

ADULT AUTISM ISSUES IN WATERLOO-WELLINGTON

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

AAIWW Newsletter No. 30, February 2005

Guelph Spring Conference

CREATIVE SUPPORTS FOR VULNERABLE ADULTS

"Creative supports demand that we be personal. Being personal includes taking time to understand people personally and deeply. Being personal means being "person-centred," and treating all involved with respect. Person-centred also embraces human rights. Personalized supports work best when they are accompanied by individualized funding which goes either directly or indirectly to the person to purchase or create supports that fit his or her needs and goals, much like a tailored suit" –John Lord

Most of this newsletter consists of information about the conference being organized by Guelph Services for the Autistic on Friday, April 29. Please note that pre-registration before March 11 qualifies for lower fees.

The event is distinctive in several respects, including:

- Its relevance to folks who live with various kinds of disabilities (in physical and mental health, cognitive and sensory abilities, movement and communication differences)
- Its focus on implementing a wide range of creative strategies
- Being part of a continuing process of collaboration.

We offer a rich program including:

1. Opening keynote address and closing call to action by Dr John Lord who writes:
2. Four concurrent workshops led by notable advocates in the areas of:
 - a) Person-centred and person-directed planning and support circles
 - b) "Making housing into my home"
 - c) Building meaningful supports for work and recreation experiences
 - d) How communities and families can make creative options work in
3. Poster sessions and brief presentations illustrating a range of living supports from which persons and families may choose to suit their situations and needs--in the areas of the four workshop topics
4. Informal connections and discussions
5. (If we obtain funding) an electronic record of the conference event to encourage a lasting process of consultation and implementation that will also reach those who cannot attend

At this time, we are specially interested in reaching people, families and groups that have developed good support strategies and pioneering initiatives to "show and tell" what they have done.

Sympathy

Two families who have been active for many years in the autism cause have lost loved ones recently. On behalf of all who work with and for people with autism in our Waterloo-Wellington region, we express our sympathy to the Ensing and Hollingsworth families.

***Inge Ensing** died on January 18. Inge and Henk Ensing were founding members and directors of the Autism Society (Wellington County Chapter) nearly 30 years ago and of Guelph Services for the Autistic 25 years ago. Inge served as treasurer for much of the Chapter's first 10 years and also as treasurer of Guelph Services for the Autistic when it first organized itself as a housing trust. Henk was also a director of WWAS in the early 1990s and has been a director of GSA since 1997.*

***Florence Hollingsworth** died on February 13. Her son Roger has been a director and president of Waterloo-Wellington Autism Services since its founding in 1991. The family has asked that gifts in memory of Florence Hollingsworth be made to WWAS, as this cause was dear to her heart*

AAIWW BULLETIN BOARD

WATERLOO WELLINGTON AUTISM SERVICES,

incorporated in 1991, is dedicated to supporting adults with autism to have good lives in their communities.

WWAS funds GSA's ASPIRE project and the new Autism Collection at the Kitchener Public Library, and continues the bursary program,

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

Please support these worthwhile projects. Cheques of \$25 or more qualify for tax-creditable receipts. Please make cheque payable to WWAS and send with your name, full address and phone number, to WWAS, C/o Dr Hollingsworth, 125 Union St E, Waterloo, N2J 4E5

GUELPH SERVICES FOR THE AUTISTIC,

incorporated in 1980, is run by volunteers, and dedicated to adults with autism and their families. What does GSA do?

-Acts as a housing trust to enable adults to live with dignity in their own homes with companions they choose

-Supports person-centred planning, self-determination and individualized funding

-Offers ASPIRE and adult needs surveys

-Recruits volunteers as friends for adults with autism

-Provides advice and support to families and friends

http://www.ont-autism.uoguelph.ca/gsa/info_new.shtml

http://www.ont-autism.uoguelph.ca/gsa/faq_new.shtml

Contact GSA about any of the following, to donate to our ASPIRE efforts or the Creative Supports conference, or to send news and queries to AAIWW: Mail: Dr Bloomfield, 16 Caribou Crescent, GUELPH, Ontario, N1E 1C9. Phone (519) 823-9232. E-mail gbloomfi@uoguelph.ca

ASPIRE: AUTISM SUPPORT PROJECT: INFORMATION, RESOURCES, EMPOWERMENT

An initiative to help persons and families and persons plan for and realize good lives and secure futures. Organized by GSA; supported by funds from WWAS.

ADULT AUTISM NEEDS SURVEY is associated with ASPIRE, but also offered more generally to help adults and families measure quality of life. GSA and OAARSN treat data confidentially to generalize current situations and needs of adults with ASD. Long-form and short-form surveys may be completed on paper or online.

ONTARIO ADULT AUTISM RESEARCH AND SUPPORT NETWORK (OAARSN) offers up-to-date information and communication tools, with opportunities for mutual support, encouragement and information sharing.

Click on <http://www.ont-autism.uoguelph.ca> to reach OAARSN's main page, then use the buttons to reach the site's features.

You may ask to be on the OAARSN List to receive weekly bulletins of autism news and announcements of events.

MARCH MEETINGS

Wednesday, March 30, 7-9pm

"My Sad is all Gone":

Various therapeutic techniques for helping people with autism

Meet Thelma Wheatley, author, teacher & parent in the Kitchener Public Library's Schneider Room, at 85 Queen Street North, Kitchener
Sponsored in association with Waterloo Wellington Autism Services & Autism Society Ontario.

Thelma Wheatley is described as the only Canadian parent of an autistic adult who has published a book about him. "My Sad is All Gone" was published in October 2004 and now you can meet the author and her son Julian.

Thelma will speak about the specific drug protocol that helped her son control his violence and aggression, also about other helpful therapy techniques including music and art therapy.

HOW SERVICE DOGS CAN HELP ADULTS AND CHILDREN WITH AUTISM SPECTRUM DISORDERS

Andrew, a man with autism whose life has been enhanced for the past 5 years by his service dog Amy, will show the benefits at a meeting of the Autism Society Ontario: Waterloo Chapter on Thursday, March 10, at KidsAbility.

A video will be shown about National Service Dogs, the distinctive agency that provided Amy for Andrew.

Spring Conference on CREATIVE SUPPORTS FOR VULNERABLE ADULTS

Friday, April 29, 2005 in Guelph (in Ignatius Hall/Orchard Park)

What does this conference offer?

A rich program (see next page) including:

- Opening keynote address and closing call to action by John Lord (see profile and ideas on page 4)*
 - Four concurrent workshops led by Judith Snow, Barbara Leavitt, Peggy Hutchison, Marlyn Shervill and Michelle Friesen (see profiles and key questions on pages 5-6)*
 - Poster sessions and brief presentations illustrating a range of living supports from which persons and families may choose to suit their situations and needs*
 - Informal connections and discussions*
 - A record of the conference event to encourage a lasting process of consultation and implementation that will also reach those who cannot attend*
- See registration form on page 3***

Who is organizing the event?

Guelph Services for the Autistic and the Ontario Adult Autism Research & Support Network are taking the lead. Various organizations of and for persons who are vulnerable because of disability have expressed support, including:

- Autism Society Ontario*
- Canadian Mental Health Association: Waterloo Regional Branch and Wellington-Dufferin Branch*
- Community Living Ontario*
- Families for a Secure Future*
- Family Alliance Ontario*
- Individualized Funding Coalition of Ontario*
- Kerry's Place Autism Services*
- Planned Lifetime Networks*
- Waterloo-Wellington Autism Services*

Creative Strategies and Success Stories to be illustrated include:

- "deep listening" to vulnerable persons who do not speak
- helping self-advocates to direct their own supports
- creating and maintaining circles of support to supplement and succeed living parents
- circles of support for vulnerable persons who have no family creative options to have a home of one's own
- independence technologies
- recruiting volunteers to be informal friends
- ways to screen, train and appreciate excellent volunteers
- bridging gaps between adults with special needs and their neighbourhoods and communities
- supporting adults who want to continue learning, formally and informally
- enabling people to develop micro-enterprises
- artistic expression
- contributing to our communities
- lifesharing communities in households or larger units
- planning good lives now, to be effective through future transitions when parents can no longer support vulnerable adults
- caring for the caregivers
- how brokerage works
- what aroha/microboards can do

Where is the conference?

Ignatius Hall
Ignatius Jesuit Centre of Guelph
5420 Hwy 6 North
Guelph, Ontario, N1H 6J2
See maps at <http://www.loyolahouse.ca/map.htm>

Guelph Spring Conference on CREATIVE SUPPORTS FOR VULNERABLE ADULTS

Friday, April 29, 2005 in Guelph (in Ignatius Hall/Orchard Park)

You are invited to a gathering of Ontario people who want to be creative in supporting good lives with and for adults who are vulnerable because of their disabilities. Guelph Services for the Autistic and the Ontario Adult Autism Research & Support Network are taking the lead in this event.

- *Our experience with people who live with Autism Spectrum Disorders makes us aware of very complex challenges. We think these are shared in varying combinations by adults with other exceptionalities. We particularly want to encourage self-advocates, families and friends to take part.*
- *Our conference is timely, given the Ontario Government's stated intention to transform its funding and services for persons with a developmental disability.*
- *Our concern is practical—with how to plan and implement the elements of a good life for each person, by learning from each other's effective strategies and success stories.*
- *Our approach is comprehensive and holistic. We hope to put our minds and imaginations around various strategies, to show the connections among them, and to help persons and families think about and choose combinations that may work for them.*
- *We plan a process of collaboration in discussion and sharing resources--before and after the conference, using the OAARSN website and other media.*

Conference Outline:

8:30-9:00 Registration; light refreshments
9:00-10:15 KEYNOTE ADDRESS by Dr John Lord: *"Values, principles and processes that work--the why of creative supports: individualized supports building community and inclusion."*

10:15-10:45: Break with refreshments

10:45-12:00: FOUR CONCURRENT WORKSHOPS about creative support areas:
I: Building supports with individuals, led by Judith Snow.

"Nothing about me without me", "deep listening" and "why support networks are good for our health and communities."

II: Creating meaningful living spaces, led by Barbara Leavitt

"Making housing into my home"

III. Building meaningful supports for work and recreation experiences, led by Dr Peggy Hutchison

IV: How communities and families can make creative options work in Ontario, by Marlyn Shervill and Michelle Friesen

12:00 to 1:15 Lunch

1:15-2:30: Short presentations about a few creative strategies, chaired by Judith Snow.

2:30-3:00: Break with refreshments

3:00-4:00: Reconvene for ACTION STEPS with John Lord on *"What it means to be creative and innovative"*, so people go home charged up with practical skills for being creative.

Who should come?

Persons and families who live with autism or other challenging conditions (including physical disabilities, mental health, cognitive and sensory impairments), agency representatives, community friends and advocates who care.

Why?

- to be inspired and gain confidence to implement person-centred and self-directed plans
- to share a full range of success stories and creative individualized strategies that work through displays and poster presentations
- to drive a concerted and collaborative process involving all parties (persons, families, communities, agencies and Governments) concerned to support all who are vulnerable because of disability

If Funding Allows

We intend to reach people who usually miss such events by

1. assisting persons and families who could not otherwise afford to take part
2. making electronic and print resources that can be shared and studied by people who live too far away to attend in person.

Please see registration information on next page. For more information: phone (519) 823-9232 or <http://www.ont-autism.uoguelph.ca/CSC-info.pdf>

***Guelph Spring Conference on CREATIVE SUPPORTS FOR VULNERABLE ADULTS
Friday, April 29, 2005 in Guelph (in Ignatius Hall/Orchard Park)***

Registration Form

Registration:

We can accept only 120 participants, but will hold names on a waiting list in case of cancellations.

Fee includes lunch, snacks and information.

Please check the appropriate box:

- SELF-ADVOCATE: \$35
- PARENT/FRIEND: \$50
- PROFESSIONAL/AGENCY: \$90

I cannot attend but really want to keep informed and know of any resources coming out of this conference.

Please copy and complete the form and send with your cheque payable to Guelph Services for the Autistic to:

CREATIVE SUPPORTS CONFERENCE
GSA

16 Caribou Crescent
Guelph, Ontario, N1E 1C9

Please let us know of any special needs (such as accessibility or diet).

We will confirm your registration and send directions etc by email (preferably) or otherwise. Your registration package will be waiting for you on arrival.

We regret we cannot refund fees for cancellations received after April 1.

NAME _____

ORGANIZATION (if applicable) _____

ADDRESS _____

CITY/POSTAL CODE _____

PHONES _____

EMAIL _____

Please send cheque in the correct amount, payable to GUELPH SERVICES FOR THE AUTISTIC, to: CREATIVE SUPPORTS CONFERENCE, 16 Caribou Crescent, Guelph, Ontario, N1E 1C9

Please rank your preferences for the four concurrent workshops, by writing 1 by the title of the workshop you most wish to attend, 2 for your second choice, and so on:

..... I: BUILDING SUPPORTS WITH INDIVIDUALS

..... II: CREATING "HOMES OF OUR OWN"

..... III: BUILDING SUPPORTS FOR MEANINGFUL WORK AND RECREATION

..... IV: HOW TO MAKE CREATIVE OPTIONS WORK IN ONTARIO

You may wish to add more about your reasons for wanting to attend this conference

We regret we cannot refund fees for cancellations received after April 1.

PROFILES OF KEYNOTE SPEAKER AND WORKSHOP LEADERS

John Lord is a researcher, consultant, and family member. He was a co-founder, and first director, of the Centre for Research and Education in Human Services in Kitchener, where he and his colleagues pioneered participatory action research in human services. He has published widely in areas related to deinstitutionalization, personal supports, individualized funding, and innovation. In 2001, he was the chair and author of the Ontario Round Table Report on Individualized Funding. He is currently writing a book on innovative approaches to community supports with vulnerable citizens. He is part of his daughter's support circle and has been training facilitators for circle development and person-centred planning. John has advised in planning the event on 29 April 2005. These are some of his ideas.

Why We Need Alternative and Creative Strategies and Resources

"The helping professions and community services for vulnerable citizens have expanded dramatically since the 1960s. This trend has had both positive and negative outcomes. Today, there are clearly more programs and supports available to vulnerable citizens. Yet, many of these programs and services treat to people as "clients" and demand compliance from the people they serve. It is not unusual for people who require support to have to "fit into" programs that have narrow criteria and procedures. These traditional approaches do not

address the isolation and exclusion experienced by many citizens who are vulnerable."

"Many people are concerned about vulnerability, social isolation, and lack of inclusion. Young families raising a child with a disability often feel alone. Families who have a friend or family member with a mental health problem may be frightened when reading in the newspaper about shortages in hospital staff or community follow-up programs. Neighbourhoods with aging members who are isolated may not know where to turn. People with disabilities may have some services in their community, but not feel they come close to being suitable or appealing. The need for innovative options, projects, and resources could not be more important than right now. Fundamental to the innovations we have studied is the belief that people who require support should have power and control over those supports as part of their right of citizenship."

Leadership in Innovation and Change

"Leadership is a key to innovation and change, and there is great wisdom coming from leaders who develop and implement creative supports. And, I am not just talking about leadership being one person. Inspirational leadership comes from individuals, families, and their allies who work together with others to create innovative community initiatives. Leaders express the values and principles in the way they live and in their energy and commitment for change. We also have learned that sustaining l

leadership is as important as the leadership that initiates innovation."

Creative Supports for Persons in Communities

"Creative supports demand that we be personal. Being personal includes taking time to understand people personally and deeply. Being personal means being "person-centred," and treating all involved with respect. Person-centred also embraces human rights. Personalized supports work best when they are accompanied by individualized funding which goes either directly or indirectly to the person to purchase or create supports that fit his or her needs and goals, much like a tailored suit.

"Creative supports really reflect a paradigm shift in the way we view "services" and "community" - community is no longer seen as alien and services are no longer seen as "the answer." This paradigm shift in some ways is subtle and in other ways quite dramatic. Leaders, whether family members, self-advocates, or paid facilitators are coming to understand that this shift is about moving from service development to capacity building. Capacity building means community is a "first resort" and friends, family, neighbours, and community associations become vital in the quest for a good life. Capacity building also means that self-advocates and families are supported to express their voice and build on their strengths."

See following profiles of workshop leaders

Judith Snow – An Introduction



Themes

What it takes to truly step up to the plate
Living life powerfully
Leadership training
Results

TRANSFORMATIONAL LEADER

Speaker, Trainer, Coach

Judith Snow has been called the “Julia Roberts of the disability community”. You cannot be in her presence without experiencing a shift and seeing new possibility for yourself and others. Powerful, energetic and joyful, her passion is matched only by her commitment. Her entire life is dedicated to making a difference for people all over the world.

Judith is a powerhouse in her own right. “You can give me an impossible situation (with kids, teenagers, or adults!) and together we get results. I keep moving forward because I believe in what’s possible, and I believe in contribution and I live my life for that cause. I know I’m blessed to have amazing people who believe in me too. It’s all about people.”

“Put me in front of people and I transform lives. At a local university I had 60 young women for 2 hrs every week. We restructured the curriculum and had them work together. Some of these women created support circles for kids from their former high schools who had been excluded. These kids got jobs and friends. Another group built a group for a woman with anxiety disorder and supported her in presenting in front of the class without medication. Another group developed a board game for teaching inclusion. All 60 students got A’s and every one of them had earned them legitimately.”

For almost 30 years, Judith has pioneered education and training programs that have resulted in changing the lives of thousands of people labeled ‘disabled’. Her vision is to create a world in which

everyone is included and contributing to their communities.

Judith Snow is a trailblazer, having led training and education programs for over 30 years throughout the US, Europe, the Caribbean and Canada. Her models have resulted in thousands of people with disabilities getting jobs, homes, new relationships and support systems that lead to full community participating and respect.

Working with her mother, Rita, in the 70’s, Judith was instrumental in the development of a model called Support Service Living Units. This service format has been widely adopted throughout North America. A little later she created Canada’s first post-secondary learning support program, enabling students with physical and intellectual disabilities to attend University and to excel academically and socially.

In 1980 she became Canada’s first person to receive individualized funding from the Government in Ontario. Shortly thereafter, she chaired the first ever attendant care action coalition, which caused the government to provide funding for 600+ people in Ontario. Also during those years, she developed a model that puts government funding directly into the hands of the people who need the support. Since then some form of liberating individualized assistance has been adopted by most provinces for people with all sorts of disabilities.

In the 90’s Judith Snow focused primarily on training and education of families, individuals and human service providers. Judith also wrote the book “What’s Really Worth Doing and How To Do It”, co-authored “From Behind the Piano” with Jack Pearpoint, and has written many articles in various publications worldwide.

In the past seven years Judith Snow has concentrated on the contributions of people who don’t speak. She has created several day-long workshops for ‘quiet’ people, along with their friends and family, to come together and explore what it takes to make a difference in their lives and make evident what they are contributing.

“If a kid’s really included violence and drug use decline at their school. We need to start telling everywhere the real life stories of students with challenging disabilities who are positively, even dramatically, changing schools in North America and Europe.” Judith Snow was a consultant and trainer with the National Home of your Own Alliance for 8 years. This project operated in 23 states in the US, resulting in hundreds of people living in their own homes with their own support systems.

Judith also starred in a documentary for VISION TV called Friendship. This video featured the unlikely friendship and results-creating partnership between Marsha Forest and Jack Pearpoint, demonstrating that commitment, passion and action can be nurtured between people with very diverse backgrounds. Their friendship has led to transforming the quality of the lives of many, many people labeled disabled.

Judith Snow is a faculty member with the Asset Based Community Development Institute at Northwestern in Evanston, Illinois. She is also the Director of Laser Eagles, an organization sponsoring the opportunity for people with very limiting disabilities to create art. Using a revolutionary technology invented by Tim Lefens and brought to Canada by Judith and her friends, people who don’t speak are showing what they’re feeling and thinking, and painting spectacular pieces of their own design.

Judith Snow shows people that there really is no disability. “People are always contributing something. The work is to see the value and opportunity in what they’re contributing and build that through relationships into community opportunities.”

Contact:

Judith A. Snow, MA
108 Hallam St. Toronto, ON, Canada, M6H 1W8
phone 416-538-9344
fax: 416-516-1691
e-mail: judiths@ica.net

Barbara Leavitt currently works with individuals, families and staff involved with Community Living St. Marys and Area. A key part of her role is as a resource to the delivery of individualized planning and supports, including helping people think about creating a home of their own. Barbara returned to southwestern Ontario in 1997 after spending three years involved in the development, implementation and coordination of individualized funding and a brokerage system of support for the Choices Project in Thunder Bay, Ontario.

“Making housing my home”

Many people don't believe they have options and control about how they can live and are waiting to be told what's available. This session will share information and stories about a variety of ways people have chosen to make a home including: having a supportive roommate; supportive neighbours; owning your own home; and working with investors to build a home. While this session will not be about how to secure funding for individual support needs, it will open minds to what is possible in terms of how people can live. Having a vision is the first step.

Peggy Hutchison is a Professor in Recreation and Leisure Studies at Brock University in St. Catharines. She has been actively involved in research, education, and advocacy related to inclusion for the past 25 years both nationally and internationally. Her areas of interest include inclusion, empowerment, IL movement, relationships, and community building. Her publications include *Leisure, Integration, and Community* (Hutchison & McGill, 1998) and *A Textured Life: Empowerment and People with Developmental Disabilities* (Pedlar et al., 1999). She is a long time editor of the *Journal of Leisurability*, advisor for *Kitchener-Waterloo People First*, and advocate with her daughter who has a disability.

Building meaningful supports for work and recreation experiences, the topic of the workshop Peggy is leading, will address several questions: How can inclusive recreation and employment be possible for people who have been marginalized? What is the difference between integration and inclusion within the employment and recreation context? And what is the role of key stakeholders in ensuring this happens, from the person, to family and friends, to other community members?

Marlyn Shervill is a broker/facilitator working with people, their families and friends through Windsor Essex Brokerage for Personal Supports. Through her varied roles she assists people to dream and to figure out how they want to live their life. Marlyn believes everyone can direct their lives and determine what they want to do communicating in their own way. In her role as a broker/facilitator, she may provide independent planning support, mediate, negotiate, facilitate the development of support networks, help write contracts and provide good and timely information. Any one or all of these roles could come into play.

Marlyn along with a steering committee started a Brokerage Project in 1997, which was based on an individualized funding model and independent planning. Today, brokerage supports are available through Windsor Essex Brokerage for Personal Supports as an ongoing service available to people and their families who choose it.

Michelle Friesen and her family have worked together to uniquely support their family member for 24 years. Lisa is a daughter, sister, neighbour, friend and member of her community. Michelle's beliefs in citizenship and inclusion lead her to champion for “out of the box” supports for her daughter. Her experiences over the years and willingness to help others have positioned her as a leader in the family movement as the in Windsor and Essex County. She has sat on numerous committees and community planning tables. She first started talking about creative supports, individualized funding and independent planning in the late 80's.

Michelle facilitated the restructuring of supports and system re-design for adults who have a developmental disability in Windsor and Essex County along with people, family members and service providing partners starting in the late 90's. Currently, Michelle is the lead coordinator with Windsor Essex Family Network.

How communities and families can make creative options work in Ontario

Marlyn and Michelle will describe what features enhanced the development of creative options for people in Windsor and Essex County. They will also share what's possible when people and their support networks work with a local autonomous family group and independent brokerage. Some concrete stories will be shared for you.