

ADULT AUTISM ISSUES IN WATERLOO-WELLINGTON

Joint newsletter of Guelph Services for the Autistic and Waterloo-Wellington Autism Services

Newsletter No 14, February 2002

VOLUNTEERS MATTER!

volunteer: to enter into or offer oneself for any service of one's own free will.

Heather Baltzer, who will soon graduate B.Sc. from the University of Guelph has become the friend of a young man with autism. She explains: *Community involvement has always been important for me, most likely because I grew up in a very community-centred town. My volunteer position with Guelph Services for the Autistic has allowed me to meet some really wonderful people and develop a friendship with XX. We spend one evening a week sharing dinner and building skills in areas ranging from music appreciation to yoga. Our hopes to learn cross-country skiing have been dashed by the mild weather! This volunteer opportunity has been both rewarding and a great learning experience and I would encourage anyone to become more involved in the Guelph community as a volunteer.*

Autism Awareness Boosted by The Times (UK)

The Times adopted autism as its Christmas charity for 2001. Each issue in December includes an autism-related story that is relevant to people anywhere who are concerned about autism. An idea we might use in Canada in 2002? Notes with links to individual stories are given below. For a summary link: http://www.thetimes.co.uk/section/0_421_00.html

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ASPIRE:

Autism Support Project: Information, Resources, Empowerment

Guelph Services for the Autistic, supported by Waterloo-Wellington Autism Services, proposes a project of interest to individuals with autism who live in Guelph-Wellington County or the Region of Waterloo. We expect to help two main groups: young people aged 18-20 who are leaving school-based services for adulthood; and older adults who still live with their parents and need to consider other options for the future.

ASPIRE offers hope of a good life in community by:

- Building knowledge of how adults experience autism spectrum disorders and the most effective strategies of supporting them to cope with their disabilities and achieve the best possible quality of life, and
- Modeling a facilitation service to inform and empower autistic individuals, with their families and friends, to plan and find resources for all the elements of a good life, including relationships with a personal support network, a home of one's own, ways to make choices and contribute to the community, and a safe and secure future.

In the first stage of ASPIRE, a survey is being taken of the status and needs of individuals with Autism who were 17 years or older by the end of 2001. A pilot version of the survey is posted on the OAARSN website at <http://www.ont-autism.uoguelph.ca/aans2001.shtml> and may be completed efficiently online. It takes about 30 minutes. If you would like to take part but lack computer access, leave a message at phone (519) 821-7424, requesting a paper copy.

See more at: <http://www.uoguelph.ca/oaar/aspire.shtml>

If you would like more information and/or to be involved in ASPIRE, leave a message at phone (519) 821-7424 or email a message to gbloomfi@uoguelph.ca

EATING WELL:

How can Diet Help with the Symptoms of Autism?

Most people on the autism spectrum may be intolerant of certain foods, and dietary intervention has resulted in some remarkable improvements. Family members and caregivers in the Guelph area are invited to a Focus Group in the home of one young man who successfully follows a special diet. Karen Hook, graduating student in the Applied Human Nutrition program at Guelph, has a field experience placement on dietary intervention in autism.

Discussion of questions and issues will form the basis for a cost-benefit analysis and for planning supports and resources to help families.

Date and Time: Tuesday, 5 March 2002, 7-9 pm

If you have experience with dietary intervention or are interested in the pros and cons of trying it, phone 823-9232 or email ebloomfi@uoguelph.ca for an invitation.

Reviews and notes about **Books on the Autism Spectrum** may be found on OAARSN's site:

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

Here we present three reviews by Amar Arneja of Guelph, who has recently joined the board of GSA as a director.

Other books recently reviewed on the OAARSN website:

-Cooperative Learning and Strategies for Inclusion:

Celebrating Diversity in the Classroom, by JoAnne W. Putnam (1998). Reviewed by Kirsty Forsyth.

-Developmental Disabilities in Ontario, edited by Ivan Brown and Maire Percy (2000).

We welcome suggestions of new books that should be noticed or reviewed on OAARSN and AAIWW. We appreciate the efforts of our volunteer reviewers—including in the past year: Lucie Milne, John Clifton, David DeVidi, Kirsty Forsyth and Amar Arneja. Various other reviews are now under way.

Irwin Publishing is Canadian agent for important titles in Autism and special needs and mental health generally—such as those published by Jessica Kingsley and Paul H. Brookes Publishing, several of which have been reviewed by OAARSN.

The Irwin Book Club offers 20 % off various professional titles.
www.irwinpublishing.com

Autism, Advocates, and Law Enforcement Professionals: Recognizing and Reducing Risk Situations for People with Autism Spectrum Disorders by Dennis Debbaudt (Jessica Kingsley, 2002), 142 pages.

All parents want to provide their kids with safety and security. Parents of kids with autism are no different. But the challenges we face are often very different from other families. These are the words of Dennis Debbaudt and he should know. Dennis is a licensed private investigator and is the owner of Debbaudt Detective Agency. He is also the father of 18 year old son who has autism.

The book not only advises parents about how to prepare their children for the outside world but also provides information for Law Enforcement Professionals about how to recognize potentially unfortunate situations when a person with autism could become a suspect just because he or she is not acting properly or not answering promptly. When asked by a policeman "where do you live?" the answer after a delay may be "in my home." The proper question should be, "what is your home address?" But how does the policeman deal with the person who has autism? Dennis Debbaudt has written articles for the FBI Law Enforcement Bulletin and given information to law enforcement professionals and advocacy organizations in the U.S., Canada and United Kingdom.

Reading this book reminded me the fact that how important it is to ask questions properly. I am the father of a 25 year old. This recent incident is an example of how difficult it is sometimes to get proper information. We went to a nearby grocery store where the shopping carts are chained and you need a

quarter to free the cart. After we finished shopping I asked my son to return the cart and get the quarter back. When he returned I asked him if he got his quarter back. Following is the sequence of conversation. My son's answers are in italics.

Did you get the quarter back?

No.

Why not?

A man took it.

A man took the quarter?

No the man took the cart.

And he did not give you the quarter?

No, the man said he did not have a quarter.

Well that is strange.

Yeah.

You did not complain?

Well he gave me money.

I thought you said he did not give you a quarter?

No, he gave me two dimes and a nickel.

As you can see, it can be quite difficult to get proper information from persons with autism. Recognition and response are key elements for the law enforcement professionals to understand the needs of the rising autistic population. Law enforcers need to recognize the signs of autism in order to provide for the welfare and safety of all citizens.

Individuals with developmental disorders are seven times more likely than other people to come into contact with police and their responses to encounters with the law may not be appropriate. How can the needs and responses of people with autism be reconciled with the duties of the police to serve and protect the community? In this book Dennis Debbaudt provides essential information for both groups. I highly recommend this book specially for the police and mall security people although it is quite useful for the caregivers too.

Hitchhiking through Asperger Syndrome by Lise Pyles (Jessica Kingsley, 2002). 286 pages.

This book is by a mother about her teenage son who has been identified as having Asperger Syndrome. Any parent who has a child with a similar condition can identify themselves with this book. As the father of a 25-year-old autistic child, reading this book was, for me, like looking in the mirror. As I was reading of Lise Pyles' experience with John, I was saying to myself, "This is exactly how it was with us."

Although your child is late in walking and talking, don't worry too much, especially if one of the parents was also late during their development in childhood. It is usually the staff at the day care centre who sound the first alarm that something is seriously wrong. After trying some other day care centres, you come to the conclusion that your child needs a special environment where one-to-one instruction is given. It is either home schooling or having a teacher's aid assigned to your child all the time. Home schooling is explained in detail in this book.

The first few years are quite hard as you are fighting the school system to get special provision for your child while also trying to get a proper medical diagnosis. As there is no sure way to diagnose from blood or urine samples, it is up to the neurologist to guess. Attention Deficit Disorder is what the first neurologist said about John, and he prescribed Ritalin. Side effects outweighed the good effects of Ritalin. Once John started home schooling, he was taken off the prescribed drug.

During home schooling, food was carefully monitored. Food items that had negative effects on John's mood were eliminated or reduced. After one year of home schooling, the family moved to England, where John managed to go to school because of the small classes at the military base. The biggest problem at school was bullying by other kids. This was causing depression. Instead of trying anti-depressant drugs, Lise ordered mega-vitamins that are specially formulated for the autistic population. For John, taking these vitamins made all the difference between a depressed unhappy young boy and a happy and confident young man. Information about the vitamins and side effects is given in the book.

Asperger Syndrome Employment Workbook: An Employment Workbook for Adults with Asperger Syndrome by Roger N Meyer (Jessica Kingsley, 2001), 319 pp.

Written to help adults with Asperger Syndrome understand their own abilities and limitations by looking into their experiences with employment histories, this is also an excellent guide for human resource personnel who can tap into pool of dedicated workers. Personnel Officers are usually reluctant to offer employment to persons who are classified as Autistic or having Asperger Syndrome because of the unknown. Once the employer knows that these people are extremely honest, meticulous and are happy to perform routine jobs day after day, they might find them valuable employees. However these employees have certain limitations that should be made known to the prospective employer beforehand. These limitations could be as simple as being bothered by the flickering fluorescent light, certain noise that may be associated with danger such as fire alarm or not having a fixed time for lunch break. If the employer is sympathetic, he will come to some arrangements by making minor changes to the work environment and modifying the job description.

You cannot go and tell the employer that you have been diagnosed as having AS and you have the right to the job, as this attitude will not work. This is where this book comes in very handy. The book helps people diagnosed with Asperger Syndrome and high functioning autism to list their skills, experiences, style of learning and coping with unexpected changes in their routine. Even successful adults with AS face certain conditions that they try to hide but it causes them great stress. By following step by step your three job histories you can list your capabilities, your limitations and your concerns about the work place. Then there are rules to telling i.e. who you tell, when you tell, how you tell, what to tell and why to tell. Your point in disclosing your AS is to provide just enough information for people to understand your particular job challenges.

By analyzing the three jobs that you have held in different life periods and knowing your interest and talents you can seek employment in a relevant field. For example if you have a keen interest in maps and directions may be you should seek to become a cartographer. Find out what qualifications you need and see if you can get training for it.

Overall this is a good book for persons diagnosed with Asperger Syndrome and high functioning autism to better understand themselves. It is also an educational guide for vocational counselors and human resource personnel as it provides in-depth guidance about these potential dedicated employees.

Time for Change:

Allocation of MCSS Funding for 2002 for People with Developmental Disabilities

The Mastermind Strategy Group for Individualized Funding in Ontario calls on those who live and work with or who care about people with developmental disabilities to speak up for allocation processes that will expand individualized support and funding and provide choices and a better future for all.

Concerned organizations, individuals and families are urged to write to the MCSS Minister, John Baird, with copies to the Deputy Minister and your local MPP supporting the *Funding Individuals Directly - A Statement from Ten Ontario Disability Organizations*. This statement asks that:

-25% of all new moneys be allocated for individualized funding.

-Local planning groups be reformed to create a mechanism for funding individualized support, by including at least 50% representation of individuals with disabilities and their families.

Why? Families need to be a major part of policy development and planning of supports that really help vulnerable people. MCSS should to promote and fund investments that enhance natural family homes and individualized support arrangements in community, thereby increasing the potential for inclusion and reducing the need and demand for costly institutional care or support through service programs. Individualized funding leads to better quality of life through individually directed solutions and has been proven to give more value for the dollar.

OAARSN has posted more information from the Mastermind Group of the Individualized Funding Coalition, with a sample letter that you may adapt to describe your circumstances and viewpoint at: <http://www.ont-autism.uoguelph.ca/if.html>

Write to: Mr. John Baird, Minister
John Fleming, Deputy Minister
Ministry of Community and Social Services,
80 Grosvenor Street,
6th Floor Hepburn Block,
Toronto, ON M7A 1E9
Fax: to (416) 244-6543
Email the minister directly at minmcss@gov.on.ca

Read a good account of IF by OACL's Keith Powell, interviewed by Linda Viscardis at: http://www.acl.on.ca/Daily_News/2002/Jan_02/jan14.htm

AAIWW BULLETIN BOARD

ADULT AUTISM NEEDS SURVEY

OAARSN is co-operating with an important new initiative by GSA and WWAS. See more about ASPIRE on the front page and at <http://www.uoguelph.ca/oaar/aspire.shtml>

By completing the AANS, you will get a clearer picture of the needs and abilities of the person you care about. You will also provide a general information base for the ASPIRE project. Details about individuals will remain confidential. To view the survey and, if you wish, complete and submit it, look up: <http://www.ont-autism.uoguelph.ca/aans2001.shtml>
Completing the survey takes about 30 minutes, but you may wish to look at it first, then return later to complete it.

GUELPH SERVICES FOR THE AUTISTIC functions as a housing trust, to help adults with autism to live happier and more fulfilling lives in homes of their own. GSA also encourages individuals, with their families and friends, to plan for good lives as adults in their home communities. See GSA pages at: http://www.ont-autism.uoguelph.ca/gsa/info_new.shtml
http://www.ont-autism.uoguelph.ca/gsa/faq_new.shtml

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.

ONTARIO ADULT AUTISM RESEARCH AND SUPPORT NETWORK <http://www.ont-autism.uoguelph.ca>

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 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. We welcome news items, new information, discussion questions and comments, and accounts of experience.

Check out the News Scroller and What's New on the opening page for new additions to the site. You may request to be on the OAARSN List to receive regular e-mail bulletins of autism news and announcements of events.

WATERLOO-WELLINGTON AUTISM SERVICES

Information about WWAS may be found at <http://www.ont-autism.uoguelph.ca/wwasinfo.shtml>

Become a member with a donation of \$25 or more. Or 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 request.

