



Autism....a part of our world, not a world apart

AUTISM BC

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The Appropriate Use of Diagnostic Terminology in Autism

A ROSE BY ANY OTHER NAME...

Almost every family who has had a child on the autism spectrum has gone through the bewildering experience of trying to understand where their child fits in, according to the Diagnostic and Statistical Manual of Mental Disorders - Fourth Edition, commonly known as the DSM-IV. It is on the basis of interpretations of the DSM-IV that eligibility to services from the Provincial Ministries is often determined. Dr. Vikram Dua, a Child and Adolescent Psychiatrist based in Vancouver, argues the appropriateness of tying funding and service provision solely to a diagnosis through DSM-IV.

In the last two decades there has been an explosion of research on autism-like disorders. Mainstream medical nomenclature (best exemplified by the *Diagnostic and Statistical Manual of Mental Disorders - Fourth Edition; DSM-IV*) has introduced the umbrella term *Pervasive Developmental Disorders (PDD)* under which autism has been splintered into subtypes, including *Autistic Disorder*, *Asperger's syndrome*, and *PDD - Not Otherwise Specified (PDD-NOS)*. Although these developments have arguably enhanced the sophistication and precision of research and treatment of autism, the proposed boundaries between the subtypes remains tentative and controversial. Many experts prefer a dimensional diagnostic label such as *Autism Spectrum Disorder*, arguing that the science does not yet reliably support subtle distinctions.

Given the lack of scientific consensus, it is not surprising that studies have found wide variability in how autism is diagnosed in the community. Predictably, these inconsistencies are disorienting for both families and administrators who determine eligibility for services. In contrast to the clinical recognition of a wider range of autism variants, third-party administrators often insist on a specific subtype diagnosis (such as *Autistic Disorder*), before granting intervention services. Precise labels, although uncertain and incidental, can have major ramifications on what treatment and support services patients receive.

I believe that part of this unfortunate situation has resulted from a misunderstanding of how diagnostic classification (or nosology) is conceived. Far too often there is a wholesale misappropriation of systems such as *DSM-IV* into settings where it has no legitimacy. My purpose in this piece is to shed some light on the basis of psychiatric nosology, and to clarify its limitations.

The word *autism* was introduced to psychiatry in 1930 by Eugene Bleuler in reference to the social withdrawal of individuals with schizophrenia. In 1943 Leo Kanner proposed the term *early infantile autism* for a discrete childhood disorder with profound social withdrawal and cognitive impairment. However, for many years the distinctions between autism and schizophrenia remained unresolved. The nature of atypical autistic-like conditions was equally elusive. Children with these

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Treatment Profile Diet Therapy for Autism

Some people believe that autism can be caused by severe allergic reactions to certain foods. Proponents of the allergy theory believe that certain foods can cause cerebral allergies where the tissues of the brain become swelled and inflamed. Detection of this type of allergy is not recognized by normal allergy symptoms such as a runny nose, but rather by the person's inability to learn and behave in a typical manner. More recently, theorists have begun to suggest the reason for dietary intervention success may be due to the coexistence of an allergy in a child with autism. When the allergy is treated, the child's negative behaviours reduce as his discomfort reduces. Many different foods have been implicated in causing allergic reactions in individuals with autism. The most common ones are: milk, eggs, wheat, chocolate, citrus fruits, sugar or artificial additives. Food allergies can be found through professional sublingual food testing or by implementing a rotation diet at home. Allergy symptoms can be alleviated by several different methods. The most effective way is to remove all traces of the allergen from the diet. However, you could also take allergy extracts, certain drugs or additional nutrients to boost the immune system in order to keep the allergy under control.

Although most dietary interventions are not nutritionally harmful, they have often been shown to cause negative psychological effects in children as they are unable to eat out with friends and they stand out from their peer group. Also, many children with autism are very picky eaters and instituting a special diet may be difficult. Keep in mind that there have been no controlled clinical trials on allergy-induced autism. Most evidence is anecdotal, and highly individualized; what may work for one person may not have any effect on another. However, it should be noted that this is a kind of "chicken soup" treatment, in that it could rarely hurt and is relatively inexpensive to try out. While control through diet is not a cure, it may alleviate some of the more serious behavioural symptoms. ASBC has many different diet books in its library - check out some of the information available.

Many different foods have been implicated in causing allergic reactions in individuals with autism. The most common ones are:

- *milk*
- *eggs*
- *wheat*
- *chocolate*
- *citrus fruits*
- *sugar*
- *artificial additives*

We'd Like to Hear From You!

Autism Society of BC's Newsletter welcomes stories, articles, poems, and personal accounts from its readers. The next deadline for submissions is July 7th, 2000.

IT'S THE MILLENIUM BUG!

Perhaps something in the air, at least! We're saying goodbye to a number of staff this spring. Chris Dowling is leaving us after two years of successful fundraising. We wish her well...we also say goodbye to Steve Hardy, our Coordinator of Volunteers. Please note we've put our Buddy Program "on hold" until we have replaced him. The good news is both Chris and Steve have agreed to stay on and volunteer to help our awareness and fundraising campaigns.

A final goodbye can be said to...well, *me*. After three and a half years as Executive Director of ASBC, I will be leaving at the end of June to return to postgraduate studies. I've enjoyed the opportunity to meet and get to know many of you, and I leave with many special memories. Thanks to all of you for what you have taught me.

-Rhonda Garside

DEADLINE FOR SUMMER REIMBURSEMENT PROGRAM

Remember, applications for this program must be returned to the ASBC Vancouver office postmarked by June 17th ! This popular program offers reimbursements of up to \$250 to current ASBC members residing in BC to apply toward extra support for their child [adults with autism are also eligible] in a summer activity. For an information sheet and application, contact Kelly Munro at 1-888-437-0880.

Virtual Newsletter!

Starting with the June 2000 issue, you will be able to receive your newsletter online at our website. Check out the Newsletter page at our Website at www.bbr.ca/autism . If you would like to just receive your newsletter online and would like us to avoid the expensive use of treeware*, give us a call at the Vancouver office. [*paper]

Thank you

The friends and supporters who make our work possible

Individuals

Victor Barwin
Janice & Peter Bruce
Mrs M. Carter
Byron & Tracey Chan
G. & L. Chenier
Babs Cohen
Leslie Crittenden
Chris Dowling
R & K Fisher
Mr. & Mrs.Hamilton
Katy Harandi
Vicki Harford
Wendy Hodgkin
L. Jakay
C. Kalmacoff
C. & W. Kapralik
J. & L. Kowalenko
Kay Kroeker

R.Y. MacDonald
Grace & Ken McNicoll
Kathleen Maximuik
S. & R. Messier
Simone Messier
Mr. & Mrs.Morrison
Kelly Munro
Guan Neoh
Shirley Nelson
Taylor & Nelson
Mr. & Mrs. M. O'Connor
K. Sayer
W. & N. Sharpe
Margaret Smith
Glen & Vera Swenson
M. Takei
Sew Cheng Tan
J. & B. Wismer

Corporate

BC Hydro Hydrecs
Canadian 2 for 1 Pizza

Service Clubs, Employee Funds, Foundations

Legion # 61
Legion # 229
Chris Spencer Foundation
North Island Infant Development
United Way
WCB Helping Hands
Vancouver Snowball Society

CONFERENCES & WORKSHOPS

Around BC & the World

June 1-3, 2000 – University of Wisconsin at Madison
21st Annual Symposium of Research in Child Language Disorders
CONTACT: www.waisman.wisc.edu/srclid/

June 1-3, 2000 – Vancouver, B.C.
10th International Nursing Conference – Ending Violence Against Women: Setting the Agenda for the Next Millennium
CONTACT: (604) 822-4965; Fax: (604) 822-4835(?)
e-mail: elaine@cehs.ubc.ca

June 10, 2000 – Burnaby, BC
Picture Communication Symbols and Other Visual Support Strategies
SPEAKER: Brenda Fossett
CONTACT: Autism Society of BC 1-888-437-0880

June 14-17, 2000 – Philadelphia, Pennsylvania
Best Practices In Dual Diagnosis
NADD International Congress IV
CONTACT: 1-800-331-5362; Fax: (914) 331-4569
E-mail: thenadd@aol.com
Website: www.thenadd.org

June 26-28, 2000
National Educational Computing Conference – Connecting at the Crossroads
CONTACT: 404/894-0777; Fax: 404/894-9675
Website: www.neccsite.org

July 2-5, 2000 – Atlanta, GA
The 2000 ASA National Conference on Autism
CONTACT: ASA Conference Hotline: (888-684-4630)

July 27-29, 2000 – Washington, D.C.
NDSS Conference – The Visions for the 21st Century
CONTACT: Phone: (800) 221-4602
e-mail: info@ndss.org
Website: www.ndss.org

July 29-31, 2000 – Seattle, Washington
Funding, Freedom and Citizenship First International Conference On Self-Determination and Individualized Funding
CONTACT: Denise Marshall – email: dmarsh@tash.org
Website: www.members.home.net/directfunding

LIBRARY

Highlights of new titles available from the ASBC library

Here are some new books from our collection.

ADULT GUARDIANSHIP ACT, PART 3 SUPPORT AND ASSISTANCE FOR ABUSED AND NEGLECTED ADULTS, A GUIDE FOR COMMUNITIES. Public Trustee of British Columbia, January 2000.

ASPERGER SYNDROME, PRACTICAL INFORMATION SUGGESTIONS AND ANSWERS TO COMMON QUESTIONS. Cimprich, Marie E. 1999

USING TANGIBLE SYMBOLS FOR COMMUNICATION PURPOSES: AN OPTIONAL STEP IN BUILDING THE TWO-WAY COMMUNICATION PROCESS. Vicker, Beverly. Indiana University, 1996.

NOT GOOD ENOUGH: SPECIAL REPORT ON GOVERNMENT SERVICES FOR CHILDREN AND YOUTH. Office of the Youth and Family Advocate, BC. 1999 Annual Report.

AUTISM RESEARCH DATABASE [CD-ROM]. National Autistic Society, England, 2000.

THIS BOOK IS ABOUT CHILDREN, PARENTS AND CHILD PROTECTION. BC Self Advocacy Foundation, 1999.

Is there is a book, video or journal that you would like ASBC to order?

Please contact our librarian Ana Lucia Wagner and we will give it serious consideration. If you have autism related books you no longer need, please consider donating to our library.

JUST A REMINDER:
ASBC has videos and books available for sale at a discount to ASBC members

BROTHERS AND SISTERS:
members price \$25.00 (Video)

This is a video about siblings for siblings of children with autism. Children and young adults candidly share their feelings about growing up with a disabled brother or sister, having to pick up family responsibility at a young age, and coping with the challenges that a child with autism brings to a family. The special relationship that develops between siblings when one has autism, is a unique and powerful bond. This video communicates the love of these very special brothers and sisters.

Ashley's Success

Ashley's mother Chris Bowling wrote to tell us that Ashley placed 3rd at her school in the Public Speaking Finals. Way to go, Ashley! Ashley is in Grade 7 at Philip Sheffield Elementary School in Abbotsford, where she is a B student and also active in BC Special Olympics. Below is a transcript of Ashley's speech.



May I have your attention? Anyone with autism or not, please listen in.

Chairperson, honorable judges, ladies and gentlemen, and fellow students. I have High Functioning Autism. If you don't know what autism is, you have come to the right place.

In the year 1998, I was diagnosed with autism. That meant that I was born with autism. Sometimes I am teased by other kids and this makes me very mad. I usually get in trouble for being too loud, too excited, talking too much, and being bossy. Sometimes I have a lack of eye contact. I am just like any other person. I eat and sleep, I brush my teeth, I wear my favorite clothes, I go places such as the grocery store, I visit my doctor for a check up, I love to listen to music and work on the computer, and I like to learn new things. I hope other people will give me a chance, and try their best to understand me and be patient with me.

Having a cold or the measles are diseases, but autism is a developmental disability. A developmental disability is something in my brain that makes it work differently than other people's brains. If you think that autism does not stay with a person forever, you are wrong. Autism will always stay with that person. When people have autism, they have different thinking skills and a change in their behaviour. With different thinking skills, they don't think clearly as others, and they have trouble writing things down on paper. When they have a change in their behaviour, they act different, fight a lot, and yell a lot. Some people with autism do not like to be touched. They sometimes have a lack of eye contact as well as a lack of response.

If you know anybody with autism, please, care about them.

Parents of Children in Care

Has your parent portion of costs increased to an unmanageable level? You may be interested in meeting with other parents facing this crisis. Is anyone interested in meeting as a group in the month of June to discuss this matter? If so, please contact Valerie Newton ASAP at (604) 597-6630. Please leave a message on the answering machine if not at home and I will return your call.

Training Opportunity

The Provincial Resource Program for Autism and Related Disorders are offering a one week training course. Topics include an overview of autism spectrum disorders, communication issues and strategies, positive behaviour supports, strategies to reduce anxiety and stress, and many other important issues. The five-day course is free to parents of individuals receiving PRP or Gateway Society services, \$225 to others.

Accommodation may be arranged at Gateway Society's Guest House in Delta, where the course is offered. The next session is June 5-9, 2000, with sessions running several times a year. Contact Pat Czuczor at (604) 946-3610.

Let us put our minds together and see what life we can make for our children.

—Sitting Bull

COMMUNITY GROUPS

Groups you can join and what they are doing around BC!

Community Groups

ASBC's Community Groups are the backbone of our connection to you, our membership. They provide community information, insights into autism spectrum disorders and a great deal of fun for families striving to provide for their children. If you are interested in starting a group in your region, please call Deborah Pugh, ASBC's Program Director, to discuss what's involved.

Lower Mainland:

DELTA
 Stacey del Fabbro 604-940-2751
 SOUTH LANGLEY
 Elma Kozak 604-534-0207
 NORTH LANGLEY
 Kathryn Fischer 604-888-1354
 MISSION & ABBOTSFORD
 Virginia Renaud 604-820-2645
 NEW WESTMINSTER
 Stephanie James 604-521-7551
 NORTH SHORE
 Heather McCracken 604-980-0881
 RIDGE MEADOWS
 Lee-Ann Knight 604-463-1202
 RICHMOND
 Trish Campbell 604-277-7232
 SURREY
 Tracey Chan 604-581-9467
 VANCOUVER
 Debbie Morin 604-327-9824
 WHITE ROCK
 Barbara West 604-535-4094
 PARENTS OF ADULTS WITH AUTISM GROUP
 Lori Wall 604-990-4019

Asperger Syndrome Group
 Betty Bronson 604-874-1153
 MANDARIN-SPEAKING
 Carol Ywan 604-594-8986

Vancouver Island:

CAMPBELL RIVER
 Judy Hollywood Bonnet 250-923-5654
 COURTENAY
 Megan Phillips 250-897-1676
 DUNCAN
 Dot Douglas 250-748-3994
 PORT ALBERNI
 Karen Hovestad 250-714-0801
 NANAIMO
 Joy Becker 250-758-0271

Interior & Northern BC:

BULKLEY VALLEY
 Jan Morrison-Hines 250-847-5740
 WEST KOOTENAY
 Dave & Sue Henke 250-367-6373
 EAST KOOTENAY
 Mike Fisher 250-427-9629
 KAMLOOPS
 Bob Walter 250-374-KIDS
 CENTRAL OKANAGAN
 Janice Harvey 250-768-9098
 NORTH OKANAGAN
 Cindy Methot 250-542-5213
 Lorraine Donald 250-549-1281
 KITIMAT
 Karen Jonkman 250-632-7947
 PRINCE GEORGE
 Heather Borland 250-963-7926
 PRINCE RUPERT
 Larissa Goruk 250-624-7947
 PEACE RIVER REGION
 Zita Cole 250-788-2989

ASBC's Online Community Group – run by Julie Robinson of Autism-Spectrum. Julie's email address is: julie@autism-spectrum.com. Their website is www.autism-spectrum.com

Other Groups Welcoming ASBC Members

Parent Groups for Special Needs (not specific to autism)
 -This group is run by the Simon Fraser Society for Community Living- Coquitlam
 Bev Rempel 604-525-9494

Parents Support Group for Families of Mentally Handicapped Adults Living at Home
 Gwen Lee 604-321-6253
 Janice Reithofer 604-438-1291

Parent Discussion Group focusing on ABA programs (Lower Mainland)
 -run by F.E.A.T. of B.C.-
 Call Jean Lewis (604) 925-4401 or Judy Anderson at (604) 986-1975

Victoria Society for Children with Autism
 President -
 Michael Yarr (250) 385-3862

Parents for Inclusive Education (Powell River)
 April Sweet 604) 485-5885
 Linda Leutz (604) 485-5386

Parents of Children with Invisible Disabilities (Penticton)
 Brenda Morgan (250) 493-2171

If you would like to organize an ASBC Community Group in your region, please call Deborah Pugh, ASBC's Program Director, to discuss what's involved



The Appropriate Use of Diagnostic Terminology in Autism cont.

latter disorders were labeled with a variety of diagnoses that were essentially backward extensions of diagnoses used in adult psychiatry.

In the early 1980's genetic research demonstrated the associations between autism variants. Fostered by the re-discovery of the work of Hans Asperger (a contemporary of Kanner), the clinical conception of autism and related disorders shifted. Asperger had described a group of children very similar to Kanner's patients, but who had stronger language and intellectual abilities. Asperger's writings validated what many researchers were already thinking - that autism is a heterogeneous disorder with varying degrees of impairment. In response to the developments in the field of autism, *DSM-IV* (released in 1994) for the first time proposed subtypes of autism, each with its own "diagnostic criteria".

Since *DSM-I* (published in 1952), there have been four substantial revisions of the manual, with each edition attempting to keep abreast with evolving psychiatric knowledge. Categories of mental disorders are created by a *consensus* of experts charged with the task. Specific diagnostic criteria for a disorder are frequently not validated and often represent the best approximation of widely divergent points of view. As clinicians we accept this compromise in order to promote communication between professionals. However, we also recognize the flux in the field. As stated in the most recent practice parameters of the American Academy of Child and Adolescent Psychiatry, it is incumbent on the clinician to not only observe *DSM* criteria, but also be attentive to "the emerging literature on this topic."

There is a frequent and erroneous assumption that *DSM* subtypes are arranged in a hierarchical fashion. For example, it is often assumed that Asperger's syndrome and *PDD-NOS* represent milder or sub-threshold diagnoses of autism. Although this may be true in some cases, it is by no means a rule. *DSM* diagnoses are categorical – not dimensional – other aspects of the diagnostic schema (such as the severity specifiers and Global Assessment of Functioning) describe the degree of impairment. As well, the introductory section of the *DSM* instructs that although the *not otherwise specified* designation may be appropriate for a "sub-threshold" presentation, it is also appropriate when the presentation is atypical, mixed, uncertain, or when there is insufficient information available. The *NOS* category is provided for every major disorder because of the inherent recognition that categorical nomenclature cannot cover all possible presentations.

It is also critical to appreciate that the *DSM* is strictly a *clinical* manual, designed to "enable *clinicians* and *investigators* to diagnose, communicate about, study and treat" individuals affected with mental disorders [*italics added*]. The preface specifically cautions against use of the *DSM* "clinical and scientific" categories for "legal or other non-medical" purposes. It is specifically stated that *DSM* categories are not relevant for disability determination. It appears that administrators who establish the criteria to qualify for service provision have ignored this fundamental.

DSM offers clinicians a useful guide to facilitate consistency and communication. *DSM* or any other systems of clinical classification for autism are meaningless for social policy decisions. In the current environment of limited resources, eligibility criteria for services are to be expected. However, just as with other forms of illness, these criteria should be based on relevant factors. This includes the burden of illness, pain and suffering, likelihood of treatment response, expected degree of improvement with intervention, and so on. In addition, it is inappropriate to view subtypes as hierarchically reflecting severity of illness. As well, there is no medical evidence that society is better served by providing intensive treatment to only the most disabled. *There is no rational or scientific basis establishing the relevance of autism subtypes to the determination of service need.*

Precise labels, although uncertain and incidental, can have major ramifications on what treatment and support services patients receive.

**AUTISM SOCIETY OF
BRITISH COLUMBIA**
200 - 3550 Kingsway
Vancouver, BC
V5R 5L7



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<input type="checkbox"/> \$ 5.00	Student/Low Income	_____
<input type="checkbox"/> \$ 25.00	Family	Name on card _____
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<input type="checkbox"/> \$ 500.00	Life	Signature _____
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Your donations allow us to provide extra services such as the Buddy program and the summer reimbursement program.

This information is for our files and is optional and strictly confidential. It is designed to help us better plan services for our members. We do NOT sell our membership list.

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Child's name _____		Date of birth _____
Name & age of siblings _____		
Parent's Occupation or employer _____		Language(s) spoken/written at home _____