

# ADULT AUTISM ISSUES IN WATERLOO-WELLINGTON

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

AAIWW Newsletter No 18, January 2003

## GOOD NEWS!!!

### **Waterloo Wellington Autism Services and Kitchener Public Library Establish Autism Resource Collection**

*The Kitchener Public Library Foundation, Kitchener Public Library and Waterloo-Wellington Autism Services are pleased to announce a new, exciting partnership. Through a generous donation from Waterloo-Wellington Autism Services, the Kitchener Public Library will establish a special collection of materials on the subject of autism.*

*This unique collection will include resources for researchers, health workers as well as individuals and families who work and live with autism.*

*In presenting a cheque to the Kitchener Public Library Foundation, Dr Roger Hollingsworth, President of Waterloo-Wellington Autism Services, expressed his pleasure in knowing that such an important resource would now be available to anyone in the community in need of information.*

*Mr Michael Schmitt, President of the Kitchener Public Library Foundation shared his appreciation, noting the growing demand for authenticated and timely information for educators, the public and families alike in understanding this challenging condition.*

*The Kitchener Public Library will hold a special launch of the collection and services in the Spring of 2003.*

*For more information, please contact Dale Dyce, Marketing Coordinator, Kitchener Public Library (519) 743-0271 KPL Press Release, 19 December 2002*

### **PLEASE NOTE GSA'S NEW ADDRESS**

The Canada Post outlet, where Guelph Services for the Autistic used to have a mailbox, has been closed. GSA's new address, effective immediately: GSA/Guelph Services for the Autistic  
16 Caribou Crescent  
Guelph, ON, CANADA, N1E 1C9

## SOBERING NEWS AND COMMENT

At the start of another new year, we note what a long way we still have to go--for people who live with autism to be better understood and supported as members of our communities. We think this applies particularly to teenagers and adults, but the families of young children can also feel alienated. One adult with ASD feels "we no longer exist in society after age 18, or even age 12."

Our mail and e-mail bring us word every day of adults and families in acute need of understanding and support. Men in their 40s, 60s or 70s who are just being diagnosed. Single-parent mothers and their children all with forms of ASD. Young adults leaving school to find no supports or services. Individuals moving from one region to another, having to prove their eligibility for the most basic disability and income supports all over again. It's a cold, hard world out there.

Recent public inquiries have pointed to defects in "the system" more than to failures by individual carers. The inquest into the death of Stephanie Jobin, under restraint in a Brampton group home, recommended that services that should be made available to all children with complex special needs and their families must include: full-time residential support, professional in-home support, respite care in residential facilities, shared parental and foster care, and improved access to education programs for special-needs children. The inquest into the suicide deaths of a single mother and her son in Durham, England, called on agencies to develop a "despair-proof" support system for children and adults "with complex and challenging behaviour".

It should not take tragedies like these for us to see and do all we can. The Ontario Ministry of Community, Family and Children's Services requires its funded agencies to provide "investment supports and services" early, before an individual or family reaches crisis and to avoid or alleviate the personal costs of a prolonged delay in receiving services.

May 2003 be the year when we all try to make a real difference for people who live with autism spectrum disorders!

### **ALSO IN THIS ISSUE:**

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## *Books on the Autism Spectrum*

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 appreciate the efforts of our volunteer reviewers and welcome suggestions of new books that should be noticed or reviewed for OAARSN and AAIWW. See our lists of books and videos at: <http://www.ont-autism.uoguelph.ca/books.shtml#6> <http://www.ont-autism.uoguelph.ca/books.shtml#7>

### *Aiding the Vision*

By Janice I Adams  
Family Support & Resource  
Network: Chatham-Kent 2002  
Reviewed by Jan Cooper

How often have you sat down with a case manager, psychologist, teacher, doctor etc. and they ask you to describe your child's skills? Social skills, communication skills, life skills, independent and work-related skills; the list seems almost endless, as do the answers. There is no way you could hope to remember it all, even on a good day. If your child is about to launch himself off your doctor's bookshelf, the answers will escape you even faster! Parents with autistic children typically have huge binders filled with reports and case notes, and organizing all that information into a coherent source of information for your support team can be a daunting task. We know that information can change. So how do you keep up without getting swamped? I suggest getting a copy of *Aiding the Vision*.

Janice Adams is a parent of a disabled child and professional working with similar families who created this book as an inventory tool. In order to develop an effective plan for the individual, you need to know his or her skill levels in a variety of areas. An inventory checklist is a good way to get a realistic picture of their current level of performance and future needs. Once this is accomplished, the 'team' can set goals and determine strategies that will ensure the best possible outcome. Janice stresses that you must "choose only a few goals at a time and set up reasonable time frames, in which to revisit them" (p.1). While I talk about

this book as a useful tool for parents with children with autism, it is equally valuable for those who are planning for the future of a child who is transitioning out of school. The same holds true for an adult and/or his family looking to make important decisions about life changes.

The skills lists are quick and easy to check off, providing a good visual chart for others to review easily. The lists could also serve as away of charting progress or regression of skills. The inventory checklists include social skills/non-verbal communication, living skills and chores, personal care, and leisure and recreation. As the child moves through school, one of the questions for parents and teachers is: "what will adulthood look like for this individual? Will it involve day programs, employment or perhaps a combination of the two? With this question in mind, Janice included a Play/leisure skills checklist that she says are precursors to the workplace and independent living. "Skills related to the workplace and independent living need to be nurtured and developed long *before the individual becomes a teen*" (p.16).

In the next section, Janice addresses a critical issue: changes or transition. In this chapter she demonstrates how the use of videos and photos can be incorporated into a transition portfolio to aid everyone in helping the individual navigate new situations. There are checklists for types of changes that may cause distress so you can best determine what kinds of things you would include in videos or photo albums.

Because these sheets are useful for individual transitioning from High

School to the community, assessing potential barriers is a crucial step in planning for the future.

Understanding the barriers is necessary if you are to "incorporate a best practices approach in order to try and overcome them" (p.30). This section not only provides good checklists but many useful strategies for overcoming communication, personal, social, physical, sensory and behavioral barriers.

There is a special section for those with communication difficulties, examples of how to modify various settings, and a good "Know Your Individual" checklist.

The book ends with pages to be used in creating a Profile Binder for personal and team data. It covers personal, school, work, a summary for the older individuals, motivators, adaptive aids and functional skills. There are examples of completed worksheets at the back of the book. All the checklists are reproducible and "to be used directly in the classroom and by parents or caregivers" (Janice Adams).

This is definitely a 'book of lists' but presented in a way that I'm sure that anyone reading it would find something that would be useful and informative. It can be used at all stages of life and I think that would make it a valuable addition to your family resource library.

*Aiding the Vision* may be ordered for \$30 from Family Support & Resource Network, 143 Wellington Street West, Suite 104, Chatham, Ontario, N7M 1J5. For more about books by Janice Adams, visit <http://www.adamspublications.com/>

***A PLACE CALLED HOME:  
for families of children with  
a disability and the  
professionals who serve them***

By Alison C. Ouellette, 2001, 56 pages. Reviewed by Amar Arneja

All parents have dreams of building futures for their children. Parents naturally worry when their children leave home to go to university or when they settle down on their own. But for children born with a disability, these dreams require a lot of planning and hard work.

For Alison and Paul Ouellette, making it possible for their 26-year-old son David move into a house of his own was a special challenge. With David's requirements for extensive health care and a house that is wheelchair-friendly, safety and security needs were overwhelming. With the help of a friendly real estate agent, a suitable house was purchased and renovations were done by the family to suit David's needs.

For David, living independently has taken the form of living in his own place with a housemate who is a student at the local university, and for agreed responsibilities, enjoys a great companion and a rent-free home.

For parents, letting go so a disabled child can live independently

brings heartache of its own. Alison felt lonely and sad as David was not there to care for and also there were no more support workers coming in and out of the house. She felt a constant urge to go and check on David or at least make a phone call to see if everything is fine. However if you have a responsible housemate who is going to stay for an agreed period or longer, things can work out mutually beneficially to both parties.

Currently Alison is coordinating all David's support workers and nurse schedules. She calls daily to say hello to Dave and check with Gerry (house mate), to see how things are. Once a week Paul and Alison visit Dave.

Buying and subsequently running a house or apartment for your disabled child is quite expensive, but there are certain ways by which this burden can be reduced. To buy a house under "Home Buyers Plan", both parents can withdraw up to \$20,000 each from their Registered Retirement Savings Plan without having to pay tax on it as long they qualify for the Disability Tax Credit.

Also when your loved one is living independently, the Disability Pension is increased by about \$200 a month. All these small things help towards achieving the ultimate dream of independent living.

Initially Alison felt that there was no need to establish a support circle for David. But after a few months she realized that a support circle was needed to keep things going smoothly especially if she or Paul were not available on some days. A group of friends and family was invited to become David's "Consulting Circle". This group would take over if Paul and Alison were away or not available for some reason.

This book makes valuable reading for any parent, who is caring for a child with a disability and is planning the future for the child. Parents of a disabled child can identify themselves in similar situations and in that respect can learn a lot by reading this book.

Alison has achieved the difficult challenges of "A Place Called Home" for her son with dignity and respect. Let us hope that other parents in similar situations can have their dreams come true.

*To obtain a copy of A PLACE CALLED HOME, send cheque for \$12 CAN plus \$3 shipping & handling to A.C. Ouellette, 10810 Riverside Dr. E, Windsor, ON, CANADA N8P 1A4.*

*Ms Ouellette is available for keynote addresses and workshops entitled "Celebrating Achievements: Anything is Possible."*

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## **AAIWW BULLETIN BOARD**

### **WATERLOO-WELLINGTON AUTISM SERVICES**

<http://www.ont-autism.uoguelph.ca/wwasinfo.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/gsainfo\\_new.shtml](http://www.ont-autism.uoguelph.ca/gsainfo_new.shtml)  
[http://www.ont-autism.uoguelph.ca/gsafaq\\_new.shtml](http://www.ont-autism.uoguelph.ca/gsafaq_new.shtml)

Tax-creditable receipts are issued for donations of at least \$10. Please mail to GSA, 16 Caribou Crescent, GUELPH, Ontario, N1E 1C9. To reach GSA, leave a message at (519) 821-7424 or e-mail [gbloomfi@uoguelph.ca](mailto:gbloomfi@uoguelph.ca)

### **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

## ***Learning to Listen: Positive Approaches and People with Difficult Behavior.***

By Herbert Lovett. Paul H. Brookes Publishing Co., 1996. ISBN: 1-55766-164-2. Reviewed by Heidi Klaming.

In 1989, Herb Lovett, a clinical psychologist and research associate with the Institute of Disability at the University of New Hampshire, traveled across the United States to give talks on managing difficult behaviour.

This book is an expansion of Herb's talks. Reading it we also become actively involved in his presentation.

Those of us familiar with difficult behaviour may feel that we will walk away with tangible goods, i.e., concrete methods and technologies to handle behaviour. We do indeed walk away with something, less tangible perhaps than the package we expected, but far more powerful.

By following the exchange of shared personal experiences between Herb and the service providers for the disabled, we begin for the first time to listen to the issues surrounding behaviours. In doing so, our focus moves away from a need to manage behaviours to learning more about them. As the discussions progress, we find ourselves evolving with the participants to embrace behaviour in a totally new manner. Our thinking continues to shift and expand, to accommodate our new way of perceiving behaviour long after the discussions are over and the book is read.

Herb admits that behaviours challenge and confuse us. However the case studies that he uses to support his talks clearly demonstrate that new methods for managing difficult behaviours are not the answer.

With Herb as our guide, we begin to examine the lives of the vulnerable—the ones we have labeled retarded and disabled—to understand

that these individuals are known primarily for their behaviours. The interesting side effect of our examination is the unique opportunity it affords us to witness our own behaviour.

Herb's openness to explore fosters the interactive dialogue by which the participants can illustrate the negative impact of our "control and correct" methodology for managing difficult behaviour.

The familiar scenario unfolds as follows:

- A client exhibits an unwanted behaviour;
- A method is found or created to be effectively applied to change, deflect or ignore the undesired behaviour;
- The prized goal, "a change of behaviour" has not happened and neither side is satisfied;
- The failed attempt to get a client to comply with the chosen method of control frustrates the service provider;
- Depending on the situation and the degree of distress, those responsible for maintaining order feel compelled to increase their efforts of control by resorting to more drastic and at times even more dangerous methods;
- The good intentions to help have backfired. Through a need "to control and correct" we have successfully created the formidable barrier that separates, isolates and alienates us from those we are here to serve.

The picture is a grim one. However, participants have managed accurately to describe the context in which many of them are forced to function. The awareness of their own behaviour and how it contributes to this disturbing state of affairs shocks and horrifies them. At the same time they feel trapped by the dynamics of

"control" which take on a life of their own.

To recognize that we are in trap of our own making is integral to understanding what the trap really is in order to find our way out. Herb elaborates to give us clarity.

Our initial response to an unwanted behaviour, he says, is to react, to correct what we perceive to be unacceptable, inappropriate behaviour. The thinking behind this perception, he adds, is that the person exhibiting the behaviour has lost control and that those who are in charge—in control—are responsible for regaining it through the application of methods and technologies specifically designed for this purpose.

Is it any wonder then, Herb asks, that the idea that those who are vulnerable might need help in other significant ways never occurs to us? This realization prompts an appreciation of the fact that these individuals are paying for the help they need with their freedom, their dignity and a general loss of control over their own lives.

Through Herb's passionate caring, clear insights and positive approaches, we have firmly established a basis for the continuation of this interactive dialogue. Together we continue an exploration of finding a way of life that moves from control to collaboration.

To work with people rather than on people is the step we need to take as our positive approach to helping them. With this attitude we learn to look beyond the behaviour to learn more about an individual as a person. The behaviour then recedes into the background as we discover more about it to realize that it is often the only form of communication available for many individuals. As we learn to listen to the messages behind behaviour, we learn to help the vulnerable live the quality of life they deserve.

***Pressure Points and Possibilities: 25 issues facing human service organizations and what to do about them***, by Tom Little and Nancy Mouldsdales. Published by 1466523 Ontario Limited: Ajax, ON, 2002. *Reviewed by David DeVidi*

This book is intended as a guide for people running non-profit human service organizations. The authors, who are the principals of *cmcs*, a consulting firm that specializes in advising such organizations, advertise this self-published booklet as “filled with concrete tips on what non-profit organizations can do to improve services, create a productive working environment and get the most out of their volunteer boards.” The bulk of the book is organized around 25 areas the authors have found to present obstacles to the successful management of non-profits in their years as consultants, along with tips intended to help organizations steer clear of the obstacles.

The authors are obviously after a niche market here—sadly, the people with a keen interest in management issues related to non-profit human service organizations don’t make up a huge chunk of the reading public. But the target market for much of the book is probably even smaller than advertised. The intended audience seems to be board members and upper management of organizations which are large enough for this distinction to mean something—several of the issues considered as problems confronting boards of directors have to do with appropriate relationships with executive directors and other high executives. A striking piece of advice is this: “When hiring a new Executive Director, a Board’s first priority should be to fund a changeover of other Management personnel.” Other management personnel? People involved on boards for many non-profits will no doubt become wistful at the very thought of an executive director, let alone other management personnel. So it’s the larger outfits that the authors have in mind—roughly speaking, those large enough to possibly have budgets for hiring consultants, I suppose.

This by no means makes the book useless for people involved in smaller organizations, though. Reading it is sure to provide useful advice and good ideas to anybody playing a leadership role in a non-profit organization. That’s a pretty good payoff for reading this book, since reading it won’t take long. It checks in at 95 pages, but there’s lots of white space in those pages. The style is mostly straightforward and mercifully free of jargon—which is an achievement in itself, as the authors faced the twin temptations of the obscurity of human-services-speak and the pretend sophistication of management “science”.

On the other hand, what makes the book easy to read is also one of its frustrations. It won’t take long to get past the stuff that isn’t important to the organization you care about, and the stuff you do care about is likely to prove

stimulating. However, the stuff you care about is also very brief, and you may find yourself wanting a lot more detail in *those* parts. To take one example where this happened to me, the authors advise that organizations should “make recruitment of independent Board members a key function of the Board.” Good advice, of course. But if you’re part of a board that’s keen on getting new blood, what you want is some strategies for carrying it out, which you don’t get. You do get the feeling that a lot of the point form text might have begun life on slides for presentations the authors give when hired as consultants.

In summary, if you are part of a non-profit human services organization of any size, you should consider getting a copy of this book and having several members of the board and upper management flip through it. It at least can serve as a starting point for useful discussion about things you’ll want to think about—whether it’s the relationship between the board and management in a larger organization or, in any organization large enough to employ staff, how to better ensure staff satisfaction with working conditions in the notoriously low-paid human services field.

That said, I’d like to conclude with a couple of complaints. (These should be taken with a grain of salt, as I’ve always got something to complain about. I’ll have complaints about this review when I reread it tomorrow.)

First, in a discussion of the “problem” of board members with a self-interest in the services of an organization, the authors uncork the following claim: “A board made up solely or primarily from this constituency is one that is likely to have difficulty leading the organization to the forefront in service delivery.” Now, as I understand it, a common complaint against larger human service organizations is that they tend to set up services then expect people to conform themselves to what’s available, instead of making the services conform to what people actually want or need. People sometimes get onto boards, or form their own organizations, precisely to allow the dog to wag the tail for a change. But it looks rather like the authors might incline to the view that the mysterious forefront of service delivery requires that the tail be in charge. A worry one should always have when somebody tries to apply management techniques developed in one field in another is whether they’re appropriate in the new field. There are other places in the book where I get the feeling that it’s management theory rather than on-the-ground experience that’s driving what the authors say. This is why I think you’d be wise to take the advice in this book as a starting point for discussion, and not as gospel.

Secondly, the authors must recommend a dozen times that non-profit organizations consider hiring consultants to, for instance, help them with year-to-year planning or to evaluate their organization. Curiously, these seem to be precisely the sort of consulting jobs *cmcs* specializes in. This lends an otherwise laudable book the flavour of an advertisement. Too bad.

## PLANNING AHEAD

*Families of a child with a complex and pervasive disability (such as Autism Spectrum Disorders) may delay making firm plans for the future.*

- *We may be too busy, exhausted and intimidated to have the energy or imagination to face anything more than the immediate present.*
- *We may put off such planning, because we hope or believe our child may recover or improve enough to become independent and thus not need any special plans.*
- *We may leave the future to take care of itself, assuming that we can depend on several siblings or other family members.*
- *We can't believe that anyone else will care or do well enough for our loved one.*
- *We may assume that the Government, through traditional agencies, will take over the responsibility and make the decisions.*
- *We all tend to procrastinate, and to delay doing anything inconvenient or out of the ordinary.*

*To some extent, these concerns and assumptions are just.*

- *It is good to focus on the present: if we do the best we can now, the future will be better.*
- *We cannot know exactly how a child will develop and mature through adolescence.*
- *Detailed arrangements we might plan for a 10-year-old could be negated by changes in government legislation in the next ten years.*
- *In most cases, only families (or family-like friends) have the necessary insights and commitment.*
- *A family's ability to plan a certain level of security for a child with a disability may be undermined by changes in the business cycle or in career paths, or by death or severe injury to a parent or sibling.*
- *We cannot absolutely shape the future to ensure our child will have a certain kind of life.*

From experience, we suggest these incremental ways to plan wisely for a good life in the community and a more secure future. Guelph Services for the Autistic (GSA) through ASPIRE: Autism Support Project: Information, Resources, Empowerment can offer more guidance to families in the Waterloo-Wellington region.

-The following timetable may be used as a checklist.

-If you are starting the planning process later—say your family member is now 20—you should review all the goals and activities suggested for younger people.

### **By the time our daughter/son is 10 years old:**

*We probably have some sense of how the disability is going to affect her/his ability to -express herself/himself in everyday ways and on important life-shaping topics and thus to make choices and decisions and explain what may be causing discomfort or anxiety*  
*-have good relationships with other people without being abused or exploited*  
*-live independently*  
*-hold a full-time job with some prospects of security*  
*-exercise initiative in using time and leisure opportunities*

### **Priorities at this time:**

- *Develop and stimulate effective communication by whatever unique ways work for each child.*
- *Find and foster friendships with wise and humane people of all ages to be a support group (circle, cluster or network) for our person with a disability and the family. These friends will be given opportunities to spend time with our daughter/son, to “learn to listen” to them, to believe in their abilities, to scout for opportunities for work, leisure and new friends.*
- *Keep informed of helpful interventions in physical health and learning strategies.*
- *Consider how what's happening in school is preparing person for adolescence and the future.*
- *Make flexible contingency plans for how our child's life would be secure if parents should die or become incapacitated prematurely—by making a will and appointing guardians and trustees, with provisions that should be reviewed annually*

## **By the time our daughter/son is 15:**

*We have experienced puberty and the stresses of early high school years. We want to ensure the remaining high school years are as useful as they can be.*

### **Priorities: All the above plus:**

- Read and act upon the wise advice contained in Al Etmanski's *A good life for you and your relative with a disability* (PLAN, 2000).
- Undertake MAPS and PATH planning exercises, including expressing and sharing a vision of life 5, 10 or 15 years in the future, and plan specific steps to get there from here.
- Consider how what's happening in high school is preparing person for adulthood.
- Apply for disability and income supports for which person is eligible (such as ODSP from the Ontario Ministry of Children's, Family and Community Services, MCFCS, at age 18).
- Consider incorporating an aroha entity for empowerment and support with legal powers to receive and manage resources.
- Ensure that any planning ideas and options are understood by your daughter/son, who has opportunities to comment and ask questions.
- Evaluate or self-evaluate quality of life through, for example, the Adult Needs Survey

## **By the time our daughter/son is 20:**

*S/he should be receiving ODSP (or equivalent, if eligible) and we are facing the end of school and the regular structure it provides.*

### **Priorities: All the above plus:**

- Firm up plans for the transition from school at age 21:
- opportunities for understanding and self-expression (including alternative modes if necessary)
- more independent living
- contributing to the community through paid and voluntary work
- continued learning
- expanding opportunities for friendships
- leisure time options
- how all elements of a good life are to be co-ordinated

## **By the time our daughter/son is 25:**

*We have got through the transition from school, but may be facing the end of some transitional programs. As parents, we need to think of how the good life can continue beyond us.*

### **Priorities: All the above plus:**

- Review all aspects of transition from school to adulthood.
- Strengthen the circle of friends and ask core members to be directors, with the focus person and family members, of an aroha entity of empowerment and support (if not already incorporated)
- Make firmer plans in case of parents' death or inability to support son/daughter's life
- Make firmer plans for focus person to have home of her/his own (as in some variant of the GSA model)

### **IN PREPARATION:**

*ASPIRE proposes summaries of advice and resources, especially for people with autism, on the following topics:*

- Effective communication strategies
  - Finding friends and developing personal support networks
  - Getting the most out of the high school years
  - Wills, trusts and financial planning by families
  - MAPS and PATH planning exercises
  - Government-funded resources for people with disabilities
  - Managing the transition from school to adulthood
  - Incorporating an aroha entity for personal empowerment and support
  - Supported decision-making
  - Evaluating quality of life
  - Finding and keeping good support workers and caregivers
  - Residential options including: "How to have your own home"
  - Employment and small business options
  - Continued learning
  - Keeping healthy
  - Relationships
  - Spiritual life
  - Leisure time options including: Contributing to the Community
  - Roles of siblings
  - A whole life: co-ordinating everything
  - Managing the transition as parents die
  - Seniors with autism
- Suggestions and contributions are welcome.*

## **Speak up for Individualized Funding as a basis for a good life and a more secure future for our friends who are vulnerable because of disability.**

All individuals, families and friends concerned with planning a good life in the community and a more secure future for people with autism are urged to write to the Minister, saying something about your own circumstances (or those of your daughter, son, other relative or friend) and how you know individualized funding will help. It's important to do that very soon--this week---as budgets will soon be set for the 2003-2004 fiscal year. Quite brief letters of support for IF, from hundreds of families across Ontario, will have an impact.

The address of the Minister is:

The Hon. Brenda Elliott,  
Minister of Community, Family and Children's Services,  
80 Grosvenor Street,  
6th Floor Hepburn Block,  
Toronto, ON M7A 1E9

Note that you may email your letter supporting IF directly to the Minister. Click on <http://www.gov.on.ca/CSS/page/minister.html>

An eloquent statement of why an IF option is needed, by the Peel Family Network is "Individualized Funding in Ontario: Statement of problems and recommendations to the Hon. Brenda Elliott, Minister" on 19 November 2002. Find a copy at <http://www.ont-autism.uoguelph.ca/IF-nov02.html>

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### ***Asperger's syndrome: the invisible disability***

"You could teach a child the theory of relativity once and he'd get it. But you'd have to tell him the rules for lining up for recess 500 times." Margot Nelles, founder and chair of the two-year-old Asperger's Society of Ontario, in an article that cites situations in the Peel District School Board. Published in *Professionally Speaking*, journal of the Ontario College of Teachers.

[http://www.oct.on.ca/en/CollegePublications/PS/december\\_2002/aps.asp](http://www.oct.on.ca/en/CollegePublications/PS/december_2002/aps.asp)

## ***Our schools need more than money***

(from a letter to the Toronto Star about the Rozanski report on funding education in Ontario, by Janis Jaffe-White of the Toronto Family Network)

...The education of our children is about much more than money. It is about the inherent value and dignity of all children and the rights of all children to full participation and citizenship within our society.

Mordechai Rozanski gave everyone what they asked for — more funding — but he failed to recognize the import and effect of the underlying tenets and the fundamentals of the whys, hows, whats, and wherefores for said funding. Although he acknowledged that many families and associations had clearly demonstrated the discriminatory, negative and stigmatizing approach of the funding formula for children with additional needs, Rozanski did not include these concerns in his written report. This makes him complicit in perpetuating attitudes that allow for the isolation and marginalization of our children.

Although Rozanski recognized the need for flexibility, he did not fully understand that flexibility is inherent within an individualized funding approach. Unfortunately, the "student-focused" funding approach of the government totally disregards individual needs and requirements. The government process forces the individual to be viewed through the lens of a rigid, limited and limiting classification system. This approach not only devalues the individual but also denies them the right of access to equal opportunity for accommodation under the Ontario Human Rights Code. This disregard of the rights of all children to full participation within the educational community illustrates how the Ministry of Education's use of language and its underlying attitudes have completely undermined opportunities for equity to individuals with additional needs.

Rozanski got far too much information from the bureaucracy and far too little information from the primary stakeholders, the families whose children are affected by the funding formula.

It is time for all of us to take a stand, to say to the government of Ontario that money is not the basic problem — attitudes are. It is time for all of us to say to the government of Ontario that we value equity, diversity, dignity, autonomy and justice.

It is time for us to empower and embolden all of our children — they are our future.

## ASPIRE

- ASPIRE stands for Autism Support Project: Information, Resources, Empowerment. It is an initiative that will interest parents, families and friends of adults who have Autism Spectrum Disorders.
- ASPIRE is offered as a free public service in Wellington and Dufferin Counties and the Region of Waterloo by two charitable non-profit organizations, Guelph Services for the Autistic (which is steering the project) and Waterloo-Wellington Autism Services (which is providing most of the funding). ASPIRE has no Government funding.
- ASPIRE is designed to help families and friends who want to be involved in planning a good life in the community now as well as the foundations of a more secure future. We can share some successful experience, help you to develop the potential in your situation, and put you in touch with resources.
- ASPIRE has two main parts:
  1. A confidential survey of situations and needs of adults and older teens with autism. Count yourself in, at least by completing the short survey. If you are seriously planning for the future and wish ASPIRE's help, we ask you to submit the more detailed survey. You may complete either survey online if you have Internet access.
  2. Individual meetings with ASPIRE's part-time Advocate, in which individuals and families who are seriously committed to longterm planning can express their concerns and dreams and ask for specific information about positive strategies and community resources.

## *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 was 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](http://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](mailto:gbloomfi@uoguelph.ca). Completed paper surveys (both short-form and long-form) may be mailed to GSA (ASPIRE), 16 Caribou Crescent, Guelph, ON, CANADA, N1E 1C9

More information about ASPIRE is available on the Guelph-based website of the Ontario Adult Autism Research and Support Network at <http://www.ont-autism.uoguelph.ca/aspire-project.shtml#pu>

ASPIRE's co-ordinator is Dr Elizabeth Bloomfield at (519) 823-9232 or [ebloomfi@uoguelph.ca](mailto:ebloomfi@uoguelph.ca)

## Ontario's first aroha

Ontario first aroha was incorporated with and around Adam in Guelph in early 2002. What is aroha? Why might it interest families and friends of other adults who are vulnerable because of disability?

The Maori word "aroha" from Aotearoa/New Zealand is being used as the generic term for an incorporated entity for personal empowerment and support that is similar in values and functions to a "microboard" in British Columbia or a "self-directed support corporation" in various American states.

Adam and his friends wanted a distinctive word to evoke the qualities of the personal support relationships that a vulnerable person needs. Aroha means the various qualities and values in a caring circle of friends. Its meanings include affection, love, charity, compassion, empathy, concern, trust, pity, understanding and true friendship—all expressed in active ways, not just well-intentioned ideas or feelings. Adam was born in New Zealand, so that's another reason for choosing aroha.

Like microboards and self-directed support corporations, an incorporated aroha also has legal identity and powers to receive and manage all resources in ways the focus person chooses and which support her/him best to have a good life, now and in the future. Adam's aroha has letters patent as a non-profit corporation in Ontario. But it does not have charitable status with the federal revenue agency, as it exists for the benefit of a single individual.

Adam is a director of his aroha, together with his parents and several friends who are of different ages, all younger than his parents. Directors of his aroha are core members of his wider circle of friends who are also members of the aroha. Adam specially needs friends, as he has no relatives in North America beyond his parents. He was very anxious about the uncertainties of his future. Two years ago, he explained his acute anxiety in these words: "***I am terrified when night comes and I fear that I will be left alone. The thing I am scared about is seeing the day my parents die.***" Now his aroha is incorporated, he says: "***I feel good knowing about aroha. I know my future is safer. Proud to feel I'm a pioneer. I feel safer knowing that my aroha would be in charge. Not some strangers. I'm glad that I can express this.***"

Friends who care about Adam and his parents would need legal powers to administer resources with and for him after his parents can no longer support him. The other directors of Adam's aroha bring various kinds of qualifications and life experience to their roles. They all know Adam well, show respect for him, and keep in touch by sharing parts of their lives with him. One is a specialist in speech, language and communication: she has a special interest in ensuring that Adam has real opportunities to express himself and be listened to, as he does not speak with his voice. Another (who is president of the aroha) is a

professor about Adam's age who shares interests in physical fitness and also serves on the board of the charitable housing trust that owns and maintains Adam's home for his lifetime occupancy. A third director is younger than Adam; she was his full-time tutor for two years and is now a teacher.

### What can Adam's aroha do for him?

- Its general purpose is to empower and support Adam to prepare now for a smooth transition from his parents' large role in his life to a future in which he will eventually be without them.
- Its directors are pledged to respect and support Adam's powers of informed decision-making.
- It has legal powers to receive and manage resources to help him cope with his disabilities.
- It now receives individualized disability support funds approved for Adam from a transfer payment agency that functions simply as a banker. The funds are deposited in a corporate bank account and disbursed to the housing trust that maintains his home, to independent service providers and consultants that provide personal support and expert advice, and to agencies and businesses that provide other goods and services.
- At present, Adam and his parents still look after the business side of his life and disability support. But his friends who are directors of his aroha are kept informed, and procedures are becoming more formal, so that they can continue when Adam's parents cannot do this work.
- Adam's aroha also has the powers to advise on the most effective use of family trust funds that will be left by his parents after their deaths.

Adam's aroha could have additional powers and roles. It might own and maintain his home, even renting out part of it for income to offset some of his expenses. It might support him to operate a small business or micro-enterprise. It might receive disability support funds directly from the Government.

Adam and his friends have designed his aroha for his needs and situation. The essential qualities and powers of an aroha can be adapted for the specific needs and situations of other people who are vulnerable because of some disability. They are compatible with the values and goals of personal support networks and circles of friends, individualized funding, supported decision-making, and community building.

Adam and his friends are willing to share their aroha experience with other circles of families and friends who want to incorporate. They prefer to respond individually to calls for advice and help. Adam's aroha is still new and needs to be nurtured carefully—for his sake and also for the others who want to follow in his pioneering steps.

There's more information about aroha on the OAARSN website. <http://www.ont-autism.uoguelph.ca/entities.shtml#4>