Mental Disorders among Manitoba Adults with and without Intellectual and Developmental Disabilities: A Population-based Study

by

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Acronyms

CCHS	Canadian Community Health Survey
DD	Developmental Disabilities
FASD	Fetal Alcohol Spectrum Disorder
ICD	International Classification of Diseases
ID	Intellectual Disabilities
IDD	Intellectual and Developmental Disabilities
MCHP	Manitoba Centre for Health Policy

Disclosure

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In writing this thesis, I adhered to the strength-based language and guidelines advocated by the United Nations Disability Office at Geneva for disability-inclusive language (United Nations Disability Office at Geneva, n.d.)

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Dedication

To my Mom and Dad

Abstract

Introduction: Approximately 20% of Canadians live with a mental disorder each year. Prior population-based research from other jurisdictions suggested that persons with intellectual and developmental disabilities (IDD) have a higher prevalence of mental disorders compared to the general population. There has been no previous research looking at the prevalence of various mental disorders among persons with IDD in Manitoba. Provision of health care, including mental health care, is primarily a provincial/territorial responsibility. Each province and territory are responsible for organizing and delivering health care services to their residents. Thus, the local evidence from this study can be utilized to promote equity, enhance mental health outcomes, and ensure that persons with IDD living in Manitoba receive the necessary support and services to enjoy a high quality of life. Therefore, the purpose of the study was to calculate and compare prevalence of mental disorders between Manitoba adults with and without intellectual and developmental disabilities.

Methods: A retrospective matched cohort study was conducted. Population-based administrative data was analyzed from the Manitoba Population Research Data Repository housed and maintained by the Manitoba Centre for Health Policy. Five years of administrative data and registries (April 1, 2015, to March 31, 2020) were linked to identify mental disorders. All years of data available prior to April 1, 2015, were used to identify the study cohort (i.e., adults with IDD) and the matched comparison group. Adults with and without IDD were matched by age, sex, and region of residence at a 1:3 ratio. Descriptive analyses were conducted to describe the study population. The generalized estimating equation technique was used to estimate and compare the prevalence of mental disorders between the IDD study cohort and the matched

comparison group. The odds ratios and their 95% confidence intervals were used to determine statistically significant differences.

Results: Adults with IDD had a significantly higher prevalence of any mental disorders (OR = 2.13; 95%CI: 2.06, 2.21), mood and anxiety disorders (OR = 1.87; 95%CI: 1.80, 1.94), psychotic disorders (OR = 7.43; 95%CI: 6.82, 8.09), and substance use disorders (OR = 1.9; 95%CI: 1.78, 2.03) compared to the matched comparison group. Prevalence of mental disorders among persons with IDD varied by age, sex, and region of residence.

Discussion: This study aimed to address the current knowledge gaps on mental disorders among persons with IDD in Manitoba. This was the first Manitoba study examining the prevalence of any and specific types of mental disorders among persons with IDD using population-level data. Consistent with the studies from other jurisdictions, it was found that prevalence of mental disorders was higher among adults with IDD compared to those without IDD. Study findings can help with the development of interventions, policies, and programs, as well as advocacy, to provide more accessible mental health supports to promote the mental health of Manitobans with IDD. Findings also provide current information for future surveillance efforts. Future research should examine causes and treatments of mental disorders among persons with IDD.

Chapter 1: Introduction

Mental disorder has been defined as "a clinically significant disturbance in an individual's cognition, emotional regulation, or behaviour" (World Health Organization, 2022, para. 1), whereas mental illness has been defined as "changes in an individual's thinking, mood, behaviour and is usually associated with significant distress or impaired functioning in social, occupational or other activities" (Government of Canada, 2020, para. 1). Although mental disorder and mental illness has been used interchangeably in the literature, mental illness has been broader in scope. It included not only the disorder, but also the whole person impact. Mental disorder has referred to a specific list of symptoms that was experienced to meet the criteria for that specific disorder.

Mental illness has been a treatable medical condition that could impact anyone (American Psychiatric Association, 2018). Globally, it was estimated that between 1 in 8 and 1 in 5 individuals live with mental illness (Canadian Mental Health Association, 2021; National Institute of Mental Health, 2023; Smetanin et al., 2011; Steel et al., 2014; World Health Organization, 2022) and, in Canada, 1 in 5 individuals are impacted by mental illness each year (Canadian Mental Health Association, 2021; Smetanin et al., 2011). As well, the lifetime prevalence of mental illness in Canada was estimated at 33% (Government of Canada, 2020). Living with a mental illness negatively affects individuals' quality of life, leading to feeling hopelessness (Connell et al., 2012; Evans et al., 2007).

Much of what was known about the occurrence of mental disorders among Canadians was based on self-reported data from national surveys, such as the Canadian Community Health Survey (CCHS)– Mental Health conducted in 2012 (Canadian Community Health Survey: Mental Health, 2012). Certain population groups were excluded due to systematic barriers for

participation in national health surveys, for example, residents of territories and those living in remote regions. Unfortunately, it is not possible to identify those with intellectual and developmental disabilities (IDD) in these large national surveys. At the same time, the Canadian Survey on Disability (Statistics Canada, 2022a), which asks questions about type of disability, provides very little information on health in general and even less related to mental health.

Prior research showed that adults with IDD have higher rates of mental disorders (Ricciardi, 2013; Whitaker & Read, 2006) compared to persons without these disabilities. However, many of the prior studies were sample-driven and only a few studies were population based. Population-based studies have been useful for examining prevalence and incidence as they have been based on data for much of the population, rather than using data for a sample of population. Few Canadian studies have examined mental disorder prevalence in persons with IDD using population-based data (e.g., Lunsky et al., 2013; Ouellette-Kuntz et al., 2009; Shooshtari et al., 2017). Earlier studies were based primarily on community samples or clinic based data (Whitaker & Read, 2006); however, several studies from different countries had more recently demonstrated using population data that rates were higher among persons with IDD compared to the general population (e.g., Dunn et al., 2020; Hughes-McCormack et al., 2017; Shooshtari et al., 2017), In Manitoba, using provincial administrative data, it was found that 28% of Manitoba adults were living with at least one mental illness (Chartier et al., 2018). However, the study did not examine the odds of mental disorders among persons with IDD.

The use of population-based administrative data has been valuable when conducting studies comparing persons with and without IDD (Balogh et al., 2019; Lin et al., 2013). Accurate estimation of prevalence has been necessary, as it could be used for planning of services and meaningful comparisons on care quality and access (Lin et al., 2013). The present study

examined prevalence of mental disorders (of any type) and also specific types among Manitoba adults without these types of disabilities (i.e., without IDD). Information on prevalence of health conditions has been important as it helps us to know how many in the population have the disease or condition of interest so that we can organize health and social services to better support these individuals.

The results of this study can be used to inform policy and practice. Although there was previous research on this topic in other jurisdictions, it was important to research Manitoba to provide the most accurate estimations for Manitobans with IDD. Provision of health care, including mental health care, is primarily a provincial/territorial responsibility. Each province and territory have been responsible for organizing and delivering these services to their residents. In essence, there have been variations in populations and different services offered between jurisdictions. Thus, the local evidence from this study can be utilized to promote equity, enhance mental health outcomes, and ensure that persons with IDD living in Manitoba receive the necessary support and services to enjoy a high quality of life. It was important to examine rates of mental disorders at the population level to support decision-making, as well as inform and plan better services and interventions with quality data to prevent negative effects on quality of life. These findings help inform provision of targeted mental health services and supports, promotion of mental health, as well as improved policies, and funding allocations. The knowledge generated in this study will be useful because future interventions could be put in place to address the needs of persons with IDD. This includes informing family members and staff of persons with IDD to be aware of possible mental disorder symptoms, with the purpose of decreasing negative impacts of the condition.

The overall goal of the study was to examine and compare prevalence of mental disorders between Manitoba adults with and without intellectual and developmental disabilities.

Study Objectives

The specific objectives of the research study were to:

(1) Calculate and compare the prevalence of *any mental disorder* between Manitoba adults with and without IDD, matched by age, sex, and region of residence; and

(2) Calculate and compare the prevalence of *specific types of mental disorders*, including mood and anxiety disorders, psychotic disorders, and substance use disorders, between Manitoba adults with and without IDD, matched by age, sex, and region of residence.

Chapter 2: Literature Review

The literature review is arranged in the following four sections: (1) epidemiology of intellectual and developmental disabilities, (2) prevalence of mental disorders among adults in the general population, (3) prevalence of mental disorders among adults with IDD and (4) conceptual framework. A summary of the findings is presented at the end of this section.

Epidemiology of Intellectual and Developmental Disabilities

There have been several terms including intellectual disability, developmental disability, learning disability and mental disability that have been used interchangeably in the literature. However, the definition of these conditions changed over time and varies by jurisdiction. The terminology affects the epidemiology. For example, federally, in the US, a **developmental disability (DD)** is defined as

> "a developmental level or status that is attributable to a cognitive or physical impairment, or both, originating before the age of 22. Such an impairment is likely to continue indefinitely and results in substantial functional or adaptive limitations. Examples of developmental disabilities include, but are not limited to, intellectual disability, pervasive developmental disorders, learning disorders, developmental coordination disorder, communication disorders, cerebral palsy, epilepsy, blindness, deafness, mutism, and muscular dystrophy. Also called developmental disorder." (American Psychological Association, n.d.a, para. 1).

According to the same source, **intellectual disability (ID)** is defined as

> "a developmental disability characterized by mild to profound limitations in cognitive function (e.g., learning, problem solving, reasoning, planning) and in adaptive behavior, impairing one's ability to acquire skills typical for one's age group as a child

> or necessary for one's later independent functioning as an adult. In *DSM–5*, a diagnosis of intellectual disability, including its degree of severity, requires clinical assessment of an individual's level of difficulty with conceptual skills (e.g., reading, writing, arithmetic), social skills (e.g., communication, emotion regulation), and practical skills (e.g., self-care, ability to manage activities of daily living). Deficits in cognitive function may be assessed with standardized intelligence tests, but an individual's IQ as measured by such tests is less emphasized in the diagnostic criteria for intellectual disability than in the traditional criteria for mental retardation. Also called intellectual developmental disorder." (American Psychological Association, n.d.b, para.1).

In the United Kingdom, the term learning disability has been used for the same conditions defined as intellectual disability (University of Hertfordshire, n.d.). In Canada, there have been variations in the terminology used by jurisdiction. For example, in Ontario, developmental disabilities have been defined through the Ontario's Services and Supports to Promote the Social Inclusion of Persons with Developmental Disabilities Act and defined in the Act as "A person has a developmental disability for the purposes of this Act if the person has the prescribed significant limitations in cognitive functioning and adaptive functioning and those limitations, (a) originated before the person reached 18 years of age; (b) are likely to be life-long in nature; and (c) affect areas of major life activity, such as personal care, language skills, learning abilities, the capacity to live independently as an adult or any other prescribed activity." (Government of Ontario, 2008, para. 3; Lunsky et al., 2013, p. 8).

In Manitoba, the term used for intellectual disability has been in the Adults Living with an Intellectual Disability Act, where they defined intellectual disability as "significantly impaired intellectual functioning existing concurrently with impaired adaptive behaviour both of which

manifested before the age of 18 years, but excludes an intellectual disability due exclusively to a mental disorder as defined in section 1 of *The Mental Health Act"* (The Legislative Assembly of Manitoba, n.d., para. 27). The IDD research area has been involved in a large transformation to involve a more integrated approach to the field (Schalock et al., 2019). Therefore, operational definitions were re-examined to become more exact (Schalock et al., 2019). IDD terminology has varied in combinations, such as using ID/DD or ID-DD (Schalock et al., 2019). **Intellectual and developmental disabilities** have been defined as combining both intellectual and developmental disabilities (Schalock et al., 2019), which have been disabilities that start at birth and/or childhood where there is a developmental impact. Specifically, "IDDs are differences that are usually present at birth and that uniquely affect the trajectory of the individual's physical, intellectual, and/or emotional development. Many of these conditions affect multiple body parts or systems." (National Institutes of Health, 2021, para. 1).

The epidemiology of disabilities has varied due to differences in methodology. Globally, approximately 15% of the population have had a disability (World Health Organization, 2011; United Nations, n.d.). Of which, 2-4% have had serious functioning difficulties (World Health Organization, 2011) and 1-3% have had IDD (Harris et al., 2006; World Health Organization, 2001). In terms of intellectual disabilities, 10.4 per 1,000 persons of the population across the globe have had intellectual disabilities (Tomlinson et al., 2014). More specifically, in Canada, approximately 1.5% of persons have had developmental disabilities (Statistics Canada, 2023a). Disabilities were measured in a few ways. In Canada, it was namely through post-censal disability surveys, the Health Utilities Index Mark 3, and the Washington Group question set (Statistics Canada, n.d.). In the Canadian province of Manitoba, the prevalence of IDD has been reported at 4.7 per 1,000 persons (0.47%) for persons of all ages using five years of

administrative data (Ouellette-Kuntz et al., 2009). Using all years of administrative data from multiple sources, Shooshtari et al. (2017) estimated that there were about 9,000 adults with IDD living in community in Manitoba, which has been around 0.97% of population.

Prevalence of Mental Disorders among Adults in the General Population

Globally, 12.5%-20% of the population live with a mental illness (World Health Organization, 2022; Steel et al., 2014). In Canada, 18% of Canadians have met criteria for a mental disorder in 2022 for substance use anxiety or mood disorders (Statistics Canada, 2023b); and within a year, 20% of individuals lived with a mental illness (Canadian Mental Health Association, 2021; Centre for Addiction and Mental Health, n.d.; Smetanin et al., 2011). In Manitoba, 27.6% of adults had a diagnosis of mental illness between 2010/11 and 2014/15 recorded in their medical record (Chartier et al., 2018). Table 1 summarizes the prevalence estimates of mental disorders by type globally, in Canada, and in Manitoba. It is important to note that the reported estimates are not comparable due to differences in the definition and methodology including different data sources used.

Table 1

Differences amongst prevalence estimates internationally, in Canada, and in Manitoba

	International	Canada/Other Provinces	Manitoba
Any mental disorder	12.5%-20% Data Source: World Health Organization, Systematic Review and Meta-analysis (Years of data: 1980 to 2013) (World Health Organization, 2022; Steel et al., 2014)	33% Data sources: Canadian Community Health Survey – Mental Health (Government of Canada, 2020)	27.6% Data source: Linked administrative data from Manitoba using a 5-year period prevalence (Chartier et al., 2018)
Mood and anxiety disorders	5.4% mood disorder 6.7% anxiety disorder Data Source: Systematic Review and Meta-analysis (Years of data: 1980 to 2013) (Steel et al., 2014)	11.6% (above 18 years) Data Source: Living with Chronic Diseases in Canada Survey, 2014 (Government of Canada, 2015)	23.2% Data source: Linked administrative data from Manitoba using a 5-year period prevalence (Chartier et al., 2018)
Substance use disorders	3.8% substance use disorder Data Source: Systematic Review and Meta-analysis (Years of data: 1980 to 2013) (Steel et al., 2014)	11.0% Data Source: Canadian Community Health Survey 1.2 (Veldhuizen et al., 2007)	5.9% Data source: Linked administrative data from Manitoba using a 5-year period prevalence (Chartier et al., 2018)
Psychotic disorders	4.6/1,000 persons Data Source: Systematic Review and Meta-analyses (Years of search: 1990 to 2015) (Moreno-Küstner et al., 2018)	51.4/100,000 person/years to 74.5/100,00 person/years * Data Source: Health administrative data from Ontario using a follow-up period of ten years (Rotenberg et al., 2021)	2.3% Data source: Linked administrative data from Manitoba using a 5-year period prevalence (Chartier et al., 2018)

Note. *Incidence was reported. This tables provides a summary of the prevalence estimates. It is not a comparison.

Prevalence of Mental Disorders among Adults with Intellectual and Developmental Disabilities

Mental disorders have been considerably more common among persons with IDD at all ages than among persons without IDD or the general population (Buszewicz et al., 2014; Dunn et al., 2020; Hughes-McCormack et al., 2017; Kalb et al., 2020; Lunsky et al., 2021; Lugo-Marin et al., 2019; Munir, 2016; Pinals et al., 2022; Simpson et al, 2020; Weyrauch et al., 2017), including substance abuse disorders (Durbin, et al., 2019), psychotic disorders (Durbin, et al., 2019; Simpson et al., 2020), and severe mental disorders (Sheehan et al., 2015). A systematic review including 16 papers found that the prevalence of co-occurrence of mental disorders was between 13.9%-74% for population studies and 29%-75.2% for sample-based studies for persons with intellectual disabilities (Buckles et al., 2013). The large range difference could be attributed to the selected diagnostic criteria and selected samples (Buckles et al., 2013). Another study not included in this systematic review from Scotland found that, on March 27, 2011, 23.4% of adults with intellectual disabilities, compared to 5.3% of adults without intellectual disabilities, had a mental illness from Scotland's 2011 Census data (Hughes-McCormack et al., 2017). In another study using population-based data, it was found that, on March 31, 2007, the risk of mental health problems was twice as high among persons with intellectual disabilities compared to persons without intellectual disabilities, and that they have up to three mental health problems more than persons without a disability from Scotland (Cooper et al., 2015).

There have been multiple studies that examined the prevalence of specific mental disorders. Particularly, studies focused on specific psychiatric diagnoses reported higher rates of every diagnosis in those with versus those without IDD. For example, several studies estimated higher rates of mood disorders, including major depressive disorder (e.g., Shooshtari et al., 2011)

as well as anxiety disorders (e.g., Edwards et al., 2022). Conversely, there were studies showing similar rates between persons with and without IDD, and the authors discussed it may have been due to under recognition or undertreatment of certain mental disorders in healthcare (Cooper et al., 2018; Sheehan, 2015). In regards to psychotic disorders, a population-based study from Western Australia reported that schizophrenia was considerably more prevalent in persons with intellectual disabilities compared to persons with intellectual disability without a mental disorder (Morgan et al., 2008). In regards to substance use disorders, it was found in a literature review that using illicit drugs and alcohol was relatively low in persons with IDD; however, there has been limited studies that investigated substance-use problems in this population (Chapman & Wu, 2012). In a population-based study in Ontario, Canada, 6.4% of adults with IDD were found to have substance-related and addictive disorders compared to 3.5% of adults without IDD in 2009 (Lin et al., 2016).

To best address and support people with IDD and mental disorders, it has been important to know which individuals have a higher prevalence. Potential contributors that have been discussed in the literature include sociodemographic contributors, such as age, sex, and region of residence; therefore, examining age, sex, and region of residence can help us determine those individuals. It was highlighted in the literature that the impacts of age and sex on prevalence of mental disorders among individuals with IDD were not well understood (Munir, 2016).

In regard to age, prior research has revealed inconsistent results. Previous research findings showed that mental disorder prevalence is different across the lifespan, such as among children, middle-aged adults, and older adults. In a systematic review and meta-analysis including 192 articles by Solmi et al. (2022), they found that the onset of a mental disorder increased with age. In particular, 34.6% for age 14, 48.4% for age 18, and 62.5% for age 25, with

14.5 as the peak age (Solmi et al., 2022). In the IDD population, impact of age varied depending on the study. The prevalence of mental disorders was found to be high regardless of age (Cooper et al., 2015). The prevalence of mental disorders seemed to have increased with age. For example, a study from Cooper et al. (2015) using population-data from Scotland found that mental disorders occurred more often as people aged but stayed relatively the same among those aged 20-25 and aged 50-54. As well, mental disorders occurred earlier among persons with intellectual disabilities compared to the general population (Cooper et al., 2015). Another study from the United States using longitudinal data found that older adults with IDD were found to have higher frequency of anxiety disorders (Hsieh et al., 2020) than younger adults with IDD. Conversely, from the 2012 Canadian Community Health Survey – Mental Health, mental disorders were more common among Canadians aged 15-24 compared to other age groups (Centre for Addiction and Mental Health. n.d.b., Pearson et al., 2013).

Sex and gender are not synonymous. Sex has been defined as "a set of biological attributes in humans and animals" (Canadian Institutes of Health Research, 2015, para. 1), whereas gender has been defined as "socially constructed roles, behaviours, expressions and identities of girls, women, boys, men, and gender diverse people" (Canadian Institutes of Health Research, 2015, para. 2). Previous research has found that women are more likely to live with mood and anxiety disorders, whereas men were more likely to live with substance use disorders among Canadians using 2012 Canadian Community Health Survey – Mental Health data (Centre for Addiction and Mental Health. n.d.b., Christiansen et al., 2022, Pearson et al., 2013, Suanrueang et al., 2022). Studies that examined sex and gender differences in prevalence of different mental disorders among people with IDD have revealed mostly consistent results (e.g., Axmon et al., 2017; Lunsky et al., 2009; Martin et al., 2021). For example, some studies found

that women with IDD had a higher prevalence of mood disorder diagnosis compared to men with IDD, and higher rates of substance use disorders among men (Axmon et al., 2017; Hsieh et al., 2020; Lunsky et al., 2009; Munir, 2006).

Previous research has reported findings by age by sex. For example, using data from 2012 Canadian Community Health Survey – Mental Health, women were more likely at any age to have depression during 2012, with the highest prevalence for women and men in the age 15 to 24 age group (9% vs 5.3%), followed by the 25 to 44 age group (6.8% vs 4.1%), 46 to 64 age group (5.6% vs 3.4%), and 65+ (1.8% vs 1.4%) (Pearson et al., 2013). Among persons with IDD compared to persons without IDD, using population-data from Scotland, women were more likely to have mental disorders at all ages compared to males (Cooper et al., 2015).

Another factor could be region of residence, which was found to perhaps impact service access (Best et al., 2022; Sibley & Weiner, 2011), and therefore rates of diagnosed mental disorders. Prior research has been mixed. For example, one study in India found a higher prevalence of depressive symptoms among rural settings compared to urban areas using data from the Longitudinal Aging Study (Muhammad, 2023). Whereas another study found that people living in urban regions had a higher prevalence of depression and generalized anxiety disorder from a randomized controlled trial using survey responses in the USA (Bonnel et al., 2022). Yet, another study found no differences among US adults among serious mental disorders or major depression using data from the National Survey of Drug Use and Health (Breslau et al., 2014). There has been less research examining mental disorder prevalence differences by region of residence among persons with IDD. One study from the United Kingdom using the Leicestershire ID Register found that the prevalence of mental disorders between rural and urban settings did not differ (Kiani et al., 2012).

Prior studies conducted in Manitoba examined the prevalence of IDD (Ouellette-Kuntz et al., 2009; Shooshtari et al., 2011), mental disorders (Martens et al., 2004; Chartier et al., 2018), and overall health-related outcomes (e.g., Balogh et al., 2010; Chartier et al., 2015; Hansford et al., 2024). A study on mental illness among Manitobans examined the prevalence for the general population of Manitoba, and for specific sub-populations, for example those residing in a personal care home (see Table 1 for main findings) (Chartier et al., 2018). They did not, however, examine the prevalence of mental disorders among those with IDD. Shooshtari et al. (2011) examined and compared risk of depression and dementia among Manitoba adults with and without IDD using five years of administrative data (from 2000 to 2005). However, depression was the only mental disorder that was examined in that study. They found a significantly higher prevalence and risk of depression among persons with IDD compared to persons without IDD (Shooshtari et al., 2011). In that study, they did not compare prevalence of depression by sex and region of residence. The current study addressed these knowledge gaps for Manitobans with IDD, creating new knowledge about one of the at-risk populations, which was not included in previous studies on mental disorders of the adult Manitoban population.

Conceptual Framework

There have been various disability frameworks that evolved over time. The medical model of disability and the social model of disability have been examples. The medical model of disability has been a conceptual framework that perceived disability as a medical problem, and defined and labelled as the disability (Olkin, 1999; Retief & Letšosa, 2017; World Health Organization, 2002). Disability was defined as impairments that the person has (Olkin, 1999; Retief & Letšosa, 2017; World Health Organization, 2002). It lacked looking at the needs of people (Disability Nottinghamshire, n.d.). In addition, this model did not consider individuals'

characteristics and the environmental factors that may prevent persons with impairments to function, leading to disability, and focused on interventions to treat (World Health Organization, 2002). The social model of disability described disability as a result of how society is organized that led to disability (Disability Nottinghamshire, n.d.). From this perspective, disability was the outcome of how society is allowing or failing to support the person with the health condition (Disability Nottinghamshire, n.d.). The major flaw with this model was that it lacked looking at activities and participation. Another limitation was that this model perceived society being the cause of disability (Owens, 2015; World Health Organization, 2002). Other conceptual frameworks, for example, biopsychosocial models have been used as a valid and holistic approach to study health and mental disorders (Tripathi et al., 2019). According to such a model, the combination of the three domains (biological, psychological, social) influenced the potential to have a mental disorder (Tripathi et al., 2019). In addition, when looking at the etiology of a disability, it may have been caused by one or more of the three domains.

The International Classification of Functioning, Disability and Health (ICF) proposed by the World Health Organization in 2001, served as the conceptual framework informing this study (World Health Organization, 2001). This framework integrated both the medical and social models of disability, offering a biopsychosocial perspective (Centers for Disease Control and Prevention, n.d.). The ICF has been defined as "a framework for describing and organising information on functioning and disability. It provides a standard language and a conceptual basis for the definition and measurement of health and disability" (Centers for Disease Control and Prevention, n.d., para. 1). Within this framework, disability was regarded not only based on individual-level impairments, but also restrictions in activities, and barriers for participation (World Health Organization, 2002). Functioning was explained by body functions (World Health

Organization, 2002). There was a strong emphasis on functioning and health in ICF, instead of disability (World Health Organization, 2002). The past frameworks viewed disability when health stopped, and disability was placed in a separate category (World Health Organization, 2002). The ICF stepped away from this view and looked at social functioning regardless of impairments (World Health Organization, 2002). In other words, the ICF viewed that all humans can experience a health decline, meaning they may have experienced some degree of disability, which moved the focus on health conditions to a common ground (World Health Organization, 2002). "Body function/structure", "activities", and "participation" were included in this framework because they may have impacted individuals' health status. The inclusion of body functions and structures in this framework allowed us to examine functioning at the level of the body to determine impairments. The "activities" component referred to functioning at the individual level and helped us to determine if the person may be experiencing any activity limitation. The "participation" component helped us to better understand the functioning of the person as a member of society. According to this framework, impairments may have led to activity limitations, but not necessarily disability, when people face difficulty functioning as a member of society. According to this framework, environmental factors played a key role in either facilitating, or preventing persons with impairments and activity limitations to be functional members of society.

The ICF helped inform this study through assisting with the selection of the study factors including personal factors (e.g., age, sex), environmental factors (e.g., health region of residence), and disabilities that individuals had in relation to their health, more specifically presence of different types of mental disorders. See Figure 1 for an illustration of the ICF framework and Figure 2 with the variables selected for this study in the ICF categories.

The ICF also helped explain the study design and justified some of the methodological decisions, for example matching based on personal and environmental factors. This framework fits with this project because it provided a perspective on environmental factors that affected disability etiology, related relevant health conditions, and their impacts (Centers for Disease Control and Prevention, n.d.). In addition, as per human rights mandates, the ICF was seen as an appropriate model to use (Centers for Disease Control and Prevention, n.d.; World Health Organization, 2001)

For the purposes of this study, the health conditions of interest were mental disorders. IDD were indicators of the body functions and structures. Age and sex were classified as personal factors. Region of residence was classified as an environmental factor. Age, sex, and region of residence have an impact on individuals' level of functioning and participation, and health conditions (i.e. mental disorders). Conversely, mental disorders can impact other health conditions, body function and structures, activities, participation, personal factors, and environmental factors affecting individual's participation. This framework also informed sub-population analyses by age and sex, because biological, psychological, and social factors may impact each age group and sex differently.

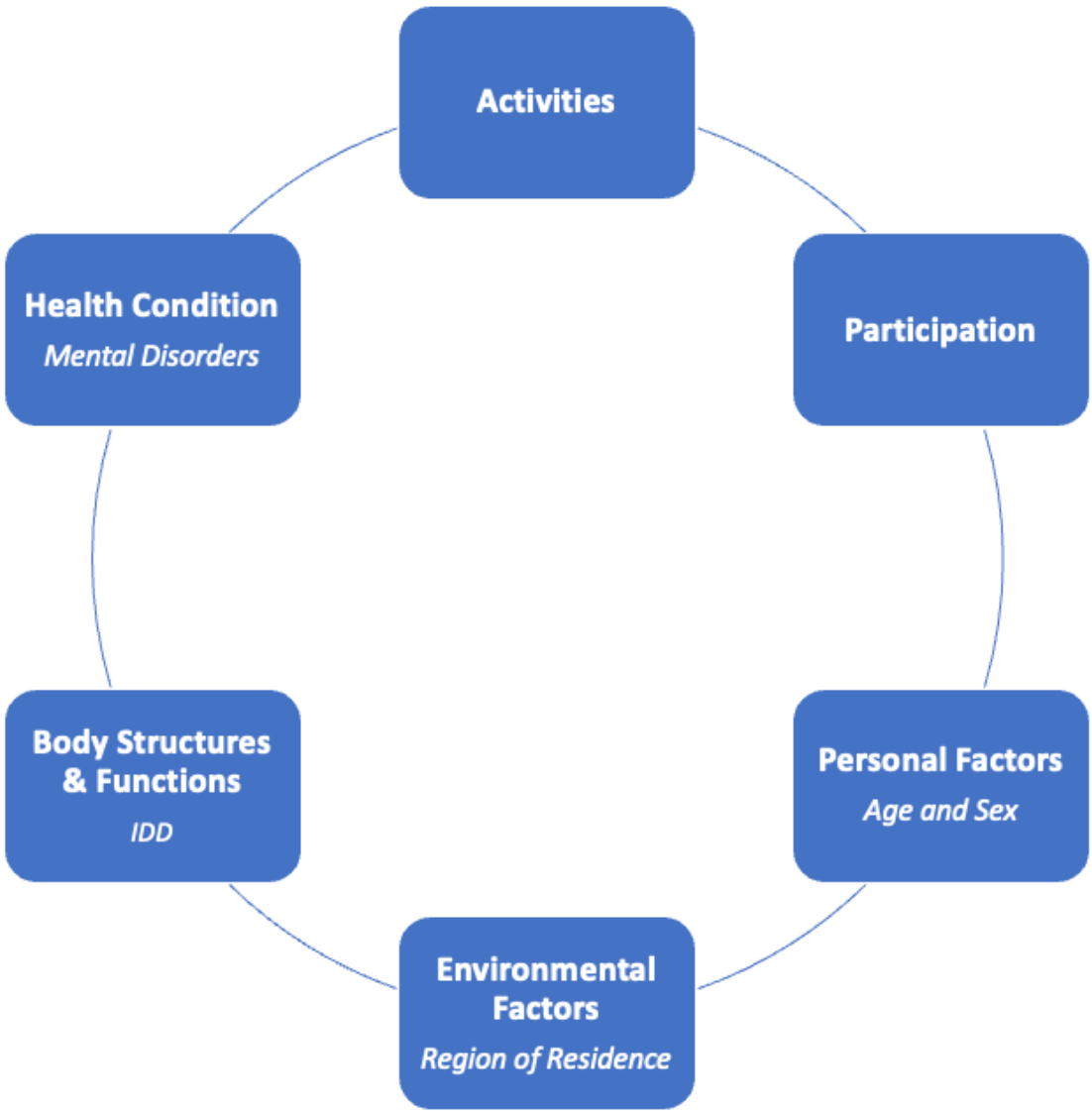
Figure 1

International Classification of Functioning, Disability and Health

Note. PowerPoint was used to create this figure. Built upon content from Centers for Disease Control and Prevention (n.d.). No endorsements are implied. Information from the Centers for Disease Control and Prevention website is free of charge.

Figure 2

International Classification of Functioning, Disability and Health with study variables



Note. IDD = intellectual and developmental disabilities. PowerPoint was used to create this figure. Built upon content from Centers for Disease Control and Prevention (n.d.). No endorsements are implied. Information from the Centers for Disease Control and Prevention website is free of charge.

In addition, the ICF framework helped with the interpretation of the study findings. In the context of mental disorders, an article explained that ICF goes beyond a diagnosis code (Reed et al., 2009). ICF can provide a better description of the situation of the person, what they need, what treatments are appropriate, and systematically describe the therapeutic goals (Reed et al., 2009). In addition, the ICF has been a framework that has been used for policy decision-making and related planning (World Health Organization, 2002); therefore, the ICF helped inform this research through a policy decision-making and planning lens. This research can help policy decision-making and planning, therefore the ICF helped inform these aspects.

Summary

Most of the studies reviewed reported a higher prevalence of mental disorders among adults with IDD compared to those without IDD, or the general population. However, there has been inconsistencies across the studies in terms of their findings and the reported estimates. While the studies discussed above have laid important groundwork in this area, the need for more current research existed. Many of the studies on this topic were over 10 years old, mostly not population-based, and not conducted in Canada. The inconsistent reported findings could also be due to the variation in type of disabilities included (ID versus DD versus IDD). Most of the studies reviewed focused on persons with intellectual disabilities. Although the existing evidence suggested that the prevalence of mental disorders varied by age and sex, reported results were not conclusive. As a population-based approach was found to be a key element for evaluating valid prevalence estimations (Buckles et al., 2013), this study took what we knew a step further by examining and comparing the prevalence of mental disorders between Manitoba adults with and without intellectual and developmental disabilities. This study also provided needed information on the prevalence of Manitobans with IDD. As services and demographics

vary per jurisdiction, it was important to conduct this study using Manitoba data to inform Manitoba policies and services. This thesis provides a solid foundation for surveillance of mental disorders in persons with IDD in Manitoba.

Chapter 3: Methods

Study Design

This research used a retrospective matched cohort study design using linked administrative data.

Setting

This study used population data from Manitoba, Canada. Manitoba has been a central province in Canada with a population of approximately 1,390,000 (Manitoba Bureau of Statistics, 2022). There have been 5 regional health authorities in Manitoba, namely Interlake-Eastern Regional Health Authority, Northern Health Region, Prairie Mountain Health, Southern Health, and Winnipeg Regional Health Authority. Manitobans have been registered for health insurance within 1 of the 5 regional health authorities. In addition to the 5 regional health authorities, Manitoba has had Shared Health, which has organized all Manitoban preventive and clinical services and has assisted in business and administrative operations of health organizations (Shared Health, n.d.a). The Canadian healthcare system has been publicly funded, and some health services have been covered (Government of Canada, 2019). However, not all mental health visits have been covered and captured. Provinces and territories have been entitled to provide the majority of health services that fall in accordance with the Canada Health Act (Government of Canada, 2019).

Data Sources

The Manitoba Centre for Health Policy (MCHP) has housed and maintained the Manitoba Population Research Data Repository, which has been a collection of datasets including registries and administrative data (University of Manitoba, n.d.). The Manitoba Population Research Data Repository has contained data from various government departments

(e.g., health, families, education) and registries on Manitoban residents and has been usually updated yearly (University of Manitoba, n.d.). The de-identified and anonymized data covered all Manitoba residents who were eligible for health care from Manitoba Health. These data could be linked for the purpose of specific research projects, facilitating population-based health studies. Research conducted using MCHP administrative data has added value to the community (e.g., creating and sharing resources, informing policy and practice), as well as had relevancy to regions out of Manitoba (Marchessault, 2011).

Study Population

Manitoba residents, who were at least 18 years of age in 2015, were selected for this study. The cut-off age of eighteen years was used to identify adults, as that is the legal age in the province of Manitoba. Only adults were included in this study, because most of the selected mental disorders are diagnosed in late adolescence or adulthood. All adults in Manitoba who were covered by Manitoba Health to receive healthcare were included in this study, regardless of the duration of their coverage. This included adults who were living in institutions (Manitoba Developmental Centre, St.Amant's Health & Transitions Services, and other long term care facilities), living in the community, and supported by the Public Trustee. For the purpose of this study, we did not have approval to use personal care home data; therefore, we could not identify individuals living in personal care homes to exclude them.

The study population was divided into two groups: (1) the IDD study cohort and (2) the matched comparison group, which consisted of adults without IDD. Members of the IDD cohort were matched with the comparison group without IDD based on age, sex, and region of residence using a ratio of 1:3.

Creation of the IDD cohort

All years of data available were used to identify adults with IDD based on the linked data from January 1, 1979, to March 31, 2015. The de-identified data from these datasets were all linked using a scrambled Personal Health Identification Number (PHIN) for each person through LINKPRO (Katz et al., 2019).

Different datasets became available for the purpose of research through the MCHP Repository at different points in time. Consequently, the years of data used from each dataset was slightly different. Sources of data, years of data, and the indicators used to identify persons with IDD are provided in Table 2.

There has been no validated method to identify individuals with IDD using administrative data. Some individuals may have received their initial diagnosis from a physician, however, in some instances, persons with IDD may have originally received their diagnosis as a child through the education system. Researchers, as noted by Lin et al (2012), have developed province-specific algorithms based on linked data from multiple health and non-health datasets to identify persons with IDD. All these operational definitions use International Classification of Diseases (ICD)-9 and ICD-10 diagnostic codes in medical datasets in addition to other criteria based on other administrative data sources.

To identify persons with IDD in this study, the operational definition of IDD was used, which was originally developed by Ouellette-Kuntz et al. (2009) and further refined by Hansford et al. (2014). Manitoba residents with an IDD were identified within our study population using lifetime data (January 1, 2019 to March 31, 2015) from several datasets including: 1) Hospital Abstracts, 2) Medical Claims/Medical Services, 3) Enrollment, Marks, and Assessments, 4) Employment Income Assistance (EIA)/Social Allowances Management Information Network

(SAMIN), 5) Community Living Disability Services, and 6) Manitoba Fetal Alcohol Spectrum Disorder (FASD) data. Individuals were classified as having an IDD if they met one of the following criteria: "≥1 hospital admission with an eligible IDD diagnosis, or 1≥ education record, ≥ 1 social assistance record, ≥1 community living disability service record, or presence of a confirmed diagnosis in the FASD database, or ≥ 2 physician visits with an eligible IDD diagnosis" (Hansford et al., 2024, para. 4).

The specific data sources, years of data, and diagnostic codes that were used to identify persons with IDD are summarized in Table 2, and further detailed in Appendices 1 and 2.

Table 2

Data sources, years of data, and indicators used to identify persons with intellectual and developmental disabilities

Database Name	Data Provider	Data Years/Months	Indicator/Operational Definition
Enrollment, Marks, and Assessments	Education	January 1, 1995- December 1, 2014	Approved funding for ASD, as detailed: Variables: Categoryn AND statusn Values: 'ASD' AND "approved status"
Hospital Abstracts	Health	January 1,1979-March 25, 2015	1) DXCODE1 TO DXCODE25, values '317', '318', '319', '299', '758', '759', '760' 2) DX10CODE1 TO DX10CODE25, values F700–F701; F708–F711; F718–F721; F728–F731;F738–F739;F780–F781; F788–F791;F798–F799; F840–F841; F843–F845; F848–F849;P043; Q860–Q862;Q868; Q870–Q873;Q875;Q878; Q898; Q900–Q902; Q909–Q917; Q930–Q939; Q992.
Manitoba Fetal Alcohol Spectrum Disorder	Health	January 1, 1999- March 20, 2015	Variable: DIA_diagnosis

			Values: “ARBD”, “ARND”, “ARND/ARBD”, “FAS”, FAS/ARBD”, “PartiaFAS”
Medical Claims/Medical Services	Health	January 1, 1979-February 24, 2015	Variable: DIAG Values: '317', '318', '319', '299', '758', '759', '760'
Children’s disability Services/Community Living disability Services	Social	April 1, 2009-March 31, 2015	An existing record
Employment Income Assistance (EIA)/ Social Allowances Management Information Network (SAMIN)	Social	April 1, 1995-March 1, 2015	Variable: disabilityMRIND Value: ‘Y’

Note. ICD = International Classification of Diseases. International Classification of Diseases are guided and quoted from Chartier et al. (2018) Manitoba Centre for Health Policy Report examining Manitoba adults with mental illness. Details of the IDD codes are in Appendix 2.

Matched Comparison Group

Manitoba adults who did not meet the above definition were classified as those without IDD and formed the eligible pool for creating the matched comparison group. Each Manitoba adult with IDD was matched with three adults without IDD (a matching ratio of 3:1) at the beginning of the study (i.e. April 1, 2015) based on age, sex, and region of residence. Birth year was used for matching by age. All persons with IDD were successfully matched with 3 persons without IDD, except for 1 person with IDD who was matched with 1 person without IDD, based on age, sex, and region of residence. The 1 person with IDD who was matched with 1 person without IDD remained in our cohort because they were a valid match. This procedure has been common at MCHP, as it did not violate the assumption of the statistical testing as matched sets

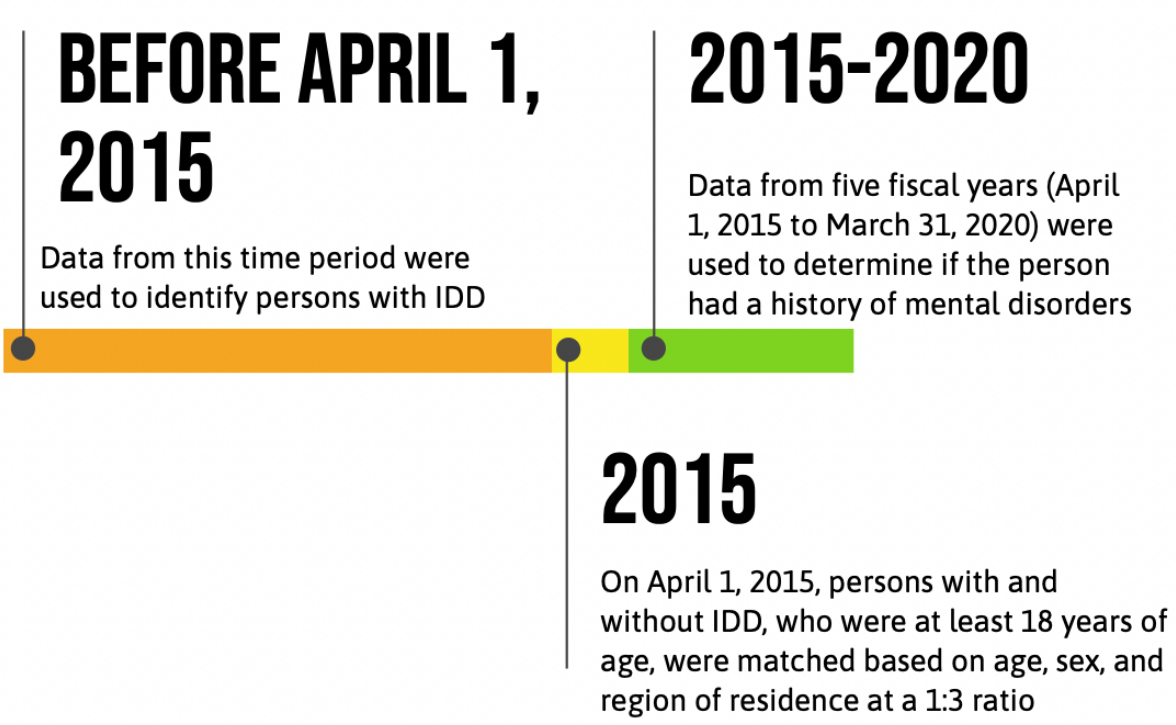
and clusters were allowed to vary in size and exposure ratio; it was more inclusive to keep them and their case in the study.

Prior studies from Shooshtari et al. (2011) and Shooshtari et al. (2017) matched persons with and without IDD at the beginning of the study. This study used similar methodology, implementing hard matching at the beginning (April 1, 2015) of the study where a person with IDD was identified based on the criteria outlined in Table 2 and the rest of the population were potential matches. Socio-economic status was not used to match persons with and without IDD because a significant number of persons with IDD are with the Public Trustee Office and an income quintile would not be assigned to a Public Trustee Office (Manitoba Centre for Health Policy, 2013).

The purpose of having a matched group was to have a comparison group and to attempt to control for possible confounding variables, as well as decreasing bias because of covariates (Stuart, 2010). In addition, a matching group of 3:1 rather than 1:1 was used to have more accurate estimation of the association being studies, increasing precision, and therefore enhancing reliability and validity of the study findings (Rassen et al., 2012). Figure 3 illustrates the timeline of the study measures.

Figure 3

Study measures timeline overview



Note. IDD = intellectual and developmental disabilities. Piktochart was used to create this figure.

Study Measures

Socio-demographics

Age. Age was defined as the time period the person has lived from birth to age at index (April 1, 2015). Age was categorized by transition age youth (18-24), middle age (25-49), and older age (50+ up).

Sex. Sex was defined as the assigned sex at birth of the person. The Manitoba Centre for Health Policy data repository did not contain any data on gender; therefore, we were only able to study sex.

Region of Residence. Manitoba has had 5 regional health authorities and region of residence was described as 1 of the 5 regional health authorities by examining the postal code of residence.

Study Outcomes

To identify mental disorders, five years of data (April 1, 2015-March 31, 2020) were used. Years of data available from each source varied depending on when they became available through the MCHP Repository for the purpose of research. Mental disorder operational definitions, and the methodology used to define them were consistent and guided by the research conducted by Martens et al. (2004) and Chartier et al. (2018). Table 3 provides information on data sources, years of data, and indicators used to identify mental health outcomes used in this study.

Table 3

Data sources, years of data, and indicators used for mental disorders

Database Name	Data Provider	Data Years/Months	Indicator/Operational Definition
Hospital Abstracts	Health	January 1,1979-March 31, 2020	To identify mental disorders through International Classification of Diseases (ICD)-9 and ICD-10 codes: "One or more diagnoses for the following mental disorders: - mood and anxiety disorders - substance use disorders - psychotic disorders (including schizophrenia)" (Chartier et al., 2018, p. 127)
Medical Claims/Medical Services	Health	January 1, 1979-March 31, 2020	To identify mental disorders through International Classification of Diseases (ICD)-9 and ICD-10 codes: "One or more diagnoses for the following mental disorders: - mood and anxiety disorders - substance use disorders

	- psychotic disorders (including schizophrenia)" (Chartier et al., 2018, p. 127)

Note. ICD = International Classification of Diseases. International Classification of Diseases are guided and quoted from Chartier et al. (2018) Manitoba Centre for Health Policy Report examining Manitoba adults with mental illness. See Appendices 1 and 3 for further details on types of mental disorder codes included and more information on the dataset.

Diagnostic Prevalence of Mental Disorders. Diagnostic prevalence indicated the proportion of the population who had a specified condition based on the ICD diagnosis codes (Chartier et al., 2018). Specialized physicians and nurse practitioners diagnosed Manitobans (Chartier et al., 2018). The 5-year diagnostic period prevalence was calculated for the following mental disorder diagnoses: any mental disorders, mood and anxiety disorders, psychotic disorders, and substance use disorders. Mood and anxiety disorders were combined into one category to follow the MCHP approach (University of Manitoba, 2020). This provided the proportion of individuals with a certain condition throughout that 5-year period (Chartier et al., 2018). The operational definitions (not validated) of the mental disorders used are summarized in Table 3.

International Classification of Diseases codes for Mental Disorders. Table 4 summarizes the international classification of diseases codes to be used for mental disorders.

Table 4

Data sources used, years of data, and International Classification of Diseases (ICD) Codes used for identifying a history of mental disorders

Database Name	Main Categories	Definition	Data Fields/Variables	Rationale
- Hospital Abstracts - Medical Services	Any mental disorder	"Any mental illness consists of having at least one of the following disorders examined in this report: mood and anxiety	"One or more diagnoses for the following mental disorders: - mood and anxiety disorders - substance use disorders	To define mental disorders

		disorders, substance use disorders, psychotic disorders (including schizophrenia)" (Chartier et al., 2018, p. 2)	- psychotic disorders (including schizophrenia)" (Chartier et al., 2018, p. 127)	
- Hospital Abstracts - Medical Services	Mood and anxiety disorders	"Mood and anxiety disorders consist of a broad group of mental disorders including depressive (depressed mood and lack of interest in activities), bipolar (periods of elevated mood and increased energy, and periods of depressed mood), and anxiety disorders (excessive fear, anxiety or worry and often avoidance). Examples of anxiety disorders include panic disorder, post-traumatic stress disorder and obsessive-compulsive disorder." (Chartier et al., 2018, p. 2)	"-One or more hospitalizations with a diagnosis for depressive disorder, affective psychoses, neurotic depression, adjustment reaction, bipolar disorder, an anxiety state, phobic disorders or obsessive-compulsive disorders: ICD-9-CM codes 296, 311, 309, 300 or ICD-10-CA codes F30, F31, F32, F33, F34, F38, F40, F41.0, F41.1, F41.2, F41.3, F41.8, F41.9, F42, F43, F53.0 OR - Two or more physician visits with a diagnosis for depressive disorder or affective psychosis, adjustment reaction or for anxiety disorders (including dissociative and somatoform disorders): ICD-9CM codes 296, 311, 309, 300." (Chartier et al., 2018, p. 127)	To define mood and anxiety disorders
- Hospital Abstracts - Medical Services	Psychotic disorders	"Psychotic disorders are a broad group of disorders characterized by extreme impairment of the ability to think clearly, respond emotionally, communicate effectively, understand reality and behave appropriately. Included	"One or more hospitalizations with a diagnosis of psychotic disorders: ICD-9-CM codes 295, 297, 298 or ICD-10-CA codes F11.5, F12.5, F13.5, F14.5, F15.5, F16.5, F18.5, F19.5, F20, F22, F23, F24, F25, F28, F29, OR	To define psychotic disorders

		in this group is schizophrenia and delusional and psychotic disorders." (Chartier et al., 2018, p. 2)	- One or more physician visits with a diagnosis of psychotic disorders: ICD-9-CM codes 295, 297, 298." (Chartier et al., 2018, p. 127)	
- Hospital Abstracts - Medical Services	Substance use disorders	"Substance use disorders are characterized by the excess use of and reliance on a drug, alcohol or other chemical that leads to severe negative effects on the user's health and well-being or the welfare of others." (Chartier et al., 2018, p. 2)	"- One or more hospitalizations with a diagnosis for alcohol or drug psychoses, alcohol or drug dependence, or nondependent abuse of drugs: ICD-9-CM codes 291, 292, 303, 304, 305 or ICD-10-CA codes F10-F19, F55, Z50.2, Z50.3; OR - One or more physician visits with a diagnosis for alcohol or drug psychoses, alcohol or drug dependence, or nondependent abuse of drugs: ICD-9-CM codes 291, 292, 303, 304, 305." (Chartier et al., 2018, p. 127)	To define substance use disorders

Note. ICD = International Classification of Diseases. International Classification of Diseases are guided and quoted from Chartier et al. (2018) Manitoba Centre for Health Policy Report examining Manitoba adults with mental illness. Mental disorder definitions are guided and quoted from Chartier et al. (2018). See Appendices 1 and 3 for further details on types of mental disorder codes included and more information on the datasets.

Data Analysis

Descriptive analyses were conducted to describe the IDD cohort and the matched comparison group and to calculate prevalence of mental disorders for both groups among our study population through the PROC FREQ and PROC MEANS procedures.

To address the first and second research objectives, the crude 5-year period prevalence was calculated using the following equation consistent with MCHP methods (University of Manitoba, 2016):

For persons with IDD:

$$\text{Period prevalence} = \frac{\text{Those who live with mental disorders (type) between April 1, 2015- March 31, 2020}}{\text{Population of persons with IDD}}$$

For persons without IDD:

$$\text{Period prevalence} = \frac{\text{Those who live with mental disorders (type) between April 1, 2015- March 31, 2020}}{\text{Population of persons in the matched comparison group}}$$

The period prevalence was crude and not adjusted. Specifically, to address the first objective, the period prevalence of any mental disorder was calculated and compared between the two study groups (i.e., the IDD cohort and the matched comparison group). To address the second research objective, the prevalence of specific types of mental disorders (i.e. mood and anxiety disorders, psychotic disorders, and substance use disorders) between the two study groups were calculated and compared. The generalized estimating equations (GEE) technique was used to test for statistically significant differences of the prevalence of mental disorders between the IDD study cohort and the matched comparison group. The PROC GENMOD command with a repeated statement code was used. The GEE has been a method to examine correlated data that can be used in longitudinal studies to provide a precise estimate of every variance's effect (University of Manitoba, 2006). The GEE logistic method has been a valid approach for the analysis of matched cohorts. GEE has been typically used for correlated data. For this study, a matched set was considered as having correlated responses, by virtue of belonging to a set of individuals sharing the same value for the confounders. The GEE was

modeled as a logistic regression. Odds ratios and 95% confidence intervals were provided by the GEE, which assessed if the observed differences of the prevalence estimates were statistically significant at $\alpha = 0.05$. The models were not adjusted for any confounders. The GEE was separately calculated for any mental disorder, mood and anxiety disorders, psychotic disorders, and substance use disorders using the repeated statement. As well, when accounting for mental disorder prevalence estimates between April 1, 2015 to March 31, 2020, we did not remove people who may have left the province or passed away during that time; however, we examined the data and around 10% of the people left the cohort in the 5-year period for both persons with and without IDD at a similar rate per year, causing our decision to keep the cohort as defined. All statistical analyses were conducted using SAS version 9.4 remotely.

Feasibility of the Study and Ethics

A feasibility application was completed and submitted to MCHP to evaluate the feasibility of the study. MCHP deemed the study to be feasible. Ethical approval was obtained from the Health Research Ethics Board of the University of Manitoba, #HS26005 (H2023:157). The study was also approved by the Provincial Health Research Privacy Committee (PHRPC#P2023-58), and all the other data providers including the Department of Families, Manitoba Education, and the Rehabilitation Centre for Children. Upon securing all the approvals, the MCHP researcher agreement was completed and approved to access the linked data, specifically developed for this study.

Chapter 4: Results

Demographic Characteristics of the Study Population

A total of 16,524 adults aged 18 years and older living with IDD in Manitoba were identified using lifetime data. These individuals were matched with 49,570 individuals to form a comparison group. To demonstrate matching, Table 5 presents the comparison of age, sex, and region of residence of the IDD cohort and the matched comparison group. The age, sex, and regional distribution of the IDD and the matched comparison group were the same, demonstrating the successful matching between the two groups.

Table 5

Demographics of IDD cohort and the matched comparison group

		IDD	**Matched Comparison Group**
Number of People		16524	49570
Age	Mean	36.95	36.95
	Median	32	32
	Min	18	18
	Max	104	104
Sex (%)	Female	44.49	44.49
	Male	55.51	55.51
Region of Residence (%)	Interlake-Eastern	8.27	8.27
	Northern Health Region	5.4	5.4
	Southern Health-Sante Sud	12.98	12.98
	Prairie Mountain Health	13.44	13.44
	Winnipeg	59.91	59.91

The demographics of persons with IDD are illustrated in Table 6. Of the 16,524 persons with IDD identified, most were in the 25-49 age category, but there was a large group in the transition (18-24) age group considering it represented 5 years. Furthermore, 25% of the cohort was above 50 years of age. There were more males than females. Most of the cohort lived in the Winnipeg Regional Health Authority.

Table 6

Demographics of persons with IDD

		n	Percent (%)
Age	18-24	5263	31.85
	25-49	7128	43.14
	50+	4133	25.01
Sex	Female	7352	44.49
	Male	9172	55.51
Region of Residence	Interlake-Eastern	1367	8.27
	Northern Health Region	892	5.4
	Southern Health-Sante Sud	2145	12.98
	Prairie Mountain Health	2221	13.44
	Winnipeg	9899	59.91

Table 7 illustrates the demographics by age by sex of persons with IDD. In this table, we can see that there are more males than females in those aged 18-24 and 25-49, and more females compared to males in those aged 50+.

Table 7

Demographics of persons with IDD by age by sex

	Sex	
Age	Male	Female
18-24	62.02	37.98
25-49	55.18	44.82
50+	47.79	52.21

Note: Percentage within each age group is reported.

Mental Disorder Prevalence

Any Mental Disorder

The prevalence of any mental disorders was compared between persons with IDD and their matched comparison group. As shown in Table 8, mental disorders were more prevalent among persons with IDD compared to their matched comparison group. Persons with IDD had higher odds of any mental disorders compared to their matched comparison group (OR = 2.13; 95%CI: 2.06, 2.21). The observed difference was statistically significant ($p < .0001$).

Table 8

Prevalence of any mental disorder of persons with IDD and their matched comparison group

	Any Mental Disorder	
	n	% (95%CI)
IDD	7051	42.67 (41.69-43.68)
Matched Comparison Group	12818	25.86 (25.42-26.31)

Mood and Anxiety Disorders

The prevalence of mood and anxiety disorders in persons with IDD compared to their matched comparison group are presented in Table 9. As shown in this table, the prevalence of mood and anxiety disorders among individuals with IDD was higher compared to their matched comparison group. Persons with IDD had higher odds of mood and anxiety disorders compared to their matched comparison group (OR = 1.87; 95%CI: 1.80, 1.94). The observed difference was statistically significant ($p < .0001$).

Table 9

Prevalence of mood and anxiety disorders of persons with IDD and their matched comparison group

	Mood and Anxiety Disorders	
	n	% (95%CI)
IDD	5918	35.81 (34.91-36.74)
Matched Comparison Group	11388	22.97 (22.56-23.40)

Psychotic Disorders

The prevalence of psychotic disorders was compared between persons with IDD and their matched comparison group. As shown in Table 10 psychotic disorders were more prevalent among persons with IDD compared to their matched comparison group. Persons with IDD had higher odds of psychotic disorders compared to their matched comparison group (OR = 7.43; 95%CI: 6.82, 8.09). The observed difference was statistically significant ($p < .0001$).

Table 10

Prevalence of psychotic disorders of persons with IDD and their matched comparison group

	Psychotic Disorders	
	n	% (95%CI)

IDD	1764	10.68 (10.19-11.19)
Matched Comparison Group	785	1.58 (1.48-1.70)

Substance Use Disorders

The prevalence of substance use disorders was compared between persons with IDD and their matched comparison group. As shown in Table 11, substance use disorders were more prevalent among persons with IDD compared to their matched comparison group. Persons with IDD had higher odds of substance use disorders compared to their matched comparison group (OR = 1.9; 95%CI: 1.78, 2.03). The observed difference was statistically significant ($p < .0001$).

Table 11

Prevalence of substance use disorders of persons with IDD and their matched comparison group

	Substance Use Disorders	
	n	% (95%CI)
IDD	1544	9.34 (8.89-9.82)
Matched Comparison Group	2550	5.14 (4.95-5.35)

Sub-analyses of Mental Disorder Prevalence

Table 12 demonstrates the diagnostic prevalence of any mental disorder, mood and anxiety disorders, psychotic disorders, and substance use disorders by age, sex, and region of residence among Manitobans with IDD (i.e., the study cohort). For any mental disorder, the diagnostic prevalence was higher among those aged 25-49, females, and in the Winnipeg Regional Health Authority. In regard to mood and anxiety disorders, the diagnostic prevalence was higher among those aged 25-49, females, and in the Prairie Mountain Health region. Psychotic disorders were more prevalent in those aged 50+, in males, and in the Winnipeg

Regional Health Authority. Substance use disorders were more prevalent among the younger age group (18-24), slightly higher among males, and in Northern Health.

Table 12

Prevalence of mental disorders in persons with IDD by age, sex, and region of residence

		Any Mental Disorders % (95%CI)	Mood and Anxiety Disorders % (95%CI)	Psychotic Disorders % (95%CI)	Substance Use Disorders % (95%CI)
Age	18-24	39.54 (37.88-41.28)	33.06 (31.54-34.65)	8.04 (7.31-8.84)	11.7 (10.82-12.67)
	25-49	44.37 (42.86-45.95)	38.09 (36.68-39.55)	9.81 (9.11-10.56)	10.05 (9.34-10.81)
	50+	43.72 (41.75-45.78)	35.4 (33.63-37.26)	15.53 (14.38-16.78)	5.13 (4.48-5.87)
Sex	Female	46.83 (45.30-48.42)	41.61 (40.16-43.11)	9.26 (8.59-9.99)	9.07 (8.41-9.79)
	Male	39.34 (38.07-40.64)	31.17 (30.50-32.34)	11.81 (11.13-12.53)	9.56 (8.95-10.22)
Region of Residence	Interlake-Eastern	37.38 (34.28-40.77)	31.97 (29.11-35.11)	8.19 (6.81-9.86)	6.95 (5.68-8.50)
	Northern Health	31.5 (28.03-35.41)	19.62 (16.92-22.75)	9.19 (7.40-11.41)	15.36 (12.99-18.16)
	Southern Health-Sante Sud	32.82 (30.48-35.34)	27.93 (25.78-30.25)	6.85 (5.83-8.06)	4.94 (4.09-5.98)
	Prairie Mountain Health	44.75 (42.06-47.63)	39.17 (36.65-41.86)	9.37 (8.18-10.73)	10.31 (9.06-11.74)
	Winnipeg	46.08 (44.76-47.43)	38.76 (37.55-40.01)	12.27 (11.60-12.98)	9.87 (9.27-10.51)

Prevalence of mental disorders by age, sex, and region of residence among persons with IDD compared to the matched comparison group are presented in Table 13. Persons with IDD had a higher prevalence of any and all mental disorders by age, sex, and region of residence compared to the matched comparison group. The highest prevalence of any mental disorder by age was found among those with IDD aged 25-49 and among those without IDD aged 50+ years.

For mood and anxiety disorders, the highest prevalence was found among persons with IDD who were 25-49 years of age, whereas among the matched comparison group, the highest prevalence was found for those who were at least 50 years of age. The highest prevalence of psychotic disorders was found among those who were 50 years of age and older for both groups. The prevalence of substance use disorders was the highest for the youngest age group for persons with IDD and for those aged 25-49 years for persons without IDD. In both study groups, females were more likely than males to have any mental disorder and mood and anxiety disorders, whereas psychotic disorders and substance use disorders were more common among males. Overall, any mental disorders were more prevalent among persons with IDD who were living in Winnipeg Health region, whereas the highest prevalence of any mental disorders among persons without IDD was found among those living in the Prairie Mountain Health region.

Table 14 presents the sex-specific prevalence of any mental disorder and specific types of mental disorders by age for persons with IDD compared to persons without IDD. Persons with IDD had higher prevalence of any, and specific types of mental disorders in each age group by sex compared to persons without IDD.

Table 13

Prevalence of mental disorders of persons with IDD and their matched comparison group by age, sex, and region of residence

		Any Mental Disorder % (95%CI)		**Mood and Anxiety Disorders % (95%CI)**		**Psychotic Disorders % (95%CI)**		**Substance Use Disorders % (95%CI)**	
		IDD	Match	IDD	Match	IDD	Match	IDD	Match
Age	18-24	39.54 (37.88-41.28)	23.16 (22.42-23.92)	33.06 (31.54-34.65)	20.73 (20.03-21.45)	8.04 (7.31-8.84)	1.46 (1.28-1.66)	11.7 (10.82-12.67)	4.93 (4.59-5.29)
	25-49	44.37 (42.86-45.95)	26.49 (25.81-27.19)	38.09 (36.68-39.55)	23.51 (22.87-24.16)	9.81 (9.11-10.56)	1.25 (1.11-1.41)	10.05 (9.34-10.81)	5.77 (5.46-6.11)
	50+	43.72 (41.75-45.78)	28.2 (27.29-29.16)	35.4 (33.63-37.26)	24.91 (24.05-25.81)	15.53 (14.38-16.78)	2.32 (2.07-2.61)	5.13 (4.48-5.87)	4.33 (3.98-4.72)
Sex	Female	46.83 (45.30-48.42)	32.27 (31.53-33.03)	41.61 (40.16-43.11)	30.19 (29.48-30.93)	9.26 (8.59-9.99)	1.45 (1.30-1.61)	9.07 (8.41-9.79)	4.4 (4.13-4.69)
	Male	39.34 (38.07-40.64)	20.72 (20.19-21.26)	31.17 (30.50-32.34)	17.19 (16.70-17.69)	11.81 (11.13-12.53)	1.69 (1.55-1.86)	9.56 (8.95-10.22)	5.74 (5.46-6.03)
Region of Residence	Interlake-Eastern	37.38 (34.28-40.77)	25.13 (23.64-26.71)	31.97 (29.11-35.11)	22.03 (20.64-23.52)	8.19 (6.81-9.86)	1.29 (.99-1.70)	6.95 (5.68-8.50)	5.88 (5.18-6.67)
	Northern Health	31.5 (28.03-35.41)	24.63 (22.82-26.58)	19.62 (16.92-22.75)	17.26 (15.76-18.91)	9.19 (7.40-11.41)	1.76 (1.32-2.34)	15.36 (12.99-18.16)	11.43 (10.22-12.79)
	Southern Health-Sante Sud	32.82 (30.48-35.34)	20.84 (19.75-21.99)	27.93 (25.78-30.25)	18.65 (17.62-19.73)	6.85 (5.83-8.06)	0.98 (.77-1.25)	4.94 (4.09-5.98)	3.61 (3.17-4.10)

	Prairie Mountain Health	44.75 (42.06-47.63)	29.69 (28.41-31.02)	39.17 (36.65-41.86)	26.83 (25.62-28.11)	9.37 (8.18-10.73)	1.46 (1.19-1.77)	10.31 (9.06-11.74)	5.61 (5.07-6.21)
	Winnipeg	46.08 (44.76-47.43)	26.3 (25.72-26.89)	38.76 (37.55-40.01)	23.69 (23.14-24.25)	12.27 (11.60-12.98)	1.77 (1.16-1.93)	9.87 (9.27-10.51)	4.7 (4.46-4.96)

Table 14

Comparing sex-specific prevalence of mental disorders between the IDD cohort and their matched comparison group by age groups

		Any Mental Disorder % (95%CI)		**Mood and Anxiety Disorders % (95%CI)**		**Psychotic Disorders % (95%CI)**		**Substance Use Disorders % (95%CI)**	
		IDD	Match	IDD	Match	IDD	Match	IDD	Match
Females	18-24	46.42 (43.53-49.51)	30.77 (29.40-32.21)	41.32 (38.60-44.24)	29.14 (27.80-30.54)	6.8 (5.75-8.05)	1.12 (.88-1.42)	13.86 (12.32-15.59)	4.63 (4.11-5.20)
	25-49	47.76 (45.43-50.22)	33.03 (31.90-34.20)	43.54 (41.31-45.89)	30.93 (29.83-32.06)	7.48 (6.59-8.49)	1.04 (.86-1.27)	9.55 (8.53-10.68)	5.05 (4.62-5.52)
	50+	45.83 (43.06-48.78)	32.53 (31.17-33.95)	39.02 (36.47-41.74)	30.09 (28.78-31.45)	14.18 (12.68-15.86)	2.35 (2.01-2.76)	3.94 (3.19-4.87)	3.23 (2.82-3.70)
Males	18-24	35.32 (33.34-37.42)	18.49 (17.66-19.36)	28 (26.25-29.88)	15.58 (14.81-16.38)	8.79 (7.83-9.87)	1.67 (1.43-1.94)	10.39 (9.34-11.55)	5.11 (4.68-5.58)
	25-49	41.62 (39.65-43.69)	21.18 (20.36-22.02)	33.66 (31.90-35.53)	17.48 (16.74-18.25)	11.7 (10.67-12.82)	1.41 (1.22-1.65)	10.45 (9.49-11.51)	6.36 (5.92-6.83)
	50+	41.42 (38.67-44.36)	23.49 (22.28-24.75)	31.44 (29.07-34.02)	19.27 (18.18-20.42)	17.01 (15.29-18.93)	2.29 (1.94-2.72)	6.43 (5.40-7.65)	5.53 (4.97-6.17)

Chapter 5: Discussion

The purpose of this study was to examine and compare the prevalence of any mental disorders, and specific types of mental disorders between Manitoba adults with and without intellectual and developmental disabilities, matched by age, sex, and region of residence. Record linkage was used to link several years of administrative data (January 1, 1979, to March 31, 2020) from multiple sources to identify our IDD cohort and the matched comparison group and determine 5-year period prevalence of mental disorders.

A total of 16,524 Manitoba adults with IDD were identified. The average age of Manitobans was 39.7 years (Statistics Canada, 2022b) and the mean age of Manitobans with IDD was 36.95, demonstrating a lower lifespan among persons with IDD. Although persons with IDD have had complex aging, our findings showed that 25% of persons with IDD were above the age of 50, highlighting that persons with IDD may be living longer lives (Merrick et al., 2014).

Two key findings emerged. First, we found that persons with IDD compared to persons without IDD had a higher diagnostic prevalence of any mental disorder (42.67% vs 25.86%). The difference between the IDD group and the matched comparison group was statistically significant for any mental disorder (OR = 2.13; 95%CI: 2.06, 2.21). Second, persons with IDD had a higher prevalence of mood and anxiety disorders (35.81% vs 22.97%), psychotic disorders (10.68% vs 1.58%), and substance use disorders (9.34% vs 5.14%) compared to persons without IDD. The difference between the IDD group and the matched comparison group was statistically significant for mood and anxiety disorders (OR = 1.87; 95%CI: 1.80, 1.94), psychotic disorders (OR = 7.43; 95%CI: 6.82, 8.09), and substance use disorders (OR = 1.9; 95%CI: 1.78, 2.03). These findings aligned with previous research demonstrating a higher prevalence of mental disorders among persons with IDD compared to the general population or persons without IDD

(e.g., Ricciardi, 2013; Whitaker & Read, 2006). In addition, although there were differences in methodology, such as a 2-year period prevalence compared to 5-year period prevalence, the prevalence estimates were similar to Manitoba's neighbouring province, Ontario. More specifically in Ontario, the prevalence of any mental disorder among the IDD population was 41% (vs 42.67% in Manitoba) and prevalence of psychotic disorders among the IDD population was 9.8% (vs 10.68% in Manitoba) (Lin et al., 2016). There are several possible explanations for persons with IDD having had a higher prevalence of mental disorders compared to persons without IDD.

Several environmental and personal factors as well as system-level social factors may have played a role into the higher prevalence of mental disorders in persons with IDD. Limited access to community services and resources, and also lack of training in mental health and IDD for paid and unpaid caregivers were suggested (Shooshtari et al., 2011). Other environmental and personal factors not examined in this study could also contribute to the higher prevalence of mental disorders, such as socioeconomic status, housing, social support, and family history.

The level of severity of the IDD could impact access to quality of life activities and participation in society. Persons with IDD have experienced stigma and ableism, and this could impact mental health. Traumatic event exposures were another risk that persons with IDD experience more than persons without IDD (Houck & Dracobly 2023), which could impact mental health (Benjet et al., 2016).

Other potential explanation may have related to body functions and structures. Prior research has shown that genetics, particularly genomic variants, may increase the risk of mental disorders among children with intellectual disabilities (Wolstencroft et al., 2022). They suggested conducting genomic investigations at an earlier age and/or using an online

Development and Well-Being Assessment (Wolstencroft et al., 2022). In regard to health conditions, persons with IDD have had a higher prevalence of physical health conditions compared to persons without IDD (Liao et al., 2021); therefore, this could be a contributing factor to a higher prevalence of mental disorders.

Diagnostic overshadowing from healthcare providers may have impacted the prevalence findings. Mental disorders may have been misdiagnosed, not diagnosed, or under-diagnosed due to IDD symptoms (Gentile et al., 2014). In particular, mood and anxiety disorders seem to have been under-diagnosed (Gentile et al., 2014). Whereas psychotic disorders seem to have been over-diagnosed (Gentile et al., 2014), which may assist with explaining the greater odds of psychotic disorders among persons with IDD compared to persons without IDD.

Recommendations for Future Research, Interventions and Program Planning

There has been a significant need for research in health sciences on mental disorders of persons with IDD to address their health needs in future studies and augment their quality of life. This research was essential to better comprehend what was effective in the healthcare system and what Manitobans needed to improve mental disorder services (Chartier et al., 2018). The organization of mental health services in other provinces have been different than Manitoba. We need services developed in Manitoba from Manitoba data because socio-demographic information in various jurisdictions (e.g., Ontario) and regions of residence are not the same, such as Manitoba has had a higher proportion of Indigenous people compared to Ontario (Statistics Canada, 2022c). The knowledge of demographic information among the prevalence estimates of mental disorders can assist with developing mental health policies and programs guided towards improving the aging process and service accessibility among persons with IDD, as recommended in previous literature (e.g., Anderson et al., 2013).

In Manitoba, mental health services have been offered through various options by Shared Health, a health authority in Manitoba that works with all the individual health authorities: Interlake-Eastern, Northern Health, Southern Health, Prairie Mountain Health, and Winnipeg Health (Shared Health, n.d.a). There are many kinds of services offered for mental health in Manitoba, such as rural services, a mental health centre, community mental health services, and self-help services (Government of Manitoba, n.d.a). Depending on the age group, different service options are offered (Shared Health, n.d.b). For example, if someone is not coping and would like to receive services that day, a list of resources is provided, such as by the Klinic Crisis Line, and for youth an example is the Kids Help phone (Shared Health, n.d.b). If someone would like a service for ongoing support, other services are offered, such as the Turning Pages service for people above the age of 50 years (Shared Health, n.d.b). Additionally, there are service navigation specialists from the Canadian Mental Health Association, and they can help inform a person of a service that can help them (Canadian Mental Health Association, n.d.).

As for persons with IDD, they have access to publicly funded mental health services available in the community listed above. The Community Living Disability Services helps to navigate mental health services for adults with intellectual disabilities (Government of Manitoba, n.d.b). The Manitoba Adolescent Treatment Centre offer supports for mental health in youth (5 to 18) with neurodevelopmental issues that are complex (Manitoba Adolescent Treatment Centre, n.d.). Specialized Services for Children and Youth (SSCY) and St.Amant are other organizations in Manitoba supporting Manitobans with IDD with their health including mental health needs. Although there are some tailored services for specific for children and youth with IDD, there are less services, including mental health services available for adults with IDD in the community (Community Living Manitoba, 2021).

Findings from this study inform the mental health care of persons with IDD. Existing services are not adequate for persons with IDD, and specific services should be created to help address the significantly higher prevalence of mental disorders among persons with IDD compared to persons without IDD. The findings from this study are relevant to how mental health services are offered to persons with IDD. This information can be used to better equip and provide mental health services to this population by informing policy decision-makers. Other resources and programs can be created to enhance the social determinants of health of persons with IDD to perhaps reduce mental disorder prevalence estimates. Prior training of staff has been inadequate (Community Living Manitoba, 2021; Pinals et al., 2022); these findings can also be used for training of staff with regards to recognizing and supporting the mental health needs of persons with IDD. Methods to train staff could be in-person or online courses, workshops, as well as program curriculum review to add IDD as a topic (e.g., nursing or medical school). Information on common types of mental disorders can be used for training of families and support staff, and advocacy for preventive measures, such as screening.

The 2018 Canadian Consensus Guidelines on the primary care of adults with IDD provides many recommendations for the mental health and mental disorders of persons with IDD (Sullivan et al., 2018), and Manitoba can implement programs and policies for persons with IDD following these guidelines. An example from this guideline includes “proactively plan with the persons with IDD, caregivers, and appropriate services to attend to predictable developmental challenges and stressors and to ensure that the necessary supports will be in place” (Sullivan et al., 2018, Table 3). In particular, a series of point of care tools were developed to help primary care providers to adhere to the 2018 Canadian Consensus Guidelines with focus on mental health (Surrey Place, n.d.). These may be helpful in Manitoba. For example, Manitoba can also

implement recommendations to screen for trauma at all times and not prescribe antipsychotics as a first line intervention for challenging behaviour (Surrey Place, n.d.).

Findings can also provide updated information for surveillance on selected types of mental disorder prevalence in Manitoba. Persons with IDD were mentioned to be often unseen in surveillance (Krahn & Havercamp, 2019); therefore, results bring needed knowledge to surveillance. Future research based on this study can be conducted, for example, to understand reasonings to why persons with IDD are at a greater odds for mental disorders and how to best treat and minimize negative mental health outcomes for persons with IDD. Future research should examine information not captured in this study from this study using the ICF framework to better understand the whole context, such as through a qualitative study.

Strengths and Limitations

This was the first population-based study conducted looking at the prevalence of mental disorders among adults with IDD in Manitoba using population data. Earlier studies have called for this type of research, such as the recommendation to use population-based methods to examine prevalence (Buckles et al., 2013; Shooshtari et al., 2011), to minimize health disparities (Anderson et al., 2013), to decrease anxiety impacts (Adams & Malone, 2021), and to assess substance use problems in persons with intellectual disabilities (Chapman & Wu, 2012).

Multiple years of health and non-health administrative data from multiple sources housed and maintained in Manitoba Population Research Data Repository of the MCHP were linked and analyzed to identify our study groups (i.e., Manitoba adults with and without IDD) to determine prevalence of mental disorders. As well, the population coverage from the MCHP repository was another strength. We were able to get data from most residents of Manitoba, except for people federally insured (i.e. military and federal incarcerations) and on-reserve Indigenous populations

due to data collection not occurring in a few reserve communities (Katz et al. 2019). Our operational definitions of IDD and mental disorders followed previous studies that used and reviewed these operational definitions. These definitions have been the standard used at MCHP and were refined over time. Further research should examine the validity of these definitions.

This research was a step to improving the health of persons with IDD living in community in Manitoba. Given the higher prevalence among persons with IDD, there is clearly a need for mental health supports and attention to how to prevent mental disorders are needed. Furthermore, this research provides important information for surveillance that could improve the services and health of persons with IDD. In addition, this research can help plan psychiatric disorder diagnosis and treatment programs and services (Chartier et al., 2018).

There were a few limitations to this study, especially with using administrative data with the selected datasets. With regards to mental disorders, only physician diagnosed psychiatric disorders were included in the datasets, and therefore in this study. This would exclude people who were not diagnosed with a mental disorder by a physician. Similarly, these data did not include private healthcare; therefore, private healthcare visits (e.g., psychologist visits) and subsequent diagnoses are excluded. The Canadian health care system does not publicly cover many mental health services, such as services offered by a psychologist in a private setting. As a result, the prevalence may have been underestimated since many diagnoses may be missed. In addition, there were limitations with cohort identification. Not all adult residents of Manitoba were included in the study as data were only available for those who were eligible for health coverage. Furthermore, the definition for defining the IDD cohort has face validity as it was reviewed and developed in collaboration with clinicians, and researchers who have expertise in this area. However, the validity of the IDD operational definition was not formally tested and

was only tested for face validity. This thesis also did not examine many types of mental disorders, and further examination into other types is warranted, including separating mood and anxiety disorders. Administrative data also has limited social determinants of health variables. A further examination of variables encompassing social determinants of health are needed. Furthermore, we did not present information about co-morbidities (i.e. other health conditions and/or other mental disorders) and we did not know about severity of the disability, which could impact what they do and how they participate, therefore impacting mental health.

Information from the Drug Program Information Network was not included in this study because a mental health medication could be prescribed for another health condition. Inappropriate prescribing practices and polypharmacy have been common among persons with IDD and could create an over-estimated prevalence (Lonchampt et al., 2021; O'Dwyer et al., 2018). However, excluding the Drug Program Information Network may have caused an under-estimation in the prevalence. In addition, personality disorders were excluded because it was inappropriate to estimate this prevalence among persons with IDD (Gentile et al., 2022).

In addition, there were a few limitations with the selected datasets. For mental disorders, only 1 diagnosis could be included in medical claims per visit, whereas over 20 records could be included in hospitalization per visit. As persons with IDD have been more likely to be hospitalized (Balogh et al., 2010), this may have caused an over-estimation in the prevalence of mental disorders for persons with IDD. Furthermore, the datasets selected for IDD posed some limitations. See Appendix 4 for details on the proportion of persons with IDD in each dataset and the total overlapped number in each dataset. There were some datasets that had a considerably higher number of people included compared to others, and the overlap between datasets should be considered. As well, for both mental disorders and IDD datasets, the diagnostic code reported

is not clinically diagnosed. More specifically, a healthcare provider may have entered a code suspicious of the condition, but after further investigation, they were deemed to not have the condition. However, the code was still in their records, and therefore included in this study, causing a potential over-estimation in the prevalence.

Knowledge Translation

Findings will be shared with study data providers (Manitoba Health, Department of Families, Manitoba Education, and Rehabilitation Centre for Children) through e-mailing them dissemination products related to this project. Most importantly, findings will be shared with persons with IDD and their families. User friendly research summaries will be created and shared with persons with IDD, their families, and care providers in the community. For example, we will share information about this study with the St.Amant Parents Association and Inclusion Winnipeg to get their feedback on this research, and in particular, we will consult with them for the interpretation of the study results. I can provide a brief presentation of the findings at one of their meetings, as well as distributing simple user-friendly and accessible materials through their organization. In addition, I will disseminate the study findings through infographics and a media release. For example, I will create and disseminate a summary of these research findings in the form of an infographic with a focus on mental health in persons with IDD to different organizations focused on the well-being of persons with IDD in collaboration with my committee members. Furthermore, this project will be published in the scientific literature through journals. In addition, findings will be shared through conferences by first applying with an abstract to selected conferences. A poster and/or slides will be presented to various audiences.

Chapter 6: Conclusion

This was the first population-based study in Manitoba examining any and selected types of mental disorders among persons with IDD. This thesis provided insight into the prevalence of mental disorders among persons with IDD. It was found that the prevalence of any and specific types of mental disorders were significantly higher among persons with IDD compared to persons without IDD, matched by age, sex, and region of residence. Future research should examine and explore methods to understand the underlying factors leading to the higher prevalence among persons with IDD. In addition, findings from this thesis demonstrated the need for more effective and new policies and programs to promote mental health of persons with IDD. It is evident that training for healthcare professionals and direct support staff and provision of accessible mental health services to support all Manitoba residents, and in particular those with IDD are required. The study results contribute to providing evidence to advocate for more effective allocation of resources to support persons with IDD, to advocate for policy decisions around the allocating of funds, and to support disability policies that are being developed at the federal and provincial level.

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Appendix 1

Databases Used

Database Name	Description	Indicator from the Source
Enrollment, Marks, and Assessments	"Education data maintained by Manitoba Education that provides information on enrollment, courses, marks, standard tests, assessments, graduation status, level of funding, and demographics for Manitoba students from Kindergarten to Grade 12. Students from public and private schools, as well as those that are home schooled, are included. Information concerning First Nations schools is unavailable. Data are available at the individual student, school division, and district levels."[1]	To identify persons with intellectual and developmental disabilities
Hospital Abstracts	"Health data maintained by Manitoba Health consisting of hospital forms/computerized records containing summaries of demographic and clinical information (e.g., gender, postal code, diagnoses and procedure codes) completed at the point of discharge from the hospital. Several hundred thousand abstracts per year are submitted for all separations from acute and chronic care facilities in Manitoba and for all Manitobans admitted to out-of-province facilities. The Hospital Abstracts Data includes records of both Manitoba residents and non-Manitoba residents hospitalized in Manitoba facilities and information about inpatient and day surgery services."[2]	- To identify persons with intellectual and developmental disabilities - To identify the following mental disorders: any mental disorder, mood and anxiety disorders, substance use disorders, psychotic disorders
Manitoba Fetal Alcohol Spectrum Disorder (FASD)	"Clinical health data that provide details concerning Manitoba preschool children, school age children, adolescents, and adults with Fetal Alcohol Spectrum Disorder (FASD) identified through the	- To identify persons with intellectual and developmental disabilities

	Manitoba FASD Centre program. In conjunction with several Regional Health Authority Diagnostic Coordinators, the Manitoba FASD Centre provides referrals, assessments, and access to community resources following a diagnosis of FASD, as well as education, training and research. To be included, individuals must have known prenatal alcohol exposure, developmental and learning concerns, and consent of their legal guardian if under 18 years of age. Information available includes reason for referral, history, growth parameters, developmental assessment, genetic assessment, diagnosis, and behavioural/OT concerns."[3]	
Medical Claims/Medical Services	"Health data maintained by Manitoba Health consisting of claims for visits to physicians/primary care providers in offices, hospitals and outpatient departments; fee-for-service components for tests such as lab and x-ray procedures performed in offices and hospitals; payments for on-call agreements (e.g. anaesthetists) that are not attributed to individual patients; as well as information about physician specialties. These data files contain records for both Manitoba and non-Manitoba residents who visit Manitoba providers. Some information is also included for services received by Manitoba residents from providers in other provinces. In Manitoba, fee-for-service providers must submit claims to Manitoba Health for reimbursement; a small proportion of salaried physicians/providers also submit evaluation claims (shadow billing)."[4]	- To identify persons with intellectual and developmental disabilities - To identify the following mental disorders: any mental disorder, mood and anxiety disorders, substance use disorders, psychotic disorders
Manitoba Health Insurance Registry	"A longitudinal population-based registry maintained by Manitoba	- To match and describe age and sex

	Health of all individuals who have been registered with Manitoba Health at some point since 1970. The registry includes individual-level demographics, family composition information, residential postal codes, and data fields for registration, birth, entry into province, and migration in/out of province. It provides the needed follow-up information to track residents for longitudinal and intergenerational analyses. Individuals who are insured federally, such as military personnel and federal inmates, are not included in this dataset. RCMP were previously excluded but began to be included as of April 1, 2013. MCHP receives "snapshot files" of registry data semi-annually from Manitoba Health; these files are central to the use of the Data Repository."[6]	
Children's Disability Services/Community Living Disability Services	"The Children's Disability Services (CDS) / Community Living DisABILITY Services (CLDS) data contains information on the conditions, services and supports provided to participants of the disability programs provided by the Manitoba Department of Families. Participants are assessed and must have a specific disability in order to be eligible for the services / supports offered. Depending on individual needs, specific services / supports are available. The data is divided into two files: children's services and adult services. The data contains participant demographic information (e.g. date of birth, gender, language, and marital status if applicable); referral sources; associate relationships and roles; primary disability / diagnosis and other (e.g. hearing, mobility) disability / limitation indicators; assessment information and dates;	- To identify persons with intellectual and developmental disabilities

	eligibility decision status; participant and program status indicators; and family status / assessment information. The CLDS data also includes primary and secondary funding source information; requested services from referral sources; living arrangements; days activities; areas of impaired adaptive behaviour (AIAB); legal status of the participant; and other information / special considerations important to case planning."[8]	
Employment Income Assistance (EIA)/ Social Allowances Management Information Network (SAMIN) Data	"The Social Allowances Management Information Network (SAMIN) database contains data on Manitoba clients who are part of the Employment and Income Assistance (EIA) Program. This data is maintained by the Manitoba Department of Families and provides information on Manitoba residents who receive financial help who have no other way to support themselves or their families. EIA data files contain one record per person (client) for each month they are present in the Social Allowances Management Information Network (SAMIN) database. Data are available at the client or family level, and include client demographics, case level details and characteristics, education level, income, and employment details."[9]	- To identify persons with intellectual and developmental disabilities

Note. [1]http://mchp-appserv.cpe.umanitoba.ca/dataDescriptions.php?ds=EMA [2]http://mchp-appserv.cpe.umanitoba.ca/dataDescriptions.php?ds=Hospital [3]http://mchp-appserv.cpe.umanitoba.ca/dataDescriptions.php?ds=MBFASD [4]http://mchp-appserv.cpe.umanitoba.ca/dataDescriptions.php?ds=MedicalClaims [5]http://mchp-appserv.cpe.umanitoba.ca/dataDescriptions.php?ds=DPIN [6]http://mchp-appserv.cpe.umanitoba.ca/dataDescriptions.php?ds=Insurance [7]http://mchp-appserv.cpe.umanitoba.ca/dataDescriptions.php?ds=Census [8]http://mchp-

appserv.cpe.umanitoba.ca/dataDescriptions.php?ds=CDS-CLDS [9]http://mchp-appserv.cpe.umanitoba.ca/dataDescriptions.php?ds=Samin

Appendix 2

IDD Diagnostic Codes

Database Name	Code
Enrollment, Marks, and Assessments	Categoryn – special needs category for special education funding Statusn –status of funding (approved/not approved, etc.)
Hospital Abstracts	"317 = Mild Mental Retardation (MR) 318 = Other MR 319 = Unspecified MR 758.0 - 758.3 = Chromosomal Anomalies (includes Down's, Patau's and Edward's syndromes) 759.81 - 759.89 = Other and unspecified congenital anomalies (includes Fragile x and Prader-willi syndromes) 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, F84.5, F84.8, F84.9 = Pervasive developmental disorders; P04.3 = Fetus and newborn affected by maternal use of alcohol (this excludes fetal alcohol syndrome = Q86.0) Q86.0, Q86.1, Q86.2, Q86.8 = Congenital malformation syndromes due to known exogenous causes, not elsewhere classified; Q87.0, Q87.1, Q87.2, 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, Q90.9 = Down's syndrome; Q91.0, Q91.1, 91.2, Q91.3, 91.4, Q91.5, 91.6, Q91.7 = Edward's syndrome and Patau's syndrome; Q93.0, Q93.1, Q93.2, Q93.3, Q93.4, Q93.5, Q93.6, Q93.7, Q93.8, Q93.9 = Monosomies and deletions from the autosomes, not elsewhere classified; and · Q99.2 = Fragile X chromosome”[1]
Manitoba Fetal Alcohol Spectrum Disorder (FASD)	DIA_diagnosis – diagnosis from provider at visit "ARBD" - alcohol-related birth defects, "ARND" - alcohol-related neurodevelopmental disorder, "ARND/ARBD", "FAS" - fetal alcohol syndrome, "FAS/ARBD", or · "Partial FAS".”[1]

Medical Claims/Medical Services	"317 = Mild Mental Retardation (MR) 318 = Other MR 319 = Unspecified MR 299 = Autism and other psychoses with origin specific to childhood"[1]
Children's Disability Services/Community Living Disability Services	If a child/adult had a record in this database, they had a disability and were included by default.
Employment Income Assistance (EIA)/ Social Allowances Management Information Network (SAMIN)	disabilityMRIND = Mental Retardation Disability Indicator Involvement (Y/N) for those who receive income/employment assistance for themselves or family members

Note. [1]http://mchp-appserv.cpe.umanitoba.ca/viewConcept.php?conceptID=1365

Appendix 3

ICD codes for Mental Disorders

Mental Disorder	Code
Mood and anxiety disorders	296, "bipolar i disorder, single manic episode, unspecified"[1] 311, "depressive disorder, not elsewhere classified"[1,3] 309, "adjustment reaction"[1,3] 300, "anxiety states"[1] F30, "manic episode"[2] F31, "bipolar disorder"[2] F32, "major depressive disorder, single episode"[2] F33, "major depressive disorder, recurrent"[2] F34, "persistent mood [affective] disorders"[2] F38, "other single mood [affective] disorders"[2] F40, "phobic anxiety disorders"[2] F41.0, "panic disorder [episodic paroxysmal anxiety] without agoraphobia"[2] F41.1, "generalized anxiety disorder"[2] F41.2, "mixed anxiety and depressive disorders"[2] F41.3, "other mixed anxiety disorders"[2] F41.8, "other specified anxiety disorders"[2] F41.9, "anxiety disorder, unspecified"[2] F42, "obsessive-compulsive disorder"[2] F43, "reaction to severe stress, and adjustment disorders"[2] F53.0, "puerperal psychosis"[2]
Psychotic disorders	295, "simple type schizophrenia, unspecified"[1] 297, "paranoid states"[1] 298, "other nonorganic psychoses"[1] F11.5, "mental and behavioural disorders due to use of opioids : psychotic disorder"[2]

	F12.5, “mental and behavioural disorders due to use of cannabinoids : psychotic disorder”[2] F13.5, “mental and behavioural disorders due to use of sedatives or hypnotics : psychotic disorder”[2] F14.5, “mental and behavioural disorders due to use of cocaine : psychotic disorder”[2] F15.5, “mental and behavioural disorders due to use of other stimulants, including caffeine withdrawal state : psychotic disorder”[2] F16.5, “mental and behavioural disorders due to use of hallucinogens : psychotic disorder”[2] F18.5, “mental and behavioural disorders due to use of volatile solvents : psychotic disorder”[2] F19.5, “mental and behavioural disorders due to multiple drug use and use of other psychoactive substances : psychotic disorder”[2] F20, “schizophrenia”[2] F22, “delusional disorders”[2] F23, “brief psychotic disorder”[2] F24, “shared psychotic disorder”[2] F25, “schizoaffective disorders”[2] F28, “other psychotic disorder not due to a substance or known physiological condition”[2] F29, “unspecified psychosis not due to a substance or known physiological condition”[2]
Substance use disorders	291, “alcoholic psychoses”[1] 292, “drug psychoses”[1] 303, “alcohol dependence syndrome”[1] 304, “drug dependence”[1] 305, “nondependent abuse of drugs”[1] F10-F19, “alcohol related disorders, opioid related disorders, cannabis related disorders, sedative, hypnotic, or anxiolytic related disorders, cocaine related disorders, other stimulant related disorders, hallucinogen related disorders,

	nicotine dependence, inhalant related disorders, other psychoactive substance related disorders"[2] F55, "abuse of non-psychoactive substances"[2] Z50.2, "alcohol rehabilitation"[2] Z50.3, "drug rehabilitation"[2]

Note. Resources used to find codes: [1]https://icd.codes/icd9cm, [2]https://icd.codes/icd10cm, & [3]https://www2.gov.bc.ca/assets/gov/health/practitioner-pro/medical-services-plan/diag-codes_mental.pdf

Appendix 4

IDD Dataset Counts

The count and percent of the IDD datasets are listed in Table 15. The dataset with the highest count of persons with IDD was from the Medical Claims/Medical Services dataset and the one with the lowest count was the Manitoba Fetal Alcohol Spectrum Disorder dataset. The number of cases from each database source overlapped is as follows:

- Children's Disability Services dataset only = 155
- Community Living Disability Services only = 602
- Enrollment, Marks, and Assessment dataset only = 769
- Fetal Alcohol Spectrum Disorder dataset only = 177
- Hospital Abstracts only = 2026
- Medical Claims only = 2733
- Social Allowances Management Information Network dataset only = 1481

Table 15

Percentage of persons with IDD identified from the datasets

	Children's Disability Services	Community Living Disability Services	Enrollment, Marks, and Assessments	FASD	Hospital Abstracts	2+ Medical Claims	SAMIN
n	1401	6703	3943	441	6321	8040	7333
%	8.48	40.57	23.86	2.67	38.25	48.66	44.38

Note. FASD= Fetal Alcohol Spectrum Disorder. SAMIN= Social Allowances Management Information Network. The total number of people across all seven data sources is larger than the total number people in our IDD cohort as a result of overlap.