

# **ADULT AUTISM ISSUES IN WATERLOO-WELLINGTON**

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

AAIWW Newsletter No 19, April 2003

## **WWAS BULLETIN BOARD**

*Annual General Meeting of  
Waterloo-Wellington Autism Services  
Tuesday 3<sup>rd</sup> June 2003 at the Stanley Park Baptist  
Church, 31 Lorraine Ave, Kitchener.  
Current members of WWAS will also receive formal  
notices of this meeting. Agenda:  
7 pm - Registration  
7:30 pm - AGM business meeting  
8 pm - General discussion of adult autism issues, with  
refreshments. Representatives of the three local  
chapters of Autism Society Ontario and of Guelph  
Services for the Autistic are being invited, so we can  
share ideas about priorities and problems in our  
region. There will be reports on current WWAS  
projects: the Victoria Bloomfield Bursary program,  
progress of ASPIRE, and the forthcoming launch of  
the Kitchener Public Library's Autism Collection.*

*The WWAS Board invites applications for Victoria  
Bloomfield bursaries. Since early 1996, WWAS has  
offered one-time grants of up to \$2,500 each to  
individual adults with autism/pdd to help make a  
difference in their lives by developing abilities or  
obtaining therapies for which funds are not otherwise  
available. The bursaries are named in honour of the  
WWAS volunteer who helped to plan this project but  
was killed in a traffic accident in February 1996.  
More information and an application form are  
enclosed and also posted at  
<http://www.ont-autism.uoguelph.ca/wwasbursary.shtml>*

*Please 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.*

*Please 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,  
N2N 2M2.*

## **Do you wonder .... what it's like to be me?**

*by Andrew who types instead of speaking*

I'm a bundle of sensations  
I get the urge  
to touch and pick  
and I must follow my urges.

Can you see my urges?  
I can't tell you  
I just show you.

I'm a bundle of nerves  
and a jumble of thoughts.  
I'm in constant motion  
and my mind's always going.

I wonder what it's like to be you.  
Do you wonder what it's like to be me?  
I'm a time bomb waiting to explode

We neurotypicals on the sidelines do wonder what it's really like. We can learn more from the growing number of books by people who live with autism (see the commentary and lists on our Books on the Autism Spectrum pages inside).

We who are parents, siblings, friends and caregivers of persons with autism also need to take to heart the good advice of David and Fay Wetherow about the value of true community, in "Keeping the Balance."

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AAIWW is published 4 to 6 times a year for Waterloo-Wellington Autism Services and Guelph Services for the Autistic.

# *Keeping the Balance* by David and Faye Wetherow AAIWW 19, April 2003, p.2

*As parents of children with disabilities, one of the vulnerabilities we face is the prospect of personal isolation, a thinning out of relationships to the point where our family's circle (and ultimately that of our child) narrows down to service providers and 'others like us' – other families who have children who live with disabilities.*

## **This 'narrowing' stems from four sources:**

- It is an unhappy fact of contemporary North American life that people remain uncomfortable with disability in general. And people may be particularly uncomfortable when someone close to them is 'struck by' a disability. We 'don't know what to say'; we 'don't want to interfere'; and we are afraid that if we open up communication we will touch a thread of sorrow that may be uncontrollable;

*Fear is the mind's reaction against the inherent generosity of the heart. Because the heart knows no bounds to its giving, the mind feels called upon to define limits. - Ram Dass*

- Because our society is uncomfortable, the *family* is likely to feel uncomfortable about the prospect of 'being a burden' to their friends; we become reluctant to 'impose', to ask our friends to extend practical assistance;
- The family may find themselves overwhelmed in terms of time, energy and attention by the child's specific needs and the new demands of engaging with 'the system'. As any parent can tell you, caring for a young child seems to take up all of your time. Caring for a child with a significant disability is likely to be even more demanding, and the parents may find themselves swamped with disability-related appointments, meetings, support group gatherings, and so on;
- Finally, in North America, family and community ties are fragmented at the best of times. Our society prides itself on being highly mobile, independent, ready to 'move on' at the slightest whim or to relocate quickly in a search for solutions to economic, social or family problems.

## **However (and this is a big however)...**

- If it is true that the quality of our child's life (and his family's life) will be greatly enhanced by the presence of a large circle of people who know him, love him, aren't afraid to touch him or to be touched by him, and know that they will be part of his future and he will be part of their future, forever...
- If it is true that our child's opportunities will be greatly enhanced by long-term, thoughtful, on-purpose connections with many 'civilians' – people

whose lives are anchored in the larger world, the broader cultural, economic, congregational, cultural and social environment...

- If it is true that our child's development can be greatly enhanced by loving and enduring connections to other children and adults who help us define our identity -- who shape our understanding, expectations, hopes, social expressions, etc....
- Then it is important to focus *at least* as much of our effort, thinking, learning, and personal action in the direction of 'the boundary with community' as we invest in 'the boundary with the service system'.

## **What does this mean in practice?**

- Working on 'the boundary with community' doesn't mean excursions to McDonalds. It means an intentional pattern of invitation, conversation, deep listening, dreaming together, reflection, sometimes repentance and forgiveness, and always celebration.
- Working on 'the boundary with community' doesn't mean recruiting community members into the world of disability. It means remembering (another form of conversation) that we are all part of a larger world, and that a great community systematically identifies, mobilizes and celebrates the gifts of *every one* of its members.
- It doesn't mean just yearning for connection. It means taking the difficult step of *asking* for involvement. It means coming to terms with the fact that true friendship is woven of threads of joy and threads of sorrow. And it means taking the even more difficult step of coming to terms with our own self-isolating behavior.
- Finally, it means recognizing and consciously resisting the powerful magnetic attraction of formal service systems, especially when professionals and other parents keep sending us the message that "The most important work you can do as a parent is to get skilled at finding services, using services, advocating for services" (a regrettably consistent emphasis in early intervention services, child guidance clinics, diagnostic and treatment centers, advocacy groups, and disability 'support' groups).
- Of *course*, these conversations are difficult at first. It is difficult to say to our old friends, "I need you

more than ever now". It is difficult to say to our church, "More than ever, we're called to be community for each other". The good news is that people are yearning to be *asked*. We've so often heard people say, "We wanted to do something, but we didn't know what to do".

- And where 'we hear people singing' because people are *making* music, rather than consuming music, *making* art rather than consuming art.

Some time ago we developed a graphic of a 'family pattern' – an intentional pattern of thought and action that, ideally, should be 'there' for any child, in any family. You can find it on the Internet at:

<http://www.communityworks.info/familypattern.html>

As we begin to navigate the boundary with the community (Faye suggests calling it a shoreline), we make a discovery. Beyond the 'sweet places' of friendship and extended family life, there are other places in the community that can be particularly welcoming and fruitful. Think about the places where people feel most deeply valued and deeply 'at home' – our churches, synagogues and mosques, places where a shared culture or a shared passion for justice, for the environment, or creating beauty draw people beyond the usual boundaries of age, economic status, and even disability.

If we pay close attention, we may discover that this is not only a place of hospitality, it is a place of *abundance*. The congregation of a small church touches dozens, perhaps hundreds of other 'places' in our community. Harry goes to work at the tractor plant. Tom prints the local newspaper. Laurie's father is a member of a group that rebuilds antique airplanes. Lillian is connected with the Swedish Cultural Society. Jack plays a great bluegrass banjo and has dozens of good friends in the music community.

If these friends understand that one of the gifts they can offer is to look for our child's gifts, delights, and interests, and to introduce him to people whom they already know and trust, and build bridges to the places where those interests will be welcomed and celebrated, we discover that we live in an abundance of connections. Far too often, though, we turn Harry, and Tom, and Lillian into fundraisers for the service system, or we recruit them into volunteer roles that are mere reflections of traditional 'service' roles, and ask them to leave their real identities at the door. We move from abundance to scarcity.

Our friend John McKnight has shared some ways of helping us recognize some of the sweet places in our communities. John reminds us to look for places...

- Where people come together by consent, rather than by control; where relationships are centered on affiliation, instead of exchange;
- Where people are always identifying, inviting and mobilizing one another's *gifts*;
- Where the culture shows up in the form of stories, rather than data;

The reality is that even with children who do not live with disabilities, the family isn't 'big enough' to do everything alone. Our highly mobile, fragmented society is living with the consequences of fragmentation, as families become more and more separated from extended family, friends, congregational life, and community life. This is a *far* more pressing reality when a child lives with a disability – the family just isn't 'big' enough. We may try to fill the gap with 'services', but the truth is that our sons and daughters need the ongoing commitment, support, devotion and connections that can be offered by true friends, and which can never really be 'delivered' by formal services.

Wendell Berry reminds us:

*We hear again the voices out of our cultural tradition telling us that to have community people don't need a 'community center' or 'recreational facilities' or any of the rest of the paraphernalia of 'community improvement' that is always for sale. Instead, they need to love each other, trust each other, and help each other. That is hard. All of us know that no community is going to do these things easily or perfectly, and yet we know there is more hope in that difficulty and imperfection than in all the neat instructions for getting big and getting rich that have come out of the universities and ... corporations in the past fifty years.-- Wendell Berry, Home Economics*

*A final note... We are not saying that services are 'bad', misguided, or irrelevant. We are simply saying that they cannot be a sufficient foundation for a good life. We need to do everything we can – which means taking action – to keep our lives in balance, our relationships in balance, and our hearts in balance. Remembering to pay close attention to the shoreline with community and having the courage to call upon the bonds of friendship can play a big role in helping us keep that balance.*

David and Faye Wetherow share their lives on Vancouver Island with an adopted daughter who has complex mobility and communication challenges. They have long been involved in innovative service development, PATH and creative facilitation training and community-building. Phone: 250 248-2531  
Email: [wetherow@communityworks.info](mailto:wetherow@communityworks.info)

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. See our lists of books and videos at:  
<http://www.ont-autism.uoguelph.ca/books.shtml#6> and <http://www.ont-autism.uoguelph.ca/books.shtml#7>

## BOOKS BY PEOPLE WITH AUTISM SPECTRUM DISORDERS:

### Commentary and lists by A M Baggs

Probably the first \*ever\* book by an autistic person was called *Understand: Fifty Memowriter Poems* (1985), by David Eastham [of Ottawa, Canada], who never used speech. Other books, published by 1999 by people who had not used speech are *Forever Friends* (David Eastham, 1990), *A Child of Eternity* (Adriana Rocha and Kristi Jorde, 1995), *I Don't Want To Be Inside Me Anymore* (Birger Sellin, transl. 1995); *In Dark Hours I Find My Way* (Birger Sellin, transl. 1995); *I Had No Means to Shout!* (Charles Martel Hale Jr., 1999). *Through the Eyes of Aliens* by Jasmine Lee O'Neill was written in 1998 by someone who, while she has used speech, does so no longer.

The work by Temple Grandin and Donna Williams might make us think that more books are published by female authors with autism than male authors. But there are actually both more male autistic authors and more books by autistic male authors. Only slightly, but still more. Books by male autistic authors are more likely to be written through facilitated communication, less widely known, and more likely to go out of print. Books by female autistic authors are better known, more widely distributed and read, and less likely to go out of print. In the following lists, the authors are numbered, and their books are also numbered.

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#### FEMALE:

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1. Jen Birch: f1. *Congratulations! It's Asperger Syndrome* (2003)
2. Lucy Blackman: f2. *Lucy's Story: Autism and Other Adventures* (1999)
3. Jennifer Fan: f3. *Cinderella With Wrong Shoes: Poems by a Young Woman with Autism* (2001, with Autumn Fan)
4. Gunilla Gerland: f4. *A Real Person: Life on the Outside* (1996) - translated from Swedish, *En riktig människa*, by Joan Tate; f5. *Finding Out About Asperger's Syndrome, High Functioning Autism and PDD* - translated from

- Swedish, *Det är bra att fråga... om Asperger syndrom och högfungerande autism* (1997)
5. Temple Grandin: f6. *Emergence: Labeled Autistic* (1986); f7. *Thinking in Pictures and Other Reports from My Life With Autism* (1995)
  6. Alison Hale: f8. *My World Is Not Your World* (1998)
  7. Ppinder Hundal: f9. *"now you know me think more": A Journey with Autism using Facilitated Communication Techniques* (2003) - with Pauline Lukey
  8. Nita Jackson: f10. *Standing Down, Falling Up: Asperger's Syndrome from the Inside Out* (2002)
  9. Therese Joliffe: f11. *Autism: A Personal Account* (year unknown)
  10. Wendy Lawson: f12. *Life Behind Glass: A Personal Account of Autism Spectrum Disorder* (1998); f13. *Understanding and Working with the Spectrum of Autism: An Insider's View* (2001)
  11. Mary Newport: f14. *Autism - Asperger's and Sexuality: Puberty and Beyond* (2002) - with Jerry Newport
  12. Jasmine Lee O'Neill: f15. *Through the Eyes of Aliens: A Book About Autistic People* (1998)
  13. Dawn Prince-Hughes: f16. *Aquamarine Blue 5: Personal Stories of College Students with Autism* (2002) - editor; f17. *Songs of the Gorilla Nation: An Autistic Person's Emergence among an Ancient People* (2004) - memoir not yet published, planned for 2004
  14. Adriana Rocha: f18. *A Child of Eternity: An Extraordinary Young Girl's Message from the World Beyond* (1995) - with Kristi Jorde
  15. Clare Sainsbury: f19. *Martian in the Playground: Understanding the Schoolchild with Asperger's Syndrome* (2000)
  16. Georgiana Thomas: f20. *Overcoming Autism* (year unknown)
  17. Liane Holliday Willey: f21. *Pretending To Be Normal: Living with Asperger's Syndrome* (1999); f22. *Asperger Syndrome in the Family: Redefining Normal* (2001); f23. *Asperger Syndrome in Adolescence: Living with the Ups, the Downs and Things in Between* (forthcoming)
  18. Donna Williams: f24. *Nobody Nowhere: The Extraordinary Autobiography of an Autistic* (1992); f25. *Somebody Somewhere: Breaking Free from the World of Autism* (1993); f26. *Not Just Anything: A Collection of Thoughts on Paper* (1995); f27. *Like Color to the Blind: Soul Searching and Soul Finding* (1996); f28. *Autism - An Inside Out Approach: An innovative look at the mechanics*

of 'autism' and its developmental 'cousins' (1996); f29.  
*Autism and Sensing: The Unlost Instinct* (1998); f30.  
*Exposure Anxiety - The Invisible Cage: An Exploration of Self-Protection Response in the Autism Spectrum* (2002)

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MALE

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1. Sean Barron: m1. *There's A Boy In Here* (1992) - with Judy Barron
2. John Brine: m2. *Confusion, Loneliness, Depression: Asperger's Syndrome - A Journey* (2000) - with Patricia Brine
3. David Eastham: m3. *Understand: Fifty Memowriter Poems* (1985); m4. *Forever Friends* (1990, posthumous)
4. Lincoln Grigsby: m5. *The Light Within* (2001)
5. Charles Martel Hale, Jr.: m6. *I Had No Means to Shout!* (1999) - with Mary Jane Hale
6. Kenneth Hall: m7. *Asperger Syndrome, the Universe, and Everything* (2001)
7. Luke Jackson: m8. *A User Guide to the GF/CF Diet for Autism, Asperger Syndrome and AD/HD* (2001) - appendices by Jacqui Jackson; m9. *Freaks, Geeks and Asperger Syndrome: A User Guide to Adolescence* (2002)
8. Patrick McCabe: m10. *Living and Loving with Asperger Syndrome* - with Estelle and Jared McCabe
9. Thomas A. McKean: m11. *Soon Will Come the Light: A View from Inside the Autism Puzzle* (1994); m12. *Light on the Horizon: A Deeper View Inside the Autism Puzzle* (1996)
10. Desmond Meldrum: m13. *Growing Up With Asperger Syndrome* (1994); m14. *Coping with Asperger Syndrome* (1997); m15. *The Asperger Experience* (1999)
11. Roger Meyer: m16. *Asperger Syndrome Employment Workbook: An Employment Workbook for Adults with Asperger Syndrome* (2001)
12. David Miedzianik: m17. *My Autobiography* (1986); m18. *Now All I've Got Left Is Myself* (by 1996); m19. *Taking the Load off My Mind* (by 1996)
13. Tito R. Mukhopadhyay: m20. *Beyond the Silence: My Life, the World and Autism* (2000)
14. Jerry Newport: m21. *Your Life Is Not a Label: A Guide to Living Fully with Autism and Asperger's Syndrome for Parents, Professionals and You!* (2001); m22. *Autism - Asperger's and Sexuality: Puberty and Beyond* (2002) - with Mary Newport
15. Tomas S. Page: m23. *Caught Between Two Worlds: My Autistic Dilemma* (2002)
16. Chammi Rajapatirana: m24. *The Vial* (2002)
17. Craig Romkema: m25. *Embracing the Sky: Poems Beyond Disability*
18. Edgar Schneider: m26. *Discovering My Autism: Apologia Pro Vita Sua (With Apologies to Cardinal Newman)* (1999); m27. *Living the Good Life with Autism* (2003)

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19. Marc Segar: m28. *Coping: A Survival Guide for People with Asperger Syndrome* (1997)
20. Birger Sellin: m29. *I Don't Want To Be Inside Me Anymore: Messages From An Autistic Mind* (1995) - translated from German, *Ich will kein in mich mehr sein, botschaften aus einem autistischen kerker* (1993), by Anthea Bell; m30. *In Dark Hours I Find My Way: Messages From An Autistic Mind* (1995) - possibly translated from the same book (1993) - note that he did write two books \*in German\* (other is "*Ich deserteur einer artigen autistenrasse*" - *neue botschaften an das volk der oberwelt*).
21. Stephen Shore: m31. *Beyond the Wall: Personal Experiences with Autism and Asperger Syndrome* (2001)
22. Christopher Slater-Walker: m32. *An Asperger Marriage* (2002) - with Gisela Slater-Walker
23. William Stillman: m33. *Demystifying the Autistic Experience: A Humanistic Introduction for Parents, Caregivers, and Educators* (2002)
25. Stephen Wiltshire: m34. *Drawings* (1985); m35. *Cities* (1987); m36. *Floating Cities* (1991); m37. *Stephen Wiltshire's American Dream* (1993)

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**SOME NEW BOOKS  
TO LOOK FOR SOON IN  
THE AUTISM COLLECTION  
AT KITCHENER PUBLIC LIBRARY**

***A Parent's Guide to Asperger Syndrome and High-Functioning Autism: How to Meet the Challenges and Help Your Child Thrive.*** By Sally Ozonoff, Geraldine Dawson and James McPartland. Guilford Press, 2002. ISBN: 1572307676. 278 pages; appendix of resources, references, index. Highly recommended. See OAARSN review at <http://www.ont-autism.uoguelph.ca/AS-HFA-ap03.html>

Two Books about Living with Asperger's:  
<http://www.ont-autism.uoguelph.ca/bookrevs-ap03.html>  
(for siblings and other children)  
***Buster and the Amazing Daisy: Adventures with Asperger Syndrome,*** by Nancy Ogaz. 2002. ISBN: 184310721X Distributed for Jessica Kingsley Publishers by UBC Press in Canada.

(by a mother with hindsight about her adult son)  
***Finding Ben: A mother's journey through the maze of Asperger's.*** By Barbara La Salle. McGrawHill, 2003. ISBN: 007140225X.

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# More Useful Books

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***Caregivers and personal assistants: how to find, hire and manage the people who help you (or your loved one!)***. By Alfred H. DeGraff, Author-Publisher. Saratoga Access Publications, Inc. 2002. ISBN: 0-9621106-1-2. 507 pages. Price US\$ 24.95 (CAN\$ 37.95) in most bookstores, online, or by calling 1-800-266-5564. Saratoga Access Publications, PO Box 1427, Fort Collins, CO 80522-1427.

Several million Canadians depend on daily help from family caregivers or paid personal assistants or both. Help recipients include patients being discharged early from hospital, people with lifelong disabilities, and seniors undergoing the increasing limitations of aging. In the United States, the National Family Caregivers Association estimates that 26 per cent of adult Americans provided caregiver services to loved ones within the last 12 months. A similar proportion here would mean that at least 5 million family caregivers in Canada.

***Caregivers and Personal Assistants*** is billed as “a bible for people who must depend on others to get through the day.” We highly recommend the book to all people with disabilities (and their agents) who need others to help with their daily personal needs and to family caregivers who need to hire paid help because they are becoming chronically tired and heading for depression. Its advice is vital for people with useful also for health care facilities and agencies that always need more hired help. Its lessons are vital for supporting people with developmental disabilities though their needs are not explicitly discussed.

Alfred H. “Skip” DeGraff is uniquely qualified to provide this advice. For over 30 years a tetraplegic (since a diving injury at 18), he uses motorized wheelchair mobility and has been dependent each day on help providers. While completing graduate school and pursuing professional careers, he has personally employed over 350 personal assistants (PAs) after interviewing over 1,500 applicants. He learned about recruiting, hiring and managing help providers in various settings, including:

- his mother’s home (using family caregivers);
- a community college (using fellow students);
- three residential university campuses (with dorm room-mates as live-in student aides);

- large urban apartment complexes while pursuing careers (live-in roommates helping in exchange for room and utilities);
- extensive business and vacation travel by car and air (by using help from aides, friends and caregiver-relatives in exchange for their transportation, room and board);
- inpatient hospital stays (instructing and managing physicians and nursing staff for routine disability-related needs and accepting their instruction and care for the new, temporary acute needs);
- his private home, while married, by balancing help from his caregiver-wife and salaried outsiders;
- his private home, before and after marriage, by combining live-in and salaried help

DeGraff has shared his management strategies widely through seminars, courses, and publications. He has provided one-on-one counseling to help recipients, family caregivers, and paid providers. He has also taught formal 16-week courses on PA management and hosted magazine columns. This experience is reflected in the book’s crisp style and clear presentation. There are many memorable examples and strategies. Such as RISHTMP—the cyclical process you go through with each new aide or group of aides (recruiting, interviewing, screening, hiring, training, managing, and parting ways)?

The scope, style and layout of ***Caregivers and Personal Assistants*** are finely honed, as this is third and completely revised edition of a book on this topic first published in 1978. In addition, DeGraff invites readers to subscribe to a free e-newsletter at [saratoga-publications.com](http://saratoga-publications.com)

Amid all the detailed step-by-step strategies, the reader receives powerful messages about the importance of each help recipient’s “*right to maintain control over your own lifestyle and daily schedule—your quality of life. You enjoy and hold sacred the freedom of doing what you wish, when you wish. You recognize that your disability has imposed some limitations on this freedom; however, you strive each day to enjoy life to its fullest—to seize the day (carpe diem).*” (p.19). A valuable (though brief) concluding section discusses the need to balance and co-ordinate the rights of help recipients, help providers and family caregivers, so that relationships can be harmonious and reciprocal.

***Enzymes for Autism and other Neurological Conditions: a practical guide.*** By Karen L. DeFelice. 2002. Paperback. 367 pages. ISBN: 0972591877. May be ordered from Amazon for \$US 18.95.

The complex and pervasive symptoms of autism spectrum disorders include gastrointestinal, immune and sensory problems for a large majority of people on the autism spectrum. Recognition of the biomedical aspects of autism in the past decade has supported dietary intervention as one treatment strategy. Three years ago, the publication of Karyn Seroussi's ***Unraveling the mystery of Autism and Pervasive Developmental Disorder: a mother's story of research and recovery*** (Simon and Schuster, 2000) launched the gluten-free casein-free (GFCF) diet for families determined to help their autistic children. Karen DeFelice's new book is doing much the same for enzyme therapy—and for other conditions besides autism.

***Enzymes for Autism*** is really several books rolled into one:

- It is partly a compelling story of personal and family experiences of gastrointestinal problems and of various other treatments, especially by the author herself and her two young sons. The findings of a survey of 260 individuals who tried enzyme therapy for seven months are reported, 90 per cent showing positive results.
- Karen L. DeFelice also draws upon her training in science and education to explain autism (and other neurological conditions) as sets of neurobiological disorders affecting the immune, nervous and sensory systems and her conviction that digestive enzymes can be key players in more efficient functioning of the gastrointestinal tract. This aspect of the book is supported by more than 300 bibliographic references, most published in scholarly journals.
- It is also a practical guide to help other affected individuals and families—especially those with autism but also with sensory dysfunction, migraines, AD(H)D, yeast/bacteria, food intolerances, chemical sensitivity, intestinal problems, chronic fatigue, MS pain, fibromyalgia, bowel dysfunctions.
- And the book is also a work in progress. Moved by relief at finding that enzyme therapy worked for them, the author and some others started an electronic message board at [enzymesandautism-owner@yahoogroups.com](mailto:enzymesandautism-owner@yahoogroups.com). Questions are posed and answered, experiences are shared, and successes are celebrated. The material in the book is constantly being validated, qualified and updated in these electronic messages.

***Enzymes for Autism*** will appeal mainly to people who live with autism and other neurological disorders and have tried various interventions already. Such readers are motivated by the prospect of significant improvements in health, pain reduction, food tolerance, language and socialization to persevere in reading the book right through. A second updated edition could probably present the essential information more systematically and succinctly.

## **GUELPH SERVICES FOR THE AUTISTIC**

A not-for-profit charity incorporated in 1980, run by volunteers, and dedicated to adults with autism spectrum disorders 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, and provides advice and support

[http://www.ont-autism.uoguelph.ca/gsa/info\\_new.shtml](http://www.ont-autism.uoguelph.ca/gsa/info_new.shtml)

[http://www.ont-autism.uoguelph.ca/gsa/faq\\_new.shtml](http://www.ont-autism.uoguelph.ca/gsa/faq_new.shtml)

## **WHAT IS 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**

An important initiative by GSA and WWAS as part of the ASPIRE project. Long-form and short-form surveys may be completed on paper or online.

## **ONTARIO ADULT AUTISM RESEARCH AND SUPPORT NETWORK**

OAARSN offers a rich and expanding collection of up-to-date information and communication tools that can put you in touch with others. We can all benefit from the opportunities for mutual support, encouragement and information sharing. We hope that OAARSN's efforts to promote positive approaches and best practices in supporting adults with autism can help all who live and work on the front lines. Click on <http://www.ont-autism.uoguelph.ca> to reach OAARSN's main page, then use the buttons to reach the site's features. The Communications features are updated most frequently. Check out the News Scroller and What's New on the opening page. You may ask to be on the OAARSN List to receive weekly bulletins of autism news and announcements of events.

To reach GSA about any of the above:

16 Caribou Crescent, GUELPH, Ontario, N1E 1C9

Phone (519) 821-7424 or (519) 823-9232

E-mail [gbloomfi@uoguelph.ca](mailto:gbloomfi@uoguelph.ca)

May 12, 2003 in Brampton, Ontario  
Kerry's Place Autism Services offers  
**Long Term Planning Workshop**  
Brampton Public Library - Four Corners Branch, 65  
Queen St. E. No cost.  
To register, please call (905) 457-1130 X 200

May 30 & 31, 2003: in Toronto  
2nd National Conference on Aspergers  
Syndrome : **Celebrating our achievements:  
Setting our sights**  
Metro Toronto Convention Centre - South Building  
Presented by The Aspergers Society of Ontario.  
Speakers include: Peter Szatmari, Patricia  
Romanowski Bashe, Trina Epstein, Jennifer  
Saltzman-Benaiah. Jeremy Goldberg, Lonnie  
Zwaigenbaum, Paula Aquilla, Fern Lee Quint,  
Isabelle Henault, Kevin Stoddart, Debra Farmham,  
Valorie Salimpoor.  
Tel: 416-651-4037 Email: [conference@aspergers.ca](mailto:conference@aspergers.ca)  
[http://www.aspergers.ca/whats\\_new.html](http://www.aspergers.ca/whats_new.html)

June 3, 2003 in Kitchener Ontario  
Waterloo-Wellington Autism Services  
Annual General Meeting--see page 1

June 8, 2003  
Waterloo County Chapter, ASO's Cycle for  
Autism to raise funds for summer camp, education  
and awareness. Begins and ends at Kitchener City  
Hall: 5, 10 and 40k routes to be walked, run or biked.  
Phone 519-742-1414

June 20-22, 2003 in Vancouver BC  
Vela Microboard Association of British Columbia  
announces the **First Training Institute on  
Developing and Supporting Microboards**  
Learn more about the intent and philosophy, the  
practical tools needed, how to support and sustain  
these personal support entities, and how to assist in  
creating a healthy Microboard network. Cost for  
weekend \$1,000.00 Canadian. More details:  
<http://www.ont-autism.uoguelph.ca/Vela-jun03.html>

June 21 & June 22, 2003 at  
Ryerson University, Toronto, Ontario,  
**BIOMEDICAL CONFERENCE: Opening  
Windows of Hope for Children with  
Developmental Disorders**  
"Open Windows Essential Training" is presented by  
the International Child Development Research Center  
(ICDRC) in conjunction with the Autism Canada  
Foundation. This conference will teach you how to  
integrate Biomedical, Behavioural, Nutritional and  
other effective treatment options in a "whole  
approach" therapy style, so that you can help  
maximize the potential of individuals living with  
Autism, PDD and Related Disorders.  
Guest Speakers include Jeffrey Bradstreet, Jerry  
Kartzinel, Karyn Seroussi, Stephen Shore, Lynda  
Thompson... For more information:  
<http://www.autismcanada.org/openwindows.htm>

July 4-6, 2003, in Kingston Ontario:  
**5th Canadian Fragile X Syndrome and  
Autism Spectrum Disorders Conference**  
Speakers: Elizabeth Bloomfield, Marcia Braden,  
Susan Connors, Jeanette Holden, Kevin Munhall,  
Barb Kemp, Mark Sabbagh, Garth Smith, Margaret  
Spoelstra, Becky Ward. More information and  
registration form at:  
<http://www.ont-autism.uoguelph.ca/FragileX-jul03.pdf>

July-August 2003  
**Cycle for Autism: Help Solve the Puzzle**  
Beginning July 6th, 2003, John Keating and Luc  
Vandeermeeren, both fathers of children with Autism  
Spectrum Disorders (ASD), will cycle across Canada,  
stopping in many cities along the way for fundraising  
events. Our goal is to promote awareness of Autism  
Spectrum Disorders (ASD) and raise \$1,000,000 in Canada  
for ASD research through an annual cross Canada Cycle  
for Autism. Find out more! Be part of the support team!  
Phone: 905-832-3959 <http://www.cycleforautism.com/>

Jim Timmins is the new Autism Consultant for Guelph-  
Wellington County, Kerry's Place Autism Services  
Orchard Park Office Centre, Suite 138  
5420 Hwy 6 North, RR#5, Guelph, Ontario N1H 6J2  
Phone: 519-763-5812 Cell Phone: 519-831-1737  
Email: [jtimmins@kerrysplace.org](mailto:jtimmins@kerrysplace.org)

# **WATERLOO-WELLINGTON AUTISM SERVICES**

## **VICTORIA BLOOMFIELD BURSARY GUIDELINES**

The WWAS Board of Directors offers small grants to help individuals aged 18 years and over, who are diagnosed with autism spectrum disorders, and who live in Waterloo Region or Wellington County.

We welcome proposals for projects that:

- are designed to match each individual's unique strengths and needs
- are bright ideas that might be later extended to help other adults as well
- are achievable with one-time grants of no more than \$2,500, with funding not available from other sources.

Examples of projects that might be funded are:

### **Assessments of:**

- Skills, aptitudes and challenges as basis for designing effective support strategies
- Communication abilities and needs
- Behaviour management needs
- Dietary, psychological, psychiatric or sensory needs

### **Tutors, coaches or companions for:**

- Literacy
- Work experience or job training
- Leisure skills and exercise
- Anxiety and stress management
- Music therapy, art therapy, horticultural therapy etc
- Life skills development

### **Equipment or adaptive aids**

- Bought or leased to learn a skill or overcome a challenge
- Training in the use of communication or other devices

### **Special Training for support workers**

### **Important Limitations**

A WWAS bursary cannot:

1. Pay for services that are routinely available from government programs, such as Special Services at Home, Respite Workers, or school services (but WWAS may consider your application if you have tried and failed to obtain such funds or are on a waiting list).
2. Pay for long-term, ongoing services that will continue to be needed when the bursary is spent.
3. Provide detailed administration of supervision of your Bursary project (WWAS has no paid staff).

### **How to Apply**

-Fill in the application form. We want ideas to come from adults with autism; so the form is set out to be answered in their words, even if they are helped by family members or others.

=Please tell us on the form:

Section 1: About yourself, who you are and how we get in touch with you

Section 2: What are the specific goals for which you need a bursary?

Section 3: How the bursary would be spent to achieve the goals

Section 4: How much money is needed, who should receive it, when you need it

Section 5: How the bursary will help you to cope better with life, and how you will continue after it is spent.

-If you need some advice in deciding whether to apply, or in completing the form, contact WWAS president Dr Roger Hollingsworth (see details below). WWAS has no paid staff; Board members will do their best to help.

-Sign the application, to say that you agree to the bursary guidelines, and send the completed application form (with other information that would help us to understand your needs and plans) to WWAS.

-Keep a copy of your application and these guidelines for your records

### **The Selection Process**

1. All applications will be reviewed by the Board. We may need to discuss your application with you so it fits WWAS bursary guidelines.
2. All applications will not automatically receive bursaries. Selection will be based on a combination of needs and bright ideas that promise to help the individual and, perhaps also, other adults in future.
3. Unsuccessful proposals may be considered again. The WWAS Board reserves the right to make no awards if applications do not match the guidelines or if WWAS resources are insufficient at any time.

WATERLOO-WELLINGTON AUTISM SERVICES,  
125 Union Street East, Waterloo, ON, N2J 4E5  
Dr Roger Hollingsworth (519) 885-2683 (home);  
Email: [rm.Hollingsworth@rogers.com](mailto:rm.Hollingsworth@rogers.com)