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Managing Behavior

What Are Some Behavioral Challenges Typical In Persons with Down Syndrome?

The definition of a "behavior problem" varies but certain guidelines can be helpful in determining if a behavior has become significant.

- Does the behavior interfere with development and learning?
- Are the behaviors disruptive to the family, school or workplace?
- Is the behavior harmful to the child or adult with Down syndrome or to others?
- Is the behavior different from what might be typically displayed by someone of comparable developmental age?

The first step in evaluating a child or adult with Down syndrome who presents with a behavior concern is to determine if there are any acute or chronic medical problems related to the identified behavior. The following is a list of the more common medical problems that may be associated with behavior changes.

- Vision or hearing deficits
- Thyroid function
- Celiac disease
- Sleep apnea
- Anemia
- Gastroesophageal reflux
- Constipation
- Depression
- Anxiety

Evaluation by the primary care physician is an important component of the initial work-up for behavior problems in children or adults with Down syndrome.

The behavioral challenges seen in children with Down syndrome are usually not all that different from those seen in typically developing children. However, they may occur at a later age and last somewhat longer. For example, temper tantrums are typically common in 2-3 year olds, but for a child with Down syndrome, they may begin at 3-4.

When evaluating behavior in a child or adult with Down syndrome it is important to look at the behavior in the context of the individual's developmental age, not only his or her chronological age. It is also important to know the individual's receptive and expressive language skill levels, because many behavior problems are related to frustration with communication. Many times, behavior issues can be addressed by finding ways to help the person with Down syndrome communicate more effectively.

WANDERING/RUNNING OFF

The most important thing is the safety of the child. This would include good locks and door alarms at home and a plan written into the IEP at school regarding what each person's role would be in the event of the child leaving the classroom or playground. Visual supports such as a STOP sign on the door and/or siblings asking permission to go out the door can be a reminder to the child or adult with Down syndrome to ask permission before leaving the house.

STUBBORN/OPPOSITIONAL BEHAVIOR

A description of the child or adult's behavior during a typical day at home or school can sometimes help to identify an event that may have triggered non-compliant behavior. At times, oppositional behavior may be an individual's way of communicating frustration or a lack of understanding due to their communication/language problems. Children with Down syndrome are often very good at distracting parents or teachers when they are challenged with a difficult task.

ATTENTION PROBLEMS

Individuals with Down syndrome can have ADHD but they should be evaluated for attention span and impulsivity based on developmental age and not strictly chronological age. The use of parent and teacher rating scales such as the Vanderbilt and the Connors Parent and Teacher Rating Scales can be helpful in diagnosis. Anxiety disorders, language processing problems and hearing loss can also present as problems with attention.

OBSESSIVE/COMPULSIVE BEHAVIORS

These can sometimes be very simple; for example, a child may always want the same chair. However, obessive/compulsive behavior can also be more subtly repetative, manifesting through habits like dangling beads or belts when not engaged directly in an activity. This type of behavior is seen more commonly in younger children with Down syndrome. While the number of compulsive behaviors in children with Down syndrome is no different than those in typical children at the same mental age, the frequency and intensity of the behavior is often greater. Increased levels of restlessness and worry may lead the child or adult to behave in a very rigid manner.

AUTISM SPECTRUM DISORDER

Autism is seen in approximately 5-7% of children with Down syndrome. The diagnosis is usually made at a later age (6-8 years of age) than in the general population. Regression of language skills, if present, also occurs later (3-4 years of age). Potential intervention strategies are the same as for any child with autism. It is important for signs of autism to be identified as early as possible so the child can receive the most appropriate therapeutic and educational services.

How Should Parents Approach Behavior Issues in Their Child With Down Syndrome?

- 1. Rule out a medical problem that could be related to the behavior.
- 2. Consider emotional stresses at home, school or work that may impact behavior.
- 3. Work with a professional (psychologist, behavioral pediatrician, counselor) to develop a behavior treatment plan using the ABC's of behavior. (Antecedent, Behavior, Consequence of the behavior).
- 4. Medication may be indicated in particular cases such as ADHD and autism.

Intervention strategies for treatment of behavior problems are variable and dependent on the child's age, severity of the problem and the setting in which the behavior is most commonly seen. Local parent support programs can often help by providing suggestions, support and information about community treatment programs. Psychosocial services in the primary care physician's office can be used for consultative care regarding behavior issues. Chronic problems warrant referral to a behavioral specialist experienced in working with children and adults with special needs.

NDSS thanks special guest author Bonnie Patterson, MD for preparing this piece.

NDSS RESOURCES

- Associated Conditions
- Aging and Down Syndrome: A Health & Well-Being Guidebook
- Health Care Guidelines
- Atypical Behavior and Down Syndrome: Webinar Slides
- Children with Down Syndrome Perspectives on Development and Behavior: Webinar Slides

EXTERNAL RESOURCES

- Association for Positive Behavior Support www.apbs.org
 An international organization dedicated to improving the support of individuals in order to reduce behavioral challenges
- Beach Center on Families and Disability www.beachcenter.org
 Conducts reseach and provides information on topics concerning behavior and disability
- Center for Motor Behavior and Pediatric Disabilities
 www.umich.edu/~cmbds
 Conducts and disseminates basic scientific research to better understand the complexity of individuals with Down
 syndrome, cerebral palsy, and spina bifida
- National Association for the Dually Diagnosed (NADD) www.thenadd.org
 An association for persons with developmental disabilities and mental health needs
- National Dissemination Center for Children and Youth with Disabilities (NICHCY) www.nichcy.org 800-695-0285
 NICHCY is a central source of information on pre-adolescents and teens with disabilities. It features a clear and detailed guide to IDEA, the law authorizing early intervention services and special education, and State Resource Sheets to help you connect with disability agencies and organizations in your state
- Positive Behavioral Interventions and Support Technical Assistance Center www.pbis.org
 Established by the Office of Special Education Programs, US Department of Education to give schools information and technical assistance for identifying, adapting, and sustaining effective disciplinary practices
- Research and Training Center on Family Support and Children's Mental Health www.rtc.pdx.edu
 Dedicated to promoting effective services for families and their children who are, or may be affected by mental, emotional or behavioral disorder

DVDS

Using Visual and Behavioral Cues in the Home. Behavioral Services and Products Inc. (2002)

BOOKS

- Body Talk, Teaching Students with Disabilities about Body Language. Crissey, Pat. Bethesda, MD: Woodbine House. (2013)
- Challenging Behavior and Developmental Disabilities. Sigafoos, J., Arthur, M, O'Reilly, M. Baltimore, MD: Brookes Publishing. (2003)
- Challenging Behaviors in Young Children. Hanlon.G. M. Fair Haven, NJ: Edvantage Media Inc. (2006)
- Families and Positive Behavior Support. Lucyshyn, J. M., Dunlap, G., Albin, R.W. Baltimore, MD: Brookes Publishing (2002)
- Individualized Supports for Students with Problem Behaviors. Bambara, L. and Kern, L. New York, New York: The Guilford Press. (2005)
- Learning Disabilities and Challenging Behaviors: A Guide to Intervention and Classroom Management. Mather, N. Ph.D., & Goldstein, S Ph.D. Second Edition. Baltimore, MD: Brookes Publishing. (2008)
- Learning to Listen: Positive Approaches and People with Difficult Behavior.Lovett, H. Baltimore, MD: Brookes Publishing. (1996)
- Parenting with Positive Behavior Support: A Practical Guide to Resolving Your Child's Difficult Behavior. Hieneman, M., Childs, K., Sergay. J. Baltimore, MD: Brookes Publishing (2006)
- Positive Behavioral Support: Including People with Difficult Behavior in the Community. Koegel, L., Koegel, R. & Dunlap, G. (Eds.) Baltimore, MD: Brookes Publishing. (1996)
- Practical Ideas for Addressing Challenging Behaviors. Sandall, S., Otrosky, M. Denver, CO: Division for Early Childhood of the Council for Exceptional Children (1999).
- Teaching Children with Down Syndrome About Their Bodies, Boundaries, and Sexuality. Couwenhoven, T. Bethesda, MD: Woodbine House (2007).