

Adult Autism Issues in Waterloo-Wellington (continuing wwasnews)

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

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Two non-profit organizations are concerned with the challenges faced by adults with autism spectrum disorder in our region. WWAS and GSA have decided to produce a joint newsletter, continuing WWASnews which was published by WWAS 27 times since its formation in 1990. WWAS and GSA share concerns for the interests of adults with autism and their families. This joint newsletter shows their intent to co-operate in their goals and to make the best use of limited resources.

This first issue includes a description of the present functions of WWAS and GSA in the context of a brief survey of autism groups in our region and Ontario. Future issues of AAIWW will combine news of GSA and WWAS and bulletin boards of announcements of events and services with stories on themes and aspects of autism spectrum disorder.

Also in this issue: The theme of the lead story and of other items is central to the mystery and challenge of autism spectrum disorder. For reasons which are still unclear, people with autism have pervasive problems of expressive communication and thus of social relationships. Yet they do have something to say, with sometimes quite remarkable insights. But most of our people cannot get over or through their barriers without the direct support of others. Behind every "success story" of a person with autism, we may see the faith, imagination and patience of a parent, sibling, friend, teacher, support worker, therapist--perhaps several working together.

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RECORDING LIFE WITH PENCIL, PAINT AND PAPER

By LUCIE MILNE

An invitation from a local artist and subsequent visit to his art exhibit at the Aurora Library proved to be an interesting and pleasurable experience. Art shows in Ontario localities are frequent; I have attended several. However, this February 1998 show was different because the artist is a special person. Paul Sadgrove has autism; he is mute, cannot read or write, and is profoundly deaf. In his silent inner world art is an avenue for the communication and emotional expression that he is unable to display physically, though on a visit to his home he gave a momentary blush of shyness mixed with pride when I gestured that I liked his work.

In his paintings of animals - a favourite theme - Paul communicates the depth of his emotional understanding in the proud strut of his rooster, in the bored 'what do you want?' expression of a cow, and the royal haughtiness of the swan. Paul's work is created from his imagination and from his photographic memory. His drawings of buildings are elaborate and meticulously detailed - even after he sees a building only once! At one time Paul did not have an awareness of human shape or form or perhaps did not perceive how to draw them; he drew stick drawings of men and women. The sticks now are gone; people in his paintings have dimensions.

I learned that for the Blooming Art Show at the Sir Sam Steele Art Gallery in Orillia two of Paul's paintings were chosen for exhibition and that half of the 65 submissions by artists were rejected! Paul's paintings of orchids are drawn botanically and the flowers demonstrate his sensitivity to colour and beauty.

Paul Sadgrove has spent 34 years of his life at the Huronia Regional Centre in Orillia. He is now 42. It was at Huronia that his talent was encouraged. The occupational and program therapist, who started the art program, claims there was nothing she could teach Paul. He had a gift and natural ability.

In August of 1996 Paul left Huronia to live in his new home in Newmarket, which he homeshares with his sister Kim, her husband Mike and their three teenagers. Paul has a large extended family whose attendance at the opening of the art show reflect the family closeness and supportiveness for their son, brother, and uncle.

At his house Paul studies weekly with an art teacher. His office holds a tidy array of paper and art supplies, as well as his box of carefully cut up pieces of paper and cardboard.

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Recycling is an 'obsessive' task, important to Paul and for the environment. In the community Paul does volunteer work at the Food Bank, and he walks the dogs at the Humane Society. He swims and works out, attends church regularly and would not miss attending the sports games of his nephews and nieces.

Paul is learning to type words, under the guidance of his tutor-companion. He goes twice a week to a Literacy Centre in order to learn to read. It would be a wonderful tool for communication if Paul could learn to read. I wish, for now, that I could sign, for I have questions about the paintings at Paul's art show. If I could I would ask Paul: Why do you put small crucifixes in some of your paintings: I could tell him that the famous Canadian painter William Kurelek did the same thing in many of his paintings. I would ask if the shape in the night sky of one painting was an angel. And the stars, moon and sun in many of his skies - I wonder if they are symbols of something he feels or understands, or are they there because Paul sees them as part of creation and just likes to place them in his scenes. Perhaps Paul would not be able to answer my questions. After all, art, like so much of life, cannot be explained, only experienced, felt, enjoyed and recorded.

Paul sells prints of his works and he has more shows scheduled. His life is very busy, and he records its fullness with pencil, paint and paper.

** Lucie Milne of Newmarket is a published author who volunteers her writing talents to serve people with autism/pdd. She and her husband Bill, both retired Presbyterian ministers, are members of WWAS. In the 1980s, they served at Knox Presbyterian Church in Guelph.*

AAIWW has been produced by Linda Foster of Cambridge and Elizabeth Bloomfield of Guelph. Formatting and layout by Marie Puddister of Guelph. Andrew Bloomfield prepared the newsletters for mailing.

“Being unable to speak doesn't mean I have nothing to say!” A study sponsored by the Joseph Rowntree Foundation in England has found that "silent" children and young adults who cannot speak are being neglected because care workers assume they are unable to communicate. Many young people with severe communication difficulties can express themselves through noises, signs or electronic communication aids. But social workers and care staff routinely overlook such non-verbal abilities.

Dr Jenny Murray's report paints a picture of institutional callousness, indifference and even abuse toward disabled children and young adults who do not speak. Many social workers and care staff assumed that people who could not talk had no right to express choices. "The painful and sometimes downright awful experiences that young disabled people described confirm that the basic right to communicate is being violated in a routine--if sometimes unintended--fashion."

The report recommends that independent advocates, with specialist communication skills, be appointed for each disabled child or young adult in care to establish her/his needs and wishes. (This item is based on a report by Social Affairs correspondent Alexandra Frean, in The Times of London, 1 April 1998).

Review of A healing family

Nobel prize-winning author, Kenzaburo Oe, has written a memoir about life with his severely autistic son, Hikari entitled A healing family: a candid account of life with a handicapped son. In addition to his autism, Hikari was born with a growth on his brain that apparently made him look as if he had two heads. Though this was operated on and Hikari had excellent medical care, he still had constant seizures and poor vision. His rages required constant attention, patience and reassurance.

As a child, Hikari never cried and never seemed to dream, and words seemed ineffectual for him. Only as he grew older did it become apparent that he could express himself through music. Music was an interest that he had since he was very young, and as a toddler he had listened intently to the songs of birds. Encouraged by his parents, Hikari composes music that according to his father expresses "a core of sorrow" and a "wailing soul." The father continues, "In the very act of expressing himself, there is a healing power, a healing to mend the heart...and this is the miracle of art."

This book describes how a family endured great hardships over which they had no control, and got on with their lives. Not only does it tell about Hikari's musical creativity, the book is illustrated by his mother, and the writing itself is a testimonial art form to the life of the handicapped.

The book is translated by Stephen Snyder and published by Kondansha International.

Adult Autism Issues in Waterloo-Wellington... how far have we come?...

Autism was defined just 55 years ago by Leo Kanner--as a distinct, pervasive disorder with lifelong and severely disabling effects for most sufferers. But it was not until 1973 that an organization was formed by parents and professionals in Ontario--the Ontario Society for Autistic Children (OSAC). Until then, many autistic children were institutionalized, while those with milder forms of the disorder who remained with their families may have received help as slow learners, mentally retarded, or learning disabled (to use the terms of the day).

Always
Unique
Totally
Intriguing
Sometimes
Mysterious

Autism Society of Southeastern Wisconsin, hosting 1996 ASA Conference

OSAC was formed through the efforts of the late Corinne Gross of Toronto. Early chapters were established in Toronto itself, and in Ottawa, Hamilton and Waterloo-Wellington in 1973-4. Gerald Bloomfield of Guelph was a founding director of the OSAC Board, serving also as vice-president, president and past-president during his 17 years of service to OSAC. He was instrumental in negotiating a major grant from the Trillium Foundation to strengthen the provincial society from the mid-1980s. Groups were founded in other areas so that in early 1998 there are 24 chapters of what is now called Autism Society Ontario. They are in Brant &

County, Chatham Kent, Dufferin, Durham Region, Grey Bruce, Greater Kingston, Halton, Hamilton-Wentworth, London, Metro Toronto, Niagara Region, Ottawa, Ottawa, Peel, Peterborough, Renfrew County, Sarnia/Lambton, Sault Ste Marie, Simcoe County, Sudbury & District, Thunder Bay, Waterloo, Wellington, Windsor Essex, and York.

The main functions of Autism Society Ontario have been advocacy at the provincial level and support to local chapters to provide member services. Understandably, the main emphasis has been on promoting early diagnosis of the disorder and special education programs for children. The provincial organization has provided information and referral to services, especially in the Greater Toronto area. It supported the founding and growth of **The Geneva Centre**, which dates from the mid-1970s and is funded by the Ministry of Community and Social Services as the provincial resource agency for autism and for consultation services.

Autism Society Ontario is dedicated to working to improve the quality of life for persons with autism and pervasive developmental disorders and their families, and to ensure that they live with dignity within their own communities.

Efforts of the provincial organization and its local chapters have been concentrated on advocacy for and services to young children and their families. Local chapters are represented on the Special Education Advisory

Committees (SEACs) of local Boards of Education (public and separate). They organize summer programs to continue the structured programs of the school year. Parents are likely to be most concerned and to have more energy when their children are younger. Later, they may be too tired or feel less incentive if their children and teenagers are being relatively well served in schools and respite programs. Some children with autism may do so well in school and supplementary programs that they may be able to cope in regular school classes by their teens.

But for most adolescents and adults with autism, the challenges get harder. A significant proportion develop seizures or other health problems at puberty. Their greater size and strength, combined with frustrations when they cannot make their needs and wishes understood, may also pose problems of managing moods and behaviour.

Perceptions of the special needs of teenagers and adults with autism led to the incorporation of distinct service organizations that are legally able to fund and deliver services that were not otherwise available.

Kerry's Place was incorporated by the mid-1970s, with support from OSAC, to establish first a residential program for autistic teenagers funded as a Children's Mental Health Centre.

Kerry's Place Autism Services now operates half a dozen residential centres for adults with autism in Toronto, York and Peel Regions, Dufferin and Hastings Counties, as well as some community programs. **Ottawa Valley Homes** was also

incorporated in the 1970s, and **St Francis Advocates** in Sarnia-Lambton by the late 1980s, both with OSAC support. These various organizations have focused their efforts on establishing group residential programs with services designed for young adults with autism, and some have also developed community outreach programs for other children and adults.

Non-profit organizations have been incorporated to advocate and develop more individualized services for adults in Toronto (**HAADD or Homes for Adults with Autism and Developmental Disabilities**) and Windsor as well as in Waterloo and Wellington.

In our region, the **Waterloo-Wellington Chapter of OSAC** was formed in 1973-4, its executive members including Stan Shalay of Kitchener and Elizabeth Bloomfield of Guelph. The joint chapter, led by Stan Shalay as president and with substantial effort by Joanne Seip (teacher of the autism class for the Waterloo County Board of Education), organized pioneer summer programs for both counties, and engaged in advocacy and fund-raising. The Waterloo chapter has continued to organize group summer programs to the present. In the summer of 1976, the OSAC Board decided that local chapters should correspond with the territories of county boards of education.

So since the mid-1970s there have been Waterloo and Wellington chapters of the provincial autism organization. The Bloomfield and Ensing families were very active in the Wellington chapter for its first ten years. As well as its summer programs, as run by most local chapters, Wellington did some distinctive things in the mid-1980s. It published and distributed Dr Andor

Tari's Bibliography of Autism 1943-1983. It also negotiated and organized an exciting GASROD project (**Guelph Autistic Services: Research, Outreach and Development**) through 1986, and advocated successfully with the Minister of Community and Social Services, John Sweeney, to fund an autism case management service for children in Guelph-Wellington. This is now administered by Family Counselling and Support Services in Guelph.

Members of the Waterloo and Wellington chapters were very aware of the unserved needs of teenagers and adults with autism and began to research and plan local services for them. As unincorporated chapters could not legally provide funded services, leading members of each chapter took steps to incorporate non-profit charitable organizations that would have such powers. **Guelph Services for the Autistic** was incorporated in August 1980; its directors and officers have included Henk and Inge Ensing and Gerald and Elizabeth Bloomfield. GSA did not operate financially but used personal funds and volunteer efforts to sponsor a series of workshops, surveys, service proposals and special meetings through the 1980s. GSA's efforts to draw attention to the unserved

needs of adults with autism led to a survey of their needs across the province. With two insightful essays by Dr Susan Bryson, this survey was reported in Our Most Vulnerable Citizens: Report of the Adult Task Force of Autism Society Ontario (1991).

Woodgate Residence for Autistic Adults was incorporated in the Region of Waterloo in the early 1980s, with Stan Shalay as long-serving president. Woodgate members devoted their energies to a

detailed proposal for a farm community for autistic adults and to fund-raising for this purpose.

Various co-operative efforts by GSA and Woodgate to get Ministry support for proposed adult autism services in our region met with some resistance from the Area Office, though it was clear that local needs were not being met by existing community agencies. The Area Manager declared that she would only fund autism services for adults in Waterloo-Wellington, if the two groups got together in one charitable organization. So we did that too, first through an Action Group from the late 1980s and then incorporating **Waterloo-Wellington Autism Services** by renaming and revising the bylaws of Woodgate Residence, effective in August 1991.

During the 1990s, the WWAS president has been Roger Hollingsworth and its vice-president Bernard Hermsen. Its secretary to 1994 was Elizabeth Bloomfield, followed by Jane Forgay to 1997. Its treasurers have been Stan Shalay, Stephen Jones and Bill Barnes. Other WWAS directors have been Susan Honeyman and Will Boeschstein who continue to serve, as well as

Mavis Badham, Henk Ensing, Paul Martin and Garrett Wickens.

WWAS has the following goals, for adults with autism/pdd in Waterloo-Wellington:

- * To ensure that they have a range of purposeful work experience and safe and caring places of residence in which various of skills can be learned
- * To support families by collaborative planning for services that meet individual needs
- * To co-operate with professionals and agencies to

increase social, communicative, recreational, vocational and other skills

* To share with our community its successes in meeting the needs of "our most vulnerable citizens."

WWAS received fiscal grants from the Ministry of Community and Social Services, of an average \$50,000 for four years, which enabled it to start a small office with paid staff. James Perry, with Karen Hillis Bowen, surveyed the needs of adults with autism/pdd, started a library and information service, studied model programs anywhere for their possible relevance to Ontario, and represented autism on regional councils and committees concerned with the developmentally handicapped population. WWAS had some early success in being approved for housing grants which might have enabled it to start a residential program for nine adults if matching grants had been forthcoming from MCSS.

In 1993, WWAS planned and committed itself to a pilot project called Supported Employment Enhancement Program (SEEP). During the next two years, vocational instructors

Elizabeth Debergh and Katherine Robinson were directed by James Perry and guided by various committees of the WWAS Board in their efforts to develop work skills and find paid or voluntary work for some 14 young adults with autism. WWAS received donations from organizations and individuals for its SEEP project, and a significant grant from the Kitchener-Waterloo Community Foundation. But SEEP ended in late 1995, mainly because of the uncertainties involved in fiscal funding from the Ministry.

From early 1996, WWAS has offered grants of up to \$2,500

each to individual adults with autism/pdd to help make a difference in their lives. The grants are known as Victoria Bloomfield Bursaries in memory of the WWAS volunteer who helped to plan this project but was killed in a traffic accident in February 1996. Donations to WWAS in her memory form the nucleus of the bursary fund. Watch our next issue for stories of how these bursaries have made a difference.

The other partner in this newsletter is **Guelph Services for the Autistic** which was first incorporated in 1980. GSA has redefined its focus in 1997-98 to become a housing trust supporting adults with autism to live in homes of their own and to live more fulfilling, happier and more productive lives. GSA will look after the financial administration and maintenance of homes for people who need such support but want to have a sense of pride and security in living in their own homes.

GSA supports its adults, who are active members of the corporation, to make choices about their lives and with whom they will

share their time and their homes. GSA's new focus is associated with person-centred planning and individualized funding that makes the best possible use of natural and community resources. One feature is the provision of residential support by homesharers who are carefully selected to give emotional and practical care and companionship in return for rent-free or below-market-rate accommodation. Homesharers are selected, trained and encouraged by a support cluster made up of people who care about the homeowner.

Some of the advantages of homesharing:
* It provides disabled people with the pride and security of owning

their own home

* It gives a greater chance of making real connections with homesharers, neighbours and the surrounding community
* Costs are lower than arrangements involving around-the-clock care.

GSA's roles include:

* Purchasing properties and negotiating mortgage financing
* Making legal agreements giving each disabled person lifelong occupancy of her/his house
* Ensuring that the houses are properly maintained and conform to all provincial and municipal regulations
* Providing advice and support to the support clusters around each homeowner.

During the first half of 1998, GSA has taken possession of its first house. While the first few houses will need to be largely financed by the families of the homeowners, once GSA owns several houses, it should be able to use its equity to help those without such financial resources.

CHARTER FOR PERSONS WITH AUTISM

proposed at the 4th Autism-Europe Congress, Den Haag, May 1992

People with autism should share the same rights enjoyed by all the population where appropriate and in the best interests of the person with autism. The following rights should be enhanced, protected and enforced by legislation, declared the Congress....

THE RIGHTS OF PEOPLE WITH AUTISM

1. to live independent and full lives to the limit of their potential;
2. to an accessible, unbiased and accurate clinical diagnosis and assessment;
3. to accessible and appropriate education;
4. to be involved (with their representatives) in all decisions affecting their future, so that their wishes are ascertained and respected;
5. to accessible and suitable housing;
6. to equipment, assistance and support services to live a fully productive life with dignity and independence;
7. to an income or wage sufficient to provide adequate food, clothing, accommodation and the other necessities of life;
8. to participate, as far as possible, in the development and management of services provided for their wellbeing;
9. to appropriate counselling and care for their physical, mental and spiritual health; this includes the provision of appropriate treatment and medication administered in the best interests of the individual with all protective measures taken;
10. to meaningful employment and vocational training without discrimination or stereotype and with regard to the ability and choice of the individual;
11. to accessible transport and freedom of movement;
12. to participate in and benefit from culture, entertainment and sport;
13. equal access to and use of all facilities, services and activities in the community;
14. to sexual or other relationships, including marriage, without exploitation or coercion;
15. (with their representatives) to legal representation and assistance and to the full protection of all legal rights;
16. to freedom from fear or threat of unwanted incarceration in psychiatric hospitals or any other restrictive institutions;
17. to freedom from abusive physical treatment or neglect;
18. to freedom from pharmacological abuse or misuse;
19. (with their representatives) access to all information contained in their personal, medical, psychological, psychiatric and educational records.

OPEN LETTER TO WWAS FAMILIES

Dear Families,

Hello, my name is Susan T. Solursh, a Masters student in Psychology. For my MASc research, I am studying some of the factors involved in adult outcome, for individuals with autism/PDD. I would be honoured to have your family participate in this research. I believe this to be an important area of research for assisting individuals with autism/PDD and their parent(s).

The parent interview, involving some questions about childhood and current functioning, will take no more than 1/2 hour. The adult interview will take no more than 1 1/2 hours, and will also involve questions about childhood and current functioning. Individuals with autism/PDD using almost any communication method (e.g. sign language, communication boards, etc.) will be accommodated. Unfortunately, however, I cannot have participants who use facilitated communication, due to a requirement that all answers to questions be given directly by the respondent.

When this research is completed, I will have an information session to describe the findings, answer any questions, receive any feedback you have regarding this study, and discuss future research you think needs adding.

Thank you very much for taking the time to read this information. If you and your family would be interested in becoming part of this study, please contact me immediately (as I need to conduct the interviews during July and August):

Susan T. Solursh

University of Waterloo, Dept. of Psychology

Note: Families wishing to withdraw from this study may do so at any time.

NOTE: The Bulletin Board printed with the original newsletter has not been reproduced in this Internet version.