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Children with ACC and Their Siblings

How Alike Are They?

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The following report is a summary of the research presented by Gary Schilmoeller, Ph.D., at the ACC Conference 2004 in Madison, Wisconsin, in August, 2004. The full report may be viewed at the National Organization for Disorders of the Corpus Callosum (NODCC) website (www.nodcc.org) by clicking on "2004 Conference Handouts." Questions regarding this report can be directed to Gary Schilmoeller, Ph.D., via e-mail at: RHD351@maine.edu

In 2002 and 2003, the ACC Network conducted a survey of 189 individuals with agenesis of the corpus callosum (ACC) and their siblings (a total of 378 persons). Survey questions were based on information presented in studies of people with ACC by O'Brien (1994) and Schilmoeller and Schilmoeller (2000). We also considered reports from parents and persons with ACC who have shared their information with the ACC Network and on the ACC-L listserv (an online discussion group for topics pertaining to ACC).

The results of the survey include information on individuals with complete or partial ACC. We included persons with conditions in addition to ACC, such as seizures, autism, or mental retardation, and those who may be diagnosed with "ACC only." Differences between children with ACC and their siblings may be due to ACC, to some combination of ACC and other coexisting conditions, or to the other conditions and not ACC. Therefore, these results must be interpreted with caution. Nevertheless, these

differences may have an impact on the daily lives of individuals with ACC and their caregivers. We discussed some of these implications in this report.

Achievement of developmental milestones

We compared the age when children with ACC and their siblings met several developmental milestones usually monitored by health providers when they assess normal development, such as rolling over, crawling, sitting, standing, talking, and toilet training. We found that children with ACC achieved these abilities much later than their siblings for all the milestones we studied except for lifting their heads. Compared with the norms published by the Denver Developmental Screening Test (a standard widely used by health care professionals), children with ACC acquired these milestones later than most (90%) of typically developing children. Clearly, children with ACC experienced significant delays in achieving typical developmental milestones.

Motor skills

When asked about specific motor skills, such as throwing and catching a ball, running, hopping, and jumping, parents reported that their children with ACC were less skilled at these activities than their brothers and sisters. Children with ACC also had more difficulty than their siblings handling self-help skills, such as buttoning clothes, zipping, and brushing their own teeth.

Children with ACC who have not mastered age-appropriate self-help skills may require more time and energy to get dressed or perform personal hygiene than a same-aged

child without ACC. In addition, if children lack good motor coordination, peers may not want to play with them. As they get older and coordination and skill in sports and hobbies become important, this issue may become more problematic.

Eating and elimination

Many parents reported their children with ACC had more problems with eating and elimination than their brothers and sisters. In particular, they reported difficulties such as poor sucking at birth, need for a gastric feeding tube for nourishment, and problems with swallowing and chewing. Respondents also indicated constipation and difficulty with bladder control were more prevalent in children with ACC than in their siblings.

Infants with ACC may have more difficulty breast or bottle feeding successfully. This can lead to inadequate nutrition and hydration for the child and increased stress for parents. As children get older, parents and caregivers may think a child with ACC is a picky eater, when in fact they are having difficulty chewing and swallowing. Normal childhood growth in height and weight may be affected if a child is unable to take in enough nutrition to meet their needs. Toilet training also can be more difficult or delayed for children with ACC who have difficulty with bladder control and/or constipation.

Sensitivity to touch and pain tolerance

Comparing sibling pairs, parents and caregivers reported that many more children with ACC showed more or much more sensitivity to being touched by others than did their siblings. On the other hand, many more children with ACC showed little, less than average, or no pain perception when compared with their siblings, suggesting that the children with ACC have a significantly higher tolerance for pain than their siblings.

High tolerance for pain could result in a greater chance for children with ACC to become seriously ill or get hurt without even

realizing they are sick or injured. Because of this, some parents may be suspected of neglect or abuse if professionals discover injuries that seem unusual or that were undetected by parents.

Social behavior

Parents reported their children with ACC were slightly less capable in their social interactions with peers, strangers, and family members than were the siblings. When we compared them in pairs with their sibling, we found that children with ACC have a significantly lower average (mean) score for social interaction skills than their siblings.

The children with ACC (more often than their siblings) displayed behaviors that could make interactions with others more difficult, such as dominating conversations or making unusual facial expressions. Parents and caregivers also reported children with ACC more often showed autistic-like behaviors, were less happy or slightly moodier, and were slightly more aggressive than their siblings.

Children who are moodier, have more social difficulties, or show autistic-like behaviors may have difficulty making and keeping friends. These social challenges, combined with some of the motor and self-help skill challenges discussed above, may result in greater social isolation for children with ACC.

Learning

Respondents reported children with ACC experienced several areas of concern for learning. Almost 60 in 100 (59.1%) of children with ACC showed difficulty staying on task when learning, compared with only about 10 in 100 (10.3%) of the siblings. Almost one half of children with ACC perseverated on learning tasks, compared with only about 6 in 100 of the siblings. Children who perseverate have difficulty stopping inappropriate or incorrect behaviors.

Teachers may perceive children who perseverate or show difficulty staying on task

when learning as challenging in schools. These children may need closer attention from teachers or even assistance from aides in a classroom.

Additionally, children with ACC showed significantly higher scores for difficulty with abstract reasoning when compared with their siblings. About 74 of 100 children with ACC were reported to have often or almost always had difficulty with abstract reasoning, compared with only about 13 of 100 of their siblings. As children with ACC move into the later elementary school grades and high school, and abstract reasoning skills become increasingly important, this can become much more challenging for children with ACC who have difficulty with this type of reasoning.

The information presented in this article was reported by parents and caregivers who

participated in the survey. We did not require further documentation, observe the behaviors or abilities of the individuals involved, or differentiate between individuals with ACC only and those with additional conditions. Thus, the results must be considered cautiously as researchers continue to tease out what characteristics are related to ACC and which ones may be due to other conditions. This research project is one step toward greater understanding, and much more research is necessary to understand the specific effects of ACC on individuals. ☞

Gary and Kathy Schilmoeller teach at the University of Maine and are the co-founders of the ACC Network. Shihfen Tu teaches at the University of Maine and is co-coordinator of research and evaluation at the University Center for Excellence in Developmental Disabilities.

Being the “Other Child” Part 2: Issues Faced by Older Siblings

In the last issue of The Callosal Connection we introduced you to Amy and Kathleen Tulley in Amy’s article about young children growing up with a sibling with a disability. In this issue Amy completes the discussion by writing about issues that face older siblings.

When siblings of persons with disabilities reach young adulthood and begin to plan for their futures, a crop of practical issues emerge. A publication by the National Information Center for Children and Youth with Disabilities (NICHCY) notes that these issues involve romantic partners, future reproduction, and plans for future care of siblings with disabilities. It is important that families address these issues so that all family members are prepared for the future.

One issue cited by the NICHCY publication involves questioning whether a potential dating partner or spouse will adjust to and accept your sibling with a disability. This is a practical concern; it would be difficult for a relationship to last if one partner could not accept a member of the other’s family.

I would never consider dating someone I thought would not accept and respect my sister, Kathleen. In an e-mail interview, Brian Schilmoeller, now a graduate student whose older brother, Matt, has complete agenesis of the corpus callosum (ACC), agreed with my assertion. He said, “I have never had a negative reaction to my brother’s condition from anybody that I really care at all about. I guess I don’t want to associate with the type of people that would have a problem with it. My

girlfriend, Tali, has gone out of her way to learn about ACC. She's fascinated by Matt's condition and really likes Matt, to boot."

My resources did not offer any suggestions for dealing with this issue. In my experience, I have learned that siblings must work out this issue on their own. Many young adult siblings that I know see it the way Brian and I do: as more of a test of a person's character rather than as a negative thing. Indeed, several adult siblings I have met over the years have mentioned using their sibling with a disability as a "litmus test" for potential partners. Partners who accept their sibling pass; those who do not fail.

A second practical issue some young adult siblings face is the possibility of passing their sibling's disability on to their children. Mary McHugh, a columnist for the organization iCAN and the sister of a man with cerebral palsy, suggests that siblings may have one of several different reactions. Some refuse to have children because they do not want to go through what their parents went through. Some feel they are better equipped than most people to parent a child with a disability because of their experiences with their siblings. Others fall somewhere in the middle, wavering between the two choices.

I worry about this issue occasionally, and I am sure I will worry about it more when I am ready to start a family. No one is sure whether the cause of my sister's disabilities—a 1q chromosome deletion and complete ACC—are hereditary. In thinking about future children, I find that I fall into McHugh's last category. I sometimes feel that bringing a child with a disability into a hostile and unaccepting world would be difficult and wrong, but I also feel that my experiences with Kathleen would make me a great parent for a child with a disability. McHugh advises that, although these decisions are very difficult, tests such as pedigree analysis and genetic screening before conceiving and amniocentesis, alpha-fetoprotein screening, and ultrasound during pregnancy can help a

person make a more informed decision about having children.

The NICHCY publication identifies a third and very pressing practical issue: what will happen to a sibling with a disability after their parents can no longer care for them. Some siblings may choose to gain guardianship and take over the care of their siblings, while others may seek to place their siblings in group homes or other supervised living situations. Every option requires future planning, creates anxiety about whether or not the placement will be right, and can lead to feelings of guilt, resentment, or anxiety once decisions are made.

This issue concerns me the most right now. If my parents were to pass away tomorrow, I have no idea what would happen to Kathleen. Both my older sister, Molly, and I have volunteered to be Kathleen's guardians and caretakers if anything ever happened to my parents, but now I am re-thinking my decision. Although I love Kathleen very much, I worry that I might resent the way that responsibility would affect my future career, relationships, and family. I also worry that I might not be able to meet Kathleen's needs and wonder if an assisted-living program would be better for her because it would allow her to be more independent and to interact more with other people. On the other hand, the idea of Kathleen living away from family members who love her breaks my heart. This issue is difficult to discuss with my family, because none of us wants to think about anything happening to my parents. I think it is important, however, and I will continue worrying about it until my family discusses it and comes to a decision.

The NICHCY publication advises people to do just that: discuss the issue and make decisions as a family. The publication offers practical suggestions for doing so, such as developing financial plans for future care, understanding laws about guardianship and independence, learning how to access your sibling's records, and discovering the types of

available community resources. Practical and complete plans for the future care of a brother or sister with a disability not only ease a sibling's anxiety, they also ensure that the entire family will be well prepared for the future.

Young adult siblings of people with disabilities face unique emotional, social, and practical issues that can adversely affect their emotional well-being, social experiences, and family relationships. If parents and siblings address these concerns, however, the experience of having a sibling with a disability can be a positive one. My experiences with

Kathleen illustrate how addressing my own issues has helped me accept Kathleen and experience the immense love and joy she offers me.

Amy Tully wrote this piece while a student at the University of Wisconsin-Madison. She graduated in December 2004 with a degree in Communication Arts with an emphasis in rhetoric. Amy has four siblings, including Kathleen, who is 16 and has complete ACC and a 1q chromosome deletion.

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