

ADULT AUTISM ISSUES IN WATERLOO-WELLINGTON

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

Newsletter No 12, September 2001

VOLUNTEERS MATTER

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

2001 is proclaimed International Year of the Volunteer. But a national survey has found that fewer Canadians volunteer now than in the past or give charitable donations.

How important are volunteers for folks who live on the autism spectrum?

Volunteers can make a real difference by:

- Serving on boards and committees of organizations devoted to people in need, as do the directors and officers of GSA and WWAS
- Contributing their special abilities to increasing awareness of autism, as Peter McCaskell has for the past 18 months in creating and maintaining the OAARSN website
- Being friends with those who live with autism—opening doors and windows and building bridges to the community. GSA welcomes Heather Baltzer and Catherine Ferguson, University of Guelph students who have volunteered to be such friends.

GSA and WWAS need your time, your creativity, and your donations. We welcome your offers of help. See the Bulletin Board on the back page for contact numbers and addresses.

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FOCUS ON MICROBOARDS

- What are Microboards and how do they work?
- Is Ontario ready to use Microboards to support folks who live with disabling conditions?
 - How can we facilitate that process?

Guelph Services for the Autistic, in co-operation with other organizations, is offering two opportunities on November 8 and 9, 2001, to learn about Microboards and map out a PATH to make them happen in Ontario.

Facilitators David and Faye Wetherow of British Columbia invented the concept of the Microboard, and have much experience with other innovative ways of supporting persons with disabilities.

Help us to think about how Microboards could work in Ontario! For planning to go ahead, we need 40 definite registrations for the November 9 event by September 28th Special pre-registration fee of \$45 per person if payment received by September 28th. Fee for later registration \$60 per person See pre-registration form enclosed.

PLEASE NOTE: We regret that if not enough people pre-register by September 28, these events will have to be cancelled and pre-registration cheques will be returned. Assuming the events go ahead, pre-registrations cannot be refunded, but may be transferred to someone else.

Thursday evening, 8th November 2001, 7-9 pm:

At the Evergreen Centre, 683 Woolwich Street, Guelph, as the public portion of the AGM of Guelph Services for the Autistic, with a brief business meeting either before or after the presentation

- Information meeting open to all family members and friends of persons with disabilities.
- A guided tour through the chronology and strategy of the cooperative, Microboard, and individualized funding initiatives.

Friday, 9th November 2001, 9 am-4 pm

At the University of Guelph Arboretum Centre

- Activist parents and friends, self-advocates, professional allies, allies in government, potential project funders, and allied community members
- The objective is to develop a body of people who are well informed, decisive and committed to moving forward with a Microboard / direct funding initiative.

For more on Microboards and these events see next page

Microboards Ontario 2001

Friday, 9th November 2001, 9 am-4 pm

University of Guelph Arboretum Centre

Morning:

-Microboard concept and practice; safeguards issues; structures designed to reduce conflicts of interest; and 'second-level' structures to support Microboards and individualized funding initiatives over the long haul;
-Extended question-and-answer session - to align the presented ideas, structures and strategies with local political, service and institutional realities in Ontario's regions.

Afternoon:

An extended "organizational PATH" planning process to elicit and identify:

- A shared vision
- How much specific progress the group might be able to make in the direction of that vision over the course of the next two or three years,
- General strategies and specific time-lines for development,
- Resources needed to support a serious microboard initiative in Ontario,
- Limits and potentials of current resources and challenges,
- Who will need to be enrolled in order to make progress, and what they will be asked to do,
- What the group will need to do to sustain the focus and energy required to accomplish the work, and
 - Specific 'next step' commitments.
-

The PATH will generate a detailed graphic that can serve as an aid to memory, a focus for future reflection and evaluation, a way of testing emerging strategies and projects against the shared vision and principles, and a vivid document for communicating the plan to others.

Those who attend on Friday should be willing to get involved in making microboards work in Ontario.

Please accept this invitation and pass this message on.

For more information visit [http://www.ont-](http://www.ont-autism.uoguelph.ca/mba.PDF)

[autism.uoguelph.ca/mba.PDF](http://www.ont-autism.uoguelph.ca/mba.PDF) or phone 519-821-7424

To pre-register, please reply using the form provided (also possible by email) and mail cheque to:

Guelph Services for the Autistic, Root Plaza Postal Outlet Box 23016, Guelph, Ontario, N1H 8H9

- a) \$45 per person if received by September 28th, or
- b) \$60 per person if received later

What is a Microboard?

A Microboard is formed when a small group (micro) of committed family and friends join together with a person with challenges to create a non-profit society (board) that is legally incorporated. Together this small group of people addresses the person's planning and support needs, creates solutions, and manages resources in an empowering and customized fashion.

Microboards have great potential interest for everyone concerned with supporting persons with disabilities—and are particularly relevant for adults with autism.

- *They allow families and friends to create tailor-made solutions for children and adults with disabilities. In BC for example, 150 Microboards have become vehicles for the practical involvement of over 700 friends and family members.*
- *Microboards can provide platforms for inviting community support to broaden and continue the good things already or optimally done by family and friends.*
- *Governments are reassured that, as a legal entity and an employer of record, the Microboard functions enough like an agency to receive disability support dollars and provide fiscal management.*
- *Prospective government and foundation supporters appreciate Microboards for their success in leveraging family and community investments.*
- *In the long term, an experienced Microboard can keep a good life going smoothly after parents are no longer available or able to hold 'the 10,000 details'.*

Internet Information on Microboards

<http://www.microboard.org> is the Vela Microboard Association site

<http://www.communityzero.com/microboards> is our microboard intranet

<http://www.community-works.net> is our base website (meet David and Faye) and <http://www.community-works.net/articles/microboard.htm> about microboard design and development (incl. a brief history)

<http://www.uoguelph.ca/oaar/STRATEGIES7.shtml> on the Ontario Adult Autism Research and Support Network in the context of Circles, Clusters and Networks of friends to provide support and continuity

GUELPH-WELLINGTON: HELP FOR ADULTS ON THE AUTISM SPECTRUM

AIR means Access, Information and Referrals at Family Counselling and Support Services: Contact Andrea Robinson, who kindly provided most of the following suggestions, at 824-4015 or 1-877-216-1116

advocacy

Autism Society (AIR or Louisa Kuitert 787-8701)

assessment/diagnosis

Community Mental Health Clinic (referral via AIR)
- Complex Developmental Disorders Team

behaviour management

Community Mental Health Clinic (referral via AIR)

counselling

Community Mental Health Clinic (referral via AIR)
Family Counselling & Support Services (referral via AIR)

crisis

Community Mental Health Clinic (referral via AIR or directly 821-2060 / 1-800-265-7723)
If after office hours: Distress Line 821-3760 or 1-888-821-3760, nearest Hospital, or 911)

day program

Guelph Wellington Association for Community Living (referral via AIR)

dual diagnosis

Community Mental Health Clinic (referral via AIR)
Canadian Mental Health Association (AIR or 836-6220)

employment/vocational

School to Work Transition (if adult attending secondary school, contact teacher)
Torchlight Industries (via AIR or directly 822-7600)
Guelph Wellington Association for Community Living - ARC or Supported Employment Program (AIR)
Second Chance (16-24 yrs.) (via AIR or call directly 823-2440 or 1-800-478-0961)
Lutherwood (25 yrs & up in Guelph) (via AIR or call directly 822-4141)
Employment Supports (via AIR or call 822-7500 or 1-800-567-2953)

family support

Autism Society (AIR or Louisa Kuitert 787-8701)
Guelph Services for the Autistic 821-7424

information

Resource Library at Family Counselling & Support Services (via AIR)
Mailing list for upcoming events (via AIR)
Geneva Centre for Autism 416-322-7877

in-home

Special Services at Home (referral via AIR)
Respite (referral via AIR)

occupational therapy

Community Care Access Centre (referral via AIR)

referrals

Access Information & Referral (AIR) 824-4015 or 1-877-216-1116

residential

Guelph Wellington Association for Community Living - Supported Independent Living Program or Group Home (referral via AIR)
Family Home Program (referral via AIR)
Kerry's Place (referral via AIR; directly 519-941-7038)

respite

Community Mental Health Clinic (referral via AIR)
Family Home Program (referral via AIR)
Guelph Wellington Association for Community Living (via AIR)- weekend *for children of ageing parents*
Blooming Acres (referral via AIR or direct 705-689-9096)
Sunrise Equestrian (referral via AIR or directly 837-0558)
Camp Belwood (info via AIR or directly 843-1211)
Kerry's Place (referral via AIR or call 519-941-7038)

social skills

PAL & Leisure Access Card (Guelph Parks & Recreation) 837-5625
Music Therapy (referral via AIR)
Special Olympics (Guelph - Paul Turner 763-0899)
Sunset Club (Guelph - referral via AIR)
Special Friends (Hillsburgh - Cricket Yule 855-6216)
Continuing Education 836-7280
Action Read 836-2759
Conestoga College 763-9525

speech

Community Care Access Centre (referral via AIR)

supported independent living

Guelph Services for the Autistic (housing trust) 821-7424
Guelph Wellington Association for Community Living (referral via AIR)

AAIWW welcomes equivalent information about services and supports for adults in the Region of Waterloo

AAIWW BULLETIN BOARD

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.

See GSA pages on the OAARSN website:

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

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

GSA's Annual General Meeting is on Thursday, 8th November 2001. Persons whose applications for membership are accepted by the Board at least 30 days before the AGM are entitled to vote and to run for election to the Board.

Tax-creditable receipts are issued for donations of at least \$10. Special donations to support the Focus on Microboards are also needed. 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. Regular autism news bulletins for example, and reviews such as:

A User's Guide to the Brain: Perception, Attention and the Four Theaters of the Brain, John M. Ratey M.D. (New York: Pantheon, 2001).

Reviewed by David DeVidi, Philosophy, University of Waterloo at

<http://www.ont-autism.uoguelph.ca/revaugust01.html>

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 message.

Messages From An Autist

1. Order and structure help me to understand and organize my world and to foresee what is going to happen.
2. Respect my rhythm. If you understand my needs and my special way of seeing reality, you won't find it hard to relate to me. Don't let my autism depress you; I can progress and grow more and more.
3. Please don't speak too much or too fast. For you the words fly as feathers, they don't weigh for you; but for me words can be a very heavy load.
4. Like all other children and adults, I need to share the pleasures of doing things well and having my efforts recognized.
5. It is hard for me to understand the sense of a lot of things you ask me to do. Please help me to understand, and don't allow me to become brutalized and inactive.
6. Other people are sometimes very unexpected, too noisy and excessively exciting. Please respect the space that I need, but don't leave me alone.
7. Whatever I do, I am not against you. When I am irritated, hurt myself, when I break something or I am too anxious, when it's too hard to do what you ask me, I am not trying to upset you. Don't think I have bad intentions.
8. My development is not irrational, although it is not easy to understand. It has its own logic. Most behaviours you might want to change are my ways of coping with the world. Please make efforts to understand me.
9. My world is not complex or closed; it is a simple world, innocent and open without hoaxes and lies. I am much less complicated than the people who are considered normal.
10. As well as being autistic, I am a human being who shares most of the feelings of normal people. I like to play and have fun, I like my parents and the people around me; I am happy when I do things well. In my life there is more to share with other people than to separate me from them.
11. Please don't attack me chemically!
12. Nobody should be blamed for my autism. Parents and professionals should work together. The idea of accusing anyone only causes suffering.
13. Be realistic in what you ask me to do, but keep supporting me towards more autonomy, towards understanding and communicating better.
14. It can be worthwhile and satisfying to live with me. Don't change your life completely because you live with an autistic person. It doesn't help me for you to feel isolated, obsessed, depressed—under the weight of an unbearable load. I need stability and emotional well-being around me to feel better. It helps me for you to have rest, time for your own activities, and some balance in your life.
15. Please accept me as I am, and don't make your acceptance conditional on curing me of autism. My life can be very satisfactory if it is simple and calm. To be autistic is a way of being.

Adapted from the original by psychologist Angel Riviere Gómez (technical adviser of APNA in Madrid, Spain) and contributed to OAARSN by Maria Luiza de Brito Mendes of Brazil.