not lift her head and appeared to be favoring her right hand. Mrs. Clarke explained this key life event saying,

I started going back to my pediatrician, and my pediatrician told me that he thought a lot of it was my anxiety because I had been told I couldn't have any kids and my daughter was a complete surprise. We had been to infertility specialists and the whole nine yards and then basically said that we're just going to bag that for awhile. So he thought that I couldn't accept my good fortune that I had a baby and told me that I was kind of showing signs of being a neurotic, older mother. It makes me laugh because I was only thirty when I had her, which nowadays is normal. So I ended up in counseling because after doing research, I thought I might have that Munchhausen, or whatever it's called. Because I thought well, maybe they're right. Maybe I'm looking for things that aren't there. Maybe I can't believe my good luck and I'm looking for problems that are going to work themselves out. So I went to counseling for awhile, but of course, as I'm in counseling and my daughter's progressing, she's not progressing. I started to notice things like she didn't reach with her left hand and although she seemed
alert and responded to me, I didn’t think it was autism because she did respond. She would smile, she would follow me and what I did. She would do that part very loving part, and loved to be snuggled and tickled and all those normal things.

At six months old, her mother sensed there was something wrong with her daughter and had her evaluated because she wasn’t attempting to roll over. She received early intervention services out of the local hospital because of her being on an apnea monitor, and other developmental delays. Paige’s early intervention six month summary, 1986, indicated that she had difficulty transitioning from position to position and was experiencing motor planning problems. This summary indicated that she uses her right hand predominantly and frequently retracts her left hand back. Her mother reflects on those days stating,

She wasn’t doing the things. So by now, we’re at six months and we’re not even attempting to roll over. We’re not doing anything. She didn’t roll over until she was almost eleven months old…She was doing none of that. She wasn’t scootching in her crib. She wasn’t doing any of that.

Paige had surgery to remove a scalp hemangioma at the insistence of her mother who noticed that her head was tilted to the right in a photograph. Mrs. Clarke was very attentive to the needs of her daughter and kept going back to her doctors. Relational-cultural theorists believe that the infant grasps an early sense of herself through this connectedness as she has the ability to understand and to be understood by the mother’s ability to listen, respond, and empathize (Miller, 1976). The female infant begins to
influence the relationship and sees the mother as an active caretaker in tuning into her affective states. Mrs. Clarke said,

During early infancy she also had a head tilt to the right, but this resolved after a scalp hemangioma was removed... She has a hemangioma on her arm and she had one on the back of her head... I thought it was interfering with the way she laid down at night... She had to sleep. She couldn't lay with her head flat... When you look at pictures of her at that age, which is when I brought in the photograph (to the doctor), that I really noticed... that's when they agreed that they had to have that removed because they actually realized that it had affected the muscle... because she couldn't put her head back properly... in a baby seat or the swing or anything because of that bump on the back of her head. So we had to go through that surgery and she also had tubes in her ears.

ACC, a mysterious, low-incidence, form of brain injury is marked by inconsistent behavioral and emotional manifestations that may be confused with other neurological injuries. Other health and behavioral outcomes associated with ACC include seizures, dysmorphic features, intellectual disability, psychomotor retardation, language deficits, psychosocial deficits, as well as visual and hearing impairments (Sztriha, 2005; Marszak et al., 2000; Doherty et al., 2005). Paige had a neurological consultation at age two because of left monoparesis. At that time, Paige could sit independently for an indefinite amount of time with trunk rotation but cannot assume the position without assistance. Paige could roll side to side but cannot roll to prone or supine. Stomach creeping skills are still emerging. It was reported that she has moderate hypotonia and tight right
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sternomastoid muscles causing her to maintain a head tilt to the right. She is very sensitive to touch in the neck area.

Another epiphany happened when Mrs. Clarke recalled the confusion of getting an accurate diagnosis to help her child. She stated,

They thought, perhaps she had a mental disability and that's when we started at a children's hospital, which was a nightmare in itself because we went to different types of specialists. Each diagnosis was not carried through. They thought she had some sort of orthopedic problem with muscle weakness that could not be explained... I was standing in the middle of children's hospital screaming at my husband... My husband is screaming at me, "We're at children's hospital for God's sake! They can't be wrong!"

I kept saying, "He's wrong! He's wrong!" I mean just a complete meltdown. People looking at us... I was hysterical because I just didn't think that was it. I can't explain it. I just knew in my gut... "There's something wrong with my baby! There's something wrong!" And nobody would listen to me.

There were many frustrating visits to different doctors. Mrs. Clarke persevered to find out what was happening to Paige stating,

We went back to my pediatrician and he said, okay, let's try (she drew a blank on the names of the specialists) I can't remember where we went last... We went to a local hospital to a heart specialist and sleep apnea doctor that was supposedly world re-known and she spent the night at a sleep study and they couldn't figure out what was wrong with her... We're seventeen months old and we're still on an
apnea monitor...Nobody knew what was wrong...now they're saying to try neurology... She didn't take her first step until she was seventeen months old.

She never crawled, ever, ever, ever! She got to the point where she could hold herself up on a table and walk, but never crawled...she was walking by that point holding on to your finger or cruise as I used to call it. You know when you go from thing to thing.

When Paige was seventeen months she went to a young neurologist who noticed that the left side of Paige's body was smaller including her hand, thigh, and foot. The neurologist thought that Paige suffered a stroke. Mrs. Clarke recalls every detail from this key point in Paige's life,

You could have blown me out of the chair. I said, "A stroke?"

He picks her hands up and he puts her hands together and he said, "Didn't anyone ever notice that her left hand is smaller?...Didn't anybody ever notice her left thigh is smaller?...Didn't you notice her left foot was smaller?...No. I don't mean length. I mean her whole foot is smaller...I think her whole left side's been affected." He pulls out reports and he says, "Well, right here, you were saying she doesn't grab her left hand." He said, "You know, you were buying the two handed rattles...I think that's it." They ended up doing a CAT scan and that's when we found all this information out that it certainly was much more than that. But that's how long it took.
When Paige was in early intervention, Mrs. Clarke had difficulty in social situations trying to be around others who did not have children with disabilities. Mrs. Clarke tried to reach out to others during this challenging time in the life of her daughter. She recalled,

There are times you just don't want to get into it. I think it's hard to handle social situations where your child's in a social situation and can't keep up with the other kids. Do you intervene or do you kind of let them do their own thing? That's the difficulties that I had because how can you be part of the group if you can't be part of the group? I mean, my daughter never crawled, and she never walked. So when kids were roaming and running around, she can't. I can remember being at her house and she was in a walker because that's all she could do at that point. One of the little boys wanted to play so he grabbed her by the hair and dragged her in the walker across the room because he wanted to play with her. He didn't understand the whole concept... We would get together for a playgroup and then the moms would start talking about something. I could tell they got uncomfortable around me. I understand that they didn't want to talk about all the stuff that was going on because they knew my daughter couldn't do it. On one hand, I would come home upset because it just brings it out even more that your child has a disability. On the other hand, I can't sit home in the house with her all day long. That was hard for me... Even though people were supportive, sometimes I felt like it we had our token handicapped child, you know. Let's teach our kids about compassion so make sure we invite our daughter. She was kind of the poster
child in the community for a child with a disability. I remember somebody saying something to me once when I said there was no children on my street to play with. They told me that they had spoken to someone who lived near me who had a child my daughter's age. The woman replied, “That child? Isn't she in that retard class?”

Mrs. Clarke talked of the strong connections she made with other women who had children with disabilities. She shared,

I met some people. I met this one friend who had a disabled daughter and another one in the community who actually just kind of knocked on my door one day when she heard that I knew her daughter has cerebral palsy. And she became a great, great help for me because she lived with it every day. She was a great person I could bounce things off. I think one of the things that you really need support is that I was so angry at everybody

Mrs. Clarke talked about relationships she made with the mothers in early intervention when Paige was six months of age and the importance of getting together with them. She stated,

She was not moving along with things she should have been doing...they were looking for all different causes before they actually found out her disability was. She wasn't moving along so my pediatrician had recommended that I get her in early intervention. Early intervention, at the time, was you took the child to a place with the other moms and they had a psychologist on staff and the speech therapist and everyone was in like a big playroom and the child moved from
therapist to therapist, whatever that particular child needed. The thing that I liked about it, which they don't offer now, is that I got to speak with other parents of children that had disabilities...I know the program now where they go into the home; but you don't have that parental support.

There was a lot of support from both sides of Paige's family to help her during this difficult time in her life. Mrs. Clarke said,

I'm very close to my mother-in-law now and my father-in-law at the time was very supportive. It started being so overwhelming and I was not ready to have this baby. I mean seven weeks early, we didn't have furniture. The nursery wasn't done...So from the very, very beginning, I was overwhelmed. I've been very lucky. I have a very unique family and we're kind of a fun dysfunctional family. I think it's been very good for my daughter. I'm very close to my sister...

We live a mile from each other.

Paige's father played an active role in supporting them during this time period. Mrs. Clarke talks about the strong relationship she has with her husband, his belief in her, and the support she received from him stating,

My husband was very supportive. He never had any doubt that I couldn't handle the situation. I had moms telling me in counseling that husbands said to their wives, "You're not going to hear the monitor"... I never had that with my husband. He never felt that I wasn't doing the best possible job that could be done. That was never even in the equation. On Saturdays he would make me get out of the house. You become very afraid. You are so limited on those
monitors...So you get to the point where your whole life centers around your house because you can't even take a shower. You're nervous to be downstairs when she's upstairs.

Paige was an infant who has a pleasant personality despite her struggles with mobilizing. She communicated to others and especially liked a popular news commentator. Mrs. Clarke speaks of the positive connection she had with her daughter as an infant saying,

She was very affectionate and she loved to be cuddled and held and played with...She loved news commentators...I think she thought they were talking to her...She would talk back to them. I think she really thought it was like a person. That was one of her favorite things on TV...She was very happy, but pretty calm. She really could entertain herself. I was lucky. She was the kind of kid at Christmas that literally would open one thing at a time. She wanted the whole thing unwrapped and put together and examined. Then she would play with it for awhile and would literally go to the next gift. She was never that kid that tore into the packages ...When she got her little stove, she wanted the dishes unwrapped. She wanted to put all the dishes inside the little kitchen. Then she would take the baby she'd unwrapped before and go show the baby the stove.

An educational assessment done at age three in early intervention indicated that Paige's motor areas were the only areas of significant depression as she achieved one standard deviation below the mean on the McCarthy Scales of Children's Ability. At that time, she could not jump in place, balance, jump over an object, kick a ball in movement,
or imitate postures. She was missing her corpus callosum and cerebellum that allows for the transfer of sensory and motor information between the brain's hemispheres and coordinates motor planning and control.

Paige was placed in the preschool handicapped class in her local community school so she could receive physical therapy because of gross motor delays. It was reported that she became toilet trained in the preschool program and was learning to express her wants and needs. Her gross motor skills continue to be delayed. Paige was performing at age appropriate levels in speech and language, cognitive development, and self-help skills. Paige was given the Bankston Language Screening Test at age four and it was found that she had difficulty with categorization, opposites, pronouns, future tense, plurals, and visual association/sequencing. Paige was given speech and language services the second year of preschool.

*Early Elementary (Grades K-5)*

A major theme during this time period had to do with Mrs. Clarke fighting for her daughter's rights in school. In September of 1989, Paige was reevaluated and classified as Multiply Handicapped. According to a psychological evaluation she was intellectually functioning in the average range. The *Weschler Intelligence Scales for Children-Third Edition* was used and Paige demonstrated relative strengths in vocabulary, similarities, and comprehension and relative weakness in block design and puzzle completion. She also demonstrated weakness in abstract language and problem solving. A letter from the child study team confirmed Mrs. Clarke's determination to see her daughter succeed in school as she provided the results from the *Gesell Institute of Child Development School*
Readiness Screening Test. The report indicated that her left hand does not track left to right or guide her in manipulating objects. Mrs. Clarke demanded that Paige be pushed to reach her academic potential and fought for Paige to be placed in a developmental kindergarten in the morning and a class for Multiply Handicapped (MH) kindergarteners in the afternoon. She recalls what she went through during this period saying,

That's when I started the arguments about the developmental kindergarten. To keep her out because of fine and gross motor skills, I didn't think was fair and my argument with them was well, if she didn't have a leg you would take her, if she was in a wheelchair you'd take her, so she can pass the test you need to take her... I felt that there was no reason to turn her down because she did know colors, shapes, numbers... It kind of started off on a bad foot because I certainly understand that they did not want developmental kindergarten to be a dumping ground for kids who had disabilities whose parents did not want to admit it or didn't realize it or weren't aware. Academically she could pass the kindergarten test... They wanted me to hold her out (of kindergarten) and pay for it myself. My problem was that she was out of early intervention; I would have had no services for a year. I felt that was wrong... So she did that for two years, developmental kindergarten in the morning and five-year old MH class in the afternoon... she's the kid that needed the extra year. She also needed the OT, PT, speech/language, and socialization.

An occupational therapy (OT) evaluation completed in May of 1989, indicated that Paige had difficulty isolating movements with her left arm and hand and will
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sometimes shift her weight or move her entire body instead of crossing her body’s midline. There was no indication that she has ACC or a missing cerebellum in the Individualized Education Program (IEP) conference report for the 1989-1990 school year.

Later in her kindergarten year, Occupational Therapy (OT) was provided at Mrs. Clarke’s request because of mild left hemiparesis and things were harder for her to do on her left side. The OT reported that she displayed improved visual motor coordination and could copy all simple shapes with the exception of a diamond. Paige demonstrated improved motor planning ability was able to cross the midline three out of four times and imitates demonstrated posture. Paige also demonstrated significant improvement in bilateral coordination skills. A PT report written in March of 1991, stated that Paige displayed anxiety when going down the stairs and gravitational insecurity when her vestibular systems were challenged. He further indicated that she displayed left sided weakness and significant deficits in her sensory motor processing.

Child study team conclusions from her classification conference report in May of 1992, indicated that Paige was functioning within normal limits for her chronological age but depressions were evident in visual closure and visual motor integration. On the Vineland Adaptive Behavior Scale Paige achieved a composite score one-half year above her chronological age across all domains. She was classified as Perceptually Impaired and placed in a regular second grade class with support from a special education teacher.
Her mother reports,

Because inclusion was coming to the forefront, I felt that I wanted her around other children more than they were offering her and really pushed through, actually through the county, to offer some kind of inclusion at least for language arts in the classroom.

According to a PT summary from 1992, Paige’s muscle power improved in the left upper and lower extremities. She hopped on her left foot three to four times without support. Vestibular processing improved as she was less anxious encountering balance challenges. Paige alternated her feet without holding onto railing going up the stairs and held onto the railing when alternating feet descending the stairs. Deficits persisted in motor planning, bilateral coordination, balance, muscle power, and sensory motor learning.

An OT evaluation written in 1992 indicated that Paige displayed increased processing time for motor learning and output, a decreased ability to plan motor activities, and difficulty visually attending to manipulation tasks. Fine manipulation with isolated fingers needed practice. She demonstrated improvement in manuscript writing and spacing of letters. Paige continued to be tutored at home one time per week in reading and math. Paige’s second grade teacher stated on her report card in April of 1993, that she was a delightful child and conscientious worker that continued to make consistent progress especially in reading. Her teacher reported that she worked hard in math, and the extra help she received at school and home tutoring was very beneficial.
Paige displayed weakness in math concepts and applications according to the *California Achievement Tests, Fifth Edition* given in second grade.

Her Annual Review for second grade reported that Paige is a shy, motivated, visual learner who received in-class support for reading/language arts and math. Paige was on grade level in reading/language arts and is near grade level in math. Academic strengths were in reading comprehension, sight word recognition, and written language. Weaknesses were in listening comprehension, and mathematical application skills. It was reported that Paige had difficulty attending to and understanding oral directions in the large group.

Despite math and language arts tutoring once a week in third grade, Paige was beginning to struggle and her mother was concerned about her educational needs. Her final report card reflects very good effort in every subject. With in-class support from a special education teacher in a mainstreamed reading class, she achieved a “C+”. Mrs. Clarke was overwhelmed with anxiety when she would visit her daughter’s team taught class and recalls a specific time when she had a conference with her third grade teachers. She says,

"Her classroom teacher said to me, “If I wanted to be a special education teacher I would have gone to school to be a special education teacher.” To my face she said this.

The special education teacher said, “I don't think my kids can handle a regular classroom.”

I kept telling them that I was doing it and it was working. I don't think either of
the teachers were for it. I don't know why you would take two teachers that don't believe in inclusion and have them in a team teaching situation where neither one thinks it going to work. Well, of course, it's not going to work.

Mrs. Clarke was very unhappy when Paige’s teacher told her that her daughter did not know how to write and worried that they were not teaching writing skills in class. She says,

The only writing that came home was a description of Santa Claus, which I thought was rather bizarre for a public school. When I asked the teacher about it she said, “Well, they don't know how to write.”

I said, “Who's they? My child? My child knows how to write. She writes every night with me. So don't say they don't know how to write. They just wouldn't try.” I just kept saying, “Try, try. I don't care if there are two sentences that really don't make any sense. What difference does it make? Try.”

Mrs. Clarke recalled another key incident in third grade where her teachers did not seem to want to work with Paige. This is another period of feeling disconnected with the school system. She says,

They sent home a paper and this one really killed me. I know I'm rambling, but I'm on a rampage now. The paper was about Claire Barton, common nouns and proper nouns. …on one side was common nouns you had to list…on the other side was proper nouns. My daughter got them completely mixed up. She realized what a common noun was and she knew what a proper noun was, but she put them under the wrong heading. The teacher marked every one wrong with a red
pen and put an "F" on her paper. Now this is an inclusion classroom. My
daughter comes home, of course, devastated and crying. I called up and said,
"Where was the inclusion teacher? The teacher should have walked around the
room to tell my daughter that she was getting her topics mixed up." P is proper
like a proper person. To mark my child's paper with everything wrong and then
say this shows that inclusion isn't working. Come on. I've been teaching twenty­
three years. I have kids in the gifted program that would make a mistake like that.
I don't put an "F" on it. That's the kind of stuff I just couldn't take in the public
school. I thought, "I just can't do it anymore."

Mrs. Clarke, an inclusion teacher, decided to pull Paige out of public school and
put her in private school because of their attitude towards special education kids. Mrs.
Clarke was on the verge of a nervous break down and was sick of fighting the public
school system. Mrs. Clarke decided to send Paige to a more nurturing environment in
private school. She says,

I just couldn't do it anymore. I just felt like I was pushing and pushing and
pushing and pushing and pushing. I reached the frustration level and put her in
private school. She had five girlfriends whose parents pulled them out of school
and home-schooled them because they were so frustrated...We had all had it. We
should have banded together and fought, but we were fought out. We couldn't do
it anymore. None of us. At least we had each other for support...We tried to
search around and to find out what we could ask for, but it was just going up
against a brick wall. We were all sick of fighting... If you have the option of home
schooling; I think it's great if the parents are good home schooling parents. I've
seen it done horribly, where the kid sat around and didn't do anything. The
parents I knew did a great job. They took the kids on trips like when they were
studying a war, they went to the battle field. When they were studying fish, they
grew to the aquarium

Paige’s parochial school was a few miles away. It was a small nurturing
environment where teachers accommodated to help her specific needs in physical
education and math. Mrs. Clarke describes the environment in private school. Mrs.
Clarke describes her experience with this school system,

  I just felt it was a much healthier environment for her. You know, she didn't do
particularly well but that was okay with us because to her, "C's" were the best she
could do. She can't do math, never could do math. But I at least felt the
atmosphere was supportive. She had a sense of belonging. Even though socially,
she didn't really make any friends there. At least she was happy when she was
there. They had a lot of things to involve parents in the school. It was something
like family schooling more than the isolation of plopping her in a special
education room and not mixing her up with anybody. I don't live in a very
ethnically diverse area and I think when you are different for whatever reason, my
daughter had no opportunities to see anybody that was different in any other way.
So in a school with a lot of ethnic diversion, it did have a religious component,
which I felt was nice because all the things that my daughter strengths are her
compassion and her kindness would be cultured there and motivated...She's kind
and compassionate and caring, and these are the things that a private, religious school you're going to be commended for.

Paige enjoyed school a lot better and she got the attention that was needed. She was placed in small classrooms and the teachers would try hard to diversify her instruction particularly in math and physical education. Mrs. Clarke talks about the methods of accommodation in private school saying,

I thought that that would help her self-esteem because the class was so small that she would be able to keep up with the work with some help on the side or some diversion of program which they were willing to do for her...I mean they would try to help her all that they could, but she really didn't get too many adaptations...

The classes were small and the teachers kind of did a neat kind of team teaching type of thing where the math teacher would cover a couple different areas so the kids could be split up into even smaller groups. The kids that weren't very good in math got help...That is all that I was asking for in the public school. They diversified within this very small private school through the way they taught. The teachers there were great. They were very progressive and really wanted each student to learn and be comfortable where they are. So that worked out pretty well. In the private school, the gym classes were small and they didn't really have to make any modifications for her because they could adapt the program to what my daughter was capable of doing.
Paige recalls her elementary school years saying,

When I was real little I didn’t know. I couldn’t tell that I couldn’t remember. I couldn’t tell that I couldn’t remember right. I thought that everybody was the same as me. And then, as I got older, I started to realize that I couldn’t remember everything that my friends were remembering. When I started elementary school in fourth grade we had a Christmas pageant and I couldn’t carry my chair down the steps and some of my classmates asked me why I couldn’t carry my chair down the steps and I said that I wasn’t strong enough. And they were okay; they understood. It was okay to them. They never made fun of me for not being able to do certain activities as well as them or hold heavy stuff. In fifth grade, our teacher put up different names on the wall and every time we had a spelling test we got an "A" or "B" we could move up. And it took me five spelling tests to move up while everybody else was up; already had moved up. I felt sad. When I finally passed the spelling test and moved up my teacher was excited. She let me go to the other classrooms and tell my previous teachers. My teachers always encouraged me. They were always excited about a test that I would show them. They would help me understand what we were going over a little more. When I got a good grade, they would get really happy for me and tell me that I had to go tell the other teachers. That was really exciting to me.

When Paige was in elementary school she didn’t have a lot of friends so she spent time with her mother. Mrs. Clarke recalls her relationship with her daughter when she
was in elementary school saying,

We spent a lot of time together because she really didn't have a lot of friends. She was in Daisy Scouts. She sang in the choir at church. But she never really made connections with anyone. Even when she was in the private school, the teacher had told us that she knew that one of the girls had had a sleep over and my daughter was the only girl that wasn't invited. She's not made fun of. She's kind of ignored and didn't realize that she wasn't invited. But part of me was like how could you not invite her? I mean there was only like six girls in the whole class... She was kind of the social outcast even with scouting. As she got older in scouting the girls were very click-ish. Most of it revolved around sports. Their parents became friendly because they played on the same team, but since she didn't play sports we weren't really friendly with those people. We knew them, but we weren't really friendly with them. So we spent a lot of time together. She's a very easy child. She's never really asked for anything. She's never wanted special clothes.

*Upper Elementary School (Grades 6-8)*

In December of her sixth grade year, Paige was evaluated by her neurologist because of educational, social and emotional issues raised by her mother particularly with abstractions in writing essays and arithmetic. They report that she had to work very hard to get fair grades. Paige experienced headaches, dizzy spells, and blanking out spells during this time period as she began menstruation. The neurologist reported in a letter to the family physician in December 1997 that Paige has congenital anomalies of the brain
including complete agenesis of the corpus callosum and agenesis of the left cerebellar hemisphere. Her neurologist reported that despite these considerable deficits, she has done really quite well developmentally and in learning. Her neurologist reported that Paige has motoric difficulties that preclude her being able to do all the things that others her age do. An MRI was done which found Coordination Disorder and unchanged findings due to the missing left cerebellar hemisphere affecting balance, and fine motor abilities particularly on her left side. Paige has considerable dysmetria which is defined as a lack of coordination of movement. She also has an intention tremor when carrying out targeting activities with the left hand. Her neurologist reported that Paige has fared much better than most children with the known deficits shown on her MRI scan, although she is neurologically impaired which affects her educationally, motorically, and socially.

Sixth grade academic reports indicated that she was a "C" student in most of her academic classes in parochial school with no academic support. Teachers commented that Paige did well with current chapters but had trouble remembering previous lessons. They reported that she tried, but still had difficulty with vocabulary, writing assignments, and processing. Paige was attentive, completed every assignment with care, and was a pleasure to work with. Teachers reported that she was a constructive class participant. They stated that additional help at home helped her clarify points learned in class.

*The Metropolitan Achievement Tests (Seventh Edition)* were given in sixth grade and were reported in May, 1997 which assessed her skills. Below average content clusters included reading interpretation and critical analysis, geometry, estimation, algebra, physical science, science research skills. She achieved above average clusters in:
solution sentences, mathematics as communication, procedures, computation, prewriting, political science, social studies research skills.

In the summer before Paige’s seventh grade year in parochial school, an independent evaluation was performed because of concerns that she could not be successful in a regular school program and concern that she was socially isolated in private school. Paige had a strong desire to return back to a four year public high school before applying for a four-year college.

A learning disability evaluation was conducted in August of 1997 using the following instruments: Berry Developmental Test of Visual Motor Integration, Peabody Picture Vocabulary Test Forms L & M, the Detroit Test of Learning Aptitude, and Kaufman Test of Educational Achievement. Paige’s reading capacity was reported in the average range to understand word meanings, and to formulate the correct image associated with that unit of meaning. It was reported that she has average short term verbal memory and has average ability to automatically encode and retain verbal materials. Paige displayed difficulty with higher order abstract reasoning and in inferential comprehension. Her visual spatial skills were below average. She achieved average mathematical computation skills but her quantitative reasoning skills were below her ability to apply rote calculations.

A psychological evaluation was conducted as part of the reevaluation using the WISC-III. She demonstrated abilities in the average range of intellectual functioning. She demonstrated an area of relative strength in her short term rote auditory memory. She demonstrated weakness in visual sequencing skills, visual analysis, and synthesis.
According to a classification conference report held on October 2, 1997 it was determined that classification was not warranted because Paige’s achievement scores were at the level expected for grade and cognitive potential. Recommendations included private peer group counseling to address parental concerns about her social skills development. Monitoring of her progress in mathematics occurred because of her weakness in sense of spatial relations. Paige remained in parochial school through seventh grade.

She demonstrated primarily “B’s” and “C’s” in her academic subjects on her seventh grade report card. Her teachers reported that she was a hardworking young lady and was beginning to understand the material better. They reported that her organizational skills were improving greatly as she took notes and was organized. Paige did her homework regularly and displayed care and a positive attitude in the classroom. She was enthusiastic and always willing to participate. Her computer teacher reported that she had very good word processing skills. She loved to do reports on countries in geography and did very well on them. Paige was encouraged to get extra help if she didn’t understand something according to advisor comments on her report card in January 1998.

Her seventh grade achievement tests called The Comprehensive Testing Program III, were given in May of 1998. The following percentile ranks were reported: Verbal Ability-42, Vocabulary-51, Reading Comprehension-46, Writing Mechanics-46, Quantitative Ability-47, and Mathematics-52.
Another key life experience occurred during Paige’s eighth grade year. A 504 Plan was developed as she reentered the public school system at the beginning of eighth grade to help her during any physical education activities. The 504 Accommodation Plan stated that Paige demonstrated age appropriate skills with the exception of a significant lag in areas of visual analysis and synthesis. It went on to state that she had delays in the motor skills area so adjustment should be made in physical education. Accommodations allowed for multiple stepped tasks to be broken down, monitoring of her coping skills for written tasks, word banks, notes, and study guides in history and language arts.

Paige reported that her experience in eighth grade when she returned to public school was frustrating. She reported that eighth grade was a difficult year for her saying, I wasn’t frustrated in sixth grade or seventh grade, but when I back to another school in eighth grade I got confused. It was more frustrating in eighth grade. In eighth grade, I went back to public school. The classes were bigger and the teachers, they were helpful, but they weren’t as helpful as my old teachers. I had difficulty with the structure of the class and the way the class was taught. I had a note-taker. It helped a little bit for history. I would receive a shorter test. But it very rarely helped”. I can not remember happy memories. Two of them (teachers) would help me. One teacher was our resource room teacher. So she would help me with my homework.

When asked at a later time about positive experiences in eighth grade, Paige was able to remember an award she received at her graduation ceremony. She was awarded a letter from the president of the United States stating that she got the Presidential Award
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*for Educational Improvement* given to students who show outstanding educational growth, improvement, and commitment despite obstacles. The award letter was read at the graduation ceremony in front of parents, peers, and staff. Paige recalls,

Eighth grade graduation I got an award for most improved signed by President Clinton.

Mrs. Clarke regrets listening to Paige’s idea of returning to public school in eighth grade because it was such a difficult year for her. She says,

I wanted her to stay in private school but she argued with me and I relented. It was so hard after trying to come back after being out. Socially it didn't help her. It wasn't what she thought it was going to be. I think it didn't turn out to be a positive thing. I think they felt that they were going to have to do a lot of things for her they didn't feel like doing. I mean the child study team just didn't want to cooperate. At that point, I was worried about GEPA (*Grade Eight Proficiency Assessment*). My daughter's chances of passing the math GEPA were nil, whether she had stayed in that school system or not. She didn't pass and then ended in remedial math in high school. Eighth grade was not a good year for her. We both realized later that we should have left her in private school because there were only about fifty kids per grade level. All the clicks were made in public school. She didn’t play sports so the same social problems that she had before actually intensified because there was really no little group she could hook up with. I think academically in private school it was better because they gave her what everyone else was getting.
The theme of fighting for the rights of her daughter in school emerged again during this time as Mrs. Clarke advocated to have Paige reevaluated for special education and related services because she felt that the 504 Accommodation Plan was not enough as she still struggles to receive passing grades in her major classes with private tutoring in the home. Mrs. Clarke enlisted the help of a friend who was a learning consultant who reviewed all of her records to help her get the point across about her daughter’s struggling. The learning consultant wrote a letter to Mr. and Mrs. Clarke in February of 1999, stating that a medical doctor reported that she was neurologically impaired which affects her educationally, motorically, and socially. The learning consultant stated in her letter that a significant lag in two measures of visual analysis and synthesis could create problems in terms of inefficient processing of visual information, general difficulty in organization, and strategy development as well as some difficulty processing subtle social cues. Mrs. Clarke reflects on this time period saying,

They didn't want to classify her when she was in private school. She was privately tested by a group from a local college. Because of the tutoring and karate and piano lessons for fine motor skills, I had actually gotten her to the point where she didn't have enough differential to be classified. I absolutely flipped out and said, "You know, if I hadn't paid for the karate, paid for the piano lessons, paid for the tutor and let my daughter just go through school, then she would have been classified. If I kept her dumb enough she would have been classified."

Because of the medical aspect of it, I went to some outside people that I knew and I appealed my case and they did classify her. They wanted to give her a 504,
which I was adamantly against. I mean my daughter has a permanent disability; she's not getting a 504.

A reevaluation commenced and Paige was given a psychological evaluation. Significantly delayed scores were reported using the *Bender Visual Motor Gestalt Test* indicating poor visual motor integration skills. Social concerns and counseling were ruled out by the school psychologist using the *Behavior Assessment System for Children* rating scales. She completed the *Stanford Binet Intelligence Scales –IVth Edition* and scored in the average range in all four factors of ability tested. A significant discrepancy was found between her abilities in the areas of Short Term Memory and Quantitative Reasoning, as well as between Short Term Memory and Abstract/Visual Reasoning.

A social case history was also conducted that had new information not reported in earlier evaluations. It explained that Paige was seen by a neurologist who ordered an MRI and EEG because of fainting spells which confirmed that she had agenesis of the corpus callosum with under development of the left cerebellar hemisphere and white matter thinning. The case history confirmed that her transition was difficult in eighth grade as Paige was tearful in class and somewhat overwhelmed with the amount of work. Paige’s quality of work was reported not to be on grade level and that she makes significant effort to achieve “C’s” and “D’s”. It was reported that she prefers to be around younger children. Paige reported that things are not fair when she fails a test and becomes very angry. Mrs. Clarke reported that the hardest thing about raising her daughter is the frustration she experiences with her schoolwork and feelings that she expresses about being stupid.
The last part of the reevaluation done in her eighth grade year involved an educational evaluation using the *Woodcock-Johnson Psycho-Educational Battery-Revised (WJ-R, 1989)* Tests of Achievement. Paige achieved the following grade level and percentile scores: Basic Reading Skills, Basic Mathematics Skills—Broad Written Language were assessed in the 11th grade level. Factual Knowledge was at the eighth grade level. It was noted that inspection of her test scores shows a significant variability in performance.

Paige was found to be eligible for special education services in 1999 with a traumatic brain injury classification according to an eligibility conference report held in June of her eighth grade year. This was the first time in Paige’s school career that a brain injury was mentioned to get her services. The report read that she should receive in-class support to address poor broad knowledge, psychosocial factors, poor information processing, and poor abstract thinking. It was written in the classification conference report that she can become overwhelmed by academic functioning. The most significant part of the report stated,

> Her acquired injury to the brain affects her in the following areas: cognition, problem solving, abstract thinking, psychosocial behavior, information processing, sensory, perceptual, and motor functions.

*Experiences in High School*

It was remarkable that the only IEP in Paige’s school experience that stated that she had a brain injury was in an IEP Conference Report and Annual Review for Grade 9. It indicated that Paige was found eligible for special education because she has
significant neurological impairment as she was born with agenesis of the corpus callosum and left cerebellar hemisphere. The CST determined that Paige had a specific learning disability based upon a significant discrepancy between short term memory and quantitative reasoning as well as between short term memory and abstract/visual reasoning. The CST reported that there was a discrepancy between current achievement in academic testing and classroom functioning in all areas. Paige was given one period per day of resource center support and was able to go to adaptive physical education if she felt the mainstreamed physical education class was too challenging. The IEP indicated that Paige was a highly motivated student who works hard, but struggled to receive passing grades. Socially, it was reported that she has friends but had difficulty relating to peers and felt more comfortable with younger children.

Mrs. Clarke reflects on the confusion about Paige’s learning difficulties and how long it took to get CST’s to listen to the medical aspect of her struggles,

By the time I got to her high school, I had all that straightened out because of the medical aspect that I had forwarded to them. The Child Study Team said that absolutely she was classifiable. Her doctors had said that she was classifiable because of her disability. I was very happy she could be classified so I told them to pick one, any one. I didn't care which one they picked, just pick something. I definitely wanted her classified. Now I understand that under the 504 she would have been protected also. I didn't want it off her record that she has a true disability that is going to follow her for life. I didn't want to have that not on her record.
Mrs. Clarke was always fighting to do the right thing for her daughter academically and socially. She recalls that she still had to keep on advocating for Paige during her freshman year for summer reading book lists, appropriate foreign language instruction, and appropriate physical education. She reflected on this time period saying,

Even going into high school was frustrating. They sent home a reading list between eighth grade and high school. It's called summer reading. They had thought that she would end up in remedial language arts because they did not have test results. So they did not send a list of books home...Not offering a lower level foreign language class. I said, "You have to." It's not just the special ed kids; it's the basic skills kids too or the kids that just don't have that high of an IQ. How can you expect them to take a state required foreign language and not offer it on a level three or four? When she got to Shawnee, one of the things I absolutely wanted in her IEP was that she couldn't have anything go against her because she couldn't do something. She had a very good case manager in high school. Thank goodness. They scheduled her gym class the same time an adaptive PE class was going on so that my daughter would have the option to take herself out of a particular activity if she didn't feel comfortable doing it or felt it was out of her realm. She could have gone into the Adaptive PE class and if they moved onto to something she felt she could do, she would go into the regular PE class. The only good thing about that was that she realized there are a lot of kids as uncoordinated as her. She kind of made her own little gym class with some friends and the gym teacher. My daughter said, as long as they were participating they would pass. It
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wasn't on how well you did, so they kind of did their own thing. If there was
basketball going on, the kids that weren't very good at basketball played their own
game.

When asked if the high school listened to her and was able to do anything about
helping others in their system Mrs. Clarke said,

Yes, they did start offering a level three Spanish, which was more of a cultural
thing. You know, she had to make up a little menu and they had to order in
Spanish and things like that, which I think was great! I mean that's what it's all
about. The kids got more out of that class than anything else. They don't even
have electives for kids on that level. My daughter tried to take a cooking class.
Well, the vocabulary was astronomical. They don't even offer an elective on a
lower level for a lot of these kids that are struggling. I mean, a lot of them would
have just given up, saying, "I can't do this! I get no break! I'm in remedial math
and in remedial language." They offer lower levels for social studies and stuff
like that, but then they go to take an elective and we're right back on level two
again. They can't handle it. They just need something more of a life-skill. And
then I tried to get them to let her take some basic math classes. They said, "Well,
you can't take basic math because you're not a business major." Come on! Let's
teach these kids how to balance a checkbook or something.

Paige's IEP in Grade 10 indicated that Mrs. Clarke would like her to develop
friendships as she is concerned about social isolation. She received one period of
Resource Center support daily. Her teachers reported that she was a welcome addition to
any class. Socially it was reported that she related to her peers but was quiet in large settings and had difficulty in dealing with situations involving conflict. Paige adjusted to high school life as she was the manager of the girl’s gymnastic team. Paige reported that she took in karate, babysat, and planned to go into the childcare field. Modifications included note taking assistance, extra time for tests, and no scantron. Paige was inducted into the National Honor Society for recognition of academic achievement when a grade point average of 3.25 is maintained and the qualities of character, leadership, and service to others are exhibited.

Mrs. Clarke talked about the experience Paige had being the manager of the gymnastics team and babysitting experiences stating,

She didn't get involved much in high school. The only thing she did do, which happened to be through a connection with me, was manage the gymnastics team for four years. I don't know if manage is the right word, but she was their score keeper. At least that got her involved in something with school. She didn't get real involved with the girls, of course, when you have a physical disability and you’re with gymnasts. But she did go to the meets and the away meets. She got to the point where she was keeping score for tournaments and I think was well respected. I mean there was a dispute one time. She started getting upset. Other coaches actually came to her defense and said, “She doesn't make mistakes. Just give her a couple minutes. I'm sure that she has it right.”…

This coach started to jump down her throat and other people came to her defense. She got upset later and cried because it kind of threw her off guard. At least,
people saw in her that she tried her best and was very diligent about doing a good job. So she babysat a lot in high school...She was very well liked by people... lawyers who gave her a lot of responsibility... took kids for haircuts, orthodontists, and doctors appointments. Things I don't think I would ever let a babysitter do. She got really close to the families. She traveled with families as a nanny. So that's been positive for her to do that.

Paige's junior year was full of decisions as to what four year college she would attend. She took her college boards, visited a few campuses and was on her way to deciding where she would attend. Paige had many individuals willing to write her letters of recommendation and was reevaluated for college as she knew she was going to use support services there. Mrs. Clarke recounts this busy time period stating,

Now we're on the hunt for college, which was another devastating experience.

She had chosen a college and went online and checked it out. It looked beautiful! We arranged an interview because she did want to discuss the fact that she does have a learning disability and we drove up there. It was very, very nice. We got a room in a hotel and went and looked at the golf course because my husband plays golf. She said, "Oh, this is great mom! You know, you and dad can come up and he can play golf and we can do some things." We went in for the interview. My daughter sat down and was very well dressed. My daughter is very well spoken, I think. She introduced herself and explained why she looked at the college. When she started to talk about her disability, he literally rolled his eyes. My daughter cried for the entire two hour trip home. So she was devastated! So then everyone
tells her to go to community college. She told me that she was adamant about going away to school. I went away to school and she said, “Mom, I'm never going to be able to make that up, even if I go as a junior.”

Mrs. Clarke remembers the time that Paige got very excited about the college that she is about to graduate from. Paige went to a college fair and was very excited that this college actually had a pamphlet on students with disabilities. Paige visited the school with her family and friend. They met with the head of the special services department at school who was very enthusiastic about her job. Mrs. Clarke recalls the time waiting for her SAT results and wondering if she would get into this college. Paige scored in the 27th national percentile on the verbal section of College Board SAT and in the 11th national percentile in the math section. Mrs. Clarke says,

I told my husband later that I looked at her face and I've never prayed so hard in my life for anything. I wanted to get her into that college. I could just tell by looking at her that this is really where she wanted to go. This poor kid has had so many disappointments in her life, just please help her get into this college... because of her disability, she had to take her SATs with a scribe, which also turned into a disaster because they kept telling us they couldn't find one. We waited and waited for her results... The clock was ticking and he said that he didn't have her SAT results. So I called the portion of SAT that works with kids with disabilities and they apologized and sent her results. I was like, “Please God just get her in there! I mean for those two points. If it had been two points the
other way, I don’t know what would have happened. She would have been so devastated at that point. She got letters of recommendation that were beautiful.

Paige had an excellent junior year in high school. She received “smart cookie” awards for applying herself and working hard. Teachers reported that she has a good relationship with peers and is always willing to help them with difficulties they are experiencing. They also reported that Paige had an excellent relationship with all adults and the faculty. Her support teacher stated that she can adjust and adapt to most situations. Paige was seen as a self motivated young lady conscientious about completing all assignments. She achieved A’s and B’s on her report card and was provided modifications in physical education class if needed.

Paige was referred to the CST in August, 2002, to complete the necessary requirements to continue receiving accommodations as a college student with learning disabilities. A psychological evaluation, 2002, accurately presented in detail a profile of her strengths and weaknesses. It reported her intellectual functioning using the *Weschler Adult Intelligence Scale for Children-Third Edition (WAIS-III)* in the following manner: She displays below average reasoning skills with novel material. Those with ACC display difficulties with problem solving in novel situations (Brown et al., 2005; Brown & Paul, 2000). Her fund of word knowledge was in the low average range. She scored in the average range in her knowledge of factual information linked especially to the content areas of history and geography. It appears that she has at least an average crystallized knowledge base from which she is able to retrieve information on request. It is apparent that she is not able to elaborate on her verbal language skills to arrive at the correct
answer. She is very literal in her interpretation of language and does not appear to pick up on the subtleties of language. She appears to chatter about what she is being asked to do. When she is unsure of herself she will answer quickly in a few short words. If the language becomes too figurative maintaining a conversation with her will be difficult. Figurative language impairments are reported in those with ACC as it is suspected that interhemispheric communication is required for successful idiom comprehension (Huber-Okrainec, et al., 2005; Brown et al., 2005). She seemed unsure of her responses as her correct response was phrased in the form of a question. She scored poorly on these subtests which involve fluid verbal reasoning. This reasoning deals with social conventions and cause and effect situations. She displayed an average ability to retrieve math facts from long term memory. She displayed an excellent use of working memory where she was able to retrieve alphabetical and numerical templates from long term storage and manipulate them. She can not retrieve from long term storage visual images as she is able to retrieve math facts, and the alphabet. The ability to accurately visualize general configurations of concrete objects is an area of weakness for her as she could not figure out how to make the pieces fit. It appears that those with ACC may have difficulty transferring bilaterally presented visual stimulus information from one hemisphere of the brain to the other which involves the complexity of callosal transfer (Hannay, 2000; Brown et al., 1999). The Rey Complex Figure Test had her copy a figure of abstract geometric elements onto a sheet of paper. The executive functions needed to engage in the remembering of the design were much too difficult for her and appeared overwhelming.
Paige had an excellent senior year. She was accepted at a four year college of her choice and planned to study education, communications, or hotel management. Her goal was to work for the Disney Corporation. Paige was driving independently which helped her babysitting and volunteer work for the International Lions Club. At graduation, she was presented a scholarship from the International Lions Club. It appeared as if all of the advocating Mrs. Clarke did to attend to her daughters needs paid off as Paige was developing her own attitudes and beliefs. As girls move through adolescence, they try to remain connected to their mothers as they develop their own values and views about life (Jordan et al., 1991; Jordan et al., 2004). Growth does not occur in a discrete series of stages with independence and separation as the final goal. Instead, self esteem and self affirmation occurs through empathetically sharing and maintaining the well being of relationships. Mutually empathic interactions help adolescents develop feelings of relational competence as they learn that they can build relationships. Their goal is to remain connected with their mothers while they are developing their own values and beliefs. An adolescent wants to take care of her relationship which is a large part of her self worth. An interesting personal artifact seemed to express what Paige was feeling about her high school days. The following are some excerpts from Paige’s young adult magazine project in her words,

*Life philosophy*- What goes around comes around. I have found that if I am patient enough that people will get what they deserve, both good and bad. I have put forth a lot of effort into my schoolwork, and I was accepted into the college I wanted to go to. Many people did not believe that I could be accepted into a four year
college. I feel that I was paid back for the effort I put forth...My mom taught me this quote a long time ago. She knows from experience that if you are nice to people, they will usually be nice to you... I try to treat everyone like I want to be treated".

_Influential person_-Since I was little my mother has influenced me on how to treat people, how to act, and how not to judge other people that I see or know...My mother always says if you want to do something, just go and try it...When I took karate, my mother would help me practice all my moves. I made it all the way to brown belt, but then it became too hard for me to do... When I was little, I had a stroke. So when I went to kindergarten, I was behind all the other kids. My mom kept telling me that I could do anything that the other kids could do...When I went to grade school there were kids from different backgrounds. My mom did not care that I had a friend at school that was a different race. She always taught me not to be judgmental about how people walk or act. I guess that's where my compassion for disabled people came from. To me all people are the same even though they are disabled.

_High School_-When I leave high school, the one thing I will bring with me is the memory of all the great teachers that I had through out the four years at school...I can remember my individual studies teacher...I was doing very well in her class and when I didn’t do well on a test, she told me to keep trying and I will succeed...All of these teachers that I had, I will never forget.
Influential person—When I went into second grade, I started having trouble in school... Mrs. C became my math tutor... She would sit right next to me at the table until I understood what I was doing. Even though I would argue with her almost every time she came, Mrs. C never gave up on me. When she stopped being my tutor, Mrs. C became a really good and close friend of mine. Every time I got good grades in school she would reward me by taking me to the movies. To this day she still rewards me for getting good grades in school. I think I am too old to still be receiving rewards for doing an excellent job in school, but she does not. Mrs. C always tells me how proud she is of me. She believes in me a lot... She has never put me down, has made fun of me or turned her back on me... She has influenced me to be patient with other people if I am assisting them."

Defining moment: A defining moment in my life is when I met John. John is a child who is handicapped. John cannot walk, talk, or sit up by himself... I always wanted to work with kids. As soon as I met him, my whole perspective on people changed..... The babysitting job started out like any other job.... At first I was a little scared, but then I realized that there was nothing to be scared about. I mean to me at the moment, he was just a little boy who could not do certain things... At that moment I knew no matter what the child looks like, I should not judge them. That made me realize that all people are the same on the inside they just look different on the outside... It taught me how to be a better person in life to myself and to other people".
Predictions-I plan to have a good part-time job while in college...I will feel great about being able to juggle both school and work...I plan to have passed my first year of college by studying hard and getting good grades to pass my classes. I will feel very proud of myself for passing with good grades...Five years from now I plan to be graduating out of college...I will feel excited about graduating from college...I plan to be in a job that I love, supporting myself. I don’t want to depend on anyone to take care of me...I plan to be owning my own home and paying my own taxes...I will learn how to spend my money wisely and what not to spend it on...I will be happy that now I am living on my own...I plan to be in a good relationship...I plan to owning my own business.

When Paige was asked to reflect upon her high school days she was not frustrated when looking back upon that experience. It appeared to be a positive time in her life as she stated,

I can't remember specific time in high school when I was frustrated. Those school years were better for me. I got to change classes. The classes that I took were adapted so that I could understand and get good grades like A's and B's. I graduated! Yeah! I was in two high level classes. They were English and Spanish...A happy time in high school is when I got a high "A" on a test or did well on a project. My science teacher used to give out candy to the two kids who got the highest grade on the science test. My child study team case manager loved me and still does. She loved me because I tried. They made sure that I got everything that I needed to make high school fun for me. I was in a team taught
room...I sort of understood my IEP, but not fully. I just knew I had one. It had extra time, no scantron, and small class setting. I knew that it had some benefits for me, and I knew I had to be at the IEP meeting, but I did not understand what people at the meeting were saying. They would have to explain to me what was going on. I sat there and the team would talk and when they were finished I would look at my mom and say, “What?” And my mom would explain it to me.

*College and Beyond*

Mrs. Clarke reflected about her determination to raise Paige to achieve to her fullest potential. She says,

If I didn't push would she be in college? Absolutely not. If I didn't drag her everywhere and make her order her own food where would she be? If I didn't have her take her own watch in for a battery and do things that other people do for their kids would she be graduating? Would she have what it took to go to college and speak to her professors? I don't think she would. I forced her to do it because I just didn't want this clingy kid who wasn't her own advocate.

It has been the ultimate dream of Paige to graduate from a four year college. She is very proud that she is about to graduate in May. She reflects on the importance of her goal setting as she states,

I am a senior in college and right now, and I am graduating in May. Woohoo! I am a liberal arts major. I am currently working at a Blockbuster. I have the same goal as I did in high school which is working for the Disney Corporation or in a hotel. I live off campus in an apartment by myself.
Paige was asked to describe her experiences and frustrations in college. Paige described her classes and how she studied saying,

I got frustrated in Spanish because the class was moving to fast for me and I did not know what the professor was talking about. I went to my advisor and told her that is was too hard for me. Nothing happened until my mom called very upset and talked to my advisor. I realized that a lot of the other kids didn't understand what the teachers were saying either. That made me feel better. I feel great about college every time I pass a class. Especially this one class I had my sophomore year...It was a drug and alcohol class. And I thought I wasn't going to do well. My professor only gave two tests, a mid-term and a final exam. And there was a lot of information we had to know for the final. I thought I wasn't going to pass the class, but I ended up with a "C" which was great.

Paige described how to get assistance in college. This was a defining moment in her life as she is now advocating for herself as her mother did for her since the day she was born. Paige remarked,

At my school, there's this place that you can go to if you have a disability and you fill out paperwork and you can get a VISA form that tells your professor what kind of accommodations that you require. I have a note taker, extended time on tests which I go into a room which is completely silent and I can take as long as I need to on my tests. Sometimes it helps and sometimes it doesn't. Sometimes I like the noise and other students around me. Biology was another challenging class. Everything was challenging about it. My teacher was a nut case. She did not
know how to teach. The lectures were long and my professor didn't really try to make it fun for us to sit there and pay attention to her. She just lectured. She did eventually help me when the difference between two of my tests went from an “F" to a “C”. I did very good in the lab part of the class because it was hands-on. Because then I can touch it and I can remember. Okay, I remember touching this or remember touching that. I remember feeling this and picking it up. So it's easier for me to remember what I am doing. I like to touch things. It is visual. I do not do okay when teachers are saying, “Okay. This is the skeleton and you need to know this bone, this bone, and this bone, and blah, blah, blah.” The ones that I need to know, I remember. I could remember some of them, but not all of them.

Paige reflected upon the classes that she really enjoyed taking. Philosophy was a class where your opinion was appreciated and there was no right or wrong responses. She shared,

Philosophy classes were the best. I don’t know why I did good in philosophy classes. I just did. The only philosophy class I did not do good in was Introduction to Philosophy because he did not know how to teach the class well and gave three mini quizzes a class. I gave him my VISA form and he did not know what to do with it. He told me that I had done my part, but he did not know what to do for his part to help me. In my other philosophy class your opinion is not scrutinized because nobody else liked it. Philosophy is always your opinion, it isn’t about what the right answer. What you’re talking about, your opinion is accepted well
by other students and the faculty member teaching that class. I could state my opinion freely. I like to hear opinions of others. I liked how he taught. He was not like the professor that I have for most of my philosophy classes. He was not a note-taking kind of professor. He was more of a “We are going to go to class, you read this for homework and we're going to sit here and we are going to discuss it. And that's going to be our class. I study by putting on headphones and listen to music loudly so it drowns out all other sounds. Eventually the music fades out and I don’t hear it while I study. I just use it as noise.

Mrs. Clarke recalled what it felt like when she moved away from home to go to college. Paige was learning to be on her own without her mother at her side. She says, Now at college, things have gone well. She did well. She went from being very, very homesick her freshmen year, calling me up crying, crying, and crying until I said to her, “If you call me up and cry, I'm coming to get you and you're not going back.” So I said, “Cry to yourself, but when you call me you can't be crying. You make me feel like I have you in a prison camp! If you miss me that much, you need to come home.”

So she came home at Christmas and said, “I'm okay.” And that was it. Now I beg her to call me. I can't even get her to call me. So it's totally different, totally different from calling me everyday crying.

When Paige went away to college Mr. Clarke made sure that his daughter was protected and had everything she needed for college. Mrs. Clarke reflects on their
relationship during when she left for college,

  My husband misses her a lot too, you know. She's daddy's little girl, so he misses her. He worries more about her than I do in a lot of ways... He never wanted her to have a car up at school. This year, she had to because she's in an apartment. She's in her fifth year of college and she had to have a car. Her apartment has a fire extinguisher and extra smoke detectors because he doesn't trust the one there. He gave her a flashlight that plugs into the wall so that she has a battery. She has all emergency numbers plugged into her cell phone. I mean he's cautious that way. In some ways she is a little naive and he is afraid that she's going to answer the door to the apartment. When we picked the apartment we found one that has a secure entrance. You have to use your key to get into the apartment. She's right across from the rental office. It's in a very nice neighborhood. Her door does not open right out to the outside.

  Paige had a roommate for three years who has graduated from college with whom she remains in contact with. Paige is scheduled to visit her roommate who is studying abroad as a graduation present from her parents. She states about her relationship with her roommate,

  She graduated last year and we are still friends. We get along. We are still friends. We talk to each other all the time. We got along very well when we lived together and we still get along. We have the same type of personality. We both are calm, and we like to just have fun with each other. We can make each other laugh by saying stupid stuff. We just clicked with each other.
Socially, Mrs. Clarke is still worried about Paige’s ability to connect with her peers and have a quality of life. She worries about her daughter’s happiness in the future saying,

Socially, I think part of it’s just the disability. I don’t think what I would have done, one way or the other, would have made a difference. She’s beyond a lot of the kids she went to early intervention with socially, but she’s not up to most kids her age. She’s very immature. I don’t know what the right answer is with that. I’d like to see more activities for people like her. I know there’s a local church where a family lost a daughter in her twenties who had disabilities that actually started a social group at the local church. It’s where kids can get together. She has speakers come in and everything. When my daughter went there, the kids were a lot more disabled than her. She’s just on that cusp. If she was more disabled there are a lot of programs available, but she’s above that, yet she’s not up with her normal peers of twenty-three years old. So, I think that’s been very hard for me. She’s always kind of ridden on that line because I would not give up. I wouldn’t stick her in the special education class and be happy because she’s cute. I wouldn’t accept that.

She really never joined anything on campus. She joined a club that her roommate was into. She helped the homeless by camping out a couple nights...She doesn't really have a very large group of friends. Some girls that she knew freshmen year, who I didn't think she was particularly friendly with, have really become good friends of hers after really not talking to her for a couple of years.
Agenesis of the Corpus Callosum

Relationships with men are an area that Mrs. Clarke is worried about for her daughter. She is concerned about Paige’s weight and her ability to find a partner. Mrs. Clarke says,

As far as boys go, there were a couple of boys she sort of liked, but weren't really anybody I was thrilled with anyway. They were kind of like her; I don't think completely on the ball. But she's very heavy. When I spoke to my family doctor about her weight he told me that she has overcome so much in her life. She's not a drinker...doesn't do drugs or smoke, and is not sexually active. Her doctor said food is not the worst crutch that she could have right now. I would like to see her get her weight under control, but I think now she just wants to graduate college. I'm hoping that once she gets out of school, she'll be able to work on her weight. I think socially her looks are important...She has male friends that she is friendly with. They all come over to her apartment or do something together... she doesn't really have a boyfriend at all and really never has. She went to the prom with a friend. I don't know with her disability if some of these feelings are affected by your brain. I've never really found anything about how it affects her emotionally or her sexuality.

Mrs. Clarke reflected on the jobs Paige has as an adult. Her mother continues to worry about her future even though she is so proud of her accomplishments. Mrs. Clarke reflects on this time period stating,

One of my major concerns is that when I look into her disability her future does not seem very bright. It's very scary to see that her future does not look very
optimistic. I'm hoping she keeps great expectations because she's worked very hard. Even though we all have disappointments, I think she's going to be disappointed if some of these things don't work out. Now she's working at Blockbuster. She tried retail which was as little overwhelming for her. She had on headphones where they are always telling you to come do this, come fold this. It was not for her, but I'm proud she tried it. Blockbuster is working out great as she is at the cash register and filing the videos. She was a secretary one summer in an office... Someone happened to overhear us speaking and offered her a job for the summer and it was just a one summer job... She enjoyed working with the people in the office and answering the phones and filing and shredding and rearranging the furniture. That was a good experience for her. Will she ever live away from home? I hope so. Will she ever be able to get a job where she can make enough money to live away from home? Unfortunately, I don't think so. I don't think she's ever going to be able to get a job that she's going to be able to pay, in this area, to rent an apartment. So that's difficult for us too... we'll probably help her financially for the rest of her life... She always says, “I don't want to be the fat girl that lives at home with her parents.” That kind of breaks my heart too. I think that's very important to her....Whatever she chooses to do, I don't think she's going to make enough money to be able to do that. Even if she lives a mile from my house she can feel independent.
Mrs. Clarke has a dream job for Paige which values her beliefs nurturing relationships and giving back to the community. Mrs. Clarke is very passionate about this saying,

I would really like to see her work with handicapped kids because she's like a magnet to them. Kids just love her. She loves kids. Every place we go, people comment all the time. I don't care where we are, kids just flock to her. But I think maybe she wants to try something else. But I don't know. I keep trying to tell her that she's never really been in a school system. I think she would make a wonderful aide, even for older kids with disabilities, because she does love music and movies which would give them somebody to talk to that's kind of a little more hip than maybe their teachers are. I think she would be very good at that. But she has to find that out for herself. I'm worried that if she doesn't find a job that nurtures her, she may get into kind of some of the depression and some of the other problems... Not being in a nurturing relationship can be very sad. She's certainly nurtured by her family. I would love her to find something that she can nurture. I think that everybody needs that. Everybody needs to know what it's like to be the nurturer. I'm hoping that she'll find something that she really enjoys doing. Like I said, I'm lucky that I love my job so much. I would like the same for her.
Now that Paige is about to graduate from college, Mrs. Clarke planned a big celebration for her. Paige has been involved in planning her party that she is looking forward to. She says,

Her closest friend from school is in graduate school in England graduate school. We bought her tickets so she's going to England for two weeks for her college graduation. We're having a party at the house, which she's looking forward to. I'm going to get choked up again when I think about her guest list. When she was doing her guest list, she started writing down names that I thought were kind of interesting. I said, "You want to invite them?"

She said, "Mom. They are people that always made me feel special."

I thought, "What twenty year old kid feels that way?" We were talking about her invitations we kind of came up a theme such as for everyone who encouraged when we were so discouraged. She really remembers every kind thing that people have said to her. She remembers those who had confidence in her with babysitting. All those people that have been in her life. She's been very lucky. She's had a lot of support.

The following is a timeline of Paige’s school history:
### School History Table 3.2

<table>
<thead>
<tr>
<th>Year</th>
<th>Event</th>
</tr>
</thead>
<tbody>
<tr>
<td>1987</td>
<td>August-Born 7 weeks premature by cesarean section.</td>
</tr>
<tr>
<td>1987</td>
<td>Early intervention-6 months.</td>
</tr>
<tr>
<td>1987</td>
<td>Early intervention-average cognitive scores, well developed vocabulary. Average self help skills except toileting, gross motor delays.</td>
</tr>
<tr>
<td>1987</td>
<td>Preschool handicapped-OT services, age appropriate speech language, cognitive, and self help.</td>
</tr>
<tr>
<td>1987</td>
<td>Kindergarten 1/2 day; Multiply Handicapped kindergarten the other half. Speech delays in categorization, opposites, pronouns, future tense, plurals, sequencing, abstract language, and problem solving. PT &amp; OT.</td>
</tr>
<tr>
<td>1990</td>
<td>Grade 1 classification changed to Perceptually Impaired-Speech, OT, PT. Mainstreamed in first grade with 1-2 periods pull out support when needed.</td>
</tr>
<tr>
<td>1993</td>
<td>Grade 2, special education in class support, PT</td>
</tr>
<tr>
<td>1995</td>
<td>Grade 4 Parochial school-no special education services.</td>
</tr>
<tr>
<td>1995</td>
<td>Grade 6 Parochial school-was evaluated at request of parents and it was found that classification was not warranted because her achievement scores are at the level expected for grade and cognitive potential.</td>
</tr>
<tr>
<td>1999</td>
<td>Grade 8 returned to public school with a 504 plan. Reevaluated when 504 plan was not working. Found eligible for Special Education and Related Services under classification of Traumatic Brain Injury. Presented with Presidential Award for Educational Improvement.</td>
</tr>
<tr>
<td>2000</td>
<td>High School Freshman: 1 period Resource Room; college prep classes. Gymnastics scored: c/p/g.</td>
</tr>
<tr>
<td>2002</td>
<td>Inducted to National Honor Society with a maintained GPA of 3.25</td>
</tr>
<tr>
<td>2003</td>
<td>High School graduation. International Lion's Club Scholarship.</td>
</tr>
<tr>
<td>2004</td>
<td>Lives on campus in college.</td>
</tr>
<tr>
<td>2004</td>
<td>Lives in off campus apartment.</td>
</tr>
<tr>
<td>2005</td>
<td>May-receives Bachelor of Arts Degree</td>
</tr>
</tbody>
</table>
Chapter 4: Discussion

Introduction

The purpose of this investigation was to understand the journey of Paige and Mrs. Clarke as they learned to deal with Paige’s brain injury through relational connection. Their story is significant in that Paige is about to graduate from college when doctors in her life thought she would not complete high school. Life course stages defining key events known as epiphanies were the focus of the investigator. The data gleaned from these epiphanies resulted in themes concluding in a model of relational resiliency taken from the secure mother-daughter connection. From this a question has emerged: “How does a school psychologist or other child study team member use relational connection to promote resilience in those with brain injury?” A reconstruction of their stories along with school and medical documents arranged in chronological order highlighted the unique experiences of Paige’s life. First, Paige’s lifespan is documented in five developmental stages and is analyzed using relational-cultural theory. The mother-daughter relational connection will be explained through each of Paige’s life stages. From this example of secure mother-daughter relational attachment, a model of relational resilience is presented.

Themes from the key events that emerged throughout her life span centered upon: 1) feelings of frustration, and anger when dealing with the medical and school systems, 2) establishing secure attachment through mother and daughter connection, 3) desire for positive connections through supportive relationships to heal, 4) issues regarding educational values of competency, perseverance, and a focus on strengths, 5) issues
involving advocacy for the underdog. Through connection with her daughter and moving through her pain, and anger to reconnection, Mrs. Clarke promoted relational resilience in Paige.

Paige’s Lifespan Development

The following stages of Paige’s development were taken from interviews of Paige and Mrs. Clarke along with medical and school records. Each stage is analyzed using relational cultural theory to look at relational connections and disconnections during various times in their lives. It is vital to understand how these relationships have contributed to the growth and well-being of Paige who has achieved to her fullest potential, well beyond what her doctors predicted for her future. Themes agreed upon by the validation team will be discussed in each life stage.

Stage 1: Infancy

Mrs. Clarke and her husband tried for several years to have a baby and had to deal with the frustration and anger immediately after the premature delivery of Paige in an unfamiliar hospital. Paige was born by cesarean section seven weeks early. The theme of anger, and frustration leading to isolation started immediately. Mrs. Clarke recalls an encounter with a social worker and early times in the hospital saying,

...you're in a completely different hospital, with people you don't even know, a total stranger is delivering your baby. There is no support from anyone that you know in that medical community. I started out overwhelmed. I was in another state...for people to come visit me was very difficult. You're so overwhelmed with what they're telling you that people kind of come and go. It had not even
sunk in yet that there's something wrong with your baby. At that point, the only thing I knew was that she was pre-mature...They sent a social worker in who had the personality of a log who kind of put a pamphlet down and...walked out of the room. I don't think he knew my name or my daughter's name. I don't think he knew anything. He should have had a little more compassion for somebody who just delivered a baby that's a preemie in the intensive care nursery.

Mrs. Clarke’s concerns started when Paige came home from intensive care and was placed on an apnea monitor for seventeen months. She was worried that Paige couldn’t lift her head off of Mrs. Clarke’s shoulder. She recalled the fear of taking a shower and leaving her baby alone. Mrs. Clarke recalls this scary time period saying,

My concerns started because she came home from the hospital on an apnea monitor. The original prognosis was that she would be off approximately around her due date. By her due date, her numbers were no better than when she was born...She could not even lift her head off my shoulder. My sister had twins that were premature. My four pound nephew, when I held him for the first time snuggled him up to me, could actually turn his head and lift his head off my shoulder. My daughter at, I’m going to say, two months, probably still could not do that...you become very afraid. You are so limited on those monitors...You can’t do that. Even though I had the baby monitor...I mean how am I going to jump out of the shower if my kids not breathing? So you get to the point where your whole life centers around your house because you can’t even take a shower. You're nervous to be downstairs when she's upstairs. Then they tell you that you
should be able to get to that baby in a matter of seconds. How far are you going to go? If my kid's not breathing I don't want to be two minutes away. I don't want to be in the shower.

Paige received early intervention services out of the local hospital at six months of age because of developmental delays. Mrs. Clarke was very attentive to the needs of Paige and was coming to terms with having a baby who has special needs. Mrs. Clarke recounted many of the numerous visits to the doctor when she was sure something was wrong with Paige as she seemed to be favoring her right hand. She recalls the frustration, anger, and isolation that she felt,

They thought, perhaps she had a mental disability and that's when we started at children's hospital, which was a nightmare in itself because we went to different types of specialists. Each diagnosis was not carried through. They thought she had some sort of orthopedic problem. And I started to notice things like she didn't reach with her left hand...we're at six months and we're not even attempting to roll over. We're not doing anything. She didn't roll over until she was almost eleven months old... kids are going to want to crawl, explore, and scootch.” She was doing none of that. She wasn't scootching in her crib.

Mrs. Clarke recalls a major life event where she was so frustrated at the lack of concern by an orthopedic specialist screaming at her husband stating that the doctor was wrong. She recalls this visit saying,

We went to the orthopedic guy and he said, “Well, you know, I just think she had an overall muscle weakness that can't be explained.” They did some biopsies and
he made the comment to me, “Well, I'm a doctor because I couldn't do a lot of physical things. So I would sit under trees and read a book.” That was my meltdown. Probably one of my major meltdowns...I can't explain it. I just knew in my gut. I kept saying in my gut, “There's something wrong with my baby! There's something wrong!” And nobody would listen to me.

The first symptoms of ACC include difficulties with walking and standing as well as delays in holding the head erect. Diagnosis is usually made by because a parent reports that their child experienced language delays, visual impairments, seizures, and/or low muscle tone (Schilmoeller, 1995 Marszak et al., 2000; Shevell, 2002). When Paige was two, a neurological consultation report indicated that she had mild to moderate left monoparesis, and a significant depression of motoric ability. It was reported that she had a limited curiosity with objects as she appears reactive rather than active. Paige was reported to have a limited understanding of cause and effect and reasoning about perception. She displayed age appropriate speech and language, self help skills, and cognitive development. During this developmental stage, Mrs. Clarke made Paige feel comforted and secure. Paige learned to connect with her loving and attentive mother. According to Erikson's model, Paige learned to appreciate connectedness through feelings and learning to trust.

Another key life event happened during this time period as Mrs. Clarke had difficulty connecting to others. Relational-cultural theorists believe that chronic disconnection is the primary cause of human suffering. She talked about not feeling connected to other women who do not have a child with a disability. Mrs. Clarke recalls
birthday parties when she did not know how to tell other mothers about Paige’s brain injury saying,

There are times that I've been embarrassed. I can remember going to a birthday party and they had a little wading pool that had the slide attached. I was helping my daughter up to the top of the slide... Do you say, “No she won't. No, she can't. No, she has problems.” I could just feel myself welling up... You don't want to go through the whole thing saying, “My daughter has a brain injury.” There are times you just don't want to get into it. I think it's hard to handle social situations where your child's in a social situation and can't keep up with the other kids. Do you intervene or do you kind of let them do their own thing? That's the difficulties that I had because how can you be part of the group if you can't be part of the group?... I got to the point where I avoided a lot of social things because I just couldn't bare it because I didn't want to talk about my daughter.

Stage 2: Early Elementary School (Grades K-5)

After early intervention services, Paige was ready for kindergarten and was classified as Multiply Handicapped. Her mother advocated for her to go to a developmental kindergarten class and a multiply handicapped class for five year olds at the end of her school day. A psychological evaluation indicated that Paige was functioning in the average range with weakness demonstrated in abstract language, and problem solving. Her left hand was reported to not track left or guide her in manipulating objects. Paige was unable to cross the midline with her body. It was reported that she had gravitational insecurity and displays left sided weakness with significant deficits in her
sensory motor processing. She received speech and language services as well as physical therapy. Her mother had to fight again to have her get Occupational therapy at the end of her kindergarten year. Effects of ACC may include the need for speech therapy, physical therapy, and occupational therapy (Shevell, 2002). This was certainly the case for Paige and her mother fought hard to make sure she received these services.

In first grade Paige had difficulty with visual closure and visual motor integration and her classification was changed to Perceptually Impaired. Studies of split brain patients indicate that the left hemisphere has marked limitation in perceptual function and the right hemisphere has even more limitations in cognitive function (Gazzaniga, 2000). A PT summary indicated that Paige had deficits in motor planning, bilateral coordination, balance, muscle power, and sensory motor learning. An OT evaluation indicated that she displayed a decreased ability to plan motor activities, and had difficulty with visually attending to manipulation tasks. Interhemispheric transfer, one of the believed functions of the corpus callosum, involves the integration of information from the left to the right hemispheres of the brain. Deficits like Paige displayed have been studied for over fifty years on adults and children with ACC which is similar to the “disconnection syndrome” seen in commissurotomized patients who display deficits on sensory motor and tactile functioning (Sperry, 1974; Kernc,b Schumacher, and Wallesch, 1991; Paul, Van Lancker-Sidtis, Schieffer, Dietrich, and Brown, 2003). It was found that individuals with ACC were different than the split brain patients in that they were able to use interhemispheric integration for simple visual information but not for complex visual tasks.
In second grade, it was reported that Paige demonstrated strengths in reading comprehension, sight word recognition, and in written language. Her weaknesses were in the areas of listening comprehension, and mathematical application skills. She was reported to have difficulty attending to and understanding oral directions in a large group. This is interesting to note in that ACC is also being linked to various neuropsychiatric disorders including Attention Deficit Disorder (Taylor & David, 1998; Rourke, 1995; Cleaver & Whitman, 1998; Dughartey, 2000; Thompson, 1998; Nopoulos, Berg, Castellanos, Delgado, Andreasen, & Rapoport, 2000). Other health and behavioral outcomes associated with ACC include seizures, dysmorphic features, intellectual disability, psychomotor retardation, language deficits, psychosocial deficits, as well as visual and hearing impairments (Sztriha, 2005; Marszak et al., 2000; Doherty et al., 2005). None of the child study team members, teachers, or tutors had any idea that Paige was suffering from a brain injury.

Mrs. Clarke was attuned to her daughter’s needs as she realized that Paige may have difficulties making friendships. Paige and her mother spent a lot of time together as Mrs. Clarke reported that she did not have a lot of friends and was a social outcast stating,

We spent a lot of time together because she really didn’t have a lot of friends. She was in Daisy Scouts. She sang in the choir at church. But she never really made connections with anyone. Even when she was in the private school, the teacher had told us that she knew that one of the girls had had a sleepover and (my
daughter) was the only girl that wasn't invited. She's not made fun of. She's kind of ignored and (my daughter) didn't realize that she wasn't invited.

One of the reasons there may be social emotional issues with ACC is the information that interhemispheric communication may be a contributing factor in language competence as the right hemisphere may no longer be ignored (Van Lanker, 1997; Bryan, and Hale, 2001). Language is an integral part of social skills. The corpus callosum is important the transfer of cognitive functions and language functions possibly because of this interhemispheric communication (Gazzinga, Kutas, VanPetten, and Fendrich, 1989; Huber-Oluainec, et al., 2005). When the corpus callosum is severed, language processing is not as proficient and comprehension is weaker when words are presented to one visual half field (Mohr, Pulvermuller, and Zaidel, 1994; Huber-Oluainec, et al., 2005). Those with ACC may be slower than their peers in the interpretation of idioms because idiom comprehension requires the rejection of the literal meaning and accepting the figurative meaning of the phrase. Figurative language comprehension is disrupted because of interhemispheric communication deficits related to ACC (Huber-Okrainec et al., 2005). Other research has revealed impaired processing of affective prosody and nonliteral interpretation of words in adults with normal intelligence that are diagnosed with ACC. Prosody involves the right hemisphere of the brain where marked difficulties with social communication skills can occur.

In fourth grade, Paige went to private school because her mother was exhausted from always having to fight the public school system for her daughter’s rights and thought she would be better supported in a nurturing environment. Mrs. Clarke also felt
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that private school would reflect her own educational values of competency, perseverance, and focus on strengths.

Stage 3: Later Elementary School (Grades 6-8)

In 1997, Paige was evaluated by a neurologist because Mrs. Clarke felt that she was experiencing educational, social, and emotional concerns. At times Paige would stare with her mouth open and complain of dizzy spell where the room started to spin. The neurologist reported in December 1997 from a brain MRI that she has Coordination Disorder, ACC and agenesis of the left cerebellar hemisphere. He reported that despite these considerable deficits, Paige has fared much better that most children with theses deficits both developmentally and in learning because of the tutoring her parents provided. This seemed to indicate recognition that Mrs. Clarke was very attentive to Paige’s needs challenging her to be the best that she could be. Her doctor stated that Paige has mild dysarthia and considerable deficit in coordinative abilities on the left side due to the missing left cerebellar hemisphere affecting balance, and fine motor abilities. He reported that Paige has considerable dysmetria and an intention tremor on carrying out targeting activities with the left hand.

Teachers in sixth grade reported that Paige had difficulty remembering past chapters. She was reported to have difficulty with vocabulary and writing assignments. Paige achieved mostly C’s on her report card and displayed good organizational skills. Mrs. Clarke had an independent evaluation done because of concerns that she would not be successful in a regular public school. According to an educational evaluation she displayed difficulty with higher order abstract reasoning and inferential comprehension.
Her visual spatial skills were below average and quantitative reasoning skills were below her ability to apply rote calculations. Paige demonstrated abilities in the average range of intellectual functioning. She demonstrated weakness in visual sequencing skills, visual analysis, and synthesis. Classification was not warranted in 1997 because her achievement scores were at the level expected for grade and cognitive potential.

Eighth grade was a turning point in her life as the woman with ACC advocated to go back to public school so she could be better prepared for high school. The 504 Accommodation Plan stated that Paige demonstrated age appropriate skills with the exception of a significant lag in areas of visual analysis and synthesis. The plan stated that adjustment should be made in physical education and that multiple stepped tasks should be broken down for Paige as well as monitoring of her coping skills for written tasks. Mrs. Clarke advocated to have the 504 plan amended to allow for word banks, notes, and study guides in history and language arts.

Mrs. Clarke fought to get Paige more assistance in eighth grade as she enlisted the help of a friend who was a learning consultant who reviewed her records. The learning consultant noted that the neurologist stated in a report that she was neurologically impaired which affected her educationally, motorically, and socially. Paige demonstrated a significant lag in two measures of visual analysis and synthesis that could create problems in terms of inefficient processing of visual information, organization, strategy development, and difficulty processing subtle social cues. A reevaluation commenced. It was found that she was eligible for special education services with a traumatic brain injury classification. Finally, her brain injury was mentioned to get her services in school!
Stage 4: High School

It was finally identified for the first time in her IEP that Paige had ACC and agenesis of the cerebellar hemisphere. The child study team determined that she had a Specific Learning Disability based upon a significant discrepancy between short term memory and quantitative reasoning as well as between short term memory and abstract/visual reasoning. The child study team reported that there was a discrepancy between current achievement in academic testing and classroom functioning in all areas. Paige was given one period per day of resource center support and was able to go to adaptive physical education if she felt the mainstreamed physical education class was too challenging. Her mother reported that there always seemed to be confusion about her learning difficulties saying,

When she was in the private school, it would have been like fourth, fifth, and sixth grade is when (the independent Child Study Team) said they didn't think she was classifiable. Then by the time I got to her high school, I had all that straightened out because of the medical aspect that I had forwarded to them. The Child Study Team said that absolutely she was classifiable. Her doctors had said that she was classifiable because of her disability. I was very happy she could be classified so I said, “Pick one (eligibility category).” I didn't care which one they picked, just pick something. I definitely wanted her classified. Now I understand that under the 504 she would have been protected also. I didn't want it off her record that she has a true disability that is going to follow her for life. I didn't want to have that not on her record.
Social isolation and hanging around with people younger than her was always a concern for Mrs. Clarke. Paige’s teachers reported that she relates to her peers but will be quiet in a large setting and has difficulty with situations involving conflict. Paige demonstrated difficulty forming friendships during this time period and preferred to be around younger children. People with ACC have social deficits that include appreciation and recognition of social dynamics, overlooking complex socio-emotional material, misinterpreting meaning to emotional stimuli, lack of social judgment, and lack of self awareness (Paul & Brown, 2000). The processing of speech that involves social communication is a significant deficit to those with ACC. Parents of children with ACC report that their children interpret speech very literally, misinterpret nonliteral language, and engage in meaningless conversation (O’Brien, 1994; Stickles, Schilmoeller & Schilmoeller, 2002). Anecdotal reports from parents indicate that their children with ACC display deficits in the comprehension of jokes, miss the point in subtle stories, and display difficulties with problem solving in novel situations (Brown, Paul, & Symington, 2005; Brown & Paul, 2000). All of this is essential to maintaining and forming new friendships, particularly in high school.

Freshman year was a period of transition as her major area of academic difficulty was in keyboarding and Spanish class. Once she was moved into a lower level Spanish class, she did well. She had difficulty with keyboarding during timed lessons. Communication between school and home seemed to be a problem and her mother was in
the position of fighting for her daughters rights again as she recalls the time when she was failing computer class,

My daughter's excellent on the computer. How can you keep up in computer class when you can't even manipulate your left hand very well? They couldn't cut her assignments back. How many words do you need to type? Is that what you're really in there to learn? I don't think so. She understands formatting, and spreadsheets. All of that she is fine on. Can she type a four-page document in twenty minutes? No! What made me even angrier was that there was a lower level class at the exact same time. We didn't have to change her schedule. All she had to do was move over to the next room which had an aide in there. They could have done this if they had just put on the interim that there was a problem. She would have been out of the class and into another class. Little things like that with the public school system makes me crazy. I said, "Let's try not to put the child in the slot. Let's try to change the shape of the slides." Like puzzles you have when you're a kid. The star goes in the star slot and the square goes in the square slot. No, they're trying to put a square peg in a round hole! It never worked. It's never going to work. Why do we keep trying? As public school teachers, by God, if I pound hard enough, I'll get that kid into that slot. It's not going to happen.

Research on those with ACC found that sensory information may be affected as the corpus callosum allows for the transfer of sensory and motor information between the brain's hemispheres and coordinates motor planning and control. Jeeves studied
interhemispheric communication of those with ACC and normal controls on a task involving reaction time to light stimuli and hand movements and found that those with ACC responded at a slower pace to the stimuli than the normal controls (Brown, Jeeves, Dietrich, & Burnison, 1999; Berlucchi, Aglioti, Marz, and Tassinari, 1995; Paul et al., 2003).

By sophomore year, Paige was inducted in the National Honor Society which required a maintained grade point average of 3.25. She began her hunt for a four year college in junior year and was reevaluated by the child study team to help her with support services in college. Paige’s weaknesses as reported in a psychological evaluation were demonstrated in reasoning skills, vocabulary, and verbal language skills for elaboration purposes. She also demonstrated weakness in subtest involving fluid verbal reasoning which deals with social conventions and cause and effect situations. Paige displayed difficulty recalling visual images when administered The Rey Complex Figure Test which had her copy a figure of abstract geometric elements onto a sheet of paper. The executive functions needed to engage in the remembering of the design were much too difficult for her as she was unable to retrieve the visual images from long term or short term storage to produce a copy of the design. One of the believed functions of the corpus callosum is to transfer all types of sensory information and coordinating the processing between the right and left hemispheres. The role of the corpus callosum in bilateral integration of visual-information was studied by Brown, 1999 who demonstrated that those with ACC show deficits in complex spatial patterns as they were unable to recognize a pattern of five dots, but were able to recognize a single letter (Brown et al.,
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1999; Paul, VanLancker-Sidtis, Schieffer, Dietrich, & Brown, 2003). It appears that those with ACC may have difficulty transferring bilaterally presented visual stimulus information from one hemisphere of the brain to the other which involves the complexity of callosal transfer (Hannay, 2000; Brown et al., 1999).

The Behavior Rating Inventory of Executive Functions was used to assess Paige’s executive functions in her junior year. A problematic area for her includes the ability to make transitions, problem-solve flexibly, switch attention, and change focus from one mindset to another. Paige’s ability to modulate emotional responses is a problematic area for her. The desire to succeed, but not know how to get started, is somewhat problematic for her. Working memory defined as the capacity to hold information in mind for the purpose of completing a task, is somewhat problematic for her. The ability to anticipate future events, set goals, and develop appropriate steps to carry them out is an area that may be somewhat problematic for her. Paige’s ability to check the effect that her behavior has on others is an area may be somewhat problematic for her. The few case studies of those with ACC report deficits in psychosocial coping and personal awareness manifested in appreciation and recognition of social dynamics, overlooking complex socio-emotional material, misinterpreting meaning to emotional stimuli, lack of social judgment, and lack of self awareness (Paul & Brown, 2000).

The psychological evaluation summed up her areas of strength by reporting the following information processing skills: self management and motivation; an awareness of her strengths and limitations; ability to recall information from stored long term memory; ability to draw upon her short term memory if the material is familiar to her;
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ability to rely upon rote memory and rote mathematical calculations; has an average store of knowledge of verbal information typically required in school settings; utilizes adequate auditory working memory to manipulate familiar material; utilizes sustained attention and concentration on tasks she enjoys.

Stage 5: College and Beyond

Paige has achieved her dream of graduating from a four year college. It seems as if she has learned many things from living away and gaining a sense of achievement. Paige recalls some of her frustrating classes in college and how she learned to advocate for herself stating,

I got frustrated in Spanish because the class was moving to fast for me and I did not know what the professor was talking about. I went to my advisor and told her that is was too hard for me. I realized that a lot of the other kids didn't understand what the teachers were saying either. That made me feel better. Biology was another challenging class. The lectures were long and my professor didn't really try to make it fun for us to sit there and pay attention to her. She just lectured. Paige reflected on the manner in which she learns best. She says,

I feel great about college every time I pass a class. I have a note taker, extended time on tests which I go into a room which is completely silent and I can take as long as I need to on my tests. Sometimes it does (help) and sometimes it doesn't. Sometimes I like the noise and other students around me. I did very good in the lab part of the class (Biology) because it was hands-on. Because then I can touch it and I can remember. Okay, I remember touching this or remember touching
that. I remember feeling this and picking it up. So it's easier for me to remember what I am doing. I like to touch things. It is visual.

Philosophy classes were some of Paige’s favorite. Paige explained why she liked these classes saying,

I don’t know why I did good in philosophy classes. I just did. Philosophy is always your opinion, it isn't about what the right answer. What you're talking about, your opinion is accepted well by other students and the faculty member teaching that class. I could state my opinion freely. I like to hear opinions of others. I liked how he taught.

Familial Characteristics and Resiliency

Familial Structure Promoting Resiliency

Protective factors decrease the probability of a negative outcome contributing to resilience in children (Brooks, 1994). The family environment is one protective factor that may have contributed to the positive outcomes of Paige. Researchers have identified that familial characteristics play a part in protective factors. These familial characteristics are qualities of the family environment that reflect the interpersonal relationships within the home (Barron-McKeagney, 2002). Strong expectations, structure, emotional support, and connection with extended family members are some of the protective factors promoting resiliency (Brooks, 1994; Cowen, & Work, 1998; Werner, 1997). Paige’s
parents and extended family engaged in many activities to create strong relationships that were supportive to all. Paige reflects on long trips these happy times saying,

My cousins only live a mile away from me and when I was younger my cousins and I would go everywhere together especially on trips with my parents. My cousin who is a year older than I am would go on trips with us and everyone would always ask us if we were brother and sister because we look so much alike. Like we would go to like Florida and it would two weeks to get there because we would stop and go to other places and look around. We'd stop in Myrtle Beach and would always stay at Days Inn and we eat at Shoney’s Restaurant. We stopped at South of the Border, walked around there, and we had fun. We were staying at a hotel and we were in conjoining rooms...At Williamsburg, my mom and family walked around for awhile because my younger cousin wanted a cheeseburger and none of the restaurants had one but then we found one and she did not want a cheeseburger anymore so my mom made her leave the trip. My aunt and uncle came and got her.

Mrs. Clarke speaks of the strong family bonds they all share. She talked about the expectations of her own mother who treated Paige just like any other family member. She remembers,

I've been very lucky. I have a very unique family and we're kind of a fun dysfunctional family. I think it's been very good for my daughter. I'm very close to my sister. She has a set of twins now that are in their thirties and each expecting their second child. She has a son who's twenty-four and who just got
out of the military and she has a son who is nineteen so my daughter fits right in there. We traveled a lot with them. My sister and I are very close so my daughter been very lucky. She's had family all the time. We live a mile from each other. She's had the opportunity to really spend a lot of time with her cousins. So we've been lucky from that standpoint. My husband comes from a much larger family. We have all the family gatherings. We've had Easters with 45-50 people. Fifteen kids are running around the yard and getting Easter eggs. My daughter has had a lot of family support and nobody ever treated her any differently than anybody else. She has been given a lot of kudos for anything that she did...She's had a lot of positives, and she surpassed a lot of her nieces and nephews that didn't have problems academically and otherwise...My mom was really a very strong woman. My grandfather is Irish, right off the boat and my mother really had a very strong will...she played classical piano, sewed, painted, and was like a renaissance woman. She always loved to travel and would take us on all kinds of trips and would pay for us to come down to Florida. Not just to Disney, but to the space station, the Everglades, and to a museum with cars and an old light house. My mother was very big on exposing kids to a lot of difference things. I think that's helped my daughter. One of my goals with my daughter is to expose her to many things. She loved her Mom-mom and my mother was the same way. She didn't treat my daughter any differently than any of the other grandkids. She was
expected to do what everybody else did. Even though it took her longer and she had difficulty learning how to do it, my mother said, “Quit crying and zip your pants.”

Mother-Daughter Relatedness

No one can underestimate the role of the mother in promoting well-being in a child with brain injury. Recent research has demonstrated a strong link between the psychological health and wellness of children and adolescents and caring or confiding relationships with adults (Holahan, Valentiner, & Moos, 1995; Spencer, Jordan, & Sazama, 2002). As a Mrs. Clarke related to her daughter, she identified with her emotional state. This relationship is reciprocal, as Paige related to her mother. They both are aware of each other’s needs as they tune in to each other and understand. There is a desire to believe that a woman’s sense of self and well-being is organized around relationship building and is be connected to one another. Relational-cultural theorists believe that a woman is defined by the ability to take care of others. Empathy is at the heart of the mother daughter relationship. This is defined as the capacity to attune to and understand the affective experiences of the other. The infant sees the mother as the active caretaker in tuning into her needs. The experience of self is developed and refined in this relationship (Jordan et al., 2004). Paige recalls the fun times she shares with her mother saying,

We have a good time together. We have our typical mother daughter fights but we have fun hanging out together. She is always there for me when I need her.
Whether it is to talk or just to give me a hug and tell me how much she loves me and how proud of me she is. We have fun together.

Mrs. Clarke reports the same reciprocal relationship where there is mutual respect, empowerment/zest (inspired to take action), and mutuality (commitment) (Jordan et al., 1991; Jordan et al., 2004; Walker, & Rosen, 2004). She reflects on her present relationship with her daughter as she sounds proud that they have been well connected throughout adolescence and beyond. Her mother talks of their relationship saying,

We have a good relationship. I push her. I mean if you tell me you're going to do something then I expect you to do it. I mean this is even with my community stuff...That's just my personality. So we have a nice relationship now. I'm a mom and she gets mad at me just like you always get mad at your mom. We've had very, very few really bad arguments and we had a couple of really upset and yelling at each other arguments since she's been growing up. We really have not gone more than, I'm going to say, maybe three weeks without seeing each other. By the third week, she asks if I can you come up or says she's coming home. This is fine with me because I miss her. We do have a nice relationship. We still enjoy shopping together and going out to eat together and things like that.

The Relational Resilience Model in Mother Daughter Connection will examine Paige's competent sense of self, which developed from her sense of connection with her mother. This model has a series of five stages based on the relational-cultural model, the themes and the transcripts of Paige's and her mother's interviews, and the conclusions of the investigator and research team. These stages are thought to have contributed to
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Paige’s well-being and are labeled in the following manner: Stage 1) Realization, Stage 2) Acceptance, Stage 3) Confidence, Stage 4) Move into Action, Stage 5) Advocacy for a greater good.

Model of Relational Resilience in Mother-Daughter Connection Table 4.1

<table>
<thead>
<tr>
<th>Stage 1: Realization</th>
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<tr>
<td>• Aware and understands needs of daughter.</td>
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<td>• Deals with daughter's issues.</td>
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<td>Stage 2: Acceptance</td>
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<td>• Mother learns to reach out to others for help.</td>
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<td>• She affiliates genuinely with others.</td>
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<td>Stage 3: Confidence</td>
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<td>• Mother gains strength through positive relationships.</td>
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<td>• She focuses on her daughter's strengths and moves forward.</td>
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<td>Stage 4: Move into Action</td>
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<tr>
<td>• Mother joins with others to affect growth and change.</td>
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<td>• She makes a commitment through determination and perseverance.</td>
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<td>Stage 5: Advocacy for the Greater Good</td>
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<td>• Mother has a higher sense of purpose as she advocates for mankind.</td>
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<tr>
<td>• She has a compassion for those that are suffering.</td>
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[Through this process the daughter is aware that her mother looks out for her needs and will always be there for her.]

Relational Resilience in Mother Daughter Connection

Stage 1: Realization

Mrs. Clarke tried for many years to have a baby. Finally, Paige was born six weeks premature by cesarean section. Paige came into the world with great anticipation as her parents tried for years to have her. The event of her birth brought joy and pain to Mrs. Clarke as she realized she had to deliver in a strange hospital, leave her daughter in intensive care, and worry that there was something wrong with her new baby. She
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brought her baby home attached to an apnea monitor and the fear, and anger persisted.

Mrs. Clarke stated,

... not being able to get pregnant... then we had a baby... I would say, “Why did I have to get the factory reject?... What in God's name did I do that I can't have a normal kid?” I was angry... I was resentful... I'm going to scream! I can't do it!

Mrs. Clarke felt alone and isolated as she learned that something was wrong with her daughter. She was aware of the needs of her daughter and had difficulty explaining to other young mothers about Paige’s needs during a birthday party. Mrs. Clarke seemed to have the sense that she should not isolate herself from others even though she had a strong need to disconnect from them. She explained,

... just keep getting them out there socially and not get yourself so isolated... To just isolate myself from everybody and isolate her to protect her. It's very easy to do because there's something wrong with them and you get very attached to them. It's very hard to let go... You know your kid. You're the one with them. You may probably know your child more than most normal moms because you're in a situation that's uncomfortable... I can remember going to a birthday party and they had a little wading pool that had the slide attached. I was helping my daughter up to the top of the slide and a mom said, “Oh she'll be fine...” I could just feel myself welling up and I said, “Well, you know, she has some problems climbing... My daughter has a brain injury.”
The medical community did not seem to understand what Mrs. Clarke was going through contributing to another disconnecting experience for her. She remembers the isolation and pain as she recalled a doctor who thought that she could not face the good fortune that Paige was born after many years of trying. She reports this painful time saying,

...So he thought that I like couldn't accept my good fortune that I had a baby and told me that I was kind of showing signs of being a neurotic, older mother...So I ended up in counseling because after doing research...I thought well, maybe they're right. Maybe I'm looking for things that aren't there. Maybe I can't believe my good luck and I'm looking for problems that are going to work themselves out.

Mrs. Clarke recalls remembering those first few months of bonding with her daughter, responding to her every need and feeling that something was not quite right. She went for numerous visits to specialists who said that she may have a mental disability and overall muscle weakness. She would have experiences where doctors did not understand her, but she kept reaching out to others to get answers. Mrs. Clarke remembered the things Paige was and was not doing as she stated,

...I'm in counseling and my daughter's progressing, she's not progressing. And I started to notice things like she didn't reach with her left hand and although she seemed alert and responded to me, I didn't think it was autism because she did respond. She would smile, she would follow me and what I did. She would do that part very loving part, and loved to be snuggled and tickled and all those
normal things... She wasn’t doing things... we’re at six months and we’re not even attempting to roll over.

Her persistence of reaching out to doctors paid off as she was connected to a neurologist who appeared to listen to her story of Paige. This was a huge epiphany as she realized that there was something wrong with her daughter and was able to accept what the doctor said. The neurologist told Mrs. Clarke that he thinks her daughter had a stroke as he noticed that Paige’s hand, thigh, and foot and the left side of her body was smaller than the right. She recalls this key life event saying, A key life event, known as an epiphany occurred when Paige was evaluated at six months of age by a young neurologist because of Mrs. Clarke’s concerns. She recalls in great detail about the time she learned that her daughter may have suffered a stroke because of the difference in the size of her left side. Mrs. Clarke recounts,

...he just said, “I think her whole left side's been affected.” He pulls out reports and he says, “Well, right here, you were saying she doesn't grab her left hand.” He said, “You know, you were buying the two handed rattles.” You actually had to put it into her left hand and help her grasp it so that she could manipulate it. He said, “I think that's it.” They ended up doing a CAT scan and that's when we found all this information out that it certainly was much more than that. But that's how long it took.
Stage 2: Acceptance

Mrs. Clarke was beginning to feel comfortable about reaching out to others for mutual support. Social support systems are protective factors that can help with stressful life problems promoting resiliency (Beardslee, & Podorefsky, 1988). These social support systems are desired by women to help them grow through and heal in connection with others. Through early intervention, she connected to women who had children with difficulties and stories were shared between them. Connection, the core of human growth and development, is defined as an active process with a quality of respect, curiosity, and openness to possibility that leads to a desire for further relationship (Walker, & Rosen, 2004).

These relationships seemed to help with the stress of raising a child in need promoting positive growth in relation. Mrs. Clarke seemed to understand that she needed support and acceptance to develop a sense of close connection with others. The skill of empathy has a healing aspect as a person moves out of isolation and begins to feel worthy of respect and connection with others. Mutual empathy is a term used by relational cultural theorists that is defined as a deeper, more resilient connection when women take in cognitive/affective aspect of the other's experience (Walker, & Rosen, 2004). It was with other women that she could let out her frustration and anger by connecting with them. This empathetic skill has a healing aspect as a person moves out of isolation and begins to feel that she is worthy of respect and connection with others.

It was with other women that she could let out her frustration and anger by connecting with them. She remains friends today with a mother that she met in early
intervention. Both of their daughters are friendly also even though they are not on the same path educationally. Mrs. Clarke talks about a card her friend gave her that helped her accept Paige's brain injury by identifying with her pain,

I made some friendships because of her injury. The one friend that has a daughter who is much more developmentally delayed than my daughter and we've remained friendly. She sent me a card after I had my daughter and I was devastated. The card was about going on vacation to Paris and you're so excited and you go on the internet and you research everything about Paris and you planned your whole itinerary and you go shopping and you buy your clothes and you get your passport and you go to airport and you're just so excited and the plane lands and you're not in Paris, you're in Australia! You get off the plane and you say, "I'm not ready for Australia. I don't know anything about Australia! I didn't pack for Australia. I don't have an itinerary for Australia."

They say, "Too bad! You're in Australia."... You're in a different country with a different language because you don't know the language. I don't know medical talk. I don't know medical terms. It's like their speaking another language and then you feel stupid... I'm in a new country and I had to adapt to that country and realize that this is not the country that I was packed and planned for... The girls have literally been friends since they were six months old. This mom and I could vent to each other. People don't understand the anger that you feel and the resentment and how pissed off I would get. But I can kind of spew off to another mom with a handicapped child and they realize that it's just getting that out of
...You get mad at everybody. I got mad at every pregnant woman that had a kid that was healthy...People say things and don't mean it, but you say, “Come walk in my shoes. Watch your kid at the playground that can't do the stuff that the other kids can do.” It's heartbreaking.

To make and maintain an affiliation with others is essential for women’s growth in relational connection. Mutual empathy is a key component to relationships where a deeper, resilient connection to others is made as women listen to both the cognitive and affective experience of the other (Walker, & Rosen, 2004). It is through these friendships that women learn to find their own voice. The support network of early intervention helped Mrs. Clarke move away from powerlessness and isolation as she began to feel worthy of respect and connection with others. She recalled,

Early intervention, at the time, was you took the child to a place with the other moms and they had a psychologist on staff and the speech therapist and everyone was in like a big playroom and the child moved from therapist to therapist, whatever that particular child needed. The thing that I liked about it, which they don't offer now, is that I got to speak with other parents of children that had disabilities. And with the psychologist there, at times, we would go into a separate room while the kids were getting their therapy and we could hash out with the psychologist, you know, things like toilet training. How do you toilet train a kid with a disability? You know different problems that you were going through that other people didn't understand because they didn't have a child with a disability... The thing I liked about early intervention was that I got to be around
parents of kids who had disabilities. That's one thing I don't like about the program now. I think the program itself is great, but you have no guidelines. You have no gage... By the second year of early intervention was when you actually left your child there and you had like an hour and a half to yourself. The moms used to go out and go somewhere for a cup of coffee and just talked about a lot of things. The conversation even got into your relationship with your husbands and how things were going at home. We talked about simple things like cutting button holes in sleepers to run apnea wires. I mean things that you're not going to sit around with normal moms and talk about. Like what do you do with the wires from the monitor because she was starting to yank on them... It was little, silly things, but it solved a problem. You had somebody to talk about a problem with that you're not going to discuss with other people. So from that standpoint, I liked early intervention. I thought it did a lot for her.

It is interesting to note that Mrs. Clarke though early intervention did a lot for Paige as she innately recognized that women may help other women heal through connection affecting a positive self image. Therefore her self image is reflective of her daughter's self image. Women learned to problem solve together in early intervention through empathic listening. Mrs. Clarke put her daughters need before her own needs as she seemed to realize she was a part of something greater.

Stage 3: Confidence

Through early intervention and reaching out to other women with disabled children, Mrs. Clarke was ready to take on the challenge of fighting against the school
systems to advocate for the needs of her daughter. Relational cultural theorists explain that systems can have a “power over” relationship where the rules are decided in a one-way method (Walker, & Rosen, 2004; Jordan, et al., 1991; Jordan, et al., 2004). Unequal power distributions are not collaborative or supportive. Unfortunately, this is what Mrs. Clarke faced when Paige entered the public school system as they wanted Mrs. Clarke to hold her daughter out of school for a year. Issues regarding educational values of competency, perseverance, and a focus on strengths were the themes taken from Mrs. Clarke’s interviews as she advocated for her placement. At this time in her daughter’s education Mrs. Clarke had to trust the educational system to listen to her needs as a parent.

She recalls very vividly fighting for the placement of Paige in kindergarten to push her to be the best she could be. She advocated for her to have developmental kindergarten in the morning and go to an afternoon kindergarten class for Multiply Handicapped students so that she could get her OT and PT services. Mrs. Clarke became the active caretaker for her daughter and mobilized her to get what she needed from the system of power. Mrs. Clarke’s beliefs regarding educational values of competency, perseverance, and a focus on strengths is a theme throughout her job as a teacher and advocator for her students as well as Paige. She recalls her first educational experience in the public school system with her daughter saying,

That’s when I started the arguments about the developmental kindergarten. To keep her out because of fine and gross motor skills, I didn't think was fair and my argument with them was well, if she didn't have a leg you would take her, if she
was in a wheelchair you'd take her, so she can pass the test you need to take
her... And I felt that there was no reason to turn her down because she did know
colors, shapes, numbers, and all that kind of stuff that she would need to be
successful educationally... It kind of started off on a bad foot because I certainly
understand that they did not want developmental kindergarten to be a dumping
ground for kids who had disabilities whose parents did not want to admit it or
didn't realize it or weren't aware. Academically she could pass the kindergarten
test. I just felt it was not a real good transition. They wanted me to hold her out
(of kindergarten) and pay for it myself... I would have had no services for a year. I
felt that was wrong. Not that I minded paying for kindergarten for a year, but
how was she going to get any services? So she did that for two years,
developmental kindergarten in the morning and five-year old MH class in the
afternoon... I thought it was unfair to offer that to a normal child and not offer that
to a child with a disability. If anything, she's the kid that needed the extra year.
She also needed the OT, PT, speech/language, and socialization... I think that year
did her a lot of good. I'm very, very happy that I did not back down on that.

Mrs. Clarke attended to her daughter's feelings and provided a model to Paige in
doing for others providing her with a sense of her own abilities. Paige felt that she is a
part of this relationship and her mother would be there to support her. When she was
asked to review her transcripts, Paige stated that her mother and she are a team. Paige recalls this feeling of connection saying,

My mom, since I was little, and found out that I had a disability, has always pushed me and has always fought for me to get what I needed from school or daycare or whatever. She’s always pushed me to try and try and try. We have a good relationship. We have a good time together. We have our typical mother daughter fights but we have fun hanging out together. She is always there for me when I need her. Whether it is to talk or just to give me a hug and tell me how much she loves me and how proud of me she is. We have fun together.

Stage 4: Move Into Action

Mrs. Clarke seemed to realize the limitations of her daughter as she pushed her to do many things to help her cognitive, and motor skills. Paige’s elementary school years involved private tutoring, karate, and community service activities. Mrs. Clarke put the needs of her daughter first as she was always trying to find ways to help Paige grow and change. Mrs. Clarke empowered her daughter to feel effective and competent in the skills she was trying to develop. Their mother daughter relationship was growth fostering in that Mrs. Clarke included her daughter in all activities so she did not feel alone. She reflects on involving her daughter in activities saying,

...the whole motor planning is so difficult... Karate for her was a very positive experience. They worked with her so patiently. That really helped her self-esteem. I think it helped her patterning. I think that was really something that I would recommend. I'm not saying necessarily karate, but to get them involved in
something where they're going to get applause from in athletics. I think that's one thing that I'm really happy that I did because we couldn't play the sports. I'm glad I didn't ignore that aspect completely. Golf or bowling. I think anything where you're working on some kind of motor planning and hand-eye coordination. If you can nurture that at a young age, you know, I think that's good. Plus, it gives them a feeling of accomplishment that they're out there. It gives them something to do because there are few bowling leagues (for those with disabilities) and things like that they can do.

Mrs. Clarke spoke about not making things easy on herself as she demonstrated patience to let her daughter experience a sense of accomplishment as Paige learned to button her shirt on her own. They engaged in shared experiences of learning together about her brain injury, which is a necessary ingredient of relational connection. Mrs. Clarke remembers about a writing activity her daughter had in elementary school where Paige’s teacher or inclusion teacher did not seem to have the belief in her ability to write. She recalls,

When I asked the teacher about it she said, “Well, they don't know how to write.”

I said, “Who's they? My child? My child knows how to write. She writes every night with me. So don't say they don't know how to write. They just wouldn't try.” I just kept saying, “Try, try. I don't care if there are two sentences that really don't make any sense. What difference does it make? Try.”
Mrs. Clarke’s values of nurturing and supporting others was demonstrated when she decided to give up the fight with public school after third grade and place Paige in private school that values diversity and compassion. She states,

Private school can do a lot of things in their curriculum that a public school can't get to do. I understand that. They had small classrooms and a very nurturing school. Everybody knows everybody. I just felt it was a much healthier environment for her...But I at least felt the atmosphere was supportive. She had a sense of belonging. Even though socially, she didn't really make any friends there. At least she was happy when she was there. They had a lot of things to involve parents in the school. It was something like family schooling more than the isolation of plopping her in a special education room and not mixing her up with anybody. I don't live in a very ethnically diverse area and I think when you are different for whatever reason, my daughter had no opportunities to see anybody that was different in any other way. So in a school with a lot of ethnic diversion, it did have a religious component, which I felt was nice because all the things that my daughter strengths are her compassion and her kindness would be cultured there and motivated...So I thought this is the one thing she has going for her. She's kind and compassionate and caring, and these are the things that a private, religious school you're going to be commended for... I thought that that would help her self-esteem because the class was so small that she would be able to keep up with the work with some help on the side or some diversion of program which they were willing to do for her.
What is interesting about Paige’s elementary school years is that she did not have any realization that she was different than her peers. Mrs. Clarke did a remarkable job bringing tutors to her home and working with her daughter on her academic skills. Paige remembers,

When I was real little I didn’t know. I couldn’t tell that I couldn’t remember. I couldn’t tell that I couldn’t remember right. I thought that everybody was the same as me. And then, as I got older, I started to realize that I couldn’t remember everything that my friends were remembering... when I started elementary school in fourth grade we had a Christmas pageant and I couldn’t carry my chair down the steps and some of my classmates asked me why I couldn’t carry my chair down the steps and I said that I wasn’t strong enough. And they were okay; they understood. It was okay to them. They never made fun of me for not being able to do certain activities as well as them or hold heavy stuff.

*Stage 5: Advocacy for the Greater Good*

Through successfully advocating for her child by being present and authentic in her relationship Mrs. Clarke gained the confidence to advocate for others in need. She recalls when she advocated for all special education students to get a summer reading list in high school saying,

They had thought that she would end up in remedial language arts so they did not send a list of books home. So I called the high school and said, “My daughter’s hysterical crying because they think she’s too dumb to read... I don’t care what level the book is on, give them a choice or have them read a book of their choice.
You can't ignore this entire population of children going into high school. I found that now I've become an advocate for a lot of special education kids. People were giving my name to a lot of other people, but I got to the point that I just couldn't do it anymore. I was having enough problems with myself. But to not send kids a summer reading list when you're going into high school is once again isolating them socially, which I am so angry about.

Then Mrs. Clarke spoke about the time she advocated for all kids to have a different academic level foreign language class in high school. Not offering a lower level foreign language class. Mrs. Clarke said,

It's not just the special education kids; it's the basic skills kids too or the kids that just don't have that high of an IQ. How can you expect them to take a state required foreign language and not offer it on a level three or four? That's ridiculous. I don't care if it's just conversational or cultural; let's adapt the program to the child. Let's not try to get the child to fit into a program. That is never, ever going to work.

Not only did she recognize that her daughter needed help with social skills, she also recognized that she needed to start an after school club for students that did not seem to fit in socially. She recalls how far her school system has come in helping those with special needs saying,

Teaching these types of kids in my own school everyday and realizing how great my school system is. My school has gotten better, better, and better. When we started inclusion there were teachers that wanted no parts of it, just like where my
daughter went to school. Now, my school is like a revolving door. We've got so many classes for so many different reasons so kids with special needs don't feel out of place. We even have a lab period that was put into our school curriculum so that the kids that need help will go to resource room while the other students are going to a lab class, a science lab, or a math lab...Kids that are special education, basic skills math, or basic skills language arts that need extra help during this time because we don't want to make them feel any different... Before kids were falling through the cracks. The quiet ones are going to fall through the cracks and the parents that don't complain are really going to fall through the cracks.

Relational-Cultural theorists analyzed stories of women and identified themes that were related to having fun with adults and those who really cared about them for who they were (Spencer et al., 2002). Through relational confidence, Mrs. Clarke became the aunt who always took her nieces and nephews to extended vacations down the east coast. Paige remembers these good times shared with her cousins saying,

She is always there for me when I need her. Whether it is to talk or just to give me a hug and tell me how much she loves me and how proud of me she is. We have fun together. She used to take me and some of my cousins on trips and we had a lot of fun on those trips to Disney World and South Carolina. We would drive, and take two weeks to get to Disney World.

Mutual respect was another theme taken from transcripts analyzed by relational-cultural theorists and is defined as the adult’s willingness to allow the child to have a direct impact on her (Spencer et al., 2002). Through reaching out to her daughter Mrs.
Clarke gained confidence in her mothering ability and reached out to one of Paige's friends who has a mother who had a stroke. Mrs. Clarke became her surrogate mother taking her shopping and listening to her stories. Paige's friend even calls her "Mom".

Mrs. Clarke got Paige involved with the International Lions Club and worked in the food bank together. She got her daughter involved with babysitting and encouraged her to be a mother's helper. Together they moved through the community and involved themselves with nurturing activities. Structured interviews of college age women at Wellesley College found that the majority of the women selected their mothers as the most important person in their lives (Kaplan et al., 1985). The relational process between the mother and daughter is an integral part of the daughter's sense of self as a competent and able being. Mrs. Clarke remembers some of the activities saying,

I did get my daughter involved in community events. My daughter actually joined the Lions. She helps me in the food bank whenever she's home. So I did always have her involved in community things. I think that's important, in the ways that she could be involved... the church choir. I mean she couldn't do a lot, but it is one thing she could do where she could certainly sing. So it's hard to find and you have to keep looking. You really do have to keep looking and you just have to go out there and just start beating the bushes. And you know, people that you would never think would have an idea, you know, sometimes can give you a suggestion of something to do... I think to reach out to people. I mean I have friends that don't have disabled kids that have been really good advocates. You know the fact that people put their faith in her to watch their kids really meant a
lot to me. I mean she started even as a mother's helper, you know, at ten or eleven because she loves kids.

It appears that Mrs. Clarke has moved beyond her suffering of Paige’s brain injury to a more relational integration with community. She has learned to make healthy connections with others and is teaching those around her to do the same. Mrs. Clarke is a wonderful example to her daughter as she has demonstrated many ways of empathic listening, and the power of serving others in their community.

**Future Research**

As more premature babies are being saved and may grow up with chronic illness, research is needed focusing on how family relationships can be supported in helping those children achieve to their greatest potential. Studies tracking diseases over the course of a lifetime are also needed. There is much debate over the brain’s ability to recover from insult therefore in-depth studies of individuals are needed to find out what works. Mrs. Clarke is so proud of her daughter yet she still worries about her future. We need to listen to her words of concern. She puts this out to others with her heart saying,

One of my major concerns is that when I look into her disability her future does not seem very bright. It’s very scary to see that her future does not look very optimistic. I’m hoping she keeps great expectations because she’s worked very hard. Even though we all have disappointments, I think she’s going to be disappointed if some of these things don’t work out. Like working at Disney World or working with children. But she has to find that out for herself. I’m worried that if she doesn't find a job that nurtures her, she may get into kind of
some of the depression and some of the other problems. Although I do think that she'll find some niches.

Further research is needed to identify how relationships with all kinds of adults promote psychological health and well-being in youth. Human development needs to be understood in the context in which it is experienced, therefore it is vital to understand the relational-cultural model through the words of fathers and sons. Even though this theory was initially developed to understand women's development, there is recognition that relational connection is necessary for all human development. Children are being raised in all kinds of families and today more than ever, fathers may be raising their sons by themselves and it is vital to hear their struggles. There is a need to examine the father-son relationship to understand this valued connection throughout the lifespan. Understanding the function of the father-son relationship can promote healing and well-being in all of mankind. Fathers need to be able to make an active contribution to the development of their sons who need to be empowered by connection.

Parents need to be able to promote well-being in their children, therefore more qualitative studies need to be done investigating positive relationships. They need to be able to find specific interventions designed to foster strength and resiliency through relationships. There are few studies looking at relationships with children and it appears outcomes can be enhanced through positive connection.
The following conclusions are offered for consideration by Child Study Teams to help those with brain injury and their families by listening to their experiences to provide appropriate educational services.

How does a school psychologist or other Child Study team member use relational connection to promote resiliency in those with brain injury?

*Education for Child Study Teams (CST’s) in Relational Connection* - When the validation team met to review the transcripts of Paige’s life, it became apparent to them that CST’s were not empathically listening to the stories of Mrs. Clarke. The validation team members realized that they needed to listen to their parents a lot better than they had been in the past. Empathic listening by CST members can create a sense of respect, worth, and connection to the parents they serve. Active listening by using appropriate eye contact, tone of voice, and body posture is an essential skill in developing rapport. Relationship building activities should be done with school members. The CST member must be aware of their own biases to not promote a power over mentality. Reflective listening to a child’s parent can foster a mutual understanding and sense of commitment. It is vital to learn to understand the perspective of another to prevent disconnection in the relationship. The CST member must be aware of their own views and biases about resiliency and brain injury. The well being of the relationship must be protected at all times even though a CST member may have a different belief system than the parents.
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Confidentiality and trust must be promoted in the relationship giving both parties a sense of competence.

*Training for CST Members in Resilience*- CST members must be able to identify protective factors that enable an individual to adapt well in the face of serious health consequences such as brain injury. They must have a realization that positive school experiences, and connections with significant adults may contribute significantly to a student’s and their parents’ well-being. CST’s must possess a knowledge that families play a critical role in promoting well-being to their child’s brain injury. Families must be supported in small parent groups so they can discuss the challenges of raising a child with a brain injury. This family support is vital in reducing stress.

*Training for CST Members in Neural Plasticity*- We are learning more about the brain and it’s wiring on a daily basis. There is much research to be sifted through as more studies are made available on the brain because of new neuroimaging techniques. More premature babies are being saved because of recent technology and they need to be treated with an appropriate education. Paige has taught me that her possibilities are endless in that she always believed in herself. No one can underestimate the power of the brain to make new neural connections. CST members need to understand how the brain works to come up with strategies to explain behavior and implement lessons. CST members must never underestimate the potential of a student in their care.

*Development of Social Skills Groups*- People with ACC have challenges motorically making it difficult to get involved in the athletic part of school. They also have challenges with pragmatics and figurative language skills, which makes it difficult to read body
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language and fit in with peers. It is easy to overlook this because those with ACC are verbal and have an average IQ. It seems that they do not fit in with the after school groups for the developmentally challenged, but also don’t fit in with the athletically inclined. It appears that it is hard for them to make their place in school. Buddies Clubs should be started for those with ACC or other nonverbal learning disabilities.

Final Thoughts

If it is through relationships with others that we grow in connection, then Mrs. Clarke and Paige demonstrated that through their stories. Mrs. Clarke accepted her daughter just as she was and had an awareness of her needs different than any of the professionals working with Paige. If hope is defined as making sense out of what is going on in life when others cannot, Mrs. Clarke accomplished this task. Mrs. Clarke instilled a sense of self confidence in her daughter as she believed in her abilities when others said that she would fail. She persevered and did not give up, even when the doctors gave her devastating news about Paige’s brain injury. Mrs. Clarke had the courage to fight the health and public school systems for what she thought was best for her daughter. Paige and Mrs. Clarke defined their lives by practicing human kindness and acceptance of all.

Mrs. Clarke was in a supportive, caring relationship with her daughter, which taught her how to solve problems and believe in herself. She taught Paige how to interpret her brain damage in a positive manner creating a strong belief in her own abilities. As they shared and learned about ACC together they were empowered to move forward and problem solve during each developmental life stage. Paige continues to challenge herself in every area of her life and there is every reason to believe that her
future looks bright. Cognitive behavior therapists focus on belief systems of individuals and try to figure out how children interpret their experiences. Through connection with her daughter, she helped Paige achieve a positive belief system about herself and her actions prove this as she continues to strive to be the best she can be.
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disabilities, Asperger’s syndrome, pervasive developmental disorder-Should we


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http://www.ldonline.org/ld_indepth/nonverbal/Thomson_nldstress.html

http://www.ldonline.org/ld_indepth/nonverbal/nld_revisited.html


Appendix A

INFORMED CONSENT FORM

TITLE OF STUDY
A Narrative Biography of a Woman with Agenesis of the Corpus Callosum: A Story of Hope and Inspiration.

TITLE OF STUDY IN LAY TERMS
A Story of Hope and Inspiration from a Woman with Agenesis of the Corpus Callosum

PURPOSE
The purpose of this research is to find out what it is like to have Agenesis of the Corpus Callosum (ACC) through lived experiences. The investigation will chronicle a life history in detail of a woman with ACC and describe how it impacts educational, emotional, and social functioning.

You and your child are being asked to be in this research study because of how you achieved to your fullest potential and can give hope to others with brain injury. If you are not a young adult woman with ACC attending college or living with her mother, you can not be in this study.

INVESTIGATOR(S)
Principal Investigator: Rosemary Mennuti, Ed.D. Co-investigator:
Philadelphia College of Osteopathic Medicine Institution:
Department: Psychology Department:
Address: 4170 City Ave. Address:
Philadelphia, PA 19131 Phone:
Phone: 215-871-6414 Phone:
Responsible (Student) Investigator: Robin Comerford, MA

The interview you and your child are being asked to volunteer for is part of a research project.
If you and your child have questions about this research, you and your child can call Dr. Rosemary Mennuti, Ed.D. at (215)871-6414.
If you and your child have any questions or problems during the study, you and your child can ask Dr. Rosemary Mennuti, Ed.D., who will be available during the entire study. If you and your child want to know more about Dr. Rosemary Mennuti, Ed.D.’s background, or the rights of research subjects, you and your child can call the PCOM Research Compliance Specialist at (215)871-6782.

DESCRIPTION OF THE PROCEDURES
If you and your child decide to be in this study, you and your child will be asked to participate in a series of up to five interview at a mutually agreed upon time and location. These interviews will be audio-recorded to accurately understand your responses. You and your child will be asked if you would like to use pseudo-name for research purposes. You and your child do not have to answer every question and can stop the interview at any time. Your child will be asked to provide the researcher with any medical or school records as well as any items at home that may help the researcher understand your life.
story. These items will be stored in a locked file cabinet and the names of you and your child will be removed.
The study will take about 2 hours for each visit. There will be 5 visits over the course of 24 months, for a total of 10 hours of you and your child’s time.

**POTENTIAL BENEFITS**
You and your child may not benefit from being in this study. Other people in the future may benefit from what the researchers learn from the study.

**RISKS AND DISCOMFORTS**
Reviewing the life history of you and your child may evoke emotional stress. You will be provided a list of counselors/therapists if support is needed at any time during this study.

**ALTERNATIVES**
The other choice is not to be in this study and you will be thanked for your time.

**PAYMENT**
You and your child will not be paid any money for being in this study.

**CONFIDENTIALITY**
All information and records relating to you and your child’s participation will be kept in a locked file. Only researchers, members of the Institutional Review Board, and the U.S. Food and Drug Administration will be able to look at these records. If the results of this study are published, no names or other identifying information will be used.

**REASONS YOU AND YOUR CHILD MAY BE TAKEN OUT OF THE STUDY WITHOUT YOU AND YOUR CHILD’S CONSENT**
If health conditions occur that would make staying in the study possibly dangerous to you and your child, or if other conditions occur that would damage you and your child or you and your child’s health, the researcher may take you and your child out of this study.
In addition, the entire study may be stopped if dangerous risks or side effects occur in other people.

**NEW FINDINGS**
If any new information develops that may affect you and your child’s willingness to stay in this study, you and your child will be told about it.

**INJURY**
If you and your child are injured as a result of this research study, you and your child will be provided with immediate necessary care.
However, you and your child will not be reimbursed for care or receive other payment. PCOM will not be responsible for any of you and your child’s bills, including any routine care under this program or reimbursement for any side effects that may occur as a result of this program.
If you and your child believe that you and your child have suffered injury or illness in the course of this research, you should notify the PCOM Research Compliance Specialist at (215)871-6782. A review by committee will be arranged to determine if the injury or illness is a result of your and your child’s being in this research. You should also contact the PCOM Research Compliance Specialist if you and your child believe that you and your child have not been told enough about the risks, benefits, or other options, or that
you and your child are being pressured to stay in this study against you and your child’s wishes.

**VOLUNTARY PARTICIPATION**

You and your child may refuse to be in this study. You and your child voluntary consent(s) to be in this study with the understanding of the known possible side effects or hazards that might occur during this study. Not all possible effects of the study are known.

You and your child may leave this study at any time.

If you and your child drop(s) out of this study, there will be no penalty or loss of benefits to which you ad your child are entitled.

I have had adequate time to read this form and I understand its contents. **I have been given a copy for my personal records.**

I agree to be in this research study.

Signature of Subject: ______________________
Date: _____/_____/______
Time: _________________ AM/PM

Signature of Witness: ______________________
Date: _____/_____/______
Time: _________________ AM/PM

Signature of Investigator or Designee:
(circle one)
Date: _____/_____/______
Time: _________________ AM/PM
Appendix B

Semi-Structured Interview-Paige

The investigator will provide the following instructions to the participant with ACC at the beginning of the interview. As you already know, over the next two hours, I’m going to ask you a few open-ended questions about your remarkable experience of living with ACC when you were in elementary school, high school, and college. These questions will allow for your complete story to be told. The questions will allow you to talk about your own personal experience of living with ACC and hearing your true feelings about it. I will ask you about your relationships with your mother, roommate, and case managers to help me understand your relationship with them. It is my hope that information learned throughout this process will give a voice to others with brain injury. Your participation in this interview may help others never lose sight that their relationships and positive connections to those with brain injury aid in their development. Please feel free to answer as fully as you are able to do so. Following these questions, I will ask you several more specific questions related to experiences and relationships you have had during your life stages. These specific questions will help me to clarify and understand your story of living with ACC.

You may, of course decline to answer any question, for any reason. At the end of my questions, please feel free to add any additional information that may be helpful in helping others know what it is like to live with ACC. I will be audio taping the interviews so I can write it out at a later date. At this time, do you have any questions that I can answer for you? Okay, let us begin!
General Overview Questions

1. Briefly tell me about yourself and what you are doing at this time in your life.

2. In your own words tell me the definition of ACC.

3. What are your strengths?

4. What have been the challenges of living with ACC?

Open-Ended Questions

1. Tell me about yourself as an elementary school student.
   a. Can you remember a specific instance when you were frustrated in school and how you dealt with that frustration?
   b. About any joyous or happy times and what they were like for you.
   c. Tell me about your teachers. (How may they have helped you? How they were not helpful?)

2. Tell me about yourself as a middle school student.
   a. Can you remember a specific instance when you were frustrated in school and how you dealt with that frustration?
   b. About any joyous or happy times and what they were like for you.
   c. Tell me about your teachers. (How may they have helped you? How they were not helpful?)

3. Tell me about yourself as a high school student.
   a. Can you remember a specific instance when you were frustrated in school and how you dealt with that frustration?
b. About any joyous or happy times and what they were like for you.

e. Tell me about your case managers in high school. (How may they have helped you? How they were not helpful?)

4. Tell me about yourself as a college student.

a. Can you remember a specific instance when you were frustrated in school and how you dealt with that frustration?

b. About any joyous or happy times and what they were like for you.

c. Tell me about your relationship with your roommate.

5. Looking back tell me about your relationship with your mother (How was she helpful/not helpful in your growing to be a young woman? What were the challenges and conflicts?)

6. What suggestions do you have to help others understand the challenges of living with ACC? (school and home)

7. Do you think there is anything else that I need to know?
The investigator will provide the following instructions to the mother of the young adult woman with ACC at the beginning of the interview. “As you already know, over the next two hours, I’m going to ask you a few open-ended questions about your remarkable experience of raising a daughter with ACC throughout her developmental years. These questions will allow for her complete story to be told and hearing your true feelings about her circumstances. I will ask you about your relationships with her to give hope to those dealing with loved ones who have brain injury. Your participation in this interview may help others never lose sight that their relationships and positive connections to those with brain injury aid in their development. Please feel free to answer as fully as you are able to do so. Following these questions, I will ask you several more specific questions to help me to clarify and understand your story of living with a daughter who has ACC.

You may, of course decline to answer any question, for any reason. At the end of my questions, please feel free to add any additional information that may be helpful in helping others know what it is like to live with ACC. I will be audio taping the interviews so I can write it out at a later date. At this time, do you have any questions that I can answer for you? Okay, let us begin!”

General Overview Questions

1. Briefly tell me about yourself and what you are doing at this time in your life.
2. What are your strengths?
3. What have been some of the major challenges you have faced in your life?

4. In your own words tell me the definition of ACC.

5. Briefly tell me about your daughter.

6. What are her strengths and challenges?

Open-Ended Questions

1. Tell me about her preschool, elementary school, middle school, high school, and college years.

2. Looking back, can you remember any specific instance when you were frustrated with her school experiences?

3. Tell me about your relationship with her. (infant, preschooler, school aged, middle school, high school, currently?)

4. Tell me about support systems that you had as a parent of a child with a brain injury?

5. What suggestions do you have to help others understand the challenges of living with ACC? (school, home, social, etc)

6. Do you think there is anything else that I need to know about you or your daughter?
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Appendix D

Medical Records

Boston University School of Medicine’s Drug Epidemiology Unit (2/28/85)

State Department of Health Letter (4/12/85)

Special Child Health Services Letter (4/17/85)

Special Child Health Services Letter (10/10/85)

Department of Human Services Family Service Agreement (6/3/85)

Early Intervention Program Six Month Summary (6/1/85 through 1/1/86)

Neurological consultation (10/15/86)

Early Intervention Program Six Month Summary (12/24/86)

Physical therapist report to neurologist (3/21/91)

Letter from neurologist to family physician (12/19/97)

Neurological consultation letter to family pediatrician (3/19/97)

Children’s Hospital Department of Radiology (3/19/97)

Department of radiology report (3/19/97).
Appendix E

School Records

Educational Assessment- (6/20/88)

Speech and Language Evaluation-Preschool Language Assessment Instrument. (4/18/89)

Letter from Child Study Team Gesell Institute of Child Development School Readiness Screening Test (4/20/89)

Occupational therapy Evaluation-. (May, 1989)

Classification and Individualized Education Program Conference Report- (6/21/89)

Educational Assessment- (June, 1989)

Classification Conference Report and Basic Plan for school year 1989-1990

IEP Addendum- (10/25/89)

Occupational Therapy Summary- (3/27/90)

California Achievement Tests, Forms E & F (4/16/91)

Individualized Educational Program Plan First Grade- (5/31/91)

Kindergarten Final Report Card- (June, 1991)

Classification Conference Report- (May, 1992)

Social Case History- (5/1/92)

Physical Therapy Summary- (5/7/92)

Occupational Therapy Evaluation- (May, 1992)

Grade 2 Teacher Comment Form- (4/30/93)

California Achievement Tests, Fifth Edition- (3/29/93)

Child Study Team Letter to Parent/IEP Addendum- (4/1/93)
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Support Services Progress Report- (April 30, 1993)

Physical Therapy Summary-. (5/1/93)

Annual Review for Grade Two-. (5/10/93)

Grade 2 Final Report Card- (June, 1993)

California Achievement Tests, Fifth Edition- (4/19/94)

Final Third Grade Report Card- (June, 1994)

Sixth Grade Academic Report Second Quarter- (1/24/97)

Sixth Grade Academic Report Third Quarter- good effort. (3/21/97)

Metropolitan Achievement Tests (Seventh Edition) Sixth Grade- (May, 1997)

Seventh Grade Academic Report First Quarter- (10/31/97)

Learning Disability Evaluation- (8/6/97)

Psychological Evaluation- (8/6/97)

Classification Conference Report Grade 7- (10/2/97)

Seventh Grade Academic Report Second Quarter- (1/26/98)

Seventh Grade Academic Report Third Quarter- (3/20/98)

Comprehensive Testing Program III 7th grade achievement tests- (May, 1998)

Letter from Child Study Team Director- (8/6/98)

ADA 504 Accommodation Plan- (9/29/98)

ADA 504 Accommodation Plan Amended November 25, 1998

Learning Disability Teacher Consultant letter to parent after review of records- (2/1/99)

Statewide Assessment System Grade Eight Proficiency Assessment Individual Student Report: (March, 1999)
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Psychological Evaluation- (4/14/99).
Social Case History- (4/19/99)
Educational Evaluation- (6/4/99)
Final Eighth Grade Report Card- (June, 1999)
Presidential Award for Educational Improvement-(7/12/99)
Individualized Educational Program Conference Report Annual Review Grade 9-(5/10/99)
Individualized Educational Program Conference Report Annual Review Grade 10-(6/7/00)
National Honor Society Letter- (11/7/01)
Individualized Educational Program Conference Report Annual Review Grade 11-(5/24/01)
Individualized Educational Program Conference Report Annual Review Grade 12-(9/5/02)
High School Proficiency Assessment Individual Student Report: (March, 2002)
The College Board SAT Student Score Report- (December, 2002)
Letter of Recommendation- (12/2/02)
Psychological Evaluation- (8/28/02)
College VISA (Verified Individualized Services and Accommodations)
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Appendix F

Personal Artifacts

Poems - 7th grade

An Interview on My Grandmother - 7th grade

Uzbekistan Report - (3/9/98)

Autobiography of Bill Peet - (10th grade, 2000)

4 Renaissance Smart Cookie Awards from high school

Secondary School Driver Examination - (1/17/01)

Young Adult Magazine Project senior year in high school (Senior year in high school, 2002/03)

College Current Event Paper - (2/1/04)

College Final Exam Essay - (12/8/04)

Fellowship Research and Reaction Paper - (3/10/05)

College Drug Policy Paper - (4/6/05)

College Darfur Paper - (3/12/07)

Examination Blue Book Introduction to International Relations - (3/29/07)

World Hunger and the Marketplace - (4/12/07)

Examination Blue Book Philosophy of Love - Grade: (3/15/07)

Examination Blue Book Philosophy of Love - Grade: (4/19/07)

Examination Blue Book Introduction to International Relations - (5/3/07)