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New surgical treatment offers hope for children with rare disorder often diagnosed as autism

Although she didn't know it at the time, Jane Rudick's three-year-old son Cameron was a classical case of Landau-Kleffner syndrome (LKS). A bright, affectionate and verbally precocious toddler, he lost—literally overnight—the ability to understand what others were saying to him.

"I remember asking him to pick up a napkin from the floor," Rudick commented in a Chicago Sun-Times *article, "and he stared at me blankly . . . he couldn't understand what a napkin was."*

Shortly afterward, Cameron's speech deteriorated and he developed symptoms of autism. He began avoiding eye contact, appeared deaf to many sounds, smelled his food before he ate it, stopped sleeping, and began wandering from the Rudicks' home at all hours of the day and night. Most of the many specialists who examined him diagnosed him as autistic.

One specialist, however, mentioned Landau-Kleffner syndrome in his report. Through the National Organization for Rare Disorders, Rudick contacted the parents of another child with LKS and learned that doctors in Chicago were treating the disorder successfully with a new surgical technique. Cameron Rudick, one of the first children to undergo this surgery, regained his speech and comprehension and now attends a regular first-grade class with other seven-year-olds, where he routinely makes the honor roll. While he is still relearning some language skills, his autistic symptoms have disappeared.

Identified in 1957 and considered extremely rare, Landau-Kleffner syndrome usually strikes formerly normal children between the ages of three and seven—although it may also occur in children whose early development was abnormal.

Typically, children with LKS first lose the ability to understand others, and then lose their ability to speak. Symptoms may appear suddenly or develop gradually. Children with LKS appear to realize that something is wrong; the physicians who first identified the syndrome, William Landau and Frank Kleffner, described a typical child with LKS as "behaving in a stable and intelligent fashion, although he was clearly frustrated by his difficulties in understanding and using speech."

The abilities of children with Landau-Kleffner may fluctuate, with periods of remission followed by deterioration. While losing the ability to speak, they often can read and write, and can learn sign language.

Another classic symptom of LKS is the development of abnormal EEGs, with or without seizures. EEG abnormalities may be detectable only on extended sleep EEG recordings and accurate readings may require implanted electrodes and evaluation by specialists trained in detecting LKS. (Typically, EEGs performed on children with LKS show bilateral paroxysmal spike or spike-and-wave discharges from the temporal lobes. The pattern of the discharges varies during the course of the disorder.)

About one third of children with LKS never develop seizures, in spite of their abnormal EEGS; and in the remainder, seizures are easily controlled and generally disappear by adulthood. Anticonvulsive medications, while they usually control seizures, have little or no effect on speech, comprehension and behavior problems.

Autistic symptoms common

About 70% of children with LKS have behavior problems. According to Jane Rudick, now director of C.A.N.D.L.E. (Childhood Aphasia, Neurological Disorders, Landau-Kleffner Syndrome and Epilepsy), "the aspect of autistic behavior is the one most seen and has not been widely mentioned in connection with Landau-Kleffner. Our children . . . may aggressively attack others [one child attacked his family with scissors, knives, and pieces of glass], retreat, fail to make eye contact, eat only a small variety of foods, demand that things must be perfect and done exactly . . . lick or smell foods before eating, have difficulty getting to sleep and awaken often during the night, bedwet, and are hyperactive at times.

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Facilitated communication reports generate heated controversy

As noted in ARRI 4/4, reports by Douglas Biklen and Rosemary Crossley of remarkable success with "facilitated communication" techniques have generated tremendous controversy, particularly in Australia, where Crossley's D.E.A.L. (Dignity Through Education and Language) program is located.

The type of facilitated communication used at the D.E.A.L. program involves a nondisabled facilitator giving physical assistance (for instance, touching the hand or arm) to an autistic individual using a spelling device. (D.E.A.L. frequently uses the Canon Communicator, a small electronic typing device with a tape printout.)

Concerned that facilitators at D.E.A.L. may be unwittingly influencing the typed responses—the so-called "Ouija Board" effect—the Intellectual Disability Review Panel of Victoria noted that "this becomes a critical issue where major life decisions are being made."

The panel notes that there is considerable skepticism about the high-level conversations, grammatical fluency and excellent spelling shown by very low-functioning and previously noncommunicative individuals at D.E.A.L. In addition, panel members say that the use of facilitated or "assisted" communication is problematical when other, more independent forms of communication (such as sign language, speech or picture boards) are available, or when autistic individuals remain dependent upon a facilitator's help for a long period of time rather than learning to type without help.

They also are concerned, they say, by the inability of many D.E.A.L. program participants to communicate with a range of facilitators, making the disabled individual dependent on one or a few facilitators, and possibly "creating emotional problems for the parents or care givers with whom the client does not communicate."

Autism professionals who are members of an Inter-Disciplinary Party of Issues in Severe Communication Impairment, a group skeptical of D.E.A.L.'s techniques, believe

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