



# SOUTHERN NETWORK OF SPECIALIZED CARE NETWORK HIGHLIGHTS

FALL 2014

## Southern Network of Specialized Care 7<sup>th</sup> Annual Research Forum

The 7<sup>th</sup> Annual SNSC Research Forum was hosted on September 22<sup>nd</sup>, 2014 in Brantford, Ontario. Fifty-five (55) cross-sector participants attended from across the region and including guests from Bethesda Services, Twin Lakes, HBBS, Woodview Mental Health Services, Christian Horizons, Salvation Army Ministries and Regional Support Associates (RSA), as well as the participants from Healthcare, Justice and the Education sectors.

The over-arching goal of the Research Forum is to provide an opportunity to showcase an eminent researcher in the field of developmental disabilities and to actively celebrate our growing list of SNSC-sponsored community-university (local) research & evaluation projects. The key note speaker at the Forum was Dr. Jonathan A. Weiss, Ph.D. (York University), a Clinical Psychologist registered with the College of Psychologists of Ontario.

Jonathan focused his remarks at the 7th Annual Research Forum on current research which examines the impact of Special Olympics on the psychological well-being of participants and of cognitive-behavioural and social skill interventions that promote resilience and improve the mental health of children and adults with developmental disabilities.



*Keith Anderson, Dr. Jonathan Weiss, Dr. Melanie Kelly, and  
Beth Anne Currie*

Findings thus far (more to come!) suggest there are correlations between athletes well-being and scores of happiness and aspects of healthy parenting. Athletes with Autism Spectrum Disorder (ASD) appear to struggle more in their lives and that a current profile of children and youth in Special Olympics show more involvement with ASD than even 10 years ago. The researchers wonder if Mental Health, (i.e. well-being) can be fostered by these well-designed community programs? As we all know, research is costly and takes time with gains that may not be directly apparent in the short term and we wish Jonathan well on his research journey.

For more information on Jonathan's research try: <http://ddmh.lab.yorku.ca/jonweiss/>) and (<http://ddmh.lab.yorku.ca/publications/>).

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# Southern Network of Specialized Care Sponsored-Research Projects

## APEX – Adapted Physical Exercise Project: (phase 2) University of Windsor

Presenters were Chad A. Sutherland, M.Sc., PhD Candidate, Applied Learning Coordinator Department of Kinesiology and Kelly Carr Kelly Carr, MHK, PhD Student, Department of Kinesiology at the University of Windsor. This project focused on exploring results when adapted physical exercise is applied with adults who have disabilities (ASD and IDD). The adults participated in an adapted exercise program (with assistance) twice weekly for 1.5 hours. Measurements were taken at the beginning (baseline), midway and at the end of the program. Stay Tuned!!

## Curriculum of Care Project (collaboration between Bethesda Services, McMaster University School of Medicine and Nursing (Niagara Campus) and the SNSC)

Presenter was Tom Archer, Regional Healthcare Facilitator, SNSC. The Associated Medical Services (AMS) has awarded a fellowship grant to enhance and advance a Niagara-based initiative that introduces medical and nursing students to people with developmental disabilities. The AMS Phoenix Fellowship grant is being used to create video-based resources aimed at fostering compassionate, person-centered care.

**The Curriculum of Caring currently has three phases of valuable experiential learning:**

1. The first phase introduces learners to people who tell their own stories about their needs, experiences and what they want from health care professionals. Videos were shared with the audience.
2. The second phase emphasizes communication and clinical skills.  
(Communicate CARE - Clearly, Attentively, Responsively and Engaging) .
3. The third phase encourages application of **C.A.R.E** in health care settings.

Send a note to Tom Archer @ [tarcher@bethesdaservices.com](mailto:tarcher@bethesdaservices.com) if you'd like to learn more about this evolving research!

## Resiliency in Families Caring for Adult Children with Developmental Disabilities at Home

Presenters were Dr. Irene Carter and Dr. Jim Coyle - Professors in the School of Social Work at the University of Windsor. Their research explored families (quality of life among other measures) who have adult children with developmental disabilities. Findings for these families included that they have increased health risks, a lower quality of life and that their ability to experience effective coping and personal growth depends upon Strengths & Resilience Based approaches and well-time community (service provider) interventions.

## Niagara Transitional Age Youth Project: “In transition: the Journey toward Adult Life”

Presenters were Natasha Durdan (OT – private practice) & Nancy Rushford (Alzheimer’s Society, Niagara) Their findings point to the need to reframe this “Transition” time. **Coaching was the phrase “coined” as the necessary vehicle for collaboration with youth in transition.** This Pilot research points to the need for the development of a Community of Practice that connects caregivers, parents and community-members who have Youth in Transition.

### **SUCCESSFUL TRANSITIONS**

Preparation (lots)  
Journey (patience)  
Landing (safety)

### **REALITY FOR YOUTH AND FAMILIES**

Uncertainty about next steps  
Fragmented Support  
Limited access to supports

### **BEST SUPPORT PRACTICE**

Capacity  
Navigation Help  
Collaboration between partners  
Education & research needed about this phase in the lives of youth with DD

**Save the date : 8<sup>th</sup> Annual SNSC Research Forum:  
September 21, 2015**



## Training In Partnership—Fall 2014

Fall arrived quickly and along with that, another Training in Partnership (TIP) series has begun. Once the flyer announcing the training was circulated mid-July, there was quick response and the training was filled by the end of August. Twenty two participants are currently enrolled in TIP. Many thanks to Community Living Brant who has generously provided the space for training at the Dunn Centre in Brantford. Participants attending come from throughout Hamilton, Brant, Haldimand Norfolk & Niagara counties.

The training generally has more representation from developmental services than the mental health sector, however this does not prevent lively discussion and valued learning from taking place.



*TIP Participants with Faculty member Kim Dillon at this fall's TIP session held in Brantford*

### When the Training in Partnership began in 2010, a number of principles were established in order to guide the training:

- Both the developmental services and the mental health sectors have a shared responsibility to serve people with dual diagnosis.
- When the sectors work together, there is improvement in quality of care for clients and their families.
- There are differences between developmental disability and mental health sectors that need to be mutually understood.
- The guiding framework for effective service to people with dual diagnosis is the bio-psycho-social model.
- Meaningful partnerships between and among services from the developmental disability and mental health sectors fill gaps in service and avoid duplication.
- The current training concludes in early December and planning will begin to offer TIP in the spring. Watch for the flier announcing its location in the New Year!

*The inclusion of family and caregivers as partners in each and every step and decision is imperative.*

## Message from SNSC's Coordinator, Liz Froese

As our sectors continue to transform, the Southern Network persists to reorganize our operational structure. With a community consultation process in May 2014 and the pending Community Networks of Specialized Care Ontario Evaluation report, we are about to land on a new way of working in the community. To guide our own transformation, we have outlined four goals as a road map to our continued work in supporting the system for people with a dual diagnosis, challenging behaviours and unmet health needs.

1. Collaboration	2. Training & Education	3. Research & Evaluation	4. Building Health Care Capacity
Developing consistency for specialized service delivery throughout SNSC	Dual Diagnosis: Trauma; Aging	Funded Community Based Research projects	Education & Training of Health professionals; DS Sector; Caregivers, Individuals
Each region—Crisis Protocol System map	Challenging Behaviour: FASD; Dots project	Supported Community Based Research projects	Complex Health needs system navigation
Regional aggregation of data: Specialized providers; Specialized Accommodation; DDJCM; DSO; ALC	Management: Cross Sector in Dual Diagnosis: TIP	Knowledge Translation and Exchange: Annual Research Forum; Research Digest	Curriculum of Caring partnership with McMaster & Bethesda
Collaborative projects	Self-Advocates	Evaluation	Community, University & College Partnerships

**Liz Froese**, MSW, RSW

Coordinator, SNSC



# The Neurobehavioural Model Comes to Niagara!



Nancy Hall, Master Facilitator in the delivery of the NB Model

The Neurobehavioural Model, developed by Fetal Alcohol Spectrum Disorder (FASD) expert Diane Malbin, is considered emerging best practice for the successful support of people impacted by prenatal exposure to alcohol. This model is the knowledge transfer piece for over fifty years of research on the brain, which gives us understanding and insight into the cause of behaviours and, ultimately, what to do about them. Nancy Hall, Facilitator for the Southern Network of Specialized Care in Niagara, Haldimand, Norfolk and Brant, has been mentored by Diane Malbin for close to two years, in the delivery of the Neurobehavioural Model (NB Model). She has successfully received her Master Facilitator certificate in the model and continues to develop her skills with ongoing mentorship and

networking. In September 2014, Niagara professionals began attending the first of four sessions being held in Vineland, focussed on the understanding and application of the NB Model. A total of 80 people, working in health, justice, developmental services, mental health, education and youth services signed up for this valuable training.

## Logic model: Is FASD a physical condition?

Genetics, trauma, and a wide range of teratogens and events cause physical changes  
Alcohol kills cells, including in the brain  
Alcohol and other drugs affect the structure and function of the brain  
Behaviors are usually the only symptoms...

It follows then.....that FASD is an invisible physical disability with behavioral symptoms

## ***If FASD is an invisible physical disability***

***Then providing*** accommodations for people with FASD is as appropriate and effective as providing accommodations for people with other physical disabilities. (D. Malbin)

When presenting symptoms of a physical disability are behavioral, identification of accommodations is more elusive, e.g., modifying timelines, providing alternative instructional strategies, or recognizing developmental rather than chronological age. However, just as outcomes are improved for others with visible, physical disabilities whose needs have been addressed, preliminary clinical findings show improved outcomes for children, families and professionals when a brain based approach is adopted by caregivers and support individuals.

This is very different from using behavioural interventions and requires a shift in our behavioural paradigm or perspective. This new paradigm redefines the meaning of behaviors and supports development of a more holistic and integrated method for considering all facets of the person – physical, developmental, and cognitive. The NB model provides an organized approach for rethinking the meaning of behaviors, and generating person-centred, relevant accommodations.

***“This training is both beneficial and necessary for those supporting individuals with FASD, and will help decode some of the mystery behind this commonly misunderstood disability.”***

***-Maria Cosco, Lawson Ministries***





## Developing Capacity Across the Sectors: Aging and Intellectual Disabilities

In the winter of 2012, the Haldimand Norfolk Senior Partnership group decided to apply for Trillium funding, for a three year project, focussed on developing capacity to better support adults with Intellectual Disability, as they age. The Senior Partnership is a collection of partners, from multiple sectors such as Mental Health, Health, Developmental Services and Long Term Care; who came together in 2006 to collaboratively explore ways to enhance current awareness and understanding of this specific population.

The proposal submitted described a three year training plan that included both a large community initiative to recruit internal champions from a variety of agencies to participate in a Training of Trainers on Aging and Intellectual Disabilities as well as an online component to both increase access to the curriculum information as well as to provide an expansion of the curriculum content to include topics of interest to families and caregivers. In the spring of 2013, Trillium approved the request for funding and the project began!

Year one of the project has focussed on development of a curriculum with the support of consultants with expertise on the various subjects. The curriculum prioritized; a brief history of developmental services and the experiences limiting access to good health care, information about people with developmental disabilities and the changes that can take place as they age,

dementias and, lastly, reactive behaviour and what to do about it. The draft curriculum was vetted by two experts in the field, once completed, to ensure that best practices were being highlighted and taught. On Sept. 15<sup>th</sup> and 16<sup>th</sup>, 2014, 28 trainees received their training, practiced delivering the material and had an opportunity to discuss topics or ask questions. The staff team included Lisa Whittingham, Behaviour Consultant; Susan Wavell,



Lisa Whittingham, Behaviour Consultant, supporting a new trainee.

Executive Director, Community Living Haldimand; Susan Cumming, Public Education Coordinator and Kathie Savage, Psychogeriatric Resource Consultant both from the Alzheimer's Society of Haldimand Norfolk.

Evaluations of the trainings will be completed, ongoing, to confirm the development of increased capacity within the 14 local participating agencies. News about this project has spread and response to date reflects the need for this capacity to be developed across the province.

### ***Training Grants Now Available!!***

The Southern Network of Specialized Care (SNSC) is pleased to share that funding is available to assist agencies address the training needs of staff who are dealing with specific challenges related to an individual/s who are dually diagnosed and/or have challenging behaviour and/or unmet health needs. Working with their local clinical provider, and meeting the grant criteria, funds to a maximum of \$5,000.00 can be made available. An eligible request for the training and education grant will provide specific knowledge and expertise that will enhance the participant's skills to support individuals with a developmental disability and co-existing mental health issue and or challenging behaviour and/or unmet health needs. The requests may be made to train staff teams and where possible and appropriate, the training can be opened to the larger community as an opportunity for knowledge transfer. The SNSC Education and Training Grant Request Form can be found on the CNSC website ([www.community-networks.ca](http://www.community-networks.ca)). Click on Resources, then enter "SNSC training grant" in the search box and you will find the training application in one of two formats, a fillable electronic form and a PDF that can be printed. Once the form is completed, forward to the SNSC staff in your area. These names can be found on the last page of the application form.



## BUILDING HEALTHCARE CAPACITY

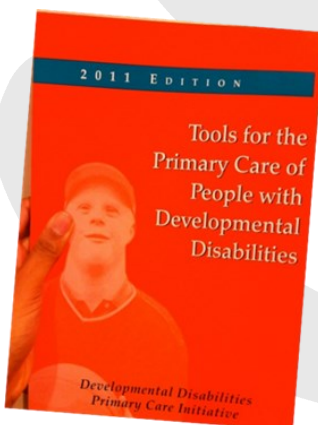
The Southern Network now has its full complement of Healthcare Facilitators with the addition of Cindy Chatzis, RPN as the Healthcare Facilitator for the Southwest Region of the network. Welcome Cindy!



Tom and Cindy have been pounding the pavement from beautiful Niagara Falls to the home of Wiarton Willy providing training and education to healthcare practitioners, developmental service agencies and students in a variety of fields.



In the Southwest, most of the Healthlinks tables are still in the planning stages and the Healthcare Facilitators remain active in the steering committees for these valuable resources. We strongly believe that positive outcomes for some of the people we support will be seen with the wrap around model of the Healthlinks. This will serve as a collaborative view on preventative health measures and problem solving for individuals who are high users of the Emergency departments and those with difficulty in getting out of hospital and back into their home community. We look very forward to this work. Tom and Cindy have, individually and collaboratively, provided support to individuals with unmet health needs, helped their caregivers to manoeuvre the complex healthcare system, identify where health outcomes could be improved through the sharing of resources/collective learning and provided support on issues such as Healthcare Consent, Swallowing Difficulties and Plain Language Guides.



Some of the focus of this year has been the development of capacity on the Primary Care Guidelines and associated tools for staff working in Developmental Service agencies. We know that having this information and these tools on hand when attending medical appointments or for ongoing

monitoring of the health status of the people they support can be monumental in getting equitable and quality healthcare specific to their needs.

The health needs of an aging population of people with developmental disabilities are becoming more complex. Tailored training can be proved to support the learning and development of staff teams. Contact your local Facilitator to let them know about your needs in this regard.

### HOT TOPIC—DIAGNOSTIC OVERSHADOWING

Perhaps the most detrimental barrier to adequate assessment and care of individuals with Developmental Disabilities is Diagnostic Overshadowing.

The tendency of caregivers and health providers is to overlook symptoms of health or mental health issues by attributing the symptoms to being a part of the person's developmental disability. Although unintended, this prejudice clouds thinking, interrupts analysis and shrinks the number of questions being asked.

When we are looking at the problem behaviours of people with disabilities we need to understand, and always remember that some human problems result in some human behaviours. Problems can cause behaviours, but behaviours aren't always problems.

The first step when you notice a change in the behaviour of someone you are supporting is to rule out all possible health concerns. Research has shown that a large portion of behaviour challenges can often be attributed to unmet health needs. If these health issues are not addressed, a person can experience tremendous suffering and, in some cases, early death as a result.



## CURRICULUM OF CARING

A wonderful luncheon was held on September 20 to celebrate the people and accomplishments of the Curriculum of Caring (CoC). The Curriculum of Caring was initiated in 2010 as a way to provide medical and nursing students with exposure, communication / clinical skills, and application of these skills so that they can provide capable, compassionate, collaborative, and person / family centred health care to people with developmental disabilities. Over 100 people involved in the work attended, including members of the Momentum Choir, simulated patients who acted in the education / training individual videos, family members who contributed in the project, faculty and students from the Niagara Regional Campus of McMaster's Medical program and Brock University's Nursing and Applied Disability Studies programs, staff support from Bethesda, and many other people who committed their time and energy to this important work. Guests were 'walked up' a red carpet and had an opportunity to pose for fashion photos at a photo booth. Many guests volunteered to describe their experiences with the project and their hopes for the future in a video booth.



*Tom Archer, SNSC Healthcare Facilitator, pictured here with Terry Broda, Nurse Practitioner, Ottawa; Kevin Hobbs, Standardized Patient Educator, McMaster; and Dr. Kerry Boyd, CoC Founder, Bethesda*



*Tom Archer, SNSC Healthcare Facilitator, with Anjie (Actor in education videos, Singer in Momentum Choir)*

The luncheon featured musical performances from Momentum Choir, the viewing of several education/training videos used in the project, and Dr. Boyd's announcement of additional funding from the Associated Medical Services Phoenix Project for enhancements. In the coming years, the project will focus on expanding the Curriculum of Caring to other health care education centres across Ontario. To support this work, a website <http://communicateCARE.machealth.ca> has been created. The website currently features "voices of experience": videos of people affected by disabilities and caregivers sharing their perspectives and wisdom. Over the next year clinical skills videos illustrating adaptations for interviewing people with developmental disabilities will be added as well as video interviews of provincial experts on providing health care to people

with developmental disability and links to resources. Other activities planned include the mapping out of current developmental disability medical education at Ontario universities and colleges, and the development and sharing of additional medical education resources for this population. In addition to the AMS Phoenix Project, the CoC receives sponsorship from Bethesda and the SNSC.

A recent on-line information session on the CoC can be found on the Ontario Telemedicine Network's Web Archive system. To access this and other CNSC webinars, enter <http://webcast.otn.ca> into the address bar of any browser and you will see the options "Archived Events" and "Live Events". All CNSC events are PRIVATE. Enter cns1 as USERNAME and network1 as PASSWORD.

Click [here](#) to access the Curriculum of Caring webcast.





## PROFILING: Cindy Chatzis

Having received her education through Mohawk College and McMaster University, Cindy has been in the healthcare field for over 20 years with 8 of those years spent in Developmental Services. Cindy has held both front line nursing and management positions within the developmental services sector and with her additional experience in Emergency, Complex Medical and Psychiatry, the role of the Healthcare Facilitator with the Southern Network merges all of her prior career paths into one.

Cindy also sits on the Board of Directors at Brantwood Community Services, has taken the Executive Leadership course through Queen's University and is trained as a Restorative Justice Facilitator.



### Upcoming Events

- ⇒ **Nov. 21, 2014: A Guide to Eating and Drinking Safely**
  - ⇒ **Jan. 16, 2015: Dynamic Strength-based Peer Groups**
  - ⇒ **Feb. 27, 2015: The Importance of Faith & Culture for People with Intellectual Disabilities**
- Connect with Sue Benko for the above events at:  
[sbenko@wgh.on.ca](mailto:sbenko@wgh.on.ca)
- ⇒ **May 7, 2015: Hamilton Trauma Conference featuring Lori Haskell. For further details, contact Nancy Hall at: [nhall@bethesdaservices.com](mailto:nhall@bethesdaservices.com)**



[www.community-networks.ca](http://www.community-networks.ca)

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