

ADULT AUTISM ISSUES IN WATERLOO-WELLINGTON

No. 2

Fall 1998

The two charitable organizations in Waterloo-Wellington, concerned with adults who have autism/pdd, co-operate in producing this newsletter. It continues the earlier *WWASnews*.

GSA ANNUAL GENERAL MEETING

The first Annual General Meeting of Guelph Services for the Autistic will be held on Tues, Nov. 17 at 7:30 at 23 Waverly Drive. The organization is looking for new Board members to work together towards its goals of person-centred plans and individualized approaches to funding.

IN MEMORY OF DAVID ENSING

We would like to extend our sympathy to Henk and Inge Ensing whose son, David, died at the age of 33 on October 21. In addition to his rare gift of music, David had been a strong supporter of his autistic brother before Jeff's death in 1981. Inge and Henk were founding executive members of the Wellington County Chapter of ASO; they have also served WWAS and are now both on the Board of GSA. We would like to convey the same sense of comfort and commitment to the Ensing family that they have always demonstrated to others. At the request of the family, anyone caring to make a donation in memory of David could contact the Casey House Hospice Inc., 9 Huntley St, Toronto, ON, M4Y 2K8.

WWAS BOARD MEETING

The Directors of Waterloo Wellington Autism Services will be holding a Board meeting November 26 to discuss the future direction of the non-profit charitable corporation. The group would like to contribute in some way to a Homesharing plan, but alternatively it may decide to remain with the status quo, during which a new focus may be developed. It been difficult to recruit new Board members, and some of the present Board members have been holding office for many years. Anyone with an interest in becoming a Board member or anyone with comments or questions about the meeting should contact a member of the Board: Bill Barnes (570-1824), Will Boeschstein (836-4725), Bernard Hermsen (742-9655), Roger Hollingsworth (885-2683), and Stan Shalay (576-3508).

SUSAN HONEYMAN RETIRES FROM WWAS BOARD OF DIRECTORS

Congratulations are in order for long-time WWAS director, Susan Honeyman who has recently taken on a new position in Hamilton-Wentworth. Many thanks for all the work that she has done and continues to do for the autistic people and their families in southern Ontario. Best wishes from WWAS and GSA members in your new job.

INSIDE THIS ISSUE

Making a difference?

WWAS Bursaries offer hope for new opportunities p.2-3

Provincial symposium plans person-centred supports p.4

Ten "easy steps" to realize a person-centred plan p.5

Autistic Mode of Being, a poem by Brian Henson p.6

Margaret Schneider's report on the 1998 International Symposium on Autism p.6

This issue of AAIWW has been produced by Linda Foster of Cambridge, formatted by Marie Puddister of Guelph, and prepared for mailing by Andrew Bloomfield of Guelph.

GSA and WWAS welcome members, donors and volunteers. This is the time of year when you might become a member, renew our membership and/or make a donation. Both organizations are registered with Revenue Canada ; their treasurers issue tax-creditable receipts for donations. You may also subscribe to receive AAIWW. Membership/subscription forms are enclosed.

Both WWAS and GSA are run entirely by volunteers and have no paid staff. We will do our best to respond to inquiries and requests.

Waterloo-Wellington Autism Services
125 Union St E, Waterloo, ON, N2J 4E5
Phone 742-1414 (answering machine only)

Guelph Services for the Autistic
Root Plaza Postal Outlet, P.O. Box 23016
GUELPH, ON, N1H 8H9
Phone (Voicemail) 821-7424

Attention: Father of children with autism

My name is Margaret Schneider, and I am a graduate student in The Recreation and Leisure Studies program at the University of Waterloo. For my thesis I am conducting a study of fathers of children with autism. Much of the research so far on autism and the family focuses primarily on mothers, and rarely considers the role of fathers. I would like to interview fathers so that we may learn more about their experiences, and invite you to call me at (519) 747-5989 or email me at mschneil@netcom.ca, if you are interested in participating or would like to know more. This promises to be an important study and I hope that the results will be useful to families with children who have autism. I look forward to hearing from you.

MAKING A DIFFERENCE...

TWO WWAS BURSARIES OFFER HOPE FOR NEW OPPORTUNITIES

Two recipients of WWAS bursaries, who applied for funds to buy computer systems, report in this issue. One, who has had his system for a year longer than the other, notes some difficulties he has experienced in being accepted as a volunteer for other community organizations.

In Appreciation: Why Gratitude is Often Difficult for People with Autism/PDD

In the Spring of 1997, I was the proud recipient of a WWAS Bursary, from the Victoria Bloomfield Bursary Fund. It was received in the form of a new Pentium home computer system including most of the up-to-date equipment. This bursary was applied for because I was looking forward to a new career in desktop publishing, and because the equipment that I had at the time was quite outdated, small in capacity, and slow, too.

When I say career change, this was not a sudden idea. I was planning a change over the previous decade, taking non-credit as well as credit courses. Unfortunately, the credit courses, after one year of full-time studies, could not be continued, due to health problems. Acquiring a disability pension, I was still trying to pursue my original goal of a new career at a desk, as opposed to a construction trade; I had been a practising electrician for twenty years. I found (as most of us do) that one doesn't have the energy or endurance at fifty the same as at twenty, and I was not able to keep up with the pace of construction.

I, therefore, was determined to exercise my skills in a different framework - namely, desktop designing and layouts. In applying for the WWAS bursary, I outlined the above, and was granted the equipment directly.

What I have been able to do with this package in the meantime? Many things, for sure, but not too many of what I would call constructive challenges.

I was able, for about six months in 1997, to volunteer to do the biweekly activities calendar for a local association for people with developmental challenges. When the personnel had their positions shifted, I was told that the new person to handle the activities calendar would be in touch. Despite repeated attempts to contact this person, nothing developed.

In volunteering for an adult program of crafts, recreation, and literacy, I was able to design layouts for crafts as well as cards for literacy training (with alphabet letters on one side and common objects whose spelling starts with these letters on the other side), which could be used by the other volunteers. However, when I went directly to the literacy council office and volunteered to do any desktop literacy designs or programs that they may have in mind I was told that my services were not needed.

Various employment agencies have offered individual counselling, but, as I explained my situation to the person(s) involved, they indicated that they could not advocate for me or find any positions that I may be able to fit into. The path away from disability income is fraught with people who can only say "Sorry, I don't know. Your situation is too unique."

This leaves me in a position that I can neither complain about, nor relish. Why should I complain, in any

way, about my life with a solid pension, no physical disabilities (other than those due to aging, as mentioned above), no academic or learning disabilities, a home of my own, this modern computer system, and many other assets that are too numerous to mention here? On the other hand, I feel like a motorist at a railway crossing, where the train has stopped, and nothing has happened for quite a while. How long do I wait? How can I get things moving again? To whom do I turn, or what exactly do I do?

Some people have told me simply to count my blessings, not my troubles, but this does nothing to release my potential while I am alive! Others have given me vague statements like "It's up to you..." I am still lost. Is it up to me whether or not an employer hires me? At this point I am usually accused of "taking things too literally" or of being cynical.

Cynicism, in many ways, is seen as the opposite of appreciation. No, I do not want to imply, in any way, that I do not appreciate what the Waterloo-Wellington Autism Services (through the Victoria Bloomfield Bursary Fund) has done for me. What this group has done for me was wonderful, indeed! What else can I say but "Thank You, Very Much!"

How the Victoria Bloomfield Bursary has made a difference in my life, by Jon, a young man with autism

This past spring, I was very fortunate to receive a Victoria Bloomfield bursary. As it is very important to me to increase my communication as well as work and learning possibilities, my family and I had decided to ask for a bursary to help towards the purchase of a new Pentium computer.

I started working on a computer in a formal way one year ago, when the president of the Wellington County Chapter of Autism Society of Ontario asked me if I would help compose a Bibliography of his library of books about autism and other challenges. This Bibliography list would help families and other interested people to find information they need and to learn more. Prior to this I typed a few messages, vocabulary lists my tutor coached me with and an excerpt from National Geographic. I have been familiar with the QWERTY keyboard since 1987, when I began doing some educational computer games. In 1992, for Facilitated Communicating, I started to use an Epson computer, which also incorporates this style of keyboard.

The computer I was using until this past spring was more than ten years old and I learned a bit about Word Perfect 5.0 software. When I first had the new Pentium set up in my living room, I spent some time working on each computer, as a transition and comparison. I then felt comfortable with the look and feel of the new hardware and software that include: a mouse, CD-ROM, colour printer and scanner. My computer also features a lot of software such as Microsoft Office (mainly for word processing projects), Pagekeeper (for scanning), access to the Internet, Encarta Encyclopedia and Reference CD and Boardmaker.

The Boardmaker software is particularly important and useful because through its expansive dictionary of word picture symbols I can achieve my three significant goals of learning, communication and work. My tutor says the first thing I have learned using this software is how alternate between the keyboard and the mouse. The mouse is a new concept for me and I still have to practice matching my

movement of the mouse on the pad to the arrow/cursor on the screen. I am also learning about all the different ways I can expand on my multi-modal communication abilities by creating graphics I use in my everyday life like prompts, schedules and choices of activities. I like the feeling of independence this gives me.

My computer is a tool in moving towards my goal of long-term work that helps people. Supported by my family and friends, I am embarking on starting my own small business called ABCcommunications. The main function of my job would be designing Picture Communication Symbols for others with communication challenges (i.e. picture communication boards/ schedules which may include lamination and/or velcro). In addition to creating these communication aids and devices, I also provide collating and copy-typing services. I have done collating work on a volunteer basis for several years, most recently a job assembling packages for 840 high schools across Ontario for the University of Guelph. Since the beginning of this year, my copy-typing work on the computer has included a 150-page document for the Credit Valley Conservation Authority and a philosophy paper for a university professor. For future requests for collating jobs, such as assembling newsletters for distribution, a mailing list of 100-300 people is an appropriate length for me.

I have a lot of energy for work, exercise and shared experiences with family and friends. Because variety and balance are important in my daily schedule, I see computer work and ABCcommunications as an important complement to other parts of my life such as taking care of my house and being out in the community. I am grateful for the bursary and all the opportunities it provides in practical ways and the ways it

PROVINCIAL SYMPOSIUM PLANS PERSON-CENTRED SUPPORTS

"Positioning for Change," an action-directed symposium concerned with individualized supports for people with disabilities, was held from October 18th to 20th at Geneva Park on Lake Couchiching. It was convened by the Individualized Funding Coalition, an umbrella group of 35 special-needs organizations representing more than 30,000 members, which support choice and self-determination for persons with disabilities. The Coalition's Accord declares that:

"All people should have control over decisions concerning where they should live, with whom they associate, and how they spend their lives. In order to achieve this, we believe that Ontario must develop a system of funding whereby the person requiring assistance, supported as appropriate by family and/or significant others, has access to and control over the funds allocated for her/his supports."

"Community leaders" from across Ontario were invited to share ideas and experiences, with some others coming from Manitoba and Alberta as well. Elizabeth Bloomfield, invited because of the innovative person-centred support plan that has been implemented around Andrew, was among those who attended. Elizabeth has been in touch by e-mail during the past two years with others who are concerned with alternative services for people with special needs. She estimated that two-thirds of those attending were there because they are employed in social services or serve on boards of agencies, while the other third comprised family members and other supporters.

Autism Society Ontario is one of the provincial member organizations, and K-W Counselling Services-Community Support Program and K-W Extend-A-Family in our region are also members of the Coalition. Bob Butella, director of Guelph-Wellington Association for Community Living, attended the symposium.

One of the key organizations represented at the conference is the Family Alliance Ontario. From its base at the Kinsmen Building at York University, the Alliance works for "the development and implementation of policies, practices and funding mechanisms which are consumer-directed, flexible and responsive to the needs and values of individuals and families." This goal is to be pursued through advocacy, connecting families with each other, representation to government and networking on a regional basis.

Many government officials had been invited to attend, but few actually appeared. One MCSS official who spoke and also stayed to listen to various seminars was Brian Low, Director of the Developmental Services Branch at Queen's Park.

The symposium had five main points of discussion or building blocks, as illustrated in the diagram: 1) person-centred planning; 2) building personal support relationships; 3) individualization of funds; 4) management supports/managing the plan; and 5) community development/transitional support to service providers. Each of these topics was introduced by three panellists who spoke only briefly, then everyone divided into groups to discuss the issues involved. Each group then submitted what its sense of the three most important priorities for that subject. On the last day, people divided up into focus groups which

took the priorities already established and used them to develop strategic action plans.

Though most conference time was spent in small focus groups, a consensus about broad goals, specific strategies and certain issues was clear by the end of the meeting. A case in point is the issue of the amount of pay received by workers who help the disabled outside traditional programs. Currently, there has been a trend towards hiring more part-time workers who receive fewer benefits and less pay, in an effort to be creative with the limited funds. The consensus determined at this conference was rather in favour of solidarity with the workers and in support of their rights as well as the rights of people with special challenges.

The social movement for the rights of people with disabilities has three imperatives, according to co-chair and lawyer Catherine Frazee, who is herself physically disabled.

Creativity (or no one template suits all needs)

Solidarity (those who have won rights affirm and work for the rights of those who have not yet)

Hope and faith (this is an urgent life-or-death issue, as the largest single factor in the deaths of vulnerable people is despair).

For further information about the IF Coalition and its symposium, check the Internet at <http://www.lefca.com/ifco/>

TEN "EASY STEPS" TO REALIZE A PERSON-CENTRED PLAN

1. I DECIDE TO BEGIN THE PROCESS (encouraged in self-determination by the people closest to me)
2. I FORM MY SUPPORT CLUSTER (circle or network) of family members, friends and professionals
3. WE DRAW UP MY PERSON-CENTRED PLAN:
 - Using maps and paths (facilitated dreams of where I want to be in say 5 years, and brainstorming about ways and means to get there)
 - Taking stock of my evolving abilities and challenges
 - Making plans about: how and where I will live, satisfying things to do with my time (continued learning, real work, exercise, and recreation), how I will understand my options and make choices, and how all parts of my plan will continue to work together smoothly.
 - Keeping records
4. WE ASSESS WAYS AND MEANS TO REALIZE THE PLAN AND SUSTAIN IT INTO THE FUTURE We look at all essential costs and any available resources (including informal or non-monetary ones). We ensure that I have applied for disability pension or other allowances for which I may be eligible.
5. WE WEIGH UP ALL THE OPTIONS AND DECIDE WHICH COMBINATION IS BEST FOR ME.
6. WE FIND A BROKER WE CAN TRUST WHO WILL WORK FOR MY INTERESTS IN NEGOTIATING ANY SUPPORTS I NEED FROM AGENCIES AND THE PUBLIC FUNDS TO PAY FOR THESE supports.
She/he will advocate for resources so I can live safely, and have hope and quality of life.
I need a way to receive and administer funds that is right for me.
Any agencies have to share the values and priorities underlying my person-centred plan
Any support staff must be people I trust and who believe in my plan
Resources to realize my plan must be flexible and portable
7. WE FIND A PLACE TO LIVE
 - OPTIONS
 - SUPPORTS NEEDED
8. WE SET UP A SATISFYING WAY OF LIFE (continued learning, real work, exercise, recreation and friends)
 - OPTIONS
 - SUPPORTS NEEDED
9. WE SET UP WAYS TO UNDERSTAND AND MAKE CHOICES
 - OPTIONS
 - SUPPORTS NEEDED
10. WE SET UP WAYS OF CO-ORDINATING ALL PARTS OF MY PLAN AND WAY OF LIFE, so they work together

smoothly and keep going, even when other things and people may change.

Autistic Mode of Being

To whom am I grateful?
And why do I live?
For what is the floor below?
The trees -- they exist,
And some do persist,
But why do they even show?

Just what is a right?
And what is a wrong?
And when was the year 410?
These questions exist,
And others persist,
Repeating again and again...

They say I'm alive--
My parents who strive
To teach me their way how to cope;
But lost as I am,
And far, far away,
I just can't get grasp on the rope!

O please don't despair:
The effort is there,
And I see the wave of the hand;
But the harder I try,
The sooner I'll die
By sinking way down in the sand.

The screaming won't do;
Anything is a clue
Of how one must feel at this time!
I'm living a dream
As I follow a stream
Without any reason or rhyme.

The stream, first, is straight,
And then the bend's great
Through villages, forests, and fields,
But where e'er it goes,
The land near it knows
That this land is lessor, and yields.

The stream is autism,
The land is the system
By which people interact.
To me--an "autie",
The flowing is free,
And this is no fiction: it's fact!
- Brian Henson

On Thursday, November 5, 1998, I (and approximately 2000 others) eagerly awaited a keynote address from Temple Grandin. It was worth the wait. Temple provided a humorous personal account of being an adult with autism. She spoke of how she "thinks in pictures", and used slides to complement her speech and to provide a visual representation of her thoughts. She told us that she does experience emotions, but that they are simpler than those of the typical person. She attested to the importance of assisting individuals with autism in developing their talents and in participating in personally meaningful activities. It was evident from her speech that she is an extremely confident and accomplished career woman.

Carol Gray presented another incredible session. She discussed the use of "Social Stories" to assist individuals with autism with their activities of daily living. She spoke of how typical people enjoy being alone by choice, but not being alone by circumstance. She emphasized that individuals with autism are often alone by circumstance, and that it is up to us to assist them in understanding and interacting with the world around them. She underlined the point that both an individual with autism and a typical person have equally valid but different perspectives and that we should respect both.

On Friday, November 6, there was a session titled "The Daddy Difference" in which three fathers of children with autism discussed their varied experiences with the disorder. This session was of great interest to me because I am currently researching this very topic for my Masters thesis. All three fathers presented different, but equally poignant perspectives. The love and respect they felt towards their children were evident, along with the struggles and frustrations that accompany this disorder. I was delighted to see a session geared towards fathers, because I do believe that in order to help the family it is important to understand the experiences of all family members. This session was heartfelt, honest and, I believe, helpful for those in the audience.

Overall, I thoroughly enjoyed this conference. In the future, I would like to see more emphasis placed on information and strategies to nonverbal people, since they are reported to form at least half of the population with autism. I also found that most of the sessions I attended were geared towards early intervention, rather than acknowledging the need for continued services as the children grow up and then get older. This is a critical area on which to focus, given the shortage of services geared towards these individuals once they have completed high school. I was glad that I decided to attend the 1998 symposium. It was refreshing to learn some new ideas and to hear the valuable perspectives of those very people we intend to serve.

- Margaret Schneider

**Highlights of the International
Symposium on Autism, Toronto,
1998**