

ADULT AUTISM ISSUES IN WATERLOO-WELLINGTON

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

Newsletter No 16, August 2002

ASPIRE BEGINS IN AUGUST:

Aspire: to be ambitious; to long for or yearn; to seek to accomplish something high and great; to rise, ascend, soar.

These dictionary definitions describe qualities of the new initiative being launched this month by Guelph Services for the Autistic (GSA), with generous financial support from Waterloo-Wellington Autism Services (WWAS). But the word is also an acronym for the project: **Autism Support Project: Information, Resources, Empowerment**, for and with people with autism and their families in Guelph-Wellington County or the Region of Waterloo. We expect that two main groups will be interested: 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 by:

- Building knowledge, through the OAARSN surveys, of how adults experience autism spectrum disorders and the most effective strategies of coping with their disabilities and achieving the best possible quality of life, and
- 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 part of ASPIRE, we are trying to record a picture of the situations and support needs of adults (or older teenagers) with autism in Waterloo and Wellington regions. We urge everyone who is, supports or knows any person on the autism spectrum who will be 17 years or older by the end of 2002, to co-operate with one of the two OAARSN surveys.

-First, there is the more detailed "long-form" survey that takes about 30 minutes to complete; it has questions about abilities and challenges, treatments and therapies, quality of life, and planning for the future. This is for people and families who are actively concerned with planning for the future.

-The more basic "short-form" survey takes only 5 minutes to complete. This is for people who do not wish or are unable to take part in any other ASPIRE activities. However, it's important for you to complete the short-form survey at least, as the numbers and needs profiles that come out of this survey will help planners and agencies in

the social service system to provide and fund resources needed by people with autism in our communities.

A copy of the short-form is enclosed with this issue of AAIWW. We urge you to complete the survey (long or short) online, if at all possible. This is the most confidential and efficient way. If you fill in the long-form survey (or have already submitted this) you don't need to do anything now, unless your situation has changed. If you fill in a short-form survey now, you may later submit a long-form survey as well, if you wish.

The surveys are posted on the OAARSN website at <http://www.ont-autism.uoguelph.ca/aans2001.shtml> You may request a paper copy of the long-form survey by leaving a message at phone (519) 821-7424 or email gbloomfi@uoguelph.ca. Completed paper surveys (both short-form and long-form) may be mailed to GSA (ASPIRE), P.O. Box 23016, Root Plaza Postal Outlet, GUELPH, Ontario, N1H 8H9.

ASPIRE will run for 20 months. In its second part, which will run concurrently with the surveys, ASPIRE will help families who are ready to begin the process of planning for the future of their daughter/son. GSA has made an agreement with Ms Jan Cooper to work part-time as ASPIRE Advocate. The ASPIRE Steering Group, which reports to the GSA Board, consists of Amar Arneja, Dave DeVidi, John Verhart, Stan Shalay (representing WWAS Board) and Elizabeth Bloomfield. Peter McCaskell, who volunteers with the technical side of the OAARSN website, has offered to do the confidential processing of the survey data. The WWAS Board has further supported ASPIRE and OAARSN by paying for a new computer to handle these tasks. We thank all these volunteers and the Boards of WWAS and GSA for supporting this initiative.

For more details of ASPIRE, click on: <http://www.ont-autism.uoguelph.ca/aspire.shtml>
Please tell any other individual, family or support group about ASPIRE and the needs survey.

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New Books on the Autism Spectrum

SPECIAL LIBRARY COLLECTION

Waterloo-Wellington Autism Services has resolved to make a substantial gift to start a special autism collection of books, videos, and other information resources, at one of the public libraries in its region. Details are still being discussed, but we hope the special collection will be set up and in use by early 2003.

We are involved in recommending titles of books etc, and will keep you posted on progress, in AAIWW and on the OAARSN website. Patrons of other libraries will be able to borrow these books through Inter-Library Loan.

We congratulate WWAS on its great idea and splendid initiative!

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 on OAARSN and AAIWW.

We appreciate the efforts of our volunteer reviewers—including in the past year: Lucie Milne, John Clifton, Jan Cooper, David DeVidi, Kirsty Forsyth and Amar Arneja. Various other reviews are now under way.

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.

Independence Bound: A Mother and her Autistic Son's Journey to Adulthood. A guide for professionals, families and those persons who associate with adults having autism

By Jacquelyn Altman Marquette.
Foreword by Nancy Dalrymple.
Harmony House Publishers, P.O. Box 90, Prospect, Ky. 40059, USA. 2002. 133 pp. ISBN 1 800 809-9334. \$US 19.95

Jackie Marquette, Transition Consultant for families of adults with disabilities, has published *Independence Bound*, about the transition to adulthood of her son Trent. She shares the insights and strategies that helped her through the fears and crises of the transition process moving into a good new life of quality and independence.

Independence is defined as “the control people with disabilities have over their own lives” and Ed Roberts is quoted that “independence should not be measured by the tasks one performs without assistance but by the quality of one's life with adequate

support” (xix). These are some of the myths that may deter and delay parent and family efforts to support their young adults to live with independence (p.68):

- Independent living cannot occur without an agency
- Independent living won't work for my daughter
- It will mean changing everything
- The state (not parents) should provide and an agency to arrange independent living
- Let's just wait until our son is ready
- It's too expensive and where are we going to get the money
- It's too risky, and I do not trust people
- I'll think about it a few years from now
- Somebody would have started it already in our community it is was any good
- We don't have the time to design it
- What's the rush? Let's not move too fast

- My son is too disabled: he has autism and cannot communicate his needs
- It's just too soon to start independent living

Trent's transition time coincided with several severe crises in his family, so Jackie's story offers hope to families seeking way to hold together against great odds. Families and friends who also want independent living for their adult with a disability can learn from the strategies that built Trent's self-determination and prepared him for independent living. Very significantly, Jackie shows how important it was for her son to understand the changes, to be reassured that certain people and activities would continue from his old life, and to have a say in all aspects of his new life.

Independence Bound also offers professionals and policymakers insights into the supports that individual and families need during the transition to adulthood as well as evidence that adults with autism can have good independent lives as long as supports are in place.

An outline of the book's contents can help to see its scope and value:

Part 1: Struggles to Solutions, with sections on: family crises; perspectives learned from crises; surviving; how the perspectives; can other families find independent living?; adult agencies; necessary supports; limited financial resources; sweeping changes; transition and person-centred planning; letting go of the old; saying goodbye to the old life; surviving the transitional phase; Trent's understanding of his new life; the old and the new merge; facing new beginnings; change; change means; change was inevitable; accept change—questions to consider; A checklist: developing a family perspective; how to manage endings.

Part 2: Expect to Grieve, with sections on: mourning the old life; shock; losing trust; denial at a cost – a family falling apart; the lesion – letting go of a clouded vision; adult day care – is it appropriate or just functional; the lesson – moving forward with fear; creating a safe temporary place within; the transition phase; denial and protection; Trent resists the winds of change; Trent surrenders to his grief; Trent's work experiences; Trent is accepted.

Part 3: Designing an Independent Living Arrangement, with sections on: security, a false sense of security; try believing in this; start today; help people help you; how to ask for what you want; stay motivated; try the exercise; take mini steps toward your goal; Jackie's personal goal; strategies for coping with the blues; helping Trent stay self-determined; educating the community.

Part 4: Trent's Message, with section on: how you can help me; ways you can talk with me; meeting new people; recreation; exercising at the YMCA; going to the library; going to the zoo; gardening; cooking; laundry; how to introduce me to the new environment and to help me to adapt to a new situation; teach me to attend to you when you speak to me; help me to understand my feelings; changing my routine; help me to handle changes in my work environment; waiting is sometimes difficult for me; interventions that help me build my self-determined behavior; waking in the morning; challenging the obsession with my clothes; my TV shows; my vocalizations; getting frustrated; help me understand your intention; speaking harshly or vague; encourage me; a problem solving chart; what I learned to do about anger; angry feeling checklist; ways I learned how to work through my anger; thinking

good thoughts; checklist for evaluating my environment; I need your patience; without words.

"I found the book, *Independence Bound*, fascinating and would indeed recommend it to any person interested in knowing about the coping skills of any individual (with family) who struggles to find his or her independence, in the face of such a wide spectrum disability, as autism surely is. I believe it can provide guidance, encouragement and hope-- for the parents, siblings, friends, support workers, and professionals who maintain a relationship with any adult having autism. I would also like to say about the author, Jacquelyn Altman Marquette, that her writing style is very refreshing and down to earth. You can assume by her writing that she truly does want to teach others by her example and to give hope to the hopeless. The simplicity of this valuable teaching tool will indeed attract many a interested reader, and I believe, cause change to happen in many lives."

- Wanda Best for OAARSN

Jackie Marquette offers many examples, self-evaluation questions and checklists to help other families. For more information, with excerpts and a photo album, visit:

<http://www.independencebound.com>

LOOKING FORWARD

A presentation to the AGM of Waterloo-Wellington Autism Services 28 May 2002

Elizabeth Bloomfield sketched the philosophy and values of future planning for our sons and daughters who are disabled by autism spectrum disorders.

-Each person must be considered as an individual.

-The more complex the challenges, the more individualized the supports must be.

-It's much more productive to focus on abilities than on deficits.

-The service system must allow for options and choices.

-Families' knowledge and experience are vital.

Current initiatives that offer hope:

-Foundations for Life (Region of Waterloo only): a transitional initiative for young adults (18-29) with developmental disabilities. Very positive and empowering—person-centred planning, time-limited paid supports. However, note that the amount of money is fairly small, and it is highly dependent on parental involvement. Contact Adult Intake, DSAC, (519) 741-1121

-Planned Lifetime Networks (Waterloo-Wellington-Oxford), an incorporated not-for-profit charity in Ontario and affiliate of PLAN™ of Burnaby, British Columbia, that has pioneered personal support networks for people with disabilities since 1988. PLAN's A Good Life is a great book about planning for the quality of life in the present and the future. Contact: Lynne or Roz at (519) 746-7950 or email plnww@sympatico.ca

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Books by Janice I. Adams

Janice Adams is an Ontario special education teacher who also has a son with autism. She started her career as an artist. She studied painting, drawing, sculpture and printmaking at McMaster University and in 1977 she began a career teaching visual arts to High School students in Blenheim, Ontario. During her first ten years as a teacher she also had showings of her several galleries, illustrated a skating manual and began the painting three large murals.

The birth of her second son, Ethan in 1987 changed life dramatically. By the age of five, he had diagnoses of asthma, autism and a very severe pediatric seizure disorder. She took leave from teaching to study Ontario programs that had been successful teaching and integrating children with autism. She and her husband were trained in the Hanen Early Language program, and she developed and designed augmentative communication visual aids for her son.

Since 1992 Ms Adams has also designed and directed a summer program of integration for children with autism. In 1991 she co-founded the Chatham-Kent Chapter of Autism Society Ontario, and served as president for five years. She also founded a cross-disability parent group that has since grown into the "Family Support and Resource Network" and is linked with a dozen other such parent groups across the province.

As she collected more ideas related to "best practices" when teaching and living with the disorder of autism, she began to write manuals in order to share those strategies. In 1996 she obtained a grant from the Trillium Foundation. After talking with parents and professionals from across Canada as well as within the United States, she wrote and published *Autism-P.D.D: More Creative Ideas from age eight to early adulthood*. Adams Publications, 1997. 155 pages

Her *Guide Related to Support Workers* is grounded in her family's long experience. Janice Adams has also been working on a book that chronicles the journey that her child and family have undergone.

For more information, including details of how to obtain Janice Adams' books, click on:

<http://www.adamspublications.com/obtain.html>

A GUIDE Related to: Support Workers, and Your Individual with Exceptionalities. By Janice I. Adams. Adams Publications, 2001, 52 pages

Reviewed by Amar Arneja

As more and more adults with autism and related pervasive developmental disorders (PDD) are coming out of the school system into the community and are living with their families, there is a great need to find and hire support workers. Through funding such as Special-Services-at-Home that allows families (or caregivers) to hire support, Governments are also encouraging individuals with exceptionalities to stay within their homes and communities rather than move to institutional environments.

Locating prospective workers can be very time-consuming and difficult. This guide helps families make informed choices by following the simple process of how to find a worker. There are guidelines for each step in the process of finding workers from the community, interviewing, training, and maintaining the team.

The first step is to write down the job description and your expectations. Formal job requirements could address such matters as the way you wish the worker to dress in public with your child, number of hours per week, rate of pay, amount of notice you expect them to give you if they leave the position and so on.

The next item is to write a profile of the individual, including medication, food and drug allergies, likes and dislikes of the individual and modifications needed in a sport, an academic task or living skill.

Where to look for prospective workers? You can put an ad in the local newspaper, and contact local colleges and universities, local employment center and community bulletin boards.

It is very important to select the best person from the list of candidates. Pages 4 to 9 explain the techniques to profile the candidate during the interview. What to ask the candidate prior to arranging an interview? What things to check prior to telephoning for an interview? What questions to ask during the interview? These and other suggestions are in the checklist so that you don't miss to ask some relevant information to your particular situation such as if the candidate has valid CPR certificate, drivers license, current First Aid certificate, Early Childhood Course or Police check etc.

It is wise to observe the worker with the individual and see how the two are getting along. During a training period, modifications may be required. It is beneficial to have more than one person watching in order to notice things you might miss. Does the worker greets the individual, using his/her name, in a friendly manner? Ask the worker what he/she observed of the child and what this might mean. This will give you an indication as to his/her powers of assessment, observation and thinking processes.

The final section is about resolving any issues that may come up and the worst case scenario where you feel that the worker has to be replaced. Advice is given about how to handle this situation.

Overall I found this guide to be very well written and extremely useful for the parents and caregivers to follow when looking for support workers.

Life Behind Glass: A Personal Account of Autism Spectrum Disorder. By Wendy Lawson. Jessica

Kingsley Publishers, 2000, 118 Pages.

ISBN: 1 85302 911 4 Order from Irwin Publishing at www.irwinpublishing.com

Reviewed by Jan Cooper of Guelph

Life Behind Glass is about a journey of struggle and triumph. The author, Wendy Lawson says she has always known she was 'different' from other people, or at least different by society's standards. It was her "insatiable appetite for knowledge" (p. 1) that has enabled her to overcome alienation, misdiagnosis and misunderstanding by society to become a survivor. There are people who have committed themselves to helping her face the obstacles, the challenges of being autistic. There were many that shunned her because of her inability to act 'normal'. It is a remarkable story; one that Wendy says took over twenty years to write. Her reason for the delay? Wendy says she didn't think we were ready to hear the message. Now, perhaps it is time.

Wendy describes her life as a world behind glass, one where she is generally an onlooker and occasionally an active participant. Like Jasmine O'Neil (*Through the Eyes of Aliens*, 1999) Wendy sees the autistic person not as someone who "lacks the ability to operate as a complete person" but rather someone who may just "view life differently and, therefore, actually help to make up for the 'lacks' that others experience." (Pg. 1)

This is a woman who sees the world as an environment rich in colours, smells and tastes. To read her descriptions of times by the sea, decorating a nursery for her unborn child, experiencing the tastes and textures of foods one can tell that Wendy is a person keenly in touch with life around her. She says that colours and fragrances are so vibrant for her that she can 'feel' them, they stir up all sorts of feelings in her. She knows that others around her do not understand how completely she can become immersed in this sensory thrill. "My friends tell me that most people do not stop and take time to notice the bright colours around them...lost in the wonder at the 'feeling' that colour evokes". (Pg. 3) When you read this you wonder if maybe she is trying to remind us to 'take time and smell the roses'.

Perhaps she is the richer one for being able to experience her world so intensely while we rush about our lives missing out on the little miracles happening all around us. At the same time Wendy recognizes that she is unable to have this same rich experience when it comes to understanding human emotions and behaviour. In one chapter she demonstrates this situation by describing the incredible beauty of a new-fallen snow

one winter morning. The colours and fragrance were so intense she could 'feel' them yet she was unable to share the sadness and grief of her fellow nursing staff at the death of a patient who had died during the night.

Wendy chronicles her life interspersed with chapters on love and feelings, friendship, coping and change. Through it all Wendy struggles to understand how and why people act the way they do and how she can learn to 'fit' in. Trying to develop friendships with people who thought her behaviours eccentric or just plain weird was fraught with emotional minefields. In Chapter 2 Wendy talks about the how emotions of kindness, intimacy and love can be confusing for a person with autism because they do not seem to have a purpose. Likewise anger, frustration and disappointment are equally difficult. But Wendy has learned to study postures, voice tones and facial expressions and can now usually figure out what people close to her are feeling. Strangers still remain a challenge. She does make the point that while communication is a difficult thing for autistic people, if we just acknowledge that autistics "operate on a different level of communication ... strategies for mutual understanding can be developed" (Pg. 16)

Language is an integral part of the difficulty in understanding and expressing feelings. People with autism often take the literal meaning of words and phrases and the result can be traumatic or embarrassing. Wendy demonstrates this with a couple of stories. One is of a rare trip with a schoolmate to a holiday caravan park. When told she will be staying in a mobile home you can imagine the turmoil in Wendy's mind as she struggles with the thought of the home moving around while she slept! Needless to say, the week was disaster with Wendy spending most of her time up in a tree. Building of friendships and social interaction were a nightmare as well when the inability to understand the rules of social interaction created confusion. As Wendy put it "my clumsy efforts to socialize usually ended up in trauma - an experience common to most Aspergers teens." (Pg. 16)

Thankfully there were people in Wendy's life who were able to touch her behind her glass wall. One was a nurse who took a real interest in her, someone who must have sensed that a quiet, calm manner might soothe and reassure the young girl. Wendy says that nurse was one of the very few people who truly believed in her, allowing her to cautiously let herself share what feeling she could without ridicule. It was a turning point as she finally explored the thought that she was valuable human being. "Thirty years later, she is still one of the most significant people in my life" (Pg.49) Wendy says.

The following years are tumultuous ones for the author. She was diagnosed as Schizophrenic after two hospitalizations for severe depression. As she left the hospital she vowed she would never allow herself to endure that experience again. "If they think I am mad, then I

must prove them wrong." (Pg. 77) She immigrated to Australia with four young children. It was a time of intense emotional upheaval as Wendy dealt with the final breakdown of her marriage and a determination to find more about depression and schizophrenia. Through reading she became convinced that the symptoms did not describe her condition at all. It wasn't until she reached the age of 42 that she was finally given the proper diagnosis of Asperger's Syndrome.

Wendy began to feel she was capable of doing something more positive with her life so she studied hard for 2 years to upgrade her education and was then accepted into university. She was ecstatic and described it as *"like being the first person to ever discover gold, or a genie who had the cork pulled out of her bottle – now I was free! I felt the 'sky was the limit' and I would fly forever."* (Pg. 96)

The end of the book is close now, but not the end of Wendy's story. Four years have passed at university and much of her day-to-day life is still a struggle as she tries to understand relationships and 'get it right'. The last chapter is entitled "It's My World Too" and in it Wendy describes an incident involving the transformation of a cicada from a dull brown bug into a beautiful, bright creature. That it took 1-½ hours in 28°C weather is irrelevant to her. A neighbour coming over to see what the excitement was all about no doubt thought Wendy was a little crazy. I loved Wendy's response: *"By choosing to not stand and watch, they missed out on sharing an experience that was so beautiful and exhilarating. A miracle can be happening all around us and no one is aware of it. I know how it feels to be underground, trapped in a silence that vibrates only more silence. I also know the joy of the moment when I have been able to break through the silence and life has made sense to me..."* (Pg. 115)

Wendy ends her story to date by saying that she has tried to fit in by watching other people's behaviours and she feels she has made some significant gains in this respect. However, it has come at a personal cost. *"This process is hard work and although it helped me to be more observant of others, it robbed me of spontaneity and enjoyment of the richness of my own experience."* (Pg. 116) but she also acknowledges that there has been a sense of freedom as well that has accompanied this discover of self and others. Wendy feels life is very good and that she is a valuable person with a place in this world. She has learned to 'blend in' while dealing with the daily challenges of being autistic. And she is continuing her journey of understanding and acceptance, by others and herself.

As she says *"My adventure is not finished yet!"*

LISTEN by Tony Diamonti

Don't just see me, hear me.

Don't just read my words, listen to them.

Listen to me, then look at me.

If you look first, you'll probably not see.

Listening is the path to understanding me.

Only seeing me, is blindness.

I'm not an empty dysfunctional carcass
you may see before your eyes,
wallowing in a state of despair.

I am filled with joy and passion.

I have a spirit that moves me, frees me,

and lets me defy all those who say

I cannot live life to its fullest.

I have a lot of love inside, with a
passionate heart.

I have the humour and laughter of a circus
clown.

I have creativity and intellect,
and I am a sexual being.

In essence, my character identity is stifled
by the lack of free flowing dialogue and
interaction with you.

Yet, my inner voice often cries out
LISTEN TO WHO I AM, AND SEE ME AS I
TRULY AM!!!

We, who use alternative means of
communication, need to be heard.

We need to be LISTENED to.

Don't just read our words; don't just hear
our mechanical voices.

Listen to us as you would listen to others,
speaking to you with their own voices.

Reprinted with permission from LOUD 'N CLEAR (Vol. 1, #1, June 2002), the first quarterly newsletter of Speaking Differently - A national organization for persons with disabilities who communicate in different ways. Speaking Differently (SD) now has a website at:

http://home.istar.ca/~marshall/Speaking_Differently You will find a membership application form there. Annual Membership in Speaking Differently is \$4.00 for AAC users, \$10.00 for Non-user Friends, \$50 for Non-user Benefactors, and \$100 for Non-user Patrons. Send your cheque to Speaking Differently, c/o Department of Speech-Language Pathology, 6 Queen's Park Crescent West, Toronto, ON M5H 3H2

Bright Splinters of the Mind: A Personal Story of Research with Autistic Savants. By Beate Hermelin. Foreword by Sir Michael Rutter. Jessica Kingsley Publishers, 2001. ISBN: 1-85302-932. 176 pp. Reviewed by John Clifton

Beate Hermelin's *Bright Splinters of the Mind* is a fascinating and frequently surprising account of what must surely count as one of the glories of the autistic world. For at least a hundred years (since Alfred Binet coined the term "idiots savants"), there have been anecdotal references to persons who possessed remarkable talents despite generally low levels of intelligence. Hermelin's book appears to be among the first to go beyond documentation and to attempt a scientific explanation as well. That a sort of "autistic thinking" plays a role in this inspiring phenomenon will be welcomed as good news by both researchers and members of the autistic community.

In the early pages of her book, Hermelin tells us of her amazement when she first began to encounter autistic persons who possessed startling abilities. She describes meeting a thirteen year old boy whose reasoning ability was equivalent to that of a four year old but who could instantly tell her the day of the week on which she had been born. Another autistic boy of fifteen who attended a special school for children with severe learning disabilities was able to play the piano remarkably well. Still another, also attending a special school, was able to draw amazingly accurate and detailed pictures from memory.

Since the early sixties, Hermelin has been pioneering experimental investigations into the thoughts and language use of children with autism. In 1970, she co-authored a book with Neil O'Connor entitled *Psychological Experiments with Autistic Children*. This was at a time

when (she tells us) hardly any controlled investigations of such individuals had been published (p.43). Since the majority of persons with savant talents are autistic (80%), Hermelin began to wonder whether there might be something about the "autistic style of thinking" that might help to facilitate these startling abilities.

Citing various theories of intelligence and the "block design test" originated by Shah and Firth, Hermelin begins with the view that persons with autism have "weak central coherence". What this means is that, while non-autistic persons "tend to obtain and recall a general impression of things and events (a 'gestalt')", autistics perceive "parts and local details of a display" (p.45). On the down side, weak central coherence can account for the autistic tendency to see the world as unpredictable and chaotic. In the forties, Kanner noted that autistics prefer stability and routine. He surmised that this was part of an effort to inject order into an otherwise disordered experience. On the up side, while autistics tend to perceive individual details, they are also able to do this with greater focus and accuracy. This explains, for example, why they are better able than their non-autistic intellectual counterparts to remember a string of unrelated words (such as "book, horse, white, three) versus meaningful phrases (such as "the dog is hungry"). According to Hermelin, "the 'weak central coherence theory' allows not only for mental deficits, but also for certain assets that may result from such a style of information processing" (p.48). Gifted autistics initially "focus on details and segments" and this eventually leads to the "production of pictures, music, calendar structure, and even poetry and knowledge of foreign languages" (p.48). With this as her starting point, Hermelin and her associates devised a series of ingenious experiments to learn whether indeed the weak central

coherence theory might help to account for savant talents.

Hermelin's study of talented individuals commences with a poet whose I.Q. could not be measured because she could not understand the questions. Despite her intellectual limitations, including the inability to utilize language efficiently in her ordinary life, Kate was able to produce effective poetry of similar merit to that of another "talented amateur" who was her intellectual superior. By comparing and contrasting the work of these two poets, Hermelin established that Kate employed similes, metaphors, and other poetic devices with equal facility to her non-autistic counterpart. This seemed especially surprising since Kate's talent lay in the area of language processing, an area where she was typically weak. For Hermelin, what this suggested was that language is not a "unitary function". For savants and probably for the rest of us, intellectual functions can be "subdivided into quasi-modular sub-domains" (p.62). Therefore, excellence in the area of poetry can coexist alongside an otherwise inefficient use of language. What this chapter establishes is that weak central coherence in general does not preclude the ability to arrive at strong coherence in certain areas of cognition.

In the chapters that follow, Hermelin investigates the abilities of several savants in a variety of domains. "Christopher" had a remarkable ability to learn languages. He mastered much of the vocabulary of several and was able to supply accurate person-verb agreement when necessary. What Christopher was less able to achieve was the assimilation of new grammar: "His syntactic errors indicated that he appeared to 'filter' new grammars through the parameters of his native English" (p.74). Hermelin maintains that Christopher's autistic tendency to focus upon details accounts for his ability to acquire a

vast knowledge of words and morphological units. However, while this ability made him very strong in one area of language acquisition, it did not affect "his limited skill in setting new grammatical parameters" (p.76). It was here that Christopher's deficits in the area of "central coherence" became apparent. Regarding calendar calculators, Hermelin maintains that it is "probably the most frequently observed ability in savants" (p.78). She begins her chapter on this topic with an exploration of the complexity of our present Gregorian calendar lest there be any doubt that the ability to say that August 8, 1953 falls on a Tuesday is a remarkable feat indeed. Hermelin maintains that autistic calendar calculators begin with a fascination for individual dates such as birthdays and holidays. Attention to these details gives way to knowledge of dates for its own sake. Eventually, such an intense contemplation of calendrical events gives rise to an "implicit" knowledge of calendrical structure. Although savants cannot say how they know, Hermelin argues that they do know, albeit unconsciously. In this, they resemble the child who cannot say how she knows that the subject precedes the verb though she will employ this rule in her speech. Savant calculators take account of the length of individual months, leap years and such calendrical symmetries as that in certain months of a given

year, the days of the week will fall on the same number date.

Hermelin cites several experiments to confirm this account of how calendar calculators have implicit knowledge of calendrical structure. For example, in one experiment, savant calculators were presented with pairs of dates. Some pairs were matched by the experimenter so that they both fell on the same day of the week but in a different month of the year. Other dates were chosen so that they differed in that respect. When asked to remember the date pairs, there was a significant statistical likelihood that the pairs matched according to weekday would be remembered better. Hermelin argues that this ability reflects the savant's implicit knowledge of a connection between some dates that does not exist between others. The presence of this connection marks certain date pairs and expedites their speedy retrieval from memory.

In subsequent chapters, the talents of savant musicians and artists are explored. Of particular interest is Hermelin's analysis of the manner in which savant talents can reveal themselves "in the doing". For example, she cites an experiment wherein several savant artists were asked to remember and subsequently identify a geometric shape. While they were unable to do this (vis a vis a control group of more intelligent but equally talented non-savant artists), they were able to achieve success when asked to draw from memory what they had seen. Hermelin takes

this as confirmation of the view espoused by art historian Ernest Gombrich that "the artist tends to look more at what he does than at what he sees" (p.128).

The foregoing quotation is only one of Hermelin's many intriguing references to a variety of scholars, poets, musicians, artists and philosophers, including Chomsky, Diderot, Delacroix, Eratosthenes, Kandinsky, Schonberg, Nietzsche, and Tennyson. That Hermelin makes these connections testifies both to her capacious erudition and to her immense respect for savant talents. Early on in her account she states that her wish is not to diminish our "wonder about the apparently mysterious, extraordinary abilities of those gifted individuals who are otherwise emotionally and cognitively impaired" (p.26). However, despite such proclamations, Hermelin is ultimately cautious in her appraisal of the achievements of autistic savants. She maintains that for savants, music, art and poetry serve primarily as "means of self expression rather than communication...there is no aim for the greatest possible perfection". Also, "the mental impairments from which savants suffer set boundaries to the development of their talents. There are no savant geniuses about" (p.177). From the magnificent evidence provided in several pages of Hermelin's book showing the paintings and drawings of "Stephen" and "Richard", one wonders whether she isn't being too pessimistic.

LOOKING FORWARD

Presentation to AGM of WWAS, 28 May 2002 (continued from page 3)

Other hopeful initiatives include:
-Incorporated entities for personal empowerment and support- more formal personal support networks with legal powers to receive and manage resources to support an

individual with significant disabilities. Focus person, family and friends are directors. Based on values of person-centred plans, individualized funding, self-determination and the rights to be heard and to choose. A Guelph man is now pioneering such an incorporated entity in Ontario.

-Guelph Services for the Autistic is a housing trust for adults who want

their own homes. GSA, with support from WWAS, is launching the ASPIRE project to survey adult autism needs, and model a facilitation service for families and adults plan and find resources for a good life.

Watch ***Adult Autism Issues*** newsletter, and the OAARSN website at <http://www.ont-autism.uoguelph.ca>

Autism: A Summary of Recent Research and Clinical Findings

Selected issues from the 2002 DAN! Conference (Boston) and the 2002 Montreal Autism Convention

By Joan Jory, MSc, PhD, RD, Nutrition Consultant, Pediatric Specialization

A presentation to the Autism Society Ontario's Wellington Chapter, 13 June 2002

Noting that autism is a uniquely complex medical condition, for which there is as yet no single causative factor, Dr Jory stressed that children and adults with autism are individuals first and foremost, and their autistic symptoms and responses to interventions are highly individualized. People with autism may have a genetic vulnerability to environmental factors that would not cause dysfunction or injury without this genetic vulnerability. Several environmental factors have been proposed as the initiating agents in the cascade of autistic symptoms known as Autistic Spectrum Disorder (ASD), but the evidence for these is still being further researched. Simultaneously, researchers are seeking to understand better what happens in the body of an autistic child, once the injury has occurred. Better understanding of the pathophysiology of autism may lead to improved interventions.

Research supporting several recent theories:

1. Brain autoimmunity or neuro-immunopathogenesis in autism, the theory and research of Dr V.J. Singh, University of Utah. Environmental factors including viruses, toxins and heavy metals may initiate immune dysfunction among genetically vulnerable individuals. Resultant changes in immune function lead to production of brain antibodies (i.e., the brain develops a pathological autoimmune response to its own brain tissue). This response leads to a spectrum of neuro-immune development disorders.
2. Deficits in sulfur metabolism are reported by Rosemary Waring of University of Birmingham, UK, who found autistic children to have higher excretion of urinary sulphate and low blood sulphate levels. Sulphates in the body help rid the body of waste products by making them water soluble and therefore easily excreted; reduced levels may impede detoxification. The gut lining contains sulphated glycoproteins that rely on sulphation to maintain their structure. Low sulphur is associated with reduced plasma cysteine levels (sulphur-containing amino acid) in autism. Cysteine is critical in the production of glutathione and metallothionein, which if reduced, may result in increased oxidative stress, lowered immune function, neurotransmitter dysfunction, accumulation of lead and mercury, and viral persistence. Reduced sulphation may thus be associated with gut inflammation, gut dysfunction and increased permeability.

3. Metallothionein abnormalities are reported by William Walsh, Pfeiffer Treatment Center, Naperville IL, based on finding that autistic children had significantly higher copper to zinc ratios. Metallothionein is a zinc-dependent protein and a carrier molecule for zinc. Generalized metallothionein dysfunction may result in zinc deficiency, impaired immune function, altered detoxification, decreased appetite and altered taste perception. Metallothionein dysfunction in the gut may reduce production of zinc-dependent enzymes responsible for the digestion of casein and gluten peptides. Metallothionein dysfunction in the brain may temporarily disrupt normal neuron development.

4. Abnormal Liver Detoxification was found in all autistic children in research by Edelson and Cantor.

5. Gastrointestinal Abnormalities in ASD: In research led by Hovarth, significant numbers were found to have chronic esophagitis, chronic gastritis and chronic duodenitis, and a majority had low carbohydrate digestive enzyme activity. The pain and discomfort from chronic inflammatory GI conditions may be associated with the behavioural symptoms of autism.

6. Automimmune Inflammatory Bowel Disease, in a new form in autistic children, is reported in at least two projects.

In summary, children and adults on the autism spectrum may be affected by the following gastrointestinal factors :

- Chronic inflammation through the length of the GI tract
- Autoimmune inflammatory bowel conditions
- Low sulphate leading to increased gut permeability, and sensitivity to damage
- Decreased digestive enzyme production (low sulphate and zinc)
- Increased food sensitivities (altered immune status)
- Possible presence of parasites, bowel bacterial overgrowth
- Diarrhea and/or constipation associated with altered nutrient absorption

Current dietary interventions in ASD are:

- a) **Gluten-free, casein-free (GFCF) diet.** Clinically, people with ASD seem to have inappropriate digestion of gluten and casein. This may be related to a reduction in zinc and sulphur-dependent digestive enzymes, chronic inflammatory bowel conditions, a shift in immune functions,

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increased food sensitivities and allergic responses. Although gluten and casein sensitivities are not a biological cause of autism, they may exacerbate autistic symptoms. In the guts of autistic people, gluten and casein are often inadequately digested, leading to the formation of opioid byproducts. In a damaged gut, there is increased permeability of the upper GI tract, allowing movement of the opioid byproducts into the bloodstream and across the blood brain barrier. These opioid byproducts resemble heroin in their addictive capacity, making the consumption difficult to break, and withdrawal symptoms fairly severe. Implementation of a GFCF diet is the easiest and safest of all interventions currently in use for autism, and should be the first step. The GFCF diet may be implemented in stages, beginning with elimination of all casein (in any form or trace) for a period of three weeks. Removal of all gluten-containing foods could be next or simultaneous--it's all or nothing, and response to gluten removal may take 3-6 months to be effective.

b) Essential fatty acid supplementation. The second safest dietary intervention is supplementation with Omega-3 plus a small source of Omega-6. Omega-3s are derived primarily from fish and oily seeds (esp. flax seed oil). Choose a high-quality product that has been tested as free of contaminants. Choose capsules, especially if they have vitamin E as an antioxidant.

c) Vitamin and mineral supplementation. Because of self-imposed restrictions on diet or because of GI complications, many people with autism are at risk of micronutrient deficiencies (including but not limited to A, B6, magnesium, selenium and zinc). Expert guidance should be sought for testing and supplementation. A good minimum investment is a high-quality product that meets the RDA for the nutrients, and is free of gluten, casein, sugar, artificial colours and flavours.

d) Digestive enzyme supplementation. This is an area of considerable contention. Digestive enzymes can help cases of persistent GI distress, diarrhea and/or constipation. But they are not now considered an alternative to a GFCF and may be completely unnecessary for people without GI symptoms. Guidance by a trained health professional is essential.

e) Investigation of concomitant parasite infections in gut or gut flora dysbiosis. Some people with autism have multiple food sensitivities that may not be true allergies but can cause considerable distress and behaviours. The classic method of identifying food sensitivities is an elimination diet--a restrictive food rotation diet, starting with a base of the 4-10 foods least likely to cause sensitivity, then adding foods systematically on a rotational basis, monitoring the gut and behavioural results, and then eliminating the offending foods. Some practitioners offer other methods of food sensitivity testing, such as the Vega machine. Because of alterations in immune function, many people with autism appear to have increased susceptibility to parasitic infestations and bowel flora alterations. Stools may be tested, and a probiotic supplement may be taken to increase the proportions and activity of benign bacteria in the gut.

In conclusion, Dr Jory noted that she had not touched on some issues because of political sensitivity, biological complexity, or because there is insufficient evidence to recommend them at this time. Practitioners with experience intervening in autism are scarcer in Canada than the US, but numbers are increasing as peer-reviewed research becomes more prolific. She stressed that we should seek the guidance of a trained practitioner before attempting to intervene in any way other than a gluten-free/casein-free diet, fatty acid, digestive enzyme, and/or a basic multi-vitamin/mineral supplementation regime.

We thank Dr Jory for permission to print this report. For a full transcript, click on:

<http://www.ont-autism.uoguelph.ca/jory-autism-jun02.html>

AAIWW BULLETIN BOARD

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Tax-creditable receipts are issued for donations of at least \$10. Please mail to GSA, P.O. Box 23016, Root Plaza Postal Outlet, GUELPH, Ontario, N1H 8H9. To reach GSA, leave a message at (519) 821-7424

ONTARIO ADULT AUTISM RESEARCH AND SUPPORT NETWORK

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

OAARSN offers up-to-date information and communication tools that can put you in touch with others. Check out the News Scroller and What's New on the opening page. You may request to be on the OAARSN List to receive regular e-mail bulletins of autism news and announcements of events.

ADULT AUTISM NEEDS SURVEY

OAARSN is co-operating with this important initiative by GSA and WWAS as part of the ASPIRE project. Long-form and short-form surveys may be completed online.

