

ADULT AUTISM ISSUES IN WATERLOO-WELLINGTON

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

Newsletter No 15, May 2002

WWAS BULLETIN BOARD

You are invited to the **Annual General Meeting of Waterloo-Wellington Autism Services**, which will take place on Tuesday 28th May 2002, from 7:00 pm, at Stanley Park Baptist Church, 31 Lorraine Ave, Kitchener. Current members of WWAS will also receive formal notices of this meeting.

As well as the formal AGM business, Elizabeth Bloomfield is arranging for presentations on:
-the new Adult Autism Needs Survey and the ASPIRE project,
-opportunities for young adults leaving the school system,
-person-centred planning, personal support networks, and microboards for quality of life now and security in the future.
Please let us know that you plan to attend by leaving a message at (519) 742 1414.

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**.

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.

ALSO IN THIS ISSUE:

Reviews of Four Books about the Autism Spectrum and Community Inclusion. These are abbreviated from the full reviews on the OAARSN website.

ASPIRE *Autism Support Project:*

Information, Resources, Empowerment

Guelph Services for the Autistic, supported by Waterloo-Wellington Autism Services, proposes a project of interest to individuals with autism who live in Guelph-Wellington County or the Region of Waterloo. We expect to help two main groups: young people aged 18-20 who are leaving school-based services for adulthood; and older adults who still live with their parents and need to consider other options for the future.

ASPIRE offers hope of a good life in community:
a. Building knowledge of how adults experience autism spectrum disorders and the most effective strategies of supporting them to cope with their disabilities and achieve the best possible quality of life, and
b. Modeling a facilitation service to inform and empower autistic individuals, with their families and friends, to plan and find resources for all the elements of a good life, including relationships with a personal support network, a home of one's own, ways to make choices and contribute to the community, and a safe and secure future.

In the first stage of ASPIRE, a survey is being taken of the status and needs of individuals with Autism who were 17 years or older by the end of 2001. A pilot version of the survey is posted on the OAARSN website at <http://www.ont-autism.uoguelph.ca/aans2001.shtml> and may be completed efficiently online. It takes about 30 minutes. If you would like to take part but lack computer access, leave a message at phone (519) 821-7424, requesting a paper copy.

See more at:

<http://www.uoguelph.ca/oaar/aspire.shtml>

If you would like more information and/or to be involved in ASPIRE, leave a message at phone (519) 821-7424 or email a message to gbloomfi@uoguelph.ca

TIME magazine for 29 April 2002 features AUTISM as its cover story. There are articles on the explosion in numbers diagnosed, the vaccine factor, and the "Geek syndrome" and personal profiles of a son, a brother and of Temple Grandin (by herself).

New Books on the Autism Spectrum

More reviews and notes about **Books on the Autism Spectrum** may be found on OAARSN's site: <http://www.ont-autism.uoguelph.ca/books.shtml>. We welcome suggestions of new books that should be noticed or reviewed for OAARSN and AAIWW and appreciate the efforts of our volunteer reviewers—including in the past year: Lucie Milne, John Clifton, David DeVidi, Kirsty Forsyth, Jan Cooper and Amar Arneja.

Irwin Publishing is Canadian agent for important titles in Autism and special needs and mental health generally—such as those published by Jessica Kingsley and Paul H. Brookes Publishing, several of which have been reviewed by OAARSN. The Irwin Book Club offers 20 % off various professional titles. Visit www.irwinpublishing.com

Reweaving the Autistic Tapestry: Autism, Asperger Syndrome and ADHD. By Lisa Blakemore-Brown. Jessica Kingsley Publishers. 2002. 224 pages. ISBN: 1853027480

This book is concerned with the links among autism, Asperger syndrome, attention deficit and hyperactivity disorder (ADHD) and other developmental disorders—in their characteristics and in the strategies and interventions that can improve the life chances of those who suffer.

Lisa Blakemore-Brown uses extended metaphors of weaving and tapestry throughout her book “at various levels of explanation to illustrate the complexity and interweave of genetic potential and environmental triggers, in a story of how people themselves develop” (p.33). While

“normal developmental tapestries require the careful execution of a plan” and a “weaving process” with “repetitive, rhythmic and balanced actions” (p.34), genetic differences and environmental triggers (including failures in the service system) can disrupt the weaving process and result in tangled tapestries. Pragmatic tapestries of risk factors and resilience factors are proposed, to provide a better basis for “more focused and finely tuned interventions” (p.27) that may reweave the tapestries. The tapestry model can show time-lines of critical events, and the context of relationships and environmental factors. Variations in texture and colour may be used conceptually to illustrate individual differences in responses to interventions.

Weaving and tapestry are attractive metaphors that may help us to include the complex and pervasive symptoms of autism and to understand

the concept of a spectrum of related disorders. The idea of individual and unique tapestries for each person is valuable, in imagining the possible effects of interventions in the fabric of a person's life. It may help us guard against the dangers of over-simplifying the difficulties by expecting that a single intervention will fix all.

Lisa Blakemore-Brown, an independent applied psychologist specialising in ADHD, Asperger Syndrome and related disorders, writes almost entirely about children. But she suggests that “it's never too late to reweave the autistic tapestry” beyond the childhood years and that the approach could help the “golden children” for whom very little has seemed to work (p.30).

While we wish for more graphic illustrations of the tapestry and weaving metaphors, we can be grateful for the imaginative word picture which the author closes the book (p.302):

Tapestry blanket to wrap around your child

To weave this rainbow blanket you need the following strands of silk:

SHIMMERING GOLD: Positive, non-blaming support for parents and children who take priority I in our society – they represent the future

SYMPHONY SILVER: touch-talk-gaze—woven sensory skills

FLUORESCENT YELLOW: attention and engagement

INDIGO BLUE: taking turns and listening

PINK: regular pauses threaded throughout

BREEZE BLUE: imitation—expression, gesture, motor action and language

PURPLE: rich, respectful novel experiences

AQUAMARINE: calm, cool, non-confrontational responses when tempers flare

SUNRISE RED: times for fun, fast, joyful delivery

SEA GREEN: balanced, wave-like interactions

MELLOW YELLOW: recognition of child's need for quiet times alone

TERRACOTTA: down-to-earth, straightforward descriptions of skills and problems

SUNSET ORANGE: consistent, salient rewards for all successes and positive behaviour

SOLID SILVER: functional analyses weaving basic “unique child tapestry”

PACIFIC BLUE: clear, simple, precise instruction—one at a time

BRIGHT WHITE: keeping simple clear records of progress, for ongoing fine-tuning

BURNISHED BLACK: protecting the human rights of your child, through legal action if necessary

Understanding and Working with the Spectrum of Autism:

An Insider's View by Wendy Lawson. Jessica Kingsley, 2001. ISBN: 1-85302-971-8

Recommended by John Clifton

Wendy Lawson's book is a lively and eclectic blend of analysis, argument, autobiography and poetry. The author was diagnosed as having Asperger Syndrome at the age of 42, after years of being regarded as intellectually disabled and/or schizophrenic. Despite many years of misdiagnosis, Lawson appears to have been a formidable person. She married (she is now divorced) and raised four children. One of her sons has Asperger syndrome. Since receiving the diagnosis of Asperger syndrome for herself, she has blossomed even further. She is, at the time of her book's publication, pursuing a Ph.D. in Social Work. She lectures at conferences and has written one other book, an autobiography entitled "Life Behind Glass," as well as many poems.

Lawson is especially interested in exploring the ways in which autistic thinking differs from the thinking of neurotypicals. For her, many problems encountered by persons with autism arise because of misunderstandings in this area. For example, persons with autism are likely to be "monotropic". This means that they will "focus in on one aspect of communication, or upon one interest at a time" (p.33), and thus be unable to cope readily with change in their environment. For persons with autism, route changes, unannounced visitors, or other variations in routine can be deeply disturbing. If neurotypicals do not understand this, it will appear that the person with autism is getting upset about nothing. Such a misunderstanding can impact negatively on the autistic person's self-esteem and sometimes lead to

intolerable stress and anxiety, not only for persons with autism but for their caregivers and families as well.

Lawson argues persuasively that it is crucial that the distinctive cognitive processes of persons with autism be recognized. She makes many recommendations on practical implications and interventions. For stress and anxiety, she recommends music, open space, walking and judicious indulgence of obsessive activities.

Throughout her discussions, Lawson often illustrates her points with autobiographical examples. Some of her poems shed light upon the agonies and the joys of having autism. Her poetry is also hopeful and informed by her view that, while autism can cause delays in development, these delays do not necessarily turn into permanent disabilities. This is especially true if an effort is made to recognize and accommodate autistic thought patterns and the anxiety that persons with autism are likely to experience.

Lawson notes that people with autism have been often told that they suffer from "mindblindness" or an inability to understand that other people hold their own thoughts and beliefs quite separately from one another. Lawson agrees with this assessment of one aspect of autistic development but does not regard it as a permanent disability. Her message is profound and filled with a longing for community. On the one hand, she acknowledges the difficult divide that mindblindness appears to entail. Neurotypicals care about other people; persons with autism only care about themselves. It is because persons with autism are perceived as being selfish and indifferent to others that they present an especially great burden to neurotypical empathy. On the other hand, what Lawson's book also affirms is that both persons with autism and neurotypicals are capable of "Love". With the help of greater mutual understanding, both groups can achieve a lot more of it.

Through the Eyes of Aliens: A Book About Autistic People

By Jasmine Lee O'Neill. Jessica Kingsley Publishers, 1999. 144 pages. ISBN 1-85302-710-3
Highly Recommended by Jan Cooper of Guelph

Jasmine O'Neill describes herself as a poet, writer, painter, illustrator and musician. She is also a "classical Kanner autistic with Asperger's Syndrome traits" (p.15) and writes with authority about her subject. Though she is described as a mute autistic savant on the book cover her 'voice' comes through strong and clear on a wide range of topics: emotions, communication, intelligence, relationships, health, recreation, idiosyncrasies, even a chapter of those tumultuous teenage years.

Two chapters in particular gave me some of those "ah ha" moments (to borrow a phrase from a well-know talk show host). In the first, Jasmine asks you to walk in the shoes of a child with autism entering the school environment for the first time. She calls this experience the end of bliss for the child, and uses words like fragile, shattered, confused, afraid.

The second chapter that touched me as a caregiver was titled Idiosyncrasies and Special Traits. Jasmine encourages anyone whose life touches that of an autistic person to really get to know him or her. Read what they write, look at their art, listen to their voices, ask questions, show respect, and learn from them. Jasmine says she wrote this book to educate those truly interested in what it means to experience life as someone with autism. Living with autism is challenging, often painful and frustrating. Jasmine wants everyone to know that there can be joy, excitement and growth as well.

***Part of the Community:
Strategies for Including***

Everyone. Edited by Jan Nisbet & David Hagner. Baltimore: Paul H. Brookes Publishing Co., 2000. ISBN 1-55766-456-0. 299 pages,

Most of the 22 contributors to this book, including the two editors, are with the Institute on Disability (IOD) at the University of New Hampshire that has been a crucible of systems change since the late 1980s. Nearly all work in some capacity with New Hampshire children and adults who live with disabilities. Books of essays by many authors may seem uneven and fragmented. This book is unified by the authors' shared understanding of (in John O'Brien's words) "inclusion as a horizon for goal setting and problem solving...the right starting point—morally, legally, economically—for practice and policy. Disability poses no barrier to meaningful and rewarding participation in every aspect of community life."

In the first two chapters, the editors reflect generally on the IOD experience of systemic reform and the potential for change in the context of the two major paradigm shifts in the disability field since the late 1960s—first, from the facilities paradigm to the programs paradigm, and second, from programs to supports. Jan Nisbet (IOD Director) sums up the lessons of the 1990s:

- Celebrate achievements but recognize failures
- Balance systemic reform with individual support
- Avoid advocating at the expense of systems change
- Stay close to people
- Have a big picture with a clear focus
- Invest in leadership but don't rely on leaders

- Commit to reforming personnel preparation at all levels
- Remember that systems are made up of people
- Encourage support-committed champions
- Watch out for beavers (colleagues and associates who learn their own personal power and strength to create change but move away to an agenda contrary to inclusive education and community)
- Retreat when necessary to regroup the troops
- Look nationally but retain local ties
- Create an environment in which new ideas are required as a matter of practice

The essays in ***Part of the Community*** go far beyond the abstract rhetoric of inclusion and systems change to tell us about the details—"the difficulties and tragedies, the successes, the vast scope of strategies and tactics required, the subtle decisions made on a daily basis, and the human side of change for both the change agents and those affected by change" (xv). Scores of fascinating personal stories illustrate the generalizations.

The middle chapters of the books are concerned with achieving inclusion for successive age-groups through the life-cycle. "Catching the wind, changing the rules" is about enhancing inclusion for preschoolers and following the guiding principles of "All children and families belong in communities" and "Supports and services should only be as special as necessary." Three chapters are case-studies of inclusion in the state's schools. Two discuss adult issues, of concern to our OAARSN network. "Postcards on the refrigerator: changing the power dynamic in housing and assistance" is about New Hampshire's Home of Your Own Project. "A multielement approach to creating change in a state employment system" describes the

New Hampshire Natural Supports Project.

Chapter 9 is about the roles of individuals with disabilities and their families in "the discovery of a vision of disability rooted in high expectations and positive dreams of making a lasting impact on the culture in which we live." In projects like the Minnesota's Partners in Policymaking or New Hampshire Leadership Series during the 1990s, family members and individuals with disabilities have been recognized as key agents in systems change and have been supported to assume these roles. Factors found to be critical in facilitating systems change include:

- Supporting people who share similar struggles to come together to exchange information and strategies for change;
- Encouraging an atmosphere conducive to collaboration, dreaming of positive futures, and shared problem-solving;
- Providing resources for participants to maintain their basic needs without worry;
- Delivering the "latest and the greatest" information on recommended practices in the field of disabilities;
- Participating in leadership-building events with technical assistance from recognized leaders in the field;
- Using the legislative process and community organizing strategies, with an emphasis on skills for negotiation;
- Telling personal stories, of the utmost importance in changing hearts and minds.

In the final chapter "Witnessing the possible for people with disabilities", Thomas M. Reischl ponders the implications of the message of the community inclusion movement in the 1990s: ***"Expect success, and expect to be creative to make it happen."***