

ADULT AUTISM ISSUES IN WATERLOO-WELLINGTON

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

AAIWW Newsletter No. 28, November 2004

SPECTRUM, KALEIDOSCOPE OR TAPESTRY

All three terms have been used as visual images of the complexity of autism. Spectrum, now commonly and officially used in diagnostic definitions, may suggest too orderly an image for the jumbled variety of symptoms and challenges experienced by those who live with autism. Kaleidoscope appeals in suggesting dynamic and ever-changing perceptions and abilities.

Tapestry has been proposed as an extended metaphor by Lisa Blakemore-Brown to illustrate "the complexity and interweave of genetic potential and environmental triggers, in a story of how people themselves develop." Each personal tapestry is unique, and variations in texture and colour can be used conceptually to illustrate individual responses to interventions. The metaphor of reweaving a tangled tapestry can help us envision how to plan and carry through interventions and also guard against the dangers of oversimplifying the difficulties in expecting that a single intervention will fix every symptom or all people equally. (*Reweaving the Autistic Tapestry: Autism, Asperger Syndrome and ADHD*, by Lisa Blakemore-Brown. Jessica Kings Publishers. 2002).

This varied contents of this issue of *AAIWW* illustrate the complex abilities and needs of persons with autism. There are no easy answers. We must keep our minds and imaginations open. We must combine patience, vigilance and sensitivity in our everyday support. In planning better futures with our friends and loved ones, we must be alive to the qualities and desires we all share as human beings. We must build on abilities and strengths. This time we bring you news of chance to have a voice in shaping developmental services for Ontarians for decades to come; glimpses of a vision for a farm community; report on a workshop about a "home of one's own"; poetry, biography and new books; GSA's annual report; and news of a conference about "Creative supports" in Guelph next April.

This week, the sad death of Randy Mogridge of Oakville has made Ontarians more aware than usual of the needs of vulnerable adults with autism. Let us learn from the failures and weaknesses of the system. Most families and caregivers have had frightening experiences when sons or daughters with autism have wandered or run away. Let's work harder to create a tracking system so that people with autism can have some freedom to move about safely. Last year, Nancy Cherry of Waterloo researched and reported on various options that should now be reviewed.

Homes of Our Own, not just "housing options", are a goal of Guelph Services for the Autistic and growing numbers of other groups:

"Our homes are more than where we sleep, eat and hang our clothes, they are the base from which we move out into the world, and the sanctuary to which we return to gather ourselves together again...."

"People with disabilities need a place where they can be safe and comfortable, but also a place where they can live."

*"In the book, **A Good Life For You and Your Relative with a Disability**, Al Etmanski writes of the cumulative living that makes a house a home: the 'sweat and laughter, bruises and tears, rug stains and cobwebs, flowers and slammed doors, failures and promises, kisses and fingerprints.'*

"A home is for living with all the grace and space that each of us requires".

Source: Sandra Shields in The Ties That Bind: Internet Documentary, National Film Board of Canada, www.nfb.ca/tiesthatbind

SEE INSIDE:	page
<i>Transforming Services in Ontario...</i>	2
<i>Expectations of a Farm Community</i>	3
<i>Home Sweet Home: report of a workshop</i>	4-5
<i>Mark Heinmiller's Profile</i>	6
<i>Poetry and Books on the Spectrum</i>	7
<i>GSA's Annual Report</i>	8-9
<i>AAIWW Bulletin Board</i>	10

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SPECIAL NEWS AND AN OPPORTUNITY!

Transforming Services in Ontario for People with a Developmental Disability

In May 2004, the Ontario Budget announced that the Government "will be transforming services for people who have a developmental disability in order to create an accessible, fair and sustainable system of community-based supports." In early August, we reported that the Ontario Ministry of Community and Social Services was setting up a steering committee to advise the Minister on how to proceed with the "transformation" of Developmental Services in Ontario. With other advocates, we were concerned that the committee should be fully representative of persons and families who live with disabilities and that its deliberations and recommendations should be open and well reported.

A Preliminary Discussion Paper has just been released by the "Joint Developmental Services Sector Partnership Table." Responses during November 2004 are invited, especially from groups of people and families concerned with disabilities. It is said that "this very important process will profoundly affect developmental services for many years to come." The paper will be "the basis for broad public consultations to be completed by Feb/March 2005." The committee and paper will "define the all-important terms of reference for the broader provincial consultations." So this is a unique opportunity....

Persons and families with disabilities have been represented so far by three members of Family Alliance Ontario and two members of People First. The Partnership Table includes 12 representatives of agencies grouped in the Provincial Network on Developmental Services, as well as five senior officials of the Ministry of Community and Social Services and one of the Ministry of Children and Youth Services.

The Discussion Paper's purpose is to raise questions to help people share ideas and make suggestions, initially by November 30. "Feedback will help the Ministry to prepare a draft plan to transform services in Ontario, as the basis for a broad public consultation. It is noted that "the ideas in this document are presented for the purposes of discussion only and do not represent proposed directions or policy on the part of MCSS."

Families and friends concerned with ASD and disability advocates generally will be pleased by the tone of the discussion paper, with its references to inclusion, removing barriers, building on community, self-determination and choices, individualized funding, and possible alternatives to traditional services.

A vision is proposed, based on *In Unison* (1998): *Persons with disabilities participate as full citizens in all aspects of Canada society. With commitment from all segments of society, persons who have a developmental disability will maximize their independence and enhance their well-being through access to require supports and the elimination of barriers that prevent their full participation.*

A clear set of principles should be embodied in any transformed system:

- dignity and respect
- building on community
- fairness and responsiveness
- accountability
- practicality
- sustainability

Questions are posed, to which we are all invited to respond, initially during November 2004:

1. What should be the roles and responsibilities of different parts of society in supporting individuals who have a developmental disability?
2. What strategies and resources would help individuals receive seamless supports throughout their lives, including points of transition?
3. What supports and services that are currently available work well should be built on for the future?
4. How should a reasonable level of government funding for an individual be determined?
5. Services are changing in Ontario for people who have a developmental disability. What would you like to see happen?
6. What do you think are the priorities the government should address?

What can we all do?

1. Read and think about the discussion paper, in your personal and family situation. Find it at <http://www.ont-autism.uoguelph.ca/Transform-1.pdf> As John Lord notes, the paper hints at key elements of transformation, such as Individualized Funding, the funding of Innovations, and the need for Independent Planning supports. But the Ministry needs many more ideas about how to implement such key factors. So we must spell them out... in reactions to the paper.
2. Discuss the paper with others who have similar concerns, with a view to presenting a combined submission. Meetings are being convened in various cities, such as Kitchener on Saturday morning, Nov 13.
3. OAARSN will co-ordinate responses from persons and families who live with Autism. Do the principles and questions of the Discussion Paper speak to your situation? How can the vision be implemented so that each person with Autism has a good life? If you'd like to air your thoughts, email ebloomfi@uoguelph.ca or phone 519-823-9232

GSA and WWAS sponsored the **AUTISM AND COMMUNITY WORKSHOP** in Guelph on November 1. We'll report further as ideas develop but, to whet your interest, here is facilitator Bruce Kappel's summary of the range of expectations for a farm community to support persons and families with ASD in our region. If you are interested but not yet involved, please contact GSA.

FARM LOCATION

Large acreage in rural Ontario	Close to family (family might move close to farm)	Close to City to take advantage of broader community opportunities
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SIZE OF THE FARM

25-30 people	Under 100 or About 100	200 people
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WHAT "FARM" MEANS

Rural Country Being Outdoors	A place with farm activities and choices	A productive farm or productive rural enterprises to earn income/revenue ➤ general ➤ organic
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WHAT "COMMUNITY" MEANS

On-site community that is cloistered and protected	On-site community with visitors	On-site community with healthy interactions with broader community. People come to the farm. People on the farm go out into the wider community.
Protected, Isolated		Safe, Inclusive
On-site community mainly people with autism and supporters		On-site community includes all kinds of people, including families who choose to move to the farm

THE NATURE OF SUPPORT

Primarily a staff model Staff hired by the organization	Mentors Life sharers Supporters live on the farm and/or share household	Individualized arrangements (for instance, supporters are hired by circle/aroha group)
Group living and programs are OK (including group home type arrangements on the property)		Home not housing Individual arrangements

DEGREE OF INTEREST

<u>THE</u> option This is my option of choice	<u>AN</u> option This in an option, if needed. Other options might come up sooner.	<u>A piece</u> of the solution This is part of a broader package of arrangements we are developing
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FUNDING

Government funds to a transfer payment agency	Some government funding, some from other sources – individual, family, farm business, etc.	Mainly free of government funding
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GOVERNANCE

An agency model	A corporation that owns land and flows money for supports	A co-operative model A circle of circles
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SUPPORT NETWORK

Nice, but not necessary		Required if individual or family to be involved, so can manage supports
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STAGING

BUY IT And develop over time		TRY IT Start one or more projects to test out interest and strategies (for instance, start gardening at the Ignatius site)
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WAYS TO COMBINE ELEMENTS:

Long Term Residential, Work, Day Program, Therapies, Respite, Centre of Excellence/Resource Centre, Health services

All in one place (the farm)	One place (such as the farm) as a central focus, but also a network of places/arrangements supported by the farm community People can live on the farm or elsewhere People can work on the farm or elsewhere	A network of places and arrangements, one of which might be a farm
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HOME SWEET HOME

Brian Henson reports on a workshop "for people with disabilities, families and service providers about unique and different ways people have created a home for themselves."

Some 70 participants met at the St Marys Friendship Centre under the auspices of Rekindle the Excitement. The first speaker, Don Justrabo of Ingersoll, had one message: "Picture Your Dream Home". It was not a matter of affordability and other restrictions: a person should dream about what type of home they want.

Mary Muir, a parent of a disabled daughter, told the group about all the trials in getting a diagnosis and treatment for her daughter and how, eventually, she was able to get a home of her own with support staff.

Bill Chartrand and Richard Martin spoke about a partnership live-in arrangement of two room mates, one disabled and the other there to provide support when needed, with a written contract, and how encouraging it was for the person with a disability.

Helen Watson surveyed historical aspects of housing for people with disabilities in Ontario, from the earliest asylums and the "eugenics scare" that discouraged or even forbade disabled people from having children. So the genders were quarantined in the disability institutions of the time. The parents' movement started in the late 1940s in Kirkland Lake, becoming an international movement that led to the formation of what is now Association for Community Living. Parents found they often had more knowledge than the experts of what was happening to their disabled children, and they organized to get people out of institutions and into community group homes. The Vocational Rehabilitation Act was passed, and schooling was open to everyone by 1982. A tri-ministry project began in 1982 to get persons out of nursing homes. A self-advocacy movement led to the "People First Movement" begun in 1981. This movement supported closing large institutions, starting a trend towards the current plan to close the last three large institutions in Ontario. Moving people to nursing homes was just not good enough for the families who dreamed that their disabled member would have a home of his or her own. Helen ended by quoting Margaret Mead: "Never doubt that a small group of people can change the world."

Barb Leavitt outlined the various ways that others have found a home, emphasizing the dream of home ownership for persons with disabilities. She quoted the saying: "He is happiest be he king or peasant who finds peace in his home." Control of what the home is must be shared with the disabled person. She listed ten conditions, inspired by David Letterman, in how to tell a house from a home. She showed Maslow's Hierarchy of Needs and how "self-actualization" is a matter of safety to the individual, quoting the saying: "to the man who only has a hammer in the tool kit, every problem looks like a nail." Then ten different ways that people can live in the community,

including supportive neighbours, co-op housing, intentional community, and supportive housing were discussed.

Dave Murray, Sarah Agar, and Katherine Robinson spoke about "subsidized housing". They reported their failure to find existing housing for a disabled person (Dave Murray) but that they found out about new homes for disabled persons were being built in the US. They went to a local builder in Stratford to get a home built with two units, one for the disabled person and one for the support staff. A new investor was contacted, and a meeting was set up with this investor, an agent from the government (about funding), and a real estate agent. They found a way of getting the home built and support staff (as a live-in family), and finally the disabled person was able to get a roommate and cat.

How you know you are in a house, not someone's home...

Barb Leavitt's TOP TEN Indicators

1. There is stuff just for staff that you are not "allowed" to go near.
2. Paid people call it "my house"
3. Family are "allowed" to visit.
4. Paid people don't knock or ring the doorbell when they arrive.
5. Spare keys are kept at an agency office without your knowledge or consent.
6. The house has a name (such as "Jones St residence").
7. You have to earn the right to have a snack or use the phone.
8. You are not allowed to come home before 3 pm.
9. The phone is answered with more words than "Hello"
10. Staff don't take off their shoes when they enter

After lunch, Jim Henry of Perth County spoke about "Rent-to-Own" Housing--how he managed to get it established in his property development, and how other organizations (such as the Association for Community Living) could use the same principle to help low-income disabled persons obtain their own homes. He quoted the saying: "You can only learn what you already know." This was an analogy for people wanting to have homes of their own, despite their disabilities. Jim said he supported the concept of Habitat for Humanity, but that the "Rent-to-Own" plan can do far more in achieving affordable housing. The need for allies in the dream could not be emphasized enough: "The wisdom of community will always exceed the knowledge of experts."

Jim explained how his "Rent-to-Own" concept and operation had been going on for about ten years. He showed how the "Rent-to-Own agreement is a partnership, and how it has been growing incrementally over the years from Stratford, and is now being expanded into Huron County and London.

Jim then outlined conceptual thinking, in four steps: Finding out how to think, talking to others, picturing the project, and finally nailing it down. In Ontario, Jim pointed out, 47% of government taxation goes to Health care, 14% to Community and Social Services, 27% to Education and Training, and the rest (16%) goes to the other government ministries. Therefore, private funding investment is needed for disability housing (as increased government funding is not realistic). This will produce a win-win situation for both the government and the private investor. Today, 3.6% of all tax payments come from retirees; and it is projected to drop to 1.6% by 2050, with even fewer tax-paying individuals. So self-reliance is necessary when it comes to funding.

Rent-to-Own is a stepping stone to home ownership. It is a private system making home ownership affordable. It involves a concept of home ownership, an investor, an advocate, a consumer (buyer), some risk management, and property management, as well. Jim said that the Association for Community Living should begin to become landlords in helping disabled people with home ownership.

Jim pointed out that the property management is up to the tenant (buyer) in Rent-to-Own. In explaining how the "Rent-to-Own" program works, Jim showed how he markets middle-income workers for his projects. There is a large market for the lower income; and one problem is how to close the gap between those who can afford "Rent to Own", as it stands now, and those in the lower income bracket who cannot afford it. But, despite this obstacle, Jim emphasized that home ownership is the best RSP anyone could ever have. In the agreement for "Rent-to-Own", there is an amortized schedule in the contract, and a "long-term agreement for the sale of land". The vendor is not the landlord; the contract is registered in the land registry office; and the house stays in the company (vendor) name until (or unless) default of complete payment is received.

In his contract with the buyers of a "Rent-to-Own" property, there is a fixed price with the utilities and taxes added; and a down payment of \$1900 is required. The percent increase over the previous price multiplied by five years is equal to the capital cost of a house sold under "Rent-to-Own". Improvements are built-in to the settlement price; and by a cash-back home improvement allowance, specific allowances are made for specific repairs or upgrades. The amortization is for 30 years, but after five years, there is often enough equity in the home for the person to obtain an individual mortgage, and pay off the "Rent-to-Own" contract. It is all laid out in a "Letter of Understanding" by the parties to the contract. Jim reiterated his concern that "Rent-to-Own" is a partnership with each party being a partner in the deal.

Jim concluded by showing how people will contribute to the community when they are economically advantaged. In investing funds into these homes under a system of "Rent-to-Own", the private investment system needs down payment money. One percentage point above GICs goes to a non-profit corporation, but this cannot be guaranteed (as a GIC) except by a promissory note. Jim stated: "To advantage people is to use the money out of your own pocket, as your investment into the non-profit corporation." A promissory note is not secured, according to the banks.

Other points made in question-and-answer periods:

1. Smaller communities may be more open to innovation in housing, whereas large cities are subject to government red tape.
2. Legacy funding, as developed by Brockville Community Living, as a means for parents to pass their legacy to the next generation.
3. The need for parents, government and agencies to work together as allies in the campaign for disability homes.
4. A warning of how can backfire was quoted from Maritime Canada, where a survey asked "How much money is being raised by private fund-raising?" After the survey results were published, the government funding was cut to the areas receiving the most private funding.
5. A shared equity arrangement was described as a tool for fighting inflation, with the equity of homes rising with the cost of living.
6. Bruce Kappel then advised the group, when answering a government survey put out by the Ministry of Community and Social Services about people getting out of nursing homes, to "ignore the questions, and say what you need to say!" It was pointed out that the family responses to the survey were being kept separate from the professional and institutional responses, and that the more responses that came from families, themselves, the greater the impact on government policy and planning.
7. The question of how Habitat for Humanity could help the cause of disability housing was raised. Some had approached Habitat for Humanity about individualized housing but had been told that just new family housing for low-income families was considered. One participant asked if anything could be done to persuade this organization to open their policy to individualized funding and to renovation work (as opposed to limiting it to new homes). A few from the Waterloo-Wellington area told how the Canadian head office of Habitat for Humanity was located in Waterloo, and that they would not mind contacting this office if it would help. Bruce Kappel offered to coordinate an approach to the organization with the participant and the volunteers from Waterloo and himself as a group to try to get the issues of disability housing for individuals through to the head office. This was hailed, by some, as the epitome of the "Home Sweet Home" conference in showing how allies and teamwork can really help individuals with disabilities in their approach to owning a home.

Mark Heinmiller's Profile

Mark gives excellent presentations about growing up with Asperger's Syndrome. He recently addressed a group in Guelph and has kindly allowed us to print this account.

I was born and raised in Georgetown, Ontario. My parents were great with me, encouraging me to do my best without pushing me too hard. It soon became apparent, however, that something was wrong. I could read before anyone in my nursery school class, but could not handle a pair of scissors or draw a recognizable picture. I had a vivid imagination, but had difficulty playing with other children. I was a fussy eater, only liking certain foods and refusing to eat any fruits or vegetables. I was taken to different doctors and specialists, including those at the Hospital for Sick Children. Various theories were proposed, including mild Cerebral Palsy, but no one knew for sure.

When I was in Grade 4, I was reassessed at the Credit Valley Treatment Centre for Children in Mississauga (now called Erinoak). By this time, my social difficulties were more apparent. I spent a great deal of time, both at school and at home, engaged in a bizarre activity my parents called "flitting." During this activity, I would imagine that I was Luke Skywalker from the Star Wars movies, a comic book character like Spiderman, or a professional baseball player on a team like the Toronto Blue Jays. I saw myself performing great heroic feats. To others, however, this behavior appeared quite bizarre. I would run back and forth, waving my arms in the air, totally oblivious to what was going on around me. I would talk to myself as though I were speaking to someone else. If people spoke to me, I would ignore them. This unusual behavior, combined with my difficulties with sports, made making new friends difficult. We still did not know what was causing these actions. My parents enrolled me in ongoing counseling at Erinoak. I met regularly with a counselor to discuss how to develop social skills and solve problems. This counseling helped me considerably.

Despite my difficulties, my marks were good. Unlike most children, I actually enjoyed school. It was one area in which I could excel. I had an excellent memory. I would memorize obscure facts about various subjects, such as dinosaurs or American presidents. I had the self discipline necessary to do my homework. My lack of social interaction actually helped me with my school work; I did not talk or fool around when I was supposed to be working. But my mind would often wander when I was supposed to be working. I also had difficulty with tasks that required working with my hands. I could understand the concepts in classes like Calculus and Physics, but had difficulty with the graphs and experiments. In Geography, I could remember facts about countries but had difficulty drawing and using maps.

Particularly in earlier grades, most of the assignments and projects involved creative arts and crafts. Other students no doubt enjoyed them better than written assignments, but I had difficulty with them. When I was in Grade 8, for example, we designed fictional newspapers. My articles were well written, but I could not make my newspaper look as good as the other students.

I also had difficulty with exams. I could remember the facts, but had difficulty writing them down in the time given. My writing was messy and awkward. I had difficulty articulating my ideas. Usually a quarter of the exam would be blank when time ran out. When I was in Grade 12, someone suggested that I write my exams in special rooms for people with disabilities. That helped immensely. I could now finish my exams with less stress. As my schooling progressed, I could choose courses that I did better at, such as English, History, or Law.

When I graduated from high school, I started an English and History program at the University of Waterloo. The disability office on campus was great, providing helpful counsel, extra time for exams, and even the use of a computer to write my exams (I can type much easier than I can write). I lived at a Christian college affiliated with the university. The people there were very friendly and helped me get involved in many social activities. There were more people my age that shared my interests. We were still not sure what we were dealing with. All I knew was that I had an odd combination of learning disabilities, motor difficulties, and social challenges that seemed to have little to do with each other.

Then, in November 2000, my mother noticed an article about Asperger's Syndrome in an issue of *Canadian Living* magazine. She thought it sounded exactly like what I had experienced as a child. My father and I agreed. At the end of the article were the addresses of two web sites on autism. One was for the Geneva Centre for Autism. I called them for more information; they referred me to Kerry's Place. I initially had difficulty finding a doctor who worked with adults with Asperger's Syndrome. I was finally diagnosed with Asperger's Syndrome in February 2001 by a psychiatrist with the Centre for Addiction and Mental Health in Toronto.

Since then, I have become involved with the social groups at Kerry's Place. I recently completed a Master of Library and Information Science degree at the University of Western Ontario in London. I developed a collection of books and other materials on Asperger's Syndrome for one class. For other courses, I designed two web pages on Asperger's Syndrome, which I invite you to visit. <http://publish.uwo.ca/~mheinmil/asperger1> and <http://publish.uwo.ca/~mheinmil/asperger2>

I am now searching for employment as a librarian, preferably as a cataloguer in a university library. I have completed many other work assignments. Last winter, I worked as Technical Services Librarian with the New Brunswick Public Library. *continued page 7: see Mark...*

Congratulations Brian!

Brian Henson of Brantford, poet, photographer and columnist on autism topics, has been chosen as the first "featured poet" in this year's "The International Who's Who in Poetry." Brian's poem "Friendship" is reprinted together with his self-introduction:

As a person on the autistic spectrum all of my life, but only finding out recently, I feel that poetry is a means of communication that transcends the rigorous social norms of society. This poem was written in my adolescence, when neither I nor my family had any idea of what was going on in my life with the lack of friends and social interaction... This poem was an attempt to show that friendship was, indeed, something that I looked forward to, despite the different lifestyle that I had from my peers and siblings; it was an attempt to reach out to others in the deeper philosophical sense, while still showing that the need for friends was a personal issue, not just for myself, but for others, everywhere.

The Pebble

He went to the brook and he found a wee pebble,
But could not quite throw it, as others would throw.
The pebble was bigger than his thumb, but jagged.
He found it so vibrant, he could not let it go.

But how could he keep it, this wonder before him?
It had no "life" to it; this was just a "rock".
But he was attracted to it beyond "reason";
It was his one focus each moment 'round clock.

But others began to tease him to the limit:
They said he had taken his rock as "pet";
And they would go further, and call him just "crazy",
But not put a finger on him, as of yet...

But he was determined to live out his own life,
As he was not just but a slave for the crowd,
And when he was jeered at, and labelled as "mental",
He called his defenses, and showed he was proud.

But this did not stop them, the jerks and the bullies,
From throwing their weight right against him, with shame,
'Cause all that they knew was that they had to beat him,
As knocking him down was the name of the game.

But he still found strength in that little wee pebble,
And would not cave in to these bullies, no way;
And now he's enjoying his life to the fullest,
With his fascination--this rock.... to this day!

-Brian Henson©2004

Everyday Heaven is the much-awaited fourth installment in Donna Williams' series of best-selling autobiographies about her life with autism. A humorous, riveting, roller-coaster of a book, it covers the monumental nine years from the time Ian left their accidental, 'autistic marriage', to Donna's candid, funny, often bumbling explorations of sexuality and orientation, the challenge of coming to terms with the sudden deaths of those closest to her and finally knowing what life was like without the invisible cage of her 'Exposure Anxiety'. Described as enthralling, deeply moving and gripping, this book will strike a lasting chord not only with autistic readers and professionals seeking to better understand those on the autism spectrum but all of us who simply dream of daring to love deeply, to adventure and to deal triumphantly with the losses along the way. Donna Williams was born in Australia in 1963 and grew up in a working-class inner-city area in Australia. Like many able people with autism born in the 60s and earlier, she was not formally diagnosed with autism until adulthood. As well as writing, composing and sculpting, she has given lectures and workshops on autism all around the world. After 13 years living in the UK, she now lives back in Australia.

Everyday Heaven: Journeys Beyond the Stereotypes of Autism, by Donna Williams, Jessica Kingsley Publishers 2004. 176 pp. ISBN 1 84310 211 0. Paper £12.95/US\$18.95

Published this month:

Children, Youth and Adults with Asperger Syndrome: Integrating Multiple Perspectives. Edited by Kevin P. Stoddart. Jessica Kingsley Publishers. November 2004. Paperback 1-84310-319-2, Nov 2004, 336 pages, £19.95 \$34.95. Hardback 1-84310-268-4, Nov 2004, 336 pages, £45.00 \$79.95

A comprehensive overview of clinical, research and personal perspectives on Asperger Syndrome, with contributions from parents and experts in the fields of psychology, social work, psychiatry, genetics, sexology and vocational counseling, and first-hand accounts from adults with AS, highlighting their difficulties in areas such as social competence and education.

Mark Heinmiller's Profile Continued from page 6

I have also worked at the reference desk for the Office of the Auditor General in Ottawa and as a cataloguer with the Archives of Ontario in Toronto. I would also be willing to work for an organization that assists people with autism. Kerry's Place has been quite pleased with the work that I have done organizing and cataloguing their resource centre. My skills include excellent communication skills, strong attention to detail, and proficiency with computers.

I offer many thanks to all those who have helped me over the years, especially my parents and my friends at Kerry's Place. May God be praised for His many blessings!

GUELPH SERVICES FOR THE AUTISTIC (GSA) PRESIDENT'S REPORT FOR 2003-2004

Don't walk in front of me,
I may not follow.
Don't walk behind me,
I may not lead.
Walk beside me
And be my friend.
-Albert Camus (1913-60),
French novelist, essayist,
playwright, philosopher

The special events around our Annual Meeting on 1 November 2004 mark the seventh anniversary of GSA's mission as a housing trust. Our focus has been on helping adults with autism to have their own homes and to live with dignity and safety in our communities, with person-centred and self-directed planning and funding of necessary supports and services.

GSA also celebrates co-operation with Waterloo-Wellington Autism Services to further the well-being of adults in our larger region of Waterloo, Wellington and Dufferin. WWAS has financially supported several initiatives, notably ASPIRE--Autism Support Project: Information, Research, Empowerment—which we began during 2002 for adults and their families in our region.

The past year has seen renewed enthusiasm for a regional farm community and centre of autism expertise and services. This annual meeting is to be followed by a workshop about the meanings of community for persons with autism and the goals and purposes of such a centre.

GSA AS HOUSING TRUST

GSA can look after the financial administration and maintenance of homes for people who need such support but want to have a sense of pride and security by living in their own homes. GSA recognizes the rights of each focus person to make choices about their lives and the people with whom they will share their time and their homes. Each adult is supported by a cluster or network of family members, friends and professionals.

GSA's energies as a housing trust have been concentrated on making a success of its first house and organizing itself to extend its services to other vulnerable adults. GSA's first focus person (and active member) has lived in his own home for more than seven years. With his parents, he has helped to prepare the house for occupancy by others he may choose as personal support workers and living companions. He has also pioneered for Ontario the incorporation of an entity of

personal empowerment and support which we call an aroha (aka microboard).

Because of this first success, GSA has been approached by other adults and/or their families who want various kinds of help with housing and person-directed planning and support. GSA shares its experience and the legal documents drafted for its unique services and supports with other persons and families.

ASPIRE

For the past two years, GSA has made special efforts with the Autism Support Project: Information, Resources, Empowerment, using funds generously provided by Waterloo-Wellington Autism Services. ASPIRE has two main parts. One is surveying the present situations, abilities and needs of adults with autism, in relation to available supports and services. The other is modeling effective ways to inform and empower autistic persons, with their families and friends, so they can plan and find resources for all the elements of a good life, including relationships with a personal support network, a home of one's own, ways to make choices and contribute to the community, and a safe and secure future.

Our first ASPIRE Advocate, Jan Cooper, made a good start in meeting with 15 families at least once, for in-depth discussion of needs and goals. After training at the Marsha Forest Centre for Inclusion, Family and Community, she co-facilitated a workshop in September 2003 to introduce ASPIRE adults and their families to PATH planning strategies (Planning Alternative Tomorrows with Hope). We are sorry Jan could not continue in this role because of family commitments.

GSA welcomed Nancy Miles as our second ASPIRE Advocate in July 2004, initially for five months. Her tasks include a combination of:

- a) Following up key focus persons and families, and noting and reporting good models, issues, concerns, supports and services that require further investigation and advocacy.
- b) Compiling a list of really helpful resources and services that already exist in this region for adults—both publicly funded and user-pay--and identifying gaps,
- c) Planning small group discussions, focused on aspects of person-centred planning for a good life in the community.

Three ASPIRE adults with their families have had PATH events during 2004—GSA paying the facilitators' fees in each case. All found the experience most worthwhile and would recommend this form of planning event to others.

GSA OUTREACH AND COLLABORATION

GSA also works with other organizations in seeking to understand and draw attention to the needs of adults on the autism spectrum and to develop effective ways helping them to live with dignity and fulfilment in their home communities. GSA and Waterloo-Wellington Autism Services (WWAS) co-operate in the quarterly newsletter *Adult Autism Issues in Waterloo-Wellington (AAIWW)*. Information and communications about adult autism issues have been strengthened since 2000 by the *Ontario Adult Autism Research and Support Network (OAARSN)* website at URL: <http://www.ont-autism.uoguelph.ca>.

GSA directors and volunteers represent us at various meetings outside the region. Vice-president Andrew Foster reported on the Individualized Funding conference in Toronto in February 2004, and Brian Henson represented us at two workshops in October. Elizabeth Bloomfield represents GSA and adult autism issues on various committees and working groups. She helped organize a Guelph workshop in early May about Adult ASD issues across Ontario (called by Autism Society Ontario), at which the record was kept by Mandeep Arneja.

GSA also speaks up on issues and supports movements that enhance quality of life and self-determination for and by adults with autism and related disabilities. We share our experience and documentation with other organizations and family groups who want to use housing trusts for residential support so individual adults may have homes of their own or incorporated aroha entities so adults may direct their own lives with understanding support by family members and friends.

Organizing the Guelph conference on CREATIVE SUPPORTS FOR VULNERABLE ADULTS on 29 April 2005 will be a major effort for GSA. We are convening a gathering of Ontario people who need to be creative in supporting good lives with and for adults who are vulnerable because of disability. We particularly want to encourage self-advocates, families and friends to take part. Our concern is practical--how to plan and implement the elements of a good life for each person and so that we can learn from each other's effective strategies and success stories. Our approach is comprehensive and holistic. We hope to put our minds and imaginations around various strategies, to show the connections among them, and to help persons and families think about and choose combinations that work for them. We plan a process of collaboration in discussion and sharing resources--during the conference and also beforehand and afterwards--using the OAARSN website and other media. Highlights of keynote, workshops and poster presentations will be recorded and edited into electronic and video resources to share with people and groups who cannot attend.

The conference is especially timely, given the recent announcement that the Ministry of Community and Social Service intends to transform services for persons with developmental disabilities in lasting ways.

Several provincial and regional organizations want to collaborate in the conference--Community Living Ontario, Individualized Funding Coalition of Ontario, Kerry's Place Autism Services, Autism Society Ontario, Waterloo-Wellington Autism Services, Planned Lifetime Networks (Waterloo-Wellington-Oxford), Family Alliance Ontario, Families for a Secure Future and the Ontario Federation for Cerebral Palsy.

PAST, PRESENT AND FUTURE

GSA is 24 years old, having been incorporated in August 1980 by core members of the Wellington County Chapter of the provincial organization now known as Autism Society Ontario. In its earlier years, GSA acted as a "ginger group" advocating on behalf on teenagers and adults with autism, planning services and supports, collaborating with other community and provincial agencies, and meeting with government officials. Our new initiatives can draw upon these efforts and experiences.

Autism is a very present reality for people who live with it. But it is also becoming part of recorded history. Thirty years after autism support groups were first formed in Waterloo-Wellington, their records have been welcomed in a public repository--the Wellington County Museum and Archives. The Autism Fonds contains the official records of Waterloo-Wellington Autism Services (1990-1997) as well as autism records and papers maintained by Gerald and Elizabeth Bloomfield during their service as directors and officers of various autism organizations between 1973 and 2003. These include Ontario Society for Autistic Children from 1973 (now Autism Society Ontario), the Waterloo-Wellington and Wellington County Chapters of OSAC, Guelph Services for the Autistic (1980) and its special GAS-ROD project in 1986. Thanks to Jane Forgay for this bright idea, and to Archives volunteer Ian Easterbrook for describing the materials.

GSA's work is maintained by volunteers. To broaden our volunteer base, GSA recently became a member of the Volunteer Centre of Guelph-Wellington. We invite all our friends and supporters to help with our various efforts, in whatever ways they can.

We thank members and directors of GSA for their faithful service in 2003-2004--notably Andrew Foster (vice-president), Amar Arneja (recording secretary), John Verhart (treasurer), as well as Paramjeet Arneja, Eleanor Fairbairn and Henk Ensing. We greatly appreciate the service of Mary Johnston and Grace Swartz as Audit Committee for GSA's accounts for each of the past five years.

Gerald Bloomfield, President, 1 November 2004

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 (<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/gsaFAQ_new.shtml

Contact GSA about any of the following, to donate to our ASPIRE efforts or the Creative Supports conference, 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.

Guelph conference on CREATIVE SUPPORTS FOR VULNERABLE ADULTS

When? Friday, 29 April 2005

Where? In Guelph, at the Ignatius Jesuit Centre

Who should come? Persons and families who live with autism and other challenging conditions (including physical disabilities, mental health, cognitive and sensory impairments), agency representatives, community friends and advocates who care. We hope to reach those who cannot usually attend similar events: by assisting persons and families who could not otherwise afford to take part; and by making electronic and print resources that can be shared and studied by people who live too far away to attend.

Why?

- to be inspired and nerved to implement person-centred and self-directed plans
- to share a full range of creative individualized strategies that work
- to power a concerted and collaborative process involving all parties (persons, families, communities, agencies and Governments) concerned to support all who are vulnerable because of disability

How shall we achieve these goals?

1. A rich program including:
 - Opening plenary keynote session and closing call to action
 - Four concurrent workshops
 - Poster sessions and brief presentations on a whole range of living supports from which persons and families may choose to suit their situations and needs
2. Informal connections and discussion
3. Video record of poster presentations and summary highlights
4. Process of consultation and resources beforehand and afterwards, using the OAARSN website and other media

What can we all do now for this conference?

1. Plan to attend, watch the OAARSN website for updates, email gbloomfi@uoguelph.ca or phone 519-823-9232 to express your interest
2. Tell others who are themselves vulnerable because of disability or have disabled friends or family members.
3. Let us know of creative support strategies that are being pioneered by families, support groups or agencies