

ADULT AUTISM ISSUES IN WATERLOO-WELLINGTON

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

AAIWW Newsletter No. 22, December 2003

Seeing Each Other's Point of View: Working Together For and With Everyone Who Lives with Autism

People who live with autism can seem much more different than alike. If 20 people with autism were to be gathered in one room, the differences among them would seem much more striking than the similarities. This used to be said years ago, when the definition of autism was narrower and more specific. Now that we have a much broader concept of autism spectrum disorders, with a prevalence of nearly one per cent of the population, the range of personalities, abilities and needs is far greater. Persons with a diagnosis at the high end of the autism spectrum may seem hard to distinguish from those who are "neurotypical" or non-autistic.

People involved in the autism cause--as persons with autism, parents and caregivers, or support workers, researchers and administrators—sometimes seem to be at odds with one another. Some may be concerned only with their particular need or a specific treatment or therapy, and seem intolerant of all others. Parents of young children may describe autism as a monstrous affliction that has to be defeated, while high-functioning adults with autism want to celebrate the autistic traits that are part of their identity. When resources seem scarce, funding for preschool children may mean that teenagers and adults have to go short. Supports and services may be reserved only for the most high-functioning (as they have the best potential for independence) or for the least able (as they need help most). Parents and caregivers may be over-protective or under-estimate the abilities and dreams of persons with autism. Administrators and researchers may not consult with persons who have autism, so that research and service priorities may not meet their real needs.

Yet people with autism spectrum disorders share some very important differences from other people, especially in social communication, even if their degree of impairment can range from slight to profound. With their families and supporters, they have usually had to cope with misunderstanding and delays in recognition of their special needs. These insights and experiences should help us all to understand and support each other better. Let's do it better in 2004!

Season's greetings and best wishes to all from the board members of Guelph Services for the Autistic, Waterloo-Wellington Autism Services and the ASPIRE and OAARSN teams.

Some Myths and Misunderstandings

People with autism do not give or receive physical affection.

People with autism do not notice others and don't pick up cues from peers/adults.

People with autism do not want friends.

People with autism could talk if they wanted to.

When a person with autism does not respond to a question/direction to which he has previously given a correct response, he is being stubborn/non-compliant/obnoxious.

Autism can be outgrown.

Autism is an emotional disability.

People with autism cannot learn.

People with autism show no imagination.

Bad parenting causes autism.

Autism is rare.

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AUTISM IN ADULTS

Exploring (and Exploding) the Myths

Report on the Regional Support Associates workshop in London in October, by Marlene Klimkosz who represented GSA's ASPIRE project and is secretary of the Autism Society Ontario's Wellington Chapter

Thursday's program began with a panel of two parents and a consumer giving "Adult Perspectives on Autism Spectrum Disorders". Zack Smith spoke on how he likes to pace and how he was drawn to long objects as a toddler. He felt different and was diagnosed when 6 years old. He uses medication to control the anxiety he feels. His biological father denies his disorder. His stepfather accepts him with good humour. When he was in elementary school he had help from an OT. Zack spoke to us with confidence and later we learned that he had been interviewed that morning by CBC Radio and was also going to be delivering his Valedictorian speech later that day. Zack answered questions directly and to the best of his ability. He said that he does feel emotion but he finds it difficult to display it to others. Gloria Vasey spoke next on the challenges she faced while raising her son, Kevin who is now 34. Her son uses facilitated communication and Gloria feels that we need more experienced facilitators and more study of this method to confirm its usefulness. She spearheaded the formation of St. Francis Homes because she could not find any other way to give her son the space that he needed. She emphasized that it does involve a lot of work but in the end it is worth all the effort.

Patricia Gallin spoke about her challenges with three teenagers, including one son, John, 18, who is diagnosed with Asperger's. She shared some of her experiences with the interaction between the children but she also emphasized the need to help people gain understanding and knowledge about Autism. Her advice to other parents: "Educate teachers, workplaces, and general practitioners."

Most of the questions were directed to Zack because service providers and parents wanted to know and understand how the world looks to the person affected by ASD. Mothers spoke about where they were able to succeed and about the services that they see needed. Some questions were raised about "Facilitated Communication," as some of us did not know what it was. The message was a positive one and things are improving. Increased awareness is getting us noticed.

Margaret Spoelstra presented information about the Autism Society Ontario, of which she is Executive Director. She spoke about working with campers when she first encountered folks with autism and went on to give a brief history of her experiences. She then presented a video about a self-sufficient adult who belongs to an Adult Group that Marg works with in Toronto. This person spoke plainly and

clearly about her life growing up with autism. She talked about how things have happened since she was young and growing up knowing she was different. She has been successful working and making her way in society and she is proud of her accomplishments. She is able to drive a car and lives how she wants to live. She does take medication but it is her choice.

After lunch, we had a presentation titled, "Everything you Need to Know about PDD, but didn't know to ask." Dr. Lillian Burke began her speech by saying, "Everyone is an individual. Everyone doesn't respond to the same medicines or treatments." She then gave a thorough presentation touching on sensory, emotions, speech and language, visual thinking, diet, movement, vision, misinterpreting cues, not understanding social rules. She used examples to illustrate what she was explaining to us. She addressed the following myths as examples:

- Can't produce creatively.* But there are artists, musicians, creative writers, actors with ASD
- Don't experience emotion.* They do, but find it hard to connect with others & interpret social cues
- Can't engage in vocational activity.* They can be superb workers when they find activities that suit their strengths
- Can't engage socially.* They need support & practice to gain confidence & skill
- Aren't motivated:* They need startup support; may not know how to fill empty time/space

To end the first day, we listened to Dr Robert Carey on his "Positive Systems Approach with High Needs Individuals with ASD." Dr Carey gave us an overview of his system and then presented the following case study, illustrated with a video. Peter is a person with severe autism, almost no communication skills, and a high level of aggression and self-injurious behavior. The video was presented to us of Peter. He still needs restraint but he indicated that he wanted his restraints put back on after he ate and drank and his injurious impulses started to take over. He has a guide dog to help him and his diet is carefully monitored, as he has been diagnosed as having celiac disease. Brenda, his caregiver, says that they try to give Peter a different variety of activities each day and his condition has improved very much since they started their treatment.

Friday began with a presentation from Dr Jeanette Holden, who spoke to us of her life's work in "Unravelling the Mystery of Autism: Amazing New Research." As well as her extensive presentation about the advances that are being made in genetic research and mapping of faces, detailing common characteristics, brain wave patterns, etc, Jeanette shared the good news about her brother, Jim, who is now 50. Since acquiring a small FM hearing aid that filters out background noise Jim is now hearing and is now starting

to learn new skills, such as playing the piano. And just four months ago he started talking continuously. Jeanette is very happy and she continues to emphasize that we should never give up. Each day there are new discoveries, new devices, new medications and new therapies to help people with autism.

Gail Hawkins, Director, Mission Possible then spoke about "Work & Education." She began by stating that one would need to have job target already identified. From here Gail went on to give a fun presentation on "How to Present Candidate to Potential Employer" with resume using a chronological functional format focusing on skills. Individualize everything giving 3 attributes and 3 facts. Include any incentives that may be offered, i.e. job coaching (which is a support to the prospective employer). Prepare employment package: resume, wage subsidy form, job coach information, information on disability (at your discretion, but it will come up). Gail then gave advice about How to find jobs in the Hidden Market – 5 steps for Networking:

1. Brainstorm about what you're looking for
2. Be prepared!
3. Follow up – call them and tell them that you are looking for work
4. Be clear – know exactly what you are looking for
5. Be organized.

Some jobs that ASD folks are excellent in are jobs where they are interested in that field. I know for my son it's computers and electronics so in his case, he would love to spend all day talking about computers and electronics i.e. powerful sound/picture systems, etc. so if he could work for a store like Radio Shack or Future Shop, it would be a job to go to work each day.

Dr Bob King from North Bay gave us an extensive presentation on **PDD Psychopharmacology – Process, Progress & Pitfalls**. Dr. King gave us a thorough overview of the medications that are available. He stressed that we need to work with a doctor who is knowledgeable and to closely monitor the reactions that the patient has to his medications. He presented a video introducing Garrett, who is out working with the public every day but who uses medication to control his impulsive behaviors. Garrett shared some of his thoughts and feelings that he has. Dr King also explained studies that had been done on different types of medication.

Finally, Dr Kevin Stoddart gave us a brief presentation about "Young Adults with Aspergers." He emphasized that

"Adults with Asperger's are a positive and integral part of society." He spoke of the transition from living with parents to becoming independent. Planning for the future should begin in Grade 10. Dr Stoddart's time was limited but I spoke to him afterwards as he had participated in several studies that were displayed around the room. The one that caught my eye was about studies that had been done about a higher incidence in hearing loss in individuals with PDD. He has also done other studies and I would urge you to contact him if you would like to find out more. His email address is kevin.stoddart@aspergers.net.

A total of 190 people attended the conference, representing all groups involved with adults who have ASD. I would like to thank GSA for the opportunity to attend and to meet other parents with adult children. There were parents with children just newly diagnosed at 40 years of age. The message that I took home from this conference was to never give up. Jeanette Holden's brother is 50 and is now learning to talk. Autism research continues – new devices are being developed, new therapies are being tried, and new pieces are being found to unravel the puzzle of autism.

"Able autistic individuals can rise to eminent positions and perform with such outstanding success that one may even conclude that only such people are capable of certain achievements ...

Their unswerving determination and penetrating intellectual powers, part of their spontaneous and original mental activity, their narrowness and single-mindedness, as manifested in their special interests, can be immensely valuable and can lead to outstanding achievements in their chosen areas."

--Hans Asperger (1944).

See reviews and notes about books on the OAARSN site at <http://www.ont-autism.uoguelph.ca/books.shtml> We appreciate the efforts of our reviewers and welcome suggestions of new books that should be reviewed here. Please note the fine and growing collection of books about autism at the Kitchener Public Library.

Spirituality and the Autism Spectrum: Of Falling Sparrows, by Abe Isanon (Jessica Kingsley Publishers, 2001). ISBN 1 84310 026 6. 143 p.

Abe Isanon has been teaching for 22 years, the last 12 as a specialist with children and adults who have autism spectrum disorders. He now works as a residential care manager with autistic adults. He tells us in the preface that writing this book has been a labour of love, based on twelve years of “listening and learning” to people with special needs, who “have opened up my mind and heart to the beauty of the lost and the broken... They have afforded me the opportunity to shelve my cultural baggage and personal bias. I have been both touched and humbled by their courage, patience, integrity and humility” (p.9).

In the first two chapters, the author discusses definitions of autism and suggests that it is more helpful to think in terms of autism-related problems. The impairments may be cognitive (problems of systems integration, left-right hemisphere integration, perception, attention, or thinking in pictures), emotional (sensitivity and anxiety), sensory hypersensitivities, and behavioural (including compulsions and obsessions and the resulting tensions and frustrations).

The third and fourth chapters are concerned with how people with autism may cope with, or compensate for, their impairments. Isanon quotes Temple Grandin and especially Donna Williams, but he mainly draws upon on the narrative and poetry of

“Adam,” a man with high-functioning autism. Adam’s difficulties with cognitive and especially emotional conceptualization meant that he could not come to terms with his spirituality through traditional institutionalized religion. Instead he has developed a “liberation spirituality (that) places experience before the rationality of dogma and canon law.” Like many other autistic people, Adam is said to have an innate sense of justice, a strong inner certainty about his spiritual self, and a profound sense of compassion. He can give affection but cannot cope with receiving it. Adam values solitude and silence as aids to spirituality and regards St Francis of Assisi as the “most autistic of saints”—a man of warmth who seemed always to be present and attending to the needs of others, regardless of the consequences to his health or personal circumstances.

In the final pair of chapters, Isanon explains his understanding of a liberatory spirituality that addresses the needs of both people with autistic-related conditions and their carers. He identifies most closely with the call by Jean Vanier, founder of L’Arche, for an approach that is both contemplative and active, and with the “preferential option for the poor” that is at the heart of the spirituality of L’Arche. He quotes Vanier on what this means: *People who are powerless and vulnerable attract what is most beautiful and luminous in those who are stronger: They call them to be compassionate, to love intelligently, and not only in a sentimental way. Those who are weak help those who are more capable to discover their own humanity and to leave the world of competition in order to put their energies at the service of love, justice and peace. The weak teach the strong to accept and integrate the weakness and brokenness of their own lives which they often hide behind masks.* (Jean Vanier, ***Tears of Silence***, 1997, p.2).

Based on his experience of caring for people with autism who seemed incapable of self-reflection and self-expression as well as his understanding of L’Arche communities, Isanon considers several elements he believes are central to liberation spirituality. Honesty means “grasping the truth of concrete reality.” Compassion is the primary response to concrete reality. Presence means listening deeply with love. Relatedness is intuitive rather than conceptual, experiential rather than abstract. Touch that is loving and respectful may be the primary means of communication when caring for those with severe and pervasive autism.

Isanon concludes by quoting Jean Vanier again: *To love someone does not mean first of all to do things for that person; it means helping her to discover her own beauty, uniqueness, the light hidden in her heart and the meaning of her life. Through hope a new hope is communicated to that person and thus a desire to live and to grow. This communication of love may require words, but love is essentially communicated through non-verbal means: our attitudes, our eyes, our gestures and our smiles.* (Jean Vanier, ***Tears of Silence***, 1997, p.5).

“Striking the Balance – Rights, Risks and Responsibilities”

Kerry’s Place Autism Services offered a workshop on this subject before its Annual General Meeting on 22 November 2003. Orville Endicott, Barrister & Solicitor, opened the workshop with an outline of the key principles, especially those that stem from the significance of Section 15, subsection 1 of the Canadian Charter of Rights (1982):

“Every individual is equal and under the law and has the right to equal protection and equal benefit of the law without discrimination and, in particular, without discrimination based on race, national or ethnic origin, colour, religion, sex, age or mental or physical disability.”

Disabilities were added only at a late stage of the drafting of the chapter. Many of the rights are still subject to debate in the political arena and are still being tested in the courts.

A new booklet prepared by the Ontario Association for Community Living spells out some of the key rights for disabled persons—to a safe environment, relationships and privacy; to say no and make decisions; to respectful support, self-advocacy and reasonable risk; of access to community, to be disabled, to grow up, and to dream.

The translation of principles into practical everyday rights for disabled persons was the focus of the presentation by Bill Allerton, CEO of Accreditation Ontario. He emphasized the effects of the new approach to the rights of disabled persons on the traditional agency model that has inevitably tended to curtail individual rights. Clearly there are many challenges to administrators and staff in developing and supporting a broader and deeper sense of rights and responsibilities among the people in their care. One mechanism to enhance the process was suggested—the creation of rights committees. Such a committee within an agency could review and monitor emergency procedures, consider reports of abuse and neglect, develop policies to help in the exercise of individual rights, and ensure provision for receiving and resolving complaints. All committees would include some members who were not employees of the agency.

A half-day workshop could only provide some very basic outlines of the complex issues. Its focus was almost entirely from an agency perspective and gave little guidance to parents and others who have major responsibilities for care and individual development.

- How can the general principles of rights be focused more clearly to recognize the distinctive qualities of each disabled person?
- How can family members, teachers, care workers and friends “listen” to thoughts, wishes and dreams of people who may have profound difficulties in communication?
- After listening, how can the carers learn to translate the thoughts and wishes into meaningful improvements in quality of life?

Clearly there is much to be done, and all of us—including family members and agency staff—need to be much more active in the search for ways to bring the legal principles into everyday living. *Gerald Bloomfield, Guelph, November 2003*

Expanding Individualized Funding: The Time is Now!

February 20 to 22, 2004
Inn on the Park in Toronto

The goals of this "workfest" weekend are:

- To develop an action plan for implementing IF in Ontario; and
 - To develop strategies for building the capacity of families & communities for citizenship & IF.
- Key stakeholders from all parts of the province are invited to think carefully about who needs to be invited in order to create and train a diverse, energetic and motivated leadership team.

Families and Individuals will be the primary participants. Sponsors are aiming to have a mix of new and old leaders, representation from different ethnic groups, young parents and individuals labeled disabled.

Goals of the event are to develop an action plan for implementing Individualized Funding in Ontario and to develop strategies for building the capacity of families and communities for citizenship and Individualized Funding.

To achieve regional representation at this event, 10-12 participants will be invited from each region in Ontario - resulting in the creation of groups in every region that are committed to creating individualized supports for those who want such options.

IF YOU WOULD LIKE TO BE INVITED PLEASE SEND AN EMAIL TO: barbara@acl.on.ca or call Barbara in the Individualized Funding Coalition office at (416) 447-4348

Good News from the Front Lines by a mother in Waterloo-Wellington's ASPIRE group.

My son "DJ" still hesitates to tell his story. There is still a lot of pain because he wasn't diagnosed until he was 15. He was frustrated a lot and could not understand why others did not see how hard he was trying to be a good boy and be accepted. In private, in the past, he has cried, and asked me, "What is wrong with me?" I swear, I did not know! and because I knew so little, I did not even suspect anything like autism. It wasn't until a psychologist mentioned a term I had never heard before, "Pervasive Development Disorder", and I started to read about it, that the puzzle started to come together to form an answer. Once we had a name, the clouds began to clear, and then we found a whole new understanding and explanation for what was happening.

Now, because of the hard work of people in the autism cause, there was information available to us. Some very special teachers (one was responsible for his meeting with the psychologist), understood Autism, stepped in and from there on the world opened its arms to my son. He was treated more fairly, his classmates were informed and when they understood his difference then they could accept him. Instructors found time to help my son and to encourage his interests. I had teachers stop me in the hall of his school and tell me how wonderful it was to work with him. He gained the self-esteem he'd not had for so many years.. He was able to complete high school and graduate with his name on the honor roll.

Today he goes to work each morning to a full time job where he is paid the same and treated the same as anybody else. He has ambitions to advance himself. Maybe, one day he'll go to college to learn more about his favourite thing, computers. He's young, he's not afraid to try and he knows that he is special.

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/gsa/faq_new.shtml

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

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.

Contact GSA about any of the above, to donate to our ASPIRE efforts, or to send news and queries to AAIWW: Mail: 16 Caribou Crescent, GUELPH, Ontario, N1E 1C9. Phone (519) 821-7424 or (519) 823-9232. E-mail gbloomfi@uoguelph.ca