A resource for
families and others interested in
Down syndrome & developmental disabilites

Disability Solutions

A publication o
Creating Solutions

Volume 3, Issue 5&6

September/October 1999

Special Issue

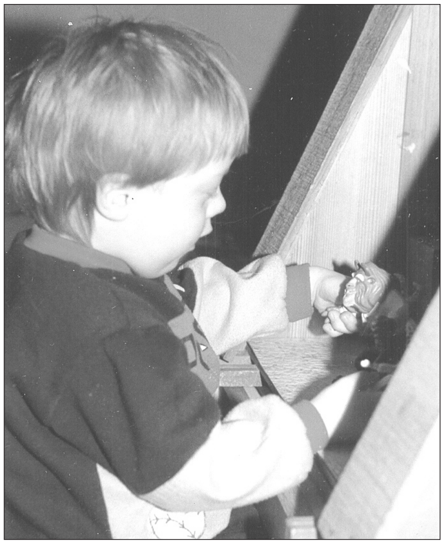
Down Syndrome & Autistic Spectrum Disorder

More Than Down Syndrome: A Parent's View

by Joan E. Guthrie Medlen

It must have been in a different life…when my greatest concern was "Down syndrome." In those days, I'd find Andy in his room re-enacting "Beauty and the Beast" with rubber figures in his dollhouse. Andy gave "Beast" a particularly throaty voice. We saw pretend play; we saw personality in his play. He imitated his brother's every move, which Ryan found endearing. Together they investigated the corners of the house, gleefully chased me with their cars, or ran to the window to see the fire truck go by. Our lives looked like what you expect from a family of a child with Down syndrome. But it must have been a different life because it bears no resemblance to our lives with Andy today.

Today, at age 10, an unexpected or unfamiliar visitor to our home sends Andy running to hide in his room until he decides to investigate them. Today I must say "look at me" a hundred times to ensure he notices and listens to me. Today I see him watch other children and want to play with them, yet be overwhelmed or scared. This means he begins to "flap," and the other children are equally afraid of him. Friendships require a lot of work, training, and facilitation by the adults in Andy's life. At the end of today I will gather up the jump ropes and clackers that are inseparable from Andy and put them in the "dangly things" box for him to earn access to again tomorrow by working through a specific task with me. Today I know the isolation of being the mother of a child who is different from his peers with Down syndrome.



Continued on page 3

in this issue

The Journey Continues

This issue of *Disability Solutions* contains the largest collection of articles for families of children with Down syndrome and autistic spectrum disorder available. These articles address the first concerns a family may have about DS-ASD. They include: developing effective language and communication skills, sensory integration, tips on changing inappropriate behavior, teaching new skills, a medical overview, and more. But there is simply too much information to cover. In the future we will look at other equally important topics such as: teaching strategies, strategies for communicating, developing family support, and looking ahead to the adult years.

It's been a few months since I wrote the article about our journey with Andy (see page 1). As I write this, it seems unfair not to let you know how things are going as we head to press. After so many years of complicated school situations, we have begun the best school year I can remember (knock on wood!). Andy has grown tremendously in the 17 months since he received the diagnosis of autistic spectrum in addition to Down syndrome. He has a gaggle of friends who honestly enjoy being with him. Sometimes that means they all just hang out in the sun. Sometimes, when he is "stuck" in a transition, it is his classmates who are successful in helping him understand where he needs to go next. From my view as his mother, the greatest changes have been the rediscovery of the child I knew years ago. I thought I had lost that part of him forever: his laugh, his teasing, his love of dancing and more. Even more astounding is the rate at which he is growing emotionally and academically, in ways I didn't expect. I can't keep up!

Even with all of these good things, we still face sleep deprivation, the need for 24-hour positive behavior support, time-consuming teaching methods to learn everyday tasks, and the struggle of trying to be a family. To deal with this, we have begun a process of asking people into our lives as a part of our circles of support. It is hard. It is scary to let people into our lives. It's even harder to ask. It is, however, necessary if Andy and Ryan are going to have meaningful and fulfilling lives. If you are interested in developing this type of support for your family or for someone else, Ann and Rud Turnbull of the BEACH Center in Lawrence, Kansas have developed a method worth investigating called *Group Action Planning*. You can find information and materials related to setting up a GAP at the Beach Center Website (http://www.lsi.ukans.edu/beach/html/products.htm) or give them a call (785/864-7600).

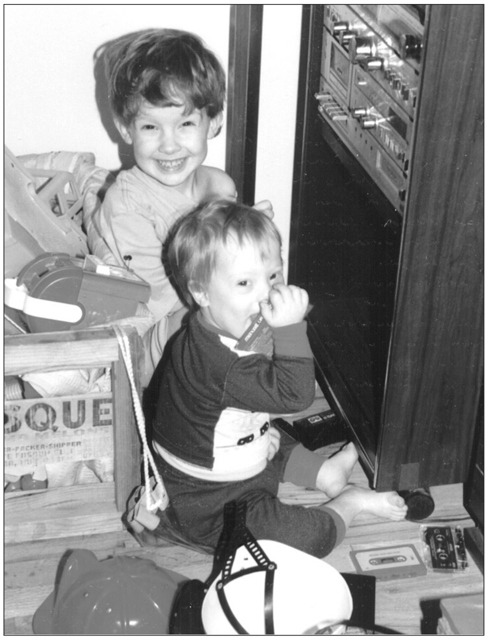
It has been four years since our lives dramatically changed due to Andy's autism. I don't want to live them again. They were lonely and full of despair. If you have a friend or know someone in your support group who is having similar struggles, don't wait for them to ask you for help. They aren't coming to you or to the group meetings because it hurts or it is too hard to leave their child right now. If you want to help, show up at their door and offer to clean, cook, do the laundry, sit and talk, drive their other child to soccer, or be with their child while they sleep for a while. The gift of your time, without judgement, will mean the world to them. It *still* does to me. After all, we're far from done with this journey.

—*Joan E. Guthrie Medlen*

More Than Down Syndrome

Continued from page 1

And yet, today is better than yesterday. "Yesterday," somewhere around age 5-7, he seemed to magically "forget" nearly everything: potty training, eating with utensils, his signs, word approximations, all of it. He was afraid of everyone and everything. So intensely afraid, he lashed out at us with no warning and for no reason we could understand, hitting, biting, with wild eyes and a beet-red face. It seemed Andy never slept more than three hours a night. He spent his nights dangling socks and jump ropes endlessly while I sat nearby waiting for the right time to suggest we try to go to bed one more time. And yesterday I had trouble finding someone to listen to my despair and questions about his developmental regression. Yes, it must have been a different life, a different child....



And so goes the story of our journey, one that leads to a dual diagnosis: Down syndrome and autistic spectrum disorder. Discovering the reason for Andy's developmental history and giving it a name has been a long and very difficult journey. It is full of controversy, arguments, heartache, and unending questions.

It began similar to many parents of children with Down syndrome. During my pregnancy we were informed I had a low AFP value, which led to an ultrasound, and for us, nothing more. Somehow in my heart I already knew Andy had Down syndrome. The day he was born and the extra chromosome confirmed, I did what I seem to do best: ask questions and investigate. This intense, never-ending inquiry, coupled with the belief that my children deserve my best effort, serves me well. I'm not sure where it came from except perhaps from my training as dietitian—it's always better to say, "I don't know, but I'll go find out." I didn't know anything about Down syndrome and I was determined to find out.

I read articles in the medical library at work and saved money to buy books about Down syndrome. I asked our Early Intervention Home Consultant about teaching Andy sign language when he was about 7 months old. She didn't know what to think. Like me, she headed to her best resources: the team speech language pathologist and recent literature on the topic. The speech language pathologist felt that we should begin with concrete objects instead: a nipple to say he wants a bottle, a piece of a toy to ask for it, and so on. She felt that he didn't have the prerequisite skills for sign language. But Andy didn't like using objects. So, our EI Consultant and I chose some first signs and gave it our best shot on our own. He learned to sign "more" almost immediately. Information is powerful. I kept reading, asking questions and challenging.

During this time, my two boys were inseparable. Andy loved his big brother. He followed him everywhere even before he could walk. He dressed like him, he wanted to sleep with him, they played together with cars, on the slip-n-slide, and so on. There were times when people would stare at us or we would feel the "usual" pains of having a child with a disability, but for the most part, I had grown to accept this twist to my family. We had *fun*.

I can no longer pinpoint when things began to change. After so many years it is hard to tell the difference between the change from his being with me at home all day to attending a preschool environment and the possible signs of autism. In preschool, though he enjoyed it and most of the staff was positive, I was asked for the first time to demonstrate Andy's ability to make a choice. I insisted the key was in how things were presented. If I had known how many times I would have this same conversation about "choosing," I would have videotaped it. After letting the special education consultant pick two toys for Andy to choose between, I interrupted his play and asked him to come talk with me for a minute. We sat on the floor cross-legged with a connection I've always known with him. I asked him to scoot closer and told him we needed to show his teacher how he likes to choose his toys. I showed him both toys and asked him which one he wanted to play with. He chose one, we played for a few minutes and he wanted to leave. I told him it was fine he wanted to be all done, but he needed to say "good bye" to

Continued on page 4

More Than Down Syndrome:

Continued from page 3

the toy first. “Bah,” he said, and he was off to greater prospects. With that demonstration, I returned to the consultant expecting to hear validation that Andy could, after all, make a choice. Instead she asked, “Is that about the length of time you would expect him to play with that toy?” Always a challenge, always a test, always a question, but never belief. I felt defeated and insulted, but I still believed in my son.

I began to wonder why Andy wasn’t talking. One of the assistants in his classroom said he seemed to do well with another student’s picture book. I couldn’t find anything written about children with Down syndrome using symbols. He increasingly didn’t fit my image of a “typical” kid with Down syndrome. When I shared my concerns with other parents they replied, “There is no ‘typical’ Down syndrome.” It must be my imagination, I decided. Years later, I looked through the notes I kept and found multiple references to a regression in his skills. I attributed this to teaching strategy and environment, but I quietly wondered if there was more.

Our induction to school-aged services was a rough one. Andy had not continued with his acquisition of sign language despite our work at home and with a private speech pathologist. He used about 10 sign approximations (though he understood many more) and only a few word approximations. Communication was a problem and his struggles in this area were seen as a reason not to be included in a general education classroom. I received my label, “mother in denial.”

During this year Andy began to play excessively, almost obsessively with strings, ropes, and other “dangly things.” To me, this was a sign that we really needed to work on finding a way for him to communicate. He also didn’t seem to enjoy being with the other children like I expected. He preferred to watch and was careful in his attempts to join in. He delighted in watching his classmates perform skits and puppet shows, but would resist participating. His play at home lacked the imagination we had seen in the past: he no longer created his own version of “Beauty and the Beast” in his dollhouse or imitated what we did around the house. But I was so mired in philosophical warfare about his placement, I missed these subtleties in his development. The focus shifted from advocating for the best strategies for teaching Andy to learning the laws surrounding his rights to a Free and Appropriate Education—and reacting to blatant violations of those rights. I often wonder how different things would be if my energies weren’t distracted by these concerns.

Even so, we moved him to a different school, in a different neighborhood, where he was to spend part of his day in a general education classroom and part of his day in a special education classroom “remediating” some of his skills. For us, this was a disaster. At the time I was certain it was solely because of the incompetence of the teacher and her inability to control a classroom. These troubles were horrific for Andy, who couldn’t come home and tattle on everyone to his parents. He was poked, pushed, prodded, and teased by other children. We sent a copy of the photo cards he used at home to communicate to school with him. They were left in a closet. In this classroom, within the first three months of school, my son lost virtually every skill I had cherished: no more trip-training, no more word approximations, no more signing, no more happy child. He began biting us and reacting violently for no apparent reason. His eyes would grow wild and his face red with combined fear and anger. He would lash out at me with no warning. I was covered in dozens of bite marks. This was *not* “typical” Down syndrome. Where did my child go? He was 6 years old.

Today I believe this is when Andy’s autism fully entered our lives, even though we didn’t recognize it. Yes, the classroom was unacceptable, but his reaction and the regression are, I think, primarily due to autism. I’ve heard parents and professionals say that with the onset of autism, it’s a downward spiral until you hit bottom. Once there, there is nowhere to go but forward and up. I don’t think Andy’s “low” needed to be quite so devastating.

We moved Andy mid-year into a life skills classroom where the teacher wanted him. She had experience with children living the hell Andy was in and believes in and values all of them. In two weeks, the biting decreased dramatically, he was trip-trained again, but he still dangled things—anything—incessantly.

Over time we noticed Andy doing other things that were puzzling. Things that were not what I equated with Down syndrome:

- ✧ He liked being alone. He didn’t seem to miss us if we didn’t interact with him. He was content, though not productive.
- ✧ He seemed lost to us in his world of his own filled with dangling objects and watching videos.
- ✧ He seemed interested in other children, but scared of them.
- ✧ He was afraid of everyone. When we had visitors or family, he would run to his room and slam the door.

A Parent's View

- ✧ He had no speech, nor did he have communicative intent.
- ✧ He didn't know how to "play." He seemed to forget the imaginary games he played and never imitated anymore.
- ✧ He would be overcome by certain situations, such as a large room (like a gym) and either "belly flap" (lay down on his stomach, arch his back, and flap his arms and legs) or run around in circles flapping his arms.
- ✧ Various evaluations mentioned his "scattered skills" instead of a global developmental delay. He seemed to learn step 3 before steps 1 or 2.
- ✧ He seemed to need very little sleep. He would sleep for 3 or 4 hours and then go to school. I was exhausted and dreaded the night.

What did all this mean? His teachers, therapists and I would talk about it often. In those discussions I would hear questions and comments about his scattered skills and other things, but no solutions.

When I have questions, I begin that same process that started when he was born: I question and investigate. I believe Andy deserves more than an "adequate" education or support. He deserves best practices in all disciplines so he can be successful. Every child does.

Any time there are concerns about a child's development, it is best to begin by looking at possible medical concerns. Andy is very healthy really. He did not have any complications at birth. He had pneumonia when he was young followed by recurrent ear infections, middle ear fluid, and eventual tubes. He now has "permanent" tubes that will need to be removed soon. His hearing is "low normal," his vision is fine, and though he will get every virus traveling through the air in a classroom, he is generally well.

Having ruled out medical concerns my focus hovered intensely around finding a way for Andy to communicate. I believe that behavior is communication and that odd behaviors are Andy's way of telling me things. Discussions with the speech pathologist at the school were frustrating. I was told Andy didn't have the prerequisite skills, he didn't have communicative intent, and he didn't know how to choose. It felt like a recurring nightmare. At home, though, Andy did make choices using a Yak Bak (a hand-held message recorder) and pictures. I focussed on step three where we were seeing success and everyone else was looking at steps one and two. I don't believe this happens because people don't want to teach Andy, but because they want an ordered progression. It is true that all the steps serve a purpose. But to engage him you must capture his interest. And what Andy wanted was some *control* over his life.

Reading all I could understand about Augmentative and Alternative Communication (AAC), discussing it with a friend, and armed with BoardMaker™, a computer program to generate Picture Communication Symbols, I dove in with both feet. Before I knew what happened, I was constantly running to the kitchen to answer my son's demands on his voice output device. At first, he pushed *any* button just to see me run. What power! "Golly, I push this button and everyone comes running. How funny. Let's see how many times I can make them do it." I didn't get much support for using this method in the classroom, but our private speech pathologist worked along with me devising games and methods that helped us see what Andy might like to say.

And you know what? He played games. He played pretend games with Bert by activating buttons that said what his Bert figurine wanted to do (eat, drink, or read a book) and together they would make Bert do what he commanded. We were going forward again. The key was not focussing on steps one and two, but meeting him at step three, where he got what he was interested in, then reaching back to pick up steps one and two.

Understanding what makes Andy tick is like a drug to me. It's addictive. Success leaves me wanting even

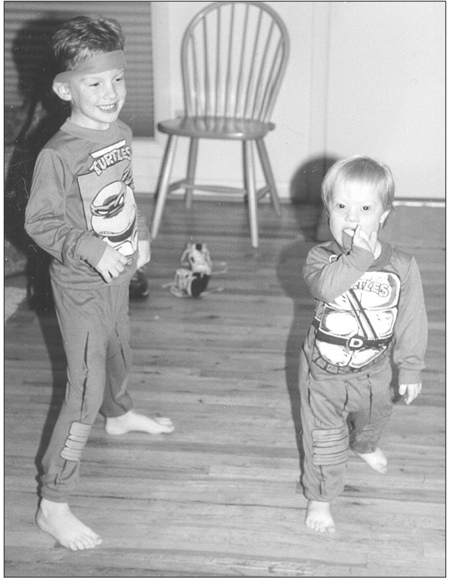
Continued on page 6

More Than Down Syndrome:

Continued from page 5

more. Having nothing more tangible to go on than Down syndrome, I read Pat Oelwein's book, *Teaching Reading to Children with Down Syndrome* (Woodbine House, 1995) again. Using my computer and photographs, I began making books for Andy. They all had themes: "I See..," "I Like...," and "Who Is...." Andy loved them and was drawn to the pictures. But I soon realized he was endlessly looking at the pictures. It became another way for him to leave our world for his. I was stuck. He still spent most of his life with his jump ropes, staring at the photos in his books, and flicking any picture cards we tried to use.

Frustrated and unable to find a way in to my son's world of dangly things, I began to look through journals, IEPs, photo albums, and videotapes for ideas. One night I pulled out an old video of Ryan and Andy playing. Andy was not yet walking. He was two years old, and Ryan 5. I was mesmerized by the joy of their play. They chased an electric car, danced to music, and ran to the window to wave goodbye as their Dad left for work. There sat Andy, being hugged and smothered by his brother, beaming into my camera. Looking directly at me. I slipped in a tape of Andy working with his voice output device the week before at a speech session 7 years later. I was stunned. They did not resemble the same child; his brightness was gone. He looked up at the camera that invaded the therapy session, but there was no real connection with the person behind it. He didn't look at me. My heart sank. I cried. That toddler will never be back.



I shared the tapes with a few friends. One friend asked me in a way I couldn't misunderstand, "Have you considered autism? Have you considered having a full-blown evaluation done? It'd be hard, but I think you owe it to Andy." It wasn't the first time he had mentioned it, but it was the first time I heard him. I didn't *want* to consider it, but I had no other choice.

Over the years I have made some connections that I hoped would be helpful. I e-mailed a co-director of the Down Syndrome Medical Interest Group, of which I am a member. I explained to him that I wanted to investigate the possibility of Andy having autism, but that I was unwilling to go to "just anyone" for this evaluation. There is no Down Syndrome Clinic in my state, nor is there one nearby. In order to feel confident about what I learned in an evaluation, I wanted to see someone who really understood Down syndrome *and* autism. If we had to travel, I wanted to go to the best.

There were two doctors who had the experience I sought. Both were three time zones away from us. When I contacted them, they were helpful, compassionate, and very knowledgeable. For the first time I was telling someone about my child who had seen it before. Neither made me feel I was over-reacting or in denial, nor did they question what I shared about Andy.

I shared with Andy's teacher that we were taking a week off to get an evaluation for autism by someone who had experience with other children who have Down syndrome and autistic spectrum disorder. To my surprise, she told me she was relieved I was doing this because she had been wondering how she could suggest this to me about Andy. I often wonder how many people felt this way.

Over the course of five days, we were scheduled for a full evaluation: Medical, Neuropsychology, Behavior Psychology, Speech and Language, Augmentative Communication, and Occupational Therapy. We were scheduled for an EEG, but due to scheduling conflicts that was postponed for another time.

Andy scored well within the range of autistic spectrum. Medications designed to help with some of Andy's more difficult behaviors (impulsivity, fear, and repetitive motions) were suggested. I always thought that moment would be devastating, but it wasn't. I've pondered why that is and now realize that it is because every person we met with, including the neuropsychologist who conducted Andy's first—and last—IQ test (I don't believe they're very helpful), greeted Andy with respect and looked for all the things he *could* do. For the first time I wasn't hearing about prerequisite skills or what he couldn't do. In fact, during our visit with the augmentative communication specialist, I was able to share my frustrations about making choices and prerequisite skills for using augmentative communication. She spent time trying to understand everyone's concerns, but in the end, she agreed with my assessment of Andy. He made choices for her.

A Parent's View

He liked using voice output. She felt he understood communication and had communicative intent, but that he didn't understand the rules to communicating because they were different at home, at school, and in the community.

At the end of our week I left a new mother. I learned a lot about my son and he was given a new diagnosis. Most importantly, I was validated in the overall direction I was taking with him. What a gift. It is still among the best things I have done for Andy and for myself.

The diagnosis or label of Down syndrome and autistic spectrum disorder (DS-ASD) came as no surprise. Even so, I had no idea what to do with the information. How does it change what I do with Andy? How does it change how he learns? Literature searches turned up next-to-nothing on the subject.

Since our visit I have focussed my questions and investigation on solutions for Andy: teaching methods, communication strategies, and even behavior plans. We chose to try one of the medications suggested to us with what I consider good results. He doesn't get lost in his own world anymore. He is staying in ours, along with his jump ropes and other favorite toys. He is clearly making choices, and beginning to answer questions with his picture symbols and voice output device. And this year he made some friends at school.

This issue of *Disability Solutions* is a collection of information that I feel is essential for parents who are either concerned their child may have DS-ASD or is diagnosed with DS-ASD. It is all information I wish I could have had immediately:

- a medical and research overview,
- steps to communication,
- suggestions for teaching,
- suggestions for changing inappropriate behaviors,
- an explanation of sensory integration,
- observations of gross motor skills, and
- resources.

Every resource in this issue has been helpful to me in some way. There isn't information specifically about how to teach children with DS-ASD, but there is information about teaching children with Down syndrome and information about teaching children with autistic spectrum disorders. One of the best pieces of advice I received early was from a father of an 18-year-old with DS-ASD: "Consider the autism as the primary disability. Andy may have Down syndrome written all over him, but it's the autism that gets in the way of his learning and reacting in a way that you expect from a child with Down syndrome." This approach has worked well.

Andy and his cousin, Kealey Medlen, play with a

Don't be afraid to admit that you need help. I wish I had asked for help earlier. The needs of a child with DS-ASD are immense. It is exhausting. The obstacles you face in going forward will always be there. This is especially true because the idea that children with Down syndrome can also have autistic spectrum disorder is relatively new to professionals.

I have found it difficult to accept that I cannot do this alone. But I can't. There really is no reason to try to except for my pride and fear of being rejected when I ask for help. I am now beginning to work on developing a better support network for our family. Even this takes time and energy that is in short supply. Yet I can see the impact it will have on our quality of life. It gives me hope.

Yes, it must have been a different life when my greatest concern was "Down syndrome." We are here now, in a new life, we are going forward again, and Andy is happy. We have a long way to go with him. There is still much to learn. I hope that by sharing our journey to this point other parents and professionals will open their hearts and minds not only to the idea of the dual diagnosis, but to the possibilities that exist in every child. If you are a parent of a child

✧ ✧ ✧

Joan E. Guthrie Medlen is the mother of Ryan, 13, and Andy, 10, who has Down syndrome and autistic spectrum disorder. Joan is a registered dietitain and the editor of Disability Solutions*. She and her family reside in Portland, Oregon*

Down Syndrome and Autistic Spectrum Disorder: A Look at What We Know

by George T. Capone, M.D.

During the past 10 years, I've evaluated hundreds of children with Down syndrome, each one with their own strengths and weaknesses, and certainly their own personality. I don't think I've met a parent who does not care deeply for their child at the clinic; their love and dedication is obvious. But some of the families stand out in my mind. Sometimes parents bring their child with Down syndrome to the clinic—not always for the first time—and they are deeply distraught about a change in their child's behavior or development. Sometimes they describe situations and isolated concerns that worry them such as their child has stopped learning new signs or using speech. He is happy playing by himself, seeming to need no one else to make the odd game (shaking a toy, lining things up) he is playing fun. When they call to him, he doesn't look at them. Maybe he isn't hearing well? He will only eat 3 or 4 foods. The suggestion of a new food, or even an old favorite, brings about a tantrum like no other. He is constantly staring at the lights and ceiling fans. Not just while they pass by, but obsessively. Getting him to stop staring at the lights is sometimes difficult and may result in a scene. He requires a certain order to things. Moving a chair to another spot in the room upsets him until it is returned to its usual spot.

Some families do their own research and mention they think their child may have autistic spectrum disorder (ASD) along with Down syndrome. Others have no idea what may be happening. They do know it isn't good and they want answers *now*. This article is for families in situations like this and other, similar ones. If your child has been dually-diagnosed with Down syndrome and autistic spectrum disorder (DS-ASD) or if you believe your child may have ASD, you will learn a little more about what that means, what we are learning through data collection, and insights to the evaluation process.

There is little written in the form of research or commentary about DS-ASD. In fact, until recently, it was commonly believed that the two conditions could not exist together. Parents were told their child had Down syndrome with a severe to profound cognitive impairment without further investigation or intervention into a diagnostic cause. Today, the medical profession recognizes that people with Down syndrome may also have a psychiatric-related diagnosis such as ASD or Obsessive Compulsive Disorder (OCD). Because this philosophy is relatively new to medical and educational professionals, there is little known about children and adults with DS-ASD medically or educationally.

Over the past six years we have gathered data and studied DS-ASD at Kennedy Krieger Institute. We have collected and analyzed data from clinical medical evaluations, psychological and behavioral testing, and MRI scans of the brain. We now follow a cohort of approximately 30 children with DS-ASD through the Down syndrome Clinic, possibly the largest group of children with DS-ASD that has been gathered.

What Should I Look For?

Signs and Symptoms

As parents, it is common, if not expected, for you to worry at times about your child's development. It is also common to hear only part of the criteria for a particular label. This is especially true when it comes to DS-ASD because there is little information available on the topic. This can be especially troublesome if your child suddenly picks up a new habit you associate with ASD such as incessantly shaking toys. The children we have seen at Kennedy Krieger Institute who have DS-ASD present symptoms in several different ways, which we have separated into two general groups:

Group One

Children in this first group appear to display "atypical" behaviors early. During infancy or toddler years you may see:

- Repetitive motor behaviors (fingers in mouth, hand flapping),
- Fascination with and staring at lights, ceiling fans, or fingers,

A Look at What We Know

- Extreme food refusal,
- Receptive language problems (poor understanding and use of gestures) possibly giving the appearance that the child does not hear, and
- Spoken language may be highly repetitive or absent.

Along with these behaviors, other medical conditions may also be present including seizures, dysfunctional swallow, nystagmus (a constant movement of the eyes), or severe hypotonia (low muscle tone) with a delay in motor skills.

If your child with Down syndrome is young, you may see only one or a few of the behaviors listed above. This does not mean your child will necessarily progress to have autistic spectrum disorder. It does mean that they should be monitored closely and may benefit from receiving different intervention services (such as sensory integration) and teaching strategies (such as visual communication strategies or discrete trial teaching) to promote learning.

Group Two

A second group of children are usually older. This group of children experience a dramatic loss (or plateauing) in their acquisition and use of language and social-attending skills. This developmental regression may be followed by excessive irritability, anxiety, and the onset of repetitive behaviors. This situation is most often reported by parents to occur following an otherwise "typical" course of early development for a child with Down syndrome. According to parents, this regression most often occurs between ages three to seven years.

The medical concerns and strategies for these two groups may be different. There is not enough information available to know at this time. However, regardless of how or when ASD is first discovered, children with DS-ASD have similar educational and behavioral needs once they are identified.

ASD 101: A Crash Course

Signs and Symptoms Vary

Although we are documenting some similarities in the way DS-ASD presents, autism is what is considered a spectrum disorder. This means every child with DS-ASD will be different in one way or another. Some will have speech, some will not. Some will rely heavily on routine and order, and others will be more easy-going. Combined with the wide range of abilities seen in Down syndrome alone, it can feel mystifying. It is easier if you have an understanding of ASD disorders separate from Down syndrome.

Autism, autistic-like condition, autistic spectrum disorder (ASD), and pervasive developmental disorder (PDD) are terms that mean the same thing, more or less. They all refer to a neurobehavioral syndrome diagnosed by the appearance of specific symptoms and developmental delays early in life. These symptoms result from an underlying disorder of the brain, which may have multiple causes, including Down syndrome. At this time, there is some disagreement in the medical community regarding the specific evaluations necessary to identify the syndrome or the degree to which certain "core-features" must be present to establish the diagnosis of ASD in a child with Down syndrome. Unfortunately, the lack of specific diagnostic tests creates considerable confusion for professionals, parents, and others trying to understand the child and develop an optimal medical care and effective educational program.

There is general agreement that:

- Autism is a spectrum disorder: it may be mild or severe.
- Many of the symptoms overlap with other conditions such as obsessive-compulsive disorder (OCD) or attention deficit hyperactivity disorder (ADHD).

Continued on page 10

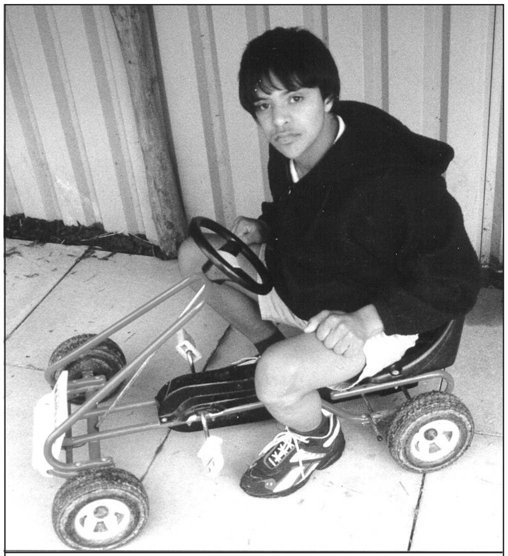
Down Syndrome and Autistic Spectrum Disorder:

Continued from page 9

- ✧ ASD is a developmental diagnosis. Expression of the syndrome varies with a child's age and developmental level.
- ✧ Autism can co-exist with conditions such as mental retardation, seizure disorder, or Down syndrome.
- ✧ Autism is a life-long condition.

The most commonly described areas of concern for children with ASD include:

- ✧ Communication (using and understanding spoken words or signs),
- ✧ Social skills (relating to people and social circumstances),
- ✧ Repetitive body movements or behavior patterns.



Of course there is inconsistency in any of these areas in all children, especially during early childhood. Children who have ASD may or may not exhibit all of these characteristics at any one time nor will they consistently demonstrate their abilities across similar circumstances. Some of the variable characteristics of ASD we have commonly observed in children with DS-ASD include:

- ✧ Unusual response to sensations (especially sounds, lights, touch or pain),
- ✧ Food refusal (preferred textures or tastes),
- ✧ Unusual play with toys and other objects,
- ✧ Difficulty with changes in routine or familiar surroundings,
- ✧ Little or no meaningful communication,
- ✧ Disruptive behaviors (aggression, throwing tantrums, or extreme non-compliance),
- ✧ Hyperactivity, short attention, and impulsivity,
- ✧ Self-injurious behavior (skin picking, head hitting or banging, eye-poking, or biting),
- ✧ Sleep disturbances, and
- ✧ History of developmental regression (esp. language and social skills).

Sometimes these characteristics are seen in other childhood disorders such as attention deficit hyperactivity disorder or obsessive compulsive disorder. Sometimes ASD is overlooked or considered inappropriate for a child with Down syndrome due to cognitive impairment. For instance, if a child has a high degree of hyperactivity and impulsivity only the diagnosis of ADHD may be considered. Children with many repetitive behaviors may only be regarded as having stereotypy movement disorder (SMD), which is common in individuals with severe cognitive impairments.

Most parents agree that severe behavior problems are usually not easily fixed. Finding solutions for behavioral concerns is one reason families seek help from physicians and behavior specialists. Compared to other groups of children with cognitive impairment, those with Down syndrome, as a group, are less likely to have behavioral or psychiatric disorders. When they do, it is sometimes referred to as having a "dual-diagnosis." It is important for professionals to consider the possibility of a dual-diagnosis (Down syndrome with a psychiatric condition such as ASD or OCD) because:

1. It may be responsive to medication or behavioral treatment, and
2. A formal diagnosis may entitle the child to more specialized and effective educational and intervention services.

If you think your child may have ASD disorder, share this before or during your evaluation. Don't wait to see what might happen.

Incidence

Estimating the prevalence or occurrence of ASD disorder among children and adults with Down syndrome is difficult. This is partly due to disagreement about diagnostic criteria and incomplete documentation of cases over the years. Currently, estimates vary between 1 and 10%. I believe that 5-7% is a more accurate estimate. This is substantially higher than is seen in the general population (.04%) and less than other groups of children with mental retardation (20%). Apparently, the occurrence of trisomy 21 low-

A Look at What We Know

ers the threshold for the emergence of ASD in some children. This may be due to other genetic or other biological influences on brain development.

A review of the literature on this subject since 1979 reveals 36 reports of DS-ASD (24 children and 12 adults). Of the 31 cases that include gender, an astonishing 28 individuals were males. The male-to-female ratio is much higher than the ratio seen for autism in the general population. Additionally, in reports that include cognitive level, most children tested were in the severe range of cognitive impairment.

Generally, the cause of ASD is poorly understood, whether or not it is associated with Down syndrome. There are some medical conditions in which ASD is more common such as Fragile-X syndrome, other chromosome anomalies, seizure disorder, and prenatal or perinatal viral infections. Down syndrome should be included in this list of conditions. The impact of a pre-existing medical condition such as Down syndrome on the developing brain is probably a critical factor in the emergence of ASD disorder in a child.

Brain Development and ASD

The development of the brain and how it functions is different in some way in children with DS-ASD than their peers with Down syndrome. Characterizing and recording these differences in brain development through detailed evaluation of both groups of children will provide a better understanding of the situation and possible treatments for children with DS-ASD.

A detailed analysis of the brain performed at autopsy or with magnetic resonance imaging (MRI) in children with autism shows involvement of several different regions of the brain:

- The *limbic system*, which is important for regulating emotional response, mood and memory,
- The *temporal lobes*, which are important for hearing and normal processing of sounds,
- The *cerebellum*, which coordinates motor movements and some cognitive operations, and
- The *corpus callosum*, which connects the two hemispheres of the cortex together.

At Kennedy Krieger Institute, we have conducted MRI studies of 25 children with DS-ASD. The preliminary results support the notion that the cerebellum and corpus callosum is different in appearance in these children compared to those with Down syndrome alone. We are presently evaluating other areas of the brain, including the limbic system and all major cortical subregions, to look for additional markers that will distinguish children with DS-ASD from their peers with Down syndrome alone.

Brain Chemistry and ASD

The neurochemistry (chemistry of the brain) of autism is far from clear and very likely involves several different chemical systems of the brain. This information provides the basis for medication trials to impact the way the brain works in order to elicit a change in behavior. An analysis of neurochemistry in children with ASD alone has consistently identified involvement of at least two systems.

1. *Dopamine:* regulates movement, posture, attention, and reward behaviors; and
2. *Serotonin*: regulates mood, aggression, sleep, and feeding behaviors.

Additionally, *opiates*, which regulate mood, reward, responses to stress, and perception of pain, may also be involved in some children.

Detailed studies of brain chemistry in children with DS-ASD have not yet been done. However, our clinical experience in using medications that modulate dopamine, serotonin or both systems has been favorable in some children with DS-ASD.

How Do I Find Out?

Obtaining an Evaluation

If you suspect that your child with Down syndrome has some of the characteristics of ASD or any other condition qualifying as a dual-diagnosis, it is important for him to be seen by someone with sufficient experience evaluating children with cognitive impairment—ideally Down syndrome in particular. Some of the same symptoms which occur in DS-ASD are also seen in stereotypy movement disorder, major depression, post-traumatic stress disorder, acute adjustment reactions, obsessive-compulsive disorder, anxiety disorder, or when children are exposed to extremely stressful and chaotic events or environments.

Continued on page 12

Down Syndrome and Autistic Spectrum Disorder:

Continued from page 11

Sometimes when children with Down syndrome are experiencing medical problems that are hidden—such as earache, headache, toothache, sinusitis, gastritis, ulcer, pelvic pain, glaucoma, and so on—the situation results in behaviors that may appear "autistic-like" such as self-injury, irritability, or aggressive behaviors. A comprehensive medical history and physical examination is mandatory to rule out other reasons for the behavior. When cooperation is elusive, sedation or anesthesia may be required. If so, use this "anesthesia time" effectively by scheduling as many specialty examinations as are feasible at one session.

In addition to the medical assessment, you will be asked to help complete a checklist to determine whether or not your child has ASD. I use the Autism Behavior Checklist (ABC), but there are others that are also used such as the Childhood Autism Rating Scale (CARS) and the Gilliam Autism Rating Scale (GARS). Each of these is completed either in an interview with parents or done by parents before coming to the appointment. They are then scored and considered along with clinical observation to determine if your child has ASD.

Obstacles to Diagnosing DS-ASD

> *"If it looks like a duck, and it quacks like a duck... guess what?"*

Parents sometimes face unnecessary obstacles in seeking help for their children. Parents have shared several reasons demonstrating this. Some of the more common include:

Failure to Recognize the Dual Diagnosis

Problem:

Failure to recognize the dual diagnosis except in the most severe cases.

Result:

This is frustrating for everyone who is actively seeking solutions for a child. If you are in this situation and feel that your concerns are not taken seriously, keep trying. The best advice is to trust your gut feeling regarding your child. Eventually you will find someone willing to look at all the possibilities with you.

Diagnostic Confusion

Problem:

Diagnostic confusion with other behavioral or psychiatric conditions such as ADHD, OCD, or depression.

Result:

Parents may feel forced into demanding a referral for another medical evaluation at a Down syndrome clinic or Child Development Center. This often is a considerable cost for families because of insurance concerns. Many HMOs and PPOs will not refer out or take on part of the cost for evaluations outside of their system. The same is true for educational evaluations. Many school systems may be hesitant to provide additional, intensive, and costly services for kids with DS-ASD. The combination of frustration and lack of acceptance by professionals (medical and educational) of the dual diagnosis may lead parents to abandon traditional services in favor of nontraditional solutions to their child's medical and educational needs. This is not necessarily a bad thing. Individual, creative problem-solving is a great asset when support is elusive. However, total withdrawal from "the system" may lead to feelings of abandonment and isolation, which makes it difficult for families to help their child and build the support systems needed to deal with stress. There will be plenty of frustrating and stressful moments in the future. Parents deserve support.

Lack of Acceptance by Professionals

Problem:

There is sometimes a lack of acceptance by professionals that ASD can coexist in a child with Down syndrome who has cognitive impairment. They may feel an additional label is not necessary or accurate. Parents may be told, "This is part of 'low functioning' Down syndrome." We now know this is incorrect. Children with DS-ASD are clearly distinguishable from children with Down syndrome alone or those who have Down syndrome and severe cognitive impairment when standardized diagnostic assessment tools such as the ABC are used.

A Look at What We Know

Result:

Parents become frustrated and may give up trying to obtain more specific medical treatment or behavioral intervention.

Confusion in Parents

Problem:

Lack of acceptance, understanding, awareness, or agreement on the part of parents or other family members, particularly of very young children, about what's happening. Initial reactions by families and parents vary considerably from, "This too shall pass" to "Why isn't he doing as much as other kids with DS?"

Result:

Parents in this situation may find themselves at odds with each other about the significance of their child's behavior and what to do about it. As a result, marriages are stressed, parenting relationships with other children are strained, and life is tough altogether. Unfortunately, I have found that parents in this situation almost universally withdraw from local Down syndrome support groups or other groups that may provide support. There are a variety of reasons for this including "the topics discussed don't apply to my child," It's just too hard to see all those children doing so much more than my child," and "I feel like people think I'm a bad parent because of my daughter's behavior."

Ideally someone in the parent group would recognize this when it is happening and offer *additional* support instead of watching them withdraw. What is worrisome is that the very parents who are most in need of support and assistance cannot or do not receive it within the context of their local parent group. In fact, there may not be another parent in the group with a child who is similar because DS-ASD is uncommon and not easily shared.

It is critical that parents have an opportunity to meet and learn from other parents whose children also have DS-ASD. Despite the underlying medical condition (trisomy 21), the neurobehavioral syndrome of ASD may mean that a support group for families of children with autism will be helpful as well. However, because of the lack of acceptance or knowledge about the dual diagnosis, these support groups can be equally daunting.

What Does it Mean?

Behavioral Findings

Obtaining a diagnosis of DS-ASD is rarely helpful in understanding how ASD effects your child. It is complicated by the lack of information available, making it difficult to discern appropriate medical and educational options. To determine what behaviors are most common in DS-ASD we are conducting case-control studies which randomly match (for gender and age) a child with DS-ASD with a child who has Down syndrome without ASD. These comparisons are based on the information obtained from the ABC together with a detailed developmental history and behavioral observation. Through this process we have been able to determine the following:

Children with DS-ASD were *more* likely to have:

- History of developmental regression including loss of language and social skills,
- Poor communication skills (many children had no meaningful speech or signing),
- Self-injurious and disruptive behaviors (such as skin picking, biting, and head hitting or banging),
- Repetitive motor behaviors (such as grinding teeth, hand flapping, and rocking),
- Unusual vocalizations (such as grunting, humming, and throaty noises),
- Unusual sensory responsiveness (such as spinning, staring at lights, or sensitivity to certain sounds),
- Feeding problems, (such as food refusal or strong preference for specific textures), and
- Increased anxiety, irritability, difficulty with transitions, hyperactivity, attention problems, and significant sleep disturbances.

Other observations include:

- Children with DS-ASD scored significantly higher than their peers with Down syndrome alone on all five subscales of the ABC: sensory function, social relating, body and object use, language use, and social skills.
- Children with DS-ASD show less impairment in social relatedness than those with ASD only.

Continued on page 14

Down Syndrome and Autistic Spectrum Disorder:

Continued from page 13

- ✧ Children with DS-ASD show more preoccupation with body movement and object use than children with ASD alone.
- ✧ Children with DS-ASD scored higher on all five subscales of the ABC than children with severe cognitive impairment alone.
- ✧ Among children with Down syndrome only, even those with severe cognitive impairment do not always meet the criteria for ASD.

The conclusion I draw from this data is children DS-ASD are clearly distinguishable from both "typical" children with Down syndrome and those with severe cognitive impairment (including children with Down syndrome). Thus, it is probably incorrect to suggest autistic-like behaviors are entirely due to lower cognitive function. However, the fact that autistic features and lower cognition are associated indicates there is some shared determinant(s) that are common to both features (ASD and lower cognition) of the condition.

Associated Medical Conditions

There are questions about the possibility of similarities in the variety of medical conditions associated with Down syndrome in general in children with DS-ASD. To determine this we used the same matching scheme as described above. It is important to point out the number of matched pairs currently in our study is quite small and, as a result, some of these findings may not hold up as we examine more children.

DS/ASD children were *more* likely to have:

- ✧ Congenital heart disease and anatomical GI tract anomalies,
- ✧ Neurological findings,(i.e., seizures, dysfunctional swallow, severe hypotonia and motor delay),
- ✧ Opthamologic problems,
- ✧ Respiratory problems (i.e., pneumonia and sleep apnea), and
- ✧ Increased total number of medical conditions.

What Now?

After the Evaluation

If your child has DS-ASD, obtaining the diagnosis or label may be a relief of sorts. The addition of ASD brings new questions. From a medical perspective it is important to consider use of medication, particularly in older children, for specific behaviors. This is especially true if these behaviors interfere with learning or socialization. While there is no cure or remarkably effective treatment for Down syndrome and autistic spectrum, certain "target behaviors" may be responsive to medication. Some of these behaviors include:

- ✧ Hyperactivity and poor attention,
- ✧ Irritability and anxiety,
- ✧ Sleep disturbance,
- ✧ Explosive behaviors resulting in aggression/disruption (can sometimes be reduced),
- ✧ Rituals and repetitive behaviors (can sometimes be reduced), and
- ✧ Self-injury (can sometimes be reduced).

As you continue to take care of your child, make a point to take care of yourself and your family—in that order. You have a life and a family to consider. Recognize that there is only so much time, energy and resources that you can put into this "project." Of course there will be cycles, of good times and bad, but if you can't find some way to renew your emotional spirit, then "burn-out" is inevitable. There is a higher rate of anxiety, sleep problems, lack of energy, depression, and failed or struggling marriages under these circumstances. Learn to recognize your own difficulties and be honest with yourself and your spouse about the need for help. Counseling and medication may go a long way in helping you to be at your best, for everyone's sake.

Conclusion

Clearly there is a great deal to be learned about children with Down syndrome who are dually diagnosed with autism spectrum disorder. In the meantime, it is essential for parents to educate themselves and others about this condition. Families must work on building a team of health-care professionals, therapists, and educators who are interested in working with their child to promote the best possible outcome. Research efforts must move beyond mere description to address causation, early identification, and natural history. Specific markers in the development of the brain which can distinguish DS-ASD from "typical" Down syndrome and "typical" autism need to be sought; and the possible benefits of various treatments need to

A Look at What We Know

be more carefully documented. Realizing these goals will take a very long time to accomplish and must be approached with a spirit of support, cooperation, and caring both for individual children and the larger community of children with DS-ASD.

✧ ✧ ✧

George T. Capone, M.D., is the Director of the Down Syndrome Clinic and Attending Physician on the Neurobehavioral Unit at Kennedy Krieger Institute in Baltimore, Maryland.

References:

1. Kent, L., Evans, J., Paul, M., and Sharp, M. "Comorbidity of Autistic Spectrum Disorders in Children with Down Syndrome." *Developmental Medicine and Child Neurology* 41:153-158 (1999).
2. Howlin, P., Wing, L., and Gould, J. "The Recognition of Autism in Children with Down syndrome: Implications for Intervention and Some Speculations About Pathology." *Developmental Medicine and Child Neurology* 37:406-414 (1995).
3. Ghaziuddin, M., Tsai, L., and Gahziuddin, N. "Autism in Down's Syndrome: Presentation and Diagnosis." *Journal of Intellectual Disability Research* 36:449-456 (1992).
4. Rapin, I., "Autism." *New England Journal of Medicine* 33(2): 97-104 (1997).
5. Campbell, M., Schopler, E., Cueva, J., and Hallin, A. "Treatment of Autistic Disorder." *Journal of the American Academy of Child and Adolescent Psychiatry* 35(2):134-143 (1996).
6. Rogers, S. "Neuropsychology of Autism in Young Children and Its Implications for Early Intervention." *Mental Retardation and Developmental Disabilities Research Reviews* 4:104-112 (1998).
7. Forness, S. and Kavale, K. "Autistic Children in School: The Role of the Pediatrician." *Pediatric Annals 13(4):319-328 (1984).*

Resource Organizations

Autism Society of America
7910 Woodmont Avenue
Bethesda, MD 20814-3015
301/657-0881
www.autismsociety.org

National Association for Dual Diagnosis
132 Fair Street
Kingston, NY 12401-4802
www.thenadd.org

Kennedy Krieger Institute
Down Syndrome Clinic
707 N. Broadway
Baltimore, MD 21205
referrals: 888/554-2080

Cincinnati Center of Developmental Disorders
Down Syndrome Clinic
3333 Burnett
Cincinnati, OH 45208
513/636-6755

National Down Syndrome Society
666 Broadway
New York, NY 10012
800/221-4602
www.ndss.org

National Down Syndrome Congress
7000 Peachtree-Dunwoody Road, NE
Lake Ridge 400 Office Park
Bldg #5 - Suite 100
Atlanta, GA 30328
800/604-9500
www.members.carol.net/~ndsc

Dual Diagnosis: The Importance of Diagnosis and Treatment

by Bonnie Patterson, M.D.

In the past, it was thought children with Down syndrome who exhibited autistic behaviors were simply exhibiting these behaviors secondary to severe or profound retardation. We now realize children with Down syndrome can also have true autism spectrum disorder and that this occurrence is not rare. Little has been written regarding the dual diagnosis of Down syndrome and autistic spectrum disorder (DS-ASD) and currently only 12 cases are reported in the medical literature.

Because so little information is available about the incidence and diagnosis of DS-ASD, parents frequently share with me the frustration they feel as they try to understand why their child is not developing in the same way as other children with Down syndrome. Many relate a specific age when their child's development either regressed or slowed. These atypical patterns of development are most often reported in the areas of language and behavior. Parents describe their child as becoming more withdrawn, obsessively attached to certain objects, engaging in repetitive or stereotypic behaviors, not engaging in imaginary play and losing language skills. These are all behaviors classically described in children with autism spectrum disorder.

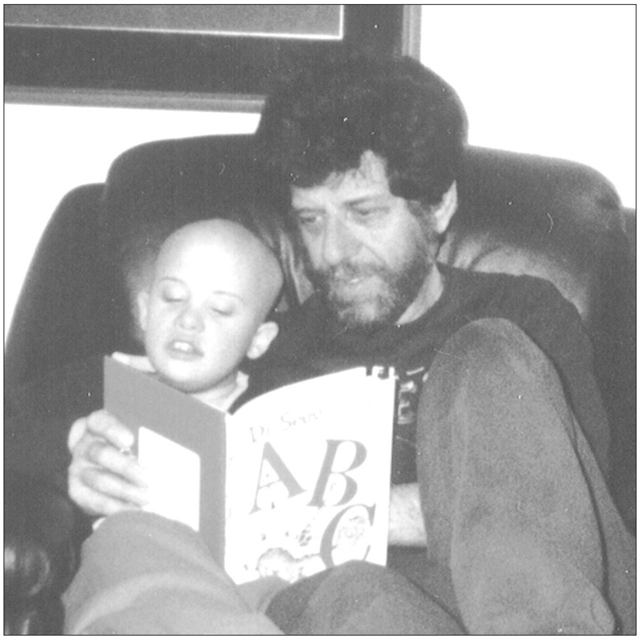
> *"It is critical for children with Down syndrome and autistic spectrum disorder to be identified as early as possible because of the impact on educational and therapeutic interventions..."*

Professionals are often reluctant to diagnose a child who has Down syndrome with a second serious developmental disorder such as autistic spectrum disorder. Many believe that the behaviors and atypical language development are related to severe or profound mental retardation they associate with Down syndrome or believe they are "protecting the parents" by not giving a second diagnosis. Our experience has been that the majority of children we see with autism spectrum disorder and Down syndrome are not severely or profoundly mentally retarded, but function in the moderate to severe range of cognitive delay. In addition, parents are relieved when the diagnosis is finally made which helps them understand their child's differences. It also opens the door to investigating and obtaining appropriate intervention services. It is critical for children with Down syndrome and autism spectrum disorder to be identified as early as possible because of the impact on educational and therapeutic interventions, and in some cases the need for further medical assessments and treatments. There are many educational and therapeutic programs that have been developed specifically for children with autism spectrum disorder, including Applied Behavioral Analysis (ABA or Lovass), developmental social programs (Greenspan), sensory integration therapy, and picture exchange communication systems (PECS) (see resources, page 36). Without a diagnosis of autistic spectrum, these strategies will probably be overlooked for a child with Down syndrome. It is as important for a child with DS-ASD to access this intervention, and for the family to know what information to research, as it would be for any other child with the diagnosis of autistic spectrum disorder. Additionally, there are some medical tests that may be beneficial in further evaluating and choosing possible medical treatment for a child with autism. Although every child with the dual diagnosis of DS-ASD does not require all of the following, some may need blood lead levels, chromosomes including DNA probe for fragile X, urine metabolic screen, MRI scan of the brain, or prolonged EEG.

It is important for the medical community to make progress toward a better understanding of this dual diagnosis. With information, we will be able to put some of the disputes regarding occurrence aside and focus on effective medical and educational interventions. For example, there are reports of increased frequency of seizures and abnormal EEG findings in children with autism. The current recommendation

Diagnosis and Treatment

is that prolonged EEG studies (23 hours) be done, particularly for those who have a history of language loss or regression (6). With this in mind, a study is currently underway at the Cincinnati Center for Developmental Disorders evaluating a group of 10 children with DS-ASD with prolonged EEG's. The result of the EEG determines whether or not we should consider treatment with seizure medication. The use of these medications may improve language or behavior if a child with DS-ASD shows evidence of abnormal electrical activity on the EEG. This could be particularly important for children with Down syndrome and autistic spectrum, as the frequency of seizures has been reported to be greater than that of the general population (5-10%). The association between autism and epilepsy is also high, with ranges reported from a low of 7% to a high of 42%. Prolonged EEG studies (23 hours) have been found to be better at identifying abnormalities in children with autism over routine EEG studies. The current recommendation for children with autism spectrum is for those with significant expressive and receptive language dysfunction, or a history of regression of language, to receive a prolonged EEG study including a significant amount of sleep recording. It seems only appropriate that children with DS-ASD be evaluated in the same way in order to determine if any abnormalities are detected, which could affect medical management strategies.



Peter Ben Paul shares a moment with Dad.

Early recognition and diagnosis of autism spectrum disorder in children with Down syndrome has significant implications for a family's understanding of their child's needs in regards to therapeutic and educational interventions, as well as the need for medical evaluations and treatments. Continuing research is needed in the area of dual diagnosis to explore environmental and familial risk factors, MRI findings, biochemical changes, and the relationship of the EEG abnormalities to autistic behaviors, particularly in those children with a history of language regression. With this research, we hope to gain a greater understanding of Down syndrome and autistic spectrum disorder which will help reduce barriers to diagnosis and access to appropriate medical and educational interventions.

✧ ✧ ✧

Bonnie Patterson, M.D., is a developmental pediatrician at the Cincinnati Center on Developmental Disabilities and the director of the Down Syndrome Clinic. She is the co-chair person of the Down Syndrome Medical Interest Group and a member of the Clinical Advisory Board for the National Down Syndrome Society.

References

1. Bregman J., Vlkmar F.R., "Autistic Social Dysfunction and Down Syndrome." *Journal of American Academy of child and Adolexcent Psychiatry* 27:440-441 (1988).
2. Ghaziuddin, M., Tsai L., and Gahziuddin, N. "autism in down's Syndrome: Presentation and Diagnosis." *Journal of Intellectual Disability Research* 36:449-56 (1992).
3. Howlin P., Wing L., Gould J., "The Recognition of Autism in Chidlren with Down Synrome–Implications for Intervention and Some Speculations About Pathology." *Developmental Medicine and child Neurology* 37:398-414 (1995).
4. Kent l., Perry K., Evans J., "Autism in Down's Syndrome: Three Case Reports." *Autism* 2(3):259-67 (1998).
5. Wakabayashi I. "A Case of Infantile Autism Associated with Down's Syndrome." *Journal of Autism and Developmental Disorders* 9:31-36 (1979).
6. Tuchman R., Rapin I. "Regressoin in Pervasive Developmental Disorders: Seizures and Epiliptiform Electroencephalogram Correlates." *Pediatrics* 99:560-66 (1997).
7. Stafstrom C. "Epilepsy in Down Syndrome: Clinical Aspects and Possible Mechanisms." *American Journal on Mental Retardation* 98:12-26 (1993).

Language & Communication: The Key is Effectiveness

by Julie Bierman Gee, M.S.,CCC-SLP

Sam is a 14-year-old high school student who carries a dual diagnosis of Down syndrome and autistic spectrum disorder DS-ASD. At home, he shares many of his wants and needs by making different vocalizations, which his mother understands and interprets for him. At school, Sam is less successful communicating, and often is unable to get his point across. To date, Sam's speech and language services have been centered primarily on production of speech and improvement of oral motor skills, with infrequent and inconsistent attempts at using pictures. Sam is beginning to show frustration at school by acting out physically and not following directions. As he gets older, his mother is growing weary of being his interpreter. She realizes that he needs a more effective way to interact with the world around him because she cannot always be present.

Catherine is an active 5-year-old girl who, like Sam, also has a dual diagnosis of DS-ASD. When she was in early intervention, her communication services focused on using total communication, a method of combining speech and sign language to encourage communication. Catherine is able to communicate her wants and needs through sign approximations. She also understands more signs than she is able to make. Using sign language has allowed Catherine to communicate effectively with people other than her family.

While Sam and Catherine both have DS-ASD, they are examples of children whose very different types of communication intervention yielded very different results. Clearly, no two children with Down syndrome and autistic spectrum disorder are exactly alike, and no two approaches to therapy will be exactly the same. All children with these diagnoses do, however, share unique speech, language, and communication needs. As you meet therapists, teachers, and other professionals, you may become discouraged by the things it seems your child can't do. What's important to remember, though, is that all children can learn to communicate. That communication may take different forms for different children: your child might use sign language, while his classmate uses an augmentative communication device. However, creating an intervention program that focuses on communication is sure to let you and your child see positive effects. This article will offer you information about things to consider as you begin intervention, and give you ideas about ways to begin to focus on communication with your child.

Implications for Therapy

The good news is that myriad options exist to help your child learn how to communicate. Even better news is with a dual diagnosis of Down syndrome and autistic spectrum disorder, communication intervention through the school for your child is almost guaranteed. This is because children with Down syndrome alone often "age out" of speech and language services in the school setting. This happens when a child is determined to be eligible for special education services under the label of mental retardation. When their language abilities reach a level that is seen as equal to their level of cognitive skill, they are often discharged from service, based on reports that they have reached their communicative potential. In contrast, children with autistic spectrum disorders typically continue to need support using language to meet their needs as well as to apply the language and communication skills they learn to new or unfamiliar situations. Because of this, the majority of public school settings provide speech or communication-related services to children with autism throughout their school careers. If your child is determined to be eligible under both categories she is likely

Language & Communication

to continue to qualify for speech related services and support such as augmentative communication systems for as long as she is in school.

Learning to communicate will look different for each child as options are chosen that build on your child's strengths. Focusing on the process of communication, rather than on the form communication takes, will yield many positive outcomes for you and your child. An intervention program with a focus exclusively on the development of speech and related skills limits the opportunities that your child will have to communicate independently. Excluding other techniques to focus primarily on speech creates a situation where other options may be ignored. Including techniques that are motivating and effective for your child such as total communication (simultaneous speech and signing), low technology augmentative communication supports (e.g., picture symbols, communication displays), and higher technology augmentative communication devices greatly enhance your child's communicative potential. Developmental milestones such as "first sign" or "first point to a picture" aren't likely to be found in child development manuals. However, attention to these types of early communication signals is just as important, if not more so, than attention to milestones such as "child's first word." It is communication in any form (not just speech) that allows your child to begin to express herself with clarity and independence. In turn, that communicative independence furthers her intellectual and social development.

Your child's ability to communicate is a vital part of her life. It is essential to remember this as you advocate for your child. Communication is the key to everything in life. Without appropriate and effective language and communication skills or tools available your child may become a passive participant in the world around her. She may be limited to the choices that others make for her based on what may be faulty interpretations of her communicative attempts. Over time, because she lacks control over these interactions, a feeling of helplessness emerges. Why bother trying? In educational literature, this is called learned helplessness. Some children even stop their attempts at communicative signaling because the choices are meaningless or they are ineffective or unsuccessful at using the communication tool. Others become frustrated and resort to physical means such as hitting, kicking, or biting as their main way to communicate—unpleasant, but it works. Remember your child can learn to communicate more systematically, and less painfully. By remembering this, you'll be able to work with her therapist to find a method that's most effective for her.

Regardless of the method of communication you choose for your child (such as signing, pictures systems, or voice output), focusing on communication, rather than speech production alone, increases your child's opportunities to participate in meaningful, communicative interactions. She will express her choices and exert environmental control in ways that actively involve her. These experiences expose her to interactions she can use to increase her level of language comprehension. In addition, ensuring that your child has a way to independently communicate her wants and needs increases her level of functional independence, by decreasing her reliance on you as her sole interpreter. In turn, this gives you a break.

General Guidelines Intervention

As your child begins therapy, keep the following general guidelines in mind. While a private therapist is likely to have more time to spend with you and may involve you more directly in your child's intervention, the following guidelines apply to therapy in all intervention settings.

You are an integral part of the process.

Communication does not occur in a vacuum. It is critical that the techniques or methods used with your child during sessions are ones that can be carried over into her home, classroom setting, and community. To make sure this carryover occurs, you must be an active participant in the process. If you have questions about why your therapist chose a particular sign or symbol to teach or a particular strategy to use, ask. Don't be afraid to speak up if you think a particular recommendation is not right for your child, or if there are other communication skills you want your child to learn first. You and your therapist must work together by listening to each other and respecting each other's knowledge. A good therapist will listen to you and respect your knowledge of your child's needs outside of the therapy room just as you respect her knowledge and ability about communication strategies. Together you will work to develop communication objectives that fit your child's developmental abilities and communication needs.

Continued on page 20

Language and Communication

Continued from page 19

The "look" of your child's communication intervention may change over time.

As your child grows and develops, her communication needs will change, and she will learn new skills. Because of this, the form of communication you begin with may not be the same one you use several years down the road. For example, while total communication is a common early intervention for children with DS-ASD, you may find that you are able to add methods such as picture symbols or communication displays. It isn't necessary to rely on any single method of communication for your child. All of us communicate using a variety of techniques (speech, facial expression, pointing, eye contact, body language, etc.). Your child will use a combination of methods (signing, vocalization, picture pointing, device use) to communicate, too.

*All members of your child's intervention team **must** work together to be effective.*

Often, children with Down syndrome and autistic spectrum disorder work with a variety of professionals at school and privately. If your child receives therapeutic intervention both in and out of her school setting, it is crucial that everyone involved communicate with each other. While this type of coordination is important for all disciplines, it is essential in communication intervention. If your child is using communication displays with a therapist outside of school, but does not have access to picture supports in her classroom, she will make limited progress due to lack of consistency in her programming. In a situation like this, she will be confused and frustrated about communication in general. Who wouldn't be? The rules for communicating must be consistent everywhere. Encourage all therapists involved with your child to talk with each other and with you. If meetings in person aren't possible, create a phone list of key people involved in your child's education and care, or set up a "communication log" in a binder that travels between home, school, and outside therapy appointments. If you use a communication log, be sure that you write messages in it, too, so that you can give your therapists feedback about your child's progress at home and let them know about any new developments or additional concerns.

Useful Early Therapeutic Techniques

Regardless of the method of communication intervention that you choose for your child, one of the first goals for speech-language therapy should be improving her ability to clearly express communicative intent. Demonstrating communicative intent involves producing a communicative signal that is directed toward a specific person to achieve a specific objective. Here are suggestions to enhance your child's development of this important communicative skill:

Follow Your Child's Lead

Developing clear communicative intent requires that your child be able to establish and maintain joint attention, a state in which you and she focus simultaneously (or jointly) on the same object. One common frustration expressed by parents, teachers, and therapists of children with Down syndrome and ASD is their child's or student's reduced attention span, and need to shift frequently from one activity to the next. A natural tendency in this situation is to "force" your child to maintain attention to a single activity or toy, or to redirect her shifting attention back to the activity or toy she started with. Surprisingly, results of a variety of research studies have shown that it is more effective to follow the shifting focus of your child's attention. Following your child's lead increases her understanding of words and their relationship to the world around her (i.e., her receptive language skill). In order to help your child develop the ability to achieve and maintain a state of joint attention, your chances are best if you let your child take the lead, while you find ways to engage her interactively with whatever object captures her interest.

For example, there are a variety of interesting, engaging, and developmentally appropriate toys you might use while playing with your child to introduce the concept of "in" and "out." She may reject all of these options in favor of your purse—an object you initially deem slightly less appropriate. If you follow your child's lead, however, capitalizing on her interest in your purse, you're likely to help her achieve joint attention. You might model spoken and signed phrases such as "tissues out," "lipstick out," "keys out," "pen out" and maximize her opportunity for attaching meaning onto a single word ("out"). While you always have to be sure that the objects your child chooses for play are safe, tolerating a healthy degree

Language and Communication

of flexibility and a willingness to change plans as your child's interests dictate will increase her chances for improving language comprehension skill.

"Sabotage" Some Situations

Although it sounds as though it runs counter to what any good parent might do, setting up some situations in which your child is bound to be unsuccessful actually serves a positive purpose in teaching communicative intent. For example, if your child is playing with a favorite wind-up toy, you can interrupt her activity briefly by placing the toy inside a tightly sealed, transparent plastic jar (old peanut butter jars work well for this purpose). Most likely, she will be unable to open this jar independently, and will try a variety of means (including shaking, banging, biting, or rolling the jar) to try to get the toy. If unsuccessful in these attempts, a child who has developed clear communicative intent will seek out someone who can help, and signal the need for help by vocalizing, signing, or handing over the jar for assistance. If your child is learning to ask for help, using sabotage in this way gives you an excellent opportunity to model clear communicative signaling. In this case, you might hold your child's hands in your own and shape them into the sign for "HELP." (Similar opportunities can be created by keeping some of your child's favorite toys out of reach, so she has no choice but to signal you in some way if she wants to gain access to a preferred toy.) Creating situations in which your child will require assistance from you builds in opportunities for her to begin to learn to initiate clear communicative signals.

Use Portion Control

Similar to "sabotage," you can encourage your child to practice initiating communicative interactions by offering smaller portions of food or shortening the length of time she plays with a favorite toy. The objective is not to deprive her of food or play, but to set up opportunities for her to communicate with you or others.

For example, during snack-time give your child one or two goldfish crackers at a time, instead of the entire package. Once she has eaten the crackers before her, show your child how to request more to eat if she does not initiate this request independently. Depending on the method of communication you are using, this may mean that you model the word and/or sign "more," that you touch a picture of crackers, or that you push a key on a simple communication device that speaks a request for "more."

Another example of this is when your daughter is interested in watching a favorite video on the VCR. Sit with her and occasionally pause or stop the movie she is watching. When you do, if she does not signal you to start the movie independently, model a signal that would enable her to make the movie continue. Using this strategy requires a little patience because it disrupts the routine flow of interactions everyone expects. However, structuring your child's environment in a way that creates a need for initiating communication is an essential component that, over time, increases her independent functional communication skills and sense of control over the world around her.

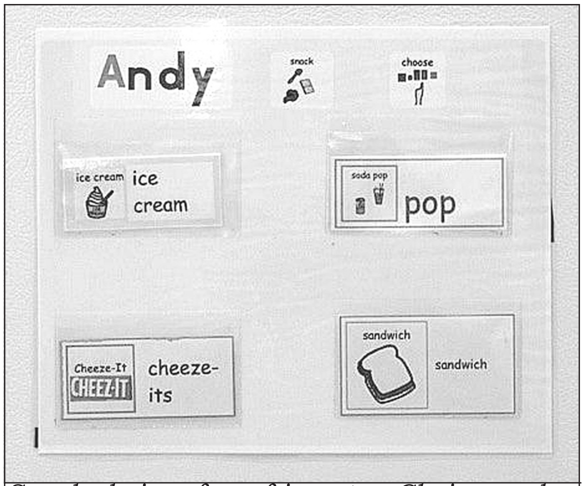
Build in Choices

As mentioned earlier, when children do not have a way to meaningfully participate in interactions, there is a risk they will become passive participants in the world around them. They fail to develop a strong sense that they can make choices to make things happen in their life. Providing your child with choices within activities and throughout her day will prevent this and increase her sense of communicative power and environmental control. Choice-making opportunities look different depending on the method of communication being used, but the process of offering your child a choice remains the same. If your child recognizes packaging from preferred food items, you

Continued on page 22

Language and Communication

Continued from page 21



Snack choices for refrigerator. Choice cards are inside clear business card size pockets with adhesive backs.

can use these to offer her a choice of snacks. In this case, glue empty packaging from two favorite foods to a piece of cardboard and attach the cardboard to the front of the refrigerator using velcro dots or magnet strips. When snack time comes, encourage your child to touch or point to the package that represents the food she wants to eat. A similar procedure could be used with photographs of preferred foods, individual picture symbols (e.g., Mayer-Johnson symbols), or symbols on a communication display or communication device, depending on your child's need. Regardless of the method of communication you are using with your child, the goal is to encourage her to express her own wants and needs, thereby teaching her that communication is a tool she can use to exert control on the world around her.

Closing Thoughts

Parenting any child is a challenge, full of highs and lows. Parenting a child who is dually diagnosed with Down syndrome and autistic spectrum disorder brings with it its own set of challenges. Although many may focus on the things that your child can't do, or on the skills that your child won't achieve because of her disability, remember that your child can and will communicate. Keeping the focus on the process of communication, rather than on the form that it takes, will allow you to rejoice over each of your child's important communicative achievements. Whether she is signing, pointing, gesturing, vocalizing, or activating a communication device, your child will be communicating with you and with the world around her, in her own way, and taking positive steps toward maximizing her level of independence. There are no words to express the joy you will feel as you watch your child's communicative potential increase. Maybe just a hearty "thumbs-up" sign will do.

* * *

Julie Bierman Gee is a speech-language pathologist who was a member of the Down Syndrome Clinic team at the Kennedy Krieger Institute in Baltimore, Maryland from 1995 – 1998. Presently, she is the Assistant Director of The Learning Center at the Boys' Latin School of Maryland, and in private practice.

References

1. Coggins, T.E. and Stoel-Gammon, C. "Clarification Strategies Used by Four Down Syndrome Children for Maintaining Normal Conversational Interaction." *Education and Training of the Mentally Retarded* 17:65-67 (1992).
2. Cunningham, C. *Down Syndrome: An Introduction for Parents*. Cambridge, Massachusetts, Published by Brookline Books,1987.
3. Fowler, A. "Determinants of Language Growth in Children with Down Syndrome." In Nadel (ed), *The Psychobiology of Down syndrome.* pp 217-245. Published by MIT Press, 1988.
4. Kumin, L.*Communication Skills in Children With Down Syndrome: A Guide for Parents*. Published by Woodbine House, 1994.
5. Manolson, A. *It Takes Two To Talk: A Parent's Guide to Helping Children Communicate.* Published by The Hanen Centre, 1992.
6. Miller, J. "Language and Communication Characteristics of Children with Down Syndrome." In S. Pueschel, C. Tingey, J. Rynders, A. Crocker, and D. Crutcher (eds.), *New perspectives on Down syndrome* (168 – 198). Published by MIT Press, 1987.
7. Miller, J. "Facilitating Speech and Language Development." In C. Tingey (ed.), *Down Syndrome: A Resource Handbook.* Published by College Hill Press, 1988.
8. Ostrosky, M.M. and Kaiser, A.P. (1991). "Preschool Classroom Environments That Promote Communication." *Teaching Exceptional Children* Summer:6-10 (1991).
9. Stoel-Gammon, C. "Down Syndrome: Effects on Language Development.". ASHA, September: 42 – 44 (1990).

Gross Motor Development in Children with Down Syndrome and Autistic Spectrum Disorder: Clinic Observations

by Patricia C. Winders, PT

As a part of my work at Kennedy Krieger Institute's Down Syndrome Clinic, I have seen 17 children with Down syndrome and autistic spectrum disorder (DS-ASD). Of these 17, I only saw 8 enough to observe their gross motor development. The others ranged in age from 4.5 to 16 years. I have noticed some similarities among the children I have seen, but because there are so few, I am not certain these observations are true for all children with DS-ASD.

Based on the additional diagnosis of autistic spectrum disorder, you might expect children who have DS-ASD to be slower in developing gross motor skills. This does not seem to be the case. In my small sample, children with DS-ASD did seem to follow the usual patterns of development seen in children with Down syndrome. There also did not appear to be any regression in gross motor development with the onset of autistic spectrum, though it is seen in other areas of development. However, children with DS-ASD do seem to be slower to master the more advanced motor skills such as walking down stairs, alternating feet, or jumping.

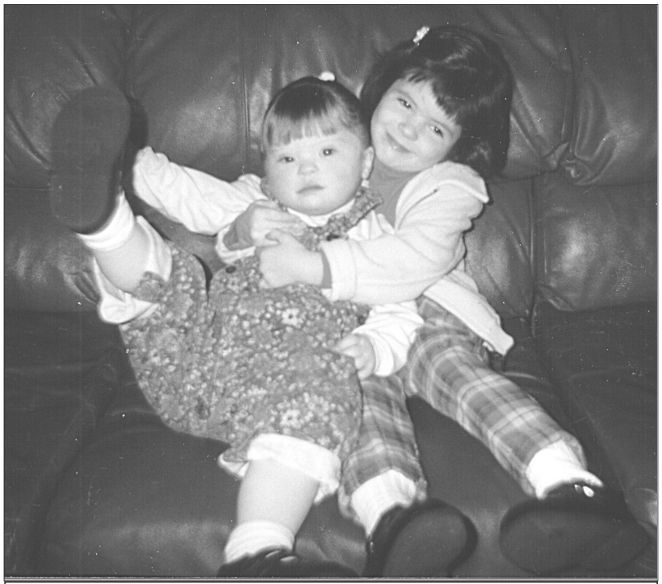
Children with Down syndrome characteristically have one of two temperaments. Temperament is the characteristic way a child thinks, behaves, and reacts when learning motor skills. The first temperament is *motor driven:* children who love to move and take risks physically. The second group are *observers:* children who prefer to be stationary, observe their surroundings, and like to be careful and in control. All of the children I have seen with DS-ASD are clearly observers. They prefer being stationary to moving and they tend to be cautious rather than being a risk-taker. Participating in new motor activities, or attempting to do them, was scary for them.

For example, when I asked Scotty to walk up and down a ramp, he found it frightening. He wanted hand support and moved very slowly. To make things worse, the ramp at the clinic has black non-skid strips, which he found visually confusing, and he did not like the feel of them on his feet. In addition, to walk down a one-inch curb Scotty slid his foot off the edge to feel for the floor before stepping down. Scotty is an example of an *observer.*

All of the children with DS-ASD wanted to walk at a slower pace than I asked and resisted moving too quickly. To limit how far we went, they sat down to stop. They needed motivation to continue walking. When I gave them my hand, they were open to walking more quickly and frequently smiled at me. This told me they had the energy to walk faster and farther, but needed hand support as encouragement to try.

It is important to understand and respect your

Continued on page 24



Madison and Alison Duffey share a hug

Gross Motor Development: Clinic Observations

Continued from page 23

child's temperament as well as other factors such as sensory issues your child may have because of DS-ASD. For instance, children with DS-ASD are often overwhelmed by things going on around them such as loud noises, children crying, or a lot of activity. They often do better in familiar surroundings or in situations that have some routine. This means in a clinic or school setting, children with DS-ASD may become upset because the environment is unfamiliar and they are bombarded with new experiences and stimuli. Madison is an example of a child who prefers a familiar environment in which she feels she has some control. When she came to clinic there were many new skills for her to try. The clinic was full of sounds and commotion that are usual for a clinic, but were overwhelming and new to her. Her mother and I thought a less busy area would be best, which is where we have the balance beam. Madison was afraid to try, so her mother did it with her. During the session she resisted participating, but she watched out of the corner of her eye. At the end of the session when we were discussing a home program for her, Madison initiated practicing walking on the balance beam on her own and learned to do it independently. She demonstrated that she would try new skills if she could try them on her own terms at her own pace. It was important that we did not impose ourselves in the process because that would upset and scare her. The way activities are set up for Madison needs to be just right to get the best performance.

Children with DS-ASD often have sensory needs (see page 32). I am surprised by how many children with DS-ASD have a great love for swimming and water activities. One parent said when her child is swimming, he is in constant motion, has great endurance, and is highly motivated to participate. Another said her child loves to swim to the bottom of the pool and pick up pennies or pool toys, can hold his breath for 30 seconds, and swims using a dog paddle stroke. Another mother reports that her child learned the back stroke and another child loved just floating on the water.

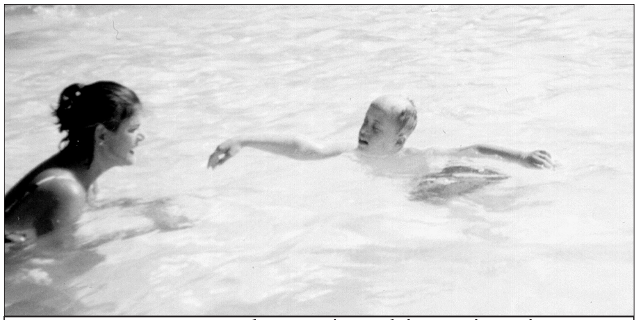
Even though these observations are based on a few children, they do suggest that similarities exist in children with DS-ASD. Gathering more observational data may provide additional clues that will be useful to parents and professionals. We need to understand how children with DS-ASD perceive and react to life experiences so we can interact with them in a way that respects their preferences. They will be, like anyone, more open to new experiences if they are presented in a way that is acceptable and not frightening.

✧ ✧ ✧

Patricia C. Winders, P.T., is a physical therapist who has a special interest in children with Down syndrome. She is currently the senior Physical Therapist for the Down Syndrome Clinic at Kennedy Krieger Institute and author of the book, Gross Motor Skills in Children with Down Syndrome: A Guide for Parents and Professionals. *She also serves on the Professional Advisory Board of the National Down Syndrome Congress and the Clinical Advisory Board of the National Down Syndrome Society.*

References:

- Winders, P. *Gross Motor Skills in Children with Down Syndrome: A Guide for Parents and Professionals.* Woodbine House, 1997.



Peter Ben Paul practices his swimming.

Changing Behavior... & Teaching New Skills

by Naomi Swiezy, Ph.D.

Taking your child to a clinic for an evaluation is an intimidating process. Often a variety of diagnoses or labels are discussed and considered, confusing the big picture you have of your child. You leave with one question: "Now what do I *do* about it?" This article will address this issue by presenting practical tips for managing your child's inappropriate behaviors while also teaching some appropriate behaviors and alternative skills.

Parents of children with Down syndrome and autistic spectrum disorder (DS-ASD) are especially in need of these tips because there is so little information available about this dual diagnosis for parents or professionals. As parents, you become comfortable accommodating your child's learning style based on information about Down syndrome and your own experiences. Then the latter diagnosis, autistic spectrum disorder, is superimposed on the first. At this point many parents are overwhelmed. They feel as though all hope for modification is lost. However, if you approach your child's behavioral difficulties that are often associated with autistic spectrum from a systematic, behavioral perspective, you will feel renewed hope for not only behavioral management, but also for skill development.

One methodology that has proven effective for children with autistic spectrum disorders, including those with Down syndrome, is applied behavioral analysis or ABA approaches. ABA approaches are based on the idea that we know when children misbehave, they often have some motivation to do so. We also know children learn from their environments and adapt their behavior to gain access to what motivates them the most. What becomes confusing is that each child is motivated by different factors and sometimes more than one factor at a time. To address this, ABA uses systematic and empirical ways to assess the individual motivational factors of each child. With this information, individual programs or plans are created addressing both what happens before the behavior as well as the consequences for the behavior itself.

There are several general guidelines you can use to improve behavior-related problems without conducting a formalized assessment. These strategies will improve your child's behavior regardless of the specific motivation behind them. However, we first need to look at some general facts about children with Down syndrome and autistic spectrum disorder (Ds-ASD) that form the basis for working effectively with your child:

✧ Children with DS-ASD do not misbehave because they are mean-spirited or obstinate.

All behaviors serve a purpose. That purpose may be to communicate wants and needs. Particularly children who are nonverbal or just learning to communicate will communicate in whatever method is most effective and successful in getting what they want, whether it is appropriate or not.

✧ Children with DS-ASD *can* learn.

Learning may take longer and you may need to use different teaching strategies that are more explicit and direct than for other children, but they do learn.

✧ Children with DS-ASD have three major areas of concern: communication, socialization, and interests or activities.

A child with DS-ASD may or may not have a different amount of language, socialization, and leisure behaviors from other children her same age. What is distinct is the way interactions vary from what is expected from other children their same age and developmental ability, particularly in the area of communication, socialization, and activities.

✧ Common behavior problems such as aggression, tantrums, and "noncompliance" are not part of DS-ASD.

For instance, it is not necessary for a child to have these behaviors to meet diagnostic criteria for the DS-ASD. However, children with DS-ASD tend to respond with aggression, tantrums, or "noncompliant" behavior as a way of communicating a frustration or need. The behaviors are the result of the

Continued on page 26

Changing Behavior...

Continued from page 25

syndrome, not a symptom of it. Some suggestions regarding how to respond to these behaviors are discussed later in this article.

✧ A comprehensive, individualized program is the most effective way to affect behavior.

A comprehensive program will not only address consequences for inappropriate behaviors, but also focus on training appropriate alternatives such as functional communication and play skills. If you seek only to reduce inappropriate behavior, you may be decreasing the only effective form of communication your child has. It is as important to teach a child what *to* do as well as what not to do.

Helping Your Child Achieve Her Potential

The most effective approach to shaping appropriate behavior for children with DS-ASD is to create opportunities in the environment for the behavior you want to occur. It is equally important to respond to inappropriate behaviors with effective management strategies. Below are some general guidelines that address both of these angles. If you are overwhelmed or faced with behaviors that are very difficult or pervasive in nature, please consult a trained behavioral specialist who is familiar with ABA strategies. A trained ABA specialist will work with you and your family to build specific recommendations and plans for your child.

Environmental Controls

✧ Do not set expectations too low.

Your child *is* capable of learning. However, she may learn many essential skills such as functional communication, toileting, social skills, play and engagement more effectively by using explicit teaching than by picking the skills up naturally. Regardless, your child will develop skills. Expect progress and growth.

✧ Do not set expectations too high.

Set goals that are realistic. It helps to break tasks down into separate steps that you prompt and respond to independently. This encourages success and reduces the stress or frustration and, ultimately, behaviors that arise when expectations are too high.

✧ Change activities often and always try to end with success.

Just as it is important to set reasonable expectations, it is important to know when and how to end a teaching session or change activities. When you are teaching your child a new skill, take a break before she becomes fatigued or frustrated and misbehavior arises. If possible end the activity at a point where she has achieved some success. As much as possible, plan to end any specific teaching time on a positive note. This will build your child's positive feelings about her abilities, and yours too. Consistently working until she is fatigued is frustrating for everyone; she feels she has lost control of her situation and will act out accordingly.

✧ Use things your child enjoys as reinforcement.

When your child has done something that you want to encourage, it's important she sees your response as a worthwhile reward. Keep in mind many children with DS-ASD may take particular pleasure from some things that others would not find particularly reinforcing or gain pleasure from. That's OK. What is important is that your child sees the reward as a reinforcement for her behavior or work that she has done.

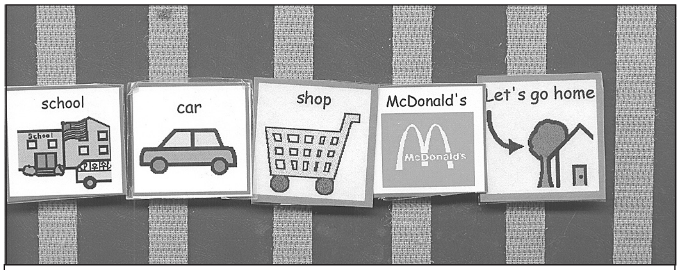
✧ Allow *choices* whenever possible.

If your child does not feel she has control over her environment, she will be frustrated (and misbehave) as a result. Provide the illusion of control by giving her choices regarding aspects of the task without lowering your expectations. For example, if you would like her to sit down, you can say, "you need to sit—do you want to sit in the big chair or the little chair," or "you need to get dressed—do you want to put on your pants or shirt first?"

✧ Incorporate structure and routine into the environment.

Children with DS-ASD often do not pick up on vague cues that others do to detect changes in rules, expectations, or events. Therefore, building predictability through structure and routine encourages appropriate responses and increases the chance of success while decreasing frustration and resulting inappropriate behaviors.

...& Teaching New Skills



- ✧ Plan ahead for transitions.
  Children with DS-ASD have difficulty with changes or new activities. You can help your child by allowing for adequate time and using prompts that are effective for your child about the change as it is about to occur. This may mean specific verbal cues, a visual schedule, or physical cues (a touch or gathering specific items) that communicate what is coming next.
- ✧ Make eye contact.
  Children with DS-ASD may not pick up on verbal cues even though they understand the request or comment. Achieving eye contact in any interaction, spoken or visual, will increase the chance your child is attending to the interaction.
- ✧ Be as concrete as possible.
  Using abstract ideas, analogies, exaggerations, or sarcasm may only serve to confuse your child. She may take your comments literally or thoroughly misunderstand. Keep your comments simple, clear, and concise to encourage her understanding. For example, give short, direct, instructions: "Alice, turn off the T.V. " Then follow the guided compliance procedure described below. This will be more effective than saying, "Why are you watching T.V. when you're supposed to be getting ready for school?"
- ✧ Use more than verbal instruction.
  Use a combination of verbal, visual, modeled, and physical prompts to get your point across.
- ✧ **Be consistent in every way.**
  Your child will be most successful when the environment is predictable in terms of structure, routines, and expectations.

Use these ideas and methods to set the stage for your child's success and encourage appropriate behavior. It takes planning, but it is an important part of shaping your child's behavior. Once this is done, take a look at teaching your child what it is you would like them to do.

Using Prompts to Teach New Skills

Children with Ds-ASD may do better using specific teaching methods for new tasks. Your child must understand the request, what action to take to follow the direction, and then do those things. To do this, your child may need a variety of cues (visual, verbal, and physical) for her to understand and then follow-through with action. In addition, her interest in repetitive or other behaviors may interfere with her ability to follow your direction. Teaching your child to follow simple commands is a basic tool for managing your child's behavior. If your child is not attentive or receptive to your demands then this will limit your child's ability to learn more adaptive ways of responding.

One way to present new directions and teach the requested response is called *guided compliance procedures*. This method is effective with gaining compliance in most cases. There are three basic steps to the procedure:

Verbal prompt: Give your child a clear instruction and wait five seconds. If she follows your direction (complies), praise her in a manner that specifically and concisely details what she did well. (e.g., state "That's good for….." and insert the task completed). If she does not comply, move to the next step: a gestural and verbal prompt.

Gestural prompt: Show your child the exact response you desire. As soon as you complete the task, return things, or yourself, so they are exactly the same as before you gave the prompt. Tell her, "now you do it." Wait five seconds without providing any other cues. If she complies, praise her specifically for her actions. If she does not comply, move to the next step: a verbal prompt with physical prompt follow-through.

Physical prompt: Take your child hand-over-hand through the entire response as you say, "you need to (repeat instruction)."No praise is issued if you must utilize this step.

Important Pointers:

- ✧ The basic premise behind this procedure is that sometimes your child may not be attentive, may

Continued on page 28

Changing Behavior...

Continued from page 27

not hear you, or may not understand what is being asked of her. The middle step is added to provide the benefit of the doubt. Even if you are convinced that these things are not occurring, attempt this strategy and observe behavioral change. You will learn more about your child in the process.

✧ The timing of 5 seconds between each step allows for some opportunity for compliance and keeps the pace moving. However, for some children, this processing time is not long enough and the time interval may be expanded to more like 10 seconds. If the interval is too much longer, the procedure is not as smooth and allows too much for diversions and task evasion.

✧ The way you say things when talking to your child is very important. Your child is more likely to do what you ask if you avoid some common pitfalls of giving instruction. These include: giving long or multiple requests at one time, providing vague requests such as “Be a good girl,” issuing questions rather than statements, repeating instructions, giving instructions when there is not enough time or energy to follow through, and failing to achieve eye contact. Use one-step, concrete instructions as much as possible.

✧ When using the physical prompt, it is important to demonstrate the exact response you want. This is where you are teaching your child what is expected of her. It is important to teach it correctly the first time.

✧ When using the physical prompt, it is important to be sure that your child is fully involved in the task and is not just loosely held while you complete the task. That is, even if the task may be completed with one hand, if physical guidance is necessitated, then you should use hand-over-hand from behind the child and guide both hands.

✧ Initially, you may want to practice this prompt sequence within the context of one specific task (e.g., dressing, eating). That way, you can practice the sequence in a natural, time-limited situation and your child will master a new skill that makes life a little easier.

✧ Establish a standard schedule and routines for your child. The more predictability your child has in her day, the less often you will need to guide her through specific tasks.

✧ Large tasks, such as cleaning her room, are best broken into several smaller tasks for better success. This presents more opportunities for praise and is reasonable for everyone if she needs gestural or physical prompts.

✧ Do not give an instruction unless you are willing to provide follow through. Consistency in follow-through to the gestural or physical prompt as needed is more important than giving the instruction alone.

✧ Set up situations so your child earns more attention for compliance than for noncompliance.

✧ Misbehavior during the three-step procedure should not allow escape from the task—rather, this behavior should be ignored and the sequence continued.

Behavior Management Strategies

Understanding what motivates your child’s behavior and deciding how to approach it can be a daunting task. Although a formal, functional assessment is the most thorough method, there are some general and effective strategies to consider as a starting point. It is important to individualize them for your child. Some of these techniques, such as positive reinforcement and planned ignoring, are straightforward and intuitive in theory, but will prove to be quite difficult to implement. Therefore, remember to set reasonable expectations for yourself and your child and seek the support of a trained professional.

Differential Responding

Children typically enjoy receiving attention. If they do not receive enough positive attention for their good behaviors, they will often resort to behavior that results in negative forms of attention (e.g., yelling, nagging, “time out”). They would prefer to receive this negative attention than to do without attention all together. Over time, they learn which actions are the most effective in getting a response—positive or negative. This is called differential responding.

It is important to show your child more attention for acting appropriately than for acting inappropriately. This will motivate her to continue with positive behaviors. When used along with procedures to reduce inappropriate behaviors, such as ignoring (see below), it will encourage her to discriminate which behaviors will gain approval. It is important for chil-

...& Teaching New Skills

dren to learn that only appropriate behavior receives a response.

This makes sense to most people. When your child engages in appropriate behavior, she should receive a positive and heightened response; when she misbehaves, attention should be limited. Unfortunately, it is natural to respond oppositely to what is effective and aggravate the situation. That is, when your child acts appropriately, you (the parent or teacher) tend to ignore her good behavior fearing that if you respond it will "rock the boat." Conversely when she behaves negatively you respond dramatically. In reality, the best way to teach your child how to act appropriately is to attend to the positive behaviors and ignore the inappropriate behaviors. Particularly for children with DS-ASD, the easier it is to discriminate between responses to positive and negative behaviors, the quicker she will learn that the best (and only) way to get any form of attention is through good behavior.

Differential responding is most effective when both positive attention and ignoring are implemented. In this way, your child learns inappropriate behaviors result in no attention and acceptable behaviors result in positive attention. This eliminates at least one motivation for inappropriate behaviors such as attention seeking.

The components of these strategies, positive attention and ignoring, are detailed below.

Giving Positive Attention Effectively:

✧ Make eye contact with your child and speak enthusiastically.

✧ Be specific about the behavior that you liked.

For instance, "Good being quiet" or "Nice hands to self," instead of: "Good girl."

✧ Keep praise statements simple.

For instance, "Good picking up toys" instead of, "That was good picking up your toys so that no one would trip on them."

✧ Give attention immediately following the behavior that you liked.

Delays in rewards make it more difficult for her to determine what she did to receive attention.

✧ Withhold attention to an inappropriate behavior (or anything following it) occurring within the last 30 seconds.

For example, your child should exhibit at least 30 seconds of good behavior before you praise her with positive attention after a negative behavior. This helps her discriminate between the behavior being rewarded as the most recent positive behavior rather than a previous misbehavior.

✧ Give the type of attention that your child enjoys.

Children with DS-ASD find different things pleasurable than other children. Make note of the type of attention your child enjoys such as tickles, hugs, or a specific touch. It is important that the attention you give to reward appropriate behavior is positive to your child.

✧ Catch your child being good.

The gains you see in your child seem like small improvements or behaviors which would only be expected due to chronological age. However *all* gains and appropriate behaviors are important and should result in positive attention. Statements such as, "Nice sitting on the toilet" or "Nice brushing teeth" are important for your child to hear.

✧ Provide positive attention for behaviors that cannot occur at the same time as inappropriate behaviors.

For example, if your child tantrums often, praise her for playing quietly and using a normal voice during her play. If she is disruptive to others frequently during her independent play, praise her when she is playing independently and not being disruptive. These methods will teach her acceptable alternatives for misbehaviors.

✧ Get in the habit of catching good behavior and providing positive attention at least once every five minutes.

You will know you are praising your child enough, when you feel you are doing it too much or too often.

✧ Be sure that good behaviors receive more attention than inappropriate behaviors.

✧ Provide many opportunities for positive attention. It is easier to promote appropriate behaviors when your child is doing something she likes to do and you are both focussed on that one activity (instead of cooking dinner, correcting homework, or folding laundry while your child plays). The more you arrange the environment to be conducive to appropriate behavior the better the chance she will learn how to act appropriately.

Continued on page 30

Teaching New Skills

Continued from page 29

Using Planned Ignoring

- ✧ Determine what is "ignorable behavior." Ignorable behavior is typically defined as behaviors that are not harmful to the child, others, or others' belongings. It is important that all family members and caregivers be aware of the definition to be consistent in their response.
- ✧ Ignore as soon as the behavior occurs. Delaying your response (ignoring) will confuse your child if too much time passes between her action and your response.
- ✧ Ignore consistently. Whenever ignorable behaviors occur, be consistent in your response. The best way for your child to learn the limits to her behavior and to determine which behaviors will result in the desired attention is through consistent responses.
- ✧ Make ignoring obvious. To have an impact on behavior, your child must be aware that attention is being removed because of specific behaviors she has done. This is particularly challenging for children with Ds-ASD who are less aware of social cues. Therefore, ignoring must be made obvious by:
  - looking away,
  - keeping a neutral facial expression,
  - talking with others in child's presence,
  - restricting physical contact,
  - tuning the child out, or
  - engaging in household tasks.
- ✧ Expect behaviors to escalate.

  Things often get worse before they get better. This is because your child increases the frequency of behaviors to receive the attention she is accustomed for them. This does not mean that ignoring is not working—quite the opposite—she is merely testing the new rules that have changed.
- ✧ Distract yourself from attending to difficult behaviors.

  When your child's behaviors escalate, it may be best to leave the room, turn on the radio or TV, pick up a magazine, or call someone on the phone to prevent you from reacting to your child's behaviors. Keep an ear out for situations that require your immediate attention, however.
- ✧ Do not allow your child to escape a task due to ignorable behaviors.

  If you are working on a task, such as putting toys away, continue to follow through with the task even if behaviors you have defined as "ignorable" occur.

Ignoring is a very active strategy that requires that you withhold eye contact and make no verbal response to the child. However, it does not mean to stand back and allow destructive or other behavior to occur. It is important at times to prevent and block behaviors as well as removing or diverting a child from an area or situation. It is important to keep everyone and everything safe.

Conclusion

Children with Down syndrome and autistic spectrum present a unique blend of characteristics. The dual diagnosis also complicates intervention strategies, particularly from a behavioral standpoint. Parents and professionals are often unsure what to do for behavioral issues when the dual diagnosis is present.

A practical approach is to use teaching strategies and behavior management methods that address the specific needs of your child and your family. Although this is best done with the assistance of a behavior specialist, some of the strategies described in this article are effective in helping you begin to make progress with your child.

Once you understand the main areas of need for your child and your family and the individual motivations for behavior, treatment of behavioral issues your child with Down syndrome and autistic spectrum is less mystifying. The core to effective teaching and appropriate behavior is consistency, consistency, and

✧ ✧ ✧

Naomi Swiezy, Ph.D., is a Clinical Assistant Professor of Psychology in Psychiatry in the Autism Clinic at the Riley Hospital for children at Indiana University Medical Center. Prior to this she was the director of the Autism and Pervasive Developmental Clinic and behavioral consultant to the Down Syndrome Clinic at Kennedy Krieger Institute.

Sensory Integration: Observations of Children with Down Syndrome and Autistic Spectrum Disorders

by Mary Lashno, OTR

For many children with Down syndrome and autistic spectrum disorder (DS-ASD) Sensory Integration (SI) is one intervention to consider. Many times the way a child with DS-ASD behaves or reacts is because he processes sensory information from the situation differently than other children. This article explains sensory integration, how it effects behavior in children with DS-ASD, and offers some suggestions for common sensory-related behaviors you can use while you set up an appropriate SI program with a trained therapist.

Sensory integration is the process of taking in information from the environment through various sensory systems (touch, smell, sight, movement, sound and the pull of gravity on the body). Information is processed through the brain. The brain then interprets, organizes and directs the body to respond appropriately to that sensory information. Sensory experiences happen continually and as they do, your child continues to learn and respond to his environment in more complex ways.

If you watch a small baby play, you may be able to get a better sense of what sensory integration is. A baby's primary learning senses include vision, skin (tactile), movement and gravity (vestibular), and muscles, joints and ligaments (proprioception). As a child lies on his belly, his mother may place a musical ball in front of him. Following initial movement and sound, the child may try to lift his head to view the object. Initially, this will be difficult due to the pull of gravity, pushing his head back to the floor. Normal curiosity and "inner drive" will engage the child to continue to work on raising his head (vestibular). His arms and legs will also move (proprioception) in an effort to help keep his head up in order to view the toy. His brain is organizing and sequencing all the sensory information received with each movement of arms, legs, and head. His muscles are responding in a way to help him achieve his goal of looking up to see the toy. With each "adaptive response," he continues to refine his skills. As he achieves a certain level of success, he continues to "up the ante" and eventually he will be able to reach forward, touch the ball, make it move and pull it towards him to play. This child's sensory system is organizing information in order to allow him to learn and successfully master his environment. When basic senses are integrated, the child continues to learn and grow from sensory information. Through movement and experiences, he learns how to move against the pull of gravity and feel comfortable with his body awareness in space. He begins to develop a mental picture of where his body parts are and how they are related to him.

If you watch a small child learn a new task, initially a great deal of concentration and effort are noted. The task appears clumsy but as he continues to "practice", his skills become more proficient and not only has he mastered the task but will continue to make it more challenging. This is sensory integration.

Unfortunately, there are some children whose sensory systems do not develop efficiently. They may have a sensory processing disorder. A child with a sensory disorder gathers information from sight, sound, touch, movement and pull of gravity like any other child. However, when the data enters the brain, it is not organized or processed correctly. As a result, the brain sends out an inappropriate response. Learning is based on this information and abnormal response or behavior are usually noted. The brain can respond in two ways.

Hyporesponsive: in spite of large amounts of sensory input, the brain fails to register and doesn't respond to input.

Hyperesponsive: the brain "short-circuits" and registers sensations too intensely.

Let's break this down to get a better picture of these responses. Most children enjoy being touched by their parent. A light touch on the hand or head usually makes a child respond positively. However, there are some children who view this touch as a "fight or flight" response. That is a *hyperesponsive* response. The brain records this as danger and the child reacts by screaming, pulling away, or avoiding this touch

Continued on page 32

Sensory Integration: Clinic

Continued from page 31

or sensory input. The response is comparable to walking down an unfamiliar dark alley at night. All of our senses are on "alert" in order for our body to respond to danger. Our eyes widen, our breathing is shallow, our heart beats faster, and we are preparing our body to respond by either running or fighting to avoid danger. Imagine if your system was always on alert and you felt that every touch or movement meant danger. It would be very difficult to explore your environment and learn from those experiences because your brain is constantly registering danger. As a result, many children who are hyperesponsive avoid any form of input through tactile (touch), vestibular (gravity), or proprioceptive (movement). Due to the brain's abnormal response to sensory input, this child usually avoids input and doesn't actively explore his environment, thereby missing out on valuable sensory learning experiences. This child may also prefer certain positions and scream with any type of transition or change in daily routine. He may avoid certain clothes, food textures, hate movement, or sit in one position and perform a perseverative (same action repeated over and over) movement in an effort to "calm" down his system.

The *hyposensitive* child may be viewed as someone who constantly bombards his sensory system in an effort to gain appropriate sensory information. This child may be constantly touching objects, mouthing everything in sight, bumping into walls, or falling repeatedly. He may fall or hurt himself, but doesn't appear to respond to pain in a way you expect such as crying, rubbing his arm, and so on. A hyposensitive child doesn't process information correctly: he may bang into the same object repeatedly. For example, a child with a normal sensory system may run into the room and not see a toy on the floor. He may trip and fall, get up and continue to play. If he comes into the room again, he will not necessarily look at the toy on the floor, but rather his body and postures will adjust to run around the object rather than falling into it again. Suppose you were in a darkened room, unable to see and you were told to find your way out. You would immediately try to "call in" all other senses available in order to gather as much information to find your way out of the room. You would touch the walls, feel the floor, and listen for clues to be successful. This works fine if your sensory system works well; however, someone who is hyposensitive will use his brain to constantly search for information in this intense way to "make sense" of the world.

Madison Duffey takes a bath with her favorite ball and rubber ducky.

Although it seems as though a child could fall into either category, the majority of children with a sensory processing disorder fall into both categories. This means they can be *hyporesponsive* to some input and *hyperesponsive* to other types of input. Also, even though their brains are not processing information in a "normal" format, they will exhibit behaviors that may appear "weird." In actuality, they are trying to make sense of input and will often seek out what they feel their brain is requesting. For example, if they feel they need proprioceptive input they might jump, push, or pull; for vestibular input they might spin or rock; for tactile input they might seek deep pressure. They may also demonstrate odd behaviors, such as playing only in a specific area, not explore a room, avoid certain toys, move or run around constantly, purposely run into walls, or push people.

Children tend to know what sensory information they need and although these behaviors appear strange to us, it is the child's way of making sense of his environment and trying to adapt to daily life. It should be noted that all of us will have quirks about certain types of input and we adapt to the conditions. However, as long as it does not impact our ability to learn and function within our environment, it is not considered an issue. Children with a sensory dysfunction are unable to learn and function within their daily routine and until they can "make sense" or modulate the input (turn up or down the sensory response for the brain to process and respond appropriately) they will continue to demonstrate a dysfunctional sensory system.

Sensory Integration: Clinic

Through therapeutic intervention, an Occupational Therapist provides the appropriate sensory input in order to help the child modulate information correctly. The child will then begin to register, modulate and respond in a normal fashion which will increase exploration and allow learning to happen.

Some of the children I have seen through the Down Syndrome Clinic who have DS-ASD demonstrate the areas of concern discussed above. Families will usually report that their child was developing within normal limits for a child with Down syndrome only up until they were around a year old. At that time, they began to demonstrate decreased skills in playing, social interaction, and many abnormal behaviors. Some on these reported behaviors include shaking fingers, chains, and similar objects in front of their face, food refusal, looking directly into a light source, and preservative type motions rather than purposeful play. Some of the other behaviors that have been reported or observed by families of children with DS-ASD include:

- ✧ Decreased or no eye contact,
- ✧ Excessive mouthing of objects,
- ✧ Decreased or no purposeful play with toys,
- ✧ Staring directly into lights,
- ✧ Abnormal hand movement (such as flicking fingers in front of eyes or waving hands away from body),
- ✧ Refusal to hold objects (such as clothing or a spoon to self feed),
- ✧ Picky eater (especially for specific textures),
- ✧ Flat affect,
- ✧ Self-stimulatory behaviors (such as rocking, banging head, humming, or screaming), and
- ✧ Decreased interaction with people.

If your child sounds like the one listed above, he may be diagnosed with DS-ASD. Many of the behaviors listed are also noted in the children with autistic spectrum disorder. Additionally, it is well documented that many children with autistic spectrum have significant difficulty with sensory processing. It is easy to see that many of these "odd" behaviors could possibly be related to your child's attempts to calm down or make sense of the world through the sensory input they are receiving.

If your child has behaviors like the ones listed above and the behaviors are impacting developmental growth, therapeutic intervention is essential. The goal of a therapeutic sensory integration program for your child with DS-ASD is to normalize and help the child "make sense" of sensory input so he can explore and learn from his environment. Below is a list of goals and types of therapeutic intervention that may be helpful.

Peter Ben Paul and his friend, Laura Collier, enjoy a pile of leaves.

The first step of sensory integration therapy is to combine an informal observation with information you share about your child that is specific to sensory processing. You may be asked to fill out a questionnaire regarding your child's responses to various types of sensory input. This information determines your child's sensory processing function: what areas are hyper- or hyporesponsive to sensory input. The observations, evaluations, and intervention for sensory dysfunction should be done by a therapist who is trained in and has experience with Sensory Integration. Through therapeutic intervention, the therapist will be able to provide the input needed which allows your child to begin to "register" and respond more appropriately. Recommendations can then be made suggesting ways to provide specific sensory activities throughout your child's daily routine. The focus of SI Treatment is to regulate your child's ability to register and modulate sensory input in order to allow the normal process of exploration and learning to develop.

Children with DS-ASD usually do not need to participate in a true Sensory Integration type of therapy. This is usually a very intensive therapy performed on a weekly basis for at least a year. SI Therapy for a

Continued on page 34

Sensory Integration: Clinic

Continued from page 33

child with DS-ASD most likely involves intervention once or twice a month. The goal is to determine sensory issues and provide treatment and to train you to carryover activities at home and encourage them at school. As your child's sensory processing improves, therapy is reduced and focuses on providing activities for you to use with your child that increase his tolerance of sensory input.

Although therapy is highly recommended, it may not always be practical. It is not always covered by medical insurance, so the cost may be a problem as well as the availability of a trained Occupational Therapist. With that in mind, here is a list of some common behaviors seen in children with sensory processing concerns, possible reasons for the behavior, and suggestions that may be helpful. The bottom line is that as parents you spend the most time observing your child and, most likely, you have already begun to provide the child with the types of input that they are seeking.

Constant mouthing of objects, chewing on clothes, and other objects.

If your child is constantly mouthing or chewing it may be one method he uses to calm himself. Here are some suggestions:

✧ Give your child various types of textures or stimuli to mouth such as the *Discovery Toy* that is rubber and has 4 different types of tips or nubs. Each provides a different type of sensory input.

✧ Give some deep pressure to the face with your hands, his hands, or a terry cloth towel going in a slow, downward direction.

✧ Vibration is often enjoyable if it is introduced slowly. Be cautious with this type of sensory input and use it sparingly. Try to let your child dictate how much or little vibration massage he receives.

✧ Chewing on therapy tubing or drinking milkshakes or Slurpees through a straw are often helpful.

✧ Chewy or crunchy foods such as pretzels, trail mix or Starburst may also be a preferred activity for your child.

Refusal to hold items in hands

If your child is hypersensitive in the hands, he will resist holding objects in his hands. He may become very upset if his hands are dirty or need to be cleaned. When he holds an object, it is with a very weak grasp that is more at the fingertips than the palm. Yet he may hold onto certain, preferred objects. Instead of purposeful play, however, he will use a preservative type motion, such as banging 2 blocks together or throwing off a tray, shaking and so on. He is only able to process limited amounts of information from the object, which is seen more in loud, banging activities rather than purposeful play. If this sounds like your child, he may benefit from the following activities:

✧ Provide deep pressure to the hands, such as placing your hand firmly on top of his and guiding him through an activity.

✧ Offer vibration on his hands from toys such as a BumbleBall™.

✧ Provide various types of textures, such as soft, hard, scratchy. Be sure to consistently monitor your child's response to the input.

✧ Provide various types of textures within a child's reach (such as a basket or box) which will allows your child access to explore these items on his own.

Purposely banging into walls, furniture, pushing or knocking over objects.

If your child seems to purposefully bang into walls, furniture, or knock over objects, he probably is not processing movement. Through these activities he is seeking the sensation of movement either through rocking, spinning, banging into objects, or walls. He may also be trying to provide his body with deep pressure in an effort to calm his system. Some suggested activities include:

✧ Fill a wagon or box with heavier objects that the child could push or pull around the room.

✧ Fill a backpack with heavier books (within reason) and put the backpack on your child's back. This may provide the feedback the child needs to understand where his body is in space.

✧ Other activities that provide proprioceptive input, such as deep pressure, roughhousing, jumping on a small trampoline (with supervision), tug of war, or wrapping up in a blanket, may help him calm and process information more appropriately.

Excessive spinning or rocking:

If your child spends too much time rocking or spinning, he may be trying to calm his system down. He may also be seeking movement input. Activities that may be helpful include:

Sensory Integration: Clinic

- Using of a child size rocker, rocking horse, or you slowly rocking him in your lap with deep pressure provided (holding him snugly).
- Watch your child during these activities. If your child calms with the rocking, he may also benefit from your singing rhythmic songs or playing calm music while he rocks.

Looking into bright lights, flicking fingers and dangling objects in front of the face.

If your child likes to look into lights, flick his fingers, or dangle things in front of his face, he is probably looking for ways to increase visual input. To do this he is exhibiting a self-stimulatory type of behavior, such as light flashing on a shiny object being moved in front of the eyes, staring at a bright light, and so on. Although he will want to continue these behaviors, you may want to try to put a purpose to the activity. Some ways to do this include:

- Providing toys that provide bright lights that turn on and off with a switch. Provide hand-over-hand assistance with the switch as needed to encourage your child to activate the toy independently.
- Provide deep pressure over his hands when he dangles objects in front of his face. When you do, help "walk" him through placing objects in various type containers, shaking, opening, closing and hiding objects.

Learning to add purpose to these self-stimulatory behaviors is a slow, process and may take some time to transition child into use of the object in a more purposeful task.

In addition to these suggestions, I highly recommend sensory integration treatment be performed and guided by an Occupational Therapist trained in Sensory Integration. Although the suggestions listed above may prove helpful, they are only general suggestions and may not work for your child. Continue to observe, be patient, and use creativity as you work with your child. As he begins to accept sensory input that he is able to process and "make sense" of, his ability to use hands and body will increase along with his ability to play and interact within his environment.

✧ ✧ ✧

Mary Lashno, O.T.R., is a registered occupational therapist trained in sensory integration therapy. She currently practices at Kennedy Krieger Institute in Baltimore, Maryland.

Let Me Hear Your Voice: A Family's Triumph Over Autism by Catherine Maurice. Published by Ballantine Books, 1994. ISBN: 0-449-90664-7. $12.00.

This widely acclaimed book offers a mother's story of the process she went through as two of her children were diagnosed with autism. Catherine Maurice writes of the intense, tenacious, heart-wrenching battle she wages with the "autism beast" that has invaded their lives. She settles on a program of Applied Behavioral Analysis for her children, which proves effective. The story is not sugar-coated, nor does it claim success for everyone. Notably, it does not hide the emotional strain of implementing an intense ABA program in the home.

Targeting Autism: What We Know, Don't Know, and Can Do to Help Young Children with Autism and Related Disorders by Shirley Cohen. Published by University of California Press, 1998. ISBN: 0520213092. $14.95.

A comprehensive overview of the most commonly discussed teaching and treatment options for children with autism. Dr. Cohen uses her analytical skills to raise questions regarding each approach in a way that encourages parents and professionals to consider the personality and needs of the child rather than philosophical issues. For families of children with Down syndrome who have just been given a diagnosis of autistic spectrum disorder, *Targeting Autism* is an easy-to-follow guide through a complicated maze of information.

Children with Autism: A Parents' Guide edited by Michael Powers, Psy.D. Published by Woodbine House, 1989. ISBN: 0-933149-16-6. $14.95.

Children with Autism is a general guide written for parents covering topics related to medical and educational decisions for young children up to age 6. Although it contains helpful information, the reference to age may make it difficult for families who are introduced to the idea of autism later in their child's life (age 7-10). One of the most helpful aspects of this book is the correlation made between decisions and programs used in childhood and their use or generalization of skills in adulthood.

The Child with Special Needs: Encouraging Intellectual and Emotional Growth by Stanley I. Greenspan, M.D. and Serena Wieder, Ph. D. Published by Addison-Wesley, 1998. ISBN: 0-201-40726-4. $27.10.

After years of domination by ABA and Lovaas strategies, Drs. Greenspan and Wieder offer a completely different approach to connecting with a child who has autistic spectrum disorder. The strategy is based on a method they call "Floor time" which centers on joining your child in *their* world first , gradually enticing them to *our* activities rather than a harsh collision or battle of wills. The book is difficult to read, with language that can leave a parent confused or dulled by its complexity. You need to be sitting in an uncomfortable chair if you read it at the end of a long day. It is, however, worth the time and effort.

Right From the Start: Behavioral Intervention for Young Children with Autism. A Guide for Parents and Professionals by Sandra L. Harris, Ph. D. and Mary Jane Weiss, Ph. D. Published by Woodbine House, 1998. ISBN: 1-890627-02-X. $14.95.

Educational programs and teaching strategies are among the first decisions parents of children newly diagnosed with DS-ASD must make. In *Right From the Start,* Sandra Harris provides an in-depth look at one type of strategy available: Applied Behavioral Analysis. Harris provides a balanced, realistic discussion of what parents must consider before choosing a particular program for their child and what key elements an intensive behavioral intervention program should have. If you are considering Applied Behavioral Analysis, this resource gives you what you need to be an informed consumer.

Parent Survival Manual: A Guide to Crisis Resolution in Autism and Related Developmental Disorders edited by Eric Schopler. Published by Plenum Press, 1995. ISBN: 0-306-44977-3. $29.95.

In this book, Eric Schopler pulls together a variety of topics parents of children with DS-ASD will find worthwhile information for crisis intervention at home. One of my favorite sections is "repetitive behaviors and special interests." Schopler has compiled a variety of solutions used by other parents to solve or reduce those "behaviors" that can be nerve-wracking for families. There are 350 anecdotes shared by parents that are, in turn, analyzed by behavior therapists. This analysis helps the reader, perhaps new to the idea of autistic spectrum, follow the process of problem-solving. If you think your child is the only one who…I will bet you will find a similar situation in this book.

Autism Through the Lifespan: The Eden Model by David L. Holmes, Ed.D. Published by Woodbine House, 1997. ISBN: 0-933149-28-X. $21.95.

The Eden Family of services provides comprehensive behaviorally based services to children and adults with autism in Princeton, NJ. In his book, Dr. Holmes shares the philosophies, methods, and goals of this successful program. Because of the detail in program description, this book may be overwhelming to parents new to DS-ASD. However, I found it particularly helpful as I struggled to understand the term "aversive" in literature detailing behavior modification. I often re-visit this book as a reference when I am confused. Each time I find a different idea or concept that causes me to re-think how I am addressing the immediate situations in my home.

Activity Schedules for Children with Autism: Teaching Independent Behavior by Lynn E. McClannahan, Ph.D. and Patricia J. Krantz, Ph. D. Published by Woodbine House, 1999. ISBN: 0-933149-93-X. $14.95.

Imagining a child with DS-ASD who requires constant prompting to get through a task doing things independently might be difficult. In the book *Activity Schedules for Children with Autism,* Krantz and McClannahan spell out a way it can be done. Using this method children are taught to follow prompts they see in pictures schedules (photos or symbols) for each step of a task. Although they begin this process with an adult or peer to prompt them, the authors stress the importance of fading those prompts allowing the child to use the pictures as their guide. The authors detail the process of making the schedule, determining what pictures you need for a task, how to teach the visual prompt, and a method for setting your child up to accomplish a series of tasks independently using visual cues. My vision of what is possible dramatically changed when I read this book. Coupled with *Visual Strategies for Communication* the possibilities seem endless.

Visual Strategies for Improving Communication: Volume 1: Practical Supports for School and Home by Linda A. Hodgdon, M.Ed., CCC-SLP. Published by Quirk Roberts Publishing, 1998. ISBN: 0-9616789-1-5. $39.95.

Using visual strategies is a way to promote independence, learning, and sanity for everyone. Linda Hodgdon promotes picture use for more than transitions. She suggests using photos or picture symbols to make the “house rules” and expectations clear to everyone. In *Visual Strategies* Hodgdon focuses on activities and methods for both home and school, which takes one step out of problem-solving for parents. I have found it an invaluable resource for structuring our home and broadening my ideas of what is possible using visual systems. *Visual Strategies for Improving Communication* is the perfect companion to *Activity Schedules for Children with Autism.*

Steps to Independence: Teaching Everyday Skills to Children with Special Needs (Third edition) by Bruce L. Baker and Alan J. Brightman. Published by Brookes Publishing, 1997. ISBN: 1-55766-268-1. $28.00.

Steps to Independence is a step-by-step guide to help parents teach children essential life skills. With great detail, a variety of skills are broken down into manageable, teachable steps. Different strategies for teaching skills such as making a bed, brushing teeth, or getting dressed are outlined. Once you try a few of the strategies you will gain confidence in your own ability to break a task apart to small steps and choose an appropriate strategy to encourage your child to work to doing them independently.

Siblings of Children with Autism: A Guide for Families by Sandra L. Harris, Ph. D. Published by Woodbine House, 1994. ISBN: 0-933149-71-9. $12.95.

Brothers and sisters of children with disabilities often fall between the cracks. It isn’t hard to imagine how quickly this might happen during times of crisis. In her book, Dr. Harris shares strategies for dealing with specific issues related to brothers and sisters of children with autism. She stresses the importance of communication and balance in personal and family time, which is something that is easily forgotten.

Views From Our Shoes edited by Donald J. Meyer. Published by Woodbine House, 1997. ISBN: 0-93149-98-0. $14.95.

Views From Our Shoes is a collection of 45 essays written by brothers and sisters of children with a variety of disabilities. Included are essays written by siblings of children with Down syndrome alone and autism alone. For siblings or classmates who are too old for most books written on this subject, *Views From Our Shoes* offers insight and compassion from true experts in dealing with kids with disabilities. This year, these essays were the perfect addition to Andy’s fourth grade class unit on differences. Many of the essays are written by brothers and sisters who are the same age as Andy’s classmates offering more age appropriate and thoughtful perspective than typical disability awareness stories.

Andy and His Yellow Frisbee by Mary Thompson. Published by Woodbine House, 1996. ISBN: 0-933149-83-2. $14.95.

I originally purchased this book merely because it had my son’s name: Andy. When I read the story, I realized that if I substituted a jump rope for the Frisbee it *was* Andy. It has been useful to share this book with his classmates, which often starts a discussion about *how* to play with Andy. His friends and mentors like the girl in the story, Sarah, approach Andy slowly and at his level. *Andy and His Yellow Frisbee* sends a much-needed message about tolerance for and acceptance of each other. I found using *Andy* along with the book, *We’ll Paint the Octopus Red* as introductions to my son’s disabiilty to his classmates a good combination. Both offer questions and answers at the end of the story that initiated positive discussions.

We'll Paint the Octopus Red by Stephanie Stuve-Bodeen. Illustrated by Pam DeVito. Published by Woodbine House, 1998. ISBN: 1-890627-06-2. $14.95.

We'll Paint the Octopus Red is my favorite book to use for an introductory story about Down syndrome to young children. Common questions and concerns about Down syndrome are either answered in the story or in the Question and Answer section in the back of the book. Together with *Andy and His Yellow Frisbee* the stories begin to create an image of my son for his classmates.

Just the Facts edited by H.F. Johnston, M.T. Witovsky, and J.J. Fruehling. Published by The Wisconsin Child Psychopharmacology Information Service. CPIS, 6001 Research Park Blvd. #1568, Madison, WI 53719-1176. Fax: 608/263-0265. www.psychiatry.wisc.edu. $15.00 for four issues, $25.00 for eight.

Just the Facts provides information about psychiatric disorders such as Obsessive Compulsive Disorder and autistic spectrum as well as the medications that may be used in these situations. Since there are many medications that may be suggested for a variety of reasons, it is helpful to have information in writing that explains the reason for its choice and what to look for (both good and bad). I have found it to be an understandable resource for very technical information.

Sleep Better! A Guide to Improving Sleep for Children with Special Needs, by V. Mark Durand. Published by Paul H. Brookes, Co., 1998. ISBN: 1-55766-315-7. $21.95.

When was the last time you can remember sleep schedules being routine in your home? Many children with autism and other disabilities have disrupted sleep patterns that can leave families chronically tired. In his book, *Sleep Better!,* Durand offers methods to understand your child's sleep problem and multiple strategies for solving them. With carefully woven case studies, Durand illustrates the art of modifying theory to meet the needs of each family and their child. It is refreshing to read a resource on this subject that considers the unique emotional and routine-related needs of children with special needs and their families. Don't be fooled into thinking the answers are easy, however. Solving sleep problems takes a commitment to investigating the problem as well as implementing a plan for a solution, which may need to be changed. Yet with the idea of a reliable 8 hours of sleep as motivation, reading *Sleep Better!* and committing the time to the process is palatable.

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.

DS-Autism Listserv. Joan E. Guthrie Medlen, owner.

DS-Autism is an email list for families and others interested in discussing issues related to the dual diagnosis of Down syndrome and autistic spectrum disorder. The listserv is intended to be a virtual support group where we share funny, challenging, exciting and often exhausting moments in our lives. There are two ways to join the list:

1. Go to: http://www.jps.net/jmedlen/ds-autism.htm and follow the instructions for signing up, or
2. Send an email to: join-ds-autism@telelists.com.

Once you are subscribed using either method, a welcome letter will be sent to you explaining how to post to the list.

Down Syndrome and Autism Parent Support Group. Glenn Vatter, coordinator. 3124 Henneberry Rd., Jamesville, NY, 13078. 315/677-3844. glendot@worldnet.att.net.

The DS/Autism Parent Support Group is a list, maintained through the mail, of parents who have children with the dual diagnosis of Down syndrome and autistic spectrum disorder. The listing includes parents' names, addresses, phone number, email where applicable, name and age of all children and any other interesting info such as treatments tried, parent involvement in organizations, special education teaching, or nursing. Only members receive the list of families. It is not provided to researchers, students, or other parent groups. The family list is also not sent through email, to discourage unwanted distribution. Many members have email and also are on the DS-Autism Listserv. Information packets are available giving information on the dual diagnosis, case studies, and so on. This is available to anyone, whether on the list or not.

Related articles from earlier issues of *Disability Solutions.*

"Augmentative and Alternative Communication Techniques in Inclusive Classrooms," by Pat Mirenda, Ph.D. *Disability Solutions* Volume 3: 4, July/August, 1999.

"Comunicating *with* Your Child: Observe, Wait, and Listen," by Jane Grosfield, CCC/SLP. *Disability Solutions* Volume 3: 4, July/August, 1999.

"Teaching Sign Language," by Claire Donovan, S-LP (C). *Disability Solutions* Volume 2: 5, January/February, 1998. Out of Print.

"Strategies for Augmenting Communication," by Kimberly Voss. *Disability Solutions* Volume 2: 2, July/August, 1997. Out of Print.

These articles and other back issues of *Disability Solutions* are available free from our website (www.disabilitysolutions.org) as Adobe Acrobat Reader files. Back issues of *Disability Solutions* are available for $2.50 from the publication address (see page 2).

Picture and Symbol Resources

Boardmaker. Concept developed by the staff at Erinoak, of Mississauga, Ontario, Canada. Published by Mayer-Johnson Company. P.O. Box 1579, Solana Beach, CA 92075. 800/550-0084. www.mayer-johnson.com. $399.00 (Mac or Windows).

Though at first blush this may seem like a big investment, it is a fantastic tool for parents to own. Boardmaker uses the Pictures Communication Symbols (PCS) created by Mayer-Johnson. These symbols are widely used by schools and speech pathologists to create communication boards, PECS symbols, and other materials. Using this program, families can create communication boards, schedules, books, curricular adaptations, and whatever else your family needs. I have found it much easier to be able to create my own materials knowing that if it doesn't work I can try again rather than worry about how I will get more symbols from the speech pathologist if this doesn't work or I lose what I have.

KidAccess. 6526 Darlington Road, Pittsburgh, PA 15217. 412/521-8552. www.kidaccess.com. Prices vary.

Kid Access Co. makes "eye-cons." Eye-cons are a set of symbols for organizing the worlds of non-readers and other visual learners. Concrete, visually engaging, and customizable, they can be used to develop and reinforce important cognitive and communication skills. They are another form of symbol or picture that can be used for visual strategies, schedules, and communication boards. You can purchase standard packs or customized packs that include symbols you are most interested in. Prices of the different symbol packs vary, ~~but are reasonable.~~

Picture This... CD. Created by Silver Lining Multimedia, Inc. P.O. Box 2201, Poughkeepsie, NY 12601. 914/462-8714. Fax 914/463-0437. www.silverliningmm.com. Also available through Woodbine House, Inc. 800/843-7323. www.woodbinehouse.com. $49.95.

Picture This... is an easy-to-use computer program with over 2400 high-resolution photos shot against a plain background. The photos are sorted into the following categories: actions, animals, bathroom, bedroom, body, buildings, clothing, colors, electronics, emotions, food, furniture, holidays, household, kitchen, lineart, music, nature, opposites, people, places, prepositions, rooms, sequences, shapes, sports, tools, toys, travel and vehicles.

If your child is using photos instead of line-drawn symbols, they are perfect for communication boards, lotto, schedules, teaching emotions, social stories, and so on. The CD provides what you need to create individual cards in different sizes as well as lotto boards. The only disadvantage is to use them to their maximum effect, you need to have some computer savvy.

Other Resources

KidKit. P.O. Box 1,1Clarendon Hills, IL 60514. 630/415-1870. sarah@kidkit.com. www.kidkit.com

KidKit is a hands-on way to enhance communications opportunities and structure for children with autism and language delays. *KidKit* products are designed by educators interested in helping parents of children with Autism communicate effectively at home. *KidKit* produces hands-on tools to communicate with children using visual systems for communication. *KidKit* uses clear, concrete presentations of concepts such as counting, reading, and social behavior. Children with language delays often rely on their visual strengths to learn. *KidKit* addresses this strength and reduces the anxiety of transition through the use of picture schedules, social stories and sensory integration materials.

The San Francisco Foundation
Community Initiative Funds
Creating Solutions
14535 Westlake Drive
Suite A–2
Lake Oswego, OR 97035

Disability Solutions

A Resource for Families and Others Interested in Down Syndrome and Developmental Disabilities

Editor, Joan Guthrie Medlen, R.D., L.D.

Disability Solutions is published four times a year by Creating Solutions.
Creating Solutions is a project of The San Francisco Foundation Community Initiative Funds (TSFFCIF), a 501(c)3 public charity, our fiscal sponsor.

Subscriptions

No donation or fee is required to receive *Disability Solutions*, available in print in the United States and to FPO addresses. To request a subscription, send your mailing address. If you would like to help with the cost, you may send a tax deductible gift to Creating Solutions (see donations).

Writing Guidelines

We welcome your articles, reviews, letters to the editor, photographs, commentary, and ideas for *Disability Solutions*. For information about writing for us, please contact us for guidelines by mail, fax, or visiting our website.

ISSN: 1087-0520

Creating Solutions

14535 Westlake Drive
Suite A-2
Lake Oswego, OR 97035
www.disabilitysolutions.org
subscriptions@disabilitysolutions.org
503.244.7662 (msg)
503.443.4211 (fax)

Back Issues & Multiple Copies

The first printed copy of *Disability Solutions* is free. Additional printed copies are available for $5.00 each as long as supplies last. You can download every issue of *Disability Solutions* on our website as an adobe reader file (pdf) from our website. For multiple copies for exhibits or parent groups, please contact us by fax or email copies@disabilitysolutions.org.

Reprint Policy

Creating Solutions supports sharing information in the public domain, especially for families. For information about reprinting articles please contact us or visit our website.

Donations

We are deeply grateful for your support. You are the heart of the work of Creating Solutions and its projects, including *Disability Solutions*. We cannot fulfill our mission to improve the quality of life for people with developmental disabilities and their families without your support. If you want to help with the cost of *Disability Solutions* and the projects of Creating Solutions make your donation to: TSFFCIF for Creating Solutions and send it in the envelope provided or to the publication address.