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## The Role of Occupational Therapy for Children with ACC

By Erin Goldblatt, OTR/L

Occupational therapy is skilled treatment that helps individuals achieve independence in all of life's functions. For a young child with ACC, that may mean learning how to sit or eat or learning how to write the letters in his or her name for the first time. It may mean learning how to use the tools necessary to complete a new activity. Occupational therapists (OTs) work with people of all ages to give them the tools they need for the job of living.

As a pediatric occupational therapist, I have had the pleasure of working with several children with ACC. They ranged in age from newborn to 8 years. The children I worked with presented with low-normal muscle tone, difficulties with bilateral hand tasks (e.g. cutting), and demonstrated difficulty with executive functioning (the brain's ability to absorb information, interpret this information, and make decisions based upon this information).

Low muscle tone impacts overall strength and can create difficulty with fine motor control and handwriting. Difficulty with executive functioning makes organizing multi-step tasks more challenging. An occupational therapist has both medical and education-based knowledge to assist in identifying and treating challenges that your child may face.

### An OT may provide:

- Comprehensive evaluations (for home- or school-based difficulties)
- Treatment programs designed to help your child become more independent with activities at home or school
- Recommendations for adaptive equipment
- Guidance and education for family members and caregivers

- Consultation to school teachers
- Contributions to the individual education plan (IEP) team

### What does an OT evaluate?

An occupational therapy evaluation may include the following areas of development. If you or your pediatrician have concerns in only a particular area of development, a focus of the evaluation would be placed on that area.

- Fine motor skills (skills requiring the use of the small muscles of the hands)
- Postural stability (the ability to sit upright in a chair)
- Self-care skills (dressing, bathing)
- Oral-motor skills (feeding/the ability to organize/tolerate oral input)
- Visual-perceptual skills (the ability to understand what is seen)
- Visual-motor skills (the ability to coordinate pencil/paper tasks)
- Bilateral hand coordination (using both hands together, e.g. cutting)
- Sensory processing skills (the ability to process different kinds of sensory input including tactile, vestibular/balance, smell, etc.)
- Motor planning, praxis, and organizational skills (the ability to plan and execute an activity with desired output)
- Overall strength/tone (examination of muscle strength and tone and how that affects functional skills)

### What will the OT do with my child?

Pediatric occupational therapy is often fun for a child. OTs may use resistive putty to strengthen muscles of the hands used in handwriting. They may use arts and crafts to work on cutting skills, or use multi-sensory

activities to teach your child how to plan and write letters. The OT may teach your child how to organize or write sentences or teach your child how to draw.

Treatment varies from child to child and is dependent on what the family and therapist feel is important for that child to work on. The occupational therapist often works closely with a team of physical therapists and speech pathologists to optimize your child's progress.

### **How do I know if my child needs OT, and where do I turn for help?**

Your child's healthcare provider can help you determine whether or not your child is meeting the milestones expected for his or her age. If a delay is noted in an area of development, you may get referred to an early intervention program (a government program that provides services to children from birth through 3 years). Early intervention therapists typically come to your home to evaluate and treat your child. As a parent, you can also refer yourself to early intervention if you have questions or concerns about your child's development.

If your child is older than 3 years, your child's teacher or caregiver may notice an area of developmental delay and may recommend that the school-based team at your local public school evaluate your child. An evaluation is done, and then a team meeting is held to create a plan called an individualized education plan (IEP). To qualify for school-based services, your child must demonstrate an inability to keep up with the requirements of the academic curriculum.

Another option for parents is to consult the pediatric team at your local hospital or a private clinic. Your health insurance may cover hospital-based or clinic-based care, but a referral from your pediatrician may be required.

In all cases, a standardized assessment tool is administered to determine if your child qualifies for occupational therapy. Once that has been determined, the OT may provide

services ranging from consultative services to direct service in the clinic, home, or school.

### **How do I know if my child would benefit from an OT evaluation?**

- Is your child having difficulty meeting age-appropriate developmental milestones?
- Has your child been diagnosed with a delay in visual motor, visual perceptual, or sensory processing skills?
- Does your child have low muscle tone?
- Does your child have difficulty holding a writing tool?
- Does your child have difficulty with feeding or with activities of daily living (including self-care)?
- Does your child have difficulty sitting in a chair at school?
- Does your child have difficulty planning or executing new tasks?
- Does your child have difficulty with bilateral hand tasks like cutting?
- Is handwriting difficult for your child?

If your child exhibits some of these behaviors or challenges, consult your child's healthcare provider or your child's teachers to see if an OT consult would be beneficial.

It has been my experience that children with ACC often experience delays that are subtle and can be difficult to detect. I believe the best results occur with early intervention, which may include OT, and a supportive network at home, school, and play.

*Erin Goldblatt, OTR/L, is the president of Children's OT Connection, in Westwood, Massachusetts. For further information, please visit their website at <[www.cotcweb.com](http://www.cotcweb.com)>.*

## What Is Early Intervention?

Early intervention refers to services provided to infants and toddlers (from birth to 3 years) who have a disability or who are at risk for developmental delays and to their families. As outlined in Part C of the Individuals with Disabilities Education Act (IDEA), the purpose of early intervention is to maximize the potential of infants and toddlers and to minimize the need for special education when they reach school age.

The IDEA also states that preschoolers (3-5 years of age) with disabilities have a right to a free appropriate public education and that these services will be provided in

the least restrictive environment. Inclusive preschool services allow children with disabilities or developmental delays to learn and play in the same environment as their typically developing peers. The children involved in this setting are able to develop friendships and achieve skill development through peer modeling and interactions.

*Written by Margo Brown, M.Ed., coordinator, Child Development Learning Center, University of Maine. For more information about early intervention services and your rights under IDEA, see our resource list.*

## Resources for the Early Years

### Publications

*When Your Child Has a Disability: The Complete Sourcebook of Daily and Medical Care*, by M. L. Batshaw (Ed.). (2001). Baltimore: Paul Brookes Publishing Co.

*Finding Help for Young Children with Disabilities (Birth to 5)*, (2nd ed.). A publication of the National Dissemination Center for Children with Disabilities (NICHCY). (2005). Available to download <[www.nichcy.org/parents.asp](http://www.nichcy.org/parents.asp)>

Or contact: NICHCY e-mail: [nichcy@aed.org](mailto:nichcy@aed.org)  
P.O. Box 1492 Phone: 1-800-695-0285  
Washington, DC 20013-1492

### Websites

<[www.nectac.org/contact/ptccoord.asp](http://www.nectac.org/contact/ptccoord.asp)> National Early Childhood Technical Assistance Center website. Lists state contacts for early intervention services.

<[www.ed.gov/policy/speced/guid/idea/monitor/state-contact-list.html](http://www.ed.gov/policy/speced/guid/idea/monitor/state-contact-list.html)> U.S department of Education: Special Education & Rehabilitative Services, state contacts, Part B and Part C.

*This list was compiled with the assistance of Nikki Chirco, Heather Honey, and Heather Richmond.*

# Research Report from the ACC Network

## Health-related Issues in Individuals with Agenesis of the Corpus Callosum

*By Donna Doherty, M.S., R.N., Shihfen Tu, Ph.D., Kathryn Schilmoeller, Ph.D., & Gary Schilmoeller, Ph.D.*

**Introduction:** This research project draws on data from a large survey study initiated by the ACC Network in March 2000. We are grateful to the ACC Network families who took the time to complete and return the extensive survey that made this project possible. We presented our findings to a variety of health professionals in a poster session at the American Public Health Association Annual Meeting and Exposition, November 7, 2006, in Boston, Massachusetts. We are happy to share this summary with you now. For a more extensive report, including statistical results, see the information listed at the end of this article.

**Purpose of Study:** Researchers report a variety of health and behavioral outcomes sometimes associated with ACC. In addition, parents frequently report health concerns such as feeding or sleep issues, elimination problems, and atypical response to pain. The purpose of this study was to explore and compare the prevalence and expression of specific health-related features in a large sample of persons with agenesis of the corpus callosum (ACC) and their siblings

**Methods:** We mailed 2,100 surveys to caregivers who had been in contact with the ACC Network. We derived survey questions from a literature review, anecdotal information collected at the ACC Network, and themes raised on the ACC listserv. The response rate to this initial stage was 35%. We mailed a modified version of the survey to 590 families who had completed the first survey and who indicated there was a sibling in the family. The response rate to this phase was 37%. The data set used for this study consisted of surveys for 189 siblings and 189 persons with complete or partial ACC. We analyzed data related to diagnostic information, physical features, neurological and sensory information, feeding, elimination, and

sleep issues, and some behavioral features.

**Sample:** There were 189 sibling pairs. The average age was 8.1 years for persons with ACC and 11.9 years for the siblings. There were more males (55.6% ACC; 57.7% siblings) than females (44.4% ACC; 42.3% siblings). Most individuals were white (93.1% ACC; 94.7% siblings), but other races/ethnicities were represented.

### Major Findings

Persons with ACC are more likely than their siblings to:

- Suck inadequately at birth and experience problems with chewing, swallowing, and reflux
- Experience developmental delays
- Have difficulty getting to sleep, wake up during the night, and wet the bed (enuresis)
- Experience problems with bladder control, constipation, and diarrhea
- Accomplish toilet training at a later age
- (At 5 years of age, 59.5% of children with ACC were toilet trained, with 25.7% of those accomplishing this task “very late.”)
- Display less sensitivity to painful stimuli
- Have diagnoses related to their vision and eye structures
- Show increased sensitivity to touch
- Have diagnoses of additional physical, medical, and behavioral conditions
- Have diagnoses of mental retardation, learning disabilities, and seizure disorder
- Engage in self-injurious or aggressive behaviors, (e.g. hitting, lashing out), though in most cases, these behaviors occurred rarely or only occasionally

### Implications

- Persons with ACC should receive

comprehensive evaluation and treatment for problems related to feeding/eating, sleep disorders, bowel/bladder dysfunction, and behavioral issues.

- The high incidence of developmental delays supports the need for early and regular developmental assessments with appropriate referrals to specialists (PT, OT, SLP, etc.).
- Children with ACC require careful assessment due to an increased risk for additional physical, sensory, and health-related conditions.
- Parents and caregivers should receive information regarding the increased risk for developmental delays, sensory deficits, learning disabilities, and seizure activity.
- The absence of a typical response to pain in some persons with ACC places

them at risk for undetected or late detection of injuries and illnesses and places caregivers at risk for allegations of abuse/neglect.

Much more research is needed to better clarify these and other health-related issues in this population.

***For more information:***

Doherty, D., Tu, S., Schilmoeller, K., & Schilmoeller, G. (2006). Health-related issues in individuals with agenesis of the corpus callosum. *Child: Care, Health, and Development*, 3 (3), 333-42.

Visit our website:

<[www.umaine.edu/edhd/research/accnetwork.htm](http://www.umaine.edu/edhd/research/accnetwork.htm)> and click on the research link to find our full research report.

If you have questions about this report, or need assistance obtaining the full report, contact the ACC Network directly for more information .

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