

ADULT AUTISM ISSUES IN WATERLOO-WELLINGTON

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

AAIWW Newsletter No. 27, October 2004

PATH: Planning Alternative Tomorrows with Hope

Nancy Miles, ASPIRE Advocate, writes:
Witnessing a PATH was enlightening. It heightened my awareness about our responsibility to try to discover approaches that reach and empower those with disabilities. It was a demonstration of the potential that each one has to live a good life, and when facilitated well, a demonstration that no matter the disability, the unique make up of each person and their strengths can allow them to be part of determining their own futures. Though my exposure to PATH is limited, the families I have been talking to that have experienced one have been very clear about how valuable the experience has been. It has helped to define goals and give direction and concrete strategies to achieve these. As an observer and participant in one PATH, I had scope to get involved without fear of being overwhelmed or getting lost – it gave me a sense of what I could realistically do and achieve in terms of participating in, and supporting a dream, for this one young man. The fact that this is not a static process lends itself to creating a hope that is rooted in reality. I would recommend this process for each one of us !!!, but even more so for someone who needs the structure and network of people to identify, articulate and support what is needed to create a good life.

GSA's AGM

Guelph Services for the Autistic will hold its 2004 Annual General Meeting on Monday, November 1, from 5:30pm in the Community Mental Health Association offices at Orchard Park, 5420 Hwy 6 North, Guelph, Ontario). GSA members will receive invitations and agenda. See Bulletin Board (back page) for information about GSA.

Workshop on Autism and Community

Guelph Services for the Autistic and Waterloo-Wellington Autism Services offer a Facilitated Workshop on Autism and Community including discussion of ideas of a farm community and centre of autism service and expertise. Facilitated by Bruce Kappel

When? Monday, November 1, 2004, 7-9pm
Where? Ignatius Jesuit Centre/Orchard Park
In the CMHA Boardroom (5420 Hwy 6 North)
Who may come? ~Open to all interested~
but pre-registration required.
Please contact Elizabeth Bloomfield
ebloomfi@uoguelph.ca or (519) 823-9232

Read more about the focus of this workshop inside on page 2.

Look up more about the ideas on the OAARSN site, searching for "farm community".
Join our Yahoo discussion group:
<http://groups.yahoo.com/group/ASDFarmCommunityandCentre/>

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A Process for Developing a Vision and Strategic Plan for a Farm Community and Regional Centre for Autism Spectrum Disorder Expertise by Bruce Kappel

Quite a few families involved with Guelph Services for the Autistic and Waterloo Wellington Autism Services are interested in the idea of an intentional farm community involving people with autism and supporters. The idea includes a regional centre of ASD expertise. Among the interested families, there have been presentations and discussions. Some families have visited other intentional communities and collected information about others. Some have written about their hopes and expectations of such an intentional community and a regional centre.

The discussions so far have included many different options in terms of what might be included, whose needs might be addressed, urban/rural involvements, how different aspects are developed and at what pace, and so on.

The Boards of GSA and WWAS think it is time to consolidate our various thoughts and come to some agreements about our shared vision and how we should focus our work in the future.

To accomplish that focussing, we are taking two steps. The first is an evening workshop to reach some general consensus about the features we want to see in a farm community, and, identify those who are willing to work on developing the concept. The second step, if warranted, will be a day long working session to develop statements of vision and mission, agree on the steps we need to take over the short and long term, and make personal commitments to accomplish the work.

The Evening Session (1 November 2004)

The primary focus of the evening event is to identify what families want a farm community to be for them. Some have an interest in having a family member live in the community. Others see it as an opportunity for work. Others are looking for respite. Others are primarily interested in the idea of a centre of expertise. Some want a farm that is a working farm, not just housing in a rural area.

Some want to make sure the advantages of urban life are not lost. There are many possible components. There are also a variety of ways that such components might be "packaged". Some of those ways could involve a farm community. Others might not.

The evening session will be a chance for people to talk about what they think a farm community might mean for them. Once we have identified what people are hoping for, we can make an initial decision about whether a farm community actually makes sense. If we work to build something, it would be nice to know someone would actually come. If it does make sense to proceed, we will then do more work at the day long working session.

Preparation for the Evening Session

1. Think about what you want a farm community and/or regional centre of ASD expertise to mean to you and your family.
2. Review some of the information produced so far. Check the OAARSN site, using the Search function on the main page to look for "farm community"
3. And look at the messages, files and folders of our Yahoo group at <http://groups.yahoo.com/group/ASDFarmCommunityandCentre/>

A Day Long Workshop (Sat Nov 27 or Sun Nov 28) may be organized to bring together those who are clearly interested in working toward a farm community. We will develop vision and mission statements, be very clear about the principles that will inform future developments, consider and decide on the components that we want to include in the community, and develop practical action plans for the future. These discussions will include principles and practicalities related to funding, leadership, which big or small steps to take first, and so on. This workshop depends on interest and commitment expressed in the first.

GSA Organizing Day Conference in Spring 2005 on CREATIVE SUPPORTS FOR VULNERABLE ADULTS

When? Friday, 29 April 2005

Where? In Guelph, at the Ignatius Jesuit Centre

Who should come? Persons and families who live with autism and other challenging conditions (including physical disabilities, mental health, cognitive and sensory impairments), agency representatives, community friends and advocates who care. We hope to reach those who cannot usually attend similar events: by assisting persons and families who could not otherwise afford to take part; and by making electronic and print resources that can be shared and studied by people who live too far away to attend.

Why?

- to be inspired and nerved to implement person-centred and self-directed plans
- to share a full range of creative individualized strategies that work
- to power a concerted and collaborative process involving all parties (persons, families, communities, agencies and Governments) concerned to support all who are vulnerable because of disability

How shall we achieve these goals?

1. A rich program including:
 - Opening plenary keynote session and closing call to action
 - Four concurrent workshops
 - Poster sessions and brief presentations on a whole range of living supports from which persons and families may choose to suit their situations and needs
2. Informal connections and discussion
3. Video record of poster presentations and summary highlights
4. Process of consultation and resources beforehand and afterwards, using the OAARSN website and other media

What can we all do now for this conference?

1. Plan to attend, watch the OAARSN website for updates, email gbloomfi@uoguelph.ca or phone 519-823-9232 to express your interest
2. Tell others who are themselves vulnerable because of disability or have disabled friends or family members.
3. Let us know of creative support strategies that are being pioneered by families, support groups or agencies

We plan a special contribution by making a record of the event and encouraging a lasting process of consultation and implementation to reach also those who cannot attend the conference.

Conference Outline:

8:30-9:00 Registration

9:00 Welcome and KEYNOTE ADDRESS, integrating various elements of support, by Dr John Lord of Kitchener:

“Values, principles and processes that work--the why of creative supports: individualized supports building community and inclusion.”

10:30: break

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

“Making housing into my home” led by Barb Leavitt of St Marys Community Living

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

IV: How communities and families can make creative options work in Ontario, led by :

12:00 to 1:00 Lunch and time to visit/discuss poster exhibits

1:00–2.45: Short presentations (15 minutes each) in either whole group (6 presentations) or in four workshop areas (24)... as above.

2.45: Break

3:00-4:00: Reconvene for debriefing summary and action steps: John Lord on *“What it means to be creative and innovative”*, so people go home charged up with practical skills for being creative

The Cave Dwellers

Each one of us is in a cave--a cave of fear of social rebuke, that is.

Yes, each person on the autistic spectrum lives in a cave, metaphorically speaking.

Our caves are the only means of personal security that each one of us has.

If we try, as we do, to venture forth from our personalized caves, we risk more than the loss of security.

We risk never having a place to call "home", because that is what the cave is for each of us--a home.

From this cave, we can signal, as primitive humans did, in various ways, to others beyond the cave.

Some caves might be strikingly similar, whereas others are strikingly different.

Some caves are so tight, as far as an entrance, that once a person has entered the cave, there is virtually no way to exit the cave. The person is bound by his or her cave for a lifetime.

Others have very large and easily accessible entrances, and these people seem to be able to leave the cave at will, only to return as soon as there is any threat on their security.

Some caves are so full of echoes that when a person on the spectrum tries to say anything, all he or she hears is constant echoes which will never stop, and hence the person is in constant fear of uttering anything, lest it become a permanent echo in the cave. Other caves are far more open with less chance of reverberations, but still some feedback nonetheless.

Each person's cave is a repertoire of his/her visual works, as was the case of the early cave dwellers, millenniums ago. The works are still there, but only the cave dweller can appreciate those works, as others who live beyond the cave treat the cave as a danger, and many refuse to enter, even if invited.

The caves are scattered over the landscape, with caves in most of the hillsides and areas of rough topography.

Each cave, though, is quite unique, and there are no caves identical to others, when it comes to layout, details, or repertoire of impressions. Some caves are easy to access, but others are very difficult, if not impossible to gain access to from the severe rock formations and potential for earthquakes in the regions.

Each autistic spectrum person speaks from inside his/her cave, and expresses himself in graphical means in the cave, as well. What one autistic person says from inside one cave is the message from that one cave.

Unlike the general public, which does not live in caves, metaphorically speaking, the spectrum person's life is built in the cave, with moderate to very little contact with the world outside the cave.

The few who are able to contact the external world from their individual caves are treated in various ways, either as people worth exploring (as a study case), or people who are "disabled" in that they are not able to exit their caves for very long without having to rush back for personal security--based mostly on physical sensitivity issues that exist beyond the cave. In the cave, the echoes, if any, can be controlled, mostly by silence to constant "humming" or other repeated tone, but, beyond the cave, it's an uncontrollable world out there, with no means of exercising a control on the volume. Also, the light is far more controllable in the cave, as one can get away from the glare of the sun a lot faster than in an open field.

However, once a person has been able to contact the world beyond his or her cave, a problem of identity becomes apparent. Is this person an example of the way that people who live in these caves think and feel about life in general? Can this person's outlook and descriptive forebodings be an indicator of how the others (especially those who dare not venture beyond their caves) see life and all its diversities?

So far, the anthropologists and other social scientists studying these cave dwellers have been trying to get a general outline of how these individuals live in these caves and according to the theories so far, the cave people are lacking in a special chromosome that permits others to absorb the physical sensations (sound, light, taste, smell, and touch) in all their intensity, and lacking this, these people are horrified at what, to others, is just an everyday event that is just taken for granted.

These cave dwellers, once developed in their individual ultra-sensitivity, will notice sounds, sights, and other details that most people could not hope to grasp. They become perseverated on the sound or light lest it be lost, as others around them seem indifferent to what they hear or see, and when the volume is increased, and they find that they have no control over the volume, they have but one choice--to escape to the cave.

The more they feel threatened for being in their caves, the more they dig deeper, especially in early years, and any attempt to show them life beyond the cave is met with fierce resistance.

However, a few that did escape to their personalized caves managed to become experts at areas of life that can only be seen or heard within the caves. The caves offered silence from the usual chit-chat of everyday living in society, and permitted the cave dweller to become a genius or expert in music, art, physics, poetry, or mathematics, to name a few fields that these cave dwellers have touched upon and made daring discoveries not found in everyday society.

The problem for those outside the caves is to differentiate, when applicable, between those who do need help in their living arrangements within the cave, and those who are not in need of help, and are capable of living independently. Some cave dwellers might have times for both--help and independent living, and to know when help is needed is very difficult, at present, to determine.

Some cave dwellers are sending out messages that say, in effect: "Leave me alone", whereas others are saying "I speak only to other cave dwellers, as they, alone, will understand me!". Still others will send out no message at all, and it is these cave dwellers, in all their silence, who present the problem of whether or not to give any form of assistance, whether needed or not. If a person does not say if he or she is hungry, how does one know whether to give food or not? Sometimes, the messages are very sublime, and only those who have studied the cave dweller for a long time can decipher the messages that he or she is sending...

There is no presumption of what each cave dweller is trying to say, or how he or she feels about any situation, or about life in general. Each cave dweller is unique, and what one cave dweller has to say is no indication (however supported) of how other cave dwellers feel about any issue. That person speaks for himself or

herself only, and even if a lot of other cave dwellers who can express themselves show support, that does not mean that most of the other cave dwellers support that person's perspective. Many cave dwellers are so deep in their caves that there is no way of knowing how they feel about a particular perspective, and their deep methods of communication shed little light on their support or lack of support for any opinion or perspective.

As each cave dweller can only see life from his/her cave, and the caves can be so extreme in diversity, it is next to impossible to describe, in a general way, the life of a cave dweller. As more come forward, and more are discovered, each outline of life inside the cave becomes more unique, and each perspective a lot more different than the perspective given by any other cave dweller.

Whereas, one cave dweller might have needed more water in his her cave, which was high above the ground, the next cave dweller, whose cave was constantly inundated with water, was forever searching for a way to get away from water. The same could be said of shadows, precipices, cliffs, and skylights in the caves, as well as the presents of other predators or pests in the caves. Each cave presents its own problems and potential to cave dweller, and what is needed by one cave dweller is often the very item that the other cave dweller wants help in trying to eradicate.

So far, these cave dwellers have no geographical or time boundary; they have existed for centuries in all continents and defied any attempt to classify them by race or genealogical pattern. They might live close together, when cave topography permits, or one might live beyond the horizon of any other cave. The pattern of living of these cave dwellers is so diversified that it goes, to use an analogy, beyond the visible spectrum (as to the frequencies present in the visible spectrum of light), and we are still tapping into the invisible spectrum as we try to unearth how these cave dwellers have continued to permeate this planet since the dawn of time. As each cave dweller lives alone, the only way others have, for centuries, looked upon them, as being utterly selfish in their attitude, and that is why, today, they have been given the label of "autism", as the root of this English term literally refers to "selfishness". It is a cruel and degrading term, to say the least.... No wonder many of these cave dwellers have problems with self-esteem!

Brian Henson©2004

Brian, who lives in Brantford, was diagnosed with autism in middle age. He is also poet and photographer

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 administers the Victoria Bloomfield bursary program begun in 1996 (see <http://www.ont-autism.uoguelph.ca/wwasbursary.shtml>). It also funds GSA's ASPIRE project and the new Autism Collection at the Kitchener Public Library. 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 William Barnes, 26 Yellow Birch Drive, Kitchener, N2N 2M2.

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/gsainfo_new.shtml
http://www.ont-autism.uoguelph.ca/gsafaq_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: 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 a collection of 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.

FC Gatherings: Support Group started for Users of Facilitated Communicating

Seven men who do not speak and have used FC for up to 13 years have begun meeting, with their supporters and friends. Their conversations together are very powerful and moving. They discuss the blessings and challenges of their lives with autism. They also compose poems. Here are some examples:

John K declared: *I think the world is too messy. I think the world needs autistic people to tidy up.*

The Beach (by John M-D)

The beach was calm and serene
early in the morning.
The water was moving very very little
towards the seashore.
The sand was as fine as grains of salt
under my bare feet.
The air smelled of seashells
and sand.
The sky was a clear soothing blue.
A feeling of peace permeated the air

Words (by Andrew)

Words are our way
of reaching each other.
In words I tell my story.
I say who I am
and who you are to me.
My words can sail to you
or hit their mark like a dart.
I tell you I love you
or can complain if I'm hurt.
I'm grateful I found my way
to share words,
very grateful indeed.