



Research and Support Network

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

March 2006 marks the 6th anniversary of the Ontario Adult Autism Research and Support Network (OAARSN) website and electronic news bulletins.

Why did we start OAARSN?

For more than 35 years, we have learned so much through raising our son, who has quite severe autism. At all stages, we have felt ourselves to be on the front lines. Like other "autistic parents" of our generation in Ontario, we had to find out relevant information for ourselves, with very little help. We "diagnosed" our son by reading the review of Lorna Wing's first book, *Autistic Children: A Guide For Parents*, in an English newspaper in 1970. We have often had to invent and pioneer effective supports and services. We have realized how important it is to share information and experiences that may help others.

OAARSN expresses values and principles that reflect our long experience in living with autism. When OAARSN began, our son had been an adult for more than ten years. No existing services had worked for him. He had been very distressed through most of his twenties. We were keenly aware that there was virtually no official or professional interest in or support for adults with autism—just an assumption that nothing constructive could be done. More positive outcomes were up to us. In 1997-8, we managed, with our son and a circle of friends, to help him set up his good "whole" life. At critical times in the mid- to late-1990s, we were helped by e-mail contact with some Ontario professionals and advocates, notably Martha Leary and Malcolm Jeffreys.

As we and others began to get Internet access, we could reach information about alternative ways of helping people with autism or related handicapping conditions. Pioneering autism resources that we discovered in the late 1990s were the distinctive Canadian website, "Oooops.....Wrong Planet Syndrome", that had been started in 1995 by Janet Norman-Bain (aka "jypsy") of Prince Edward Island, and the frequent electronic newsletters put out by Lennie Schafer from Los Angeles (now called the Schafer Autism Report). Like OAARSN, both these information resources have been produced by voluntary effort. Their authors have expressed very different points of view on the potential and rights of people with autism.

OAARSN represents a connection between the forms of support that our son and family have been pioneering since 1996-7 and all the big developments "out there" in autism spectrum disorders and creative ways of supporting vulnerable adults. We continue to find it valuable to make connections between the particular microcosmic details of individual lives and the broader, more general trends.

How was OAARSN started?

Our first aim was modest: to be simply a means of posting minutes and other documents among a small group of Board and Executive members of Guelph Services for the Autistic. But our friend Peter McCaskell, in Computing Services at the University of Guelph, was then preparing to advise members of the university community on how to create personal websites. Peter felt inspired to develop a more ambitious website for us. So OAARSN began

as a voluntary by-product of learning and practical experience for another purpose. As we looked at what little else existed then, in information resources for adults with autism spectrum disorders and their friends, it seemed worth pushing our little project a bit farther. And this was justified by the enthusiastic responses we have received from around the world—as well as the many appeals for help from people who feel isolated and sometimes desperate.

OAARSN offers a collection of information and communication tools, with opportunities for mutual support and encouragement among adults with autism, family members, caregivers, friends, support workers, teachers, administrators and policymakers. The website was designed with a clear and logical structure. All its features can be reached by clicking live keys on its main opening page. The main-page live keys are also provided at the bottom of most of the other pages of the site, to facilitate exploration and use of the site. Some of the features:

- LOGO AND SITE NAME explain why the site was created.
- SITE NAVIGATION TIPS are reached by clicking on the compass.
- AUTISM INFORMATION opens up content, specially written for OAARSN and including references to Internet and print resources, about autism spectrum disorders, treatments and therapies, and strategies for supporting quality of life.
- Directory guides to autism ORGANIZATIONS AND SERVICES in Canada, with Internet links
- COMMUNICATIONS, including a Bulletin Board with an Autism News Bulletin, Announcements of Special Events, Needs and Opportunities, and a Discussion Area (already offering various Boards and Topics on important issues).
- LINKS TO AUTISM-RELATED WEBSITES in various categories, as well as to a tutorial for searching the Internet.
- UNIQUE RESOURCE DOCUMENTS, including surveys of adult autism needs, model service proposals, newsletters of adult autism organizations, and first-person accounts of living with autism
- SEARCH OUR SITE allows one to type in names, keywords and phrases to find specific material anywhere in the pages of our site. For example, you can learn more about creative strategies in planning for adulthood such as aroha, PATH, MAPS, CIRCLES, personal support networks, inclusion, homeownership, homesharing, micro-enterprises, person-centred planning, individualized funding.
- Users may CONTACT BY E-MAIL from various pages on the site, to comment or ask questions. You may ask to be added to the OAARSN Listserv to receive weekly bulletins of autism news, announcements of events, new books and other resources, and new content added to the OAARSN site.
- DISCLAIMER STATEMENT: OAARSN tries to verify information we are asked to post and to present both or all sides of controversial issues, but we cannot take responsibility for everything on others' websites to which we may provide references or links.

Is there still a role for OAARSN?

There has been a huge expansion in autism awareness through the Internet in the past six years. In March 2000, we used the Dogpile search engine to find nearly 300,000 pages on the World Wide Web that mentioned the keyword "autism." A Google search in March 2006 produces 63 times that number. Adult autism resources were very scarce in March 2000, but a search for "adult autism" now turns up 22,000 references, with 10,000 for "autistic adults". Autism issues in Canada were scarcely reflected on the web five years ago. A search for "autism spectrum disorders" and "Canada" in March 2006 finds more than 134,000 hits. There are even 443 hits that combine the keywords "adults" and "Canada"

with the phrase "autism spectrum disorders" and do not include "children".

However, we are not quite ready to wind up OAARSN, attractive as it might be to have more time for other diversions! It still seems important to provide a means for people with various perspectives to read and be aware of the needs and priorities of adults with autism. OAARSN is frequently contacted by people in various kinds of need, from all over the world. We try to discuss their needs and refer them to other sources of information and help.

In 1990, Autism Society Ontario set up a Task Force to survey the numbers of autistic adults and their needs in relation to currently available services. Dr Susan Bryson, a member of the Task Force, wrote two fine essays which were printed with a statistical report in *Our Most Vulnerable Citizens* (a copy is posted on OAARSN). Sad to say, none of its excellent and essential recommendations has been implemented. Only a tiny number of Ontario adults have appropriate supports to lead good and fulfilling lives in their communities. Too many have restricted lives in custodial care with no support for their autistic disabilities. Some are incarcerated with no social contact and some die tragic deaths. Professionals, agencies and caregivers may see autistic adults as mainly challenging because of their severe behavioural problems. No new exemplary services have been started in the past decade. As children and teenagers have grown up, there are much longer waiting lists for the few services that already existed in 1990. Too many adults with autism and their families or other caregivers are barely coping.

These are the values that OAARSN stands for:

1. Adults, even with quite severe autism, can continue to learn and grow past age 18 or age 21. Adult years last a great deal longer than childhood and contain various phases. It is vital to keep open minds about the changing possibilities. Autism is highly complex and affects each person in a unique combination of ways. Whatever their original symptoms, autistic adults may also bear the scars of faulty assessments and less-than-optimal treatment in the childhood and early adult years. We should focus on abilities and "what helps?" more than on deficits and "what's wrong?" We must help everyone to understand that a good and fulfilling life is possible for every person with autism spectrum disorders
2. To be effective and just in supporting vulnerable people, we should learn first from them about what matters most. We must encourage and support whatever means of self-expression each person has, and respect and "listen" deeply to them. We are for person-centred and self-directed planning and individualized funding to enable adults with autism to have good lives in their home communities, with informed choices about how and with whom to live. The more complex the disorder, the more individualized the supports must be.
3. Real personal relationships with families and friends are critical in the good lives of adults with autism. We know families, heroically and passionately dedicated to their adult sons or daughters, who want to keep supporting them for as long as they have life and breath. We also know families who deeply regret having had to make compromises for lack of some encouragement.
4. All of us, who are concerned with autism, must pull together with compassion and understanding of others' points of view and circumstances. This has always been challenging: the searing experience of feeling isolated, without helpful resources, focuses the mind and emotional energy on one's own situation. It is even harder than it used to be—with the widening of the definition of autism and the greater numbers and complex symptoms of those identified on the autism spectrum.

Towards Better Lives and More Secure Futures for Adults with ASD

Start early, from childhood, and keep evolving these interrelated strategies. Find more information about these good ideas and practices on the OAARSN website.

- Encourage self-expression and choices by whatever means.
- See the humanity, abilities and potential in your son/daughter, however severely challenged. "Listen" to them (even when they do not speak) to understand their point of view and priorities. Observe and record what strategies work best.
- Find and keep friends of various personalities, ages and abilities, who get to know the person very well and can support and continue the parents' roles. Friends can support one another as well as the person when organized as a Circle or Personal Support Network. Adults with ASD needs friends and allies in addition to family and those who are paid to be in her/his life.
- Plan with the person. Planning tools developed by Inclusion, such as PATH (Planning Alternative Tomorrows with Hope), MAPS and CIRCLES, are helpful in working through transitions, envisioning a good life and devising strategies to attain it.
- Be creative and flexible in setting up key parts of the person's plan for a good life. Don't be limited by the traditional service system. Consider what's really needed and find ways to make it happen. Have a clear understanding of your general goals. But also be open to the opportunities, even serendipity, at some unexpected turns in the PATH.
- Consider the best kind of living situation for each person. Adults with ASD need choices. A person with hypersensitivities may need her/his own home, supported in the ways s/he needs and shared with companions s/he chooses. Guelph Services for the Autistic (GSA) is pioneering a model of home ownership that includes choice and self-direction by the person, longterm capital investment by the family, support circles and networks, and recruitment and matching of homesharers and volunteers.
- Daily activities must be real and fulfilling and include continued learning, healthful exercise, and contributions to the community. Each person should have a way of life that is uniquely suited to her/his needs and interests. S/he should be able to comment and make requests and suggestions. Support workers should be chosen by the focus person and carry out their wishes.
- A good life must be sustained, beyond the lives of parents. A new mechanism is the aroha, that can give good friends of the person and parents the legal powers to strengthen and continue family efforts. An aroha can own property, and receive and manage resources to match needs and wishes.

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