Southern Network of Specialized Care

RESEARCH DIGEST

Winter 2015

Welcome to Volume 8 of the Research Digest

Intoduction

Welcome to Volume 8 of the Southern Network of Specialized Care (SNSC) Research Digest. In this issue, we bring you some key highlights from the 7th annual Research Forum that was held on September 21st, 2014, in Brantford. The remainder of this volume will focus on Knowledge Mobilization and Exchange of SNSC research and evaluation projects that are across the Network. Each abstract is a quick summary of the work that has been done by researchers in the field and will include a title, method, findings, recommendations, supporting literature and email contacts for the researchers. This is the first issue where we have been able to grow so many projects to share with our readers. Congratulations to all our hard-working community-university collaborations and researchers!

We continue to appreciate your support and interest in these research and evaluation possibilities. Please continue to share your feedback on any aspect of the work we do as we would be happy to hear from you.

SNSC Research Committee

- Dr. Jay Rao (Associate Professor Developmental Disabilities Division Department of Psychiatry, University of Western Ontario and Lead, Dual Diagnosis Program, Regional Mental Health Care)
- Dr. Maurice Feldman, Professor and Director, Brock University | Centre for Applied Disability Studies and Clinical Lead at Bethesda Services, St. Catharines,
- Dr. Melanie Kelly, (Psychologist, Regional Support Associates, Windsor),
- Keith Anderson (Manager, Hamilton Brant Behaviour Services (HBBS), Hamilton),
- Leo A. Massi (Executive Director, REACH),
- Lisa Paananen (Senior Behaviour Consultant, HBBS, Hamilton),
- Cindy Chatzis (Healthcare Facilitator, SNSC, Woodstock),
- Liz Froese (Coordinator, SNSC),
- Beth Anne Currie (Research & Evaluation Facilitator, SNSC).

We especially want to thank the members of the research committee as well as the members of our SNSC Research Ethics Committee for their time, energy and intuitive wisdom about ethics, research and evaluation.

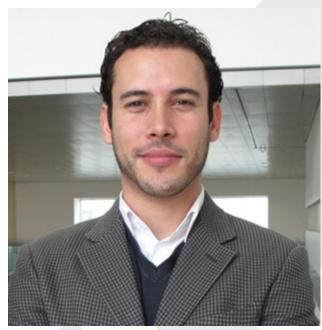


SNSC Research Committee members, Keith Anderson, with Dr. Jonathan Weiss (keynote speaker at the 2014 Research Forum), Dr. Melanie Kelly and Beth Anne Currie

HIGHLIGHTS FROM THE 7TH ANNUAL RESEARCH FORUM (2014)

Keynote Speaker Dr. Jonathan Weiss

Jonathan A. Weiss, Ph.D. (York University), is a Clinical Psychologist registered with the College of Psychologists of Ontario. He completed a pre-doctoral internship at Surrey Place Centre (Toronto) and a post-doctoral fellowship in the Dual Diagnosis Program at the Centre for Addiction and Mental Health, and was a fellow in the Department of Psychiatry at the University of Toronto.



Dr. Jonathan Weiss, PhD

His research focuses on the prevention and treatment of mental health problems in people with autism spectrum disorders and/or intellectual disabilities across the lifespan. He conducts studies into how people with developmental disabilities access mental health care in Ontario, and is interested in their health service needs, their emergency service use, and their experiences of psychiatric crisis. He is interested in program development and evaluation, and in particular on the impact of Special Olympics on the psychological well-being of participants, and of cognitivebehavioural and social skill interventions to promote resilience and improve the mental health of children and adults with developmental disabilities. Dr. Weiss holds the CIHR Chair in Autism Spectrum Disorders Treatment and Care Research, as well as operating funds from the Canadian Institutes of Health Research and Social Sciences and Humanities Research Council.

Summary of Research

Jonathan's current study focuses on children and youth who participate in Special Olympics, Ontario. His team is exploring: the degree and type of involvement in Special Olympics, the health and well-being of the athletes and their families; as well as, factors related to emotional difficulties and well-being of the athletes. Of interest is that Special Olympics is the *largest sport organization* for individuals with intellectual and developmental disabilities (IDD) in Canada, and the world.

There are an estimated 35,000 athletes with IDD in Canada, and

- Most participate at local events and are not elite athletes,
- This research can be useful to explore the determinants of health and well-being, and how this intersects with sport involvement, and,
- Trust was an important aspect of the success of this research project and was enhanced by the fast that Jonathan has volunteered with Special Olympics for many years.



For the purpose of this study, the researchers emailed and mailed all the caregivers of young athletes between the ages of 11-21 years that were registered with Special Olympics Ontario in years 2011-2012. In the end approximately 3000 athletes were invited into the study.

This study

- Largest study of athletes in Canadian Special Olympics
- Has a sample size N= 510 made up of Parent/Caregivers (excluded athlete participants for this phase)

Geographic location of the young athletes with IDD in this study (N=510)

- Remote area of Ontario = 3%
- Rural area of Ontario = 27%
- Suburban area of Ontario = 44%
- Urban area of Ontario = 26%

Physical health of young athletes with IDD in the study as determined by their Weight (according to BMI) as based on Centers for Disease Control and Prevention (2003) criteria

• Underweight: 10%

Healthy weight: 57%Overweight/obese: 33%

Overall, child health was rated by parents over all as:

- 88% Good (or Very Good)
- 34% were noted to have "one or more recurrent health conditions that required regular, ongoing care" reported as heart conditions, asthma, seizure disorders, and/or diabetes

Other data that Jonathan's team analyzed included

- IQ levels (as determined by testing)
- living situation
- type and length of involvement with Special Olympics
- outcomes perceived with involvement in Special Olympics
- diagnosis of the athlete.

To consolidate their analysis, researchers combined demographic data with results from validated tools (appropriate for this population) to gain access to their perceptions of

- · Well-being,
- · Developmental strengths,
- PYD (positive youth development), and,
- External factors that predict secondary problems.

The researchers strengthened the meaning of the data through a series of face-to-face interviews to provide context for athlete's happiness and sense of well-being.

Findings thus far (more in 2015) 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 how MH, i.e. well-being can be fostered by well-designed community programs? Research on this scale is costly and takes time with gains that may not be directly apparent in the short term. The Southern Network wishes to thank Jonathan and the other researchers and extend well-wishes for this year's work.

For more information on this research try

http://ddmh.lab.yorku.ca/jonweiss/) and (http://ddmh.lab.yorku.ca/publications/).

Jonathan's BLOG:

http://asdmentalhealth.blog.yorku.ca

Jonathan's TWITTER: @DrJonathanWeiss



Summary of SNSC Sponsored Research and Evaluation Projects (2012-2014)

Title: The impact of motor skill training on balance, hand-eye coordination and reaction time in a group of adults with autism and intellectual disability (2013).

Author: Phillip McKeen, M.Sc University of Windsor

Summary: Individuals with autism and intellectual disability (ID) commonly display motor impairments and these impairments are positively correlated to intellectual level and autism symptoms. In the present study, an intervention involving motor skills training, whole body exercise, sports and games was used to improve balance, fine and gross motor manual control and reaction time in a group of adults with autism and ID. Fine motor skill, gross motor skill of the upper extremities, and reaction time were measured. Additionally, medial-lateral

(ML) and anterior-posterior (AP) displacement and velocity, as well as sway area of each participant's Centre of Pressure (COP), were measured. Significant fine motor improvements occurred at retention when compared to baseline and gross motor improvement approached statistical significance but only when the sums of both trials at each session were taken. Statistically significant improvements were not found for reaction time nor for any static balance variables. Future studies should include a control group and assess for hand dominance, repetitive behaviour and gender differences.

Link to author's thesis:

http://scholar.uwindsor.ca/cgi/viewcontent.cgi?article=5985&context=etd.

Title: In Transition: The Journey to Adult Life for Youth with Dual Diagnoses (2014).

Authors: Natasha Durdan, MSc. OT Reg. (ON) narns@yahoo.com and Nancy Rushford, M.A., MSc. OT Reg. (ON) nrushford@yahoo.ca

Objectives: The transition to adulthood for youth with disabilities has been described as a time of uncertainty, characterized by lack of planning and support. Youth with dual diagnoses in particular, more challenges in accessing a encounter coordinated and responsive system of support rooted the effective orchestration relationships. Best practice guidelines for youth with disabilities identify collaboration as a key aspect in transition, but the complexity of the phenomenon itself is often overlooked despite its essential role in a successful transition to adult life. The intention with this research was twofold: first, to gain a better qualitative understanding of how youth with dual

diagnoses and their families experience the critical period of transition; and second, to gain an understanding of the nature of collaborative relationship between youth/their families and community supports during periods of successful transition.

Method: The method combines a phenomenological approach with the critical incident technique to elicit stories about transition through focus groups and in-depth interviews.





Participants included 12 youth between the ages of 13 and 21 with a dual diagnosis, parents, educators and community partners. Data was analyzed through constant comparison within and across participant groups to identify key themes and concepts related to collaboration.

Results: From the research, the following themes and sub-themes were identified:

Broadening and 'Reframing' Transition:

Emphasis on the fact that the process of transition and the development of skills related to transitioning occur earlier than the critical periods (i.e. school-to-work, move from pediatric to adult services) in many smaller series of transition 'events'. This involves drawing upon networks of support (both formal and informal) to sustain meaningful engagement in everyday life.

Collaborative Engagement through 'Coaching':

All participants identified the youth, and his/her activity of interest and the relationship with support networks as the core components in any transition event. These core components are held together by and nurtured through a coaching process whereby the coach may be the parent, the educator or the service provider.

Discussion/Conclusion: Given the current reality in accessing formal transition services (i.e. waitlists, gaps between services), the themes identified in this research suggest that nurturing networks of support through the coaching process identified may help to fill in some of these gaps and enable more successful transitions for youth with dual diagnoses.

FASD (2014).

Authors: Valerie Temple¹, Jane Hoy², Beth Anne Currie³, Lynda Legge³

Surrey Place Centre¹, Community Living Kincardine and District², Southern Network of Specialized Care³

Objectives: In 2010, Cunningham, Jones and Hall 18-41 years and 11 of their key support providers. published a position paper outlining a series of Key support providers - selected by the participants support strategies for adults with FASD which they included family members, staff, and friends. named Effective Practices. The Effective Practices 6 participants and their key supports resided in the were established through literature review and interviews with service providers in Ontario and they included the following: early diagnosis of FASD; training/education for and collaboration between support providers; provision of supervision, structure, routine: philosophy of life-long and interdependence for adults with FASD; strength-based approaches to support; adapted communication strategies; and consideration of sensory sensitivities.

Title: Exploring Effective Support Practices and The goal of this research project was to explore if Criminal Justice System Involvement in Adults with individuals with FASD and their support providers reported the presence of Effective Practices in their lives and whether this was related to criminal justice system (CJS) involvement for the individuals living with FASD in community.

> Methods: Structured face-to-face interviews were completed with 14 adult participants with FASD ages



city of Toronto and 8 in rural areas across Grey and Bruce counties. Each participant interview was recorded and then transcribed.

Cont'd on pg. 6



Participant narratives were organized into themes under each of the Effective Practices and also examined for any additional emergent themes. Narratives were then coded for the stated presence or absence of each Effective Practice and this coding was related to any reported contact with the CJS using simple frequencies and percentages.

Results: 8 of 14 (57%) individuals with FASD were reported to have CJS involvement, either presently or in the past. The mean age of FASD diagnosis for individuals with and without CJS involvement was age 20 years and 17 years, respectively. Of the 6 without CJS involvement, 100% were reported to have supervision, structure, and routine in their lives whereas only (50%) of those with CJS involvement reported these supports. Participants with FASD

frequently reported ambivalence regarding their need for life-long interdependence. Information about alcohol and street-drug use was also collected in the course of this study and use was found to be more frequent for individuals who had CJS involvement (88%) compared to those without (33%).

Discussion/Conclusion: Although the occurrence of CJS involvement was high in the individuals studied here, early diagnosis, abstaining from alcohol and street drugs, and the reported presence of supports

such as supervision, structure, routine may help mediate risk for adults with FASD.

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Title: Family Characteristics Which Promote Effective Coping and Growth in Families Who Have Members with an Intellectual Disability (2014).

Authors: Irene Carter and James P. Coyle, University of Windsor School of Social Work, and Stephanie Cragg (Graduate student) University of Windsor and Beth Anne Currie, Research and Evaluation Facilitator, Southern Network of Specialized Care.

Keywords: Disability, child and family welfare, family resilience, coping

Abstract: Background: The World Health Organization estimates that three per cent of children are affected by an intellectual disability (ID) which includes developmental disabilities, such as autism, cerebral palsy, and Down syndrome. These children and their families face increased health, economic, and social risks. Current supportive strategies for healthy development of children and adults with an ID acknowledge the importance of family strengths, accessible resources, a life-span approach, and intervention with individuals and their families (World Health Organization, 2010). Effective coping and growth depends upon the overall health of the family and family members' ability to promote positive wellbeing for all family members.

Method: The presenters conducted several studies using a family resilience framework (Bayat, 2007) to explain how positive family beliefs, cohesion, flexible family roles, communication, and problem-solving influence wellbeing in families affected by risk factors. Interviews and surveys were used to identify characteristics associated with positive coping and growth for a) parents caring for children with ID, b) parents caring for adult children with ID, and c) siblings of children with ID.

Findings: Family beliefs, cohesion, problem-solving, and external resources influenced positive coping and growth for all family members with varying influences for parent and sibling adjustment at different life span stages. The presenters plan to discuss the implications of these findings, including how these family characteristics inform the development of social policy and social work practice, such as strategies for enhancing family coping and recommendations for supportive family social policy.

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Title: Adapted physical exercise (APEX): Improving fitness and functional movements in adults with autism and an intellectual disability (2014).



Authors: Kelly Carr, <u>carrk@uwindsor.ca</u>, Chad A. Sutherland, Sean Horton, and Nadia R. Azar, <u>azar5@uwindsor.ca</u>

Affiliation: Adapted Physical Exercise (APEX) Research Group, Department of Kinesiology, University of Windsor

Objectives: To assess the impact of a 12-week adapted physical exercise (APEX) program on fitness and functional movement in adults with autism spectrum disorder and an intellectual disability (ASD-ID).

Methods: Fourteen adults diagnosed with ASD-ID (age range = 18-62 years; 2 females; IQ scores from previous clinical assessments = 20-70) participated in a 12-week APEX program focused on strength and conditioning. Each participant received one-on-one training to complete two, 90-minute exercise sessions per week. Each APEX session followed a standard protocol: warm-up, 20 minutes of cardiovascular exercise on a stationary bike, 20 minutes of strength training using machines and free weights, 30 minutes of sports and games, and a cool-down. Fitness and functional movement skills testing was conducted pre-, mid-, and post-program.

Each fitness and motor skills test session assessed

- 1) resting heart rate and blood pressure through use of an automated blood pressure cuff,
- 2) flexibility measured by the sit-and-reach test,
- upper-and lower-body isometric strength measured by customized equipment and software,

- 4) gait parameters measured by an instrumented walkway,
- 5) static balance control measured by a force platform, and
- 6) simple manual reaction time measured through use of a computerized test. A series of repeated measures ANOVAs were conducted to examine differences in performance on each fitness, static balance, and gait measure from pre- to post-program. Reaction time data was analyzed through employment of linear mixed models.

Results: Significant improvements in upper body strength from pre- to post-program were found for the right ($M_{pre} = 21.61$ lb.; $M_{post} = 28.83$ lb.; p = 0.049) and left bicep ($M_{pre} = 20.62$ lb.; $M_{post} = 29.82$ lb.; p = 0.017). Significant increases were also found from pre- to post-program for flexibility ($M_{pre} = 10.72$ cm; $M_{post} = 16.63$, p = 0.036), while significant decreases were found from pre- to post-program for reaction time ($M_{pre} = 570$ ms; $M_{post} = 385$ ms; p = 0.02). No significant changes were found for resting heart rate, systolic or diastolic blood pressure, or lower body strength (p > 0.05). Similarly, there were no significant changes in any of the gait variables, nor in any of the static balance variables (p > 0.05).

Conclusion: Twelve weeks of APEX programming provided a significant improvement in upper body strength, as well as flexibility in adults diagnosed with ASD-ID. While the remaining fitness measures did not experience significant changes, the observed improvement in lower body strength (right quadriceps: 18% increase) has potential to yield practical health benefits for participants. Additionally, the lack of improvement in gait and static balance may be related to the APEX program format, as none of the exercises included in the APEX program specifically focused on these specific domains. Therefore, an APEX program focused on strength and conditioning is a worthwhile service option for adults with ASD-ID, however future exercise programming should include components that specifically target skills in which improvements are desired.



Title: Self-Reporting of Healthcare Experiences and Advice to Future and Current Health Care Practitioners-Influencing a Curriculum of Caring for People with Developmental Disabilities (2014).

Authors: Dr. Kerry Boyd, <u>kboyd@bethesdaservices.com</u> Tom Archer, <u>tarcher@bethesdaservices.com</u>

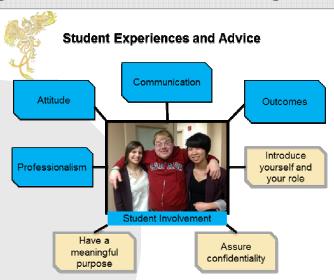
Objectives: Studies in developed countries have shown that people with developmental disabilities (DD) have poorer health, increased morbidity, and earlier mortality yet are poorly supported by health care systems. Healthcare provider compassion, empathy and person-centred approaches have been associated with improved clinical outcomes although these characteristics decline as students move through their training. It is recommended that medical curricula for DD emphasize person-centred attitudes in addition to knowledge and skills. The Michael G DeGroote School of Medicine's Niagara Regional Campus, Brock University School of Nursing, Southern Network of Specialized Care (SNSC) and Bethesda have developed an initiative whereby health care students have interactive experiences with people with DD to foster compassionate, person centered care.

Our study advances the concept of involving people with DD as teachers by soliciting their perceptions of health care experiences and advice to enhance a Curriculum of Caring for health care professionals. The goal of this study is to increase the capacity of health care professionals to provide competent and compassionate care.

Methods: This qualitative research involved seven focus groups of 3 to 4 participants

(N=22, Female = 17, Male = 5) during February and March 2014.





A pilot focus group of 7 participants was used to test and enhance study methodology. Results from the pilot focus group were not included in study findings.

Participants, from Niagara, Brant, Hamilton, Haldimand and Norfolk, were provided a guestionnaire in advance to assist with their preparation for discussions related to medical experiences and advice for health care learners and practitioners. Some participants brought care providers to assist with comfort or communication. Groups were facilitated by two health care students and a Health Care Facilitator from the SNSC. Participant responses to questions about health care experiences were audio recorded. Some participants submitted additional responses using the questionnaire. Audio transcripts and questionnaires were analyzed for emerging themes. **Investigators** translated information from the study into achievable recommendations for developmental disability medical education curriculum enhancement.

Results: Study investigators identified important themes from the analysis of participant responses. Themes were grouped based on either:

- 1) their general health care experiences, or
- 2) their experiences with health care students, and
- 3) their advice to health care students





1. General health care experiences

- ⇒ Person-centred health care: Participants wish to be consulted about their health care needs and preferences.
- ⇒ Barriers to access: Participants identified a number of significant barriers: reliance on caregivers, convincing others of illness, transportation, cost, clinic hours, emergency department busyness and wait times.
- ⇒ Attitudes: Participants valued friendliness and honesty from health care providers.
- ⇒ Communication: Listening, non-verbal communication, speaking, and choice of words (plain language) are important. Positively reinforcing the person's efforts towards good heath/dental maintenance was appreciated.
- ⇒ Professionalism: Respectful communication, explaining/obtaining permission, punctuality, soliciting informed choice/consent, and maintaining privacy are central to successful health care experiences.
- ⇒ Outcomes: Clear diagnosis, treatment success, relief from their discomfort, pain management, and improved health are important outcomes of health care interactions.
- ⇒ Continuity of Care: Consistency and communication among health care practitioners are valued.
- ⇒ Inter-professional Care: Involvement and collaboration from multiple health care disciplines was noted repeatedly.

2. Experiences with healthcare students

- ⇒ Introductions: Participants would like students to introduce themselves using their name and role.
- ⇒ Purpose: Whether their role is to observe or take part in care, this should be introduced and the person given the opportunity to decline (a few stated they prefer to see only their own doctor).
- ⇒ Confidentiality: Participants noted they want to be assured that their information will remain private.

3. Advice to healthcare students

⇒ Participants highlighted the importance of students learning and practicing the themes identified throughout the study: person-centred care, attitudes, communication, professionalism, outcomes, continuity of care, and inter-profession care.

Discussion/Conclusion

Education of health care professionals is an essential

component of addressing health care inequity with the vulnerable population of people affected by developmental disability. Effective curriculum must address health care clinician-related barriers, including attitudes, in addition to knowledge and skill acquisition. This research reinforced the invaluable benefits of directly involving people with developmental disabilities in research related to the



supports and services they require to live full and healthy lives. This research provided valuable personal perspectives that led to patient-centred recommendations to guide the enhancement of a Curriculum of Caring for People with Developmental This curriculum has being developed through a partnership of McMaster University, Michael G DeGroote School of Medicine (Niagara Region Campus) and Brock University Centre for Applied Disability Studies, Department of Nursing and Bethesda Services. This additional focus group input will be used for curriculum refinements for broader health care training. This research was one of a number of Curriculum of Caring related initiatives supported by a 2013-2014 Associated Medical Services (AMS) Phoenix Fellowship granted to the principal investigator. An extension of the AMS Phoenix Fellowship has allowed further enhancements to developmental disability medical education. The research findings have also informed education / training initiatives of the Building Health Care Capacity Initiative (SNSC).

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The Community Access to Transportation project (CAT): Increasing independence for individuals with developmental disabilities through a sustainable travel training program (2011-2014).

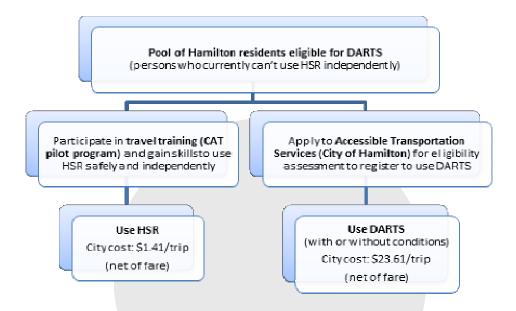
Authors: Sarah Mayo, smayo@sprc.hamilton.on.ca Michelle Martin, michellemartin@lawsonministries.org

In 2011, the City of Hamilton responded to a proposal from the Developmental Services Transportation Committee (DSTC), a group of representatives from developmental services agencies across the city, to pilot a fixed-route transit training project, in order to divert trips for clients with developmental disabilities from specialized transit (DARTS) to conventional transit (Hamilton Street Railway - HSR). The City provided \$400,000 to a two-year project for this purpose, called Community Access to Transportation (CAT). DSTC agencies provided trainers from available personnel, giving the project trainers who were knowledgeable and experienced with this population.

The curriculum developed, including was instructional videos filmed in collaboration with the After in-class lessons, field trainers took HSR. trainees on the bus to teach them the safest way to execute the specific routes they wished to learn, using a detailed task analysis to evaluate trainee performance. Of 201 trainees who enrolled in the project, 75% were able to learn one or more bus routes successfully; 9% dropped out, and 16% were unable to travel safely by bus. Field trainers taught a total of 258 bus routes, and successful trainees learned an average of 1.7 routes each.

In 2012, the Hamilton Wentworth Catholic District School Board and the Hamilton Wentworth District School Board joined the project, to obtain bus training for transition-aged youth (from 18 to 21 years) with special needs so they could explore opportunities in their community. Trainers taught CAT curriculum at high schools across the city, and connected directly with teachers, educational assistants and job coaches to accomplish field training. Of 75 youth who were referred by school boards or who were in school at time of training, 69% successfully learned one or more bus routes.





CAT third party evaluator, the Social Planning Research Council of Hamilton (SPRC), reports a potential net savings to the City of with a low estimate of \$916 per trainee and a high estimate of \$6,646 per trainee, depending on different assumptions of how many trainees would have become regular users of specialized transit if no training program had been available. This represents 26%-187% annual return on investment for the CAT pilot program.

Predicted Net Savings

Low estimate	Net savings per year, averaged over 10 years	\$137,836
	Net savings per year, averaged over 10 years per successful trainee	\$913
	Annual return on investment	26%
High estimate	Net savings per year, averaged over 10 years	\$1,000,630
	Net savings per year, averaged over 10 years per successful trainee	\$6,627
	Annual return on investment	186%

To accommodate both outstanding referrals to the program from last year and transition-aged youth this coming school year, the HSR has provided some funds from its existing budget to ensure some access to training in September 2014, pending a request to Council for a budget enhancement in 2015 to renew the program for another two years.



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.

Next Steps:

The Southern Network of Specialized Care with the SNSC Advisory Committee are pleased to support opportunities for linking with researchers in the field of Dual Diagnosis. Please consider joining us at the annual Southern Network Research Forum Day on **September 21st, 2015.** If you would like more information on the annual SNSC Research Forum, or, if you would like to discuss a potential research or evaluation project — please email the SNSC Research Facilitator, Beth Anne Currie at bethannecurrie@sympatico.ca or the SNSC Coordinator, Liz Froese at froese.network@sympatico.ca

Also, please find links to research publications, research funding, research applications and more on our website at www.community-networks.ca

