BEHAVIOR AND DOWN SYNDROME: A PRACTICAL GUIDE FOR PARENTS

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Parenting can be a bit like setting off on a journey without a map. With each unexpected fork in the road, the caring parent uses intuition informed by prior experiences to choose a path. For some families, this works out just fine. For most of us, a little extra guidance to understanding our children's behavior can make a huge difference. While there are several very good books that address general child behavior, there is not much information available for families specifically designed to support positive behavior for children with Down syndrome. Dr. Stein's guide fills this gap beautifully providing sound, practical advice for parents of children with Down syndrome. Recognizing that each child is unique but also that there are some common areas that can present challenges and also particular strategies that have proven successful, Dr. Stein gives advice that you can start using today. I am so pleased to recommend this guide to the families who come to the Down Syndrome Program at Children's Hospital. I hope you find it sheds light on the road ahead for a more peaceful and fulfilling journey for your family.

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The Down Syndrome Program at Children's Hospital Boston offers specialized services for children with Down syndrome and their families. Program staff work closely with children, parents, medical specialists, community physicians, and educators. The program is a subspecialty service of the Developmental Medicine Center at Children's Hospital Boston.

For more information or support, please call 857-218-4329 or visit our website at *www.childrenshospital.org/downsyndrome*

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WHY DOES MY CHILD WITH DOWN SYNDROME HAVE BEHAVIOR PROBLEMS?

Behavior problems are very common in ALL children. 1 in 10 children has behavior problems that are serious enough to be diagnosed by a professional.

Behavior problems are even more common in children with Down syndrome. 1 in 3 children with Down syndrome has behavior problems that are serious enough to be diagnosed by a professional. Even more children with Down syndrome have behavior problems that might not be diagnosed, but still cause problems for kids and their families.

SOME REASONS THAT KIDS WITH DOWN SYNDROME OFTEN HAVE BEHAVIOR PROBLEMS:

TROUBLE CONTROLLING IMPULSES

Children with Down syndrome often don't notice the "stop signs" that tell them not to behave in certain ways.

TROUBLE COMMUNICATING

When people cannot express themselves or understand others easily, they become frustrated. Children with Down syndrome often have this difficulty.

TROUBLE RELATING TO OTHER CHILDREN AND ADULTS

Many children with Down syndrome are social and affectionate. But often, they may not know how to play efficiently with peers. This can be very upsetting to the child with Down syndrome, and can cause misbehavior.

TROUBLE MANAGING FRUSTRATION

We've already established that children with Down syndrome have reason to be frustrated. Unfortunately, many also struggle to calm down and feel better when frustrations come up. This can worsen behavior problems.

REMEMBER...

YOUR STYLE OF PARENTING DIDN'T CAUSE THESE PROBLEMS

But you can make a big difference by making some changes. That's how this brochure can help you!

KEEP DOING WHAT WORKS

Parenting is a hard job. You are probably already going many things very well as a parent. Some of the tools in this pamphlet may help you do even better!

BE CONSISTENT

Behaviors can change quickly; the hard part is changing behaviors for the long-term. That's why setting up a realistic plan is important. We'll give you some ways to do that in this brochure.

KEEP YOUR EYE ON THE LONG-TERM GOALS

Making some changes now can make a big difference in your child's future (e.g., level of independent living, ability to work, etc.), even you don't see dramatic improvements right away. Remembering the big picture can help you get through daily frustrations.

BEHAVIOR IS A WAY OF COMMUNICATING

A child's behavior—even really difficult behavior—can tell us that she doesn't have a skill that she needs, that she is frustrated, that she is physically uncomfortable, or countless other important messages. Remembering that your child is trying to communicate something can make it easier to deal with difficult behavior.

SAME IDEAS, NEW APPROACH

Use the same approach you would with another child—and modify it. Many of the same behavioral techniques that work with most children are also effective for kids with Down syndrome. You just have to learn to use them in a way that fits your child.

YOU ARE NOT ALONE

Your child's healthcare providers, school system, and community resources are available to give you information, services, and support.

This guide is designed to help you use proven behavioral techniques, with the unique needs of children with Down syndrome in mind. These techniques can help improve your child's behavior. Some are ideas you might feel comfortable trying out on your own. For others, you might ask for help from a professional.

PEOPLE WHO CAN HELP

PEDIATRICIAN

Your pediatrician can speak with you about behavior problems, and can help to rule out medical causes, such as poor sleep. Your pediatrician can also refer you to a mental health professional such as a psychologist, psychiatrist, or social worker.

A consultation with a professional will allow you to understand your child's specific needs and how best to intervene. This might include looking at factors that affect your child's behavior, such

as communication style, cognitive skills, academics, classroom setting, and social and emotional well-being.

SCHOOL

Today's laws state that an education must address all areas of a child's development. If behavior is a problem, it is reasonable to ask the school for some help.

You might ask the school to conduct an assessment of your child's behavior. The formal version of this assessment is called a Functional Behavior Analysis (FBA). This should be conducted by an expert in behavior who can observe your child closely and determine what things come before behaviors, what behaviors are problematic, and what happens after behaviors to keep them going. A comprehensive FBA includes observation of your child at school, at home, and in the community.

STAY POSITIVE

Children with Down syndrome tend to respond to positive behavior techniques rather than discipline. So remember, stay positive and use other tools before resorting to discipline."

THINGS TO TRY AT HOME

While there are many things that experts and professionals can help with, simple daily actions you take at home can also have a huge impact.

GIVE SIMPLE, CLEAR DIRECTIONS

Language is often difficult for children with Down syndrome. The more complicated your speech, the less likely your child is to do what you want. So directions should be specific, directive (a request, not a question), and contain the fewest steps possible.

For example, say: "Brush your teeth now, please."
Don't say: "Can you please go upstairs and brush your teeth before we have to leave for school?"

Say: "Please put your pajamas on."
Don't say: "I already told you it's time to get ready for bed! If you put on your pajamas, I'll come read you a story."

You may wish to speak with your child's school speech pathologist or with a private provider about other options, such as sign language or the use of a picture exchange system.

ESTABLISH A ROUTINE, AND STICK TO IT

Every morning, most adults do their routine in the same order. For

example: use the bathroom, take a shower, get dressed, have breakfast, brush teeth, get lunch ready to take to work. Having a routine makes life easier!

The same is true for children with Down syndrome, but routine is even more important. Your child is likely to do best when the day's structure is the same as it was the day before. Try your best to make a routine and to help your child understand what that routine is.

USE VISUAL SCHEDULES

Many schools use this approach. Here is an example of an after-school routine shown visually. It tells a child that after she gets home from school, she needs to hang up her coat, have a snack, play, read a book, and then eat dinner.

Hang up coat	Have a snack	Play	Read a book	Eat dinner

This chart was easy to make and is easy to follow. Something like this might help your child move more smoothly through his day without so much work on your part.

PLAN FOR DIFFICULT SITUATIONS

We all do better with structure, but we can't always keep things the same. As a parent or caregiver, you know your child best. You probably are aware of some things that are difficult for your child. Anticipating these events can be helpful and you can help your child prepare for changes in order to reduce his or her worry or behavior problems.

One approach to getting ready for what's coming is called Social Stories. This technique involves outlining coming events for your child using a book format. This is often through pictures, but may also involve some words. Social stories can help your child prepare for difficult or complex events such as having blood drawn, going to a new classroom, or having a birthday party.

For more information, see: www.thegraycenter.org/social-stories/how-to-write-social-stories

MAKE TIME FOR THE FUN STUFF

When children are having behavior problems, they tend to get lots of negative attention. It is important to have positive interactions with your child, even when things are at their worst. Make time each day to play a game, read a book, draw, cook a fun dish, or watch a video with your child, even if things have been hard around the house.

REWARD GOOD BEHAVIOR

Set up a system to reward the behaviors you want to encourage. Start by answering these questions:

- What are two or three things you would like your child to do more often?
- Could your child do these things if he or she were willing?
- Does your child need to be rewarded right away to understand the connection between completing a job and getting a prize?
- Can he understand being rewarded later on for something he did earlier in the day or week? (This is quite difficult to do!)
- What does your child like that could be used to reward? Stickers? Poker chips? Quarters to buy something later on? Time to play a game with someone special?

Choose a few behaviors that are important to you, and use a chart to help your child achieve them (see below).

MAKING A GOOD-BEHAVIOR CHART

Children with Down syndrome often respond to visuals better than to being told what to do. Make a chart with pictures of what you'd like your child to do and put it up where he or she can see it, maybe on the bedroom wall or refrigerator. You can draw the pictures, cut them out of magazines, takes photos, or photocopy them from books.

When you're starting out, make the goals really simple and positive. We want your child to like this so he keeps trying! It's okay to help out at first, but encourage your child to do jobs independently to earn a prize after he has tried the chart out for a few days. As you go, add in some more difficult jobs to go with the ones your child has mastered. Remember, go slowly and keep it simple.

Be consistent with your use of the chart. This will not work if you stop doing it when it's going well (or not so well). If you are having trouble keeping it going or are not having success, troubleshoot with a professional to figure out why.

On the following page is an example of a sticker chart to track your child's progress on some morning jobs.

Many parents worry that creating a good-behavior chart is too much work. And it does take some effort. But remember, it also takes effort to instruct your child to do tasks each day and to fight, argue, or try to get her to do things against her will. Some upfront effort and time now can actually save you time later by setting routines that your child understands and will be willing to follow. Involving your child in making the chart can also be a fun activity.

	Change	Wash hands	Draw picture	Use bathroom	Prize
Monday					
Tuesday					
Wednesday					
Thursday					
Friday					

Helping your child learn to complete jobs is not just to make your life easier. It is also important for his future. Children with Down syndrome tend to learn best through repetition and structure. If you can help teach these skills now, your child is more likely to be able to complete them independently as an adult. That can make a big difference in his life later on.

Charts have to be adjusted frequently to reflect new skills and changes. You may want to consult with a professional to help you do this.

PICK YOUR BATTLES

Wouldn't it be great if we could make everyone in our lives behave exactly as we'd like them to? With other adults, you know that you can't always get what you want. The same is true of your child. A lot of arguments, standoffs, and heartache can be avoided by simply choosing your battles. It is often beneficial to step back and consider whether a certain behavior is worth reacting to.

Consider the following when determining which battles to pick:

- Is the behavior dangerous? If so, then you need to intervene.
- If the behavior is not dangerous, is it one of the two or three behavior problems that you'd most like to decrease? If not, you might want to let it go...for now.
- If the behavior is not dangerous but is just bothersome, you might be best to ignore it. Not only will you save yourself some headaches, but this might even get rid of the behavior.

AVOID POWER STRUGGLES BY OFFERING CHOICES AND EMPOWERING YOUR CHILD!

Power struggles are very common between parents and children. A power struggle means that a child wants to do one thing, and a parent wants her to do another. And nobody wants to give in.

Power struggles can be very upsetting, and are often very hard on both parents and children. They can be particularly hard for children with Down syndrome, who are often social and affectionate and may find it very upsetting to be fighting with a loved one.

When thinking about power struggles, keep these things in mind:

- Just like you, your child would like some control over his or her life.
- You are the boss, but people tend to like bosses who listen to them and given them some power.
- When you offer people even a little bit of control, they tend to feel better.

To avoid a power struggle, you might try the following:

- Offer your child a choice. If there are three things that need to be done, allow your child to decide in what order he or she will complete those things.
- Provide your child with an "if-then" option. If she does what you want first, she can do something of her choosing next.

MAKE HARD TASKS MORE FUN

If a child struggles with bath time, bring a favorite toy to bath time to make it less challenging.

DISARM AND DISTRACT

Picture a two-year-old boy who is crying because his pacifier was taken away. This child is too young to respond to most forms of punishment, and this behavior is not something that

should be punished anyhow. Many parents, whether they know it or not, use the “disarm and distract” principle. That is, they would simply give this toddler a new toy to help him stop crying.

This same principle can be used to manage behavior problems or strong emotional reactions in older children and children with Down syndrome. Forget about the old behavior, or whatever triggered it, and introduce something new to help your child calm down and shift her focus.

KEEP IT INTERESTING

In the car you can sing, put on a DVD, look for letters outside the car. In the market, you can give the child a list or pictures of food items so they can find them.

CORRECTING: MODEL A BETTER WAY

Sometimes, children misbehave because they don’t have any other options to cope with a situation. For example, a preschool-age child who is struggling with speech might kick another child because he does not know how to ask that child to play.

In cases like this, it may still be necessary to discipline your child, but you should also consider doing some teaching or coaching. Your child’s teachers or healthcare providers may be able to help instruct you in this technique.

In the example presented above, you or your child’s teacher would tell your child that kicking is not OK. Then you might model how to ask another child to play. Since children with Down syndrome often learn best with repetition, this may need to be modeled many times. Schools are often willing to assist with this type of intervention.

Another option is “replacement behaviors”. This is another behavior the child can do to avoid a negative behavior. For instance, a child who pinches his peers might be taught to give high fives!

THE POWER OF IGNORING

Many children with Down syndrome are very social. They often love to receive attention, even if it is negative. If a behavior is not unsafe, try ignoring it and giving no feedback. Sometimes this is enough to get rid of a behavior!

USE TIME-OUTS WISELY

These days, most parents are familiar with the idea of a “time-out.” But many parents, teachers, and others working with children find time-outs difficult to use effectively.

To understand time-out, we have to think about why kids behave badly in

the first place. Most of the time, there is something that makes a difficult behavior fun or rewarding for the child.

For example, imagine that a child is in the doctor's office with her parents and her pediatrician. In the middle of the conversation, the child turns out the lights in the office. The doctor and the child's parents all jump out of their seats, run over to scold the child, and scurry to turn the lights back on.

Before the child turned off the lights, her parents and doctor were probably chatting away and not paying much attention to her. Turning the lights off changed that quickly!

Time-out is based on the idea that, in order to stop children from doing something, we have to make that behavior less fun and/or rewarding. In the case of turning the lights out, a good response would be to have everyone stay very calm, turn the lights back on, and go back to their conversation. This removes the motivation for the child to repeat this behavior.

The practice of time-out takes this one step further. In order to remove anything fun or interesting about a behavior, we find an area of the home or classroom that has nothing rewarding about it. This might be a corner of the room or a hallway. It is important that in the time-out space, there are no toys, television, or people to make it fun.

Reacting to your child's bad behavior by yelling, crying, scolding, and becoming upset isn't fun for you. But remember that these reactions (getting a rise out of you) can be interesting or rewarding for your child. When your child misbehaves, try to avoid these reactions. Keeping calm makes it less likely that your child will repeat the behavior in question. Stay calm, and feel free to use other terms like "take a break."

TAKE AWAY PRIVILEGES

Another way to discipline effectively is to take things away from your child when he or she misbehaves. For example, if your son hits his sister, he may lose TV time.

Keep in mind that discipline is only going to work if your child understands it. Therefore, you should only take something away from your child for misbehavior if he or she understands the reason for this.

The solutions we've presented in this brochure are only some of the many ways you can help your child with Down syndrome improve his behavior. You'll need to work with your family, school, and professionals to se what's the best fit for you and what's most effective for your child. For more information or support, please contact the Down Syndrome Program at Children's Hospital Boston at 857-218-4329 or www.childrenshospital.org/downsyndrome

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Dr. David Stein is a pediatric psychologist within the Developmental Medicine Center at Children's Hospital, Boston and an Instructor at Harvard Medical School. He specializes in assessment and behavioral treatment of children with developmental disabilities. Dr. Stein is the staff psychologist for the Down Syndrome Program at CHB and completes neurodevelopmental evaluations, behavioral consultations, and parent training for children with Down syndrome. He also designed a successful parent training group program for providing positive behavior support to children with DS. Dr. Stein began his work with children with Down syndrome during his own childhood as a volunteer with local disability support groups. A Boston native, he attended Tufts University where he majored in clinical psychology with a focus in child development. Dr. Stein then completed his doctoral degree in clinical psychology at the Massachusetts School of Professional Psychology. He completed his pre-doctoral internship in child psychology at Harvard Medical School-The Cambridge Hospital and his post-doctoral fellowship in pediatric psychology at Children's Hospital, Boston. Dr. Stein also completed a fellowship with the Leadership and Education in Neurodevelopmental Disabilities (LEND) Fellowship Program in 2010.