The 5th Health & Wellbeing in Children, Youth and Adults with Developmental Disabilities Conference

Moving From Diagnosis to Practical Strategies

POSTER ABSTRACTS

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HMH: Health/Mental Health
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Increasing Community Capacity and Supporting Smooth Transitions - Creating an Effective Education Series

Jennifer Altosaar, Megan Primeau

PRESENTERS:
Jennifer Altosaar, Coordinator, Toronto Network of Specialized Care, Surrey Place Centre, Toronto, ON
Megan Primeau, MSc, Education and Research Coordinator, Central Region Community Network of Specialized Care, Surrey Place Centre, Toronto, ON

PURPOSE: The Toronto Networks of Specialized Care, in partnership with the Developmental Services Toronto’s (DSTO) Shared Learning Forum and ConnectABILITY.ca, developed a 3 part education series for direct support professional’s to help meet the complex needs related to transitioning planning. When individuals with a developmental disability reach certain milestones (i.e. adulthood, moving out of the family home, older adulthood) and start using different systems, they will leave behind some—if not all—supports they previously had; many services don’t continue past certain ages. The Transitions Series was created to help prepare individuals and the people who support them to move through transitions relating to various ages and life events with confidence and with resources.

METHODS: The planning committee for the event utilized the process laid out in the Community Networks “Toolkit for Planning Education Events” to plan the event; this toolkit is based on best practice in the field of adult education and helps groups plan, develop and deliver educational events for adults that provide a meaningful experience for all. The various stages the committee worked through included: determining the target audience, assessing the learner’s needs, determining the learning outcomes, determining the delivery method, structuring the agenda and activities, constructing the evaluations and managing the event logistics.

RESULTS: The group developed a 3 day education event (Day 1: youth; Day 2: adult; Day 3 aging), delivered over a 3 week period. Participants included direct support professionals from the developmental services sector, as well as community partners from health, education and justice. The event has only just completed and initial feedback is very positive; the results of the session evaluations and a 3-6 month follow-up survey will be analyzed and presented. The learning outcomes for this event, with respect to transitions across the lifespan and sectors, were to help participants to be able to:

• Identify effective strategies to improve system access and navigation for clients and families
• Use effective planning and decision-making to improve client wellbeing
• Support client needs relating to their rights and lifestyles
• Construct a network of individuals who can provide expertise and support

IMPLICATIONS: The results of this training demonstrate the benefits of applying best-practices when developing and designing of education sessions for adults. Through good planning and engagement of various perspectives, anyone can follow a similar process to create an education event that is engaging and also provide practical and relevant information for participants to take back and apply on the job.

REFERENCES: Toolkit for Planning Education Events

LEARNING OBJECTIVES:
1. Describe the main features and results of the Transitions Series education event
2. Discuss the key factors to develop and deliver meaningful educational events
Identifying and Addressing the Health Care Needs of Children with Complex Intellectual Disability Using an Online Health Communication Platform

Tammie Dewan
H-Brain

PRESENTER:
Tammie Dewan, MD, FRCPC, Pediatrician, Department of Pediatrics, University of British Columbia, Vancouver, BC

BACKGROUND: Rapid advances in technology have made it possible to diagnosis rare causes of intellectual disability (ID). This clearly benefits patients and families, but can also place them on a long diagnostic odyssey. Communication is challenging, especially when additional chronic conditions exist. Families are often required to take on the role of care coordinator for their child. Families of children with rare or undiagnosed ID (“complex ID”), have the added stress of diagnostic uncertainty and ongoing investigations. Online-based care models have the potential to support these families and health care teams with continuity and communication.

RATIONALE: There is little known about the unique experiences of families of children with complex ID who are also struggling to find a diagnosis. A different model of care may be needed to support these individuals and online communication tools could mitigate some of the existing barriers and challenges.

STUDY DESIGN: Participants were recruited through the TIDE-BC (Treatable Intellectual Disability Endeavour of British Columbia) Complex Diagnostic Clinic and met the following criteria: (1) “Complex intellectual disability,” defined as undiagnosed intellectual disability with other prominent features; and (2) Ongoing care from at least three health providers (HCPs). For each child, a private social-networking site was created including the parent and HCP. Parent and HCPs could communicate through private messaging, documents and a shared calendar, over one year. Semi-structured interviews with parents explored their access to health care, communication strategies and conceptualization of the health care team at baseline, 6 months and 12 months. Questionnaires (from parents and HCPs) and data extraction from the sites were used to establish acceptability and usage patterns.

RESULTS: 10 parents were enrolled, along with 46 HCPs. The most common challenge reported was accessing physician care. Parents perceived unacceptable waits, a lack of provider follow-up and long delays in response to questions. Most families experienced relationship breakdowns with physicians as a result. Parent priorities included improved access to physicians and their child’s medical information. They wanted more connection between members of their child’s health care team, so that communication could take place directly. Acceptability of the intervention was rated highly, both by families and HCP. No significant safety or privacy concerns arose. Overall usage was moderately low. Major barriers were low physician engagement, time constraints and technical deficiencies.

CONCLUSIONS: Significant existing barriers regarding health care access and communication were identified by parents of children with complex ID. Parents emphasized their need for ongoing connection with physicians, which may be more challenging during a long diagnostic process. Physicians may perceive their role quite differently, which should be the focus of future study. Although the intervention was acceptable, usage was low. Technical difficulties and limitations were factors. Future interventions targeting this group should be tailored to physician engagement and information sharing, priorities identified by our participants.

LEARNING OBJECTIVES:
1. To determine common themes, challenges and barriers in the access to and communication with health care providers for children with complex ID
2. To evaluate the use and acceptability of an online health communication platform
Adolescent Medical Clinic for Youth with Developmental Disabilities
Diane Munz
H-Body

PRESENTER:
Diane Munz, MD, FRCPC, FAAP, Associate Professor, Part-Time, Department of Pediatrics, McGill University, Montreal, QC

PURPOSE: We report on our experience with 88 youth with developmental disabilities aged 10-18 years seen 2008-2015 at the Adolescent Clinic of Montreal Children’s Hospital. 64 had a diagnosis of autistic spectrum disorder, 24 had a diagnosis of intellectual impairment.

METHODS: Youth with special needs are referred to the author at adolescent clinic by community physicians, neurologists, psychiatrists, parent support group Autism Montreal, and by social workers and nurses from youth protection services and from CRDIs. Medical concerns are documented by the pediatrician at each visit, with input from caregivers, social workers, and nursing staff. Strategies were used to examine patients that minimized sensory aversions and tactile defensive reactions. Caregivers were given advice on preparing patients for medical exams.

RESULTS: The majority of youths [52] lived in their own home; 18 lived in youth protection foster homes, 15 lived in group homes for people with intellectual disabilities, and 3 lived in psychiatric hospitals. Although autism is more four times more common in boys than girls, the majority of youth with autism referred to adolescent clinic were girls. In youth with cognitive disabilities, similar numbers of boys and girls were seen. 19% of autistic youth and 17% of intellectually impaired youth had epilepsy. Gastrointestinal problems were frequent, with constipation affecting 21 youth; serious GI pathology was documented in 3 patients [2 had Crohns and 1 had celiac disease]. Endocrine problems such as diabetes, thyroid disease, and menstrual disorders occurred with frequency similar to the general population. Menstrual problems may require increased medical intervention in youth with developmental disabilities because of the impact on their behavior [PMS, irritability, triggers epilepsy] and difficulties managing hygiene.

IMPLICATIONS: Youth with developmental disabilities often suffer from medical comorbidities but have difficulty to communicate symptoms and need special strategies to enable meaningful physical exams. Over time, with a supportive and structured approach, many fearful youth learned to tolerate physical exams. Cooperation between caregivers and medical staff is needed to understand the causes of behavioral deterioration and remedy underlying medical problems.

REFERENCES:
4. Improving Health Outcomes for Children and Youth with developmental disabilities: Rae Roebuck, Marion Paquet, Judy Coultes-Macleod, Ontario 2008

LEARNING OBJECTIVES:
1. Find ways to examine youth who are averse to medical exams.
2. Understand medical co-morbidities in youth with developmental disabilities.
3. Recognize that physical problems can present as behavior deterioration.
Health Conditions and the Population of Individuals with Intellectual/Developmental Disabilities: Results from the National Core Indicators
Alexandra Bonardi
APA

PRESENTER:
Alexandra Bonardi, OTR/L, MHA, Director, National Core Indicators Program, Human Services Research Institute, Cambridge, MA

PURPOSE: Despite documented disparities in health outcomes, little is known about the prevalence rates of clinical health conditions within the population of adults with Intellectual/Developmental Disabilities (IDD) using state developmental disability (DD) public services. Information on these rates could support more targeted policy interventions and can provide context for outcome and quality-of-life studies. This presentation will describe recent health data from the National Core Indicators (NCI) Adult Consumer Survey (ACS). We'll also detail how health data from the ACS can be used for aggregation across multiple states, benchmarking, and monitoring of population health measures, as well as health related social conditions on an ongoing basis.

METHOD: We analyzed reported health data derived from a random, representative, sample of people with IDD in 33 states voluntarily participating in the ACS in 2014-2015. The total sample size was 25,820 cases. The ACS, which collects demographic, health and personal characteristics of the individual being surveyed, is completed using information from system records.

RESULTS:
7% of respondents reported a diagnosis of cardiovascular disease, 12% reported diabetes, 3% reported cancer, 22% reported high blood pressure, 18% reported high cholesterol, 2% reported pressure ulcers, 12% reported limited or no vision, 8% reported hearing loss, 3% reported Alzheimer’s or other dementia. Health conditions that were included as write-in included weight issues, sleep issues, thyroid issues and asthma.

IMPLICATIONS:
The prevalence of health conditions within the population of adults with IDD within the DD service system merits further investigation. In the pursuit of accurate data on health conditions for the population with IDD within the DD service system, data collected as part of NCI, an ongoing state-level quality monitoring tool, offers a promising approach due to its broad reach, and flexibility for adding questions for examining particular health and health outcomes.

REFERENCES:

LEARNING OBJECTIVES:
1. Understand how data collected as part of National Core Indicators Adult Consumer Survey, an ongoing state-level quality monitoring tool, can be used to assess prevalence rates of clinical health conditions within the population of adults with Intellectual/Developmental Disabilities (IDD) using state developmental disability (DD) public services.
2. Perceive why the collection of data on prevalence rates of clinical health conditions within the population of adults with Intellectual/Developmental Disabilities (IDD) using state developmental disability (DD) public services is important to the design of targeted interventions.
Physical Activity Programs for Children with Neurodevelopmental Disabilities: Strengthening Families Through Social Network Supports

Michelle Chakraborti

PRESENTER:
Michelle Chakraborti, PhD Student, University of British Columbia, Vancouver, BC

PURPOSE: The International Classification of Functioning, Disability and Health acknowledges “family” as a salient contextual factor for childcare/development. Families are responsible for ensuring continuity of care throughout the lifespan of children and youth with neurodevelopmental disabilities (CYND). Navigating through challenges for CYND care, family functioning is often destabilized by an ongoing need to adapt to the CYND needs and demands of service providers. Furthermore, common disruptive behavior among CYNDs contributes to the families’ social isolation, which further affects the CYND’s support for learning/development. This highlights the need for programs that are capable of supporting the child’s development, and simultaneously, strengthening families through social integration within the community. Research on physical activity programs (PAP) e.g. Special Olympics, suggests there are benefits for children and youth. We hypothesize that attending PAPs will strengthen families by providing support through development of social networks; increasing resilience, empowerment and family quality of life (FQOL); and decreasing stress.

RESEARCH QUESTIONS/OBJECTIVES: (1) How do families attending PAPs interact and support each other? (2) How are new families integrated within this network? (3) What is the effect of social-integration on FQOL, resilience, stress and empowerment, and on the perceived CYND care self-efficacy? (4) What is the respective importance of PAP attendance among different interventions, to support families of CYND?

METHODOLOGY: Mixed-methods approach: prospective cohort study to collect information through standard scales, surveys, interviews and ethnographic observation over 3 months. Participants: Families with CYND between 6 to 19 years and attending PAPs: 120 families from 10 to 15 programs. Two family groups: (i) Prevalent: in PAPs for >3 months; and (ii) Incident: joined PAP in the last 3 months or will join during the study. Procedure/Instruments: Baseline: families complete the demographics questionnaire about respondent’s family, child and social networks. Also, families will complete standard scales on family social integration (SSI), FQOL, resilience (FRAS), stress (PSI-SF), empowerment (FES), and child behavior (NCBRF-PV). 3 months: complete same scales, a survey and interview on the perceived reasons for changes observed in their personal network, and family’s perceived self-efficacy for CYND care, personal support and resource access.

ANALYSIS: Non-parametric and parametric tests will be used. Results (final results will be presented on poster): We will examine for correlations among changes in family integration (SSI) and FQOL, FRAS and FES, PSI-SF, NCBRF-PV within the 3-month period. Interviews will be used to better interpret any correlations found.

IMPLICATIONS: PAPs represent a unique platform that can potentially strengthen both families and CYND simultaneously, thereby enabling a possible continuous improvement in their health outcomes. This research aims to establish a solid evidence base in this important area.

REFERENCES:

LEARNING OBJECTIVES:
1. Social isolation among families with CYND is a major issue
2. PAPs strengthen families by breaking social isolation, improving resilience, empowerment, FQOL and stress levels. Ultimately, strengthened families provide optimal care to their children.
Evidence Informed Program Planning and Evaluation: Incorporating a Mixed Methods Approach to Support Community Based Service Transitions

Charmayne Dubé, Beverley Temple

APA

PRESENTERS:
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PURPOSE: Evidence informed program planning and evaluation (EIPPE) involves all aspects of service delivery including administrative personnel and practitioners in various settings that support people with IDD. Policies and practices that ensure evidence influences future changes also present an opportunity for organizations and researchers to build on extant literature. This poster will show, real-life examples of specific EIPPE activities will be shared highlighting the iterative stages of evidence review, dissemination, planning and subsequent evaluation needs. The aim of this poster is to explore how EIPPE is implemented within a multi-faceted organization’s strategic plan identifying specific service transition goals. Application of a general EIPPE model highlighting the main components of the primary research activities embedded within the service transition process will also be discussed.

METHODS: A) Evidence Review, Dissemination, and Planning: Available scientific evidence was reviewed with regard to best practices in transitional planning. Identification of the most appropriate and important service quality and outcomes measures was identified within an evidence briefing. Strategies identified within this evidence report were disseminated to the organization’s Administration. This review informed the planning process of moving people from the institution to community. The evidence review also concluded there was a lack of research focusing on the transition process particularly in Canada (Temple et al., 2015). Moreover, the literature did not adequately focus on the transition team’s perspectives to determine effective strategies for the transitional process. B) Further Evaluation, Data Collection and Results: Based on this report, a qualitative research project was designed. Initial data collected from the Transitional Team will be shared highlighting key themes from the focus group. The iterative nature of EIPPE will also be summarized.

RESULTS: This study will identify findings that highlight over-arching themes of facilitators and barriers inherent within the current transition process. As well, recommendations for future practice and additional research steps will be described. (Note: QL research in process-completed by June, 2016).

IMPLICATIONS: Study findings will be disseminated in relevant formats offering an opportunity for individuals with IDD, families, direct support staff, various disciplines and administrative personnel to integrate these findings into practice. Additional EIPPE activities will highlight further practical steps for planned changes to service delivery.

REFERENCES:

LEARNING OBJECTIVES:
1. Understand one method of incorporating evidence into practice settings.
2. Learn about how experiences and findings from a multi-disciplinary team of practitioners can apply to other community service transitions.
3. Consider application of an EIPPE process to inform future policy and practice shifts.
**PRESENTER:**
Casey Fulford, BSc, Student, University of Ottawa, Ottawa, ON

**PURPOSE:** People with intellectual and developmental disabilities (IDD) are frequently socially isolated and report more loneliness than those without IDD [1, 2]. Although there have been major strides forward in promoting their rights, opportunities for individuals with IDD to form friendships are limited [3]. The purpose of this project was to review qualitative studies on the perspectives of persons with IDD regarding friendships, to better understand how to support their friendships.

**METHODS:** A literature search was conducted (online-database search, hand search, and grey literature search), including studies published between 2004 and 2014, involving participants 14 years of age or older, who had IDD, and participated in focus groups or interviews. The results section of relevant studies were coded using constant comparison; the thematic structure was grounded in the data.

**RESULTS:** Eighteen studies were included. Two master themes were identified: 1) How do I know someone is my friend and 2) What helps and hinders friendships. Participants discussed feeling supported, communication, and similarities between friends. Factors such as caregiver control, living situation, finances, and transportation affected opportunities to spend time with friends. Quotes to support these themes will be presented.

**IMPLICATIONS:** There are a variety of barriers that impede the development and maintenance of friendships for persons with IDD. Family caregivers and staff at service agencies play a major role in this process. They need to know how to implement effective strategies for supporting friendships, while still ensuring the safety of individuals with IDD. There is a need to evaluate and translate the existing evidence on how to support friendships among individuals with IDD into practice, to enhance the support provided by caregivers.

**REFERENCES:**


**LEARNING OBJECTIVES:**

1. Understand the importance of friendships and associated barriers experienced by individuals with IDD.
2. Understand the major role that staff and family caregivers play in supporting friendship of individuals with IDD.
Supporting Mental Health in Children with Autism Spectrum Disorder via Developing a Family-driven Assistive Technology

Parisa Ghanouni

PRESENTER:
Parisa Ghanouni, Graduate Research Assistant, University of British Columbia, Vancouver BC

PURPOSE: Children with developmental disorders such as autism spectrum disorder (ASD) have limited and immature socio-emotional communications, which preclude them from fully participation in the daily activities. These children are usually ostracized and have fewer social networks of support, which inadvertently affect family’s and children’s mental health, wellbeing, and quality of life. Supporting children and families in the long-lasting therapeutic interventions via developing an inexpensive virtual reality (VR) assistive technology informed by stakeholders and families is warranted. This project aimed to uncover barriers experienced by stakeholders on the ASD's social participation and aggregate ideas on suitable features of a VR assistive technology to support mental health among kids with ASD.

METHODS: We interviewed 12 stakeholders, including (a) parents of children with ASD aged 8-14 years old, (b) clinicians working with individuals with ASD with at least one year working experience, and (c) high functioning youth with autism aged 13-17 years old. Participants set priorities on the socio-emotional skills the program should address, and express their ideas on different aspects of developing a VR assistive technology to support kids with ASD. All interviews were transcribed verbatim and analyzed using thematic analysis.

RESULTS: Using thematic analysis resulted in emerging three themes on barriers to social participation. Participants mentioned that “financial barriers”, “stigmatization and social barriers”, and “lack of existing social opportunities” impede children with ASD to escalate social skills. Participants also expressed their ideas on potential features of the assistive technology for children with ASD, resulting in three themes, “promoting clinical utility”, “fostering generalization of the skills”, and “increasing motivational factors”.

IMPLICATIONS: This study bridges the existing gap between families and various disciplines in the field of ASD, using the client-centered and community-based participatory approach to support children’s mental health. Valuing the family’s and stakeholders’ ideas and incorporating the identified needs will ensure the sustainability of the program, inform policy makers in investing on the identified areas, and will support families and children with ASD in the long-lasting therapeutic interventions.

REFERENCES:

LEARNING OBJECTIVES
1. To highlight three barriers of social participation in individuals with ASD
2. To highlight three features of VR assistive technology to support mental health in children with ASD
3. To highlight the importance of using the client-centered approach in developing an assistive technology program for children with ASD
Supporting Attachment in Preschool Children with FASD: A Descriptive Study using The Circle of Security Home Visiting Program

Ana Hanlon-Dearman

PRESENTER:
Ana Hanlon-Dearman, MD MSc FRCPC FAAP, Section Head Developmental Pediatrics, Department of Pediatrics and Child Health; Medical Director Child Development Clinic, Medical Director Manitoba FASD Centre and MB FASD Network, Specialized Services for Children and Youth; Associate Professor Pediatrics and Child Health, University of Manitoba, Winnipeg, MB

BACKGROUND: Over 4 decades after Fetal Alcohol Syndrome (FAS) was first identified, there are still few studies of the effectiveness of interventions for preschool children with FASD. Yet, it is recognized that evidence-informed quality early intervention must be accessible to families caring for alcohol affected children in order to maximize child developmental potential, support optimal family functioning, and prevent secondary disabilities. Research suggests that prenatal alcohol exposure increases the risk of insecure caregiver-child attachment and related negative child emotional behavioural outcomes. Research has also shown positive effects of attachment-focused interventions in preventing disrupted caregiver-child attachment relationships; however, such interventions have not been specifically adapted for children with FASD.

PURPOSE: This presentation will describe the implementation, challenges, and results of a community home-based attachment intervention, Circle of Security (Marvin, 2002), with young children prenatally exposed to alcohol.

METHODS: This attachment based program is currently delivered as part of the Government of Manitoba’s FASD Outreach program (Winnipeg, Manitoba, Canada) for children under 6 years of age. The delivery of this home based attachment approach was modeled from the COS program. Children and families who participated were referred by the provincial FASD diagnostic clinic to the FASD Outreach program for behavioural support and were on a wait list for intervention. Families on the waitlist were approached for participation; those who consented were randomized to COS or the standard behavioural support program. Intervention for each family took place over 9-12 month period.

RESULTS: Twelve parent/caregiver – child dyads completed the FASD adapted COS intervention. Children’s ages ranged from 2 years 11 months to 5 years 11 months. Most children were with foster families, the remaining with grandparents or birth parents.

Results showed a significant reduction in parent stress that was maintained at 3-month follow-up. A clinically significant reduction in child behavioural issues was noted. Parents/caregivers reported their children were having fewer tantrums, sleep and mealtime challenges, and were generally less resistant and aggressive. Parents became more confident taking charge and setting limits. They became more effective at organizing their child’s emotions and managing tantrums, and they developed capacity in welcoming the needs of child and staying with their feelings.

CONCLUSIONS: Home based attachment focused intervention is an effective method of supporting complex families of pre-schoolers prenatally exposed to alcohol. Implementation challenges will be presented for discussion.

IMPLICATIONS: Improvements in parental sensitivity and reduction in parental stress are essential components of healthy brain development. This research provides evidence of successful intervention at young ages for complex families and provides evidence to inform the development of future programming.

REFERENCES:

LEARNING OBJECTIVES:
1. To review attachment behaviors in children with prenatal alcohol exposure/FASD.
2. To illustrate and discuss home-based attachment intervention results in this study.
3. To discuss implementation challenges for community-based attachment programming.
P10A

Common Thread Initiative: Strengthening the Community of Support for Persons with Challenging Behaviours

Tara Hyatt, Megan Primeau

HMH

PRESENTERS:
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Megan Primeau, MSc, Education and Research Coordinator, Central Region Community Network of Specialized Care, Surrey Place Centre, Toronto, ON

PURPOSE: The overall aim of the Common Thread Initiative (CTI) is to improve the quality of life for individuals with developmental disabilities who have behaviours associated with complex and challenging mental health needs (dual diagnosis). CTI promotes a team-based, problem solving approach to making evidence based decisions to best support persons with challenging behaviours in a residential program. A key goal is to improve communication between program staff and across the trans-disciplinary team, with clinicians and across organizations.

METHODS: The CTI is evidence-informed and was developed in consultation with individuals with experience and expertise in adult education, knowledge transfer, and behavioural analysis. The initiative was designed using a blended learning approach that integrates in-person learning, online learning and other strategies in a purposeful, thoughtful and complementary way to enhance engagement and support transfer of knowledge to practice.

RESULTS: The CTI pilot program was launched in May 2014 and two cohorts have completed the training. The evaluation results of the first cohort showed that that initiative resulted in changes to team processes, improvements in individual outcomes/goals, and Behaviour Support Plans were better understood and more consistently applied. Data from the 2nd cohort, which ended in March 2016, is currently being analyzed and these evaluation findings will also be presented.

IMPLICATIONS: This initiative demonstrates the benefits of integrating a knowledge transfer approach to support the use of evidence within practice and service delivery as well as policy and management decision-making in organizations.

LEARNING OBJECTIVES:
1. Describe the aim, objectives and design of CTI
2. Discuss the overall impact of CTI, including program team and organizational changes made, that resulted in overall improvements for the individuals they support
3. Consider how the Common Thread approach may inform your own capacity building initiatives
Using Population Based Administrative Data to Study Families with Children who have a Developmental Disability

Sandra Marquis
H-Body

PRESENTERS:
Sandra Marquis, MSc, PhD Candidate, University of Victoria, Victoria, BC

BACKGROUND: The study is using population based administrative data available through Population Data B.C. to examine the health of families who have a child with a developmental disability over a twenty-nine year period. This is the first time that population level administrative data has been used for this purpose. Health will be measured through the number and type of doctor visits and hospital admissions. Families of children with a developmental disability will be compared to control families (families without a child with a developmental disability). Fathers, mothers and siblings will be examined separately.

This study is on-going, early results will be available in November 2016.

The implications of this study include recommendations for health and mental health policy and practice for parents and siblings of children who have a developmental disability.

REFERENCES:

LEARNING OBJECTIVES:
1. Introduce recent findings from population level studies on families of children with a developmental disability.
2. Introduce the use of population level administrative data and how to access it.
3. Provide initial findings from the current study
Paths for Future Research: A Preliminary Conceptual Model of Effective Support for Pregnant Women with Intellectual and Developmental Disabilities

Lynne Anita Potvin

PURPOSE:
With an increase in fertility rate [1] and uptake of maternity services [2] among women with intellectual and developmental disabilities (IDD), improving the quality of support for this high-risk population [3] should be a social and clinical priority. However, research regarding support for pregnant women with IDD remains sparse. Our purpose was to develop a conceptual model which explains factors associated with effective maternity support for women with IDD. This conceptual model will be used to guide the development of a large qualitative study.

METHODS:
We conducted a pilot qualitative study. Adult women with IDD who had given birth in the last five years (n=4) were recruited at developmental services agencies in Ontario. Data were collected through semi-structured interviews based on the Social Support Self Report (SSSR) and a social circles task. In an initial analysis using a grounded theory approach, structure and functions of social support received during pregnancy and childbirth, and their perceived quality, were explored [4]. Following this initial analysis, a descriptive case study (n=2) was used to explore, in depth, the role of women’s perceptions about attitudes of support persons toward their pregnancies [5]. Together, these analyses were used to propose a preliminary conceptual model.

RESULTS:
Preliminary results suggest that women with IDD perceived support as most effective when desired functions of support were provided by preferred support persons. Effective support was further characterized by its accessibility, by its compatibility with the woman’s level of autonomy, and by support persons’ attitudes toward pregnancy in persons with IDD [4]. Reciprocity (e.g., collaboration with support persons) and frequency of contact between support persons and pregnant women with IDD were related to women’s perceptions about the attitudes of support persons [5].

IMPLICATIONS:
The preliminary conceptual model which emerged from these analyses will serve as the framework for a larger qualitative study aiming to develop a model of support for pregnant women with IDD. Understanding support in this way will inform the development of strategies to optimize maternity supports and services for women with IDD, which may increase their physical and psychological health during pregnancy.

REFERENCES:

LEARNING OBJECTIVES:
1. Identify practical strategies to optimize maternity supports and services for women with IDD.
2. Generate awareness about the support needs of pregnant women with IDD.
Creative Arts Camp for Children with Special Needs: Camp Benefits and Caregiver Experience

Nicole Reinders, Brianne Redquest

APA

PRESENTERS:
Nicole Reinders, MSc, PhD Student, Wilfrid Laurier University, Waterloo, ON
Brianne Redquest, MSc, Wilfrid Laurier University, Waterloo, ON

BACKGROUND: It is estimated that 155,000 children aged 5 to 14 have a disability in Canada (Statistics Canada, 2008). These children often require supplementary services; however, many children experience barriers to access these services, especially in Ontario (Kohen, Uppal, Khan & Visentin, 2006). Creative arts programs may be beneficial for children with special needs and provide caregivers with a form of respite care for their children. The purpose of the current study was to explore the lived experiences of children who participated in a creative arts camp located in southwestern Ontario from the perspectives of their primary caregivers. Eight primary (one male; 7 females) caregivers were interviewed for this study. Children had differing disabilities including cerebral palsy, fetal alcohol spectrum disorder, chromosome 18 rearrangement complex, Angelman syndrome, congenital muscular dystrophy, autism spectrum disorder and Down syndrome. Two salient themes emerged from the data: (1) Camp Benefits and (2) Caregiver Experiences. Overall, caregivers felt the camp was a positive experience, both for themselves and their children; however, suggestions to improve the camp are provided from the perspectives of the caregivers and researchers. Inclusive camps such as the one presented here are not only beneficial for participants, but also for caregivers in the form of respite care.

REFERENCES:

LEARNING OBJECTIVES
1. Share information about a successful inclusive camp offered in Southwestern Ontario
2. Show how the creative arts influenced the well-being of individuals with special needs as perceived by their caregivers
3. Highlight the importance for development and enhancement of similar inclusive camps across Canada
Social Interaction and Physical Activity in Individuals with Autism Spectrum Disorder (ASD): A Scoping Review

Kristen Wright

ABSTRACT:
Autism Spectrum Disorder (ASD) is a developmental disorder affecting one’s language skills and ability to think, feel, and relate to others (APA, 2014). Worldwide, approximately 1 in 160 individuals are diagnosed with ASD (WHO, 2016). Individuals with ASD display symptoms in three main areas: deficiencies in social interaction, communication skills, and motor performance (APA, 2014). These characteristics as identified by the Diagnostic and Statistical Manual of Mental Disorders (DSM-5) indicate potential barriers to physical activity (PA) for individuals with ASD. However, there is evidence that social skills can promote positive peer relations and personal competence, making PA more attainable (Pan et al., 2011). In addition, exercise-based interventions have been shown to improve motor and social skill deficits (Sowa & Meulenbroek, 2012). Therefore, the purpose of this scoping review was to explore the relationship between social factors and PA in individuals with ASD.

This review followed the 5 stages in the methodological framework of Arksey and O’Malley (2005) for conducting a scoping study. Four databases were chosen to search for recent and relevant articles published between 2006 and 2016 that included participants with ASD and both social and PA factors, irrespective of the intervention or measurements. An initial search warranted 804 articles meeting the inclusion criteria. To identify the most relevant articles duplicates were removed, then the titles, abstracts, and methods were investigated successively. To confirm all possible articles were obtained, hand searches of common journals were conducted. The full text of 30 articles were analyzed to investigate the purpose of this review.

Most of the articles utilized quantitative methodologies, mainly in the form of questionnaires. The articles were primarily focused on children with ASD, with majority being male participants. Articles were categorized as either intervention programs (including swimming, horseback riding, jogging, and recreational activities) or correlational analyses between PA and social factors. The majority of the articles reported a relationship between PA and social factors. Upon preliminary analysis there appears to be a positive trend between social factors and PA. This review will be helpful for the implementation of PA programs in schools and in the community and provide evidence of the benefits of improving social skills for individuals with ASD.

REFERENCES:

LEARNING OBJECTIVES:
1. Improve understanding of the relationship between social factors and PA in individuals with ASD
2. Increase awareness of the importance of social skills and PA for individuals with ASD
Clinical Conference in Toronto - Community Collaboration at its Best!!
Jennifer Altosaar
HMH

PRESENTER:
Jennifer Altosaar, Coordinator, Toronto Network of Specialized Care, Surrey Place Centre, Toronto, ON

BACKGROUND: Clinical Conference and CAIR (Collaborative and Individualized Resource) work together to provide coordination, planning and clinical resources to support individuals (ages 18 years and older) with a developmental disability who may also have mental health needs and challenging behaviours.

PURPOSE: Clinical Conference is a sub-committee of the Toronto Network of Specialized Care (TNSC) and, as such, is charged with receiving and responding to client referrals where the service system has not been able to meet the needs sufficiently.

All situations that cannot be addressed by consultation and support from the TNSC Coordinator and/or the CAIR Facilitator are presented to Clinical Conference for problem solving, e.g., development and implementation of an integrated service plan and assignment of additional resources as required. The TNSC, in its position of providing a service resolution process, will ensure equitable access for all individuals having a developmental disability, including those with mental health needs and/or challenging behaviours.

METHODS OF CLINICAL CONFERENCE:
1. To provide consultation through monthly case presentations and provide recommendations to the client service team regarding situations presented by the TNSC Coordinator where there is not a need for CAIR services and supports.
2. To provide clinical consultation as required to the client service team and the CAIR Facilitator related to a particular individual situation.
3. To identify situations that cannot be resolved using our current available resources and to bring to TNSC/Service Resolution by the Clinical Conference Chair(s) or Coordinator for resolution.
4. To hear requests for treatment beds and to determine suitability.
5. To receive updates from the CAIR/ALC program.
6. To receive updates from treatment bed providers on current residents, Alternative Level of Care (ALC) and system issues.

RESULTS: Recommendations that include collaborative responses to increase the quality of life for the individual.

IMPLICATIONS OF CLINICAL CONFERENCE: to have more community collaboration and more continuity of care as these complex individuals move between the different systems. This means that the quality of support that these individuals receive from the multiple sectors they are supported is better.

REFERENCES:
1. Clinical Conference Process document
2. Toronto Systems Map

LEARNING OBJECTIVES:
1. Describe the main features and results of the Clinical Conference process.
2. Discuss the key factors to develop and coordinate a collaborative response process.
The Intersection of Developmental Disability and FASD

Dorothy Badry, Audrey McFarlane

APA

PRESENTERS:
Dorothy Badry, PhD, RSW, Associate Professor, Academic Lead Working with Homeless Populations, Faculty of Social Work, University of Calgary, Calgary, AB
Audrey McFarlane, Executive Director Lakeland Centre for FASD, Lakeland Centre for FASD, Cold Lake, AB

PURPOSE: The purpose of this presentation is to provide linkages between intellectual developmental disability (IDD) and fetal alcohol spectrum disorder (FASD) in relation to policy and practice. The need exists to create collaborative intersections as both IDD and FASD are positioned somewhat uniquely in child welfare and adult services in Canada. Children with FASD are in frequent contact with the child welfare system. A current project is underway to examine social policy in this area within the Canada FASD Research Network (CanFASD).

METHODS: A literature review was undertaken to examine both IDD and FASD and policy examinations are in progress. Additionally, relevant policy and research projects through CanFASD will be highlighted.

RESULTS: The current state of evidence will be presented and key policy intersections highlighted. There is a growing body of research conducted on FASD in Canada that will be considered for presentation and gaps in service delivery identified.

IMPLICATIONS: Lange, Shield, Rehm & Popova (2013) estimated that approximately 22% of children in care in Canada have either Fetal Alcohol Syndrome (FAS) or FASD. Thanh, Jonsson, Salmon & Sebastianski (2014) in a new study focused on estimating the incidence and prevalence of FASD through Alberta health records indicated that prevalence ranges from over 700 to as high as 1800 annually and estimate prevalence anywhere from about 14 to 43 in a thousand births. Further, Thanh & Jonsson(2016) published an alarming study on morbidity for individuals with FASD in Alberta using health data from 2002-2012 indicating that the estimated lifespan for individuals with FASD is about 34 years, largely due to risks and vulnerabilities associated with the disability.

It is important that services provided to individuals with FASD be recognized from a developmental disability lens and that service systems are prepared and knowledgeable about FASD informed care and the similarities/distinctions between FASD and IDD. From a child protection stance the report authored by Saskatchewan Child Advocate Bob Pringle (2014), Two Tragedies: Holding Systems Accountable, offers clear policy directions including challenges in service delivery in rural and remote communities. This presentation will highlight concerns and challenges while identifying pathways to promote the case for integrated service delivery.

REFERENCES:
Support Needs of Adults with Intellectual and Developmental Disabilities when Attending Annual Health Exams
Casey Fulford, Lynne Anita Potvin

PRESENTERS:
Casey Fulford, BSc, Student, University of Ottawa, Ottawa, ON
Lynne Anita Potvin, Research Coordinator, University of Ottawa, Ottawa, ON

PURPOSE: In Canada, an annual health exam (AHE) is recommended for persons with intellectual and developmental disabilities (IDD) [1]. AHEs lead to early identification and treatment of undiagnosed conditions [2], and prevention of more complex health problems [3] among adults with IDD. In a previous study, in Ontario, only 22% of individuals with IDD were found to have an AHE over a two year period [4]. The purpose of this study was to gain information about the experiences and perceptions of adults with IDD when booking and attending AHEs to identify barriers and facilitators to attendance of AHEs.

Methods: This study included 13 adults with IDD, recruited through convenience sampling. Participants engaged in semi-structured interviews about their perceived experiences when booking, traveling to, and attending an AHE. An a priori coding structure was developed with categories relating to:
1. their support needs
2. whether their needs were met or unmet
3. who helped meet their needs, and
4. how their needs were met

RESULTS: The support needs of adults with IDD when booking and traveling to AHEs were primarily instrumental, requiring practical support (related to communication and transportation), and these needs were primarily met by family caregivers. Support needs when attending AHEs were predominantly emotional (related to trust, empathy, and respect), and were expected to be met by their physicians.

IMPLICATIONS: Individuals with IDD comprise a heterogeneous population with varying support needs when booking, travelling to, and attending AHEs. Therefore, patient-centered care, in which family caregivers and physicians adapt to an individual’s needs and preferences, is crucial to support adults with IDD in accessing AHEs. Individualized support may increase the likelihood that adults with IDD will attend AHEs, ultimately improving their health and wellbeing, and leading to increased quality of life.

REFERENCES:

LEARNING OBJECTIVES:
1. Importance of AHEs for adults with IDD;
2. Unique needs and experiences of individuals with IDD when attending AHEs;
3. Importance of patient-centered care for adults with IDD.
PRESENTER:
Mojgan Gitimoghaddam, MD, PhD Student, University British Columbia, Vancouver, BC

PURPOSE: Children with neurodevelopmental disabilities (CND) often have a lower level of participation in physical and recreational activities than typically-developing children. Consequently, they miss important opportunities for motor skills development and socio-cultural learning. Organized, community-based physical activity programs (PAPs) can provide an adapted environment that enables CND to participate in activities that contribute to motor skill acquisition, and opportunities for social interaction and friendship with peers. Presently, however, rigorous documentation of the effects of PAPs on the learning and development of CND remains limited.

Aim: To explore changes in daily life functioning (DLF) and quality of life (QOL) among CND who participate in PAPs; and to identify PAPs’ characteristics that may be associated with changes in CND.

Hypothesis: We expect specific PAPs’ characteristics to be associated with different patterns of change in DLF and QOL.

METHODS: This is a mixed methods prospective cohort study. We are recruiting 150 CND 5-10 years of age from 10-15 PAPs. We will compare changes among CND attending PAPs that differ by main activities (e.g. physical literacy, social gathering) or by operating process (e.g. use of ‘structured scaffolding’). We are assessing CND every 6 months with standardized measurement tools with regard to their physical skill, psychosocial wellbeing, DLF and QOL. Every 3 months, parents complete a survey assessing perceived recent changes in specific domains followed by a short interview to investigate causal attributions for reported changes. Analyses will use repeated measures ANOVA and multivariate hierarchical models. Techniques from conversational analysis and cognitive linguistic discourse analysis will be used for interview data.

PRELIMINARY RESULTS: The study is presently recruiting in one PAP that focuses on movement therapy. Preliminary results are from the interviews of eleven parents at baseline and six at 3-month follow up. Parents reported improvements in their children’s motor skills, psychosocial functions, social interaction, and self-confidence. Parents attributed some changes to PAP attendance but they also reported the role of other programs in which their child has been involved to explain the changes. Data from standardized scales are being collected.

IMPLICATIONS: If ongoing data collection confirms changes in CND functioning in relation to PAPs’ characteristics, this study will contribute to establishing PAPs a relevant and potentially valuable resource for development, health and wellbeing of CND, and worthy of further rigorous and large scale studies.

REFERENCES:

LEARNING OBJECTIVES:
1. Bring attention to, and begin proper documentation of, possible effects of participating in community-based PAPs on development, health and wellbeing of CND.
2. Understand the challenges of CND to participate in PAPs and the consequences on their development.
PRESENTER:
Lisa Gonzalez, Extension Agent and Educator, University of Maryland Extension, Derwood, MD, USA

PURPOSE: The purpose of this poster/presentation will be to showcase community programming efforts that promote improved health and wellness outcomes for developmentally disabled participants in Maryland through nutrition education, wellness and vegetable gardening programs.

METHODS: This poster/presentation will describe health and wellness educational programs with developmentally disabled adults led by the University of Maryland Extension. The presenter will share highlights and successes of these extension programs as well as strategies for addressing the unique health needs of the developmentally disabled through innovative community partnerships and programming. Examples will be provided from successful health and wellness programs including nutrition and food safety education, cooking classes, vegetable gardening and grocery store programs for developmentally disabled adults and their caregivers. This will include a discussion of multi-layered interventions that target all the various sectors of influence including the individual, family, community and society.

RESULTS: Results will be shared regarding the nutrition and wellness behavior changes of the developmentally disabled adult participants as observed by family members, educators and caregivers as described in surveys and qualitative narratives. This will include results from current research looking at preference for healthy foods and the development of enhanced skills regarding choosing, preparing, consuming and understanding the importance of healthy and safe foods.

IMPLICATIONS: This poster/presentation aims to provide educators and caregivers with strategies for designing, implementing and evaluating community based educational programs for developmentally disabled adults and their caregivers as well as ideas for supporting the health and wellness of developmentally disabled adults through multi-layered interventions that target multiple spheres of influence from the individual to society.

REFERENCES:

LEARNING OBJECTIVES:
1. Provide an overview of the unique health and wellness needs of developmentally disabled adults including the higher incidence of chronic disease, the need for skills training for participants in food preparation and grocery shopping, and strategies for increasing physical activity for those with sensory or physical limitations.
2. To provide participants with strategies and tools for developmentally disabled adults, educators, family members and caregivers regarding engaging in discussions with their medical professionals about health and wellness strategies. Factsheets on this topic will be available for poster session participants to take home.
3. To provide participants some ideas of best practices for providing health and wellness programming to developmentally disabled adults and to describe successful initiatives led by the University of Maryland Extension.
4. To provide participants some methods for creating multi-layered interventions including programs that provide education for family members, caregivers/educators and the larger community.
Proactive Program Development to Assist Patients with Complex Transitions to Adult Supports and Services

Megan Henze, Melanie Randall

APA

PRESENTERS:
Melanie Randall, DSW, Community Liaison Service Navigator, Surrey Place Centre, Toronto, ON
Megan Henze, Transition Specialist, Hospital for Sick Children, Toronto, ON

PURPOSE: Difficulties in transition to adult services and supports for patients with comorbid medical condition and developmental disabilities are well documented. A 2014 MOHLTC study of the care in the long term for youth and young adults with complex care needs revealed a high risk of and experience of crisis for families/patients during the transition process, including a gap in funding, services and supports while struggling to navigate a new system of eligibility criteria, intake processes and new service providers.

METHODS: Good 2 Go Transition Program at SickKids, internal clinics at SickKids (22q deletion, epilepsy, sickle cell, aftercare oncology, complex care program) and Developmental Services Ontario (DSO) Toronto region have worked together to create a proactive system to flag patients that would meet eligibility for DSO and provide family education to increase awareness of application process and the need to start early. Resources and program development are tailored to the needs and capacity of the clinic teams, patients and families to provide ‘service navigation support’ at early ages (12 and up).

RESULTS: While numerous transition readiness scales exist for youth with “simple” transitions they are absent for this population. We have been piloting a Complex Transition Preparedness Scale (CTPS) measure as part of our Good 2 Go Transition Clinic. Its development was based on input from adult service organizations and has shown utility in use for transition planning in our clinic. Transition preparedness for youth with complex transitions is a combination of tangible requirements and subjective measures. Tangible requirements include gathering the appropriate eligibility criteria prior to age 16 and applying at the earliest age possible to adult services. Subjective measures include factors such as caregiver distress and satisfaction with transition support. This project is currently ongoing and results are not yet available. We anticipate that cohorts that have years of transition planning embedded into clinical care will score higher on measure of transition preparedness than cohorts that did not benefit from early and proactive clinical intervention.

IMPLICATIONS: Programs and services that support children with special needs can proactively identify which young people will ultimately qualify for specific adult supports and services well in advance to paediatric supports ending to minimize gaps in services and funding. Service navigation support can be adapted to a variety of contexts and can include ‘easy interventions’ on a population based level (handouts or mailouts) or more intensive intervention for families at high risk of crisis.

LEARNING OBJECTIVES:
1. To review the evidence that documents the consequences of a lack of service navigation support for patients and families approaching transition to adult services and supports
2. To provide examples of proactive models of service navigation support in program development with specific examples in varying contexts (low staffing, high patient volume, etc).
3. To demonstrate how transition preparedness measures can be built to incorporate context specific objective measures and more subjective factors.
**PRESENTERS:**
**Melanie Randall**, DSW, Community Liaison Service Navigator, Surrey Place Centre, Toronto, ON
**Angie Gonzales**, RN, MN, Health Care Facilitator, Surrey Place Centre, Toronto, ON

**PURPOSE:** To further explore how collaborations across sectors can change practice, offer practical supports and strategies informed by evidence-based research, within both health and developmental services in the provision of service to the most complex care situations, including but not limited to Alternative Level of Care, Long Term Care and Dual Diagnosis.

**METHOD:** Clinical experience, case and literature reviews will inform the presentation content and interactive discussion about how frontline collaboration can offer practical application of research evidence within the developmental sector, how it has changed Developmental Service Ontario Toronto Region and Toronto Network of Specialized Care collaborative pathways.

**RESULTS:** Collaborative pathways e.g. with health, mental health and developmental services have been established and are being utilized. We will demonstrate that practical applications of evidence-based resources (e.g. from HCARDD, Developmental Disabilities Primary Care Program, ALC CCAC initiatives, etc.) allow for easier navigation of complex situations within sectors.

**IMPLICATIONS AND LEARNING OUTCOMES:**
The audience will be able to apply best practice guidelines, clinical examples and practical strategies discussed, regarding how to use collaborative pathways to navigate complex systems and situations. Without continued efforts to support the frontline application of the collaborative best practices, disparities in health and wellbeing of persons with developmental disabilities will continue to exist.

**REFERENCES:**
3. Primary Care of Adults with Developmental Disabilities Canadian Consensus Guidelines (and tools): http://www.surreyplace.on.ca/Primary-Care
Factors Associated with Fatigue in Mothers and Fathers of Children with Autism Spectrum Disorder

Sarah Ivens

PRESENTER:
Sarah Ivens, Graduate Student, University of Regina, Regina, SK

PURPOSE: Fatigue is detrimental to parental health and parenting efficacy, and there is reason to believe that it is especially problematic for parents of children with Autism Spectrum Disorder (ASD). However, fatigue research often focuses on understanding fatigue in mothers of typically developing infants. Furthermore, the existing research generally is conducted without a theoretical model and focused on understanding parental correlates of fatigue, despite evidence that child-based correlates (e.g., child behaviours) are also important. This study examined child and parental factors associated with fatigue in parents of children with ASD by using the Middle-Range Theory of Unpleasant Symptoms (TOUS) model. The research was designed to 1) extend our understanding of fatigue in parents of children with ASD by investigating fatigue in both mothers and fathers, 2) identify and examine the associations between fatigue and psychological, physiological, parental situational, and child-based situational factors and 3), extend our understanding of the relationship between fatigue and parenting variables such as parenting self-efficacy and parenting satisfaction.

METHOD: Mothers (N = 78) and fathers (N = 34) of children with ASD aged 2-12 years were recruited from across Canada. Participants completed an on-line questionnaire battery assessing levels of fatigue as well as psychological factors (i.e., depressive, anxious, and stress symptoms; perceived caregiver burden), physiological factors (i.e., general health, sleep quality), parental situational factors (i.e., social support, martial satisfaction), child situational factors (i.e., child sleep quality, child behavioural problems), and parental cognitions (i.e., parental self-efficacy, parenting satisfaction).

RESULTS: Parents reported similar levels of fatigue regardless of child age. Fathers reported lower levels of fatigue than mothers. Psychological factors predicted fatigue in both mothers and fathers. (i.e., depressive, anxious, and stress symptoms; perceived caregiver burden). However, child situational factors (i.e., child sleep quality, child behavioural problems) predicted fatigue only in mothers, while employment status predicted fatigue only in fathers. Fatigue was negatively correlated with parenting self-efficacy and parenting satisfaction for both mothers and fathers.

IMPLICATIONS: Among parents of children with ASD, fatigue is a problem regardless of child age and interventions should therefore not be focused solely on parents of young children. In understanding fatigue, it is important to consider the similarities and differences in the correlates of fatigue for mothers and fathers. For both mothers and fathers, targeting psychological factors (i.e., depressive, anxious, and stress symptoms; perceived caregiver burden) may be an important focus of fatigue interventions. Interventions for maternal fatigue may also include approaches that focus on child behaviours, while for fathers, support around employment issues that impact fatigue may be a more appropriate intervention. This study improves our understanding of factors that impact parental fatigue, allowing mental health professionals to better support parents, and through them, their children.

LEARNING OBJECTIVES:
1. Understand that fatigue is a problem for mothers and fathers of children with ASD, regardless of the child's age
2. Know the similarities and differences in the correlates of fatigue for mothers and fathers of children with ASD
3. Understand the relationship between fatigue and parenting cognitions, specifically parenting satisfaction and parenting self-efficacy
Relationship Pathways for Parents of Individuals with Autism Spectrum Disorder: Results from a Meta-ethnography Review

Rae Morris

PRESENTER:
Rae Morris, MSW, RSW, Individual Couple and Family Therapist, the Redpath Centre, Vancouver, BC

ABSTRACT:
There is growing attention to the impact of rearing a child with autism spectrum disorder (ASD) on individuals and parental dyads, but information about navigating and maintaining positive co-parenting relationships is sparse. It is important for researchers, practitioners, and parents alike to develop an understanding of the co-parenting experiences of parents who have children with ASD, in order to provide more effective services and supports aimed at enhancing these relationships. A systematic meta-ethnography review was conducted of 19 qualitative studies that explored couple relationships among a collective sample size of 1551 participants parenting an individual diagnosed with ASD. Results highlight three phases of the ASD parenting experience that are noteworthy for couple relationships: the diagnosis phase, the service planning phase, and the maintenance phase. This study provides insights and strategies for parents and those who support them about how to potentially enhance couple cohesion, shared visions, and feelings of hope while navigating the pathways in relationship development through these three phases.

REFERENCES:

LEARNING OBJECTIVES:
- Highlight trends in current qualitative research exploring co-parenting relationships among parents of individuals with ASD
- Provide strategies for parents and clinicians to navigate and maintain positive parenting relationships and enhance quality of life across the lifespan for parents of individuals with ASD
The Action-Project Method as a Way to Assist Parents and Young Adults with Intellectual Disabilities in Working Together to Construct and Refine Transition-to-Adulthood Projects

John Murray
APA

PRESENTER:
John Murray, Student Research Assistant, University of British Columbia, Vancouver, BC

PURPOSE: To explore the ways in which parents and their young adult children with intellectual disabilities utilized the context of the research setting, specifically the action-project method (A-PM), to construct, explore, and refine their goals and action steps within transition-to-adulthood projects.

METHODS: Eight parent-child dyads participated in a qualitative study to examine how they construct and understand the young adult’s transition to adulthood. The age of the young adult ranged from 18 to 31 years old. Each dyad was interviewed by two research assistants in a three-part interview (warm-up, conversation, self-confrontation/video playback) that was then analyzed by the research assistants for strategies, goals, and joint projects. The analyses were then reviewed by the research team and a participant check was conducted with the dyad. Final analyses of each dyad were reviewed for emerging constructs and cross-case analyses were conducted across all eight data sets.

RESULTS: Projects of the young adults were often parent-driven with input from the young adult. The research setting became a place for a number of these dyads to construct, explore, and refine their transition-to-adulthood projects. These projects involved varying levels of anticipated independence of the young adult, from very little to separate but needing support. One project involved the use of the research interview in order to practice having a conversation to help the young adult in his development of conversational skills so that he could better function when interacting with other persons in the general public. Other projects involved various themes, including exploration of helping the young adult with moving out of the parental home into attached suites or completely separated condos or apartments, planning for the future, and setting boundaries. Within all of these, parents displayed various levels of expectations for the young adult’s ultimate independence, and the young adults displayed various levels of expectation of support.

IMPLICATIONS: The applicability of the A-PM is suggested for parents and their young adult children with intellectual disabilities, wherein the procedures of the A-PM are used to enable these dyads to communicate about their expectations and hopes, and to construct, explore, and refine projects that will better empower these young adults as they transition to adulthood.

LEARNING OBJECTIVES:
1. To understand the stages of the A-PM interview
2. To understand how these methods can be used to assist parents and youth with ID in jointly creating goal-directed projects for the transition to adulthood
International Perspectives on Decision Making and Capacity for Adults with Developmental Disabilities

Yogesh Thakker, Joanne Legasse

ABSTRACT:
This poster presentation talks about issues of capacity and decision making from an international perspective based on a review of current academic literature by a MSW student from the University of Calgary, and practice experience of a Developmental Disability Psychiatrist from the United Kingdom. The United Nations Convention on the Rights of Persons with Disabilities (CRPD) calls for a paradigm shift from substitute decision making towards a system of supported decision making for people who have developmental disabilities (Gooding, 2015; Gurbai, 2014). To this end, the aim of this presentation is to generate discussion about the role that everyone has in helping people with developmental disabilities exercise their right to legal capacity so that they can make their own decisions. It is hoped that this conversation will aide in integrating theory into practice that can be carried forward and implemented by those who are carers for people who have developmental disabilities.

REFERENCES: