



# SOUTHERN NETWORK OF SPECIALIZED CARE RESEARCH DIGEST Making Research Real

Spring 2012

## Welcome to Volume 4 of the Research Digest

Welcome to the 4th edition of the Research Digest, the Southern Network of Specialized Care's forum for sharing current developments in the field of dual diagnosis research and evaluation.

The Research Digest is designed and published twice per year with the intent to inform, educate and engage a wide team of direct service professionals and clinicians. The Research Digest is also a great way to showcase academic and locally-grown research and evaluation projects that can make a difference in the care and treatment of persons who have dual diagnosis.

Everyone agrees that research can be a bit boring unless it is written in a meaningful way for its intended readership. We want to hear from you about your reaction to the Research Digest. Please send us an email and tell us what you think! In the next year, you may be asked to tell us what you think about the Research Digest in a paper or an on-line survey. We look forward to hearing from you!

### OPPORTUNITY!!

To ensure the Research Digest continues to meet your needs, the Southern Network seeks to engage two direct support professionals as corresponding members of the Research Digest Editorial team. Each corresponding member will receive a stipend to support their time. See contact information below.

### About Volume 4

This volume will introduce you to a real-live researcher who concentrates all of her time on persons with developmental disabilities. You'll find out why she chose a career in research and why she thinks it's important for you to read about research findings whenever you can!

You'll also read about two locally-grown evaluation projects in the Southern Network. They were funded and supported by the Research Committee of the Southern Network of Specialized Care and we are very proud of them!

If you have any comments or questions, or would like to discuss a research or evaluation project, please send an email to Beth Anne Currie, the Southern Network's Research Facilitator. Similarly, if you are a direct support professional and would like to help us on the editorial side of producing the Research Digest, please send me an email at [bethannecurrie@sympatico.ca](mailto:bethannecurrie@sympatico.ca)

Sincerely, *Beth Anne Currie*

#### in this Issue:

Welcome to the 4th edition of the Research Digest .....	page 1
Introduction.....	page 1
Research Committee/Review of Huron Perth Research Project.....	page 2
Review of Haldimand and Norfolk Research Project.....	page 3
Feature Interview with Researcher on Intellectual Disabilities.....	page 4-5
Disclaimer.....	page 6
Next Steps .....	page 6

## Southern Network Research Committee



*Leo Massi*

*Liz Froese*

*Dr. Jay Rao*

*Keith Anderson*

*Dr. Melanie Kelly*

*Beth Anne Curie*  
(Research Facilitator)

Absent from photo:  
*Alyson Wilson*

## **REVIEW OF SNSC FUNDED PROJECTS:**

### **A Review of Secondary School Transitions to Work Experience in Huron and Perth Counties**

The secondary school transitions work experience project began in the fall of 2009 with a group of key stakeholders committed to exploring the benefits associated with providing enhanced employment opportunities for students with developmental disabilities in Huron and Perth counties. Youth who transition from secondary schools to full adult life experience a myriad of problems including finding and maintaining meaningful paid employment, difficulties accessing affordable housing, social or recreational networks, support workers and other issues.

A partnership was formed between the Avon Maitland District School Board, Community Living Ontario, Community Living South Huron, the Huron Perth Catholic District School Board and Partners in Employment (PIE) Huron and Perth. A collaboration agreement supported the delineation of roles and responsibilities and helped establish an advisory committee to support this project.

#### Why was the research deemed important in the first place?

The secondary school transitions work experience project recognized the importance of evaluating the effectiveness of a “made in Huron Perth” enhanced employment model in order to make future program planning decisions. The researchers also knew it would make a valuable contribution to learn about how employers, employment facilitators, teachers, parents, students with disabilities and school boards can work together to support programs that introduce meaningful work experiences, on-the-job skills and resume writing skills to students with developmental disabilities while they attend secondary school.

#### What was actually done?

The researchers explored the perceptions and experiences of five target audiences (6 students ages 16-23; their parents, their employment facilitators, their teachers and their employers) who were involved in the project.

#### How was it done?

The researchers designed key informant interviews that were used to gather information from the target audiences. These in-depth person-to-person interviews were conducted in person and by phone using open-ended questions. The researcher removed identifiable and confidential information and prepared a final report where common themes were identified.

#### Why did we use this research method?

Key informant interviews provide an excellent starting place for understanding context, complex issues, problems and unexpected factors. It is also useful for gathering facts, lessons learned (the kinds of things that are less clearly collected in an on-line survey). A key informant interview allows for participants to express how they believe problems can be alleviated or fixed as well.

#### What will you do with the findings?

This research will help the secondary school transitions work experience project team determine if this model is sustainable and effective for students who have developmental disabilities in Huron and Perth counties.

*Research Steering Committee: , Dave Higgins,  
Barbara Leavitt, Lynda Legge and Maureen Saubin  
and Beth Anne Currie*



# The Haldimand and Norfolk Dual Diagnosis Environmental Scan (2011-2012)

*Authors: Haldimand and Norfolk Local Service Delivery Table Research Subcommittee*

## The Project

The Haldimand and Norfolk Local Service Delivery Network (LSDN) is a group of cross-sectoral professionals who concern themselves with system issues and services that impact persons (and families) who have dual diagnosis in Haldimand and Norfolk counties. A research sub-committee determined that a lack of clarity about types of service provision, wait times and the number of persons with suspected or confirmed dual diagnosis receiving services was missing or unclear. The research sub-committee recommended we complete an environmental scan that would illustrate current trends in service provision and note any gaps and barriers for this population. The environmental scan was completed by designing and piloting an on-line survey tool that was distributed widely to key stakeholders and service providers (child and youth agencies, First Nations, developmental sector, mental health and hospital sector) across the two counties.

## SNSC Sponsorship

The H & N research subcommittee prepared a submission to the Southern Network of Specialized Care Research Committee. The Research Committee examines a project for merit in terms of research method and importance in the field. Financial support was granted for the project and work began in the winter of 2011. SNSC research ethics was not completed fully, hence the study will not be made public; instead the final report will be used for local quality improvement and system planning.

## The Study

The on-line survey was developed in collaboration with two lead members from mental health and developmental services and was supported by Nancy Hall, Facilitator for Haldimand and Norfolk counties and Beth Anne Currie, Research Facilitator for the Southern Network of Specialized Care. The on-line survey was predicted to take participants about one hour to complete.

## The Data

The data came from the service year 2009-2010. About 18 of a possible 28 service provider agencies (64%), completed the on-line survey tool.

Further inquiry through a phase 2 on-line survey strengthened the committee's understanding about gaps in existing services as participants ranked the availability of specific services for persons with dual diagnosis in Haldimand and Norfolk counties. The results showed a lack of respite services, short term crisis beds, specialized mental health services and day/peer support programs.

## Outcomes

The survey highlighted a number of potential action plans and directions for the Local Service Delivery Network in Haldimand and Norfolk counties, including;

- to implement a consistent approach for mental health providers to screen and identify clients with dual diagnosis;
- to engage in a client outreach campaign as the survey data reflected that only 60% of the individuals impacted are connected to existing services;
- to increase knowledge about access to and eligibility for existing services;
- to work towards developing a plan to support more consistent hospital discharge planning;
- to increase the capacity of service providers to better manage clients with challenging behaviours due to long wait times for behaviour therapy; and,
- to provide training and education to reduce stigma and resistance to court supports and mental health diversion in the justice system.

*Submitted by Nancy Hall and Beth Anne Currie*



## The Making of a Researcher in Developmental Disabilities

It is my pleasure to introduce, Professor H el ene Ouellette-Kuntz - an Associate Professor in the Departments of Community Health & Epidemiology and Psychiatry at Queen's University and an epidemiologist at Ongwanada - a



non-profit, developmental service agency that offers a wide range of individualized services and community supports to approximately 600 people with developmental disabilities (DD) and their families in Kingston and Eastern Ontario.

She graciously offered to be interviewed for Volume 4 of the SNSC Research Digest – and will share part of her inspiration for research in developmental disabilities with us!

### What does she do at Queens?

H el ene teaches undergraduate students in life sciences and graduate students in Epidemiology. One of her favourite things is to get people to think about the research questions like; What makes a good quality of life? How do we explore a

sense of belonging? Who gets to say what a sense of inclusion looks like? and, How do we promote choices for persons who have DD?

Part of her teaching role involves “enticing students” to study persons (and families) who have DD. H el ene enjoys helping people think about the “ethics” of doing research with persons who have DD and the various ways that data can be collected and stored, particularly by government agencies like the Ministries of Health and Long Term Care and of Community and Social Services in Ontario so we can learn more about gender issues and DD, rural versus urban issues and DD, and how well we have diagnosed and programmed for and with persons who have DD. She says it's currently not easy but not impossible to access reliable data in Ontario and Canada.

### How is a researcher inspired to work with persons with DD?

H el ene started out in nursing and was interested in DD even before doing her Master's in epidemiology. Epidemiology is the study of the distribution and patterns of health-events, health-characteristics and their causes or influences in well-defined populations. H el ene worked as a nurse at Ongwanada and had the opportunity to meet the famous, Dr. Bruce McCreary (psychiatrist), Barb Stanton (coordinator of the Developmental Consulting Program) and the recently deceased Dr. Jeanette Holden. H el ene attributes part of her inspiration for research and study on topics related to DD on her working relationship with these leaders. H el ene finished her Masters in Community and Epidemiology and proceeded to work full time at Queen's with a joint appointment to Ongwanada in service, teaching and research in the field of developmental disabilities.

### How does a Researcher collaborate?

Currently, H el ene collaborates with Dr. Yona Lunsky and Dr. Barry Isaacs at CAMH in Toronto and Dr. Lynn Martin, Public Health at Lakehead University as well as many others from across Canada and the world – some of this work has been enhanced through her engagement with IASSID (International Association for the Scientific Study of Intellectual Disability), of which she is the Secretary. H el ene collaborates on all her research projects and has a long list of publications to her name.



## Why should we (in the field) care about research?

When asked why you think it's important for direct support professionals to have access to current research, H el ene responded that often research raises more questions than it answers - so one of the most valuable aspects of research is to help keep us all on our toes!

- Research keeps us thinking and reflecting on what we're doing and why.
- We need to always be thinking about client outcomes from our programs and what's happening to the people we work with?
- Is this the best way to do something?

H el ene suggests that research should be discussed and debated with others in order to gain other's perspective. We should never become complacent in our work because we never know everything there is to know. H el ene also mentioned that very rarely does one piece of research change practice – instead after several years, and much research, things can change in our practice world. For example, she reports that there is a growing body of research that is changing practice right now on aspects of Quality of Life. We have improved our understandings about quality of life and this has influenced the way we support people in community.

## How do you think we can make research “understandable” for all?

### H el ene thinks everybody can be involved with research!

H el ene tries to have as much contact as she can with families and persons with DD as well as those who work in agencies or at the Ministry level. She says it's very important for her to hear what direct support professionals are saying about their work in order for her to shape a new research proposal. H el ene imbeds what she calls a consumer consultation approach into her style of doing research; so, she brings together adults and families and they talk about the research method she and her colleagues are thinking about in order to get their reactions. She also believes that research approach “keeps things real” and grounded; she relies heavily on clinicians and direct support staff to help her “keep it real”.

## Tell us about your research that contributed to some “real life” changes on the ground?

### Title:

“Students' Behavioural Intentions Towards Peers with Disability” (Journal of Applied Research in Intellectual Disabilities, 2011).

The study explored the intentions and reasons for certain behaviours of high school students toward their peers with intellectual and/or physical disabilities. They used a sample of 319 (grade 9 and grade 12 students) who completed a questionnaire about their feelings and behaviours towards peers with disabilities.

They found that the behavioural intentions of students towards kids with intellectual disabilities (ID) were more negative than their behavioural intentions toward kids with physical disabilities.

### Findings:

High school students were more willing to interact with peers who have disabilities when they could maintain a 'social distance' (eg. lending a pencil or pen or standing near them in the hallway) compared with activities that were more personal such as inviting someone to go somewhere after school.

Themes emerged about the perception of “difference” in that students were less likely to want to interact with peers with ID/DD if they appeared dissimilar to themselves either because of a lack of common interests (socially) or because of a different level of functioning (in class).

*“At an age when blending is important, adolescents without disabilities may resist interacting with individuals with disabilities – people who have been grouped and deemed to be 'different' on several social criteria”. (p. 8).*

Another theme that emerged was the fear that interaction may require more responsibility for the 'other' on the part of the person who responds to a person with ID/DD.

So in class, students felt that they would need to spend more time helping a person with DD or would need to exert greater effort themselves in order to get a task done or get the grade they desired – particularly towards peers with ID. When exploring social inclusion, students reported feeling they would have to 'babysit' or make accommodations for the person with a disability.

Students however, indicated that they were not trying to be 'mean' about their responses to peers with disabilities – in fact, that no social offense was meant, but that they were just uncomfortable or uneasy with interacting with someone who has a disability.



## Disclaimer:

Neither the Southern Network of Specialized Care or its Advisory Committee endorse the views and recommendations discussed in this publication. The views and recommendations discussed are those of the authors and the journals in which these are published. We accept no responsibility for the views discussed, as this paper is for informational purposes only.

## Next Steps:

The Southern Network of Specialized Care with the SNSC Advisory Committee are pleased to support opportunities for linking with other researchers in the field of Dual Diagnosis during our annual Southern Network Research Forum Days that occur each fall. If you would like more information on the annual Research Forum, please contact your local Facilitator.

Also please find contact information regarding research publications, research funding, research applications and more on our website at: [www.community-networks.ca](http://www.community-networks.ca)

If you would like to discuss a research or program evaluation project please email our Research Facilitator at: [bethannecurrie@sympatico.ca](mailto:bethannecurrie@sympatico.ca)



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