

# ADULT AUTISM ISSUES IN WATERLOO-WELLINGTON

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

AAIWW Newsletter No. 26, August 2004

## AUTISM RECORDS ACCEPTED BY WELLINGTON COUNTY MUSEUM & ARCHIVES

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 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.

## Advance Announcement

*GSA AGM on Monday, 25 October will include a facilitated workshop on Autism and Community, with special reference to the idea of a farm community in our region.*

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AAIWW is published 4-6 times a year and mailed from 16 Caribou Cres, Guelph, ON, N1E 1C9. Phone (519) 823-9232. E-mail [gbloomfi@uoguelph.ca](mailto:gbloomfi@uoguelph.ca) For more frequent bulletins of news, events, issues visit OAARSN site at <http://www.ont-autism.uoguelph.ca/>

## ASPIRE Update

The board of Guelph Services for the Autistic is pleased to announce that Nancy Miles of Waterloo is the new ASPIRE Advocate. Nancy has made a very good start in her role--to support adults and their families in the Waterloo-Wellington region of Ontario to plan for and implement better lives.

ASPIRE was originally launched two years ago for a period of 20 months. GSA took stock of ASPIRE's achievements to early 2004 and decided it should continue. Continued financial help from Waterloo-Wellington Autism Services is greatly appreciated.

The new ASPIRE Advocate's responsibilities include:

- Relating to key focus persons with ASD and their families, and noting and reporting good models, issues, concerns, supports and services that require further investigation and advocacy.
- 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,
- Planning small group discussions, focused on aspects of person-centred planning for a good life in the community, such as: MAPS and PATH planning; supported decision-making; personal support circles and networks; incorporated aroha entities; finding and keeping support workers; recruiting, matching, supporting and appreciating volunteers; housing options; future planning beyond parents.
- Assisting with interpretation of Adult Needs Survey returns.

This is from Nancy's first message to the ASPIRE families: "As the parent of a 13 year old boy with autism, I understand the general experience of people with ASD and their families and that this involves a huge range of concerns, frustrations and confusions – and successes. Of course, the details are all different, but there certainly are commonalities in our experiences... I not only have an interest in, I have a passion for involvement in ASD issues, and for helping your person with ASD and your family to achieve all that you possibly can for him or her... By facilitating your awareness of options and supporting your choices, I hope to optimize the potential of each person with autism, help give expression of who they are, and aid in establishing a good life."

If you'd like to have some ASPIRE help with planning and implementing better lives for adults with autism, please phone 519-823-9232 or send a message to "ASPIRE" at [gbloomfi@uoguelph.ca](mailto:gbloomfi@uoguelph.ca)

## How to Improve Quality of Life for Adults with Autism in Ontario

When asked how the lives of adults with autism could be better, people are inclined to say “more funding.” Of course, people who are vulnerable because of autism need more resources. But, even more, they need good ideas and attitudes—a willingness by their families, friends and supporters to think creatively. Without these, all the money in the world will not be effective.

### What’s Happening Now?

1. A few agencies provide comprehensive, specialized supports for adults with ASD—notably Kerry’s Place Autism Services, Woodview Manor, and St Francis Advocates. These organizations also provide some community outreach services to children, youth and adults in their regions.
2. Some transition support from school to adulthood has used MCSS Foundations funding. The Geneva Centre offers the Choices for Adult Living program specifically for young adults with autism. Some other young people with ASD may be served in other projects funded by Foundations (or similar funding), among those with other disabilities.
3. Some adults with ASD receive direct care from Community Living associations—in residences, workshops, daycare—but we know little about how their special autism needs are met.
4. Parents and families whose adult children have ASD may belong to ASD-specific support groups (such as the Autism/PDD Family Alliance in Hamilton, HAADD in Toronto, GSA and WWAS in Waterloo-Wellington). There are also support organizations for families concerned with various disabilities, such as local chapters of Family Alliance Ontario and Families for a Secure Future.

### What More Could Be Done in Ontario?

- Increase our knowledge of the range of needs, supports, services and quality of life of adults with ASD—such as through OAARSN Adult Needs Surveys
- Commission another report to update *Our Most Vulnerable Citizens* (Autism Society Ontario, 1991). Much has changed, including widening

of autism spectrum and many retrospective adult diagnoses, the disappearance of institutions, awareness of intelligence in ASD people who don’t speak, new insights into health factors.

- Advocate for individualized planning and funding in Ontario—to match the great diversity of needs and abilities across the spectrum, and achieve flexibility, consistency and portability—by joining the Individualized Funding Coalition of Ontario.
- Provide information on the range of health-related needs of people with ASD and advocate for better access to healthcare sensitive to ASD needs.
- Advocate for continuing education that is sensitive to special ASD needs.
- Advocate for communication supports (e.g. access to subsidized communication devices and software).
- Provide information on creative personal support strategies such as person-first planning tools, homeownership, brokerage, and aroha/microboards.
- Project positive images to increase community awareness of wide-spectrum needs and abilities. Celebrate success stories where bright ideas, courage and energy have made a difference.
- Look for opportunities to encourage adults with ASD and their parents and caregivers to network by being connected to Internet.
- Recruit volunteer mentors in each region to respond to distress calls.
- Publicize and co-operate with other cross-disability initiatives.
- Support good initiatives that support best practices.
- Encourage research on topics that seem likely to improve adults’ quality of life.
- Encourage bright ideas that increase self-expression and quality of life. One example: a summer workshop for otherwise isolated non-speaking adults who are poets, writers, musicians, artists.
- Share information on dispute resolution mechanisms in each region, to help adults who are excluded from programs.

*Your ideas are welcomed!*

## ***Idea of a day conference on CREATIVE SUPPORTS FOR VULNERABLE ADULTS***

**When?** late April 2005: probably Friday, April 29

**Where?** In Guelph (probably Ignatius Hall)

**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 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?**

A program with:

-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

Informal connections and discussion

-Video record of poster presentations and summary highlights

-Process of consultation and resources beforehand and afterwards, using the OAARSN website and other media

***We plan a special contribution by making a record of the event and encouraging a lasting process of consultation and implementation to reach also those who cannot attend the conference.***

**Why is GSA planning this event?**

- To build on GSA's experience with the ASPIRE project (Autism Support Project: Information, Resources, Empowerment) since 2002.
- To empower persons and families to move ahead in implementing their person-centred and self-directed plans.
- To honour of Malcolm Jeffreys (1944-2003) of Windsor Community Living, who encouraged our group of families as he helped so many others.

Various provincial and regional organizations being invited to collaborate.

### ***Conference Outline:***

8:30-9:00 Registration

9:00 Welcome and KEYNOTE ADDRESS, integrating various elements of support, by Dr John Lord of Kitchener:

*"Values, principles and processes that work--the why of creative supports: individualized supports building community and inclusion."*

10:30: break

10:45-12:00: FOUR CONCURRENT WORKSHOPS about creative support areas:

I: Building supports with individuals

*"Nothing about me without me", "deep listening" and "why support networks are good for our health and communities."*

II: Creating meaningful living spaces

*"Making housing into my home" led by Barb Leavitt of St Marys Community Living*

III. Building meaningful supports for work and recreation experiences, *led by Dr Peggy Hutchison (Brock University)*

IV: How communities and families can make creative options work in Ontario:

12:00 to 1:00 Lunch and time to visit/discuss poster exhibits

1:00-2:45: Short presentations (15 minutes each) in either whole group (6 presentations) or in four workshop areas (24)... as above.

2:45: Break

3:00-4:00: Reconvene for debriefing summary and action steps: John Lord on *"What it means to be creative and innovative"*, so people go home charged up with practical skills for being creative.

Watch the OAARSN website for updates, email [gbloomfi@uoguelph.ca](mailto:gbloomfi@uoguelph.ca) or phone 519-823-9232

## Autism and the Family

### What is Autism?

Autism is a spectrum disorder that affects social and communication skills. It generally is apparent during the first three years of life. Its symptoms vary from person to person. Autism knows no racial, ethnic, or social boundaries and occurs in families of all income, lifestyle or educational levels. It is four times more dominant in boys than girls. It is believed that as many as 1.5 million children and adults in America have Autism. Autism is not a disorder that can be "outgrown" but the symptoms often may lessen as the child develops.

### Common Characteristics of Autism

- Insistence on sameness; resistance to change
- Difficulty in expressing needs; uses gestures or pointing instead of words
- Repeating words or phrases in place of normal, responsive language
- Laughing, crying, showing distress for reasons not apparent to others
- Prefers to be alone; aloof manner
- Tantrums
- Difficulty in mixing with others
- May not want to cuddle or be cuddled
- Little or no eye contact
- Unresponsive to normal teaching methods
- Sustained odd play
- Spins objects
- Inappropriate attachments to objects
- Apparent over-sensitivity or under-sensitivity to pain
- No real fears of danger
- Noticeable physical over-activity or extreme under-activity
- Uneven gross/fine motor skills
- Not responsive to verbal cues; acts as if deaf although hearing tests in normal range.

For children with autism, sensory integration problems are common. Their senses may be over or under active. Some children are particularly sensitive to sound, finding even the most ordinary daily noises painful, others may be sensitive to light and need to wear protective glasses and some may be sensitive to touch and find that they are unable to wear certain fabrics or to keep their socks and shoes on.

### What Causes Autism?

Through brain scans, scientists have found that children with autism have abnormalities in brain structure and function. The scans show that they have different shape and structure. The causes of autism are not yet known. Theories include: genetic factors; problems during pregnancy or delivery as well as environmental factors such as viral infections, metabolic imbalances, and exposure to environmental chemicals; and vaccines. Children are born with autism or are born with the potential to develop it. Bad parenting does not cause

*Autism affects families enormously. They are challenged physically, emotionally and financially. Everyday things that most of us take for granted have to be carefully planned and executed. It affects the social patterns of the families and friends. More support through government agencies and community services are necessary. Better understanding through education for friends and families should be more available. Autism is a lifelong disorder and help needs to be available and affordable from childhood to old age. Every human life is something to cherish.*

autism; the children are not unruly kids who choose not to behave.

### The Effects of Autism on the Family

The following summary is based on responses from five mothers of sons with autism. The children are 4 ½, 11, 13, 19 and 36--an interesting range of ages.

### Living Arrangements

Four of the children currently live at home with their families. The oldest subject lived at home until he was 12. From 1980, before Special Education was compulsory for Boards of Education, he attended a residential school from age 12 to 21. He came home on weekends and holidays, so was home about half the time. Currently he lives in his own home where he tries to do all he can for himself. His mother spends most of her time in his home providing support and companionship and coordinating any other people who help him as support workers or volunteers.

### Diagnoses

Most of these families suspected their child had a disability by age 2 but usually diagnoses took 2 to 3 more years. Three out of the five families had other children with disabilities such as language difficulties; deafness; and math, reading, and writing challenges.

### Major Adjustments for the Family

Families with children older than the one with autism were asked if the family had to make major adjustments when it became evident that the younger sibling was autistic. Most families underwent drastic changes in family practices and behaviours. Mothers in particular now found they were exhausted all the time and found it hard to function well. One mother commented that she loved to sing to her children but had to stop because her son would scream and go into fits. Everything had to have locks and be put away, nothing could be left out that could get broken. Some families had to change their diet. One mother said that her home lost the quality of relaxation that "home" implies. Attending appointments and having people coming to the house for evaluations were very time consuming and draining.

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*Report by Melissa Hart of Guelph for her Grade 12 course, Individuals and Families in a Diverse Society.*

### **Communication**

Most of us would agree that love and support are the backbone of the family with communication next in line. Communication varies drastically in autistic children. All the children in this report communicate with their families, some easier than others. The 4 ½ year old and the 19 year old both have normal speech. The 11 year old does not speak. He uses sign language to a certain degree, plus gestures. He understands what is said to him. The 13 year old does not communicate verbally but uses picture exchange symbols (PECS) to make requests. He also uses gestures and a little bit of sign language. He understands what is said to him. The 36 year old has not spoken since the age of 4 or 5. He uses sign language, PECS and facilitated communication (FC) which is most reliable for him.

### **Sibling Awareness and Interaction**

In all of the families the children are very aware that their brother has autism. The siblings all spend quality time with their brothers. However, behaviour and health concerns occasionally limit activities for some. In one family, siblings find it best to do things that he already has developed a level of competency. In another family where the autistic child is the youngest, the children often play together on the trampoline, swim in the pool, sing songs with him and chase him around the house. The older two sisters often babysit him on their own. In another family the twin sister spent quality time with her brother when they were young but found it more difficult in their pre-teen and early teen years, but became good companions and friends later. His sister was a strong supporter and was proud of his efforts. She passed away when they were 27.

When asked if the autistic child attended school with his siblings only one out of the five had. During difficult times in class the sibling was able to help out.

In all these cases the mothers found it difficult to spend equal time with both the neurotypical children and the autistic child. The autistic children need so much more attention and care. All the families have both parents and they work very hard together to make time for everyone.

Autistic children often get help with outside services such as respite and home services. Generally this extra attention to the autistic child does not affect the other children in the house. In one family the siblings enjoy meeting and getting to know their brother's workers. They appreciate the time that someone else watches and entertains him. Only one family said that they used to use services but currently found it too expensive and unaffordable.

In all of these families, the autistic child does do some household chores. Even the 4½ year old clears his dishes from the table and picks up his toys. The 11 year old occasionally wipes up spills that he has made but is usually not aware of messes that he has caused. This sometimes annoys his sisters when they are asked to clean up after him. Yet they are very understanding that he is not capable of helping with household chores. The 13 year old empties and fills the dishwasher; he has set the table in the past but with lots of supervision. The 19

year old helps out with many household chores. He can cook; do dishes, clean floors and dust furniture. The 36 year old sets the table and has developed more kitchen skills as an adult.

When asked if the siblings are comfortable having friends over to the house when their autistic brother is home, I got a mixture of answers. Most siblings had no problems when their brother was young. Those who experienced problems or embarrassments were usually in their teens. One because of some unusual behaviours, such as suddenly disrobing, whining, and sometimes becoming aggressive or violent. This boy is currently experiencing times when he is well and doesn't behave like this at all but there seem to be a cycle so the other children in the family have to wait for those times to come around. One boy is very popular with his sibling's friends as he shares an excellent knowledge of computers and electronics with them. When the oldest boy in this report was about 6 (1974), children were less tolerant of differences and disabilities and he was taunted by them making it uncomfortable for his sister to have friends over. Children were much less understanding than they are today.

### **Awareness and Interaction of Others**

Posing this same question to the mothers about their friends' comfort levels with the autistic child, I also received an assortment of answers. Each case varied. One mother answered that she wasn't sure but had never received a negative response from her friends. Another answered that some friends were uneasy and uncomfortable with the way he acts, as he is very loud and has a lot of energy. He can be overly friendly and sometimes will sit on people's laps and some friends do not like it. In general, most of her friends take it in stride but don't really interact with him. Another mother responded with "what friends, we have no friends and even family don't come around any more". This child has an aunt that has moved into the vicinity who has experience with these types of children but because of health problems she needs to be careful. The mother finds it nice to have her around, though it is not often. This mother finds that her friends tend to be other people that she meets through autism-related activities but they are more acquaintances than friends. Another mother also found that most of her friends were involved in autism support groups and planning services.

### **Family Outings**

Family outings can be quite an ordeal for these families. In one family, one person usually stays home to look after the autistic boy or they get respite help when everyone needs to be away, as this boy gets very upset when he goes places he doesn't like. Occasionally showing him pictures before hand helps. Another family always takes two vehicles, that way when they see behaviour that indicates that he is breaking down one parent can leave. If not, it is likely that the boy will have a full-blown tantrum, which is often accompanied by violence and aggression. If they see signs of heightened autism before going out they will choose not to take him. Keeping a regular schedule of very well balanced meals and regular water along with his supplements and enzymes are a must. The foods are specialty items and he cannot have the regular treat foods that children usually get on outings. This requires carefully prepared and packaged food before the trip and sometimes separating him from the rest of the children on the outing so that he doesn't see them getting treats. Careful

attention to this is imperative so that he doesn't feel badly about this. He is aware of what treats he likes and it hurts when he sees the other children getting them. Another mother said that they avoid crowded situations where there are a lot of strangers. Their son prefers predictable surroundings where he has a safe place to go if he feels agitated. However in 2003 when he was 18 he was able to travel by airplane to Texas with the family with only his Gameboy and Walkman for safety. The mother of the oldest boy involved in this report found family outings and holidays were very hard when the children were little. But once the children were in their mid twenties they loved to travel together with the family dog. He continues to love traveling though his special diet and sensory integration needs mean that they have to take a lot of stuff along. The youngest boy involved in this study has sensory issues but they can usually be dealt with at the time.

### **Support and Services**

All families agree whole-heartedly that there is not nearly enough support or services, from diagnosis to treatments to family supports made available to everyone. Raising an autistic child calls for extraordinary and super human resources. Access to early diagnosis is essential. ABA (Applied Behavior Analysis)/IBI (Intensive Behavioral Intervention) and discrete trial therapy/education needs to be made available to every autistic person/family that wants it. Parents would also like to have access to medical tests to investigate what is wrong with their child. Many autistic children cannot communicate how they feel or many do not even know what it feels like to be well. Full physicals should be available regularly to check for illnesses or pain they are coping with. This would help to alleviate a lot of negative behaviours.

Financial issues can also be a major concern. Special services at home and respite are available but are very expensive and it can be hard to find good workers and families often go through long periods of time with no one available. One family says they only get two hours a week of home services. As autistic children need constant care and attention, two hours a week is hardly enough. Families often find that friends and family don't understand and tend to draw away. With more knowledge given to explain autism the fear and rejection by others could be lessened.

These mothers had great ideas and opinions on services they would like to see be made available. It was suggested by one mother that she would like to see a place in the community with trained workers where the kids could go and play and be accepted. A camp geared only for autistic children was also suggested. In Britain there has been discussion among political parties on a ten year plan to insure that every family that lives with autism will have its own support person who provides guidance as to how to get services from the system. There is a region in northern Ontario in which such as support person may be provided. This kind of help everywhere would make a great deal of difference. A great form of

support that no longer exists was available in the Guelph area in 1980. It matched "natural" families who had children with special needs with "host" families (in essence, volunteers that wanted to understand and be friends). They visited each other and built up friendships until the host family felt comfortable having the special child visit by himself overnight or for a weekend. It was wonderful as a humane and natural form of respite and also increased general community understanding of what it is like to live with special needs.

### **Advice to Others**

All the mothers had great advice to give others, particularly those just finding out that their child is autistic.

- Always remember that autism is just a label and it is not who the child is.
- Take every bit of help you can get but be realistic. Not every therapy helps every child.
- Get support immediately and look into all aspects of therapies that you feel comfortable with.
- Do not give up!
- Get ABA therapy right away if you can regardless of the costs – it will pay off in the long run.
- Make sure you get complete medical and nutritional profiles done on your child.
- Document everything. Be carefully what you sign (particularly institutions such as schools).
- Don't make your child your life's work.
- Have fun in whatever way they are able to.
- Work hard with your child but have some fun along the way.
- Don't become obsessed in trying to make your child better. They will progress as far they are meant to.
- Don't rush your child or yourself and above all do not blame your child or yourself.
- Never feel like a failure. We can only give what we can.
- Educate yourself.
- Meet other parents. Find out how they handle things.
- Keep in close contact with your case manager.
- Stand up for yourself and your child.
- Research at your library and see what others have found that helps.
- Participate in the research that is going on.
- Love and believe in the child beneath the autism.
- Find ways for the child to express himself/herself in whatever forms it takes.
- Find and cherish true friends for the child with special needs and for the family.
- Plan time with your other kids. Set aside a date even if it is with one parent once a month.
- Take care of yourself.

## **NEWS of MCSS Consultations – Immediate Action Required!**

According to another disability organization, the Ministry of Community and Social Services is appointing a steering committee to advise the Minister on how to proceed with her "transformation" of Developmental Services in Ontario. This very important process will profoundly affect developmental services for many years to come. A Steering Committee is being formed, to begin meeting in early August 2004 and create a "high level paper" by early September. This paper will be the basis for broad public consultations to be completed by February/March 2005. There is not much time. This committee and paper will also define the all-important terms of reference for the broader provincial consultations.

Unfortunately the Steering Group is composed almost entirely of service providers who tend to oppose any additional consumer representation. However families and self-advocates are requesting equal representation at the table. If the goal is transformation of the current system, why is the committee stacked with upholders of the status quo?

Fortunately the final decision on the composition of the steering committee will be the Ministry's. Let the Ministry and your elected representatives know how you feel about this. If you or your group feels that families and people receiving supports/services should have an equal voice and equal representation at these consultations, then you should communicate your opinion and recommendations IMMEDIATELY to Deputy Minister Kevin Costante. GSA and OAARSN have written to the Minister and Deputy Minister, with copies to local MPPs, asking that persons and families be informed and more fairly represented in a more open and transparent consultation process.

For further information about the consultation process, contact Deputy Minister Kevin Costante, or Assistant Deputy Minister Andrea Maurice. Kevin Costante, Deputy Minister  
Ministry of Community and Social Services  
Hepburn Block  
6th Floor, 80 Grosvenor St  
Toronto ON M7A 1E9  
General Inquiry: 416-325-5225  
Fax: 416-325-5240

Andrea Maurice, Assistant Deputy Minister, 416-325-3592

## ***Some Autism Titles***

***Taking Care of Myself: A Hygiene, Puberty and Personal Curriculum for Young People with Autism*** by Mary Wrobel (Future Horizons) \$24.95. Mary Wrobel offers an unique combination of social stories and easy-to-understand activities which reduce the fear and/or confusion surrounding subjects such as brushing teeth, using toilet paper, eating fruits and vegetables, the need to go to the doctor/dentist, when it's proper/not proper for people to touch you, being naked, and personal hygiene in private areas, shaving, periods, among numerous other important subjects.

### ***Ask and Tell: Self-Advocacy and Disclosure for People on the Autism Spectrum***

Editor: Stephen Shore, author of ***Beyond the Wall: Personal Experiences with Autism and Asperger Syndrome***. Foreword by Temple Grandin; contributing authors: Kassiane Sibley, Stephen M. Shore, Roger N. Meyer, Phil Schwarz, Liane Holliday Willey. \$21.95. ***Ask and Tell*** is unique in being the first book to help people with autism to self-advocate in their pursuit of independent, productive, and fulfilling lives and in consisting exclusively of contributions by those on the autism spectrum for persons on the spectrum.

### ***Living in the Spectrum: "Autism and Asperger's"***

Mindscape Productions of Michigan announces a new audio CD contains interviews with those in the spectrum as well as parents and professionals. Poetry and music by those who have Autism and Asperger's is also featured. Brian Henson of Brantford, Ontario is featured on the CD with a couple of his poems. Click on the headline for more information, reviews and some audio clips. Phone 1-800-937-3397 or (508) 820-8738 (9am-6pm EST Mon-Fri)

### ***Silent No More: Communication Boards Available***

Susan Rzucidlo, of Philadelphia developed this outstanding tool for law enforcement, fire rescue, EMT's and ER first responders. The laminated board features 24 key communication situations. It utilizes picture icons and words and phrases in English and Spanish as a way for first responders to communicate with persons with autism and other cognitive conditions, as well as non English speakers. Contact Susan for details: Email [srz@dol.net](mailto:srz@dol.net) Phone 610-274-2364

From Dennis Debbaudt's Autism Safety & Risk Newsletter Summer 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 (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 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/gsaifo\\_new.shtml](http://www.ont-autism.uoguelph.ca/gsaifo_new.shtml)  
[http://www.ont-autism.uoguelph.ca/gsaifaq\\_new.shtml](http://www.ont-autism.uoguelph.ca/gsaifaq_new.shtml)

Contact GSA about any of the following, to donate to our ASPIRE efforts, 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](mailto: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.

### **Support Group started for Users of Facilitated Communicating in Southern Ontario**

Seven men who have used FC for up to 13 years have begun meeting, with their FC supporters and friends. Their conversations together are very powerful and moving. Before a recent meeting, three of the men had not known that anyone else in the world used FC. One man is just graduating from high school; he has been permitted to use FC through his high school years. If you or someone you care about uses FC, or could benefit from this form of augmentative/alternative communication, please contact GSA and we'll put you in touch.

### **Adult Autism Needs Survey**

used in the ASPIRE project has been revised after a pilot test period. We have also taken the opportunity to adapt the survey to new SNAP software. OAARSN (on behalf of GSA and WWAS) is conducting this survey as a free public service. Private information about individuals will not be shared with or passed on to any agency or researcher. We offer two versions. It's important for everyone concerned with autism in adulthood to complete at least the short-form survey.

1. The "long-form" survey takes about 25 minutes to complete. It has questions about abilities and challenges, treatments and therapies, quality of life, and planning for the future. This is for persons and families who are actively concerned to achieve the best possible quality of life in adulthood.

2. The more basic short-form survey takes only 5 minutes to complete. We hope you will respond online. Visit the OAARSN site at the address in the column to the left, and use our Google Search function to find "AANS 2004." If you prefer to complete and mail a paper survey, please request the form from GSA (see contact details in the column to the left).