

ADULT AUTISM ISSUES IN WATERLOO-WELLINGTON

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

AAIWW Newsletter No. 29, January 2005

New Year Resolutions: Welcome to 2005

This issue of AAIWW is being prepared over the New Year weekend. Who can tell what 2005 will bring for adults who live with autism and others who are vulnerable because of disabling conditions?

Wonderful connections and opportunities sometimes happen. Good plans are also in the works!

A year ago, we did not expect that WWAS and GSA would host discussions of a regional farm community and centre of excellence for people with autism. Read its vision and strategic plan on pp.5-7, and note the survey of interest to try out its feasibility (p.16).

GSA is pleased that several families took the opportunity in 2004 to have PATH events for their young adults. We present PATH information, with questions and answers based on the experience of the pioneering families (pp.2-4). GSA invites other families to consider PATHs—perhaps for some older adults as well.

The Ontario Government's intention (announced last May) to transform developmental services gives us all opportunities to think of how our people could be better supported to have good lives. John Lord's essay (pp.8-9) reflects on four essential factors. There's much more on the OAARSN and IFCO websites.

Social housing projects now seem to be starting to move, after nearly ten years of stagnation. As a housing trust, GSA is particularly interested. Read our report on various hopeful signs of more public and private involvement at a workshop in our region (p.9).

GSA's day conference, planned for 29 April 2005, is timely and fits well with these new hopeful currents of thought and policy. In planning **CREATIVE SUPPORTS FOR VULNERABLE ADULTS**, our concern is practical, inclusive and comprehensive. Read more on pages 10-11 and keep in touch with plans through the OAARSN website. We need lots of volunteer help in the weeks before the conference and on the day. We also welcome donations to meet the costs of bringing together excellent speakers and workshop leaders. Most of all, we want to reach people eager to show and tell about their creative strategies and to share and learn from others. To emphasize our concern with implementing personal plans, we review an important collection of essays on p.15.

Hopeful dreams and plans, but the realities can be so different. Through OAARSN we know of tragic situations and inadequate supports throughout Ontario and elsewhere. We

still have so far to go! Thelma Wheatley's book (p.14), reminds us of some of the challenges of living with autism.

Andrew Foster's essay about autism and trains (pp.12-13) might seem a bit frivolous. But it draws attention to some distinctive symptoms of ASD and the need to plan fun activities and quality of life. We have a dream—that some benefactor would provide a private rail car so train enthusiasts with ASD could explore some of North America, as a highlight of their lives!

We thank you for your past interest and support and ask you to renew your commitment to persons and families with ASD in our region.

- Let us know if AAIWW is still useful. Costs keep rising and we receive no government or corporate funding. We need to increase and conserve our resources to help our vulnerable friends. Please let us know, at the addresses below, if you want to receive AAIWW only by email (please give your email address) or to stop receiving it.

- If you wish to remain connected, please consider becoming a member of WWAS (details on p.16) for at least \$25/year (tax-creditable receipt), or an AAIWW subscriber (\$10/year). See addresses on p.16.

-In any case, WWAS and GSA need your support:

- Donations are always welcome (both organizations issue tax-creditable receipts).
- Please volunteer to help with the April conference, or with other tasks.
- Most precious, you could be a friend of a person with ASD or a family.

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PATH: Planning Alternative Tomorrows with Hope

As part of its ASPIRE project, GSA has encouraged persons and families to use PATH as a creative planning tools for the future. Here are some ideas about PATH and CIRCLES as planning tools for better lives and more secure futures, based on a PATH workshop and several PATH events for young adults with ASD. GSA has made it possible for these PATH experiences to be led and recorded by a pair of professionally skilled facilitators.

What is PATH?

PATH is a powerful, creative and useful planning tool
PATH is daring, bold and action-oriented
PATH is personal
PATH is life-giving and life-changing
PATH is feeling the fear and doing it anyway
PATH is flying into the unknown and having a circle there to support the dream
PATH is a social process, a journey of self-discovery
PATH is an opportunity to give and receive a gift

What PATH is not....

PATH is not a prepackaged set of steps
PATH is not a guarantee
PATH is not a test

Who are PATHFINDERS?

People who want to create their own future
Individuals with a dream or desire to move forward
Families who want to work together
Friends who want to make a difference in someone else's life

What are the Steps of PATH?

Create a clear picture or vision of where you want to be
Identify your goals—focus for the next year
Ground yourself in the now
Identify people to enroll on the journey
Recognize ways to build strength
Chart Action Steps needed to achieve your goal

What is a Circle of Support?

A group of people who agree to meet on a regular basis to help a person with a disability to accomplish certain personal visions or goals, by overcoming obstacles and opening doors to new opportunities.

PATH was developed by Jack Pearpoint, John O'Brien and Marsha Forest beginning in 1991. Facilitators are trained by Pearpoint and associates at the Marsha Forest Centre for Inclusion-Family-Community in Toronto.

One Family's Experience of PATH

With the encouragement and support of ASPIRE, we recently had a PATH meeting for our son, Anthony, and would like to share a few thoughts to help any other families who may be wondering whether to embark on this process for their own son or daughter. We were initially a little reluctant to host such an event for our son as we felt awkward about inviting others outside our immediate family to participate. In reality, we discovered that people were honored to be invited, willingly gave of their time and offered much in the way of support, concern and ideas.

Our PATH event was on a Saturday from 10 until 3pm with lunch provided. Our two wonderful facilitators led the informal discussion with nine of us present and, to our amazement, Anthony actually stayed in our circle for much of the session even though he is nonverbal and could only participate very indirectly.

Although initially our thoughts were directed at an ideal future for Anthony--which is not immediately attainable--we did come up with some practical ideas which within 2-3 months enhanced his life.

At the preliminary meeting with the PATH facilitators we were encouraged to contact Foundations as they are funded by the Ontario MCSS to help individuals transitioning from school to work. Foundations staff were indeed been able to help us with support hours and ideas for structuring Anthony's time, now that he has left school and has no access to a day program.

Other ideas that came up at the PATH resulted in placing an ad at the local university to find a volunteer who could take Anthony swimming. We were successful in finding a student willing to do this. We have a "Best Buddy" who will also be taking him to some other community activities and we have a new male support worker who is spending about 10 hours a week with Anthony. There were many other thoughts and ideas that are yet to be utilized. We have reduced some of his perseverative behaviour and are getting him to do more household tasks which, of course, requires more effort from us but it is really worthwhile.

In conclusion: families may tend to put limitations on the possibilities for the future for their son/daughter. There are also services and options out there that they may not be aware of. We certainly thought we were well educated in this area but still discovered some useful opportunities for Anthony. We feel that a family has everything to gain and nothing to lose by doing a PATH. In the end, we felt we owed it to Anthony to make this effort for him.

QUESTIONS AND ANSWERS ABOUT PATH

1. We worry that we don't know anyone interested in helping in this way and that none of the friends and family members we invite will want to come.

- More than 20 came to our son's PATH! It's as if people who know us hesitated because they didn't what would be useful or appreciated. They seemed really glad to be asked.
- Knowing that various others—family, school, church, neighbours—have been invited and are coming seems to make everyone feel comfortable and know that they can share roles and responsibilities of being our daughter's friend.

2. We hesitate to ask people to give up a large chunk of their time for a PATH meeting.

- Five hours (including a meal break) is quite a long time, but it's really necessary to focus in enough depth.
- The atmosphere was informal and relaxed and it seemed that our guests were enjoying it and feeling good about their own contributions.
- They felt really good that they had been able to help our family. They all commented that they found the experience very rewarding.

3. How can we find a time that will suit everyone interested in coming?

- I suggest that families make a list of the key people they would like to attend and get an idea of their availability before they settle on a date.

4. We often feel so different from other families because our son has autism, we hardly dare to hope that others could understand what life is like for our son/daughter and our family's situation and fears.

- Taking part in a PATH helps everyone to think more creatively and positively. The facilitators led us to focus on visions and goals and the steps we might take to realize our dreams.
- Some other meetings and case conferences we have attended because our daughter has autism seem to go on and on about what's wrong with her. The PATH was special because the facilitators led us to listen to the person with autism and to focus on her/his strengths and goals.
- PATH helps everyone taking part to see and feel the things we have in common rather than the differences.

5. The guests sharing in our son's PATH don't know one another already. They might not be understanding and tolerant of each other's attitudes.

- All the varied responses were treated with respect and built into the total PATH picture.

- Older family members who may be pessimistic were listened to with the utmost respect and thus gained a sense of relief over their feelings of helplessness in not being able to do more for the family.
- Above all, our son really felt it to be his PATH, had a very definite voice and felt very proud to be important!

6. We already know that the local service system offers nothing for adults like our son. How could a PATH meeting help us?

- PATH's brainstorming and informal contacts opened up new possibilities we had not thought of when we were looking only to the traditional agencies.
- Because of the people we meet through PATH, we may find agencies and groups that can help. So we do not feel that we have been cast afloat to figure things out alone.
- We also found a second support worker, the son of one of the participants at the PATH, who is eminently suitable for the job having a brother with autism.
- We looked around our community and found two volunteers who now share time with our son.
- We also decided to add a little more structure to our son's life at home by having him do more for himself and more simple chores.

7. When, in a person's life, is the best time to have a PATH meeting?

- A PATH can help at any time, and ideally should be experienced at intervals in a person's life. A PATH can be especially helpful at transition times, such as between school and adult years, or facing life beyond one's parents.
- I think the timing was perfect for us. Our son no longer had school and I was feeling a bit overwhelmed and needed to develop some strategies.
- I'm glad it came when it did as I was very low on hope and might have not gone through with it if we'd left too long getting started. I wish I had the opportunity several years ago.
- Yes earlier in my son's life would have been helpful, say about age 14 or 15, instead of over 18. It would have put more order in our lives. However, I'm not sure I was ready to let others take on some of the load at that time.
- The PATH helped me feel that I could start to let go of the tremendous weight of responsibility for everything in my son's life.

8. How many participants should be invited for a PATH?

- Including the person and her/his parents, perhaps at least six, to allow for varied ideas.
- A much larger group may pose problems of timing and balance for everyone to contribute, but there is also joy that so many people with varied experiences and perspectives care about and are interested enough to share in the PATH.

9. Could a family and friends do a PATH by ourselves, without trained and skilled facilitators?

- Discussions among a vulnerable person's family and friends who really care can be useful. To get the full benefits of a PATH, families should ask the help of experienced PATH facilitators who are not personally involved in the person's life and thus have some detachment.
- Having two facilitators working as a team is best—one may have the special role of drawing out people's thoughts while the other sketches ideas and suggestions in the graphic record. The facilitators have a preliminary meeting a week or two earlier with the person and parents.
- The earlier meeting served to put our minds at ease for us, by realizing that the facilitators truly understood our son's wishes, and that he and we knew what to expect.
- It was particularly helpful for us as it was during that informal meeting that I was encouraged to approach [a transition program for young adults].
- The facilitators seemed to bring out relevant areas for discussion and made sure we had some action steps at the end.

10. How realistic are our hopes of what PATH can do?

- We knew in advance that PATH was a time for brainstorming and sharing creative ideas rather than the nuts and bolts of funded services.
- Some very specific benefits and contacts came out of the PATH, enriching our son's life.
- Our son really loved having so many friends come to the PATH for him; and the graphic poster is a precious record of what we all talked about. His fearful bad dreams stopped.
- For us as parents, it was a small light at the end of the tunnel, a renewed sense of hope, a temporary high after a long period of feeling low.
- As parents, we both felt really good about the experience—it was very worthwhile.
- The PATH poster is a great visual and organized plan for the future
- One benefit was contact with church members who, as a result of the PATH, understand our son better as to his positive abilities, not just as having behaviours that need to be controlled.

- It was a chance for family members to get relief from any guilt and to express their feelings.
- We had a clearer understanding of where people stood in their desire and willingness to be with our son in his life journey.
- Friends said they felt really good that they had been able to help our family; they all commented that they found the experience very rewarding
- Friends seemed glad of the chance to express their thoughts, and to know better how they might help and not do or say the "wrong thing."

HOWEVER:

- It's vital to keep following up. Six months after our PATH, no one is taking the initiative to keep in touch and follow up the offers and bright ideas they expressed at the PATH.
- I hope for future possibilities if I could get a strong Circle of Friends going. Our son needs a circle that would take on a life of its own and provide strength for the family. A circle would help bond individuals with a sense of purpose. We need more ideas of how to get and keep a circle going.

11. How is a Circle of Support developed?

The focus person decides to ask help from people they know and trust. These people are called together to focus and collaborate to reach a common goal.

Creating a PATH or Circle involves three challenges for the parents and family of person with a disability:

- Asking others to get involved is hard, as we think we have so few friends and fear being refused
- Opening our lives to share responsibility for our person with a disability
- Believing that there are community people we can trust to share in a CIRCLE or PATH

12. Do I need a Circle of Support to do a PATH?

No. Your Circle of Support will evolve and grow with you. It may start with a small intimate group of 4 or 5 people with whom you plan and set some goals. Then you will invite others to join you, to join in celebrating successes and coping with challenges. As time goes by, your PATH will change and grow and your Circle will change and grow with it.

Inclusion Press Books include:

All My Life's a Circle. Using the Tools: Circles, MAPS and PATH

PATH: Planning Possible Positive Futures

Hints for Graphic Facilitators

Person-Centered Planning with MAPS & PATH:

A Workbook for Facilitators

Inclusion Press Videos include:

All Means All: Introduction to Circles, MAPS and PATH

PATH Action Pack: Collection of 2 videos + PATH Workbook

PATH Training Video-Joe's PATH

A Vision and Strategic Plan for a Farm Community & Regional Centre AUTISM AND COMMUNITY WORKSHOP

A full-day workshop was held on Sunday, November 28, 2004 at the Orchard Park Conference Centre in Guelph. Participants included four self-advocates, 11 parents of adults with ASD, five parents of children with ASD, six friends and supporters, and two with professional interests in the project, one being our facilitator and reporter, Bruce Kappel. Guelph Services for the Autistic and Waterloo-Wellington Autism Services co-operated in funding this event and the earlier facilitated workshop on November 1st.

This Vision and Strategic Planning session was the final step in a process that included the earlier workshop, discussions through the web site, the preparation of background papers, and reviewing those background papers. Through this process, we accomplished the following:

- Identified the Core Values that will inform what we develop.
- Identified the Components of the Farm Community and Centre, including some principles related to each.
- Decided to proceed with some development steps that will help us get some things done soon, develop some experience with various approaches, and provide the context for us working together toward a common goal.
- Formed four working groups that will develop ideas further and report back to the larger group.
- Agreed to continue to meet monthly to develop as a community and to continue our discussions.

DECISIONS AND OUTCOMES

1. VALUES AND VISION

We agreed on the following **Core Values and Rights**.

They are based on our review of the values stated in "ASD Farm Community and Centre" and "Vision, Mission and Values of Camphill Communities Ontario". The discussion modified some of those statements and added additional ones.

a. VALUES AND RIGHTS

- Respect for the individuality, self-expression and quality of life of each person with ASD.
- Tolerance of diversity and respect for other members.
- Accommodation to individual sensitivities.
- A community that inspires a sense of shared purpose and hope among all its members.
- Ensuring that families continue to have voices and leadership roles, with self-advocates also represented, as well as supporters from the larger community. We have to guard against domination by paid staff or managers, or by any particular group in the ASD cause.
- Support for the right and responsibility that "everybody contributes".
- Inclusion and inclusiveness –
 - include people with the full range of gifts and support needs as resident members of the community
 - inclusion of community members as resident members of the community, as well as visitors and participants, and
 - full inclusion of supported members in the life of the outside community.
- Support the whole human being. This best happens in the context of living together as family, caring for and supporting each other, and providing:
 - continuity of care and a lifestyle designed to maximize health
 - a learning process towards the greatest possible extent of independence
 - relationship building
 - security and safety for individuals with disabilities
 - a sense of feeling at home
 - an environment to develop social capabilities.
- Welcome people to the community without discrimination on the basis of level of ability, religion, sexual orientation, race, gender, colour, national, creed, or ethnic origin. And protect people from discrimination.
- We recognise the rights of the individual, including the right to:
 - participate and contribute in all aspects of community life within both the Farm Community and the larger community as a citizen with full rights.
 - freely choose to be a member of the Farm Community. Choice can be expressed in many different ways – through many means of communication, deep listening, watching how individuals react to situations, and so on. Choice should involve the chance to try things out before making a final commitment. Choice involves the individual and support circle.
 - supports for personal choices that direct personal planning and decision making process. Supported decision making involving individual and support circle.
 - a community culture that safeguards human dignity in an environment free from sexual, emotional, or physical abuse of any kind.
 - fill one's daily life with meaningful work, meaningful dialogue and conversation, and meaningful cultural and educational experiences

- freedom of religious expression in the context of respect for others' beliefs and values.
- choose complementary medical and therapeutic treatments.
- a safe, aesthetic, and personalized home.
- autonomy of movement.
- experience fulfillment, happiness in life, and satisfaction in the environment.

b. COMPONENTS OF THE VISION

There are four major components to this enterprise. Each involves supports and services to people who might live as members of the Farm Community and/or in the wider community.

- **A HOME** (meaning any form of housing – single detached, townhouse, apartment, etc):
 - We will support individuals to live on the Farm. We will also support individuals to live in their own homes in the wider community.
 - We want an inclusive, integrated farm community. This means that the ratio of people with autism to others in the community should be 25:75 (or for every one person with autism, there should be three people without autism in the community).
 - If the “farm community” is located on more than one site, we want to ensure this level of integration at each site.
 - We believe that such a community will help ensure that natural supports are available from other members of the community. Paid support will supplement natural supports rather than the other way around.
 - To achieve this level of integration means that most people will be living in their own homes or apartments with support, home sharing arrangements with families and other supporters, house parent arrangements, and so forth. One or two people with autism might share a home. Group living arrangements will be uncommon.
- **WORK.**
 - One of the reasons we like the idea of a farm or large rural property is that it provides the opportunity and flexibility for many different kinds of work, all the way from true agriculture to woodworking.
 - The possibility of productive agriculture is an important part of our vision. This will help attract other members to the community and also provide work opportunities for supported members.
 - The farm will provide many opportunities for work, paid and voluntary, for instance, in caring for crops, livestock and trees, and in related rural

business services or services for other members of the ASD community.

- Individuals with ASD who do not live on the Farm will be able to work on the Farm.
- Individuals with ASD who live on the Farm will also be supported to work elsewhere in the broader community.

- **ACTIVITY.**

- The farm may be used as a base for co-op day programs, respite and summer camps.
- It will provide an opportunity for people with ASD and other members of the broader community to enjoy a rural setting.

- **CENTRE FOR EXCELLENCE AND EXPERTISE.**

- A centre of excellence and expertise that brings together professionals with a key focus on ASD.
- Consultations and therapy of various kinds, to suit complex individual needs, can be provided to people living onsite and offsite in a comprehensive package, so families do not have to run around.
- The need for a resource centre of this kind does not necessarily mean it should be located on the Farm property. The need for the Centre is region-wide. It might be more conveniently located elsewhere.

LOCATION OF FARM COMMUNITY

- For practical reasons, the Farm Community should be located closer to an urban community so that interactions between the Farm and the broader community are easier.
- For zoning reasons, it might be necessary to locate a cluster of houses on one property and farming and business activities on an adjoining or very nearby property.

2. NEXT STEPS – Strategies and Task Groups

We agreed that we should not go out and look for a property at this time. There are specific next steps we can take, however, that can:

- help us learn about individual interest,
- help us figure out if we can attract other people to such an integrated community,
- provide opportunities for people right now, and
- begin development of the Centre.

From preliminary conversations, we think that the Ignatius Community could be open to our using parts of their lands and facilities for various purposes that would be compatible with the other users of Orchard Park and the Ignatius Jesuit Centre of Guelph. The next step is to develop some concepts and proposals.

Four Task Groups were identified. See next page....

Each of the four task groups will:

- develop an idea
- bring it back to the larger group for discussion and direction
- once the idea is developed, identify what kinds of resources will be required to move ahead
- bring the resource plan back to the larger group for discussion and direction.

In other words, the Task Groups will be accountable to the larger group.

Group 1: Agricultural Work

Three men agreed to develop ideas of how we might work on the parts of the Ignatius lands (and other land, if indicated) for such things as gardening, agriculture, pruning the orchard, woodlot management, cutting grass, trail maintenance and related activities. These can provide opportunities for work and small business development. Individuals can discover if they enjoy or are interested in such work.

Group 2: Summer Camp, Respite, Day Program Initiatives

Two members of our group agreed to develop ideas related to the possible use of resources at Ignatius for various other activities such as summer camp (residential or day), respite, and day program initiatives.

Group 3: An Initial Community

Another idea is a first effort at community involving the 25/75 ratio, attracting other people to be part of such a community, and being able to include people with ASD who have a variety of support needs. This would involve a smaller group of people living on one property. This idea would take longer to develop.

Group 4: Centre for Excellence

One member will develop the idea of starting some Centre activities at Ignatius.

3. GOVERNANCE

One of the values stated in the ASD Farm Community and Centre paper was – “A community that inspires a sense of shared purpose and hope among all its members—persons with autism, family members, friends and professionals—so that all are represented in its leadership, management and sustained development.” This raises the question of how leaders and managers will truly represent people with autism who live on the Farm or are supported by it, their family and friends, other members of the Farm Community, and professionals. We have agreed that “we have to guard against domination by paid staff or managers, or by any particular group in the ASD cause.”

The larger issue is where control is vested and how decisions get made, by whom, and about which issues. For some things, there may have to be one or more corporations. For others, individuals and their support circles may be in control. Some of the areas of decision making and control include

- the overall effort – final control of the vision, values, and direction of all components of this enterprise
- property – ownership of and decisions about the farm property
- Farm Community – who belongs, what the community does, etc.
- farm activity – actually managing farm enterprises
- support arrangements for individuals
- hiring of personnel for support
- what the Centre does.

Possible decisions makers could include:

- the person with ASD
- family, friends, support circle
- other members of the Farm Community
- organization(s) that might receive support dollars
- organization(s) that might own property
- organization(s) that control the Centre.

For the time being, it is agreed that the group of people interested in moving the idea of a Farm Community and Centre forward will be the centre for discussion and decision. The various issues of governance do not necessarily have to be resolved in the near future. Various efforts and projects can proceed using existing organizations to flow money.

Our Vision

A community that inspires a sense of shared purpose and hope among all its members—persons with autism, family members, friends and professionals—so that all are represented in its leadership, management and sustained development. Values and rights include:

- *Respect for the individuality, self-expression and quality of life of each person with ASD.*
- *Tolerance of diversity*
- *Accommodation to individual sensitivities.*
- *Support for the right and responsibility that “everybody contributes”.*
- *Inclusion and inclusiveness*
- *Support the whole human being: this best happens in the context of living together as family, caring for and supporting each other,*
- *Welcome to the community without discrimination, and protection from discrimination.*

Some Lessons from British Columbia that Provide Insight Into the Transformation of the Developmental Service Sector in Ontario, by Dr John Lord*

The Ministry of Community and Social Services in Ontario has initiated a process of what they call “transformation of developmental services.” A partnership table of families, self-advocates, service providers, and government created a “consultation paper,” that groups throughout Ontario have been responding to. The partnership table and the government will now review the submissions and propose policy alternatives for transforming developmental services. In this piece, John Lord reflects on some lessons from British Columbia, where transformation is a few years ahead of Ontario.

A new report by Cam Crawford and the Roehrer Institute, called **Gathering Momentum**, provides a glimpse into the transformation of community services that has been occurring in British Columbia over the last few years. Having read the report carefully, and having worked a fair bit in BC over the last three years, I would like to add some further reflections. Behind the power plays, the procedures, and the technical details in BC so aptly described by Crawford, I think there are **four key things we can learn** from that province that we must remember in Ontario. The transformation process underway in Ontario requires diligence, focus, and collaboration if we are to achieve some of the changes we so desperately need in this sector.

1. **We must find levers that can transform the system**, and try to get governments to work with us on that transformation. The BC leadership understood those levers even if they did not execute them extremely well. I am only hoping in Ontario that some of the submissions from the stakeholders to the MCSS consultation begin to identify those levers. Examples of transformative levers in Ontario would be changing a very traditional residential service system by de-linking housing and support (moving away from bricks and mortar). Another lever might be to build in ways to stimulate innovation (a key lesson from BC and Australia). Another would be to implement a comprehensive initiative of individualized funding. We must think strategically about levers for transformation if we are to make positive changes.

2. **We must be sure to build IF (individualized funding) with appropriate infrastructure support.** Where IF funding has worked, it is because independent planning/facilitation (and related things) are in place. BC has understood this, but are now involved in a struggle to implement this in a principled way. Separating planning and facilitation from service delivery must be part of the Ontario experience, especially after families have experienced more than twenty years of individualized support through Special Services at Home. *Hundreds of families are now ready for IF*

and for continued control over individualized supports as their kids become adults. We also have an advantage over BC in that we have a few places in the provinces that are already doing this well and we can learn from them (and government could too). Initiatives in Windsor, St. Mary’s, Durham Region, Toronto and Kitchener-Waterloo can teach us a great deal about the process and dynamics of independent planning and facilitation.

3. **In Ontario, it is likely that the province will be interested in phasing in IF - our challenge is to figure out how to do this phasing in an equitable and meaningful way.** In BC, they wanted to do it all, which in some ways is the honest and correct thing to do. Phasing and tinkering, while politically more palatable, is tricky to do well. One way to phase in IF is to build on those who have already experienced individualized supports. So, one could envision a five year plan of implementation, beginning with SSAH graduates and Foundations graduates, just as one example, and then moving on to other groups. Of course, there are many other phasing strategies. This will require lots of strategic thinking.

4. **We must focus on citizenship and community inclusion.** Many in BC understood this, but like in Ontario, many service providers do not understand citizenship, and thus undermine this approach. ***A citizenship and community approach means we do not think service or placement, but we think capacity building and participation.*** Moving to this new paradigm will be our biggest challenge. There is growing evidence that a placement approach cannot produce many positive outcomes for people. As well, there is no point in hiring independent planners/ facilitators if they are not committed to citizenship and community. Some of the training of facilitators in BC has been exquisite and we can learn from that experience. Fortunately, there is a strong and growing element in Ontario of self-advocates and families with Family Alliance groups, the Individualized Funding Coalition, and many other groups that understand this in their hearts and minds. We need to nurture each other in this citizenship and inclusion work, since it is likely to take the government a long time to fully understand such a focus.

So, my caution for the MCSS partnership table from the BC experience is not to get side tracked with details, but to ***build principles that all stakeholder groups can understand and work together to implement.*** For this, the Roehrer Institute Report offers us some important insights. Unfortunately, there has not been consensus in BC about the principles that will reform the system. Once we have the principles in Ontario, then we need to be strategic and collaborative in their implementation...

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**A Community that Cares:
Creating affordable housing through
leadership, innovation and collaboration**
Report by Gerald Bloomfield of GSA

About 100 participants met in the Arden Park Hotel, Stratford on 9 November 2004 for an intensive hour-hour workshop on affordable housing possibilities.

The workshop was organized by the Community Services Advisory Committee, a Perth County municipal committee also supported by the City of Stratford and the separated Town of St Marys. Dale Howatt, the consultant to the Committee, opened the meeting with an overview of the situation in the area. Factors include the demographics of an ageing population, rising housing costs with very few houses in the price range of \$100,000 or power, and an increasing proportion of the workforce in Stratford commuting from London and Kitchener-Waterloo.

Presenters in the workshop focused on the spectrum of need for seniors housing (Fred Zehr, Tri-County Mennonite Homes); success stories from the initiatives of the Region of Waterloo (Ken Seiling and Rob Horne); the work of Habitat for Humanity in the Stratford area (Jinny McDonald); new development by Menno Homes (Rick Cober Bauman and Martin Buhr) and issues of shelter for homeless teenagers in Stratford (Donna Pammer and Theresa Millen).

While housing for people with disabilities was not directly addressed in the presentations, several speakers referred to issues which are relevant to the housing needs of autistic adults. Group action and self-help were important themes.

Tri-County Mennonite Homes has three major projects. Two are for seniors--Nithview, New Hamburg (250 people) and Greenwood Court, Stratford (170 people). There is also Aldaview Services in New Hamburg which houses 15 disabled people in four-person dwellings and 5 others in SIL (supported independent living) units. The capital funding arrangements have some interests:

1. Life-lease—prepaid rental programs
2. Partnerships—service club/individuals purchasing housing facilities which are then rented back to Tri-County
3. Private investment—Some new construction has been financed by personal loans which bear interest rates a little above the bank's rates, but are lower in cost than commercial loan rates.
4. Fund raising—Largely used for furnishings in the amenity/shared space. A major fundraising drive is underway by Aldaview to build a new four-person house with full sound-proofing.

The Tri-County website (www.tcmhomes.com) has more information about the organization.

The Habitat for Humanity speaker highlighted the self-help approach. Each family aided by the organization has to contribute at least 500 hours of volunteer work, some directly on construction. Habitat for Humanity seems to be well supported by volunteers on the construction work but is limited by available financing. The cost of serviced lots is a major barrier to development. About seven houses have been built in the past decade.

Menno Homes, incorporated in September 2001, was established by the Mennonite Central Committee as a contribution towards providing affordable homes especially for large families. The organization has built a 16-unit complex in the Queen Street South area of Kitchener during 2004. Each 3-bedroom duplex unit of 1,100 sq ft was constructed at a cost of \$106,000. The basic financing of the units was 40 per cent equity (including the cost of land, sold by a church) and a 60 per cent mortgage. The only income for the housing is provided by rents.

Presenters at this well organized meeting gave a very useful view of affordable housing needs and emphasized ways in which innovative organizations have developed housing schemes. The Perth County area has a particularly supportive municipal organization and could be a model for other places. All the organizations showed willingness to share ideas and information with other groups who are searching for housing solutions.

..continued, from page 8:

As we learn from BC, this can only happen if government and community work together the whole way. So, I urge the partnership table to demand continued involvement as you move from ideas to principles to strategies to implementation. Leaving strategies and implementation to government alone will be inadequate, as we know from so many government changes in the past, such as deinstitutionalization, access centres, and levels of support. Convincing government that community can be a genuine and effective partner will be difficult but essential to this journey of change.

Transformation can only happen with dialogue, commitment, and strategic thinking. The Liberal government has begun the dialogue, and for this they are to be commended. The hard work now commences, as government and the community partners begin their strategic thinking, and build their commitment for change through common principles and policy development.

John Lord is a researcher, consultant, and parent from Kitchener-Waterloo

Guelph conference on CREATIVE SUPPORTS FOR VULNERABLE ADULTS Friday, April 29, 2005 in Guelph (at Ignatius Centre/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 folks who live with Autism Spectrum Disorders, such as through our ASPIRE project, 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--during the conference and also beforehand and afterwards, using the OAARSN website and other media.

We have applied for an Ontario Trillium Foundation project grant, among other purposes:

- *to enable needy persons and families to attend*
- *to record highlights of keynote, workshops and poster presentations, editing them into electronic and video resources to be shared with people and groups who cannot attend*

We welcome the following forms of collaboration with other groups:

1. Ideas of good strategies and models that should be included and represented and of needs that could be addressed by this conference.

2. Display materials illustrating creative strategies and success stories developed by your group or known to you, for the poster presentations and shorter sessions in the afternoon. These are some examples we know ourselves, but we want to include more:

- "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 and 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 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
- 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
- How brokerage works
- What aroha/microboards can do

3. Someone to be the liaison person for your organization or support group, who will pass on news and updates to your members.

Please watch the OAARSN website at <http://www.ont-autism.uoguelph.ca/> for updates. Email gbloomfi@uoguelph.ca or phone 519-823-9232 to express your interest.

Elizabeth Bloomfield for GSA and OAARSN

Day Conference in Spring 2005 on CREATIVE SUPPORTS FOR VULNERABLE ADULTS

When? Friday, 29 April 2005

Where? In Guelph, at the Orchard Park/Ignatius 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 inspire and give people the confidence to implement person-centred and self-directed plans
- to share a full range of success stories and creative individualized strategies that work
- 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

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 at <http://www.ont-autism.uoguelph.ca/> for updates, email gbloomfi@uoguelph.ca or phone 519-823-9232 to express your interest and request registration
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 also plan to make a record of the conference event and encourage 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 Marlyn Shervill and Michelle Friesen of Windsor*

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

Autism and the railway: an unscientific meditation

by Andrew Foster of Cambridge, Ontario

I have two qualifications for writing this essay: I am an engineer, and I have a friend who has classical autism. Engineers see things that other people can't see, and people with autism feel things that other people can't feel. They see everything with a fresh and differently structured outlook. You can't look at something and say to yourself, "Ah! I know exactly what an autistic person will think of this!" But perhaps the engineer has a small advantage, because he or she is more conscious of structure and order in things.

Nothing on earth can be more structured and ordered than the railway. A car or a bicycle on the road can swerve in any direction at any time, at the whim of its operator or because of an external influence, or because something has affected its performance in some way. A ship, even these days, is to some extent at the mercy of the weather and other traffic. As for aircraft, the uncertainty of every small thing that makes it fly and stay in the air places the disorder of its physical environment in the most disorderly category of them all.

The railway is a peaceful structure. On its own, it disrupts its environment less than any form of modern transport. I say 'modern', because it is tempting to remember the slow and quiet canal boats that preceded the railways in the eighteenth and early nineteenth centuries. But they are no longer a significant part of our environment, and we can only see them in a few special places now. Despite the scorn that John Ruskin let loose on the railways for devastating the prettiest parts of the north Midlands of England, they mostly settle unobtrusively into their surroundings and draw smooth lines sweeping through the land; quiet until aroused by a train, and then become quiet again. The railway invites the best of architecture and civil engineering, though perhaps it has been a long time since we have seen much new railway architecture that will endure and become part of what we have become accustomed to call our 'heritage'.

When you stand beside the railway to watch the trains, or when you travel in the train, you usually do so with a sense of relaxation, sometimes interrupted by moments of excitement. You don't even have to wear a seat belt; surely the last form of transport that feels safe enough to dispense with them. Even buses have them in some places now. No; you know that the train will be guided by its rails, and the very worst that could happen is that something ends up on the line that shouldn't be there. Of course this can happen, but not very often.

Not very long ago I saw a photograph of a section of railway under reconstruction. The rails had been removed while the track bed was regraded, and it looked like a road. To my astonishment, I felt a flash of insecurity, even though I didn't know the place in the photo. It was as though my insurance policy had been cancelled. This made me stop to think about how my autistic friend sees the railways. I'm quite sure he has never analysed them to find out why they feel so enjoyable and comfortable, any more than I had up to that point, but my mind went off in a number of directions after that odd experience. For example, I have never liked suspension bridges.

Anyone looking at a suspension bridge – without being an engineer – can see that it is flexible, and is sustained only by the tension in the suspension cables. That constant, living tension transmits itself to the consciousness of the onlooker and is felt. Of course, bridges are carefully analysed and constructed with enormous factors of safety, and the failure of a suspension bridge is almost unknown in modern times. The original Niagara Falls railway bridge was a suspension bridge, and the engineers quickly learned the lesson that with a heavy moving load on such a flexible structure, something like a bow wave passed through the deck of the bridge ahead of the train, and safe or not, it was a remarkably unpleasant experience for all concerned. In a high wind that might cause the deck to twist, the bridge was unusable. The result of that is that there are very few railway suspension bridges: order and stability were returned to the railway by masonry and concrete arches, and by an amazing diversity of steel girder structures that give a sense of great stability from their evident structural stiffness. Naturally, there are exceptions. The Tay bridge in Scotland fell into the river in a great storm, and a section of the Quebec Bridge fell – twice – into the St Lawrence river during construction. The nice thing about being an engineer is that I know there was a perfectly good explanation each time, and I don't need to let it bother me any more. But a suspension bridge... There's no mechanical Valium that will ever take that tension away from the bridge to stop it bothering those who travel over them.

Any discussion of why certain people like railways will usually lead into model railways. What is the attraction of them? There isn't the same need for safety and order that affects one's life directly. Or is there? I find that watching the random movements of fish in an aquarium is anything but the relaxing experience it is supposed to be. Like rats in a cage, perhaps? Watching cars on the road is not so very different, and while the uncertainty of the next movement of every one of them might appeal to those with the instincts of a gambler, it will not do for those in need of predictability in their lives, whether over

the next few moments, hours, or the rest of their lives. The model railway is peaceful, allowing its operator to direct the locomotives in an orderly fashion; telling them where they must go, how many freight or passenger cars they must have in their trains, when they must start, and where they must stop. It is hard to be unsettled by the appearance and behaviour of a train. But why watch it at all? Perhaps it really is an alternative to the therapeutic aquarium.

I would like to know if my autistic friend is much interested in different types of locomotives – is he at all impressed by the relative beauty and function of the various types? Probably not, would be my guess. The concept of mechanical beauty is not shared by all people, and much of what we think of as beautiful in railways is superficial. My own family has taught me that sad truth. Like the biblical Dorcas, a locomotive may be ‘full of good works’ but we don’t see them – they are hidden away inside, and we only admire the exterior, while some of us affect a profound appreciation for those worthy things hidden from the human eye. Even there, there may be a hint of an explanation. There’s a particular railway in the highlands of Scotland that has absorbed my affections for many years, and I have always found its buildings, its bridges, and its locomotives to be especially attractive; even comforting. The key to this, I am quite sure, is the association with places that I love and go back to at every opportunity. But this is a different discussion, though a useful one of which to be aware.

The autistic person seems to have a very strong grasp of the bases - the structures - of the environment that affects, and to an extent, controls, his life, and can disregard the superficialities that the rest of us find so absorbing and distracting. This is surely a necessity, when his body will not always perform the way he wants it to, and he must always have a reliable and trustworthy frame of reference to provide his security. I wonder if this is a reversal of the familiar concept of autistic behaviour, because some of us have got used to the idea that the autistic person can be overly concerned with superficialities? Perhaps an interesting idea is emerging here, and all this time, I have been confusing details with structure. A railway is made up of millions of details, but with each one in its place and carefully maintained, there is no more reliable and orderly structure to be found.

As usual, people with autism can be remarkably effective teachers!

Why do trains and railways appeal to people with autism?

In 2001, The National Autistic Society (UK) found from a survey of 81 parents that children with autism spectrum disorders associate far more strongly with Thomas the Tank Engine than with other children’s characters. “One reason is that children with autism are often attracted to objects arranged in lines (like cars on a train), as well as spinning objects and wheels.... The unique stop-action photography of the videos [also] allows the background and scenery to remain still, allowing for greater focus on the "big picture" with less distraction... Children with ASD often have the need to identify, list, collect and create lines with favorite objects. Thomas is especially suitable for these activities.” Other reasons are the bold depiction and friendly faces of Thomas and the other characters, and the clear story lines). <http://www.nas.org.uk/nas/jsp/polopoly.jsp?d=368&a=2683>

Adults with ASD may also find trains very appealing. Train systems and timetables are orderly and predictable, satisfying the passion for order and providing material for those who love to collect facts. A obsessive passion has led Darius McCollum (who probably has Asperger’s) to hijack subway and other trains in New York City, for which he has spent more than a third of his life in prison. <http://www.boystealstrain.com/darius.html>

For those who can be overwhelmed by the vast array of sensations of the real world, it can be easier to take it in from the perspective of train windows or by working miniature model railways.

Riding by train may be the best part, as the rhythmic rocking sensations of the train’s movement stimulate the vestibular sensory system, which can be pleasurable and therapeutic. The vestibular system affects balance, muscle tone, equilibrium responses, the ability to use both sides of the body together, coordination of the head, neck and eye movements, auditory language, and plays a role in arousal.

We asked our friend who is severely affected by autism why he likes to travel by train. He responded with this poem

Trains move me in many ways;
I like to be moving with them..
My movement problems are inconsequential
because the train speeds along the track
in the right direction.
It feels like the motion
becomes a part of me
and I am part of it.
The sounds calm my nerves
and I am happy.

Thelma Wheatley, *My Sad is All Gone: A Family's Triumph over Violent Autism*. Lucky Press, 2004, 284p. \$18 US. ISBN 0-9760576-0-3. Available from Parentbooks, Toronto; phone 416-537-8334.

Reviewed by Heidi Klaming

Thelma Wheatley's book is a personal narrative about parenting her autistic son Julian, whose violent rage outbursts accompanied by self-mutilation escalate in his teenage years, so that raising him and finding age-appropriate placements for him become next to impossible. What is so very disturbing about Thelma's story is that AUTISM/IMPOSSIBLE is intrinsically interwoven into Julian's diagnosis—AUTISTIC/RETARDED.

For parents who have never even heard of autism, the sudden impact of the totally unexpected confirmation of the severity of their son's condition brings with it a foreboding that from this moment on becomes part of the family experience. By sharing the intimate details of her family's life, Thelma transmits to the reader what this feels like and why she believes that it is an integral part of issues surrounding autism at the time of her son's diagnosis. Her personal researches into autism inform much of the book and support her findings.

Several factors help us to appreciate and understand the parents' dilemma. Julian was four and a half years old in 1976 when his condition was confirmed. Early intervention that would have benefitted him was not available at that time. The sense of wasted time adds to the distress. Also, the minimal contact that Thelma and her husband—both teachers—have had with the “retarded” in no way matches the abilities they witness in their son.

What begins to be apparent is that the experts—medical health professionals and educational advisors from whom the family expected direction—present the same conflicting and confusing mix of information that was already part of the parenting experience. Once Julian's condition had been identified, it seems that the entire support system is irrelevant as, according to the famous diagnostician, Julian would never amount to anything anyway! The firm recommendation to send him to a treatment centre accompanies the diagnosis and is documented in reports that only the experts are privileged to see. Any concerns or problems related to the extreme challenges of parenting Julian are subtly and conveniently silenced or dismissed by referrals to a placement equipped to handle him. Over and over again, parents receive the message that they are defying authority in choosing to raise their son and overestimating their parenting abilities.

What is remarkable about the parental perspective, as opposed to that of the experts, is that it embraces Julian's condition as helplessness rather than a case of hopelessness. The parents' dedication, determination and strength in supporting their son's unique needs, despite the roadblocks they meet at every turn, is fuelled by their love for this child, whose bright

intelligence radiates through the mask of very unusual and bizarre behaviours.

Fortunately, another diagnosis by Dr Joseph Huggins can help Julian in his teenage years when his rage outbursts are at their most extreme. The thorough assessment includes observation and explanation of the biochemical and neurological causes that are manifested as rage. A drug regimen specifically designed to stabilize Julian's biochemistry is implemented. His parents have to monitor his behaviour carefully to ensure the dosages are appropriate. For the first time since Julian's initial diagnosis, parental involvement is acknowledged, valued, encouraged and supported. The ultimate sigh of relief comes with Dr Huggins' reassurance that Julian is neither retarded nor psychotic.

By voicing all the issues and challenges surrounding her son's Autism/PDD, Thelma has successfully disentangled the impossible out of autism to place it in the very demanding context of the family's parenting experience. We are shaken by what we read.

O-n-e ...in autism

“We” is plural;
“I” is one;
But one is not defined
Even by science or faith.
Can cognition accept one,
If it is not defined?
And with one not defined,
How is two or five defined?
The multiple cannot be
If the singular has not been,
And the singular--one--is what I am,
With all the multiples around me...
What are these multiples?
Are they extensions of me?
Are they defined by my cognition of them?
Or are they totally devoid of me,
And how do I cognize their being?
That not only applies to people,
But to all that exist beyond my being,
Whether a leaf or a train or a musical note...
Once one is defined, then the process is there
For the multiples to be re-cognized,
And the faces known,
And the names remembered;
But without the one, there is nothing,
Not even the need or desire to speak,
As nothing is beyond the wall of separation
That keeps the one apart from the plural.

-Brian Henson©2004

Implementing Person-Centered Planning: Voices of Experience,

By John O'Brien & Connie Lyle O'Brien, Editors.

Toronto: Inclusion Press, 2002. 420 pages, paperback.
ISBN 1-895418-50-X. \$25.00 (A sequel to the authors' *A Little Book About Person-Centered Planning* (1998).

Michael W. Smull observed in 1996 that "person centered planning [had] undergone a transformation [since 1991]. It has gone from something mysterious that only a few dedicated and skilled people did to something where nearly everyone says 'I have been doing person centered planning for years.' Person centered planning and person centered services have become trendy. It has become a litmus test for being politically correct. Any activity where people are asked what they like or want is seen as person centered. Further, states, regions, and counties are beginning to require (or to consider requiring) person centered planning for everyone receiving services or entering services." <http://www.elpNet.net/foreveryone.html>

This collection is not about the trendy or easy uses of PCP, as the editors write in their introduction: "There is a hard way and an easy way to narrow the gap between current capacity and vision enough to make person-centered planning simple. The hard way involves increasing capacity so that a system finds it easier to offer personalized supports and a community is more familiar with people with disabilities as active participants. The easy way shrinks vision to match current capacity by keeping people's expectations within whatever a system can do without changing much. People get stuck within the box made by whatever a system finds it easiest to do. Person-centered planning activities can serve either people who choose the easy way or people who choose the harder way." (p.5).

Thirty contributors explore different ways to think about PCP, its possibilities and limitations, and the conditions for its success.

- Pete Ritchie, A Turn for the Better (defining features of PCP with reference to mental health)
- Connie Lyle O'Brien & John O'Brien, The Origins of Person-Centered Planning (history)
- Michael Smull, A Plan Is Not an Outcome (people need control of resources to implement their plans)
- David & Faye Wetherow, Community-Building & Commitment-Building (with some Canadian examples)
- Beth Mount, John O'Brien & Connie Lyle O'Brien, Increasing the Chances for Deep Change (12 resources that increase chances of real change in people's lives)
- Steve Holburn, The Value of Measuring Person-Centered Planning (including a bibliography of measuring processes and outcomes)
- David Pitonyak, Opening the Door (exploding typical ways of understanding challenging behaviour)
- Mary Romer, Two Is Not Enough (n family experience)

- Steve Holburn, The Weird Guy (a short story about encountering capacity)
- John O'Brien, Great Questions and The Art of Portraiture
- Beth Mount, The Art and Soul of Person-Centered Planning
- Jo Krippenstapel, The Rhode Island Facilitators Forum
- Mary Jo Almina Caruso & Kathy Lee, Some Words Along the Way (based on a long term project to develop competent facilitators)
- Michael Smull, Helping Staff Support Choice (a helpful way to clarify staff responsibility as people's freedom increases)
- Mayer Shevin, Communication Ally: the "missing-link" in PCP. Reflections on how people with communication impairments can take part in their own planning, starting with a nightmare scenario of how their team meetings etc must seem to many vulnerable people who don't speak:

"Imagine this: You arrive, unaccompanied, at a party you've been told in being held in your honor. When you get there, you find that all the others are wearing formal gowns and tuxedos—everyone but you. There is an elaborate array of food and drink, but you are allergic to everything on the buffet. Periodically, the other guests start to engage in an elaborate, intricate dance, which you have never seen before, to music you cannot hear. Hardly anyone speaks to you; eventually, someone does, but turns away before you reply. You feel increasingly helpless and ghostlike" (p.197)

- Karen Green McGowan, Getting Beyond Sick (medical obstacles and health benefits of PCP)
- Susannah Joyce, Mutual Learning: Involving People Who Use Mental Health Services
- Sally Shemsdorf, Sequoia: Planning with Senior Parents
- Connie Lyle O'Brien & Beth Mount, Pathfinders: Transition to Adult Life (in NYC)
- Connie Lyle O'Brien & John O'Brien, Large Group Process for Person-Centered Planning
- Debra McLean, A Simple Half-Hitch (using PCP to assist people succeed in jobs)
- Anne O'Bryan, Vocational Profiles (a form of PCP focused on supported employment)
- Jack Pealer & Sandra Landis, Some Beginnings (a process to influence a state's deinstitutionalization plans)
- Michael Smull, Thinking About Support Broker Roles (conditions necessary for service coordination)
- Helen Sanderson, Person-Centered Teams (team development process to ensure that PCPs are implemented in the daily reality of service settings)
- Pat Fratangelo & Jeff Strully, The Challenges of Person-Centered Work to Agency Leaders (moving their agencies from group-based programs to personalized supports)
- Martin Routledge, Helen Sanderson & Rob Greig, Planning with People: A National Strategy (in the UK).

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 (see <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.

To Adults and Families of Adults with ASD

Waterloo-Wellington Autism Services and Guelph Services for the Autistic are co-operating to support discussion of a possible farm community for adults with ASD. Our vision is of a community that may be able to offer some services for children also. We are thinking of a potential site for this project that would be excellent for testing some components of a farm community. We are asking you to participate in this survey in order to assess both the need and the interest in the following programs. At this time this is only in a discussion phase but your answers will allow for further development of ideas. Please respond before Jan 30, 2005.

This survey pertains to adults with autism spectrum disorders - 18 years and over (or those who will be 18 in the next year or so).

A survey form is included with this newsletter to people we think may be interested. If you have not received a survey and you or someone who know could be interested, please contact Moira with information on the following points.

1. Are you interested in:
 - a. Day programs (full or part time)
 - b. Weekend respite
 - c. Summer Day Camp
 - d. Overnight camp
2. What type of support would be required?
 - a. None/minimal
 - b. Moderate
 - c. One to one support
3. Can you contribute time or funds to the development of these projects?
4. Would you be interested in a trial day program consisting of some work (tree pruning or other outdoor chores) and a variety of other activities?
5. Any additional comments on your own needs and interests?
6. Your name, telephone number and email address.

We look forward to hearing from you and will discuss the results of this survey at our ASD Farm Community meeting on Jan 30, 2005. Please send your responses to:

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