

**by Jeanne
Buesser**



THE QUIET CHILD

When silence may mean more.

If your child is on the late side of speech development, it could be significant. Many parents find it hard to differentiate between late talkers and children with apraxia. Apraxia is a severe neurological speech disorder that controls the input from the brain to the oral motor muscles providing speech. It is like having a loose wire or connection in the brain.

In a child, the disorder is referred to as childhood apraxia of speech (CAS), and it's a frustrating disorder for both parent and child to deal with. What happens is that children cannot produce the correct sounds to verbally make themselves understood. When the connections are aligned, the approximate words or beginning sounds are recognizable. However, when they are misaligned, the words come out garbled.

One of the most difficult aspects of the disorder is that it is challenging to detect in a child's early years of development. But with the proper knowledge, families can better understand the signs and symptoms of apraxia.

According to *The Late Talker Book: What to Do If Your Child Isn't Talking Yet* (St. Martin's Griffin) by Dr. Marilyn Agin, M.D., Lisa Geng and Malcom J. Nicholl, there are four types of apraxia to note. The first type is verbal, affecting the programming of the articulators and rapid sequences of muscle movements for speech sounds. This is often associated with hypotonia and sensory integration disorder. The second type is oral, involving non-speech movements like blowing, puckering and licking food from the lips. The third type of apraxia is global, pertaining to the head, meaning the child cannot visually track things with relation to verbal inputs. In other words, the child cannot follow a ball if you tell him to look to the right or left. The fourth aspect of apraxia is limb, describing muscle weakness that most frequently affects the entire limb. It can be either uni or bilateral, and it impacts activities of daily living including walking and grasping. Low muscle tone or hypotonia and sensory defects are frequently associated with this condition.

Many people have never heard of apraxia. If they have, they commonly associate the condition with adults who have had strokes— not children. The proper diagnosis is crucial because there are specific therapies for children who have autistic tendencies and those who do not. Unfortunately, at this point, the medical field doesn't have the technology to diagnose apraxia prior to birth.

Apraxia frustrates children with the condition because they aren't able to make their wants and needs known— often leading to tantrums. Along with frustration, another sign is hypotonia, which can be in the face, lips, mouth, tongue, cheeks and body. The child can also have feeding issues because of a low muscle tone and a poor sensation of chewing regular food, or the child may only be able to eat very soft foods.

Some warning signs include lack of babbling or cooing when an infant is growing, not being able to respond to one's name, having problems sitting up or having weakness in certain muscle areas of the body.

As a parent, be extremely aware of your child's developmental stages. Over the years, I have found that speech isn't frequently talked about or asked about on intake forms. Therefore, speech may be neglected during check-ups at regular pediatricians' offices. Additionally, many parents don't know if a problem exists regarding speech and language, or where to get help. If you're unsure if your child has a problem with speech, then get a second opinion from a developmental pediatrician. Or, look up Early Intervention under "Board of Education" in your town's Blue Pages.

When full-term babies are born, staff at hospitals should hand out forms to new parents with the warning signs of speech problems. If there is a problem as the child develops, then parents will have some insight about where to go for help. Many parenting and family-oriented magazines in local stores fail to cover speech development in their articles— even with doctors on their boards. This is why many people remain in the dark.

This lack of awareness led me to start the Apraxia Network of Bergen County. I had seen an article about the Cherab Foundation, another grassroots nonprofit in central New Jersey run by Lisa Geng, who parents a child with apraxia. I started attending Geng's meetings and became good friends with her. However, I wanted something similar in northern New Jersey.

Besides that group, nothing was around for support or resources in my area for my son, who was diagnosed with apraxia and was nonverbal at that time. Little by little, I learned how to start doing the paperwork to form a grassroots nonprofit organization. Eight years later, the The Apraxia Network of Bergen County is a grassroots organization that relies on contributions and donations. It is a support group for families of children and adults with all aspects of apraxia. The organization is grateful for donations to help pay for postage, which goes toward reproducing articles about apraxia at the meetings and sending them out by mail.

One of the organization's dreams is to produce two documentaries: one for parents and one for professionals— both are sorely needed. To assist in any way, contact me at (201)741-4035 or e-mail me at jbmistletoe@optonline.net. If e-mailing, write "documentary" in the subject line.

Log on www.speechville.com/communication-station/new-jersey-network.html to learn more.

Jeanne Buesser is the president of the Apraxia Network of Bergen County. She has written many articles on apraxia, been published in a few local papers and been interviewed on AllTalkRadio.com— The Rose Moore Show, along with Lisa Geng. Buesser was awarded as one of the integral Volunteers of Morris County in 2005 and has spoken at many conferences and clubs.