

**Characteristics that Determine Complete Physical Examination Rates in Manitobans with  
an Intellectual or Developmental Disability: A Retrospective Cohort Study**

by

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## Abstract

Research from Canada and abroad shows significant health disparities between persons with and without intellectual and developmental disabilities (IDD). Physical examinations are not found to be beneficial on an annual basis for asymptomatic adults. However, the *Canadian Consensus Guidelines on Primary Care of Adults with Developmental Disabilities* recommends an annual comprehensive preventive care assessment which includes a complete physical exam (CPE) as one of the strategies to reduce health disparities experienced by persons with IDD. The objectives of the study were to 1) examine and compare rates of complete physical examinations (CPE) among Manitobans aged 18 and over with and without IDD; 2) identify the demographic, socio-economic, and health-related characteristics that are associated with the likelihood of receiving a complete physical exam among persons with and without IDD.

This was a retrospective cohort study based on several years of health and non-health administrative data (1995/96 - 2014/15) from the Manitoba Population Research Data Repository housed and maintained by the Manitoba Centre for Health Policy (MCHP) at the University of Manitoba. The overall trend between the IDD and non-IDD group indicated that CPE rates have been decreasing over time and that both the crude and modelled rates of complete physical examination rates were higher among the IDD population. History of CPE, history of mental illness, majority of care, region of residence, sex, and socioeconomic status appeared to be significant predictors of one receiving a CPE. The results from this study have potential to influence policies, programs, and guidelines affecting individuals with an IDD and in turn contribute to improving the health of this population

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conclusions are those of the authors, and no official endorsement by the Manitoba Centre for Health Policy; Manitoba Health, Seniors and Active Living; or other data providers is intended or should be inferred.

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## Acronyms

|           |   |
|-----------|---|
| 95% CI    | 95% Confidence Interval   |
| CSD       | Canadian Survey on Disability   |
| CPE       | Complete Physical Examinations  |
| FASD      | Fetal Alcohol Spectrum Disorder   |
| ICD-9-CM  | International Classification of Diseases, 9 <sup>th</sup> Revision, Clinical Modification                           |
| ICD-10-CA | International Statistical Classification of Diseases and Related Health Problems, 10 <sup>th</sup> Revision, Canada |
| IDD       | Intellectual and Developmental Disability   |
| MCHP      | Manitoba Centre for Health Policy   |
| OR        | Odds Ratio  |
| SEFI-2    | Socioeconomic Factor Index- 2   |
| SES       | Socioeconomic Status  |

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## Chapter 1: Introduction

Research shows that significant health disparities exist between persons with intellectual or developmental disabilities (IDD) compared to those without IDD (Foley, Lloyd, Vogl, & Temple, 2014; Krahn, Hammond, & Turner, 2006; Ouellette-Kuntz et al., 2005). The IDD population experiences significantly higher rates of morbidity (Krahn, Walker, & Correa-De-Araujo, 2015) and mortality (Emerson, Robertson, Baines, & Hatton, 2014). An individual with IDD is also more likely to experience health risks (e.g. obesity) as well as have lower rates of preventive care (Havercamp & Scott, 2015). Even though persons with IDD have greater needs and poorer health than the general population, they have difficulty accessing proper health care (Ouellette-Kuntz et al., 2005). These unmet needs along with inadequate access to quality health care leads to poor health outcomes for the IDD population. It is reported that mortality from preventable causes is three times higher among persons with IDD compared to the general population (Hoghton, Martin, & Chauhan, 2012).

A review of the evidence regarding complete physical examinations concluded that physical examinations are not beneficial on an annual basis for the asymptomatic adult population (The Canadian Task Force on the Periodic Health Examination, 1994). More recently the campaign Choosing Wisely Canada has also supported the idea that annual physical examinations provide little, if any benefit to adults with no symptoms of disease (The College of Family Physicians of Canada, 2017). However, based on the highest level of evidence, the *Canadian Consensus Guidelines on Primary Care of Adults with Developmental*

*Disabilities* recommends an annual comprehensive preventive care assessment which includes a complete physical exam (CPE) as one of the strategies to reduce health disparities experienced by persons with IDD. The highest level of evidence in these guidelines consisted of at least one properly conducted randomized control trial, systematic review, or meta-analysis (Sullivan et al., 2011b).

Several studies have found evidence supporting the value and benefit of CPEs for persons with IDD. Complete physical examinations identify unmet needs and result in the detection of undiagnosed conditions such as cancer and heart disease which could be potentially life threatening (Hoghton et al., 2012). CPEs also lead to secondary health benefits such as weight loss, reduction of seizure severity, stabilization of mood (Robertson, Roberts, Emerson, Turner, & Greig, 2011) and increased immunization rates (Gordon, Holden, Ware, Taylor, & Lennox, 2012). An additional benefit of CPEs is the collection of baseline health information. Persons with IDD often face high turnover of paid caregivers who in turn might not have a thorough understanding of a client's medical history. An annual physical examination allows the family physician to gather medical information over time. There is also evidence that shows that CPEs identify and address health conditions early on, thereby reducing future costs to the health system around hospitalizations and other resource use (Robertson, Hatton, Emerson, & Baines, 2014).

However, there are still several barriers to persons with IDD receiving the best possible care such as poor physical access, communication problems, and over-reliance on caregivers or

family members to identify health concerns. Some physicians also reported that they are skeptical about the benefits of an annual physical examination (Walmsley, 2011). As discussed, studies clearly show the numerous benefits of complete physical examinations for this population but studies are reporting that CPE rates are lower among the IDD population (Lunsky, Klein-Geltink, & Yates, 2013). A gap this study aims to address is the lack of information around the uptake of complete physical exams for Manitobans with IDD. We currently do not have a clear understanding of the CPE rates at a provincial level. Therefore, the main purpose of this study was to report rates of complete physical examinations among the IDD and non-IDD population over time and to identify characteristics that lead to one receiving a CPE. It is important to note that using the currently available data in Manitoba, we are unable to distinguish between CPEs done as part of a periodic health examination (those scheduled in advance as purely preventive measures) and CPEs that are conducted as part of an assessment of a separate diagnosis or to fulfill pre-operative requirements. However, this information will provide policy makers information around the current state of primary care in the IDD population in Manitoba and allow for the implementation of policies and programs geared towards improving quality of care.

### **1.1 Research Objectives**

The objectives of the proposed study are to: 1) examine and compare rates of complete physical examinations among Manitobans aged 18 and over with and without IDD over time; 2) identify the demographic, socio-economic, and health-related characteristics that

are associated with the likelihood of receiving a complete physical exam among persons with IDD and without IDD.

The results of this study are necessary to understand the current status of complete physical examination practices in Manitoba. Measuring the rates of CPE in the IDD population allows us to examine the trend over time and put forth recommendations to improve the uptake in CPE use. Understanding which factors increase or decrease likelihood of receiving a CPE is useful in developing and implementing targeted policies to ensure one of the most vulnerable segments of our population receives the level of care that all other Manitobans receive.

## Chapter 2. Literature Review

This chapter provides an overview of the relevant literature relating to the topic of complete physical exams in adults with intellectual and developmental disabilities. To begin, the epidemiology of intellectual and developmental disabilities will be discussed. Secondly, an overview of the peer-reviewed published and grey literature on health disparities experienced by adults with IDD, their preventive care, and their access to primary health care will be presented and discussed. Thirdly, an overview of annual physical examinations in the IDD and non-IDD population will be discussed along with what is known about factors that are found to be associated with increased or decreased likelihood of receiving a complete physical exam. Finally, the key concepts and conceptual frameworks will be defined and explained.

### 2.1 Epidemiology of IDD

Approximately 1-3% of the world's population is living with an IDD (World Health Organization, 2000). A study that used data from the Canadian Community Health Survey reported that 0.2% of Canadian adults lived with an IDD (Bielska, Ouellette-Kuntz, & Hunter, 2012). However, a study that used data from the Participation and Activity Limitation Survey estimated that 0.5% of Canadian adults lived with an IDD (Bielska et al., 2012). The Canadian Survey on Disability reported a prevalence rate of 0.6% (Statistics Canada, 2015).

These differences in rates can be attributed to the evolution of diagnostic criteria, varying survey questions, different sample populations, and rules around the use of a proxy to

answer the survey. For example, the Participation and Activity Limitation Survey used a hybrid definition of disability which incorporated aspects of a social and medical model. The survey questions that were used to identify those with a disability are as follows: “Do you have any difficulty hearing, seeing, communicating, walking, climbing stairs, bending, learning or doing any similar activities? Does a physical condition or mental condition or health problem reduce the amount or the kind of activity you can do at home? Does a physical condition or mental condition or health problem reduce the amount or the kind of activity you can do at work or at school? Does a physical condition or mental condition or health problem reduce the amount or the kind of activity you can do in other activities, for example, transportation or leisure?” (Statistics Canada, 2016).

The Canadian Survey on Disability (CSD) categorized a person as having a disability if his or her daily activities were limited by their disability. The CSD survey aimed at identifying 10 disability types. Similar to the PALS, it asked questions around the level of difficulty in doing tasks along with the frequency of the limitation. The survey classified a person as having a disability if they reported “sometimes”, “often”, or “always” for frequency of difficulty or if the frequency was “rarely” but combined with a level of difficulty of “a lot” or “cannot do” (Statistics Canada, 2016).

In Manitoba, the administrative prevalence of IDD based on five years of data from multiple sources was reported as being 0.47% (Ouellette-Kuntz et al., 2009). Administrative prevalence refers to a proportion of the population in a defined area who receive certain health

care and social services. It is important to note that this data is heavily reliant on the care and service seeking behaviour of individuals and is often not reflective of true prevalence (Ouellette-Kuntz et al., 2009). More recently, Shooshtari and colleagues linked 33 years of administrative data using the Manitoba Health Insurance Registry, Hospital Discharge Abstracts, Medical Services, Social Assistance Management Information Network, Long Term Care Utilization, Canada Census (2011) and reported that approximately 9000 adults with IDD live in Manitoba (0.97% of adults aged 18+) (Shooshtari et al., 2015).

## **2.2 Health Disparities Experienced by Persons with an IDD**

Numerous studies have reported on the health disparities between persons with and without IDD across the life span (Foley et al., 2014; Krahn et al., 2006; Ouellette-Kuntz et al., 2005). For example, Havercamp & Scott (2015), reported that 1% of their non-IDD study population reported poor health in comparison to 14% of their IDD study population. Along with their intellectual or developmental disability, they are also 2.5 times more likely to experience comorbidity with long-term diseases (Hoghton et al., 2012). The IDD population experiences higher rates of chronic conditions such as diabetes, hypertension, arthritis, chronic pain, and heart disease (Havercamp & Scott, 2015), epilepsy, neurological disorders, gastrointestinal disorders, and psychiatric disorders (Krahn & Fox, 2014), physical disabilities, mental health conditions, vision and hearing impairments, and communication disorders (Ouellette-Kuntz et al., 2005).

There are also other disability-related conditions that the IDD population faces such as pressure ulcers and dysphagia (Havercamp & Scott, 2015). A study by Krahn & Fox (2014) found that cardiovascular disease rates were 3 to 4 times higher in the IDD population and that they were 5 times more likely to be diagnosed with diabetes compared to the general population. Another study found that the risk of depression is 3 times higher in the IDD population compared to the general population (Shooshtari, Martens, Burchill, Dik, & Naghipur, 2011). Persons with IDD are also more likely to self-report that their health is significantly worse than their non-IDD counterparts (Emerson et al., 2014).

Health risks such as smoking, obesity, physical inactivity, and inadequate emotional support are also common among this population (Havercamp & Scott, 2015). Even though persons with IDD have greater needs and poorer health than the general population, they have difficulty accessing proper health care (Ouellette-Kuntz et al., 2005) and receive inadequate attention to care needs and health promotion (Krahn et al., 2006). A study conducted in South West England reported that 42 percent of deaths among their study population with intellectual or developmental disability were deemed premature or unexpected (Perry et al., 2014). It is evident that the health care disadvantages faced by this population can be severe, often leading to numerous unmet health and social services needs. Shooshtari, Naghipur, & Zhang (2012) reported that compared to persons with other types of disabilities, those with IDD were more likely to rely on social assistance as their main income, report their health as “fair” or “poor”, require help with activities of daily living, and report unmet healthcare and social support

needs. A common reason cited for unmet needs was the service being too expensive and not being covered under insurance.

### **2.3 Preventive Care**

Amidst these health disparities, research also shows that the IDD population is less likely to receive preventive health care services. Studies have found that women with IDD were less likely to receive routine breast and cervical cancer screening (Havercamp, Scandlin, & Roth, 2004; Lunsky, Balogh, Cobigo, et al., 2014). Lunsky et al (2014) reported that only 52% of women aged 50-64 received a mammogram compared to 70% of non-IDD women of the same age and only 33% of women with IDD received cervical cancer screening in comparison to 66% of their counterparts. Men with IDD were also significantly less likely to undergo PSA testing for prostate cancer, compared to non-IDD males (Havercamp & Scott, 2015). Studies have also reported that only 32% of the IDD population underwent screening for colorectal cancer, compared to 47% of the non-IDD population. There are major disparities around oral health care as well, with one study finding that persons with IDD were more likely to not have their teeth cleaned in the past 5 years or to never have had their teeth cleaned (Havercamp et al., 2004).

When individuals visited the emergency room for mental health related conditions, 41% of them did not receive follow-up from a family physician or psychiatrist within 30 days even though the primary care recommendations for this population stresses importance of follow-up

(Lunsky, Balogh, Cobigo, et al., 2014). These issues are exacerbated further by lifestyle factors such as diet, low physical activity, poor oral hygiene practices etc., (Krahn & Fox, 2014).

## **2.4 Access to Primary Health Care**

Primary care typically refers to “the provision of integrated, accessible care services by clinicians who are accountable for addressing a large majority of personal health care needs, developing a sustained partnership with patients, and practicing in the context of family and community” (Aggarwal & Hutchison, 2012, p.7). As discussed before, individuals with an intellectual or developmental disability are more likely to experience untreated morbidity and are less likely to receive health promotion and disease prevention services. There is an extensive body of literature on the benefits of primary care such as reduced health care costs, decreased mortality, and improved health outcomes (Lennox, Van Driel, & van Dooren, 2015). Even though it is clear that the IDD population has higher needs, they do not have better access to primary care. This population often experiences delays in diagnosis and/or treatment and also has problems around identifying changing needs and receiving appropriate care (Perry et al., 2014). Studies conducted in Canada, the United States, the United Kingdom, and Australia have reported that the IDD population does not receive adequate support from the health care system (Sullivan et al., 2011a).

Individuals with IDD often face numerous barriers to accessing health care services. Among these barriers are difficulties with communication (Gibbs, Brown, & Muir, 2008;

Sowney & Barr, 2007), feelings of anxiety and fear about health care procedures (Gibbs et al., 2008), discrimination (Gibbs et al., 2008), challenging behaviour (Gibbs et al., 2008), dealing with health professionals that have insufficient training regarding IDD (Iacono, Bigby, Unsworth, Douglas, & Fitzpatrick, 2014), and insufficient lengths of medical visits (Drainoni et al., 2006). The IDD population also faces delays with diagnosis and treatment (Castles, Bailey, Gates, & Sooben, 2014), lack of continuity of care (Wood, Hall, Hou, Wludyka, & Zhang, 2007), high rates of hospitalizations and emergency department visits (Boulet, Boyle, & Schieve, 2009). and longer length of hospital stay (Wu, Desarkar, Palucka, Lunsky, & Liu, 2013).

Hospitalizations related to ambulatory care sensitive conditions are often indicative of the access to and quality of primary care. Ambulatory care sensitive (ACS) conditions refer to conditions “which timely and effective outpatient care can help to reduce the risks of hospitalization by either preventing the onset of an illness or condition, controlling an acute episodic illness or condition, or managing a chronic disease or condition” (Manitoba Centre for Health Policy, 2014). Diabetes, epilepsy, chronic obstructive pulmonary disease, asthma, angina, and dental conditions are several examples of ACS conditions (Manitoba Centre for Health Policy, 2014). A population-based study in Ontario, conducted by Balogh, Lake, Lin, Wilton, & Lunsky in 2015, reported that an individual with an IDD is 2.6 times more likely to be hospitalized for a diabetes-related condition.

Shooshtari et al. (2015) found that a higher percentage of persons with IDD (13.95%) were hospitalized for dental conditions compared to their non-IDD counterparts (1.78%). Another study that examined hospitalization rates for ACS conditions reported higher rates among the IDD population (Balogh, Brownell, Ouellette-Kuntz, & Colantonio, 2010). An individual with IDD was 6.1 times more at risk of being hospitalized for an ACS condition compared to an individual without IDD. In fact, an individual with IDD is 54 times more likely to be hospitalized for epilepsy (Balogh, Brownell, Ouellette-Kuntz, & Colantonio, 2010).

Weiss, Slusarczyk, & Lunsky (2011), reported that an individual with an IDD was more likely to use the emergency department if they present with psychiatric symptoms, a history of behavioural problems, or a recent negative life event. Disparities exist even within the IDD population; those who experience high levels of comorbidity, live in rural areas or areas with a high proportion of First Nation residents appear to be at greater disadvantage (Balogh, Ouellette-Kuntz, Brownell, & Colantonio, 2013). A study conducted in the Netherlands reported that persons with IDD utilized 9.0% of all healthcare services (Polder, Meerding, Bonneux, & van der Maas, 2002) despite comprising only 0.7% of the population (van Schrojenstein Lantman-de Valk et al., 2006). It is evident that, as a result of low access to primary care, the IDD population becomes high users of downstream health services that require hospitalizations or emergency room visits which often incur higher cost to the system.

The IDD population also faces difficulty after accessing the healthcare system. A content analysis on hospital experiences among persons with IDD reported that this population

experiences delays in receiving diagnostic procedures, inadequate pain control, lack of appropriate discharge planning, and a lack of staff knowledge on IDD (Iacono et al., 2014). There are also communication issues since an individual with an IDD may not understand health care jargon and health professionals may not be able to fully understand non-verbal communication from patients with IDD. This is particularly challenging in rushed environments such emergency rooms (Bradbury-Jones, Rattray, Jones, & MacGillivray, 2013).

Caregivers often play a key role in the care received by a person with IDD. Most caregivers spend the entire hospital stay with the patient. Health care professionals report that this allows them to more accurately assess the patient with the caregiver help in interpreting communication. However, caregivers tend to report that health professionals over-rely on them for caring for the person with an IDD and are rarely offered a break or help with caring for the patient (Bradbury-Jones et al., 2013). These interactions with the health care system are often challenging to the individual and their family, as well as costly to the system. Therefore, initiatives that prevent hospitalizations and emergency room use among this population, such as high-quality primary care, need to be supported and encouraged.

## **2.5 Annual Complete Physical Examinations in non-IDD population**

Historically, complete physical examinations have been perceived as being an important aspect of improving preventive care, reducing patient worry, and fostering the relationship between a physician and patient. These examinations are referred to by various names across Canada and around the world. “Comprehensive visit,” “complete physical examination,”

“general health check”, “complete exam,” “periodic health visit,” “periodic health examination,” “annual health examination,” “major complete examination,” are some of the terms used in reference to physical examinations (The College of Family Physicians of Canada, 2013).

For the purposes of this study, we will be using the term “complete physical examination” (CPE). In 2011, a systematic review was conducted on the value and benefits of CPEs. One of the primary objectives of this review was to “evaluate the value of the routine (e.g. annual) physical examination in asymptomatic adults. This review of the evidence regarding complete physical examinations concluded that physical examinations are not beneficial on an annual basis for the asymptomatic adult population (Bloomfield & Wilt, 2011).

In 1994, the Canadian Task Force on the Periodic Health Examination published guidelines that supported the idea that a “periodic health examination” would be more beneficial at preventing and controlling disease compared to an “annual complete physical examination” (The Canadian Task Force on the Periodic Health Examination, 1994). This notion has continued to be supported by the medical community with more current evidence reviews (Birtwhistle, Bell, Thombs, Grad, & Dickinson, 2017). The annual complete physical exam occurs once a year, whereas the timing of the periodic health examination usually varies and is determined by the physician. There are mixed opinions on this matter with some evidence stating that even periodic health examinations show no benefit to the asymptomatic adult.

A Cochrane review conducted in 2013 reported that general health checks do not reduce morbidity or mortality (Krogsbøll, Jørgensen, Grønhøj Larsen, & Gøtzsche, 2012). Following the Cochrane study, other studies have also reported similar findings (Prochazka & Caverly, 2013). Several studies have also reported benefits of periodic health assessments such as improved delivery of preventive health services, less patient worry (Boulware, Marinopoulos, Phillips, & Hwang, 2007; Mavriplis, 2011), and relationship building between patients and health care providers (Mavriplis, 2011).

Despite these controversies, some healthcare systems such as the National Health Service (NHS) in the United Kingdom, still recommend health checks for the general population and consider it to be a national priority (Krogsbøll, Jørgensen, & Gøtzsche, 2013). There are some studies that also recommend conducting components of a physical examination such as blood pressure monitoring, measurement of body mass index, and pap smears instead of a comprehensive routine physical examination (Bloomfield & Wilt, 2011).

In Canada, there appear to be differences among provinces and territories around complete physical examination practices with physician billing schedules being a main influencer. Most provinces and territories, except for British Columbia, Newfoundland & Labrador, New Brunswick, Nova Scotia, and Nunavut, allow physicians to bill for annual physical examinations (The College of Family Physicians of Canada, 2013). Using health administrative databases, Fransoo and colleagues found that 45.8% of Manitoba women and

37.4% of Manitoba men received at least one complete history and physical examination in 2003/04 (Fransoo et al., 2005).

## **2.6 Annual Complete Physical Examinations in IDD population**

There is a different opinion about the use of a complete physical examination to detect and treat health conditions among the IDD population. The *Canadian Consensus Guidelines on Primary Care of Adults with Developmental Disabilities* recommends “annual comprehensive preventive care assessments” which includes a complete physical exam, as one of the strategies to reduce health disparities experienced by persons with IDD (Sullivan et al., 2011b). In some cases, differentiating between IDD symptoms and symptoms of physical or mental conditions such as psychosis can be challenging (Deb, Thomas, & Bright, 2001). Research shows that health assessments result in an increase in clinical activity that is conducive to positive health outcomes for persons with IDD (Lennox, Ware, Bain, Taylor Gomez, & Cooper, 2011; Robertson, Hatton, Emerson, & Baines, 2014).

A CPE offers physicians an opportunity to prevent, diagnose, and treat conditions while gathering baseline information to help assess the patient’s health status over time. A review of CPE use among the IDD population reported that conducting a CPE resulted in identifying unmet, unrecognized, and treatable health conditions (Robertson, Roberts, & Emerson, 2010). For example, in their study, Robertson and colleagues reported that those who underwent a CPE were almost twice as likely to have previously undetected heart disease, psychiatric disorder, reflux disease etc. diagnosed (Robertson et al., 2014). Conducting a CPE also

improves the health professional's knowledge of individual patient needs and identifies gaps in the services provided to patients (Robertson et al., 2014). Complete physical examinations lead to increased case finding and enhanced care for IDD patients, but do not increase overall cost to the healthcare system (Gordon et al., 2012).

Primary care often tends to be reactive and addresses concerns brought in by patients; however, a person with IDD may be unable to interpret and communicate medical symptoms as many individuals with IDD are lacking communication skills (Gibbs et al., 2008; Sowney & Barr, 2007). Studies have confirmed that CPEs lead to increased preventive services such as screening and health promotion activity. Several other studies have shown that CPEs in the IDD population lead to weight loss for those that are overweight or obese (Hunt, Wakefield, & Hunt, 2001), stabilization of mood (Bollard, 1999), reduction of seizure severity (Bollard, 1999), improvement in challenging behaviours, and effective treatment of conditions such as diabetes, anemia, hypothyroidism, infections etc. (Robertson et al., 2014).

Currently there is no information on the uptake of complete physical examination by persons with IDD in Manitoba. However, a recent study conducted in Ontario reported that persons with IDD have lower rates of complete physical exams in comparison to the general population. In Ontario, approximately 22% of the IDD population received a CPE compared to 26% of the non-IDD population (Lunsky, Klein-Geltink, & Yates, 2013). It appears that barriers to access may not be the main cause of low CPE rates. In the prior cited Ontario study, 3 out of 4 individuals with IDD had contact with a physician during the study period but only 1

out of 5 received a CPE. It seems that physician visits occur when the need arises; however, the majority of IDD patients do not receive a pro-active approach to managing their health (Lunsky, Balogh, Sullivan, & Jaakkimainen, 2014). Currently there is no information on the uptake of complete physical examination by persons with IDD in Manitoba. The findings from this study will fill in the knowledge gaps in this very important area.

## **2.7 Factors Associated with the Uptake of CPE in the IDD Population**

A common barrier to providing patients with CPEs, cited by many health professionals is time constraints. Complete physical examinations of IDD patients often require a longer visit, and gathering patient history may be difficult due to multiple comorbidities and communication issues. Some countries such as Australia and the United Kingdom offer extra financial incentives for physicians who conduct these examinations on IDD patients. In Canada, physicians are remunerated the same amount for an individual with an IDD and an individual without an IDD (Lunsky et al., 2014).

Another barrier to conducting CPE among the IDD population is the lack of training provided for treating this population among health professionals (Lunsky et al., 2014). A study that interviewed physicians about providing care for the IDD population identified several educational needs. Physicians reported discomfort in treating IDD patients, a lack of confidence, the need for more exposure in treating this population, and anxiety related to dealing with difficult patient behaviours. Physicians also suggested modifications to their

education, in order to improve their knowledge and confidence in caring for the IDD population (Wilkinson, Dreyfus, Cerreto, & Bokhour, 2012).

## **2.8 Factors Associated with the Uptake of CPE in the non-IDD Population**

Research has been conducted to examine factors that are associated with the uptake of CPE in the general population. Studies have found that an individual was less likely to receive a CPE if they were between the ages of 25 to 44 (Culica, Rohrer, Ward, Hilsenrath, & Pomrehn, 2002), male (Culica et al., 2002; Dryden, Williams, McCowan, & Themessl-Huber, 2012), unmarried (Dryden et al., 2012), low income (Culica et al., 2002; Dryden et al., 2012; McConkey, Taggart, & Kane, 2015), and unemployed (Dryden et al., 2012).

A higher likelihood of receiving a CPE was associated with being over 40 years of age (Brunner-Ziegler et al., 2013; Dryden et al., 2012), higher education (Blackwell, Martinez, Gentleman, Sanmartin, & Berthelot, 2009; Brunner-Ziegler et al., 2013), being married (Culica et al., 2002; Dryden et al., 2012), high household income (Blackwell et al., 2009; Brunner-Ziegler et al., 2013; Culica et al., 2002), occupation (Sun et al., 2014), presence of chronic diseases (Brunner-Ziegler et al., 2013; Culica et al., 2002), ethnicity (Dryden et al., 2012), health knowledge level (Sun et al., 2014), fair and poor health status, and physical exercise (Culica et al., 2002).

## 2.9 Key Concepts and Theoretical Framework

### 2.9.1 Intellectual and Developmental Disability

Developmental disability is an umbrella term that includes cognitive or physical disabilities or both that emerges during childhood. An intellectual disability is defined as “significant limitations in both intellectual functioning and in adaptive behaviours, which covers many everyday social and practical skills” and originates before the age of 18 (American Association on Intellectual and Developmental Disabilities, 2017). If an individual has an IQ score of around 70, it is considered an indication of limited intellectual functioning. However, IQ testing alone is insufficient to diagnose an IDD and adaptive behaviour should be tested. An individual may have a developmental disability such as cerebral palsy or epilepsy but not have any cognitive limitations. Some conditions such as Down Syndrome and Fetal Alcohol Syndrome may result in a physical disability as well as a cognitive disability (American Association on Intellectual and Developmental Disabilities, 2017). Often times intellectual and developmental disabilities co-occur; therefore, for the purposes of this study the term “intellectual and developmental disabilities” was used.

In order to be diagnosed with an IDD condition, an individual must show signs of limited intellectual functioning (low IQ) and difficulties with adaptive behaviour. Adaptive behaviour includes conceptual skills (language and literacy, money, time), social skills (interpersonal skills, social problem solving), and practical skills (activities of daily living, occupational skills) (American Association on Intellectual and Developmental Disabilities,

2017). It is important to note that varying patterns, severity, and trajectories exist within IDD conditions.

### **2.9.2 Health**

The World Health Organization defines good health as a “state of complete physical, social and mental well-being, and not merely the absence of disease or infirmity” (World Health Organization, 2016). The advantage of this definition is that defines health broader than just absence of disease, or disability. However, this definition has been criticized for defining health in terms of “complete well-being”. The absoluteness of the term “complete” is a concern. Given the aging of the population around the world, and the increasing rates of chronic physical and mental health conditions, the WHO definition of health does not seem to be useful any longer and for sure does not work for studying health and well-being in the IDD population. It is important to note that individuals with IDD can be healthy and well despite living with a life-long disability (McDonald, 2005).

### **2.9.3 Health Inequality and Health Disparities**

Health inequality and health disparities are both terms that are used interchangeably and refer to “population-specific differences in the presence of disease, health outcomes, or access to care” (Ward, Nichols, & Freedman, 2010, p.281). Meaning they refer to differences in health status or differences in the distribution of health determinants or health services between difference populations (World Health Organization, 2017). Certain subgroups in a population

may experience health inequality due to factors such as age and socioeconomic status (Ward et al., 2010). An example of health inequality would be differences in mortality rates between different age groups.

#### **2.9.4 Health Inequity**

Unlike health inequality which is measurable, health inequity is difficult to measure. The concept of health inequity emerged in the early 1990s where Margaret Whitehead defined it as unnecessary, avoidable, unfair, and unjust differences in health (Whitehead, 1992). Health inequity is present when health disparities arise as a result of systemic social disadvantages (e.g. disability, income, race etc.) (Braveman, 2006). There is a long history of social disadvantages faced by persons with IDD due to institutionalization, forced sterilization etc. Some may argue that health outcomes of the IDD population are poorer as a result of their disability. However, there are rates of certain preventive health measures such as mammograms and blood pressure checks that should remain equal between IDD and non-IDD populations, regardless of disability status. Studies have consistently reported that persons with IDD are less likely to receive clinical preventive services (Krahn et al., 2015). This is an example where a person's status (i.e., disability in this case) resulted in a health inequity that is unfair, unjust, and avoidable.

#### **2.9.5 Theoretical Framework**

This research study was guided by the Andersen and Newman Framework of Health Services Utilization (Andersen, 1995). This framework aims to identify factors that facilitate or

impede the use of health services. This framework, which serves as a model that measures access to medical care, states that health service utilization is dependent on three sets of characteristics: predisposing factors, enabling factors, and need factors.

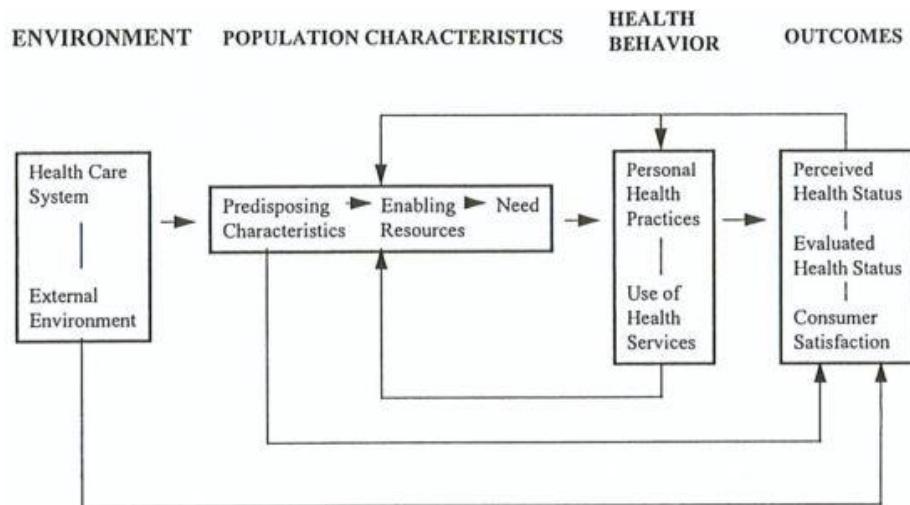
*Predisposing factors* are further categorized in three areas: social structure, health beliefs, and demographics. Social structures include factors such as one's education, occupation, ethnicity, culture, social networks, and social interactions. Health beliefs include attitudes, values, and knowledge of the health system that may influence the need for and use of the system. Demographic factors such as age and gender are underlying factors that may have an effect on an individual's health service utilization (Andersen, 1995).

*Enabling factors* include both community and personal factors. Community enabling factors refer to the presence and availability of health care personnel in the community. Personal enabling factors are factors that affect individuals who use the available resources and their access to health care services. Factors such as knowledge on how to access services, income, health insurance, regular source of care, and travel play a role in enabling service use.

*Need factors* such as perceived need and evaluated need also have an effect on an individual's use of services. Factors such as health education and financial incentives to seek medical care play a role in influencing perceived need. The effect of evaluated need can be seen as the care an individual receives as guided by clinical guidelines. This framework has mostly been used to examine health services utilization in the general population and not the

IDD population. However, the principles of the framework are applicable to the IDD population. This framework guided the selection of the study variables in the present study. The study variables were classified according to this framework (see Table 1) and were discussed in relation to update of CPEs in the IDD and non-IDD populations. Then use of the framework helped to identify variables that were important to this research, but were missing in the administrative data. The data gaps are discussed later in this document.

Figure 1. Andersen and Newman Framework of Health Services Utilization



Andersen, R. (1995). Retrieved from <http://www.ncbi.nlm.nih.gov/pubmed/7738325>

Table 1. Study Variables and Andersen and Newman Framework of Health Services Utilization

|                                     |  |
|-------------------------------------|--|
| <b>Predisposing characteristics</b> | Age, sex   |
| <b>Enabling Resources</b>           | Region of residence, socioeconomic status, majority of care, history of complete physical examinations |
| <b>Need factors</b>                 | Mental health status, comorbidities  |

## Chapter 3: Methods

### 3.1 Study Design and Data Sources

This research was a retrospective cohort study based on 20 years of the linked health and non-health administrative data (1995/96 – 2014/15) housed in the Manitoba Centre for Health Policy (MCHP) Population Data Repository at the University of Manitoba.

Administrative data is “information collected, usually by government, for some administrative purpose, but not primarily for research or surveillance purposes” (Manitoba Centre for Health Policy, 2013b). MCHP houses datasets from various domains such as health, education, and social services (Manitoba Centre for Health Policy, 2013b). This study was based on data from the Manitoba Health Insurance Registry (1995/96-2014/15), Medical Services (1995/96 to 2014/15), Hospital Discharge Abstracts (1995/96-2014/15), Social Assistance Management Information Network (1995/96 to 2014/15), Manitoba Fetal Alcohol Spectrum Disorder data (1999/00-2012/13), Long Term Care Utilization (1995/96-2014/15), and Enrollment, Marks, and Assessments, Special Needs data (1996/97-2014/15).

Individuals with IDD were identified using data linkage technique across multiple datasets. Unique identifiers were used to link data across datasets to identify individuals with an indication of IDD, without duplication. In order to protect the privacy of Manitobans, the linking of records occurred at Manitoba Health, before being transferred to MCHP. An encrypted Personal Health Information Number (PHIN) was assigned to all records in the

dataset and personal information such as name, address, and original PHIN was removed from the dataset prior to arriving at MCHP.

Table 2. Data Sources

| Data Set   | Years           |
|--|-----------------|
| Manitoba Health Insurance Registry                     | 1995/96-2014/15 |
| Medical Services                                       | 1995/96-2014/15 |
| Hospital Discharge Abstracts                           | 1995/96-2014/15 |
| Social Assistance Management Information Network       | 1995/96-2014/15 |
| Manitoba Fetal Alcohol Spectrum Disorder data          | 1995/96-2014/15 |
| Long Term Care Utilization                             | 1990/91-2012/13 |
| Enrollment, Marks, and Assessments, Special Needs data | 1996/97-2014/15 |

### 3.2 Study Populations

The IDD cohort consisted of Manitobans who were at least 18 years of age or over and had an indication of intellectual or developmental disability. The operational definition of IDD developed by Shooshtari and colleagues (Manitoba Centre for Health Policy, 2013a) was used to identify members of the study cohort. Persons with IDD were those who met at least one of the following four criteria: 1) received funding in support of their education due to multiple handicaps; or 2) received income assistance for the reason of “mental retardation” identified in the Social Assistance dataset; or 3) had at least one ICD diagnostic code for IDD in Medical Services or Hospital Discharge Abstracts databases. In addition, those listed in the Manitoba FASD Registry were included in the IDD study cohort. This included individuals with Fetal

Alcohol Syndrome (FAS), and Partial Fetal Alcohol Syndrome (pFAS), Alcohol-Related Brain Damage (ARBD), and Alcohol-Related Neurodevelopmental Disorder (ARND). Table 3. shows the number of cases that were identified using each database. Most of the IDD cases were identified using the Manitoba FASD registry. This registry includes individuals up to age 21 years who have received a diagnosis of FASD. This might be one of the reasons why the IDD study cohort is mostly young. It is important to note that individuals could be present in multiple databases due to accessing multiple services.

Table 3. Number of Cases by Data Source

| Data Source  | Number of Cases |
|--|-----------------|
| Medical Services                                       | 7,266           |
| Hospital Discharge Abstracts                           | 7,141           |
| Social Assistance Management Information Network       | 2,408           |
| Manitoba Fetal Alcohol Spectrum Disorder data          | 9,222           |
| Enrollment, Marks, and Assessments, Special Needs data | 6,734           |

*Note: due to overlap, the total number of cases across the five individual databases may be larger than the total number of IDD in the study cohort*

The study cohort only included community dwelling individuals and excluded institutionalized individuals who live in long-term care facilities, or received support from St.Amant, or the Manitoba Developmental Centre. St.Amant and the Manitoba Developmental Centre are both agencies in Winnipeg and Portage la Prairie that provide comprehensive

services for Manitobans with IDD. Since individuals receiving these supports or those who live in long-term care facilities tend to receive different levels of care they were excluded from this study.

Tables 4 and 5 include a comprehensive list of ICD codes that were used to identify persons with IDD based on medical records in this study. Medical Services use ICD-9-CM codes while Hospital Abstracts data use ICD-9-CM codes until 2003/04 and ICD-10-CA from 2004/05 onward. The Hospital Abstracts data contain the complete 5 digit ICD codes while the Medical Services database only contains 3 digit ICD codes. This is problematic because using the 3 digit ICD codes could inaccurately capture unwanted diagnoses. For example, 759.81 is considered to be an intellectual disability, however, 759.4 (conjoined twins) is not. Therefore, searching for 759 within the Medical Services database would have resulted in errors. To avoid this, 758, 759, and 760 ICD codes were not searched in the Medical Services database. Individuals with Autism Spectrum Disorder (ASD) were not included in this study because not every individual with ASD will present with an intellectual disability and may result in an overestimation of cases.

A matched comparison group consisting of Manitobans aged 18+, without any IDD was used for comparison. The matching was conducted using fine matching and was matched at a 1:3 ratio. Individuals were matched based on age, sex, and region of residence. These variables were used to create the matched comparison group due to their known effect on the outcome variable. Studies have found that age, sex (Keene & Li, 2005), and region of residence (Lahana, Pappa, & Niakas, 2011) are associated with health services utilization patterns.

Ensuring both groups are equivalent based on these variables reduces the likelihood of these variables skewing the results. 1:3 matching was chosen because in 1:1 matching, any differences could be attributed to chance. Also, attempting to match more than 1:3 is challenging and could lead to smaller sample sizes.

Table 4. ICD-9-CM Codes Used in Hospital Discharge Abstracts and Medical Services Data

| <b>ICD-9<br/>Codes</b> | <b>Description</b>  | <b>Hospital Discharge<br/>Abstracts Data</b> | <b>Medical Services<br/>Data</b> |
|------------------------|---|--|----------------------------------|
| 317                    | Mild Mental Retardation (MR)  | ✓  | ✓                                |
| 318                    | Other MR  | ✓  | ✓                                |
| 319                    | Unspecified MR  | ✓  | ✓                                |
| 758.0 -<br>758.3       | Chromosomal Anomalies<br>(includes Down's, Patau's and<br>Edward's syndromes)                       | ✓  | ✗                                |
| 759.81 -<br>759.89     | Other and unspecified<br>congenital anomalies (includes<br>Fragile X and Prader-willi<br>syndromes) | ✓  | ✗                                |
| 760.71                 | Fetal Alcohol Syndrome (FAS)  | ✓  | ✗                                |

Table 5. ICD-10-CA Codes Used in Hospital Discharge Abstracts and Medical Services Data

| <b>ICD-10 Codes</b>   | <b>Description</b>  |
|---|---|
| F70.0, F70.1, F70.8, F70.9  | Mild mental retardation   |
| F71.0, F71.1, F71.8, F71.9  | Moderate mental retardation   |
| F72.0, F72.1, F72.8, F72.9  | Severe mental retardation   |
| F73.0, F73.1, F73.8, F73.9  | Profound mental retardation   |
| F78.0, F78.1, F78.8, F78.9  | Other mental retardation  |
| F79.0, F79.1, F79.8, F79.9  | Unspecified mental retardation  |
| F84.0, F84.1, F84.3, F84.4,<br>F84.5, F84.8, F84.9                            | Pervasive developmental disorders   |
| P04.3   | Fetus and newborn affected by maternal use of alcohol                                     |
| Q86.0, Q86.1, Q86.2,<br>Q86.8   | Congenital malformation syndromes due to known exogenous causes, not elsewhere classified |
| Q87.0, Q87.1, Q87.2,<br>Q87.3, Q87.5, Q87.8                                   | Other specified congenital malformation syndromes affecting multiple systems              |
| Q89.8   | Other specified congenital malformations  |
| Q90.0, Q90.1, Q90.2,<br>Q90.9   | Down's syndrome   |
| Q91.0, Q91.1, 91.2, Q91.3,<br>91.4, Q91.5, 91.6, Q91.7                        | Edward's syndrome and Patau's syndrome  |
| Q93.0, Q93.1, Q93.2,<br>Q93.3, Q93.4, Q93.5,<br>Q93.6, Q93.7, Q93.8,<br>Q93.9 | Monosomies and deletions from the autosomes, not elsewhere classified                     |
| Q99.2   | Fragile X chromosome  |

### **3.3 Study Measures**

#### **3.3.1 Complete Physical Examination**

Consistent with prior research based on MCHP data, a “complete physical exam” was defined as an ambulatory visit with any of the physician tariffs (codes physicians use for billing purposes) included in Table 5. These tariffs refer to ‘complete’ physical exams—not regional exams or specialty-specific histories (Fransoo et al., 2005). All CPEs conducted in hospitals were excluded. The dichotomous dependent variable used in the logistic regression was whether an individual has a CPE in the 2014/15 fiscal year.

Table 5. Complete Physical Examination Tariff Codes

| <b>Tariff Code</b> | <b>Type of Visit</b>   |
|--------------------|--|
| 8450               | Complete history and physical exam with gynaecological exam including cytological smears—cervix<br>(Patients aged 70 years and over)             |
| 8460               | Complete history and physical exam with gynaecological exam excluding cytological smears—cervix<br>(Patients aged 70 years and over)             |
| 8495               | Complete History and Gynaecological Examination including the taking of cytological smears for cancer screening—cervix                           |
| 8498               | Complete History and Physical Examination with Gynaecological Examination, including the taking of cytological smear for cancer screening—cervix |
| 8499               | Complete History and Physical Examination with Gynaecological Examination, excluding the taking of cytological smears for cancer screening       |
| 8500               | Complete History and Physical Examination<br>(Patients aged 70 years and over)   |
| 8540               | Complete History and Physical Examination  |
| 8594               | Complete History and Physical Examination—Unassigned patient   |

\*Definitions are extracted from the 2016 Manitoba Physician's Manual (Manitoba Health

Healthy Living and Seniors, 2016) .

### 3.3.2 Socioeconomic Status

The Socioeconomic Factor Index 2 (SEFI-2) was used to measure socioeconomic status (SES). It is an area-based score that is calculated using census data and is reflective of the social determinants of health. The following factors are considered when calculating this score: average household income, percent of single parent households, unemployment rate, and high

school education rate. This score is assigned to individuals based on their postal code of residence. A score greater than zero signifies worse socioeconomic conditions, while a score less than zero signifies better socioeconomic conditions (Manitoba Centre for Health Policy, 2009). This is a continuous variable.

### **3.3.3 Comorbidities**

The Elixhauser Comorbidity Index was used to identify individuals with comorbidities in the study population and create a binary variable. This original index was developed by Elixhauser and (Elixhauser, Steiner, Harris, & Coffey, 1998) it predicts related resource use for 30 conditions. The version used in the study has been previously used by MCHP, and contains 31 conditions. Examples of health conditions included in the Elixhauser Comorbidity Index are depression, renal failure, diabetes, cancer etc. See Appendix 1 for a complete list of health conditions that are included in this index. Comorbidities among the study population were examined for the years of 2009/10 to 2013/14. If an individual visited a physician or was hospitalized for one or more of the conditions (as identified by diagnosis codes in the hospital and medical services data) in the comorbidity index, they were categorized as having a comorbidity.

### **3.3.4 History of Mental Illness**

History of mental illness was measured using “Cumulative Mental Illness” which is an indicator for the prevalence of mental illness, while taking into account the co-occurrence of

mental disorders. This indicator reports the proportion of the population who received treatment for depression, anxiety disorders, substance abuse, personality disorders, or schizophrenia (Manitoba Centre for Health Policy, 2012). For the purposes of this study, history of mental illness anytime between 2009/10 to 2013/14 was defined as a binary variable (having a history of mental illness coded as “1” and no history of mental illness coded as “0”), and considered in the multivariate analysis as an independent variable.

### **3.3.5 Majority of care**

Majority of care is a concept developed by the Manitoba Centre for Health Policy and it measures whether an individual receives most of their care by one health care provider. When calculating this measure, low users (i.e. fewer than 3 ambulatory visits in three years) were excluded. Majority of care was measured between 2009/10 to 2013/14 for the study population. This measure indicates if an individual had the majority of their medical visits to the same physician or not. Using this indicator, the study participants were classified into one of the following three categories: 1) those who had less than 50% of their medical visits to the same physician; 2) those who had more than 50%, but less than 75% of their medical visits to the same physician, and 3) those who had more than 75% of their medical visits to the same physician.

### **3.3.6 History of Complete Physical Examinations**

If at least one of the complete physical examination tariff codes was recorded in an individual’s medical history between 2009/10 to 2013/14 that individual was classified as an

individual who had a “history of complete physical exams”, coded as “1”. Otherwise, the individual was classified as someone with “no history of complete physical exam”, and coded as “0”.

### **3.3.7 Other Study Measures**

Age, sex, and region of residence were also included as study measures. An individual’s age and region of residence in 2014/15 were used for analysis purposes. Age was included as a continuous variable. Region of residence was classified by the Regional Health Authority (RHA) an individual lived in. The RHAs were as follows: Winnipeg Regional Health Authority, Prairie Mountain Health, Interlake Eastern, Southern Health- Santé Sud, and Northern. Sex was classified as either male or female.

### **3.4 Data Analyses**

The objectives of the proposed study were to 1) examine and compare rates of complete physical examinations among Manitobans aged 18 and over with and without IDD, over time; 2) identify the socio-demographic characteristics that are associated with the likelihood of receiving a complete physical exam among persons with IDD and without IDD.

The first research objective involved comparing rates of CPE among Manitobans with and without IDD over time. A Poisson Regression was used to compare the rates of CPE from 1995/96 to 2014/15 between the two study groups. The rates were compared over the entire study period and between the study cohort and the matched comparison group to determine

whether the change in rates over time was significant and whether the difference in rates between the two groups was significant. There appeared to be a curvilinear relationship between time and rate of complete physicals, which was tested using a quadratic function. Modelled rates were also calculated to fit the quadratic function.

The second research objective involved determining factors that were statistically significantly associated with increased or decreased odds of receiving a complete physical exam. A logistic regression model was conducted in order to assess this objective. The dependent variable was CPE status as a binary variable: the person either received a CPE in 2014/15 or did not receive a CPE in 2014/15. The independent variables were as follows: age, sex, region of residence, socioeconomic status, history of mental illness, comorbidities, majority of care, and history of CPE. All data analysis was conducted using SAS version 9.4.

### **3.5 Assumptions**

A poisson regression was used to address the first research objective; however, assumptions were not checked because the regression was only used to calculate rates. There were several assumptions that were checked prior to conducting the logistic regression. All required assumptions were met and the section below discusses assumptions that were examined.

### **3.5.1 Linearity**

Logistic regression assumes a linear relationship between continuous independent variables and the logit transformation of the dependent variable. This assumption was tested using cubic splines. The two continuous predictors (age, socioeconomic status) were confirmed to have a linear relationship with the logit transformation of the dependent variable.

### **3.5.2 Multicollinearity**

Multicollinearity exists when there is moderate to high correlation between two or more independent variables. The univariable and multivariable models were compared to identify any signs of multicollinearity. None of the coefficients changed significantly in size or direction between the univariable models and multivariable model. Therefore, there appeared to be no signs of multicollinearity.

### **3.5.3 Independence**

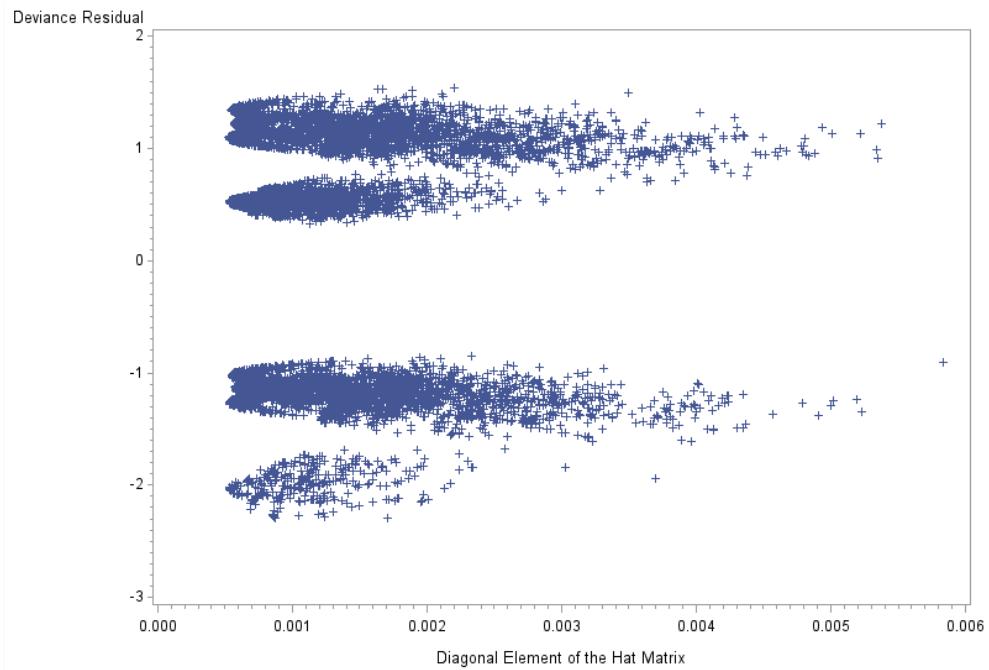
Logistic regression also requires all observations to be independent from each other. The logistic regression was conducted for one year (2014/15) of data and did not have any repeated measures; therefore, the issue of dependence is avoided.

### **3.5.4 Outliers**

The data was examined for potential outliers that may have an undesired effect on the results. In Figure 3, any observations that have high residual and high leverage (top right or

bottom right) would be considered outliers. As shown in this figure, there are no such observations; therefore, there are no major outliers that should be removed from the analysis.

Figure 3. Residual Plot



### 3.6 Approvals

Ethics approval was obtained from the University of Manitoba, Health Research Ethics Board (HS19971 (H2016:276)). Approval was also obtained from Health Information Privacy Committee (HIPC) of Manitoba Health, Healthy Living and Seniors (HIPC: 2016/2017-25), Manitoba Education and Advanced Learning, Manitoba Jobs and the Economy, and Winnipeg Regional Health Authority.

## **Chapter 4: Results**

This chapter provides a summary of the descriptive characteristics of the study population, rates of complete physical examinations (CPE), and factors that predict them among the study groups. Using the Andersen and Newman Framework of Health Services Utilization, the descriptive characteristics are defined as predisposing (age, sex), enabling (region of residence, socioeconomic status, majority of care, and history of complete physical examinations), and need factors (history of mental illness, comorbidities).

### **4.1 Descriptive Characteristics of Study Population**

Using data from 1995/96 to 2014/15, a total of 9,576 Manitoba adults with an intellectual or development disability (IDD) were identified using administrative data. Each one of these 9,576 individuals were matched to three other Manitobans without an IDD using age, sex, and region of residence. The IDD group consisted of 9,576 adults with IDD and the matched comparison group consisted of 28,728 non-IDD adults, which resulted in a study sample of 38,304.

Table 6 describes sociodemographic and health-related characteristics of both these groups. The distribution of individuals between both groups was similar for age, sex, and region of residence since both groups were matched on these factors. Each IDD case in the cohort was matched to 3 non-IDD cases. Aligning with previous research that examined health care need in this population, it was evident that individuals with IDD showed higher need

compared to their non-IDD counterparts. Almost 40% of individuals with IDD indicated a history of mental illness compared to only 21% of non-IDD individuals. Comorbidities were also higher in the IDD group at 10.8%. Among the non-IDD group only 8% had comorbidities.

Interestingly, majority of care patterns appeared to be slightly better among the IDD group. The summary statistics for this variable are reported in Table 7. Those with a higher number of ambulatory physician visits over 5 years, tend to have worse majority of care. Approximately 19.3% of the IDD group and 18.1% of the non-IDD group indicated visiting the same physician more than 50% of the time which isn't a large segment of the population. Six percent of the IDD group and 6% of the non-IDD group visited the same physician more than 75% of the time.

Table 6. Socio-demographic and Health-related Characteristics of Study Population

| <b>Variable</b>                    | <b>IDD<br/>n (%)</b> | <b>Non-IDD<br/>n (%)</b> | <b>Overall<br/>n (%)</b> |
|------------------------------------|----------------------|--------------------------|--------------------------|
|                                    | 9,576 (25)           | 28,728 (75)              | 38,304 (100)             |
| <b>Age</b>                         | 18-24                | 3,059 (31.9)             | 9,278 (32.3)             |
|                                    | 25-34                | 3,331 (34.8)             | 9,886 (34.4)             |
|                                    | 35-44                | 1,951 (20.4)             | 5,939 (20.7)             |
|                                    | 45-54                | 1,191 (12.4)             | 3,526 (12.3)             |
|                                    | 55-64                | 44 (0.5)                 | 99 (0.3)                 |
| <b>Sex</b>                         | Male                 | 5,535 (57.8)             | 16,605 (57.8)            |
|                                    | Female               | 4,041 (42.2)             | 12,123 (42.2)            |
| <b>RHA</b>                         | Winnipeg             | 5,359 (56.0)             | 16,077 (56.0)            |
|                                    | Prairie Mountain     |                          | 21,436 (56.0)            |
|                                    | Health               | 1,345 (14.0)             | 4,035 (14.0)             |
|                                    | Interlake Eastern    | 916 (9.5)                | 2,748 (9.5)              |
|                                    | Southern Health-     |                          | 5,380 (14.0)             |
|                                    | Santé Sud            | 1,231 (12.9)             | 3,693 (12.9)             |
| <b>History of Mental Illness</b>   | Northern             | 725 (7.6)                | 4,924 (12.9)             |
|                                    | Yes                  | 3,801 (39.7)             | 2,175 (7.6)              |
|                                    | No                   | 5,775 (60.3)             | 2,900 (7.6)              |
| <b>Comorbidities</b>               | Yes                  | 1,036 (10.8)             | 6,030 (21.0)             |
|                                    | No                   | 8,540 (89.2)             | 22,698 (79.0)            |
| <b>Majority of Care</b>            | <50%                 | 2,298 (8.0)              | 28,473 (74.3)            |
|                                    | 50-75%               | 7,124 (74.4)             | 3,334 (8.70)             |
|                                    | >75%                 | 1,844 (19.3)             | 5,207 (18.1)             |
| <b>History of CPE</b>              | >75%                 | 608 (6.4)                | 7,051 (18.4)             |
|                                    | Yes                  | 1,723 (6)                | 2,331 (6.09)             |
| <b>Socioeconomic Status (Mean)</b> | No                   | 7,130 (74.5)             | 24,916 (65.0)            |
|                                    |                      | 2,446 (25.5)             | 13,388 (35.0)            |
|                                    |                      | 0.34                     | -0.03                    |
|                                    |                      |                          | 0.05                     |

Table 7. Majority of Care Summary Statistics

| <b>Majority of Care</b> | <b>Mean</b> | <b>Median</b> | <b>25<sup>th</sup> Percentile</b> | <b>75<sup>th</sup> Percentile</b> | <b>Standard Deviation</b> | <b>Minimum</b> | <b>Maximum</b> |
|-------------------------|-------------|---------------|-----------------------------------|-----------------------------------|---------------------------|----------------|----------------|
| <50%                    | 71          | 47            | 20                                | 92                                | 78                        | 3              | 1,090          |
| 50-75%                  | 62          | 39            | 18                                | 79                                | 74                        | 3              | 1,116          |
| >75%                    | 37          | 19            | 7                                 | 41                                | 65                        | 3              | 1,346          |

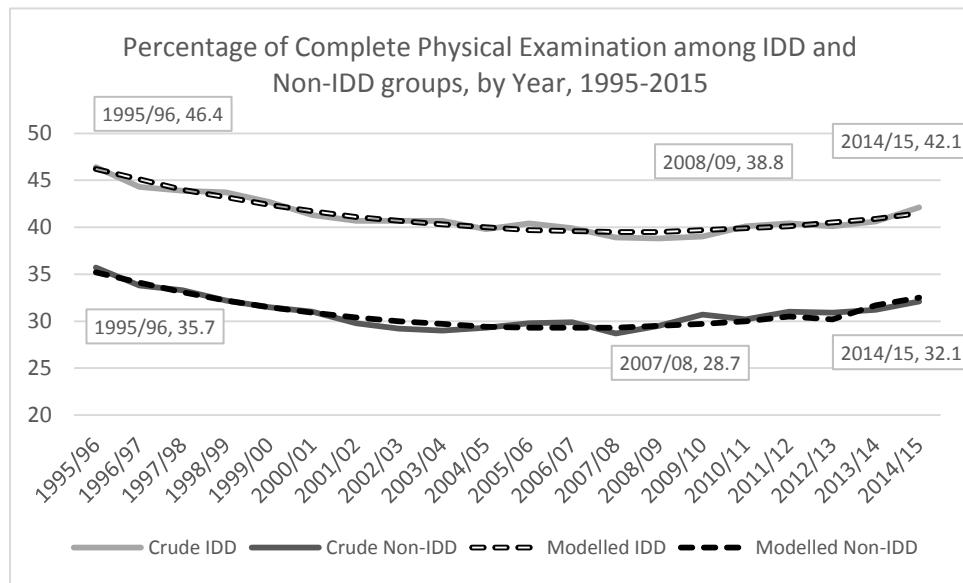
#### **4.2 Crude & Modelled Rates of Complete Physical Examinations between IDD and Non-IDD Population**

The overall trend between both groups indicated that CPE rates have been decreasing over time. However, both the crude and modelled rates indicated that complete physical examination rates were higher among the IDD population compared to the matched non-IDD groups. In 1995/96, 46.4% of the IDD population received a CPE compared to 35.7% of the non-IDD population. Rates decreased for both groups with the lowest rate for the non-IDD group being 28.7% in 2007/08 and 38.8% in 2008/09 for the IDD group.

When examining the modelled rates, the quadratic effect was weaker for the IDD group. The IDD group had a quadratic effect of 0.0011 ( $X^2 = 12.12$ ,  $p > 0.0005$ ) and the non-IDD group was 0.0016 ( $X^2 = 353.75$ ,  $p < 0.001$ ). This simply means that the downward trajectory for the IDD group takes longer to stop compared to the non-IDD group and doesn't increase as much in the final years. The change in rates over time was significant ( $p < 0.001$ ), with the time effect

being stronger for the IDD group. The difference in rates between the two groups was also significant ( $p<0.001$ ).

Figure 2. Percentage of Complete Physical Examinations among IDD and Non-IDD Groups, by Year, 1995-2015



#### 4.3 Factors Associated with the Uptake of CPE in the IDD Population

Several socio-demographic and health-related characteristics were examined to understand their influence on a person with IDD receiving a CPE. History of CPE, history of mental illness, majority of care, RHA, sex, and socioeconomic status were all significant predictors among this group. Age and comorbidities did not have any significant effect. Individuals with a history of CPE and history of mental illness were 4.8 and 1.3 times (respectively) higher odds of receiving a CPE compared to their counterparts. While majority of care was significant, those who received more than 75% of care by the same provider had

lower odds of receiving a CPE compared to those that received less than 50% of their care by the same provider.

There seems to be a rural versus urban gap with individuals living in Interlake, Northern, Southern, or Prairie Mountain Health Regional Health Authorities showing lower odds of receiving a CPE compared to their Winnipeg counterparts. Similar to previous research, we found that women had higher odds (1.3 times) of receiving a CPE compared to men. There also seems to be socioeconomic disparities in this group, higher SEFI scores (i.e. less favourable socioeconomic status) predict lower odds of receiving a CPE. Table 9 shows how the probability of receiving a CPE decreases with worsening socioeconomic status. An individual with a -4 SEFI score (high SES) has a 0.52 probability of receiving a CPE compared to an individual with a +5 SEFI score (low SES) who has a 0.29 probability of receiving a CPE.

Table 8. Unadjusted and Adjusted Odds Ratios for the IDD Population

| <b>Variable</b>                    | <b>Unadjusted</b>              |                  | <b>Adjusted</b>                |                  |        |
|------------------------------------|--------------------------------|------------------|--------------------------------|------------------|--------|
|                                    | <b>Odds Ratio<br/>(95% CI)</b> | <b>p value</b>   | <b>Odds Ratio<br/>(95% CI)</b> | <b>p value</b>   |        |
| <b>Age</b>                         | 1.00 (0.99-1.00)               | 0.904            | 1.00 (0.99-1.00)               | 0.75             |        |
| <b>Sex</b>                         | Male (ref)                     | <0.0001          | 1.37 (1.25-1.49)               | <0.0001          |        |
|                                    | Female                         |                  |                                |                  |        |
| <b>RHA</b>                         | Winnipeg (ref)                 | <0.0001          | <0.0001                        | <0.0001          |        |
|                                    | Interlake Eastern              |                  | 0.95 (0.81-1.10)               |                  |        |
|                                    | Northern                       |                  | 0.76 (0.63-0.91)               |                  |        |
|                                    | Southern Health-Sante Sud      |                  | 0.73 (0.63-0.84)               |                  |        |
|                                    | Prairie Mountain Health        |                  | 0.82 (0.72-0.94)               |                  |        |
|                                    |                                |                  |                                |                  |        |
| <b>History of Mental Illness</b>   | No (ref)                       | <0.0001          | 1.35 (1.23-1.48)               | <0.001           |        |
|                                    | Yes                            |                  |                                |                  |        |
| <b>Comorbidities</b>               | Yes (ref)                      | 0.15             | 0.97 (0.84-1.12)               | 0.72             |        |
|                                    | No                             |                  |                                |                  |        |
| <b>Majority of Care</b>            | <50% (ref)                     | <0.0001          | 0.0006                         | 0.0006           |        |
|                                    | >50%                           |                  | 1.02 (0.91-1.14)               |                  |        |
|                                    | >75%                           |                  | 0.68 (0.55-0.83)               |                  |        |
| <b>History of CPE</b>              | No (ref)                       | <0.0001          | <0.001                         | <0.001           |        |
|                                    | Yes                            |                  | 4.83 (4.28-5.46)               |                  |        |
| <b>Socioeconomic Status (SEFI)</b> |                                | 0.86 (0.83-0.89) | <0.0001                        | 0.89 (0.85-0.93) | <0.001 |

Table 9. Probability of Receiving a CPE by SEFI score

| <b>SEFI Score</b> | <b>IDD</b> | <b>Non-IDD</b> |
|-------------------|------------|----------------|
| -4                | 0.52       | 0.31           |
| -2                | 0.46       | 0.29           |
| 2                 | 0.35       | 0.25           |
| 5                 | 0.29       | 0.23           |

Among the non-IDD population, history of CPE, history of mental illness, majority of care, RHA, sex, and socioeconomic status were significant predictors of receiving a CPE. Comorbidities and age appeared to have no effect on this group receiving a CPE. Those with a history of CPE had 4.8 times higher odds and those with a history of mental illness had 1.4 times higher odds of receiving a CPE. Similar to the IDD group, those with more than 75% of their care provided by the same physician had lower odds of receiving a CPE compared to those with less than 50% of care provided by the same physician. Those who lived in the Southern, Northern, and Prairie Mountain Health Regions also had lower odds of receiving a CPE compared to their counterparts in Winnipeg. Also, similar to the IDD group, with an increase in SEFI score (i.e. less favourable socioeconomic conditions) there were lower odds of CPE for the general population.

Table 10. Unadjusted and Adjusted Odds Ratios for the non-IDD population

| <b>Variable</b>                    | <b>Unadjusted</b>              |                | <b>Adjusted</b>                |                |
|------------------------------------|--------------------------------|----------------|--------------------------------|----------------|
|                                    | <b>Odds Ratio<br/>(95% CI)</b> | <b>p value</b> | <b>Odds Ratio<br/>(95% CI)</b> | <b>p value</b> |
| <b>Age</b>                         | 0.99 (0.99-1.00)               | 0.49           | 0.99 (0.99-1.00)               | 0.38           |
| <b>Sex</b>                         | Male (ref)                     | <0.0001        | 1.72 (1.63-1.82)               | <0.0001        |
|                                    | Female                         |                |                                |                |
| <b>RHA</b>                         | Winnipeg (ref)                 | <0.0001        | <0.0001                        | <0.0001        |
|                                    | Interlake Eastern              |                | 0.92 (0.84-1.02)               |                |
|                                    | Northern                       |                | 0.75 (0.66-0.85)               |                |
|                                    | Southern Health-Sante Sud      |                | 0.78 (0.71-0.85)               |                |
|                                    | Prairie Mountain Health        |                | 0.76 (0.70-0.83)               |                |
|                                    |                                |                |                                |                |
| <b>History of Mental Illness</b>   | No (ref)                       | <0.0001        | 1.47 (1.37-1.56)               | <0.0001        |
|                                    | Yes                            |                |                                |                |
| <b>Comorbidities</b>               | Yes (ref)                      | 0.0009         | 0.95 (0.86-1.05)               | 0.31           |
|                                    | No                             |                |                                |                |
| <b>Majority of Care</b>            | <50% (ref)                     | <0.0001        | <0.0001                        | <0.0001        |
|                                    | >50%                           |                | 1.04 (0.97-1.11)               |                |
|                                    | >75%                           |                | 0.72 (0.63-0.82)               |                |
| <b>History of CPE</b>              | No (ref)                       | <0.0001        | 4.84 (4.51-5.20)               | <0.0001        |
|                                    | Yes                            |                |                                |                |
| <b>Socioeconomic Status (SEFI)</b> | 0.88 (0.86-0.91)               | <0.0001        | 0.94 (0.92-0.97)               | 0.0002         |

Table 11. Factors that Predict CPE among IDD and non-IDD groups

| <b>Variable</b>           | <b>IDD</b> | <b>Non-IDD</b> |
|---------------------------|------------|----------------|
| History of CPE            | <b>Yes</b> | <b>Yes</b>     |
| Age                       | No         | No             |
| History of mental illness | <b>Yes</b> | <b>Yes</b>     |
| Comorbidities             | No         | No             |
| Majority of care          | <b>Yes</b> | <b>Yes</b>     |
| RHA                       | <b>Yes</b> | <b>Yes</b>     |
| Sex                       | <b>Yes</b> | <b>Yes</b>     |
| Socioeconomic Status      | <b>Yes</b> | <b>Yes</b>     |

## Chapter 5. Discussion

### 5.1 Trend in CPE Rates between the IDD and non-IDD Population

The first objective of this study was to examine and compare rates of complete physical examinations among Manitobans aged 18 and over with and without IDD over time. Using a Poisson Regression, we found that the rates of complete physical examinations have decreased over time for the IDD and non-IDD populations. The overall decrease in CPE rates start in 1994/95 which coincides with the recommendation put forth by the Canadian Task Force on the Periodic Health Examination and other emerging evidence. The guideline stated that a periodic health examination is considered more effective than an annual physical examination for the general population. According to the task force, periodic health examinations that targeted preventing and detecting specific conditions, and controlling for risk factors such as age, sex, and high risk groups were more likely to be effective than a routine annual examination (The Canadian Task Force on the Periodic Health Examination, 1994). The Canadian Task Force did not make any recommendation as for the IDD population.

We see the rates of CPE decrease and reach its lowest point in 2008/09 (38.8%) for the IDD population and 2007/08 (28.7%) for the non-IDD population. The CPE rates for the IDD and non-IDD population started to increase around 2008. In 2011, *Canadian Consensus Guidelines on Primary Care of Adults with Developmental Disabilities* was published and stated that annual complete physical examinations were recommended for the IDD population. It is possible that these guidelines may have had an effect on this increase in CPE rates among

the IDD population but it unlikely. Mainly because the increase in rates occurred in both groups.

In the IDD group, the increase was minor (approximately 4% between 2008 and 2015). Even though 42% received a CPE in 2014/15, the actual percentage of the population that receives CPEs on an annual basis could be lower. Only 25% of the IDD population received a CPE in both the 2013/14 and 2014/15 years. This means that, a large percentage of the IDD population is not receiving CPEs on an annual basis. Overall, the CPE rates for both populations remained lower in 2014/15 compared to 1994/95 rates. The rate of CPE in the non-IDD population (32.1% in 2014/15) is similar to previous findings where Fransoo et al (2005), found that 37.4% of Manitoba men and 45.8% of Manitoba women received a CPE in 2003/04.

An interesting finding that emerged from this study was that CPE rates were higher among the IDD population. So far, there have been mixed findings in this area. For example, an Ontario study found that 22% of IDD adults received CPE versus 26% non-IDD adults at least once within the two year time period between 2009 to 2011 (Lunsky et al., 2013). A more recent Ontario study found that individuals with IDD showed higher rates of CPE compared to their non-IDD counterparts. In this study, CPEs were referred to as “true health exams”. Approximately 12% of non-IDD females versus 14% of IDD females received a true health exam. Among males, 12% of IDD males received a true health exam versus 8% of non-IDD males in 2014/15 (Smith, 2016). Even though the rates of CPEs are higher in the Manitoba

IDD population, there is still a clear need for improvement. The rate of CPEs in the IDD population should be closer to 100% because everyone with an IDD should be receiving a CPE.

It's interesting to note that rates of CPE for Manitobans with IDD is much higher compared to individuals living in Ontario in 2014/15. Manitobans with IDD had a 42.1% CPE rate compared to 14% females and 12% males living in Ontario. We can assume that one of the major driving factors of this difference in rates is due to coding practices. In Manitoba, the tariff codes that are used to identify CPEs are "complete history and physical examination" codes. For example, if an individual visits his or her family physician with a health concern and the physician conducts a full physical examination, this visit will be captured as a CPE. Complete physical examinations done for preoperative purposes will also be captured through these tariff codes. This will result in an over estimation of CPE rates in Manitoba. Currently, there are no codes to identify a true annual complete physical examination. However, Ontario is able to identify visits as "true CPE" visits by defining "true CPE" visit billings as those combining a general assessment (A003) code with another annual health examination code (917 or 319) or by using the periodic health visit (K131) code (Smith, 2016). This difference in tariff codes probably explains much of the differences in rates between the provinces.

Another driving factor for higher rates of CPE in Manitobans with IDD could be related to licensing guidelines related to community living resources available for the IDD population. Community Living Disability Services in Manitoba offers a range of residential services (e.g. group homes, supported independent living, home share model). One of the licensing and

funding requirement of a group home in Manitoba is that they complete an annual “life plan” document for each resident. One of the requirements is that they visit a General Practitioner at least once a year. Individuals living in supported independent living or the home share model do not have such requirements but an annual visit to a General Practitioner (GP) is strongly recommended by support staff.

In 2014/15, a total of 4,017 Manitobans with IDD accessed residential services (Manitoba Family Services, 2015). With an IDD cohort of 9,576, we are able to assume that approximately 42% of our IDD group accessed residential services in 2014/15 and either had a requirement to visit a GP or was strongly encouraged to do so. Our results found that 42.1% of IDD individuals had a CPE in 2014/15 which is almost an exact match to the percentage accessing residential services. Therefore, the licensing requirements of group homes most likely influence the high rates of CPE among Manitoba residents. With many studies showing that the IDD population often has poor access to health care, the findings of this study are encouraging. However, there still remains room for improvement in ensuring the best quality of care for individuals with IDD.

## **5.2 Factors Associated with the Uptake of CPE in the IDD Population**

The second objective in this study was to identify the demographic, socio-economic, and health-related characteristics that are associated with the likelihood of receiving a complete physical exam among persons with IDD and without IDD. Among the predictor variables examined in this study, there appeared to be no differences between the IDD and non-IDD

population. History of CPE, history of mental illness, majority of care, regional health authority, sex, and socioeconomic status predicted CPE while age and comorbidities had no effect. History of CPE was the most significant predictor with those with a history having almost 5 times higher odds of receiving a CPE. It is safe to assume that those that receive continuous annual CPEs are those with strong family advocates, those receiving residential services from the province, or those with a family physician that is trained to provide care to the IDD population. However, examining these factors was not feasible due to the lack of such information in administrative databases.

It is encouraging to find that those with a history of mental illness also have higher odds of receiving a CPE. Future research should explore psychiatric services received by this subgroup compared to the general populations to ensure equitable care by both groups. While majority of care was significant, it was those that received more than 75% of care by the same provider that showed significance. This group had lower odds of receiving a CPE compared to those that received less than 50% of their care by the same provider. If an individual is receiving excellent continuity of care (75% or more), one might postulate that the family physician has a good understanding of the person's health and may view CPEs as being unnecessary. It is also important to note that the median number of visits for the <50% was 47, 50-75% was 39, and >75% was 7. As majority of care improves, the number of visits decreases. Therefore, it may also mean that those with better "majority of care" may just have less contact with their family physician and therefore, fewer opportunities to receive a CPE.

Females showed higher odds of receiving a CPE which is consistent of previous research done in the general population (Culica et al., 2002). Generally, females more actively seek care, compared to males (Bertakis, Azari, Helms, Callahan, & Robbins, 2000). Individuals living outside of Winnipeg had lower odds of receiving a CPE most likely due to the low access to primary care and family physicians in communities outside of Winnipeg. A finding that is not unexpected was that individuals with low socioeconomic status (SES) had lower odds of receiving CPEs. There is ample evidence pointing to poorer access to health services among low SES populations (Hystad, Carpiano, Demers, Johnson, & Brauer, 2013; Reinier et al., 2011) and this trend is apparent in the IDD population as well. There appears to be a large disparity between those with low SES and those with high SES. Those with a SEFI score of +4 (high SES) had a 0.52 probability of receiving a CPE compared to only 0.29 at the +5 (low SES) level. It is also evident that SES status impacts the IDD group more than the non-IDD group. The difference in probabilities between the highest and lowest SEFI scores is 0.23 for the IDD group and only 0.08 for the non-IDD group.

It's interesting that comorbidities did not have any effect on CPEs. Comorbidities in this study were identified through visits to health care providers; therefore, it is evident that individuals with comorbidities are receiving care for their health conditions. Therefore, family physicians may view CPEs as being less important because there are conditions such as diabetes, hypertension etc. that are being treated and managed. Identifying the factors that

influence persons with IDD not receiving a CPE is useful when developing programs and policies that target better health for this population.

### **5.3 Limitations**

There are a few limitations to this study that are important to note. Firstly, there are limitations associated with using administrative data sources. Administrative data only captures those that accessed the system (either health care, family services, or education). There are individuals that may never access supports such as income assistance; therefore, there may be certain groups of people excluded if they do not access these services. When identifying individuals with IDD, there is no provincial registry or any other complete data source that identifies all Manitobans with an IDD. Relying on diagnosis codes and social support services to identify persons with IDD often results in an underestimation of the target population. Some physicians may not code visits under an IDD diagnosis and some individuals may never seek social supports such as disability income supplements.

Another limitation of this study is being unable to confirm if all CPEs are a true annual complete physical examination. Using the Manitoba tariff codes, we are unable to distinguish between those that visit a physician for a health concern and receive a physical examination versus those that schedule a physical examination for purely screening purposes. Being able to make this differentiation would have been useful for the purposes of this study. Administrative health data also does not capture information from Nursing Stations which could be providing

primary health care services to the communities in northern and remote areas. This could also result in missing data which may affect the study findings.

## Chapter 6. Policy Implications & Conclusion

### 6.1 Policy and Practice Implications & Future Research

The results from this study have potential to positively influence policies, programs, and guidelines affecting individuals with an IDD and in turn contribute to improving the health of this population. Even though 42% of the IDD population received a CPE in 2014/15 that also means that 58% did not receive a CPE that year. According to the *Canadian Consensus Guidelines on Primary Care of Adults with Developmental Disabilities* each individual with an IDD should be receiving a CPE; therefore, we should aim for every single Manitoban with an IDD to receive a CPE. From these findings, we know that persons with IDD with low socioeconomic status, males, and those living in non-urban environments are less likely to receive this important health service. There is a need for programs that target these vulnerable sub-groups to ensure they are receiving optimal health care.

As discussed previously, licensed group homes in Manitoba are required to ensure their clients visit a physician at least once a year. Compliance with this regulation is checked using the annual life plan document that group homes submit to funders. The life plan document indicates whether an individual visited a General Practitioner and the date of visit. However, there are no details around what type of visit it was (i.e. annual CPE, follow-up appointment etc.). Requiring agencies to provide more information about the nature of the visit and if it was a true annual health examination and whether health promotion, preventive services etc. were received will lead to better understanding of the type of care this population receives.

There are also health assessment tools such as the “Comprehensive Health Assessment Program” that was developed in Australia that could play a major role in improving primary care for persons with IDD. The Comprehensive Health Assessment Program (CHAP) was designed to identify poorly managed and under-diagnosed conditions in this population. The CHAP could be carried out during annual CPE visits and provide physicians with an effective tool to care for this group. There have been several studies conducted around the benefits of the CHAP (Gordon et al., 2012; Lennox et al., 2007, Lennox et al., 2013). There has been a feasibility study conducted in Manitoba to further understand factors that facilitate or impede implementation of the CHAP (Shooshtari et al., 2016). As the completion of a comprehensive health assessment requires a longer appointment time, other jurisdictions (e.g., Nova Scotia) have implemented financial incentives for physicians (B. Hennen, personal communication, 2016) who complete them. This ensures that physicians are fairly compensated and persons with IDD receive the best possible care. If the requirement for an annual comprehensive health assessment using a validated tool such as the CHAP is implemented in Manitoba, it is important that there is a separate tariff code assigned to it in order for future research to measure the short-term and long-term effectiveness of these comprehensive health assessments.

Other jurisdictions have implemented different practices to improve the quality of primary care received by the IDD population. New South Wales, Australia implemented a five-tier service framework to reduce health inequalities experienced by the IDD population. One of the tiers in this framework is primary care and working with primary health care providers to improve CPE rates is one of the goals of this framework (New South Wales Ministry of Health,

2012). Other jurisdictions have policies that allow health care professionals to provide reasonable adjustments for persons with IDD. Longer medical visits, having specific days with extra support staff, providing easy to read health information pamphlets, employing nurses trained to care for this population are some of the adjustments provided. Some jurisdictions (e.g. United Kingdom) also provides physicians with financial incentives to complete CPEs (Swarna, 2016). Future research initiatives should focus on further exploring the long-term benefits of CPE in this population. Understanding sex differences within this population, how repeated CPEs affect health outcomes, health utilization patterns such as emergency room use, hospitalizations etc. is important in establishing the importance of CPEs for this population. Future studies should also attempt to measure the true rate of CPEs in Manitoba.

## **6.2 Conclusion**

The findings from this study have been crucial in understanding whether Manitobans with an IDD are receiving the level of care outlined by the *Canadian Consensus Guidelines on Primary Care of Adults with Developmental Disabilities*. The results showed that approximately 40% of the IDD population received a CPE in 2014/15; however, only 25% of those individuals received a CPE in both 2013/14 and 2014/15. Therefore, we can assume that a large proportion of the IDD population is not receiving a CPE on an annual basis. It is also important to note that certain characteristics of an individual such as being male, living outside of Winnipeg, low socioeconomic status, and high majority of care means lower odds of receiving a CPE.

Therefore, there is a need for policies and programs that aim to improve CPE rates in this population as well as target those specific sub-groups to ensure they are receiving appropriate health care recommended for the IDD population. Ensuring Manitobans with IDD receive high-quality primary care that is recommended for this population will decrease future downstream costs to the healthcare system such as hospitalizations and emergency room use. It will also aid in reducing the health disparities and barriers to accessing health services experienced by this population.

In 2010, Canada ratified the United Nations *Convention on the Rights of Persons with Disabilities* (CRPD). This international human rights treaty framework, emphasizes the importance of addressing access issues faced by this population for decades. As part of the CRPD, the Canadian government has pledged to support initiatives that improve access to health care, chronic disease management, primary health care etc. for this population (Council of Canadians with Disabilities, 2010). It is clear, that there is a global movement towards ensuring persons with disabilities have equal access to all types of services including health care. Therefore, it is important for federal and provincial governments to support further research in this area as well as implement programs that will ensure individuals with IDD are receiving equal access to healthcare. In the general population, there are programs that have been implemented to ensure individuals are receiving recommended health care services (i.e. cancer screening). However, there are no such programs that advocate to enforce the recommended standard of care for this vulnerable population. As a society, it is our duty to ensure this population receives the standard of care that is recommended. Future research will

be critical in further understanding this complex issue and implementing new solutions will bring us closer to a more equitable society.

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## Appendices

### Appendix 1. Elixhauser Conditions

1. Congestive Heart Failure
2. Cardiac Arrhythmia
3. Valvular Disease
4. Pulmonary Circulation Disorders
5. Peripheral Vascular Disorders
6. Hypertension without complications
7. Hypertension with complications
8. Paralysis
9. Other Neurological Disorders
10. Chronic Pulmonary Disease
11. Diabetes without complications
12. Diabetes with complications
13. Hypothyroidism
14. Renal Failure
15. Liver Disease
16. Peptic Ulcer Disease excluding bleeding
17. HIV/AIDS
18. Lymphoma
19. Metastatic Cancer
20. Solid Tumor without Metastasis

21. Rheumatoid Arthritis/Collagen

22. Coagulopathy

23. Obesity

24. Weight Loss

25. Fluid and Electrolyte Disorders

26. Blood Loss Anemia

27. Deficiency Anemia

28. Alcohol Abuse

29. Drug Abuse

30. Psychoses

31. Depression

## **Appendix 2. History of Mental Illness**

An individual was considered to have a history of mental illness if they had any one of the following five mental health conditions between 2009/10 to 2013/14.

### **Mood & Anxiety Disorders**

- One or more hospitalizations with a diagnosis for depressive disorder, affective psychoses, neurotic depression, adjustment reaction or bipolar disorder (looking at ICD-10 only) ICD-10-CA codes F30, F31, F32, F33, F34, F38, F41.2, F43, F53.0.

- One or more hospitalizations with a diagnosis for an anxiety state, phobic disorders or obsessive-compulsive disorders: ICD-10-CA codes F40, F41.0, F41.1, F41.3, F41.8, F41.9, F42.
- Two or more physician visits with a diagnosis for depressive disorder or affective psychoses: ICD-9-CM codes 296, 31.
- Two or more physician visits with a diagnosis for adjustment reaction: ICD-9-CM code 309.
- Two or more physician visits with a diagnosis for anxiety disorders (including dissociative and somatoform disorders): ICD-9-CM code 300.

### **Substance Use Disorders**

- One or more hospitalizations with a diagnosis of substance use disorders:  
ICD-9-code - '291','292','303','304','305'.  
  
ICD-10 codes- 'F10','F11','F12','F13','F14','F15','F16','F17','F18','F19','F55', Z50.2 & Z50.3
- One or more physician visits with a diagnosis of substance use disorders:  
ICD-9-code - '291','292','303','304','305'

### **Personality Disorders**

- One or more hospitalization with a diagnosis for personality disorders:

ICD-10-CA codes: F21, F60, F61, F62, OR F69

- One or more physician visits with a diagnosis of personality disorders:

ICD-9-CM code: 301

### **Schizophrenia**

- Physician visits with a diagnosis of schizophrenia

ICD-9-code - '295'