

RESEARCH DIGEST

2016

Welcome to Volume 10 of the Research Digest

Welcome to Volume 10 of the Southern Network of Specialized Care (SNSC) Research Digest. This issue will feature highlights from the 9th Annual Southern Network of Specialized Care Research Forum that was hosted in the newly renovated Toyota Room at Woodstock and District Developmental Services (WDDS) agency in Woodstock on Monday September 19th, 2016.

The WDDS staff and social-enterprise caterers made us feel welcome and we'd like to thank the whole team for helping us host a productive and energizing day for our guests, presenters and colleagues from across the province of Ontario.

Almost 60 people gathered to hear updates from a strong line-up of presenters that included not only the SNSC-sponsored research/evaluation projects but other thought leaders and provincial researchers who are shaping the agenda in developmental services.

Dr. Maurice Feldman, Professor and Director, Brock University, Centre for Applied Disability Studies set the tone for the day with his timely research talk entitled: **Contextual analysis of child protection & child outcomes in families led by parents with intellectual disabilities.** The audience response to this study was brisk with many questions and answers and connections being made to hear more about this applied research.



Dr. Feldman can be contacted directly to arrange workshops, presentations and clinical discussion related to this topic at mfeldman@brocku.ca

SNSC Health Care Facilitator, Cindy Chatzis with Dr. Maurice Feldman and SNSC Research & Evaluation Facilitator, Beth Anne Currie

HIGHLIGHTS FROM THE 9TH ANNUAL RESEARCH FORUM (2016)

Title: Contextual Analysis of Child Protection & Child Outcomes in Families Led by Parents with Intellecutal Disabilities

Authors: Dr. Maurice Feldman, Ph.D., BCBA-D, C.Psych., Centre for Applied Disability Studies, Brock Univ.

Parents with intellectual disabilities (ID) are at increased risk of having their parenting rights terminated (Feldman & Aunos, 2010). Parental cognitive disability is often used in isolation to justify removing the child based on a presumption of inherent inadequacy in parents with ID (Callow et al., in press). Considerable evidence is amassing that challenge this univariate assumption. Parenting competence and child and family outcomes are better predicted by a contextual model of parenting by parents with ID (Feldman & Aunos, 2010). The contextual model examines the interactions across time of parental and environmental variables that may impede or support parenting competence. Parental variables that are more prevalent in parents with ID than parents without ID and predict parenting abilities in parents with ID include parental history of trauma, and physical and mental health (Aunos et al., 2008; McGaw et al., 2010).

influencing External factors parenting success include society's attitudes towards disability, social support, low family income and resources, child age and functioning child protection worker and experience and caseloads (Feldman & Aunos, 2010; McConnell et al., 2011; Wade et al., 2011). The more risk factors (other than parental ID) accounted for substantially reduces the singular role of parental ID as the predictive factor in negative child protection outcomes for the family.

Feldman & Aunos (2010) designed a parenting capacity assessment approach based on the interactional model. The Step-by-Step Parenting Program[©] comprehensive parenting assessment examines idiosyncratic contextual impediments and supports to successful parenting as well as conducts direct observational assessments of parenting skills and parent-child interactions in the home setting. These assessments help to identify needed services and supports, including evidence-based parent education, that increase the likelihood of family preservation (Feldman et al., 1993).

Research is needed to further evaluate the Step- by - Step comprehensive assessment model, training of workers and family court system in evidence-based practice, community capacity to support families where parents have ID and large-scale dissemination of evidence-based parenting assessment and education models.



References available upon request

Dr. Maurice Feldman presenting at this year's SNSC Research Forum



Health Link (HL) Coordinato hired & trained Recruit 30 adult with IDD whom have been identified by Developmental Services as complex. complete & distribute CCPs Initiate HL approach Pre- and post-CCP surveys and interviews Review of health care services usage data

Richelle Uens-Health Care Facilitator, East



Tara Hyatt—Coordinator, Central West



Jo-Ann Trahan—Coordinator, North

Community Networks of Specialized Care - ON

Eastern Network

Lisa Holmes & Richelle Uens provided an update on a project called: How a health links approach can facilitate intervention for change toward adults with an intellectual disability. This project will rely on Kingston area Health Links early outcome data, recruitment, consent by family doctors, pre-surveys, post-surveys and care plans that will be distributed to health care providers & uploaded onto a hospital electronic data base.

Central Network

Tara Hyatt reviewed a project called the Common Thread Initiative (CTI) that looks at how organizational change can best support persons with a dual diagnosis and challenging behaviours in residential programs. This will be a 10-month team-based multimodal (i.e., online, telephone, and in-person) knowledge translation activity that uses a real-time, problem-solving approach to making evidence-based decisions. CTI impacts frontline staff, management, and clients. It will involve coaching, monitoring, evaluations and sustained factors. They will be running a third cohort this year.

North Network

Jo-Ann Trahan & Tina Benevides gave an update on the Skills System evaluation project that involves collaborating with participants in remote areas of northern Ontario via VC-trained facilitators. The Skills Systems is a psycho-educational program for people with IDD that involves skilled coaches, breakout sessions, exercises and role play over a 12 week session. It uses a quasi-experimental design, interviews, anonymous surveys and post survey results. This project will be shared at the NADD conference in Niagara Falls, 2016.



Summary of SNSC-Sponsored Research & Evaluation Projects (2015-2016)

Suzanne Ali, a graduate student from the University of Windsor (SNSC sponsored) provided preliminary findings from her study of: Acute and long-term effects of aerobic exercise on repetitive behaviours (RBs) and task performance for adults with an autism spectrum disorder and an intellectual disability. Her research looked at the impact of intense exercise as an intervention on repetitive behaviours. She shared some vignettes of participants and some interesting outcomes on RB's.

Carmen Hall, a Ph.D candidate and teacher from Fanshawe College & Consultant with Regional Support Associates (London) shared updates from her research entitled: College education for a life skills program for people with severe to profound intellectual disabilities. This SNSC Sponsored project examined how teaching skills in the Community college environment can enhance inclusion and skill development for adolescents, TAYs and emerging adults. Several participants with moderate to profound delay between the ages 16-30 years were invited to Fanshawe College for a Summer Institute of hands-on learning. Terrific results!

Dr. Ann Fudge-Schormans, McMaster University, along with co-researchers: **Jade Stewart, Donovan O'Neil- Allen &** Project Coordinator, **Lisa Watt** shared updates from their SNSC-sponsored project called: Partnering for change: mapping connections between disability, education and employment among young people with intellectual disability/developmental disability who have experienced homelessness.

Their presentation highlighted intersections between disability & homelessness for youth including myths. The audience appreciated talking with co-researchers with IDD, Jade and Donovan.



Beth Anne Currie with Nancy Wallace-Gero, Executive Director, Community Living Essex, Suzanne Ali and Sean Horton, UWindsor.



Beth Anne Currie pictured here with Carmen Hall



Lisa Watt, Donovan O'Neil-Allen, Nathan Gray, Dr. Fudge-Schormans, McMaster University, and Beth Anne Currie.



Summary of SNSC-Sponsored Research & Evaluation Projects (2015-2016)



Angela Gonzalez with Dr. Robert Balogh

Institute of Technology & Angela Gonzales, R.N., and Health Care Facilitator, Central Region, shared their work entitled: The health and social needs of adults with developmental disabilities and complex mental health problems. Their research (funded over 2 years by the Ministry of Community and Social Services, Policy Research Branch) is based on exploring a knowledge gap about the social and health profile of people with IDD who are accessing treatment from healthcare facilitators in parts of Ontario.

Dr. Robert Balogh, University of Ontario

Leslie Auger, M.A., A.B.A, Niagara District School Board & Dr. Becky Ward, Ph.D, C.Psych, BCBA-D shared an update on their research: Case study review of complex transitional age youth; where are they now? This SNSC-sponsored project looked at the lives of up to 6 adults who had previously received residential treatment in a High Risk Behaviour unit — within a long term treatment program offered by Bethesda Services in Niagara Region about 10 years ago.



Leslie Auger, Niagara School Board



Dr. Laura Mullins and Pauline LeDrew-Bonvarlez, RSA

Dr. Laura Mullins & Pauline LeDrew-Bonvarlez, Regional Support Associates, provided an update on their Advanced Behaviour Training Evaluation. This project looked at the history of a collaborative model of service in South Western Ontario called: Enhanced Specialized Services (ESS), including the community partners and curriculum components which involve an urgent response system, in-home, and a safe treatment space model.



Acute and Long-Term Effects of Aerobic Exercise on Repetitive Behaviours and Task Performance for Adults with Autism Spectrum Disorder and Developmental Disability

Co-Researchers: Suzanne Ali, Chad A. Sutherland, Nadia Azar and Sean Horton, University of Windsor

Objectives: One of the main characteristics of Autism Spectrum Disorder (ASD) is engaging in repetitive behaviours (RB). This may interfere with an individual's ability to learn new tasks and/or perform familiar tasks. Exercise is a common intervention to reduce the number of RB exhibited. The purpose of this study was to determine whether adults with ASD and ID (ASD-ID) would:

- 1) exhibit fewer RB immediately following exercise,
- **2)** improve in task performance immediately following exercise, and
- **3)**exhibit a long-term reduction in the severity of the RB after engaging in a number of exercise sessions.

Methods: Case studies were conducted on eight adults with ASD-ID throughout an eight-week exercise program. Participants engaged in aerobic exercise on a stationary bike for 20 minutes, twice a week. Immediately before and after exercising participants engaged in eight minutes of free time for the purpose of tracking RB, and performed a test of hand function (Jebsen Hand Function Test). Before and after the completion of the program, the participant's support worker, parent, or guardian completed a modified version of the Repetitive Behaviours Scale. Additionally, the participant's support worker, parent, or guardian completed a post-intervention interview and/or filled out weekly written responses.

Preliminary Results: An overview of three case studies are provided. Based on the video observations, we have focused on specific RB for these participants.

<u>Case Study #1:</u> Video observation results and exercise performance were variable, with the exception of sessions 11 to 14. These sessions displayed a reduction of RB with more vigorous exercise. This suggests a number of sessions may be required before finding consistent reductions in RB.



Suzanne Ali, University of Windsor

<u>Case Study #2:</u> This participant exhibited an overall medium-to-high exercise performance and ceased engaging in pacing behaviours after session five. Conversely, there was a slight increase in bodyrocking behaviours throughout the program. For this participant, reducing one behaviour may influence the appearance of another.

<u>Case Study #3:</u> This participant exercised at a high level, yet displayed a gradual increase in RB throughout the program. Notetaking after each exercise session indicated that this individual may exhibit certain RB when they are excited/happy.

Discussion/Conclusion: Changes in RB post-exercise may be unique to each person.

This study highlights the need for more in-depth case study research. Responses from caregivers and support workers indicated the exercise sessions were beneficial. Future studies may benefit from providing multiple forms of aerobic exercise and exploring various techniques to increase motivation while exercising.

Partnering for Change: Uncovering and Mapping Connections between Disability, Education and Employment among Young People with ID/DD who have Experienced Homelessness

Researchers: Stephanie Baker Collins, Ann Fudge-Schormans, Becky Idems, Tina Wilson and Lisa Watt Co-Researchers: Donovan O'Neill Allen, Nathan Gray, Kyla-Jade Stewart, Tyler Henderson, Karissa Horan-LaRoche, Heather Allan, and Lisa Woelfl.

Summary: Youth with intellectual and developmental disabilities (including learning disabilities) are a particularly vulnerable, and significantly under-reported and under-analyzed part of the population identified as having disabilities, and, as a group, they face particular barriers to housing, education, and sustainable and meaningful employment. This is in part due to the assumption that homelessness and disability are discrete experiences, and as a result populationspecific educational, support, and employment services work in siloes in practice. The failure to attend to the intersectionality of social problems and social identities makes it much more difficult to support people to access entitlements, supports, and services.

To address the lack of integration of services and to better understand this intersection, a team of researchers at McMaster University is working collaboratively with community organizations that offer educational, employment, and support services to disabled and homeless youth, and seven self-advocate co-researchers with lived experiences of disability and homelessness on a unique community partnership, the Partnering for Change research project. The intent of this research project is to systematically map the intersections of developmental and/or intellectual, learning disabilities (ID/DD/LD), homelessness, education, and employment among young people living in three Canadian cities: Toronto, Hamilton, and Niagara. To do so, three types of data are being collected: quantitative intake and program data on youth characteristics; an environmental scan mapping referral pathways, connections, and gaps in services; and key informant interviews with front-line staff and interviews with young people ID/DD/LD have experienced with who homelessness. The comprehensive data will enable us to make visible to policy makers the referral pathways and blockages for youth maneuvering between discrete support sectors and make recommendations for improving service delivery. Fundamentally, the project attempts to figure out better support the educational. how employment, developmental, and housing needs of disabled youth experiencing homelessness.

> The adoption of a participatory, co-researcher model in project is in line with the growing demands and support for including people with ID/DD/LD in research about them to empower disabled individuals, transform relationships in knowledge production, and facilitate a critical understanding of societal responses people with ID/DD/LD as a means of working towards social and structural change.



Lisa Watt with Dr. Ann Fudge-Schormans (McMaster University),
Donavon O'Neil-Allen & Nathan Gray



The Evolving Health and Social Needs of Adults with Developmental Disabilities and Complex Mental Health Problems: A Needs Assessment

Co-Researchers: Dr. Robert Balogh, University of Ontario Institute of Technology (UOIT) Dr. Yona Lunsky (CAMH), Kristin Dobranowski, Johanna Lake, Carly McMorris and Angela Gonzales.

Almost 50% of adult Ontarians with developmental disabilities have a mental illness, a situation sometimes referred to as 'dual diagnosis'. Adults with a dual diagnosis are poorer than the general population, experience a higher prevalence of chronic diseases, and use a disproportionately higher amount of health services (e.g. hospital stays and visits to emergency departments). These issues become more complex with age and are indicative of an increased need for both health and social services for this population.

The Ontario Ministry of Community and Social Services (MCSS) has made a significant investment in Health Care Facilitators (HCFs) to help persons with a dual diagnosis navigate the health and social service systems. The role of HCFs is to help coordinate services for individuals with a dual diagnosis, their families, and agencies supporting them, by facilitating referrals and linkages to medical resources and social services. Some HCFs also provide direct clinical care. However, little is known about individuals with a dual diagnosis who access HCFs, including information on their demographics and clinical characteristics, as well as their complex health and social needs.

The researchers were granted \$76,070 by the Ministry of Community and Social Services over two years to conduct a project with the overall aim of addressing two of their research priorities: understanding service models for complex need clients and understanding their evolving support needs.

Among a group of adult Ontarians with dual diagnosis who live in complex situations - our objectives are to:

- identify socio-demographic and clinical characteristics (e.g., prevalence of physical and mental illnesses,
- determine health and social needs,
- develop an understanding of typical health and social service pathways, and,
- identify health and social service barriers and facilitators (e.g., service availability).

In order to address these objectives:

- 1) We conducted chart abstractions of records (approx. 200 files) kept by HCFs in the Toronto and Northern Networks of Specialized Care. To accomplish this we consulted with clinicians and developed a chart abstracting tool, using an existing tool as a template. The data collected from charts include items such as age, sex, reported forensic involvement and diagnoses.
- 2) We are currently conducting semi-structured interviews of Ontarians receiving HCF services and/or their caregivers. These participants are clients of HCFs from each of the Toronto, Southern, Northern, Central West, and Eastern Networks of Specialized care. This sample of participants will be generated by consecutively recruiting new clients over a 1-year period. The data collected will include socio-demographics, reasons for referral, and needs assessed using the Camberwell Assessment of Need for Adults with Developmental and Intellectual Disabilities (CANDID). The CANDID is a standardized needs assessment interview tool developed specifically for people with dual diagnosis.
- 3) We plan to organize 2 focus groups:
 - i. A focus group with all 9 of Ontario's HCFs (completed) and
 - ii. A focus group with the HCF service users and/ or their caregivers from the Central Region Network of Specialized Care (date TBD).



The Evolving Health and Social Needs of Adults with Developmental Disabilities and Complex Mental Health Problems: A Needs Assessment ...cont'd

The interview schedules created for the focus groups contain broad, open-ended questions. The resulting data will be analyzed using open coding to identify categories, codes and themes.

Our preliminary results provide a glimpse of what contributes to the complex situations of individuals with a dual diagnosis in Ontario. The following highlights preliminary findings from the chart abstractions and the focus group conducted with HCFs.

Chart abstractions of individuals seeking HCF services showed that the majority were young (ages 16-35: 60%) and close to 30 % reported forensic involvement (forensic involvement ranges from an encounter with the police but no charges laid to incarceration). We also found that two out of three of diagnoses reported were for psychological development, neurotic/stress-related/somatoform (e.g. anxiety disorder), or schizophrenia/delusional disorders.

The focus group with HCFs determined their perspective on pathways to service and service utilization. They were also asked to discuss their experiences working with caregivers and service users (e.g. what challenges they have faced) and provide suggestions on how to improve services. We have identified some preliminary themes which include: access issues, teaching/training/education needs, mental health agencies' capacity-building needs, discharge planning issues, burnout, complexity of care and health care issues, and HCF role clarification issues.

The ultimate goal of our project is to use the results to inform decisions regarding the health and social services of persons with dual diagnosis in complex situations.

If readers would like to learn more about this project please contact:

Project Lead Dr. Robert Balogh (Robert.balogh@uoit.ca) or

Project Coordinator, Kristin Dobranowski (Kristin.dobranowski@uoit.ca) and look out for posts on twitter (#DD_NA) and on the University of Ontario Institute of Technology website (http://healthsciences.uoit.ca/people/faculty/robert-balogh.php#fndtn-tabresearch-1).

Profiles:

Robert Balogh: Assistant Professor at the University of Ontario Institute of Technology, co-researcher.

Kristin Dobranowski: Master's in Health Sciences in the Community Health, project coordinator.

Carly McMorris: Assistant Professor at the University of Calgary, Department of Psychology, co-investigator.

Johanna Lake: completing her Clinical Psychology supervised practice at Reach out Centre for Kids (ROCK), co-investigator.

Angie Gonzales: Healthcare facilitator for the Community Networks of Specialized Care based, co-investigator.

Yona Lunsky: Clinician Scientist at the Centre for Addiction and Mental Health, Adult Neurodevelopmental Services, co-investigator.



Tom Archer, Beth Anne Currie, Angela Gonzalez & Dr. Robert Balogh



Where are they Today? Case Studies about Quality Of Life for Adults With Developmental Disability with Experience in Residential Treatment for High Risk Offenses.

Co-researchers: Leslie Auger, M.A., and Dr. Rebecca Ward (Phoenix Centre for Learning)

In the past two decades numerous programs have emerged that treat individuals with a developmental disability and high risk behaviours. However, very few examined the effects of long term treatment and the long term effectiveness once these individuals are back in the community. This project will examine the outcomes of six individuals who received long term treatment at the Highlands Program (2006) and who have been living in the community for 10 years. Participants will complete three assessment tools: and participate in an interview. Staff who have supported the individuals will also be interviewed.

Purpose: The purpose of this study was to complete case studies for up to six individuals (ages 25-40 years) who were part of the 2006 study. This was not an evaluation of the long-term effects of the Highlands residential treatment program. Instead, we are interested in exploring services and supports received by these six individuals over the nine years since living in communities of origin, as well as assessing adaptive and maladaptive behaviours during this time, and perceived quality of life of these individuals, including their physical, emotional, and behavioural wellbeing.

Hypothesis: Nine years following involvement in a long term multi-component residential treatment program, participants will have maintained low rates of challenging behaviours, mental health concerns, and psychotropic medication use, with some improvements in quality of life that is consistent with their post-residential treatment scores on the Psychopathology Inventory for Mentally Retarded Adults (PIMRA), Emotional Problems Scales (EPS) and Quality of Life Questionnaire (QOL-Q).

Method: The researchers utilized the following assessment tools in the study. Each participant who consented to involvement in this project was given the following questionnaires and was asked to complete these while in the presence of the

Bethesda researcher who can help with understanding of all the assessment questions.

- To assess functioning ability as well as mental health status Psychopathology Inventory for Mentally Retarded Adults (PIMRA)
- To assess behaviour changes Emotional Problems Scales (EPS), based on behavioural data including recidivism rate, if available
- To assess Quality of Life Quality of Life Questionnaire (QOL.Q).

Semi-structured interview questions for Individuals Living with a Dual Diagnosis and living in the community- revised

Participants: The 6 adults who participated in the 2006 study will be invited to participate in this follow up study. They all reside in the Southwestern Region of Ontario (London, Barrie, Hamilton, Niagara Falls, Toronto) and all are over the age 18 and have diagnoses of mild intellectual disability and a mental health issue (Dual Diagnosis). There are potentially 5 males and 1 female participant.

Limitations: There are only four participants in the study so far; therefore, we cannot generalize these findings to all individuals who went through the Long Term Residential Treatment program.

Future Directions: It appears that these four individuals had good outcomes; however we cannot draw any conclusions about the relationship of the treatment program to these long-term outcomes. A prospective study of a larger sample (>20) of participants that have received long term residential treatment would be beneficial, including follow up with individuals on a long-term basis post intervention (10+ years).

Contact information: Leslie Auger: leslie.auger@icloud.com
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Evaluation of Advanced Behaviour Training within Enhanced Specialized Services

Co-evaluators: Dr. Laura Mullins, BCBA, Behaviour Analyst, Regional Support Associates and Pauline LeDrew-Bonvarlez, Community Consultant-Capacity Development, Regional Support Associates

The Enhanced Specialized Services (ESS) was implemented in April 2008 following significant planning between the Ministry of Community and Social Services, Regional Support Associates (RSA), local communities and key agencies within the RSA catchment area. ESS provides the opportunity to enhance the support services available within the community to persons who are exhibiting challenging behaviours or who may have a dual diagnosis as well as increasing the capacity of the person's support system. Supports are offered through assessment, treatment and stabilization in the least intrusive way possible. ESS is a collaborative service model that is comprised of an Urgent Response mechanism for accessing supports as well as one of three utilizations: In Home Services, Safe Space and Treatment Spaces. Under the guidance of the ESS Planning Committee, RSA provides the clinical oversight and manages the ESS resources. Community Agencies provide the staffing and physical resources. The Advanced Behaviour Training (ABT) was developed to prepare direct support professionals (DSP) for the use of positive behavioural approaches in partnership with clinicians and other professionals to assist in the provision of ESS utilizations. In addition, DSP should develop knowledge and skills applicable to the provision of daily supports for individuals who are exhibiting challenging behaviours.

Current support system, through assessment, treatment and stabilization, in the least intrusive way possible.

Pauline LeDrew-Bonvarlez , RSA

Given that a critical component of the ESS model is to increase community capacity, recent discussion with the ESS Planning Committee led to the evaluation of the training to determine the extent to which these objectives are being accomplished. This evaluation included a multiple phase evaluation utilizing mixed-methods design, including:

- a survey to review the training objectives for each module to assess their applicability for ESS utilization and for direct support;
- 2. a pre-post training evaluation to determine knowledge gained through the training;
- 3. a survey to determine the extent to which participants are able to apply this information during ESS utilization and for daily supports at three and six months following training.

In general, feedback from DSP, RSA Clinicians and Community Agency Representatives who participated in the training, have all indicated that the objectives of the training are relevant for ESS utilization and for daily supports. Further, the DSP significantly increased in their knowledge related to supporting individuals with challenging behaviours. We are currently in the process of completing follow-up evaluations.

The evaluation results will be used to inform future revisions to the ABT curriculum. Initial efforts point to the potential benefits of the realignment of the content of the modules to relate directly with Core Competencies for DSP. In addition, the results may lead to improvements in the larger Enhanced Specialized Services model. The process began in March 2016 and will continue throughout the remainder of the fiscal year. Once completed, a formal summary and dissemination of the complete evaluation will be shared with our community partners.

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Disclaimer:

Neither the Southern Network of Specialized Care nor its Advisory Committee endorses the views and recommendations discussed in this publication.

The views are those of the authors and the journals in which these are published. We accept no responsibility for the views discussed, as this publication is for informational purposes only.

The Southern Network of Specialized Care with the SNSC Advisory Committee are pleased to support opportunities for research, evaluation and knowledge translation and exchange in the field of Dual Diagnosis.

Please consider joining us at the annual Southern Network Research Forum on **September 25th, 2017.** If you would like more information about Network projects, contact the SNSC Research & Evaluation Facilitator, Beth Anne Currie at bethannecurrie@sympatico.ca or the SNSC Coordinator for Hamilton Brant Niagara, Liz Froese at Ifroese@bethesdaservices.com.

Also, find links and updates about leading researchers, publications, and evaluation updates on our website www.community-networks.ca.

