



Welcoming a Child with CHARGE Syndrome Into Your Classroom

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Children with CHARGE syndrome are first and foremost children. While their genetic condition is rare and their sensory impairments can be daunting, for the most part their behavior challenges are similar to other students. They may fuss or have a tantrum if they do not get what they want; they may throw materials or cry if their work is too hard; and they may engage in any number of disruptive or undesirable behaviors to get attention from adults and other students. These behavior issues generally respond well to an appropriate treatment based on a thorough functional analysis of behavior. A behavior analyst should be sought to help sort through these challenges. A behavior analyst will observe the student and talk with the educational team and family. The behavior analyst will then offer recommendations for treatment, design a behavior plan, train staff and family members to implement the plan and provide on-going monitoring, follow up and treatment adjustments based on outcomes. To be most effective, behavior analytic treatment requires a regular on-going commitment. If you do not have access to a behavior analyst, you can obtain the name of a behavior analyst by going to www.BACB.com and searching for a Board Certified Behavior Analyst by your city or zip code. You also can call organizations that serve developmentally disabled children and adults such as the ARC, Easter Seals Foundation, children's hospital or university hospital developmental disabilities unit and special education or psychology departments at a nearby university.

Students with CHARGE syndrome may display a number of unusual behaviors. Some may be significant enough to require extra treatment, such as psychiatric and/or medical intervention. These behaviors can include:

- a high level of anxiety or nervousness
- repetitive questions about the same topic
- inflexible behavior
- upsets over changes or disruptions in schedules or routines
- repetitive non-functional behaviors (OCD-like)
- aggression or self-injurious behavior as a result of redirection from repetitive non-functional behaviors
- withdrawal
- autistic-like behaviors
- sleep problems; both falling asleep and staying asleep

The best way to address these behaviors is to work together with the family to design a consistent response to the behaviors. Communication about schedule changes, repetition of the facts, rules and reinforcement can help with anxiety over routines and changes in routines. Time to relax or regroup (this is not time out – see article by David Brown) can alleviate many behavioral difficulties. The best approach appears to be to “work around” many of the behaviors rather than trying to suppress them. Generally speaking, negative feedback, reprimands, physical redirection and punishment have not been found to be effective in treating these behaviors in these children.