



# SOUTHERN NETWORK OF SPECIALIZED CARE

## NETWORK HIGHLIGHTS

Spring and Summer 2013

## CNSC-ON Hosts Education Event for Clinicians

The Community Networks of Specialized Care brought together over 150 developmental service and mental health clinicians from across the province on May 1 & 2 to learn more about Functional Analysis and Treatment of Severe Problem Behaviour in individuals with a developmental disability from Dr. Brian Iwata of the University of Florida.

Dr. Iwata is the leading expert in functional behaviour analysis (FBA), which is considered to be the standard in the field for both clinical research and practice, and is mandated in U.S. federal law (IDEA, 1997). FBA identifies environmental factors that maintain and exacerbate problem behaviour and is essential to the development of reinforcement-based (non-aversive) behavioural interventions.

Dr. Iwata received his Ph.D. in Psychology from Florida State University and is currently Professor of Psychology and Psychiatry at the University of Florida, where he has served as director of the Florida Center on Self Injury and the UF-ARC Prader-Willi Syndrome Program. He previously held faculty appointments at the Johns Hopkins University School of Medicine and at Western Michigan University. His primary area of interest is disorders of learning and behavior. He has published over 225 chapters and articles on these topics. Brian is the former editor of the Journal of Applied Behavior Analysis and former president of the Association for Behavior Analysis, the Society for the Advancement of Behavior Analysis, the Society for the Experimental Analysis of Behavior, Division 33 of the American Psychological Association, and the Florida Association for Behavior Analysis.

During the two-day conference, Dr. Iwata reviewed the history, logic, and techniques of FA methodology as well as alternative approaches to assessment, suggested solutions for dealing with the practical constraints of assessment, and linked the outcomes of assessment to the development of treatment strategies. Recent research and case studies illustrating the use of assessment and treatment procedures were also presented.

Held in Guelph, the conference was a collaboration between the four provincial Community Networks of Specialized Care and was offered at no cost to staff and clinicians working in the province's specialized accommodations (treatment homes) for individuals with a dual diagnosis.



*Dr. Iwata with the Community Networks of Specialized Care Coordinators, Marnie McDermott, Lisa Holmes, Liz Froese, Sandie Bricker & Trevor Lamb*

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In addition, the Southern Network of Specialized Care sponsored a full-day session on May 3rd for the region's clinicians where they had the opportunity to present current cases and seek feedback from Dr. Iwata.

Many clinicians took advantage of this opportunity to hear how functional assessment can be utilized in their current practice to improve outcomes for the individuals they support.

The Community Networks of Specialized Care have a mandate to train and build capacity in the community.

Events such as the Dr. Iwata conference are one of the ways in which the Networks assist developmental and mental health service providers to increase their knowledge and skills to support individuals with complex behaviour in the community.

***Pictured above and below are Dr. Iwata, clinicians and family members at the 3rd day of the conference held this past May 3rd in Port Colborne.***

The third day was a real gift for the clinicians of the Southern Network. We are very appreciative of our two regional MCSS offices for providing resources so this day could happen. It was transformative to take the theory and knowledge of the two-day conference and on day three, experience Dr. Iwata's caring, compassionate responses to the families and clinicians that presented their complex situations to him for consultation. It had a huge positive impact on the families.

The Dr. Iwata conference continues to spark discussion and is prompting great clinical debate. One behaviour consultant commented that "it is prompting great clinical conversations and we are getting better quality clinical judgements because of the discussions happening from the Dr. Iwata conference". All three providers of behavioural services in the Southern Region are bringing the theory and knowledge learned at the conference to their team meetings, and resolving to continue the discussion to improve behavioural services.





# A Message from our Network's Coordinator Liz Froese



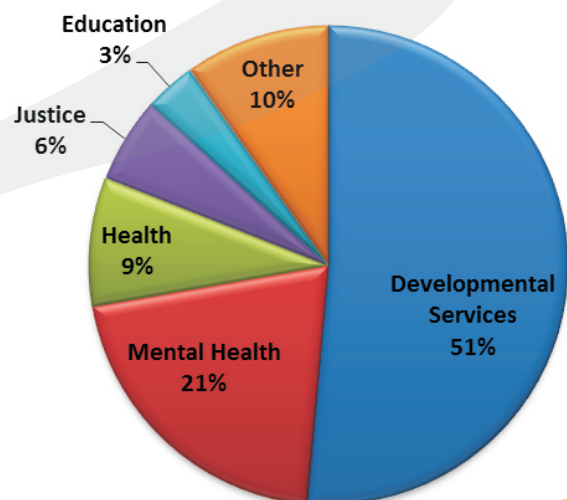
**Co-leads Brian Davies (on left) and Jason Young pictured here with Liz Weaver of the Tamarack Institute for Community Engagement at our May 13th Annual Southern Network's Advisory Committee and Co-Chairs meeting.**

May 13th was a day for the Southern Network's Advisory Committee and Co-Chairs of the Local Network and Dual Diagnosis Committees to gather and reflect on where we have been in 2012/2013 and where we need to move as a collaborative body in 2013/2014.

The Southern Network has healthy cross-sectoral representation at our local and regional collaborative tables. Liz Weaver, Vice-President of the Tamarack Institute for Community Engagement, lead us in an engaging day exploring tools to enrich our collaborative work and strategies to influence greater community impact. To find out more about the Tamarack Institute go online to [www.tamarackcommunity.ca](http://www.tamarackcommunity.ca)

The Southern Network's Annual Report for 2012/2013 can be obtained from me or any of the Southern Network Facilitators or by going to our website [www.community-networks.ca](http://www.community-networks.ca)

## Sector Representation at SNSC Planning Tables



*Liz Froese*, MSW, RSW  
Coordinator  
Southern Network of Specialized Care



# Update on the Primary Care Initiative



*SNSC Health Care Facilitators, Deb  
Laurence and Tom Archer*

Life expectancy of people who have developmental disability has increased dramatically over the last 20 years. Individuals who have mild developmental disability have very similar life expectancy to the general population. Individuals with multiple / severe disabilities and/ or Down syndrome tend to have shorter life expectancy.

In addition to aging issues that affect the general population, there are health issues more prevalent with people who have developmental disabilities.

Higher health risks have been associated with developmental disability. Pre-existing health conditions often become more concerning as the individual ages.

Here is a list of two conditions and some of their associated health risks:

- **Down syndrome:** vision & hearing, cardiovascular, sleep apnea, osteoporosis, epilepsy, dry skin, dementia, hypothyroidism, testicular cancer
- **Fragile X syndrome:** vision & hearing, cardiovascular, gastro esophageal reflux disease, abdominal hernia, scoliosis, epilepsy, early menopause

A considerable amount of attention has been focused on the high rates of dementia associated with Down syndrome. Dementia occurs earlier, progresses faster and becomes more severe. Dementia is not seen in higher rates with other conditions associated with developmental disability.

A number of other factors contribute to an increase in the frequency and intensity of health care concerns for people who have developmental disability as they age. As a group:

- Their health issues are more difficult to assess and treat early if they have difficulty communicating signs and symptoms of illness;
- They take more medication and therefore experience more adverse drug affects;
- They have higher rates of obesity related to lower levels of exercise and poor nutrition;
- They have lower participation rates in health promotion activities;
- They have lower rates of annual physicals as well as dental and vision assessments.

A number of resources are available to assist health care providers, caregivers, and individuals to improve the health of people who have developmental disability. Tom and Deborah, your SNSC Health Care Facilitators, are available to help.

Additional information on this subject can be found at:

[www.opadd.on.ca](http://www.opadd.on.ca)

<http://shrtn.on.ca/community/aging-and-developmental-disabilities-add-community-practice>

<http://aadmd.org/ntg/task-groups>

Healthy Aging Education/Training and Planning Activities in the Southern Region:

The Southern Network of Specialized Care (SNSC) has been involved in hosting or supporting a number of activities related to healthy aging over the past 6 months, including:

- Dec 06: SNSC provided a community networking day on Healthy Aging with Developmental Disabilities;
- Jan 21: SNSC participated in a seniors community resource fair hosted by St. Joseph's Hospital (Hamilton);
- Feb 22: SNSC hosted a video conference on Healthy Aging;
- Mar 15: SNSC hosted a training event for Behaviour Services Ontario & Long Term Care Homes in LHIN 4;
- Mar 20: Ontario Partnership on Aging and Developmental Disability (OPADD) hosted Cross Sector Education and Collaboration Conference brought together speakers and key planners in the developmental and the senior sectors in Stoney Creek.





# An Update from our Research Facilitator, Beth Anne Currie

The Southern Network of Specialized Care (SNSC) is pleased to support a number of different research and evaluation projects that are evolving across the Network. The projects are sponsored financially or facilitated by SNSC staff leadership along with active partners and collaborators across the region. This update provides a regional context and a snapshot of key projects within geographical areas.



Beth Anne Currie

## **NETWORK RESEARCH ON-LINE SURVEY** *(research)*

The Network Gaps/Barriers/Strengths and Solutions research project was launched regionally in January 2013 through an on-line survey to over 200 key stakeholder and partners in the developmental, health, justice and educational sector across the region. There have been repeated calls for participation (N=92) before the survey closes on April 12th, 2013. We anticipate a strong regional response that will help build a robust data base that will strengthen the understanding of the gaps, barriers, strengths and solutions that exist at local and regional tables for ongoing planning in the service and support of people who have dual diagnosis.

## **TRI-COUNTIES** (Windsor-Chatham-Sarnia) *(research)*

There are (2) SNSC-sponsored research projects that continue to evolve in the Windsor region.

One project (McKeen et al) received some radio and TV notoriety early this year with some excellent coverage about their research project and findings in the Windsor region. An article appeared in the Windsor Daily News <http://www.uwindsor.ca/dailynews/full-issue/2012-12-13> and The Windsor Star carried a similar version. McKeen's project examined the impact of training (physical) on fine-motor skills strengthening for people with ID/autism over a period of time. The results have excited the University of Windsor's kinesiology department who plan to expand their focus and research on this target population.

Another Windsor-based project (Carter et al) is recruiting and interviewing candidates for a research project that has been funded and supported by the SNSC. Their project seeks to explore the resiliency and coping strategies of parents who are continuing to "parent" their adult children with IDD at home. The researchers will be using both a qualitative interview guide as well as a quantitative tool to examine how support and service systems can work to support aspects of resiliency and coping strategies of parents with adult children living at home.

## **GREY BRUCE - SURREY PLACE FASD PROJECT** *(research)*

The Grey Bruce -Surrey Place FASD research project received funding and ethics approval from the Southern Network of Specialized Care Research Ethics Committee and some start up funding from the SNSC. The researchers are made up of 2 members of the SNSC, a Community Living Kincardine and District supervisor and a psychologist from Surrey Place. The researchers would like to acknowledge that core funding has been provided by the SW Regional HSJCC table (Human Services Justice Coordinating Committee) that fostered the hiring of a research assistance who has completed 14 participants (adults with confirmed FASD) and 14 key support professional interviews (N=28) to date. The rich narrative data is being synthesized at present and the researchers have submitted an abstract for consideration in hopes of presenting their findings at the Provincial HSJCC Conference in November 2013.

## **NIAGARA** *(research)*

An SNSC-funded project is being lead by two Occupational therapists and their community-based collaborators in the Niagara region. They seek to explore and examine issues/strengths and gaps/barriers in their community around Youth in Transition ie. those youth with IDD who are transitioning from secondary school to adult life. They are currently recruiting participants for their study and will be presenting some preliminary findings at the upcoming Research Forum in September 23, 2013.

## **NETWORK RESEARCH DIGEST** *(publication)*

The Research Digest is a bi-annual Network-supported publication that aims to bring relevant research and evaluation findings to the front line. Volume 6 (2013) was developed and distributed both electronically and in print to a wide audience in May 2013. This Volume highlighted in plain language, the important findings of Ontario-based researcher and ID specialist, Dr. Yona Lunskey and associates, who have been researching the experiences of both individuals, families and hospital staff around Emergency Department (ED) visits in the last few years.

See the Research Digest (on-line) at:  
[www.community-networks.ca/en/resources?tx=&pos=9](http://www.community-networks.ca/en/resources?tx=&pos=9)

## **NETWORK TRAUMA INITIATIVE** *(evaluation)*

A regional trauma initiative is being lead by a multi-agency steering committee that supports an evaluation sub-committee who are working to develop and test pre/post instruments and other evaluation tools to determine and evaluate the impact and effectiveness of trauma-informed training for clinicians and direct support professionals that is rolling out across the Network via its specially trained collaborating partners and clinicians.



# SNSC Local and Regional Facilitators' Updates

## Grey-Bruce Noticed by the Province for Fetal Alcohol Spectrum Disorder Work

April 22, 2013 – Representatives from the Grey/Bruce Fetal Alcohol/Neurodevelopmental (FA/ND) Leadership Team proudly walked to the front of the room to receive the Community Award for Excellence at a Toronto symposium recently. The event was hosted by the Public Health Agency of Canada and the Fetal Alcohol Spectrum Disorder Ontario Network of Expertise (FASD ONE).



*The Grey-Bruce FA/ND Leadership Team with their FASD ONE Award*

The focus of FASD ONE Blueprint for Action: Collaborating Toward Effective Practice is to define Ontario's response to the significant health, social, and economic issue as it relates to fetal alcohol spectrum disorder.

FASD is estimated to affect 1% to 3 % of Canadians. It causes brain damage resulting in a range of disabilities including mild to severe delays in cognitive, physical, emotional, social and behavioural skills and is the leading cause of preventable brain based, developmental delays. It is a life-long disability for which there is no cure.

The symposium highlighted the impact of cross-sector collaboration on outcomes for individuals and caregivers living with FASD to discuss service efficiencies and effectiveness.

The Grey-Bruce FA/ND Leadership Team was established a year and a half ago, and clearly understands how gaps, barriers and opportunities within this field impact on our collective interest in making services more accessible and effective for those affected by FASD, directly or indirectly.

According to the June 2008 Canadian Community Health Survey, 34% of Grey-Bruce Residents who drink alcohol engage in binge drinking, 12% higher than the

provincial or national average. Another study revealed that 4% of babies born in Grey Bruce had been significantly exposed to alcohol in utero, also much higher than the provincial average. The financial cost alone to support an individual with FASD is \$1.5 million throughout their lifetime. These staggering statistics motivated local agencies to form the leadership team realizing the need to collaborate services on this critical issue.

Members of the local committee include representatives from agencies such as Developmental Services, including the Southern Network of Specialized Care and Regional Support Associates, Court Services, Child Welfare System, Educators, Ontario Works, Mental Health, Public Health, and Justice.

Their vision "The community of Grey Bruce will have a shared understanding, acceptance, and support for individuals with Neurobehavioural conditions specific to Fetal Alcohol Spectrum Disorder" drives all of the hard work this group is involved in. They are focused on prevention, developing a diagnostic clinic, justice issues, family support, communication and promoting policy change.

For additional information please contact Lynda Legge, Co-Lead of the Grey/Bruce FA/ND Leadership Team, 519.881.0922 ext. 2405 or Toll Free 1.800.640.4106 or [llegge@wgh.on.ca](mailto:llegge@wgh.on.ca)





# The Neurobehavioural Model: Into Action

## Specialized Training of Trainers for Increased Capacity to Serve Persons with FASD

The core concept of Into Action is that brain function is the source of behaviours and that a neurobehavioural approach applies to Fetal Alcohol Spectrum Disorder / Neurobehavioural (FA/NB) brain-based conditions regardless of specific cause. It is an alternative foundation for re-framing the meaning of behaviours, a neurobehavioural paradigm. The goal of Into Action is to contribute to establishing informed networks of care and application of this understanding all settings.

Into Action answers the questions, "What is FA/NB?" and "What do we do?" by linking brain function with behaviours and providing a method for implementing a neurobehavioural approach. This approach considers the person and fit within environments, providing a structure for systematically developing appropriate strategies and managing the complexity associated with the spectrum of symptoms.

Diane Malbin, MSW, from FASCETS in Portland, Oregon, developed this model and a 'Train the Trainer' curriculum to provide individual professionals, working in the field, an opportunity to become Facilitators to deliver this model to local communities. The training included an extended four day in-person training in Oregon in March of 2013, and will continue with one year of mentorship, for all participants, from Diane Malbin.

22 individuals participated representing the United States, Canada, and Tanzania. This group included the Southern Network's Nancy Hall, who works out of Niagara, Haldimand and Norfolk counties. She will be available to provide this specialized training across Ontario beginning in January of 2014! For more information contact Nancy at [nhall@bethesdaservices.com](mailto:nhall@bethesdaservices.com).



*Nancy Hall, SNSC Facilitator with Diane Malbin of FASCETS*

## Chatham-Kent Establishes an FASD Network



*Sue Benko, SNSC Facilitator for Chatham-Kent, Windsor-Essex and Sarnia-Lambton*

January 2012 saw the development of the Chatham-Kent Fetal Alcohol Spectrum Disorder Network. With Chatham-Kent Public Health Unit taking the lead, the Network's membership has grown over the past 15 months and now includes representation from the C-K Public Health Unit, Boards of Education, Canadian Mental Health, Restorative Justice C-K, Community Living, C-K Children's Services, Walpole Island First Nations, C-K Community Health Centre, the Southern Network of Specialized Care, Thamesview Family Health Team and Caregivers who are able to share their lived experience with FASD.

This energetic group of community partners have already accomplished a number of projects. Most recently the FASD Network was host to an educational opportunity for professionals. On April 4th, 88 people attended a 3 hour evening session with Nancy Hall, Facilitator with the SNSC. In addition, the group has developed an information brochure for educators which is now being distributed throughout the Public and Separate School Boards and holds monthly support groups.



## Profiling: Doris Thérien

Doris was born in Lac-St-Jean Quebec and moved to Woodstock ON when she was 5 years old. She has a certificate in professional photography from Fanshawe College. After working at Nelson's Photography for over 20 years she then moved on to London Life Assurance Company for 8.5 years where she held the role of Assistant Team Leader. Doris, eager to begin work in the Developmental Services sector, joined the Southern Network of Specialized Care in February 2013. She is our new Bilingual Administrative Assistant and is based out of the Woodstock Hospital within Regional Support Associates. Doris is married to her husband, Yves and has two daughters; Alexandra attending University of Ottawa and Nicolas attending École Secondaire Notre Dame in Woodstock.



## Upcoming Events Mark Your Calendars!!

- June 21st* - Aging Gracefully: Issues of Aging in People with a Developmental Disability/ Dual Diagnosis - Presented by Terry Broda - Stratford; [llegge@wgh.on.ca](mailto:llegge@wgh.on.ca)
- June 25th* - Dual Diagnosis and the Bio-PsychoSocial Approach presented by Terry Broda [www.tricountytraining.org](http://www.tricountytraining.org)
- July 12th* - VC Training: Ethical Considerations in Program Evaluation vs Research, Denise Grafton - [sbenko@wgh.on.ca](mailto:sbenko@wgh.on.ca)
- September 23rd* - Annual Research Forum - [bethannecurrie@sympatico.ca](mailto:bethannecurrie@sympatico.ca)
- September 27th* - FASD: Building on the Basics with Louise Scott - [www.fasdelmo.wordpress.com](http://www.fasdelmo.wordpress.com)

## SNSC Advisory Committee

- Dr. Jay Rao** - Regional Mental Health Care London  
**Leo Massi** - Haldimand-Norfolk R.E.A.C.H  
**Lynda Nicholson** - Community Living Six Nations  
**Mary Westerhof** - St. Joseph's Health Care Hamilton  
**Maurice Voisin** - South-East Grey Support Services  
**Nancy Wallace-Gero** - Community Living Essex  
**Shelley McCarthy** - Family Counselling Centre of Brant  
**Mark Benner** - Fanshawe College  
**Connie Smits** - Community Living Sarnia  
**Heather Callender** - St. Leonard's Community Services, London  
**Jenny Barretto** - HNBHN LHIN  
**Dawn Maziak** - Erie St. Clair LHIN  
**Patty Chapman** - South West LHIN  
**Lea Pollard** - DSO Hamilton Niagara  
**Kevin West** - Probation and Parole Services, Niagara Falls  
**Bob Fehir** - CMHA Oxford  
**Mary Gregg** - Alexandra Marine and General Hospital, Goderich
- Co-Leads  
**Brian Davies**  
Bethesda - Network Co-lead  
**Jason Young**  
RSA, Woodstock Office - Network Co-lead
- Ex-officio  
**Liz Froese** - SNSC Coordinator  
**Rosanne Perron** - MCSS Southwest Region  
**Wilma Van Staaldunin** - MCSS Hamilton

