

## Keynote

**Title:** Navigating a Complex World: Lessons Learned from a Complex Case Management Pilot Project

**Presenters:** Wade Durling, Karen Menzies, Lisa Holmes, Jessica Waller

### **Abstract:**

In 2015, Ongwanada was selected to lead a regional complex case management pilot within the South East section of the East Region. Through a collaborative process, the pilot set out to build specialized case management capacity in partnership with and complementary to the existing community case management responsibility. A Community of Practice was established and was central to the development and ongoing evaluation of the pilot. The work was strongly linked to the local specialized clinical supports and the Community Networks of Specialized Care. Individuals identified to participate in this pilot presented with complex support needs and service coordination requirements that crossed multiple sectors – 5 were residing in various hospitals at the time. The outcome was a community service plan for each individual that identified needed changes and supports to enable the person to be accommodated within community. Outcomes often had impact on other resources and individuals. As an example, to achieve the outcome for one individual who was in hospital, a small financial adjustment in combination with resource reallocation and planning supported positive changes with 8 other individuals and enabled this individual to be successfully accommodated. The initial success of the pilot led to its extension for a second year and has identified some positive lessons to support the refreshed mandate of the Community Networks of Specialized Care. In this panel presentation, we will review the model and process as well as some outcomes and lessons learned.

## Session 1A

**Title:** Technology can Transform Well-being

**Presenters:** Shelby Pillon, Corey Dalgleish

### **Abstract:**

It's amazing what technology does for you and me on a daily basis so why should that be any different for people with intellectual disabilities? Technology and smart devices are revolutionizing nearly every aspect of personal life and business. Extending that power to developmental services has the potential to create support options that were simply not possible or affordable in the past. We will share the innovative ways to complement supports and services for people to further reach their goals with 'right-fit' smart devices and technologies to increase well-being, free up resources to support people waiting for service and expand the traditional model of support. Smart Support Technology Enabled Services is now embedded in the agency's culture and is a successful model that is being replicated.

We have adapted a process of evaluating and assessing the skills and abilities an individual possesses and an understanding of when technology can further enhance the support a person is receiving.

The modernization of support delivery redefines the vital role of direct support professionals, with a focus on each person's abilities. Success stories will be shared of people who are now living a life that was once only a vision!

Come and learn more about technology and how it transforms well-being for the people receiving support and their families to expand the array of support options and open doors to greater independence, more inclusive communities, strengthened support networks and more possibilities than ever before!

## Session 1B

**Title:** Hospice Palliative Care and Advance Care Planning

**Presenters:** Sarah Brisbin, Julie Martin-Jansen, Cheryl Peterson

### **Abstract:**

Community Living Dufferin and Elmira District Community Living are partnering to present Advance Care Planning and Palliative Care. Ideally, we would like to have two, back-to-back, 75 minute sessions.

Community Living Dufferin has been providing Hospice Palliative Care since 2009 and piloted an Advance Care Planning project in 2013 aimed at giving people supported a voice in their end-of-life care. Since then, each person supported has been given the choice to complete an advance care plan, and we have supported 4 people at end-of-life using their Advance Care Plan to honor their values and wishes. This session will cover our Advance Care Planning document and staff training guide, tools in delivering its content, and how to store, use and update it once it is complete.

In 2004, the Elmira District Community Living provided its first hospice palliative care to an individual in their own home. Over the last thirteen years we have cared for 19 people at end-of-life. Our knowledge of Hospice Palliative Care has grown considerably and with each person we support, we learn more. This session will walk participants through:

- The process from diagnosis to death;
- The Five Domains of Palliative Care;
- The Circle of Care that typically includes the individual, professionals, caregivers, families and house-mates;
- Resources for families, caregivers and individuals;
- The after care.

## Session 1C

**Title:** A Collaborative & Holistic Approach: The story of one man's journey from a locked unit to coffee at Starbucks

**Presenters:** Natalia Sollazzo, Sarah O'Donoghue, Krystal Street

### **Abstract:**

Comprehensive support packages are often necessary for individuals who exhibit severe and challenging behaviour to aid in the transition from segregated environments to inclusive communities. With multidisciplinary supports and intensive training, the high degree of intrusive measures previously utilized to manage behaviour can be reduced to near zero rates. Consistent oversight and monitoring through the work of competent and compassionate caregivers ensures these individuals continue along the road to increased independence and inclusion in the community. This new model provides individualized packages of support that allows the opportunity for individuals with an array of complex behavioural challenges to be supported within a community-based setting tailored to their specific needs. The success of this model to date will be demonstrated.

### Session 1D

**Title:** Self-Advocates Perspectives on How to Provide Respectful Supports

**Presenters:** TBA

**Abstract:**

As the self-advocates movement continues to move forward, more people who are supported are gaining their voice and embracing their ability to make decisions for themselves.

During this session the audience will hear from self advocates about their definitions of respectful supports. Who better to learn from than the people who receive supports and services?

This session is for anyone who provides support.

### Session 2A

**Title:** Aging & Intellectual Disability, when is it dementia?

**Presenters:** Dr. Katherine Buell, Sean Kerry, Janice Elms, Lori Burt

**Abstract:**

Persons with Intellectual Disability are living longer. Supporting persons with intellectual disability is a relatively new phenomenon. Persons with ID have actually led the field in how to support those with aging impairments, if we only knew! Changes in health status, psychological factors, and social factors have a significant impact on the individual's functioning. Our session will share some common decision points (system, administrative, supportive), and some ways we in the ID field can improve aging care within the ID population.

As front-line clinicians, we will explain our process by going through three cases. We will present some of our Behaviour Therapists / Psychological Services staff working through some of our cases, assessment and intervention related to a possible dementia diagnosis. The cases reflect a variety of living situations (family home, community home, SIL).

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### Session 2B

**Title:** The Cross-Sector Complex Care Program

**Presenters:** James Sejjengo, Cindy Dodd, Karen Whitehead-Lye

**Abstract:**

The Cross Sector Complex Care program is a collaboration across Health, Developmental Services and Housing with the shared objective of providing a community based supported living solution for 9 young adults with complex health needs and a developmental disability. This program has just been honoured with the Ministry of Health's medal honour role. In addition this model was recently evaluated with the support of both MCSS and MOH-LTC with a comprehensive report that has been shared provincially. The partners include Central LHIN, Central CCAC, March of Dimes Canada (MODC), Developmental Services Ontario Central Region, Reena, Community Living York South (CLYS) and York Region Housing. The program became fully operational in August 2016. Individuals with complex health needs and developmental disabilities are typically supported in either a Health/Medical based model or a Developmental Services model of support. This collaboration brings the services together under one roof to provide seamless support delivered by a multi-disciplinary team. The model is driven by the individual needs and preferences of the persons being supported as well as family/supports where identified as substitute decision makers.

The model leverages the strengths and expertise from across the partners to create an environment where the individual is supported in a holistic manner.

This presentation will describe how the partnership was developed and how this unique model was created including lessons learned through a cross-sector implementation. The team presenting will encourage questions and discussion on how to develop similar models.

### Session 2C

**Title:** Collaboration and Consensus: A Unified Approach

**Presenters:** Kathleen Peters, Juanita St. Croix, Maurice Voisin

**Abstract:**

Case Management

The presenters experience is in case management including facilitating discussions and plan development within a community, including DS providers, health providers, education, justice and clinical providers to mitigate risks to individuals and families who are experiencing an urgent need. This session will provide an overview of the Case management model used including a risk assessment and plan development resulting in a short term response to an urgent need. This model has existed for the past 4 years within twelve counties and to date has provided case management/urgent response to over 500 individuals/families. It is essential when planning to liaise with other service providers and identify appropriate supports across multiple sectors. The case manager is responsible for the coordination of services and supports across the various sectors. The focus of plan development is not to simply manage the urgent need but to facilitate a collaborative approach from the community and all services available. It will outline the various roles of the case management team including the Enhanced Community Response (ECR) Case Manager, Local ECR Network (LECRN) members and Chairperson. It will demonstrate the effectiveness of this mechanism using statistics gathered to illustrate the reduction of risks to individuals living in the community as well as hospitalization/abandonment of individuals. The significance of developing a cross sectoral network and strategies to do this will be elaborated upon. A case scenario will be presented for discussion and allow the participants to experience the process of case managing an urgent need in their community.

### Session 2D

**Title:** Difficulties and Challenges of Supporting those with DD in Long Term Care

**Presenter:** Vincent Gauthier

**Abstract:**

This presentation has the intention to bring forward concerns which are developing in the field of long term care and developmental disabilities.

With the influx of aging populations in combination with the ever growing need for community programs to support; for those with Developmental Disabilities, long term care homes appear to be becoming a quick fix solution to place this demographic when there are no alternative resources. This however, is not a realistic solution. We, as a community, are risking returning to the days of institutionalization. A long term care home does not have the appropriate Staff or Resources to work with this demographic. Community teams such as Developmental Clinical Services, and

Behavioral Support Ontario do excellent work within their perspective demographic. When intervention strategies are needed for someone with a developmental disability in a long-term care facility, such strategies do not yet exist as the current strategies do not play into the functioning of long-term care.

Within the coming years a need for services to come together to better understand the difficulties and struggles a Person with a developmental disability may come to face while in such programs as long-term care homes will increase. Attention is required today as to not repeat the mistakes of the past.

### **Session 3A**

**Title:** Improving Health Outcomes Through Collaboration

**Presenter:** Cindy Chatzis

#### **Abstract:**

This presentation will describe a project that has been developed by cross sector representatives to build relationships and practices between hospitals and community providers in the developmental service sector.

This project includes the development of a process map and protocol with a major health centre In Southwestern Ontario to reduce ALC (Alternate level of Care) length of stay and build accountability to take action and plan for transitional discharge by both the hospital and the community service sector.

It includes capacity development of both hospital and community agency staff for managing crisis to minimize hospital admissions and manage difficult behavioural and psychiatric challenges with an over-arching goal of improving health outcomes for people with developmental disabilities.

### **Session 3B**

**Title:** Engaging the Experts: People Using Services as Co-designers of Clinical Services

**Presenters:** Jennifer Keilty-Friesen, Janeen Halliwell, TBD

#### **Abstract:**

Co-design is grounded in the belief that the people who use services are the experts of their own experiences, and that organizations need to provide opportunities for the people to co-design service 'solutions.' In this session, participants will hear how Bethesda Support Services endorsed this belief when recently embarking on its "Clinical Services Excellence" initiative. Bethesda went beyond asking people who use their clinical services for feedback, to intentionally creating opportunities for the people to be part of designing future services. People Minded Business Inc., the consultancy hired by Bethesda to develop and facilitate the process, used design thinking and creative problem-solving to bring people into the solutions space.

The presenters will share with you some of their tried and tested "how to" tools that can be used to purposefully involve people who use supports in generating ideas to solve problems, and co-design their supports. You will come away with an insider's view of how, through Bethesda's recent Clinical Services Excellence initiative, the experts (people using supports) were given an opportunity to generate ideas and direct the way of their future services.

### Session 3C

**Title:** Enhanced Specialized Services: A Partnership between Direct and Clinical Supports in the Treatment of Challenging Behaviours in Persons with Developmental Disabilities

**Presenters:** Laura Mullins, Debra MacIntosh

**Abstract:**

In Southern Ontario, enhanced clinical resources for persons with developmental disabilities who engage in challenging behaviours are provided through Enhanced Specialized Services (ESS). ESS represents collaboration between Regional Supports Associates (RSA) and over thirty Direct Service Agencies. ESS was designed to provide increased supports within the community and improve capacity of the person's support system. ESS includes short-term Treatment provided in partnership among RSA and Crest Support Services (CSS).

In 2015, focus groups were completed with CSS Direct Support Professionals (DSP) and RSA clinical staff to determine strengths and areas of improvement. This evaluation indicated the need for a formal revision to the program's framework which was undertaken by a small working group consisting of members from both agencies. The framework now includes clinical oversight from RSA's Behaviour Analyst as well as the completion of 1) a functional assessment, 2) a Treatment Plan centered on specific treatment goals and 3) a Behaviour Support Plan to generalize gains upon return to the community. A pyramid training module is utilized to ensure DSP are adequately trained in the interventions. DSP complete checklists and feedback forms to ensure consistency of interventions and gain insights regarding the interventions to inform revisions.

This presentation will review the evaluation results, the revised process, and highlights from the first year of formal implementation. It will emphasize strategies used to address common areas of concern in the treatment of challenging behaviours, such as communication, multi-disciplinary collaboration, data collection, treatment adherence and increasing competencies.

### Session 3D

**Title:** Weaving the Tapestry of Community Supports. We can individualize treatments within existing service mandates

**Presenter:** Justine Wiegelmann

**Abstract:**

The Clinical Behaviour Service at Geneva Centre for Autism (GCA) provides families with behavioural support for treatment of individuals engaging in significant problem behaviour. Responding to the growing number of individuals and families with complex needs, the Clinical Behaviour Services team identified the challenges impeding on the families' ability to participate in the current service model. Mediator readiness, safety concerns, as well as the need for direct treatment and additional community supports (e.g., respite and service coordination) were identified as significant barriers to the success of the treatment package within this service framework. These challenges lead the team to seek support within the larger community to help find solutions to reduce barriers to families accessing services. This presentation will discuss how a local community table consisting of numerous service providers, the Special Needs Advisory Group (SNAG), collaborated with the Clinical Behaviour Services team to fund a comprehensive behaviour treatment plan for an 11 year old boy who engaged in high rates of aggression. This will highlight the need for services providers to collaborate and think creatively about how services may be individualised within existing mandates to suit the specific needs of our clients.

#### Session 4A

**Title:** Something New, Something Good: the happy marriage between technology and innovation

**Presenter:** Virginie Cobigo

**Abstract:**

An innovation is not only new to those who want to adopt it; it must be designed to benefit persons with intellectual and developmental disabilities (IDD). Information Technologies, used to store and exchange information or to communicate with others, offer exciting new opportunities for promoting social inclusion and self-determination for all users with IDD, and especially those with complex needs. This presentation aims to discuss the risks and benefits perceived by persons with IDD and their caregivers when using technology to support persons with IDD. Six persons with IDD and 6 formal and informal caregivers participated to a series of focus group discussions. Persons with IDD perceive the benefits of using technology and are aware of some of the risks associated with their use. However, their knowledge and behaviours are strongly influenced by those of caregivers who tend to prioritize safety over autonomy. Using the example of an innovative application to help persons with IDD take their medication safely, we will discuss the implications of these findings for innovative care for those with complex needs.

#### Session 4B

**Title:** Nuts and Bolts of Health Care for Direct Support Professionals

**Presenters:** Mais Malhas, Erin Orr, Heather Hermans

**Abstract:**

Adults with developmental disabilities have higher rates of chronic disease and mental illness than other adults (Lunsky et al., 2014). Despite this, they experience challenges accessing appropriate health care services. Vita Community Living Services has identified a need to build the capacity of direct support professionals (DSPs) to better support the health care needs of the individuals they serve. The Nuts and Bolts of Health Care project is a collaboration between Vita Community Living Services, the Health Care Access Research and Developmental Disabilities Program at the Centre for Addiction and Mental Health, and the National Alliance for Direct Support Professionals in the US. The project involves developing the right kind of resources for DSPs in the sector to help them in their role as health advocates for those that they support. In this workshop, we will share information about the key areas that DSPs and agency administration have flagged as priorities, and talk about proposed solutions to addressing these issues, taking into account the importance of setting, and how DSPs learn best. We will talk about the process of co-creating tools that can be used to help understand and navigate health care issues together with health care providers, researchers, and DSPs. We will also show examples of existing useful tools. The identified knowledge and training gaps that we share in this workshop will inform the next phase of this project which includes the development of a toolkit for DSPs that will be available to all developmental services agencies in Ontario.

#### Session 4C

**Title:** Confronting Complexity with innovation: Supporting People with Developmental Disabilities Experiencing Homelessness

**Presenters:** Frances MacNeil, Dr. Sylvain Roy, Monica Waldman

**Abstract:**

City of Toronto's Shelter, Support and Housing Administration Division including Seaton House and Streets to Homes, worked in partnership with Community Living Toronto, Inner City Family Health Team, St. Michael's Hospital, Centre for Addiction and Mental Health and Developmental Services Ontario Toronto Region, to offer multi-disciplinary, flexible, practical, affordable supports in an effort to provide streamlined access, meet the complex needs of the target group (often street-involved, substance use, complex health needs) and appropriate housing. This also served to reduce the reliance on other costly provincially and municipally funded services. The Bridges to Housing project aimed to identify 25 homeless individuals through the emergency shelter system (primarily from Seaton House shelter for men), assess them with the primary care partner, confirm eligibility for Developmental Services – Adult Protective Services, provide them with housing allowances and link them with community-based services and housing. The ultimate outcome is to successfully support them to manage living independently and thrive in the community. The project received funding from MCSS through the Housing Task Force in 2015. Bridges to Housing not only achieved its objectives; it led to the identification of a substantial group of people with developmental disabilities that are experiencing homelessness and have support needs that exceed what can be met through Adult Protective Services. The presenters will provide an overview of the findings from the B2H project, its achievements, the unintended consequences that emerged from this work and ongoing efforts to continue meeting the needs of this group within the emergency shelter system.

**Session 4D**

**Title:** Intersections of Support: Using an Ecological Approach to Support Sexuality Treatment Needs

**Presenters:** Michael Cleary, Christa Outhwaite-Salmon

**Abstract:**

Intersections of Support: Using an Ecological Approach to Support the Treatment Needs of Persons with an Intellectual Disability who have Engaged in Concerning Sexual Behaviour.

Providing sustainable support to persons with an ID/DD who participate in treatment for sexually concerning behaviours is often complex, and involves the collaborative, transdisciplinary orchestration of many stakeholders. Adapting the use of an ecological model of disability (Simplican, Leader, Kosciulek & Leahy, 2015), promotes a perspective which considers an individual's experiences with the environment as fluid, interactive and interdependent, revealing the vital, and oftentimes delicate, nature of the individual's support milieu. An ecological approach will be used to consider the intersectional array of supports which form a treatment team which is coordinated by The Program for Assessment and Treatment of Healthy Sexuality (P.A.T.H.S) at Mackenzie Health.

With the overarching goal of minimizing risk for everyone, while maximizing a person's opportunities for adaptive skill-building, community engagement and social inclusion, the interactive elements of peoples Treatment Ecologies will be exemplified. The use of a transdisciplinary lens across the treatment team (of which the person supported is an active participant) will be promoted to highlight the ever-present need for innovation, creativity, and relationship building.

## Session 5A

**Title:** Opening/Managing a Complex Behavioural Home

**Presenter:** Adrian Schadenberg

### **Abstract:**

A year ago, I was approached by Sunbeam Centre to consult on the opening of its first truly behavioral home. It had a target population of transitionally aged men with primary diagnosis of Autism Spectrum Disorder; in our region the waiting list for supports and placement within this demographic were substantial. Sunbeam wanted to provide some relief to this list. The potential residents were all in crisis states: two had spent time (one to two years) in secured mental health units in Hospital, not because it was an appropriate placement but because it was the safest option due to their potential aggressive behaviors; one had a parent who after constant battles with the system, and several injuries to herself, had chosen to legally "abandon" her son, it was the quickest way to receive the support he needed; the last had been removed from his home when his primary caregiver had passed, lived in foster then group care, overcame many great obstacles throughout his journey, but just needed a place to call a permanent home. These four were just examples of the people in need of support in our region.

In my presentation I would like to speak to this growing need throughout our province. I would like to address that although this is a very difficult population to support, with a patient consistent approach great leaps can be made, and goals thought unobtainable can be obtained. Questions such as what lead to developing this program? How were residents selected? What steps were taken after selecting residents? How did we go about building our staff team? What kind of programming is incorporated into the home? Who is involved? Will all be addressed. I will also spend time on the importance of pacing progress, highlighting the little steps of advancement. I will speak on the family dynamics that need to be considered when supporting persons who experienced the kind of crises and trauma that many in this population have. In closing, find potential and capitalize!

## Session 5B

**Title:** Work and Career Experiences in Ontario's Developmental Services Sector

**Presenters:** Dr. Robert Hickey, Emilio Frometa, Anna Fields

### **Abstract:**

We propose to present the findings of an evaluation of the Developmental Services Human Resources (DSHR) Strategy as it reaches its ten-year mandate. The DSHR Strategy has been a joint effort by the Ministry of Community and Social Services and organizations in the sector to make working the sector a career of choice and support the ongoing transformation of the sector. As part of the evaluation, researchers at Queen's University are interviewing Human Resource managers, Direct Support Professionals and other stakeholders to assess the impact of the strategy on local HR practices and workers. The evaluation project supplements these qualitative insights with two large-scale surveys. We survey the HR lead at organizations to assess participation in the strategy and its impact on HR capacity, practices and outcomes. We are also conducting a survey among employees to gain their perspectives on work and careers in the sector. The session will review the findings of the evaluation and help inform strategies for continuing efforts to improve HR practices, workforce development, and ongoing improvements to services and supports.

## Session 5C

**Title:** Transition and Frailty – Supporting and Planning for Aging Individuals with a Developmental Disability

**Presenters:** Sandy Stemp, Don Walker

### **Abstract:**

Reena and Mary Centre were successful in an modernization grant proposal to examine 3 areas related to aging and developmental disability - frailty, planning and transition. This presentation will discuss this project but also pose questions and engage discussion to help inform the outcomes of this initiative. We will describe how we are testing the frailty index developed by Dr. Helene Ouellette-Kuntz- Queen's and Dr. Lynn Martin – Lakehead. This will include a process of testing a sample of individuals with a developmental disability in Toronto and understanding whether they are non-frail, pre-frail or frail. The second area is hiring Transition Coordinators who will develop comprehensive cross-sector care plans for these individuals to see if we can reduce or impact the level of frailty.

The third part is the updating of the OPADD (Ontario Partnership on Aging and Developmental Disability) transition guide. This includes providing information that will be helpful in understanding and implementing the new LTC Guidelines just released from MCSS and MOH-LTC. The project is doing extensive consultation through facilitated sessions cross-sector to review what materials will enable good planning, collaboration and support for individuals aging with a developmental disability. We will be providing time for in this session to share the material that has come forward as well as seeking further input on this resource.

## Session 5D

**Title:** How to Implement Evidence-based Friendship Support Strategies for Adults with Developmental Disabilities who have Complex Needs

**Presenters:** Casey Fulford, Virginie Cobigo

### **Abstract:**

Individuals with developmental disabilities (DD) report higher levels of social isolation than those without DD. They often benefit from the support of family members or paid support workers to form and maintain friendships. However, carers of individuals with DD experience challenges when providing this support and require additional training and tools to develop more effective and relevant methods. This presentation is informed by a project assessing the knowledge mobilization process of implementing evidence-based friendship support strategies into service agency practices.

This presentation will provide findings from applied research that is relevant to front-line staff and managers who offer social support to individuals with complex needs. First, we will present an overview of the evidence-based friendship support strategies for adults with DD. These strategies target individuals who have varying levels of verbal communication and have a range of physical abilities/health problems. We will then discuss the aspects of current friendship supports that adults with DD and family caregivers find helpful and unhelpful and review their suggestions on how to improve these services to better meet their needs. These findings include opinions expressed by individuals who experience chronic physical and mental illnesses, or their caregivers. Finally, we will discuss effective ways in which service agencies can coordinate with adults with DD and caregivers to develop and implement friendship support strategies that meet the needs of their service-users. This information is crucial to assisting community-based agencies to implement effective support strategies that are tailored to their unique settings.

## Session 6A

**Title:** Prevention of Fetal Alcohol Spectrum Disorders: Confusion and Mixed Messages

**Presenters:** Shelley Watson, Kelly Harding

### **Abstract:**

Prenatal exposure to alcohol is a preventable cause of disability that is now considered to be the most significant cause of developmental disability in the Western world. Fetal Alcohol Spectrum Disorder (FASD) is an umbrella term that is used to describe a continuum of effects associated with prenatal exposure to alcohol, which has been identified as a major public health concern in Canada. Individuals who have FASD often have mental health needs, struggle with the law, plus often present with several behavioural challenges. Consequently, there is a need for accurate dissemination of information about the potential negative outcomes associated with alcohol use during pregnancy to increase awareness and prevent FASD. However, much of society is confused about “safe levels of alcohol” during pregnancy as well as the long-term consequences of prenatal alcohol consumption.

Providing clear and consistent information about the risks of drinking is critical, as mixed messages can lead to varying perceptions and interpretations. Current information is also of the utmost importance as recent misinformation of the facts propagated by the media has created challenges for individuals who work in FASD prevention, plus have perpetuated stigma surrounding birth mothers and FASD.

In this interactive presentation, participants will learn about what Ontario women of childbearing age know about FASD, plus how Ontario physicians and midwives provide advice around alcohol consumption during pregnancy. The presenters will also discuss media messaging around alcohol consumption (e.g., LCBO campaign; shame based media) during pregnancy and the ensuing barriers to FASD prevention

## Session 6B

**Title:** Partnerships and Pathways, Linking Health and Community Supports

**Presenters:** Melanie Randall, Megan Henze

### **Abstract:**

Evaluating services and supports for high risk complex clients with developmental disabilities is necessary for accountability and program improvement. While all services collect information about their clients and service processes it is often not effectively used in evaluation. A common reason for this lack of use is that the information is not designed or housed with the goal of program evaluation in mind. The objectives of this presentation are to explore ways that services can:

- Use the information that they currently collect to answer evaluation questions
- Improve their data and data collection methods to enable more effective program evaluation

A case example of a service that provides temporary supports to clients at risk of losing their natural supports will be used. The service is a multi-agency collaboration. The providers had noted that many of the clients receiving supports designed to be temporary were being re-referred after discharge. The process of how the service providers worked with evaluation expertise to seek a data driven understanding of the problem and improve their data collection methods for future program monitoring will be described. Key aspects of the process include:

- Reorganizing intake information into a database
- Analysis of existing data

- The identification of important data elements to improve evaluation
- The development of new ways to collect and store information so it can be easily used in program evaluation

The importance of clear roles in such a process is often overlooked. Therefore, the collaborative process itself and the functions of various partners will be described.

To download a copy of the power point presentation [click here](#)

### Session 6C

**Title:** Health Care Experiences of Individuals with IDD

**Presenters:** Elizabeth Lin, Rob Balogh, Yona Lunsky

**Abstract:**

The Health Care Access Research and Developmental Disabilities (H-CARDD) program studies how adults with intellectual and developmental disabilities (IDD) experience health care in Ontario, with the goal of improving their health outcomes. Our prior work has found that Individuals with IDD are more likely to visit emergency departments (ED) and be hospitalized, less likely to access preventative care, have a higher rate of mental and physical health problems, and receive prescriptions for multiple medications without regular follow-up. We decided to dig a little deeper into the health care experiences of individuals with IDD. Specifically, we focused on how negative experiences of health care differ between those with IDD to adults without IDD in our province. To achieve this, we identified five problematic outcomes that may serve as flags for issues with delivery of care, and compared how often these occur in each group. These five outcomes are: repeat hospitalization within 30 days, return ED visits within 30 days, alternate level of care (ALC) days (extra days in hospital while ready for discharge), admissions to long-term care, and death. In our workshop, we will describe how and why these five outcomes may indicate problems in health services, the differences we found between adults with and without IDD, and what this means for the health care of adults with IDD moving forward. We will discuss with the audience ways to shift care and achieve so together we can support an improved and integrated model of health care for individuals with IDD.