

# **ADULT AUTISM ISSUES IN WATERLOO-WELLINGTON**

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

*AAIWW Newsletter No. 32, August 2005*

"It is better to light a candle than to curse the darkness" – Chinese proverb.

## **TWO GSA WORKSHOPS IN GUELPH**

### **1. Wednesday, August 17, 2005, from 7pm Graeme Treeby of the "Special Needs" Planning Group**

"The SNPG made up of parents of people with disabilities. Our focus is to assist families in preparing financial and estate plans that will ensure that their sons or daughters with a disability will enjoy a decent quality of life now and in the future. Our plans make use of Henson Trusts, Wills, Funding Mechanisms like family estates and life insurance programs and Life Plans which are designed to provide for our children after we are gone without affecting entitlement to ODSP benefits.

"We do not charge any fees for our services, which means that everyone can take advantage of our knowledge and expertise no matter what their financial situation. For further information, please visit our web based resource materials at [www.specialneedsplanning.ca](http://www.specialneedsplanning.ca) "

### **2. Wednesday, September 14, from 7pm John Lord on Making Citizenship a Reality: The Role of Person-Directed Planning and Individualized Funding**

**A WORKSHOP FOR PEOPLE WHO WANT TO MAKE IT HAPPEN**

In recent years, citizenship has become a goal for people with disabilities. To be a citizen means to experience self-determination and community.

This workshop is designed for people who want to build a good life and community connections with a vulnerable person. With individualized funding growing in importance, the role of facilitation and the importance of building a support plan will also be explored.

John Lord was the keynote speaker at the recent Guelph Conference on Creative Supports. This workshop will build on his speech at that event and give people ample opportunity to ask questions, and work with others on issues of common concern.

John Lord is a researcher, consultant, and parent from Kitchener-Waterloo. Some of John's recent publications on individualized funding can be viewed at [www.individualizedfunding.ca](http://www.individualizedfunding.ca)

Workshops are free, but space is limited. If you are interested, please request an invitation from Nancy <[nancy.cherry@sympatico.ca](mailto:nancy.cherry@sympatico.ca)> or (519) 884-3309.

## **Adult Autism Matters**

*AAIWW has been produced and distributed for WWAS and GSA since winter 1998, following 7 years of **wwasnews** before that. There have been 60 newsletters in 14 years. Both newsletters have been sent to members and friends of the organizations, to families who have sons, daughters or siblings with autism, and to agencies and other organizations concerned with ASD, both in our region and beyond.*

*Both organizations collaborate in other initiatives such as ACES which is taking steps towards an intentional community in our region, perhaps farm-based, and to a centre of autism resources and expertise.*

*We think the time has come to end the print newsletter distribution in its present form, so we can use our resources where they are most needed. Neither WWAS nor GSA at present receives or seeks Government funding as an agency. That gives us freedom to speak up and to try various initiatives, but we have to use our limited funds with care.*

*We welcome the ideas and contributions of all people of goodwill who want to help adults with autism to enjoy good lives in our communities. Please note the details of our projects on the back page, with address of both organizations.*

*In March 2000, GSA launched the Ontario Adult Autism Research & Support Network (OAARSN) at <http://www.ont-autism.uoguelph.ca> The OAARSN Autism News Bulletin is put at least twice a month. If you are not already on that List, but want to keep up with adult autism issues and news, please send a request to [gbloomfi@uoguelph.ca](mailto:gbloomfi@uoguelph.ca).*

## ONTARIO AND CANADIAN NEWS

### ***Ontario Government Boosts Support for Adults with Developmental Disabilities***

"We are taking action to make sure individuals who need our help the most get the supports and services they require," MCSS Minister Papatello said. "This investment will really help families to support their loved ones with daily living activities and help our community agencies to provide even better care for their clients." An additional \$59 million is being provided annually to support:

- Families who are caring for family members with a developmental disability at home
- Young adults with a developmental disability who are moving from school to a wide range of community participation activities or work
- People who are in a situation that requires immediate care, many of whom previously received services from the child welfare system or have aging parents
- Community agencies so they can strengthen staffing and make their residences even safer for their clients.

### **Development and Testing of a Resource Kit for Parents of Young Adults Who Receive Individualized Funding for Support, 2004-2007**

*The goal is to develop a Resource Kit that can be broadly circulated to families who receive individualized funding. It is expected to enhance the quality of life and community participation of young adults with disabilities. This five-year project will assist them in the management of the funding and their work as parents to find supports for their children and family. The Resource Kit will be developed with the 10 families who are involved in the Opening Doors project. Researchers will seek input from all families as to the content and format of such a kit. Another goal is to evaluate the Resource Kit as to its use, utility and impact. A prototype of the Research Kit will be given to all families to use during the Opening Doors project in years two to five. This study is funded by the Ministry of Community, Family and Children's Services*

### **Oaklands Regional Centre**

is about to undergo a transformation that will give it a new mandate and focus in providing community-based care for people with a developmental disability and other complex medical, psychiatric or behavioural challenges. There is no word in the Ministry of Community and Social Services' news release about what will happen to the present 70 residents, a significant number of whom may have autism.

### ***"Over to you. Have we done enough?"***

"We won't always be here to care for Heather. We have to trust in others." Florence McKie of Alberta writes of the plans for her daughter Heather (46) when her parents are no longer here. "It is easy to put physical and financial matters in place -- but it takes a lifetime to build the trust that will help Heather cope with whatever the future holds. We can only hope that what we have done will be enough. And that those in her life will care enough to protect and respect her." In *Macleans Magazine*, 15 July 2005.

**Human Rights Commission Takes On Safe Schools Act**  
*The Ontario Human Rights Commission has filed a complaint against the Ministry of Education, reiterating its position the Safe Schools Act is having a "disproportional" impact on students with disabilities and those of visible minorities... Students with emotional/behavioural disorders, intellectual and learning disabilities, autism, and Tourette Syndrome and associate disorders such as attention deficit disorder, obsessive-compulsive disorder and difficulties with impulse control were particularly affected. The information in the report was collected based on interviews with a variety of sources including a social worker, a community worker, lawyers, mental health experts and advocates for people with disabilities.*

### ***Canadians invited to provide views on policies and programs for persons with disabilities***

Minister of Social Development, Ken Dryden, today launched online consultations on the topic of persons with disabilities. The consultations, which are on the department's website, will give Canadians an opportunity to share their stories and provide feedback into Social Development Canada's effort to advance the full social participation and well-being of persons with disabilities. "We want to hear from as many people as possible about disability issues that are important to them," said Minister Dryden. "These consultations are designed to get the input of all Canadians and will add to our ongoing dialogues with stakeholders and others from the disability community." The Government of Canada recognizes that Canadians with disabilities continue to face barriers and experience exclusion in learning, work and community life. The Government is committed to strengthening the country's social foundations and ensuring the full social inclusion of all Canadians — including the 3.6 million Canadians with disabilities.

SDC launched its first online consultations in May inviting Canadians to share their stories and work through questions on "family/unpaid caregiving." Using a similar format, this new site now seeks input into future policy and program work related to persons with disabilities. Consultations on the social well-being of seniors, children, families and communities are expected to be added to the site between now and the fall.

***Autism and the Myth of the Person Alone*** edited by Douglas Biklen, presents case studies of successful communicators using FC. Now listed at hardcover \$65 US; will be \$21 in paperback.

### ***Philia Dialogue on Caring Citizenship***

*The Philia Dialogue is an initiative of PLAN Institute that brings the wisdom of the disability community to our quest for a more inclusive society. Caring citizenship (or what some simply call neighbourliness) lies at the heart of this quest for a society in which the participation and contributions of all citizens are welcomed and valued. Rooted in the work of PLAN, Philia believes that everyone has a contribution to make, and that those contributions benefit all of us. We want to change how our society thinks about disability and citizenship, so that belonging becomes "part of the air we breathe and the water we drink." The new website is a place to share ideas, information and links relating to caring citizenship. You may ask to receive the Philia e-zine. Visit <http://www.philia.ca/>*

### ***Contact Point***

Contact Point, supported by The Counselling Foundation of Canada, produces the quarterly Contact Point Bulletin. The spring 2005 edition focuses on people with disabilities...

### ***Global Experts Set For Autism Summit***

People with autism, their parents and carers and a host of experts in the field will attend the National Autistic Society's (NAS) annual conference in London on September 23-24. Conference speakers include Dr Temple Grandin, Dr Lorna Wing who will open the conference and give an overview of the current situation facing people with autism around the world. David Ameral of the University of California, will speak in more depth about the nature of autism and how it affects people in many different ways. Dr Ami Klin will talk about his latest research findings about psychological and biological mechanisms that affect socialization in people with autism. For more information, visit [www.nas2005.org.uk](http://www.nas2005.org.uk) or call +44 (0)20 8334 6517.

### ***Autism advice centre declared a 'tremendous achievement'***

*A one-stop advice centre for adults with autism has formally opened in Edinburgh. The service is managed by Autism Initiatives UK and has more than 70 regular users. The centre - the first of its kind in the Lothian region and one of just two in the country - includes a resource library to provide information and advice, internet access and meeting rooms.*

Featuring **Running Boy** (also known as "Marathon") the best-selling film in South Korea in 2005. It is well worth seeing anywhere in the world!

It is a movie about disability, and about the lack of tolerance society has for people who are different. Based on the true story of an autistic boy who completed the Chuncheon Marathon four years ago, the film's protagonist is 20-year old Cho-won (played by Jo Seung-woo), who was diagnosed with autism at the age of five. His mother, played by Kim Mi-Sook, is a major character in the film, vividly illustrating the hardships experienced by families living with autistic people.

"Running Boy" is probably one of the first Korean films backed with solid acting to treat the subject of mental disability without falling into the trap of romanticizing it, or resorting to a "victim" mentality. Perhaps its success is owed in part to the witty dialogue, a pleasurable surprise for audiences who are not used to that kind of humor in Korean films dealing with disability. Throughout the film, the boy's unusual verbal expressions become cheerful ways of interacting with others.

The film also honestly depicts what the disability does to Cho-won's family. His mother is determined to make him finish a Marathon in less than three hours; while this is for her son's good, the film is also frank about how her own personal ambitions are motivating her as well. Cho-won's exhausted father, who is often intolerant toward his son, is depicted as neither evil nor a saint; the focus is mostly on his dilemmas. Overall, the film refrains from judging any of its characters; the audience will likely suspend judgment, too. They'll also feel a sense of hope, and perhaps some guilt. But the film's greatest success may be in what it's done for people in Korea who are living with mental disabilities, who finally have a film that's broken the silence about the subject.

"Running Boy" has become the most popular movie in the country (according to the Daum Internet portal), and has already had the positive effect of spreading awareness about the issue through media coverage. That in itself is a credit to the people who made the movie. We have viewed the original movie, but look forward to the version with English subtitles.

## Announcing... CREATIVE SUPPORTS FOR VULNERABLE CITIZENS

An electronic bulletin for adults who are vulnerable because of disability, and for their families, friends and supporters who care about them

This new bulletin is one outcome of the Guelph Spring Conference on Creative Supports held 29 April 2005, in Guelph, Ontario, Canada. It is for everyone who is vulnerable because of any kind of disability, and for their families, friends and supporters. We can share dilemmas and difficulties as well as bright ideas and successes. There are announcements of events and special projects, discussions of issues and concerns, and links to useful books, websites and other resources. Our focus is mainly on Ontario, but we have wider contacts as well.

In organizing the Guelph conference, we were moved by a desire to be positive and resourceful amid challenges--by the idea expressed in the Chinese proverb: *It is better to light a candle than to curse the darkness.*

The bulletin is being sent first to email addresses on our Aroha Listserv. Why Aroha? Practically, it's good for a Listserv or website to have a short, distinctive codeword unlikely to be confused with any other purpose. More importantly, Aroha, a Polynesian Maori word from Aotearoa/New Zealand, means the various qualities and values that are needed in a caring circle of friends. It can mean affection, respect, love, charity, compassion, empathy, concern, trust, pity, understanding and true friendship—all in active ways, not just ideas or feelings.

If you wish to be on this Listserv, please send an email request to [gbloomfi@uoguelph.ca](mailto:gbloomfi@uoguelph.ca) We welcome news items, announcements of events, new information, discussion questions and comments, and accounts of experience.

The Creative Supports bulletin will shortly present details of the resources coming out of the Guelph Spring conference on April 29. We believe it is vital to build on what was learned then. Many people, registering for the conference and thanking us afterwards, noted that the scope of the conference was exactly what they needed. There was a heavy demand for places at the conference: if there had been space, we could have registered twice as many participants. Many were interested in more

than one workshop topic, and wished there could have been time to take part in two or more instead of just one. We've heard from people all over Ontario who were unable to attend on April 29, but want to be kept informed. So these are some plans to share the conference ideas and keep the discussion going. We are producing a videotape of the conference highlights (probably at least 60 minutes). We have also edited the keynote and workshop presentations, illustrated with diagrams and pictures, into a book of conference proceedings. There are chapters by John Lord on "Creative Supports that Work: Values, Principles and Processes;" Judith Snow on citizenship and the value of support circles; Barbara Leavitt on how to create real homes not just housing; Peggy Hutchison on creative approaches to work and recreation; and Marlyn Shervill, Michelle Friesen and Alice Quinlan of Windsor-Essex on how to realize and sustain good lives.

There are also notes on the various many organizations that set up displays and the creative strategies that were illustrated in the early afternoon. Peter Dill introduced an advance viewing of the film *Revel in the Light* by and about Rebecca Beayni of Scarborough. Thelma Wheatley described how Mississauga parents organized the Options project of work and recreation from 1991. Judith Rosenberg explained the Spark of Brilliance initiative promoting healing through the arts, that she founded in Guelph in 1999, and showed its video. Shirley Edwards spoke of her unique service, Balancing Act, which is devoted to caring for the caregivers. Michelle Friesen shared some of the experience of the Windsor-Essex Family Network.

Thanks to Kerry's Place Autism Services and the Community Mental Health Clinic in Guelph for grants that help us make these resources available at modest cost.

We hope you are interested in obtaining the video and book. For more information, please send an email message to [gbloomfi@uoguelph.ca](mailto:gbloomfi@uoguelph.ca) or leave a phone message at 519-821-7424

## **POINT OF VIEW FROM THE FRONTLINES: "Better Than Thou..."**

*A man with Asperger Syndrome describes how professional people often show a lack of empathy*

It seems as though many professionals and administrative personnel that I have come in contact with, were fully determined to practice their own form of hierarchy at any cost--to prove that their way of seeing things is always a "better", "more efficient", "happier", ...way of looking at any situation than anyone else's.

Many times, when I try to tell a hurtful situation to someone in the medical or social services, I get the remark: "Why do you let something like that bother you?" I cannot get through to these "pros" that it is not a matter of "letting it" bother me; it is a very painful area of life, just like someone with rheumatoid arthritis (to someone who has never experienced it). They agree that rheumatoid arthritis is painful--anything "physical" like that can, according to them, be painful, but anything outside of the physical realm, ...well, as they see it, it's just a matter of not "letting it" cause one any problems. Even if I give the example of the pain of loss in a family where a member has been killed by a hit-and-run driver, they are willing to accept such pain, but say that it (the pain) is "real", as the family did, indeed suffer a "real" loss, but what I am going through in the painful situation that I described to them is "just in your head", and that I should "snap out of it, and get on with your life!"....

To me, that points to a complete lack of empathy on the part of those who feel this sense of "moral superiority". We autistics and aspies are always accused of lacking empathy towards others, when we are only searching for empathy from others, and, not being able to find it (or very rarely finding it), we are driven to withdraw from many contacts in life, as all we get is tons of advice on how to "spruce up" our act, and "think positive", when we are not looking for such advice whatsoever, but for an empathetic ear from someone who will share our feelings about life, even for the moment.

This is not to say that all aspies are in a "sad state" of affairs; far from it. Often, for example, when I want to explain that I have been able to experience sheer joy at just following the outline of a tree against the sky (while others around me are, for example, playing golf, swimming, or enjoying a carnival atmosphere at some park), I am told that it is "very inappropriate" to ignore what others around me are doing, and that it is incumbent on me to get rid of my "silly obsession" with trees, and start to engage in what others are doing. This only adds more woes to my life, as the sheer joy of following the silhouette of the tree against the sky is seen as a "disability" by these folks, when I am trying to find others who are willing to share in this joy.

These pros are very quick at using the attitude of "yes, ...but" in their conversations, such as: "Yes, you do find beauty in that image, but you are depriving yourself of contact with others by perpetuating such ideas as though the

world should stop what it is doing, and come over to you, just so that you do not feel isolated!"

I tell them that I was not expecting "the world" to come over to me, at all, but just to find one other person in the crowd who also could find affirmation in that image that the rest of the crowd seem to be totally oblivious to, or just plain ignoring. Again these pros say that I am expecting too much in others as they are going to do what they are used to doing, and no one could be expected to change his or her life, even for the moment, just to "serve" me and my obsession with this "thing" that is nothing but a diversion away from others, an "escape" from the "reality" of personal contact with others.

When I ask why others cannot make personal contact with me, again they say that the onus is on "me" to change my ways, and that it is just "foolhardy" to expect others to change their ways just to "accommodate you and your clever ways at avoiding full integration in the social scenes around you!"

This seems to go on, and on, until I can no longer get the "guts" in me to remain in contact with that medical doctor, social worker, psychologist, counsellor, or associate or even a "friend". The bridge that I thought would bring a way of bonding to others is abandoned, as I cannot take the "heat" of being reminded constantly that it is I who must change, and that the other person has no "need" to change, at all, even if the other person has severe problems in other areas of life. For example, one lost friend who was told all about AS, and outlined that friend's problem with panic attacks, said, one day, that there had to be a way of finding a "cure" for AS, when that same person had no interest, at all, in finding a way of getting help for their panic attacks.....

No wonder others have problems in understanding why persons on the autistic spectrum have difficulty in making or keeping "friends"--many (but not all) of these contacts are far, far too conditional in their approach, even if they claim to offer "unconditional love". They sure do not know how to practice what they preach!

### **Autistic Success**

Brief to The Senate Standing Committee on Social Affairs, Science, and Technology, by Janet Norman-Bain of PEI.

Excerpt: ***"In our world, autism makes us different. Not defective, not in need of 'medically necessary treatment', not in need of being made 'indistinguishable from our peers'. Not mentally ill. Yes, autistics and parents/caregivers need appropriate services, support and help, but those services must be as unique as each of us. We need choices."***

## AAIWW BULLETIN BOARD

### WATERLOO WELLINGTON AUTISM SERVICES,

incorporated in 1991, is dedicated to supporting adults with autism to have good lives in their communities.

WWAS funds the ACES Youth Day Program, the Autism Collection at the Kitchener Public Library, and continues the bursary program, <http://www.ont-autism.uoguelph.ca/wwasbursary.shtml>

Please support these worthwhile projects. Cheques of \$25 or more qualify for tax-creditable receipts. Please make cheque payable to WWAS and send with your name, full address and phone number, to WWAS, C/o Dr Hollingsworth, 125 Union St E, Waterloo, N2J 4E5

### GUELPH SERVICES FOR THE AUTISTIC,

incorporated in 1980, is run by volunteers, and dedicated to adults with autism and their families. What does GSA do?

-Acts as a housing trust to enable adults to live with dignity in their own homes with companions they choose

-Supports person-centred planning, self-determination and individualized funding

-Offers ASPIRE and adult needs surveys

-Recruits volunteers as friends for adults with autism

-Provides advice and support to families and friends

[http://www.ont-autism.uoguelph.ca/gsaainfo\\_new.shtml](http://www.ont-autism.uoguelph.ca/gsaainfo_new.shtml)

[http://www.ont-autism.uoguelph.ca/gsafaq\\_new.shtml](http://www.ont-autism.uoguelph.ca/gsafaq_new.shtml)

Contact GSA about any of the following, to donate to our ASPIRE or ACES efforts or the Creative Supports workshops, or to send news and queries to AAIWW: Mail: Dr Bloomfield, 16 Caribou Crescent, GUELPH, Ontario, N1E 1C9. Phone (519) 823-9232. E-mail [gbloomfi@uoguelph.ca](mailto:gbloomfi@uoguelph.ca)

### ASPIRE: AUTISM SUPPORT PROJECT: INFORMATION, RESOURCES, EMPOWERMENT

An initiative to help persons and families and persons plan for and realize good lives and secure futures. Organized by GSA; supported by funds from WWAS.

**ADULT AUTISM NEEDS SURVEY** is associated with ASPIRE, but also offered more generally to help adults and families measure quality of life. GSA and OAARSN treat data confidentially to generalize current situations and needs of adults with ASD. Long-form and short-form surveys may be completed on paper or online.

**ONTARIO ADULT AUTISM RESEARCH AND SUPPORT NETWORK** (OAARSN) offers up-to-date information and communication tools, with opportunities for mutual support, encouragement and information sharing.

Click on <http://www.ont-autism.uoguelph.ca> to reach OAARSN's main page, then use the buttons to reach the site's features.

You may ask to be on the OAARSN List to receive weekly bulletins of autism news and announcements of events.

## EVENTS OF INTEREST

Sunday, August 28, from 7am  
Cambridge Chapter of Autism Society Ontario announces its Second annual golf tournament in support of individuals with autism and their families at Grand Valley Golf & Country Club, 1910 Roseville Rd, RR#2, Cambridge ON N1R 5S3, (519) 623-8811. For more information: Stacey at (519) 653-8056 [thezoo@rogers.com](mailto:thezoo@rogers.com)

September 17, 2005, morning:  
Presentation: *Personal Victories - Conceive, Believe and Achieve*, before the afternoon AGM of Kerry's Place Autism Services and Kerry's Place Residential Services at The Columbus Centre, 901 Lawrence Avenue West, Toronto (Lawrence and Dufferin). The morning event will be facilitated by Judith Snow, who left an indelible impression on all who attended last year's AGM. For more information about Judith and this presentation, call 905-841-6611, ext. 314.

October 16, in Hillsburgh  
Families for a Secure Future offers *Creating a Home of One's Own*: Morning of story telling, afternoon of small group discussions. Register ahead by phoning Judith McGill 10 (905) 770-2819 or email [JLMCGILL@rogers.com](mailto:JLMCGILL@rogers.com)

October 20-23, 2005, in Toronto  
Come to Your Senses...From Theory & Research To Practice: Sensory Therapy & Disabilities *An International Conference for professionals, parents, caregivers & consumers*. Presented by Muki Baum Assn. Program includes 37 presenters from 8 countries and a special presentation by Dr Oliver Sacks.