

ADULT AUTISM ISSUES IN WATERLOO-WELLINGTON

Joint newsletter of Guelph Services for the Autistic (GSA) and Waterloo-Wellington Autism Services (WWAS)
Newsletter No 10, March 2001

Celebrating our first anniversary! The Ontario Adult Autism Research and Support Network

is just one year old.

OAARSN is the electronic cousin of AAIWW. Started with a focus on adults with autism in Ontario, it has attracted wider attention around the world and among those who are most concerned with autism in children. OAARSN has subscribers from all over North America and overseas, as far away as Tasmania and Thailand.

*Click on: <http://www.ont-autism.uoguelph.ca>
You will find a rich and rapidly expanding collection of up-to-date information and communication tools that can put you in touch with other individuals with autism, parents, caregivers and concerned professionals. We can all benefit from the opportunities for mutual support, encouragement and information sharing.*

We believe that providing access to more and better information can help to improve the quality of life of adults who have been described among "our most vulnerable citizens." Families and friends of autistic adults can also feel less isolated and more empowered to support their loved ones most effectively.

Even if you do not own a personal computer or are not used to exploring the World Wide Web, it's possible to use Internet terminals in public libraries, for example. You need only type in our URL to reach the main page; then follow site navigation tips to reach all features from live keys on the main page. Our Search feature allows you to type a term or topic, click on Search, and be guided to relevant resources.

Let us know by email at gbloomfi@uoguelph.ca if you would like to be on the OAARSN List to receive weekly email bulletins alerting you to the news and other features added to the site. You could also receive AAIWW through the website or by email and save us the costs of postage and paper.

Inside this issue of AAIWW:

Page 2

The Adult Autism Needs Survey 2001

- Why this survey?
- Who should take part?
- How to respond?

<http://www.ont-autism.uoguelph.ca/aans2001.shtml>

Page 3

What Causes Autism?

Are Vaccines Responsible?

Pages 4 and 5

Books on the Autism Spectrum

A Positive Approach to Autism by Stella Waterhouse

Autism: Preparing for Adulthood, by Patricia Howlin

Autism: A New Understanding! Solving the Mystery of Autism, Asperger's and PDD-NOS, by Gail Gillingham

Page 6

OAARSN Discussion Board Topics

From the Front Lines...Living with Autism

Join in the discussion! Share your experience...

Page 7

Ten Steps to Realize a Personalized Plan (a poster)

Page 8

AAIWW Bulletin Board

- Waterloo-Wellington Autism Services
- Guelph Services for the Autistic
- Planned Lifetime Networks (Waterloo-Wellington-Oxford)
- Family Conference, Friday evening April 20, and Saturday April 21, in Cambridge

Announcing the Adult Autism Needs Survey 2001

<http://www.ont-autism.uoguelph.ca/aans2001.shtml>

Why this survey?

OAARSN is taking this survey to learn about how many people have autism and to understand their abilities and needs. This information will help various organizations that wish to provide the most useful support to adults with autism and to their families. The last survey of Ontario adults with autism was taken in 1990 (and reported in *Our Most Vulnerable Citizens*, published by the Autism Society Ontario and posted on the OAARSN website). A great deal has changed during the 1990s, but adults with autism are still among our most vulnerable citizens.

Taking part in this survey may help you--as an adult with autism or as a family member, friend or caregiver--to consider your current situation, various treatments and therapies, and how you are planning for the future. Please be assured that the results of this survey will be grouped, and your individual responses will not be revealed to anyone else without your permission.

You can ask us to send you a summary of the general findings of this survey, or to let you know of an autism services organization that may be able to offer relevant support and resources in your region. For example, Guelph Services for the Autistic and Waterloo-Wellington Autism Services are interested in responding to the needs revealed by this survey for the Region of Waterloo and Wellington County-Guelph.

Who should take part in this survey?

A person who has any form of autism spectrum disorders, and who was at least 16 years old by 31 December 2000. For this survey, autism spectrum disorders include classic autism, Kanner's syndrome, pervasive developmental disorder (PDD), Asperger's syndrome, autistic tendencies, autism in some form or degree combined with another diagnosis as well. We are particularly interested in the points of view of persons with autism themselves, so the survey questions are expressed in terms of "you" and "your." But you (i.e., a person with autism) may be represented by a parent, sibling, other relative, trustee or caregiver

who understands your circumstances, how you experience autism and any treatments, and your goals.

How to respond to this survey

We encourage you to complete this form electronically, on the OAARSN website by clicking the appropriate responses, and submitting it by e-mail. This is the most efficient and confidential way for us to store your information and also to analyze all the responses we receive. It is helpful to have your response even if you are completely satisfied with your present pattern of life and supports. Completing this survey takes about 30 minutes.

You may wish to print out the survey first, so that you can think about your responses, and then connect later to complete and submit them.

A printed version of the pilot survey may be requested by leaving a request message with your full name, address and phone number at phone (519) 742 1414 in the Region of Waterloo, or at phone (519) 821 7424 in Guelph-Wellington. If you prefer to use this or a printout of the electronic survey form, please mail your completed survey to Guelph Services for the Autistic, Box 23016, Root Plaza Postal Outlet, GUELPH, ON N1H 8H9. In this first phase, we would like to hear from you by 1 May 2001.

The AANS survey has six parts:

- 1: BASIC PERSONAL INFORMATION (7 questions)
- 2: UNDERSTANDING YOUR ABILITIES AND CHALLENGES (12)
- 3: YOUR PRESENT LIFE CIRCUMSTANCES (18)
- 4: TREATMENTS AND THERAPIES (3)
- 5: QUALITY OF LIFE (2)
- 6: PLANNING FOR THE FUTURE (14)

WHAT CAUSES AUTISM? Are Vaccines Responsible?

Autism - like cancer, heart disease and most of the other big killers - is a "complex" disorder, probably caused by a complicated mix of multiple genes and environmental factors. There is no single and clear cause. Autism is manifested in unique combinations of symptoms and varying degrees of handicapping conditions in each individual. It now seems that some people may be predisposed by inheriting a complex combination of genes. As a neurodevelopmental disorder, autism may be triggered in these individuals by a type of food, a drug, exposure to a chemical, or an infection. The complexity of autism means that there is no quick fix or treatment strategy to suit all.

During the past year, autism has been in the news more, probably, than in all the previous 55 years combined. One reason is the remarkable increase in the numbers affected, which cannot be explained simply as the result of greater awareness or better diagnosis. A new study in England has found that one child in 175 has autism, an elevenfold increase over the rate of classic autism in the 1960s. Second, there has been a lot of publicity around the MMR vaccine, given to children at 15-18 months, and again, usually at 4-5 years.

According to Dr Bernard Rimland of the Autism Research Institute in California, the most plausible cause of the increase is changes in vaccination programs generally, such as:

- 1) The extraordinary increase in the number of vaccines given to children from birth to age two - from 8 in 1980 to 22 in 2000;
- b) The amount of extremely toxic mercury, used as a preservative in many vaccines; and
- c) The combination of three vaccines, Measles, Mumps, Rubella, previously given singly, into one, the MMR.

The MMR controversy has hit the headlines since Dr Andrew Wakefield, a gastroenterologist at the Royal Free Hospital in London, England, published his theory of a possible connection between autism and a viral infection associated with the MMR vaccination. His research suggests that a subset of autistic people may suffer brain inflammation resulting from infections that began in their intestines after they were inoculated with the MMR vaccine. He considers that MMR could be

linked to a syndrome called autistic enterocolitis and insists that the vaccine was inadequately tested and should never have got a licence.

The medical and public health establishment shows strong support for total vaccination of the child population against all infectious diseases, based on success in eliminating smallpox, polio and tuberculosis from developing countries. Supporters point to dramatic decreases in almost all childhood diseases, including the deaths that used to follow complications. They dismiss theories of any links between the MMR vaccines and autism by pointing out that autism had been identified long before there was any MMR vaccine.

While the case against the MMR vaccine is not yet proven, many parents and physicians have decided to be cautious. The controversy has drawn wider attention to the mysteries of autism and is an impetus to increased research on its causes.

For OAARSN's review of vaccines as a factor in Autism:
<http://www.ont-autism.uoguelph.ca/mmrrefs.shtml>

If the MMR Vaccine does not cause Autism, what on earth does?

Dr Jeanette Holden, a molecular geneticist at Queen's University, Ontario, has been awarded \$4.3 million over 5 years for a multidisciplinary project entitled "Unravelling the mystery of autism: from genotyping and phenotyping to prospective identification and prevention." Dr Holden, a member of the board of Autism Society Ontario, has a 48-year-old brother with autism. Holden's team, comprising 41 partners from 23 institutions, will endeavour to identify genes involved in the susceptibility to autism spectrum disorders (ASD).

In the US, Congress has ordered the Institute of Medicine to investigate the alleged link between childhood vaccinations and autism, as well as alternative hypotheses. The US National Institutes of Health also offer major research funding

The British Government is funding a study to re-examine the causes of autism, to obtain a "clear and comprehensive" picture of what is currently known. The study will draw upon the experience of people with autism and their families as well as the research findings of experts.

BOOKS ON THE AUTISM SPECTRUM

A Positive Approach to Autism by Stella Waterhouse. Jessica Kingsley Publishers, 2000. Foreword by Donna Williams. 382 pages. Includes glossary, appendices, useful addresses, bibliography. ISBN 1 85302 808 8 paperback.

As Donna Williams notes, it is unusual for a professional to come so close to an autistic perspective and to have such a holistic approach to understanding autism. "Stella takes the loose ends of sensory and perceptual, cognitive, anxiety, self-control and biochemistry problems, tracing them back to the spool from which these seemingly disconnected tangles came."

In place of the common fallacies about autism—"one of the most awful handicaps presently known to man"—the author set out to prove that:

- "The vast majority of people with autism are of potentially normal intelligence and all are educable if provided with the right kind of help;
- "They begin life with all the potential for feelings that "normal" people have, and do want to communicate even though they may have difficulties in doing so in a "normal" understandable manner;
- "Most parents are warm and caring people, coping with immense difficulties which are frequently compounded by unthinking attitudes. Waterhouse finds four factors are combined in most people with autism and Asperger's syndrome.
- A faulty digestive system which affects the functioning of the brain, causing normal development to be disrupted.
- Neurodevelopmental delay which severely disrupts the perceptual system and effectively hampers the child's interaction with other people and bars him from exploring his environment and thus reduces his ability to learn from or understand the world around him.
- Severe and ongoing stress.
- Chronic and acute anxiety.

In autism these factors combine to trigger a fifth:

- Withdrawal and/or obsessive/compulsive behaviours that are the symptoms we know as autism, which further detach the child from "normal" childhood experiences.

For more about autism books, click on:

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

Autism: preparing for adulthood, by Patricia Howlin. Routledge, London and New York, 1997. 294 p. Figures, tables, references, index. ISBN 0-415-11531-0

The author concentrates on more able adults. Difficulties in communication and social interaction and with obsessive and ritualistic behaviours persist through adulthood of people with autism, whatever their functioning level. More able adults are usually well aware that they are different, feel frustrated that they are unable to make use of their special skills, and experience acute emotional distress. Society tends to be much less sympathetic with adults who seem more mildly disabled and to have unrealistically high expectations of them.

Most chapters explain an area of difficulty and discuss strategies that can be used to overcome or minimize the impairments. No magic cures are proposed and the author is very sceptical about the claims of particular intervention programs to be the answer to autism. Various strategies can be adapted to the individual's needs and circumstances.

In the last (brief) chapter about "Fostering independence," Howlin comments on changing expectations and attitudes by others, problems of lack of self-drive and initiative, the need for flexible and individualized living arrangements, and the need to experience various options in order to exercise choice and self-determination. A wide range of different environments is needed, and it should be possible for individual adults to change their living environments as their needs or skills change. She offers a few basic guidelines (p. 265), which we think apply to all adults with autism.

- Plans for adult life should be made as early as possible, preferably by the mid- to late-teens, with regular respite to get used to separation.
- There should be NO expectations that other family members will take on the role of caring for the adult with autism.
- The government should be made aware early of the individual's potential need for care.
- Additional support networks, and outside activities and interests should be encouraged.
- Whatever plans are formulated for living, daily occupation or leisure, the one sure thing is that these will require financial support.

BOOKS ON THE AUTISM SPECTRUM

Autism: A New Understanding! Solving the Mystery of Autism, Asperger's and PDD-NOS, by Gail Gillingham. 2000. 191 pages. ISBN: 0-9687863-1-6. \$30 plus \$7 p & p.

Autism: Handle With Care! Understanding and Managing the Behavior of Children and Adults with Autism, by Gail Gillingham. 1995; 3rd edition 1998. 134 pages. ISBN: 0-9684219-1-1. \$25 plus \$7 p & p. Order both books from Tacit Publishing Inc. 8744-81 Avenue, Edmonton, Alberta, Canada, T6C 0W6. Phone 780-466-2445. Fax: 780-463-6433.

Email: tacit@telusplanet.net

These books are highly recommended for all people who live and work with autism. Gillingham tells how she came to realize that the symptoms of autism are a direct result of the high level of stress in which autistic people live all the time. Her thesis is that they are hypersensitive to sensory stimuli, far above and beyond any "normal" level or range—so that they are "superabled" rather than "disabled." The longterm result of acute sensitivity and over-stimulation on development is the autistic lifestyle. A low-functioning individual with autism has higher levels of sensory response than someone who is high-functioning and thus has a greater need to protect herself from intolerable bombardment by sensory stimuli in the environment by spending most of life isolated in a world of her own. While an adult with autism may be less sensitive than when a child, she may continue to live in a state of anxiety, waiting for the pain to return.

Both books are remarkable for taking seriously what autistic people say about their condition. The author's "sensory theory of autism" is based on hundreds of vivid quotations from people who live with the reality of autism, some of whom have discovered their expressive powers with facilitated communicating. Gillingham declares that "when we listen to those with autism, we discover a totally new picture of the condition. We find individuals who long for relationships with us, who have cognitive skills intact and are able to communicate with us in ways we never dreamed possible. It is definitely time for us to try to listen even more carefully in order to give up the hopelessness and despair that overwhelm so many of our parents and professionals."

Fragile Success: Ten Autistic Children, Childhood to Adulthood by Virginia Walker Sperry. Paul H. Brookes Publishing Co., Baltimore, 2001. 242 pages. Includes appendices, bibliography, index. ISBN 1-55766-458-7 paperback.

Professional and public interest in autism disorders often begins and ends with early childhood and diagnosis. But children with autism grow up into teenagers and adults. They are assumed to have normal life expectancy. Longitudinal studies of outcomes, or how children with autism develop as adults, are very rare. That is the special value of *Fragile Success*, which was published in a first edition in 1995. A significant amount of material has been added for this second edition.

The ten case studies that make up most of the book are preceded by two chapters. "Childhood Autism and Related Disorders" outlines successive explanations of autism from the 1950s. "The World of the Ives School" explains the founding of the pioneering school for autistic children that the author directed in New Haven, Connecticut.

Fragile Success is valuable for incorporating parents' views in most cases. While unique in details, the parent and family experiences share many features. In the first edition these were mainly "the search for answers and understanding; the feelings of despair and hope; the pain, anger, sadness and frustration." By 1999, much of the parents' bitterness and frustration had been "replaced by a growing sense of pride and acceptance of their children's accomplishments

How representative are these case studies of all adults with autism who are now in their thirties? The adults profiled in *Fragile Success* have probably done better than most. As children, they did get expert and dedicated help, as well as generally appropriate services as they grew up into adulthood. Their parents fought for them when they were children and are still very important in their lives.

The full reviews of these books, with reviews or notes of many other books about autism, may be found on the OAARSN website at <http://www.ont-autism.uoguelph.ca/books.shtml>

OAARSN DISCUSSION BOARD TOPICS

Do you have similar concerns?—or suggestions that could help? Join in the discussion!

<http://www.uoguelph.ca/~gbloomfi/cgi-bin/Ultraboard/UltraBoard.pl>

These are some of the Topics:

- Are More People Autistic Now?
- Should an Adult who suspects she may have ASD seek a Diagnosis?
- How useful is Autism as a Label for Adults?
- Applied Behavior Analysis-does it help adults?
- Finding the Right Medication-or managing anxiety without drugs?
- Dietary Intervention: Is a gluten-free/casein-free diet worth the hassle for an autistic adult?
- Secretin-does it help an adult?
- Picture Communication Exchange Symbols-how to find PECS that are more age-appropriate?
- Facilitated Communicating-how can we find professional support in Ontario?
- Social Stories-readymade resources for adults?
- Sensory Integration dysfunction-who else is using strategies to support adults
- Sleep Disorders-how to help a young adult who cannot take drugs?
- Challenges: understanding and responding to violent behaviour?
- Applying understanding of energy flows within the body to reducing or eliminating anxiety in people with ASD.
- Pros and cons of a campus-style caring community in Ontario for young adults with moderate to severe autism.
- Pros and cons of homesharing
- Challenging Some Assumptions: Reflections on the Latimer Case

News items and links to the full stories are posted in OAARSN's Autism in the News each weekend. Look up the Bulletin Board in the Communications area of the website or use URL http://www.ont-autism.uoguelph.ca/bulletinboard_new.shtml#autism

Let us know by email at gbloomfi@uoguelph.ca if you would like to be on the OAARSN Listserv to receive weekly email bulletins alerting you to the news and other features added to the site.

FROM THE FRONT LINES...

...LIVING WITH AUTISM

OAARSN wants to sharpen its focus on adult autism and disability issues in Ontario. The scarce news of autistic adults is almost all negative, about disasters and abuses. Most adults with autism are simply overlooked and forgotten except by their direct caregivers. Good news about satisfying lives, successful strategies, and “best practices” would encourage and inspire all of us on the front lines.

We appeal to all who live with autism in any way to share their stories and insights through the OAARSN website! The stories should be true, but names may be changed to protect privacy. You might like to discuss the idea of your story first.

We use the phrase “the front line” with its two main meanings. One is the war zone—the area of active engagement with an enemy, in our case is one of the “most awful handicaps presently known” to humankind. The other meaning is the most advanced or responsible position in any field of activity—being out in front as a pioneer of the most sensitive and effective ways to support people to do their best and enjoy life.

Isaac's Story is already posted in OAARSN's

Unique Resource Documents at

<http://www.ont-autism.uoguelph.ca/from.shtml#a>

Isaac allows his true story to be shared so it may inspire others. He hopes others will feel encouraged by knowing that he has taken several steps towards a better life. There are installments about:

- Isaac's Special Diet
- Sensory Integration: its Benefits for Isaac
- How Sleep Hygiene Helps Isaac
- How Isaac Communicates
- Isaac's Desire to Continue Learning
- Structure in Isaac's Life
- How Isaac Learns New Skills
- Isaac's Home
- Isaac's Garden
- How Isaac Contributes to his Community
- Isaac's Parents' Perspective
- Isaac's Friends and Neighbours
- Ways to Support Isaac's Support People

This page of the printed newsletter presents a page-size version of the electronic poster, ***Ten Steps to Realize a Personalized Plan***. For on-line readers, it is more efficient to view it at <http://www.ont-autism.uoguelph.ca/STRATEGIES8.shtml>

By clicking on each of the ten images, you can get more detailed information.

ADULT AUTISM ISSUES: BULLETIN BOARD

WATERLOO-WELLINGTON AUTISM SERVICES

Information about WWAS may be found at

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

A present focus is on supporting individuals with autism to make a positive difference in their lives with the help of a WWAS bursary.

Information and application form are at

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

Please show your support for adults with autism and their families and caregivers.

- a) Become a member or renew your membership of WWAS, with a donation of \$25 or more. Have opportunities to share concerns, ideas and hopes about issues relevant to people with autism and their caregivers. Vote at general meetings and to be eligible for election to the WWAS board of directors. You also get a tax-creditable receipt.
- b) Subscribe to AAIWW for \$5 a year (to cover printing and postage costs).

Make cheques payable to WWAS and send with your name, full address and phone number, to William Barnes, 26 Yellow Birch Drive, Kitchener, N2N 2M2. For more information, call our answering machine at (519) 742 1414, leave your name, number and message.

GUELPH SERVICES FOR THE

AUTISTIC is a charitable non-profit corporation, formed in August 1980, which functions as a housing trust. GSA's goal is to allow adults with autism to live more fulfilling, happier and more productive lives in homes of their own. Adults with autism can become active members of GSA, which helps them to make informed choices about their lives, and in particular with decisions about with whom they will spend their time and share their homes.

GSA has taken on this role in response to moves toward personalized planning and individualized funding, both of which are attempts to improve the quality of life for people with disabilities while making the best possible use of community resources. For more information, see GSA pages on the OAARSN website:

http://www.ont-autism.uoguelph.ca/gsa/info_new.shtml

http://www.ont-autism.uoguelph.ca/gsa/faq_new.shtml

GSA also welcomes new members, volunteers and donors. Tax-creditable receipts are issued for donations of at least \$10. Please mail to Guelph Services for the Autistic, P.O. Box 23016, Root Plaza Postal Outlet, GUELPH, Ontario, N1H 8H9

Welcoming Planned Lifetime Networks (Waterloo-Wellington-Oxford)

The new organization, recently incorporated in our region, is affiliated with PLAN: Planned Lifetime Advocacy Network of Vancouver BC. It offers member families help in creating and maintaining personal support networks around their relatives with a disability to ensure a good life now and a secure future.

Copies of the wonderful book, *A GOOD LIFE* by Al Etmanski of PLAN are available for \$35. For more information, phone (519) 746-7950 (Lynne or Roz), (519) 823-9232 (Elizabeth), (519) 624-5195 (Verlyn)

Achieving Inclusion - Building Hope - Connecting Communities

A Family Conference sponsored by Family Alliance Ontario, Integrated Action Group, and Planned Lifetime Networks (WVO)

Friday evening, April 20, from 6:30 p.m. and Saturday, April 21, 8:30 a.m. to 5 p.m., at the Hespeler Scout House, across street from W.G. Johnson Centre, 31 Kribs St, Cambridge

Friday evening program includes: Sharing the Good Life, a Community meeting addressed by Nicole Santilli, *Reseaux pour L'Avenir WESP*, sponsored by Planned Lifetime Networks (Waterloo-Wellington-Oxford)

Saturday afternoon includes a panel: Planning for the Future

Registration fees by March 30 deadline:

Preconference event, Friday evening: \$10 for individual/family

Conference Day: Family \$75; 1 Adult/Parent \$50; Self-Advocate \$15;

Professional/Teacher/Service Provider \$60. Late fee of \$25 after March 30.

Make cheque payable to Integration Action Group-April 2001 and mail with your name, address, phone number and email to: FAO/IAG-Conference Committee, 181 Cowan St, Cambridge ON, N1T 1J8

Call for more information: Nancy Woronko (416) 661-9611 ext. 207, or Verlyn Rowett (519) 624-5195.

