

ADULT AUTISM ISSUES IN WATERLOO-WELLINGTON

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

Newsletter No 17, October 2002

WHY ASPIRE?

Aspire means hope to achieve a better state of being. ASPIRE has a special meaning for folks in the Waterloo-Wellington region of Ontario who live with autism spectrum disorders, in offering hope of better lives in their own communities.

How can this be possible? We have not found some magic elixir or silver bullet that will cure autism. We know that autism is too complex and pervasive for a single remedy and that each adult needs a unique and well-coordinated strategy of interventions. Governments or foundations are not about to shower us with funds (though increases would be welcome). If they did, there's no guarantee that lives would be better, as resources have to be used well to be effective for each person. Charitable agencies are not about to take complete responsibility for autistic adults from their families at 18 or 21. We know that agencies cannot make longterm guarantees, that their programs and services often do not match the needs and abilities of our adults with autism, and that families may be sidelined by agency staff.

What are the hallmarks of ASPIRE?

- ❑ Person-centred focus, respectful and sensitive to each individual's priorities and situation—expressed in a unique personal plan.
- ❑ Self-expression and self-determination by the person (by whatever means work) and deep listening by others.
- ❑ A central role for families who know their daughter/son best and have a lifelong commitment to their well-being.
- ❑ A network of real personal relationships with longterm friends who care, listen, understand, and share parts of their lives.
- ❑ Having a home of one's own that, if it is shared, is with people one chooses.
- ❑ Ways to contribute to the community by being present and through meaningful work.
- ❑ Opportunities to grow in mind and spirit and for initiative and decision-making.
- ❑ Continued research to understand symptoms and challenges and also the most effective interventions and therapies.

- ❑ Advocacy for secure and predictable disability funding that is both flexible and accountable.
- ❑ Ways of co-ordinating all resources and supports so that each person has a good whole life that seems seamless.
- ❑ Longterm security (beyond the lives of parents) that is based on a share of family resources as well as entitlement to disability supports from public funds.

How do we know it's possible?

One Guelph man, quite severely challenged by classic autism and some hard and tragic experiences, already has most of these hallmarks of a good life. He also has pioneered two legal and organizational mechanisms that make his good life more secure.

- His own home, financed by his parents, is maintained in trust for his lifelong occupancy by Guelph Services for the Autistic. GSA also protects his rights to choose homesharers to support him to live as independently as possible in his home.
- He has an *aroha*, an incorporated entity for personal empowerment and support, similar in values and functions to what is called a "microboard" in British Columbia or, in various American states, a "self-directed support corporation". He is a director of his *aroha*, together with his parents and several friends who are younger than his parents. His *aroha* has legal powers to receive and manage all resources in ways he chooses and which support him best to have a good life, now and in the future. (continued on page 2)

How to reach ASPIRE (Autism Support Project: Information, Resources, Empowerment)

Leave a message for "ASPIRE" at (519) 821-7424 or gbloomfi@uoguelph.ca

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How can ASPIRE help?

ASPIRE Advocate Jan Cooper and the Steering Group can help with information and resources so families who want a good life now and a more secure future can be empowered to:

1. With their daughter/son, make plans for a better life now and in the future, using the tools of person-centred planning such as MAPS, PATH, CIRCLES.
2. Develop a circle, cluster or network of friends who spend time with, listen to, and speak up for the person with autism.
3. Search out explanations and interventions to help cope with the symptoms of autism and achieve a better quality of life.
4. Find or create resources and supports for work, learning and recreation in home communities.
5. Consider options for having a home of one's own, shared with people one chooses.
6. Consider forming an aroha, with legal powers to receive and manage funding and other resources now and in the longer term.
7. Plan and advocate for community resources needed by other people who are vulnerable because of disability.
8. Reach other families and circles of friends who have similar ideals and concerns.

ASPIRE's goals and limitations

What caring families and friends would not want ASPIRE's free help? The project will appeal particularly to families of older teenagers and young adults facing the transition out of school placements, and to aging parents who continue to support their autistic adults at home and are very worried about the future. We are contacted also by adults who were not diagnosed as children but who suspect they may have High Functioning Autism (HFA) or Asperger Syndrome (AS).

But ASPIRE has only limited funding from non-Government sources. Its Advocate works an average of 10 hours a week for the next 18 months. She and the Steering Group cannot take over detailed planning for each individual. Her roles are to:

1. Meet with families and individuals who are interested in comprehensive planning for a better life and who have already responded to the detailed needs survey;
2. Be knowledgeable and supportive about community resources and creative options that families and individuals may choose to pursue.

A successful ASPIRE experience will help a few individuals and families to make a big difference in their lives. Documentation of its successes will provide a foundation on which more such support may be provided—in our region and others.

what is aroha?

The Maori word "aroha" from Aotearoa/New Zealand is proposed as the generic term for incorporated entities for personal empowerment and support (similar to "microboards" in British Columbia or "self-directed support corporations" in various American states).

Aroha means the various qualities and values that are needed in a caring circle of friends. Its meanings include affection, love, charity, compassion, empathy, concern, trust, pity, understanding and true friendship—all in active ways, not just ideas or feelings.

The first aroha in Ontario has been incorporated with and around a man in Guelph. This aroha is willing to share its experience with other circles of families and friends who want to incorporate.

New Adult Needs Survey

If you are not yet able to consider a full personal support plan with ASPIRE's help, do make sure that you are counted in the new survey of adults with autism. We urge everyone who is, supports or knows a person on the autism spectrum who will be 17 years or older by the end of 2002, to co-operate with one of the two OAARSN surveys.

1. The more detailed "long" survey, for people and families who are actively planning, takes 30 minutes to complete; it has questions about abilities and challenges, treatments and therapies, quality of life, and future planning.
 2. The basic "short" survey takes only 5 minutes. It's important for you to complete the short-form survey at least, as the numbers and needs profiles that come out of this survey will help GSA and other groups to advocate for people who live with autism and to plan future projects like ASPIRE. If possible, complete the online versions of these surveys at www.ont-autism.uoguelph.ca/aansurveys-2002.shtml
- Request paper copies of the long or short surveys by leaving a message at phone (519) 821-7424 or email gbloomfi@uoguelph.ca. Completed paper surveys (both short-form and long-form) may be mailed to GSA (ASPIRE), P.O. Box 23016, Root Plaza Postal Outlet, GUELPH, Ontario, N1H 8H9.

Books on the Autism Spectrum

SPECIAL LIBRARY COLLECTION

Waterloo-Wellington Autism Services has resolved to make a substantial gift to start a special autism collection of books, videos, and other information resources, at one of the public libraries in its region. Details are still being discussed, but we hope the special collection will be set up and in use by early 2003. Congratulations on this great idea and splendid initiative!

Look up the OAARSN website for a lists of likely books and videos at:

<http://www.ont-autism.uoguelph.ca/books.shtml#6>

Featured Book Review by Andrew Foster

Autistic people don't read between the lines

A layman's commentary on:

Autistic Thinking - This is the Title by Peter Vermuelen. Jessica Kingsley Pub; ISBN: 1853029955; 2001.160 pp.

This is a book that rings bells for a reader acquainted with autistic people. A few of them are alarms, but most of them ring with clear truths. It is refreshing to read, and sheds much light on things that we don't spend enough time thinking about. The title gives a hint of the easily digestible nature of the book, being a gentle autistic joke in itself.

Some very simple statements remain in the mind after reading the book. One is that there is some autism in everyone. That suggests that autism is a developmental stage through which most people pass. A second is that autism is a disability: a statement of the obvious, perhaps, but necessary for those who would suggest that autistic people will be just fine if we would only try to understand them and integrate them into society.

I know only one autistic person really well, and perhaps I only think of him as autistic now when he does something inexplicable or annoying. I use his autism as an excuse for my own responses. Most of the time his actions are familiar, even predictable, and part of the domestic continuum in which he lives. However, I've never analysed what it is that has let me feel comfortable with him, and what it is that remains a barrier to communicating clearly with him. This book goes a long way towards explaining both his thinking and my own.

Peter Vermeulen begins with the frequently used comparison between autistic people and computers, and an alarm rings. My friend isn't a computer. Over half way through the book the author makes a fundamental point whereof I wanted to be reminded at the beginning: machines have no consciousness. As an engineer, I am familiar with amazingly complex machines that are power tools of the most amazing versatility, and some of them are computers, of course. But I never expect to encounter

<http://www.ont-autism.uoguelph.ca/books.shtml#7>

Reviews and notes about **Books on the Autism Spectrum** may be found on OAARSN's site:

<http://www.ont-autism.uoguelph.ca/books.shtml>

We welcome suggestions of new books that should be noticed or reviewed on OAARSN and AAIWW.

We appreciate the efforts of our volunteer

reviewers—including in the past year: Lucie Milne, John Clifton, Jan Cooper, David DeVidi, Kirsty Forsyth, Andrew Foster and Amar Arneja. Various other reviews are now under way.

a machine that spontaneously projects passion, feelings, emotions. In the autistic person these are all present, as in the rest of us, and are expressed in ways that can range from tender to disturbing. No machine can do this, nor can it be programmed to do it. "Artificial intelligence", or "machine intelligence" are well known fields these days, but no machine can perform any action that is not ultimately the result of programming by a human. The inner, intellectual core of the autistic person is not programmed or programmable, though outward behaviour may well be moulded by observation, persuasion and practice.

If the computer analogy must be pursued - and I wish it wouldn't - the difference between early operating systems such as DOS and Windows might be worth looking at to see if we all resemble computers. DOS was one of the first systems that enabled ordinary people to operate their personal computers. It depends on the operator understanding purely logical actions and then implementing them. It was the minimum system needed to make the machine work. Perhaps the autistic person simply uses the minimum that we all need to function. At least in the early stages, Windows was no more than DOS with a myriad of small programs added to make the machine perform frequently used functions with indirect, but easier - mouse click - instructions. It was claimed to be intuitive, but needed training and much practice for the user to become proficient and for the machine to become useful. The screen had become cluttered and the user had to discern which functions were needed for his or her particular applications, and then find out how to use them. Many of the functions seemed useless to the average user, but could not be ignored if the desired function of the machine - such as opening a word processor - were to be achieved. Despite the clutter and annoyances, nobody will go back to DOS for everyday use - the benefits of the new developments are too great.

It is not so very different in the acquisition of social skills. In our human behaviour we have been programmed to do such things as smile, shake hands and wave to each other. Logically, these actions are useless, though they have come to be accepted and expected as the

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conventional marks of the various stages in human interaction. But social development has forced them on us, in the same way that Microsoft Corporation has forced useless computer functions on us if we want to be able to use their programs. The autistic person can be persuaded to smile, shake hands and wave, but surely knows that these things are not part of the core that makes a person function. On the other hand, it is often said that autistic people avoid eye contact. This is a cruel fallacy, and nothing is more poignant than the autistic person who looks you straight in the eye with a bright, intense expression that says, "I want you to know something". This is a powerful attempt at self-initiated communication, and no computer is ever going to do that.

The author happily disposes of this reader's initial concern with a thoughtful discussion of types of intelligence, showing that computers will always stop dead in their tracks at the point of needing the "integrating intelligence" that all humans possess in varying degrees. He also refutes the idea that autistic people are like robots, rather implying the opposite; that autism would be a good model for an advanced robot. Interestingly, he discusses the Turing test of an intelligent machine postulated by Alan Turing, the brilliant developer of some of the earliest modern computers, whose own life had more than a suggestion of autism about it.

A second, and intriguing, point made early in the book is the relevance of humour to autism. I had to stop a moment to think about this, since it was something I was aware of without it having aroused me like the computer analogy. The classic undergraduate psychology question is "What makes a joke funny?" A workable answer is that a joke is an expression of disorder in life as we expect to experience it. It follows that perhaps humour is a positive appreciation of that disorder. This would make sense in the autistic view of the world, because the autistic person has a powerful affinity for order and routine in all things. The mature autistic person's acute powers of observation tell him that the world around is not nearly as orderly as he would like it to be, and humour can sometimes make this tolerable. An example happened when we were working on a tree-trimming project - as orderly an activity as could be desired. However, my friend became disturbed at a few pine needles that were somehow out of place. I finally pointed out that there were millions of the things under our feet, and there wasn't a thing we could do about it. There were no more disorderly pine needles after that, and the work proceeded smoothly. The reduction of disorder to humour can make life's disturbances tolerable for all kinds of people. Humour is a serious matter, as the author points out.

In the very illuminating discussion of humour, the author has valuable insights that apply to human interactions in general, as well as to the particular case of autism. He points out that it is unreasonable to expect the autistic person to read between the lines and still expect him to appreciate the joke. One thinks of the type of drama so popular in the 1960s where the entire story seemed to be between the lines, and simply attempting to understand what was on the lines ensured that the story would never be understood. If we can learn to

communicate explicitly an illogical, or paradoxical situation to an autistic person when we want to tell a joke, then we may well become better communicators ourselves.

This book is a two way lesson in understanding thought processes. The "Green sweater situation" story is an excellent example of the thinking that non-autistic people can use to handle logical processes. It opens up the rigidly logical thinking of an autistic girl who associated a particular required behaviour in the classroom with the sweater she wore on a particular day. The example cuts through the unintentionally less logical, and more intuitive sequences that we often apply to what we do, and draws attention to every detail that affects the process. We usually make the flying leap across the details to the realisation of the expected action, while the autistic person evaluates every detail and stops when permission to proceed isn't there. In the sweater story, it seems that it was the presence of a green sweater that gave permission to proceed to the required behaviour. The author says that this indicates a confusion of identities, and the girl assumed a different one while wearing different clothes - an interesting, but harder concept to comprehend.

A change of clothing - a change of identity? Perhaps it is not so far fetched. Having seen the anguish that an autistic person experienced in using new clothes, the argument has some credibility. Being forced to relinquish even a part of a painstakingly developed identity can be excruciating. When an employer once wanted to me to wear a shirt carrying the company logo, I simply couldn't give away even that little piece of my identity to him. I took it home and tore it up for rags, feeling a certain sense of relief - relief from an attack on my identity. In the more focused and intense autistic person, that feeling must be greatly magnified.

Vermeulen quotes a touching line from an autistic child: "Mama - can you put me together, please, because I broke?" There, a small person thinks - perhaps understands - that his identity is becoming fragmented. Perhaps the event that precipitated the plea was nothing worse a cut or a graze, but it said, more clearly than a medical or scientific person could, that identity is a terribly fragile thing, surely the more so in an autistic person's mind, lacking much of the resilient emotional cushion that the rest of us have built up around ourselves.

There's plenty of basic wisdom that comes from experience in this book. For example, "... people with autism often react slowly and display delayed reactions,. Our world moves too fast for them and, frequently, we don't give them enough time to decipher it." Good advice.

Generalisations tend to set off alarms, but Vermeulen discusses one (p86) that is worth pondering and quoting in full:

People with autism all tend to commit the same mistakes in interpretation. Their inability to understand the coherence in communication (idea) is closely related to the problems they experience with social coherence (context). The social aspect of communication presents the greatest stumbling block for them. However gifted they may be, the idea behind the

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communication often escapes them. The most essential aspect of the communication (the idea) cannot be experienced in its literal sense. Ideas are seldom expressed literally, in fact, they are not expressed but rather left unsaid. For people with autism, the ideas behind the communication are, literally, a secret.

There seems to be a theme developing here:

Don't ask the autistic person to read between the lines. To do so means that you are holding a secret from him.

It works both ways, of course:

A major mystery for people with autism is finding the way to adapt their communication skills to other people, to the context. This is not to say that they don't try. But just as in the case of social behaviour, their efforts don't often proceed past some ineffective copycatting.

The author is telling us to listen carefully and to understand the limitations of the person to whom we would listen. We mustn't read between the lines, either.

After a few chapters the reader gets the impression that he or she is being taught somewhat like an autistic person. The author knows that many of the concepts and explanations will be unfamiliar, so they are repeated many times over in different contexts until the reader is trained and ready to move on. We don't usually have to be taught about cohesive thinking, because it is something that has evolved within most of us, and don't need to think about it. We have to understand what it is, though, in order to understand why our autistic friends can and can't do things. Vermeulen hammers this point home until the most resistant reader begins to grasp and believe the concept.

The chapters on rigidity and problem solving seemed closer to home for this reader. They narrowed the gap between autistic and non-autistic people considerably. Some of the behaviours discussed seemed much more familiar, and in another context might have been described by a useful word that seems to be slipping out of our language: eccentricity. It is an interesting zone where the distinction between autism and humour is pleasantly fuzzy. Still, the author cautions elsewhere against the damage that can be done by ridicule where, with care, the humour may instead be brought out and shared.

The author serves the reader well in facing quite harsh realities, speaking against some familiar conceptions. He refutes the idea that the autistic person is imprisoned in his or her own body, waiting to be released by a cure that has yet to be discovered. And not all autistic people have a high level of intelligence. He believes it to be a fact that, "Autism manifests itself on all levels of intelligence. Most people with autism also have a learning disability and are thus doubly disabled". Later, he offers the useful observation that, "We can get closer to people with autism when we do not simply romanticise their stronger skills into talents but consider them as functional survival strategies. When we want to help them, we have to build on that". This is surely a good survival strategy for those around autistic people, too. Unrealistically elevating one's expectations leads inevitably to disappointment and reduces the capacity to be a friend and supporter.

As the book ends, the author returns to the computer analogy. This time it is less threatening, and the author notes that computers and autistic people share some difficulties. Neither of them can develop or relate to analogies - similarities are as far as they can go, by comparing remembered information with observed data. A crucial difference is that the autistic person adds the new data to his memory, while the computer will only do so against a specific instruction.

I liked one of the closing statements (p147):

*It is a challenge for all coherent thinkers to assign a place in our society for people who think in literal terms. But people with autism need more than just help. They deserve appreciation for being themselves. They can, if we allow them to do so, contribute in a meaningful way to society. We do not need to offer individuals with autism a place in our society **in spite of** their autism, we need to offer them a place **because of** their autism.*

At a job interview that I thought had been going pretty well, the interviewer suddenly said, "But reading between the lines of your CV..." and I knew it was all over. I wanted him to read what was *on* the lines. Instead he drifted away into a confusion of his own making, and I lost him.

Autistic Thinking - This is The Title has a good message. If you would communicate with autistic people, don't ask them to read between the lines. Peter Vermeulen explains in admirable detail and clarity why this is so.

AAIWW BULLETIN BOARD ANNOUNCEMENT:

Kerry's Place Autism Services and Family Counselling & Support Services:

Community Education Workshops on Autism Spectrum Disorders for Guelph-Wellington

#4 Behaviour Management Supports (October 30);

#5 Communication Strategies (Nov. 13);

#6 Introduction to Applied Behaviour Analysis Principles (all of Nov. 19, 22 and 27);

#7 Long Term Planning (Nov. 28).

Most workshops are 6-9 p.m. and in Guelph's West End Recreation Centre. For more information and to register: Call Erica Gatten at Family Counselling & Support Services (519) 824-2431 ext. 36.

COMMUNITY IS NOT A PLACE BUT A WAY OF LIFE

From a speech by Herbert Lovett in Dallas, May 1996. Herb Lovett, who was killed in an auto accident in March 1998, would have been 53 on August 27. We commend his book, *Learning to Listen: Positive Approaches and People with Difficult Behavior* (1996).

We are in the beginning of a liberation movement, where people are freed from being told that rights are privileges. Rights are not privileges. People with difficult behavior are constantly being told they have to earn their way to community. But it is everybody's right.

- ❑ Community is not a place but a way of life.
- ❑ Community means you choose where you live, with whom and what you do with your life.
- ❑ You do not earn your way into ordinary schools.
- ❑ You do not prove yourself ready to a team for the job you want. You apply to your employer and start working.
- ❑ You do not prove to a team that you're ready to have a home of your own. You live in one.
- ❑ You should not have to be charming to get the help you need.

But we have people all the time having to prove they are good enough. And that is just wrong. And whose behavior is difficult behavior?

- When someone spends all day working and they get a meaningless treat at the end of it, who is behaving badly?
- When someone gets ignored for being inappropriate or sent off alone or is kept isolated, who is behaving badly?
- When someone gets drugged up or tied down, who is behaving badly?

- When someone gets to earn a trip to the mall for not annoying people, who is being manipulative?
- When someone gets ignored for being inappropriate or is sent off alone or is kept isolated who is behaving antisocially?
- When someone gets tied down or is drugged up, who is behaving aggressively?
- When people get routinely physically restrained, whose behavior is out of control? When people are kept apart from what they enjoy doing apart from the places they want to go, and apart from the people they want to be with, whose behavior is antisocial?
- And when people keep doing the same meaningless rehabilitation exercises year after year or keep the same behavior plan year after year and nothing good changes for the person, who is slow to learn and fails to profit from experience?

People with severe reputations are our teachers if we are wise enough to learn from them. Their behavior -- protests and civil disobedience if you like -- are often telling us:

- you are not giving me the help I need
- you are hurting me
- your ideas may be good but your actions aren't
- you can do better.

Community is not about therapy, though we can all grow in it. If we listen to people and heed what they are telling us not just with their words but with their actions as well, we temporarily able-bodied can grow past our difficult behavior and become honorable members of community as well.

AAIWW BULLETIN BOARD

WATERLOO-WELLINGTON AUTISM SERVICES

<http://www.ont-autism.uoguelph.ca/wwwinfo.shtml>

Become a member with a donation of \$25 or more, mailed to William Barnes, 26 Yellow Birch Drive, Kitchener, N2N 2M2.

GUELPH SERVICES FOR THE AUTISTIC See:

http://www.ont-autism.uoguelph.ca/gsaifo_new.shtml

http://www.ont-autism.uoguelph.ca/gsaifaq_new.shtml

Tax-creditable receipts are issued for donations of at least \$10. Please mail to GSA, P.O. Box 23016, Root Plaza Postal Outlet, GUELPH, Ontario, N1H 8H9. To reach GSA, leave a message at (519) 821-7424

ONTARIO ADULT AUTISM RESEARCH AND SUPPORT NETWORK

<http://www.ont-autism.uoguelph.ca>

OAARSN offers up-to-date information and communication tools that can put you in touch with others. Check out the News Scroller and What's New on the opening page. You may request to be on the OAARSN List to receive regular e-mail bulletins of autism news and announcements of events.

ADULT AUTISM NEEDS SURVEY

OAARSN is co-operating with this important initiative by GSA and WWAS as part of the ASPIRE project. Long-form and short-form surveys may be completed online.

