

ADULT AUTISM ISSUES IN WATERLOO-WELLINGTON

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

AAIWW Newsletter No. 24, April 2004

What Are Your Priorities?

As a person on the autism spectrum, or a parent, caregiver or close friend speaking for her/him: What are your greatest needs for your adult years?

- Friends who care and spend time with me
- Opportunities to continue learning
- Opportunities to work for pay
- Opportunities to work as a volunteer
- A different kind of home from what I have now
- Ways to stay in my present home
- Ways to co-ordinate all the supports in my life
- Expert consultation about:
 - communication
 - social skills
 - physical health (including diet, sensory system, sleep disorders, seizures, exercise)
 - anxiety and depression
 - job training and support
 - financial and legal planning

What else?

Generally, thinking of others beside yourself/your focus person: What supports and services should autism support groups and organizations provide or advocate?

- Increase the disability pension (ODSP)
- Social housing funds and housing trusts
- Help forming personal social networks
- Help with individualized planning and funding
- Help recruiting friends and volunteers
- Information for adults with ASD
- Information and support for parents/siblings
- Information and support for workers
- Access to more health and education services

What else?

Your perceptions are important. Please respond by email, phone or mail to one of the addresses in the next column. Please note also OAARSN's detailed Adult Autism Needs Survey described on page 6.

SUPPORTING ADULTS WITH AUTISM SPECTRUM DISORDER

Autism Society Ontario is hosting an important meeting in Guelph on May 5. This will be an initial dialogue, to discuss areas of mutual interest in supporting adults with ASD and their families and to determine how we might give voice to those interests in Ontario. The intent is to promote, develop and enhance services for adults with ASD.

When: Wednesday May 5, 2004, 10:30-2:30pm, Lunch included

Where: Italian Canadian Club, 135 Ferguson St., Guelph, Ontario

Cost: \$20 per person (collected at door)

RSVP by April 28, 2004 to:
pgallin.aso@sympatico.ca

For a flyer with more information and a registration form, please click on <http://www.ont-autism.uoguelph.ca/ASOadult-may5.pdf>

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For more frequent bulletins of news, announcements, issues and stories from the front lines, visit the OAARSN site at <http://www.ont-autism.uoguelph.ca/newpage4.shtml>

Individualized Funding Coalition Conference, Toronto, February 2004

Report by Andrew Foster of Cambridge, who is vice-president of Guelph Services for the Autistic

The conference opened with Judith Snow speaking on citizenship. She made it clear that individualized funding (IF) provides disabled people with no more than the same rights and benefits of citizenship available to all citizens, already theirs under the law. The message was effective, leaving only the question of how to implement it, which was the object of the conference.

'Empowerment' was skilfully discussed by Judith McGill, who showed the important difference between responsibility and authority, usually lost when this wretched word is used. The authority of families in the choice and administration of care was contrasted with society's responsibility for its provision, a point well made. This distinction has been of crucial significance to the quality of life of individuals, and GSA hopes to help bring this experience to others. It is an essential step in understanding the value of individualized funding.

Improvement in the lives of special needs people is often held back by lack of education as much as by the lack of physical, human and financial resources. Much of the discussion reinforced the belief that IF will give the public better value for money by the more efficient distribution of the funds, if politicians as well as the public at large can be taught this reality. A number of people mentioned that they had been told by agency staff that since IF does not exist in Ontario, they cannot apply for it. When confronted by the fact of its existence, the response is that the present examples are only pilot projects and cannot be interpreted as the government's acceptance of it.

It was good to hear that, despite the widespread dislike of agencies, there are many good people within the system who will act against policy in order to serve their clients better. However, it was disheartening to learn that some had been warned by their agencies not to use their funding to attend the conference.

I was surprised to hear from people who had not been aware of IF before the conference. This was

followed up in the discussion groups with the suggestion that priority should be given to preparing an information package to be made available, as a right, by agencies to all people who have received a diagnosis of a condition that ought to attract IF. It *must be in plain language*, and be much more than a list of useful websites. It must be a source in itself - a driver's manual for navigating the system. There needs to be a hierarchy of information, from the Ministry down to individual support resources throughout the province, and it must be made available to everyone, without them having to know that it exists before they can ask for it.

Power follows money. Take the money to the individual, and the individual holds the power - a simple enough concept, and one that seems to worry most agency people and all government officials. But if money is not enabling individuals to buy their support services, it is surely the government's business to ensure that it does. Someone stated that 80% of care funding goes to administration, compared with the most efficient charities that keep it to around 10%, even with paid employees.

Outlying and rural areas are a major concern. Regardless of the funding system, special needs people in remote areas do not have access to adequate support services. If an "inefficient" system can be justified anywhere, it is in these cases, where the cost of access simply has to be borne to fulfil society's citizenship obligations. We heard stories of families who had been intimidated by agency officials who had complete authority in the absence of any alternative or any oversight. Bringing the funding directly to the families in these cases would quickly bring about a transfer of power, and the authority that should reside in the families would be greatly reinforced.

Several people remarked that the ministry has no concept of appropriate wage levels for support workers, an issue that is aggravated in the outlying areas, with their lower incomes and higher travel costs than in urban areas.

An interesting issue was networking and sharing of information. It seems like a good idea, but must conform to privacy legislation. To what extent can we pass on family information? How much information can be shared with regard to those already receiving IF? This point was mentioned as being used by the ministry to restrict knowledge of IF in the community. Given the high level of interest, it seemed to be worth further action.

An issue that was not well covered was that of sustainability. Perhaps there has been such a big leap made to achieve IF, that taking the next stage, beyond the lives of the present supporting family, is too much to take in. Yet we have to do it, and there is surely some knowledge already accumulating that can be shared. We know where amazing work has been done in preparing surrogate families of unrelated friends who love and care for their focus person, but is it yet the lifelong, constant, reliable, unquestioning dedication that we want a family to provide? This is one of the most difficult questions in my own mind, and perhaps the conference wasn't the place to find the answer.

Some hope was expressed that the new provincial government is more concerned with genuine fiscal efficiency than with political window dressing, and the economic reality of IF may prove to be attractive to them, reinforcing the case for careful political activism.

Getting into the newspapers and the public eye was discussed. We heard that the politicians will be more easily swayed if there is a wider body of public opinion supporting IF, and not just those in need of it. The solution is to invite the press and politicians to IF related events, to meet its beneficiaries, and to offer articles to newspapers so that the public will understand that IF means the more efficient use of tax dollars. As Tip O'Neil once said, "All politics is local", and that might be a good article of faith for IF proponents. A sad reality is that when the hearts and minds of the public are to be won, economics will probably trump quality of life issues. Presenting both points of view is the best way to get the IF message across.

A Farm Community?

Could the space and daily and seasonal rhythms of a farm community suit you or your family member with autism?

A farm community, well planned and located, might be:

- *the home of some adults who want the organic wholeness of such a way of life*
- *varied opportunities for productive work and meaningful leisure*
- *a site for summer and day programs, and for weekend respite*
- *a centre of regional expertise and consultation on autism spectrum disorder*
- *a focus for family support groups and wider community awareness.*

It might use best practices in health and environmental conservation.

Come to an interest meeting on Monday, 26 April 2004, 7-9 pm at Guelph's West End Zehrs, at the corner of Imperial and Paisley Roads, in the Community Room upstairs.

We will show a video about Bittersweet Farms, exemplary farm community for adults with autism in Northwest Ohio, and discuss the possibilities for a farm community in our region..

KEVIN'S EMPOWERMENT GROUP

By Joan Gray

Our son, Kevin, was diagnosed with autism at Sick Children's Hospital in Toronto when he was four. Thirty-six years later he lives semi-independently in his own apartment with the help of a microboard.

The diagnosis of autism was devastating, but it came at a fairly early age, and we were fortunate to have Kevin enrolled in an opportunity class shortly after. The teachers were intrigued and dedicated themselves to his education. He learned to express himself through his art, then he learned to print and to type, and eventually he learned to read. He skied with his younger brother, and he swam and canoed with the family in the summer. He was included in most family outings, which included eating in restaurants and a trip to Disney. But, living with a child with autism took its toll on the family, and at age 18 when Kevin expressed a desire for more independence, he left home to live at Melanie's Place in Thomasburg, a home for adults with autism. He gained more skills, but he actually had less independence, and he began to express a desire to return to his home community. In 1989, Kevin came back to our community.

We have had a rocky ride over the years as we balanced Kevin's desire for independence with his need for help. I will never forget the first time he slept overnight in his own home. That night and for weeks after I drove by his home at 11 p.m. If the lights were still on, I drove by again at midnight and again about 1 a.m. I wasn't satisfied until the lights went out. I was introduced to many all-night doughnut shops. And my husband learned to cope with my motherly ways as I tried to let go.

We also had to learn to decipher Kevin's many varied ways of communicating. After he cut the telephone cord on three separate occasions, we finally learned that he didn't want staff chatting on the phone when they were with him, and we had the phone removed from his home. Kevin has been hospitalized on a number of occasions for a possible bi-polar disorder. The last time he had thrown a variety of foods and condiments around the apartment for several weeks, he had broken plates, etc., all behaviours connected to food and to staff. The very insightful doctor asked me just prior to Kevin's discharge how I would feel about withdrawing

staff. I admit I had thought about doing this on a number of occasions, but now the doctor was giving his approval, and it worked! Now Kevin prepares his own breakfast and lunch each day, and he sometimes offers and makes tea for guests.

He currently lives in his own bachelor apartment with limited staffing. Kevin had a very wise grandmother. When he was diagnosed at four years old, she invested a small amount of money in GICs. Last year, the proceeds from the investments were used as a down-payment on a house that was purchased in trust for Kevin. The house is an older style which backs onto a hill and which has a deep front yard. There is a house to one side but empty space on the side next to the apartment, so it provides the privacy that is needed. The apartment is over the double garage that is attached to the house, and there is a common room between the apartment and the main house.

What is a microboard?

"Microboard" is the term given by David and Faye Wetherow to the small organization they set up around a man with special needs in Manitoba about 20 years ago. The term has been patented by Vela Microboards of Vancouver.

In Ontario, we use the term aroha to mean a similar entity that is legally incorporated for the personal empowerment and support of a person who is vulnerable because of disability. "Aroha" is a New Zealand Maori word for various qualities and values that are needed in a caring circle of friends--affection, love, charity, concern, compassion, empathy, trust, pity, understanding and true friendship—all in active ways, not just ideas or feelings.

An aroha is formed when a group of committed family members and friends join together with a person with disabilities to incorporate an organization according to the laws of the province, state or nation in which they live. This entity has the objects and legal powers to address the vulnerable person's planning and support needs, to create solutions, and to manage resources in ways that are responsive and accountable.

I was introduced to the concept of a microboard in the fall of 2002. Two of my very dear friends supported my endeavours in this regard, and we visited Elizabeth Bloomfield in Guelph where she has a similar but different living arrangement for her son, Andrew. Elizabeth kindly provided us with the information we

needed to incorporate. The objects and template by-laws for Andrew's Board are posted by OAARSN at: <http://www.ont-autism.uoguelph.ca/microboards.shtml> Elizabeth is very knowledgeable and very willing to share. We completed and submitted the application form, which was provided by our lawyer, and with minimal changes, we received our letters patent in April 2003, two months after Kevin moved into his apartment and about a year after we began to investigate the possibility of a board.

We currently have five members on our Board, which we call Kevin's Empowerment Group, or KEG. My brother is the secretary, one good friend is the treasurer, the second good friend and my sister are members, and I am the president. It is preferred that the individual be a member, but for various reasons this is not the case for Kevin at the moment. The key here is that the Board makes all decisions, which brings with it a great deal of responsibility, but also the best possible program for Kevin. To assist KEG, Community Living acts as our support mechanism.

Recently, we hired a coordinator who looks after the administration, but who is also a part of Kevin's program. She, or one of two part-time staff, drop in around lunch time to make certain morning meds have been taken, and one of them supplies a hot dinner on weekends. Another woman lives in the house rent free, heat and hydro included, in exchange for which she has contracted to be on the premises from 9 p.m. to 9 a.m. every day with alternating weekends off. She provides meds for Kevin at 9 a.m. and with dinner four days a week, and she leaves a vitamin with his popcorn at 9 p.m.

KEG's vision is that Kevin will live in the community as a valued/contributing member. Board members, staff and friends work as a team to make this happen. Kevin makes his own choices when possible and staff support him in this. We try not to be intrusive, but we all find ways to spend small periods of time with him. We encourage staff to be perceptive and to listen to what Kevin is saying. He often gives clues, and we need to let him know that his words have meaning and that we are willing to help him. We all work together to help Kevin to lead an active life in the community.

It is rather difficult to determine if Kevin is satisfied with his latest living situation, but he is becoming more and more involved in his own day-to-day living, and he is beginning to reach out to people from his past. It seems apparent that giving plenty of choice is paramount to Kevin's success, and the microboard is successfully allowing this to happen.

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 on your response. Please let us know....

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
- Aroha/microboards—incorporated entities of core family and 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
- 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.

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 cheques 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/gsa_info_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

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).