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

PRESENT

THE E-NEWS

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PDD? ASD? AUTISM? PDD-NOS? **HUH?**

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Hi everyone!
One of the topics that comes up regularly in chat, through emails and on our message board is the experience of confusing diagnoses. Top offenders on this list include PDD, ASD, high functioning autism, Asperger's Syndrome and PDD-NOS. Once you have an understanding on autism spectrum disorders, you can sort it out, but most of us are unfamiliar with autism when we get that first assessment. When the assessing clinician asks us if we have any questions, we don't know what questions to ask based on our inexperience so (in most cases; frozen with numbness) we say 'no'. It is then assumed that we understand the whole thing and we are sent on our merry way.

When we get home, confusion sets in. Does my son/daughter have autism or PDD? Are they different? Is one milder than the other? If my child is diagnosed with Asperger's syndrome, does that mean s/he is better off? What is the difference between autism, high functioning autism and Asperger's syndrome? And where does this PDD-NOS fit in to the whole thing? It is really hard to move forward if you can't get an accurate understanding of the diagnosis.

So we start to read, to question others, to go on the Internet and then we find that the information confuses us even more! As we read articles written on the subject by professionals, we see that even ***they*** are not consistent. Find one definition that makes sense, and there will be six professionals refuting it. You can tell by reading our message board that our children's doctors don't always agree. The more I read on the subject, the more I start to wonder who really knows the answers.

The information in *ASD, PDD, PDD-NOS, AND MORE* is based on the DSM-IV and other reputable publications on ASD. we have cited these in the reference section. We have included a section called "The DSM-VI in English" and this is our attempt to clarify by using examples and everyday terms. It was not written by a physician.

We are also featuring some reader contributions of personal experiences from parents, which help to illustrate this topic.

An announcement: To those of you who've been asking at our workshops, Dana's site is now available in book form and you can check it out here: http://www.autismchannel.net/dana/sitebook.htm

In a side note, I would love to thank all who contributed to our anniversary issue. It was such a wonderful surprise during a challenging period of our lives. My unending gratitude goes to Michelle E. for putting it all together – I had tears in my eyes reading the notes from our subscribers. I would also like to thank those who sent personal notes of congratulations, and those who posted them on our message board (http://www.network54.com/Hide/Forum/118931). Your thoughts and ideas are **really** what make the E-News unique and successful!

Bee Cool,
Liz

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ASD, PDD, PDD-NOS, AND MORE

Autism Spectrum Disorder (ASD) is a behaviorally defined life-long disorder of higher cortical function, with onset in early childhood that affects sociability, language and communication, play, and range of interests and activities. Its severity is very variable, so that it is appropriate to speak of the autistic spectrum (referred to as pervasive developmental disorder or PDD in the Diagnostic and Statistical Manual of Mental Disorders - DSM IV) to encompass **all** cases, from the most severe to those with mild autistic traits. Simply put, ASD is an umbrella term for a group of disorders characterized by the delayed development of socialization and communication skills. PDD means the same thing as ASD. Neither PDD or ASD are diagnoses unto themselves.

Under the ASD/PDD "umbrella" or spectrum, you will find autism, Asperger syndrome, Rett syndrome, Childhood Disintegrative Disorder and Pervasive Developmental Disorder-Not Otherwise Specified. This group appears together under the heading **Pervasive Developmental Disorders** in the DSM-IV, otherwise known as the Diagnostic and Statistical Manual, 4th Edition, (©1994, American Psychiatric Association), one of the tools used in diagnosing the PDDs/ASDs.

PDD-NOS is a diagnosis given when the criteria for autism (per the DSM-IV) is not met. Please see our section 'DSM-IV in English" for a description.

'PDD' is *not:*

- something different than autism
- the same thing as PDD-NOS (although some clinicians may short-form it this way – be sure to ask for clarification)
- a milder form of autism (although PDD-NOS, ***may*** be less severe)
- A diagnosis unto itself (your diagnosing clinician should provide you with a more accurate diagnosis)

'PDD' *should:*

- get the same attention, services and funding as a diagnosis of autism
- be treated using the same therapies as autism, etc.
- be taken every bit as seriously as autism
- be explained by professionals in such a way that families understand what it means

Many parents and professionals prefer the acronym ASD as opposed to PDD because they feel it is more descriptive and recognizable.

Under the Umbrella
Asperger syndrome (AS)

There is some question as to whether AS belongs in the autism spectrum. Some clinicians, researchers and parents consider AS separate from autism, others consider it a variation of autism. It's not clear whether its underlying biology is different and, if so, how. Children with AS appear to be preoccupied with their own narrow interests and routines. AS is more common in boys and often goes undetected until after the age of 3. AS is often characterized by: *(below is a list of characteristics only, this is not a diagnostic tool)*

- clumsy and uncoordinated motor movements;

- perseveration on topics with no regard for communication partner;
- severely impaired social interactions characterized by extreme self-involvement;
- limited interests and an intense interest in one or two subjects;
- repetitive routines and rituals;
- desire for sameness in their environment;
- speech and language abnormalities (though they may seemingly develop some normal use of language initially, they are not able to use language as a way to communicate);
- very few facial expressions and emotional output;
- Excellent rote memory (usually).

Children with AS can generally function better than those with other forms of autism spectrum disorder and are less likely to require life-long care. Though even if they do learn to function independently, their social interactions are nonetheless impaired and they are often prone to anxiety due to their recognition of their 'differentness'.

Autism (also known as Classical or Kanner's Autism) AND Pervasive Developmental Disorder - Not Otherwise Specified (PDD-NOS)

The best way to describe PDD-NOS uses the DSM-IV criteria for diagnosing autism, so we've grouped these two together. While autism has a set of guidelines to follow from the DSM-IV, some children don't quite meet the criteria (criteria refers to "A total of six (or more) items from (1), (2), and (3), with at least two from (1), and one each from (2) and (3)" read about it here: http://www.autism-biomed.org/dsm-iv.htm).

A child with a diagnosis of PDD-NOS might have a different ***configuration*** of the criteria than that, which fits autism. Although this doesn't necessarily mean a diagnosis of PDD-NOS is less severe than one with autism, many clinicians tend to simplify the diagnosis by telling parents this. It is important to have a full written report of your child's assessment in order to understand the severity and gaps in development for teaching purposes. Severity and behaviors can play an important role in securing services and funding for your child.

Characteristics of children with autism or PDD-NOS include; *(below is a list of characteristics only, this is not a diagnostic tool)*

- problems using and understanding language;
- impaired ability to relate to people, objects and events;
- inappropriate play behavior;
- lack of pretend or imaginative play;
- desire for sameness in their environment;
- repetitive movements and behaviors;
- self-injurious behavior;
- impaired or unusual speech such as echolalia, pronoun reversal;
- unusual mannerisms.

Children with autism and PDD-NOS vary in their abilities and level of functioning. Children can often benefit from one-on-one, individualized attention, behavioral intervention and instruction. Behavioral problems can *sometimes* be managed with medication. Bio-medical treatments can also be helpful.

It is extremely important to note that no two children with ASD/PDD present the same; even two with exactly the same diagnosis! In the same token, no one therapy works well for all children with ASD/PDD. Our kids are individuals and it's important to keep that in mind when seeking interventions or planning teaching programs.

Rett Syndrome

Even though Rett syndrome has been recognized as a distinct disorder for over 40 years, neither its etiology nor

treatment are very well understood. It is a *progressive* neurological disorder characterized by: *(below is a list of characteristics only, this is not a diagnostic tool)*

- Some of the behaviors exhibited with a diagnosis of autism/pddnos;
- reduced muscle tone (hypotonia);
- restricted hand movements and the inability to use the hands purposefully;
- avoiding eye contact;
- inability to express feelings;
- abnormal gait;
- seizures;
- reduced brain size and weight (microcephaly).

Other symptoms may include:

- constipation;
- breathing difficulties;
- weakness of the extremities;
- cognitive regression;
- screaming.

According to the National Institute of Neurological Disorders and Stroke, Rett syndrome affects 1 in every 10,000-15,000 female newborns with symptoms usually beginning between 6 and 18 months. Because Rett syndrome only occurs in females, it's believed to have a genetic basis. There is no cure, but there are several things that can be done to manage the symptoms. Orthopedic and learning disabilities, as well as seizures, can be managed with appropriate treatment, and a special diet may be necessary to maintain a healthy weight. Most people with Rett syndrome live at least into their 40's. Death is usually a sudden, unexplained event, presumably due to some sort of brain dysfunction.

Childhood Disintegrative Disorder (CDD)

This rather rare condition was described many years before autism (Heller, 1908) but has only recently been 'officially' recognized. With CDD children develop a condition, which resembles autism but only after a relatively prolonged period (usually 2 to 4 years) of clearly normal development (Volkmar, 1994). This condition apparently differs from autism in the pattern of onset, course, and outcome (Volkmar, 1994). Although apparently rare the condition probably has frequently been incorrectly diagnosed. Research is currently being conducted through the Developmental Disabilities Clinic at Yale. ***(3)***

The condition develops in children who have previously seemed perfectly 'normal'. Typically language, interest in the social environment, and often toileting and self-care abilities are lost, and there may be a general loss of interest in the environment. The child usually comes to look very 'autistic', i.e., the clinical presentation (but not the history) is then typical of a child with autism.

Getting a Diagnosis

Autism Spectrum Disorders (ASDs) are most often diagnosed between the ages of 2 and 3*; although they can be detected earlier. Some children with ASDs present clear symptoms from birth; but some clinicians hesitate to diagnose too early. There really is no reason for this. A child can benefit from therapies early on, and the quicker interventions start, the general thinking is that the outcome will be more positive. About 1/3 of children with an ASD appear to develop typically at first, with a regression in their social and communication skills occurring at a mean age of 21 months. ***(2)***

*Exceptions to the rule of early diagnosis could be that your child's symptoms are very mild, s/he has AS (usually diagnosed later) or there is a co-existing disorder muddying the diagnostic waters. If, for example, your child has Down syndrome, it can be more of a challenge to diagnose an ASD as well.

References:

1. Diagnostic and Statistical Manual, 4th Edition, (©1994, American Psychiatric Association)
2. Neurologic Basis of Autism: Differential Diagnosis and Management by Isabelle Rapin, M.D. http://www.dcmsonline.org/jax-medicine/march2000/autism.htm
3. Yale Child Study Center: http://info.med.yale.edu/chldstdy/autism/index.html

DIAGNOSING AUTISM AND PDD-NOS PER THE DSM-IV IN LAYMAN'S TERMS: THE DSM-IV IN ENGLISH

This document takes the DSM-IV criteria for autism and PDD-NOS and puts them into layman's terms. It also attempts to clarify how a diagnosis of PDD-NOS is made. Please note that not ***all*** symptoms may ***not*** be present every day. Look at typically developing children of same age (peers) and use them as markers. This is NOT a diagnostic tool and is only to be used to help further the understanding of parents. The examples used may not be the same as those exhibited by your child. Be sure to consult a physician.

To make this easy, (1), (2), (3) are referred to as categories, the letters (a), (b); etc that appear under each category will be referred to as ***symptoms***.

299.00 **Autism**

A. To be diagnosed with autism, you must have:
   - At least SIX (6) of the below symptoms from categories (1), (2) and (3).
   - You must have TWO (2) symptoms from (1- Social)
   - And ONE (1) each from (2- Communication) and (3 Behaviors and Interests)
   - The other one (or more) can be from *any* of the categories.

(1) **SOCIAL**

Social interaction is impaired, must have TWO from below list of symptoms:

(a) Problems with nonverbal behaviors such as eye contact, facial expression, body postures and gestures used in social situations

Examples:

- **Eye contact** – different from peers, may only meet eye-gaze of certain people or have total lack of eye contact – or anything in between
- **Facial expression –** may seem inappropriate to what the situation warrants, may have blank gaze, may not greet you with a smile, may have same expression on face most of time – or any combination thereof
- **Body Postures –** may hold arms close to sides, may try to avoid certain types of social contact, may appear unapproachable due to posture
- **Gestures –** may not respond to a hand held out to shake hands, arms out for hugs etc. May not understand social 'cues' we take for granted

(b) Does not make friends like other children in same age group.

Examples:

- While peers are learning to play together, the child is off by themselves
- Children learn to play by imitation, this child is not imitating the other kids
- Seems to have no interest in socializing with peers
- May approach peers, but not to play…watch and see if the child is approaching in the same way peers approach each other

(c) Does not share objects with others for enjoyment.

Examples:

- Does not bring you something that interests them to share with you

- Does not point in the distance (i.e. to an airplane) to share with you something that interests them
- Look at peers and how they show things they are proud of (ie. Artwork) and see if child does the same thing

(d) *Lack of social (Consisting in dealings or communications with others) and emotional (characterized by emotion) 'give and take'; Does not respond to social or emotional cues*

Examples:

- Does not seem to seek out or enjoy the company of others; may be aloof
- Does not smile back when you smile at him/her (without prompting)
- Does not reply "hello" to your greeting (without prompting)
- Does not seem especially happy to see you when you return home after work
- Does not seem to pick up on the 'vibes' of others
- Does not become grateful or excited in anticipation of outing or gift (in the same way a peer would)
- Does not attempt to comfort someone who is crying

(2) **COMMUNICATION**

Communication difficulties (Must have at least ONE of the below symptoms):

(a) Delay in, or total lack of, speech, but does not use gestures to communicate (Delay = not at same level as peers)

Example:

- Does not point to what s/he wants
- Does not 'mime' his/her needs (ie. Mime 'eating' if hungry)
- Does not shake or nod head for 'no' or 'yes'
- Does not shrug shoulders to show s/he 'doesn't know'

(b) If child can speak, cannot start or hold up their end of a conversation (appropriately)

(c) May echo phrases, words, songs, parts of movies etc.

(d) Does not engage in imaginative play (as peers)

Examples:

- Will not pretend to drink from toy teacup
- Will not pretend to brush doll's hair
- Will not use items for make belief (i.e. a stick for a cane or a magic wand)
- Will not make dolls 'talk' to each other
- Will not take a toy airplane and 'fly' it around the room while saying 'zoom'

(**3) BEHAVIORS AND INTERESTS**

Repetitive behaviors, interests, and activities – child may get angry if this 'pattern' is interrupted. Must have at least ONE of the below symptoms:

(a) Child is so focused on an interest that to remove the interest will result in a meltdown

(b) Routines or rituals must be followed, they may appear to have no apparent (to the onlooker) function

Examples:

- Lining up cars is not necessarily playing 'garage'; if you attempt to join in, the child will tantrum, walk away, push you aside, etc.
- Family members must always sit in same seats; failure may result in tantrum
- Must take same route home; one deviation may cause meltdown
- Must wear red shirt on Tuesday or risk a tantrum etc
- If you go to the video store, you must rent "The Brave Little Toaster" every time or risk a tantrum

(c) Self-Stimulatory Behavior such as hand flapping, rocking, ear flicking, chewing on clothing, vocal 'stims', spinning etc.

(d) Preoccupied with parts of objects

Examples:

- Spins wheels of toy cars
- Focus on one *part* of a toy (i.e. doll's eyes)
- Cover parts of book so that s/he can look at one piece

B. Child is either delayed (not same 'age' as peers) or acts differently from peers in ONE of the following (must be noticeable before age three): (1) social interaction, (2) language as used in social communication, or (3) pretend play.
C. Child does NOT have Rett's or Childhood Disintegrative Disorder

299.80 Pervasive Developmental Disorder, Not Otherwise Specified

PDD-NOS is used when a child has symptoms of autism as above, but not in the ***configuration*** needed for an autism diagnosis. Looking at above description:
"299.00 **Autism -** To be diagnosed with autism, you must have at least 6 of the below symptoms from (1), (2) and (3). You must have two symptoms from (1) and one each from (2) and (3) – the other two can be any of the other symptoms."

A child with PDD-NOS may have the same (or more, or less) ***number*** of symptoms as a child with autism, but instead of having 2 from #1 and one each from #2, the child might (for example) have 1 symptom from #1 and all **four** from #2, plus all **four** from #3.

A diagnosis of PDD-NOS is not necessarily a less-severe one than a diagnosis of autism, but it can be.

Severity of any spectrum disorder can be determined by the amount and severity of symptoms listed above.

The CARS (Childhood Autism Rating Scale) can give you an actual numeric measure that shows severity of autism (i.e. 29 and below – not autistic; 30 – 39 mild to moderate; 40 + severe to profound).

A CONFUSING DIAGNOSIS?

By Becca
I researched PDD-NOS according to the DSM criteria before I talked with doctors concerning M's possible diagnosis. Probably because of my psychology training but I have tendency to turn here first.

Many opinions abound in many different books and/or people like doctors or say a next-door neighbor even so it can get very confusing. And doctors, bless them, have such a terrible time explaining themselves in our language.

I've always understood PDD-NOS to be some but not all criteria for a diagnosis of Autism. Nor is this "some" necessarily mild or moderate although it can be. Some of these symptoms can in fact be more severe than a child suffering from all of the classic symptoms of Autism.

PDD-NOS is not necessarily a progression in a child becoming less severe on a continuum of say Autism - PDD-NOS - Aspergers. It is a way to diagnosis more appropriately those children both mild and severe who in the past would have been excluded from the Autistic Spectrum.

By Liz
When parents receive that first diagnosis, it is unlikely they are familiar with autism or PDD. Thus, when we got these string of results, we were completely confused and it actually took us 6 months to sort it out.

Here's what happened with us:

May '97 - Audiologist - diagnosis: 'some kind of developmental delay'.
They never explained what this meant. The word 'delay' confused me. I thought it meant he was behind but would catch up naturally.

July '97 - Developmental Pediatrician - diagnosis: 'mild PDD'.
Although this doctor tried to explain what PDD was in relation to autism, it was the first I'd heard of it. I knew I was being given bad news but couldn't absorb it, and the information given couldn't penetrate the sudden grief. In retrospect, I am not sure where the 'mild' came from.

August '97 - Pediatric Neurologist - diagnosis: 'good looking boy with a speech delay'.
This very nice man stared at my son for 15 minutes and said, "I don't think he has autism." We felt such blessed relief at the time. In retrospect, J. was so severely affected by autism that I'm appalled he made those comments. Just put us into denial again.

January '98 - Psychologist, working with SLP, OT. - Diagnosis: 'global developmental delay'
Autism was not mentioned although they did a good job of explaining what GDD was plus possible prognosis. Several months later, we received the written report and the diagnosis was "GDD with autistic tendencies" - that was never mentioned verbally.

January '98 - Psychologist and psychometrist - diagnosis: 'severe autism, severe developmental delay'.
This team told it like it is and I was thankful. They also gave us direction and some hope. They explained the whole autism/PDD thing in a clear way and empowered us with education.

By Holly
My experience was that the psychologist said that my daughter wasn't autistic; she said that she has PDD-NOS. All she said that it is pervasive developmental disorder not otherwise specified. She said that she did not qualify for the Autistic Disorder or Aspergers. She didn't explain to me exactly what PDD-NOS was.

After reading everything that I can get my hands on about PDD-NOS, I really got confused by the PDD and the PDD-NOS label. PDD as stated by a lot of publications and websites is not a diagnosis or a label. PDD-NOS is an actual diagnosis. Then on other sites they state that PDD is the same thing as PDD-NOS. Okay I thought I just read that PDD is not an actual diagnoses or label but PDD-NOS was. At other times I read that PDD-NOS is not Autism at all and not even on the Autistic Spectrum. Now about 95% of the articles and books I have read states that PDD-NOS is on the Autistic Spectrum.

Now to my understanding, PDD-NOS is between Mild Autism and Aspergers. But then again I have been told that PDD-NOS is the same thing as High Functioning Autism and Mild Autism. HuH???????

See what a confusing time I had with the label PDD-NOS. Isn't that ridiculous???

Now I view PDD-NOS as the same thing as High Functioning Autism Or Mild Autism. Why?? Because it makes the most sense to me.

Holly's timeline:
December 2001 **-** Speech evaluation: my daughter is severely delayed in speech, receptive, expressive and comprehension.

Developmental evaluation: fine motor delay, and overall delay in development by 19 months.

January 2002 - Speech therapist questioned if my daughter could have autism. Questioned if she also has CAPD or Communication disorder.

Developmental therapist states that there is more to my daughter's problems than development.

(these two therapists were very concerned and worried that she may have more serious problems such as a learning disorder and autism)

Requested a Psychological evaluation:
March 2002: diagnoses of PDD-NOS

March 2002:
New developmental therapist: possible SID, not sure of autism.

June 2002: Speech therapist says that she feels that she has Aspergers vs. PDD-NOS. She said that the PDD-NOS didn't make any sense to her.

Diagnoses may change along the Autism spectrum. The new psychologist said that my daughter is on the spectrum but not sure where yet. Testing is next Thursday and we will find out next Friday (the day after testing).

By Kim
When we went for Genetics Counseling a while ago, he kept alluding to the fact that we didn't have a diagnosis. When I finally got him to explain, his answer was that Autism is not a diagnosis, but rather a description of symptoms. It is not a diagnosis, because he doesn't know what caused the autistic symptoms to appear.

Just thought I'd throw another wrench in the works. Nothing's black and white here is it?

By Lucy
My understanding is that PDD-NOS means that the child doesn't meet all the criteria for autistic disorder (ie a certain number from each of the diagnostic categories) but does fall on the spectrum. I don't think PDD-NOS gives any indication of severity. I think a child can be severely effected with PDD-NOS. JMHO, of course.

As for the high functioning/low-functioning I think that is quite subjective and it's all in how you define 'functioning.' If a child has good verbal skills but isn't potty trained are they considered high functioning or low functioning? If a child is non-verbal but is able to perform all self help skills (ie dressing, brushing teeth, toileting, etc) on their own are they considered high functioning or low functioning?

I don't know the difference. Personally, I think many doctors aren't exactly clear on where one ends and the other begins. Everything's sort of fuzzy on the spectrum, in my opinion. What's more valuable to me is an accurate assessment of his strengths and weaknesses because that gives us a path forwards - what we can capitalize on and what we need to work on. Whether his actual label is autism disorder or PDD-NOS isn't that important to me right now. As long as he has a label and can get services based on his needs then that's what really matters to me

LINKS

- **What is the Difference Between Asperger's Syndrome and High Functioning Autism?** http://www.action4autism.org.uk/faqs/qhfa.html
- **NIMH – Autism:** http://www.nimh.nih.gov/publicat/autism.cfm
- **DSM-IV:** http://www.autism-biomed.org/dsm-iv.htm
- **My Comments on the Diagnostic Criteria by Dana:** http://www.autismchannel.net/dana/dxnotes.htm
- **Diagnostic Criteria:** http://www.autismchannel.net/dana/parentin.htm#diagnostic

WELCOME TO THE ZOO

Regular Feature by Columnist Michelle E.

My Thoughts on ASD, PDD, and PDD-NOS Labels

When B was first diagnosed, we took him to a pediatrician that did not mince words with us. He told us right out -- Your son has a developmental disability and I believe he is Autistic. We were devastated and I hated that doctor and thought he was a jerk. How could he tell that he had autism -- all B did was run in circles around his office.

Since I didn't believe him, I took B to about 4 other pediatricians and they all said different things from "NAH he isn't autistic" to "he has some traits of PDDNOS" to "he might just be a late talker." I figured PDD had to be better then Autism so I went with that diagnosis and figured the old battle-axe doctor we first went to was just OUT OF HIS MIND.

Nobody told me what PDDNOS was -- and I didn't have access to the Internet. So, for a long time -- I just figured out that PDD had to be what he had because Autism was OUT OF THE QUESTION.

I even prayed to God that if B had PDD instead of autism I would do something for the Autistic Community. I am doing a lot for the Autistic community now and my son is still Autistic. (Go Figure)

Anyway, over the years I have been in and out of denial -- and finally after getting onto BBB a couple of years ago -- I realized that it is the same thing.

I even tried to get my pediatric neurologist to give B a diagnosis of Aspergers a couple of years ago and he said, "You can call it what ever you want – it's still High functioning Autism."

Then I read from somewhere that Tony Attwood said, "The only difference between High functioning Autism and Aspergers is the way it is spelled.

After that -- I stopped trying to get away from the autism label. At this point I don't care -- as long as B keeps improving.

As for the different labels -- I think the doctors are doing the wrong thing by giving them a diagnosis of PDD or PDD-NOS. Either way, the therapy is the same, and with the autism label you will get more services. And it keeps the parents (like me) in denial much longer which could keep the parents from getting the child help sooner.

I don't think the ASD label is bad -- because it still means that the child is somewhere on the spectrum. My son B was considered severe at age 2 and 3 and now he shows very few signs and is in regular 3rd grade starting this fall.

Is he still Autistic??? YES -- he will always have the Autism -- I believe. But will he be productive someday??? I sure hope so. Will he get married -- I sure hope he can find someone who doesn't mind his quirks -- But as long as he is happy -- that is what is important to me.

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ENEWS BITES:

1. **"AUTISM FRIENDS:** (www.autismfriends.com) Come check out our 800+ links, Shopping section fundraisers for parent run sites coming soon!) Family pages and our Community section for chats 5 days a week!

   Coming soon to Autism Friends! Parent tips, ponderings and wisdom!

   Autism Friends is a Member supported website run by a parent. We are always looking for parent contributions! Book recommendations, photos, best links, personal stories, poems & artwork by our creative geniuses. Contact Tina at: founder@autismfriends.com. Tina"

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2. "**My name is Susan Rosenstein** and I am an occupational therapist with Early Intervention Services, the Richmond Hill-Thornhill team. I am involved with the design team in planning for the new All Our Children Playpark, which is being built by the community, for the community, in Newmarket in August 2002.

   We have attempted to include equipment and provide spacing, which will allow for best possible use by children of all abilities.

   I am frequently told by parents that it is so very difficult to take their child, who is unaware of risks or does not follow directions, to public playgrounds as most are open to roads, ravines, the river, etc.

   I am looking for any information about safety strategies in fencing and or design, which will allow children to enjoy the playground without the worry, or risk that they will be able to leave the area and run away unnoticed. We would like to develop a "boundary" solution, which is both aesthetic and practical.

   I would love to hear of suggestions or web sites with information, which may be appropriate.

   Please feel free to answer via e-mail at Susan.Rosenstein@region.york.on.ca"

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3. JOB POSTING – **AUTISM SOCIETY ONTARIO** – Regional Support Leaders: http://www.bbbautism.com/aso_job_posting.htm

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4. **THE GENEVA CENTRE announces:** a) **Summer Training Institute** is scheduled for August 19-23, 2002 in Toronto and August 19-20, 2002 in Halifax. Brochure may be viewed in PDF format at http://www.autism.net **b) Geneva Centre International Symposium** is scheduled for October 23, 24, 25, 2002 at the Metro Toronto Convention Centre. The Symposium 2002 brochure has been mailed out and is available at http://www.autism.net. This year you have the option to register on-line; major discounts for early bird registrations. Also, for the first time, delegates from around the world can access 8 presentations of the International Symposium 2002 live through the Internet. Some presentations have special interest for adults on the autism spectrum.

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5. **Autism Children's Intervention Services Inc.** (http://www.aciscanada.com/) Grace Damouni, Director/Founder - 8171 Yonge Street, Suite 226, Thornhill ON, L3T 2C6, Tel 416. 219 2316, Fax 905. 832 3139 E-Mail: Grace@aciscanada.com

   "Certified in PECS, Sensory Integration (went to Florida and took the course/lab with Pat Wilbarger), Greenspan's Early Infancy and Childhood course (Floortime/DIR), training in Lovaas, workshop in Handwriting Without Tears, degree in psychology and most importantly, many, (9) years of clinical work with children with PDD/Autism.

   I work very closely with Dr. James Bebko of York University and Dr. Carolyn Lennox who are the consulting psychologists to ACIS.

   I am proud to say our IBI program is very comprehensive as it includes collaboration with SLPs and OTs as well as the educational team. We help develop IEPs and provide trained shadows for classroom integration.

   We do travel outside of the immediate catchments region (once every month or two depending on the time of year) to administer staff training, consultations, assessments and program development. We will travel to Guelph, Hamilton, Cambridge (for example) but only during certain times of the year. However, we do not provide ITs (mediators) to service this region although we can train staff that the family has already recruited. For parents who are not interested in hiring a "team" we can set up the programs/binder.

   We do however, provide "teams" and oversee the program for our catchment region, which is Markham, Pickering, Aurora, Richmond Hill, Thornhill, North York, Maple, Woodbridge. If families live within this region we can offer a "team" with full services (assessments, programs, supervision etc) and this ranges in price from $20,000 and up depending on the treatment plan the family has in mind (we offer different plans). In this regard we are very flexible which I believe makes us unique-we customize plans so that we are able to take into consideration the families needs/expectations. *Grace Damouni, Director/Founder*"

6. **NIDS - Neuro Immune Dysfunction Syndrome - Lecture Video Presentation**
Presented in partnership by the Dufferin & Halton Chapters of Autism Society Ontario

The incidence rate of autism has skyrocketed from 1 in 10,000 to as many as 1 in 200 in children under 7 today.
-What if the huge increase in incidence is based on a disease process?
-What if some of these children aren't autistic, they're sick?
-What if that sickness is treatable and their autistic-like behaviours can be overcome?

Historically, researchers and clinicians did not look for medical answers to autism because they believed it to be a disorder that was medically untreatable. Today, with more precise tools and technology available the medical anatomy of autism is gaining definition.

The NIDS Scientific Board has been monitoring the emerging body of evidence related to the immune system. It appears that a dysregulated immune system, whether triggered by a virus, genetic predisposition, intrauterine, prenatal, neonatal stress or trauma, may account for the cognitive processing and other deficits seen in some children.

Extensive clinical work over the past 5 years further supports the NIDS Scientific Board's hypothesis that we are facing an immune-mediated disease affecting the central nervous system.

Dr. Michael Goldberg of the NIDS Research Institute (NeuroImmune Dysfunction Syndrome) is working to answer this question. Presenting Dr. Goldberg's lecture via video presentation. Kathy Robertson RNC, MSN from New York & Vice-President of NIDS Coalition, will be joining us on the 20th to address all of your questions.

Date: July 20,2002
Time: 10:00 a.m.
Duration: 10:00 a.m. to 4:00 p.m.
Cost: $20.00 (includes lunch)

Location: Notre Dame Secondary School, 2333 Headon Forest Drive / Burlington / Lecture Hall

Registration: Open to all interested participants / Register Today - Limited Enrolment, $20.00 per person fee, payable with registration, Lunch included. E-mail asohalton@cogeco.ca

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7. **"Ontario Adult Autism Network** - OAARSN offers a rich and expanding collection of up-to-date information and communication tools that can put you in touch with others. We can all benefit from the opportunities for mutual support, encouragement and information sharing. We especially hope that OAARSN's efforts to draw attention to positive approaches and best practices in supporting adults with autism can help all who live and work on the front lines. Click on http://www.ont-autism.uoguelph.ca"

8. **Workshop Emphasizes Teaching Verbal Communication Skills to Children with Autism and Other Developmental Disabilities -** Dr. Vince Carbone is a Board-certified Behaviour Analyst with over 25 years of experience designing learning environments for people with autism and developmental disabilities. He provides preparatory training and clinical consultation to certified behaviour analysts, teaches university courses, and consults with schools, agencies, and families. He is the developer and presenter of a series of workshops on teaching verbal behaviour (verbal communication skills) to children with autism.

Dr. Carbone will be conducting a 3 day intensive workshop "Teaching Communication Skills to Children with Autism and other Developmental Disabilities: Introduction to Verbal Behaviour" on October 28, 29 & 30, 2002 in Oakville, Ontario. The cost of the workshop is $400.00 per person if registered prior to August 15, 2002 and $425.00 per person after August 15, 2002. The workshop is sponsored by Express Yourself Speech, Language and Communication Services. For more information please call 905-333-9730.

Participants in Dr. Carbone's workshop will learn (1) to conduct a Behavioural Language Assessment, (2) to select the most appropriate form of communication for a child, and (3) to identify the communication responses and supporting skills that should be taught first. He shares a special emphasis on teaching verbal behaviour to the most difficult to instruct learners.

Through methods of errorless teaching, specific quick-transfer procedures, and the use of discrete trial training Dr. Carbone has helped many children improve their communication skills. The natural environment and intensive teaching sessions are both employed during program implementation. Dr. Carbone's introductory workshop will provide parents, teachers, therapists, psychologists, and speech-language pathologists with practical information
for program planning and implementation.

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9. **"The Spectrum Community Newsletter:** The Spectrum Community Newsletter is a new email newsletter containing news, links, shared stories on the spectrum disorders. The idea is to allow each subscriber the ability, if they have the desire, to be a voice heard. To receive the first issue please send email address to communitynews@insightdirect.com. Thanks, Christopher Chapman, Chief Operating Officer, Insight Direct, Inc
800-471-4200 x231, chris@insightdirect.com, www.insightdirect.com"

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9. "**Letter Writing Campaign to Ontario MPPs by Nancy Morrison** The e-mail link is now available for all of us to promote a letter writing campaign to MPPs Clement (Health) Witmer (Education) and Elliott (COMSOC). All people need to do is fill out the info at the bottom of each letter and hit send and it will go directly to the Minister. Please promote all persons affected by our children to visit this site and forward the letters, including extended family members, friends, teachers, day care providers, co-workers, etc.

http://www.ontariondp.on.ca/news/publish/issues_30.shtml

Also, I would like to promote that each of you write to your respective MPPs regarding our issues. Our Simcoe Barrie and Bradford area MPP was on The NEW VR following the Monday, June 24th news telecast stating that they will be looking into the issues raised by us at Queens Park. He has also stated this more recently in the Barrie newspapers. We will need all our ministers updated on the topic and supporting us. You can find the snail mail or e-mail addresses for your MPP at the following site:

http://www.ontla.on.ca/Members/mailing_addresses/index.htm

Please forward this information on to any ASO contacts you may have in any other areas of the province. The more people aware of this campaign the stronger our voices will be heard. I recently added a contact in Ottawa to my mailing list for this campaign. If anybody else knows of anybody who wishes to be updated through my mailings, please have them send me an e-mail and I will add it to my growing list of contacts.
Sincerely, Nancy Morrison" MORRISONPN@aol.com

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10. "Thanks to everyone for the response to the Vaughan paper, our letters are getting attention!!!! They printed a response letter in the July 13th edition, you can view it at the following website:

http://www.yorkregion.com/yr/opinion/letter/story/456208p-571928c.html

For those that did not see the previous letters to the editor in that paper, you can view them at:

http://www.yorkregion.com/yr/opinion/letter/story/430159p-542815c.html and
http://www.yorkregion.com/yr/opinion/letter/story/442701p-556989c.html

When they called to confirm who had written the letter, they spoke with me about perhaps writing a personal story about a local family. I posted this on BBB Autism Message Board and I know of at least one family in the Vaughan area that will be contacting the paper and offering their story.

The MPPs read and react to the local papers. Through letters to editors and focus articles in our smaller community papers the MPPs across the province will receive a lot of pressure in their home ridings. It's a lot we are asking them to spend, but we have to look at the value to our children's lives and the long-term financial impact on this province if the Ontario government doesn't enhance spending for our children.

If anyone reads a letter similar to the one posted in the Vaughan paper from their local MPP advising that the Conservative Government is dedicated to assisting our children, let me know and I will again send out e-mails to all contacts to promote everyone to send in responses. The more actively we respond the better!!!!

Thanks again everyone, please keep me posted on your personal articles that get printed, I will share them with all my contacts, I am sure that everyone would love read them. Regards, Nancy Morrison MORRISONPN@aol.com"

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10. **Richmond Hill, Ontario:** "A family in Richmond Hill would like their 6 year old child with autism to join a gymnastics class and/or dance lessons. Following direction is a challenge at times, but she is very athletic in this area. Does anyone know a gym centre in the area that works well with 'our kids'?" Contact Debbie at dbounds@alertcarecorp.com

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11. **OVERVIEW OF NEW PROCEDURES AT PARAMOUNT CANADA'S WONDERLAND FOR GUESTS WITH DISABILITIES:**

    A key part of the new program will include assigning specific ride boarding times at certain park attractions for guests with disabilities.

    Guests with disabilities should stop by Guest Services to pick up a Guide for Guests with Disabilities. This free guide explains the ride entry guidelines and procedures, provides specific information related to each attraction, and includes an Attraction Boarding Pass now required for the special access accommodations. One Guide for Guests with Disabilities/Attraction Boarding Pass is required for each guest with a disability and will cover his/her accompanying friends/family members (up to maximum of three). Please note: you will need to pick up the new Guide/Attraction Boarding Pass each time you visit the Park.

    Guests should take the Guide (which includes the Attraction Boarding Pass) to the ride exit and request a boarding time. A boarding time (based on the approximate length of the line at the time of the request) will be assigned and written into the Attraction Boarding Pass in the area designated for that ride. The time will be authenticated with a special stamp when it is written into the Boarding Pass. Guests with disabilities may not acquire a second or subsequent boarding time until any previous time(s) have passed, but may take advantage of other attractions that are not on the Attraction Boarding Pass.

    Once the party has been assigned a boarding time in their Attraction Boarding Pass, they can wait in a comfortable location of their choice until it is time to board.

    When the boarding time arrives, the guest with a disability can enter the ride through its entrance/exit. Once in the station the party will load into the next available ride vehicle.

    Please call the Guest Services department (905-832-8131) at Paramount Canada's Wonderland if you have questions about this new program.

    Or if you have any difficulties please direct them to the following.

    Kris Williams
    Manager, Public Relations & Special Events
    Paramount Canada's Wonderland, a division of Viacom Canada Inc.

    9580 Jane Street, Vaughan, Ontario (Canada) L6A 1S6

(Phone) 905-832-7482 (Fax) 905-832-7419 (Media Pager) 416-484-5543

(Email) kristins.williams@paramountparks.com
(Website) www.canadaswonderland.com
(Media Centre) http://www.canadas-wonderland.com/corpinfo.jsp

Do you have an event, announcement, information or a request? Email us at liz@deaknet.com and we'll put it in an upcoming E-News issue. Email early to avoid disappointment! BBB Autism is not responsible for misrepresentations of persons or agencies utilizing this service.

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2. Epsom Salts (Calcium too) – expanded version
3. Epsom Salts – condensed version
4. Pros and Cons of telling your ASD child his/her diagnosis
5. How we advocate for our children
6. Guide to holidays and large family gatherings

NOW AVAILABLE ONLINE: OUR BBB GUIDES IN A PLAIN TEXT FORMAT SUITABLE FOR PRINTING. FIND THEM HERE: http://www.bbbautism.com/bbb_guides_contents.htm

A notice to our readers...

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