

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

A joint newsletter of Guelph Services for the Autistic (GSA) and Waterloo-Wellington Autism Services (WWAS)

Newsletter No. 3

Spring 1999

### **POSSIBILITY OF EARLY DETECTION OF AUTISM**

In a new study, Philip Teitenbaum has proposed a method of diagnosing autism at a very young age by observing abrupt or erratic movements that are significantly different from those of a normally developing child. These findings, first published in the Proceedings of the National Academy of Science, and then in the January 26th edition (1999) of the New York Times Science section, may make possible earlier and more effective treatment for autistic children, since the brain of a baby is still growing and developing.

Teitenbaum, a psychologist at the University of Florida, got his inspiration from studying the stages of recovery of brain-damaged animals. He hypothesized that brain damage might be observed through study of human stages of development. He requested videos of babies who were later diagnosed with autism, videos that recorded milestones of motor development: how the babies rolled over, sat up, stood and took their first steps. He received 17 such videos which he then compared to 15 videos of normal children.

Though no two babies developed in exactly the same way, the videos revealed some specific differences. For instance, none of the autistic babies learned to roll over as the normal children did, using a corkscrew method of turning. The autistic babies started by lying on their sides, rolled to their stomachs or backs, and then threw the upper legs forward and toppled over, moving

the body together. Some babies never did succeed in rolling over. Autistic babies also had trouble sitting up, toppling easily, and didn't break their falls with their hands. Instead of bearing weight evenly on all four limbs when they began to crawl, autistic babies moved asymmetrically: for instance, scooting a left knee on the floor but propelling themselves with the right foot. The same asymmetry was shown when walking, shifting their weight at the wrong moment which made them appear stiff.

It must be emphasized that the study is a preliminary one, based on a small sample. Also, it remains to be seen exactly which movements are specific to autism and not also associated with some other developmental disorder such as schizophrenia or attention deficit disorder. On the other hand, the study of the relationship between movement disturbance and autism is not a new idea, and readers of the autumn 1996 WWASnews will recall work reported by Martha Leary and David A. Hill on the subject. What makes Teitenbaum's study so exciting is the early age at which autism may be detected and the possibility of correcting movements through some sort of physical therapy, using feedback to help abnormal brain development. Autism might be diagnosed as early as three months, in contrast to the usual age of at least three years.

WWAS BULLETIN BOARD  
MEETING

Please plan to attend the seventh WWAS Annual General Meeting, on Monday 7<sup>th</sup> June 1999, 7:30 to 9:00 pm, Stanley Park Baptist Church, 31 Lorraine Ave, Kitchener. A proxy form is enclosed with this newsletter to persons or agencies who are paid-up members of WWAS for 1998 or 1999.

1999 MEMBERSHIPS ARE NOW DUE

Show your interest in and support for the causes of adults with autism/pdd. Become a member/renew your membership of WWAS. Memberships are \$25 (memberships or donations of \$25 or more qualify for official tax-creditable receipts). A membership gives you an opportunity to share your concerns, ideas and hopes about issues relevant to people with autism and their caregivers. As a member, you are also eligible to vote at general meetings and to be nominated and elected to serve on the board of directors or WWAS. You also receive AAIWW. Just want the facts? A subscription to AAIWW is \$5 per year, towards costs of production and postage.

Make your cheque payable to WWAS and send with a note of your name, full address and phone number, to:

William Barnes  
26 Yellow Birch Drive  
Kitchener, ON N2M 2M2

BOARD MEMBERS AND VOLUNTEERS SOUGHT

The WWAS Board meets ten times per year (one evening a month, September to June). Volunteers may be called on for special projects or activities throughout the year. For more information, call our answering machine at (519) 742 1414, leave your name, number and message. We will eagerly return your call. WWAS and adults with autism/PDD need your ideas and time. WWAS recognizes with appreciation the volunteer

service of Jane Forgay who monitors and responds to the phone messages.

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This issue of AAIWW has been produced by Linda Foster and Elizabeth Bloomfield, with formatting and layout by Marie Puddister. Andrew Bloomfield prepares the newsletters for mailing.

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Announcing....

THE AUTISM PROJECT, led by Ralph Smith of Kitchener who recently made a presentation to the WWAS Board. He describes the project as a “consumer/survivor initiative concerned with advocacy, community development, and individual support for autistic adults and transitional age youth. This is not an organization requiring membership or dues, but a personal commitment based on individual and lifelong experience.”

Since March 1998, THE AUTISM PROJECT has followed a three-phase plan. First, there has been an effort to identify adult “survivors” of autism (or PDD or Asperger’s) who live independently in southern Ontario. Ralph Smith considers that the prevalence of autism has been much under-estimated and recognizes a “lost generation” of undiagnosed or misdiagnosed adults including some who are mistreated and homeless. Phase 2 “continues to assess personal issues and views within this society of veteran interests.” Phase 3 “will engage a practical effort of public, moral and individual support.”

To learn more about The Autism Project, phone (519) 749-8523.

## **ADULTS WITH AUTISM WANT ACCESSIBLE HELP**

Autism is a mysterious and complex set of disorders that is very challenging for individuals and families who live with it. We use “autism” as shorthand for autism spectrum disorders or pervasive developmental disorders. In the past, local families usually could not find appropriate services in our region. One factor is the absence of any large hospital or centre of expertise, such as Chedoke in Hamilton or CPRI in London. Services that do exist—anywhere—are usually focused on young children. For people with autism, travelling any distance from home and being assessed in an unfamiliar environment by strange people can be very hard. Having more accessible expert services could really help adults, their families and other caregivers.

A WWAS survey found over 60 individual adults with autism in Waterloo-Wellington in the early 1990s, and statistically there should be more. Adults with autism have distinctive profiles and needs that differ from those of young children with autism. Autism will still be present in some ways, but the experience of living for more than 20 years and the success of good therapies and treatments may have helped some adults to function remarkably well. Others may have had less happy experiences, and may have also developed other physical or mental health problems during adolescence and early adulthood. The point we would make here is that each person has a distinctive mix of abilities and needs and must be considered as an individual.

For the past five months, AAIWW has been trying to compile a guide to local services that really work for adults with autism. First, we contacted managers of any relevant agencies in our Waterloo-Wellington region, and some outside it. Those who replied report serving (in any way) a total of 13 adults with autism. Six adults are served in one Waterloo Region agency’s non-vocational program, which also provides some information

and coordination of services. Four adults are served by another agency’s administration of their SSAH or contract workers. One agency provides two adults with autism with comprehensive services, including facilitation of assessment and therapy, and another agency similarly serves one adult with a known diagnosis of autism. Answers to the question: “What are your most serious problems in serving adults with autism appropriately?” include behaviour (such as “obsessive or repetitive tendencies in daily living”) and communication concerns (such as the “literal interpretation of statements”) and the lack of residential services, appropriate “placements” and family relief. The Geneva Centre for Autism, mandated to be the provincial resource agency for autism, has some important roles but does not currently provide any services at all for adults with autism in the Waterloo-Wellington region. Its director notes that the most serious problem in appropriately serving adults with autism is funding.

In the second stage of this project, AAIWW researched the effects of restructuring developmental services in Guelph-Wellington. We hoped that this exercise would make appropriate services more accessible for adults with autism. Restructuring, effective from 1 October 1998, has resulted in the streamlining of administration into three major agencies for Guelph-Wellington (some of which also serve other populations besides people with developmental handicaps).

1. Family Counselling and Support Services (FCSS) is responsible for Access, Information and Referral (with the neat acronym of AIR) as well as case management.
2. Community Mental Health Clinic (CMHC) provides parent and in-home supports for children, infant and preschool supports, and assessment and consultation resources.
3. Guelph Wellington Association for Community Living (GWACL) administers accommodation supports and employment and day programs for adults.

In January, we asked the staff of AIR to advise on how various adults with autism (based on the needs of real people) might get help, so that we could feature this information in AAIWW. We commend them for their very creative ideas of informal and private sources to supplement publicly funded and local resources. We learned that the best single hope for several forms of help would be CART--the Community Assessment and Resource Team administered by CMHC that was to provide occupational therapy, physiotherapy, behaviour consultation and psychometric services.

However, just as we were going to press in March with this good news, we learned that the Ministry of Community and Social Services has cut budgets for the new fiscal year, so that AIR would cease to exist on 31 March 1999 and CART's services would be drastically reduced. We print a summary of what CART now offers, by its manager, Fred Wagner of CMHC.

AAIWW's next issue will explain how adults with autism might get help of various kinds in the Region of Waterloo. Meanwhile, we present brief profiles of the needs of some real adults we know, with some of the sources of help that have been suggested for Guelph-Wellington, mainly by the former AIR staff.

**AAIWW readers: please let us know about your experiences and additional sources of help.**

*For each of the real-life situations, we asked:*

*-What sorts of help might be available or recommended? Are there any choices or options?*

*-Do the staff or agencies recommended have specific experience of autism in adults and of the situation or challenge we describe?*

*-How long will it take an adult with autism to get help?*

*-Is there is any cost to the adult or family?*

*-Can the adult be visited in her/his home or other familiar setting?*

*-What is involved in the process of applying for this kind of help?*

### **1. Re-assessment of adults with autism**

- Mark (now 21) was diagnosed as a young child and had typical to fairly good support services through his school years, but he began to have fairly regular seizures at puberty. Now he is just out of the school system and with no clear support services. How can he get a thorough assessment to determine his strengths and challenges?

*With a physician's referral and a wait of up to several months, Mark could get an appointment to see an out-of-town neurologist, with OHIP bearing the costs. Seeking a private neuropsychiatric assessment might be quicker but would cost up to \$1,800.*

- Eve, diagnosed and treated for classic autism as a young child more than 40 years ago, has succeeded in holding a manual job and managing without a disability pension for most of her adult life. Now she is slowing down and has to consider early retirement. How can she get a re-assessment of her abilities, needs and options?

*She might get help from the part-time psychometrist at CART, after up to 8 months on a waiting list, and paying part of the cost. She might seek case management services from FCSS.*

### **2. New assessment of adults who suspect they have high-functioning autism**

- Wayne, when a young child, had fair language skills and coped reasonably well academically, while suffering from others' perceptions of his perseverative tendencies and difficulties with social relationships and teamwork expectations in his jobs. He experiences extreme frustration and clinical depression. Having read the books by Temple

Grandin and Donna Williams, he wonders if he has high-functioning autism. How can Wayne get an appropriate assessment and guidance to sources of help?

*Like Eve, he might have to wait 8 months for an assessment by CART's part-time psychometrist. Going private would be quicker and cost up to \$1,800.*

### **3. Support with Communication**

- Michael has autism and doesn't speak and Mario's speech is a bit garbled. But both have "something to say" and can become frustrated that they have no ways of making other people understand them. How can Mario get a thorough speech, language and communication assessment with a bias towards positive empowerment? How can Michael get support with facilitated communicating, sign language, picture communication symbols, literacy training and computer skills in ways adapted to his special challenges?

*Speech pathologists could be asked what experience they have with autism. St Joseph's Hospital offers speech pathology services. Some support workers know these modes and could be hired around their regular jobs. Michael was helped by staff of the Technology Access Clinic at Chedoke to obtain a computerized device on which he types significant messages.*

### **4. Medication**

- Harvey (43) has been routinely administered anti-psychotic drugs with the idea of keeping him quiet and more amenable. But he says the drugs make him feel ill. Harvey and his support group have learned that autism is not a psychosis, and that such drugs may not be appropriate and can even cause toxic reactions. How can they get assessments and advice on alternatives to conventional medication?

*Kerry's Place Autism Services (with its head office in Aurora)*

*offers the Universal Diagnostic and Treatment Model, developed by Dr Joseph Huggins of Toronto to calculate individualized drug regimens with reduced dosages of alternatives to psychotropic drugs. This assessment costs individuals or families up to \$1,600. For alternatives to all drugs, AIR suggests calling health food stores, homeopaths and naturopaths who may have some autism experience.*

### **5. Food Allergies and Special Diets**

- During the 1990s, it has become known that some forms of autism may be induced by lifelong food allergies (sensitivities or intolerances). How can Rachel (who is 28 and lives with her family) get expert advice on her sensitivities and on alternative diets?

*Rachel was initially helped by a local naturopath (for fees) and by the dietician at the Guelph Community Health Clinic (free on OHIP). AIR suggests trying to get continuing services, that may be publicly funded, from Guelph General, VON or the Public Health Unit, or going privately to a chiropractic centre or naturopath.*

### **6. Problem Behaviours**

- Philip, in his 40s, lives with some informal support in his own home (not his parents' home or a group home). He manages very well most of the time. But when his sensory systems are too stressed (by very high temperatures or sleep deprivation) he may become upset, hyperactive, and even aggressive. This may happen only once or twice a year. How can his companion help him and protect herself at such times? If the aggression gets out of hand—at night for example--can Philip's companion call in immediate crisis help? Such a service must be closely local to be any use.

*AIR suggested that CMHC has crisis workers and CART (before the budget cuts) might have provided advice and consultation.*

## **7. Rituals, Routines and Resistance to Change**

- Marilyn (32) is extremely sensitive to touch and texture. She will tolerate only a very narrow range of clothing items that may be threadbare. She is intelligent and will agree when talking about this problem that she really wants to be able to wear clothing that is appropriate to the season, temperature or functional situation. She will go shopping, hold clothing items up to her body in front of a mirror, and agree that she will wear them. But when it is time to put on the clothes, she becomes very upset, self-abusive and even potentially aggressive. What professional help can be found to solve this long-term problem?

*CART's Occupational Therapist might have used sensory integration techniques, but OT has been cancelled by the budget cuts. OTs in private practice who are sensitive to autism and use sensory integration methods are scarce outside Greater Toronto.*

## **8. Housing**

- Alex, who is 25 and has moderate autism, wants to live as the only disabled person in a home of his own. He gets very upset if he has to share with others who have developmental challenges, but is not capable of living without some supports. He needs the assurance of longterm continuity in his own home and the support of understanding companions. What local resources can help him?

*The new service, being developed by Guelph Services for the Autistic (GSA), is probably Alex's only hope in this region.*

## **9. Physiotherapy, Exercise, Yoga, Relaxation Therapy**

- Sam (who is 27 and handicapped by the movement disorders of autism) is physically active and needs regular and structured exercise and relaxation programs with understanding companions. How can he get help?

*Sam has been lucky to find two special programs that allow companions of people with special needs to get in free if the focus person pays the regular fees. Guelph Parks and Recreation provides a PAL card and volunteers in some programs. The University of Guelph Athletics Centre has a similar arrangement. Neither place is currently able to find regular volunteers for Sam, so he goes with paid support people. But his tight budget is eased a little by not having to pay the fees of his companions.*

## **10. Community and Neighbourhood Inclusion**

- Positive social attitudes make a real difference to outcomes for individual adults with autism. How can the friends of Fred (who is 25 and lives with his parents) or Peter (43, living with his married sister and family) foster inclusion, strengthen support networks, overcome the daily barriers of discrimination, and generally educate the community about autism?

*AIR suggested mainly segregated groups sponsored by agencies that have developmentally handicapped clients, noting that "some wait lists are extremely long." Fred and Peter would rather relate to ordinary neighbours and community people. Their circles of friends could benefit from advice by Support Clusters of Ontario.*

## **11. Respite services**

- Living with autism can often be exhausting. Families and other primary caregivers may be reluctant to seek any respite because it is so hard to find relief caregivers who are well

trained and sensitive enough to support an adult with autism.

How can they get help?

*Geneva Centre, Kerry's Place and CPRI provide training and community outreach consultations.*

## **12. Financial assistance**

- Most adults with autism are moderately to severely challenged and need financial help. How do their families learn what supports and funds may be available?

*Applying and being approved for ODSP (Ontario disability benefit) takes at least 6 months, and requires supporting documentation from a physician. So does an application under the Assistive Devices program. Service Clubs might be asked for supplementary funds.*

## **13. Volunteers**

- Does any local agency help to find, check out, train and monitor volunteers who could provide some support to adults with autism and their families?

*Local volunteer resources are being linked and coordinated by the new initiative for Guelph-Wellington, Volunteer Opportunities Wellington (VOW). Its program manager, David Phelps, may be reached at 821-2060.*

## **14. Planning for the Future**

- How can an adult with autism get help with making a person-centred plan, and how can families understand how best to plan for the future?

*FCSS can provide case management at no cost for developmentally handicapped adults.*

**CART: COMMUNITY ASSESSMENT & RESOURCE TEAM FOR GUELPH-WELLINGTON**

*The developmental services system in Wellington County underwent an extensive planning process over the past four years. The purpose was to redesign the system to better serve the needs of children, adolescents, adults and families. One result was the resignation of the Community Mental Health Clinic (CMHC) in Guelph as the provider of infant and special needs child care services, family support services, and specialized assessment and therapeutic services for individuals with developmental issues and their families*

*The specialized assessment and therapeutic services, previously administered by (Kitchener-based) Community Resource Services, are now the responsibility of CMHC's CART team which also includes psychologists who do mental health assessments for adults and children. The primary objective of the team is to support the independence, productivity and community inclusion of people with disabilities through the provision of exemplary assessment, diagnostic and clinic services. The team resources devoted to individuals with developmental issues include a full-time behavioural therapist and a part-time psychometrist (3 days a week) and a part-time intake worker (2 days a week). These staff members are highly knowledgeable about a wide range of developmental issues, but do not specialize in a particular condition. Two additional staff members provide consultation to licensed daycare centres in Wellington County, with a focus on children with behavioural, social or emotional difficulties.*

*Responding to the needs of individuals with autism and their families has been identified as a significant gap in Wellington County. The CART provides services to the entire range of developmental disabilities and, consequently, its resources are in considerable demand. Although specific resources for autism are not available, CART is able to provide some assessment and consultation services for children and*

*adults. Decisions regarding the type and intensity of services to be provided depend on the nature and severity of the presenting concern. Priority is given to those most in need.*

*CMHC is exploring with its service partners ways of addressing the needs of individuals with autism, so that in future they and their families do not have to travel far distances to access appropriate services.*

Feel free to contact Fred Wagner at 821-8089 ext. 216 if you have any questions about the services available through the CART.

### **BEYOND PROGRAMS: A PARABLE**

- In the beginning, there was placement, and lo we were happy when it happened, as placement was not mandated for adults who experience severe disabilities. And so, we said, this is good.
  - And placements multiplied and filled the earth.
  - And then we said, let us make programs, which focus on serving clients. And clients were defined and labeled, and grouped according to their labels. And programs created services for each label, and agencies developed unit costs for each service. And programs prospered and multiplied, and we said, this is very good.
  - And as programs multiplied, a cry arose: Let us evaluate these programs to see how good they really are.
  - And program evaluation, regulations, quality assurance compliance plans and other program measures were created. And they multiplied and filled volumes.
- And in those times, a person arose who was a client and who was also a prophet, and said:  
***“I don’t want to be a client. I want to be a person. I don’t want a label. I want a name. I don’t want services. I want support and help. I don’t want residential placement. I want a home. I don’t want a day program. I want to do meaningful productive things. I don’t want to be “programmed” all my life. I want to learn to do the things I like, and go places which I like. I want to have fun, to enjoy life and have friends. I want the same opportunities as all of you: I want to be happy.”***
  - And there was a long silence. And lo, everyone realized that they must look beyond their programs.
  - But they were troubled and they asked:  
***“How can we do this? Would not each person need his own unique program and system of support and his own individual measure of quality?”***
  - And the prophet replied:  
***“Even as you say, so shall it be done—just as you do for yourselves.”***

-Michael McCarthy; reproduced from Contact, Sept/Oct 1991.