

ADULT AUTISM ISSUES IN WATERLOO-WELLINGTON

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

AAIWW Newsletter No. 31, June 2005

Wednesday, July 6, 2005, 7-10pm, in Guelph

An introduction to Gentle Teaching: Understanding the 'language of pain'.

*Some children and adults with significant communication challenges, express themselves through actions that are at times very difficult to understand and to support safely. These actions could include occasional withdrawal, and/or violent acts towards self and others. These actions must be understood not as 'challenging behaviors' that need to be controlled and/or eliminated, but rather as an expression of pain. As such, we need to learn to **listen** and to **respond** with loving kindness and compassion. Felicia Jervis will explore the possible roots of the 'language of pain', and will offer concrete and practical responses that are safe, empowering and life giving for everyone involved. (See more, page 2).*

Workshop is free, but space is limited. If you are interested, please request an invitation from Nancy <nancy.cherry@sympatico.ca> or (519) 884-3309.

As our ASPIRE Advocate in 2005, Nancy Cherry has been most helpful with the conference, representing our group in the current process of "transforming" services in Ontario, and researching resources.

Announcing ACES

GSA and WWAS are working towards our shared goals of a good life for our adult sons and daughters. During the past year, we have co-operated in encouraging a move by families of adults who live with autism towards an intentional community in our region. Last November, we held two workshop events, both facilitated professionally, to develop a vision, mission and sense of shared purpose. We decided not to rush out and buy a large property--even if we could afford to! Instead we are taking several small steps, to prove that we can work together constructively and that our young people can feel fulfilled and purposeful in various kinds of land-based activities.

We have adopted a name for our vision and current activities, and a logo. Read more on page 3 about ACES's first steps in 2005.

Creative Supports for Vulnerable Adults

The 2005 Guelph spring conference on this theme was organized by GSA on April 29. About 180 people joined in a full and rich program that opened with a keynote address by John Lord on "Creative Supports that Work: Values, Principles and Processes." Then there were four parallel workshops—on the value of support circles; how to make mere housing into real homes; creative approaches to work and recreation, and on how to implement good sustainable lives. Several creative strategies were illustrated in an afternoon and there were many displays by organizations from all over southern Ontario. John Lord gathered up the day's ideas and strategies in a final plenary session so that we could all "go home with awareness."

We believe it is vital to build on what was learned at this conference.

- We are editing the audio and video records that were made of the conference sessions, and plans to produce and share a summary videotape/DVD of the essence and highlights of the event, separate audio CDs of the seven sessions, and edited text transcripts as well. Thanks to Kerry's Place Autism Services and the Community Mental Health Clinic in Guelph for grants to help us make these resources available.
- We are trying to continue the dynamics and interaction of the conference in launching a new electronic bulletin called AROHA: Creative Supports for Vulnerable Adults. We will publicize creative initiatives of other groups, pose questions for discussion, and announce new books, reports, websites and events.
- We also plan some smaller workshops on helpful strategies that may encourage people and families in our region to explore the best ways of supporting good lives for their vulnerable adults. The first is on Gentle Teaching on July 6 (see box). In mid-September John Lord will lead a workshop on applying the principles of creative supports to planning person-directed lives with Individualized Funding. Other topics/speakers for the fall might include Graeme Treeby of the Special Needs Planning Group on financial aspects of longterm planning, and someone on substitute and supported decision-making and how to fit planning for adulthood with Ontario Government regulations.

An Introduction to Gentle Teaching with Felicia Jervis

Workshop Description: This workshop is an introduction to ***gentle, compassionate, and joyful*** ways of life sharing with people who are hurting and vulnerable because of: a developmental handicap, a serious mental health problem, a physical impairment, a debilitating illness; a major life crisis, a significant communication or learning challenge.

The Heart of the Matter: Some children and adults with significant communication challenges, express themselves through actions that are at times very difficult to understand and to support safely. These actions could include occasional withdrawal, and/or violent acts towards self and others. These actions must be understood not as ‘challenging behaviors’ that need to be controlled and/or eliminated, but rather as an expression of pain. As such, we need to learn to ***listen*** and ***respond*** with loving kindness and compassion. Inspired by the teachings of a number of mentors but especially John McGee, Jean Vanier, Marsha Forest, Wolf Wolfensberger, Barry Neil Kaufman, and Pema Chodron, Felicia Jervis will explore the possible roots of the ‘language of pain’, and will offer concrete and practical responses that are safe, empowering and life giving for everyone involved. This is a three part series:

Part 1: Understanding the ‘language of pain’

Exploring the possible roots of pain, distress
Some beginning strategies for getting through very difficult situations

Part 2: Listening and responding to the ‘language of pain’:

- Listening to people who have difficulty speaking with words
- Strategies for coping, supporting people through difficult challenges over time
- Developing a personalized and comfortable routine for difficult situations

Part 3: Moving beyond the pain: Experiencing the joy of living together in community

- Addressing the root causes of pain: isolation, loneliness and idleness
- Overcoming seemingly insurmountable challenges
- Looking at the big picture--the life situation of the person
- Building and maintaining mutually satisfying personal relationships and inclusion in all aspects of family/community life,
- Surrounding vulnerable individuals: building personal circles/networks

Participants will have lots of opportunity for questions, and informal discussions on how to create non-violent, inclusive living, learning and working environments for everyone. The focus will be on empowering ***both***, the person with significant challenges, and the family members, friends, and caregiving companions who surround them. Participants are invited to share their personal stories and insights if they wish to do so.

See announcement on page 1

About the presenter: Felicia Jervis B.A., B.Ed., M.S.W., R.S.W.

As a social worker and a teacher, as well as a parent of a young man with autism, Felicia has been a Gentle Teaching mentor since 1986. She has been involved with individuals and families who are vulnerable because of various challenging life circumstances such as: significant communication and learning challenges; intellectual handicaps; serious mental health problems (such as schizophrenia, mood swings, depression and drug addiction); chronic debilitating illness; physical impairments; and discrimination.

Her primary focus has been on collaborating with others to: learn and to teach about compassionate, joyful, and relationship based supports; to strengthen individuals and caregivers; and to enable everyone (regardless of the nature or degree of their life challenges) to make a significant contribution to their family and community.

Felicia has over 20 years experience with a focus on advocacy with and on behalf of individuals and families, family support work, and support staff training. She has worked (in both voluntary and paid capacity) in Durham Region; Hamilton/Niagara area, as well as GTA with: families and family groups, community based agencies, schools and mental health facilities.

Presently Felicia works as a Family Support Consultant and Gentle Teaching and Inclusion trainer/facilitator for the Durham Association for Family Respite Services. In addition she has a private practice in Burlington and GTA as an individual, family and group counsellor.

Contact Information: Felicia Jervis Tel: 905-333-4975 or fcjervis@sympatico.ca

ACES INITIATIVES TOWARDS AN INTENTIONAL COMMUNITY AND CENTRE OF EXCELLENCE FOR ADULTS AND FAMILIES WITH AUTISM

ACES initiatives are supported by our two regional organizations that work for and with adults with autism—GSA and WWAS. Through ACES we are taking early steps towards our vision of an intentional community that will include land-based work. The ACES Management Committee consists of Moira & Roger Hollingsworth, Nancy Cherry, Ted McCartney, and Gerry Bloomfield (chair).

1. We have adopted a name for our vision and current activities. ACES is an acronym:

A stands for Autism, Adults, Asperger's, Abilities, Attitudes, Accessibility

C stands for Centre, Creative, Circles, Community, Co-operation, Conservation, Communication, Confidence

E stands for Empathy, Energy, Excellence, Experience, Expertise, Ecology

S stands for Self-Directed, Supports, Spectrum, Safety, Stability, Social Skills

ACES suggests top quality, and the diversity of people interested in supporting and developing the abilities of adults with ASD. Brian Henson has designed a logo for ACES.

2. Land-Based Voluntary Work Initiatives

a) Following meetings with the director of the Ignatius Jesuit Centre of Guelph, a formal agreement of co-operation was signed covering all our group's activities at this site. GSA is also providing insurance coverage.

b) Ted McCartney has led and represented us in this area. He keeps everyone informed of opportunities to volunteer, and is our main contact person with the land manager and farm manager at Ignatius.

c) We were given responsibility for clearing and maintaining the Ignatius Courtyard, and made it presentable by the Doors Open tour on April 23. Organic methods must be used.

d) Mulch was donated and delivered by an arborist contractor, and then spread on the Courtyard paths, on trails, and around the 1,500 newly-planted trees which some of us also helped to plant.

e) We have rented a small garden plot, so our young men can have the experience of growing vegetables.

f) Our voluntary activity in the gardens and grounds has begun to earn us a welcome place in the Ignatius/Orchard Park community—a valuable basis of trust for the future development of our vision.

2. Day Program Initiatives

a) Moira Hollingsworth, supported by WWAS, has led us in setting up a Youth Day Program.

b) It was decided to offer a youth day program one day a week for four young men aged 18-27.

c) WWAS has taken financial responsibility—for contracting with a co-ordinator who is well qualified and an assistant, and leasing an Activities Room at Ignatius for one year. Families and friends have given furniture and equipment.

d) Will Wycherley has volunteered some advice on the basis of years of experience working with adults with autism in England.

e) Experience with direct group support might be expanded to include respite and summer programs in future.

3. ACES Role as Centre of Resources

Our vision includes a wider community role as a centre of expertise and resources for people concerned with ASD, especially adults.

a) The workshops in November 2004, which developed the vision for an intentional community, were an example of one kind of service that can be provided by such a centre.

b) The Guelph Spring Conference on Creative Supports for Vulnerable Adults, held at Ignatius on April 29, also fits with this ACES role.

c) ASPIRE, the project sponsored by both GSA and WWAS since 2002, has had a role that might be continued through ACES. Through ASPIRE, we are represented on various committees and working groups concerned with ASD or with developmental disabilities more generally. ASPIRE's current advocate, Nancy Cherry, attends policy meetings and discusses issues with government and agency staff. Nancy has compiled resources about the Transition to Adulthood.

d) ACES, backed by GSA and WWAS, sponsors workshops and information meetings on various issues. Three current examples are on "gentle teaching," designing person-directed plans, and financial and legal planning for people with special needs

e) The OAARSN website and bulletins can be used to share information and resources.

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 the ACES Youth Day Program, the 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/gsaainfo_new.shtml

http://www.ont-autism.uoguelph.ca/gsaafaq_new.shtml

Contact GSA about any of the following, to donate to our ASPIRE or ACES 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.

Speaking Up....

In her role as ASPIRE Advocate, Nancy Cherry has drafted letters on behalf of the ASPIRE and ACES groups that are supported by both GSA and WWAS. Our letters noted that "adults with ASD present complex combinations of abilities and challenges that require highly individualized support strategies...."

We recommended qualities of "access mechanisms" that have been successful in other regions of Ontario:

- 1. Independence from any other service agencies to avoid conflicts of interest.*
- 2. Openness to sharing current information about programs and services with individuals and families.*
- 3. Screening of service requests by a community committee composed of individuals, families and service providers.*
- 4. Independent and objective case resolution services.*

To the Director, Developmental Services Branch, of the Ministry of Community and Social Services, who is responsible for the process through which the MCSS may "transform" developmental services in lasting ways, we recommended the following priorities:

- 1. Designate a minimum 25% of the developmental services budget for individualized funding.*
- 2. Individualized funding must be portable and flexible to meet individual needs.*
- 3. Restore funding for social housing so older structures may be properly restored and new housing may be built.*

Copies of our letters were sent also to relevant Ontario Government Ministers and to the six area MPPs.