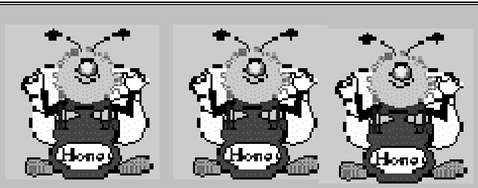

BBB AUTISM SUPPORT NETWORK/ AUTISM SOCIETY ONTARIO (YORK REGION CHAPTER)

Autism Society
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PRESENT

THE E-NEWS

http://www.bbbautism.com/about_bbb.htm

KEEPING YOUR COOL (WHILE YOUR EMOTIONS ARE ON FIRE)

Volume 2; Issue 2 September 27, 2001

About this issue....

For this issue, we wrote to some parents and professionals asking them the following questions:

1. What are your tips for keeping emotions under control in circumstances such as: school meetings, uninformed/rude public and when having to reiterate your child's history and most personal information to countless agencies.

2. How to handle the lack of respect of parties offering strategies and advice that parents are wary of. This could be a friend, stranger, agency, family who don't live with autism 24/7, offering advice that is inappropriate to every day life. (An example is the OT who told me I had to take my child to the park and swing him *five* times per day! I got so frustrated trying to explain how illogical this was to an unhearing professional that I almost lost it.)

3. How to keep your emotions under check around your kids.

We were looking for strategies on how to get our points (as parents) across, without becoming a blubbering mess!

The following newsletter is the result of the wonderful input I got from professionals and parents. These articles are originals, written exclusively for this newsletter and the links are the most useful found by these people. Many thanks to those who helped make this issue possible!

Liz

OUR FEATURED ARTICLE

KEEPING MY COOL *by BBB Member Sonya*

I live in a small town (about 3,000 people) and this town thrives on gossip and rumor. It is a terrible feeling to walk down the street and have everybody whispering behind you and pointing when your back is turned.

Generally, it is pity my fellow citizens project. What they don't understand is that I don't want their pity.

To the people always handing out advice that obviously have had no experience with an autistic child, but somehow think they are an authority of some sort, I simply nod and then turn and walk away. Generally, I walk away laughing and doing so very hard. I used to try to explain to these people why their suggestion will not work, but they just argue with you or look at you with a complete dumb expression and lack any comprehension. So, just don't bother with it. I guess the reason I wait out their "advice" is because I want them to leave the conversation with good feelings towards me. I used to dish out smartass comments to everyone until one day I realized that these people are walking away feeling that I am downright rude and then they "develop" a negative attitude towards all people with autistic children. I don't want that. It is better to respect the fact that they are not trying to tell you that you are a bad parent; they are just trying to help you. Their advice is usually worthless, but just hear them out and then go on about your business.

To the people who treat me and my family so rudely as to make comments about us, especially the people who make these comments in front of us, I hold nothing back. Whatever my mood is at that particular time, is what they deal with. I generally get right in their face and ask them why they said this or that. By putting them on the spot, they generally back down.

When they make comments about my child's behaviors, I have been know to walk right up to him/her and say something to the effect of, "This child has been diagnosed with autism. That explains his behavior.... what is your excuse? Ignorance? Or just plain stupidity?" They generally stand their in total shock that you've said this and completely silent. At that point I say, "Yeah - I thought so!" and walk away.

For the days when I'm in a good mood and refuse to let somebody get me down, I have business cards that I printed up on the computer to hand out. On one side it says, "Please don't let this child's behavior disturb you. He has Autism. Disruptive behavior is one of the many symptoms of a pervasive development disorder such as autism." And then on the back side of the card, it says, **"Autism is a neurological disorder that causes problems with communication, behavior and learning. With intensive help, many people with autism can learn to compensate. For more information, please contact: The Autism Society of America** http://www.autism-society.org/**1360 Beverly Road #300 McLean, VA 22101 800/3-AUTISM. DONATIONS GLADLY ACCEPTED".** I generally just walk up to the person making the rude comments and hand him/her a card and then walk away. SAY NOTHING.

I hope this makes them feel guilty and even causes them to send in a donation out of this guilt.

My best word of advice to everyone is to talk to their personal doctor. If you can find a female doctor in your area, I would switch to her. Don't get me wrong...male doctors are fine; they just don't understand the woman's psyche like another woman does. Do you find yourself coming to tears easily? Over every little thing? Have you concluded that you hate your life? Do you often daydream you are someone else? With a different life?

I recently began using Prozac at the suggestion of my female doctor. I cannot tell you how this has changed my life. I no longer find myself weeping and I am able to let a lot of the little bothersome things slide. I always thought that I really didn't care what others thought about me as long as I respected myself, but I found out that I felt sorry for myself.

And you can't respect yourself if you feel you've been slighted. The Prozac keeps me calm so that I do not blow up at strangers and family anymore. I am much more tolerable.

Sonya

MY EMOTIONS/MY CHILDREN

by ASO York Member Lynda

I let my kids see me cry, sob, wail, vent, boil over ... BUT NEVER GOT PHYSICAL. I then used it as a teaching opportunity after I calmed down. My then 4 year old son (not ASD) was literally my shoulder to cry on, my other therapist for my (2 yr old) ASD son's home programming etc. At that time their father's work would take him away from home for 4-5 days at a time, 4 times a month.

I firmly believed in being totally honest about my emotions, labeling it - giving them the language to understand it, modeling that it's just as natural and justified to feel sad, angry, frustrated, frightened or hopeless as it is to feel happy, excited, thrilled, grateful, goofy or melancholy. They got to see that I could feel sad and then recover. My eldest is still confused about his mother's 'just 'cause' crying at times, but he brings me a Kleenex anyway.

I feel this is how both my sons learned empathy, caring and helping others as well as not being frightened of or ashamed by their emotions. Even my now 19 yr. old ASD son will try to make me feel better if he sees I'm crying - he can't talk, but he can see my tears and will rub my arm as his way of giving comfort. He doesn't seem to understand the nuances of emotions in others, but will definitely respond appropriately to tears or laughter in others.

The way kids, all kids, perceive their world is entirely different from an adult's perspective. I clearly remember an incident when I was 8, seeing my mother sobbing for the first time ever. She wouldn't tell me what was wrong. I started crying hysterically too, firmly convinced that she MUST be dying from cancer. I was terrified. Surely only something that profound would reduce my mother to such a state.

Hours later over dinner, my parents were laughing and saying sorry to each other for such a silly argument.

Dealing with adults is completely different, however. We must keep our emotions in check, act responsibly and respectfully to others even if it seems they are intentionally hurting us. (usually there's no malicious intent, just mindlessness) However, sometimes blubbering has been an effective tool!

For me personally, suppressing emotions is deadly.

A QUESTION, AN ANSWER AND A BOOK REVIEW BY DR. ROBERT NASEEF, Ph.D. http://www.specialfamilies.com/id2.htm

1. How do you get rid of or channel the huge amount of anger you feel when you have to fight the "system" to get the services that your child needs? Recently, a mother wrote to me saying that

she felt like she could explode. "I get so drained and discouraged at all the fighting you must do to give your child what he deserves. It just isn't fair!" she stated.

It sure isn't fair. You have plenty to be angry about. Human hardship is not distributed equally, as Rabbi Harold Kushner wrote in *When Bad Things Happen to Good People*. I often recommend this little but profound book to the parents of children with special needs. Rabbi Kushner himself lost a child to a rare disease and knows all too well the struggles of parents. I remember myself all too well how angry I was when my son was seven years old. I had a hard time accepting that he would need special services for the rest of his life. I walked around with a chip on my shoulder - ready to rage and ready to cry.

If the universe is unfair, it sometimes seems reasonable to become embittered and chronically angry. But most parents don't want to go through life this way, so a new sense of what is fair is needed. Kushner speaks to this ages-old question about justice that appeared in the Bible. He reminds us that "Anguish and heartbreak may not be distributed evenly throughout the world, but they are distributed very widely. Everyone gets his share."

Sometimes even the children who are the closest to "normal" but still needing specialized services and programs can be very challenging.

Certainly many of us have felt, as you describe so well, "drained and discouraged at all the fighting you must do to give your child what he deserves." It may help you to think about what other feelings you may have besides the anger. Is there fear? Sorrow? Worry? Guilt? What would be there if the anger vanished?

Anger, one of the most intense and least understood human emotions, is probably the scariest and most socially unacceptable feelings to own up to. It often arises with the thought, "Why me? Why did this have to happen to me?" Losing something precious hurts and seems unfair. Parents want someone or something to blame. It might be themselves, each other, the doctor, toxic waste, or the local school district.

Parents who have children with special needs are trying to make sense out of what has happened - "If we are decent people, how could this happen to us?" Why do we have to push and fight for what seems only fair? Parents need loved ones and friends to allow them to experience anger, to cry, and to scream. Indeed what has happened is terrible, and it makes no sense. Trying to be patient by holding the anger in only prolongs the pain.

Resolving anger depends on coming up with a new definition of fairness in the universe. If you believe that the universe is fundamentally unfair, you will remain chronically angry and embittered - walking around "with a chip on your shoulder." On the other hand, many parents have been able to use their anger to activate and energize themselves in the struggle to get the best possible services and education for their child's special needs. In this way parents can actually make the world behave more fairly toward their child.

Psychology offers a concept that can give us a handle in channeling anger into effective assertion - in the case of obtaining services for a child with special needs. There is a continuum from passive to assertive to aggressive problem-solving styles. The characteristics of each of various styles are described by Robert Alberti and Michael Emmons in ***Your Perfect Right***, a classic self-help book.

The assertive person, in the role of the parent of a child who has special needs, thinks and acts in ways that back up the child's legitimate rights. An assertive parent can express strong thoughts and feelings without putting down the thoughts and feelings of another. She can attack a problem with respect for the professional's knowledge, and establish a pattern of respect, thus avoiding the buildup of anger often caused by miscommunication. The assertive parent is both respectful and self-confident while requesting the services his or her child needs.

One mother told me how angry she gets when professionals don't hear and understand her. The problem reminds her of difficulties she had with her mother while she was growing up. Once she could refocus on the love and dedication of the professionals who work with her daughter every day, she was able to calmly and clearly express her thoughts, which usually resolves the problem.

While these are general considerations, I would recommend that you channel some of your energy into a parent organization, such as the Autism Society of America, www.autism-society.org or the ARC, or UCP, etc. Connecting with other parents who are either just starting out on this journey or further along can be priceless. You may also want to channel some of your intense feelings into an advocacy organization that helps other families.

Anger is part of the hurt. Gaining perspective and learning how to be assertive helps to heal the heartbreak. It takes time and support. If nothing else, our special children teach us patience - with them, with ourselves, and with the world around us.

2. Accepting and Honoring Our Differences

Everybody's Different: Understanding and Changing Our Reactions to Disabilities By Nancy B. Miller and Catherine C. Sammons Paul Brookes. 359 pages. $21.95

No parent wants their child to be noticed as different from the norm. You want a healthy, happy child who fits in and makes you proud. But what do you do when your child is different? Speaking for myself, I had a hard time when my son was diagnosed with autism many years ago. I walked around looking out of the corner of my eye ready to pounce upon people for their reactions. Actually it was more my perceptions of their reactions. Not to mention the perpetual knot in the pit of my stomach. Like many parents whose children are different, it felt to me that I was battling the whole world.

I wish we had **Everybody's Different**, the new book by Nancy Miller and Catherine Sammons, much sooner. Life is definitely easier when you understand your own reactions as well as those of others while realizing that you are not alone--not by a long stretch. Everybody's Different: Understanding and Changing Our Reactions to Disabilities is an enlightened and enlightening look at the many differences that exist amongst people in every walk of life and which need not divide us socially. The authors patiently and thoroughly help the reader to understand our internal emotional reactions to disabilities and the differences that result from those conditions. They teach us strategies to build our lives and our families and our communities in a way that is inclusive and respectful of our differences.

Together the authors have over 50 years of experience as practitioners who have worked with children and adults with disabilities and their families. They begin by helping the reader understand how and why we react to the broad spectrum of differences. All too often we are limited by our assumptions about how people look, move, communicate, behave, and learn. (Each of these categories of difference has a thorough chapter devoted to it.) When people are different we tend to stare and compare, so learning how our brains are actually "wired" to notice differences that seem unfamiliar or unsettling is very useful.

From there we can move forward and develop better understanding and increased skills for interacting with people who have disability differences.

The authors present a useful model, which they call "The 4D Approach." The steps involve: first, detecting the difference; second, deciding or evaluating the situation; third, doing or taking action; and finally, debriefing to make it better the next time. This approach can be used in classrooms, communities, and work places by teachers, therapists, and trainers, as well as by parents, relatives, and friends of people who have differences caused by their disabilities.

Many of the chapters apply specifically to children and adults with autism. Perhaps the most obvious difference is that of behavior. When my son who is now almost twenty starts "stimming," I automatically want him to stop and act "normal." Internally my reaction can be rather desperate for I don't want him AND me to be noticed as different. I also still find myself trying to avoid taking photographs when he is not behaving "normally." There is a certain image I prefer of him in my head, as much as I hate to admit that. But his behaviors are, after all, a part of him.

Even though I would consider myself a veteran, Everybody's Different helped me understand and own up to these reactions. It has taken me some time, but eventually I am learning to love my son, Tariq, not despite his differences--but rather because of them. The knot in my gut is long gone. Now for the most part I can look comfortably around me. I can notice what must have been there before--the friendly faces and kind eyes of compassionate folks.

Everybody's Different provides a rare blend of compassion, scholarship, and practical guidance in a style readable by a broad audience. At times as the reader, I found myself wishing for more passion from the authors. By the end, however, I realized that it was precisely the authors' very balanced approach that is so useful. For those of us who are parents of children with autism, the journey involves understanding and changing our reactions to this very perplexing difference in our children. With Everybody's Different, Dr. Miller and Dr. Sammons can help us get there a little sooner

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Special Families Website: http://www.specialfamilies.com/

ACTING CAN HELP...*by BBB Member Becca Lynn*

As I mentioned in a post yesterday, ironically, the most successful technique that I have ever used to deal with powerful emotions is "character acting."

The emotions do not disappear... nor are they buried forever they are simply placed to the side. I literally pretend that who I am is someone completely different... strong, sure of myself, happy and confident. When my child is screaming I am the best mother that I can envision... when I go to the school I am that together very sure of herself mother.

I just create the role and play it.

People wonder sometimes... how can a bipolar mother raise special needs children. I hear from some people that they don't even think people with a bipolar diagnosis should work with any children. And their feelings are very powerful....

They are right that I experience extremely powerful anger.... what they don't understand is the power of self-control. You don't have to say this experience is about now... or that its a legitimate emotion. Maybe you are just feeling so miserable cause you are tired or burned out.

Many mothers of bipolar children actually post during a child's temper tantrum. Now as you probably know these type of explosive tantrums can last literally for hours. The parent has no control. He/She is completely helpless to stop or control the rage. She (usually it is the mother) is in a very painful place emotionally, trapped between powerful emotions of her own and no way to stop her child. And she obviously cannot leave the house so she is wedged into an emotional pressure cooker. Something is going to blow. Such a situation is definitely rife with possibility for escalating physical violence from both the parent and the child.

So what is she going to do? Many go online. Right in the Middle of a powerful temper tantrum. And begin typing. They know somewhere sometime people just like her are going to read what she wrote and understand. That offers her emotional connection. The writing itself relieves some of the emotional pressure. And the sense of community of a support society helps her focus on what is the most important as far as being a good parent. A phone buddy in the same city would also offer the same type of psychological benefit...

You are who you choose to be. In the throes of anger and other powerful emotions it is important to remember that every moment offers a new choice. The dark side or the light side.... true the farther you move towards the dark the greater its lure. But the same applies for moving towards the light.

Acting is a powerful tool.... I am exactly who I want to be. I would even suggest writing out scripts (at least in general) to address trigger situations. Run through them in your mind and visualize yourself doing things calmly and or efficiently. It does work wonders as does thinking positively.... and I can be calm attitude really does carry a lot of weight under stress.

One of the methods that works for me anyways.

Becca Lynn

MY THOUGHTS by Rhona Feldt-Stein, OT, Executive Director of York Paediatric Therapy Services

Some of things I advise parents to do in my capacity as a professional are:

1) make a list of all medical findings/results, educational or therapy assessments (within the last 2 yrs.), psychological assessments, birth history, developmental milestone history etc.

Put it in a binder under specific headings as above and make copies when you are being interviewed by a professional or agency. It is often helpful to ask the person/agency you are going to see, if you can fax/mail your information ahead of time, thereby cutting down on the interview time (they like that) and using the time remaining more efficiently. It also saves the parent a lot of aggravation and frustration going through it again, again ......

2) 'With regards to "unsolicited advice" I often tell parents to say "thanks for your interest but I've got to go" and then walk away or just say "we're having a bad day". Everyone loves to tell their story about a SIMILAR child/nephew/neighbor etc. but it takes time and makes the ASD child frustrated to get on his way and the behaviour increases. Saying "thanks" even when you don't want to leaves you smelling pretty and doesn't ruffle feathers except your own. Its unfortunate but people are not really all that interested in what you've already done but only in how they can give you more advice. Sometimes you just want to say, "OK why don't you take him and try some of your own advice and tell me what works!"

Dr. Uhmesh Jain at the Clark Institute has some wonderful parenting workshop (free) at the Clarke on Monday nights. While it is not specific to ASD it has wonderful some great behaviour management techniques.

Hope this is helpful -- Rhona

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AWARENESS FROM PEERS

by Deanna Pietramala, Director, Leaps and Bounds

I think unfortunately this needs to be done by public awareness.

I think that people should go out and talk to young children in schools as well as the older one. But when you get them young and explain it the kids grow up with it and understand. This should also be done at schools when parents meet (i.e.) curriculum night have a 10 min. talk per class. Sure it may take some time but it is worth it. Yes schools say we have the teacher talk to the kids etc. but it is not enough. They do not necessarily now how to present it, so kids get it. Probably because they do not always understand it themselves. That is not a criticism but the fact is there is still a great lack of knowledge.

For my kids I do that, it makes a big difference. The kids then see the behaviour is not on purpose and want to help rather than make fun of the child etc etc.

When I have done TV. interviews and newspaper interviews I have always asked that they include a section directed at parents to have them realize what the kids and other parents are going through. They need to be educated as well.

You know how many parent have come to me and said you know I use to see kids act like my child out in the community at school etc. I use to think what is wrong with that parent can they not control their child. But now I know, unless you experience it you do not understand it.

Parents: understand and send out the message that everyone deserve respect.

Deanna can be reached at leapsandbounds@ca.inter.net, telephone: (905) 953-0569, FAX: (905) 953-0589

Note: Leaps and Bounds provides specialized programming to special needs children and serves Ontario, Canada. Deanna has graciously offered to guest host some upcoming chats for the BBB Autism Support Network. For more information and instructions on how to attend, please contact liz@deaknet.com or check out our "Chat" section of this e-newsletter.

Parent Empowerment Workshops ~ Fall 2001 Lineup

Proudly Presented by Autism Society Ontario ~ York Region Chapter

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  - COST INCLUDES HANDOUT PACKAGES AND REFRESHMENTS.

- **Effective Advocacy & Case Management** Lyn Ziraldo, Executive Director, Learning Disabilities Association York Region **Tuesday October 9th , 7:00 pm – 9:00 pm, room B13** Cost: Members $ 10.00, Non-Members $ 20.00
- **Writing Effective Needs Statements** Lindsay Moir, Educational Consultant **Tuesday October 23rd, 7:30 pm – 9:30 pm, Room B13** Cost: Members $20.00, Non-Members $ 30.00
- **Financial Concerns & Taxes** Morty Cohen, Chartered Accountant **Tuesday November 6th, Room B13** Cost: Members $ 10.00, Non-Members $ 20.00
- **Sensory Integration Make 'n Take Workshop** Shirley Sutton, Occupational Therapist coauthor of "Building Bridges Through Sensory Integration" and the workbook "Learn to Print and Draw: A Tactile-Kinesthetic Approach". **Saturday, November 17th Room B 13 9:30 a.m. – 3:30 p.m.** Cost: includes lunch, materials, and handouts. Members $ 25.00 Non-Members $ 40.00
- **Shortcut to P.E.C.S. Picture Exchange Communication System** Shana Elman, SLP Bloorview MacMillan Centre **Tuesday November 20th, 7:30 pm – 9:30 pm, 2nd Floor Boardroom** Cost: Members $ 10.00, Non-Members $ 20.00
- **Dental Care and Autism** with Dr. David Isen ***** AT HIS OFFICE – 4800 LESLIE STREET, SUITE 111, NORTH YORK Tuesday December 4th, 7:30 pm – 9:30 pm** Cost: Members $ 10.00, Non-Members $ 20.00
- **Living With Asperger's Syndrome. Gary Waleski, An Adult With Asperger's Talks About His Experiences** Tuesday, December 18th, 7:30 pm – 9:30 pm, 2nd Floor Boardroom Cost: Members $ 10.00, Non-Members $ 20.00

OUR FAVORITE LINKS

Contributed by Becca and Bernie, thanks, guys! :)

Who is the Only Person in the World Who Can Make You Angry?

Get Your Angries Out

The Counseling Center for Human Development: Coping with Anger

Coping with Difficult Emotions

Learning to Handle Stress

Overcoming Negative Emotions

PARENTS HELPING PARENTS

A Parent's Guide to Accessing Parent Groups by NICHCY

BBB Autism Support Network

Autism Society Ontario - York Region Chapter - contact asoyork@axxent.ca

Autism/PDD Community on About.com

UPCOMING CHATS: *EVERYBODY IS INVITED!!!*

HOW TO SET UP A HOME PROGRAM - Guest hosted by **Kathy Lear**, creator of **Help Us Learn;** A Self Paced Training Program for ABA - **Thursday, October 4 at 1:00 pm**, eastern time.

SOCIAL SKILLS FOR THE ASD CHILD WHEN RELATING TO A SIBLING, SOCIAL SKILLS IN GENERAL AND KEEPING YOUR COOL...

Guest hosted by Deanna Pietramala of Leaps and Bounds (Specialized Programming Service in Ontario) - **Thursday, October 11 and Wednesday, October 24; both from 1:30 to 2:30 pm** eastern time.

Convert to your time zone here.

PLEASE NOTE: TRANSCRIPTS FROM APRAXIA, CHALLENGING BEHAVIORS, EVERYDAY SENSORY STRATEGIES AND AUTISM AND ENZYMES CHATS AVAILABLE UPON REQUEST liz@deaknet.com

COMING SOON: "Autism and Essential Fatty Acids", "Central Auditory Processing Disorders", "Siblings of Children with ASD", "ADHD/ADD and ASD", "Autism and Nutrition", "Acceptance and Denial".

Regular chats take place Mon-Fri at 1pm and 9 pm daily. If no one is in the chat room when you get there...give it a chance. You never know who might drop in!

INSTRUCTIONS ON ACCESS ABOUT.COM CHAT

Hi! Floyd Tilton of About.Com's autism/pdd community has generously invited us to borrow their wonderful chat room to use for our chats. The following is a detailed description of how to access this room.

1. Click here to access About.com's Autism/PDD Community.

2. On the grey bar (under Floyd's picture) click on "CHAT".

3. Click on "Log on to Chat".

4. On this page: (a) Under "nickname", delete "guest" and type in a name for yourself. (b) Choose your preferred "font size".

5. Click on "Connect" and after a very short time, your chat screen will come up.

6. Move your screen by clicking the icon at the top left hand side of the window. Then drag the window to centre of your screen.

For chat questions, please email **liz@deaknet.com**

SUBSCRIPTION INFORMATION

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If you think you know someone who might enjoy or benefit from these newsletters, kindly forward us their email address at bbbautism@deaknet.com

A notice to our readers...

The founders of this newsletter and the BBB Autism support club are not physicians.

This newsletter references books and other web sites that may be of interest to the reader. The founders make no presentation or warranty with respect to the accuracy or completeness of the information contained on any of these web sites or in the books, and specifically disclaim any liability for any information contained on, or omissions from, these books or web sites. Reference to these web sites or books herein shall not be construed to be an endorsement of these web sites or books or of the information contained thereon, by the founders.

Past Issues

(to request, email liz@deaknet.com and indicate which volume/issue(s) you prefer

Volume 1; Issue 1 WELCOME ISSUE!
Volume 1; Issue 2 SUMMER CRISIS ISSUE
Volume 1; Issue 3 SPOUSAL CONCERNS ISSUE
Volume 1; Issue 4 SENSORY INTEGRATION
Volume 1; Issue 5 CHALLENGING BEHAVIORS
Volume 1; Issue 6 BACK TO SCHOOL
Volume 2; Issue 1 IEP

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