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Positive Behavior Support
&
Functional Behavioral Analysis

Practical Approaches to Behaviors That Drive You Crazy (Also Known As “Challenging Behaviors”)

by Paul White

Many individuals with Down syndrome thrive on the approaches any thoughtful and loving family would use to support behaviors in typically developing children. Other children and families, though, struggle with added challenges such as a physical disability, communication abilities, or a mental health diagnosis in addition to Down syndrome. These challenges are often expressed through challenging behaviors such as stubbornness, persistent opposition, or even self-injurious behaviors. In these situations, love and thoughtful parenting are the foundation to survival, but often more is required.

Understanding behavioral support can be overwhelming. It is like navigating a rocky, windswept coast in a sailboat with too little crew and no chart. This article offers some markers for families to use to navigate their course. It is based on the practical experiences of the Waisman TIES program. In partnering with parents over the past thirteen years, three main areas of focus consistently emerge:

Attitude

Support Teams

**Considerations for
Behavior Support**

Attitude Attitude

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Kids Driving You Nuts? Here's Help

I know I'm not alone. Not because people tell me. For a long time I thought admitting our kids with Down syndrome drive us crazy at times was against the rules. But as my son gets older, I find more parents willing to join in when I start a conversation about "the time I thought I was going to scream." I'm sure you know what I'm talking about. It's that day when you really needed to skip a part of the usual morning routine, but your son wasn't going to have anything to do with *that*. Everyone knows it is impossible to brush your teeth *before* you change your clothes. Or the time when you thought you would break out in hives if you heard one more rendition of a scene from *The Spy Who Shagged Me*. Or the time your son brought his imaginary friend to the dinner table for Grandma and Grandpa to meet. That was fine, but when he began to argue with this friend about whether or not to eat the beans, it was time to crawl under the table.

As isolated events and anecdotes, these situations don't sound too bad. If told the right way, they're funny like any other family story. But when these behaviors are constant, or continue for months or years, they are difficult to deal with. They are "challenging behaviors." Learning how to cope with our children's challenging behaviors is a tough task. It requires tenacity, insight, and patience. In his article, *Practical Approaches to Behaviors That Drive You Crazy (Also Known As "Challenging Behaviors")* Paul White shares strategies for understanding, supporting, and living with someone who has challenging behaviors.

To begin the process of analyzing the myriad considerations surrounding a behavior, it is helpful to observe to *understand*. For example, when I want to understand my son's behaviors I try to write down the events, people, and emotions that surround the challenging behavior as soon as possible. When I do this, my only goal is to get information onto paper. It is days or weeks before I read through the journal to look for similarities or patterns. It is through this unemotional look at what is happening in our family that I begin to understand how we can change the situation, environment, expectations, or attitudes to lessen the intensity of the problem. Not all behaviors require this amount of work. But when faced with a particularly puzzling situation, it is a good way to remain objective.

Remember the effect of any change or consideration you make is rarely immediate. It may take several weeks to understand and try different strategies before you find the right way to handle the situation for your family. For this reason, it is very important not to forget to support *yourself* in the process. It is essential to make time for yourself, for your relationships with other family members, as well as for your relationship with your child with Down syndrome in order to remain positive. It's O.K. to admit that there are days that your child with (or without) Down syndrome drives you crazy. In fact, it's healthier to admit it than be swallowed up by the myth that "they're such happy children who never cause any trouble." But in the process of being honest about your feelings, don't let the craziness take over. Use the information in this issue of *Disability Solutions* to take steps toward dealing your child's behavior in a positive manner.

Joan E. Guthrie Medlen, R.D.

Practical Approaches to Challenging Behaviors

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Attitude

Attitude is the first place to focus when positively supporting people with challenging behaviors. It is the foundation upon which other supports are built. Parents are caught in an emotional bind with their children as they try to support them. This is especially true when challenging behaviors are involved. While you want to be upbeat and sustain positive thoughts about your child, it is, at times, nearly impossible in the face of persistent and intense behaviors such as stubbornness, anger, aggression, or destruction. It is normal to develop a “bad attitude.” Who doesn’t at one time or another? Yet parents and teams who have not developed ways to work out of these low periods cannot establish the foundations necessary for productive behavioral supports. Here are some strategies to use to return to a positive focus.

- ◆ Attempt to keep the unique aspects of your child foremost in your mind. It is sometimes easy to frame a child as a disability or mental health issue. Guard against using statements such as: “my Downs, bi-polar nine year old still can’t ride a two-wheeled bicycle.” In this statement, the child is lost in the disability. A child-first approach might be, “My son just learned to ride his three-wheel bike and he is quite proud. So are we! Considering the fact that he struggles with issues related to Down syndrome and difficult moods he is doing all right.” The way you think and talk about your child indirectly affects your attitude, particularly when things are difficult. Look for your child’s abilities as much as possible during the down times and all the time.

- ◆ Remember that behavior change is slow. There are no “magic answers.” Any approach recommended must be filtered through your definition of common sense to be effective. When considering a challenging behavior, ask yourself whether your child needs to change or if you—or someone else on the team—need to make changes. Families who make changes to reduce behaviors that are very difficult for their child to change often report greater harmony in the home. Accepting this essential understanding is an important skill for parents and takes time to learn.
- ◆ Be open-minded about what works or is worth investigating. It is often a combination of various strategies and sensible ideas that begins to lift the pressure you and your family experience when struggling to establish balance between the needs of your child who needs support, his siblings, and your own needs.

If you need to work on improving your attitude, remember to take small first steps. Any change, even ones that bring a better attitude, takes time to accomplish.

Support Teams

Support teams are a necessary nuisance. There are, however, two compelling reasons to dedicate time from your busy lives to meet with others to discuss how to support difficult behaviors. First, most of the children with special needs we see in our program warrant some level of care or support beyond what most families can provide. That means in order to be successful, someone is supporting your child all day long in various ways such as assisting with grocery shopping, being a watchful roommate, or provid-

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Guidelines for Productive Meetings Regarding Behavioral Support

Develop a team spirit and positive outlook.

- ◆ Remember the importance of working together and the difficulty of doing so when the subject is challenging behaviors.
- ◆ Begin the meeting with team members checking in with one another.
- ◆ Each team member share a recent successful experience with the person.
- ◆ Use humor.
- ◆ Include food and beverage.

Determine a facilitator.

- ◆ Develop an agenda.
- ◆ Length of meeting.
- ◆ Keep the discussion focussed.
- ◆ Balanced participation.
- ◆ Summarize team consensus.

Determine a recorder.

- ◆ Develop a written behavioral support plan that is easily read and accessible to providers for ongoing review.
- ◆ Use the support plan as a vehicle to capture new ideas generated in ongoing meetings.
- ◆ Update the plan on a regular basis.
- ◆ Record any "special tasks" members have been assigned.
- ◆ Assure that the support plan is shared with the providers who will need to see it.

Guidelines for effective meeting participation.

- ◆ Listen to the ideas of others.
- ◆ Maintain a positive focus.
- ◆ Guard against dominating the conversation.
- ◆ Guard against being too passive or not participating.
- ◆ Work toward a team consensus.
- ◆ Keep the person's best interests as the focus of the meeting.

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ing support to stay on task at work. When your child's behaviors are an issue usually each group of people working with him (at home, school, work, respite, and so on) develops their own plan for dealing with the situation. Rarely does any one group use the same approach as another. To improve behaviors these individual groups will need to discuss things as one big group, or support team. Everyone benefits from sharing ideas as well as providing some continuity in the way that support is being provided. A second advantage of teaming is providing necessary, added support that parents are entitled to (often by law) and need to be successful raising a child with special needs.

The nuisance of teams needs to be acknowledged as well. Coordinating a group of adults around behavioral support for someone is not easy. First, it is difficult to find the time for "yet another" meeting. Second, these meetings are often filled with tension. When behaviors are creating problems, everyone becomes anxious. At times like this, people tend to take it out on one another before they are able to look at a situation objectively. For instance, does this sound familiar?

(School and home are interchangeable.)

School: "If the parents weren't so lenient, John would be better behaved."

Home: "The school is pushing John way too hard. No wonder he hit the aide."

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There are many different techniques to diffuse the intense emotions that surround support meetings (see box page 4). Most important, gently remind everyone you are meeting because you are important to “Johnny.” For this meeting, the focus is on how to best support him for success. It takes time, it takes work, but a well-oiled support team is a great asset to your child as well as the rest of your family.

Considerations for Behavior Support

With a realistic attitude and a cooperative team assembled, what should you consider in an effort to lessen pressure caused by the behaviors? Here is one way for the team to determine which area of your child’s life requires specialized attention. To illustrate each area considered, I have added a vignette based on factual life stories we have encountered at the Waisman TIES Program.

Consider the Environment

Pay attention to where your child lives, plays, goes to school, and goes to work. Can the environment be modified in ways that would reduce the negative impact of behaviors? Think about ways families childproof their home for toddlers and take that same concept to a whole new level.

Our teenage son Steve spends all of his time talking to himself. He engages in two-way conversations with imaginary friends and can be quite loud. It is very hard to be around him for any period of time. Weekends seem like an eternity. While we have ideas on how to help Steve and ourselves deal with this long-standing behavior, we also need to have some peace and quiet.

We came up with a plan to arrange our house so we could live with his constant talking. Our finished basement is now Steve’s new “hangout room.” It has his stereo and other “cool” stuff down there. We insulated the room for sound and added a solid core door at the top of the stairs. Steve likes it. He spends time with the family upstairs and knows where to go when he has the urge to talk to his imaginary friends. Weekends don’t seem quite so long anymore.

Consider Your Child’s Disability

Finding time to learn about your child’s disability and how it affects behavior is difficult. However, it is important to be well-informed about your child’s interests, motivations, how they learn, and how their disability may play into their attitude. Important information is discovered through reading books about the specific disability, learning about effective teaching strategies, networking with other parents, and talking things over with school personnel and members of your support network. By continually asking questions, seeking new information, and discussing struggles you will find solutions that are often more easily implemented than you could think of alone.

For the past few years bedtime with Jeannie has been a constant battle. Every time I ask her to go upstairs, put on her pajamas, brush her teeth, and get into bed she flat out refuses. The more I ask the worse it gets. I get angry and she ends up crying.

Lately things have gotten better; not because Jeannie is listening better, but because I am a little wiser. I read an article about receptive language and developmental levels and a light bulb went off. I was giving her what they call four-step requests,

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and that was probably too much for her. She was getting too much information and too many requests at one time. We all know that when Jeannie feels overwhelmed she gets stubborn. Her reactions were reasonable when I understood how much I was asking of her at one time. I also talked with some other parents who commiserated with me about their child's stubborn ways. I think there's a lot to be said for networking and finding out how much our kids have in common. I also read that she is not the only child with Down syndrome to have a stubborn streak.

Now we are taking the bedtime routine one step at a time, which helps a lot. She still has stubborn moments such as when she'd rather watch a TV show than brush her teeth, but I have become a little more tolerant. From what I read it comes with the territory.

Consider Relationships

The primary way children receive support emotionally is through positive relationships with families and loved ones. When challenging behaviors are intense or persistent the important bond between your child and his family members becomes strained or even severed. Ironically, children with the most challenging behaviors are the ones who are most in need of positive relationships.

During periods of increased challenging behaviors, pay attention to whether relationships have been affected or are more distant. If so, strive to develop a plan to "reconnect," rebuild, or create new connections that will reestablish a relationship between you and your child or within your family.

My son Adam has Down syndrome and autistic spectrum disorder. Last fall we went through a really bad period. He wasn't sleeping at night and spent his entire day spinning objects. Adam always liked to spin but now that was all he wanted to do. I was at my wit's end. It was very hard for me to watch. We met with school staff and others to try to figure out how to get Adam back on track. As

we were talking, someone asked the entire group if the way that we were relating to Adam had been affected by his behaviors. It dawned on me that it had. I had not wrestled with Adam in the living room after supper for weeks. We always went out for a father-son donut run on Saturday morning. I couldn't recall the last time that happened. Our bedtime routine had become very rigid.

Over the next few weeks I made a conscious effort to reconnect with Adam. It was not easy and sometimes not so fun (all that spinning). Sometimes I had to set my watch and will myself to be positive with Adam for the next half-hour despite the fact that I was not getting much back. Eventually Adam worked out of that mood. We tried a lot of ideas at once so I am not sure what turned him around. Whether or not it was my efforts to reconnect that made the difference, it sure didn't hurt.

Consider Behavioral Approaches

Sometimes behavior modification approaches are not where you and the team need to place your energy in supporting challenging behaviors, and other times behavior modification is very helpful. Consider using a behavioral plan when it is apparent that challenging behavior is an inappropriate, but effective, effort in meeting a need. An example of this is when a child has learned if she screams long enough her Mom will give her a cookie. The screaming is inappropriate, but it works.

Select behavioral approaches that have a positive focus and that are compatible, easy to implement, and comfortable for your family. Find programs that break down "behavioral jargon" into everyday language that everyone will understand.

The essence of a behavior plan is to pair, or match, a positive outcome with a positive behavior that can replace the challenging behavior. For instance when the child who usually screams to get a cookie uses the sign for "cookie," she should be met with a

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warm and approving response (and maybe the biggest cookie in the batch). Behavior programs that simply punish or give negative feedback for challenging behaviors can stop the current behavior, yet create other problems (low self-esteem or strained relationships with parents). Usually behaviors have a purpose for the child who does them whether acceptable to us or not. If what they need or are trying to communicate is simply discouraged without an acceptable replacement to that behavior being offered, the child will find another, probably equally unacceptable behavior to fill that need.

Good, effective behavior plans help families and teams remain positive and consistent throughout the day. When discipline needs to be used it is done in a thoughtful and controlled manner.

Here are some simple guidelines for a positive behavior support plan:

1. How is the challenging behavior meeting a need for the child?
2. What behavior could meet that need in a way that is acceptable to the family?
3. What is the best way to teach the child to use the new behavior or skill?
4. What is the best way to pair the new behavior with a positive response (i.e., praise, rewards)?
5. Is it necessary to set limits when the child is using the behavior? If so, assure that the limits are a form of caring and not punishment.

Dan is my adopted son. Somewhere in his early teens he learned that stealing was a good way to get things he needed. It was immediate and for every time he got caught he got away with it another ten. It seemed as though the more we punished him, the worse his stealing became. Finally Dan's team made a concerted effort using some positive behavioral guidelines. The obvious behavior to replace stealing was honesty. Instead of talking to Dan about not

stealing we promoted honesty. Between home and school we spent time with Dan working with him on what he needed and how he could get it in an honest way. We made sure that we followed through on these plans.

We paid attention to periods of time of sustained honesty and provided a lot of spontaneous rewards and attention. When stealing did occur, Dan had to return the item and pay restitution. Once he had to go to court. At these times we did not overreact but we were not a whole lot of fun either. We followed the notion that sometimes negative attention can actually reinforce bad behaviors. As soon as periods of honesty reemerged (we trained ourselves to pay attention) we again provided positive attention.

We continued for about a year without much change. Gradually we noticed that the periods of sustained honesty had increased. There were no dramatic changes but things got better. Now Dan is an adult and has a good supported job with a company that makes expensive theater lights. His employers know Dan only as an honest person.

Consider Everyone's Expectations

Pay attention to what expectations you have for your child. Ask yourself if they are reasonable from your child's point of view. When expectations are too high, children with Down syndrome may become frustrated because they cannot meet them. Likewise, when expectations are too low, children with Down syndrome (or any child) will become frustrated and uninterested in activities. Sometimes this contributes to "learned dependency," particularly in children with special needs. Whenever a child is acting out and you are not sure why, family and team members should examine what is being asked of the child and whether or not it is reasonable. Developing accurate expectations for a child with Down syndrome is not easy and requires ongoing attention. The most common intervention that we use at

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the Waisman TIES Program that has positive results is to appropriately adjust our own expectations.

Jim was always referred to as an adorable boy. People liked working with Jim. He could charm the stripes off a zebra with his smile. When Jim became a teenager he began to gain weight. Jim's watchful team became concerned and wanted to turn this around early. His special education teacher, who was very health conscious, coordinated a fairly rigorous diet and exercise plan. Jim, on the other hand, saw absolutely no benefit to the plan and was not at all interested.

Jim's well-intentioned team proceeded with the plan with strong expectations that Jim participate. Soon, what used to be occasional temper flare-ups became a regular occurrence. Aggression and stealing (food or money for food) also began to emerge. The team tried to use a reward program to no avail. It seemed as though the more they tried, the worse his behaviors became. Finally the expectation of diet and exercise was significantly modified and life improved for everyone. Jim is now in his late teens and is somewhat heavy. Jim is OK with his weight and the team had to deal with its own issues of losing that cute little boy. A more reasonable and less restrictive approach was enlisted. Good eating habits are always encouraged and sometimes are successful, but the team also knows when to back off.

Consider Ways to Reduce Stress

As parents and families you do all that you humanly can to support your child. An effective team pays attention to stress families experience dealing with challenging behaviors for long periods of time. One solution is to create a plan to expand the number of people in the child's life who are providing direct care through shared parenting or respite. A good exercise is to ask one another how long you can be with your child and be positive and nurturing in the presence of challenging behaviors. The time varies from

person-to-person depending on the intensity of the behaviors and their tolerance level. It can be a day, it can be a half-day or it can be an hour and thirty-six minutes. Beyond that time, patience and nurturing are depleted and it is time for someone else to provide care and support while Mom and Dad "recharge their batteries."

Emotional recharging is a serious subject for parents. Sometimes the best thing that you can do for your child's challenging behaviors is to spend the next weekend with respite in place while you indulge in serious diversions: exercise, drama, nature, travel, humor, humor, humor, did I mention humor? Find whatever works for you that replenishes you in a deep and enduring way. Shared parenting plans take work and can never fill all the gaps. It takes time to plan for respite, coordinating behavioral support, and the ability to open your home to others to provide shared parenting. Some suggestions on setting up a type of shared parenting can be found on page 16.

I have two boys and love them both. I have a great husband and a perfect country home. My oldest, Stevie, has Down Syndrome and some complex mental health issues. We have spent a lot of time educating ourselves, teaming with school and other professionals and sustain what I hope is a positive focus for Stevie and his brother. Being with Stevie is a lot of work. He demands constant attention. If he does not need me, I have to worry why. With little provocation tantrums can emerge which are punctuated by aggression and self-injury. My stress level has been so high at times that I struggle to keep from getting depressed and find it difficult to be a good parent, not to mention spouse, friend, or co-worker.

The only way we make it day to day is with a lot of help. Stevie is in school all day and goes to an after school program until five. Every other weekend

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How to Use the Index

This issue of *Disability Solutions* marks the beginning of our fourth publishing year. This supplement contains an index of the articles, reviews, and resources included in the last 6 issues of *Disability Solutions* to help you find articles at a later date. It is our hope that *Disability Solutions* will continue to be helpful to you, or someone you know, long after the month it is published. Please remove this section (four pages) to use as a separate guide.

In this index supplement we have listed articles by their subject (some have more than one) and their title. Resources and books that have been reviewed are listed by the publication title. After each subject or title, you will find the volume number (they are all volume 3), issue number, and page number where it was published. For example, "Augmentative and Alternative Communication Techniques in Inclusive Classrooms, 3:4, p. 1, 3-9" means that the article, "Augmentative and Alternative Communication Techniques in Inclusive Classrooms," can be found in volume 3: issue 4, pages 1 and 3-9.

If you see an article or information in the index from an issue that you do not have, you can either download it from our web page (www.disabilitysolutions.org) or send a request for a printed copy for \$2.50 per issue. We have a limited supply of printed back issues and may not be able to meet everyone's needs, but we will try our best.

We hope that *Disability Solutions* has been, and will continue to be, a valuable resource for you. If you have comments or suggestions, we welcome your input.

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Practical Approaches to Behaviors That Drive You Crazy

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on Saturday a respite provider fills up Stevie's day with plenty of action. My husband and I take turns with a pretty equitable child-care plan, he does the lion's share in evening and I take the mornings. This spring our respite provider is taking Stevie for a week while we go to Florida with his brother.

We often struggle with guilt about having to have so many people in Stevie's life. I feel bad that he will not be with us in Florida. It also takes a tremendous amount of work to set all of this respite in motion. Sometimes I feel like our home is Grand Central Station. But this is our reality. It is what we need to do to balance the needs of Stevie and our family.

Consider Medication

There are some situations when behaviors occur that are resistive to non-medical behavioral supports. Sometimes parents get the sense that despite how careful they are with the environment, expectations, stress level etc. these behaviors are still pretty intense. Perhaps your child is quick to anger and can't let it go, seems to need to do the same things over and over for extremely long periods, or is responding to internal stimulation that goes beyond self-talk.

Including a psychiatrist or physician with experience in psychiatric medications on the team may be appropriate. Psychiatry is not an exact science and the doctor will need a lot of help from you and the rest of the team to determine if medications can or are helping. You might have your child use a medication on a trial basis to determine whether it has positive effects. Be sure to educate yourself on what should happen and what side effects to look for. Be good observers and reporters to the doctor. This might mean keeping a small journal of observed differences or filling out a checklist the physician gives you. Sometimes medications are tried and do not help. Sometimes it takes a few trials to find

the right medication. Sometimes the medication helps, but the side effects outweigh any benefit.

Even when medications do help, they should be used in conjunction with other positive behavioral supports. Often times the medications help the child control a certain tendency enough so other types of support can begin to be effective.

Jane is an adult with Down Syndrome and also has obsessive compulsive disorder. Her apartment had to be in perfect order. All of the plates were stacked with the patterns in the same position, numerous picture frames had to face in one direction and even dirty laundry was folded neatly in the dirty laundry container. Jane spends all of her time creating this order and becomes quite upset when this order is not in place. Since this type of perfect order is impossible to attain, Jane was upset a lot of the time and as a result it was difficult for others to be with Jane.

A behavioral consultant joined the team and exhausted his various ideas. A psychiatrist began meeting with Jane, her family and the team. She spent as much time talking with the team as with Jane. She prescribed a medication that is often prescribed for obsessive-compulsive issues. The living staff noticed that it made her restless. They tried a second medication at very low dose. Nothing seemed to happen so the dose was gradually increased. After a few weeks the team (parents, supported living and work staff) began to notice subtle changes such as a slight decrease in rigidity and increase in calmness. The medication was gradually raised over a period of a few months again with positive results. After one medication increase staff noticed that Jane was sleeping more than usual. The medication was decreased.

The behavioral consultant again joined the team to develop a structured way to teach Jane how to be more flexible approach toward her life. She responded positively. The changes were not dramatic but life is better for Jane and her loved ones.

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The Original Social Story Book

Reviewed by C.K. Campbell

The Original Social Story Book by Carol Gray. Published by Future Horizons, 1993. www.futurehorizons-autism.com. ISBN: 1885477198. \$31.95.

I am new to the use of social stories to help a child with autistic spectrum disorders master the complexities of everyday living. I was eager to see what solutions I would find in *The Original Social Stories Book*, an interesting collection of instructions and descriptions put together by high school students in psychology and sociology classes from Jenison, Michigan.

While most of the stories seem helpful, I was disappointed. Many of the stories are appropriately general, but several do not go far enough in setting goals and limits that

are required when working with people with autism. For instance, not once in the many descriptions of going to public places do the authors mention that it is a good idea to stay with the group, parents, or friends, instead of wandering off – a behavior all too common among people with autism. When describing how to play hide-and-seek, it would be helpful to mention that when the game is over, players come out of hiding, or that when taking tests, students are not permitted to look at other students' papers. The section on sharing a pencil advises that it is good to help someone by sharing, but neglected to mention that letting someone borrow something means they will return the item. And a story about taking care of fish neglects

Practical Approaches to Behaviors That Drive You Crazy

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After twenty-five years of providing support to persons with developmental disabilities, I have come to view behavioral support as an art rather than a science. According to Webster's Dictionary, the definition of art is "the conscious use of skill and creative imagination." The many families who have been given this daunting life-task and seem to cope are the ones who gather the skills required to grasp their child's disability, behavior, and related issues. With this understanding they work together with other people to create supports for the child and blend everyone's skills in creative and imaginative ways that

work for their child and family. The parents are always the experts and others (educators, psychologists, psychiatrists) are there to provide support.

Paul White, M.A., has been on staff at the Waisman Center at the University of Wisconsin for thirteen years. The Waisman Center has an international reputation in the area of research and dissemination of positive practices for persons with developmental disabilities. Paul is the director of a program titled Community TIES. The TIES mission is to offer support to adults and children with developmental disabilities and challenging behaviors in an effort to assure continued participation in community life.

The Original Social Story Book

information about how fish need to stay in the water or they will die – I know this from personal experience.

And while the chapter on how to create social stories is useful, some of the instructions go unheeded by the authors within the presented stories themselves. The instructions clearly advise avoiding the phrase “I can,” but it was used very often in the stories. In particular, I question the use of “I can” when instructing how to accept gifts. Saying “thank you” appeared to be an option for these social storywriters, instead of an etiquette requirement. I would never tell my so-called “normal” children that saying “thank you” is optional, and it seems insulting to imply that a child with autism can cut corners on socially acceptable behavior.

This extends, too, to the use of the word “try.” “I always *try* to listen to the bus driver” (italics, here and following, are mine) advises the author of one story about riding a bus. In the story about going swimming, the authors suggest “I must *try* to keep my head above the water *most* of the time.” In defense, they did go on to explain that such an action is necessary for breathing’s sake – but the wording was vague enough to be questionable.

The balance of topics seems unequal as well. While there are six stories about brushing teeth, only one discusses using a toilet, and even that one stopped at standing versus sitting. Arrangement of topics is sometimes odd or repetitive. Topics such as having lunch or going to the school library appear in multiple chapters.

For the most part, and with the exceptions mentioned above, the language is simple and instructive. There are only a few examples of wording that need more explanation.

For instance, in a story about families the writers describe them as “sounding blocks,” a phrase that should be replaced by something more appropriate. Two stories about taking a bath refer to emptying, or draining, the bathtub, but do not go into detail about how to do this. A third allows the reader to leave the bathroom with the bathtub still filled with water. The storywriters tend to use vague language throughout the stories in the book. Using words such as “usually,” “sometimes,” and “almost” tend to negate the instruction: “*Almost* every day I get dressed?” “*Sometimes* people have things that do not belong to me?”

There are several stories that were highly appropriate for people with autism. One story about brushing teeth advises changing toothbrushes is OK, and why; a story about eating cookies reminds readers that people eat differently. Taking turns is discussed in a useful way. Two big issues – changes in personal schedules and differences in television programming – are covered well. There are stories that are useful to the general population as well. I’m thinking of “Other Things I Can Do Besides Playing Nintendo” in particular.

These stories provide a good starting point for using stories to teach expected behavior. Using the suggestions in the book’s final chapter, parents and educators can write their own social stories, and modify existing stories to suit their own needs. The intent of this book is a good one; it simply would have benefited from more attention in its final editing stages.

C.K. Campbell is a freelance writer and Show Business Forum manager for Genie and Delphi online services, and mother of three children, one of whom has Down syndrome and PDD. She and her family reside in Webster, NY.

Learning to Listen: Positive Approaches and People with Difficult Behavior by Herbert Lovett, Ph. D. Published by Paul H. Brookes, Co., 1997. ISBN: 1-55766-164-2. \$27.00.

In this ground-breaking book, Lovett shares the importance of meeting the person with challenging behaviors on a human level. Lovett spends time illustrating how behavior, even when aggressive, is often communicating something that is difficult for someone with a disability to convey appropriately. Other themes include how actions we believe are respectful may be hurtful and create a barrier between you and the person with a disability. If you or someone working with your child is new to using positive behavioral supports for challenging behaviors, this is an invaluable resource.

The Inclusion Notebook. Problem solving in the classroom and community Volume III, No. 2, Winter, 1999. Post Box 8, Gilman, CT 06336. www.penneycorner.com Back issues: \$5.00 + \$2.50 s/h. Subscriptions: \$18.00

This issue of *The Inclusion Notebook* contains a wealth of practical information regarding behavior. Each article emphasizes the need to understand why a student is behaving in a particular way. The information and strategies are designed for classroom use, however, the process of understanding difficult behaviors is the same at home and at school. Parents can easily adapt the ideas and forms to meet their needs at home. A free "Pull-Out" Section regarding Functional Behavioral Analysis is available from their website (above). Advocates and educators will find effective and fair tools in this journal.

How to Make Positive Changes in Your Family Member's Life With Group Action Planning. Published by The Beach Center on Families and Disability, 1994. The Beach Center, University of Kansas, 3111 Haworth, Lawrence, KS 66045, 785-864-7600, www.lsi.ukans.edu/beach/html/products.htm. \$4.00.

This booklet is really the "how-to" for creating a *Group Action Plan* for your child. A *Group Action Plan* basically is a process of creating circles of support around your child and your family to build support in the community, in your house of worship, or in the school community. This booklet explains the steps to implement *Group Action Planning* including how to choose a facilitator and how to create successful meetings. The work of building this support network, however, remains with the family and those who support them.

"Using Functional Behavioral Assessment to Develop Effective Intervention Plans: Practical Classroom Applications" by T.M. Scott and C. M. Nelson. *Journal of Positive Behavior Interventions*, Volume 1, Number 4, Fall 1999. pp242-251. Published by Pro-Ed Publications (www.proedinc.com). Single copies, \$10.00.

This is a particularly good, but very "professionally written" article. The authors focus on the reason for understanding behavior: to create and promote the type of behavior you want, not to punish the behavior you do not want. The authors recognize the need to educate school personnel and families to effectively use functional behavior analysis.

Web Resources:

If you have access to the Internet, the following web pages are worth researching:

- *Center for Effective Collaboration and Practice:* cecp.air.org/resources/problembehavior/main.htm
- *The BEACH Center on Families and Disabilities:* www.lsi.ukans.edu/beach/pbs/html
- *The University of Kentucky Behavior Home Page:* www.state.ky.us/agencies/behavior/

Call for Everyday Solutions: What Do You Do When...?

The most effective solutions to difficult situations come from the people who are dealing with the problem every day. There is not one solution to a problem. It is collective wisdom—ideas from everyone—that is powerful when you find yourself with a new problem.

We would like to dedicate an upcoming issue of *Disability Solutions* to sharing these ideas and strategies from our readership. To do this, we need your help. Listed below are some categories for your ideas. You are not limited to that list at all. Send us ideas, strategies, tricks, games, or anything you found helpful in a situation with your child, sibling, student, or friend. Some areas to consider include:

Curricular modifications:

- ◆ Learning to tell time,
- ◆ Learning about money,
- ◆ The periodic table, or
- ◆ Writing a story for language arts.

Learning "life skills" at home:

- ◆ Daily routines,
- ◆ Choosing clothing (work, home, free time),
- ◆ Cooking,
- ◆ Keeping leftovers,
- ◆ Health care, or
- ◆ What to do when you're sick.

Community Activities:

- ◆ Riding the bus,
- ◆ Eating in a restaurant,
- ◆ Inviting friends over,
- ◆ Choosing activities (clubs, volunteer opportunities), or
- ◆ Religious activities.

Your ideas do not need to be complicated. The best idea may be very simple. You do not need to be a writer to participate. We can do the editing, but we can't come up with *your* ideas.

If you have a "solution" you would like to share, please use the form on page 19. If you do not use the form, please include the type of information requested. A sample solution is on page 18. Due to space constraints, ideas we are unable to publish will be shared on our web page sometime after publication.

Please send your solutions by March 10, 2000. You can send your ideas to us by mail, fax, or e-mail.



**Don't
Delay!**

Send your ideas to:

Disability Solutions
Idea Exchange
PMB 179

9220 S.W. Barbur Blvd. #119
Portland, OR 97219

Fax: 503-246-3869



**Deadline:
March 10, 2000**

Disability Solutions Idea Exchange

Name: Joan E. Guthrie Medlen

Phone/Fax Number: 503-244-7662

Address: 9220 S.W. Barbur Blvd #119
Portland, OR 97219

E-mail: editor@disabilitysolutions.org

Name of solution: Lotto Board Template

Describe the problem:

My son does not have much speech. He uses Picture Communication Symbols™ with printed words and photographs with words for communication boards and voice output devices to communicate. The lotto games I found in the store used photographs that had no writing to label the picture. The photographs were also too close together for his fine motor skills. Others thought he was matching incorrectly, even though the picture was half on its match. The items to match needed to be placed farther apart. We also wanted to be able to choose different words and symbols, and to begin with fewer symbols to match. We tried to make individual lotto boards for all these purposes, but it was time consuming and frustrating. We needed a greater variety and more flexibility to be able to use them effectively.

Describe the solution:

(Include information about materials, cost, directions for making the tool, or directions for implementation if appropriate.)

I created a lotto board with see-through pockets. There are four pockets on a board. They are approximately 1/2 inch apart. The pockets can be empty to reduce the number of pieces to match. I then made two picture/word cards for each match. One card goes in the pocket and the other is for matching.

Materials needed:

Poster board or cut up file folder

Laminate (contact paper will do)

Picture and word cards

Self-adhesive business card size label holders found at most office supply stores (Cardinal Holdit!® binder accessories is one brand).

Symbols with words made to fit in the pockets and laminated.

Describe how the situation changed:

This allows us to choose a variety of vocabulary quickly and to mix the words and symbols in any way we choose without having to create a new board.

We have also used this method for making selection boards. It is particularly helpful for this if your child plays with picture cards rather than pointing to the picture.

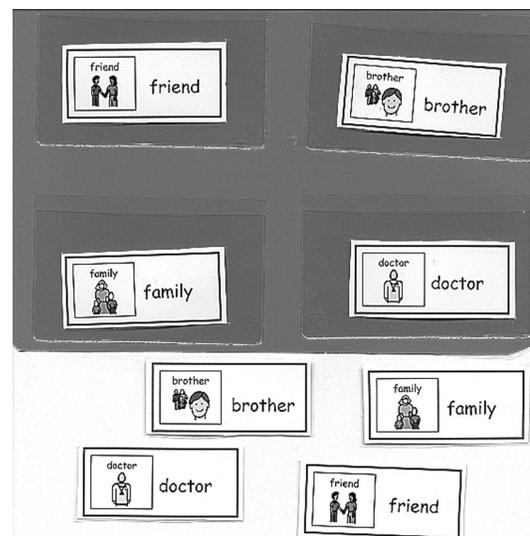
Directions

Step one: Laminate a piece of black posterboard, 9 X 14 1/2.

Step two: Affix business card sized clear pockets to the laminated poster board.

Step three: Make two sets picture and symbol cards to use for lotto.

Step four: Choose the words to work with. Put one card in the clear pocket and use the other for the child to match (see figure).



Disability Solutions Idea Exchange

Name:

Phone/Fax Number:

Address

E-mail:

Name of solution:

Describe the problem:

Describe the solution.

(Include information about materials, cost, directions for making the tool, or directions for implementation if appropri-

Describe how the situation changed:

Deadline: March 10, 2000

Send your solution to:

Disability Solutions Idea Exchange, PMB 179, 9220 S.W. Barbur Blvd #119, Portland, OR 97219

fax: 503-246-3869

E-mail: share@disabilitysolutions.org

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Disability Solutions

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