

ADULT AUTISM ISSUES IN WATERLOO-WELLINGTON

Joint newsletter of Guelph Services for the Autistic (GSA) and Waterloo-Wellington Autism Services (WWAS)
Newsletter No 9, November 2000

BULLETIN BOARD

Announcing

Planned Lifetime Networks

A newly incorporated organization in our region, to help families plan a good life and a secure future for their relatives with a disability!

Do you want:

- a good life for your relative who may be socially isolated with a disability?
- a safe and secure future supported by a personal network of caring friends?

So do others in our region.

Planned Lifetime Networks (Waterloo-Wellington-Oxford) is an incorporated not-for-profit charity in Ontario and an affiliate of PLAN™ of British Columbia, which has pioneered the formation of personal support networks for people with disabilities since 1988.

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

You are invited to a special meeting co-sponsored by Guelph Services for the Autistic to introduce Guelph families who have relatives with a disability people to the PLAN concept of planned lifetime networks.

Date: Monday 20 November 2000, 7 pm

Place: Evergreen Seniors Centre, Woolwich St, Guelph

PLN Board members will explain how PLAN works, and show two videos illustrating personal support networks. Copies of the wonderful book A GOOD LIFE by Al Etmanski are available at \$35, and PLN's new brochure will be ready.

WATERLOO-WELLINGTON AUTISM SERVICES

offers bursaries for ideas and projects that can positive difference for individuals with autism. More information may be found at

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

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

Or call our answering machine at (519) 742 1414

Please send membership donations to WWAS Treasurer William Barnes, 26 Yellow Birch Drive, Kitchener, N2N 2M2. Donations of at least \$25 qualify for tax receipts.

GUELPH SERVICES FOR THE

AUTISTIC functions as a housing trust to help adults with autism to live more fulfilling, happier and more productive lives in homes of their own.

For more information, see GSA pages at:

http://www.ont-autism.uoguelph.ca/gsainfo_new.shtml

http://www.ont-autism.uoguelph.ca/gsafaq_new.shtml

GSA 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.

SEE INSIDE:

Some samples of the wide variety of information available on the OAARSN website

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

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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 being posted in OAARSN’s Unique Resource Documents category at <http://www.ont-autism.uoguelph.ca/from.shtml#a>

Isaac is an adult in his mid-30s who is quite severely handicapped by autism. He does not speak with his voice and finds it hard to show his feelings in ways others can easily understand. He tries, but cannot always control his movement disorders and sensory integration dysfunction, especially if he is upset emotionally. His life has been hard for him in various ways. But insights into how Isaac experiences autism and the efforts of his parents and friends to help him get his life together have been succeeding.

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 will be 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

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 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.

OAARSN is working on a new survey of the status and needs of adults with autism. Much has changed since the last survey was taken by the Adult Task Force of Autism Society Ontario in 1990-91. Then, the main link in reaching adults with autism was through institutions and agencies rather than families. There was a much narrower definition of autism, with Asperger’s and high-functioning autism barely considered. It was assumed that adults with autism could not speak for themselves. The range of living options was more restricted and traditional. It’s time for a new survey. As well as learning more about the numbers of adults with autism and their range of needs, we are very interested to know more about what makes a good life for a person with autism. And we are eager to hear about success stories!

GOVERNMENT-FUNDED RESOURCES FOR ONTARIANS WITH DISABILITIES

Adults and children with autism are among at least 300,000 Ontarians who have difficulty expressing or acting upon their wishes because of a disability, medical condition, communication problem or advanced age. Government-funded resources and supports may be available through various ministries and programs. There is a useful web-based guide at

<http://www.gov.on.ca:80/MCZCR/english/citdiv/disabled/oda8.htm>

On the OAARSN site, we have posted a page about resources that might help persons with autism and their families particularly (but there is useful information also for people with other disabilities). For the full version, click on

<http://www.ont-autism.uoguelph.ca/STRATEGIES0.shtml>

Summary of Government-Funded Resources for Adults with Learning/Developmental Disabilities

Income and Employment Supports

- Ontario Disability Support Program
Complete ODSP policy manual online: everything you want to know about eligibility, benefits, administration can be found at

<http://www.gov.on.ca/CSS/page/brochure/odspis/odspis.html#>

- Employment Supports Program

Supports for People with Developmental Disabilities

(Funded by the Ministry of Community and Social Services through local and regional agencies)

- Assessment Services
- Parent Relief
- Family Support Program
- Supported Independent Living Program
- Special Services at Home Program
- Familyhome Program
- Group Homes
- Lifeskills Program
- Adult Protective Services Program
- Sheltered Workshops

Health-Related Services

(funded by the Ministry of Health, through Community Care Access Centres)

Education -- Colleges & Universities

Various potential supports are funded through other ministries

Reaching Government-funded help for Autism Spectrum Disorders

Finding relevant information is not easy and the process of determining eligibility and obtaining help may be slow. Finding help that is appropriate to autism spectrum disorders is a bit harder than for general developmental disabilities.

- Local communities and regions in Ontario now have single points of “information and referral” for services for people with developmental disabilities. In Guelph-Wellington, it is at Family Counselling and Support Services, phone 824-2431 or 1-800-307-7078. In Waterloo Region the Developmental Services Access Centre is at 741-1121.
- If you need to reach the nearest office of the Ministry of Community and Social Services about supports for people with developmental disabilities: First, locate your community on the map of Ontario at <http://www.gov.on.ca/CSS/page/offices/offices.html> Then look up the local and toll-free phone numbers for your region.
- For specific questions on any supports or resources that may be funded through MCSS or Health, phone INFOline: (in Toronto) 416-482-4359 or (outside of Toronto) 1-800-665-9092; TTY 1-800-387-5559; Fax 416-325-7136.
- You can email the Minister of Community and Social Services at <http://www.gov.on.ca/CSS/page/minister.html>

The OAARSN website includes some critiques of the present system and some ideas of good alternatives. <http://www.ont-autism.uoguelph.ca/STRATEGIES0.shtml>

We also recommend:

- *In Unison: A Canadian Approach to Disability Issues* at http://socialunion.gc.ca/pwd/unison/blocks_e.html
- Two papers by the Ontario Association for Community Living: *The Value of One: Respecting and Responding to the Unique Qualities of Individuals* (September 1997) at http://www.acl.on.ca/policy/value_of1.html and *Rights, Relationships, Resources and Restructuring: OACL's Social Policy focus for 1999/2000* at <http://www.acl.on.ca/policy/4r.html>

Sleep Better!

A Guide to Improving Sleep for Children with Special Needs by V. Mark Durand (1998). Paul H. Brookes Publishing Co., Baltimore, 1998. 282 pages. Includes appendices, bibliographic references, index. ISBN 1-55766-315-7 paperback.

"Unless you have experienced it yourself, it is almost impossible to describe the feeling in the pit of your stomach when you hear your child cry at 12:30 A.M.-- one more night of hundreds of such nights. Just as your body and your mind have begun to give up the tensions of the day, the stirring followed by the inevitable crying jolt you into the dreaded realization that it is happening one more time. One more night that your child will have disrupted sleep and, despite your feeling guilty about thinking this way, you are aware that you too will not get a full and complete night's rest -- by now a luxury for which you would be willing to trade much" (p.xiii).

Dr Durand is a psychology professor who came to write this book because of his personal experience with his son's multiple problems with sleep. As he embarked, more than 20 years ago, on work with children who have special needs, he was alarmed to find that that they are much more likely to have sleep difficulties than children in general. His work and this book express empathy with the high stress and chronic anxiety of parents whose children have special needs.

People with autism may be among the most seriously affected by sleep problems, almost all of them experiencing difficulties at some stage in their lives. For many, sleep problems persist into adulthood. Problems with sleep can be a sign of other problems, the chronic anxiety of people with autism being one. Disturbed sleep, when persistent, has a negative effect on performance and behavior and will probably mean that a person is mistakenly considered of low ability, especially if they also do not speak. Sleep problems also affect emotional well-being and may lead to or worsen self-injurious and aggressive behavior. A child's sleep difficulties

can threaten the parents' marriage, mental health and livelihood.

Sleep Better!'s text is organized in three parts. The first, The Nature and Problems of Sleep, includes overviews of sleep and sleep problems. The second, Assessing Sleep Problems, includes steps to understanding, a sleep diary, behavior log, sleep interview (with details of specific disorders and their possible causes and effects). The greater part of the book, Strategies for Change, consists of chapters on: good sleep habits; help for bedtime problems (includes two autism case studies); sleeping through the night; sleeping at the wrong times; nightmares and sleep terrors; excessive sleepiness and movement-related sleep problems (relevant to autism); other nighttime difficulties (such as bedwetting, anxiety, depression, headaches, teeth-grinding); daytime behavior problems; sleep and medications (not recommended as a long-term solution); and preventing sleep problems.

The book's appendices present information about support groups and associations, sleep pages on the World Wide Web (none include specific reference to autism), and accredited sleep disorders centers (with a warning that many centers do not accept people with autism or mental retardation), as well as details of a sleep diary and behavior log and of the Albany Sleep Problems Scale.

The good news is that the procedures recommended in ***Sleep Better!*** could well help both children and their parents to sleep better. Even within a few weeks. Many of the strategies could also be adapted to help teenagers and adult with sleep problems.

BOOKS ON THE AUTISM SPECTRUM with lists reviews and notes of many books about autism, may be found on the OAARSN website at <http://www.ont-autism.uoguelph.ca/books.shtml>