

ADULT AUTISM ISSUES IN WATERLOO-WELLINGTON

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

AAIWW Newsletter No. 33, March 2006

What Does Our Region Most Need For Adults with Autism Spectrum Disorders?

If you have concerns and ideas about this and related questions, you are invited to a discussion on Sunday, April 2, 2-4pm, at Ignatius/Orchard Park, at 5420 Highway 6 N, on the northern edge of Guelph.

Purposes

1. Discussion of priorities for adults with ASD, as a basis for advocacy and policy, with opportunities to share concerns and bright ideas with other family members and friends in our region.
2. Our discussion will also inform a special Colloquium being hosted by GSA later in April 2006, for representatives of parent support groups and agencies that do or might support adults with ASD in Waterloo Region and Guelph-Wellington.

Key Questions and Ideas

Some background questions and ideas, to think about before we meet:

- Should we support and advocate for total service for a few, or some level of support for many or most adults with autism?
- Should our efforts be focused on the most vulnerable adults with complex needs, or should they be diffused all over the spectrum?
- Do we recognize only funded and staffed models of service, or do we plan supports for the continuing involvement by family and friends in the lives of many adults with autism, including some with severe challenges?
- Is it possible to choose only one model of "best practice", or do we recognize the wide range of combinations of abilities and challenges in our adults with autism?
- If we can't achieve everything for everybody, what can we do that will improve the quality of life for the greatest number?

"It is better to light a candle than to curse the darkness"
– Chinese proverb.

- What can autism advocacy organizations like GSA and WWAS do?
- How does our advocacy for adults with autism fit with the general trends in advocacy for others with social, communication and developmental challenges?
- How helpful is it to plan within the context of person-centred planning and self-determination, individualized funding, and collaborative efforts between informal supports (family, friends and community) and formal funded agencies.

What Services and Supports are now available?

- a) What agencies now offer or might be able to provide for adults with ASD (see Nancy Cherry's work)
- b) Person-centred approach, with supports designed for and with the person

What Specific Innovations could Start to Improve Quality of Life for Adults with ASD?

- If we can't do everything all at once, these two innovations would be cost-effective, to start with:
- Brokerage/co-ordination of supports for to support person-centred planning and funding, as pioneered in Windsor
 - Autism support centre in our region (models)
- Discussion of how these innovations could help with situations based on real people on pages.

Bright Ideas Towards Introducing these Innovations in our Region.....

Please let us know that you'd like to attend on April 2. Phone (519) 823-9232 or email gbloomfi@uoguelph.ca

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“Stories” and Situations of Adults with Autism Spectrum Disorders

Some underlying thoughts:

- ODSP and SSAH are inadequate for supporting adults with autism
- The autism spectrum includes such complex and diverse needs that they need individualized supports rather than group programs
- Most families of persons with ASD want to continue being involved in the lives of their adults and this is probably best for all concerned. How can “the system” best support families that want this option?
- The present system seems to offer “all” to a fortunate few, or “nothing” to most. Can we devise supports that help everyone with some basic expertise and co-ordination?
- As well as improving support and quality of life for present adults, we need to have a range of options open for a wave of young people approaching adulthood soon--and their parents who have good advocacy skills and higher expectations than parents of the past.
- Some non-traditional options may be better for persons with ASD, and could also be more cost-effective.
- The purpose of these stories is to illustrate a representative range of needs, not just to solve or patch up a specific situation
- The stories show range of unique situations and the need for continuing lifelong support
- How can we improve general community attitudes to vulnerable people?
- It's not enough for communities to say: “Vulnerable/disabled/autistic people are allowed to ride the buses, swim/exercise in the community facilities, or live in our neighbourhoods.” More facilitation of acceptance and relationships is needed.
- How do we pull together to translate visions and dreams into real quality of life?

ANNEMARIE's family felt lucky that she was accepted into a group home ten years ago when she was 25. Now they feel somewhat excluded from her life. They perceive that her distinctive symptoms of autism are not addressed and her abilities and interests are not nurtured. They have become aware that some adults have more person-centred lives, in which their family and friends can continue to have more roles. On the other hand, they are afraid of cutting loose from the agency that supports Annemarie in the group home. What choices do Annemarie and her family now have?

ANIT is supported by an agency, living in a FamilyHome situation with one other vulnerable person, and attending a sheltered workshop. His loving and concerned parents spend every Sunday with him. As Anit has lived apart from them for 20 years, and they do not feel they could cope with everyday support. But they keep up with the research literature and wish that Anit could benefit from, for example, some of the biomedical strategies that can benefit adults with autism as well as children. How can they best work with the agency?

AIDAN is 17 with quite severe symptoms of autism. He has grand mal seizures and does not speak. His family has supported him well; they have known how to find help and have kept on good terms with the school and other service agencies. They want to continue involved, but feel that Aidan and they are about to fall into a black hole. They do not want to settle for a group home or daycare program, even if there were vacancies. They want an independent facilitator to help them get a new assessment of Aidan's needs and abilities as a young adult, and some help with co-ordinating or even developing supports that are good for him.

DOUG is 25 and has Asperger syndrome. He graduated from high school and is very good at work situations involving systems of order. Friends are what he most wants, but he is reluctant to talk about himself. He lives in the basement apartment of his family's home, and wants to stay with his parents for ever. They worry about Doug's need for support if/when anything happens to them. They'd like to find a host family or couple that could be friends with Doug and give him some experience of staying in another home sometimes. How can this be

arranged, so the host family knows how best to understand Doug's distinctive Asperger symptoms and to encourage him to express his thoughts a bit more freely?

AARON, in his late 20s, has relatively high functioning autism. His family would like to plan for his future by clubbing together with other families (and perhaps applying for some Government housing funds) to build a 6-plex of small apartments for Aaron and four others, with the 6th apartment for supportive houseparents who would keep an eye on everyone. What other co-ordination resources would be needed and could be available for such a small community?

***AMY**, in her 50s, has lived with her mother literally all her life. By serendipity, her sister found that Amy responded to adaptive communication technology which, when provided as part of her daily life, has prompted her to interest and competence in expressing herself meaningfully through both typing and speech. All aspects of her life have been enhanced. What resources may be tapped to help Amy keep developing her literacy skills? How could other persons and families obtain communication assessments and appropriate technology?*

PAUL, now in his 40s and with no verbal speech and significant health problems, has always lived at home, with some daycare and respite supports from local agencies. His parents have organized their lives around him. They would like to leave their house to a non-profit charity that would pledge to help Paul to continue living in his home, with live-in support people and perhaps another vulnerable adult. How could such an arrangement be maintained? How could all the supports Paul needs be smoothly co-ordinated when his parents cannot do this every day?

***MATTHEW**, in his later 30s, has had good person-centred supports for more than ten years in another region of Ontario. After they retire, his parents want to move into our region for various good family reasons and Mathew wants to move with them. It is rumoured that Matthew will lose his entitlement to any disability funding when he moves. His present support system took many years to develop. How could his family's transition be smoother--providing information and connections with resources in the new town, and arranging for funds to be transferred?*

ALEXANDRA does not speak with her voice, though she expresses herself in other ways. Because she is non-verbal, she is believed to be low-functioning and not capable of thinking and feeling. She expresses herself in two main ways—in art when she has the opportunity, and in frustrated behaviour when others do not understand her. Without family, she lives in a group home where the staff lack time and opportunities to understand her abilities or needs. How could her group home staff get more help to understand how she expresses herself? How could Alexandra find resources and friends to develop her artistic abilities?

***THOMAS** is now in his early 60s. He has felt different and marginalized all his life in the small towns where he has lived and worked. At age 50, he was diagnosed with Asperger Syndrome which helped him to understand why he had felt different. But he has found that there is no support at all for people of his age who have average or better intelligence but severe problems in social relationships. He feels this is unfair. He needs people to listen to him as an equal and a place where he can feel accepted and respected.*

LUIGI is 19 and moderately affected by autism. With family and friends, he has a support circle that met to make a PATH plan for his life. They felt inspired and uplifted. Luigi chose people he wanted to help him take steps to his goals, and friends volunteered to help. Some informal things have happened. But Luigi needs some help from funded supports. Nine months later, everyone feels a bit frustrated and let down. They have not been able to get the vision across to any agencies. They have heard about a “brokerage” service for personal supports, in which an independent planner matches needs with community resources.

***JON** and his family did obtain some Government funds to support a person-centred life in his own home. But they could find no local agency to act as a transfer payment agency, as Jon's plan was regarded as too individualized. Any agency that might have been a TPA would have wanted a large percentage of the funds as an administrative fee, just for flowing the funds. Jon's family and friends had to give up their dream, as they did not feel confident enough to go it alone. Jon had to accept a place in a distant group home, far from his family, where he has been very unhappy and frustrated.*

The Road Trip: Life with Autism, by Gloria Pearson-Vasey and J. Kevin Vasey (Ottawa: Novalis, 2005). ISBN 2-89507-603-0.

A powerful portrait of an Ontario family's journey with their son from age two, when he was first diagnosed with the symptoms later defined as autism, to his mid-thirties. Other parents have written of the searing experiences of learning their child has autism and of searching for real help and understanding. We can all relate to the journey into the "dark and frightening place" where "the maps were riddles, the roads abruptly merged into a maze, and the destination was hidden from view" (p.11).

What is distinctive about ***The Road Trip*** is that so much is told in Kevin's "voice", though he seldom speaks. The book began as a collection of transcribed conversations in 1992, during a family trip to Atlantic Canada, after Kevin had just been introduced to a form of alternative and augmentative communication in which his hand is steadied to type on an electronic device. Kevin's observations and statements provide evidence of his exceptional intelligence, his interests in social justice, travel, nature and music, and his sensitivity to the plight of persons who suffer injustice.

A book consisting only of Kevin's words would have been worthwhile for its glimpses of what his mother calls "the soul of a boy-man, at once innocent and wise, sometimes sophisticated, and often touchingly naïve" (p.9). But the book's editor wanted more—more about the whole family's perceptions and experiences, before 1992 and since. So the road trip became more complex, and "the journey threads its way through several dimensions" that help us to understand Kevin's life and to imagine more about the lives of other adults with autism.

Gloria Pearson-Vasey, Kevin's mother and co-author, has been a Secular Franciscan for more than 20 years. She has a Master of Divinity degree and is a pastoral minister. She has been a nurse, music teacher and journalist, and has published novels and devotional books. Gloria was also the mainspring behind the creation of St Francis Advocates, the agency created in the later 1980s that operates five residential homes and various other initiatives for adults and children with autism in the tri-county area of southwestern Ontario from its base in Lambton County. The book is infused with her life experiences and spiritual insights.

The rich material of ***The Road Trip*** is organized thematically, in chapters on major topics, each weaving together Kevin's communication of his

thoughts with discussion of contexts and the perspectives of his mother and other family members.

These are the chapters:

Communication

Community

Adjusting

Addiction

Resources

Relationships

Hope and Dreams

Limitations

Pioneers and Pilgrims

The Quest for Meaning

Going Home

The Advocates

Confronting Rejection and Loneliness

Pilgrims' Process

The epilogue, "As Far As I Can Tell" sums up the authors' Franciscan spirituality.

We recommend ***The Road Trip*** as a compelling read, through which we learn respect for the humanity and spirituality of some adults with autism, especially those who may seem most severely impaired. We also appreciate how parents and families grow through their acceptance of suffering and the love and compassion they express in their lives for and with their vulnerable sons and daughters.

William Stillman, ***Autism and the God Connection: Redefining the Autistic Experience through Extraordinary Accounts of Spiritual Giftedness***. 2006. 272p.

Sourcebooks, \$14.95 (1-4022-0649-6).

"In certain cultures, people with illnesses affecting the ability to communicate are thought to be visited by spirits. The sufferer may be regarded as a messenger for a deity, an anointed one to be revered and honored. Sadly, Western culture often relegates those diagnosed with autism and related disorders to the ranks of the incurably crippled. Worse, almost everyone, from family members to friends to primary caregivers, too easily writes off the intelligence of a person who has difficulty speaking. So written off, the sufferer is discounted and ignored. Stillman, who has Asperger's syndrome, a high-functioning form of autism, speaks out on behalf of the wisdom of considering people with autism as not just intelligent but also highly spiritual" (Donna Chavez).

RECOGNIZING DR JOAN JORY

Dr Joan Jory, MSc, PhD, Registered Dietitian and Clinical Nutritionist based in Guelph, has made a outstanding professional (and personal) contribution to the health and quality of life of children and adults with Autism Spectrum Disorders.

Originally from New Brunswick, Joan Jory has a Masters in Nutrition from the London School of Tropical Medicine and Hygiene (UK), a Doctorate in Applied Human Nutrition from the University of Guelph, and her dietetic internship from McMaster University. She is a registered DAN! Practitioner (Defeat Autism Now!) and nearly half of her practice is dedicated to children and adults with ASD.

The sibling of a brother with Down Syndrome, Joan has also worked and presented extensively in Down Syndrome, adult and pediatric mental health, and clinical support for psychiatric treatment.

Joan's principal passion is the influence of micronutrient biochemistry on physical and mental health. She specializes in micronutrient requirements and metabolism, and the role they play in growth, development, immunology, and disease treatment and prevention.

Joan's introduction to autism came in the form of a 2 year old girl suffering from significant immunosuppression, gastrointestinal dysfunction, skin affliction, autistic symptomology, and a complete shutdown of her connection with the world around her. Her extremely dedicated parents accepted no obstacles to understanding and addressing all aspects of their daughter's health in a time where autism was a foreign word to many practitioners. Together, practitioner, parents and child began a very long journey of investigation and treatment across multiple provinces, countries, fields of medical expertise and years. Today, this child has become a vivacious, verbally fluent miracle who surpasses her peers academically and musically. This first little miracle has been joined by many other miracles, children and adults, who have undertaken the journey of biochemical intervention in autism. It has truly been an epiphany and a gift for Joan to work with these individuals as they blossom into healthier, happier whole human beings.

In addition to her work with families with autism, Joan lobbies for greater public and professional understanding of the role of biochemical intervention in autism. She has presented to local pediatrician groups;

provincial dietitian, home care and naturopathic associations; and regional autism groups in Ontario. She has also been a guest speaker at autism conferences in Quebec and New York, and has just completed a US-funded research study comparing micronutrient status among children with and without autism.

Her professional expertise and warm personality and empathy are valued by people with autism and their families. These are three testimonials:

"Joan Jory has offered untiring, informed and compassionate nutritional and medical advice and advocacy, in support of our son's health and welfare, for many years. She has worked both to empower all those directly concerned - patient, parents, doctors, supporters - and to ensure that they successfully work together as a team. Her personal and professional inputs have had a major positive impact upon the quality of his life. She has demonstrated all that is best in the development of comprehensive professional support for those with complex needs."

"Since my daughter (now 6) was diagnosed with autism four years ago, Dr Jory has advised on diet and the latest biomedical treatments of autism. She even accompanied us when we went to consult a leading US authority. I know she has transformed the health and quality of life of my daughter and many other children with autism."

"We appreciated Joan's understanding and positive attitude toward our son's upset behaviour. She always spoke to him directly with kindness and respect. She is very professional and proactive in handling the nutritional requirements of autistic adults."

As well as her office in Stone Road Mall, Joan works part time for Therapy Partners Inc, and enjoys precious paperwork moments at her home office, bombarded by her two rambunctious boys. She is also a part-time marathoner. Her phone is (519) 829-5514.

Celebrating Six Years of OAARSN

The Ontario Adult Autism Research & Support Network was launched in March 2000, when autism had a smaller presence on the Internet. Our early news bulletins included items about autism in children. Autism in adults was hardly ever considered in other media. We still have a long way to go before adults with autism, in Ontario and elsewhere, have better lives. Visit OAARSN at <http://www.ont-autism.uoguelph.ca> and keep in touch through the OAARSN Listserv.

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 funds the ACES Youth Day Program and the Autism Collection at the Kitchener Public Library, and the bursary program.

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 WWAS, C/o Dr Hollingsworth, 125 Union St E, Waterloo, N2J 4E5

GUELPH SERVICES FOR THE AUTISTIC (GSA),

incorporated in 1980, has these roles:

-Acts as a housing trust to enable adults to live in their own homes, supported by family and friends

-Supports person-centred planning, self-determination and individualized funding

-Sponsors the ACES initiative with WWAS

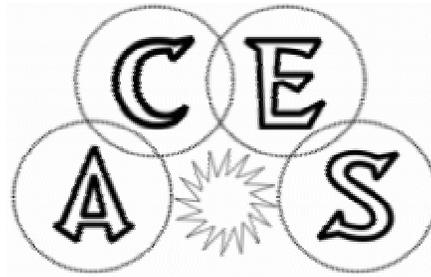
-Recruits volunteers as friends for adults with autism

-Provides advice and support to families and friends

Contact GSA to donate to our efforts, or to send news and queries to AAIWW:

Mail: Dr Bloomfield, 16 Caribou Crescent, GUELPH, Ontario, N1E 1C9. Phone (519) 823-9232. E-mail gbloomfi@uoguelph.ca

AAIWW is distributed occasionally as a print newsletter. For more news and comment on adult autism issues, please visit the Ontario Adult Autism Research & Support Network (OAARSN) at <http://www.ont-autism.uoguelph.ca> The OAARSN Autism News e-Bulletin is put at least twice a month. If you are not already on that List, please send a request to gbloomfi@uoguelph.ca.



ACES initiatives are early steps towards our vision of an intentional community that will include land-based work. This pioneering phase, supported by both GSA and WWAS, has no government funding.

ACES is an acronym in which:

A stands for Autism, Adults, Asperger's, Abilities, Accessibility

C stands for Centre, Community, Citizenship, Co-operation, Conservation, Communication

E stands for Excellence, Experience, Expertise, Ecology

S stands for Spectrum, Safety, Stability, Socialization

ACES suggests top quality, and the diversity of people interested in supporting and developing the abilities of adults with ASD. Brian Henson designed the ACES logo.

Beginning in 2005, ACES has had three main aspects:

1. Land-Based Voluntary Work on the Ignatius property.

We have maintained the Courtyard Garden, using organic methods and developing new garden areas with native plants that attract bees and butterflies. We have also helped with other outdoor tasks around the property.

2. Several young men meet each week as the ACES Wednesday Group. In summer, they worked a garden plot with organic methods and enjoyed hiking, swimming, nature studies, and computer and other games. In the fall and winter, they volunteer for land and farm tasks, and welcome indoor forms of work experience too.

3. In pioneering a Centre of Resources and Expertise on adult autism issues, ACES offers information and support to people concerned with aspects of autism. In 2005, we offered a conference and several workshops on aspects of Creative Supports for Vulnerable Citizens.