

ADULT AUTISM ISSUES IN WATERLOO-WELLINGTON

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

AAIWW Newsletter No. 21, October 2003

New Autism Collection at Kitchener Public Library-- thanks to Waterloo Wellington Autism Services

The Autism Collection of the Kitchener Public Library will be officially launched on Tuesday evening, October 21, from 7 pm. Anyone concerned with autism needs and services is most welcome to attend the event at 52 Queen Street North in Kitchener. Come to the HealthLink area of the Research Services Department upstairs.

This important resource has been made possible through the generous donation of the Waterloo Wellington Autism Services. The idea was first suggested by WWAS Treasurer, William (Bill) Barnes, who noted a similar but smaller gift to a public library while visiting the Dallas area in Texas. We think the collection is distinctive, even unique in Canada, and will make a valuable contribution to autism awareness and community understanding of autism spectrum disorders. Elizabeth Bloomfield has represented WWAS in discussions with KPL staff, especially Ann Celestine.

The Autism Collection of the Kitchener Public Library is a special, regionally accessible, resource of materials in all formats intended for the informational, instructional and research needs of the general public on this disorder. This unique collection includes resources for researchers, health workers as well as individuals and families who work and live with autism spectrum disorders. Both genders and all ages are reflected in the collection.

Classic works in the field will be acquired and retained in the collection for continuity and research purposes. Biographies, children's books, and fiction as well as multimedia, video and DVD materials are included when deemed important to a resource collection on this disorder.

The collection is housed beside the HealthLink area of the Research Services Department upstairs at the Main Library. All formats are at this one location. Clients who wish to check out materials from this collection will require a KPL Borrower's Card or a KPL Special Borrower's Card. The Special Borrower's card will be issued at the Borrower's Services Desk to any requesting individual from the regions of Waterloo, Wellington, and Dufferin, who presents correct identification and a proof of address. There is no charge to obtain this card. The special card may only be used to check out materials from the Autism Collection. All of these items are marked M-Aut and have a special spine label icon and book donation label. Customers may request items through Inter-Library Loan as well, as per normal procedures.

Autism Collection, HealthLink Services
Kitchener Public Library
85 Queen St. N., Kitchener ON N2H 2H1
InfoLink: (519) 743-7502 Fax: (519) 570-1360
Email: askus@kpl.org Website: www.kpl.org

AAIWW is published 4 to 6 times a year for Waterloo Wellington Autism Services and Guelph Services for the Autistic. Mailed from: 16 Caribou Cres, Guelph, ON, N1E 1C9. "Investing in People: IF in Ontario" and "Adults with Autism" are inserted.

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Where have all the adults gone?

We were recently invited to prepare a display on Adults with Autism for the Ontario Ministry of Education's conference on Teaching Students with Autism: Enhancing Capacity in Ontario Schools. A copy of brochure is enclosed with this newsletter. We included a table of the estimated prevalence of autism in various age-groups of the Ontario population, according to two rates--"classic" autism or 1 in 2,222 of the population (the rate assumed until the past few years) and the wider concept of autism spectrum disorders affecting 1 in 150 people. If we use the classic rate, an estimated 3,780 Ontario adults are affected (compared with 1,350 children and teens up to age 19). If we consider the wider autism spectrum, there could be more than 56,000 adults compared with 20,000 children and teens.

We all hear a great deal about the needs of autistic children and we support the claims of early and effective intervention strategies for them. But why don't we hear about, and why are we not concerned with, all the adults who must outnumber the children? We receive tragic news and appeals on behalf of adults with autism who are incarcerated, receiving no helpful treatment, and (in the opinion of family and friends) regressing. It makes some difference when family members are involved in the advocacy efforts. However, once a dependent person comes under the jurisdiction of the courts or of the Ontario Public Guardian and Trustee (or its equivalent elsewhere) and spends months or years in some form of incarceration, it is very hard to make any change. For one thing, the person may have regressed so far that everyone may be too frightened to try a more humane approach.

A concerted strategy is needed, involving family, friends, advocates, humane professionals, to create much better living environments and opportunities for self-expression and relationships with friends. We suggest that our concept and mechanism of an aroha--an incorporated entity for personal empowerment and support *aka* microboard--could help to provide the safeguard that the authorities would want to permit a change. Resources are needed to create all elements of a better life. But the financial costs would be lower than continued incarceration and justified by the chance to give a better life to someone tortured by frustration, pain and isolation.

Proactive use of person-directed plans, circles of friends and family, individualized funding, and aroha entities of personal empowerment and support, could save significant numbers of vulnerable adults from the desperate plights that are now being reported.

Estimates of Populations with Autism

- (a) Classic rate of 4.5 persons per 10,000
 (b) Autism Spectrum Disorders prevalence of 1 in 150 persons

Ontario Population, 2001 Census

| Age group | Classic rate (1 in 2,222) | ASD rate (1 in 150) |
|-------------|------------------------------|------------------------|
| 0 – 4 years | 302 | 4,473 |
| 5 –14 years | 702 | 10,407 |
| 15-19 years | 346 | 5,127 |
| 20-24 years | 323 | 4,787 |
| 25-44 years | 1,583 | 23,453 |
| 45-54 years | 736 | 10,900 |
| 55-64 years | 479 | 7,093 |
| 65 + years | 662 | 9,813 |

Children (0-19) 1,351 20,007
 Adults (20+) 3,784 56,060

Waterloo Region Population, 2001 Census

| Age group | Classic rate (1 in 2,222) | ASD rate (1 in 150) |
|-------------|------------------------------|------------------------|
| 0 – 4 years | 13 | 187 |
| 5 –14 years | 28 | 420 |
| 15-19 years | 14 | 207 |
| 20-24 years | 14 | 207 |
| 25-44 years | 63 | 927 |
| 45-54 years | 27 | 400 |
| 55-64 years | 17 | 250 |
| 65 + years | 22 | 327 |

Children (0-19) 55 814
 Adults (20+) 143 2,113

Wellington County Population, 2001 Census:

| Age group | Classic rate (1 in 2,222) | ASD rate (1 in 150) |
|-------------|------------------------------|------------------------|
| 0 – 4 years | 5 | 80 |
| 5 –14 years | 12 | 178 |
| 15-19 years | 6 | 87 |
| 20-24 years | 6 | 84 |
| 25-44 years | 26 | 382 |
| 45-54 years | 12 | 173 |
| 55-64 years | 7 | 109 |
| 65 + years | 10 | 155 |

Children (0-19) 23 345
 Adults (20+) 61 903

PATH and CIRCLES OF SUPPORT

As part of its ASPIRE project, GSA recently sponsored a workshop at which facilitators Beth Hancox and Jan Cooper introduced representatives of nine families to PATH and CIRCLES as planning tools for better lives and more secure futures. This is a summary of part of their presentation.

What is PATH?

Planning Alternative Tomorrows with Hope

PATH is a powerful, creative and useful planning tool?

PATH is daring, bold and action-oriented

PATH is personal

PATH is life-giving

PATH is life-changing

PATH is feeling the fear and doing it anyway

PATH is flying into the unknown and having a circle there to support the dream

PATH is a social process, a journey of self-discovery

PATH is an opportunity to give and receive a gift

What PATH is not....

PATH is not a prepackaged set of steps

PATH is not a guarantee

PATH is not a test

Who are PATHFINDERS?

People who want to create their own future

Individuals with a dream or desire to move forward

Families who want to work together

Friends who want to make a difference in someone else's life

What are the Steps of PATH?

Create a clear picture or vision of where you want to be

Identify your goals—focus for the next year

Ground yourself in the now

Identify people to enroll on the journey

Recognize ways to build strength

Chart the Action Steps needed to achieve your goal

What is a Circle of Support?

A group of people who agree to meet on a regular basis to help a person with a disability to accomplish certain personal visions or goals, by overcoming obstacles and opening doors to new opportunities

How is a Circle of Support Developed?

The focus person decides to ask help from people they know and trust, perhaps using a relationship map. These people are called together to focus and collaborate to reach a common goal.

Creating a PATH or Circle involves three challenges for the parents and family of person with a disability:

1. Asking others to get involved is hard, as we think we have so few friends and we fear being refused
2. Opening our lives to share responsibility for our person with a disability
3. Believing that there are community people we can trust to share in a CIRCLE or PATH

Do I Need a Circle of Support to do a PATH?

No. Your Circle of Support will evolve and grow with you. It may start with a small intimate group of 4 or 5 people with whom you plan and set some goals. Then you will invite others to join you, to join in celebrating successes and coping with challenges. As time goes by, your PATH will change and grow and your Circle will change and grow with it.

PATH was designed and developed by Jack Pearpoint, John O'Brien and Marsha Forest beginning in 1991. Facilitators are trained by Jack Pearpoint and associates at the Marsha Forest Centre for Inclusion-Family-Community in Toronto. Inclusion Press Books include:
All My Life's a Circle. Using the Tools: Circles, MAPS and PATH
PATH: Planning Possible Positive Futures
Hints for Graphic Facilitators
Person-Centered Planning with MAPS & PATH: A Workbook for Facilitators
Inclusion Press Videos include:
All Means All: An introduction to Circles, MAPS and PATH
PATH Action Pack: A Collection of 2 videotapes + the PATH Workbook
PATH Training Video-Joe's PATH

Books on the Autism Spectrum

Reviews and notes about books may be found on OAARSN's site at <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

Perspectives on the Autism Spectrum Disorders: Special Issue, Journal on Developmental Disabilities: Le journal sur les handicaps du développement. Volume 9, No. 2. 165 pp. edited by Maire Percy & Rita Eagle.

A whole book or journal devoted to autism is a very rare event in Canada. So this special issue is welcome. Its inspiration was the ECLIPSE conference at Surrey Place Centre in Toronto in January 2001, which brought together people involved in assessment, service provision, education and treatment of older children and adults with autism who are more severely affected and/or "lower-functioning." This is a focus of great interest to OAARSN, which is quoted at several points in the volume. Several other papers added for this special volume, while useful and interesting, have tended to blur the original focus. Very few papers concern themselves with adults with autism—who are, as the editors note, under-represented in research and clinical studies. We hope that the next collection of papers will be able to report more findings and on "what helps?" as well as "what's wrong?"

Fourteen papers are included, by 20 authors:

Etiology:

Advances in Understanding Causes of Autism and Effective Interventions by Indu Joshi, Maire Percy and Ivan Brown
The Relationship Between Autism and Fragile X Syndrome: A review of the research by Jenny Demark

Assessment and Diagnosis

Accessing and Assessing Intelligence in Individuals with Low Functioning Autism by Rita S. Eagle
Challenges in Identifying Mental Health Issues in Individuals with Severe Autism by Soula Homatidis
Best Practices and Practical Strategies for Assessment and Diagnosis of Autism by Adrienne Perry, Rosemary A. Condillac and Nancy L. Freeman

Intervention

Teaching Prerequisite Matching and Object Permanence Skills to Those Who Have Difficulty Communicating with Photos or Pictures by Marilyn Chassman [a case study of the author's working with her son aged 9-11 years]
Children and Adolescents with Pervasive Developmental Disorders: The role of a crisis center by Susan Sweet

Martha Kate Downey's books are packed with humour and useful tips based on the experience of raising a "flavorful" daughter with autism to adulthood. We recommend:
What Do I Do About Hitting?!! Understanding and learning to manage childhood rage, anger and frustration
The People in a Girl's Life, written as conversation/letters written to her daughter Kate
If you've ever wanted to crawl in the closet with an OREO.
Tips for parenting a child with special needs

[Youthdale Treatment Services, a "secure, 10-bed, in-patient facility" for adolescents aged 12-15 years, 10 out of 294 of whom had PDD in the study period]

Community Participation in an Admission Process to a Government-Operated Facility for Children and Adolescents with Severe Autistic Disorder by Patti Reed [new 5-bed child and adolescent home by TRE-ADD at Thistleton Regional Centre]

Consultation to a Group Home for a Young Autistic Woman with a History of Severe Trauma by Lynne Sinclair
Pervasive Developmental ("Autistic Spectrum") Disorders: Treatment issues by James Deutsch [Youthdale Psychiatric Crisis Service]

Intensive Early Intervention Program for Children with Autism: Background and design of the Ontario pre-school autism initiative by Adrienne Perry

Behavioural Issues

Self-injurious Behaviours in Autism: A literature review by Jonathan Weiss

Behaviour is Communication: Nonverbal communicative behaviour in students with autism and instructors' responsivity by Nancy L. Freeman, Adrienne Perry and James Bebko

Using the Internet Content Analysis of Online Autism Specific Sites by Jeeshan Chowdury, Jane Drummond, Darcy Fleming, and Susan Neufeld [based on a study of relevant websites in July-August 1999, too early to include OAARSN]

The Journal is published by the Ontario Association on Developmental Disabilities (OADD) whose members receive a subscription. Single copies may be ordered for \$25 from OADD, 4 Overlea Blvd, East York, ON, M4H 1A4. Visit the website at <http://www.oadd.org>

AAIWW BULLETIN BOARD

AUTISM NEWS CLIPS, EVENTS & GOOD IDEAS (continued page 6, column 2)

Making Autism a Political Issue

Best-selling novelist Nick Hornby has launched a powerful attack on the British Government for not spending enough on autistic children and families. He spoke of his son Danny (10) and described how parents face a daily battle against grinding bureaucracy, under-funded services and the seeming indifference of the authorities. To a packed meeting at the British Labour Party's annual conference in Bournemouth he said: "One of the first of many shocks one receives as the parent of a disabled child is that there is no one to help you negotiate the dense and dark forest of difficulties that has suddenly sprung up in front of you. Only a few parents are able to do this and even this fortunate minority go through hell and back to fight for what their children need and what they are legally entitled to." Hornby stressed the need for co-ordinating any services and supports, and that this depends overwhelmingly on mothers.

Girls, Boys and Autism

Newsweek's cover story for September 8 began: "Is this mysterious and sometimes devastating condition just an extreme version of normal male intelligence? That's one provocative new theory. Behind autism's gender gap."

Cooking club designed for people with autism

A love of cooking and her experience as parent of an autistic son (16) prompted Penny Gill of Hamilton to establish a cooking club for people with the disorder.

Meet My Brother

Megan McCreary (10) of the Orangeville area, who has two brothers on the autism spectrum, features in the video produced for Autism Society Ontario to promote Toonies for Autism Day. Megan is also a partner in the business called Common Senses, which designs Fidgitkitz, affordable sensory toys for children who have autism.

Celebrate Autism Society Ontario's 30th birthday!

Friday, October 24, 2003, in Toronto's Edwards Gardens "It will be a marvelous evening of good food, entertainment and silent auction items - all in support of families living with children with ASD." Call the ASO office 416-246-9592 for tickets.

2003 "Rock Star Gala"

November 8, 2003, in Peter Clark Hall, University of Guelph, as an autism fundraiser. Organized by Len Kahn in support of ASO Wellington Chapter's summer programs and Stephanie Home, a Guelph for autistic children.

Planned Lifetime Networks:

Autumn Workshop series

October 25 to November 15

Four Saturdays mornings, in Kitchener

Planning a Good Life Now

Oct. 25: Planning financial security

Nov. 1: Planning a home of one's own

Nov. 8: Planning for after we're gone

Nov.15: Planning with our disabled children (capacity assessment, powers of attorney, and supported decision-making. For more details and to register: phone 519-746-1188 or email plnww@sympatico.ca

IDIA: Inter-University Disability Issues

Association includes disability service providers from universities throughout Ontario. Working together, Universities can share ideas and strategies to overcome issues and problems, allowing disabled students across Ontario to succeed in post-secondary education.

From Bangalore to Hollywood

Julia Roberts to produce the amazing story of the Indian boy of 13, Rajarshi 'Tito' Mukhopadhyay, who does not speak but communicates through typing, telling others what it feels like to be trapped in an autistic body and mind.

Mothers of Children with Special Needs

Amy Baskin and Heather Fawcett, mothers of children with ASD, invite you to share your thoughts and experiences. They are writing a book with the working title *From Struggle to Strength: How Mothering a Child With Special Needs Transforms Your Life* to be published by Woodbine House in 2005. Information and questionnaire at <http://www.sentex.net/~abaskin/Amy%20Baskin%20Consulting.htm>

Mark Heinmiller's website: Asperger's Syndrome: Positive or Negative?

<http://publish.uwo.ca/~mheinmil/asperger2/>

Mark eagerly seeks employment in the area of Library Sciences, ideally in a university environment, having just qualified with his MLIS at the University of Western Ontario.

Lindsay Moir (Education Consultant) writes a

weekly Q & A column at Family Net on special education issues. <http://www.familynet.on.ca/AskLindsayMoir.htm>

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WATERLOO WELLINGTON AUTISM SERVICES,

incorporated in 1991, is dedicated to supporting adults with autism to have good lives in their communities. WWAS administers the Victoria Bloomfield bursary program begun in 1996 (see <http://www.ont-autism.uoguelph.ca/wwasbursary.shtml>). It also funds GSA's ASPIRE project and the new Autism Collection at the Kitchener Public Library. Please support these worthwhile projects. Cheques of \$25 or more qualify for tax-creditable receipts. Please make cheques payable to WWAS and send with your name, full address and phone number, to William Barnes, 26 Yellow Birch Drive, Kitchener, N2N 2M2.

GUELPH SERVICES FOR THE AUTISTIC,

incorporated in 1980, is run by volunteers, and dedicated to adults with autism and their families. What does GSA do?

-Acts as a housing trust to enable adults to live with dignity in their own homes with companions they choose

-Supports person-centred planning, self-determination and individualized funding

-Offers ASPIRE and adult needs surveys

-Recruits volunteers as friends for adults with autism

-Provides advice and support to families and friends

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

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

ASPIRE: AUTISM SUPPORT PROJECT: INFORMATION, RESOURCES, EMPOWERMENT

An initiative to help persons and families and persons plan for and realize good lives and secure futures.

Organized by GSA; supported by funds from WWAS.

ADULT AUTISM NEEDS SURVEY

Associated with ASPIRE but also offered more generally to help adults and families measure quality of life and GSA and OAARSN to generalize the current situations and needs of adults with ASD. Long-form and short-form surveys may be completed on paper or online.

ONTARIO ADULT AUTISM RESEARCH AND SUPPORT NETWORK

OAARSN offers a collection of up-to-date information and communication tools, with opportunities for mutual support, encouragement and information sharing. Click on

<http://www.ont-autism.uoguelph.ca> to reach OAARSN's main page, then use the buttons to reach the site's features. You may ask to be on the OAARSN List to receive weekly bulletins of autism news and announcements of events.

Contact GSA about any of the above: Mail: 16 Caribou Crescent, GUELPH, Ontario, N1E 1C9. Phone (519) 821-7424 or (519) 823-9232. E-mail gbloomfi@uoguelph.ca

Sharing the Voices of FC Users

Who else uses Facilitated Communicating? Chris Pentzell of Los Angeles, whose extraordinary brother Nick has been an FC user and poet for more than a decade, has a vision of sharing the voices of other FC users, by publishing a book of poetry, short stories and artwork created strictly by FC users. She'd like all profits from the book to go to an organization that furthers FC use, and strongly believes that FC users should be involved in the entire process, not just in the creative aspect. She wants to make sure the FC users communicate what they want to say rather than what other people think should be communicated. Chris reports that workshops are being planned in Whittier CA, Richmond VA, Philadelphia and perhaps San Francisco.

What about an FC workshop in Ontario? Please let us know if you or someone close to you uses FC and might be interested in a workshop. Please reply to GSA (see contacts at foot of previous column).

Puzzles and Co-operative Games

Puzzles and board games can appeal to people with autism who may have very good visuospatial and tactile skills and a passion for order and sequence. Playing games and solving puzzles with family and friends can provide great experience in social interaction and also some simulation of how to work out strategies to solve problems in real life. However, commonly available games and puzzles may not be so good for teens and adults with autism and no speech. There are few age-appropriate puzzles with enough geometric and spatial interest and challenge. And conventional games that usually require speech and a strong competitive spirit among players may tend to exclude those with autism.

We are pleased to recommend two lines of games and puzzles that appeal to Andrew, an adult with autism who says "games and puzzles are my life."

1. The co-operative games invented by Jim Deacove and distributed by Family Pastimes of Perth, Ontario since 1972. Why didn't we discover these years ago?

2. The clever and beautiful puzzles made by Imagination Project (I-Project) that has been developing fun, unique, award-winning products since 1994. We specially like the puzzles derived from brilliant designs by M.C. Escher.

This Newsletter also included the essay by John Lord in the series, Periodic Updates from the Individualized Funding Coalition of Ontario. "Understanding Individualized Support: The Power of Independent Planning and Facilitation" which is posted at <http://www.ont-autism.uoguelph.ca/Investing-in-People.PDF> as well as the following notes:

Individualized Funding poster
at <http://www.ont-autism.uoguelph.ca/IFflyerfao.PDF>
It doesn't cost more to have a better life.
Make Individualized Funding an option in Ontario!
Share this poster produced by the Family Alliance of Ontario.

"Expanding Individualized Funding: The Time is Now!"
February 20 to 22, 2004 at the Inn on the Park in Toronto.
The goals are:

- To develop an action plan for implementing IF in Ontario; and
- To develop strategies for building the capacity of families & communities for citizenship & IF.

Key stakeholders from all parts of the province are invited to think carefully about who needs to be invited in order to create and train a diverse, energetic and motivated leadership team.

Please contact Judith Snow at Phone: 416-538-9344 or Fax: 416-516-1691

Read the new article "Reflections on Friendship" by David and Faye Wetherow at

<http://www.communityworks.info/articles/friendship.htm>

"What steps can we take to invite and support real friendships for our sons and daughters who live with disabilities? We sometimes see other children moving along in a sea of friendship, and we see our children struggling with isolation. The natural ebb and flow of play, enjoyment and affection may seem out of reach, and we worry about the possibility of a life-long pattern of separateness. What can we do?....."