Special Olympics
British Columbia

British Columbia Framework for the Advancement of Health Outcomes for People with Intellectual Disabilities

OVERVIEW

Updated	April, 2019
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For	Special Olympics British Columbia
Purpose	Engage a provincial service network to enhance the health outcomes of individuals with intellectual disabilities (ID), thereby reducing dependence on strained services, building capacity and confidence amongst services, easing strains on caregivers, and increasing the quality of life experienced by British Columbians with ID.
Summary	This document is intended to provide a brief understanding of the need for interventions aimed at improving the overall health and well-being of individuals with intellectual disabilities living in British Columbia. It concludes with a summary of recommended interventions based on research conducted by SOBC and through engagement with external stakeholders.
Objectives	1. Establish a “Focal Point for ID Health” within government to champion sector reform and coordinate the efficient use of community resources 2. Engage ‘service network’ of community organizations and health service providers 3. Eliminate health disparities between people with ID and the general population 4. Reduce health care costs

EXECUTIVE SUMMARY

An accurate assessment of the current state of health for British Columbians with intellectual disabilities (ID) remains elusive due to insufficient data collection, dissemination, and analysis. While a lack of health data concerning a given population is always problematic, the failure to actively monitor the health outcomes of British Columbians with intellectual disabilities is particularly alarming when viewed in light of recent findings from other countries and regions at similar levels of development. Through these findings we can infer, inter alia, that British Columbians with ID likely have lower life expectancies (Friedrich Dieckmann, 2015), live more sedentary lifestyles (Eric Emerson, 2016) and are hospitalized more frequently (S. Skorpen, 2016) than the general population.

While the status quo is clearly unacceptable, there is reason for optimism. The last 60 years have seen an astonishing rate of improvement in the state of health for people with ID across the developed world. This is particularly true for individuals with Down syndrome. In the US, the mean age at death for people with Down syndrome has increased from 9 years in the 1920s to 56 years by the late 1990's (Janicki, Dalton, & Henderson, 1999) (Coppus, 2013). Despite these accomplishments, there remains a recognition that far more can and should be done.

Some regional and national governments have taken steps to implement comprehensive interventions in their communities. Perhaps, most notably, was the Government of New South Wales, Australia, who in 2012 released the "*Service Framework to Improve the Health Care of People with Intellectual Disability*." Many of these interventions, including the NSW Framework, have already yielded some results despite their infancy.

Special Olympics BC firmly believes that British Columbia has the necessary resources, expertise, and compassion to become a global leader in health services for people with ID. The "*British Columbia Framework for the Advancement of Health Outcomes for People with Intellectual Disabilities*" has been drafted based on extensive research and consultations with stakeholders.

Central to the framework is the establishment of a broad-based coalition who are willing to work cooperatively to address health outcomes of individuals with intellectual disabilities. Government is key to the success of this initiative as many ministries directly impact the lives of individuals with ID, and Government has ability to support, guide, and implement action in ways necessary for successful outcomes. This coalition, with government support and involvement, will be tasked with finalizing and implementing the framework interventions, which are best summarized by the following five pillars:

1. Enhance the capacity of existing services
2. Raise awareness of the specialized health needs of people with ID
3. Promote health and lifestyle programs that will help reduce the burden on healthcare systems, and increase the quality of life for persons with ID
4. Collect and analyse data to identify health trends and concerns
5. Structural reform

A successful intervention will produce:

1. Collection, analysis and dissemination of data to produce informed policies, programs and tactics
2. Increases to the mean age at death for British Columbians with ID
3. An elimination of health outcome disparities between people with ID and the general population
4. A reduction in hospitalization rates for people with ID
5. A decline in un-diagnosed medical issues observed at routine screenings
6. A rise in activity rates of people with ID
7. Resources and research for caregivers, educators, health professionals, and individuals with intellectual disabilities is available in an easy to find and accessible location
8. A potential reduction in health services expenditure through, inter alia, a decrease in ACS conditions and more effective pharmacological management
9. Improvements to the quality of life experienced by individuals with ID in BC
10. Recognition for the province of BC and its institutions as leaders in research, community support networks, and health services for people with ID

ADVANCING HEALTH OUTCOMES FOR BRITISH COLUMBIANS WITH INTELLECTUAL DISABILITIES (ID)

People with ID experience significant health disparities when compared to the general population. Interventions are necessary to achieve equitable healthcare for all British Columbians through enhancing existing services capacity, raising awareness of the specialized health needs of people with ID, promoting health and lifestyle programs that will help reduce the burden on healthcare systems and increase the quality of life for person with ID, collecting and analyzing data to identify health trends and concerns and structural reform.

Inputs	**Outputs**		**Outcomes -- Impact**		
	Activities	*Participation*	*Short*	*Medium*	*Long*
• Individuals with intellectual disabilities (ID) • Government Resources: staff, funding, policy, contacts • Community Resources: data, facilities, research, technology • Community Stakeholders: input, policy analysis, promotion, existing programs and services • Lifestyle support: group homes, families, caregivers, community organizations • Special Olympics BC and sport and recreation systems • Professional/ Academic: training, universities, colleges, health practitioners, associations and agencies • Corporate Partners: Sobeys, funders	• Establish broad-based coalition to address health outcomes • Promote/deliver health and lifestyle programs • Enhance capacity of existing services • Raise awareness of the specialized health needs of individuals with ID • Structural reform • Research, collect and analyze data	• Special Olympics BC, Government Ministries, Supportive agencies and individuals • Individuals with ID, caregivers, Ministry of Health, regional health authorities, community stakeholders, corporate partners, Ministry of Education, Ministry of Children and Family Services • Ministry of Health, regional health authorities, community stakeholders, academic and research institutions, health professionals, Ministry of Social Development and Social Innovation • Ministry of Health, stakeholders • Ministry of Health, regional health authorities, stakeholders, academic and research institutions, health professionals • Ministry of Health, regional health authorities, stakeholders, academic and research institutions, health professionals	• Increased understanding of health inequities, data on which to base future interventions, focal point for practitioner engagement • Community awareness of need for healthy diet • Increased participation in active healthy lifestyle activities • Reduced barriers to access, practitioners have training and guidelines for serving population	• Effective implementation of interventions • People with ID live healthier lifestyles, • More responsive services • More resources and research for stakeholders	• Elimination of health disparities • Reduced hospitalization for ASC conditions, • Increased life expectancy for people with ID • Enhance overall health and wellbeing of people with ID in BC • Position BC as a global leader in specialized ID health research and services • Reduce health care costs

PRIORITIES

Improve overall health and wellbeing of individuals with intellectual disabilities (ID) in BC
Enhance the effectiveness of health care services for individuals with ID
Eliminate health disparities compared to general population
Engage community-based stakeholders to effect positive change
Raise support and awareness of the importance of the health and wellbeing of individuals with ID
Improve the quality and quantity of health-related resources to increase effectiveness of all stakeholders
Position BC as a global leader in ID health research and services

ASSUMPTIONS

Based on Accessibility 2024 Government will be supportive; concern about health of individuals with intellectual disabilities is shared by all stakeholders; current system does not support all individuals with intellectual disabilities to the level needed.

EXTERNAL FACTORS

Stakeholder support; funding; capacity of partners and system to do more

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CORE PRINCIPLES

- British Columbia has the resources and expertise necessary to eliminate health disparities between people with ID and the general population
- Adequate data is a necessary precondition for effective public health policy development
- Populations with a higher risk of disease and morbidity should be at the forefront of policy discussions
- Healthcare should be accessible to all, with service options based in all communities where possible
- Early diagnosis and intervention are critical to effective and efficient health services
- Specialized services for ID can contribute to a reduction in health disparities
- People with ID deserve the same access to quality services as the general population
- NGOs and other community organizations are often effective mediums for health promotion and interventions

DEFINITIONS

Intellectual Disability

Intellectual disabilities are the most common form of developmental disabilities, and are generally accepted to refer to significant cognitive limitations requiring an individual to rely on external support for daily needs and activities (American Association of Intellectual and Developmental Disabilities, 2013).

For the purposes of this document, an individual is considered to have an intellectual disability if the following three criteria are met:

1. IQ is below 70-75
2. There are significant limitations in two or more adaptive areas (skills that are needed to live, work, and play in the community, such as communication or self-care)
3. The condition manifests itself before the age of 18

This definition follows WHO-Europe guidelines which include children with autism who have intellectual impairments as well as children who have been placed in institutions due to environmental factors such as perceived disabilities or family rejection who go on to develop an intellectual impairment (WHO-Europe, 2016).

Health

We recognize that a multi-faceted approach that considers improvements to both clinical services as well as community support networks is necessary. Therefore, rather than focusing on a narrow clinical definition of health, this document will use the World Health Organization (WHO) definition:

> *"Health is a state of complete physical, mental and social well-being and not merely the absence of disease or infirmity"*
>
> - *WHO*

Health Services

This document will use the WHO definition of 'health services':

> *All public 'services dealing with the diagnosis and treatment of disease, or the promotion, maintenance, and restoration of health'*

BC HEALTH STRATEGIC AND SERVICE PLANS

In February 2014 the BC Ministry of Health issued its strategic plan titled "*Setting Priorities for the BC Health System*" (Health, 2014). The document provides an overview of the strategic and operational priorities for the delivery of health services across the province. While comprehensive and ambitious in nature, the document does not address disability in a substantive way, nor has the Ministry of Health issued an additional framework as it has done for other sectors such as rural health (Health M. o., 2015).

The Governement of BC introduced the "*2017 Confidence and Supply Agreement between the BC Green Caucus and the BC New Democrat Caucus*", which laid out the key priorities of the newly established government (Canada, 2017), including health care reform. Further clarification of the administrations' objectives came in the form of the "*Ministry of Health 2018/19 – 2020/21 Service Plan*" (Horgan, 2018) and the new primary care strategy announced in May, 2018 (BC Ministry of Health, 2018). Several key population groups have been identified as neccessary beneficiaries of health service reform based on current health outcome inequities, including indigenous communities, the elderly, and those with addictions. Individuals with intellectual disabilities, however, are still absent from discussions.

The budget implications of a failure to adequately address the health needs of this population could be dire. Due to the lack of available data on health service expenditure and the cost poor health has on the system, it isn't possible to determine the full financial impact that currently exists. To complicate matters further, without information on prevelance it is difficult to project any future growth in demand. We do know that health care expenditures for people with illness or disability accounts for 50% of all health system expenditures, with liabilities reaching $5.2 billion (Ministry of Health, 2015). We also know that for those with medium and highly complex chronic conditions, expenditure is expected to increase by 76% and 98% respectively by 2036 (Ministry of Health, 2015). Service expenditure on individuals with severe disabilities is expected to grow by 45% in the same timeframe.

FRAMEWORK FOR SUCCESS

In Canada, health services for individuals with ID are determined provincially, rather than nationally. This carries the risk of a vast discrepancy between regions owing in part to financial resources, the extent of deinstitutionalization in the region, as well as the extent to which policymakers have made the needs of individuals with ID a priority (Smiley, et al., 2002). Further, there is no committee, such as the President's Committee on Intellectual Disabilities in the USA, which provides national level policy advice concerning the needs of people with ID and their caregivers.

Governments are increasingly recognizing that health services directed at the general population are often insufficient to meet the needs of people with ID, and that a coordinated intervention is required. In 2001, the UK released the "*White Paper"* (Department of Health, 2001) to ensure that the needs of individuals with ID were considered on a national level. The US released its national strategy "*Closing the Gap"* in 2002 (Department of Health and Human Services, 2002). In Europe, the *"Declaration of Rome"* (Seidel, 2003) and the *"European Manifesto"* (Meijer, Carpenter, & Scholte, 2004) were both drafted to address the issue on a regional level. Canada has yet to achieve a national policy document to effectively manage the health care needs of individuals with ID. Howver, Accrediation Canada – an NGO – recently established national guidelines for service providers (Accreditation Canada, 2018).

Like Canada, Australia lacks a national strategic framework governing health services for individuals with ID. In its absence, the state of New South Wales has taken a leadership role by establishing the *"Service Framework to Improve the Health Care of People with Intellectual Disability"* (Inter Government and Funding Strategies & Integrated Care, 2012). Pursuant to the framework, an interdisciplinary 'ID Health Network' which acts as a focal point for relevant stakeholders including government health agencies, NGOs, academia and more has been established. Additionally, three pilot studies focusing on specialized services are either currently underway or recently completed. Other benefits have arisen from the wealth of research conducted in accordance with the service framework. For example, researchers discovered that in the NSW healthcare context, the role of ID specialist nurses played a critical role in facilitating communication between specialists and people with ID or their caregivers. Another area in which critical insight has been gained is into methods for reducing reliance on acute services and encouraging the use of more cost effective and appropriate services (ACI Intellectual Disability Health Network, 2015). Further, the framework has led to the development of service guidelines in the areas of obesity and weight management, mental health and behaviour management, gynaecology and menstrual management, dental and oral health, and more.

In order to truly improve the health and wellbeing of individuals with intellectual disabilities in BC, far more is needed than efficient and effective health services. Work is needed to, inter alia, promote active lifestyles, foster inclusive communities, tackle sexual violence and substance abuse, encourage healthy diets, and promote mental health and wellbeing. Fortunately, civil society in BC is flourishing. There are dozens of support organizations operating across the province and creating positive change in the communities they reach. To date, there remains little interaction between these community organizations and health authorities.

A framework to develop a service network for ID will reduce dependence on strained services, build capacity and confidence amongst services, ease strains on caregivers, and encourage healthier lifestyles. It is our belief that BC has the resources and expertise necessary to become a national and global leader in the field of health services for individuals with ID. The following document highlights suggestions for an effective framework. It has been developed following extensive consultations with local and regional stakeholders.

WHAT WE DO KNOW

Special Olympics BC Findings

Special Olympics British Columbia recently conducted its first Healthy Athletes Screening Survey to assess the current state of health of the athletes in this program. Two separate questionnaires were given to athletes and their caregivers respectively, our key findings include:

- 32.25% (10/31) of athletes need to travel outside of their community for medical services ‘some or most of the time’
- 80% (24/30) of athletes at least sometimes find it difficult to understand their doctor’s advice or directions, yet only 31% (9/29) always have somebody accompany them to their doctor’s appointments
- 92.6% (28/30) of athlete respondents said that they would like to get in better shape
- 20% (6/30) of athletes stated that poor health had at times prevented them from competing in sports
- 57.6% (19/33) of caregivers have less than four years’ experience working with people with ID
- 7.5% (3/40) of athletes do not have a full-time GP based in their community
- 50% (20/40) of athletes visit a medical professional more than four times per year, 12.5% (5/40) visit more than ten times per year
- 12.5% (5/40) of athletes have been unable to purchase necessary medications due to insufficient funds
- 20% (8/40) of athletes are unable to purchase their required sports related medical devices in the community
- 32.5% (13/40) of caregivers said that Special Olympics BC Healthy Athletes Screenings have detected a medical concern that they were otherwise unaware of and 83.33% (30/40) of caregivers have felt that attending a Healthy Athletes Screening has helped them learn about health care

**Key data limitations: Survey responses are small and were collected predominantly at Special Olympic Healthy Athletes Screenings based in the Lower Mainland, Vancouver Island and Kootenay regions. Responses are not largely reflective of athletes/caregivers’ experiences in northern communities. Additionally, athletes involved in Special Olympics programs are frequently engaged in physical activities, able to access Healthy Athletes Screenings and receive training and advice on proper nutrition. As a result, there may be discrepancies in health outcomes between SOBC athletes and individuals with ID more generally.*

Prevalence of ID

Accurate statistics on the prevalence of ID in BC are not readily available. According to the Canadian Survey on Disability, completed in 2012, between 0.4 and 1.2% of Canadians have an intellectual disability (Statistics Canada, 2012). More recently, researchers in Ontario identified a prevalence of 0.78% (HCARDD, N.D.). These results are similar to studies comparing communities at similar levels of economic development, including NSW, Australia (Health, 2012) and the USA (Zablotsky, et al., 2015). A co-occurrence of Autism Spectrum Disorder (ASD) and ID is common and can result in poorer health and social outcomes than ID alone. Researchers in South Carolina recently identified a prevalence of ASD in ID of 18.04%, which compares to an ASD prevalence of 0.6-1.11% in the general population (Tonnsen, et al., 2016).

Life Expectancy/Mortality

The shift away from institutional care that began in the 1950's effected a dramatic change to the life expectancies of individuals with ID. In BC, these outcomes are still being realized as it wasn't until 1997 that the last of these institutions was closed (Tang, et al., 2008). A recent collaborative research effort attempted to analyze available data to determine the effect of intellectual disabilities on mortality rates in Canada, but acknowledged that our knowledge on the subject "remain(s) limited and somewhat out of date" (Ouellette-Kuntz, et al., 2015). However, the authors were able to determine that there is evidence (in Ontario and Manitoba) of excess mortality at all ages, with children and women experiencing a greater risk.

The precise effect of intellectual disabilities on lifespan is the current subject of much debate. Indeed, rapid technological and social advancements have drastically reduced health disparities. A 1987 Canadian study observed a disparity of 23 years for men and 29 years for women when comparing individuals with ID in institutions and the general population (Wolf & Wright, 1987). While an accurate assessment of the current disparities in Canada is not available, we can infer that the reduction following deinstitutionalization observed elsewhere likely occurred in Canada as well. In Germany, for example, a recent study found that men with ID lived 6.6 to 12 years less than the general population (Dieckmann, Giovis, & Offergeld, 2015). The same study found that women with ID lived 10.3 to 13.6 shorter lives. In perhaps the largest study of its kind, researchers in the UK determined that individuals with ID have an all-cause standardised mortality ratio of 3.18, and a lifespan 19.7 years shorter than the general population. The study compared the GP records of more than 5% of the total population, both with and without ID (Glover, et al., 2016).

The remaining health disparities are due, in some part, to subgroups such as individuals with Down syndrome (Torr, et al., 2010) and those with severe to profound ID. In Finland, for example, researchers found that individuals with mild to moderate ID lived, on average, 11-12 years longer than individuals with severe to profound ID (Bjelogrlic-Laakso & Salokivi, 2017). An important finding from the German study (Dieckmann, Giovis, & Offergeld, 2015) was that there are clear differences in life expectancy between regions. For this reason, it is insufficient to rely on studies conducted elsewhere in Canada. It is imperative that an intellectual disabilities effect on mortality be studied within the context of BCs healthcare system.

Researchers in Ontario at the Health Care Access Research and Developmental Disabilities (H-CARDD) research group recently linked multiple administrative databases in an attempt to better understand health trends. Information was taken from four health and one disability income support databases to establish a cohort of 66,000 individuals with ID – the largest of its kind in the world (Centre for Addiction and Mental Health, 2018) (Lin, et al., 2014). The result has been an unprecedented accumulation of data and analysis on the needs and profiles of ageing Ontarians with ID. They determined, inter alia, that by 2021, the total number of adults with ID over the age of 64 in Ontario will be double that of 2009/2010, and that adults with ID show signs of frailty at age 50 compared to individuals without ID at age 80 (Oullette-Kunz & Martin, 2014). Given the relationship between service use and frailty, and the documented practitioner anxiety about the readiness of Ontario's health system for an ageing population with ID (Martin, Ouellette-Kuntz, & McKenzie, 2017), such information has proven to be critical. Linking and enhancing existing databases would help establish answers to the important question of the effect of ID on ones' lifespan, and provide invaluable insight for policy-makers.

Mental Health and ID

Individuals with ID are far more likely than the general population to develop a psychiatric disorder (Morgan, et al., 2008) (Cooper, et al., 2015). Recent studies have identified an increased prevalence of, inter alia, depression (Morin, et al., 2010), dementia (Strydom, et al., 2009) (Shooshtari, 2017) and aggressive behaviour (Crocker, et al., 2014) amongst the population. In Ontario, researchers from the H-CARDD program found that over a two year period, 44% of adults with ID had a mental illness diagnosis (Lin, et al., 2016B). Using the same database, researchers also determined that certain subgroups, such as those with autism, have higher rates of mental illness than their counterparts with other ID's (Weiss, et al., 2018). Children with ID are particularly at risk, with a prevalence of psychiatric disorders estimated at 36%, compared to 8% of children without (Emerson & Hatton, 2007). Further disparities exist in terms of severity of illness; 26% of psychiatric diagnosis' are classified as 'severe' in individuals with ID, compared to only 8% in those with psychiatric diagnosis but no ID (Lunsky, et al., 2012B).

Social and environmental factors can have a significant effect on the expression of psychiatric and behavioral disorders in individuals with ID, particularly with children and ageing populations (Day & Jancar, 1994). A key factor contributing to poor mental health in children is social isolation; children with ID or ID and ASD report fewer friends and a lower quality of friendships than their typically developing peers (Taheri, Perry & Minnes, 2016). For adults, 'stressors' often include events such as the death of a parent or relocation, as well as social feelings of isolation (Thorpe, Davidson, & Janicki, 2002). The experience of shame, both internal and external, has been found to be particularly harmful to the psychological well-being of adults with mild to moderate ID (Clapton, Williams & Jones, 2017).

Little is known about the rate of suicide or self-injurious behavior amongst individuals with ID. This is despite the population showing a higher likelihood of risk factors than the general population, such as childhood adversity, mental illness, and lower levels of educational attainment. The lack of research is due, in part, to a longstanding belief in medical communities that individuals with ID are not capable of both forming suicidal intent and acting on the intent (Kaminer, Feinstein & Barrett, 1987). However, anecdotal evidence suggests that suicide does occur within the population, and that it is not limited to individuals with mild to moderate ID. In Australia, 77% of support workers who deal with mental health report witnessing suicidal behaviour in individuals with ID, with 76% percent noting explicit statements about the desire to end one's life (Wark, et al., 2018). Alarmingly, the same study found that 60% of respondents were unaware of a suicide risk assessment being completed by anybody in their organization.

Mental health services for people with ID have undergone a rapid transformation in recent years. Deinstitutionalisation led to a division between health services for individuals with ID and the provincial health authorities (Lunsky, et al., 2007). This division, coupled with the accompanying shift towards community-based services would see specialized psychiatric services become 'less of a priority' (Lunsky, et al., 2007). Since then, BC has gone on to develop both the Community Living BC (CLBC) Provincial Assessment Centers as well as the Developmental Disabilities Mental Health Services (DDMHS). It should be noted that the capacity of the DDMHS teams around the province varies greatly. For example, the office in Prince George – responsible for Northern BC – consists of one registered nurse and one social worker with limited access to a behavioural specialist and psychiatry services. There are currently no specialized services for individuals with ID under the age of 14 or those who require psychiatric treatment for more than 90 days. Furthermore, there no longer exists within our provincial systems which serve individuals with ID the ability to provide a case manager role. This lack of relationship with a person who has a role to ensure an individual's needs are being met contributes a great deal to the degree of vulnerability and risk of harm experienced by this population.

The lack of specialised services is particularly alarming given recent findings from the H-CARDD database concerning service utilization patterns in Ontario. Psychiatry, primary care, and emergency service utilization were all found to be higher in adults with ID and a mental illness diagnosis compared to adults with only a mental illness diagnosis (Lunsky, et al., 2018). Additionally, adults with ID and a mental illness or addiction are 1.66 times more likely to be readmitted to hospital within 30 days and 1.33 times more likely to return to emergency services within 30 days compared to individuals with only a mental illness or addiction (Lin, et al., 2016B). These findings suggest that preventative and follow-up care received by individuals with ID may not be meeting their needs. For example, 42% of individuals with ID who had a psychiatric emergency department visit received no outpatient follow-up in the month after their visit (Lunsky, Klein-Geltink, and Yates, 2013). Adults with ID and a mental illness diagnosis are also 3 times more likely than adults with a mental illness or addiction only to experience an Alternate Level of Care (ALC) day (Lin, et al., 2016B). High rates of ALC days are indicative of a lack of resources to adequately serve the population in other parts of the system.

In a comparison of mental health services for people with ID in Canada and the UK, it was noted that Canadian services are far more crisis-reactive, while the UK system is more preventative in nature (Cheetham, 2010). For example, a lack of adequate resources and trained staff to manage challenging and aggressive behaviours in people with ID in the community is believed to increase reliance on inpatient units in Canada (Modi, et al., 2015) Research from Ontario suggests that the majority of emergency room visits made by people with ID are related to psycho-behavioral issues rather than a medical concern, and these visits were more likely to result in admission (Lunksy, et al., 2012). It is suggested that more proactive outpatient clinical services are needed to adequately manage such problems in a community setting (Benson & Brooks, 2008). Doing so could potentially lead to better health, improved quality of life, and cost savings (Balogh, et al., 2010).

Health researchers globally have identified best practices that can inform efforts to enhance preventative mental health services in BC. For example, a study in the UK found that the cost of interventions for anger and aggressive behaviour would be fairly immediately compensated by savings obtained from follow-up visits (Felce, et al., 2015). American researchers found that upon referral to specialized interdisciplinary teams for problem behaviour, the proportion of individuals with hospital admissions, total number of admissions, and liability for prescriptions all decreased significantly (Owen, et al., 2016). Furthermore, a study in Australia found that the use of treatment protocols improved psychologist and counsellor confidence in areas such as assessments and interventions, thereby increasing the quality of preventative services available (Hronis, Roberts & Kneebone, 2018).

In addition to approaches utilizing public health services, it must be recognized that interventions aimed at improving the overall mental health of individuals with ID must also consider community support networks. In BC, organizations including Special Olympics, Community Living Associations, the Down Syndrome Research Foundation, and more offer regular programming that help build the social skills and coping mechanisms of individuals with ID. For example, in 2016 Special Olympics BC initiated its Strong Minds Strong Bodies (SMSB) program which aims to help athletes develop strategies to maintain emotional wellness under stress. Like all Special Olympics BC health programs, SMSB is not exclusive to their athletes, rather it is open to all members of the community with intellectual disabilities. Around the province, many of these community-based programs go under-utilized due to a lack of public awareness. Establishing an online focal point for disseminating information about available community services and programs could lead to increased utilization of community services and a decreased reliance on public health services.

Sexual Health and ID

People with ID of all ages have the same sexual desires as the general population, including the desire to enter romantic relationships and marriages (Healy, et al., 2009). However, individuals with ID often don’t have the necessary skills and knowledge to make decisions about their sexual health (Swango-Wilson, 2009) (Swango-Wilson, 2011). This often results in individuals with ID not having their sexual health needs adequately met. For example, while 84.2% of individuals with ID report having a sexual relationship, only 41.4% use condoms (Gil-Llario, et al., 2017). Further, one Ontario study found that only 34.3% of women with ID were screened for cervical cancer, compared to 66.8% of their peers (H, Plourde, et al., 2016). The same study cited the perception by physicians that individuals with ID were sexually inactive as the primary barrier to increased screenings. However, while screening rates do rise for women in Canada with ID who have had a pregnancy, they are still less likely to receive screenings than their peers without ID (Brown, et al., 2015). This suggests that factors beyond practitioner knowledge of sexual activities play a role in the disparities. Unfortunately, despite the clear need for specialized sexual education, adolescents with ID often receive less sexual education than adolescents without ID (Levy & Packman, 2004) (Murphy, 2005).

The sexual health needs of individuals with ID cannot be met exclusively through health services. Many individuals with ID feel their sexual expression is under the control of caregivers whose contextual beliefs often inhibit or over-facilitate positive displays of sexuality (Whittle & Butler, 2018). Individuals who identify as LGBT face additional stigma and discrimination (McCann, Lee & Brown, 2016). Moreover, many individuals with ID find picking up on social cues to be difficult, which can have negative repercussions on their sexual expression (Meaney-Tavares & Gavidia-Payne, 2012). Efforts are needed to increase the capacity of individuals with ID to make informed decisions about their sexual health as well as to strengthen their community support networks. Tailored educational programs are an effective way to increase individual capacity (Dukes & McGuire, 2009), while family and community support is needed to help build skills relating to healthy relationships and to deal with individual circumstances as they arise.

A lack of knowledge about sexuality, skill deficits, and the need for self-care are all cited as contributing factors to individuals with ID being over-represented as both perpetrators and victims of sexual abuse (Martinello, 2015). According to one estimate, “between 39-68% of female children and 16-30% of male children with a disability will be sexually abused” before their 18th birthday (Mahoney & Poling, 2011). Estimates concerning the rate at which individuals with ID commit sexual offence range from 4-40% (Martinello, 2015). In the UK, 38% of adolescents in specialized services for harmful sexual behaviour have ID (Hackett, et al, 2013). Sex education that focuses on addressing skill deficits and promoting a healthy understanding of relationships and sexuality can reduce the risk of an individual with ID becoming a perpetrator or victim of a sexual offence (Martinello, 2015). Manualized group cognitive behavior therapy (CBT) treatments in particular have shown to improve knowledge and reduce harmful sexual behaviour in adolescents (Malovic, Rossiter & Murphy, 2018).

Despite individuals with ID increasingly connecting to the internet, little is known about effective risk reduction strategies to avoid online sexual abuse (Norman & Sallafranque-St-Louis, 2016). CLBC does operate a website titled ‘*I can be safe online’*, which provides resources for individuals with ID and their parents/caregivers (Community Living BC, 2018). While the website has a wealth of useful resources, it does not address the issue of online sexual exploitation in a substantive way. Research is needed to identify best practices and effective interventions to reduce the risk of online sexual abuse.

Nutrition, Physical Activity and Obesity

The benefits of physical activity to an individual’s health and wellbeing are well documented and range from reduced risk of cardiovascular disease to improved mood and outlook (Center for Disease Control, 2016). It is recommended that children engage in 60 minutes of physical activity daily (World Health Organization, 2011), though even modest amounts can have a profound impact (Janssen & LeBlanc, 2010). It is true that youth inactivity is a wider problem across Canada (Statistics Canada, 2015), however studies show that children with ID are significantly less active than their peers without disabilities (Hinckson & Curtis, 2013). This results in significantly lower levels of physical fitness when compared to typically developing children (Hartman, Smith, Westendorp, & Visscher, 2015), and can have substantial implications for the ability to self-care later in life. For example, studies have identified a clear correlation between low participation in sports and low motor skills in children with ID (Westendorp, et al., 2011).

Obesity is found in children with ID at rates 2-3 times that observed in typically developing children (Rimmer J., Yamaki, Lowry, Wang, & Vogel, 2010). A large study conducted using information from Special Olympic health screenings found a high discrepancy between regions. The global average rate of obesity for children and adolescents with ID was 30%, in North America that jumped to 46.2% for boys and 57.7% for girls (Lloyd, Temple, & Foley, 2012). It is believed that environmental factors play a dominant role, meaning that effective interventions are possible (Rimmer & Yamaki, 2006).

High rates of physical inactivity are also found in adults with ID (Draheim, Williams, & McCubbin, 2002) (Peterson, Janz, & Lowe, 1001-106). It is estimated that only 13.5% of adults with ID meet the recommended daily physical activity guidelines (Stancliffe & Anderson, 2017), while 50% report more than 4 hours of screen time per day (Melville, et al., 2018). Recent literature suggests that women and adolescent females may be less active than their male counterparts, possibly due to a decreased likelihood of devoted physical activity time in their schedules (Sundahl, et al., 2016). Studies have consistently found higher rates of obesity in adults with ID when compared to the general population (Winter, et al., 2012).

Effective interventions in this area will allow individuals with ID to live healthier lives as well as reduce burdens on the public health system. US based researchers estimate that the mean additional annual healthcare expenses for an individual with ID who is obese is $2516 USD (Li, et al., 2018), approximately three times that incurred by an individual without ID (Anderson, et al, 2013). While more research into effective weight management strategies is needed (Rimmer & Yamaki, 2006), interventions adequately employing existing strategies can be very effective. Individuals with ID often lack exercise resources, particularly in the group home setting (Howie, et al., 2012). Simple measures, such as replacing sedentary video games with exergames using Wii Fit can enhance health outcomes (Silva, et al., 2017). BC based researchers have identified a need for clear policies in day training centers and accommodation services related to promoting physical activities and further training of staff (Temple & Walkley, 2007). A similar need can be found in schools, as children with ID are more likely to depend on schools for physical activity than typically developing children, yet are also more likely to remain sedentary during school hours (Einarrson, et al., 2016).

Special Olympics BC currently provides opportunities for individuals with ID across the province to train and compete in sports year-round. As of June 2018, there were more than 4,800 athletes participating in 18 different sports. Additionally, SOBC offers the Club Fit program, which allows athletes of varying skill levels to improve their health and fitness outside of participation in other Special Olympics programs. Another opportunity for children with ID to get involved is the Easter Seals program, which operates three camps to give children with physical and intellectual disabilities the opportunity to go to summer camp. In addition to these opportunities there are sport-specific specialist programs such as the Pacific Riding for Developing Abilities (equestrian). Supporting these programs and other recreation opportunities has the potential to increase physical activity levels amongst individuals with ID in the province, thereby improving health outcomes for this population.

Little research has been conducted into the eating habits of people with ID, however, one study from Ireland found that while individuals with ID often intake sufficient quantities of fat and sugar, they often fail to meet guidelines for fruit and vegetables, carbohydrates, diary and protein (McGuire, Daly, & Smyth, 2007). A prior study reported that only 7-8% of adults with ID eat balanced diets (Robertson, et al., 2000). Many people with ID often have little choice in their diets, as they usually eat in group homes or family settings

(Koritsas & Iacono, 2016). For these reasons, interventions need to be focused on educating caregivers about nutrition and dietary needs. Multi-component interventions addressing education, nutrition and exercise are particularly effective when family members and caregivers are included and supportive (Martınez-Zaragoza, Campillo-Martınez, & Ato-Garcıa, 2016). Special Olympics BC provides education on nutrition to athletes attending the Club Fit program as well as at Team BC and Performance Camps. Coaches receive specialized training in the nutritional needs of athletes with ID at capacity building summits, while parents can attend our Family Health Forums to increase their knowledge.

While public health services can play a large role in health promotion through, inter alia, public education campaigns and establishing health and lifestyle guidelines, nutrition and obesity interventions are primarily conducted at the community level. It is critical that community organizations that work with individuals with ID are assisted and encouraged to include aspects related to nutrition and exercise in their programing or refer individuals to sports programs like Special Olympics BC. In this regard, public health services can play an active role in facilitating community-based programs by, for example, ensuring that organizations are equipped with the most current information about the effectiveness of potential interventions and the availability of community-based resources. Success in this area will be dependent on sufficient integration between health care services and community actions.

Drug and Alcohol Use

As a result of deinstitutionalization, individuals with ID are increasingly becoming involved in the community. With the benefits of inclusion come some negative consequences, including increased access to alcohol and illicit drugs. It is widely acknowledged that while individuals with ID are less likely to use drugs and alcohol, they are more likely to develop a substance abuse problem (Taggart, et al., 2006) (McGillicuddy, 2006) (Chapman & Wu, 2012). For example, a study of Special Olympics athletes found that of the athletes who smoked, 79.6% were daily smokers with a mean of 10.08 cigarettes per day (Eisenbaum, 2018). Further, individuals with ID are likely to experience heightened side effects from both prescribed and illicit drugs, making the need for intervention direr (Degenhardt, 2000). The negative social implications for drug and alcohol abuse for people with ID include further isolation, increased inpatient admittance, and loss of housing (Huxley, Day, & Copollo, 2006).

A recent Ontario-based study found that alarmingly, over a two year period, individuals with ID had a prevalance of Substance-Related and Addictive Disorders (SSRD) of 6.4% (Lin, et al., 2016A). This figure is far higher than most previous reports and that of the general adult population in Ontario. The study also provided some insight into the role psychiatric comorbidity plays in the development of an SSRD, observing that the most prevalant comorbid disorders were anxiety disorders (67.6%), followed by affective (44.6%), psychotic (35.8%) and personality disorders (23.5%).

Little is known about the rates at which adolescents with ID in Canada abuse drugs or alcohol, however, evidence from the UK provides reason for concern. There, researchers found that children with ID comprised 9% of all children with potentially harmful drinking habits, and were significantly more likely than their non-disabled peers to experiment with alcohol, hold positive views about alcohol use, and hold less negative views on the social and health consequences of drinking (Emerson, et al., 2016). The same study identified risk factors associated with potentially harmful levels of drinking including smoking and having friends who use alcohol, with respondents often indicating that drinking makes it easier to forge friendships and reduces anxiety. This suggests that a preventative approach to drug and alcohol misuse utilizing community support networks is necessary to achieve the desired health outcomes.

More research is needed into the reasons behind substance abuse among people with ID; however, one study found through interviews with individuals with ID who abused drugs or alcohol that 'medicating against life's negative experiences' was a common theme (Taggart, McLaughlin, B, & McFane, 2007). The study cited psychological trauma and social isolation as the primary sub-themes. Evidence indicates that interventions directed at the general population can result in negative experiences for people with ID (Taggart, McLaughlin, B, & McFane, 2007). US based studies have found that after a referral to mainstream services, individuals with ID were less likely to engage in treatment for substance abuse (Slayter, 2009) (Slayter, 2010). Attempts to find an alternative form of treatment that would be more successful in reducing drug or alcohol dependency amongst people with ID have not yet borne fruit due to insufficient knowledge of the reasons behind substance abuse (Day, et al., 2016).

In BC, specialized drug treatment services for people with ID are provided through the Developmental Disability Health Teams located in five regional centers. Further opportunities for non-specialised services are provided through the Mental Health and Addictions Branch of the Ministry of Health (MOH) as well as by several NGOs such as Last Door and the Aurora Center. Community-based programs are also well-positioned to undertake preventive interventions aimed at reducing the need for clinical interventions. The success of many interventions in this field will depend on the ability to harness the outreach power of community groups and to provide support and training to family members and caregivers.

Access to Quality Primary Care Services

Throughout their lifespan, individuals with intellectual disabilities interact with provincial health services at far higher rates than the general population. Children with ID require significantly more ambulatory physician visits and have a higher rate of continuity of care (Shooshtari, et al., 2016). As adults, individuals with ID in Canada are more likely to require home care at an early age (Martin, Ouellette-Kuntz and McKenzie, 2017), and are almost five times more likely to be admitted to long term care (Ouellette-Kuntz, Martin and McKenzie, 2017). Increased data collection and analysis is needed to determine the extent to which health services meet the needs of individuals with ID in BC.

Following events in the UK, it has come to international attention that individuals with ID may receive significantly lower quality hospital services than the general population. In 2007, a scathing report titled '*Death by Indifference*' highlighted deaths of individuals with ID in hospitals that were believed to be a result of institutional failures within the National Healthcare Service (NHS). Campaigners interviewed for the report felt that there existed within the health care system "complacency and a lazy fatalism that these groups just do die younger" (MENCAP, 2007). Despite the public outrage and parliamentary inquiry that followed the report's release, there is evidence that little has changed (MENCAP, 2012).

A recent study found that individuals with ID are still at a significantly higher risk of readmission within 30 days of discharge for a potentially preventable cause (Kelly, et al., 2015). The effects of poor service quality extend beyond patients with ID; the perception of service quality amongst caregivers is directly related to practitioner burnout and retention (Moliner, et al., 2017).

Despite the absence of public outrage, individuals with ID in Canada have equal reason for concern. Ambulatory Care-Sensitive (ACS) conditions, sometimes known as potentially preventable hospitalizations, are used as an informal measure of access to, and quality of, primary health services (Balogh, et al., 2013). While the rate at which British Columbians with ID are hospitalized for ACS conditions needs to be studied, in Ontario, they were found to be three times that of the general population (Balogh & Ouellette-Kuntz, 2005). What constitutes an ACS condition for an individual with ID differs from that of the general population. In an effort to produce a designated list of ACS conditions for this population, one study identified 14 conditions: asthma, angina pectoris, congestive heart failure, gastrointestinal ulcer, immunization preventable infection, malignant hypertension, otitis media, dental conditions, diabetes mellitus, pelvic inflammatory disease, constipation, gastroesophageal reflux, epilepsy, and schizophrenic disorders (Balogh, et al., 2011). In Manitoba, living in a rural community or an area with a high proportion of indigenous residents as well as co-morbidity were found to be associated with an increased likelihood of hospitalization for an ACS condition (Balogh, et al., 2013).

The significant disparities individuals with ID experience in secondary prevention are a key driver of ACS admissions. For example, Canadians with ID are less likely to undergo age and gender specific screening for cancer and regular health checks than Canadians without ID (Oullette-Kuntz, et al., 2015) (Martin-Storey, et al., 2009), and the proportion of women with ID in Canada who are not screened for breast cancer is 1.5 times greater than it is for women without ID (Cobigo, et al., 2013). Studies have found that women with ID are more likely to receive a mammography if a nurse is involved with health coordination (Wilkinson, et al., 2011). This suggests that nurses with a close knowledge of the case can be effective advocates for preventative services required by individuals with ID. While there is currently no standardized tool for comprehensive health assesments for adults with ID in Canada, the use of Australia’s CHAP program has proven to be effective in the Canadian health care context (Shooshtari, et al., 2016). However, a lack of willingness by physicians to conduct comprehensive health screenings was cited as a key barrier to CHAPs adoption. Administrative tasks during GP visits take significantly longer if an individual has ID, leaving less time for medically related actions (Weise, et al., 2017). Billing supplements could allow practitioners to spend more time with patients with ID, thereby increasing their willingness to conduct assesments.

For youth in particular, parents and caregivers play a critical role in health service access; however, many parents of children and young adults with ID feel overwhelmed. While more research is needed, it is believed that parents and caregivers of those with ID experience poorer health outcomes than the general population due, in part, to increased stress (Grey, Totsika, & Hastings, 2017). This stress is significantly amplified when an individual under their care has an ID and co-morbid psychopathology, particularly so if the individual has autism (Dawson, et al., 2016). The perceived helpfulness of supports has been associated with positive psychological outcomes for caregivers (Grey, Totsika, & Hastings, 2017). In a survey of parents of children with ASD in BC, only 25% of respondents stated that they are “satisfied” with the resources available (Gardiner & Larocci, 2018). A common frustration was the lack of guidance available and the associated strain.

The absence of adequate guidance is especially problematic as children and youth with ID transition into adulthood and require new supports and services. A recent review of health service use by youth and young adults with ID found that many fall through the gaps while transitioning to mainstream adult services (Hamdani & Lunsky, 2016). The Navigator Program in BC offers youth in some regions with the opportunities to be guided through the process by a mentor. Youth across the province would be well-served by an expansion of this program as well as by efforts to increase the support provided to parents and caregivers. As individuals with ID age, the ability for family caregivers to provide support may diminish. In Ireland, researchers found that few future care plans have been developed to ensure access to care beyond the death of an individual's parents (Brennan, et al., 2017). Research is needed to identify potential service gaps and to ensure continued access to care for ageing adults with ID in BC.

Pharmacology

Polypharmacy is common amongst individuals with ID due to, inter alia, behavioural concerns, excessive morbidity and ineffective strategies for medication reduction. By analysing the Ontario Drugs Benefits claims database, researchers found that 50% of individuals with ID are dispensed multiple medications concurrently, with 22% being dispensed five or more concurrently (Lunsky, et al., 2013). Of individuals prescribed 5 or more medications concurrently, 32% did not have regular follow-up visits with the same physician, making discontinuation unlikely.

In an attempt to manage challenging or aggressive behaviour, people with ID are often prescribed multiple psychotropic medications concurrently despite a limited knowledge of the effects (Matson & Neal, 2009). Polypharmacy of psychotropic medications can lead to further medical complications, such as weight-gain and diabetes (McLaughlin-Beltz, et al., 2015), and may be a sign of the failure of previous interventions (Modi, McMorris, Palucka, Raina, & Lunsky, 2015) (Scheifes, et al., 2016). Researchers in the Netherlands looked at the rate at which Drug-Related Problems (DRPs) were present in people with ID who are taking at least one psychotropic drug and found an alarming prevalence rate of 80% (Scheifes, et al., 2016). The same study noted DRPs in 1/3 of the medications surveyed which are regularly prescribed to individuals with ID.

The use of antipsychotics for off-label indications is highly prevalent in individuals with ID. Dutch researchers found that 69% of prescriptions for antipsychotics were issued to deal with problem behaviours, while only 5% were issued as a result of a chronic psychotic disorder (Kuijper & Hoekstra, 2017). In Ontario, 39.2% of individuals with ID filled at least one antipsychotic prescription over a six year period, with rates jumping to 56% for adults living in a group home setting (Lunsky, et al., 2018). Of these individuals, 29% had no psychiatric diagnosis. Alarmingly, 20% of individuals with ID in Ontario who are prescribed antipsychotics are prescribed a second antipsychotic concurrently, a dangerous practice that puts them at increased risk of adverse events, including death (Lunsky, et al., 2013). Once commenced, individuals with ID are unlikely to be withdrawn from antipsychotics (Kuijper & Hoekstra, 2018). However, the odds of discontinuation are highly dependent on the service provider, suggesting that staff attitudes towards the use of antipsychotics for off-label indications play a significant role (Kuijper & Hoekstra, 2017). A recent study found that the majority of practitioners held unrealistic expectations towards the positive effects of antipsychotics on behavioural functioning (Kujiper & Van der Putten, 2017). The same study found that 94% of practitioners fell below the cut-off scores for knowledge of antipsychotics use for the population.

Management of mental health concerns through medication can be more difficult if an individual has ID due to a lack of decision-making capacity, a higher risk of adverse events, as well as other factors (Eady, Courtenay, & Strydom, 2015). Therefore, individuals with ID require different treatment plans, for example, by commencing medication at lower doses (Eady, Courtenay, & Strydom, 2015). Recent studies on the effectiveness of pharmacological interventions for behavioral disorders in people with ID observed that in the majority of cases there was 'insufficient or poor quality' evidence on which to base best practice (Robertson, et al., 2015). Further, there is evidence to suggest that pharmacological treatments may be less effective than other interventions. For example, a review of literature of behavioural interventions found that 80% of studies reported positive improvements (Robertson, et al., 2015). Other effective interventions have focused on the diagnostic process. One study found that working with a set of '*Diagnostic Guidelines for Anxiety and Challenging Behavior*' led to improved diagnosis and treatment plans (Pruijssers, et al., 2015).

Currently, in BC there are no national or provincial guidelines or regulations governing the use of psychotropic medications to manage mental health issues for individuals with ID. Further, there are no requirements for service providers, including nurses, to have training in the care of individuals with ID. This has had the effect of leaving group home staff who administer medication largely unsupported (Bradley & Cheetham, 2010). While some agencies and employers set in-house guidelines and conduct training exercises, efforts are usually focused on how to properly administer medication rather than the proper pharmacological management of behavioural issues (Bradley & Cheetham, 2010).

Overreliance on pharmacological interventions adds significant financial strain on provincial health services. American researchers found that prescription medication costs were the primary driver of health care expenditure on Americans with ID, with mental health status being identified as a consistent predictor of high expense users (Fujira, Li, & Magana, 2018). Further, a study conducted at an Ontario hospital-based dual-diagnosis service found that polypharmacy was a significant predictor of specialized inpatient admissions (Modi, et al., 2015). There is some research to suggest that medication reviews conducted by a multidisciplinary team – including pharmacists, physicians and psychiatrists - had a positive effect on the number, dosage and costs of psychotropic medications (Lepler, 1993)(Scheifes, et al., 2016). Another study found that specialized units were more likely to focus on medication reduction than general services, which would often prescribe increased medications on discharge (White, Lunsky, & Grieve, 2010). In Kansas, a pilot study utilizing multi-disciplinary teams which was tasked with reviewing medications and developing care plans saw a $3.1 million USD reduction in health care costs after the cost of the intervention ($900 000 USD) was deducted (McLaughlin-Beltz, et al., 2015). This was achieved through only 282 consultations, resulting in 190 medication reductions, 85 ER diversions, 134 inpatient diversions and 77 PRTF diversions.

More research is needed into the effects of medications on individuals with ID to ensure that current pharmacological interventions are effective, and to determine if individuals would be better served through non-pharmacological treatments. Providing guidelines to service providers and training to GP's, community workers, and caregivers could potentially increase the effectiveness of interventions and decrease expenditure on prescribed medications.

Practitioners and Health Care Providers

Supporting healthcare providers is critical to ensuring the needs of individuals with ID are adequately met. There are very few medical specialists in intellectual disabilities, leaving many clinicians unable to find the support they need, often fostering a feeling of professional isolation (Cheetham, 2010). An Australian survey of general practitioners saw 94% of respondents' state an interest in further training, with the areas of knowledge frequently cited as lacking corresponding to service areas deemed insufficient (Phillips, Morrison, & Davis, 2004). In Canada, a survey of occupational therapy and physiotherapy masters' students found that while 96% were willing to work with individuals with ID, more than half felt that their knowledge was insufficient to do so adequately in a clinical setting (Vermeltfoort, et al., 2014).

Attitudes amongst healthcare providers towards people with ID and the benefits of inclusion are mixed, with male staff less likely to be supportive of inclusion (Jones, Ouellette-Kuntz, Vilela, & Brown, 2008). Further, it appears that a lack of exposure to people with ID can affect some practitioners' and students' willingness and comfort to work with the population (Verger, Aulagnier, & J, 2005) (Ryan & Scior, 2015). A study of dental students found that their willingness to work with the population was directly related to the extent and scope of their experience (Waldman, Milano, & Wolf, 2004). Canadian universities do not generally include substantial training in intellectual disabilities during undergraduate medical programs; however, the University of Toronto and Queens University have both implemented some form of training. A survey of undergraduate medical students at these institutions found that while 85.6% of respondents had received some specialized ID training, 93.3% felt that more patient exposure and curriculum development was needed (Burge, et al., 2008).

Queens University in particular has positioned itself as a leader in ID health, offering the 'PGY3 Enhanced Skills program in Intellectual and Developmental Disabilities Medicine', the only national residency program focusing on ID (Queens University, 2016). Additionally, the universities' Division of Developmental Disabilities offers inter-professional learning opportunities that bring together postgraduate students from medical, nursing, rehabilitation and clinical psychology. Graduates of the program show significantly increased knowledge and skills concerning health issues affecting people with ID as well as positive attitudinal changes towards the population (Jones, et al., 2015). Negative attitudes are commonly identified as the biggest barrier to people with ID receiving equal treatment within mainstream health services (Hemm, Dagnan, & Meyer, 2015).

While enhanced student training will contribute to increased service capacity in the long-term, efforts are needed to address skill and knowledge deficits amongst professionals currently working in health services. Research suggests that a single core training package could be suitable across all health professions, with the exception of profession specific sub-themes which can be addressed complementarily (Hemm, Dagnan, & Meyer, 2015). Practitioners in BC looking for assistance can turn to resources created elsewhere in Canada. For example, McMaster University has developed a free online course titled the "*Curriculum of Caring*" (McMaster, 2018). The innovative program, which was developed in collaboration with people with intellectual disabilities is aimed at helping health care professionals enhance their services for individuals with ID.

Further resources can be found on the websites of the Developmental Disabilities Primary Care Program (DDPCP) at Surrey Place and the Health Care Access Research (Surrey Place, 2018), and the Developmental Disabilities (H-CARDD) program (Centre for Addiction and Mental Health, 2018). Resources available on the H-CARDD website include a toolkit aimed at building capacity to provide emergency services to individuals with ID (Lunsky, et al., 2016). On the DDPCP website, health care professionals can find, inter alia, a specialized '*Preventative Care Checklist'* to assist with health assessments (Hennan, 2011).

Family physicians in particular can benefit from the *'Primary Care of Adults with Intellectual and Developmental Disabilities: 2018 Canadian Consensus Guidelines'* (William, et al., 2018) which were recently published by the College of Family Physicians of Canada in conjunction with the DDPCP. The guidelines offer primary care providers guidance on, inter alia, appropriate medication uses, chronic illness prevention, and minimizing the stress of life transitions. Practitioners across the province would be well-served by efforts to increase awareness of the guidelines and to provide practitioners with the necessary training to successfully implement them. Additionally, there remains a need for further guidelines to establish a standard of care in fields not covered by the primary care guidelines, for example, in the field of oral health.

Beyond the provision of enhanced training, there is a need for health systems to address the emotional needs of practitioners working with individuals with ID. For example, a significant issue affecting health care practitioners working with ID is high levels of exposure to aggressive behavior. One study found that over a 12-month period, the prevalence of aggressive behavior was 51.8% (Crocker, et al., 2006). While often not resulting in physical harm, aggressive behavior can result in increased stress and burnout amongst practitioners and caregivers of people with ID (Hensel, Lunsky, & Dewa, 2014). Effective policy and resource development with the goal of reducing the negative effects of aggression on practitioner burnout could increase practitioner retention, particularly in hospitals where aggression is often most severe (Lunsky, Hensel, & Dewa, 2013). Staff training focused on improving emotional intelligence and improving interaction between support staff has been found to be particularly effective in this regard (Zijlmans, et al., 2015), as has educational interventions which include individuals with ID as educators (Tracy & McDonald, 2015).

A pressing concern emerged in June 2016, when Parliament enacted the Medical Aid in Dying Act, which provides the framework for individuals to seek and obtain medical help to end their lives. Many community disability organizations contributed to the discussion period, much of which focused on the '*Vulnerable Persons Standard*.' It is critical that health care authorities provide practitioners the necessary resources, guidance, and training to adequately reduce the risk of inducement and other potentially harmful influences in cases of ID (Canadian Association for Community Living, 2016). Similar complexities arise in the Do-Not-Attempt-Resuscitation (Wagemans, et al., 2016) and end-of-life for terminally-ill children decision-making processes (Zaal-Schuller, et al., 2016). Tensions between parents and practitioners can arise in the process, particularly if there have been previous negative interactions (Zaal-Schuller, et al., 2016). Efforts are needed to better facilitate communication between practitioners and caregivers during end-of-life decision-making to ensure the needs of individuals with ID are fully met.

Oral Health

Studies have shown that people with ID are more likely to have poor oral hygiene, periodontal disease and dental caries than the general population (Anders & Davis, 2010) (Nathan, et al., 2018) which "can have a catastrophic impact on their survival and ability to thrive" (Canadian Dental Association, 2010). This includes a higher proportion of filled teeth, extracted teeth, less preventive care and an increased prevalence of traumatic dental injuries (Gallagher & Fiske, 2007; Anders & Davis, 2010; Waldman et al., 2001, Pezzementi & Fisher, 2005). Good oral health is an important component of general health. It has been reported that dental caries, gingivitis, and periodontal disease are among the top ten secondary conditions in persons with ID that cause limitations in their daily activities (Owens et al., 2006). According to the Ontario Ministry of Health, additional problems arising from dental caries can include "infection, pain, abscesses, chewing problems, poor nutritional status and gastrointestinal disorders" (Ontario Minstry of Health and Long-Term Care, 2012).

The presence of physical, behavioral, and cognitive limitations makes it challenging for people with ID to perform daily oral care (Glassman and Miller, 2003). Medications frequently complicate these challenges by further affecting their mouth with xerostomia (dry mouth). The anterior teeth are often the only ones cleaned, placing the posterior oropharyngeal area at risk of infection (Glassman and Miller, 2006). Individuals with ID may require assistance or support to maintain their oral health which is largely dependent on the knowledge, attitudes, and practices of their family or care providers. If there is a lack of support, the individuals' oral health will suffer (Cumella et al., 2000). Inadequate access to dental care, particularly preventive dental treatment, is also a factor in poor oral health outcomes for individuals with ID. Research suggests that low levels of experience amongst practitioners and inadequate access to information for caregivers are key barriers to access (Ummer-Christian, et al., 2018). Poverty is another factor (Anders & Davis, 2010), given the high cost of dental care. While many of BC's ID clients receive dental benefits through various BC Ministries, it is limited to basic coverage and basic funds.

Anxiety during procedures is a common issue for individuals with ID, particularly for females (Wilson, et al., 2018). Individuals with ID who exhibit uncooperative behaviour during dental and dental hygiene visits may require behavioural modifying medications or IV sedation (Gallagher & Fiske, 2007). Many adults with ID cannot receive any dental treatment, including dental hygiene, unless they are under general anesthesia (GA) (Miyawaki, et al., 2004). Procedures involving GA are often riskier for individuals with ID, who may not be able to adequately respond if complications arise and are at risk for delayed emergence times (Higuchi, et al., 2017). Some oral health professionals are not comfortable or trained to serve clients with special needs (Waldman et al., 2004) (Dao et al., 2005) making specialized services a necessity, particularly in complex cases. Therefore, a specialized dental GA unit at a sophisticated surgical hospital that can handle both medically complex (and less complicated) special needs patients regularly and efficiently could reduce the burden on mainstream services. In addition, by funding anesthesia fees for dental treatment in GA clinics around the province, adults with ID who are not medically complex, and who meet specific health and age criteria, could receive dental treatment outside of hospital, further reducing the burden on existing services.

In order to address current health inequities, it is recommended that BC develop a written standard of care for maintaining good oral health for all individuals with ID. Further, an oral health care plan for each adult should ideally be created and reviewed annually by a practitioner who is familiar with the needs of individuals with ID, such as Dental Health Services for Community Living (DHSCL) dental hygienist and/or dentist. An oral health care plan is especially needed for those persons who cannot speak and explain that they are suffering with dental pain. Adults who cannot verbally communicate should be the first target group for this initiative, as they can be in severe pain but not be able to communicate their discomfort.

The 2006 *"Dental Health Evidence Review"* prepared for the Population and Public Health Division of the BC Ministry of Health recommended research into the oral health care needs of adults with intellectual and other developmental disabilities. The 2014 Update to the 2006 *"Dental Health Evidence Review"* noted that no research had been completed on this issue and again recommended that research be done. To date, no such research has been undertaken by the Ministry of Health. It is essential that BC conduct research to understand the current oral health status of adults with ID and to identify best practices to ensure optimal oral health for the population.

Relevant Legislative Framework

- **Community Living Authority Act (2004)** – regulates the provision of government services to individuals with developmental disabilities.
- **Public Health Act (2009)** - provides the minister, public health officials, regional health authorities, local governments, and others with important tools to deal with current and emerging public health challenges.
- **Community Care and Assisted Living Act (2004)** - provides licensing for community care facilities that offer care to vulnerable people including child day care, and youth and adult residential facilities. Further, it provides a registration process for assisted living residences that cater to seniors and persons with disabilities.
- **UN Convention on the Rights of Persons with Disabilities (2006)** – international agreement to which Canada is a signatory. Encourages governments to uphold the rights of individuals with disability. Article 25 of the Convention outlines that "persons with disabilities have the right to:
    - the same range, quality, and standard of free or affordable health care as provided to other persons
    - health services that are specific to their disabilities, including early identification and intervention as appropriate, and services designed to minimize and prevent further disabilities
    - health services as close as possible to people's own communities, including in rural areas
    - care of the same quality, including on the basis of free and informed consent by raising awareness of the human rights, dignity, autonomy, and needs of persons with disabilities through training and the promulgation of ethical standards for public and private healthcare
    - the provision of health insurance, and life insurance where such insurance is permitted by national law, which shall be provided in a fair and reasonable manner"

SPECIALIZED PUBLIC SERVICE OPPORTUNITIES FOR PEOPLE WITH ID

Navigator Program

Offered to youth between the ages of 16 – 24 in certain regions, consists of pairing with a 'navigator' who designs support teams to help individuals transition into adulthood. Participants must be eligible for Community Living BC after they turn 19.

Advocate for Service Quality

Assists individuals with ID to understand and find support through:

- The B.C. Government
- Community Living BC (CLBC)
- Health Authorities
- Community agencies, for example, the Family Support Institute

Developmental Disabilities Mental Health Services

Offers specialized mental health services to individuals with ID including psychiatric and behavioural assessment, diagnosis, psychiatric treatment, clinical counselling, speech/language assessment, music or art therapy, and other therapies to deal with behavioural disorders. Delivers one-to-one support at home or in hospital for people in crisis, case management, educational, training, and consultative services, and works in collaboration with existing community resources and support networks. Services are divided by five regions: Fraser, Interior, Northern, Vancouver Coastal and Vancouver Island.

Community Living BC (CLBC)

Funds support and services for adults with ID and their families. CLBC funded support can include:

- Helping to find housing options that encourage independence while meeting an individuals' unique needs
- Family support
- Connections with community services to support individuals, families or caregivers
- Community inclusion support that focus on employment, social and life skills

CLBC Provincial Assessment Centers - mandated to provide multi-disciplinary mental health services for referred individuals ages 14 and up with a developmental disability and a concurrent mental illness, or behaviour issue. PAC is a part of Community Living British Columbia (CLBC) and is designated as a tertiary care mental health service under the Mental Health Act.

I Can Be Safe Online – website with resources for individuals with ID and their parents/caregivers with information about how to protect themselves online.

Health Services for Community Living (HSCL)

Provides support to adults with ID, there families and their caregivers. Areas of assistance include:

- Facilitating access to a range of community health services including physiotherapy, occupational therapy, nursing, nutrition and dental hygiene
- Training and supporting family members and caregivers
- Providing referrals to health care providers
- Advocating for specialist care
- Implementing care plans for specific health concerns

SERVICE FRAMEWORK

Key Priorities

- Improve overall health and wellbeing of individuals with intellectual disabilities (ID) in BC
- Enhance the effectiveness of health care services for individuals with ID
- Eliminate health disparities compared to general population
- Engage community-based stakeholders to effect positive change
- Raise support and awareness of the importance of the health and wellbeing of individuals with ID
- Improve the quality and quantity of health-related resources to increase effectiveness of all stakeholders
- Position BC as a global leader in ID health research and services

Core Measure: Establish Government Focal Point for ID Health

- Finalize and implement the remaining framework interventions (5 pillars)
- Coordinate resources between public sector, academia and NGOs to ensure efficiency
- Collaborate and maintain contact with national organizations, such as the National Association for Dual Diagnosis, to avoid duplication of efforts and facilitate the flow of information with provincial counterparts
- Implement and coordinate pilot projects to inform best practices and foster an innovative service network
- Provide policymakers with advice and guidance on the needs of individuals with ID, and advocate for the rights of individuals with ID within the BC government

5 Pillars

1. Enhance existing services capacity

- Promote interdisciplinary cooperation and case management coordination within BC health services
- Development and ongoing maintenance of web platform hosting training courses and additional educational content for health care practitioners
- Increase responsiveness to issues affecting women with ID, particularly sexual or domestic violence
- Create staff reference manuals for ID and make them available to practitioners
- Create telephone and email links between specialized services for ID and other practitioners
- Develop health service guidelines for practitioners working with people with ID
- Encourage specialist staff to share knowledge with other practitioners
- Initiate support mechanisms for staff exposed to aggressive behaviour

2. Raise awareness of the specialized health needs of people with ID

- Development and ongoing maintenance of a centralized web platform hosting resources and educational content for parents/caregivers, educators, program facilitators, coaches, health professionals, and individuals with intellectual disabilities
- Promote the inclusion of people with intellectual disabilities in public service announcements, outreach activities and commercials concerning health promotion
- Establish award regime for individuals with ID who have taken a leadership role in health promotion activities in their communities
- Ensure access to information on existing services and proper methods of care are provided to new parents of children with ID at an early stage
- Advocate for specialist training to be included in existing medical training programs and create practical learning opportunities for medical students

3. Promote health and lifestyle programs that reduce the burden on healthcare systems

- Promote annual health screenings for people with ID
- Encourage individuals with ID to at least meet minimum daily activity levels
- Promote and encourage balanced and nutritional diets
- Encourage and facilitate vaccination programs for people with ID
- Support regional NGOs and other community organizations who offer services that promote healthy lifestyles for people with intellectual disabilities
- Establish a training program for identified individuals with ID who are passionate about health issues to increase their capacity to conduct health promotion activities in their communities
- Encourage parents/caregivers and home-care providers to support daily physical activity and healthy eating for those with intellectual disabilities living with them
- Advocate for the inclusion of specialized training in sports-focused post-secondary education programs, such as recreation and kinesiology
- Require publicly funded group homes to develop and implement nutritional meal plans

4. Increase data collection, research and dissemination

- Establish focal point to collect data under own accord with necessary resources to conduct research, convene experts, promote awareness amongst practitioners and caregivers
- Support academic research projects at existing higher-learning institutions
- Include questions specifically on ID in regional health surveys
- Develop and encourage family/patient managed care chart to facilitate flow of information between services
- Provide focal point for practitioners to raise concerns about current standards and strategies
- Link and enhance multiple administrative databases in an attempt to better understand health trends.

5. Structural reform

- Require all strategic plans, action plans, policies and programs concerning health care in British Columbia to actively consider the needs of people with intellectual disability
- Review existing strategic plans, action plans, protocols and care models in light of their suitability for serving individuals with ID
- Develop incentive regime to encourage practitioners to cater services to people with intellectual disabilities
- Incentivize primary health providers to uptake comprehensive health examinations to individuals with ID annually
- Add billing premiums for more complex care cases or related visits in which a normal time allotment would be unsuitable
- Shift rates paid under the Persons with Disability (PWD) plan from percentage to needs based
- Establish a specialized service plan for mental health for people with ID under the age of 14
- Establish a specialized service plan for sexual health for people with ID
- Develop action plan to reduce barriers to youth transitioning to adult services
- Develop practical guidelines and policies concerning people with ID and the Medical Aid in Dying Bill
- Establish mechanism for developing personalized care plans for individuals with ID
- Re-introduce the ability for an individual with ID to be guided by a case manager
- Develop standard of care for maintaining oral health for individuals with ID
- Fund anesthesia fees for dental treatment in GA clinics for people with ID
- Identify opportunities for needs-based personalized care where appropriate

REFERENCES

Accreditation Canada. (2016). Developmental Disabilities: A Draft for National Consultation.

Accreditation Canada. (2018). Developmental Disabilities. Retrieved from https://store.accreditation.ca/products/developmental-disabilities

ACI Intellectual Disability Health Network. (2015). Context Report and Toolkit for Health Services for People with Intellectual Disability. Sydney: Agency for Clinical Innovation.

Anders PL, Davis EL. (2010) Oral health of patients with intellectual disabilities: A systematic review. Special Care Dentistry, 30(3), 110-117.

Anderson, W. L., Wiener, J. M., Khatutsky, G., & Armour, B. S. (2013). Obesity and people with disabilities: The implications for health care expenditures. Obesity, 21(12), 798-804. Retrieved August 21, 2018.

American Association of Intellectual and Developmental Disabilities. (2013). Definition of Intellectual Disability. Retrieved from AAIDD: http://aaidd.org/intellectual-disability/definition#.WCe1mvkrKM8.

Balogh, R., & Ouellette-Kuntz, H. (2005). Hospital utilization among persons with an intellectual disability, Ontario, Canada, 1995–2001. Journal of Applied Research in Intellectual Disabilities.Special Issue: Health Inequalities and People with Intellectual Disabilities, 181-190.

Balogh, R., Lake, J., Lin, E., Wilton, A., & Lunsky, Y. (2014). Disparities in diabetes prevalence and preventable hospitalizations in people with intellectual and developmental disability: a population-based study. Diabetic Medicine.

Balogh, R., Ouellette-Kuntz, H., Brownell, M., & Colantonio, A. (2011). Ambulatory Care Sensitive Conditions in Persons with an Intellectual Disability – Development of a Consensus. Journal of Applied Research in Intellectual Disabilities, 150-158.

Balogh, R., Ouellette-Kuntz, H., Brownell, M., & Colantonio, A. (2013). Factors associated with hospitalisations for ambulatory care-sensitive conditions among persons with an intellectual disability – a publicly insured population perspective. Journal of Intellectual Disability Research, 2026-2039.

Balogh, R., Brownell, M., Ouellette-Kuntz, H., & Colantonio, A. (2010). Hospitalisation rates for ambulatory care sensitive conditions for persons with and without an intellectual disability - a population perspective. Journal of Intellectual Disability Research, 820-832.

BC Ministry of Health, Premier. (2018, May 24). B.C. government’s primary health-care strategy focuses on faster, team-based care [Press release]. Retrieved August 6, 2018, from https://news.gov.bc.ca/releases/2018PREM0034-001010

Benson, B., & Brooks, W. (2008). Aggressive challenging behavior and intellectual disability. Current Opinion in Psychiatry, 454-458.

Bjelogrlic-Laakso, N., & Salokivi, T. (2017). Age at Death in Individuals with Intellectual Disabilities. Journal of Applied Research in Intellectual Disabiities, 30(4), 782-785. Retrieved August 20, 2018.

Bradley, E., & Cheetham, T. (2010). The use of psychotropic medication for the management of problem behaviours in adults with intellectual disabilities living in Canada. Advances in Mental Health and Intellectual Disablitilies, 12-26.

Brennan, D., Murphy, R., Mccallion, P., & Mccarron, M. (2017). “Whats going to happen when were gone?” Family caregiving capacity for older people with an intellectual disability in Ireland. Journal of Applied Research in Intellectual Disabilities, 31(2), 226-235. Retrieved September 23, 2018.

Brown, H. K., Plourde, N., Ouellette-Kuntz, H., Vigod, S., & Cobigo, V. (2015). Brief report: Cervical cancer screening in women with intellectual and developmental disabilities who have had a pregnancy. Journal of Intellectual Disability Research, 60(1), 22-27. doi:10.1111/jir.12225

Burge, P., Oullette-Kunz, H., Isaacs, B., & Lunsky, Y. (2008). Medical students’ views on training in intellectual disabilities. Canadian Family Physician, 568-571.

Canada, BC Green Caucus and the BC New Democrat Caucus, Premier. (2017). 2017 Confidence and Supply Agreement between the BC Green Caucus and the BC New Democrat Caucus. Victoria, BC.

Canadian Association for Community Living. (2016, 06 22). Essential Next Steps in Medical Aid in Dying – Vigilance, Safeguards & Obligation. Retrieved from Press Release: http://www.cacl.ca/news-stories/blog/press-release-essential-next-steps-medical-aid-dying-%E2%80%93-vigilance-safeguards-obliga

Canadian Dental Association. (2010). Position Paper on Access to Oral Health Care for Canadians. Ottawa: Web.

Centre for Addiction and Mental Health. (2018). HCARDD Home. Retrieved October 3, 2018, from https://www.porticonetwork.ca/web/hcardd/home

Cobigo, V., Ouellette-Kuntz, H., Balogh, R., Leung, F., Lin, E., & Lunsky, Y. (2013). Are cervical and breast cancer screening programmes equitable? The case of women with intellectual and developmental disabilities. Journal of Intellectual Disability Research, 57(5), 478-488. Retrieved October 3, 2018.

Coppus, A. (2013). People with Intellectual Disability: What do we know about adulthood and life expectancy? Developmental Disabilities Research Reviews, 6-16.

Center for Disease Control. (2016). Physical Activity and Health. Retrieved from The Benefits of Physical Activity: https://www.cdc.gov/physicalactivity/basics/pa-health/

Chapman, S., & Wu, L.-T. (2012). Substance Abuse among Individuals with Intellectual Disabilities. Research in Developmental Disabilities, 1147-1156.

Cheetham, E. (2010). The use of psychotropic medication for the management of problem behaviours in adults with intellectual disabilities living in Canada. Advances in Mental Health and Intellectual Disabilities, 12-26.

Clapton, N., Williams, J., & Jones, R. (2017). The role of shame in the development and maintenance of psychological distress in adults with intellectual disabilities: A narrative review and synthesis. Journal of Applied Research in Intellectual Disabiities, 31(3), 343-359. Retrieved August 20, 2018.

Community Living BC. (2018). I Can Be Safe Online. Retrieved October 3, 2018, from https://www.communitylivingbc.ca/resources/i-can-be-safe-online/

Cooper, S. A., McLean, G., Guthrie, B., McConnachie, A., Mercer, S., & Sullivan, F. (2015). Multiple physical and mental health comorbidity in adults with intellectual disabilities: population-based cross-sectional analysis. Institute of Health and Wellbieng - University of Glasgow.

Crocker, A., Mercier, C., Lachappelle, Y., Brunet, A., Morin, D., & Roy, M. (2006). Prevalence and types of aggressive behaviour among adults with intellectual disabilities. Journal of Intellectual Disability Research, 552-661.

Crocker, A., Prokic, A., Morin, D., & Reyes, A. (2014). Intellectual disability and co-occurring mental health and physical disorders in aggressive behaviour. Journal of Intellectual Disability Research, 1032-1044.

Cumella, S., Ransford, N., Lyons, J., & Burnham, H. (2000). Needs for oral care among people with intellectual disability not in contact with Community Dental Services. Journal of Intellectual Disability Research, 44, 45–52.

Dao, L. P., Zwetchkenbaum, S., & Inglehart, M. R. (2005). General dentists and special needs patients: Does dental education matter? Journal of Dental Education, 69(10), 1107–1115.

Dawson, F., Shanahan, S., Fitzsimons, E., O'Malley, G., Mac Giollabhui, N., & Bramham, J. (553-563). The impact of caring for an adult with intellectual disability and psychiatric comorbidity on carer stress and psychological distress. Journal of Intellectual Disability Research, 2016.

Day, K., & Jancar, J. (1994). Mental and physical health and aging in mental handicap: a review. Journal of Intellectual Disability Research, 241-256.

Day, C., Lampraki, A., Ridings, D., & Currell, K. (2016). Intellectual disability and substance use/misuse: a narrative review. Journal of Intellectual Disabilities and Offending Behaviour, 25-34.

De Kujiper, G., Van der Putten, A. (2017). Knowledge and expectations of direct support professionals towards effects of psychotropic drug use in people with intellectual disabilities. Journal of Applied Research in Intellectual Disabilities, 30(51), 1-9. Retrieved August 23, 2018.

Degenhardt, L. (2000). "Interventions for people with alcohol use disorders and an intellectual disability: a review of the literature. Journal of Intellectual and Developmental Disability, 135-146.

Department of Health and Human Services. (2002). Closing the Gap: A National Blueprint to Improve the Health of Persons with Mental Retardation: Report of the Surgeon General's Conference on Health Disparities and Mental Retardation. Rockville: Office of the Surgeon General.

Dieckmann, F., Giovis, C., & Offergeld, J. (2015). The Life Expectancy of People with Intellectual Disabilities in Germany . Journal of Applied Research in Intellectual Disabilities, 373-382.

Donenberg, G., Emerson, E., Brown, L., Houck, L., & Mackesy-Airdti, M. (2012). Sexual experience among emotionally and behaviorally disordered students in therapeutic day schools: An ecological examination of adolescent risk. Journal of Pédiatrie Psychology, 1-10.

Draheim, C., Williams, D., & McCubbin, J. (2002). Prevalence of Physical Inactivity and Recommended Physical Activity in Community-Based Adults With Mental Retardation. Mental Retardation, 436-444.

Dukes, E., & McGuire, B. (2009). Enhancing capacity to make sexuality-related decisions in people with an intellectual disability. Journal of Intellectual Disability Research, 727-734.

Eady, N., Courtenay, K., & Strydom, A. (2015). Pharmacological Management of Behavioral and Psychiatric Symptoms in Older Adults with Intellectual Disability. Drugs & Ageing, 95-102.

Einarsson, I. Þ, Jóhannsson, E., Daly, D., & Arngrímsson, S. Á. (2016). Physical activity during school and after school among youth with and without intellectual disability. Research in Developmental Disabilities, 56, 60-70. Retrieved August 21, 2018.

Eisenbaum, E. (2018). Tobacco product use and smoking frequency among US adults with intellectual and developmental disabilities. Journal of Intellectual Disability Research, 62(8), 709-718. Retrieved August 22, 2018.

Emerson, E., & Hatton, C. (2007). Mental health of children and adolescents with intellectual disabilities in Britain. British Journal of Psychiatry, 493-499.

Emerson, E., Robertson, J., Baines, S., & Hatton, C. (2016). Predictors of self-reported alcohol use and attitudes toward alcohol among 11-year-old British children with and without intellectual disability. Journal of Intellectual Disability Research, 1212-1226.

Emerson, E. (2016). The physical health of British adults with intellectual disability: cross sectional study . International Journal for Equity in Health.

Felce, D., Cohen, D., Willner, P., Rose, J., Kroese, B., Rose, N., . . . Hood, K. (2015). Cognitive behavioural anger management intervention for people with intellectual disabilities: costs of intervention and impact on health and social care and resource use. Journal of Intellectual Disability Research, 68-81.

Friedrich Dieckmann, J. O. (2015). The Life Expectancy of People with Intellectual Disabilities in Germany. Journal of Applied Research in Intellectual Disabilities , 373-382.

Fujira, G., Li, H., & Magana, S. (2018). Health Services Use and Costs for Americans With Intellectual and Developmental Disabilities: A National Analysis. Intellectual and Developmental Disabilities, 56(2), 101-118. Retrieved August 23, 2018.

Gallagher, J., & Fiske, J. (2007). Special care dentistry: A professional challenge. British Dental Journal, 202, 619–629.

Gardiner, E., & Iarocci, G. (2018). Examining Family Quality of Life Within the Context of a Participant-Directed ASD Funding Program in British Columbia, Canada. Journal of Policy and Practice in Intellectual Disabilities, 15(2), 110-123. Retrieved August 22, 2018.

Gil-Llario, M., Morell-Mengual, V., Ballester-Arnal, R., & Díaz-Rodríguez, L. (2017). The experience of sexuality in adults with intellectual disability. Journal of Intellectual Disability Research, 62(1), 72-80. Retrieved August 21, 2018.

Glassman, P., & Miller, C. (2003). Dental disease prevention and people with special needs. Journal of the California Dental Association, 31(2), 149–160.

Glassman, P., & Miller, C. E. (2006). Effect of preventive dentistry training program for caregivers in community facilities on caregiver and client behavior and client oral hygiene. New York State Dental Journal, 72(2), 38–46.

Glover, G., Williams, R., Heslop, P., Oyinloya, J., & Grey, J. (2016). Mortality in people with intellectual disabilities in England. Journal of Intellectual Disability Research, 61(1), 62-74. Retrieved August 20, 2018.

Grey, J. M., Totsika, V., & Hastings, R. P. (2017). Physical and psychological health of family carers co-residing with an adult relative with an intellectual disability. Journal of Applied Research in Intellectual Disabilities, 31, 191-202. Retrieved September 23, 2018.

Hackett, S., Phillips, J., Masson, H., & Balfe, M. (2013). Individual, Family and Abuse Characteristics of 700 British Child and Adolescent Sexual Abusers. Child Abuse Review, 22(4), 232-245. Retrieved August 21, 2018.

Hamdani, Y., & Lunsky, Y. (2016). Health and Health Service Use of Youth and Young Adults with Intellectual and Developmental Disabilities. Current Developmental Disorders Reports, 97-103.

Hartley, S., & MacLean, W. (2009). Depression in Adults With Mild Intellectual Disability: Role of Stress, Attributions, and Coping. American Journal on Intellectual and Developmental Disabilities, 147-160.

Hartman, E., Smith, J., Westendorp, M., & Visscher, C. (2015). Development of physical fitness in children with intellectual disabilities. Journal of Intellectual Disability Research, 439-449.

HCARDD. (n.d.). Prevalence of adult Ontarians with developmental disabilities higher than expected (Issue brief No. Snapshot). Retrieved August 20, 2018, from https://www.porticonetwork.ca/documents/38160/99698/Snapshot 2/d6ba814d-9ec0-406b-9f59-d7402543000e

Hemm, C., Dagnan, D., & Meyer, T. (2015). Identifying Training Needs for Mainstream Healthcare Professionals, to Prepare Them for Working with Individuals with Intellectual Disabilities: A Systematic Review. Journal of Applied Research in Intellectual Disabilities, 98-110.

Health, M. o. (2015). Rural Health Services in BC: A Policy Framework to Provide a System of Quality Care. Victoria: Cross Sector Policy Discussion Paper.

Health, B. M. (2014). Setting Priorities for the BC Health Care System. Victoria.

Health, D. o. (2001). Valuing People: A New Strategy for Learning Disability for the 21st Century. A White Paper. London: Her Majesty’s Stationary Office.

Health, N. (2012). Service Framework to Improve the Health Care of People with Intellectual Disability. Sydney: Inter Government and Funding Strategies & Integrated Care.

Healy, B., McGuire, D., Evans, S., & Carley, S. (2009). Sexuality and personal relationships for people with an intellectual disability. Part I: service-user perspectives. Journal of Intellectual Disability Research, 905-912.

Hemm, C., Dagnan, D., & Meyer, T. (2015). Identifying Training Needs for Mainstream Healthcare Professionals, to Prepare Them for Working with Individuals with Intellectual Disabilities: A Systematic Review. Journal of Applied Research in Intellectual Disabilities, 98-110.

Hennan, B. (2011). Preventive Care Checklist Male and Female. Retrieved October 3, 2018, from http://ddprimarycare.surreyplace.ca/tools-2/general-health/preventive-care-checklist/

Hensel, J., Lunsky, Y., & Dewa, C. (2014). Staff Perception of Aggressive Behaviour in Community Services for Adults with Intellectual Disabilities. Community Mental Health Journal, 743-751.

Hensel, J., Lunsky, Y., & Dewa, S. (2013). The mediating effect of severity of client aggression on burnout between hospital inpatient and community residential staff who support adults with intellectual disabilities. Journal of Clinical Nursing, 1332–1341.

Higuchi, H., Maeda, S., Ishii-Maruhama, M., Honda-Wakasugi, Y., Yabuki-Kawase, A., & Miyawaki, T. (2017). Intellectual disability is a risk factor for delayed emergence from total intravenous anaesthesia. Journal of Intellectual Disability Research, 62(3), 217-224.

Hinckson, E., & Curtis, A. (2013). Measuring Physical Activity of Children and Youth with Intellectual Disabilities: a systematic review. Research in Developmental Disabilities, 72-86.

Horgan, J. (2018, February 6). Ministry of Health 2018/19 – 2020/21 Service Plan (Canada, BC Ministry of Health, Premier). Retrieved August 6, 2018, from http://bcbudget.gov.bc.ca/2018/sp/pdf/ministry/hlth.pdf

Howie, E., Barnes, T., McDermott, S., Mann, J., Clarkson, J., & Meriwether, R. (2012). Availability of Physical Activity Resources in the Environment for Adults with Intellectual Disabilities. Disability and Health Journal, 41-48.

Hronis, A., Roberts, L., & Kneebone, I. (2018). Assessing the Confidence of Australian Mental Health Practitioners in Delivering Therapy to People With Intellectual Disability. Intellectual and Developmental Disabilities, 56(3), 202-211. Retrieved August 20, 2018.

Huxley, A., Day, E., & Copollo, A. (2006). Substance misuse and the need for integrated services. Learning Disability Practice, 14-17.

Inter Government and Funding Strategies & Integrated Care. (2012). Service Framework to Improve the Healthcare of People with Intellectual Disability. Sydney: NSW Ministry of Health.

Janicki, M., Dalton, A., & Henderson, C. (1999). Mortality and morbidity among older adults with intellectual disability: health services consideration. Disability Rehabilitation, 284-294.

Janssen, I., & LeBlanc, A. (2010). Systematic review of the health benefits of physical activity and fitness in school-aged children and youth. International Journal of Behavioral Nutrition and Physical Activity.

Jones, J., Ouellette-Kuntz, H., Vilela, T., & Brown, H. (2008). Attitudes of Community Developmental Services Agency Staff Toward Issues of Inclusion for Individuals With Intellectual Disabilities. Journal of Policy and Practice in Intellectual Disabilities , 219-226.

Jones, J., McQueen, M., Lowe, S., Minnes, P., & Rischke, A. (2015). Interprofessional Education in Canada:Addressing Knowledge, Skills, and Attitudes Concerning Intellectual Disability for Future Healthcare Professionals. Journal of Policy and Practice in Intellectual Disabilities, 172-180.

Kaminer, Y., Feinstein, C., & Barrett, R. (1987). Suicidal behavior in mentally retarded adolescents: An overlooked problem. Child Psychiatry and Human Development, 18(1), 90-94. Retrieved August 20, 2018.

Kelly, C., Thomson, K., Wagner, A., Waters, J., Jones, S., Holland, A., & Redley, M. (2015). Investigating the widely held belief that men and women with learning disabilities receive poor quality healthcare when admitted to hospital: a single-site study of 30-day readmission rates. Journal of Intellectual Disability Research, 835-834.

Koritsas, S., & Iacono, T. (2016). Weight, nutrition, food choice, and physical activity in adults with intellectual disability. Journal of Intellectual Disability Research, 355-364.

Kuijper, G. M., & Hoekstra, P. J. (2017). Physicians reasons not to discontinue long-term used off-label antipsychotic drugs in people with intellectual disability. Journal of Intellectual Disability Research, 61(10), 899-908. Retrieved September 4, 2018.

Kuijper, G. M., & Hoekstra, P. J. (2018). An Open-Label Discontinuation Trial of Long-Term, Off-Label Antipsychotic Medication in People With Intellectual Disability: Determinants of Success and Failure. The Journal of Clinical Pharmacology. Retrieved September 4, 2018.

Kuskelly, M., & Bryde, R. (2004). Attitudes towards the sexuality of adults with an intellectual disability: parents, support staff, and a community sample. Journal of Intellectual and Developmental Disability, 255-264.

Larsen, F. K. (2008). The ageing population with Down syndrome in Norway, 1969–2045. Journal of Intellectual Disability Research, 644-656.

Lecavalier, L., Snow, A., & Norris, M. (2011). Autism spectrum disorders and intellectual disability. International Handbook of Autism and Pervasive Developmental Disorders, 37-51.

Lepler, S. (1993). Implementation of an interdisciplinary psychotropic drug review process for community-based facilities. Mental Retardation, 307-315.

Levy, H., & Packman, W. (2004). Sexual abuse prevention for individuals with mental retardation: considerations for genetic counseling. Journal of Genetic Counseling, 185-205.

Li, H., Fujiura, G., Magana, S., & Parish, S. (2018). Health care expenditures of overweight and obese U.S. adults with intellectual and developmental disabilities. Research in Developmental Disabilities, 75, 1-10. Retrieved August 21, 2018.

Lin, E., Balogh, R., Barry, I., Oullette-Kuntz, H., Selick, A., Wilton, A., . . . Lunsky, Y. (2014). Strengths and Limitations of Health and Disability Support Administrative Databases for Population-Based Health Research in Intellectual and Developmental Disabilities. Journal of Policy and Practice in Intellectual Disabilities, 235-244.

Lin, E., Balogh, R., McGarry, C., Selick, A., Dobranowski, K., Wilton, A., & Lunsky, Y. (2016A). Substance-related and addictive disorders among adults with intellectual and developmental disabilities (IDD): an Ontario population cohort study. MBJ Open.

Lin, E., Balogh, R., Selick, A., Wilson, A., & Lunsky, Y. (2016B). Adults with Developmental Disabilities Plus a Mental Illness or Addiction (DD-Plus). Healthcare Quarterly. Retrieved October 3, 2018.

Lloyd, M., Temple, V., & Foley, J. (2012). International BMI Comparison of Children and Youth with Intellectual Disabilities Participating in the Special Olympics. Research in Developmental Disabilities, 1708-1714.

Lunksy, Y., Balogh, R., Khodaverdian, A., Elliot, D., Jaskulski, C., & Morris, S. (2012A). A Comparison of Medical and Psychobehavioral Emergency Department Visits Made by Adults with Intellectual Disabilities. Emergency Medicine International, 1-6.

Lunsky, Y., Balogh, R., Durbin, A., Selick, A., Volpe, T., & Lin, E. (2018). The Mental Health of Adults with Developmental Disabilities in Ontario: Lessons from Administrative Health Data. Healthcare Quarterly, 21(1), 6-9. Retrieved October 3, 2018.

Lunsky, Y., Garcin, N., Morin, D., Cobigo, V., & Bradley, E. (2007). Mental Health Services for Individuals with Intellectual Disabilities in Canada: Findings from a National Survey. Journal of Applied Research in Intellectual Disabilities, 439-447.

Lunsky, Y., Hensel, J., & Dewa, C. (2013A). The mediating effect of severity of client aggression on burnout between hospital inpatient and community residential staff who support adults with intellectual disabilities. Journal of Clinical Nursing, 1332–1341.

Lunsky, Y., Klein-Geltink, J. E., & Yates, E. A. (2013). Atlas on the Primary Care of Adults with Developmental Disabilities in Ontario. Centre for Addiction and Mental Health. Retrieved October 3, 2018.

Lunsky, Y., Lee, J., Perry, A., & Lake, J. (2016). Improving Emergency Care for adults with Developmental Disabilities: A Toolkit for Providers (Publication). Retrieved October 3, 2018, from H-CARDD website: https://www.porticonetwork.ca/documents/38160/99698/Emergency Dept Toolkit FINAL.pdf/aeb7ef45-2ff1-4121-bdab-3abb817e3e6d

Lunsky, Y., Lin, E., Balogh, R., Klein-Geltink, J., Wilton, A. S., & Kurdyak, P. (2012B). Emergency Department Visits and Use of Outpatient Physician Services by Adults with Developmental Disability and Psychiatric Disorder. The Canadian Journal of Psychiatry, 57(10), 601-607. Retrieved October 3, 2018.

Mahoney, A., & Poling, A. (2011). Sexual abuse prevention for people with severe developmental disabilities. Journal of Developmental and Phyisical Disabilities, 369-376.

Malovic, A., Rossiter, R., & Murphy, G. (2018). Keep Safe: The development of a manualised group CBT intervention for adolescents with ID who display harmful sexual behaviours. Journal of Intellectual Disabilities and Offending Behaviour, 9(1), 49-58. Retrieved August 21, 2018.

Martin, L., Ouellette-Kuntz, H., & Mckenzie, K. (2017). Care in the Community: Home Care Use Among Adults With Intellectual and Developmental Disabilities Over Time. Journal of Policy and Practice in Intellectual Disabilities, 14(3), 251-254. Retrieved August 27, 2018.

Martin, L., Ouellette-Kuntz, H., & McKenzie, K. (2017). The Power of Population Health Data on Aging and Intellectual and Developmental Disabilities: Reactions of Knowledge Users. Journal of Policy and Practice in Intellectual Disabilities, 14(4), 268-278. Retrieved August 23, 2018.

Martinello, E. (2015). Reviewing Risks Factors of Individuals with Intellectual Disabilities as Perpetrators of Sexually Abusive Behaviors. Sex & Disability, 269-278.

Martınez-Zaragoza, F., Campillo-Martınez, M., & Ato-Garcıa, M. (2016). Effects on Physical Health of a Multicomponent Programme for Overweight and Obesity for Adults with Intellectual Disabilities. Journal of Applied Research in Intellectual Disabilities, 250-265.

Martin-Storey, A., Nachshen, J., Campisi, L., Stack, D., Schwartzman, A., & Serbin, L. (2009). Health and psychiatric disparities in children with cognitive and developmental delays: implications for health policy in Quebec. Journal of Applied Research in Intellectual Disabilities, 248-255.

Matson, J., & Neal, D. (2009). Psychotropic medication use for challenging behaviors in persons with intellectual disabilities: An overview. Research in Developmental Disabilities, 572-586.

McCann, E., Lee, R., & Brown, M. (2016). The experiences and support needs of people with intellectual disabilities who identify as LGBT: A review of the literature. Research in Developmental Disabilities, 57, 39-53. Retrieved August 21, 2018.

McGillicuddy, N. (2006). A Review of Substance Use Research Among those with Mental Retardation. Mental Retardation and Developmental Disabilities, 41-47.

McGuire, B., Daly, P., & Smyth, F. (2007). Lifestyle and Health Behaviours of Adults with an Intellectual Disability. Journal of Intellectual Disability Research, 497-510.

McLaughlin-Beltz, S., Medgyesi, J., Boynton, J., & Nestell, C. (2015). Polypharmacy in Individuals with Intellectual Disability. Journal of Psychology and Clinical Psychiatry.

McMaster University Health Sciences. (2018). Curriculum of Care. Retrieved from https://machealth.ca/programs/curriculum_of_caring/

Meaney-Tavares, R., & Gavidia-Payne, S. (2012). Staff characteristics and attitudes towards the sexuality of people with intellectual disability. Journal of Intellectual & Developmental Disability, 269-273.

Meijer, M., Carpenter, S., & Scholte, F. (2004). European manifesto on basic standards of health care for people with intellectual disabilities. Journal of Policy and Practice in Intellectual Disabilities, 10-15.

Melville, C. A., Mcgarty, A., Harris, L., Hughes-Mccormack, L., Baltzer, M., Mcarthur, L. A., . . . Cooper, S. (2017). A population-based, cross-sectional study of the prevalence and correlates of sedentary behaviour of adults with intellectual disabilities. Journal of Intellectual Disability Research, 62(1), 60-71. Retrieved August 21, 2018.

MENCAP. (2007, March). Death by Indifference - Following up on the Treat Me Right Report. Retrieved August 22, 2018, from https://www.mencap.org.uk/sites/default/files/2016-06/DBIreport.pdf

MENCAP. (2012). Death by indifference: 74 deaths and counting. Retrieved August 22, 2018, from https://www.mencap.org.uk/sites/default/files/2016-08/Death%20by%20Indifference%20-%2074%20deaths%20and%20counting.pdf

Ministry of Health. (2015). Enabling Effective, Quality Population and Patient-Centered Care: A Provincial Strategy for health Information Management and Technology. Victoria: Paper, Cross Sector Policy Discussion.

Miyawaki, T., Kohjitani, A., Maeda, S., Egusa, M., Mori, T., Higuchi, H., . . . Shimada, M. (2004). Intravenous sedation for dental patients with intellectual disability. Journal of Intellectual Disability Research, 48(8), 764-768. Retrieved September 24, 2018.

Modi, M., McMorris, C., Palucka, A., Raina, P., & Lunsky, Y. (2015). Predictors of Specialized Inpatient Admissions for Adults With Intellectual Disability. American Journal on Intellectual and Developmental Disabilities, 46-57.

Morgan, V., Leonard, H., Bourke, J., & Jablensky, A. (2008). Intellectual disability co-occurring with schizophrenia and other psychiatric illness: population-based study. British Journal of Psychiatry, 364-372.

Morin, D., Rivard, M., Cobigo, V., & Lepine, M. (2010). Intellectual Disabilities and Depression: How to Adapt Psychological Assessment and Intervention. Canadian Psychology, 185-93.

Moliner, C., Lorente, L., Molina, A., Gracia, E., & Martínez-Tur, V. (2017). Linking Staff Burnout to Family Members Satisfaction in Centers for People With Intellectual Disabilities: A Service Chain Approach. Intellectual and Developmental Disabilities, 55(6), 392-406. Retrieved September 18, 2018.

Murphy, G. O. (2005). Capacity of adults with intellectual disabilities to consent to sexual relationships. Phsychological Medicine, 1347-157.

Wilson, N. J., Lin, Z., Villarosa, A., & George, A. (2018). Oral health status and reported oral health problems in people with intellectual disability: A literature review. Journal of Intellectual & Developmental Disability, 1-13. Retrieved September 24, 2018.

Norman, C., & Sallafranque-St-Louis, F. (2016). Cybervictimization of Young People With an Intellectual or Developmental Disability: Risks Specific to Sexual Solicitation. Journal of Applied Research in Intellectual Disabilities, 99-110.

Ontario Minstry of Health and Long-Term Care. (2012). Oral Health - More Than Just Cavities: A Report by Ontarios' Chief Medical Officer of Health. Queen's Printer for Ontario.

Osugo, M., & Cooper, A. (2016). Interventions for adults with mild intellectual disabilities and mental ill-health: a systematic review. Journal of Intellectual Disability Research, 615-622.

Ouellette-Kuntz, H., Cobigo, V., Balogh, R., Wilton, A., & Lunsky, Y. (2015). The Uptake of Secondary Prevention by Adults with Intellectual and Developmental Disabilities. Journal of Applied Research in Intellectual Disabilities, 43-54.

Ouellette-Kuntz, H., & Martin, L. (2014). Applied Health Research Question Report: Aging profiles of adults with and without developmental disabilities in Ontario. Health Care Access Research and Developmental Disabilities (H-CARDD), September. Retrieved August 20, 2018.

Ouellette-Kuntz, H., Martin, L., & Mckenzie, K. (2017). The Risk of Re-Institutionalization: Examining Rates of Admission to Long-Term Care Among Adults with Intellectual and Developmental Disabilities Over Time. Journal of Policy and Practice in Intellectual Disabilities, 14(4), 293-297. Retrieved August 27, 2018.

Ouellette-Kuntz, H., Shooshtari, S., Balogh, R., & Martens, P. (2015). Understanding Information About Mortality Among People with Intellectual and Developmental Disabilities in Canada. Journal of Applied Research in Intellectual Disabilities, 423-435.

Owen, R., Bowers, A., Heller, T., Hsieh, K., & Gould, R. (2016). The Impact of Support Services Teams: Community-Based Behavioral Health Support Interventions. Journal of Policy and Practice in Intellectual Disabilities, 14(3), 205-213. Retrieved August 22, 2018.

Owens, P., Kerker, B., Zigler, E., & Horwitz, S. (2006). Vision and oral health needs of individuals with intellectual disability. Mental Retardation And Developmental Disabilities Research Reviews, 12, 28–40.

Peterson, J., Janz, K., & Lowe, J. (2008). Physical activity among adults with intellectual disabilities. Preventative Medicine, 1001-1006.

Pezzementi, M. L., & Fisher, M. A. (2005). Oral health status of people with intellectual disabilities in the southeastern United States. Journal of the American Dental Association, 136(7), 903–912.

Phillips, A., Morrison, J., & Davis, R. (2004). General practitioners' educational needs in intellectual disability health. Journal of Intellectual Disability Research, 142-149.

Preamble to the Constitution of the World Health Organization as adopted by the International Health Conference, New York, 19-22 June, 1946; signed on 22 July 1946 by the representatives of 61 States (Official Records of the World Health Organization, no. 2, p. 100) and entered into force on 7 April 1948.

Plourde, N., Ouellette-Kuntz, H., Vigod, S., & Cobigo, V. (2016). Brief report: cervical cancer screening in women with intellectual and developmental disabilities who have had a pregnancy. Journal of Intellectual Disability Research, 22-27.

Pruijssers, A., Meijel, B., Maaskant, M., Keeman, N., & van Achterberg, T. (2015). Quality of Diagnosis and Treatment Plans After Using the 'Diagnostic Guideline for Anxiety and Challenging Behaviours' in People with Intellectual Disabilities: A Comparative Multiple Case Study Design. Journal of Applied Research in Intellectual Disabilities, 305-316.

Queens University. (2016). Intellectual and Developmental Disabilities. Retrieved from Department of Family Medicine: https://familymedicine.queensu.ca/education/enhanced/developmental

Rimmer, J., & Yamaki, K. (2006). Obesity and Intellectual Disability. Mental Retardation and Developmental Disabilities, 22-27.

Rimmer, J., Yamaki, K., Lowry, B., Wang, E., & Vogel, L. (2010). Obesity and obesity-related secondary conditions in adolescents with intellectual/developmental disabilities. Journal of Intellectual Disability Research, 787-794.

Robertson, J., Emerson, E., Gregory, N., Hatton, C., Turner, S., & Kessissoglou, S. (2000). Lifestyle related risk factors for poor health in residential settings for people with intellectual disabilities. Research in Intellectual Disabilities, 469-486.

Robertson, J., Hatton, C., Baines, S., & Emerson, E. (2015). Systematic Reviews of the Health or Health care of People with Intellectual Disabilities: A Systematic Review to Identify Gaps in the Evidence Base. Journal of Applied Research in Intellectual Disabilities, 455-523.

Ryan, T. A., & Scior, K. (2015). Medical Students' Attitudes Towards Health Care for People with Intellectual Disabilities: A Qualitative Study. Journal of Applied Research in Intellectual Disabilities, 29(6), 508-518. Retrieved September 23, 2018.

Scheifes, A., Egberts, T., Stolker, J., Nijman, L., & Heerdink, E. (346-355). Structured Medication Review to Improve Pharmacotherapy in People with Intellectual Disability and Behavior Problems. Journal of Applied Research in Intellectual Disabilities, 2016.

Skorpen, M. N. (2016). Hospitalisation in adults with intellectual disabilities compared with the general population in Norway. Journal of Intellectual Disability Research, 365-377.

Seidel, M. (2003). The declaration of Rome 2003 – with regard to the promotion of interest and services for people with intellectual disabilities with mental health needs. Journal of Policy and Practice in Intellectual Disabilities, 103-104.

Shooshtari, S. (2017). Aging with intellectual and developmental disabilities and dementia in Manitoba. Advances in Mental Health and Intellectual Disabilities, 11(4), 134-144. Retrieved August 20, 2018.

Shooshtari, S., Brownell, M., Mills, R. S., Dik, N., Yu, D. C., Chateau, D., . . . Wetzel, M. (2016). Comparing Health Status, Health Trajectories and Use of Health and Social Services between Children with and without Developmental Disabilities: A Population-based Longitudinal Study in Manitoba. Journal of Applied Research in Intellectual Disabilities, 30(4), 584-601. Retrieved August 23, 2018.

Shooshtari, S., Temple, B., Waldman, C., Abraham, S., Ouellette-Kuntz, H., & Lennox, N. (2016). Stakeholders' Perspectives towards the Use of the Comprehensive Health Assessment Program (CHAP) for Adults with Intellectual Disabilities in Manitoba. Journal of Applied Research in Intellectual Disabilities, 30(4), 672-683. Retrieved August 22, 2018.

Silva, V., Campos, C., Cavadas, A., Pinto, J., Simoes, P., Machado, S., & Murillo-Rodríguez, E. (2017). Wii-based exercise program to improve physical fitness, motor proficiency and functional mobility in adults with Down syndrome. Journal of Intellectual Disability Research, 61(8), 755-765. Retrieved August 21, 2018.

Slayter, E. (2009). Not immune: access to substance abuse treatment among Medicaid-covered youth with mental retardation. Journal of Disability Policy Studies, 195-204.

Slayter, E. (2010). Disparities in access to substance abuse treatment among people with intellectual disabilities and serious mental illness. Health and Social Work, 49-59.

Smiley, E., Cooper, S., Miller, A., Robertson, M., & Simpson, N. (2002). Specialist health services for people with intellectual disability in Scotland. Journal of Intellectual Disability Research, 585-593.

Stancliffe, R., & Anderson, L. (2017). Factors associated with meeting physical activity guidelines by adults with intellectual and developmental disabilities. Research in Developmental Disabilities, 62, 1-14. Retrieved August 21, 2018.

Statistics Canada. (2012). Retrieved from Canadian Survey on Disability: http://www5.statcan.gc.ca/olc-cel/olc.action?objId=89-654-X&objType=2&lang=en&limit=0

Statistics Canada. (2015). Health Fact Sheets. Retrieved from Physical activity levels of Canadian children and youth, 2007 to 2009: http://www.statcan.gc.ca/pub/82-625-x/2011001/article/11553-eng.htm

Strydom, A., Hassiotis, A., King, M., & Livingston, G. (2009). The relationship of dementia prevalence in older adults with intellectual disability (ID) to age and severity of ID. Psychological Medicine , 13-21.

Sundahl, L., Zetterberg, M., Wester, A., Rehn, B., & Blomqvist, S. (2016). Physical Activity Levels Among Adolescent and Young Adult Women and Men with and without Intellectual Disability. Journal of Applied Research in Intellectual Disabilities, 93-98.

Surrey Place. (2018). Developmental Disabilities Primary Care Program. Retrieved October 3, 2018, from http://ddprimarycare.surreyplace.ca/

Swango-Wilson, A. (2009). Perception of sex education for individuals with developmental and cognitive disability: a four cohort study. Sexuality & Disability, 223-228.

Swango-Wilson, A. (2011). Meaningful sex education programs for individuals with intellectual/developmental disabilities. Sexuality & Disability, 113-118.

Taggart, L., McLaughlin, D., B, Q., & McFane, C. (2007). Listening to people with intellectual disabilities who misuse alcohol and drugs. Health and Social Care in the Community, 360-368.

Taggart, L., McLaughlin, D., Quinn, B., & Milligan, V. (2006). An exploration of substance misuse in people with intellectual disabilities. Journal of Intellectual Disability Research, 588-597.

Tang, B., Byrne, C., Friedlander, R., McKibben, D., Riley, M., & Thibeault, A. (2008). The other dual diagnosis: Developmental disability and mental health disorders. BC Medical Journal, 319-324.

Taheri, A., Perry, A., & Minnes, P. (2016). Examining the social participation of children and adolescents with Intellectual Disabilities and Autism Spectrum Disorder in relation to peers. Journal of Intellectual Disability Research, 60(5), 435-443. Retrieved August 20, 2018.

Temple, V., & Stanish, H. (2012). Efficacy of a Peer-Guided Exercise Programme for Adolescents with Intellectual Disability. Journal of Applied Research in Intellectual Disabilities, 319-328.

Temple, V., & Walkley, J. (2007). Perspectives of constraining and enabling factors for health-promoting physical activity by adults with intellectual disability. Journal of Intellectual and Developmental Disability, 28-38.

Thorpe, L., Davidson, P., & Janicki, M. (2002). Healthy Ageing - Adults with Intellectual Disabilities Biobehavioral Issues. Geneva: World Health Organization.

Tracy, J., & McDonald, R. (2015). Health and Disability: Partnerships in Health Care. Journal of Applied Research in Intellectual Disabilities, 22-32.

Tonnsen, B., Boan, A., Bradley, C., Charles, J., Cohen, A., & Carpenter, L. (2016). Prevalence of Autism Spectrum Disorders Among Children With Intellectual Disability. American Journal on Intellectual and Developmental Disabilities, 121(6), 487-500. Retrieved August 10, 2018.

Torr, J., Strydom, A., Patti, P., & Jokinen, N. (2010). Aging in Down Syndrome: Morbidity and Mortality. Journal of Policy and Practice in Intellectual Disabilities, 70-81.

Ummer-Christian, R., Iacono, T., Grills, N., Pradhan, A., Hughes, N., & Gussy, M. (2018). Access to dental services for children with intellectual and developmental disabilities – A scoping review. Research in Developmental Disabilities, 74, 1-13. Retrieved September 24, 2018.

Verger, P., Aulagnier, M., & J, R. (2005). General practitioners' attitudes towards patients with disabilities: the need for training and suppor. Disability Rehabilitation, 1343-1352.

Vermeltfoort, K., Staruszkiewicz, A., Anselm, K., Badnjevic, A., Burton, K., Switzer-McIntyre, S., Balogh, R. (2014). Attitudes toward Adults with Intellectual Disability: A Survey of Ontario Occupational and Physical Therapy Students. Physiotherapy Canada, 133-140.

Wagemans, A. M., H. M. J. Van Schrojenstein Lantman-De Valk, Proot, I. M., Bressers, A. M., Metsemakers, J., Tuffrey-Wijne, I., . . . Curfs, L. M. (2016). Do-Not-Attempt-Resuscitation orders for people with intellectual disabilities: Dilemmas and uncertainties for ID physicians and trainees. The importance of the deliberation process. Journal of Intellectual Disability Research, 61(3), 245-254. Retrieved September 24, 2018.

Waldman, H., Milano, M., & Wolf, A. (2004). Dental students' experiences with and attitudes toward people with mental retardation. Journal of the American Dental Association, 353-357.

Waldman, H. B., & Perlman, S. P. (2002). Preparing to meet the dental needs of individuals with disabilities. Journal of Dental Education, 66(1), 82–85.

Wark, S., McKay, K., Ryan, P., & Muller, A. (2018). Suicide amongst people with intellectual disability: An Australian online study of disability support staff experiences and perceptions. Journal of Intellectual Disability Research, 62(1), 1-9. Retrieved August 20, 2018.

Weiss, J. A., Isaacs, B., Diepstra, H., Wilton, A. S., Brown, H. K., Mcgarry, C., & Lunsky, Y. (2017). Health Concerns and Health Service Utilization in a Population Cohort of Young Adults with Autism Spectrum Disorder. Journal of Autism and Developmental Disorders, 48(1), 36-44. Retrieved October 3, 2018.

Weise, J., Pollack, A., Britt, H., & Trollor, J. N. (2017). Primary health care for people with an intellectual disability: An exploration of consultations, problems identified, and their management in Australia. Journal of Intellectual Disability Research, 61(5), 399-410. Retrieved September 24, 2018.

Westendorp, M., Houwen, S., Hartman, E., & Visscher, C. (2011). Are gross motor skills and sports participation related in children with intellectual disabilities? Research in Developmental Disabilities, 1147-1153.

White, S., Lunsky, Y., & Grieve, C. (2010). Profiles of patients with intellectual disability and mental illness in specialized and generic units in an Ontario psychiatric hospital. Journal of Mental Health Research in Intellectual Disabilities, 117-131.

Whittle, C., & Butler, C. (2018). Sexuality in the lives of people with intellectual disabilities: A meta-ethnographic synthesis of qualitative studies. Research in Developmental Disabilities, 75, 66-81. Retrieved August 21, 2018.

Wilkinson, J., Lauer, E., Freund, K., & Rosen, A. (2011). Determinants of Mammography in Women with Intellectual Disabilities. Journal of the American Board of Family Medicine, 24(6), 693-703. Retrieved August 22, 2018.

William, S., Diepstra, H., Heng, J., Ally, S., Bradley, E., Casson, I., . . . Witherbee, S. (2018). Primary Care of Adults with Intellectual and Developmental Disabilities: 2018 Canadian Consensus Guidelines'. Canadian Family Physician, 64(4), 254-279. Retrieved September 26, 2018.

Winter, C., Bastiaanse, L., Hilgenkamp, T., Evenhuis, H., & Echteld, M. (2012). Overweight and Obesity in Older People with Intellectual Disability. Research in Developmental Disabilities, 398-405.

Wolf, L., & Wright, R. (1987). Changes in life expectancy of mentally retarded persons in Canadian institutions: a 12-year comparison. Journal of Mental Deficiency Research, 41-59.

World Health Organization. (2011). Global Recommendations on Physical Activity and Health - 5-17 years old. Geneva: WHO.

WHO-Europe. (2016, 11 28). Definition: intellectual disability. Retrieved from World Health Orgnization Europe: http://www.euro.who.int/en/health-topics/noncommunicable-diseases/mental-health/news/news/2010/15/childrens-right-to-family-life/definition-intellectual-disability

Zablotsky, B., Black, L., Maenner, M., Schieve, L., & Blumberg, S. (2015). Estimated Prevalence of Autism and Other Developmental Disabilities Following Questionnaire Changes in the 2014 National Health Interview Survey. Center for Disease Control.

Zaal-Schuller, I., Vos, M. D., Ewals, F., Goudoever, J. V., & Willems, D. (2016). End-of-life decision-making for children with severe developmental disabilities: The parental perspective. Research in Developmental Disabilities, 49-50, 235-246. Retrieved September 24, 2018.

Zaal-Schuller, I., Willems, D., Ewals, F., Goudoever, J. V., & Vos, M. D. (2016). How parents and physicians experience end-of-life decision-making for children with profound intellectual and multiple disabilities. Research in Developmental Disabilities, 59, 283-293. Retrieved September 24, 2018.

Zijlmans, L., Embregts, P., Gerits, L., Bosman, A., & Derksen, J. (2015). The effectiveness of staff training focused on increasingemotional intelligence and improving interactionbetween support staff and clients. Journal of Intellectual Disability Research, 599-612.

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