

ADULT AUTISM ISSUES IN WATERLOO-WELLINGTON

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

AAIWW Newsletter No. 20, Summer 2003

ASPIRE: the next phase

Guelph Services for the Autistic (GSA) launched the Autism Support Project: Information, Resources, Empowerment in August 2002. ASPIRE is supported by funds generously provided by Waterloo Wellington Autism Services.

ASPIRE is designed to help families and friends plan for a good life in the community now as well as the foundations of a more secure future. Successful experiences and resources can be shared, to help families to develop the potential in particular situations. Meeting with interested families, ASPIRE consultant Jan Cooper has learned of several common concerns. One is a wish for a planning process to help to understand options and choices to help them to give heir daughter or son the best possible life now and a more secure future. Families also say they want to have more social contact with others in similar situations.

*Responding to these concerns, ASPIRE offers: **Evening Workshop on PATH: Planning Alternative Tomorrows with Hope, on Tuesday, 9 September 2003, in Guelph.** The PATH workshop will be facilitated by Beth Hancox of Waterloo and Jan Cooper of Guelph.*

Families already linked with ASPIRE have first choice. If there is more demand, we may offer the PATH workshop a second time. Read more on page 2 about ASPIRE and PATH, but please call Elizabeth Bloomfield at (519) 823-9232 or ebloomfi@uoguelph.ca immediately, to reserve places at the PATH workshop or request a consultation with Jan.

REMEMBERING LUCIE

We sadly announce the death from cancer of the Rev. Lucie Milne of Newmarket, loyal member of WWAS and keen supporter of our efforts to make autism better known in the community. An artist and writer as well as retired Presbyterian minister and educator, she wrote several articles and reviewed numerous books for AAIWW and OAARSN. She was also the author of *About Myself: Portrait of Andrew who has Autism* (1998). Our sympathy to Lucie's family who have suggested that friends might care to give to autism projects in memory of her.

New Autism Collection at Kitchener Public Library

A good-sized collection of books, videos and other information about Autism Spectrum Disorders has been made possible by a generous grant from Waterloo Wellington Autism Services. A formal launch event is planned for Tuesday, October 21, 2003, during Ontario Public Library week. After that date, borrowers from outside Kitchener can request a Limited Access Borrower's card to borrow from the Autism Collection. Materials may also be requested through Inter-Library Loan.

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AAIWW is published 4 to 6 times a year for Waterloo Wellington Autism Services and Guelph Services for the Autistic.

How can PATH help?

A PATH event can help the family and friends of a vulnerable person to think and plan about their situation, both its challenges and its potentials. It is usually led by a pair of trained facilitators--one who draws out the thoughts of everyone present while the other records these in images. A PATH event can help us, for a few hours, to raise our sights above the everyday minutiae, barriers and challenges. It can also give a voice (however this can be done) to our daughter or son who is the focus person. Through PATH, it is possible to think and dream beyond the constraints of systems and agencies. Some PATH events may chart a person's life well into the future. Some may be for more immediate purposes.

“PATH is a person-centered-planning tool--a process to define strategies for aligning and increasing the energy available to make progress on complex problems. It is a way for a person and members of their support circle to affirm the values that guide them; vividly depict their vision; feel the tension between their vision and their current reality; identify the people to enroll in making progress; specify the ways they will build the skills, knowledge and stamina necessary for the work; sketch strategies that will move them toward their vision; and define exactly who will take responsibility for which immediate next steps.” (O'Brien & O'Brien, 1998).

PATH was designed and developed by Jack Pearpoint, John O'Brien and Marsha Forest beginning in 1991. ASPIRE is fortunate to have as facilitators, Beth Hancox and Jan Cooper, who have been trained by Jack Pearpoint and associates at the Marsha Forest Centre for Inclusion-Family-Community in Toronto.

The GSA Board has committed funds to offer the PATH workshop for interested families and to pay for the facilitation fees of PATH events for ASPIRE families who wish to go ahead with hosting these. EVENING PATH WORKSHOP, in Guelph, Tuesday evening, September 9, from 7 to 9 pm, in a home setting. Please email (ebloomfi@uoguelph.ca) or phone Elizabeth (519) 823-9232 to request an invitation. If more than about a dozen sign up, we may hold a second PATH workshop as well. Ask to borrow our video and book about PATH in advance, if you like.

Matthew's New Job

Matthew is a young man of nearly 21 who lives with his family in one of the smaller towns of the Region of Waterloo. He has PDD and juvenile diabetes, but he and his family have had a very hard time obtaining appropriate supports from service agencies. He is able and eager to work with people who understand him. Recently he found a little job in a quarry about 30 km from his home. His family hopes the company will be able to keep him employed.

His mother writes: *"Matthew gets up at 6:00 am for blood testing for his diabetes and a big breakfast. We are off by 6:30 am for the drive to work as start time is 7:00 am. In the morning when I drop him off the boys and men all say "Good Morning Matthew." He is learning many skills that you and I would do automatically.*

"He has steel toe work boots (which he loves), and is surrounded by Mennonite men who are very good to him. I have explained Matthew's disability to them but they all tell me how smart he is. The physical labour is difficult but he tries and tires quickly. Loading the skids with the bricks so that the weight is balanced is difficult for him; he cannot see the pattern that is needed (suggestions are welcomed), but he really likes this work. On a rainy day they do not work in the quarry; instead they go into the workshop and make candle stick holders out of stone with the grinders, he finds this skill fascinating.

"Everyone stops work and eats lunch together. One day he came home with picked strawberries that Timothy's mom had sent in his lunch. Every Friday they go to a local village restaurant for lunch (he likes this). In the very hot weather in late June, they took an hour and went to the nearby pond for a swim on their lunch hour. At high school, Matthew could not tolerate eating in the cafeteria.

"Matthew is so tired that he is in bed by 10:00 or 10:30 pm. On Sunday he went to church in a nearby village with the owner's family and back to their home for a big lunch to see the horses (which he knows a lot about), roasters, and vegetable garden. They were very impressed with Matthew's knowledge of horses. Matthew does not think this is a big deal, but of course it is because Matthew usually does not have two-way conversation.

"This is a dream for us! Someone like Matthew is usually only accepted by kids who are much younger than him (9-13), or kids with conduct disorders. I've always found it difficult to get really good SSAH workers. I try to get Matthew to do normal things, but then I look at the simple life of the Mennonites and how they accepted Matthew as a good worker and I think how much happier he might be living this lifestyle..."

Books on the Autism Spectrum

Reviews and notes about books may be found on OAARSN's site at <http://www.ont-autism.uoguelph.ca/books.shtml>
We appreciate the efforts of our volunteer reviewers and welcome suggestions of new books that should be noticed or reviewed for OAARSN and AAIWW. See also our lists of books and videos, on which orders for the new Kitchener Public Library collection are based, at:
<http://www.ont-autism.uoguelph.ca/books.shtml#6> and <http://www.ont-autism.uoguelph.ca/books.shtml#7>

Autism Society Ontario announces its second manual (in a series of five): **Children Diagnosed with Autism, What to Expect and Where to Get Help...** See ASO website.

In **The Ride Together: A Brother and Sister's Memoir of Autism in the Family**, Paul and Judy Karasik tell the story of growing up in Chevy Chase, Md., with their parents and two brothers, Michael and David. David, the oldest, is autistic and mildly retarded, and the book follows him as he grows from infancy to middle age.

The Curious Incident of the Dog in the Night-time by Mark Haddon (David Fickling/Jonathan Cape, 2003): ..."beautifully written – and beautifully published, about Asperger's, suitable for 11-year-olds and up."

What kind of brain do you have? Really big differences between the male and female brain could help explain conditions such as autism, says Simon Baron-Cohen, director of the Autism Research Centre, Cambridge University, in **The Essential Difference: Men, Women and the Extreme Male Brain** (Penguin, May 2003).

Treating Autism: Parent Stories of Hope and Success, edited by Stephen M. Edelson and Bernard Rimland, "in-depth stories by parents and doctors who have used the rational, non-drug Defeat Autism Now! (DAN!) biomedical treatments". Order for \$22 US from AUTISM RESEARCH INSTITUTE, 4182 Adams Avenue, San Diego, CA 92116 • Fax (619) 563-6840

The Drawings of a Boy with Autism by Jonathan Lerman (George Braziller, 2002).

A Wizard Alone: The Sixth Book in the Young Wizards Series by Diane Duane (Harcourt (2002).

The Natural Medicine Guide to Autism (The Healthy Mind Guides) by Stephanie Marohn (Hampton Roads, 2002).

Demystifying the Autistic Experience: A Humanistic Introduction for Parents, Caregivers and Educators by William Stillman (Jessica Kingsley, 2002).

American Normal by Lawrence Osborne (Copernicus Books, 2002). Asperger's syndrome.

Martha Kate Downey has written several books on aspects of Asperger Syndrome, High-Functioning Autism and PDDNOS, including **TAP DANCING in the night, If you've ever wanted to crawl in the closet with an OREO...** and **What Do I Do About Hitting?** See her website at <http://www.mkdowney.com/>

Marianna Csoti of Wales writes books to help children, young people and adults with social challenges. **Assertiveness For Young Adults** (1998); **People Skills for Young Adults** (2000); **Social Awareness Skills for Children** (2001); **Contentious Issues: Discussion Stories for Young People** (2001); **The People Skills Bible** (2002); **School Phobia, Panic Attacks and Anxiety in Children** (2003); **Emotional Rescue** (2003). Several are published by Jessica Kingsley. See more information at <http://www.bookstohelppeople.co.uk/>

Dennis Debbaudt Newsletter: Volume One, Issue Number 3, June 2003. To subscribe, contact Dennis Debbaudt at ddpi@flash.net Autism Risk Management Project website at <http://www.autismriskmanagement.com/> and The Police & Autism: Avoiding Unfortunate Situations at <http://policeandautism.cjb.net/>

Sharing the Voices of FC Users

Chris Pentzell of Los Angeles, whose extraordinary brother Nick has been an FC user and poet for more than a decade, has a vision of sharing the voices of other FC users, by publishing a book of poetry, short stories and artwork created strictly by FC users. She'd like all profits from the book to go to an organization that furthers FC use, and strongly believes that FC users should be involved in the entire process, not just in the creative aspect. She wants to make sure the FC users communicates what they want to communicate rather than it being about what others think should be communicated. For more information, see <http://www.ont-autism.uoguelph.ca/Sharing-FC-voices.html> Please reply to CPentzell@aol.com

“AUTISM A PART OF WHO I AM”

Temple Grandin's presentation at the Geneva Centre For Autism International Symposium, October 2002, reported by Minna Mettinen who, with her two children, has ASD

A large crowd of people attended the presentation, yet there were very few distractions, sitting at the very front. In fact, the crowd was unusually quiet, which seemed to indicate that they were all very intrigued.

Temple spoke of her life as a child and growing up, and her mother was there to offer her own perspective and feelings during those times. Temple as a speaker captivated the attention because had seen some interesting books written by her previously at the book tables. Most specifically, wanted to learn more about her “thinking in pictures” ideas, since believe that the way this brain is organized, is like a filing system of various pictures to represent words. Did not get books though, and she didn't really speak about that topic.

Another reason for the interest in her presentation was that she was the only autistic speaker (identified as autistic) there, outside of the luncheon presentation for autistic people. Temple's speech was more informative because she spoke not only of her life experiences, but also about things that worked well for her, and things that didn't work well for her. That kind of a presentation is useful for those of us on autism spectrum because we actually can learn something, unlike the presentation in which a person merely speaks of their life, and how they grew up, what “autistic” things they did as a child... those presentations already live within us.

What was great about her presentation was the audience participation. After speaking about her life, she opened up the discussion to revolve around questions in the audience. So, most of what will report on here, are topics that she addressed as a result of audience questions. Will not write about her reflections on her childhood (unless she refers to it, in her responses) because that information apparently is well available in books elsewhere.

Anxiety and medications:

Temple Grandin talked about problems with anxiety. She indicated that puberty is when there are often increased anxiety attacks. This led her to talk about medication. She said she started taking some medications in her late 20s to early 30s. She

indicated that with high functioning autistics, fully verbal, the anxiety gets worse with age, pointing out that many HFA couldn't go to work because of high anxiety. Temple revealed that she wouldn't be able to go to work without meds. Temple Grandin went on to offer some basic information about medications used for autism.

Anti-depressants-SSRI's are often given to autistics. The typical doses are for treating depression, and these are too high in these types of drugs for autistics. In her book *Thinking in Pictures* she speaks in detail about the dosing. This advice does not include Respiradal, and other atypical antipsychotics, when being used to reducing rage attacks. She mentioned that Dr Joseph Huggins in Toronto prescribes the three drugs Respiradal, beta-blockers, and Depakote (an epilepsy drug) for the worst behaviors in low functioning persons.

Someone asked about her 6yr old boy, for which a psychiatric. doctor recommends a drug because he has screaming sessions where he screams for about 20 seconds. Temple's response was: There is no medication for autism. So, you need to look at the behaviours. There are various medications for symptoms. A good rule of thumb for any medication is that it should have an obvious dramatic effect. If you don't get a “wow, this stuff really works”, the medication is not the right thing. She suggested to the parents that they need to look at the screaming, and see what it is about. Sometimes it is seizures. Keep a log of everything that happens, and if it is absolutely random, there is no reason, they are not tired, nothing distressing is happening, then maybe it is seizures, and you can look at seizure medications. So basically it is important to use a log to see if it is behavioural.

Sensitivities:

Most autistics have problems with multitasking and sensory overload. The extent of this depends on the person. She said she was attracted to visual stimulating things, but had sound sensitivity. Some autistics have touch, or a combination of sensitivities, and these problems are exceedingly variable. For example for some people, their insides feel like a

speaker at a rock concert, when a toilet is flushed.

One kid might like it and wants to flush it all the time, another might run away screaming.

One thing to do about sound sensitivity is to put the sound that is bothersome on a tape recorder. And let the autistic individual play it, according to their preferred volume. This might help to desensitize them.

Earphones, or plugs are sometimes used in situations where a person is unable to get away from excessive sounds they are sensitive to. But the earphones have to be off for at least half of the day, otherwise you might become more sensitive because you get used to the quieter sound.

Some autistics are afraid of dogs and cats. Temple said the problem with dogs and cats is they make a noise that might hurt the ears, and you never know when it might go off. Yet, some might be especially attracted to animals. If your thinking is basically visual, auditory, touch, smell oriented, you can understand animals better than verbally

oriented people. An autistic person can relate to an animal that also doesn't talk quite well. Unlike a verbal person who might be unable to understand an animal because they are caught up in whether it can think, feel etc. an autistic person can just accept the animal as it is.

A parent discussed his son who is sensitive to trucks going by, but he plays the drums. Temple indicated that the sound sensitivity tends to be in certain frequencies, and not in others. It is inside the brain and not in the ear. A suggestion was to put the truck sounds on a tape recorder and let him control it. It is easier for the kid to tolerate it if he initiates the sounds. After all they are not sensitive to their own screams.

A parent spoke of her 4th grader who was reading at JK level. They wonder if they should take emphasis out of reading. Temple indicated that it is important to figure out why is he having trouble with reading. She had problem at age 8. Some learn whole language-memorize by sight, some with phonics. Maybe the thing to do is get a child's book on his special interest, to motivate him.

It is also important to look into his visual processing. It might be that the eyeball is fine, but the visual processing is not. The print may be wiggling on the page. If he hates escalators, squinting out of the corner of his eyes, problems with fluorescent lights, splitting of visual field, he

probably has visual processing difficulties. Get rid of white paper. Use gray, or light blue, to reduce the contrast. Coloured glasses might help also; get tested for Irlen glasses.

Stimming:

Videotape stimming is something you don't want to let a child do for long. This is completely shutting out the world. When she was a kid she liked to play with the supermarket automatic doors. It is ok to do it for a little while. But not for long. The video games are the same thing. It is ok to let a child have an hour a day. But the rest of the day you need to keep the brain tuned IN to the world rather than tuned OUT of it. Another bad thing about them, is the ones where the graphic movement is fast moving, this has a bad hypnotic tuning-out effect. There needs to be some other interaction other than just taking turns playing video games. This is a useless skill unless he is becoming a fighter pilot. Playing card games, board games, is good because while you play you talk. There is more social interaction.

She did offer praise for the SIMS computer games. This game moves slowly, it is intellectually engaging, and it could be a tool because it involves so much more planning and it can be used to engage dialogue, and talk about why you make certain choices in it. It also simulates real life. In that game, if you don't go to work you get fired.

Stimming also has a purpose. For example, when an autistic person comes home from a long day away, they have "held it together" throughout the day. When they arrive home they might want to stim out on rocks, reflection of water or other pleasant stimuli. It is ok to let a period of an hour a day to calm down. When she did the sand thing, she studied each little particle like a scientist through a microscope. It is ok to have a little bit of down time when you just do your stims. From a brain development standpoint, the brain is not doing anything during stimming, so this is not beneficial for long term.

Mainstream classroom placements:

Temple Grandin says that you need to look at it on a case-by-case basis. It also depends on a particular school. Ask yourself is he improving? It means the placement is doing something right. If he is getting worse, try a different approach. In her opinion, mainstreaming often works well with elementary kids but in high school it can be horrible. This is because social beasts- they are totally social. Often a high

school kid needs to be taken to a community college, to take a course they are interested in, to help them with their self esteem. This is because often the autistic teen is very knowledgeable about something, but because of the highly social school environment, they feel very badly about themselves.

She was asked, if someone can snap his fingers and she would not be autistic, what would she do. Temple said she can't imagine not having very detailed thinking, and wouldn't want to give that up. One of the things that happen with autism is that different departments of the brain tend to work separately. They are not well interconnected. What tends to happen is that one part of the brain specializes and sort of shines, and the rest gets a reduced workload.

Special Interests:

A parent indicated that her 6 yr old son is very visual, he draws pictures all day, but she is not sure if he is using the drawing as his way of understanding or as a way of shutting out the world.

Temple's response: Drawing is a talent you want to develop. It can become a useful skill later on. He needs to get into interacting with others. Asking questions about his drawings, and encouraging him to be drawing about various different things accomplish this. It is very important for autistics to learn to ask questions. Drawing is a useful skill, but running a video back and forth is not a useful skill. Encourage him to expand his drawing themes and use them to teach other things. Always broaden out the interest. Read a book on the history of drawing, art, read a book on a famous artist for example.

There are some autistics that are deeply depressed in puberty. This is why you need to put emphasis on developing a skill. She said autistics have a tendency to think, "I am what I do" and so they need to have something to do, this will help them feel better about themselves. Temple spoke of there being a need for specialized art programs, for visual learners. She doesn't see them getting the recognition that they deserve because of their social problems. They need someone to market their ideas. Apparently the person who came up with the palm pilot has Aspergers. A lady helped him market it. You need to get things out into the market someone has to go out there and "pound the pavement". You can sell it outside of the autism world. And someone has to be the marketing agent. Because there are lots of autistics that have fantastic talent, but need someone to make appointments and someone to make sure that others don't rip them off. Someone has to go in there and do the final

sale. The autistic person needs someone to handle all the business part of it. You need to start finding the people who can open the doors, because we are inside the special ed. box. What someone has to do is be the business head to sell their stuff. The autistic person can't do the selling. You have to find the people who can open the door, and you don't ever know where you can find them. Make a print of your work and carry it around. Show it to people show it to people in an airplane as you are traveling. Carry around a portfolio of your pictures, even if it is small to fit your purse. Sell the talent, not the personality.

Independence: What made you ready for it?

Temple indicated that it is a gradual transition, from the world of school to the world of work. Preparation must start early, a gradual transition from one thing into the next. At 14 yrs old she worked in a little sewing job, which was good work training. She spoke of the importance of a mentor. A mentor might be a good teacher. She learned social survival rules, like you cant tell your boss he is stupid, from having a mentor. A science teacher and her aunt were her mentors. Temple's aunt was her "getting along in life" mentor. They would just talk about why people do things they do. But for a skills mentor you got to have someone interested in helping, and a person who can recognize talent.

What were your biggest advantage and disadvantage?

Temple's response: Visual thinking for design is the advantage. For others it might be a language thing, music or math. She is a believer in developing talents. These are more likely to be seen in ages 7 and up. Well there is whole lot of social stuff that she doesn't have. She makes herself so busy that she doesn't worry about it. There are many people with Aspergers and autism who are very worried about the social stuff. You can join a computer club or a model rocket club and you can get some social stuff out of that. Most of her social life is through shared interests. She is a big believer in getting the kids into special interest clubs. Temple indicated that the Internet is good for connecting with others who share your special interest. There was a lady who had interest in fancy chickens. She got on the Internet and found out there is a whole world out there of people who are interested in fancy chickens.

WATERLOO WELLINGTON AUTISM

SERVICES, incorporated in 1991, has a mission of supporting adults with autism spectrum disorders 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 the ASPIRE project directed by GSA 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 a note of 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, run by volunteers, and dedicated to adults with autism spectrum disorders 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, and provides advice and support

http://www.ont-autism.uoguelph.ca/gsa/info_new.shtml

http://www.ont-autism.uoguelph.ca/gsa/faq_new.shtml

WHAT IS 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

An important initiative by GSA and WWAS as part of the ASPIRE project. 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.

To reach GSA about any of the above:

16 Caribou Crescent, GUELPH, Ontario, N1E 1C9 Phone (519) 821-7424 or (519) 823-9232

E-mail gbloomfi@uoguelph.ca

July-August 2003

Cycle for Autism: Help Solve the Puzzle

Please support autism research in Canada!

On July 5th, John Keating and Luc Vandermeeren, both fathers of children with Autism Spectrum Disorders, began their cycle across Canada, stopping in many cities along the way for fundraising events. The goals are to promote awareness and raise \$1,000,000 in Canada for ASD research through an annual cross Canada Cycle for Autism. Find out more! Be part of the support team! Phone: 905-832-3959 Website: <http://www.cycleforautism.com/>

Websites of Ontario-based autism research centres:

Autism Spectrum Disorders - Canadian-American Research Consortium (ASD-CARC) led by Principal Investigator Dr Jeanette Holden of Queen's University <http://www.autismresearch.ca/>

CAIRN: The Canadian Autism Intervention

Research Network dedicated to early diagnosis and intervention for children with autism spectrum disorders. Based at Hamilton Health Sciences, www.cairn-site.com

9-1-1 Protocol and Crisis Plans

Nancy Cherry of Waterloo has begun a project to:

1. Develop a template for calling 9-1-1 should the primary caregiver be unable to make the call
2. Register with the police so that when a 9-1-1 call is placed there is an electronic alert displayed that gives background information
3. Register with the local hospital or crisis clinic to avoid the intake procedure when dealing with an out-of-control individual who has special needs and may be non-verbal
4. Find a tracking device to monitor children who regularly wander (and adults who want to develop more independence of movement)

Nancy has done a lot of research and made many useful contacts. She welcomes the co-operation and support of others. Please contact her at phone (519) 884-3309 or email nancy.cherry@sympatico.ca

Accessible and Affordable Natural and Organic Foods

A Guelph family has formed a buying club linked with the Ontario Natural Food Co-op. A buying club is a group of individuals who get together to buy directly from the wholesaler, thus saving money and getting access to quality products. Of particular interest to families following special diets. For more information email gbloomfi@uoguelph.ca

Gail Hurren announces the publication of Wellington Needs Analysis Survey Results (based on data collected in a survey taken January-April 2003). The survey data will guide the next steps of the *Kerry's Place Autism Services initiative in Wellington County* such as:

1. Long Term Planning Workshops focusing on Legal & Estate Planning and Personal Supports Planning.
2. Resource Day Services in North Wellington area as well as Fergus and Guelph
3. Collaborative approaches in SSAH training
4. Family Support Groups in North Wellington and Guelph that will provide both guest speakers and time for family members to talk with one another
5. Social Groups for fall for school age children

For an electronic version of the survey results:
<http://www.ont-autism.uoguelph.ca/KP-survey-rept-03.pdf>
(you will need Adobe Acrobat)

Jim Timmins is new Autism Consultant for Guelph-Wellington County, Kerry's Place Autism Services, Orchard Park Office Centre, Suite 138, 5420 Hwy 6 North, RR#5, Guelph, Ontario N1H 6J2
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In Britain, a Manifesto for Autism

has been launched as a blueprint for educational, health and welfare provision over the next ten years. Published by APPGA (the All Party Parliamentary Group on Autism) the Manifesto sets out four general principles and eleven specific objectives to deliver better services and support for people with autism, to be achieved in the next ten years. The group believes that "agencies have a responsibility to work together to make a reality of social inclusion and person-centred planning for people with autism spectrum disorders" and will work to ensure that its vision is carried out by 2013.

Among its specific objectives are provision of: multi-agency diagnostic and assessment teams in every local area; appropriate early intervention programmes; training for all professionals and auxiliary staff in autism awareness; an entitlement for families to respite for a minimum of four weeks a year; access to leisure facilities and 'meaningful' activities and, for adults, support to find employment. There is also a pledge to make autism explicitly designated for a range of disability benefits and welfare support.

FOCUS ON VOLUNTEERS

GSA has been encouraging students and others to volunteer as friends of adults with autism. Offering friendship—time to share interests and activities with a someone who has few social opportunities—is the best gift we can give. It is a valuable way of extending the network of someone who may know few others beside family and those who are paid to be in their lives. <http://www.ont-autism.uoguelph.ca/focus-on-volunteers.shtml>

A section of OAARSN website has pages on:
-Objectives of Volunteering with Adults who have Autism by Stacey Johnson;
-Current Opportunities with GSA
-Why Volunteer? - Catherine experience
-Andrew's message: how volunteers matter to an adult with autism and some tips about relationships.

Perhaps most valuable of all is a relationship in which the "neurotypical" volunteer supports a person with ASD to contribute to the community as a volunteer herself/himself.

Ranju's story is a wonderful example of that. With Catherine's initial support, but by himself for the past 16 months or so, Ranju has volunteered for nearly two years in the University of Guelph's Archival and Special Collections area. His contribution in title searching and data entry is valued by his supervisor and co-workers. Ranju says: "*I like working at the library because of the kind of work I do there. I enter the titles of books on the computer. Yes I would like to work more hours, if there was need for it. I also used to enjoy shelving books and movies at the Pembroke library.*"

Mothers of Children with Special Needs

Amy Baskin and Heather Fawcett, mothers of children with ASD, invite you to share your thoughts and experiences. They are writing a book with the working title *From Struggle to Strength: How Mothering a Child With Special Needs Transforms Your Life* to be published by Woodbine House in 2005. More information and a copy of the questionnaire form may be found in the OAARSN online news bulletin for 4 August 2003 at <http://www.ont-autism.uoguelph.ca/news-20030804.html>