

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

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

AAIWW Newsletter No. 25, May 2004

*We bring you this extra bulletin with special news about adult issues, and in time to remind you of the WWAS Annual General Meeting.*

*We congratulate Autism Society Ontario for sponsoring the special workshop in Guelph on May 5. A steering group is following up the suggestions made then, to advise ASO on effective ways it may advocate for adults with ASD. ASO announces its annual meeting in mid-June in Windsor and the publication, In Our Own Words. An older man with ASD shares his thoughts on approaching retirement age and difficulties in getting mortgages and improvement loans for housing.*

*The idea of a farm community centre to support families and persons with ASD in Waterloo-Wellington region is in the air. We bring you a preliminary statement of the vision.*

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For more frequent bulletins of news, events, projects, issues and stories from the front lines, visit the OAARSN site at <http://www.ont-autism.uoguelph.ca/>

## **Waterloo Wellington Autism Services 12<sup>th</sup> Annual General Meeting**

**Monday, May 31, 2004**

**Stanley Park Baptist Church,  
31 Lorraine Avenue, Kitchener  
(SE corner at intersection with River Road)**

**AGM business meeting: 7:00 to 7:40 pm**

**Only members may vote.**

**Followed at 7:45 pm by  
special presentation and discussion of  
FARM COMMUNITY AS FOCUS FOR  
PERSONS AND FAMILIES WITH AUTISM  
SPECTRUM DISORDERS?**

**Video "Breaking New Ground"  
about Bittersweet Farms,  
model farm community for  
autistic adults in Ohio,  
will be shown.**

**Discussion of the potential  
for a farm community  
in our Waterloo-Wellington region.  
See more on pages 4 and 5**

Kerry's Place Autism Services is pleased to announce that the Wellington Resource Centre is now open. Books and resources relating to Autism Spectrum Disorder available for Use of Families, Individuals, and Community Members. Computers, printers and a laminator are available to develop additional resources, such as visual aids. Access to Boardmaker Picture Communication Symbol Program is available. Family resource days will be available one day each week.

Please call to book an appointment.  
Kerry's Place Autism Services, 5420 Hwy 6  
North, Suite 124, RR#5, Guelph, ON, N1H 6J2  
Phone/Fax (519) 763-5812  
[jtimmins@kerrysplace.org](mailto:jtimmins@kerrysplace.org)

## Supporting Adults with Autism Spectrum Disorder

About 70 people gathered on May 5<sup>th</sup>, 2004 at the Italian Canadian Club in Guelph, in a meeting sponsored by Autism Society Ontario.

Discussions were led and facilitated by Dr John Lord, who began by discussing some of the good and innovative things that have been happening in Ontario that could support adults with ASD. However, adults with ASD have been neglected in recent years, as most funding, resources, and attention currently go to children. He noted that the last time the Autism Society of Ontario had a focus on adults was in 1991, and that none of the recommendations that were made then have been implemented by the provincial government.

Participants, seated at ten round tables, were invited to consider four assumptions regarding ASD and how to support adults with ASD:

- Autism is a wide spectrum disorder. This requires individualization of supports.
- Services are only one way to address needs. This requires an understanding of community
- Deficits, problems, and needs alone cannot frame what we require. This requires also a focus on strengths and capacities.
- Professionals alone should not make all decisions about supports. This requires participation of individuals and families.

John then listed the things that adults with ASD are in need of, based on the 1991 report, and the addition of three other needs identified since then:

1. Need to **communicate**
2. Need for **structure**
3. Need to **have a safe and caring place to live**
4. Need to **work (paid/volunteer)**
5. Need for **recreation / leisure activities**
6. Need for **advocates to ensure rights are not violated**
7. Need for **relationships with people who care**
8. Need for **citizenship opportunities**
9. Need for **supports to be adequate and appropriate for each person**
10. Need for **adequate and sensitive medical services.**

Each table group was set to discuss one of these needs. If they were still needed, we were to try to rephrase the needs in terms of the four assumptions stated above. John referred to this as “new paradigm” thinking. It was agreed that all of the needs established in 1991 are still needs, and that the new needs make sense as well. The following are the new rephrased needs:

1. The need to **communicate** was rephrased with: “People with autism need the opportunity to be listened to deeply so that their individuality, strengths and needs are recognized and respected.”
2. The need for **structure** was rephrased with, “An adult with autism needs respectful structure that gives choice, alternatives, responsibility, and is flexible over time as people’s needs change.”
3. The need to **have a safe place to live** was rephrased with, “The need for safe, caring, and affordable places to live, based on individual strengths and needs, where persons are welcome and involved in their communities.”
4. The need to **work (paid/volunteer)** was rephrased with, “Supports and funding should be available to assist the individuals in exploring their interests and strengths. Employment opportunities can provide positive structure, self-esteem, and involvement in their community.”
5. The need for **recreation / leisure activities** was rephrased with, “Leisure activities need to include the following aspects:
  - a) individualization and choice
  - b) body, mind & spirit
  - c) personal relationships with people who care
  - d) accessibility (e.g. transportation costs, etc.)”
6. The need for **advocates to ensure rights are not violated** was rephrased with, “The need for advocates to ensure rights and needs are respected, and not violated, by removing barriers, and by facilitating the advocacy of those who may not have a voice in a way that each person’s uniqueness is addressed. This is done by promoting advocacy as champions and as a result is less confrontational.”
7. The need to have **relationships with people who care** was rephrased with, “The need to change community expectations so that the individual and their

families can grow relationships with people who know them. This must be in a secure and respectful environment.”

8. The need for **citizenship opportunities** was rephrased with, “People with all abilities should have the rights and responsibilities and inherent full citizenship. This includes housing, meaningful work, recreation relationships, financial well-being and security, advocacy support in times of needs, education opportunities, timely access to appropriate medical care, and transportation.”

9. The need for **supports to be adequate and appropriate for each person** is still a need, as there is still not adequate support for each person.

10. The need for **adequate and sensitive medical services** is still a need, but it is a need for all individuals in society, not just adults with ASD. After lunch, John stated that in order to provide ample services for adults with ASD, we need to call on best practices. John said that a best practice can be defined as “what is working well in Ontario right now”. An excellent example he noted of a best practice is individualized funding, which should be available for more families. Other examples of best practices include school-age funding (as it helps awareness), clustering of services, crisis funding, and the OAARSN Website at <http://www.ont-autism.uoguelph.ca>

Our next task was to meet in groups again at our tables and discuss what we should do to expand best practices. This is a list of what were suggested:

- Specialized supports for adults
- Determine number of people who have ASD
- Raising awareness of ASD/PDD
- Assistance for transition services by families and parents (who should start this when person is age 13)
- Develop mechanisms for assessing Best Practices and advertising them.
- Funding needed across spectrum & know needs clearly.
- Need clear forceful advocacy collection.
- More interagency co-operation-training
- More opportunities for networking
- Support groups for adults in all communities and for various age-groups

Read the text of ***Our Most Vulnerable Citizens: Report of the Adult Task Force of Autism Society Ontario*** (1991) on the OAARSN website at: <http://www.ont-autism.uoguelph.ca/pdf/vulnerable.pdf>

- Need better communication at all levels and among all concerned, including chat rooms and political advocacy
- Inter-ministry collaboration
- Individualized funding (note website at [www.individualizedfunding.ca](http://www.individualizedfunding.ca))
- Justice system & autism
- More funds for community parent groups
- Consistency of services across the province
- Employer funding (so they can hire people with ASD)
- Equitable funding-portability
- Communication from government

John summed up the meeting’s lessons in a conceptual diagram to show what is needed as we move toward supports that are individualized, connected with community and based on the values of self-determination and community. It showed that:

***Transformation of systems that may block best practices for adults with autism could be achieved by interaction of four processes:***

- ***continuing the dialogue;***
- ***provincial ASO leadership role***
- ***partnering with other groups***
- ***educating and mentoring for change***

#### **ACTION LIST**

1. It was decided that to write and circulate a report of the proceedings of this meeting.
2. Before leaving, everyone interested in continuing the discussion gave their contact information and a note of their connection to autism. From this, small steering groups were to be set up so that we could follow up on things that were decided at the meeting.
3. A follow up meeting was to take place some time in the future
4. A policy document would be drafted eventually.

*Report by Mandeep Arneja of Ottawa and Guelph*

## **A FARM COMMUNITY AS A FOCUS FOR PERSONS AND FAMILIES WITH AUTISM?**

A hopeful idea is being discussed among people in Waterloo-Wellington who are concerned about good lives for their sons, daughters and friends who have autism spectrum disorders (ASD). A farm community could also offer supports and resources to all persons and families with autism who do not actually live there.

A farm community might combine all these roles:

- a home and way of life for adults with autism
- a place of work for visiting adults and co-op school students
- a base for summer, weekend and day programs, and a place for weekend respite for children and youth
- a node of expertise and understanding of ASD and helpful support strategies
- a symbol and focus for families, friends, and benefactors, now isolated and dispersed
- a model community that is ecologically and environmentally responsible and also well integrated with the larger surrounding community.

These are ideas about how a farm community could help people with autism:

- People with hypersensitivities to noise, heat and crowds can feel calmer and better able to cope when their environment is more spacious and quiet.
- A small-scale farm community is easier to understand and cope with than the pressures and confusion of a complex urban or metropolitan society.
- People have a good sense of purpose and interdependency as they work together on meaningful and necessary tasks every day and through the seasons of the year
- A farm gives opportunities to develop special skills and interests in all the varied tasks of caring for the land, crops, trees, animals and poultry and in craft workshops
- Members of the community and their families and friends can have a more sense of stability and security, to balance their anxieties about the future
- Observation-based information, research possibilities and sharing of findings about “what’s different” and “what helps”.

Ideas for an ASD Farm Community and Centre in our region are being discussed. If you’d like to join in through a Yahoo Discussion Group, visit <http://groups.yahoo.com/group/ASDFarmCommunity> and request an invitation to join. This is a preliminary statement of our vision for a farm community.

## **CORE VALUES**

- Respect for the individuality, self-expression and quality of life of each person with ASD
- Ensuring that families continue to have voices and leadership roles, with self-advocates also represented, as well as supporters from the larger community. We have to guard against domination by paid staff or managers, or by any particular group in the ASD cause.
- Consensual decision-making in the planning stages--if there's disagreement on some big issue, we shouldn't act until we've worked through the problem. Perhaps use a PATH planning strategy (see below).
- Inclusion and inclusiveness--both for the range of persons with ASD, and for the ASD community in relation to the larger society.

## **ESSENTIAL QUALITIES AND FUNCTIONS**

- A **sense of shared purpose and hope** among all members—persons with autism, family members, friends and professionals—so that all are represented in its leadership, management and sustained development.
- A **centre of excellence and expertise** that provides for the needs of persons with ASD and their families, filling in the many gaps in present-day services, and going further—building on strengths, enhancing quality of life, optimizing each person's abilities, and supporting lifelong learning to reach full potentials.
- **Consultations and therapy of various kinds**, to suit complex individual needs, are provided to people living onsite and offsite so families do not have to run around.
- Various **residential options** including, for example: a) semi-independently in small individual homes but with support available when needed; b) by choice in small groups in larger homes with a family-like atmosphere and more support. There might also be on-site accommodations for parents/relatives/friends who are visiting their family member.

- Many **opportunities for work**, paid and voluntary, in caring for crops, livestock and trees, and in related rural businesses or services for other members of the ASD community.
- A **base for co-op day programs, respite and summer camps**.
- A **central store of resources** for ASD individuals/parents and community (videos, therapy equipment, computers and software, laminators, printers).
- Strong connections with **the larger society outside the farm/centre to increase understanding of and interact with persons who have ASD**.
- A base for **involvement by persons and families in research projects** concerned with ASD--its causes, treatments, best caring practices, effective learning strategies.
- Opportunities for **University and College students to learn about ASD** and train to become more effective teachers, support workers and other practitioners.

### QUALITY OF LIFE FEATURES

As well as the core values and functions, the resources of a landed property and the collective skills and enthusiasm of community members can allow for all sorts of "quality of life" features. Interesting and fulfilling activities are worthwhile in themselves for community members. They are also ways for friends from the larger society to visit and be involved in the ASD community, thus increasing awareness and understanding and making further connections.

The following are just some features that would be compatible with a rural/farm community quite close to urban centres:

- Sound ecological and environmental responsibility--in building styles, energy conservation, organic farming methods, water and waste management. (It could be possible to get special funds for these).
- Health and fitness--hiking and riding trails etc for year-round exercise outdoors; some indoor facilities as well—including relaxation rooms.
- Sharing resources about various interventions and therapies. For example, with dietary intervention: community could host an organic buying club, have a diet kitchen for community members but also for sale to offsite member

families, and co-ordinate purchase of supplements

- Intensive horticulture, including greenhouses; production of eggs and honey
- Sheltering rare plant and animal species, in keeping with our deep-rooted love and care for our special human beings. There could be breeding and sale of seeds, young stock etc.
- Open days and a small petting farm for kids
- Fostering and training young dogs that are going to be companions for children/adults with ASD
- Therapeutic horseback riding
- Craft skills of all kinds, with outlets for artistic talents and products that could be sold. Weaving has been found good for calming sensory and nervous systems, and pottery too....
- Among various ways of interacting with larger community: a roadside shop and even tearoom; a couple of community celebration days each year (spring and fall?)
- A retreat shelter for carers who need a break....

### OTHER THOUGHTS ON WHAT WE NEED

- Continued deep thinking, sharing ideas and listening to one another about elements of the vision
- Generous funding, intelligent and enthusiastic advocacy and superb community relations
- Good insurance and impeccable policies for protecting vulnerable people against abuse
- Leadership is critical: it must be constantly renewed and refreshed.
- Carefully planned and co-ordinated systems of governance and administration that are consistent with the core values.
- Ideas for how we might start—a pilot project that is effective by itself, but also part of a longer-term, consistent, holistic and integrated vision?

### MORE INFORMATION

Look up the Network of International Farm

Communities for Autism (NIFCA) at

<http://www.autismnetwork.net/history.html>

Read an interesting article (including discussion of Bittersweet Farms) by Prof. Margaret Schneider of

Wilfrid Laurier University: "In Response to

Deinstitutionalization: Farm Communities as a Housing Alternative for Individuals with Autism" *Journal of Leisurability*, 27, 1 (Winter 2000).

<http://www.lin.ca/resource/html/Vol27/V27N1A2.htm>

***Idea of a day conference on  
CREATIVE LIVING SUPPORTS  
FOR VULNERABLE ADULTS***

Whether this can be organized (by GSA (in partnership with other organizations) depends partly on your interest and response.

These are some features:

- In Guelph in September-October 2004
- Keynote address integrating various elements
- Poster sessions and brief presentations on a whole range of living supports from which persons and families may choose the particular mix that suits their situations and needs
- Informal connections and discussion
- For persons and families who live with autism but also other challenging conditions.

Creative living supports to be featured are person-centred and family-based and invite and facilitate collaboration and community engagement:

I: Supports for individuals:

- Personal-centred planning (tools like PATH)
- Communication supports so each person can express real wishes and be listened to
- Personal support networks/circles of friends
- - Recruiting/hiring personal support workers, homesharers and volunteer friends

II: Living spaces:

- Housing options, including "homes of our own", co-housing, cooperatives....
- Farm communities
- Social housing possibilities and funds for individuals and groups
- Independence technologies

III: Making creative options work in Ontario:

- Individualized funding
- Brokerage
- Aroha/microboards—incorporated entities of core family and friends
- Family support groups

IV. Supports for employment and work experience, including:

- Micro-enterprises and co-operatives
- Independence technologies

*Please indicate your interest to GSA at the phone, email or mail addresses on page 1.*

**News from Autism Society Ontario**

*In Our Own Words: First Hand Accounts by Adults on the Autism Spectrum* has been published by The Autism Group, and may be ordered for \$5 from ASO.

Contents:

- Interview with Pam Newman Button
- What Autism Means to Me by Jim Deeves
- Contradicting the Experts: Never Assume by John Gelmon
- My World of Autism by Darcy Gilliland
- Asperger's Syndrome: What it is for me by Peter Jansen
- My ASD and I by David Maloney
- The Perils of Theoretical Basketball by Vern Nicholson
- My Life and Times by Hartley Sigal
- Stilted Rainbow by Martine Stonehouse
- Green Grass by Beth Vosskuhler
- Living with Asperger's Syndrome by Gary Waleski
- Finding a Place to Be, Poem by Martine Stonehouse

**Annual General Meeting**

Friday, June 18, 2004, in Windsor

Autism Society Ontario will be presenting its first Stacy Lynne McNeice Memorial Lecture Award to Dr Margaret Bauman, who is a Pediatric Neurologist, at MassGeneral Hospital, the Director of The Autism Research Foundation and LADDERS Clinic, and an Associate Professor of Neurology at Harvard Medical School. Dr Bauman will also be guest speaker for a workshop which is associated with ASO's annual general meeting and conference the following day. Check <http://www.autismsociety.on.ca/> for conference details and registration.

A forthcoming issue of *AAIWW* will focus on Communication. If you have information or experiences to share on this important topic, please let us know. See the contact details for GSA on page 1 or page 8

## ***Perspectives on Living with Autism as an Older Adult***

Two essays by Brian Henson of Brantford

### **Approaching Retirement Years**

There is much more concern today about adolescents and young adults on the autistic spectrum than there was even ten years ago. The discussions and issues range from social cues at high school and college, when and how to tell others about being a person on the autistic spectrum, and issues involving interviews for a job. This shows progress from the days when autism was considered nothing but a childhood disease, and there is much more awareness of not just autism, itself, today, but of other aspects of the autistic spectrum, especially Asperger's Syndrome.

With the knowledge that these conditions do not go away just with time, and are life-long modes of seeing life for many, even if accompanied by severe autistic problems in some, the discussions still seem to be limited to those up to about forty years of age. When a person on the autistic spectrum reaches fifty, and, due to limitations in dealing with others, or due to some other physical or economic limitation, this person is put on disability income, what are the perspectives for this person? Are each of these persons just left to fend for themselves, and take whatever comes (including a disability income that has not changed in Ontario in ten years)?

Even those over fifty with a job, but looking forward to retirement--are they still shunned by those around them for their behavior and mannerisms, while they try their hardest to "fit in" to the pressures needed to keep themselves afloat, economically?

What are the prognoses of these persons on the spectrum, as far as retirement? What about the few who cannot look after themselves, and their parents are concerned with their safety and well being after the parents are deceased?

What safeguards, if any, could be proposed, to enable those persons on the spectrum over fifty to feel secure about their own future, despite the current support that they are getting from family, friends, or through government subsidy? Could these safeguards be put into law so that individuals or parents do not have fears about the future, as far as possible abuse from others who view these people as devalued individuals that are a "burden" to society?

### **A Housing Issue for Adults with Autism**

In January 1995, at the age of 93, my mother passed away, leaving an estate for her five children. Our father had passed away previously. Being a person on the autistic spectrum and unable to complete college work or find a job in my early fifties, I was just going into Family Benefits (as it was known back then) for income support, and was told that I could invest this income in a principal residence and a vehicle of a certain value. I got the vehicle, and started looking for a principal residence. It was not until the fall of 1995 that I found a property that suited me, both in location and price. It was a duplex, with a lot of work to get it up to current standards. I had 25% down payment, so I did not need a CMHC mortgage.

However, because of my income status, as a person with disability income, I could find no place to get a mortgage for the remaining 75% of the value of the property. After hearing about this situation, a friend (whom I had met at a local college, and was familiar with real estate and mortgages) offered to get a mortgage for me so that I would not use up the estate income before I would, again, qualify for what would be ODSP.

This friend and I signed an agreement acknowledging me as the rightful owner of the property, and as long as the payments for the mortgage, taxes, and insurance were deposited to this friend's account every month, the property would be mine, legally, even though, for mortgage purposes, it was registered in the friend's name. I heard on the media about money going from the federal government to CMHC to help low-income people to fix up their homes, and to encourage builders to remodel homes for the physically handicapped. First, I started to clear the interior of the house at the front (the part to be rented as a one-bedroom handicap unit) to get it ready for the home renovations by gutting it back to the bare walls, and removing non-supporting interior walls.

I applied for the CMHC funds (known as RRAP), but was told that, because the property was not registered in my name, that I could not apply for these funds (as grants, and as low-interest loans). In order to get the property in my own name, I have applied to various mortgage brokerage firms, and despite having paid for three appraisals, no mortgage company has been found who would be willing to take the mortgage and let me have the property in my own name. The front of the house remains like a barn, with no improvements in sight, and this issue has been going on for eight and a half years. Also, the CMHC representative said that I could get up to certain amount (depending on the municipal allocation by CMHC for the year), and, as this representative viewed it, the cost of fixing the house up to CMHC standards would be far beyond this amount, and any work started on such a project had to have the entire building up to CMHC standards within one year, or no funds would be paid.

***Is there any solution for this or other similar issues affecting people on the autistic spectrum who have housing problems?***

## 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 administers the Victoria Bloomfield bursary program begun in 1996 (see <http://www.ont-autism.uoguelph.ca/wwasbursary.shtml>). It also funds GSA's ASPIRE project and the new Autism Collection at the Kitchener Public Library. 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 William Barnes, 26 Yellow Birch Drive, Kitchener, N2N 2M2.

**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/gsainfo\\_new.shtml](http://www.ont-autism.uoguelph.ca/gsainfo_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 efforts, or to send news and queries to AAIWW: Mail: 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 a collection of 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.

**Adult Autism Needs Survey** used in the ASPIRE project has been revised after a pilot test period. We have also taken the opportunity to adapt the survey to new SNAP software.

OAARSN (on behalf of GSA and WWAS) is conducting this survey as a free public service. Private information about individuals will not be shared with or passed on to any agency or researcher.

We offer two versions. It's important for everyone concerned with autism in adulthood to complete at least the short-form survey.

1. The more detailed "long-form" survey takes about 25 minutes to complete. It has questions about abilities and challenges, treatments and therapies, quality of life, and planning for the future. This is for persons and families who are actively concerned to achieve the best possible quality of life in adulthood.

2. The more basic short-form survey takes only 5 minutes to complete. It's helpful that planners, funders, advocates and agencies can be aware of the broad patterns of need.

We hope you will respond online. Visit the OAARSN site at the address in the column to left, and use our Google Search function to find "AANS 2004."

If you prefer to complete and mail a paper survey, please request the form from GSA (see contact details in the column to the left).