

Questions and Answers About Behavior An Interview with Bonnie J. Patterson, M.D.

By: Bonnie J. Patterson, M.D.

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Q. How does behavioral development differ in children with Down syndrome as compared to their peers?

A. The behavioral challenges that we see in children with Down syndrome are not all that different from those we see in typically developing children; they may occur at a later age and last a little longer. For example, temper tantrums are fairly common in 2- and 3-year-olds. A child with Down syndrome may have temper tantrums that begin at 3 or 4 years of age. The behavior itself is really no different, neither are the techniques you would use to intervene. When looking at behavioral issues in children with Down syndrome, it is important to take into consideration the child's level of functioning. We have to evaluate behavior in the context of developmental age, not only chronological age.

It's also important to know the child's language skills. Many of the behavioral concerns in children with Down syndrome are related to their frustration with communication. We often find that we can successfully address behavioral issues by helping children find verbal and/or non-verbal ways to express themselves and communicate more effectively.

Q. What are some common behavioral concerns in children with Down syndrome?

A. One behavior I am asked about frequently is temper tantrums, which are common to all children. Because the child with Down syndrome often has communication difficulties, temper outbursts can be more difficult to manage, particularly when out in public.

Toilet training is another area of frustration to parents, because children with Down syndrome are usually a little older when they are interested in toileting - and again communication problems can be related to problems with toilet training.

Another big concern we hear from parents is their child wandering off - not because they're angry or running away, but rather, because they simply like to explore the neighborhood. Parents will report that their 6- or 7-year-old goes out of the gate and over to the neighbor's house, but because the parents do not know where the child is, it's a very scary thing. The primary goal of intervention is to keep the child safe by doing things such as making sure that there are good locks on the door and using alarms. Wandering is such common concern that Joan Medlen, editor of Disability Solutions, dedicated a whole issue to the topic.

Another challenging behavior is the child who throws himself down on the ground when he does not want to do something. This can occur in the grocery store, at home, in the classroom, or in the middle of the street. It is different from the temper tantrums because the child is not mad; he's simply saying, "I'm not going." This stubborn, oppositional behavior can happen at any age. When children are 2 or 3 years old, it is easy to pick them up and carry them, but when they are nine or ten, this is much more difficult to manage. It can also be dangerous behavior if it occurs in the middle of a street, it is important for parents to get help with how to manage this type of behavior before it gets out of control.

Q. What are some behavioral concerns in teens and adults?

A. What we are seeing often in teens and young adults are problems with withdrawn and depressed behavior. They stop wanting to go to their jobs or participate in recreational activities, and there may be having sleep problems. There are so many transitions and changes happening in their lives - for example, school is ending, they are looking for jobs, and siblings are often leaving home. They can have the feeling of, "Gee, I'm 18 or 19 - I should be on my own and I'm not. I'm still living at home with my mom and dad."

At this age, we also counsel the adolescent in regard to social skills and sexuality. We use Leslie Walker Hirsch's CIRCLES techniques when we work with our young adults in these areas.

Q. How should parents approach behavior issues in their child with Down syndrome?

A. The first step is to rule out a medical problem as some behavior problems can be directly related to medical issue. The child may have hearing loss, vision problems, a thyroid condition, sleep apnea or celiac disease. All of these things can initially present as a change in behavior. Parents should have their child's doctor evaluate the child to make sure there is not a medical problem. Once that has been done, you should consider psychological or emotional stressors that may be impacting behavior, such as depression, anxiety, changes at home, a sibling moving away, or parents going through a divorce.

Once you've ruled out medical or psychological issues, you can work with a professional to help develop a behavior treatment plan. This involves looking at what we call the ABC's of behavior: the antecedent - what precedes the behavior - the behavior itself, and the consequences of the behavior. It is important to look at both positive and negative consequences. It is always preferable to use positive consequences to reward appropriate behavior. That is something we often forget to do. When our child is being good, we think, "Now's the time to wash the dishes or fold the laundry!" We really should be reinforcing the behavior, saying things like "I really like what you're doing now." Most of us are not used to doing this, and we have a tendency to reward negative behavior by giving children attention when they're doing something we don't like.

A lot of acting out behavior is actually done to get attention, so when we use positive consequences to reinforce good behavior we can decrease negative behavior. Sometimes, however, there must be negative consequences, like "time outs" or, in the case of an older child, taking away privileges, for inappropriate behavior. It's important to remember that, particularly for younger kids, the consequence has to be delivered when the behavior happens. For example, it is often difficult for a child to make the connection between something they did wrong at school and the consequence they get for it at home.

Q. What advice would you give to parents who feel overwhelmed because of behavioral issues?

I would advise parents to remember that they cannot work on all the challenging behaviors at the same time. For example, we may have a child who comes in to the clinic whose parents say: he is having temper tantrums, we cannot get him to bed at night, he throws food, and so on. There may be five or six different concerns, but you have to target a specific behavior on which to focus your energy. As parents develop skills around managing that particular behavior, they will find that those skills carry over to management of the other behaviors.

It is important to remember that the challenging behaviors we see in children with Down syndrome are behaviors that are seen in all children. They may occur at a later chronological

age and last a bit longer. If you need extra help, there are people you can turn to, including your pediatrician, school psychologist, therapists and Down syndrome clinic staff.

About the Author: Dr. Bonnie Patterson is director of the Jane and Richard Thomas Center for Down Syndrome in the Division of Developmental Disabilities at Cincinnati Children's Hospital Medical Center. Her specialties include Down syndrome, learning disabilities and autism, with a focus on behavioral issues. Dr. Patterson is a member of the NDSS Clinical Advisory Board and co-chair of the Down Syndrome Medical Interest Group