

ADULT AUTISM ISSUES IN WATERLOO-WELLINGTON

No. 6, February 2000

Barely Coping is the working title of a book planned by a friend to describe how families live with autism. Most families and frontline support workers would probably feel that they are “barely coping” with all their challenges. *AAIWW* tries to feature trends and resources that can enable individuals, families and support networks to realize their hopes and plans. We welcome material about such resources that could be featured in future newsletters.

This issue of *AAIWW* particularly features plans for a new Internet site. We enclose a survey form and invite you to respond as to your level of interest in this free service. Thanks to Peter McCaskell of Guelph for volunteering his technical help.

The Ontario Adult Autism Research & Support Network is proposed, to offer facilitating and filtering services, with following features:

- Some guidance and commentary on what’s on the Internet about autism spectrum disorder, its various symptoms, and treatments and therapies that have been found helpful—with designated links to other sites
- A focus on adult resources and services
- A special Ontario/Canada "filter"
- Special efforts to reach and serve persons with autism and their frontline caregivers and advocates (and perhaps others who are vulnerable because of their disabilities)
- Discussion and conferencing opportunities for various interest groups
- Noticeboard with information about events, resources and service-providers.

See **Why an Ontario Adult Autism website?** (p.4) and the survey insert

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AUTISM IN THE NEWS: ASPERGER’S SYNDROME

Friends remark on how they see autism mentioned everywhere these days. A front-page story in *The Globe and Mail* (1 February 2000) was entitled “Was Glenn Gould autistic?” The possibility that Asperger’s Syndrome could explain Gould’s social deficiencies, obsessiveness and intolerance of change was raised in the 1996 biography by psychiatrist Peter Oswald, *Glenn Gould: The Ecstasy and Tragedy of Genius*, and is now elaborated by the musicologist Timothy Maloney.

Gould was acutely sensitive to light, sound and temperature, and had a phobia about shaking hands and a limited range of preferred foods. His bizarre mannerisms as a concert performer can be understood as uncontrollable expressions of his disorder. Gould’s musical genius and perfectionism match the finding that people with Asperger’s may have an exceptional talent or skill, with which they are preoccupied.

The syndrome was first described by Hans Asperger of Vienna in 1944, but his work was not generally known in English translation until 1981 and the disorder was not described in the Diagnostic and Statistical Manual of Mental Disorders (DSM) until 1994. Other people of remarkable genius who may have had Asperger’s include Albert Einstein, Vladimir Nabokov, Ludwig Wittgenstein, Bela Bartok and Andy Warhol.

Asperger’s shares with autism a severe and sustained impairment in social interaction and restricted and repetitive patterns of behaviour and interests. But people with Aspergers do not have the significant delays in language, cognition, self-help skills or adaptive behaviour that are typical in autism. Aspergers is often not recognized easily or early, and may be misdiagnosed as Tourette’s, ADD & ADHD, ODD or OCD. As with autism, the disorder is lifelong and there is not yet any complete cure.

See note of Asperger Internet sites and resources on page 2.

BULLETIN BOARD

WWAS

- ◆ Continues its bursary program to encourage adults with autism/pdd to develop their abilities, by providing one-time grants. For more details, contact president Roger Hollingsworth at WWAS, 125 Union St, Waterloo ON, N2J 4E5; phone messages may be left at (519) 742-1414.
- ◆ Welcomes your support for the causes of people with adults with autism/pdd and their families, friends and caregivers. Memberships or donations of \$25 or more qualify for tax-creditable receipts. Members are invited to share concerns, ideas and hopes, and are eligible to vote at general meetings and to be nominated and elected to serve on the WWAS Board. Send membership donations to: William Barnes (WWAS Treasurer), 26 Yellow Birch Drive, Kitchener, ON, N2M 2M2

GSA

- ◆ Helps adults with autism to live with dignity in their own homes and to make choices about their lives, by:
 - Financing and maintaining properties
 - Facilitating the roles of the support clusters or networks around each individual
 - Increasing community awareness of the abilities and needs of people with autism
- ◆ Memberships and donations are welcomed by GSA; tax-creditable receipts are issued for amounts of \$10 or more. Please give to a director you know or mail to: John Verhart (GSA Treasurer), Root Plaza Postal Outlet Box 23016, Guelph, ON, N1H.8H9. Phone messages may be left at (519) 821-7424 or 823-9232.

ASPERGER RESOURCES: Some websites...

ACCESS: www.autistics.org

Asperger Adult Resources: www.aspergers.org

FAAAS (Families of Adults Afflicted with Asperger Syndrome): www.faaas.org

OASIS (Online Asperger Syndrome Information & Support): www.udel.edu/bkirby/asperger/

Geneva Centre for Autism,

"the leading source of training, resources and support for individuals with autism/pdd" announces its calendar of training events for the first half of 2000. While focused mainly on children, most are interesting for all concerned with autism spectrum disorder. All events are at 250 Davisville Ave (Suite 200) Toronto, and include:

March 21: An Introduction to Autism/PDD, including theories of causation and current neurobiological research

March 28: Sleep Disorders, including helpful strategies (by Maureen Kay of the Waterloo District School Board)

March 28-June 16: Behaviour Management: A Positive Approach (Certificate Training Program)

April 6: Sensory-Motor Strategies for the Home

April 18: Coping with Autism & Anxiety: Techniques that help

May 2: The Gut Brain Connection in Autism and the implications for individuals and their families, by UK experts Andrew Wakefield and Paul Shattock

May 11: One Parent's Experience with a Gluten and Casein Free Diet

May 9: Asperger's Syndrome: the facts and the experience

May 15: Helping Individuals with Autism/PDD Develop Social Skills

Information will be available shortly on Geneva's Summer Training Institute (August 21-25), and the Symposium 2000 (November 8-10).

For more information on fees and the advantages of membership, phone (416) 322-7877, and check the website at www.autism.net

AAIWW is a joint newsletter produced by WWAS and GSA. We thank Marie Puddister who volunteers her help with layout and formatting, and Andrew Bloomfield and friends who collate the newsletters for mailing

ALLERGY-INDUCED AUTISM:

Is dietary intervention a cure?

PARENTS magazine in February 2000 features the account by Karyn Seroussi of how her family responded to being told that her young son Miles had autism. Trying to understand why his normal development process changed at about 15 months, when he lost his language and social skills, she came across the idea that he might have an allergy to milk and wheat. Though all professional advice was sceptical or hostile, the family tried eliminating first milk and then gluten (found in wheat, oats, rye and barley).

Miles made amazing progress in speech, social behaviour and relationships and also in his digestive processes. By the time he was 3, all his doctors agreed that his autism had been completely cured. Now 6, he is “one of the most popular children in his first-grade class. He’s reading at a fourth-grade level, has good friends, and recently acted out his part in the class play with flair. He is deeply attached to his older sister, and they spend hours engaged in the type of imaginative play that is never seen in kids with autism.”

How to explain this recovery? It is theorized that a sub-group of children with autism break down casein (or milk protein) or gluten into peptides that affect the brain and nervous system in the same ways that hallucinogenic drugs do. These children might lack an enzyme that normally breaks down the peptides into digestible form, or the peptides may be leaking into the bloodstream before they can be digested. As the opiates are addictive, these children crave the very foods to which they are allergic; they may even binge on these foods and refuse others. It is further suggested that autism is a disorder related to the immune system and that autistic children may be genetically predisposed to immune-system abnormalities. The onset of

autism may be triggered by the measles portion of the MMR (measles, mumps, rubella) vaccine that children are often given at 15 months.

Could dietary intervention help adults with autism? Hopes of cure or recovery would be slight, given the years of developmental delays. But some adults whose autism might have been allergy-induced have benefited from removing casein, gluten and possibly other foods—in their digestive processes, sleep patterns, general outlook, and behaviour.

Physical problems that could be caused by allergy-induced autism include: bloating, constipation, swollen tummy, frequent breaking of wind, pale skin and pasty face, craving vs. dislike for certain foods, giggling/screaming for no apparent reason, eating non-food items like earth, sand, paper or soap, diarrhoea, excessive thirst, excessive sweating especially at night, hyperactivity, inability to control body temperature, sleeplessness, dark shadows under the eyes, red face and/or ears, rhinitis. Family background is likely to include gut disorders, allergies (asthma, eczema, migraine) or gout.

Karyn started a newsletter and international support organization called Autism Network for Dietary Intervention (ANDI) in 1997. See its Internet site at www.autismndi.com. She recounts her family’s experience in her book *Unraveling the Mystery of Autism and Pervasive Developmental Disorder: A Mother’s Story of Research and Recovery* (published by Simon and Schuster, January 2000).

Other relevant Internet sites:

Autism Research Unit:

www.osiris.sunderland.ac.uk/autism (includes a post-diet questionnaire)

Allergy induced Autism (AiA):

www.kessick.demon.co.uk/aia

GFCF Diet Support Group: www.gfcfdiet.com

New Internet site proposed... Could it help you or someone you know?... Please complete our survey and return by mail, or by email.

<http://www.ont-autism.uoguelph.ca>

WHY AN ONTARIO ADULT AUTISM WEBSITE?

What's already on the Internet? A great deal. A simple search for documents or sites containing the word "autism," using a meta search engine such as dogpile, turns up a total of about 200,000 items (though some of these may be duplicates). Scanning through only 200 of these would take a long time and might well show that "autism" is only a minor reference in most items. We may be sidetracked into some fascinating byways but find almost nothing about the aspects of autism that concern us. We would eventually find the most comprehensive websites about autism such as the Autism Research Institute, the Center for Study of Autism, the Autism Resources Website, the Autism Research Unit, and Autism Independent UK, as well as many sites and pages on specialized facets of autism.

When we narrow the search to items that combine "autism" and "adult," the yield is much smaller—perhaps only about 50 different sites that actually use both keywords. Yet in some of these the link between autism and adults may be incidental rather than central. Other sites that could be helpful may not actually mention the word "adult," and so might be missed from the search.

Access to the Internet can put us in touch with information from around the world. It's exciting to find people in Norway, Japan, Peru or New Zealand who share some of our concerns. But the resources and services that can help persons with autism depend on where we live. Very few Internet sites or documents combine "autism", "adult" and "Ontario." Surprisingly, the good website of Autism Society Ontario may not be found by a search for all these keywords.

What will be most distinctive about the Ontario Adult Autism Research & Support Network website will be its opportunities for conferencing and discussion groups on specific aspects or issues.

The term "autism" derives from an earlier perception of "aloneness." We now know that persons with autism don't want to be alone and

realize their need for friends. But, as a result of all sorts of attitudinal and practical barriers, persons with autism and their direct caregivers can be very isolated. What we propose could help to offset feelings of isolation and even lead to more social and community interaction. People might also share the coping strategies they have developed.

This new website is proposed by Drs Gerald and Elizabeth Bloomfield of the University of Guelph, Ontario, and is being developed by Peter McCaskell as a volunteer.

We would like to know your reaction to this proposal—even if you do not now have easy access to the Internet or if you personally would not expect to use the website yourself. Do share this proposal and survey with other people who could be interested. We would like to hear from you by 15 March 2000.

Please complete this form and return it by mail to AAIWW, C/o GSA, Post Office Box 23016, Root Plaza Postal Outlet, GUELPH, ON N1H 8H9. Or you may complete the survey posted on the Internet at

<http://www.ont-autism.uoguelph.ca>. You may leave a message about this proposal at either of two Voice Mail phone numbers: for Waterloo Region at 519-742-1414; for Guelph-Wellington at 519-821-7424.

Please be assured that the results of this survey will be grouped, and your individual responses will not be revealed to anyone else.