Annual Incidence of Traumatic Brain Injury among Ontario adults with and without Intellectual and Developmental Disabilities and 30-Day Readmissions

by

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Annual Incidence of Traumatic Brain Injury among Ontario adults with and without Intellectual and Developmental Disabilities and Problematic Healthcare Outcomes

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ABSTRACT

This thesis examines Ontario adults with and without intellectual and developmental disabilities (IDD), to identify traumatic brain injury (TBI) incidence and the impact of TBI history on 30-day readmissions.

Objectives: 1) compare TBI incidence between adults with and without IDD over time and by demographic characteristics; 2) compare odds of 30-day readmissions between adults with IDD, history of TBI, or both in 2016/17.

Manuscript 1: Using a historical cohort design, TBI incidence was greater among adults with IDD versus without in all 15 study years.

Manuscript 2: This historical cohort study determined that having IDD or IDD and a history of TBI increased the odds of 30-day readmissions versus history of TBI only.

Conclusion: Results of this thesis suggest that among adults with IDD, risk of TBI is higher versus those without IDD, and 30-day readmissions are similarly increased among those with IDD with or without a history of TBI.

Keywords: traumatic brain injury; developmental disability; epidemiology; readmissions

AUTHOR'S DECLARATION

I hereby declare that this thesis consists of original work of which I have authored. This is a true copy of the thesis, including any required final revisions, as accepted by my examiners.

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The research work in this thesis that was performed in compliance with the regulations of UOIT's Research Ethics Board/Animal Care Committee under **REB Certificate number/Animal care certificate file number**.

_____ Katherine Seto

STATEMENT OF CONTRIBUTIONS

Part of the work described in Chapter 3 has been published online in the form of an abstract as:

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And a poster as:

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I performed the majority of the synthesis, data analysis, and writing of the manuscript.

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TABLE OF CONTENTS

LIST OF TABLES

CHAPTER 2

CHAPTER 3

CHAPTER 4

LIST OF FIGURES

CHAPTER 2

CHAPTER 3

CHAPTER 4

LIST OF ABBREVIATIONS

ABI	Acquired brain injury
AS-SIR	Age/sex standardized incidence rate
CAPE	Client Agency Program Enrolment
CI	Confidence interval
CIHI	Canadian Institute for Health Information
CPDB	Corporate Provider Database
CSize	Community size
DAD	Discharge Abstract Database
DALYs	Disability-adjusted life years
DSM-5	Diagnostic and Statistical Manual of Mental Disorders, 5th edition
ED	Emergency department
ESTSOB	Estimated Schedule of Benefits
H-CARDD	Health Care Access Research and Developmental Disabilities
ICD	International Classification of Diseases
ICES	Institute for Clinical Evaluative Sciences
IDD	Intellectual and developmental disabilities
IKN	ICES key number
INST	Database for Ontario-based health care institutions
IPDB	ICES Physician Database
IQ	Intelligence Quotient
LHIN	Local health integration network
LOS	Length of stay

MI	Mental illness
n-TBI	Non-traumatic brain injury
NACRS	National Ambulatory Care Reporting System
OHIP	Ontario Health Insurance Plan
OMHRS	Ontario Mental Health Reporting System
ON-Marg	Ontario marginalization database
OR	Odds ratio
POPCAN	Database for Canadian inter-censal estimates
RPDB	Registered Persons Database
SDS	Same Day Surgery
TBI	Traumatic Brain Injury
UPC	Usual Provider Continuity

1 INTRODUCTION

1.1 Introduction to Thesis

1.1.1 Intellectual and Developmental Disabilities

For this research, intellectual and developmental disabilities (IDD) were defined using the Government of Ontario (2012) definition for "developmental disability": a lifelong impairment in intellectual functioning and adaptive behaviour which developed prior to the age of 18, and is pervasive in many major life areas such as personal care, cognitive and social ability, and the ability to live independently as an adult. Intellectual functioning encompasses cognitive abilities such as an individual's ability to learn, reason, and problem solve. Intelligence quotient (IQ) tests are the typical tool employed for evaluating intellectual functioning; intellectual impairment is indicated when an individual scores 70-75 or lower (American Association on Intellectual and Developmental Disabilities [AAIDD], 2018). Adaptive behaviour is described in terms of skill level in three domains: 1) conceptual skills including language, math, and self-direction; 2) social skills including self-esteem, the ability to empathize with others, and the ability to make and maintain friendships; and 3) practical skills including occupational and self-management skills (AAIDD, 2018). Using this definition, there are approximately 66,000 adults living with a diagnosis of IDD in Ontario (Lunksy, Klein-Geltink, & Yates, 2013).

1.1.2 Ambiguities in Terminology

The definition of IDD used in this research is consistent with the definition outlined by the Government of Ontario to describe individuals diagnosed with "developmental disability" (Government of Ontario, 2012). With some minor differences, the term developmental disability refers to the same population as when the

term “intellectual disability” is used. Intellectual disability is defined in the Diagnostic and Statistical Manual of Mental Disorders, fifth edition (DSM-5) as impairments in intellectual functioning as determined by an IQ test, as well as an impairment in adaptive functioning, with onset during the developmental period (American Psychological Association, 2013). The term intellectual disability is commonly used in other countries including the United States where, until recently, the term used was “mental retardation”. In the United Kingdom, the term “learning disability” is also used for the same population. (Lin et al., 2019)

Due to the considerable overlap in definitions, the nomenclature “intellectual and developmental disabilities” has been used in scientific literature worldwide and is being adopted by international organizations such as the American Association on Intellectual and Developmental Disabilities and the International Association for the Scientific Study of Intellectual and Developmental Disabilities (National Institute of Child and Human Development, 2016). In this research, the term “intellectual and developmental disabilities” was also adopted in order to remain consistent with international literature, as well as to conduct a more thorough literature review; however, since this research will be conducted using the Ontario population, the case definition will remain consistent with “developmental disability” as defined by the Government of Ontario.

1.1.3 Health Disparities in Persons with IDD

Individuals with IDD experience a greater risk for various health concerns, and frequently experience poorer health services outcomes compared to individuals without IDD (Lunsky et al., 2013). Among health concerns observed to be more prevalent in persons with IDD are injuries. Compared to the general population, persons with IDD

experience more injuries (Slayter et al., 2006), for which a higher risk for falls is an important contributor (Cox, Clemson, Stancliffe, Durvasula, & Sherrington, 2010). Moreover, nearly one quarter of falls among persons with IDD have been found to result in a reported head injury (Cox et al., 2010).

With regard to health services outcomes, persons with IDD experience more emergency department visits (Lunsky et al., 2013), more hospital stays that include alternate level of care days (Lin et al., 2019), and overall their inpatient hospitalizations are of poorer quality (Iacono, Bigby, Unsworth, Douglas, & Fitzpartick, 2014). Notably, multiple researchers have agreed that persons with IDD have a greater risk of hospital readmissions (Balogh et al., 2017; Kelly et al., 2015; Lin et al., 2019). Recent data indicates that the rate of readmissions among persons with IDD is more than 3 times greater than seen among people without IDD (Lin et al., 2019).

There is currently a lack of any regional or international data related to traumatic brain injury at the population level for persons with IDD. Research is needed in order to understand what impact traumatic brain injury has in persons with IDD and identify how this affects health services outcomes in contrast to individuals without IDD. Knowledge on this topic is crucial for informing government, policy makers, and health care professionals to understand the burden and impact of TBI among persons with IDD so that appropriate strategies to address the additional challenges posed by TBI may be developed and implemented.

1.1.4 Traumatic Brain Injury in the General Population

Traumatic brain injury (TBI) is the most common form of acquired brain injury (ABI). ABI refers to any brain injury sustained after birth (Ontario Neurotrauma

Foundation [ONF], 2019). These injuries are not congenital, not inherited, and not related to degenerative disease, and often result in various cognitive, physical, socio-emotional, and behavioural impairments (Brain Injury Canada, 2019; ONF, 2019). ABI may be traumatic (TBI), caused by an external force, or non-traumatic (nTBI) resulting from stroke, illness, or other pathophysiology. Among Canadians, prevalent ABI is estimated to directly affect 1.5 million Canadians, and more than 160,000 incident ABIs occur among Canadians annually (Brain Injury Canada, 2019).

Among Canadians under 40 years of age, brain injury is the leading cause of death and disability (Brain Injury Canada, 2019; Chen et al., 2012). TBI alone is among the leading causes of death and disability worldwide, particularly in developed countries such as Canada (Colantonio, Croxford, Farooq, Laporte, & Coyte, 2009; Feigin et al., 2013; Hwang et al., 2008), affecting more people annually than breast cancer, spinal cord injury, HIV/AIDS, and multiple sclerosis combined (World Health Organization, 2006). Based on data from 2010, TBI alone affects more than one million Canadians and approximately 200,000 people of Ontario (Ng et al., 2015).

There is also evidence that prevalence and incidence of TBI are increasing steadily over time based on trends beginning as early as 2004 (Ng et al., 2015; Public Health Agency of Canada & Neurological Health Charities Canada [PHAC & NHCC], 2014). For instance, in the 2010/11 fiscal year, incidence of TBI in Ontario was 1.7 new cases per 1000 population, representing an increase of approximately 40% compared to 2004/05 (McIsaac et al., 2016; Ng et al., 2015). More than three-quarters of TBI cases occur among persons aged 18 and older (Ng et al., 2015), which could present further difficulty as Canada's population continues to age.

1.1.5 TBI Risk Factors and Mechanisms of Injury

Currently, much of the existing focus of research on TBI with respect to risk factors is on TBI as a risk factor for future negative health outcomes such as dementias (Plassman et al., 2000; Washington, Villapol, & Burns, 2015), depression (Fu, Jing, McFaull, & Cusimano, 2016; Holsinger et al., 2002), and long-term or permanent disability (Brain Injury Canada, 2019; Feigin et al., 2013; Langlois, Rutland-Brown, & Wald, 2006; ONF, 2019; Rao, McFaull, Thompson, & Jayaraman, 2017). However, the majority of TBIs are preventable (ONF, 2019), and if action is not taken to reduce the TBI burden, these injuries are expected to cost $8.2 billion in Canada by the year 2031 (PHAC & NHCC, 2014). Understanding factors that increase the risk of TBI is an important next step for effective planning and implementation of TBI prevention measures.

Studies using convenience samples have identified higher rates of TBI history among homeless (Hwang et al., 2008) and incarcerated (McIsaac et al., 2016) populations, however these studies provide further evidence of the negative outcomes of TBI as opposed to risk factors for TBI. Individual characteristics commonly found to be related to risk of TBI in epidemiological studies include male sex (Feigin et al., 2013; Kisser, Waldstein, Evans, & Zonderman, 2017; McGuire et al., 2017; Ng et al., 2015; Te Ao et al., 2015), age older than 80 years (Fu et al., 2016; McGuire et al., 2017), age under 30 years (Fu et al., 2016; Te Ao et al., 2015) ethnicity (Feigin et al., 2013; Kisser et al., 2017; McGuire et al., 2017), residing in a rural area (Feigin et al., 2013), poverty (Kisser et al., 2017), and recent history of falls or injuries (McGuire et al., 2017). Little has been done to identify specific populations that may have an increased risk of TBI.

1.1.6 30-Day Hospital Readmissions

Although no research has yet examined readmissions for individuals with both IDD and TBI, among persons with IDD and persons with IDD and a comorbid condition, 30-day hospital readmissions have been observed to be greater than what is reported in people without IDD. 30-day hospital readmissions occur when a patient is readmitted to hospital within 30-days of discharge from a previous hospitalization episode (Canadian Institute for Health Information [CIHI], 2018). These acute readmissions are one of many important health outcomes frequently used as a measure of health system performance in terms of the quality and integration of in-patient and out-patient care (Ontario Ministry of Health and Long-Term Care, 2002). Health outcomes indicators are used to assess the impact of health programmes and services on the health status of clients.

Readmissions data are routinely collected by hospitals (Health Quality Ontario, 2017) as they are viewed as an indication of the quality of health services provided to patients. Readmissions that occur within 30-days of discharge are acute and considered more likely to be related to in-patient and out-patient health services as opposed to patient characteristics, thus this 30-day post-discharge period has become the standard time-frame for assessing hospital readmissions (CIHI, 2018). High readmissions in particular patient groups are an indicator that not enough has been done in-hospital to prepare these patients prior to being discharged.

1. 2 Thesis Structure, Objectives, Rationale, and Methodology

1.2.1 Thesis Structure

This thesis is structured using a manuscript format and is consistent with the requirements of the School of Graduate and Postdoctoral studies at the University of Ontario Institute of Technology. Section 2 of the thesis is a literature review that summarizes relevant research in support of the content of the manuscripts. Sections 3 and 4 are stand-alone manuscripts that will eventually be submitted for journal publications, and therefore include headings and subheadings commonly required by general medical and health journals. Given the manuscript formatting used, the reader will find instances of repetition between the different sections; this was intended as each manuscript is considered a separate entity and will allow the manuscripts to be publishable independent of other thesis sections.

1.2.2 Objectives

Manuscript 1

The objective of Manuscript 1 is to describe and compare the risk of traumatic brain injury among Ontario adults with and without intellectual and developmental disabilities over time and by demographic variables.

Manuscript 2

The objective of Manuscript 2 is to describe and compare odds of 30-day readmissions among three groups of Ontario adults: 1) persons with intellectual and developmental disabilities and no history of traumatic brain injury, 2) persons with intellectual and developmental disabilities with a history of traumatic brain injury, and 3) persons with no intellectual and developmental disabilities with a history of traumatic

brain injury. A secondary objective was to identify other factor associated with 30-day hospital readmissions within the full model including all study cohorts, and separately within the cohort of persons with intellectual and developmental disabilities with a history of traumatic brain injury.

1.2.3 Rationale

As the burden and associated costs of TBI continue to rise over time, it becomes increasingly important to identify groups amenable to prevention. Since individuals with IDD are at an increased risk for injuries compared to individuals without IDD, it is important to identify whether persons with IDD also have an increased TBI risk. It is also useful to identify whether TBI has an impact on their odds of acute hospital readmissions, as persons with IDD alone or IDD and a comorbid condition have an increased risk of readmissions compared to the general population, indicating a possible synergistic effect for individuals with both IDD and TBI.

The primary motivation for this study was my personal experience with TBI and TBI-related health care encounters. As a young adult without IDD, having a new TBI was a confusing and difficult time for a number of reasons. It took over a month after the accident to receive a diagnosis, prior to which there were multiple brief health-care encounters at a number of clinics and hospitals, all of which resulted in being sent home with prescriptions for pain medications and feelings of being brushed-off. Despite the symptoms continuing to worsen over time, it was not until I was nearly unable to safely get out of bed that I finally received the diagnosis of mild TBI. Throughout my experience with TBI, there were several times when I was told by medical professionals that the symptoms must be from anxiety, as in their professional opinion, my injury was

not sufficient to cause TBI. Partly as a result of this thinking, I experienced a relatively poor recovery and experience a number of chronic symptoms that impact my day-to-day life.

Although I do not personally have IDD, I began to hypothesize that individuals with IDD may have a difficult time explaining their symptoms or advocating for themselves within the healthcare system. This is particularly important due to the potential for long-lasting TBI symptoms which may impact healthcare utilization, such as readmissions, in this population. Upon discovering the increased risk for injuries and readmissions in this population, I began to consider the implications this may have for TBI risk and how that may impact health care services including readmissions. If TBI risk is high in this population, TBI prevention should consider persons with IDD as a potential target population. Additionally, data on readmissions may provide further evidence of the need for TBI prevention and better practice guidelines for addressing TBI among persons with IDD within the hospital setting.

The aim of this study was to improve understanding of the risk of TBI among persons with IDD and identify how having had a TBI may impact acute readmissions for persons with IDD. The expected results of this study were of increased TBI risk among persons with IDD and increased odds of hospital readmissions among persons with IDD and a history of TBI compared to those with a history of TBI alone or IDD alone. These results are expected as individuals with IDD have an increased risk for injuries as well as for readmissions, and TBIs often result in long-lasting symptoms.

There is currently an overall lack of quantitative data pertaining to TBI among persons with IDD. Population-based research is needed in Canada to generate knowledge

on the impact of TBI among persons with IDD compared to persons without IDD. This information would help to inform decision-making for Canadian policy makers, health service administrators, and health professionals by providing locally-relevant data. The results of this study will provide important data about the impact of TBI among persons with IDD that is both current and relevant to residents of Ontario and Canada.

1.2.4 Thesis Methodology

Manuscript 1 employed a historical cohort design to identify the incidence of TBI among adults with and without IDD in Ontario. The study included two main cohorts: persons with IDD and a 10% random sample of the remaining population of people without IDD. Persons with IDD were identified using linked administrative health databases. Within each cohort, incident cases of TBI were identified from hospital-based administrative health databases using an algorithm with diagnostic codes for TBI. TBI incidence was compared between cohorts to identify whether the risk of TBI was different for persons with IDD compared to those without. The historical cohort design was chosen for this study due to advantages such as the ability to look back in time to study trends over a longer period than would otherwise be possible for a Master's thesis. Additionally, since persons with IDD compose less than 1% of the population (Statistics Canada, 2013), this study design allowed for a larger sample to be identified. Furthermore, the historical cohort design is cost- and time-efficient as the databases used in this study were already well-established.

For similar reasons, Manuscript 2 also employed a historical cohort design. This design was used in manuscript 2 in order to determine the influence of the presence of IDD and/or TBI on the odds of 30-day readmissions. Three mutually exclusive cohorts

were created for this study: 1) persons with IDD and no history of TBI, 2) persons with IDD with a history of TBI, and 3) persons without IDD with a history of TBI. IDD-status and TBI history were determined using administrative health databases. All individuals in each if these three groups were followed for up to 30-days after being discharged from an index hospitalization episode in 2016/17. Within each cohort, the first readmission within 30-days of discharge from an index hospitalization episode was identified using administrative databases of hospital data.

2 LITERATURE REVIEW

2.1 Literature Review

2.1.1 Aims and Methodology of the Literature Review

A literature review was conducted to provide a summary of relevant published reports and studies. This literature review is divided into four sub-reviews consistent with the needs of the two thesis manuscripts. The objectives of the first two literature sub-reviews (relevant to Manuscript 1) were focused on examining literature on persons with intellectual and developmental disabilities (IDD); the remaining two literature sub-reviews (relevant to Manuscript 2) focused on identifying information related to traumatic brain injury (TBI) in the general population.

The goals of the first literature sub-review were to identify: 1) any existing literature on TBI among persons with IDD, 2) common injuries among persons with IDD, and 3) the burden of injuries among persons with IDD. The second literature sub-review aimed to examine existing data on 30-day hospital readmissions among persons with IDD. The goals of the third literature sub-review were to identify: 1) recent estimates of the incidence or burden of TBI in the general population, and 2) descriptive information related to sex-differences and risk factors associated with TBI. The final literature sub-review was conducted to provide information related to readmissions among persons with TBI in the general population.

An overview of the databases, and search parameters of each literature sub-review is provided in the Appendix (see Appendix A, Table A1). Due to the relative lack of existing research for persons with IDD as well as for TBI, no limitations were applied to the publication year for any of the four literature sub-reviews.

2.1.2 Summary of Articles

A brief summary of the 18 articles selected for the literature review is provided in Table 2.1. A majority of the studies used cohort designs. The literature included studies on injuries and falls among persons with IDD, TBI in the general population, and 30-day hospital readmissions among persons with IDD and persons with TBI. The articles included were from the United States, United Kingdom, Netherlands, Australia, New Zealand, and Canada and publication years ranged from 2006 to 2019.

Table 2.1
Summary of selected articles for the literature review.

Literature Review- Articles Summary	
Title	Brief Summary
Injuries among Persons with Intellectual and Developmental Disabilities	
McKinlay, A., McLellan, T., & Daffue, C. (2012) The invisible brain injury: The importance of identifying deficits following brain injury in children with intellectual disability Study Design: Case study Country: New Zealand	This study examined services access for a man with Down Syndrome who experienced a severe traumatic brain injury as a child. The individual did not receive any post-injury cognitive assessments and was denied access to interventions and support even though a no-fault accident compensation and rehabilitation system was in place. All symptoms were attributed to the pre-existing intellectual and developmental disabilities.
Slayter, E. M., Garnick, D. W., Kubisiak, J. M., Bishop, C. E., Gilden, D. M., & Hakim, R. B. (2006) Injury prevalence among children and adolescents with mental retardation Study Design: Historical cohort Country: United States	This study used United States Medicare and Medicaid claims data to identify injury burden among young people with intellectual and developmental disabilities. Persons with intellectual and developmental disabilities had 1.6 times the risk of injuries compared to those without intellectual and developmental disabilities.
Cox, C. R., Clemson, L., Stancliffe, R. J., Durvasula, S., & Sherrington, C. (2010)	A medical chart audit was conducted to examine falls risk and fall-related injuries

Incidence of and risk factors for falls among adults with an intellectual disability Study Design: Historical cohort Country: Australia	among adults with intellectual and developmental disabilities. 34% of participants reported a fall within the past 12 months, among whom 84% sustained a fall-related injury. Nearly 22% of fallers experienced a fall-related head injury.
Finlayson, J., Morrison, J., Jackson, A., Mantry, D., & Cooper, S. A. (2010) Injuries, falls and accidents among adults with intellectual disabilities. Prospective cohort study Study Design: Prospective cohort Country: United Kingdom	In-person interviews and assessments were done at the time of recruitment and two-year follow-up to determine the incidence and types of injuries experienced by adults with intellectual and developmental disabilities. Of the 511 participants, 20.5% experienced at least one injury, among which falls were the most common cause.
Smulders, E., Enkelaar, L., Weerdesteyn, V., Geurts, A. C., & van Schrojenstein Lantman-de Valk, H. (2013) Falls in older persons with intellectual disabilities: Fall rate, circumstances and consequences Study Design: Prospective cohort Country: Netherlands	This study prospectively examined the rate and causes of falls, and fall-related injuries in older adults with intellectual and developmental disabilities over one year via self-report and caregiver report measures. The rate of falls was 1.00 fall per person per year on average; approximately 43% of participants had at least one fall. Age and sex were not significant factors. 11.5% of falls resulted in severe injuries.
Incidence and Risk Factors of Traumatic Brain Injury in the General Population	
Langlois, J. A., Rutland-Brown, W., & Wald, M. M. (2006) The epidemiology and impact of traumatic brain injury: A brief overview [Report] Study Design: Systematic Review Country: United States	Traumatic brain injury can lead to long-term or lifelong disability and is a significant public health problem, resulting in an estimated 57 hospitalizations globally, 235,000 of which were in the United States. The leading cause of traumatic brain injury in the United States is falls. After experiencing traumatic brain injury, individuals are at an increased risk of developing various physical and psychiatric health outcomes such as epilepsy or depression.
Te Ao, B., Tobias, M., Ameratunga, S., McPherson, K., Theadom, A., Dowell, A., … Feigin, V. L. (2015)	This study identified traumatic brain injury burden and outcomes using a prospective population-based traumatic brain injury register in New Zealand. In a

Burden of traumatic brain injury in New Zealand: Incidence, prevalence and disability-adjusted life years Study Design: Prospective cohort Country: New Zealand	single year, approximately 11,300 individuals experienced a first-ever traumatic brain injury and a total of 527,000 prevalent cases. Nearly 30% of all injury-related disability-adjusted life years were attributable to traumatic brain injury.
Fu, T. S., Jing, R., McFaull, S. R., & Cusimano, M. D. (2016) Health & economic burden of traumatic brain injury in the emergency department Study Design: Historical Cohort Country: Canada	Incidence of traumatic brain injury in Ontario emergency departments was identified using traumatic brain injury codes in the Nation Ambulatory Care Reporting System database. More than 133,000 emergency visits in the 2009 fiscal year were related to traumatic brain injury, incurring an estimated $945 million in total direct and indirect costs.
McGuire, C., Kristman, V. L., Martin, L., & Bédard, M. (2017) Characteristics and incidence of traumatic brain injury in older adults using home care in Ontario from 2003-2013 Study Design: Historical cohort Country: Canada	Demographic and health information, as well as information on traumatic brain injury and recent falls, was collected from the Ontario Association of Community Care Access Centers. Patient-related risk factors for traumatic brain injury in this study included male sex, aboriginal heritage, increasing age, having at least one fall, and having depression, dementia, or multiple sclerosis. Cumulative incidence of traumatic brain injury was stable over the 10-year period.
Feigin, V. L., Theadom, A., Barker-Collo, S., Starkey, N., McPherson, K., Kahan, M., … Ameratunga, S. (2013) Incidence of traumatic brain injury in New Zealand: A population-based study Study Design: Prospective cohort Country: New Zealand	This population-based study consulted hospitals, practitioners, databases, registries, and community services to identify traumatic brain injury incidence for 2010. Incidence rate of traumatic brain injury was 790 per 100,000 person-years. Falls were the leading cause. Risk factors identified included male sex, non-European heritage, and rurality.
Kisser, J., Waldstein, S. R., Evans, M. K., & Zonderman, A. B. (2017) Lifetime prevalence of traumatic brain injury in a demographically diverse community sample Study Design: Historical cohort Country: United States	Lifetime history of traumatic brain injury was examined among urban-dwelling adults enrolled in the Healthy Aging in Neighborhoods of Diversity across the Life Span study to identify patient-related risk factors for traumatic brain injury. In addition to male sex, a 3-way interaction between age, race, and poverty status was identified such that among African-

	Americans living in poverty, older individuals (58-64 years) had greater odds of traumatic brain injury, whereas among Caucasians living in poverty, the odds were greater among younger individuals (30-36 years).
All-cause 30-Day Hospital Readmissions- Persons with Intellectual and Developmental Disabilities	
Iacono, T., Bigby, C., Unsworth, C., Douglas, J., & Fitzpatrick, P. (2014) A systematic review of hospital experiences of people with intellectual disability Study Design: Systematic review Country: Australia	Using five databases, a search for relevant literature on the hospital experiences of persons with intellectual and developmental disabilities published between 2009-2013. Seven themes emerged indicating poor hospital experiences for persons with intellectual and developmental disabilities, including: fear of hospital encounters, carer responsibilities, and problematic care delivery including the knowledgeability, skills, and attitudes of nurses and other hospital staff.
Kelly, C. L., Thomson, K., Wagner, A. P., Waters, J. P., Thompson, A., Jones, S., … Redley, M. (2015) Investigating the widely held belief that men and women with learning disabilities receive poor quality healthcare when admitted to hospital: A single-site study of 30-day readmission rates Study Design: Historical cohort Country: United Kingdom	A retrospective audit of patient admissions and 30-day readmissions at a single hospital in East England was conducted using Hospital Episode Statistics. Persons with intellectual and developmental disabilities were identified within this data and compared to those without intellectual and developmental disabilities. Rate of readmission for persons with intellectual and developmental disabilities was 13% compared to 11% in those without. Among persons with intellectual and developmental disabilities, nearly 70% were considered "preventable" due to being readmitted within 30-days for a medical emergency.
Balogh, R., Lin, E., Dobranowski, K., Selick, A., Wilton, A. S., & Lunsky, Y. (2017) All-cause, 30-day readmissions among persons with intellectual and developmental disabilities and mental illness	This study used health administrative databases to identify odds of all-cause, 30-day readmissions among persons with intellectual and developmental disabilities only and persons with intellectual and developmental disabilities and mental illness, and compared these groups to persons with mental illness only. Persons

Study Design: Historical cohort Country: Canada	with intellectual and developmental disabilities only and persons with intellectual and developmental disabilities and comorbid mental illness had nearly 1.3 times and 1.7 times greater odds of 30-day readmission respectively compared to persons with mental illness only.
Lin, E., Balogh, R., Durbin, A., Holder, L., Gupta, N., Volpe, T., … Lunsky, Y. (2019) Addressing gaps in the health care services used by adults with developmental disabilities in Ontario [Report] Study Design: Historical cohort Country: Canada	30-day readmissions is a health care outcome frequently used as a tool for identifying health system deficiencies in terms of in-patient and out-patient care provision and service integration between the hospital and post-discharge setting. Over the six-year study period, adults with intellectual and developmental disabilities were more than 3 times as likely to be readmitted at least once within 30-days of an initial discharge compared to those without intellectual and developmental disabilities (7.4% compared to 2.3%).
All-cause 30-Day Hospital Readmissions- Persons with Traumatic Brain Injury	
Hammond, F. M., Horn, S. D., Smout, R. J., Beaulieu, C. L., Barrett, R. S., Ryser, D. K., & Sommerfeld, T. (2015) Readmission to an acute care hospital during inpatient rehabilitation for traumatic brain injury Study Design: Prospective cohort Country: United States	Using data from a previous 5-year, multicenter traumatic brain injury project, this study examined acute care readmissions for persons undergoing rehabilitation for traumatic brain injury. Of more than 2,000 participants, 9% experienced at least one readmission, with a mean time of 22±21.5 days from the start of rehabilitation.
Saverino, C., Swaine, B., Jaglal, S., Lewko, J., Vemich, L., Voth, J., … Colantonio, A. (2016) Rehospitalization after traumatic brain injury: A population-based study Study Design: Historical cohort Country: Canada	This study consulted Ontario hospital admissions data from the discharge abstract database to identify index cases of traumatic brain injury and the incidence of readmission up to 36 months post-discharge. During the 3-year follow-up, 35.5% of TBI patients in Ontario were readmitted at least once. Significant predictors of readmission included male sex, older age, fall-related TBI, greater injury severity, rurality, greater comorbidity, and comorbid mental illness.

Canner, J. K., Giuliano, K., Gani, F., & Schneider, E. B. (2016) Thirty-day re-admission after traumatic brain injury: Results from MarketScan® Study Design: Historical cohort Country: United States	Using the MarketScan database, hospitalization data on patients with a primary diagnosis of traumatic brain injury was identified. Of 26,831 patients discharged after a traumatic brain injury-related hospitalization, 6.7% were readmitted within 30-days. Significant predictors of readmission were older age, greater injury severity, greater comorbidity, longer length of stay, and discharge to rehabilitation facility.

2.1.3 Injuries among Persons with IDD

No quantitative research examining TBI among persons with IDD was found; in fact,is has been reported that some TBI studies exclude persons with disabilities (Tuerk, Dégeilh, Catroppa, Anderson, & Beauchamp, 2019). One study (McKinlay et al., 2012) addressed the topic of concurrent TBI and IDD specifically and was included for this reason, however this was a qualitative study. For this reason, the literature review was expanded to include studies addressing injuries broadly among persons with IDD. Injury-related research may provide some insight, or make it possible to make inferences, regarding TBI risk in people with IDD. Understanding the risk of injuries among persons with IDD may shed light on the need for preventative measures, and provide guidance for future research regarding TBI in this population. Studies focussing on falls were also included in this review as these publications often discuss injuries as a consequence of falls. Falls were also found to be a recurring theme within studies on injuries in general.

Only the qualitative study by McKinlay et al. (2012) examined TBI among an individual with pre-existing IDD. The researchers conducted a historical case study to identify problems in services access for a person with IDD who experienced a TBI. The participant was a 30-year-old man from New Zealand who was diagnosed with IDD

shortly after birth, and experienced a severe TBI at age 5. Based on the mother's report, the participant, health notes from his early childhood, hospital and neurosurgeon notes, and school assessments, it was found that after the initial surgery, the participant did not receive any of the care or services to which he was entitled. Most notably, due to his pre-existing IDD, the participant did not receive any cognitive or functional assessments to determine the effect of the TBI. In this case study, it was determined that the participant's needs resulting from the TBI were overlooked due to his pre-existing IDD. Not having access to the additional care and services he needed likely played a role in his future poor health outcomes, poor rehabilitation, and lower achievement in school and the work-force. Although this research was qualitative, it is useful as it provides evidence of the negative outcomes that TBI can have for a person with IDD. This study indicates that among persons who experience TBI, those with IDD may accumulate higher direct and indirect costs compared to persons without IDD due to a lack of needs recognition and poor services coordination, resulting in poorer recovery and a reduced ability to work. This also provides some context for why someone with IDD and TBI might be more likely to be readmitted.

Given the relative lack of TBI research among persons with IDD, research on injuries more broadly may be informative. Slayter et al. (2006) conducted a historical cohort study examining claims data from the Centers for Medicare and Medicaid Services to determine the prevalence of injuries among children and adolescents diagnosed with IDD in 1999. Slayter et al. (2006) revealed a 1.6 times increased risk of injury among persons with IDD compared to those without IDD. An overall increased risk of injury among persons with IDD was consistent across all age groups assessed, indicating an

increased injury risk for individuals with IDD for at least the first 20 years of life. Slayter et al. (200^) proposed that reasons for this increased injury risk include physical issues such as poor balance or coordination, functional capacity and insight, challenging behaviour and psychopathology, and seizure disorders. This study provides context for the higher rates of injury broadly among persons with IDD and indicates a need for more research into the types and mechanisms of injury experienced in this population. This also indicates that falls are an important contributor to injuries.

Additionally, a study conducted by Cox et al. (2010) used a retrospective medical chart audit to collect data on incidence and location of injuries among Australian adults (aged 18 and older) with IDD, between March 2008, and June 2009. Study participants completed a 12-page questionnaire to identify past and current medical and falls history, as well as various social determinants of health such as residential and social situation, and leisure and work participation. Despite a mean age of approximately 35 years among study participants, incidence of falls was quite high at 34% of participants, compared to the 20% reported in previous studies for the general population. Among the study participants who had experienced a fall within the 12-month study period, nearly 19% reported a fracture and more than 20% reported a head or facial injury as a result of a fall. Since this study used retrospective reports from participants, the definition of falls in this study included falls from all causes, including those resulting from epilepsy, which is more common among persons with IDD compared to those without IDD (Cox et al., 2010). In this study, having a history of seizures within the past five years was found to be a significant risk factor for falls among persons with IDD. Notably, level of IDD was not a significant risk factor in this study. This study is useful as it examines the rate and

location of fall-related injuries among persons with IDD, and provides further support of an increased rate of falls among persons with IDD compared to individuals of a similar age in the general population without IDD. This research also further contextualizes the risk of head and facial injuries as a result of falls, which could implicate TBI as a potential area of concern for persons with IDD that has not yet been examined. The study was limited due to its reliance on participants to recall information, which could result in significant underreporting of both falls in general and head injuries in particular, since head injuries which result in TBI often result in lapses in memory and consciousness (Ng et al., 2015).

Another research team, Finlayson et al. (2010), conducted a prospective cohort study to describe the incidence and types of injuries, falls, and accidents experienced over a 12-month period by Scottish adults aged 18-64 living with IDD. Beginning in 2002, the researchers collected demographic and medical information from study participants. Case records were also reviewed, and physical examinations were conducted. Participants were then followed up in 2004, at which time the researchers collected information regarding injuries, falls, and accidents sustained in the previous 12-month period in such a way as to allow direct comparison with the Scottish Health Survey 2003. Caregiver input regarding participant injuries, falls, and accidents during this period was also gathered. Finlayson et al. (2010) identified an almost two-fold increased risk of injury among persons with IDD compared to similar aged individuals in the general population without IDD, with an incidence of 20.4% among persons with IDD compared to 11.5% in people without IDD. While the rate of head and facial injuries was not identified in this study, it was determined that nearly 4.9% of reported injuries among

persons with IDD, compared to 2.6% of reported injuries in those without IDD, resulted in loss of consciousness. Based on this result, adults with IDD were thus found to have a 1.9 times increased risk of injury-related loss of consciousness compared to those without IDD. Loss of consciousness is an important indicator of a potential TBI (Ng et al., 2015; Te Ao et al., 2015), and although it is not required for a TBI diagnosis, a higher rate of loss of consciousness among persons with IDD could indicate an overall higher rate of TBI in this population. This should however be interpreted with caution as the study does not provide a definition of "loss of consciousness". This could therefore refer to other causes of injury-related loss of consciousness such as loss of consciousness due to fainting or blood loss. With regard to falls, this study determined that persons with IDD were significantly more likely to experience a fall-related injury compared to those without IDD. Notably, this study examined results with and without fall-related injuries resulting from epileptic seizure. Finlayson et al. (2010) found that more than 40% of participants reported having at least one fall during the study period compared to 34% in the study Cox et al. (2010), and the previously reported rate of 20% found in the general population. In this study, epilepsy-related falls contributed to less than 2% of fall-related injuries, and falls were the leading cause of injury regardless of epilepsy, indicating that the increased risk of falls and fall-related injuries was not dependent on the increased risk of epilepsy among persons with IDD. No information was provided on whether there were injuries resulting from epileptic seizure that were not fall-related, or the proportion of falls not resulting in injury that were related to epilepsy. This study provides further support of increased injury and fall risk among adults with IDD and identifies a rate of

injury-related loss of consciousness, providing a possible crude proxy of the risk of TBI among persons with IDD.

Another prospective cohort study by Smulders et al. (2013) was conducted using a population of persons with IDD in the Netherlands to understand falls among adults aged 50 and older. Persons with epilepsy were excluded from the study to avoid concern that any increased risk of falls could be attributed to epileptic seizures. This study found a higher rate of falls among persons with IDD compared to the general population, with a rate of 1.00 fall per person per year for persons with IDD compared to 0.45-0.65 falls per person per year among the general population. Participants with IDD in the study were younger on average compared to studies examining the general population, which is a limitation of the study and could indicate that the fall risk for persons with IDD was slightly underestimated due to the increased risk of falls with age. This study is useful as it quantifies the risk of falls for a population of older adults with IDD. This provides insight into the potential for head injury and TBI risk for older adults with IDD, as falls can result in head injury and/or TBI.

Although the only study that was found to examine concurrent TBI and IDD was qualitative and based on a case study, the findings provide evidence of the importance of examining TBI among persons with IDD. Even without consideration of the burden of TBI among persons with IDD, a lack of service access and/or coordination for these individuals could result in greater future healthcare utilization and poorer ability to live independently and contribute productively to society.

Despite the overall lack of quantitative data pertaining to the incidence of TBI among persons with IDD, existing information on the increased risk of injuries provides

evidence of a need to examine this relationship. While the finding of an increased risk of injury-related loss of consciousness should be interpreted with caution, it also offers crude evidence that TBI risk may need to be examined. Moreover, falls are a common cause of injuries among persons with IDD, many of which have been found to result in head injuries (Cox et al., 2010). Evidence of high rates of head injury due to falls provides further evidence of the importance of an investigation of TBI risk among persons with IDD.

2.1.4 Incidence and Risk Factors of TBI in the General Population

Measuring the incidence of TBI provides an estimate of the risk of experiencing this type of injury. Up-to-date information pertaining to TBI incidence is needed to guide policy and service planning and implementation. This knowledge enables policy makers and service managers to make evidence informed decisions in regards to TBI prevention, management, and rehabilitation.

A publication by Langlois and colleagues (2006) provides a brief overview of global TBI statistics and relevant TBI data for the United States. Globally, there are at least 10 million incident cases of TBI each year. In the United States, the average annual incidence from 1995-2001 was 1.4 million, resulting in more than 1.1 million emergency department visits, and approximately 235,000 hospitalizations. Notably, males are consistently found to have nearly twice the risk of experiencing TBI compared to females. Langlois et al. (2006) hypothesize that persons with TBI account for one tenth of Americans living with a disability. This publication contextualizes the risk and burden of TBI among typically developing individuals. This overview also provides evidence

for the importance of understanding TBI incidence and outcomes, as well as some indication of the increased challenges caused by TBI.

Additionally, a study by Te Ao et al. (2015) examined incidence rates and mortality statistics related to TBI in order to develop a model for estimating the national incidence, prevalence, and disability-adjusted life years (DALYs; a metric for quantifying mortality and morbidity) among the general population of New Zealand. This study focused on incidence in terms of an individual's first-ever TBI event and found a count of approximately 11,300 new cases in 2010, contributing to a total prevalence of nearly 527,000 New Zealanders. Additionally, approximately 20,300 DALYs were attributable to TBI in New Zealand for 2010, accounting for more than one-quarter of all DALYs attributable to intentional and unintentional injuries combined for that year, and nearly 2.5% of DALYs for all causes. This allows for a broader realization of the significant impact and burden of TBI internationally. This study is also useful as it quantifies the level of death and disability caused by TBI in this population, providing further context of the breadth of the impact of TBI on affected persons and loss of productivity.

Moreover, an Ontario-based study conducted by Fu et al. (2016) aimed to determine the incidence and healthcare burden of TBI in emergency departments (EDs), and to identify demographic risk factors for TBI. Fu et al. (2016) used secondary data from the National Ambulatory Care Resource System database to identify individuals who presented to an ED in Ontario between April 1, 2009, and March 31, 2010. This study identified a total of nearly 134,000 TBI-related visits to EDs in Ontario, with an incidence rate of nearly 1,031 per 100,000 Ontario residents. TBI was found to be associated with age and sex, such that it is most common among persons aged 0-24 and

75 and older, and among males. Additionally, falls were determined to be the leading cause of TBI accounting for 47% of TBI-related ED visits, while motor vehicle collisions accounted for only 10%. This provides a local context of the incidence and burden of TBI in the general population. It also provides data pertaining to demographic risk factors and common mechanisms related to TBI which helps to inform the present research with regard to associations seen in the general population and for comparison with individuals with IDD. The identification of falls as the leading cause of TBI-related ED visits provides an important basis for examining TBI among persons with IDD as these individuals have consistently been shown to be at a greater risk for experiencing falls.

Further, McGuire et al. (2017) conducted a study to examine the incidence of TBI specifically among Ontario adults aged 65 and older using home care. This study used a historical cohort design using data from the Ontario Association of Community Care Access Centers to identify individuals in their study population who experienced a TBI in 2003-2013. Cumulative incidence of TBI was found to be significantly higher among older adult population using home care compared to previous reports for hospital-based populations in the US. McGuire et al. (2017), also revealed demographic factors and other characteristics such as male sex, older age, higher level of education, and having depression as potential risk factors associated with TBI in this population. This was the first study to examine an association between depression and TBI in this direction; previous studies have examined this relationship from the perspective of TBI as a risk factor for depression as opposed to the other way around. The finding of depression as a potential risk factor for TBI could indicate a gap in research related to TBI and mental

illness. This publication provides insight into the potential under-reporting of TBI captured by hospital records alone and identifies an additional potential subpopulation in which TBI is under-researched (i.e. persons with depression or other mental illness). This is interesting as persons with IDD have a greater risk of experiencing mental illness and addictions compared to those without IDD (Lunsky et al., 2018).

While many of the incidence studies on TBI have included an analysis of potential risk factors for TBI (i.e. age, sex, mental health status), other factors should be considered in order to improve current understanding and approaches for addressing TBI risk. One study by Feigin et al. (2013) conducted a population-based cohort study to examine TBI in rural versus urban communities in New Zealand from March 1, 2010, to February 28, 2011. This study found a TBI incidence of 790 cases per 100,000 people per year, with higher rates among males and people aged under 24 and over 63. Compared to urban populations, there was no statistically significant difference in TBI risk overall, however rural populations had a greater risk of sustaining moderate to severe TBI. Notably, 26% of the TBI cases included in the study did not appear in hospital databases and were identified using non-hospital sources. Additionally, mild TBI accounted for approximately 95% of cases. This study identifies another possible demographic risk factor (i.e. rurality) that should be considered in analyses. The higher risk of moderate to severe TBI among rural populations may have important implications for readmissions risk, and may also indicate greater underreporting of mild TBI for instance due to poorer access to a hospital. This study also provides further evidence of the burden of TBI and establishes that there may be a high likelihood of underreporting and thus an underestimation of the impact of TBI.

Additionally, a study by Kisser et al. (2017) aimed to determine the prevalence of TBI and how that is influenced by different demographic characteristics among adults. This epidemiological study used logistic regression analyses to examine the effects of age, sex, race, and poverty status on the odds of experiencing TBI. Consistent with other studies, males, younger and older individuals, and persons of non-European descent had greater odds of TBI. Individuals living below the poverty line also had a greater risk of TBI regardless of race. This study provides further support for demographic risk factors including age and sex to be included in analyses, and identifies an additional risk factor (income) to be considered.

TBI is a significant health problem which significantly contributes to death and disability in various countries. Additionally, despite the already high estimates of TBI incidence, there is evidence that these figures are underreported due to individuals potentially not being captured by hospital records. Existing research has often focused on TBI itself as a risk factor for diseases such as dementia (Washington, Villapol, & Burns, 2015). Research with a specific focus on risk factors for experiencing TBI typically focus on groups within the general population involved in certain activities known to increase TBI risk such as athletes, military personnel, and individuals involved in motor vehicle collisions. There is currently a need for more research focused on risk factors for TBI rather than focusing on TBI as a risk factor for other diseases. The identification of falls as the leading cause of TBI provides an impetus to examine the rates of TBI among populations at increased risk for falling, such as those with IDD. Generating knowledge of the causes and risk factors associated with TBI can inform policy makers and

recommendations for approaches to prevention which could reduce TBI burden and its associated outcomes.

2.1.6 30-Day Hospital Readmissions

30-day hospital readmissions are an important indicator used to evaluate the quality and effectiveness of health services (Ontario Ministry of Health and Long-Term Care, 2014). Currently, there is no literature that examines hospital readmissions for persons with both IDD and TBI. There is also no available literature which compares readmissions between persons with IDD and persons with TBI. There is evidence however, comorbid conditions that have an impact on cognition increase odds of readmission for persons with IDD (Balogh et al., 2017) and persons with TBI (Saverino et al., 2016). This section of the literature review will summarize relevant literature on hospital readmissions for persons with TBI and persons with IDD separately. This information could inform policy makers of an important area for improvement in terms of patient management and quality of care, as well as reduction of financial burden for the health care system.

Persons with IDD

Currently, little is known about readmissions among persons with IDD. Examining 30-day hospital readmissions among persons with IDD will provide insight into the barriers experienced by persons with IDD in the health and social services sectors. This would help to further identify the degree to which persons with IDD experience poor healthcare access and poor quality of care.

Iacono et al. (2014) conducted a systematic review aimed at understanding the experiences of people with IDD and the opinions of their families and caregivers with

regard to using the health care system, as well as understanding the experiences of hospital staff who provide care for persons with IDD. Iacono et al. (2014) found that having IDD increases the risk of poorer hospital experiences based on factors such as having unmet needs, receiving incorrect or poorly scheduled medication, and being neglected by health care professionals. Additionally, hospital staff were found to have negative attitudes toward individuals with IDD and tended to lack the skills and knowledge required to appropriately care for these patients. While this study does not directly examine hospital readmissions for persons with IDD, it describes the hospital environment that people with IDD sometimes find themselves in and provides insight into the circumstances that can lead to readmissions.

While information on hospital experiences is useful to provide context for examining measures of the quality of health services such as 30-day readmissions, studies focussing on readmissions specifically provides information against which the present research can be compared and are useful for identifying areas of research need. At least three such studies exist on persons with IDD. A study conducted by Kelly et al. (2015) aimed to compare 30-day readmission rates between patients with and without IDD. This study was conducted using a retrospective audit of records of admissions to a teaching hospital in the East of England between April 1, 2010, and March 31, 2011. The researchers found that overall readmission rates were comparable across individuals with and without IDD, with readmission rates of 13% and 11% respectively. However, persons with IDD were found to be much more likely to experience readmissions the researchers considered to be “preventable”. The rate of these preventable readmissions for persons with and without IDD were determined to be 69% and 23% respectively.

This publication provides context of 30-day readmissions rate for persons with IDD compared to persons without IDD.

Another study by Balogh et al. (2017) was conducted to determine the influence of mental illness (MI) on 30-day readmission rates for Ontario adults (aged 19-65) with IDD using a historical cohort design. This study found that odds of readmission within 30-days for persons with IDD and MI was 14.7%, compared to 10.2% and 8.2% for persons with IDD without MI and persons with MI without IDD respectively. Persons with IDD and MI and those with IDD without MI had 1.66 and 1.27 times the odds of being readmitted to hospital within 30 days of discharge compared to persons with MI without IDD. This study provides locally-relevant data on 30-day readmissions for persons with IDD specifically and provides evidence that persons who have IDD and a comorbidity have increased odds of 30-day hospital readmissions compared to those without the comorbid condition. The study also supports the feasibility of identifying persons with IDD and comorbidities (e.g. mental disorders) to conduct health services research using an outcome measure like readmissions. The study also employed the Determinants of Hospital Readmissions framework (described in Section 2.2 of the thesis) to identify covariates used in its statistical model which proved useful to include in the analysis stage of Manuscript 2 of the thesis.

Furthermore, a recent report produced by Lin et al. (2019) examined various health care outcomes, including 30-day hospital readmissions, among persons with IDD. Using a historical cohort design, the rate of 30-day hospital readmissions was identified for persons with and without IDD over six study years. The researchers found that persons with IDD were more than 3 times as likely to be readmitted within 30-days

compared to persons without IDD (7.4% compared to 2.3%), and this was consistent for all six years. Rate of readmission increased steadily with age among persons with IDD, compared to persons without IDD among whom the rate increased only for the oldest age group. Rate of readmission was also found to be slightly higher among women versus men, and among poorer neighborhoods compared to wealthier neighborhoods. This research provides recent data relevant to readmissions among persons with IDD, with evidence that the rate of readmissions is different for this population compared to people without IDD. While the study findings support the importance of examining 30-day readmissions, it did not identify modifiable factors that could potentially be addressed to decrease the rate of readmissions among people with IDD living with a comorbidity.

Further knowledge pertaining to 30-day hospital readmissions among persons with IDD would improve understanding of the health care experiences of these individuals. Existing literature in this area provides some evidence of the need for further education and training for health care professionals in treating persons with IDD, as well as a need for further assessment into the incidence and etiology of readmissions among persons with IDD. There is evidence that persons with IDD are at a greatly increased risk of experiencing 30-day hospital readmissions compared to those without IDD, indicating a need to identify possible reasons for this discrepancy. Due to the increased risk of readmissions among persons with IDD and a comorbid condition compared to those with IDD alone, it is useful to assess whether and how TBI impacts readmission rates among persons with IDD. Understanding the impact of comorbid IDD and TBI on readmissions would be useful for addressing the high rates of readmissions among persons with IDD.

Persons with TBI

Among persons with TBI, only a few studies have examined readmissions within 30-days of discharge. Examining 30-day hospital readmissions among persons with TBI could provide insight into the burden of TBI in acute care, as well as how well it is currently being dealt with within the healthcare system. This would aid in the identification of key deficits in patient management and quality of care.

Hammond et al. (2015) conducted a study based on the TBI-PBE (practice-based evidence) Project- a multicenter, prospective observational investigation of the process of rehabilitation for more than 2,000 TBI patients aged 14 and older in 9 US facilities and 1 Canadian facility. Hammond et al. (2015) aimed to assess readmissions to an acute care hospital for these patients at any time after commencement of rehabilitation in terms of incidence, causes, and risk factors for readmission over the 5-year study period. The study determined that approximately 9% of study participants (n= 183) were readmitted to acute care at least once after being discharged to a TBI rehabilitation setting. The average time period from the start of the rehabilitation to first readmission was 22±21.5 days, indicating that 30-day readmissions may be close to this 9%. However, the study examined only TBI patients who were discharged to a rehabilitation facility and undergoing rehabilitation prior to readmission, and thus may represent a sample of patients with more severe TBI. This suggests that the setting a person is discharged to after the index hospitalization episode is an important variable to consider. The study also found significant associations between the occurrence of readmission to acute care and future rehabilitation needs. This study provides context for the rate of 30-day hospital readmissions among individuals with TBI, as well as its relationship to future outcomes.

A Canadian-based study conducted by Saverino et al. (2016) aimed to evaluate the incidence and causes of hospital readmissions among Ontario residents who have experienced TBI at 1- and 3-year follow-up. This historical cohort study followed up 29,269 patients discharged from Ontario hospitals between April 1, 2003, and March 31, 2010 for TBI using data from the Discharge Abstract Database, and stratified results by age and sex. Of the participants included in the study, nearly 23% were readmitted within 1 year of discharge, and 35.5% were readmitted within 3 years. Rates of readmission were found to increase with age, and women were found to be at higher risk of experiencing readmission within 3 years. Other risk factors for readmission included mechanism and severity of the injury, as well as general and psychiatric comorbidity. This study provides Canadian-focused background information on hospital readmissions for TBI, although the readmissions occurred after a longer post-discharge period than the 30-day period which is the focus of Manuscript 2. The examination of risk factors for readmissions among patients with TBI provides important context for healthcare and public health program planning and delivery. Additionally, the identification of comorbidities as a risk factor for hospital readmissions provides further evidence of the importance of examining TBI and hospital readmissions among persons with IDD.

Finally, Canner and colleagues (2016) conducted a study which aimed to provide an estimate of the 30-day hospital readmission rate and risk factors among insured TBI patients under 65 years old in the United States. This study used a historical cohort design to examine data contained in the MarketScan® database on patients under 65 who were hospitalized with a primary diagnosis of TBI between 2010-2012. Canner et al. (2016) found that 6.7% (n= 1,785) of the study participants were readmitted to hospital

within 30 days of discharge, among whom 28.5% were readmitted due to TBI. This study provides a North American context of 30-day hospital readmissions among patients, however the lack of universal access to hospital services in the United States limits the generalizability of findings to Canadian jurisdictions. For instance, individuals with TBI may be less likely to be captured by health records if they have little or no health insurance as they may be less likely to visit or be readmitted to a hospital, resulting in an underreporting of incidence. The United States health care system also has in place penalties for higher than expected readmissions, which may cause patients who would otherwise be readmitted to be sent away or kept in emergency beds (United States Centers for Medicare & Medicaid Services, 2019).

Current knowledge regarding the risk of 30-day hospital readmissions among persons with TBI is limited. There is also a general lack of comparison between readmission rates of patients with TBI versus those with other conditions or the general population, making it necessary to consider findings from multiple sources. For instance, the rate of 30-day readmissions among individuals with TBI of 6.7% (Canner et al., 2016) is actually lower than the rate of 9.4% found in the general population when specifically focusing on individuals who were hospitalized (Lin et al., 2019). However, comparing rates using this approach may be suspect due to differences in methodology used by different researchers, as well as differences in the study years and differences in the structure of healthcare system. Comparison with the general population overall may also be particularly misleading as hospitalizations are very heterogeneous. Notably, there is evidence that having a comorbidity, particularly psychiatric comorbidities, acts as a predictor of readmissions for people with TBI.

Current evidence points to a relationship between hospital readmissions and poorer future health outcomes for patients, which emphasizes the need for more knowledge in this area such that policy makers and hospital administrators may be able to address this problem and come up with solutions for addressing readmissions among persons with TBI. Furthermore, the available evidence from this review suggests that having both TBI and IDD could have a synergistic effect on readmission rates, resulting in higher rates among those with both conditions than would be observed among persons with only one or the other.

2.1.7 Summary

There is currently a lack of research examining TBI among persons with IDD or the effect of co-occurring TBI and IDD on readmissions. High rates and associated costs of TBI in Canada, substantiate the importance of assessing the impact of TBI for persons with IDD to help direct public health policy and prevention planning. Additionally, evidence of higher rates of readmission among persons with IDD, persons with TBI, and those with IDD or TBI and comorbid conditions is indicative of the pertinence of identifying disparities among subgroups within the healthcare system.

2.2 Theoretical Frameworks

2.2.1 Epidemiology of Chronic Diseases – Manuscript 1

Descriptive epidemiological approaches for addressing health-related events were used to direct the methods of Manuscript 1 as it aims to identify incidence. Identifying incidence of health-related events, such as traumatic brain injury, is a major aspect of descriptive epidemiology (Merrill, 2012). Descriptive epidemiology focuses on identifying and following disease or injury trends in populations in terms of three features: person, place, and time (Merrill, 2012). Person refers to individual characteristics such as age, sex, and socioeconomic status. Next, place is defined by where a disease or injury is occurring in terms of geography, such as urban versus rural communities. Lastly, time describes the identification of trends, such as variations in the burden of a disease or injury over time.

2.2.1.1 Application of the Epidemiology of Diseases

Incidence of traumatic brain injury has not previously been examined among persons with intellectual and developmental disabilities (IDD) in the literature, and previous studies on traumatic brain injury incidence in the general population have not applied any specific research framework. The focuses of descriptive epidemiology (person, place, time) influenced the study period and variables selected for Manuscript 1.

In Manuscript 1, the "person" aspect was satisfied by the inclusion of patient characteristic variables including age, sex, and income quintiles, as well as the comparison of incidence between two populations: persons with IDD and persons without IDD. Additionally, the "place" component was satisfied by the inclusion of

rurality as a variable. Finally, this study examined incidence over a fifteen-year study period, allowing for the identification of trends over time.

2.2.2 Determinants of Hospital Readmission Framework – Manuscript 2

The Determinants of Hospital Readmission framework proposed by Kangovi & Grande (2011) was used to guide the methods for Manuscript 2. This framework reconceptualizes the usual understanding of readmissions as being influenced by the quality of inpatient care to consider a more comprehensive set of potential factors. In contrast to previous interpretations of hospital readmissions, this model incorporates the role of patient factors in addition to considerations of health service access, such that access to health care and other resources are suggested to have an important impact on hospital readmissions (Kangovi & Grande, 2011). Kangovi & Grande (2011) suggest that readmissions among patients with poor socioeconomic resources will remain high if these determinants continue to be overlooked. Based on this framework, readmissions are considered to be influenced by internal and external factors of the patient, as well as both inpatient and outpatient care. The purpose of this model is to enhance the understanding of factors that influence readmissions, and thereby encourage further exploration into the interpretations and usefulness of hospital data for the reduction of hospital readmissions.

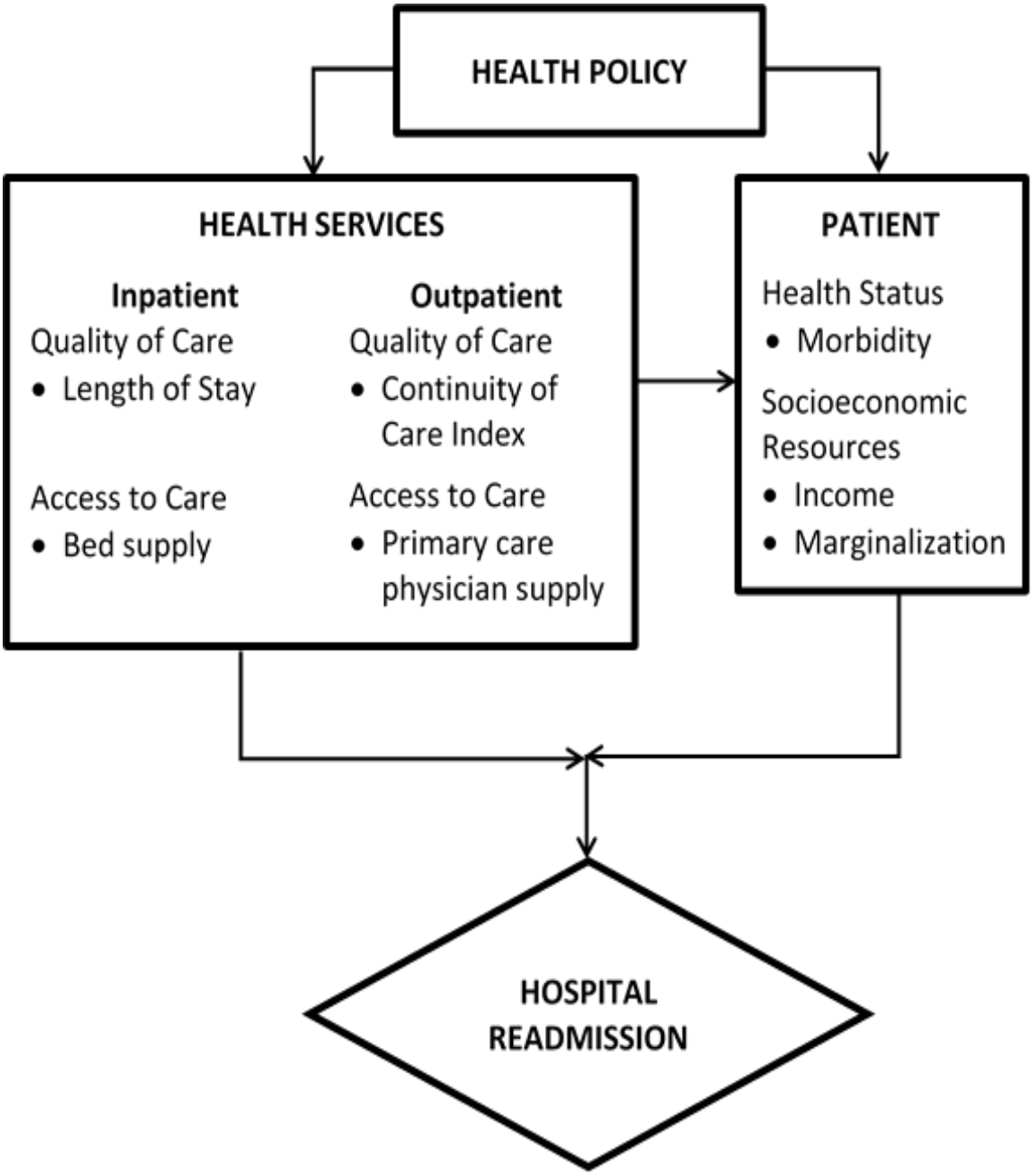
The Determinants of Hospital Readmission framework considers the roles of two categories: health services factors and patient-level factors. Based on this model, readmissions are determined by interactions between factors in these two categories (Kangovi & Grande, 2011). Within health services, inpatient health services and outpatient health services are examined separately in terms of both quality and

accessibility. Important factors considered within patient-level factors include those related to patient health status and patient socioeconomic resources (Figure 2.1). Including variables to examine each of these factors will optimize the ability to understand the reasons for readmissions and improve strategies for addressing them.

2.2.2.1 Application of the Determinants of Hospital Readmission Framework

The Determinants of Hospital Readmission framework recognizes that readmissions are influenced by factors other than just inpatient quality of care or patient health status (Kangovi &Grande, 2011) and has been used in previous readmissions research for persons with IDD (Balogh et al., 2017). This framework was applied to Manuscript 2 to enhance understanding of what factors may contribute to differences in readmissions risk between study groups. The model was used to identify additional variables to be examined and considered in the multivariable regression analysis comparing the odds of readmissions across the three study sub-groups (Figure 2.1). The variables chosen based on the application of this framework may provide a more comprehensive representation of the health and access needs of persons with IDD with and without a history TBI, as well as persons with a history of TBI and no IDD. Demographic variables such as age, sex, and rurality were also included as variables, although they are not included within the Kangovi & Grande (2011) framework. While these factors are not influenced by health policy and so are appropriate to exclude from the model, they may also be important factors for readmissions.

Figure 2.1
Determinants of Hospital Readmission framework as proposed by Kangovi & Grande (2011): Revised to include examples of variables used in statistical models (See Manuscript 2).



Health Policy

The Determinants of Hospital Readmission framework posits that health policy can influence health services factors and patient-level factors. Based on this concept, if readmissions are high, this is an indication that more can be done at the policy level. Up-to-date analyses of the impact of health services and patient factors should thus be considered pertinent for health policy recommendations aimed at reducing readmissions.

Inpatient Health Services: Quality and Access

Manuscript 2 of this thesis examined the role of indicators of health services quality and accessibility on the odds of readmissions. Inpatient health services refer to services provided to an individual who has been admitted to hospital. In this study, quality of inpatient services refers to how well patients are cared for during their index hospitalization episode. As an example of quality of inpatient care, previous research has found that patients discharged from hospital too early (i.e. without being appropriately stabilized or provided discharge planning), may be more likely to be readmitted (Figueroa, Harman, & Engberg, 2004). Based on this knowledge, this research included a variable for length of stay of the index hospitalization episode as an indicator of the quality of inpatient health services.

Access to inpatient care refers to the ease with which an individual is able to be admitted to hospital. Although a lack of hospital beds has been found to be a barrier to inpatient health services access, greater availability of hospital beds can also result in an increased demand for hospitalizations without necessarily improving health (Jencks, Williams, & Coleman, 2009; Kangovi & Grande, 2011). Thus, number of beds/1000 population for each of the 14 health planning regions in Ontario (referred to as Local

Health Integration Networks [LHINs]) was included as a variable in this research to measure inpatient health services in terms of access.

Outpatient Health Services: Quality and Access

Outpatient health services refer to services provided outside of the hospital setting, or in outpatient departments in hospital. Outpatient quality of care refers to how well patients are treated within the healthcare system as outpatients, i.e. not including services provided while hospitalized. As an example of a measure of outpatient quality, the Usual Provider Continuity (UPC) index has been used in previous research to measure continuity of care, or the degree of consistency with which an individual is provided care by the same physician for outpatient visits (Manitoba Centre for Health Policy, 2014).

Access to outpatient services depends on how easily a patient is able to make contact with the health care system without being admitted, for instance, how quickly one is able to make an appointment with a primary care physician. Thus, the number of full-time equivalent primary care physicians per 100 population in each LHIN was used to measure outpatient health services access.

Patient

This research also addressed the role of patient-level factors on odds of readmissions. Patient health status refers to the health of the patient at the time of the index hospitalization episode. A number of variables were used as measures of health status, including the presence or absence of IDD, history of TBI, and history of mental health. In addition, the Charlson comorbidity index was used as an indicator of individual disease burden (Quan et al., 2011).

Individual socioeconomic resources are uniquely identified by the Determinants of Hospital Readmission framework as an important consideration for their potential influence on readmissions (Kangovi & Grande, 2011). Patients who lack socioeconomic resources may be less able to access health services due to financial or time-related barriers. These kinds of access barriers are not related to the accessibility of the health services themselves, but to the patient's own resources. To measure patient socioeconomic resources, variables were included to assess estimates of patient income and marginalization. Individuals with lower income or a higher degree of marginalization (e.g. an area with high ethnic diversity) may have limited access to health services as they may be less likely to afford a vehicle or public transportation, or they may lack private health insurance for things such as prescription medications which are not covered by public insurance (Mikkonen & Raphael, 2010). These individuals may also feel stigmatized or discriminated against within the healthcare system (Loignon et al., 2015), which could impact both the quality and access of health services. These barriers may increase readmissions independently of other variables, or may contribute indirectly through poorer health status at the time of the index hospitalization episode.

Hospital Readmission & Framework Summary

Hospital readmission is a measure of service which occurs when an individual is admitted to hospital again after an index hospitalization episode and is the outcome of interest for Manuscript 2. An inclusive set of variables, chosen based on the Determinants of Hospital Readmission framework, was examined for individual impacts on the odds of readmission among persons with IDD, IDD and a history of TBI, and with a history of TBI without IDD.

The Determinants of Hospital Readmission framework provides a more holistic approach to understanding what causes readmissions as it recognizes the importance of accessibility not addressed in previous models (Kangovi & Grande, 2011). This framework was used to guide the variables chosen for analysis in Manuscript 2 to identify their impact on readmissions among persons with IDD and with a history of TBI.

3 MANUSCRIPT 1

Traumatic Brain Injury Risk among Ontario adults with and without Intellectual and Developmental Disabilities

3.1 Abstract

Background: There are approximately 66,000 Ontario adults living with a diagnosis of intellectual and developmental disabilities (IDD). These individuals experience injuries and falls more frequently than those without IDD. Traumatic brain injuries (TBIs) are a leading cause of death and disability in Canada. Although falls are a known risk factor for TBI, no research has examined TBI risk among persons with IDD.

Objective: Compare TBI risk among Ontario adults with and without IDD over time and by demographic information.

Methods: Using administrative data, annual crude and adjusted incidence of TBI based on the first TBI in unique individuals in a given fiscal year were compared between two main cohorts: 1) adults with IDD, and 2) a random 10% sample of adults without IDD for fiscal years 2002/03 to 2016/17.

Conclusions: Over the 15-year study period, incidence of TBI was 1.5–2.5 times greater among persons with IDD versus without IDD.

3.2 Introduction

3.2.1 Intellectual and Developmental Disabilities

According to the Government of Ontario (2012), "developmental disability" is defined as impairments in both intellectual functioning and adaptive behaviour. Intellectual functioning refers to various cognitive abilities including the ability to learn, to reason, and to problem solve, and has traditionally been evaluated using intelligence quotient tests, in which a score of 75 or lower is indicative of impaired intellectual functioning (American Association on Intellectual and Developmental Disabilities [AAIDD], 2018). Adaptive behaviour refers to three domains of skills: 1) conceptual skills such as language, math, and self-direction; 2) social skills such as self-esteem, empathy, and the ability to make and maintain friendships; and 3) practical skills including occupational skills, and personal care and self-management (AAIDD, 2018). According to the Government of Ontario, these impairments must have developed in an individual prior to the age of 18 years, are likely to be lifelong, and are pervasive in multiple aspects of the person's life such as personal care, language or learning abilities, or the capacity for independent living as an adult (Government of Ontario, 2012). This study uses the nomenclature "intellectual and developmental disabilities" (IDD) to be consistent with trends in the literature.

Based on this definition, there are approximately 66,000 Ontario adults living with a diagnosis of IDD (Lunksy, Klein-Geltink, & Yates, 2013). These individuals are at greater risk for experiencing a number of health concerns, and typically experience worse health outcomes compared to persons without IDD (Lunsky et al., 2013). Among health concerns observed to be more prevalent in persons with IDD are injuries and falls.

3.2.2 Traumatic Brain Injury

Traumatic brain injuries (TBIs) are a form of acquired brain injury (ABI); a class of brain injuries that includes all injuries to the brain that are sustained after birth (Ontario Neurotrauma Foundation, 2019). ABIs may be caused by some external force (traumatic; TBI), or may develop due to some illness or other pathophysiology (non-traumatic; nTBI). Currently, it is estimated that there are more than 1.5 million Canadians living with the effects of ABI, with an annual incidence of more than 160,000 cases (Brain Injury Canada, 2019).

TBI, the most common form of ABI, occurs when an external head injury affects the structure or function of the brain, resulting in impaired cognition, communication, physical function, and/or psychosocial behaviour (Commission on Accreditation of Rehabilitation Facilities [CARF], 2015). In 2010, there were more than 200,000 people living with TBI in Ontario alone, among which more than 21,000 were incident cases, resulting in an incidence rate of 1.7 new cases per 1000 population (Ng et al., 2015). Prevalence and incidence of TBI have been increasing steadily for several years beginning as early as 2004.

There is currently an overall lack of any regional or international data related to TBI at the population level for persons with IDD. The only article examining IDD and TBI concurrently was qualitative in nature, and focused on difficulties with access to health services (McKinlay, McLellan, & Daffue, 2012). No research could be found quantifying the burden or risk of TBI among persons with IDD.

3.2.3 Injuries and Falls: The Risk of TBI among Persons with IDD

Despite the lack of quantitative data regarding TBI among persons with IDD, it is possible to gain some insight on the risk for TBI in this population by understanding the risk of injuries broadly, as well as falls. Falls are relevant since, in Canada, they are consistently found to be the leading cause of TBI (Canadian Institute for Health Information [CIHI], 2006; Fu et al., 2016).

Compared to the general population, persons with IDD experience more injuries (Slayter et al., 2006) and injury-related loss of consciousness (Finlayson et al., 2010). Persons with IDD are up to 78% more likely than those without IDD to experience an injury. Falls in particular are also more common among persons with IDD (Cox et al., 2010). Persons with IDD have been shown to have up to 70% increased risk of experiencing a fall versus the general population, and approximately one quarter of these falls result in head injury. Additionally, older persons with IDD (age 50 and older) experience a higher rate of falls, with an average of one fall per person per year compared to 0.45 falls per person per year in the general elderly population (age 65 and older; Smulders et al., 2013).

In addition to the overall lack of TBI-related data for persons with IDD, the existing injury- and fall-related research strongly supports the need for research examining TBI risk in this population.

3.2.3 Significance

Altered brain structure and/or function caused by TBI can result in debilitating impairments in cognition and physical and psychosocial functioning (CARF, 2015). TBI is a leading cause of death and disability and is an increasingly prominent public health

concern (Fu et al., 2016; Ng et al., 2015). Based on TBI-related emergency department visits in Ontario alone, there were approximately 1,030 cases per 100,000 Ontarians in 2009, conservatively estimated to have costed nearly $300 million in medical treatment costs and more than $650 million in lost productivity (Fu et al., 2016). Since this information is based solely on emergency department visits, this is only a fraction of the total TBI burden in Ontario. Additionally, across all of Canada, TBI is estimated to cost $8.2 billion due to working age disability alone by 2031 if effective prevention methods are not put in place (Public Health Agency of Canada & National Health Charities Canada [PHAC & NHCC], 2014). Notably, the study by McKinlay et al. (2012) provides evidence which suggests that among persons with IDD, TBI may result in greater direct and indirect costs compared to the general population due to poorer services access and/or coordination.

Despite the clear need for intervention and targeted prevention methods, no studies have examined IDD as a potential risk factor for TBI. Much of the existing TBI literature examining risk factors revolves around risk factors for potential outcomes after a TBI event. Research examining potential risk factors for TBI, such as IDD, could help to inform policy planning and resource allocation, as well as reduce TBI-related costs, by identifying potential target populations for prevention efforts.

Evidence that falls are the leading cause of TBI in the general population, along with the increased risk of falls and fall-related head injuries among persons with IDD compared to the general population, supports the hypothesis that TBI risk may be higher for persons with IDD. Despite the overall lack of TBI-related data for persons with IDD, evidence of greater TBI-related costs, as well as the existing injury- and fall-related

research, indicate a clear need for quantitative research examining TBI risk among persons with IDD.

3.2.4 Objective

The objective of this research is to compare the incidence of TBI among Ontario adults with and without IDD over time and by demographic characteristics.

3.3 Methods

3.3.1 Study Design

A historical population cohort design was used to report annual incidence of TBI for each fiscal year from 2002/03-2016/17 for Ontario adults with and without IDD. This study design allowed the researcher to look back in time to identify persons with and without IDD and determine whether they were diagnosed with a new TBI at any time during a given year of study. This study included Ontario adults with and without IDD as identified in administrative databases. The study methods for this research were submitted to and approved by the Research Ethics board for the University of Ontario Institute of Technology.

3.3.2 Data Sources and Linkage

Administrative data are routinely collected for various administrative and other non-research related reasons; however, they are often also useful for research purposes (Statistics Canada, 2017). Some jurisdictions are able to collect and store health data generated by nearly all aspects of the health care system including clinics and hospitals (Cadarette & Wong, 2015). Although these data are collected for administrative or billing purposes, they are able to inform health- and health services-related research. Data within these databases are de-identified and assigned a unique code which is used to link the data between other data sources.

As a prescribed entity, ICES has access to a wide variety of Ontario-based health-related data including health and other administrative databases (ICES, 2019). ICES is renowned for producing high quality health research and for its commitment to maintaining the privacy and security of health information (ICES, 2019). Data collected

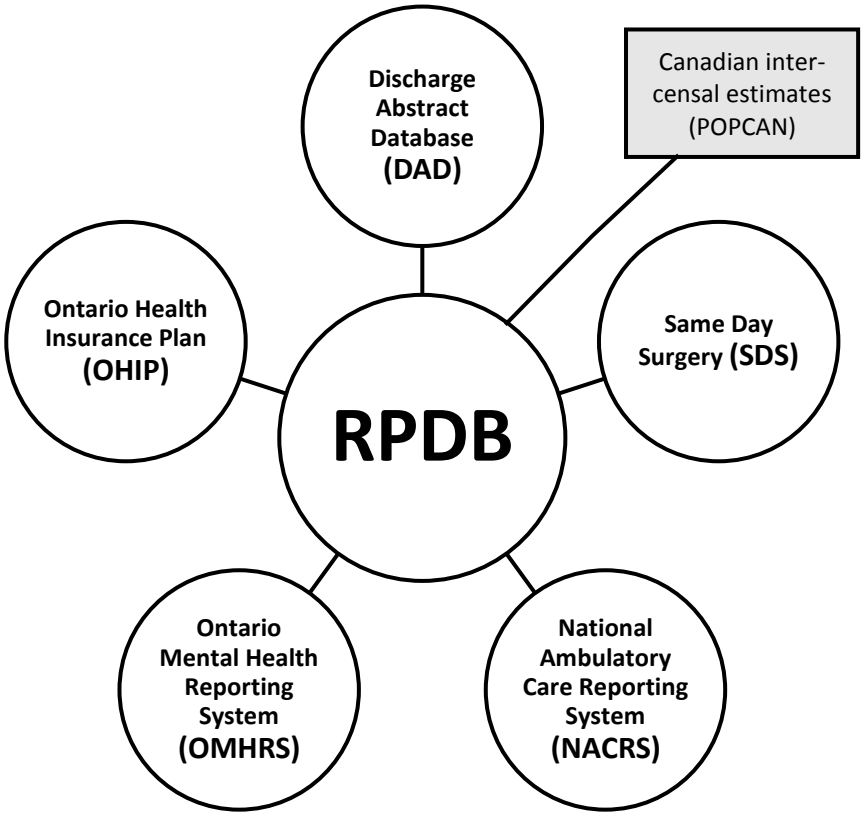
by ICES have all direct personal identifiers (i.e. health card number, first and last name, date of birth, gender, postal code) removed. Each Ontario resident eligible for the Ontario Health Insurance Plan (OHIP) is assigned a unique confidential "code", or ICES Key Number (IKN) created by a secure ICES algorithm. Each person has one consistent IKN which allows for accurate linkage across datasets via the Registered Persons Database (RPDB). The RPDB is a population-based data registry which monitors changes in OHIP eligibility over time, and is the database through which all ICES datasets are linked (Figure 3.1).

3.3.3 Databases

Persons with IDD were identified for this study using International Classification of Diseases (ICD) diagnostic codes for IDD in administrative databases held at ICES (Lunsky et al., 2013). A total of seven administrative databases were accessed including five health databases and two other data sources. The five health databases used were the Canadian Institute of Health Information Discharge Abstract Database (CIHI-DAD), Same Day Surgery (SDS), the National Ambulatory Care Reporting System (NACRS), the Ontario Mental Health Reporting System (OMHRS), and OHIP. These administrative health databases include various clinical data about Ontario residents including inpatient hospital discharges, day surgeries, emergency and ambulatory care visits, mental health services, and physician visits (see Appendix B, Table B1).

The two other data sources used included the RPDB for data linkage and for obtaining demographic information and neighborhood income data on all Ontarians eligible for OHIP, and Canadian inter-censal estimates (POPCAN) for estimates of the Canadian population and demographics (see Appendix B, Table B1).

Figure 3.1
ICES Data Linkage: Adapted to show how all databases used in this study were linked through the registered persons database (RPDB).



*Note that circles represent administrative health databases used to identify persons with IDD and TBI; databases in squares were used to derive other variables

3.3.4 Study Populations

Three cohorts of Ontario adults aged 19 years and older were created using the above-mentioned administrative databases. The three cohorts were: 1) All-IDD, consisting of all persons with a diagnosis of IDD; 2) TBI-Prior to IDD, consisting of a comparison cohort of persons with IDD with a history of TBI preceding their IDD diagnosis; and 3) No-IDD, another comparison cohort consisting of a 10% random sample of the remaining Ontario adult population without IDD.

Population of Interest

To create the first cohort, All-IDD, persons with IDD were identified using diagnostic codes from ICD-9 and -10 (see Appendix B, Table B3) in the five health administrative databases accessed from ICES (see Appendix B, Table B2). These codes were identified from the Health Care Access Research and Developmental Disabilities research centre (H-CARDD), who developed and used this algorithm for identifying persons with IDD (Lunsky et al., 2013). It is common for the diagnosis of IDD to be recorded when the individual is first assessed during childhood. Since IDD is a lifelong condition, using the widest possible lookback window allows for a greater number of people to be identified within existing databases (Lin et al., 2013). In order to maximize the sensitivity of the algorithm (i.e. inclusion of persons with IDD), Lunsky et al. (2013) searched for a history of IDD-related diagnostic codes looking as far back as the inception date of each database. Individuals identified with IDD in the databases were included only if an IDD-related diagnostic code appeared in one or more hospital or emergency department visits, or two or more physician visits. This was done to improve specificity without sacrificing sensitivity and has also been applied in validated algorithms developed for other conditions (Hux, Ivis, Flintoft, & Bica, 2002; Public Health Agency of Canada, 2009).

Comparison Cohorts

After identifying the All-IDD cohort, the additional two study populations were selected to serve as comparison groups. First, a subset of persons with IDD with a record of TBI which predates the IDD diagnosis (Cohort 2) was selected from the group of persons with IDD to serve as a sub-analysis.

To create the TBI-Prior to IDD cohort, health records of persons identified with IDD were examined for history of TBI by looking back as far as the inception of the health databases to determine if there was any indication that a TBI event occurred prior to the diagnosis of IDD based on ICD-9 and -10 codes (see Appendix B, Table B4). Persons determined to have a diagnosis of TBI that preceded the diagnosis of IDD were included in this cohort.

Finally, to create cohort 3 (No-IDD), a random 10% sample of persons without IDD was identified using the RPDB to serve as the primary comparison cohort.

Exclusion Criteria

Individuals not eligible for OHIP at any point during a given study year and persons under the age of 19 as of April 1 for a given study year (i.e. persons under 19 as of April 1, 2002 were excluded in annual incidence in 2002/03, persons under 19 as of April 1, 2003 were excluded for 2003/04 and so on) were excluded from the study. Since IDD must develop prior to the age of 18, excluding persons under age 19 reduces uncertainty regarding whether a given individual had IDD during the full study period.

This study thus examined TBI incidence among Ontario adults aged 19 years and older with IDD regardless of the cause and compared it to the incidence of TBI among persons with IDD who had a TBI prior to their IDD diagnosis (sub-analysis), as well as persons with no IDD regardless of TBI history (primary comparison). The diagrams below (Figure 3.2 a-c) show examples of who was included in each of the study groups:

Figure 3.2 (a)
Study Populations: Examples of who was included in All-IDD (Cohort 1).

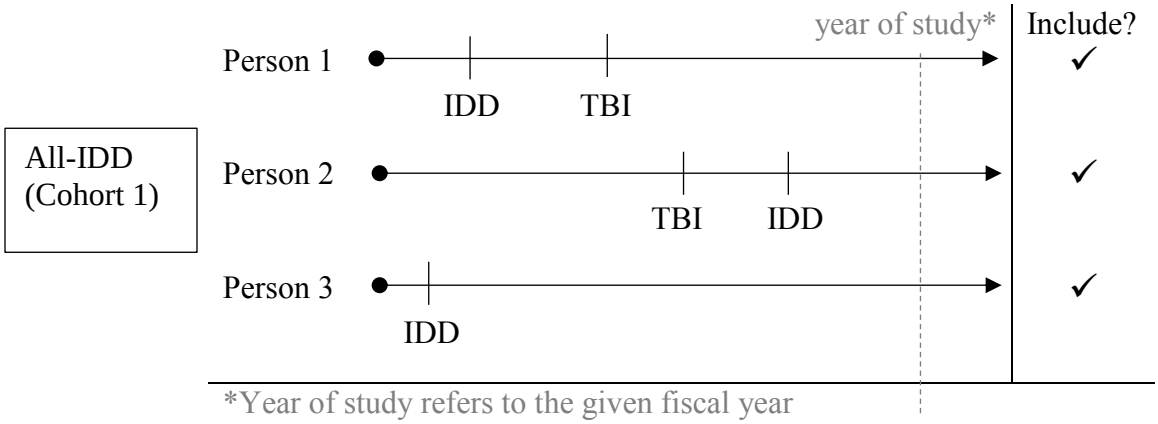


Figure 3.2 (b)
Study Populations: Examples of who was included in TBI-Prior to IDD (Cohort 2).

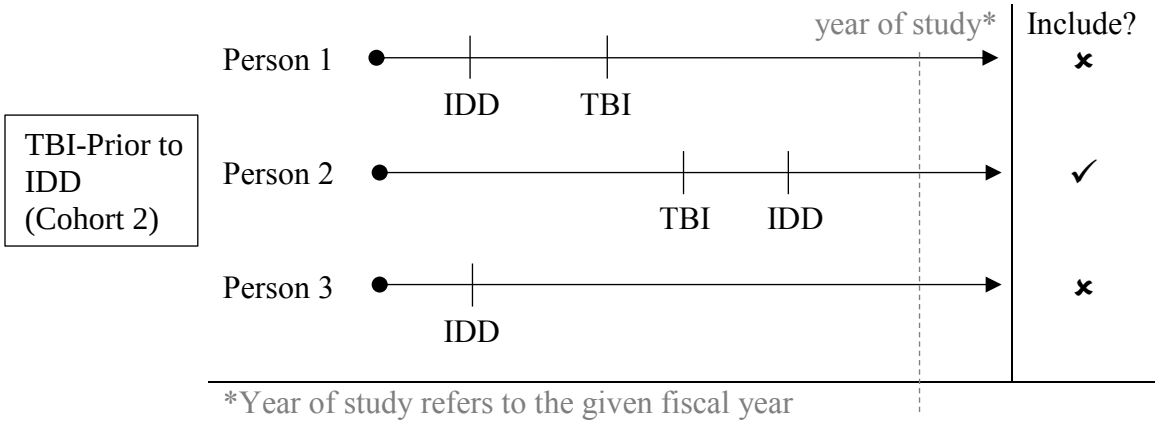
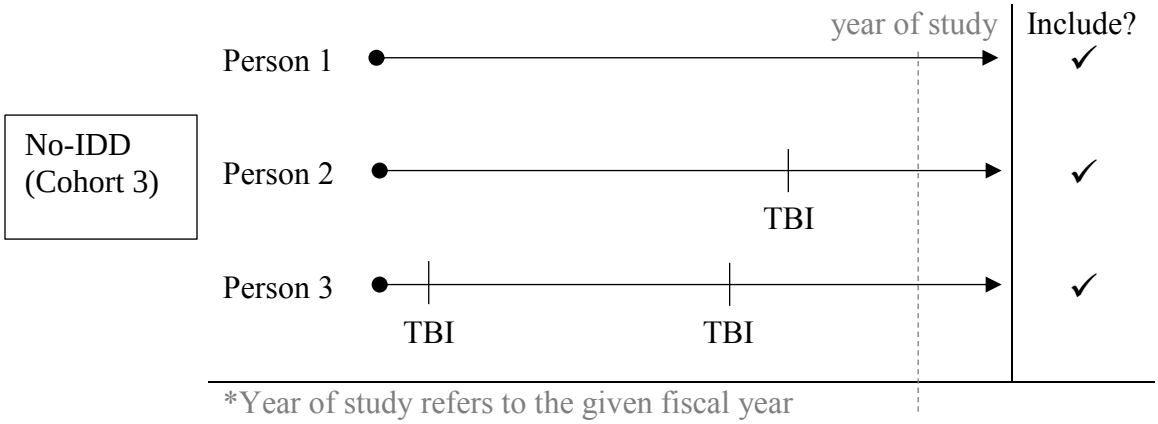


Figure 3.2 (c)
Study Populations: Examples of who was included in No-IDD (Cohort 3).



3.3.5 Other Variables and Measures

Baseline demographic characteristics including age, sex, income quintile, and rurality were described for all groups based on data obtained using the RPDB and Canadian Census data. Income quintiles were based on neighborhood income level derived from summary data from the Canadian Census of household size-adjusted measures of household income (Statistics Canada, 2015). Data on income quintiles were included to provide an indication of an individual's socioeconomic situation.

Rurality was determined using community size (CSize) which is based on census data (Statistics Canada, 2015). CSize divides community size into five mutually exclusive categories using population estimates for each census metropolitan area and census agglomeration. Using these categories, "CSize=1" indicates large urban cities with 1.5 million residents or more and "CSize=5" represents rural and small-town areas of Canada including towns with an urban area population of less than 10,000 as well as rural areas. In this study, areas with CSize=5 were designated as "rural".

3.3.6 Data Analysis

3.3.6.1 Traumatic Brain Injury Incidence

Persons diagnosed with a new TBI in all cohorts were identified using ICD-10 diagnostic codes for TBI (see Appendix B, Table B4) in the CIHI-DAD, SDS, and NACRS, and linked using the IKN. The CIHI-DAD, SDS, and NACRS have been consistently used to identify TBI in the general population in previous studies of TBI incidence (Fu et al., 2016; Ng et al., 2015). Incident cases were defined as the first new TBI diagnosis in a unique individual in a given fiscal year. Note that due to the nature of TBI, persons with a prior history of TBI were not excluded from incidence calculations

and only cases that occurred during the given fiscal year were counted, thus it is referred to as an "annual incidence".

Annual incidence of TBI was calculated in the three cohorts for fiscal years 2002/03-2016/17. The formula used to calculate incidence in all persons with IDD is shown below:

$$\text{All-IDD (Cohort 1) TBI Incidence (year)} = \frac{\text{Number of Ontario adults 19 and older with a diagnosis of IDD with a new diagnosis of TBI in (year)}}{\text{Number of Ontario adults 19 and older with a diagnosis of IDD (year)}}$$

The denominator was the population of Ontario adults 19 and older with IDD that were eligible for OHIP, as of April 1 of a given fiscal year. The numerator was the number of persons with at least one new instance of TBI in the same fiscal year based on patient records among persons with IDD.

The formula used to calculate incidence in persons diagnosed with TBI prior to IDD is shown below:

$$\text{TBI-Prior to IDD (Cohort 2) TBI Incidence (year)} = \frac{\text{Number of Ontario adults 19 and older with a diagnosis of TBI predating the IDD, with a new diagnosis of TBI in (year)}}{\text{Number of Ontario adults 19 and older with a diagnosis of TBI predating the IDD predating any TBI (year)}}$$

The denominator was the population of Ontario adults 19 and older diagnosed with IDD with a diagnosis of TBI that predates the IDD that were eligible for OHIP, as of April 1

of a given fiscal year. The numerator was the number of persons with at least one new instance of TBI in the same fiscal year based on patient records among persons diagnosed with TBI prior to the IDD.

The formula to calculate incidence of TBI among individuals without IDD is below:

$$\text{No IDD (Cohort 3) TBI Incidence (year)} = \frac{\text{Number of Ontario adults 19 and older without IDD with a new diagnosis of TBI in (year)}}{\text{Number of Ontario adults 19 and older without IDD (year)}}$$

The denominator was the population of Ontario adults 19 and older without IDD that were eligible for OHIP, as of April 1 of a given fiscal year. The numerator was the number of individuals with at least one new case of TBI in the same fiscal year based on health records of persons without IDD.

3.3.6.2 Incidence Risk Ratio

Analysis of incidence for objective 1 included a comparison of incident TBI in persons with and without IDD. In order to make this comparison, the relative risk, or risk ratio, was calculated to compare incidence rates across the three cohorts. To calculate the risk ratio, TBI incidence in persons with All-IDD was divided by the incidence in those without IDD. This calculation was also done for TBI-Prior to IDD compared to No-IDD to indicate any potential effect of TBI prior to IDD diagnosis on future TBI risk. The formulae to calculate risk ratio are below:

$$\text{All-IDD/ No IDD Risk Ratio (year)} = \frac{\text{Incidence of TBI in Ontario adults 19 and older with all IDD (year)}}{\text{Incidence of TBI in Ontario adults 19 and older without IDD (year)}}$$

$$\text{TBI-Prior to IDD/ No IDD Risk Ratio (year)} = \frac{\text{Incidence of TBI in Ontario adults 19 and older diagnosed with IDD prior to TBI (year)}}{\text{Incidence of TBI in Ontario adults 19 and older without IDD (year)}}$$

3.3.6.3 Age- and Sex-Specific Incidence

Annual cumulative age-and sex-specific incidence was calculated for fiscal years 2012/13 to 2016/17 to compare the distribution of new cases of TBI per 1000 persons in specified age categories and between males and females in all study cohorts. The general equation used to calculate age- and sex-specific incidence rate for persons with All IDD is shown below for reference:

$$\text{Age- and Sex-Specific Incidence among All IDD (year)} = \frac{\text{Number of Ontario (sex)s with IDD aged (age category) with a new diagnosis of TBI in (year)}}{\text{Number of Ontario (sex)s with IDD aged (age category) in (year)}}$$

3.3.6.4 Standardized Incidence and Incidence Risk Ratio

Annual age/sex-standardized incidence rates (AS-SIR) and age- and sex-standardized risk ratios were calculated for fiscal years 2002/03 to 2016/17. AS-SIR was

standardized to the age and sex structure of the 2011 Canadian population to adjust for differences in age and sex distribution between study groups, increasing inter-cohort comparability.

3.3.6.5 Significance and Confidence

A proxy measure of statistical significance for crude and adjusted incidence, as well as incidence risk ratios, was calculated for persons with and without IDD using 95% confidence intervals (CIs). Although the point estimate (i.e. the reported incidence) provides the best approximation of the true value, a 95% CI provides a range within which there is a 95% probability that the true value lies (du Prel, Hommel, Röhrig, & Blettner, 2009). CIs are impacted by sample size such that larger sample sizes will produce a narrower confidence interval, while smaller sample sizes produce a wider CI (du Prel et al., 2009). In order to derive significance from the confidence interval, results were considered significantly different if the CI for persons without IDD was not contained within the CI for persons with IDD.

3.4 Results

3.4.1 Baseline Characteristics of adults with and without IDD

IDD-status, age, sex, income quintile, and rurality for each cohort were identified as of April 1, 2002, and April 1, 2016. Baseline characteristics of the study populations by IDD status for fiscal years 2002-2003 and 2016-2017 are presented in Table 3.1 and Table 3.2 respectively. Persons with IDD were more likely to be male in both fiscal years, however this was more pronounced in the 2016/17 fiscal year (60.5% vs. 54.1%). In contrast, persons without IDD were similarly likely to be male or female. In both fiscal years, the majority of persons with and without IDD were between 19-49 years. In both cohorts, the age distribution between males and females was similar, with the exception that females with IDD were more somewhat older than males with IDD. Persons with IDD were more likely to be younger. For instance, in the 2002/03 fiscal year, 24.3% of persons with IDD were between the ages of 19-29 years compared to 18.6% of persons without IDD; this rose to 41.1% compared to 18.1% in the 2016/17 fiscal year. This difference was slightly more pronounced among males. Additionally, persons with IDD were more likely to reside in the lowest income quintiles with 27.4% living in income quintile 1 (lowest) and 21.4% in quintile 2 in the 2002/03 fiscal year, and 26.1% and 20.8% in quintile 1 and quintile 2 in fiscal year 2016/17. Persons with IDD were also less likely to reside in the highest income quintile (quintile 5) with only 14.6% in 2002/03 and 16.0% in 2016/17. In comparison, persons without IDD were relatively evenly distributed across all five income quintiles. Persons with IDD were more likely to be living in a rural area in 2002/03 (19.2% compared to 12.6%); rural status was more similar between persons with and without IDD in 2016/17.

Table 3.1
Baseline characteristics of Ontario adults with and without intellectual and developmental disabilities (IDD) (2002/03).

2002-03	**IDD (n=28,743)**			**No-IDD (n=941,198)**		
Sex	**Male** (n=15,556)	**Female** (n=13,187)	**Total** (n=28,743)	**Male** (n=458,948)	**Female** (n=482,250)	**Total** (n=941,198)
Age on April 1 (n, col %)						
19-29	4,156 (26.7%)	2,825 (21.4%)	6,981 (24.3%)	87,846 (19.1%)	87,337 (18.1%)	175,183 (18.6%)
30-39	3,644 (23.4%)	3,034 (23.0%)	6,678 (23.2%)	102,003 (22.2%)	102,264 (21.2%)	204,267 (21.7%)
40-49	3,598 (23.1%)	3,048 (23.1%)	6,646 (23.1%)	102,012 (22.2%)	102,138 (21.2%)	204,150 (21.7%)
50-59	2,124 (13.7%)	1,933 (14.7%)	4,057 (14.1%)	74,220 (16.2%)	74,904 (15.5%)	149,124 (15.8%)
60-69	1,060 (6.8%)	1,024 (7.8%)	2,084 (7.3%)	46,972 (10.2%)	49,697 (10.3%)	96,669 (10.3%)
70-79	660 (4.2%)	697 (5.3%)	1,357 (4.7%)	32,766 (7.1%)	40,814 (8.5%)	73,580 (7.8%)
80+	314 (2.0%)	626 (4.7%)	940 (3.3%)	13,129 (2.9%)	25,096 (5.2%)	38,225 (4.1%)
Income Quintile (n, col %)						
1 (low)	4,264 (27.4%)	3,611 (27.4%)	7,875 (27.4%)	90,476 (19.7%)	95,212 (19.7%)	185,688 (19.7%)
2	3,340 (21.5%)	2,822 (21.4%)	6,162 (21.4%)	93,412 (20.4%)	98,023 (20.3%)	191,435 (20.3%)
3	2,862 (18.4%)	2,448 (18.6%)	5,310 (18.5%)	91,785 (20.0%)	97,155 (20.1%)	188,940 (20.1%)
4	2,583 (16.6%)	2,218 (16.8%)	4,801 (16.7%)	90,990 (19.8%)	95,100 (19.7%)	186,090 (19.8%)
5 (high)	2,277 (14.6%)	1,911 (14.5%)	4,188 (14.6%)	90,781 (19.8%)	95,401 (19.8%)	186,182 (19.8%)
Missing	230 (1.5%)	177 (1.3%)	407 (1.4%)	1,504 (0.3%)	1,359 (0.3%)	2,863 (0.3%)
Region (n, col %)						
Urban	12,572 (80.8%)	10,636 (80.7%)	23,208 (80.7%)	399,664 (87.1%)	422,750 (87.7%)	822,414 (87.4%)
Rural	2,968 (19.1%)	2,541 (19.3%)	5,509 (19.2%)	58,967 (12.8%)	59,241 (12.3%)	118,208 (12.6%)
Missing	16 (0.1%)	10 (0.1%)	26 (0.1%)	317 (0.1%)	259 (0.1%)	576 (0.1%)

Table 3.2
Baseline characteristics of Ontario adults with and without intellectual and developmental disabilities (IDD) (2016/17).

2016-17	**IDD (n=66,027)**			**No-IDD (n=1,142,931)**		
Sex	**Male** (n=39,964)	**Female** (n=26,063)	**Total** (n=66,027)	**Male** (n=557,833)	**Female** (n=585,098)	**Total** (n=1,142,931)
Age on April 1 (n, col%)						
19-29	18,670 (46.7%)	8,460 (32.5%)	27,130 (41.1%)	104,466 (18.7%)	102,124 (17.5%)	206,590 (18.1%)
30-39	6,623 (16.6%)	4,310 (16.5%)	10,933 (16.6%)	94,597 (17.0%)	99,121 (16.9%)	193,718 (16.9%)
40-49	4,852 (12.1%)	4,091 (15.7%)	8,943 (13.5%)	100,552 (18.0%)	102,405 (17.5%)	202,957 (17.8%)
50-59	5,097 (12.8%)	4,475 (17.2%)	9,572 (14.5%)	109,252 (19.6%)	109,424 (18.7%)	218,676 (19.1%)
60-69	3,096 (7.7%)	2,800 (10.7%)	5,896 (8.9%)	79,655 (14.3%)	84,666 (14.5%)	164,321 (14.4%)
70-79	1,149 (2.9%)	1,185 (4.5%)	2,334 (3.5%)	44,585 (8.0%)	50,048 (8.6%)	94,633 (8.3%)
80+	477 (1.2%)	742 (2.8%)	1,219 (1.8%)	24,726 (4.4%)	37,310 (6.4%)	62,036 (5.4%)
Income Quintile (n, col %)						
1 (low)	10,349 (25.9%)	6,913 (26.5%)	17,262 (26.1%)	103,555 (18.6%)	109,336 (18.7%)	212,891 (18.6%)
2	8,286 (20.7%)	5,424 (20.8%)	13,710 (20.8%)	108,088 (19.4%)	113,709 (19.4%)	221,797 (19.4%)
3	7,499 (18.8%)	4,638 (17.8%)	12,137 (18.4%)	111,283 (19.9%)	115,896 (19.8%)	227,179 (19.9%)
4	7,163 (17.9%)	4,707 (18.1%)	11,870 (18.0%)	119,415 (21.4%)	124,798 (21.3%)	244,213 (21.4%)
5 (high)	6,372 (15.9%)	4,205 (16.1%)	10,577 (16.0%)	112,927 (20.2%)	119,003 (20.3%)	231,930 (20.3%)
Missing	295 (0.7%)	176 (0.7%)	471 (0.7%)	2,565 (0.5%)	2,356 (0.4%)	4,921 (0.4%)
Region (n, col %)						
Urban	34,703 (86.8%)	22,377 (85.9%)	57,080 (86.4%)	494,801 (88.7%)	522,461 (89.3%)	1,017,262 (89.0%)
Rural	5,246 (13.1%)	3,679 (14.1%)	8,925 (13.5%)	63,020 (11.3%)	62,625 (10.7%)	125,645 (11.0%)
Missing	15 (0.0%)	7 (0.0%)	22 (0.0%)	12 (0.0%)	12 (0.0%)	24 (0.0%)

3.4.2 Traumatic Brain Injury in adults with and without IDD

Between April 1, 2002 and March 31, 2017, there were 26,047 new cases of TBI identified, of which 1,945 were among persons with a diagnosed IDD. Characteristics of persons who experienced at least one TBI are reported in Table 3.3 and Table 3.4 for fiscal years 2002-2003 and 2016-2017 respectively. In both cohorts, TBI cases were more likely to be younger. Among persons with IDD, the proportion of individuals who experienced a TBI was greater in most fiscal years for those aged 19-29 years and lower in all fiscal years for those aged 70+ compared to persons without IDD. With regard to sex, in both cohorts, persons who experienced a TBI were more likely to be male, with the only exceptions in 2009/10 among persons with IDD (not shown), and in 2016/17 among persons without IDD. This sex difference was more pronounced among persons with IDD. Persons with IDD who experienced TBI were more likely to reside in lower income quintiles in both 2002/03 (quintile 1+2: 50.0% with IDD vs. 42.2% without IDD) and 2016/17 (quintile 1: 27.9% with IDD vs. 22.5% without IDD, quintile 2: 24.4% vs. 19.9%). In the 2002/03 fiscal year, persons with IDD were more likely to be rural (23.4%) compared to those without IDD (16.1%), however this difference was not seen in 2016/17. Characteristics related to the TBI including mechanism of injury and injury severity were similar for both cohorts, however comparison or analysis of injury severity in 2016/17 is not useful as the severity of the majority of TBI cases was “unknown” in 2016/17.

Table 3.3
Baseline characteristics of Ontario adults with a new traumatic brain injury by intellectual and developmental disability (IDD)-status (2002/03).

2002-03	**IDD (n=64)**			**No-IDD (n=896)**		
Sex	**Male** (n=39)	**Female** (n=25)	**Total** (n=64)	**Male** (n=562)	**Female** (n=334)	**Total** (n=896)
Age on April 1 (n, col%) *						
19-49	28 (71.8%)	15 (60.0%)	43 (67.2%)	379 (67.4%)	169 (50.6%)	548 (61.2%)
50+	11 (28.2%)	10 (40.0%)	21(32.8%)	183 (32.6%)	165 (49.4%)	348 (38.8%)
Income Quintile (n, col %)						
1-2 (low)	21 (53.8%)	11 (44.0%)	32 (50.0%)	228 (40.6%)	152 (45.5%)	380 (42.4%)
3	..	..	12 (18.8%)	114 (20.3%)	62 (18.6%)	176 (19.6%)
4-5 (high)	..	..	19 (29.7%)	216 (38.4%)	120 (35.9%)	336 (37.5%)
Missing	1 (2.6%)	0 (0.0%)	1 (1.6%)	4 (0.7%)	0 (0.0%)	4 (0.4%)
Region (n, col %)						
Urban	30 (76.9%)	19 (76.0%)	49 (76.6%)	463 (82.4%)	288 (86.2%)	751 (83.8%)
Rural	9 (23.1%)	6 (24.0%)	15 (23.4%)	98 (17.4%)	46 (13.8%)	144 (16.1%)
Missing	0 (0.0%)	0 (0.0%)	0 (0.0%)	1 (0.2%)	0 (0.0%)	1 (0.1%)
Mechanism of Injury (n, col %)						
Fall	17 (43.6%)	14 (56.0%)	31 (48.4%)	213 (37.9%)	184 (55.1%)	397 (44.3%)
Motor Vehicle Collision	..	..	9 (14.1%)	90 (16.0%)	52 (15.6%)	142 (15.8%)
Struck by/against an object	6 (15.4%)	6 (24.0%)	12 (18.8%)	152 (27.0%)	59 (17.7%)	211 (23.5%)
Multiple/ Other/ Unknown	..	..	12 (18.8%)	107 (19.1%)	39 (11.7%)	145 (16.3%)
Injury Severity (n, col %)						
Mild (1-2)	23 (59.0%)	15 (60.0%)	38 (59.4%)	329 (58.5%)	215 (64.4%)	544 (60.7%)

Moderate-Severe (3+)[ə]	16 (41.0%)	10 (40.0%)	26 (40.6%)	233 (41.5%)	119 (35.6%)	352 (39.3%)

.. : Data suppressed due to concern for privacy.

* : Due to small cell numbers (<6 people), age was categorized as 19-49 years and 50+ years.

[ə] : Combines "Moderate-Severe (3+)" and "Unknown"; unknown represents <10% of the total TBI cases in the IDD cohort and <2% of the total in the No-IDD cohort.

Table 3.4
Baseline characteristics of Ontario adults with a new traumatic brain injury by intellectual and developmental disability (IDD)-status (2016/17).

2016-17	**IDD (n=287)**			**No-IDD (n=2,979)**		
Sex	**Male** (n=165)	**Female** (n=122)	**Total** (n=287)	**Male** (n=1,466)	**Female** (n=1,513)	**Total** (n=2,979)
Age on April 1 (n, col%)						
19-29	76 (46.1%)	56 (45.9%)	132 (46.0%)	399 (27.2%)	408 (27.0%)	807 (27.1%)
30-39	23 (13.9%)	20 (16.4%)	43 (15.0%)	239 (16.3%)	244 (16.1%)	483 (16.2%)
40-49	16 (9.7%)	20 (16.4%)	36 (12.5%)	182 (12.4%)	184 (12.2%)	366 (12.3%)
50-59	23 (13.9%)	8 (6.6%)	31 (10.8%)	198 (13.5%)	217 (14.3%)	415 (13.9%)
60-69	15 (9.1%)	11 (9.0%)	26 (9.1%)	151 (10.3%)	141 (9.3%)	292 (9.8%)
70+	12 (7.3%)	7 (5.7%)	19 (6.6%)	297 (20.3%)	319 (21.2%)	616 (20.7%)
Income Quintile (n, col %)						
1 (low)	42 (25.5%)	38 (31.3%)	80 (27.9%)	349 (23.8%)	322 (21.3%)	671 (22.5%)
2	43 (26.1%)	27 (22.1%)	70 (24.4%)	299 (20.4%)	294 (19.4%)	593 (19.9%)
3	31 (18.8%)	29 (23.8%)	60 (20.9%)	278 (19.0%)	280 (18.5%)	558 (18.7%)
4	26 (15.8%)	12 (9.8%)	38 (13.2%)	288 (19.6%)	329 (21.7%)	617 (20.7%)
5 (high)	22 (13.3%)	15 (12.3%)	37 (12.9%)	247 (16.8%)	276 (18.2%)	523 (17.6%)
Missing	1 (0.6%)	1 (0.8%)	2 (0.7%)	5 (0.3%)	12 (0.8%)	17 (0.6%)
Region (n, col %)						
Urban	141 (85.5%)	106 (86.9%)	247 (86.1%)	1,257 (85.7%)	1,307 (86.4%)	2,564 (86.1%)
Rural	24 (14.5%)	16 (13.1%)	40 (13.9%)	209 (14.3%)	205 (13.5%)	414 (13.9%)
Missing	0 (0.0%)	0 (0.0%)	0 (0.0%)	0 (0.0%)	1 (0.1%)	1 (0.0%)

Mechanism of Injury (n, col %)						
Fall	76 (46.1%)	64 (52.5%)	140 (48.8%)	632 (43.1%)	775 (51.2%)	1,407 (47.2%)
Motor Vehicle Collision	15 (9.1%)	10 (8.2%)	25 (8.7%)	191 (13.0%)	194 (12.8%)	385 (12.9%)
Struck by/against an object	45 (27.3%)	37 (30.3%)	82 (28.6%)	454 (31.0%)	397 (26.2%)	851 (28.6%)
Multiple/ Other/ Unknown	29 (17.6%)	11 (9.0%)	40 (13.9%)	189 (12.9%)	147 (9.7%)	336 (11.3%)
Injury Severity (n, col %)						
Mild (1-2)	10 (6.1%)	0 (0.0%)	10 (3.5%)	81 (5.5%)	31 (2.0%)	112 (3.8%)
Moderate-Severe (3+)	41 (24.8%)	16 (13.1%)	57 (19.9%)	419 (28.6%)	254 (16.8%)	673 (22.6%)
Unknown	114 (69.1%)	106 (86.9%)	220 (76.6%)	966 (65.9%)	1,228 (81.2%)	2,194 (73.6%)

3.4.3 TBI Incidence among persons with and without IDD

Annual crude incidence and age- and sex-standardized incidence, as well as crude and standardized risk ratios, are presented in Table 3.6. Corresponding adjusted incidence is also graphically represented in Figure 3.3. Crude and adjusted annual incidence of TBI was greater among persons with IDD than persons without IDD. Over the 15-year study period, the adjusted annual incidence of TBI among persons with IDD was, on average, 1.86 times higher compared to persons with No-IDD with a minimum relative risk of 1.56 in 2009/10 and 2014/15, and a maximum relative risk of 2.34 in 2002/03. Annual incidence increased over time in both cohorts. Based on the confidence intervals, results were considered significant for all study years as the confidence interval for persons without IDD was not contained within the confidence interval for persons with IDD for either the crude or adjusted rates.

Annual incidence and risk ratios for persons who had a TBI prior to being diagnosed with IDD were included for the last three study years. Based on these data, annual incidence appears significantly higher in this population compared to all persons with IDD, however due to the small population size, it is difficult to interpret these results. This problem of sample size also resulted in an inability to report these data for the first twelve study years, or provide any standardized rates.

Table 3.5
Crude and age-/sex-standardized annual incidence (per 1000) of traumatic brain injury (TBI) among Ontario adults with and without intellectual and developmental disabilities (IDD) and risk ratios. (2002/03 to 2016/17).

Year	Cohort	Population at risk	New TBI Cases	Annual Incidence				Risk Ratio			
				Crude Incidence		Standardized Incidence		Crude Incidence Risk Ratio		Standardized Incidence Risk Ratio	
				Rate per 1000	95% CI[Φ]	Rate per 1000	95% CI[Φ]	Rate	95% CI[Φ]	Rate	95% CI[Φ]
2002-03	ALL-IDD	28,743	64	2.23	1.68-2.77	2.26	1.71-2.80	2.34	1.81-3.01	2.36	1.83-3.04
	No-IDD	941,198	896	0.95	0.89-1.01	0.96	0.89-1.02				
2003-04	ALL-IDD	30,280	61	2.01	1.51-2.52	2.17	1.65-2.70	2.14	1.65-2.77	2.30	1.78-2.98
	No-IDD	959,818	903	0.94	0.88-1.00	0.94	0.88-1.00				
2004-05	ALL-IDD	31,703	53	1.67	1.22-2.12	1.57	1.13-2.01	1.68	1.27-2.21	1.57	1.19-2.06
	No-IDD	977,415	972	0.99	0.93-1.06	1.00	0.94-1.07				
2005-06	ALL-IDD	33,181	62	1.87	1.40-2.33	1.72	1.28-2.17	1.86	1.44-2.40	1.71	1.32-2.21
	No-IDD	993,611	999	1.01	0.94-1.07	1.01	0.94-1.07				
2006-07	ALL-IDD	34,914	83	2.38	1.87-2.89	2.51	1.99-3.04	2.31	1.84-2.88	2.43	1.94-3.04
	No-IDD	996,213	1,027	1.03	0.97-1.09	1.03	0.97-1.10				
2007-08	ALL-IDD	37,160	81	2.18	1.71-2.65	2.19	1.71-2.66	1.87	1.49-2.34	1.86	1.48-2.33
	No-IDD	1,000,261	1,167	1.17	1.10-1.23	1.18	1.11-1.24				
2008-09	ALL-IDD	39,342	92	2.34	1.86-2.82	2.29	1.82-2.77	1.82	1.47-2.24	1.77	1.43-2.19
	No-IDD	1,010,284	1,299	1.29	1.22-1.36	1.29	1.22-1.36				
2009-10	ALL-IDD	41,914	94	2.24	1.79-2.70	2.18	1.73-2.62	1.56	1.27-1.92	1.50	1.21-1.84
	No-IDD	1,028,667	1,476	1.43	1.36-1.51	1.45	1.38-1.53				
2010-11	ALL-IDD	44,809	126	2.81	2.32-3.30	2.70	2.22-3.18	1.91	1.59-2.29	1.81	1.51-2.17

	No-IDD	1,045,951	1,539	1.47	1.40-1.54	1.49	1.41-1.56				
2011-12	ALL-IDD	47,652	159	3.34	2.82-3.85	3.38	2.86-3.90	2.09	1.78-2.46	2.10	1.78-2.47
	No-IDD	1,065,612	1,698	1.59	1.52-1.67	1.61	1.53-1.68				
2012-13	ALL-IDD	50,833	149	2.93	2.46-3.40	2.87	2.41-3.34	1.65	1.39-1.94	1.60	1.36-1.89
	No-IDD	1,084,860	1,931	1.78	1.70-1.86	1.79	1.71-1.87				
2013-14	ALL-IDD	54,238	191	3.52	3.02-4.02	3.51	3.01-4.00	1.73	1.49-2.01	1.72	1.48-1.99
	No-IDD	1,100184	2,234	2.03	1.95-2.11	2.04	1.96-2.13				
2014-15	ALL-IDD	58,000	190	3.28	2.81-3.74	3.54	3.06-4.02	1.56	1.34-1.80	1.68	1.44-1.94
	TBI-Prior to IDD$^{\Omega}$	1,144	14	12.24	5.87-18.61	¤	N/A	5.76	3.42-9.71	¤	N/A
	No-IDD	1,110,010	2,334	2.10	2.02-2.19	2.11	2.03-2.20	(ref)		(ref)	
2015-16	ALL-IDD	61,994	253	4.08	3.58-4.58	4.07	3.57-4.57	1.73	1.52-1.97	1.72	1.51-1.95
	TBI-Prior to IDD$^{\Omega}$	1,289	17	13.19	6.96-19.42	¤	N/A	5.54	3.45-8.90	¤	N/A
	No-IDD	1,124,542	2,648	2.35	2.27-2.44	2.36	2.27-2.45	(ref)		(ref)	
2016-17	ALL-IDD	66,027	287	4.35	3.84-4.85	4.24	3.75-4.74	1.67	1.48-1.88	1.62	1.43-1.82
	TBI-Prior to IDD$^{\Omega}$	1,413	19	13.45	7.44-19.45	¤	N/A	5.10	3.26-7.99	¤	N/A
	No-IDD	1,142,931	2,979	2.61	2.51-2.70	2.62	2.53-2.71	(ref)		(ref)	

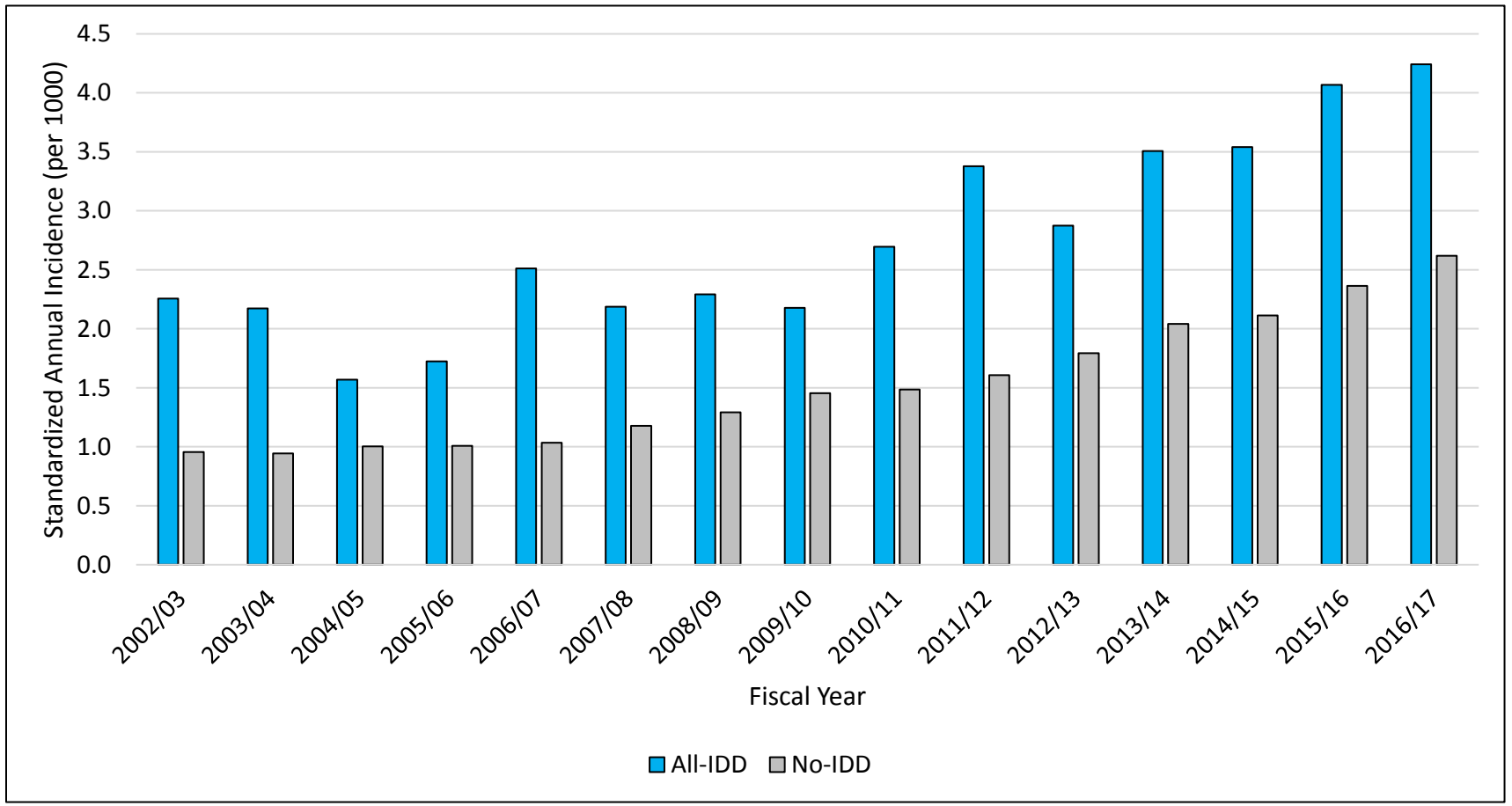
¤: Data not available due to small cohort size

$^{\Omega}$: Due to small sample size, data for this population is not available for years prior to 2014/15

$^{\Phi}$: Confidence Interval

Figure 3.3

Age-/sex-standardized annual incidence (per 1000) of traumatic brain injury among Ontario adults with and without intellectual and developmental disabilities (2002/03 to 2016/17).



3.5 Discussion

3.5.1 Summary of Findings

This population-based cohort study is the first study to quantitatively examine TBI among persons with IDD. Incidence of TBI among persons with IDD was previously unknown, with some TBI researchers excluding persons with disabilities from their study population (Tuerk, Dégeilh, Catroppa, Anderson, & Beauchamp, 2019). The results of this study provide data on the risk of TBI among adults with IDD in comparison to the general population without IDD. At baseline, persons with IDD were more likely to be male, younger in age, and residing in lower income neighborhoods compared to persons without IDD. Over the 15-year study period, the average adjusted annual incidence of TBI was 2.75 new cases per 1000 among Ontario adults with IDD compared to an average of 1.53 new cases per 1000 among Ontario adults without IDD. Over time, annual incidence of TBI increased in both cohorts, however the increased risk among persons with IDD remained significant.

3.5.2 Results in the Context of Past Research

The results of this study showed similar trends in TBI incidence as have been shown in previous research for the general population. Overall, annual incidence in both populations increased gradually over the 15-year period. This finding of increasing TBI incidence is consistent with the majority of existing research that addresses trends in TBI risk over time (Ng et al., 2015; PHAC & NHCC, 2014). This increasing trend in TBI incidence over time may be partly explained by increasing awareness of concussion (Clark & Guskiewicz, 2016), which is a common form of TBI, as well as increasing media exposure such as the film “Concussion” released in 2015. This was the first

known study to examine and compare TBI risk among persons with IDD versus individuals without IDD. The results of this study provide novel evidence that the risk of TBI is significantly greater among persons with IDD compared to those without IDD.

This study built upon existing research of TBI incidence and associated characteristics in the general population and contributed new information on TBI incidence and associated characteristics in a special population. Similar to previous studies (Fu, Jing, McFaull, & Cusimano, 2016; Ng et al., 2015; Te Ao et al., 2015), there was a noticeable sex difference in the first few study years in both cohorts such that approximately 60-65% of new TBI cases were among males. Interestingly, this sex difference began to decrease in those without IDD beginning as early as fiscal year 2009/10, and was practically non-existent by 2013/14 and remained so until the end of the study period; the sex difference remained present among persons with IDD for all study years. This diminished sex difference in the group without IDD is in stark contrast to the majority of other TBI literature, however a similar trend is seen in self-report studies (Rao, McFaull, Thompson, & Jayaraman, 2017) in which the incidence among adult females is rapidly approaching that of adult males. Hospital data from the United States also reveals the beginnings of a similar trend beginning in 2009 (Centres for Disease Control and Prevention, 2016), however this report only has data up to 2010. One possible explanation for this disappearing sex difference could be that the study excludes children under 19 years of age, among whom the sex difference tends to be greater (Fu et al., 2016; Ng et al., 2015; Rao et al., 2017). Although it is not certain why the sex difference seems to disappear in the later years of this study, this change is not due to any differences in the coding algorithm applied for identifying TBI in either

population as the same algorithm was applied to all study populations in all study years. Overall, this indicates that sex distribution of TBI cases in more recent years is different among persons with IDD compared to those without IDD.

With regard to age distribution, this study found similar results in the No-IDD group as have been found in previous research of the general population, however age distribution was somewhat different for persons with IDD compared to those without. In agreement with previous literature (Fu et al., 2016; Langlois, Rutland-Brown, & Wald, 2006; Ng et al., 2015; Te Ao et al., 2015), the highest proportion of incident TBI cases were among the youngest age group, persons aged 19-29 years. This was true in both persons with IDD and persons without IDD. Also consistent with previous literature (Fu et al., 2016; Langlois et al., 2006; Ng et al.; 2015), the next highest proportion in the No-IDD group was found among the oldest age group of persons aged 70 years and older. In contrast to those without IDD, among persons with IDD, the proportion of incident TBI cases typically decreased with age and was lowest for persons aged 70 years and older. These findings provide evidence that TBI cases among persons with IDD are younger on average compared to persons without IDD.

Additionally, although Kisser and colleagues (2017) identified poverty as having an influence on TBI risk, based on estimated income quintiles, this effect was not seen in this research. Among persons with IDD, those who experienced a TBI were more likely to reside in lower income neighborhoods. In 2002/03, of the TBI cases among persons with IDD, approximately 31% and 19% were living in income quintiles 1 and quintile 2 respectively, and only 14% were living in income quintile 5. Note that income quintile 1 represents the poorest neighborhoods, and income quintile 5 represents the wealthiest.

This difference was similar in 2016/17 with approximately 28% and 24% living income quintiles 1 or 2 respectively for a total of 52%, and only 13% in income quintile 5. In contrast, among persons with a new TBI in the No-IDD group, income quintiles were relatively evenly distributed. However, these distributions are similar to the income quintile distribution seen at baseline for each cohort, and thus the differences in distribution of TBI based on income quintile among persons with IDD is likely to be related to having IDD and not to differences in income levels.

With regard to injury variables, the leading cause of TBI in both cohorts was falls. In both 2002/03 and 2016/17, falls accounted for approximately 50% of all TBI cases in both persons with IDD and those without. Among females, falls accounted for a higher proportion of TBI cases compared to among males. This finding is consistent with the existing body of TBI research (Feigin et al., 2013; Fu et al., 2016).

Although this study intended to also analyse the impact of experiencing a TBI prior to receiving a diagnosis of IDD in the IDD population, the ability to do so was limited by the small sample size for this population. In fact, due to the small population size, incidence in this population could only be reported for the last three study years in order to minimize privacy risks. Based on the three study years for which data on this population is included, there is some evidence that having a TBI prior to being diagnosed with IDD significantly increases future TBI risk compared to the general population of persons without IDD. However, due to the small population it was not possible to calculate standardized rates, and it is difficult to say with certainty the true impact of a TBI prior to IDD diagnosis on future TBI risk.

3.5.3 Study Limitations

There were certain limitations to the study related to the retrospective nature of the study design. This study relied on the use of administrative data which depends on the accuracy and representativeness of existing data. When identifying persons with IDD, it is possible that some individuals were not identified using the coding algorithm applied to this study resulting in individuals being misclassified as not having IDD. This type of misclassification however, would result in an underestimation of the true risk ratio for TBI. Since the age, sex, and income distribution of the IDD group is consistent with past reports of this population that included other data sources for identifying IDD (Lin et al., 2013; Lin et al., 2019; Lunsky et al., 2013)., the group from the current study is also likely to be representative of persons with IDD in Ontario. Additionally, it is not possible to look back in time prior to the inception of the databases used. As a result, individuals who are older in age may also have been misclassified as not having IDD due to the tendency for this diagnosis to be recorded only earlier in life (e.g. before age 18) and before age-related health conditions mask IDD-related pathology (e.g. Alzheimer's disease).

Similarly, with regard to TBI identification, it is possible that individuals may have been misdiagnosed, or there may have been limitations to the coding algorithm applied in this study, which would result in an underrepresentation of the true number of incident TBI cases. In fact, due to the lack of consensus on case identification for TBI, this research applied a more conservative case definition that excluded unspecified injury to the head or face, which may contribute to the lower number of TBI identified compared to other literature. It is important to note however that the same coding

algorithm was applied to each cohort, so the differences in TBI incidence between cohorts was not due to any inconsistency in the case definition.

Another limitation of using administrative data is the inability to include an accurate and complete representation of some variables. For example, the Abbreviated Injury Severity score was used to assess the level of injury severity for TBI, however there were a high proportion of "unknown" cases in 2016/17, due to a lack of detailed ICD-10 diagnostic codes for injury severity.

3.5.4 Implications and Next Steps

This study provides a precedent for future detection and surveillance of TBI among persons with IDD. The results of this study provide significant evidence of the importance of examining TBI among persons with IDD. Persons with IDD were found to have a significant increased risk of TBI compared to those without IDD, and added to existing literature by indicating a trend of increasing TBI incidence. As the population of persons with IDD grows, it would be useful to repeat this study to identify if this trend remains, particularly if TBI incidence continues to increase over time.

There is evidence that as many as 95% of injuries, including TBIs, are predictable and preventable (Ontario Neurotrauma Foundation, 2019). Previous studies have already indicated the importance of further examining TBI among persons with IDD (McKinlay et al., 2012), as well as bringing to attention the importance of TBI prevention (PHAC & NHCC, 2014). This study provides further evidence of the need to understand TBI risk among persons with IDD. Since the leading cause of TBI is falls, tailoring falls prevention programs to the needs of persons with IDD may be an effective way to mitigate TBI risk. Existing falls prevention programs in Ontario are restricted to persons

aged 65 and older (Government of Ontario, 2019); adjusting this age-restriction to allow younger individuals to participate may be beneficial for persons with IDD who require falls prevention at a younger age (Cox et al., 2010; Lunksy et al., 2013). Additionally, further research to identify differences in risk factors for falls among persons with IDD versus those without IDD to provide direction for potentially useful interventions.

Further research should aim to identify additional reasons for increased TBI risk among persons with IDD in order to better address this problem. For instance, it is well established that in the general population, athletes have a higher risk of TBI, especially concussions, versus non-athletes (Clark & Guskiewicz, 2016; Theadom et al., 2014), however there has been very little research on the incidence of head injuries in athletes with IDD. One study did find that among persons with IDD, Special Olympics athletes had 1.35 times increased odds of falling compared to non-athletes (Hseih et al., 2012). This finding was not statistically significant but does suggest that TBI risk might be even higher among athletes with IDD and that falls prevention and efforts to improve balance and coordination are also important in athletes with IDD. Future research should aim to specifically examine the risk of head injuries, or TBI, among athletes with IDD. Additionally, future studies should be conducted to identify other populations at greater risk for TBI as this would help to improve recommendations for effective prevention programmes by identifying target populations. Furthermore, developing a validated algorithm for identifying incident cases of TBI from administrative databases would be useful for conducting regular surveillance.

3.6 Conclusion

The main finding of this study was that the annual incidence of TBI was significantly higher among persons with IDD compared to those without IDD even after adjusting for age and sex, over a 15-year period. These data provide evidence that individuals with IDD have a greater risk of TBI compared to those without IDD regardless of the differences in population age and sex structure. Public health policy development and prevention planning aimed at addressing the high rates and associated costs of TBI should consider targeted interventions for persons with IDD.

4 Manuscript 2

30-Day Readmissions and History of Traumatic Brain Injury among Ontario adults with Intellectual and Developmental Disabilities

4.1 Abstract

Background: In Ontario, adults with IDD have a more than three times increased risk of 30-day hospital readmissions compared to those without IDD. These readmissions are costly to the healthcare system and are considered an important indicator for health system improvement.

Objective: Compare the odds of 30-day readmissions between three cohorts: 1) persons with IDD without a history of TBI, 2) persons with IDD with a history of TBI, and 3) persons with TBI without IDD.

Methods: Population-based administrative health databases in Ontario were used to identify Ontario adults with IDD and/or a history of TBI with at least one hospitalization discharge in fiscal year 2016/17, and readmissions within 30-days of discharge.

Conclusions: The odds of 30-day readmissions was higher in both cohorts of people with IDD compared to the cohort without IDD, however TBI history had little impact on odds of readmission for persons with IDD.

4.2 Introduction

4.2.1 30-Day Hospital Readmissions

30-day hospital readmissions are defined as readmissions to a hospital within 30 days of initial discharge from an index episode of care (Canadian Institute for Health Information [CIHI], 2018). 30-day hospital readmissions are one of many indicators used to assess "health outcomes" (Ontario Ministry of Health and Long-Term Care [MOHLTC], 2002). "Health outcomes" are a category of indicators used to evaluate and improve the health system performance. These indicators help to determine the impact of health programmes and services on patient health status.

Information pertaining to readmissions are routinely collected by hospitals (Health Quality Ontario, 2017) since they are viewed as an indication of the quality of health services provided to patients. A period of 30 days post-discharge, versus longer time-periods, has become the standard time frame for assessing rates of readmission as readmissions within this timeframe are considered "urgent" and thus more likely to be related to health services (CIHI, 2018). High rates of readmissions in a particular patient group suggests that more can be done in-hospital to prepare the patient pre-discharge.

In 2011 Kangovi & Grande developed the "*Determinants of Hospital Readmission Framework*". It is used in this study because of its usefulness as a model for identifying and categorizing variables associated with readmissions. This framework is in agreement with the concept of readmission rates as an indicator of the quality of health services provided to patients, but extended to include both inpatient and outpatient care in terms of quality and accessibility. This framework further posits that

readmissions are also influenced by patient-level characteristics related to health status and socioeconomic resources.

In Ontario, the rate of hospital readmissions within 30 days after discharge is considered an important index of health system performance and is a government priority for identifying areas of health system improvement (MOHLTC, 2014). In fiscal years 2015/16 to 2017/18, Ontario hospitals reported a 30-day readmission rate of approximately 9.2%, representing an increase from 9.0% reported in 2014/15 (CIHI, 2019). 30-day readmissions are common and are costly to the health care system in terms of funding and other resources, and may also be costly for patients in terms of quality of life and future health outcomes.

4.2.2 Intellectual and Developmental Disabilities

In Ontario, "developmental disability" is defined as impairments in both intellectual functioning and adaptive functioning that develop before the age of 18 (Government of Ontario, 2012). Intellectual functioning refers to various cognitive abilities including learning, reasoning, and problem-solving abilities. Intellectual functioning is typically evaluated using intelligence quotient tests in which a score of 75 or lower is considered indicative of impairment (American Association on Intellectual and Developmental Disabilities [AAIDD], 2018). Adaptive functioning is assessed using a variety of standardized tests conducted with the individual to measure adaptive behaviours across three domains: 1) Conceptual Skills which includes language, math, and reasoning; 2) Social Skills including self-esteem, empathy, and the ability to make and maintain friendships; and 3) Practical Skills including occupational skills, personal care, and self-management (AAIDD, 2018). Consistent with current trends in the

literature, the nomenclature “intellectual and developmental disabilities” (IDD) will be used throughout this manuscript to describe this population.

Based on this definition, there are approximately 66,000 Ontario adults living with a diagnosis of IDD (Lunksy, Klein-Geltink, & Yates, 2013). These individuals have an increased risk for various health concerns including injuries and falls, and often experience poorer health outcomes compared to persons without IDD (Lunsky et al., 2013).

Past research among persons with IDD has provided evidence that persons with IDD experience worse health services outcomes based on indicators such as repeat emergency department visits (Lunsky et al., 2013), alternate level of care days (Lin et al., 2019), patient experiences in healthcare facilities (Iacono, Bigby, Unsworth, Douglas, & Fitzpatrick, 2014), and hospital readmissions (Balogh et al., 2017; Kelly et al., 2015; Lin et al., 2019). Recently, 30-day hospital readmissions among persons with IDD have been found to be more than three times more common compared to persons without IDD (Lin et al., 2019). Additionally, evidence of poorer experiences within the healthcare setting (Iacono et al., 2014) support this finding of greater readmissions, as readmissions are considered to be partly related to the quality of health care services provided to a patient during their index hospitalization.

4.2.3 Traumatic Brain Injury

Traumatic brain injuries (TBIs) are the most common of the two types of acquired brain injuries (ABIs). ABI refers to brain injuries that are sustained after birth and that are not inherited (Ontario Neurotrauma Foundation, 2019). An ABI may be caused by an external force, resulting in a “traumatic” brain injury (TBI), or may develop due to some

illness or other pathophysiology resulting in a “non-traumatic” brain injury (nTBI). Currently, more than one million Canadians are living with the effects of ABI, and more than 160,000 new cases occur among Canadians each year (Brain Injury Canada, 2019).

TBI occurs when an external head injury affects the structure or function of the brain, resulting in impaired cognition, communication, physical function, and/or psychosocial behaviour (Commission on Accreditation of Rehabilitation Facilities, 2015). Based on data from 2010, this form of brain injury affects more than 200,000 people in Ontario alone, and this number is only expected to increase over time (Ng et al., 2015).

There is a relative lack of literature examining readmissions among persons with TBI, and the existing research uses different methodologies to determine the level of risk. For example, based on recent estimates, the rate of 30-day readmissions among persons with TBI (6.6%; Canner et al., 2016) is actually less than in the general population when specifically looking at individuals who were hospitalized (9.4%; Lin et al., 2019). This comparison, however, may not be accurate due to differences in study methodology and time periods, as well as differences in the structure of the healthcare systems and populations examined as Canner et al. (2016) examined readmissions in the United States, while Lin et al. (2019) examined readmissions in Canada. Readmissions examined using the full general population also results in a very heterogeneous sample and may be biased if there is a high proportion of a specific type or cause of hospitalization. Additionally, existing literature use inconsistent follow-up periods to define readmissions. Hammond et al. (2015) and Saverino et al. (2016) examined readmissions over a longer period post-discharge than 30 days, making it difficult to compare rates across studies or to provide additional support of an expected rate of 30-

day readmissions, which has become a government and hospital standard (CIHI, 2018). Ontario-based research that uses the same data sources to identify comparison groups and uses a widely accepted metric to determine readmissions is more useful to inform health policies and hospital practices.

4.2.5 Readmissions among Persons with Comorbid Conditions

No research was found comparing readmissions between persons with IDD and those with TBI, nor any that examined readmissions among persons with both IDD and TBI. This is an important research gap to address, as there is some evidence that having either IDD (Balogh et al., 2017) or TBI (Saverino et al., 2016) and a comorbid mental illness (MI) can have a negative impact on readmission risk. Persons with IDD and MI have been found to be approximately 40% and 66% more likely to experience a hospital readmission within 30 days of discharge compared to individuals with IDD only and persons with MI only respectively (Balogh et al., 2017). Moreover, among individuals with TBI, those with a psychiatric comorbidity have 1.7 times greater odds of readmission within one year versus individuals without a psychiatric comorbidity (Saverino et al., 2016).

Like MI, TBI may work to increase the severity of cognitive conditions and impairments that manifest in persons with IDD. Both MI and TBI are also associated with behavioural components which can make patients difficult to handle in the healthcare setting, and may also increase the likelihood of engaging in behaviours which may cause them to need to come back to the hospital. For instance, TBI is often associated with emotional problems such as irritability, disinhibition, and anger which may be expressed through agitation or aggression (Tuerk, Dégeilh, Catroppa, Anderson,

& Beauchamp, 2019). These emotional and behavioural changes may cause a person to lash out, or to resort to negative coping mechanisms which may be harmful to the patient. Like MI, TBI is a condition which increases patient complexity and has an impact on cognition and behaviour, yet only the impact of MI has thus far been evaluated in people with IDD in the context of readmissions. In addition, since TBI and IDD are known to increase the risk of readmissions individually, it may be that having both conditions that affect cognition and behaviour has a synergistic effect on the risk of readmission.

4.2.6 Significance

In Ontario, readmissions cost the health care system nearly $700 million annually (MOHLTC, 2011) and are an important indication of the quality and accessibility of inpatient and outpatient healthcare services, as well as the effectiveness of discharge planning (MOHLTC, 2014). Additionally, patients who are readmitted to hospital within 30 days of discharge are more likely to experience longer recovery times and poorer health outcomes compared to those who do not experience a hospital readmission (Felix, Seaberg, Bursac, Thostenson, & Stewart, 2016). Among persons with TBI, people who experience readmissions have an increased risk of poorer recovery and a longer rehabilitation period (Saverino et al., 2016), adding to the associated costs of readmissions for this population.

Among persons with IDD, risk of readmissions is more than three times that of the population without IDD, and this risk is further increased with the presence of comorbid MI. The experiences of persons with comorbid IDD and MI may provide some insight into the experiences of those with comorbid IDD and TBI.

For instance, similar to MI, TBI is a condition which can increase the complexity of patients with IDD by adding a comorbidity that also affects cognition, as well as increasing behavioural complexity. Additionally, depression and attempted and successful suicide are often found to be common among persons with TBI (Fralick, Thiruchelvam, Tien, & Redelmeier, 2016), further contributing to the potential risk for rehospitalization.

Despite evidence of higher rates of readmissions among persons with comorbid IDD and MI and the common complexities shared between MI and TBI, no research has been conducted to assess the potential effect of TBI on readmissions risk among persons with IDD.

4.2.7 Objective

The objective of this research was to compare 30-day hospital readmissions among Ontario adults with IDD with and without a history of TBI, as well as individuals with a history of TBI without IDD. A secondary objective was to identify other factors associated with 30-day hospital readmissions, and specifically among a subgroup of persons with IDD and a history TBI.

4.3 Methods

4.3.1 Study Design

To compare 30-day hospital readmissions, this research used a historical population cohort design to report on hospital readmissions over a 1-year period (April 1, 2016 to March 31, 2017). The historical cohort is the most common design used to examine hospital readmissions in various populations, including persons with IDD (Balogh et al., 2017; Kelly et al., 2016) as well as persons with TBI (Canner et al., 2016; Saverino et al., 2016). This component of the thesis will examine readmissions rates based on IDD status and any discernable history of TBI. The primary comparisons in this study were between persons with IDD and a history of TBI (IDD-TBI), persons with IDD and no history of TBI (IDD-only), and persons with a history of TBI and no IDD (TBI-only).

4.3.2 Data Sources and Linkages

Administrative data are routinely collected for various administrative and other non-research related reasons, however they are often also useful for research (Statistics Canada, 2016). Some jurisdictions are able to collect and store health data generated by nearly all aspects of the health care system including physician visits and hospital stays (Cadarette & Wong, 2015). Data within these databases are de-identified and assigned a unique code which enables researchers to link the data between other data sources.

As a prescribed entity, ICES has access to a wide variety of Ontario-based health-related data including health and other administrative databases (ICES, 2018). ICES is renowned for producing high quality health research and for its commitment to maintaining the privacy and security of health information (ICES, 2018). Data collected

by ICES have all direct personal identifiers (i.e. health card number, first and last name, date of birth, gender, postal code) removed. Each Ontario resident eligible for the Ontario Health Insurance Plan (OHIP) is assigned a unique confidential "code", or ICES Key Number (IKN) created by a secure ICES algorithm. Each person has one consistent IKN which allows for accurate linkage across datasets via the Registered Persons Database (RPDB). The RPDB is a population-based data registry which monitors changes in OHIP eligibility over time, and is the database through which all ICES datasets are linked (Figure 4.1).

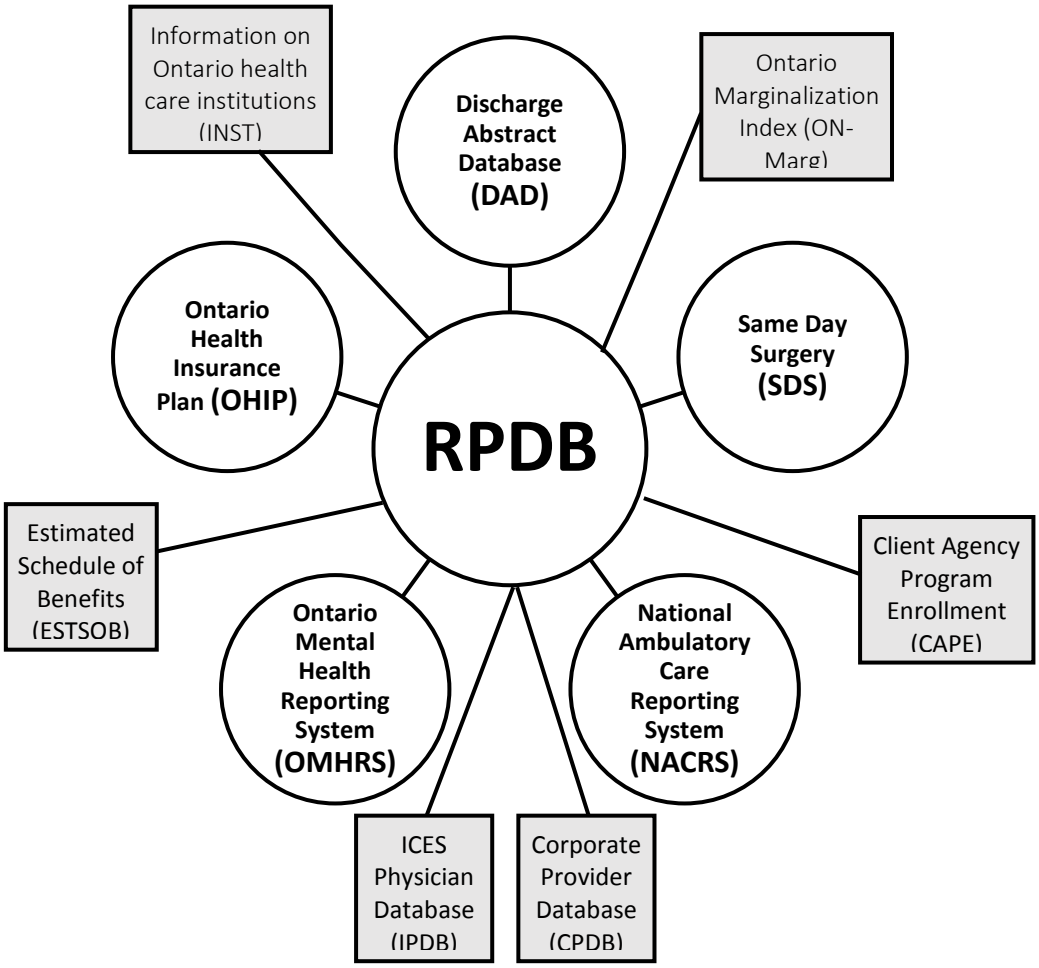
4.3.3 Data Sources

To achieve this research objective, a total of thirteen administrative databases were accessed including five health databases and eight other data sources. The five administrative health databases used to identify people with IDD included the Canadian Institute of Health Information Discharge Abstract Database (CIHI-DAD), Same Day Surgery (SDS), the National Ambulatory Care Reporting System (NACRS), the Ontario Mental Health Reporting System (OMHRS), and OHIP. These administrative health databases include various clinical data about Ontario residents including inpatient hospital discharges, day surgeries, emergency and ambulatory care visits, mental health services, and physician visits (see Appendix B, Table B1).

The eight other data sources included the RPDB, which is a registry used for data linkage and for obtaining demographic information for all Ontario residents eligible for OHIP, as well as the ONtario Marginalization Index (ON-Marg), accessed as a measure of marginalization for regions of Ontario. Data from the Client Agency Program Enrollment (CAPE), Corporate Provider Database (CPDB), and ESTimated Schedule Of

Benefits (ESTSOB) were also accessed to obtain information required to calculate the continuity of care variable. Finally, information about the number of acute care beds available and physician supply in an individual's Local Health Integration Network (LHIN) and was accessed using data from the Ontario-based health care institutions (INST) and the ICES Physician Database (IPDB) respectively (see Appendix B, Table B1).

Figure 4.1
ICES: Adapted to show how all databases used in this study were linked through the registered persons database (RPDB).



*Note that circles represent administrative health databases used to identify persons with IDD and TBI; databases in squares were used to derive other variables

4.3.4 Study Populations

Using the five aforementioned health databases and the RPDB, three cohorts were created based on IDD-status and the presence or absence of TBI prior to April 1, 2016. The three cohorts consisted of Ontario adults aged 19 years and older with at least one hospitalization episode discharge between April 1, 2016 and March 31, 2017 who have:

1. a diagnosis of IDD and no prior TBI history (IDD-Only)

2. a diagnosis of IDD and a prior TBI history (IDD-TBI); or
3. a prior TBI history, but no diagnosis of IDD (TBI-Only).

Note that in this study (in contrast to Manuscript 1), TBI-status was based on diagnostic code indicating a history of TBI which preceded the study period.

Cohort Creation

Identifying Persons with IDD

To identify persons with IDD, each of the five health administrative databases accessed from ICES (see Appendix B, Table B2) were searched for International Classifications of Diseases (ICD) Version-9 and -10 diagnostic codes for IDD (see Appendix B, Table B3).

The coding algorithm used to identify IDD in this research was developed and used previously by researchers with the Health Care Access Research and Developmental Disabilities research centre [H-CARDD] (Lunsky et al., 2013). Although IDD is a lifelong condition, its diagnosis is typically recorded only during childhood when the individual was first assessed. In order to maximize the identification of persons with IDD within existing databases, the widest possible lookback window was used to search for a history of IDD-related diagnostic codes looking as far back as the inception of each database (Lin et al., 2013; Lunsky et al., 2013). To improve specificity without sacrificing sensitivity, individuals were included only if an IDD-related diagnostic code appeared in one or more hospital or emergency department visit, or two or more physician visits. This method has also been applied in algorithms developed for other conditions such as diabetes (Hux, Ivis, Flintoft, & Bica, 2002; Public Health Agency of Canada, 2009).

Identifying TBI History

History of TBI prior to April 1, 2016 was identified using ICD-9 and -10 diagnostic codes for TBI (see Appendix B, Table B4) in CIHI-DAD, SDS, NACRS, OHIP, and OMHRS, and linked using the IKN. History of TBI was determined by looking back as far as the inception of each database (e.g. CIHI-DAD inception: 1988) to determine if there was any indication of TBI prior to the study period. Due to the relatively subtle nature of some TBIs and the tendency for TBI to go undiagnosed, using these codes in an algorithm to identify TBI has been found to be highly specific, but only moderately sensitive (Carroll, Cochran, Guse, &Wang, 2012; Fralick et al., 2016; Shore, McCarthy, Serpi, & Gertner, 2004). To maximize sensitivity, individuals were considered to have a history of TBI if at least one TBI-related code appeared in any healthcare visit.

Cohort Allocation

Persons with IDD and persons with a history of TBI were identified among all individuals with at least one hospitalization episode with a discharge between April 1, 2016, and March 31, 2017. Persons with IDD were allocated to IDD-Only cohort if no evidence of prior TBI was found in any of the five health administrative databases. Individuals with IDD with an identified history of TBI were included in the IDD-TBI group. The remaining population of persons with a history of TBI who had at least one hospitalization episode composed the TBI-Only group.

Exclusion Criteria

Individuals were excluded if they were:

- under the age of 19 as of April 1, 2016

- not eligible for OHIP at any time during the 2016-2017 fiscal year, or
- deceased prior to April 1, 2016

4.3.5 Primary Exposure

The primary exposure variable for this research was the cohort to which an individual belonged based on the presence or absence of IDD and/or history of TBI. As described in Section 4.3.4, this variable consists of three subgroups: IDD-Only, IDD-TBI, and TBI-Only. Persons with IDD were identified based on diagnostic codes adapted from H-CARDD. History of TBI was determined by looking back through the databases for TBI-related codes that appeared prior to April 1, 2016.

4.3.6 Primary Outcome

The primary outcome variable was all-cause 30-day readmissions. 30-day readmissions were characterized as a binary variable such that individuals were either readmitted within 30-days or they were not. Only the first readmission within 30-days of discharge from an index hospitalization episode for unique individuals was counted.

4.3.7 Other Independent Variables

The inclusion of other variables was guided by past research on readmissions, as well as concepts consistent with the Determinants of Hospital Readmissions Framework proposed by Kangovi & Grande (2011). Baseline demographic information for all groups was collected using the RPDB, including sex (male, female), age category, income quintile, and rurality. Information on neighborhood income level from which income quintile was derived was based on census data of household size-adjusted measures of household income (Statistics Canada, 2015). Income quintile data was included to provide insight into individuals' socioeconomic situation.

Rurality was determined using community size (CSize), which is a method of calculating rurality based on census data (Statistics Canada, 2015). CSize divides community size into five mutually exclusive categories using population estimates for each census metropolitan area and census agglomeration. Using these categories, "CSize=1" indicates large urban cities with 1.5 million residents or more and "CSize=5" represents rural and small-town areas of Canada including towns with an urban area population of less than 10,000 as well as rural areas. In this study, areas with CSize=5 were designated as "rural".

Baseline information on marginalization was also collected. Marginalization-related quintiles were determined using the ON-Marg data source, developed using census data (Matheson, 2018). Quintiles were created for four dimensions of marginalization: dependency, material deprivation, residential instability, and ethnic concentration. The dependency dimension measures area-level proportions of people who lack employment-based income. Material deprivation measures accessibility and attainability of basic material needs for individuals and communities; this measure is closely related to poverty. Residential instability measures area-level rates of family or household instability, and is an indicator of neighborhood quality, cohesiveness, and available supports. Finally, ethnic concentration measures the area-level proportions of recent immigrants and/or persons belonging to a "visible minority" group, not including Aboriginal peoples.

Morbidity level among individuals in each study cohort was determined based on the Charlson score as of April 1, 2016 using the Charlson comorbidity index. The Charlson comorbidity index, originally developed as a predictor of mortality, has been

used by many health researchers to identify disease burden (Quan et al., 2011), and has been identified as a potential confounder in previous readmissions studies (Logue, Smucker, & Regan, 2016). Charlson scores were calculated based on health service encounters within 2 years prior to April 1, 2016. The scores were then grouped into the following categories: N/A, 0, 1-2, and 3+, where N/A represents individuals with missing values and are considered to be a healthier population as they did not experience a health service encounter (Croxford et al., 2018).

History of mental health diagnosis within the past two years was examined as a dichotomous variable (yes, no). Mental health diagnoses are known to be more common among persons with IDD (Balogh et al., 2017) as well as among persons with TBI (Gravel et al., 2019; Saverino et al., 2016; Zhang, Nakua, Zhang, Jing, & Cusimano, 2019). Previous research also revealed that persons with comorbid mental illness and IDD are more likely to experience readmission compared to persons with IDD alone (Balogh et al., 2017), and those with comorbid mental illness and TBI are more likely to experience readmission versus persons with TBI alone (Saverino et al., 2016).

Within the IDD-TBI group, injury variables including the length of time from the most recent TBI to the index hospitalization episode (TBI history- When), and the total number of past TBI-related health service encounters were also examined. These variables were included to provide a better understanding of the role that a history of TBI may have on readmissions for people with IDD.

For individuals in each cohort, the circumstances of their discharge from the index hospitalization episode, or discharge disposition, was also examined. Although no previous research on readmissions in people with IDD or readmissions in people with

TBI has included this variable, past research on readmissions in trauma patients in general (Strosberg et al., 2017), and people with non-traumatic brain injury (Chan, Stock, Jacob, Cullen, & Colantonio, 2018) have found that different discharge dispositions may be associated with increased readmissions.

Information on health systems level variables was also collected for individuals in each cohort including total length of stay (LOS) of the index hospitalization episode, Local Health Integration Network (LHIN) beds per 1000 population, continuity of care, and physician supply per 100 population. Availability of LHIN beds and physician supply are considered important indicators of inpatient health services access and outpatient health services access respectively. This measure of LHIN beds identifies the proportion of available hospital beds in each LHIN, while physician supply refers to the proportion of full-time equivalent primary care physicians in each LHIN. LHIN beds per 1000 population and physician supply per 100 population were identified via INST and IPDB respectively and were included as continuous variables based on values as of April 1, 2016.

Previous research has identified that having shorter LOS results in greater readmissions due to a lack of opportunity to appropriately stabilize patients and provide discharge planning (Figueroa, Harman, & Engberg, 2004). Index episode LOS was thus included as a measure of inpatient health services quality. This variable was divided into five categories: 0-2 days, 3-5 days, 6-11 days, 12-30 days, and greater than 30 days. These categories were chosen to show whether having an index stay of longer than one month had an impact on the odds of readmission compared to shorter stays and are based

on a modified version of categories used in previous research investigating readmissions among persons with TBI (Saverino et al., 2016).

Finally, continuity of care is a measure of quality of outpatient physician care over time, used to determine the degree to which a patient receives consistent care over time (Manitoba Centre for Health Policy [MCHP], 2014). Continuity of care is associated with patient and provider satisfaction, as well as with health services outcomes such as emergency department visits and avoidable hospitalizations. This measure was identified using CAPE, CPDB, and ESTSOB, which is consistent with previous Ontario-based studies (Lunsky et al., 2013). "Usual Provider Continuity" (UPC) Index measures continuity of care with family physicians and is the proportion of an individual's family physician visits made with their usual family physician (versus all family physicians) over a two-year period (MCHP, 2014). In this study, UPC Index was based on visits from April 1, 2014 to March 31, 2016. Consistent with Lunsky et al. (2013), continuity of care was divided into three categories: persons with <3 visits (indicating that a UPC is not available as at least three visits are needed), persons among whom fewer than 75% of visits were with the UPC (<75% UPC), and persons with 75% of more of their visits with their UPC (≥75% UPC).

4.3.8 Data Analysis

4.3.8.1 Statistical Model

All analyses were completed using SAS® software. Using this software, the logistic procedure (SAS Institute Inc., 2009) was used to run bivariate and multivariable logistic regression analyses to calculate crude and adjusted odds ratios (OR). The primary independent variable was the group to which an individual was allocated based

on the presence or absence of IDD and history of TBI (IDD-Only, IDD-TBI, or TBI-Only). The binary dependent variable was the presence or absence of readmission within 30-days of discharge.

Crude ORs with 95% confidence intervals (CIs) were calculated for each subgroup in the primary independent variable using TBI-Only as the reference group. Next, bivariate odd ratios (ORs) with 95% CIs were calculated for all remaining independent variables. Adjusted ORs were then calculated using multivariable regression to determine if any initial association between the dependent and primary independent variables remained significant after controlling for potential confounders.

Bivariate and adjusted ORs with 95% CIs were also calculated separately for the IDD-TBI group. This was done to address the second study objective: identify factors that could be used to decrease readmissions in this subgroup.

4.3.8.2 Significance Testing

Statistical significance of independent variables was evaluated using p-values. The p-values were derived from chi-square tests using the results from the multivariable logistic procedure. P-values of less than 0.05 were considered significant. Statistical significance can also be estimated using the 95% CIs; a CI that does not include the value 1.00 is considered significant.

4.4 Results

4.4.1 Cohort Creation and Baseline Characteristics

The study population included a total of 117,587 Ontario adults with at least one hospitalization discharge between April 1, 2016 and March 31, 2017 (Figure 4.2). Within this population, 7,346 were persons with IDD, among whom 2,695 had a history of TBI. The remaining study population was persons without IDD with a history of TBI.

Baseline characteristics including age, sex, income quintile, and rurality for each cohort are included in Table 4.1. Regardless of TBI history, persons with IDD were younger than those without IDD; those with IDD and a history of TBI (IDD-TBI) were the youngest. Among persons with IDD-TBI, more than 40% were under 35 years of age, and only about 12.5% were 65 years of age or older. In comparison, among persons with IDD without a history of TBI (IDD-Only), nearly 35% were under 35 years of age and approximately 17% were 65 or older; among persons without IDD with a history of TBI (TBI-Only), these figures were less than 30% and approximately 36% respectively. Conversely, sex distribution was relatively even within each cohort, with a slightly higher proportion of males among persons with IDD (IDD-Only: ~53%; IDD-TBI: ~57%), and a slightly higher proportion of females (~58%) in the TBI-Only group.

The remaining demographic variables were similarly distributed between cohorts. In all three cohorts, individuals were more likely to reside in lower income quintiles versus higher income quintiles, with approximately 50-55% of individuals in each cohort residing in quintile 1 or quintile 2, however the TBI-Only group was more likely to reside in higher income regions compared to persons with IDD. Finally, with regard to rurality, less than 15% of individuals in each study cohort was living in a rural area.

Figure 4.2
Study population and cohort allocation.

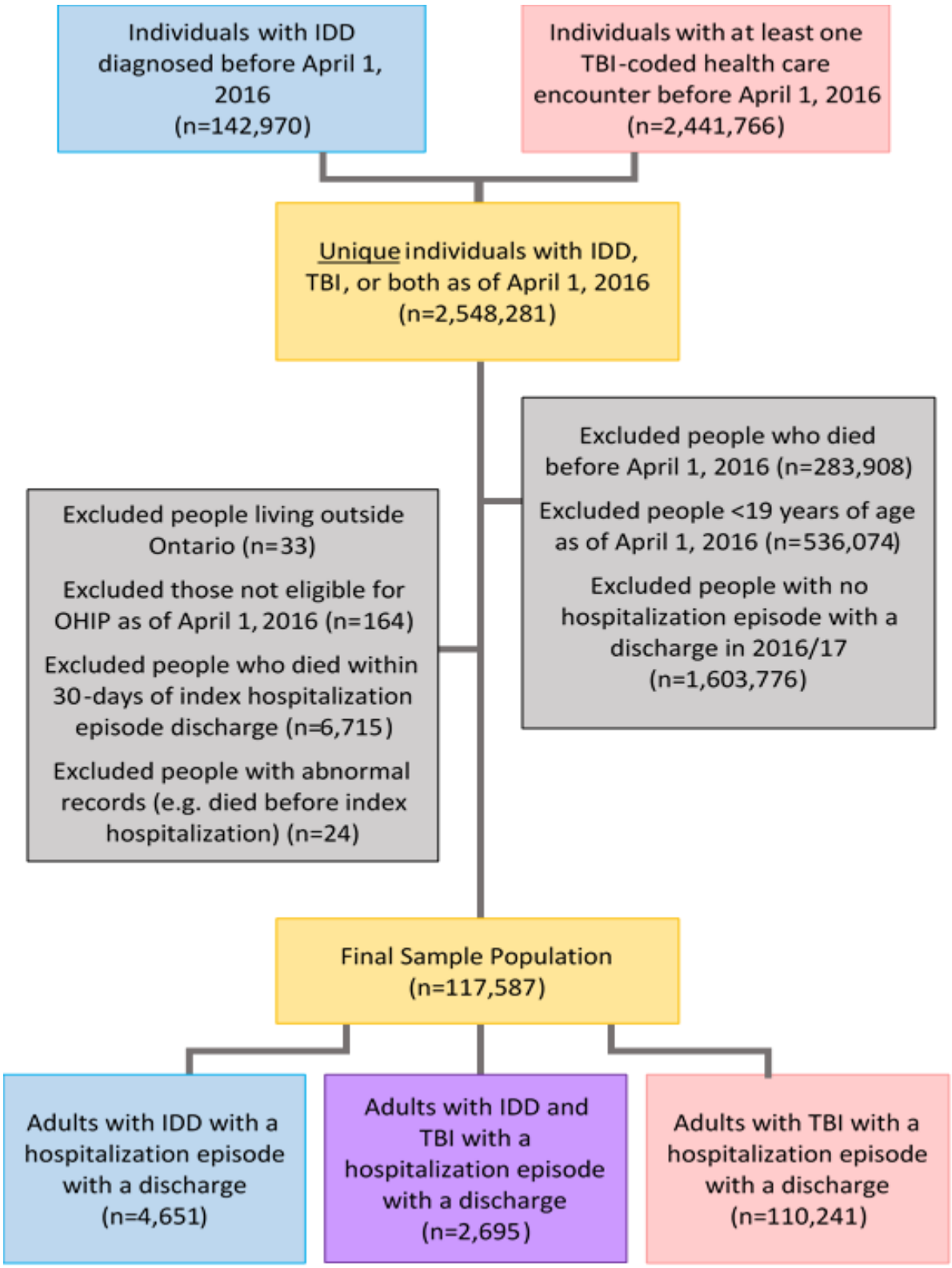


Table 4.1
Baseline characteristics of Ontario adults with intellectual and developmental disabilities (IDD) with and without a history of traumatic brain injury (TBI) and Ontario adults with TBI and no IDD (2016/17).

	IDD-Only (n= 4,651)	**IDD-TBI (n= 2,695)**	**TBI-Only (n= 110,241)**
Age on April 1 (n, col %)			
19-24 years	731 (15.72%)	502 (18.63%)	10,854 (9.85%)
25-34 years	838 (18.02%)	603 (22.37%)	21,796 (19.77%)
35-44 years	648 (13.93%)	371 (13.77%)	11,752 (10.66%)
45-54 years	797 (17.14%)	423 (15.70%)	12,047 (10.93%)
55-64 years	845 (18.17%)	461 (17.11%)	13,990 (12.69%)
65+ years	792 (17.03%)	335 (12.43%)	39,802 (36.10%)
Sex (n, col %)			
Male	2,478 (53.28%)	1,525 (56.59%)	45,886 (41.62%)
Female	2,173 (46.72%)	1,170 (43.41%)	64,355 (58.38%)
Income Quintile (n, col %)			
1 (low)	1,569 (33.73%)	983 (36.47%)	29,261 (26.54%)
2	967 (20.79%)	573 (21.26%)	23,525 (21.34%)
3	780 (16.77%)	456 (16.92%)	20,995 (19.04%)
4	718 (15.44%)	354 (13.14%)	19,078 (17.31%)
5 (high)	606 (13.03%)	318 (11.80%)	17,155 (15.56%)
Missing	11 (0.24%)	11 (0.41%)	227 (0.21%)
Region (n, col %)			
Urban	3,975 (85.47%)	2,411 (89.46%)	96,498 (87.53%)
Rural	666 (14.32%)	273 (10.13%)	13,522 (12.27%)
Missing	10 (0.22%)	11 (0.41%)	221 (0.20%)

4.4.2 Characteristics of Individuals with and without 30-Day Readmissions

Of the 117,587 Ontario adults included in the study with at least one hospitalization episode including a discharge during the 2016/17 fiscal year, 12,014 were readmitted at least once within 30-days of discharge. Of those readmitted within 30-days, 998 had IDD with or without a history of TBI. Figure 4.3 shows the proportion of each study cohort that experienced at least one readmission within 30-days of discharge from the index hospitalization episode.

Characteristics of the study population overall (i.e. the full model), and those who were readmitted versus not readmitted within 30-days of discharge are presented in Table 4.2. People who were readmitted within 30-days were older on average, with more than 42% of persons with a readmission being aged 65 years or older compared to approximately 34% for those who were not readmitted. With regard to the remaining demographic variables, distribution was similar between individuals with versus without a readmission, however those with a readmission were more likely to be male (48%) and somewhat more likely to reside in the lowest income quintile (quintile 1: 30%) compared to persons without a readmission (42% and 27% respectively). Additionally, morbidity level among persons with at least one readmission were higher, with nearly 13% having a Charlson score of 3 or more and nearly 63% with a mental health diagnosis within the previous two years. In comparison, among those who were not readmitted, only approximately 6% had a Charlson score of 3 or higher and 53% had a recent mental health diagnosis. Furthermore, individuals with at least one readmission had longer index length of stays.

Presented in Table 4.3 are the characteristics of individuals with IDD-TBI by themselves, according to readmission status within 30-days of discharge. Within the IDD-TBI cohort (n=2,695), 372 individuals were readmitted at least once within 30-days of discharge from the index hospitalization episode. Demographic characteristics including age, sex, income, and rurality in this cohort were similar between individuals who were readmitted compared to those who were not. Notably, although the distribution was similar when considering the full study population, among those with IDD-TBI, individuals who were readmitted were more likely to reside in areas with the highest ethnic concentration (quintile 5: 20.2%) and less likely to reside in the lowest ethnic concentration quintile (quintile 1: 14.5%) compared to individuals without a readmission (quintile 5: 17.4%, quintile 1: 19.5%). In terms of their TBI-status, individuals who were readmitted were more likely to have more recent TBI-history and more TBI-related health service encounters. Among these individuals, approximately 33% had their most recent TBI within 3 years of the index hospitalization episode and 15% had more than five TBI-related health service encounters compared to approximately 27% and 10% among individuals who were not readmitted. Morbidity and recent mental health history were also somewhat higher among those with at least one readmission. In contrast to the overall study population, within the IDD-TBI group, individuals with at least one 30-day readmission had similar length of stays of index hospitalization episodes, with the exception that they were less likely to have stays between 3-5 days and more likely to have stays between 12-30 days. These readmitted individuals were also more likely to be discharged against medical advice.

4.4.3 Results of Regression Analyses

Crude and multivariable odds ratios for predicting 30-day readmissions are also included in Table 4.2 and 4.3 for the full model (full study population) and for the IDD-TBI cohort respectively. Within the full study population, individuals with IDD had higher odds of readmission regardless of TBI history. After adjusting for covariates, individuals with IDD-Only and IDD-TBI had 1.25 and 1.23 times higher odds of being readmitted respectively, compared to those with TBI-Only.

Within the IDD-TBI cohort specifically (see Table 4.3), the multiple variable model showed that individuals had significantly higher odds of having at least one readmission within 30-days if they: lived in regions of higher ethnic concentration (quintile 5, quintile 3 vs. quintile 1), had a history of more than five TBI-related healthcare encounters, had an index hospitalization episode length of stay between 12-30 days, or were either discharged against medical advice or discharged to a location other than those specifically examined (home, home with support, long-term care, chronic continuing care, or rehabilitation facility), such as palliative care/hospice, addiction treatment centre, or jails. In this cohort, individuals were also significantly less likely to be readmitted if they did not have a Charlson score, indicating that these individuals are likely healthier than individuals that do have a Charlson score. At the crude level, having the most recent TBI within >1-3 years or having a mental health diagnosis within two years were also significant predictors of readmissions in this population, however they did not remain significant at the multivariable level.

Figure 4.3
Proportion of hospitalized individuals with at least one 30-day readmission among Ontario adults with an intellectual and developmental disability (IDD) without a history of traumatic brain injury (TBI), with IDD with a history of TBI, and without IDD with a history of TBI.

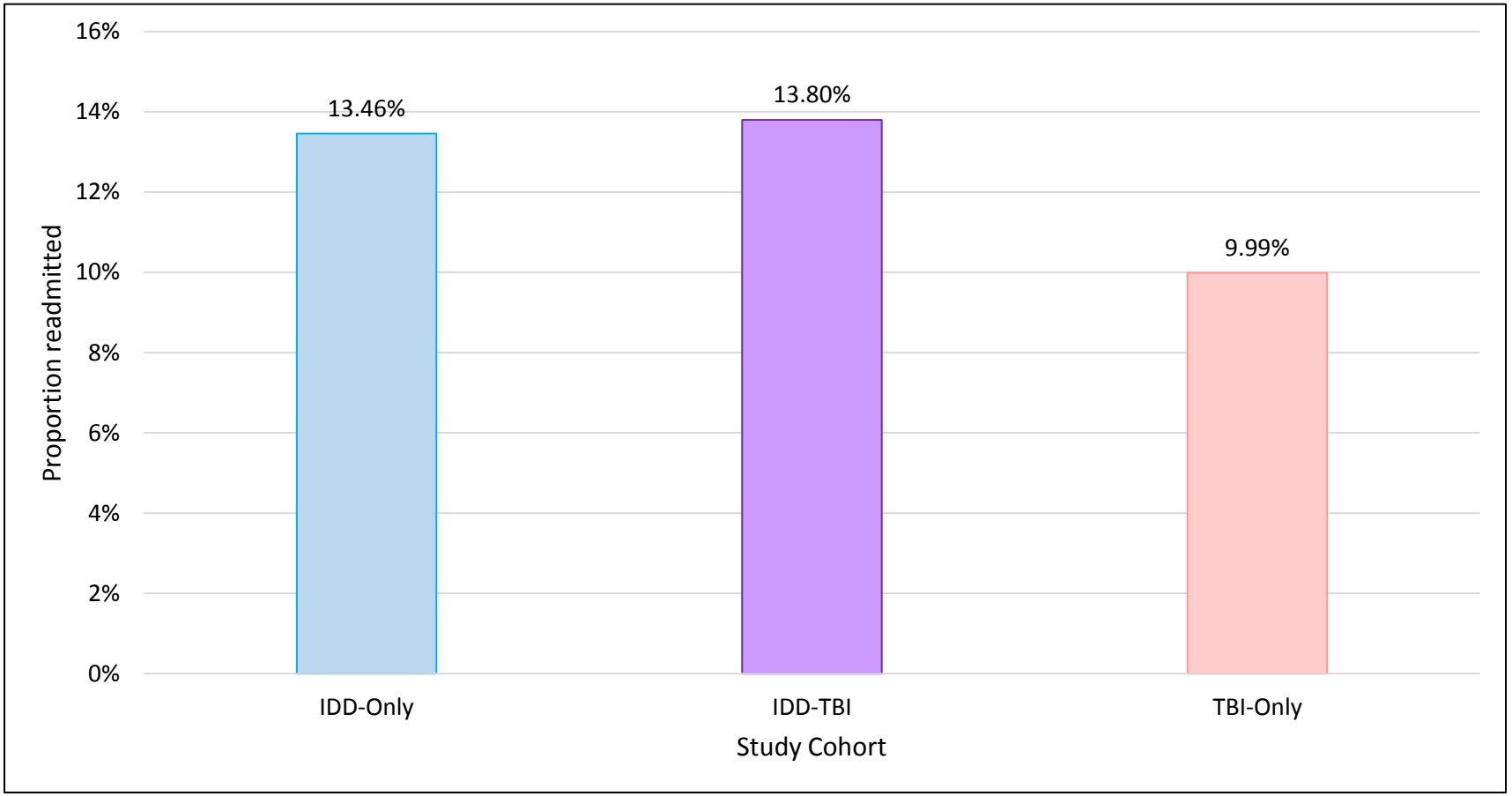


Table 4.2
Full model of odds ratios for predicting 30-day hospital readmissions among Ontario adults with intellectual and developmental disabilities (IDD) with and without a history of traumatic brain injury (TBI) and Ontario adults with TBI and no IDD with at least one hospitalization including discharge in 2016/17.

[Full Model]	Discharged from index hospitalization (n=117,587)	Readmitted within 30-days (n=12,014)	No readmission within 30-days (n=105,573)	Crude odds ratio (95% CI$^{\Phi}$)	Multivariable odds ratio (905% CI$^{\Phi}$)
Cohort (n, col %)					
IDD-Only	4,651 (3.96%)	626 (5.21%)	4,025 (3.81%)	1.40 (1.29-1.53)	1.25 (1.14-1.37)**
IDD-TBI	2,695 (2.29%)	372 (3.10%)	2,323 (2.20%)	1.44 (1.29-1.61)	1.23 (1.09-1.37)**
TBI-Only (ref)	110,241 (93.75%)	11,016 (91.69%)	99,225 (93.99%)		
Age as of April 1st, 2016 (n, col %)					
19-24 years (ref)	12,087 (10.28%)	996 (8.29%)	11,091 (10.51%)		
25-34 years	23,237 (19.76%)	1,696 (14.12%)	21,541 (20.40%)	0.88 (0.81-0.95)	0.93 (0.85-1.01)
35-44 years	12,771 (10.86%)	1,149 (9.56%)	11,622 (11.01%)	1.10 (1.01-1.20)	1.03 (0.94-1.12)
45-54 years	13,267 (11.28%)	1,370 (11.40%)	11,897 (11.27%)	1.28 (1.18-1.40)	1.08 (0.99-1.18)
55-64 years	15,296 (13.01%)	1,708 (14.22%)	13,588 (12.87%)	1.40 (1.29-1.52)	1.16 (1.07-1.27)**
65+ years	40,929 (34.81%)	5,095 (42.41%)	35,834 (33.94%)	1.58 (1.48-1.70)	1.28 (1.18-1.39)**
Sex (n, col %)					
Male	49,889 (42.43%)	5,807 (48.34%)	44,082 (41.75%)	1.31 (1.26-1.36)	1.16 (1.12-1.21)**
Female (ref)	67,698 (57.57%)	6,207 (51.66%)	61,491 (58.25%)		
Income Quintile (n, col %)					
1 (low)	31,813 (27.05%)	3,612 (30.06%)	28,201 (26.71%)	1.23 (1.16-1.31)	1.09 (1.02-1.16)**
2	25,065 (21.32%)	2,629 (21.88%)	22,436 (21.25%)	1.13 (1.06-1.20)	1.06 (0.99-1.13)
3	22,231 (18.91%)	2,204 (18.35%)	20,027 (18.97%)	1.06 (0.99-1.13)	1.03 (0.96-1.10)

4	20,150 (17.14%)	1,826 (15.20%)	18,324 (17.36%)	0.96 (0.89-1.03)	0.96 (0.89-1.03)
5 (high) (ref)	18,079 (15.37%)	1,705 (14.19%)	16,374 (15.51%)		
Missing	249 (0.21%)	38 (0.32%)	211 (0.20%)	1.73 (1.22-2.46)	<0.001 (<0.001->999.99)
Region (n, col %)					
Urban (ref)	102,884 (87.50%)	10,558 (87.88%)	92,326 (87.45%)		
Rural	14,461 (12.30%)	1,418 (11.80%)	13,043 (12.35%)	0.95 (0.90-1.01)	0.97 (0.91-1.04)
Missing	242 (0.21%)	38 (0.32%)	204 (0.19%)	1.63 (1.15-2.30)	>999.99 (<0.001->999.99)
Ethnic Concentration (n, col %)					
5 (most)	24,529 (20.86%)	2,516 (20.94%)	22,013 (20.85%)	1.01 (0.95-1.07)	1.03 (0.96-1.11)
4	23,009 (19.57%)	2,381 (19.82%)	20,628 (19.54%)	1.02 (0.96-1.08)	1.05 (0.98-1.12)
3	22,453 (19.09%)	2,260 (18.81%)	20,193 (19.13%)	0.99 (0.93-1.05)	1.01 (0.94-1.08)
2	22,978 (19.54%)	2,330 (19.39%)	20,648 (19.56%)	1.00 (0.94-1.06)	1.01 (0.95-1.08)
1 (least) (ref)	23,166 (19.70%)	2,356 (19.61%)	20,810 (19.71%)		
Missing	1,452 (1.23%)	171 (1.42%)	1,281 (1.21%)	1.18 (1.00-1.39)	1.03 (0.85-1.25)
Charlson Comorbidity Index Score (n, col %)					
0-2 (ref)	34,245 (29.12%)	4,194 (34.91%)	30,051 (28.46%)		
3+	7,845 (6.67%)	1,531 (12.74%)	6,314 (5.98%)	1.74 (1.63-1.85)	1.48 (1.39-1.58)**
N/A	75,497 (64.21%)	6,289 (52.35%)	69,208 (65.55%)	0.65 (0.63-0.68)	0.72 (0.69-0.76)**
Mental Health Diagnosis within the previous 2 years (n, col %)					
Yes	63,785 (54.24%)	7,528 (62.66%)	56,257 (53.29%)	1.47 (1.42-1.53)	1.24 (1.19-1.29)**
No (ref)	53,802 (45.76%)	4,486 (37.34%)	49,316 (46.71%)		
Length of Stay of Index Hospitalization Episode (n, col %)					
0-2 days (ref)	51,480 (43.78%)	3,936 (32.76%)	47,544 (45.03%)		

3-5 days	30,865 (26.25%)	3,015 (25.10%)	27,850 (26.38%)	1.31 (1.24-1.37)	1.18 (1.12-1.24)**
6-11 days	18,392 (15.64%)	2,599 (21.63%)	15,793 (14.96%)	1.99 (1.89-2.10)	1.65 (1.11-1.74)**
12-30 days	11,570 (9.84%)	1,784 (14.85%)	9,786 (9.27%)	2.20 (2.07-2.34)	1.84 (1.72-1.96)**
>30 days	5,280 (4.49%)	680 (5.66%)	4,600 (4.36%)	1.79 (1.64-1.95)	1.44 (1.01-1.58)**
Discharge Disposition (n, col %)					
Discharged against medical advice	1,877 (1.60%)	396 (1.29%)	1,481 (1.40%)	2.87 (2.57-3.22)	2.63 (2.34-2.95)**
Home (ref)	78,947 (67.14%)	6,722 (55.95%)	72,225 (68.41%)		
Home with support	23,495 (19.98%)	3,325 (27.68%)	20,170 (19.11%)	1.77 (1.69-1.85)	1.20 (1.14-1.26)**
Long-term care/ Chronic continuing care	4,882 (4.15%)	569 (4.74%)	4,313 (4.09%)	1.42 (1.29-1.55)	0.73 (0.67-0.80)**
Rehabilitation facility	4,048 (3.44%)	404 (3.36%)	3,644 (3.45%)	1.19 (1.07-1.32)	0.73 (0.65-0.82)**
Other	2,461 (2.09%)	443 (3.69%)	2,018 (1.91%)	2.36 (2.12-2.62)	1.73 (1.55-1.93)**
LHIN beds per 1000 (n, col %)					
				1.08 (1.05-1.12)	1.04 (0.99-1.09)
Continuity of Care Index (n, col %)					
<3 visits	19,505 (16.59%)	1,785 (14.86%)	17,720 (16.78%)	0.85 (0.81-0.90)	0.98 (0.92-1.04)
UPC <0.75	50,015 (42.53%)	5,151 (42.87%)	44,864 (42.50%)	0.97 (0.93-1.01)	1.06 (1.02-1.11)**
UPC $\geq$0.75	48,067 (40.88%)	5,078 (42.27%)	42,989 (40.72%)		
Primary Care Physician Supply per 100 (n, col %)					
				1.04 (1.01-1.06)	1.02 (0.99-1.06)

** : Statistically significant at $p<0.05$ compared to the reference value

$^{\Phi}$: Confidence Interval

Table 4.3
Odds ratios for predicting 30-day hospital readmissions among Ontario adults with intellectual and developmental disabilities (IDD) with a history of traumatic brain injury (TBI) with at least one hospitalization including discharge in 2016/17.

[IDD-TBI]	Discharged from index hospitalization (n=117,587)	Readmitted within 30-days (n=12,014)	No readmission within 30-days (n=105,573)	Crude odds ratio (95% CI$^{\Phi}$)	Multivariable odds ratio (95% CI$^{\Phi}$)
Age as of April 1st, 2016 (n, col %)					
19-24 years (ref)	502 (18.63%)	58 (15.59%)	444 (19.11%)		
25-34 years	603 (22.37%)	93 (25.00%)	510 (21.95%)	1.40 (0.98-1.98)	1.36 (0.95-1.95)
35-44 years	371 (13.77%)	49 (13.17%)	322 (13.86%)	1.17 (0.78-1.75)	1.09 (0.72-1.66)
45-54 years	423 (15.70%)	61 (16.40%)	362 (15.58%)	1.29 (0.88-1.90)	1.21 (0.81-1.82)
55-64 years	461 (17.11%)	67 (18.01%)	394 (16.96%)	1.30 (0.89-1.90)	1.30 (0.87-1.96)
65+ years	335 (12.43%)	44 (11.83%)	291 (12.53%)	1.16 (0.76-1.76)	1.26 (0.79-2.00)
Sex (n, col %)					
Male	1,525 (56.59%)	214 (57.53%)	1,311 (56.44%)	1.05 (0.84-1.30)	1.06 (0.84-1.33)
Female (ref)	1,170 (43.41%)	158 (42.47%)	1,012 (43.56%)		
Income Quintile (n, col %)					
1 (low)	983 (36.47%)	136 (36.56%)	847 (36.46%)	0.93 (0.65-1.33)	0.85 (0.58-1.25)
2	573 (21.26%)	82 (22.04%)	491 (21.14%)	0.96 (0.65-1.42)	1.00 (0.67-1.50)
3	456 (16.92%)	57 (15.32%)	399 (17.18%)	0.82 (0.54-1.25)	0.85 (0.55-1.30)
4	354 (13.14%)	48 (12.90%)	306 (13.17%)	0.90 (0.59-1.40)	0.95 (0.61-1.49)
5 (high) (ref)	318 (11.80%)	47 (12.63%)	271 (11.67%)		
Missing	11 (0.41%)	2 (0.54%)	9 (0.39%)	1.28 (0.27-6.12)	1.64 (0.18-15.17)
Region (n, col %)					
Not rural (ref)	2,422 (89.87%)	337 (90.59%)	2,085 (89.75%)		

Rural	273 (10.13%)	35 (9.41%)	238 (10.25%)	0.91 (0.63-1.32)	1.07 (0.70-1.64)
Ethnic Concentration (n, col %)					
5 (most)	479 (17.77%)	75 (20.16%)	404 (17.39%)	1.55 (1.07-2.26)	1.73 (1.11-2.70)**
4	546 (20.26%)	77 (20.70%)	469 (20.19%)	1.37 (0.95-1.99)	1.47 (0.96-2.24)
3	547 (20.30%)	85 (22.85%)	462 (19.89%)	1.54 (1.07-2.22)	1.55 (1.03-2.31)**
2	590 (21.89%)	77 (20.70%)	513 (22.08%)	1.26 (0.87-1.82)	1.28 (0.87-1.90)
1 (least) (ref)	506 (18.78%)	54 (14.52%)	452 (19.46%)		
Missing	27 (1.00%)	4 (1.08%)	23 (0.99%)	1.46 (0.49-4.37)	1.03 (0.22-4.83)
TBI History- When (n, col %)					
0-1 years	332 (12.32%)	52 (13.98%)	280 (12.05%)	1.33 (0.96-1.85)	1.09 (0.76-1.55)
>1-3 years	411 (15.25%)	69 (18.55%)	342 (14.72%)	1.44 (1.07-1.94)	1.21 (0.88-1.66)
>3-5 years	297 (11.02%)	48 (12.90%)	249 (10.72%)	1.38 (0.98-1.94)	1.21 (0.85-1.74)
>5 years (ref)	1,655 (61.41%)	203 (54.57%)	1,452 (62.51%)		
TBI History- Number of TBI-related Health Service Encounters (n, col %)					
1 (ref)	1,313 (48.72%)	163 (43.82%)	1,150 (49.50%)		
2	550 (20.41%)	79 (21.24%)	471 (20.28%)	1.18 (0.89-1.58)	1.13 (0.84-1.52)
3-5	531 (19.70%)	74 (19.89%)	457 (19.67%)	1.14 (0.85-1.54)	0.96 (0.71-1.32)
>5	301 (11.17%)	56 (15.05%)	245 (10.55%)	1.61 (1.16-2.25)	1.45 (1.01-2.09)**
Charlson Comorbidity Index Score (n, col %)					
0-2 (ref)	1,016 (37.70%)	170 (45.70%)	846 (36.42%)		
3+	109 (4.04%)	20 (5.38%)	89 (3.83%)	1.12 (0.67-1.87)	1.20 (0.71-2.05)
N/A	1,570 (58.26%)	182 (48.92%)	1,388 (59.75%)	0.65 (0.52-0.82)	0.69 (0.54-0.87)**
Mental Health Diagnosis within the previous 2 years (n, col %)					
Yes	2,064 (76.59%)	304 (81.72%)	1,760 (75.76%)	1.43 (1.08-1.89)	1.27 (0.95-1.72)
No (ref)	631 (23.41%)	68 (18.28%)	563 (24.24%)		

Length of Stay of Index Hospitalization Episode (n, col %)					
0-2 days (ref)	847 (31.43%)	118 (31.72%)	729 (31.38%)		
3-5 days	638 (23.67%)	74 (19.89%)	564 (24.28%)	0.81 (0.59-1.11)	0.84 (0.61-1.16)
6-11 days	495 (18.37%)	71 (19.09%)	424 (18.25%)	1.04 (0.75-1.42)	1.10 (0.79-1.54)
12-30 days	387 (14.36%)	70 (18.82%)	317 (13.65%)	1.26 (0.99-1.89)	1.43 (1.02-2.02)
>30 days	328 (12.17%)	39 (10.48%)	289 (12.44%)	0.83 (0.57-1.23)	0.82 (0.54-1.24)
Discharge Disposition (n, col %)					
Discharged against medical advice	70 (2.59%)	21 (5.65%)	49 (2.11%)	3.06 (1.79-5.21)	3.05 (1.74-5.33)**
Home (ref)	1,463 (54.29%)	180 (48.39%)	1,283 (55.23%)		
Home with support	561 (10.82%)	86 (23.12%)	475 (20.45%)	1.29 (0.98-1.70)	1.17 (0.86-1.59)
Long-term care/ Chronic continuing care	187 (6.94%)	15 (4.03%)	172 (7.40%)	0.62 (0.36-1.08)	0.63 (0.37-1.09)
Rehabilitation facility	47 (1.74%)	6 (1.61%)	41 (1.76%)	1.04 (0.44-2.49)	1.04 (0.42-2.56)
Other	331 (12.28%)	60 (16.13%)	271 (11.67%)	1.58 (1.15-2.17)	1.58 (1.12-2.22)**
LHIN beds per 1000 (n, col %)					
				0.91 (0.75-1.11)	0.88 (0.68-1.12)
Continuity of Care Index (n, col %)					
<3 visits	575 (21.34%)	55 (14.78%)	520 (22.38%)	0.69 (0.49-0.96)	0.76 (0.53-1.09)
UPC <0.75	1,238 (45.94%)	199 (53.49%)	1,039 (44.73%)	1.24 (0.97-1.59)	1.13 (0.87-1.47)
UPC $\geq$0.75	882 (32.73%)	118 (31.72%)	764 (32.89%)		
Primary Care Physician Supply per 100 (n, col %)					
				1.01 (0.87-1.17)	1.17 (0.96-1.43

** : Statistically significant at $p<0.05$ compared to the reference value

$^{\Phi}$: Confidence Interval

4.5 Discussion

4.5.1 Summary of Findings

This cohort study was the first known study to examine readmissions among persons with both IDD and a history of TBI, at the population-level. Health outcomes data for persons with IDD and a history of TBI has not previously been examined; the one existing study provided qualitative information on an individual with IDD and TBI focusing on problems with service access (McKinlay, McLellan, & Daffue, 2012). The present study provides information on the odds of 30-day readmissions for adults with IDD and a history of TBI in comparison to individuals with IDD without a history of TBI, as well as to individuals with a history of TBI in persons without IDD. Characteristics of individuals with IDD-TBI were similar at baseline compared to the IDD-Only cohort. In contrast, individuals in either IDD cohort were more likely to be younger in age, male, and residing in lower income neighborhoods at baseline compared to the cohort without IDD (TBI-Only). In the 2016-2017 fiscal year, 12,014 individuals in the study population were readmitted at least once within 30-days of discharge from the index hospitalization episode, of which 372 had both IDD and a history of TBI. Odds of readmissions among persons with IDD with a history of TBI were significantly greater compared to persons with TBI without IDD, however they were similar to the odds among persons with IDD without a history of TBI.

4.5.2 Results in the Context of Past Research

Addressing the first objective, the results of this study showed that the odds of readmission were greater for persons with IDD compared to those without. Among individuals with IDD (IDD-Only and IDD-TBI) who were discharged from a

hospitalization episode in 2016/17, approximately 13.6% were readmitted within 30-days of discharge, compared to approximately 10.0% in the cohort without IDD. Compared to the TBI-Only group, persons with IDD-Only and those with IDD-TBI had significantly higher odds of experiencing a readmission; this finding remained significant after adjusting for relevant covariates. Increased odds among persons with IDD compared to those without is consistent with the findings of Lin et al. (2019) and Balogh et al. (2017).

This was the first known study to compare 30-day readmissions among persons with IDD with and without a history of TBI. Using persons with TBI as the reference group, the results of this study did not show a large difference in odds of experiencing a readmission within 30-days between the two IDD groups (IDD-Only: 1.25, IDD-TBI: 1.23). Although past research has shown that having a psychiatric comorbidity increased the odds of 30-day readmissions among persons with IDD (Balogh et al., 2017) and TBI can cause similar symptoms as those seen in mental illness (Fralick et al., 2016; Langlois, Rutland-Brown, & Wald, 2006; Tuerk et al., 2019), thus increasing patient complexity, TBI did not have the same impact on 30-day readmissions among persons with IDD. Therefore, there is no evidence of a synergistic effect when examining readmissions for persons with both IDD and a history of TBI.

Addressing the second objective, this study also added to existing research by identifying other factors associated with readmissions among persons with IDD and/or a history of TBI. For ease of understanding, the term "full model" will henceforth be used to describe the multivariable results in Table 4.2; "IDD-TBI model" will describe multivariable results in Table 4.3. Similar to previous research, sex and age were found to be predictors of 30-day readmission in the full model including all study cohorts. The

study by Balogh et al. (2017) found 1.22 times the odds of 30-day readmissions among males versus females in people with IDD, and Saverino et al. (2016) found 1.11 times the odds of readmissions overall among males versus females in people with TBI. In this research, the full model showed that males had 1.16 times increased odds of 30-day readmissions compared to females, which is approximately the average of the values found by previous studies. In terms of age, prior studies of readmissions among persons with TBI have noted older age as a predictor of readmissions. This study found that overall, individuals aged 55-64 years had nearly 1.2 times increased odds of 30-day readmissions and those aged 65 years and older had approximately 1.3 times increased odds compared to the youngest age group, 19-24 years. This finding is much lower than the figures provided by Saverino et al. (2016), who noted increased odds among adults aged 50-64 years of nearly 3 times, and those 65 years and older nearly 4 times. However, Saverino and colleagues used a younger reference group (younger than 15 years) as they examined individuals of all ages; they also included readmissions up to 3 years post-discharge. The findings from the present study indicate that among individuals with IDD, TBI history, or both, individuals are more likely to be readmitted within 30-days of discharge from an index hospitalization if they are male or older in age.

Although previous studies have not noted income as a predictor of readmissions among persons with IDD or with TBI, within the full model (see Table 4.2), residing in neighborhoods with the lowest income quintile (quintile 1) was a significant predictor of 30-day readmissions in this study. Compared to income quintile 5 (highest), individuals living in income quintile 1 (lowest) had 1.1 times greater odds of experiencing readmissions. Notably, in the IDD-TBI model (see Table 4.3), none of the

aforementioned demographic characteristics had a significant role in readmissions. These findings indicate that demographic factors play less of a role among persons with IDD and a history of TBI (Table 4.3) compared to the entire cohort consisting of IDD-TBI, IDD-Only, and TBI-Only shown in Table 4.2.

Ethnic concentration was used in this study as a measure of marginalization. Although ethnic concentration did not have a significant impact in the full model, within the IDD-TBI model, individuals residing in ethnic quintile 5 (highest ethnic concentration) and quintile 3 were 1.7 times and 1.6 times more likely to experience readmissions compared to individuals residing in ethnic quintile 1 (lowest ethnic concentration). Individuals residing in quintile 4 also had increased odds (1.5 times), however this was not significant. These findings indicate that among persons with IDD and a history of TBI, individuals who are readmitted within 30-days of discharge from an index hospitalization are more likely to live in ethnically concentrated regions compared to persons without IDD. Although no existing studies of readmissions among persons with IDD have included ethnic concentration as a variable, previous research conducted in the United States has found that in the general population, odds of 30-day readmissions varied with race/ethnicity; this study found that Medicare-insured non-white individuals had higher odds of readmission (Basu, Hanchate, & Bierman, 2018).

With regard to health status, morbidity level played a role in readmissions in both the full model and among persons with IDD-TBI specifically. For instance, having a mental health diagnosis within two years prior to April 1, 2016 was a predictor of 30-day readmissions in both models. Compared to individuals with no recent mental health diagnosis, individuals with a mental health diagnosis within the previous two years had

more than 1.2 times greater odds of readmission in the full model, and nearly 1.3 times increased odds in the IDD-TBI cohort, however this was only statistically significant in the full model. This is consistent with the study by Balogh et al. (2017), which found that compared to those without, persons with a mental illness among adults with IDD had approximately 1.4 times greater odds of readmission. Among persons with TBI, Saverino et al. (2016) found a similar odds ratio of 1.7 times among individuals with a psychiatric comorbidity.

Moreover, higher level of morbidity increased the odds of readmission in both models (full and stratified by IDD-TBI), such that individuals with a Charlson score of 3 or greater had 1.5 times and 1.2 times odds of readmission in the full model and the IDD-TBI cohort respectively, compared to individuals with a Charlson score of 0-2. High morbidity level as a predictor of readmissions was however only significant in the full model. At the same time, in both models, individuals who did not have a Charlson score (i.e. did not have a health care encounter in the two years prior to the study period) had significantly lower odds of readmission, with approximately 0.7 times the odds compared to Charlson scores of 0-2 in both models. Individuals who did not have a health care encounter within two years prior to the study period are thus likely to be healthier overall than those that required medical attentions, which would explain the protective effect seen for this level of the Charlson score. This indicates that, as is suggested by Kangovi & Grande (2011), patient health status is an important consideration in terms of its role in readmissions.

As another indication of the role of patient health status, within the IDD-TBI model, the number of TBI-related health service encounters prior to April 1, 2016 also

played a role in readmissions. Compared to individuals with only one TBI-related health service encounter, those with a history of more than 5 TBI-related health service encounters were significantly more likely to be readmitted, with nearly 1.5 times increased odds. This indicates that among persons with a history of TBI, those who are readmitted are more likely to have a history of several health service encounters related to TBI. Notably, this variable was not included in previous studies of readmissions among persons with TBI. This study thus provides evidence that the number of TBI-related health service encounters should be considered in future studies of readmissions among individuals with TBI.

In terms of health services, access to inpatient and outpatient care did not play a significant role in readmissions in either model, however quality of care did. Length of stay of the index hospitalization episode, which is a measure of inpatient quality of care, was a significant predictor of 30-day readmissions such that longer stays typically resulted in greater odds. In the full model, compared to stays of 0-2 days, individuals with longer stays had increasingly greater odds of readmission (3-5 days: 1.2 times, 6-11 days: 1.7 times, 12-30 days: 1.8 times) until greater than 30 days (1.4 times). A similar pattern was seen among individuals with IDD-TBI specifically, however the only significant length of stay was for 12-30 days. This suggests that length of stay of the index hospitalization may be less informative in terms of the likelihood of readmissions among persons with IDD-TBI compared to those with IDD-Only or TBI-Only. This difference between the two models could however be due to smaller numbers in the IDD-TBI group. Balogh et al. (2017) also found that increased index length of stay was associated with readmissions. The role of length of stay also provides evidence of the

role of quality of inpatient care in readmissions among persons with IDD and/or a history of TBI, and that longer stays in hospital did not necessarily result in better health care. Although having a longer index length of stay suggests better ability to prepare patient for discharge, it may instead be a marker for patient complexity. Continuity of care, used as a measure of outpatient quality of care, also had a significant impact on readmissions in the full model, however this was very small, as individuals with less than 75% UPC (i.e. worse continuity of care) versus greater than or equal to 75% UPC (i.e. better continuity of care) had only 1.06 times increased risk of readmissions.

Finally, the location to which an individual was discharged after the index hospitalization episode, or discharge disposition, seemed to have a significant role in odds of readmissions in both multivariable models. Most notably, compared to those discharged to their home, individuals in the full model who were discharged against medical advice had 2.6 times greater odds of readmission, and in the IDD-TBI model, these individuals had more than 3 times greater odds of readmission. Additionally, individuals in the full model who were discharged to long-term care, chronic continuing care, or a rehabilitation facility were significantly less likely to be readmitted (0.7 times) compared to those discharged to home. In the IDD-TBI model, individuals discharged to long-term care or chronic continuing care were also less likely to be readmitted (0.63 times), but this was not significant. The health services and other supports provided to persons with IDD-TBI in these environments may be substantial enough to prevent readmissions from occurring. Although no previous research on readmissions in people with IDD or those with TBI examined this variable, this finding is similar to previous research on readmissions among people with non-traumatic brain injury (Chan et al.,

2018); unfortunately, this study did not examine "discharge against medical advice" separately. Overall, the results for this variable indicate that the circumstances surrounding the discharge from the index hospitalization episode have an important influence on odds of readmission, and that discharge planning to the correct setting may be an important area of healthcare system improvement to reduce readmissions.

Significant predictors of readmissions in the combined study cohort of hospitalized adults with IDD, history of TBI, or both were different from significant predictors in the IDD-TBI group individually. Some of this difference may be due to the relatively small size of the population with IDD and a history of TBI. Still, this indicates that individuals with IDD and a history of TBI have unique needs, and addressing these needs could help improve readmissions for this population.

4.5.3 Study Limitations

There were some study limitations inherent to the use of administrative data. A commonly reported issue is the possibility that some individuals with IDD were misclassified as not having IDD (Balogh et al., 2017). However, age, sex, and income distribution of the IDD groups in this study were consistent with past reports of this population that identify persons with IDD using different data sources (Lin et al., 2013; Lin et al., 2019; Lunsky et al., 2013)., thus supporting that the groups identified in the current study were likely to be representative of persons with IDD in Ontario. Furthermore, older adults may also have been misclassified as not having IDD as IDD-related pathology is often not identified later in life due to age-related conditions, and it is not possible to look back for an IDD diagnosis prior to database inception.

With regard to TBI identification, it is possible that individuals may have been misdiagnosed, or there may have been limitations to the coding algorithm applied in this study, which could have resulted in misclassification of individuals as not having a history of TBI. To minimize this possibility, ICD-9 and -10 codes consistent with past research (Faul, Xu, Wald, & Coronado, 2010; Ng et al., 2015) were used.

Another limitation of using administrative data is the inability to include some variables which may have been important in these populations. For example, mechanism of injury and injury severity have been found to be predictors of readmissions among people with TBI (Saverino et al., 2016), however when these variables were evaluated, they each generated extremely high proportions of "unknown" values resulting in an inability to accurately report on or analyze these variables. This high proportion of unknown values is likely due to the inclusion of OHIP as a source for identifying TBI history, since mechanism of injury and injury severity are only available from the NACRS and DAD databases. As a result, these data were not available for individuals if their most recent TBI was determined using OHIP.

Furthermore, the Charlson Comorbidity Index was used as a measure of morbidity in this study, however there are alternative measures such as the Adjusted Clinical Groups Case-Mix system (ACG). This morbidity index accounts for a greater number of conditions and should be considered for use in future research on readmissions.

4.5.4 Implications and Future Research

The results of this study have important implications for understanding 30-day readmissions. The study findings indicate that there is no increase in odds of readmissions among individuals with IDD-TBI compared to IDD-Only. In the future, a

larger sample size would produce narrower confidence intervals and potentially more informative data pertaining to predictors of 30-day readmissions for persons with IDD-TBI.

In Canada, hospital readmissions cost more than $1.8 billion annually (CIHI, 2019). Based on statistical assessment and the desirable direction of the indicator (i.e. reducing 30-day readmissions), Ontario is one of only three provinces/territories in Canada in which the reduction of 30-day readmissions is below the Canadian average. This indicates that more can be done in Ontario to reduce 30-day hospital readmissions. The findings of this study show that addressing readmissions among persons with IDD could benefit approximately 14% of individuals with IDD who are hospitalized in a given year. In order to effectively address readmissions in this population, it is imperative to understand the unique needs of these individuals and what factors increase the odds of readmissions. Based on findings in this research, it may be beneficial to flag people with IDD and/or a history of TBI when they are hospitalized. This could alert hospital administrators and clinicians to pay particular attention to the health and community support needs of these individuals before they are discharged. Among people with IDD-TBI, this study found that understanding the role of ethnic concentration may also be of benefit. Additionally, based on the results of this study, discharge disposition should be considered an important variable to include in future readmissions research. It would be useful to understand what conditions may lead this population to leave the hospital against medical advice, and to be able to develop interventions to mitigate this problem. Further research should aim to generate more knowledge of the role of discharge planning and how discharge planning can be improved to reduce readmissions.

4.6 Conclusion

This study found that persons with IDD (IDD-Only or IDD-TBI) had greater odds of 30-day readmissions compared to individuals without IDD with a history of TBI (IDD-TBI), however among persons with IDD, those with a history of TBI had comparable odds to those without a history of TBI. These findings suggest that having a history of TBI does not result in greater or lesser odds of 30-day hospital readmission among persons with IDD; however, individuals with IDD-TBI were found to have unique predictors of readmissions. For instance, demographic characteristics were not significantly predictive of readmissions while ethnic concentration of residence was. Further research into the reasons for higher odds of readmissions in the IDD population are essential to understand and address this issue.

5 THESIS CONCLUSION

5.1 Conclusion

5.1.1 Introduction

Intellectual and developmental disabilities (IDD), characterized by deficits in intellectual and adaptive functioning (Government of Ontario, 2012), can lead to a pattern of health very different from the general population (Lunsky, Klein-Geltink, & Yates, 2013). Individuals with IDD experience a number of health disparities compared to individuals without IDD including an increased risk for various health and health outcomes (Lunsky et al., 2013). For instance, individuals with IDD have been shown to have higher rates of injuries (Slayter et al., 2006), as well as 30-day readmissions (Lin et al., 2019) compared to those without IDD. A common cause of injuries among individuals with IDD is falls (Cox et al., 2010; Finlayson et al., 2010; Smulders et al., 2013). In Canada, traumatic brain injury (TBI) is a leading cause of death and disability (Chen et al., 2012; Colantonio et al., 2009; Hwang et al., 2008) and is expected to cost $8.2 billion in indirect costs by 2031 (Public Health Agency of Canada & National Health Charities Canada, 2014). Falls are consistently found to be the leading cause of TBI (Fu et al., 2016; Langlois, Rutland-Brown, & Wald, 2006; McGuire et al., 2017). Despite this, no known studies have quantitatively examined TBI among persons with IDD.

Furthermore, among persons with IDD (Balogh et al., 2017) or TBI (Saverino et al., 2016) individually, having a comorbid psychiatric condition was found to be a predictor for hospital readmissions. Although psychiatric conditions and TBI both increase patient complexity and share a number of long-lasting symptoms (Tuerk et al.,

2019), no research has been conducted to identify whether having a history of TBI has an impact on 30-day hospital readmissions among individuals with IDD.

5.1.2 Summary of Findings

The objective of Manuscript 1 was to identify and compare incidence of TBI in adults with and without IDD. Using administrative health databases, new cases of TBI were identified annually from 2002/03 to 2016/17 for adults with and without IDD. Among those who experienced TBI in any given year, individuals with IDD were more likely to be male, younger in age, and to reside in lower income quintiles compared to persons without IDD. In each of the 15 study years, incidence of TBI among persons with IDD was significantly greater compared to individuals without IDD, with an adjusted relative risk ranging from 1.5 to 2.5 times. These results provide evidence of a disparity between persons with IDD compared to those without IDD such that individuals with IDD have a greater risk of TBI.

Manuscript 2 aimed to identify and compare the odds of 30-day readmissions among adults with IDD, a history of TBI, or both who had at least one hospitalization episode including a discharge in 2016/17. Administrative health databases were used to identify individuals with IDD, a history of TBI, or both who were readmitted at least once within 30-days of discharge from the index hospitalization episode. Crude and multivariable odds ratios were calculated in the full model to compare the odds of being readmitted within 30-days of discharge between the three study cohorts. Multivariable odds ratios were adjusted for a number of covariates to assess their effect on readmissions. Individuals with IDD had significantly higher odds of readmission compared to those without, regardless of TBI history; individuals with both IDD and a

history of TBI had comparable odds to individuals with IDD and no history of TBI. This finding remained true after adjusting for covariates. A comparison of crude and adjusted odds ratios between the full model the model including only those with both IDD and a history of TBI revealed that the predictors of readmissions may be different for persons with IDD and a history of TBI.

5.1.3 Future Research

This thesis adds to the existing body of research on the health of Canadian adults with IDD. No previous research had examined incidence of TBI or the impact of TBI history on 30-day hospital readmissions for persons with IDD compared to persons without IDD. This thesis was the first known study to describe quantitative patterns related to TBI among adults with IDD, and provides a precedent for future research in this area. The results of this study revealed evidence that individuals with IDD have a significantly greater risk of TBI compared to those without IDD. Additionally, regardless of IDD, TBI incidence is increasing over time. Furthermore, TBI history did not impact odds of readmissions for people with IDD, however this research identifies potentially useful factors that could be used to reduce readmissions in the population and sub-groups studied.

The Determinants of Hospital Readmissions framework described and utilized in this thesis provides a more complete concept of factors that influence readmissions. This model recognized the importance of examining not only the quality of health care and patient health status, but also the accessibility of health care and patient socioeconomic status. In this research, access to health care did not have a significant impact on readmissions at the multivariate level in the study populations examined. Patient

socioeconomic status had varying roles depending on the specific variable examined and the population. In the full model, income quintile was significantly related to readmissions, however measures of marginalization were not. In the cohort of persons with IDD and a history of TBI specifically, income was not significantly related to readmissions, but marginalization as measured by ethnic concentration was a significant predictor of 30-day readmissions. This indicates that patient socioeconomic status may be an important consideration for readmissions, and provides evidence that these complex individuals with IDD and a history of TBI have different needs. Notably, in this study, the circumstances surrounding patient discharge was found to have a significant role in odds of readmissions in both models indicating that this may be an important variable to consider in future readmissions studies.

The small sample of persons with IDD and a history of TBI may have caused other important variables for predicting odds of readmissions in this population to be been missed or found to be non-significant. Larger population studies including, for example, more than one province would improve the capacity to accurately identify the significance of certain variables in this model.

Existing research has highlighted the importance of addressing and preventing TBI in Canada (Fu et al., 2016; Public Health Agency of Canada & National Health Charities Canada, 2014), improving the understanding of the effects of certain injury mechanisms on sub-populations to help target TBI prevention efforts (Centers for Disease Control and Prevention, 2015) and examining TBI among persons with IDD (McKinlay, McLellan, & Daffue, 2012). Furthermore, existing literature has emphasized the importance of understanding and addressing 30-day readmissions among persons with

IDD (Balogh et al., 2017; Kelly et al., 2015; Lin et al., 2019). Future research should focus on identifying factors that contribute to the higher risk of TBI among adults with IDD to optimize prevention efforts, as well as improving the understanding of the unique needs of people with IDD in the health care setting to better understand and address health outcomes such as readmissions. Furthermore, more research should be conducted to identify other subpopulations that may be target populations for TBI prevention, and to further investigate the impact of discharge planning on readmissions.

5.1.4 Conclusion

This thesis found that incidence of TBI was consistently significantly greater among adults with IDD compared to those without IDD. This finding provides evidence that adults with IDD have a greater risk of experiencing TBI in comparison to the general population of adults without IDD. Although TBI can result in long-term or even lifelong disabilities that can increase patient complexity, among persons with IDD having a history of TBI did not result in higher odds for 30-day readmissions. Using a readmission framework made it possible to identify and include important and relevant variables for the analysis of readmissions in the study populations. The results of this thesis are the first to begin closing the research gap of TBI among persons with IDD, and are a step toward targeted TBI prevention as well as a better understanding of the unique needs of adults with IDD in Ontario. This research suggests that a larger population study be conducted to effectively identify predictors of TBI and 30-day readmissions for people with IDD.

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APPENDICES

Appendix A

Table A1

Databases, search terms, and filters employed during the literature review process.

Literature Review 1- Injuries among Persons with Intellectual and Developmental Disabilities	
Database	**Search terms**
MEDLINE	Intellectual Disability; Autism Spectrum Disorder; Brain Injuries, Traumatic; Craniocerebral Trauma; Wounds and Injuries
PsychINFO	Intellectual Development Disorder; Autism Spectrum Disorders; Traumatic Brain Injury; Injuries; Head Injury
EMBASE	Learning Disorder; Intellectual Impairment; Autism; Injury; Head Injury; Face Injury; Neck Injury
Filters	
English language; adults; human *No restrictions regarding year of publication were set due to the relative lack of research in the area of head or brain injuries among persons with intellectual and developmental disabilities	
Literature Review 2- 30-Day Hospital Readmissions among persons with Intellectual and Developmental Disabilities	
Database	**Search terms**
MEDLINE	Intellectual Disability; Autism Spectrum Disorder; Patient Readmission
PsychINFO	Intellectual Development Disorder; Autism Spectrum Disorders; Hospital Admission, "Quality of Care"; Readmissions
EMBASE	Learning Disorder; Intellectual Impairment; Autism; Hospital Readmission
Filters	
English language; adults; human *No restrictions regarding year of publication were set due to the relative lack of research in the area of readmissions among persons with intellectual and developmental disabilities	

Literature Review 3- Incidence of Traumatic Brain Injury in the General Population	
Database	**Search terms**
MEDLINE	Brain Injuries, Traumatic; Incidence; Epidemiology; Patient Readmission
PsychINFO	Traumatic Brain Injury; Epidemiology; Risk Factors; Incidence; Hospital Admission, "Quality of Care"; Readmissions
EMBASE	Traumatic Brain Injury; Incidence; Hospital Readmission
Filters	
English language; adults; human *Note: Due to the relative lack of research in the area of traumatic brain injury, no restrictions were set to limit the year of publication.	
Literature Review 3- Readmissions among Traumatic Brain Injury Patients	
Database	**Search terms**
MEDLINE	Brain Injuries, Traumatic; Patient Readmission
PsychINFO	Traumatic Brain Injury; Hospital Admission, "Quality of Care"; Readmissions
EMBASE	Traumatic Brain Injury; Hospital Readmission
Filters	
English language; adults; human *Note: Due to the relative lack of research on readmissions among persons with traumatic brain injury, no restrictions were set to limit the year of publication.	

Appendix B

Table B1
Administrative databases accessed for this thesis from ICES.

Administrative Database	Definition
Ontario Health Insurance Plan (OHIP)	Contains claims data for health services provided by physicians to Ontario residents
Canadian Institute for Health Information Discharge Abstract Database (CIHI-DAD)	Contains patient demographic characteristics, and institutional administrative and clinical data for inpatient hospital discharges
Same Day Surgery (SDS)	Contains information related to day surgery visits
National Ambulatory Care Reporting System (NACRS)	Contains data on all hospital- and community-based ambulatory care including emergency department visits
Ontario Mental Health Reporting System (OMHRS)	Contains detailed demographic, administrative, and clinical data about adults admitted to Ontario mental health hospitals
Registered Persons Database (RPDB)	Contains demographic information on all individuals eligible for OHIP and is the database through which all other ICES databases are linked
Population of Canada (POPCAN)	Contains inter-censal estimates of the Canadian population
Ontario Marginalization index (ON-Marg)	Combines demographic indicators to provide multi-faceted estimates of marginalization of Ontario residents
Client Agency Program Enrollment (CAPE)	Contains information on patients registered with a primary care organization
Corporate Provider Database (CPDB)	Contains information on individual health care providers and organizations
Estimated Schedule of Benefits (ESTSOB)	Contains information on the price associated with OHIP claims
Institutions (INST)	Contains information on health care institutions in Ontario funded by the Ministry of Health and Long-Term Care
ICES Physician Database (IPDB)	Contains information on physicians practicing in Ontario

Table B2
Administrative health databases used to identify persons with intellectual and developmental disabilities.

Administrative Health Database	Year of Inception	Codes to Identify IDD	Criteria
Ontario Health Insurance Plan (OHIP)	1991	• dx code 299 • Or dx code 319	• For all providers (including not medical physicians) submitting to OHIP • From database inception to March 31, 2017 • Include only individuals with ≥ 2 physician visits in OHIP with an IDD code
Ontario Mental Health Reporting System (OMHRS)	2005	• Q3 = 1 • Or Q2a, Q2b, Q2c, Q2d, Q2e, Q2f in 299:, 317:, 318:, or 319: • Or l11h-l11m = any diagnosis of Qxxx as listed in Appendix B, Table B3	• For all facilities submitting to OMHRS • From database inception to March 31, 2017
Discharge Abstract Database (DAD)	1988	• Discharges with any diagnosis listed in Appendix B, Table B3	• In any diagnostic field • For all facilities submitting to DAD, SDS, and NACRS • From database inception to March 31, 2017
Same Day Surgery (SDS)	1991		
National Ambulatory Care Reporting System (NACRS)	2002		

Table B3
International Classification of Diseases, 10th edition Codes for Identifying Intellectual and Developmental Disabilities.

Code	Label
ICD-9	
299-299.99	Pervasive developmental disorders
317-317.99	Mental Retardation
318-318.99	Mental Retardation
319-319.99	Mental Retardation
758.0-758.39	Chromosomal anomalies for which a developmental disability is typically present
758.8-758.89	Other conditions due to chromosome anomalies (do not include 758.81)
758.9	Conditions due to anomaly of unspecified chromosome
759.5	Tuberous sclerosis
759.81	Other and unspecified congenital anomalies: Prader-Willi syndrome
759.821	Other and unspecified congenital anomalies: de Lange syndrome
759.827	Other and unspecified congenital anomalies: Seckel syndrome
759.828	Other and unspecified congenital anomalies: Smith-Lemli-Opitz syndrome
759.83	Other and unspecified congenital anomalies: Fragile X syndrome
759.874	Other and unspecified congenital anomalies: Beckwith-Wiedemann syndrome
759.875	Other and unspecified congenital anomalies: Zellweger syndrome
759.89	Other and unspecified congenital anomalies: other
760.71	Fetal alcohol syndrome
760.77	Fetal hydantoin syndrome
ICD-10	
F700	Mild mental retardation with the statement of no, or minimal, impairment of behaviour
F701	Mild mental retardation, significant impairment of behaviour requiring attention or treatment
F708	Mild mental retardation, other impairments of behaviour
F709	Mild mental retardation without mention of impairment of behaviour
F710	Moderate mental retardation with the statement of no, or minimal, impairment of behaviour
F711	Moderate mental retardation, significant impairment of behaviour requiring attention or treatment
F718	Moderate mental retardation, other impairments of behaviour
F719	Moderate mental retardation without mention of impairment of behaviour
F720	Severe mental retardation with the statement of no, or minimal, impairment of behaviour

F721	Severe mental retardation, significant impairment of behaviour requiring attention or treatment
F728	Severe mental retardation, other impairments of behaviour
F729	Severe mental retardation without mention of impairment of behaviour
F730	Profound mental retardation with the statement of no, or minimal, impairment of behaviour
F731	Profound mental retardation, significant impairment of behaviour requiring attention or treatment
F738	Profound mental retardation, other impairments of behaviour
F739	Profound mental retardation without mention of impairment of behaviour
F780	Other mental retardation with the statement of no, or minimal, impairment of behaviour
F781	Other mental retardation, significant impairment of behaviour requiring attention or treatment
F788	Other mental retardation, other impairments of behaviour
F789	Other mental retardation without mention of impairment of behaviour
F790	Unspecified mental retardation with the statement of no, or minimal, impairment of behaviour
F791	Unspecified mental retardation, significant impairment of behaviour requiring attention or treatment
F798	Unspecified mental retardation, other impairments of behaviour
F799	Unspecified mental retardation without mention of impairment of behaviour
F840	Childhood autism
F841	Atypical autism
F843	Other childhood disintegrative disorder
F844	Overactive disorder associated with mental retardation and stereotyped movements
F845	Asperger's syndrome
F848	Other pervasive developmental disorders
F849	Pervasive development disorder, unspecified
Q851	Tuberous sclerosis
Q860	Fetal alcohol syndrome
Q861	Fetal hydantoin syndrome
Q871	Aarskog, Prader-Willi, deLange, Seckel, etc.
Q8723	Rubinstein-Taybi syndrome
Q8731	Sotos syndrome
Q878	Other
Q900-Q939 except Q926	All Down syndrome types
Q971	Female with more than three X chromosomes
Q992	Fragile X syndrome
Q998	Other specified chromosome abnormalities

Table B4
International Classification of Diseases, 10th edition Codes for Identifying Traumatic Brain Injury.

Code	Label
ICD-9	
310.2[a]	Postconcussional syndrome
800.1	Closed fracture of vault of skull with cerebral laceration and contusion
800.3	Closed fracture of vault of skull with other and unspecified intracranial hemorrhage
801.1	Closed fracture of base of skull with cerebral laceration and contusion
801.3	Closed fracture of base of skull with other and unspecifies intracranial hemorrhage
802.6	Closed fracture of orbital floor (blow-out)
802.7	Open fracture of orbital floor (blow-out)
803.1	Other closed skull fracture with cerebral laceration and contusion
803.3	Closed skull fracture with other and unspecifies intracranial hemorrhage
804.1	Closed fractures involving skull or face with other bones with cerebral laceration and contusion
804.3	Closed fractures involving skull or face with other bones, with other and unspecified intracranial hemorrhage
850	Concussion
851	Cerebral laceration and contusion
852	Subarachnoid, subdural, extradural hemorrhage, following injury
853	Other and unspecified intracranial hemorrhage following injury
854	Intracranial injury of other and unspecifies nature
925	Crushing injury of face scalp and neck
853	Other and unspecified intracranial hemorrhage following injury
854	Intracranial injury of other and unspecified nature
907.0[a]	Late effect of intracranial injury without mention of skull fracture
907.1[a]	Late effect of injury to cranial nerve
925	Crushing injury of face scalp and neck
950.1-950.3	Injury to optic nerve and pathways
ICD-10	
F07.2[a]	Postconcussional syndrome
S02.0	Fracture of vault of skull
S02.1	Fracture of base of skull
S02.3	Fracture of orbital floor
S02.7	Multiple fractures involving skull and facial bones
S02.8	Fractures of other skull and facial bones
S02.9	Fracture of skull and facial bones, part unspecified
S04.0	Injury to optic nerve and pathways
S06	Intracranial injury
S07	Crushing injury of skull

T02.0	Fractures involving head with neck
T06.0	Injuries of brain and cranial nerves with injuries of nerves and spinal cord at neck level
T90.2[a]	Sequelae of fracture of skull and facial bones
T90.5[a]	Sequelae of intracranial injury

[a] : Used only for identifying history of traumatic brain injury (Manuscript 2), not new TBI cases (Manuscript 1)