

ADULT AUTISM ISSUES IN WATERLOO-WELLINGTON

No. 4

What promising signs can we see for the new century? People who live with special challenges have many reasons for feeling discouraged in these times. But good things are already happening, and others are being planned. We bring news of some promising possibilities and welcome notes of others for future issues of **AAIWW**. Hopeful trends include:

- More positive attitudes to the abilities of people with complex special needs such as autism;
- A focus on the distinctive needs and dreams of each individual, including the right and means to make informed choices;
- Recognizing that person-centred life plans and individualized funding are vital in helping people to rise above their disabilities;
- Realizing that parents of children and adults with special needs deserve understanding and more resources from their communities and governments;
- Families, friends, neighbours, co-workers and community members seeing opportunities to support and continue the roles of parents.

GSA presents a special meeting about some promising possibilities on Wednesday evening, 29 September 1999, from 7:30 pm at the Evergreen Seniors Centre, 683 Woolwich Street, in Guelph (immediately south of Riverside Park). See the poster printed on the back page.

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Autumn 1999

Appreciating the Abilities of Adults with Autism

‘The 21st century is going to be a good time for people with autism,’ says the senior cognitive psychologist at the Institute of Psychiatry in London. A good time--at least in comparison with periods in the 20th century when it has been almost an offence to be autistic.

Dr Francesca Happé gave the third lecture in the “Scientists for the New Century” series, sponsored by The Times and The Royal Institution last April. She thinks of autism as including a form of “mild-blindness”--an inability to guess what other people are thinking.

Through her postdoctoral research in scanning the brains of both autistic and non-autistic people, she discovered that the two groups process the same information using slightly different parts of the brain.

She predicts that people with autism will be appreciated in future for what they can do, rather than put down for what they cannot do.

“They are good at looking at details. They often have exceptional memories, and are predictable and logical, which makes them adept at interacting with computers.”

-Based on “The autistic mind” by Anjana Ahuja in The Times, 7 April 1999)

BULLETIN BOARD

GSA's second Annual General Meeting is planned for Wednesday 29 September 1999, 7:00-7:30 pm at the Evergreen Seniors Centre, 683 Woolwich Street, Guelph (south of Riverside Park). The AGM will be followed by the special meeting advertised on the back page of this newsletter. More details and proxy form are enclosed to persons or agencies who are paid-up members of GSA for 1998 or 1999.

Memberships or donations of at least \$10 are welcomed by GSA and tax-creditable receipts are issued. Please make your cheque payable to GSA and send with a note of your name, full address and phone number, to: GSA Treasurer, Root Plaza Postal Outlet Box 23016, Guelph, ON N1H.8H9. Phone messages may be left at (519) 821-7424.

Celebrating the Creativity Within

is an international art exhibit featuring artists with autism from around the world. Visit the John B. Aird Gallery, 900 Bay Street, Toronto, from October 27 to November 27 (Tuesday to Saturday, 10 am to 6 pm). Hosted by The Geneva Centre for Autism.

CYCLE FOR AUTISM – CENTURY RIDE 1999

Ride, Stride, Roll or Stroll

Wellington County Chapter as part of Autism Society

Ontario autism awareness and fund-raising

Sunday, September 26, 1999

Route: Elora Cataract Trail (10 km or 100 km)

Riding Time: 9 am to 3 pm: BBQ at Belwood Lake: 3-4

pm Free for participants collecting pledges; \$20 for others (\$15 if registered by Sept 10)

For more information or to pre-register, call Toby or Carrie at 824-2431, ext. 311.

WWAS held its seventh Annual General Meeting on Monday 7th June 1999 in Kitchener.

Directors of WWAS for 1999-2000 are Roger Hollingsworth, Bernard Hermsen, Stan Shalay and Bill Barnes.

WWAS will continue administering its bursary program. Memberships or donations of \$25 or more qualify for official tax-creditable receipts. A membership gives you an opportunity to share your concerns, ideas and hopes about issues relevant to people with autism and their caregivers. As a member, you are also eligible to vote at general meetings and to be nominated and elected to serve on the board of directors or WWAS. You also receive AAIWW.

Just want the facts? A subscription to AAIWW is \$5 per year, towards costs of production and postage.

Make your cheque payable to WWAS and send with a note of your name, full address and phone number, to: William Barnes, 26 Yellow Birch Drive, Kitchener, ON N2M 2M2

Send other WWAS mail to 125 Union St, Waterloo ON, N2J 4E5. Phone messages may be left at (519) 742-1414.

Both WWAS and GSA are run entirely by volunteers and have no paid staff. We will do our best to respond to inquiries and requests.

A HOME OF HIS OWN

GSA's first focus person has lived for two years in his own house. He has proved that it is what he wants and he has helped his parents and friends to make it ready for others to join him. Up to five homesharers will share roles as his companions and provide practical and emotional support, in return for reduced accommodation costs and enough free time to hold jobs or pursue studies.

*Andrew's House was the subject of an article in **At Guelph** (the University of Guelph news bulletin) on 24 March 1999. The background to Andrew's plan, and the forms of support he and GSA are pioneering in this region, are described in **About Myself: Portrait of Andrew who has Autism** by Lucie Milne (1998). The book was reviewed in **The Presbyterian Record** in June 1999.*

GSA recognizes and works with the support circle or cluster of family and friends around each focus person. Person-centred plans, supported decision-making, and individualized funding are all involved.

GSA would like to hear from people interested in being homesharers. The type of housing may range from a two-bedroom apartment or townhouse to a larger detached house. When the focus person's needs are less complex, a single homesharer or a couple could provide enough support while being able to continue employment or studies. Various financial arrangements may be made.

If you are interested in exploring "the GSA model" for your family member or in being considered as a potential homesharer, write to GSA, Root Plaza Postal Outlet Box 23016, Guelph, ON N1H.6H9, or leave a phone message at 821-7424.

STARTING YOUNG WITH INCLUSION

Q: What does Inclusion mean?

A: Understanding and acceptance of the rights and abilities of people with special needs to live with dignity in our communities

How many brave efforts to support people with special needs to live and work in ordinary houses in the community are bedeviled by the NIMBY effect [Not In My Back Yard]? Neighbours may fear the effect on property values or their children's health of being next door to a group home or even to a family with one person who has special needs. Simple walks through city parks and streets, or visits to stores and libraries may encounter stares or rude comments and questions.

Attitudinal barriers caused by ignorance and prejudice still hurt! What can be done? The most effective ways of overcoming them are by positive encouragement of the younger generation.

Windsor Community Living Support Services decided to take positive action to encourage real inclusion of differently abled children and teenagers in its city's schools. WCLSS provides support to about 400 people with a developmental disability, providing opportunities for them to live and grow within an inclusive community by facilitating options, promoting empowerment, and helping to maintain each individual's quality of life.

In 1998, WCLSS began an annual bursary program to recognize high school graduates who have enhanced the quality of school life for students with developmental disabilities (by including them in school functions, being a peer tutor, promoting accessibility, or expressing concerns regarding people with special needs). Such a student may also have worked or volunteered with community agencies and maintained ongoing friendships. Students, who are recognized with bursaries to help with costs of post-secondary education, agree to continue to promote inclusion awareness of individuals, and recognizing them as "people first" who are valued members of the community.

FC UPDATE

In the first half of the 1990s, the technique of facilitated communicating (FC) helped many adults and children who had not been able to speak because of their autism. Controversy over the validity and reliability of FC led the professional college of Ontario's licensed speech language pathologists to effectively forbid any consultation on FC from early 1996. Since then, Ontario has been the only jurisdiction in North America in which speech language pathologists could not consult and advise people about FC. It has been hard for people who do not speak to get expert help even with other communication modes.

Now **AAIWW** is happy to announce that speech language clinicians may again provide advice and guidance in the use of FC. But a clinician who feels that FC would be appropriate for an individual must go through an informed consent procedure that includes information on the negative results of some of the validity research. Clinicians are also strongly urged to continue trying to improve literacy among people with communication disabilities. These conditions reflect the continuing position of the American Speech-Language and Hearing Association (ASHA).

Clarification of the present position is the result of a letter written by Dr David DeVidi (Director and Secretary of GSA) to the College of Audiologists and Speech Language Pathologists of Ontario (CASLPO). Dr DeVidi pointed out that CASLPO's position denied communication expertise to adults with autism who had used FC for years before the embargo of March 1996. CASLPO's reply to Dr DeVidi in August 1999 makes it clear that CASLPO no longer adopts the position of another professional regulatory body—the Canadian Academy of Child Psychiatry—that FC is not to be used as a treatment for children with significant communication handicaps.

Being able to use FC—or whatever communication modes work best--is part of a focus on each individual's needs, dreams and rights to make informed choices.

What is FC?

A method of alternative and augmentative communication (AAC) that involves a facilitator providing varying degrees of physical support, as well as emotional and communicative support, to the user of a communication aid. Qualitative and controlled studies have shown that FC is useful for some individuals and that facilitators may influence the communication of some individuals. Many studies have concluded that the validity and reliability of FC were not established. There has been much debate over whether quantitative (controlled) or qualitative (ethnographic) methodologies are most appropriate for the study of human social interaction, communication in general, and facilitated communicating in particular.

On the other hand, the largest quantitative validation study to date reports that under controlled conditions, some FC users can pass information to a facilitator when that facilitator is not privy to the information. A critical factor in studies with positive outcomes is that students had prior practice sessions in message passing. So they knew in advance the rules of the experiment, rather than being taken by surprise.

Some people, previously silent because of their autism, have been able with FC to break out of their isolation and to show clearly that “though they cannot speak, they have things to say.” Those who have been fortunate to reach expertise and resources have been able to develop independence in typing. Some have been able to continue in literacy and further education programs.

It is good to know that adults with autism in Ontario who want to use FC among their communication skills will have a chance again.

*For a survey of FC and validation tests, see D. Biklen and D.N. Cardinal, **Contested Words, Contested Science: Unraveling the Facilitated Communication Controversy** (New York: Teachers College Press, Columbia University, 1997).

PLAN—PLANNED LIFETIME ADVOCACY NETWORK

“When you are the parent of a child with disabilities, your responsibility does not stop when you die, it stops when he dies.”

So reflects one father who agonized over how to fulfil this responsibility until he discovered PLAN.

PLAN, based in Burnaby BC, started in 1989 with 15 members and now serves 3,200 families in BC and is starting branches across Canada and the United States. It is a charitable organization that supports the efforts of parents to provide for the future of their developmentally disabled children and adults.

Founded and led by parents of people with disabilities, PLAN believes that the best guarantee of a safe and secure future is the number of caring and committed friends, family members, neighbours and supporters actively involved in a person’s life.

The Personal Network

The most important way is by facilitating the creation of support networks around each person. The idea of a circle of support had been developed earlier for persons with physical disabilities. PLAN promises lifetime members that a network will be a surrogate family that will ensure that the child, whatever his age, will be properly cared for throughout his or her life.

The Personal Network is a group of people who contribute now to the quality of life of the focus person, in preparation for their role in the future when the parents are not there. Typically they are not paid to be members of the network, and their involvement is based on caring, friendship, love and a commitment to work together for and with the focus person. They carry out functions that are hard for the focus person to manage alone. This may mean practical help with housing, employment and recreation—or developing closer ties to neighbours and the community.

Personal Networks ensure a safe future for the focus person and contribute to quality of life by:

- Keeping key players well informed
- Advocating on behalf of the focus person
- Providing links to others in the community
- Securing and monitoring supports and services
- Providing a forum for Network members to support one another
- Acting as a resource for executors and trustees
- Providing potential executors and trustees
- Acting as representative in supported decision-making
- Spending time with the focus person
- Planning, dreaming, and having fun

PLAN’s Commitment and Services to Lifetime Members include:

- Lifetime involvement with the focus person, monitoring and advocating for programs and services
- Advisory role for executors and trustees
- Maintenance of Personal Network
- Monitoring of guardianship agreements
- A personal future plan based on PLAN’s book, **Safe & Secure: Six steps to creating a personal future plan for people with disabilities**, with ten hours of consultation
- Quarterly newsletters, information bulletins and workshops

PLAN does not accept government money. Half its revenue comes from membership dues, consulting fees and book royalties. The other half comes from charitable foundations and corporate donors.

PLAN website: www.plan.bcteladvanced.com

PLAN’s philosophy and services were featured in “Surrogate families key to letting go,” **The Globe and Mail**, 7 August 1998.