Health and Wellbeing in Developmental Disabilities

Engaging Health Care Professionals

November 12-13, 2013
Toronto, Ontario

WORKSHOP ABSTRACTS

W01
The Use of Genetic Assessment in Finding a Genetic Cause for Developmental Delay, Leading to Better Health Care for the Client and the Family

Sandi Sodhi (Trillium Health Partners - The Credit Valley Hospital) Cynthia Forster-Gibson (Trillium Health Partners - The Credit Valley Hospital)

Individually, genetic disorders are rare, but collectively they comprise over 15 000 distinct conditions. Developmental delay is a component of many of these conditions. Advances in genetic test methodologies have almost doubled the detection rate for a specific genetic cause of developmental delay. Geneticists and Genetic Counsellors work together to help clients and their families understand complex genetic information and its implications for the client and family members. This workshop is designed to help healthcare providers identify that the ways in which they aid a client with developmental delay may be altered if they know the underlying cause of the delay.

W02
Using Interprofessional Outpatient Teams to Decrease Emergency Department Visits for Mental Health Issues in Individuals with Developmental Disabilities

Amanda Sawyer (University of Toronto)

A panel consisting of an interprofessional team who work with individuals with developmental disabilities and mental health issues, will discuss how they work together to reduce and eliminate emergency department visits for mental health concerns. The discussion will be facilitated through two cases: the team worked with the first case to eliminate emergency department visits, and the second case is a new case that will be presented to the team, from the perspective of the emergency department. The panel will use the cases to present an established plan and demonstrate developing a new interprofessional plan, and discuss the advantages and challenges of working as an interprofessional team.

W03
Social Skills Programming in Ontario for Individuals with Autism Spectrum Disorders: The PEERS Program

Marilyn Thompson (Autism Ontario) Tiffany Macdonald (Autism Ontario) Rebecca Ward (Brock University) Magali Segers (York University) James Bebko (York University) Margaret Spoelstra (Autism Ontario) Jessica Schroeder (York University)

It has been well established in the literature that children with Autism Spectrum Disorders face severe challenges in social communication and effective social interaction. The development of social skills contributes significantly to overall development by improving quality of life, supporting social, emotional, and intellectual development, and acting as a buffer for stressful life events (Solish, Perry, & Minnes, 2009). This interactive workshop will examine social skills programming for individuals with ASD by summarizing the most up-to-date research, describing the current state of supports and programming in Ontario, and providing new data from current programming initiatives.

W04

The Importance of Implementing Motor Skill Interventions for 3-5 Year Old Children with Developmental Disabilities: Strategies and Examples

Emily Bremer (University of Ontario Institute of Technology) Lindsay Smith (University of Ontario Institute of Technology) Meghann Lloyd, PhD (University of Ontario Institute of Technology)

Young children with developmental disabilities often experience impairments in their motor skills and social skills. The development of social and motor skills work together – motor skills help children participate in active play and this engagement in play helps improve their social skills. Participants in this workshop will gain an understanding of the importance and benefits of early motor skill interventions, as well as the basic resources required to implement a fundamental motor skill intervention.

W05

Nick Lennox - Health Assessments, Research and Beyond: What We Know and What We Don’t Know

Nick Lennox (University of Queensland, Australia)

This presentation will cover what we think we know about the effects of health assessments for people with developmental disability. The limited literature on the views and experience of those who participate in the process will be described. In addition, although health assessments have been studied over the last 20 years there remain many unanswered questions which will be explored. Ideas for refinements of the process to make it more accessible, acceptable and effective will be discussed, along with other ideas to improve health and healthcare of people with developmental disability.

W06

GO4KIDDS Sampler: A Selection of Results from the Great Outcomes for Kids Impacted by Severe DD Emerging Team

Adrienne Perry (York University) Jonathan Weiss (York University) Rosemary Condillac (Brock University) James Bebko (York University) Barry Isaacs (Surrey Place Centre) Patricia Minnes (Queen's University)

GO4KIDDS (Great Outcomes for Kids Impacted by Severe Developmental Disabilities) is a CIHR-funded inter-disciplinary Emerging Team dedicated to studying the health, well-being, and social inclusion of children with severe and complex needs (intellectual disability in the moderate to profound range, together with possible physical disability, behavioural/mental health concerns, autism, etc.) and the health, well-being, and social inclusion of their families. This session will provide selected results from a series of studies using a range of methodologies (surveys, interviews, and observational) and will solicit the audience's participation in generating recommendations for service providers and policy makers, based upon the results.

W07

Successful Collaboration Wwth LGBTQ People with Intellectual Disabilities

Tess Vo (Griffin Centre Mental Health Services) Onyii Udegbe (Griffin Centre Mental Health Services) Zack Marshall (Griffin Centre Mental Health Services & Memorial University of Newfoundland)

sprOUT is a collaborative community-based project developed in partnership with lesbian, gay, bisexual, trans, queer, and questioning (LGBTQ) people labelled with intellectual disabilities and their allies at Griffin Centre in north Toronto. Funded by the Ontario Trillium Foundation from 2008-2012, the goals of the first phase of sprOUT were to build community with LGBTQ people with intellectual disabilities across Ontario, to provide training and support to educators and service providers, and to document and disseminate best practices. In this presentation we will share the results of a recently completed sprOUT Program Evaluation including our Collaboration Tip Sheet and key findings.

W08

Assessing Pain in People with ID: A Skill for Everyone

Beverley Temple (University of Manitoba)

Many people with Intellectual and Developmental Disabilities (ID/DD) are supported to live in the community. As people with ID/DD age, there is a need to be able to identify pain in people with ID/DD and who may not be able to communicate their physical needs. It is vitally important to the quality of lives of people with ID/DD that we learn how to assess pain. We will review case studies and attendees will be encouraged to participate so that we can all gain an appreciation for how we can recognize when people we support are having pain.

W09

Health Care Access Research in Developmental Disabilities: The Primary Care Atlas and our Next Steps

Yona Lunsky (University of Toronto) + H-CARDD Team

We will present highlights from the first phase of H-CARDD, focused on developmental disabilities and primary care, and share some of our next steps as we move from knowledge into action. We will conclude with a rich discussion on how to use research to change policy and practice.

W10
Reclaiming the Meaning of the Difficult Family

Christine Grant (family member, clinician), member of the care team

This presentation will provide a case scenario and personal narrative that will describe the phenomenon of the 'difficult family'. This presentation will endeavour to reclaim the meaning of difficult family member, to offer alternative engagement strategies, including some mindfulness techniques, and to bring awareness to the costs of quality care.

W11
Designing Meaningful Movement Activities for Children and Youth with ASD

Maureen Connolly (Brock University) Elyse Lappano (Brock University) Brittany Hogan (Brock University) Andra Lenius (Brock University) Hayley Morrison (Brock University) MIchelle Caione (Brock University)

Autism Spectrum Disorder (ASD) is a complex and heterogeneous way of being in the world. Persons with ASD experience the consequences of their stressed embodiment across multiple dimensions of relationality. Our concern is the dimension of movement and physical activlty. While not directly causative, ASD nevertheless impacts typical developmental milestones in the psychomotor and perceptual motor domains. We have developed a station based embedded curriculum approach grounded in longitudinal observational studies of children, youth and young adults with ASD. This curriculum can be modified for a variety of spaces, contexts and levels of severity of ASD. Our session will introduce the components of our approach, its varoius planning and profiling tools, and provide an opportunity for participants to interact and problem solve in several aplication based scenarios.

W12
Adaptation of Evidence Based Treatment for Anxiety in Children/Youth with Intellectual Disabilities: Treatment Outcome and Parent Satisfaction

Karin Gleason, CPsych (Child and Parent Resource Institute, London, ON) Katharine Moody, BA DSW (Child and Parent Resource Institute, London, ON)

This workshop will introduce participants to the IDEAS team inter-professional assessment and treatment approach for children and youth with intellectual disabilities and anxiety/mood disorders. Discussion will include adaptation of evidence based strategies targeting children/youth with intellectual disabilities and anxiety; focussing on adaptation of cognitive behavioural treatment strategies, and the inclusion of caregivers and educators within the treatment process. Participants will engage in an adaptation exercise aimed at supporting client recognition and application of coping strategies in response to their symptoms of anxiety. The efficacy of this approach will be demonstrated through program evaluation data including client outcome and parent satisfaction.

W13
The Science of Spirituality

James Holzbauer (Adult Protective Services Community Living Toronto)

The Science of Spirituality is an exploration of the mounting research evidence that various spiritual practices and values often imbedded in the world religions (meditation, a sense of purpose, a strong community of friends, strong family ties, lasting partnerships, singing/drumming, etc.) all enhance the quality of human life. Common spiritual practices are now known and proven to increase immune system function, reduce stress, and promote feelings of happiness, contentment and over all wellness. Irrespective of individual religious doctrines or dogmas spiritual practices promote health and wellness and potentially actually extend our life.

The session includes a facilitated discussion regarding how we can incorporate spiritual practices into the services we provide that are quality of life enhancing while being respectful of individual religious practices and beliefs and unbelief. In this workshop participants will be assisted in exploring their own and others unique and traditional spiritual practices and examine the research that explores their effectiveness. The participants will learn to define "spirituality" as separate from specific religious doctrines/dogmas, "spirit practice", "spiritual experience" and "spiritual health." They will workshop together practical examples of how to recognize, incorporate and respect individual spiritual practices that enhance health and wellbeing.

W14
The 3Rs Health Self-Advocacy Educational Program

Maurice Feldman (Brock University) Frances Owen (Brock University) Dorothy Griffiths (Brock University) Barbara Vyrostko (Community Living Welland Pelham) Theresa Terreberry (Community Living Welland Pelham)

The research related to this project was supported by CIHR. The educational materials related to this program have been published by and are distributed by Community Living Welland Pelham.

The 3Rs: Rights, Respect and Responsibility Community University Research Alliance has developed a *Teaching Health Self-Advocacy Skills to Adults with ID* educational package that includes a health education program and a rights program designed to equip participants to become effective advocates for their own health care. This workshop will be led by researchers, community professionals and self-advocates who have been part of the 3Rs Project. The workshop will describe the systemic approach used to educate both self-advocates and their care providers about human rights, and results of the evaluation of the impact of the health knowledge and self-advocacy education program.

W15
The Importance of Healthcare Professional Training on Developmental Disabilities: Findings from a Survey of Parent Service Needs and Healthcare Student Training Experiences

Patricia Minnes (Queen's University) Barry Isaacs (Surrey Place Centre) Joan Versnel (Dalhousie University) Alvin Loh (Surrey Place Centre) Adrienne Perry (York University) Jonathan Weiss (York University)

Parent - professional collaboration is important to facilitate successful transition of children with developmental disabilities (DD) into school. This transition can be challenging for parents who must negotiate the shift from healthcare to education based service systems. Parents report that professionals' lack of knowledge of DD and relevant service systems is an additional challenge. The major purposes of this workshop will be to: 1) review data gathered from parents and healthcare students about their knowledge of DD, collaboration; and resource needs and 2) engage participants in discussion and activities focusing on development of strategies to improve healthcare curriculum on DD.

W16

DD CARES - Improving the Emergency Department Experience and Continuity of Care

Susan Morris (CAMH) Andrea Perry (CAMH) Johanna Lake (CAMH) Yona Lunsky (CAMH) Jacques Lee (CAMH)

Grant funding for DD CARES was received through CAMH from a CHSRF/CIHR Chair

People with developmental disabilities (DD) visit the Emergency Department (ED) more often than people without DD. **DD CARES** is an initiative aimed at promoting the improved care of individuals with DD in the ED. Tools, education, and resources were developed with one Ontario general hospital emergency department, including a Hospital Passport and Exit Summary, both of which will be discussed. By attending this workshop participants will have an opportunity to review and provide input on the tools, learn how to access this information, and how to communicate with primary care providers about recent ED visits.

W17

Cervical and Breast Cancer Screening Knowledge of Women with Developmental Disabilities

Susan Parish (Brandeis University)

Women with developmental disabilities have the worst rates of receipt of cervical and breast cancer screening of any population subgroup in the United States. Previous research has established that one major barrier to the receipt of such screenings is the lack of knowledge women with developmental disabilities have about preventive screenings. To address this gap, we used a randomized controlled trial (n=175) to test a targeted intervention designed to promote cervical and breast cancer screening for women with developmental disabilities. Women assigned to the experimental group participated in eight weekly health education sessions. Baseline and post-test data were collected using computer-assisted personal interviews. Nine individual indicators of cervical and breast cancer screening knowledge and a knowledge composite, composed of all nine items, were analyzed. Significant adjusted gains were found for breast cancer knowledge, but not for cervical cancer knowledge. Our findings indicate that women with developmental disabilities can benefit from a targeted health promotion intervention that is specifically tailored to their learning needs. These findings also suggest that the intervention is promising, but likely needs to address cervical cancer in greater depth and detail.

W18

Eating Disorders and Developmental Disability: Complexities, Collaboration and Care

Angela Gonzales, RN MN (Toronto Network of Specialize Care, Surrey Place Centre) Donna Lee, B.A., M.A. (CDS) (Vita Community Services)

This workshop will offer participants an overview of what eating disorders are, how they can present in individuals with intellectual or developmental disability (I/DD), and what supports could help with care delivery in this population. In combination with cognitive impairment associated with I/DD, assessment and treatment for an eating disorder requires more complex strategies to offer support to the individual and his/her caregivers. The workshop will focus on how interprofessional collaboration can improve the delivery of health care and caregiver supports through pooling resources and adapting treatment used for the general population for an individual with I/DD and eating disorder.

W19

Health, Mental Health, Community Involvement, and Quality of Life of Individuals with Intellectual Disabilities after Deinstitutionalization

Rosemary Condillac (Brock University) Lauren Ireland (Brock University) Keeley White (McGill University) Alison Cox (University of Manitoba) Aliya Rahim (Surrey Place Centre) Jan Frijters (Brock University) Lynn Martin (Lakehead University)

In 2004 the Ontario Government announced their plans to close the last three provincially funded facilities for people with Intellectual Disabilities by April of 2009. The Facilities Initiative Study was designed to evaluate the processes and outcomes of this final wave of deinstitutionalization. Overall results indicated that the majority of individuals were doing as well or better in the community. The longitudinal component of the study examined change over time on key factors including health, mental health, community involvement, and quality of life. In this session we will present key findings and recommendations for policy, practice, and future research.

W20

Community Engagements that Enable Effective Partnerships to Proactive Health Care Practices for people with Developmental Disabilities

Dr. Douglas Morrison (Family Physician) Paula Komenda (Community Service Provider) Tom Archer (Healthcare Facilitator)

Collaboration and education of health and social service professionals is essential to the optimum functioning of health care service delivery for individuals living with a developmental disability. Continual quality improvement, patient engagement, wellness markers and identification of best practices for maintaining and managing health and wellness is a shared responsibility. This crucial partnership helps to identify health goals, decreases the prevalence of admissions to hospital, lessens the length of stay in hospital, and could stave off the need for admission to long term care. This partnership begins with a holistic approach to supports and proactive health practices for each individual which in turn leads to better healthcare utilization and outcomes.

W21

It Takes a Community: Establishing Community Collaborations to Improve Service Delivery and Streamline Transitions for People with a Dual Diagnosis and Other Complex Needs

Sandra Bricker (Toronto Network of Specialized Care) Lisa Holmes (Eastern Network of Specialized Care) Liz Froese (Southern Network of Specialized Care) Jo-anne Trahan (Northern Network of Specialized Care)

Individuals with a dual diagnosis and/or other complex needs typically require supports and services from multiple service providers across sectors. In order to streamline service delivery, coordinate transitions and ensure needs are met, it's vital for service providers to collaborate and establish good partnerships. How do you do this when the sectors are so different and funds are limited? In this session, the Community Networks of Specialized Care will share their expertise and knowledge in establishing cross-sector collaborations and share examples of successful collaborations from across the province.

W22

Transitions and Shared Care for Pediatric Patients with Complex Care Needs

Liz Greir (Queen's University) Ullanda Niel, Patricia Mousmanis (Ontario College of Family Physicians)

Transition from child to adult health care for adolescents and children with chronic medical conditions is essential. Comprehensive literature review informs our recommendations for ‘ best practice’ models for shared care using the Patient’s Medical Home for all pediatric patients.This workshop will describe the difference between involvement and engagement in the shared care of children and apply the results of a literature review to a model of transitions and shared care between family physicians and pediatricians.

W23

Regulated Health Professions Act: Issues That Affect Primary Care Providers & Developmental Services Agencies

Camille Bigras (North Community Network of Specialized Care) Christine Fontaine-Paquet (The Ottawa Rotary Home) Angie Gonzales (Toronto Network of Specialized Care) Deborah Lawrence (Diagnosis Nurse Consultant, Regional Support Associates) Beverly Vaillancourt (Central East Community Network of Specialized Care)

The panel presentation will inform the audience about issues related to the application of the Regulated Health Professions Act (RHPA) through a case example as a basis for an interactive discussion. The example presents issues that affect prescribing primary care providers, nurses who provide training to unregulated care providers, and developmental sector staff who are requested to perform ‘controlled acts’ to care for clients. Understanding issues related to the developmental sector’s context for application of the RHPA, promoting interprofessional collaboration to discuss and implement strategies to manage issues, could improve client safety, caregiver supports and primary care delivery.

W24
Antipsychotics in Developmental Disabilities: The Good, the Bad and the Ugly

Robin Friedlander (Developmental Disorders Program, Department of Psychiatry, University of British Columbia)

There is a lot of attention currently in the media regarding the use and/or misuse of antipsychotics in children for control of aggression and disruptive behavior. A generation ago, a similar controversy existed regarding the use of antipsychotic medications in children and adults with developmental disabilities resulting in guidelines regarding appropriate use of these medications. This talk will review the current practice regarding the use of antipsychotics in this population.

W25
Autism Comes to the Hospital

Barbara Muskat (The Hospital for Sick Children) Priscilla Burnham Riosa (The Hospital for Sick Children) David Nicholas (University of Calgary) Wendy Roberts (The Hospital for Sick Children) Kevin Stoddart (The Redpath Centre) Lonnie Zwaigenbaum (University of Alberta)

Visiting an acute care facility can be a difficult experience for anyone with urgent health care needs. For individuals with Autism Spectrum Disorders (ASD), the hospital experience may be especially challenging. The purpose of the proposed workshop will be to: 1) provide participants with an overview of ASD; 2) describe current ASD-relevant hospital research; 2) explore potential barriers to successful hospitalization experiences for youth with ASD and their families, and 3) discuss proactive and reactive strategies and supports that may be helpful when caring for this population. Workshop participants will also engage in brief experiential activities and large and small group discussion.

W26
Understanding the Implications of Trauma-informed Care in Developmental Disability Services

John Keesler (University at Buffalo)

Trauma-informed care (TIC) is a systems-focused model for service delivery that recognizes the prevalence and impact of trauma in the lives of service recipients and providers, and is guided by the principles of choice, collaboration, empowerment, safety and trust. As a grass-roots effort, one organization developed a TIC day program for individuals with developmental disabilities. The program was assessed through mixed methods, including: culture surveys, individual behavior and restraint data, as well as staff interviews. Despite mixed findings, it was generally noted that individuals demonstrated improvement and staff expressed employment satisfaction, thus suggesting implications for the future use of TIC.

W27

Shifting the Paradigm: Integrating Trauma Theory into Support for Individuals with Developmental Disabilities; Phase Two

Melissa Otter, Trevor Lumb, Cathy Kuehni, Karen Klee

It has been identified that many people with a developmental disability often suffer more long-term abuse or neglect and therefore have a more complex presentation of trauma. Since its conception in 2007 the Trauma and Developmental Disabilities Committee of Central West Region has been working to identify and address specific needs and challenges in this area. Phase one began with the Central West Network of Specialized Care completing a comprehensive gap analysis and then hiring Dr. Lori Haskel to complete a literature review, construct a theoretical framework, and then make recommendations as to how to develop an integrated network of services. The committee then conducted extensive trauma training in the fall of 2009. Phase two is putting the recommendations into practice. After the completion of Phase one in 2009, the Trauma and Developmental Disabilities Committee, comprising of members from both the Developmental and Trauma service sectors, have been continuing to address the growing needs of this population through additional training and education, mapping of services, resource sharing and collaboration - all with an eye towards our future goal of developing a best practice model.

Participants in this workshop will be provided a brief overview of trauma impacts individuals with developmental disabilities. Concepts of assessment, support and treatment will be illustrated as the learner follows one woman's journey through developmental and trauma services, and how the committee hopes to use this success story to further integrate trauma theory across sectors for individuals with developmental disabilities.

W28

Increasing the Wellbeing of Individuals with Fetal Alcohol Spectrum Disorder

Nancy Hall (The Southern Network of Specialized Care/ FASD Ontario Network of Expertise)

In 2008, FASD One embarked on a province wide project to explore standard practices that are effective in supporting people with Fetal Alcohol Spectrum Disorder. This workshop will include a basic review of FASD and then will highlight the results of current research on eight practices that have been identified as critical to the effective support of people impacted by FASD. Participants will learn basic information about FASD as well as effective practices that will support their day to day success in supporting this challenging population. This application of this information will increase the mental health and wellbeing of individuals being served. The importance of diagnosis or recognition of the population is discussed.

W29

The Evolution of a Community Collaboration to Support Individuals with Fetal Alcohol Spectrum Disorder

Sally Seabrook (Coordinator of Behaviour Services, Mackenzie Health) Stefanie Smith (Behaviour Consultant, Mackenzie Health)

This presentation will describe the evolution of a community collaboration to support individuals with FASD in Simcoe County. In 2009 our community adopted the Neurobehavioural

Accommodations Model (NAM) across sectors to support people with FASD. A pilot evaluation demonstrated utilization of the NAM resulted in improved outcomes for natural care providers, but did not necessarily result in significant changes in challenging behaviour. In order to address this apparent gap, an ABA clinic was developed to enhance the community model. An overview of the clinic will be provided and illustrated using a case example.

W30

Preparing for Your Senior Years

Terry Elliott (Mary Centre - Program Director)

This session will outline the Mary Centre approach to support through a continuum of services including residential, day supports, integrated community supports and transition into long term care. We help participants understand how Mary Centre in collaboration with our community partners successfully support seniors in ageing with respect and dignity. This presentation will explore i) The changes a person with a developmental disability may go through as they age, ii) What different services and supports are available in the community, iii) How to know whether LTC is right for a person iv) How to transition plan v) How to develop partnerships.

W31

Building Coalitions through an Integrated Service Delivery Model

Sandy Stemp (Reena) Elias Brenda (Humber College)

Reena was established in 1973, dedicated to fully integrating people with developmental disabilities into mainstream society. The innovative Reena Community Residence, located in Southern York Region, offers community-based housing with supports. Integrated services within a collaborative model of social and health service providers support a mixed community of adults and seniors with developmental, physical, and mental health needs within apartment living. As a result of participating in this workshop, participants will be able to understand the benefits and challenges of integrated service delivery models.