

ADULT AUTISM ISSUES IN WATERLOO - WELLINGTON

Newsletter No. 7

May 2000

This issue features our new website,
the Ontario Adult Autism Research and Support Network
(OAARSN) at URL: <http://www.ont-autism.uoguelph.ca>

We thank all who responded to the survey of interest in the February 2000 issue of AAIWW and look forward to further comments and suggestions of how the website can help people and families who live with autism. We invite everyone to visit the site. Even if you do not own a personal computer and are not used to exploring the World Wide Web, it's possible to use Internet terminals in public libraries, for example. You need only type in our URL to reach the main page; then you are guided with site navigation tips and can reach all features of the site from live keys on the main page.

Our OAARSN site offers both a rich and rapidly expanding collection of up-to-date information and communication tools that can put you in touch with other individuals with au-

tism, parents, caregivers and concerned professionals. We can all benefit from the opportunities for mutual support, encouragement and information sharing.

What kind of information can we reach through the Internet? There are said to be at least a billion "pages" on the World Wide Web. In early May 2000, a search of the metasearch engine Ixquick for pages concerned in some way with the keyword "autism" yielded nearly 285,000. Only some of these are major sites with comprehensive information and comment; many pages mention autism more incidentally.

"Adult autism" resources are much more scarce--through the Internet and otherwise. Resources that are concerned with adults on the autism spectrum in Ontario are just about non-existent. We have



come to realize that providing access to more and better information about this major area of need could help to improve the quality of life of adults who have been described among "the most vulnerable members of society." The families and friends of autistic adults can also feel less isolated and more empowered to support their loved ones in the most effective ways.

We present an overview of the main features of OAARSN, an outline of the headings of Autism Informa-

tion, and topics opened up for discussion. We mention some websites created by parents of children on the autism spectrum, as well as some ideas about how the OAARSN website might develop.

To reach AAIWW, write
AAIWW, C/- GSA,
Root Plaza Postal Outlet
P.O. Box 23016, Guelph.
ON N1H 8H9,
or leave a phone message at
(519) 821-7424.

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AAIWW is a joint newsletter produced by WWAS and GSA. We thank Marie Puddister who volunteers her help with layout and formatting, and Andrew Bloomfield and friends who collate the newsletters for mailing

BULLETIN BOARD



The **WWAS Annual General Meeting** will take place on Wednesday 7th June 2000, from 7:30 pm, Stanley Park Baptist Church, 31 Lorraine Ave, Kitchener. A proxy form is enclosed with this newsletter to paid-up members of WWAS for 1999 or 2000.

Please show your interest in and support for adults with autism and their families and caregivers. Become a member or renew your membership of WWAS. Cheques of \$25 or more qualify for tax-creditable receipts. As a member, you have opportunities to share concerns, ideas and hopes about issues relevant to people with autism and their caregivers. You are eligible to vote at general meetings and to be elected to serve on the WWAS board of directors. You also receive AAIWW.

A subscription to AAIWW is \$5 a year, towards production and postage costs. Make cheques payable to WWAS and send with a note of your name, full address and phone number, to William Barnes, 26 Yellow Birch Drive, Kitchener, N2M 2M2.

For more information,

call our answering machine at (519) 742 1414, leave your name, number and message. Adults with autism/PDD need your ideas and time. WWAS recognizes with appreciation the voluntary service of Jane Forgay who monitors and responds to the phone messages.



Everyone concerned for and with adults on the spectrum of autism disorders is indebted to Peter McCaskell of Guelph who has volunteered his expertise, ingenuity and a great deal of time to get OAARSN going. OAARSN owes its existence and great technical qualities to Peter's substantial commitment. We also thank Marie Puddister, who has formatted AAIWW and wwasnews for years, for continuing to help with graphic design and layout for the OAARSN site.

Members of WWAS and GSA are glad to have information about their organizations now accessible through the Internet. OAARSN's qualities are valued by people far beyond our region as well as in the wider field of adult disabilities.

More Choice and Control for Adults with Disabilities: A Forum on Individualized Funding and Quality of Life

Monday, June 5, 2000, 9:30 am to 4 pm, Stirling Mennonite Church, 57 Stirling Ave N, Kitchener

Forum - A Chance to Learn

Many citizens with disabilities require support to live full lives in the community. In the last decade, there has been growing interest in finding ways to provide disability supports in a more individualized manner. Throughout the western world, many governments and communities have been exploring individualized funding as a vehicle for enhancing self-determination and community involvement of adults with disabilities. Individualized funding provides funds directly to individuals and the significant people in their lives to be able to purchase supports that they require. Research shows that people like this approach because it gives them more choice and control. Successful projects also demonstrate the importance of facilitation and planning with individuals and families. Positive outcomes include enhanced quality of life.

Forum Purpose

This Forum will provide an opportunity for adults with disabilities, service providers, government officials, and families to learn more about individualized funding, and to consider the implications for quality of life in their community and the province.

Forum

Format Presentations and provide lots of time for dialogue and questions. Directed discussion will assist Forum participants to learn how individualized planning, support, and funding can enhance quality of life.

Forum Resource People

- * John Lord, Coordinator, Ontario Round Table on Individualized Funding
- * Ana Vicente, Toronto Individualized Quality of Life Project,
- * Alison Pedlar, University of Waterloo
- * Elizabeth Bloomfield, whose son has individualized funding
- * Barb Leavitt, Choices Project in Thunder Bay (now lives in St. Mary's)

Forum Sponsor

Ontario Federation for Cerebral Palsy, Opening New Doors - Waterloo Region, Participation House Project - Waterloo Region, Independent Living Centre of Waterloo Region, Kitchener-Waterloo Association for Community

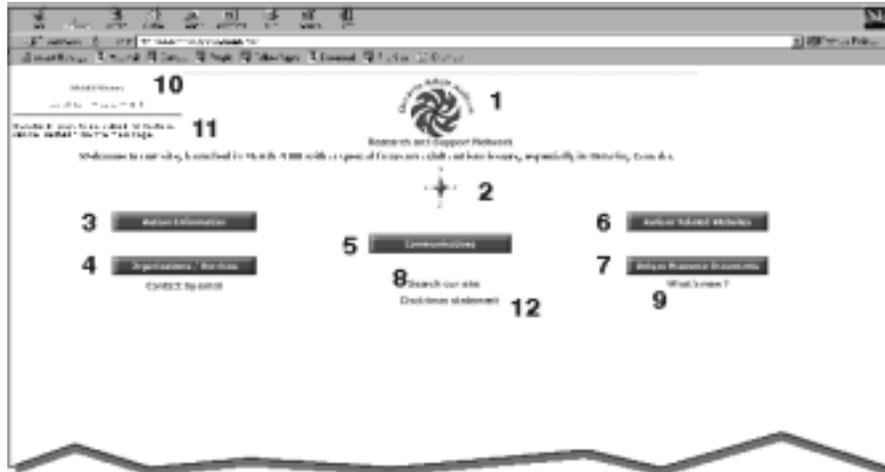
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Ontario Adult Autism Research and Support Network (OAARSN)

Passport to Autism Resources on the World Wide Web URL: <http://www.ont-autism.uoguelph.ca>

Our new site, created and maintained entirely by volunteers including parents of persons with special needs, is invaluable for its combination of:

a rich and rapidly expanding collection of up-to-date information about autism spectrum disorders, and tools that put parents and caregivers in touch with others who daily live with the challenges of supporting a loved one with such special needs, that all of us might benefit from the opportunities for mutual support, encouragement and information sharing.



The site has a very 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.

1. Logo and site name, when clicked on the main page, opens up an explanation of why this site has been created. On other pages, click on the logo to return to the main page.
2. Site navigation tips are reached by clicking on the compass.
3. 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.
4. Directory guides to autism Organizations and Services in Canada, with Internet links
5. Communications, including a Bulletin Board with weekly digest of Autism in the News, Calendar, Ontario Disabilities News, Announcements of Special Events, Needs and Opportunities (a service to link people in need with potential services and support people), and a Discussion Area (offering various Boards and Topics).
6. Links to Autism-Related Websites in various categories, as well as a link to a useful tutorial for searching the Internet.
7. Unique Resource Documents, including surveys of adult autism needs, model service proposals, newsletters of adult autism organizations (for example wwasnews and AAIWW), and first-person accounts of living with autism
8. Search our Site allows one to type in names, keywords and phrases to find specific material anywhere in the pages of our site.
9. What's New? gives visitors and users a dated summary of what has been added to the site.
10. The dynamic News Scroller at top left on the main page draws attention to current and changing concerns.
11. Users may Contact by email from various pages on the site, to comment or ask questions. Please let us know if you would like to join OAARSN Listserv, and thus receive email messages about important events and concerns, and additions to our site.
12. Disclaimer statement: OAARSN provides resources for information purposes only. We do not endorse any treatment, program, product or services. The contents of this website are not medical, legal, technical or therapeutic advice. Information should be reviewed with qualified professionals. We will not be held responsible for misuse of information or for any adverse effects of recommendations mentioned on this website or on any other websites linked to it. Views, opinions or announcements posted by subscribers do not necessarily reflect those of OAARSN and we do not assume responsibility for any discrepancies or errors.

OTHER GREAT WEBSITES!

Most advocacy and service organizations concerned with the autism spectrum now have websites. But the most innovative and helpful sites are those created by people who have personal knowledge of living with the disorder—individuals themselves or their parents. We recommend:

Autism Resources Website: <http://www.autism-resources.com/>

A very large, classified index of links to autism-related sites of all kinds, including information about treatment options, accounts of the experience of autistic people and their parents, and autism organizations. Started and maintained by John Wobus, who has a son with autism, the site was formerly hosted by Syracuse University..

FEAT: Families for Early Autism Treatment: <http://www.feat.org>

Beginning as a non-profit organization of parents and professionals in the Sacramento area, California, FEAT now has affiliated organizations all over the United States and in BC, Alberta and Manitoba. A great service to everyone interested in autism is the FEAT DAILY NEWSLETTER edited by volunteer Lenny Schafer who has a young son with autism. Our weekly digest of Autism in the News is based on the wealth of information put out by FEAT.

Ooops...Wrong Planet! Syndrome: <http://www.isn.net/~jypsy/>

A great Canadian site, with many hundreds of links and a very dramatic design, created and maintained by someone in Prince Edward Island who has Asperger's disorder herself and a son with autism.

Spectrum: <http://www.autism-spectrum.com>

Another great Canadian site started in spring 1999 and maintained from Kamloops, British Columbia, by a couple whose son has autism. The visually striking site features a comprehensive guide to BC services and resources from diagnosis to adolescence, as well as chat groups, calendar, web links, and 24-hour radio webcasts devoted to autism.

Autism National Committee: <http://www.autcom.org>

Founded in 1990 to protect and advance human and civil rights and social justice for all citizens with autism, AUTCOM is particularly relevant to adults. Includes updates on politics and judicial decisions; critiques of fundamental research and treatment issues; information about developmental and relationship-based approaches, and inclusion, homeownership and consumer choice.

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Living, Extend-a-Family of Waterloo Region, Developmental Services Access Centre

Registration

The Forum is free for families and people with disabilities and \$40 for agency and government staff and managers. Registration includes lunch. Make cheques payable to Canadian Mental Health Association and send registration to: Opening New Doors, Forum on IF, 26 College St., Kitchener N2H 4Z9 (phone 578-6944). Be sure to register soon and no later than May 30. Space is limited. You must register even if it is free for you. Registrants will receive a copy of the report of the Round Table on Individualized Funding. Linking Individualized Supports and Direct Funding: Making Money Work for People.

OAARSN's Pages of Autism Information

Autism Spectrum Disorders

- * What is autism?
- * How many people have autism?
- * What causes autism?
- * How is autism diagnosed?
- * Types of autism, such as classic autism, Asperger's Disorder, Rett's Syndrome
- * Autism in adulthood

Treatments and Therapies

- * Education and Management Programs:
- * Applied Behavior Analysis (ABA), behavior modification or Lovaas Method;
- * TEACCH;
- * Son-Rise/Options Institute;
- * Daily Life Therapy
- * Medical, Dietary, and Alternative Medicine:
- * Medication;
- * Dietary Intervention;
- * Vitamins, Enzymes and Hormones
- * Communication Therapies:
- * AAC;
- * Sign Language;
- * Picture Communication Symbols;
- * Facilitated Communicating (FC);
- * Social stories
- * Sensory, Mind and Body Therapies:
- * Sensory Integration;
- * Relaxation therapies
- * Special forms of occupational therapy
- * Art therapy;
- * Music therapy;
- * Animal-facilitated therapy;
- * Horticulture as therapy

Strategies for Supporting Adults (relevant to adults with other disabilities too)

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BOARDS AND TOPICS POSTED IN OAARSN DISCUSSION AREA

Following are some of the topics that have been proposed for discussion. Join in, by adding comments on these topics or proposing others.

A1: Are More People Autistic Now?

Reports from the US and Britain talk of an explosion in numbers of people being diagnosed in the autism spectrum. Have numbers have increased in Canada? If so, is this because greater awareness and sharper diagnostic tools are identifying cases that would have been missed in the past? Or could vaccines, viruses, environmental contaminants also be involved?

A2: Diagnosis for an Adult?

One of my clients was not diagnosed as a child but now wonders if he has Asperger's? Should I encourage him to seek a diagnosis? If so, how and where?

A3: Autism as a Label for Adults?

I work for a large agency that serves some adults who were diagnosed with autism as children, among a larger number of other developmentally disabled clients. We don't like to label people by their disabilities, but I'm a bit concerned about disregarding the autism completely. How knowledge of an adult's autism help in supporting them appropriately?

B1: I note that Applied Behavior Analysis is the current treatment of choice for young children with au-

tism, and wonder what success others in Ontario may have had in using ABA with autistic adults.

B2: Does any organization in Ontario model a program for either adults or children on the *Son-Rise Program* of the Options Institute or the *Daily Life Therapy* of the Boston Higashi School?

C1: Finding the Right Medication

One of my patients is a middle-aged woman with autism who has had paradoxical and often toxic reactions to drugs. She really hates the idea of medication, and thinks the drugs were given to punish her for some of her obsessive-compulsive behaviour. What alternatives have other professionals and caregivers developed in such cases?

C2: Dietary Intervention

I've been reading about the remarkable improvements in some young autistic children with a gluten-free, casein-free diet. My son of 35 shows most of the symptoms of intolerance. I'd like to try modifying his diet, but I wonder if it's worth all the trouble when he's already an adult. Have other adults benefited from dietary intervention? And how could I get some advice on the practical business of changing his and our diet?

C3: *Secretin* has really been in the news over the past couple years. I really want my niece who is 25 to have

the best chance of a good life. Could *Secretin* help her as an adult?

D1: Picture Communication Exchange Symbols

I'm interested in keeping in touch with others who use PECS with autistic adults who don't speak. I'd like to find PECS that are more age-appropriate.

D2: Facilitated Communicating

One of my friends (a young adult with autism) used to communicate through FC, but hasn't been able to get any support for the past four years. How can I find help for her in Ontario?

D3: Social Stories

My friend who has autism responds well to social stories as a way to prepare himself for new experiences in the community. Does anyone know any good ready-made resources for adults?

E1: Sensory Integration dysfunction

really makes sense for my adult son. I wish we'd known about sensory therapies 30 years ago. I'd like to keep in touch with anyone else who is supporting their adults with autism to cope with their movement disorders.

E2: Therapies for Adults with Autism

Some of our staff urge our agency to try these new therapies-art, music, dance, horticulture, and so on. But I need to be convinced that

they aren't just optional frills. How can they help?

E3: Sleep Disorders

The young woman whose home I share has problems getting off to sleep and can't take any drugs. I'm interested in knowing what other caregivers and support people have found helpful

F1: Emotional Hurts of Exclusion

I think we too often assume that the special children we love and care for do not notice the rebuffs and slights of being excluded in social situations. (however unintended they may be) and that we bear them instead. But various personal-experience accounts we know (through Internet connections etc) can help us to realize that our children/adults do really feel these hurts too. I would welcome discussion on this topic, and suggestions for dealing with the hurts we and our special children can feel.

G1: I'm interested in discussing the pros and cons of a *campus-style intentional community in Ontario* for young adults disabled by moderate to severe autism.

FUTURE PLANS FOR OAARSN

Various ideas have been proposed for the site's future development during 2000. They are all possible technically.

1. One is an online "bibliography" of autism spectrum disorders and of the best practices and strategies for supporting adults with disabilities.

2. Another idea is to post personal experience stories of what it is like to live on the autism spectrum and/or with major challenges. Our site already has a place for such first-person accounts, within the category of

Unique Resource Documents. An anthology of these accounts, illustrating the various facets of supporting children, teenagers and especially adults, could be published electronically.

3. How are adults with autism faring in the year 2000? A decade ago, Autism Society Ontario appointed an Adult Task Force to survey the needs and circumstances of adults with autism throughout Ontario. The Task Force report, *Our Most Vulnerable Citizens* (1991), can be reached on our site (in the category of Unique Resource Documents). The

report includes valuable essays on needs and best practices by Dr Susan Bryson, as well as statistical summary tables based on the data. What do we know about the quality of life of adults with autism and their caregivers now? What has changed since 1990? We think that it's time to update our understanding of adults with autism in Ontario. A new survey of needs and quality of life, and of effective support strategies could be managed from this site.

4. Visual material including video clips illustrating effective support strategies

could also be posted.

In our view, too little attention is paid to adult autism as a general category of disability or to individual adults who have the symptoms of autism. The OAARSN website is dedicated to the exchange of information, observations and opinions about needs and effective forms of treatment and support, so that adults with autism and their primary caregivers can use their abilities, realize their dreams, and attain the best possible quality of life.

MICROBOARDS- COULD THEY HELP?

A microboard is a small group of committed family and friends who join a person with challenges to form a non-profit society which is registered according to provincial law. Together they address the person's planning and support needs in an empowering way that is tailored to that individual's needs and circumstances. The more complex a person's needs are, the more important it is that supports are customized and individualized to meet those needs.

The ideal size is between 5 and 7 members, including the person with challenges, and the qualifications are good relationships with, knowledge of, and commitment to the person.

The role of the microboard is to ensure that the person becomes part of

the fabric of the community, thus safeguarding the person's future.

As a legal entity, a microboard in British Columbia can receive and share responsibility for spending individualized support dollars.

More information may be found on the Vela Microboards' website at <http://www.microboard.org>

Round Table on Individualized Funding Highlights Need for More Direct Funding for People with Disabilities

The Round Table's Report, entitled *Linking Individualized Supports and Direct Funding: Making Money Work for People*, outlines province-wide principles, a policy framework, as well as directions and strategies for implementing individualized funding throughout the province.

Round Table members had experience with individ-

ualized funding, whether as an individual with a disability, family member, advocate, researcher, broker, facilitator, or service provider.

Dr John Lord, co-ordinator of the Round Table (and also a member of the GSA Board of Directors) emphasized that, "successful projects do not just provide money, they encourage individuals with disabilities and their families to build strong and involved networks of support." In fact, the research points out that when people have individualized support, direct funding, and involved networks, they have a much greater chance of achieving community participation and citizenship.

Copies of the Round Table Report are available for \$5 from the Coalition on Individualized Funding, #403, 240 Duncan Mill Road, Toronto, Ontario, Canada.

M3B 1Z4 Phone:

416-447-4348 (ask for Barbara)
Fax: 416-447-8974
Email: barbara@acl.on.ca
Webpage: www.lefco.com

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- * Quality of life indicators
- * Choices and self determination
- * Individualized planning and funding
- * Support clusters... microboards
- * Long-term planning for financial and emotional security
- * Inclusion in community life
- * Housing and residential supports
- * Vocational skills development
- * Life skills and continued learning
- * Recreation and leisure
- * Model programs and services for adults
- * Disability rights organizations