Information regarding Schizencephaly and Behaviors

The Cause

The cause of Schizencephaly is unknown, although environmental and genetic factors have been proposed. Various theories exist as to the timing and nature of the defect in development. Early injury to the brain during the first trimester of pregnancy has been proposed to cause the characteristic clefts. These insults may be due to infection, poor blood flow causing stroke, or genetic abnormalities.

Symptoms

Symptoms can vary widely depending on the extent and the size of the cleft. Patients may show developmental delay that can range from mild to severe. Bilateral and open-lip clefts are associated with more severe delay. Affected individuals may have small heads (microcephaly) or
increased pressure due to fluid accumulation inside the brain, known as hydrocephalus. Paralysis of the limbs may be present. The paralysis may be on one or both sides of the body depending on the location of the clefts. Abnormal muscle tone, including decreased tone (hypotonia) and increased tone (spasticity), can be seen. Some patients may have only seizures. Seizures usually present before three years of age, but patients may present with seizures in later life as their only symptom and then be diagnosed with Schizencephaly by brain imaging.

Most Children placed in mainstream schools or special classes are stereotyped with Cerebral Palsy. This could not be more wrong. These children are often highly intelligent but have severe barriers in communication and comprehension. An IEP should reflect a very defined list of goals that are obtainable and rewarding for the child. These children often times have higher intelligence than what is noted. Due to physical challenges it is important to note the child’s ability by trying different forms of communication. Ipads show great results with many children thought to be non verbal.

**Recovery and Rehabilitation**

Due to the congenital nature of Schizencephaly, symptoms tend to be unchanging, and there is little recovery. Physical therapy may be useful in relieving symptoms of spasticity or paralysis and in improving
mobility and ambulation. Occupational therapists may help maintain hand function in those with impaired ability. Most physical abilities will be reached by age 6 but cognitive and educational abilities can flourish throughout life with this disorder. In other words a non verbal child can gain the ability to speak via communication devices or express themselves given the ability to do so with positive communication therapy.

Even severe cases of this disorder show an understanding in most verbal commands so don’t discount the child’s ability to understand and comprehend. Sometimes a simple eye gaze or head turn is a sure sign a child is paying attention and responding with the only gestures they have.

Due to visual impairment many families have stated their Schizencephaly child will respond to items placed in peripheral distance instead of straight one. The damage to the optic nerve can impair a child in the sense they have to maneuver their heads or vision to see things typical children can see in front of them. Always work on giving items or using flashcards in a way the child can see. Rather that is from the side, above or even below the normal vision line of typical children.

**Communication and Signs of Frustration in School**

Communication is crucial to life and is essential to the full human experience. We use language to express our ideas and opinions, which in turn invites interaction that helps us mature and grow. We use words to think through decisions and to tell our family and friends how we
feel and what we need. Many children with Schizencephaly are placed in a class that is classified as Physical Disability, but teachers do not understand that many children with this disorder have serious underlying disorders too.

Many families say their children struggle in school because they are overloaded with sensory and surroundings. For visually impaired children this can be extremely hard on them. In some cases of Schizencephaly there is no cortical blindness. The optic nerve is damaged meaning vision therapy is crucial and can help assist these children with learning how to use their vision to focus instead of being overwhelmed by the noises and distractions around them.

Many of these children have not had the chance to express themselves other than verbally. Please utilize Ipads and communication devices with simple yes and no applications. One in particular that works extremely well is touch switch and Ispeak.

Those who can’t speak clearly or use language effectively find obstacles at every turn. They might find it embarrassing, unrewarding, or too frustrating to participate in a class discussion, which in turn impedes their learning. It might be difficult for them to get or keep a job. Other people may be afraid to talk to them, leaving them feeling isolated and lonely.

The seriousness of these consequences can vary greatly depending on the severity of the disorder, access to professional help, and the reaction of family and friends. For those in leadership positions, it is
especially important to be sensitive to the needs of these children for acceptance and for opportunities to learn, participate, and serve.

Many non verbal children use noises to respond to a parent or caregiver. And a smile from a child with Schizencephaly is always a sign of satisfaction. These children are full of smiles especially when completing a task or when communicating with others.

Learning more about communication problems with children who have this unique and rare disorder can allay our fears and give us the courage to interact more comfortably and lovingly with those who have disabilities.

Schizencephaly and Behavior in School

(What a gigantic topic, for families and schools alike.)

School presents a unique challenge for children with behavior issues. Teachers need tools to use to help provide support and guidance, and administrators need methods for creating a positive learning atmosphere within the entire school. Schizencephaly children have damaged areas in the brain. It is not known each child’s needs because the damage (or clefts) are located in a number of areas depending on the child. Schools and teachers need information on how to work with
these children to address their child’s behavioral challenges in the school setting. They will need tools to create safe and positive learning environments for all children, while providing the informed and positive behavioral support that many students need to flourish.

SCHIZENCEPHALY IS NOT CEREBRAL PALSY!

These children are highly intelligent and can get bored with tasks when their talents are halted by what they are labeled.

Hitting or Slapping:

Physiological Reasons For Injurious Behavior

Some researchers have suggested that the levels of certain neurotransmitters are associated with injurious behavior (neurons and brain injury). Beta-endorphins are endogenous opiate-like substances in the brain, and injury may increase the production and/or the release of endorphins. As a result, the individual experiences an anesthesia-like effect and, ostensibly, he/she does not feel any pain while engaging in the behavior (Sandman et al., 1983). Furthermore, the release of endorphins may provide the individual with a euphoric-like feeling. Support for this explanation comes from studies in which drugs that block the binding at opiate receptor sites.
Pain

Another reason why an individual may engage in head banging, slapping, or hitting others is to reduce pain, such as pain from a middle ear infection or a migraine headache. But most of the time it is a breakdown in simple communication success.

Many young adults and verbal children with this disorder talk extensively about migraine headaches and severe muscle cramping.

First and foremost, you need to understand that the child may have no intention to harm anyone by his/her action. The fact of the matter is that hitting someone will not appear like a big deal to them. For them, it’s just a way to gather attention from people around them. They know from past experiences that hitting someone will fetch them the much required attention, they need for themselves. Schizencephaly is the main cause for many underlying issues, especially migraines and temper tantrums from under stimulation. For that reason, many families have chosen home school.

It goes without saying that if you stop giving a child the attention he/she is trying to gather through this act, then child will gradually stop hitting other kids. Also, there is no point in screaming at the child, rather try to explain things in a cordial manner. The best thing to do is
to give more attention to the child that has been hit so that your kid knows that he/she is doing wrong by hitting someone.

Anticipating a Schizencephaly child’s next move will also help. You will not only be able to put a dead-end to the complaints for the day, but also send a message to the child that his/her actions are wrong.

One also needs to keep in mind that some kids resort to these activities when they are extremely hungry or when they can’t take the boredom any longer. Make sure your child with Schizencephaly is being challenged enough.

Any of these factors can compel the child to vent his/her frustration on some other child.

If you were not able to catch a child in the act, then you can consider punishing a child by making him/her stand back at a boring spot so that they feel left out. Such punishment will make the child realize their wrong doings. That being said; don’t forget to bestow this same child with praises whenever he/she stays obedient. Being generous with praises is a good way to make the child figure out the difference between the good and bad things in life.

For more information or literature, please visit www.WeAreRARE.org
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