Hospitalizations for Ambulatory Care Sensitive Conditions Among Persons with an Intellectual Disability, Manitoba, 1999-2003

by

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A thesis submitted in conformity with the requirements for the degree of Doctor of Philosophy
Graduate Department of Rehabilitation Science
University of Toronto

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Abstract

This thesis examines hospitalizations for ambulatory care sensitive conditions among persons with an intellectual disability living in Manitoba from 1999 to 2003. Hospitalizations for ambulatory care sensitive conditions are considered an indicator of access to, and the quality of, primary care. Intellectual disability can be defined as a disability originating before age 18 characterized by significant limitations both in intellectual functioning and in adaptive behaviour as expressed in conceptual, social, and practical adaptive skills. Between 1 and 3% of the population has an intellectual disability. This thesis addressed three objectives: 1) To identify ambulatory care sensitive conditions that are applicable to persons with an intellectual disability; 2) To compare hospitalization rates for ambulatory care sensitive conditions between persons with and without an intellectual disability in Manitoba; 3) To identify factors associated with hospitalizations for ambulatory care sensitive conditions among adults with an intellectual disability living in Manitoba. An online survey of primary care providers with experience working with persons with an intellectual disability found consensus on fifteen ambulatory care sensitive conditions applicable to persons with an intellectual disability. Large discrepancies in hospitalization rates for these conditions were found between persons with and without an intellectual disability. Controlling for age, year, sex, and region, persons with an intellectual disability...
disability were 6 times more likely to be hospitalized for an ambulatory care sensitive condition. Future research should investigate reasons for the large discrepancy in rates between persons with and without an intellectual disability. Among adults with an intellectual disability, living in a rural area (odds ratio 1.3; 95% CI=1.0, 1.8), living in an area with a high proportion of First Nations people (odds ratio 2.3; 95% CI=1.3, 4.1), and experiencing higher levels of comorbidity (odds ratio 25.2; 95% CI=11.9, 53.0) were all associated with a higher likelihood of being hospitalized for an ambulatory care sensitive condition. Dwelling in higher income areas had a protective effect (odds ratio 0.56; CI=0.37, 0.85). The results suggest that addressing the socioeconomic problems of poorer areas and specifically areas densely populated by First Nations people would likely have an impact on hospitalizations for ACS conditions for persons with an intellectual disability.
Acknowledgments

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# Table of Contents

Abstract ........................................................................................................................................... ii  
Acknowledgments.......................................................................................................................... iv  
Table of Contents ........................................................................................................................... vi  
List of Tables ................................................................................................................................. ix  
List of Figures ................................................................................................................................. x  
List of Appendices ......................................................................................................................... xi  
List of Acronyms .......................................................................................................................... xii  

Chapter 1: Background, rationale and thesis structure ................................................................. 1  
  1.1 Introduction ....................................................................................................................... 1  
  1.2 Definition of intellectual disability ................................................................................... 1  
  1.3 Prevalence ......................................................................................................................... 3  
  1.4 Etiology ............................................................................................................................. 4  
  1.5 Disparities in mortality and morbidity .............................................................................. 5  
  1.6 Conceptual and policy perspectives .................................................................................. 7  
  1.7 Primary care and ambulatory care sensitive conditions .................................................. 10  
    1.7.1 Ambulatory care sensitive conditions and intellectual disability ............................ 13  
  1.8 Objectives and rationale .................................................................................................. 15  
  1.9 Thesis organization ......................................................................................................... 18  

Chapter 2: Ambulatory care sensitive conditions in persons with an intellectual disability –  
Development of a consensus ......................................................................................................... 20  
  2.1 Abstract ........................................................................................................................... 21  
  2.2 Introduction ..................................................................................................................... 22  
  2.3 Methods ........................................................................................................................... 24  
    2.3.1 Participants and Recruitment ................................................................................... 24  
    2.3.2 Questionnaire Development and Analysis ............................................................... 25  
    2.3.3 Criteria for inclusion ................................................................................................ 26  
    2.3.4 Other questions ........................................................................................................ 27  
  2.4 Results ............................................................................................................................. 28  
    2.4.1 Response rate and participant characteristics .......................................................... 28  
    2.4.2 Conditions meeting criteria ...................................................................................... 28  
    2.4.3 Responses to other questions ................................................................................... 32  
  2.5 Discussion ....................................................................................................................... 35  
    2.5.1 Strengths .................................................................................................................. 36  
    2.5.2 Limitations ............................................................................................................... 38  
  2.6 Conclusion ...................................................................................................................... 40  

Chapter 3: Hospitalization rates for ambulatory care sensitive conditions for persons with and  
without an intellectual disability-a population perspective .......................................................... 41  
  3.1 Abstract ........................................................................................................................... 42
Chapter 4: Factors associated with hospitalizations for ambulatory care sensitive conditions among persons with an intellectual disability—a publicly insured population perspective

4.1 Abstract .......................................................................................................................... 80
4.2 Introduction ...................................................................................................................... 81
4.3 Methods ........................................................................................................................... 84
  4.3.1 Study design ............................................................................................................... 84
  4.3.2 Study population ......................................................................................................... 85
  4.3.3 Data source and management .................................................................................... 85
  4.3.4 Dependent variable .................................................................................................. 86
  4.3.5 Independent variables .............................................................................................. 87
    4.3.5.1 Predisposing ...................................................................................................... 87
    4.3.5.2 Enabling ............................................................................................................ 88
    4.3.5.3 Need .................................................................................................................. 90
    4.3.5.4 Health care system resources ............................................................................ 92
  4.3.6 Exclusions .................................................................................................................. 93
  4.3.7 Analysis ...................................................................................................................... 93
4.4 Results ............................................................................................................................. 95
  4.4.1 Descriptive statistics and bivariate results ................................................................. 95
  4.4.2 Multivariate regression analysis ................................................................................. 98
  4.4.2.1 Evaluation of spuriousness ............................................................................... 100
4.5 Discussion ....................................................................................................................... 100
  4.5.1 Summary of main results ....................................................................................... 100

vii
4.5.2 Interpretation of results in context of prior research .............................................. 101
4.5.3 Strengths and limitations ...................................................................................... 104
4.6 Conclusions .............................................................................................................. 107
   4.6.1 Policy and research implications ...................................................................... 107

Chapter 5: Summary and general discussion ................................................................. 111
   5.1 Introduction ............................................................................................................ 111
   5.2 Summary of results ............................................................................................... 111
   5.3 Contributions ........................................................................................................ 113
      5.3.1 A Canadian perspective .................................................................................. 113
      5.3.2 Theoretical considerations ............................................................................. 114
      5.3.3 The use of administrative databases .............................................................. 115
      5.3.4 First Nations people and advocacy efforts ..................................................... 116
      5.3.5 Relevance to rehabilitation .......................................................................... 119
      5.3.5 Future research ............................................................................................. 121
   5.4 Ambulatory care sensitive conditions .................................................................... 122
   5.5 Concluding Remarks ............................................................................................ 125

References ..................................................................................................................... 126

Appendices ..................................................................................................................... 148
List of Tables

Table 2.1. Original list of ambulatory care sensitive conditions and inclusion criteria values after round 1 of the questionnaire ................................................................. 29

Table 2.2. List of ambulatory care sensitive conditions suggested by participants and inclusion criteria values after the round 2 questionnaire ..................................................... 31

Table 2.3. Perceived agreement on clinical criteria for hospital admissions (Results from round 1 and 2 of questionnaire) ........................................................................................................ 33

Table 2.4. Final and admission criteria restricted list of ambulatory care sensitive conditions ... 34

Table 3.1. Rate comparisons for ambulatory care sensitive condition hospitalizations between persons with and without an intellectual disability, by calendar year (1999-2003), Manitoba .... 59

Table 3.2. Rate comparisons for ambulatory care sensitive condition hospitalizations between persons with and without an intellectual disability, by age, Manitoba ............................................. 60

Table 3.3. Rate comparisons for ambulatory care sensitive condition hospitalizations between persons with and without an intellectual disability, by urban/rural region, Manitoba ................. 61

Table 3.4. Most common ambulatory care sensitive condition hospitalizations, among persons with and without an intellectual disability, Manitoba, 5 calendar years (1999-2003) ............ 62

Table 3.5. Hospitalization rate comparisons for specific ambulatory care sensitive conditions between persons with and without an intellectual disability, Manitoba, 5 calendar years (1999-2003) ................................................................. 64

Table 3.6. Rate ratios for asthma and diabetes adjusted for prevalence of disease between persons with and without an intellectual disability, Manitoba, 5 calendar years (1999-2003) .... 65

Table 4.1. Descriptive statistics and bivariate results for variables in relation to ambulatory care sensitive condition hospitalizations, person-90-day periods of adults with an intellectual disability living in Manitoba, 1999-2003 (n=55 449) .............................................................................. 97

Table 4.2. Multivariate regression model of the odds of being hospitalized for an ambulatory care sensitive condition: Adults with an intellectual disability, Manitoba, 1999-2003 (n=55 449). ........................................................................................................................................................................ 99
List of Figures

Figure 3.1. Age and gender distribution of population of Manitoba with and without an intellectual disability, 1999........................................................................................................... 56

Figure 3.2. Age and gender distribution of population of Manitoba with and without an intellectual disability, 2003........................................................................................................... 57
List of Appendices

Appendix A: Introductory email, internet survey information, and consent e-mail for potential participants ......................................................... 148

Appendix B: Follow up e-mail for non-responders ......................................................... 151

Appendix C: Invitation to second round version of questionnaire ................................. 153

Appendix D: Blank questionnaire (round 1) ................................................................. 156

Appendix E: Blank questionnaire (round 2) ................................................................. 161

Appendix F: Manitoba population health research data repository ............................ 165

Appendix G: List of ICD-9 codes used to identify persons with an intellectual disability from hospital and physician records ................................................. 167

Appendix H: List of included ambulatory care sensitive conditions ............................... 169

Appendix I: Age and gender distribution of Manitobans, 1999 and 2003 ...................... 171

Appendix J: Hospitalization rate comparisons by year and age group ......................... 173

Appendix K: Hospitalization rate comparisons by year and region ............................... 176

Appendix L: Summary of variables using Andersen Behavioural Model of Health Service Use ...................................................................................... 178

Appendix M: Map of regional health authorities of Manitoba ....................................... 181
List of Acronyms

AAIDD: American Association on Intellectual and Developmental Disability
ACS: Ambulatory care sensitive
ICD-9: International Classification of Diseases, 9th revision
ID: Intellectual disability
MCHP: Manitoba Centre for Health Policy
Chapter 1: Background, rationale and thesis structure

1.1 Introduction

This chapter provides background literature including definitions of relevant terms in order to provide context for the thesis. The chapter concludes with the rationale, objectives, and organization of the thesis.

1.2 Definition of intellectual disability


Intellectual disability is a disability characterized by significant limitations both in intellectual functioning and in adaptive behavior, which covers many everyday social and practical skills. This disability originates before the age of 18.

An intelligence quotient of approximately 70 or below using a standardized measure is commonly used as a criterion for intellectual functioning (Schalock et al., 2007).

Adaptive functioning is also evaluated using standardized measures for which two standard deviations below the mean is used as a cut-off criteria. While ‘intellectual disability’ is gaining wide acceptance to describe this population, globally the term ‘mental retardation’ is still commonly used while ‘learning disability’ is used in the United Kingdom (Ouellette-Kuntz et al., 2005; World Health Organization, 2007).

The way intellectual disability is defined has implications for service provision and research. The term and its definition can be used to help identify and therefore to assist people who have special needs (World Health Organization, 2007; Brown, 2007). Using
a definition makes it possible for service funders and providers to identify persons who are in need and determine their eligibility for services. Consistent with this purpose, the American Association on Intellectual and Developmental Disabilities have suggested that once persons with an intellectual disability have been identified, additional assessments should be performed to evaluate the specific supports required by the individual in order to enhance and improve functioning (Buntinx, 2006). The definition is also important to researchers who need to be able to classify different disabilities in order to distinguish between them. A clear definition makes it possible for researchers to communicate their findings and to explain about whom their results apply.

The intelligence quotient and adaptive functioning test cutoffs used for identifying persons with an intellectual disability can have negative implications for persons characterized as having a mild intellectual disability (MacMillan et al., 2006). People with a mild intellectual disability have intellectual and behavioural manifestations that are less apparent than those of their more severely affected counterparts. They are sometimes referred to as people with an invisible disability. It has been found that this population has been made vulnerable by their exclusion from services and support systems that are available to formally diagnosed persons with an intellectual disability (Scheepers et al., 2005). The arbitrary nature of the IQ and adaptive functioning cutoffs has been criticized and some have advocated that persons with a mild intellectual disability should be treated as a distinct subgroup in order to more properly target their needs (MacMillan et al., 2006).
1.3 Prevalence

An important distinction between ‘true’ and ‘administrative’ prevalence is made by researchers in the area of intellectual disability. Administrative prevalence is the number of cases that have been recorded by government for the purpose of social and health service planning and administration. The administrative prevalence may underestimate the true prevalence of intellectual disability which is defined as the total number of persons in a population regardless of whether or not they require or receive services. By using multiple administrative sources, countries that provide many services for persons with an intellectual disability have found that the administrative prevalence closely approximates the true prevalence (Westerinen et al., 2007; Yeargin-Allsopp et al., 1992).

The definition as described by the AAIDD sets an intelligence quotient of 70 or below which, statistically, means that about 2.3 percent of an entire population will fit this definition. Prevalence estimates from studies conducted in developed countries have ranged between 0.7 and 3% (Ouellette-Kuntz & Paquette, 2001; Roeleveld et al., 1997; Westerinen et al., 2007; Wullink et al., 2007). The discrepancy is attributed to variations in classification systems and the diversity of operational definitions and methodologies (Leonard & Wen, 2002). For instance, by applying the AAIDD’s additional criterion for adaptive behaviour, researchers believe the prevalence is probably nearer to 1% (Whitaker, 2004). Recent rigorous research from Finland and the Netherlands reported prevalence estimates of .7% approximating results from previous research in those countries (Westerinen et al., 2007; Wullink et al., 2007).
Research from Australia and the United Kingdom has shown higher prevalence of persons with an intellectual disability among the socially disadvantaged. In Australia 17% of children with a mild or moderate intellectual disability were born into the most socioeconomically disadvantaged portion of the population, while only 8% of children without an intellectual disability were born into the same disadvantaged group (Leonard et al., 2005). Emerson found that children with an intellectual disability were more likely to be living in poverty compared to children without an intellectual disability (48% vs. 31%) (Emerson & Hatton, 2007). The influence of living in poverty is well documented for the general population, but there is little research on the topic for persons with an intellectual disability and none originates from Canada (Emerson & Hatton, 2007).

1.4 Etiology

Several clinical series have been published on the etiology of intellectual disability. An attempt is made to summarize their findings, although difficulties arise due to differences in subject disability severity, methods used to select participants, and the lack of a universally accepted and reliable etiological classification system. Studies report that the cause of intellectual disability can be identified in approximately 40-60% of cases (Curry et al., 1997). One study found that approximately 55% can be attributed to genetics (Hou et al., 1998) of which Down syndrome (10-20%), Fragile X syndrome (2%) and Prader Willi syndrome (1%) are the most common (Hou et al., 1998; Leonard & Wen, 2002). Causes of intellectual disability can also be classified according to disorders occurring during the prenatal, perinatal or postnatal periods (Leonard & Wen, 2002). Fetal alcohol syndrome is an example of a prenatal etiology and is reported in approximately 2% of
persons with an intellectual disability. There is evidence that intellectual disability is more common in children in developing countries due to more frequent injuries at birth, childhood brain infections, and iodine deficiency (Roeleveld et al., 1997; World Health Organization, 2001b).

1.5 Disparities in mortality and morbidity

A health disparity can be defined as population-specific differences in health indicators (Ouellette-Kuntz et al., 2005). Among persons with an intellectual disability, health disparities are commonly quantified by comparing health indicators between persons with and persons without an intellectual disability (or the general population) (Krahn et al., 2006). Research has shown that persons with an intellectual disability experience disparities in life expectancy and morbidity when compared to the general population.

The life expectancy of persons with an intellectual disability has increased over the recent decades, but it is still lower than the general population’s. This is seen dramatically in population based research from the United States, where the median age at death for persons with Down syndrome increased from 26 years in 1983 to 49 years in 1997, while in the general population the median age increased from 73 years to 76 years (Yang et al., 2002). Congenital heart defects are very common among persons with Down syndrome and their increased life expectancy is in large part attributed to improvements in early diagnostic and surgical techniques for these conditions (Frid et al., 1999). In Finland, according to a population based prospective cohort study, the mean age at death for all persons with an intellectual disability born in 1962 was 59.3 for women and 56.0 for men.
These values are lower than the general Finnish population’s (women 71.4, men 64.8) (United Nations, 2006). Studies consistently find that the most common causes of death for persons with an intellectual disability are from respiratory, cardiovascular, and gastrointestinal diseases, neoplasms, and external causes (e.g. accidents and poisonings) (Durvasula et al., 2002; Patja et al., 2001). Cause of death from respiratory conditions is higher in this population compared to the general population which can in part be explained by more common swallowing problems leading to aspiration pneumonia (Sullivan et al., 2006).

Disparities in morbidity are also apparent. A Dutch study found that the prevalence for all health problems was 2.5 times higher for persons with an intellectual disability compared to those without (Van Schrojenstein Lantman-de Valk et al., 1997). The rate for mental health problems alone was 3.5 times higher for persons with an intellectual disability. Although results vary according to methodology, a recent population based study from Scotland found that 41% of adult persons with an intellectual disability also experienced mental ill-health of some type (Cooper et al., 2007). This co-occurrence of intellectual disability and mental health problems is referred to as a ‘dual diagnosis’. Reviews have identified other conditions consistently documented at high rates in persons with an intellectual disability (Beange, 2002; Fisher, 2004; Ouellette-Kuntz et al., 2005). These include: epilepsy, fractures, skin conditions, poor oral health, neurological disorders, movement disorders, respiratory disorders, gastrointestinal disorders, and sensory disorders. According to Krahn, medical conditions (e.g. Down Syndrome) that are regarded as having led to the impairment in intellectual functioning should be referred
to as the associated condition (Krahn et al., 2006). Importantly, not all comorbid conditions experienced by persons with an intellectual disability are due to the associated condition. Diagnostic overshadowing occurs when a health professional or care giver wrongly interprets the symptoms and signs of ill health as an aspect of the associated condition (Alborz et al., 2005; Ouellette-Kuntz, 2005).

The increased life expectancy combined with the ageing baby boom generation means that the number of older persons with an intellectual disability will increase significantly in the coming years (Bigby, 2002). This means that persons with an intellectual disability are increasingly experiencing age-related health concerns (Kapell et al., 1998). Some of the associated conditions for intellectual disability have led to increased risk for early development of age related diseases. An example is the early onset of visual and hearing disorders and Alzheimer’s disease among persons with Down Syndrome (World Health Organization, 2001a). On the other hand, because of the ‘healthy survivor’ effect, many of the older adults with an intellectual disability tend to have fewer activity limitations and be in better health than is the case for children with an intellectual disability (Hogg et al., 2001). Various studies have found that in later life there is a convergence in terms of health, health care, and social care needs between people with and without an intellectual disability (Holland, 2000).

1.6 Conceptual and policy perspectives

The way intellectual disability has been conceptualized over the years has influenced the health status and quality of life of persons with this disability. Since the 1970s many
developed countries have enacted legislation that led to the deinstitutionalization of persons with an intellectual disability (Mansell, 2005). Deinstitutionalization is the process of closing institutional facilities and placing their residents in more community based housing. It is based on the normalization principle which was first applied in Scandinavian countries and introduced to North America by Wolfensberg (Macdonald, 2002). According to the normalization principle, all individuals should be allowed the right to participate in activities common to similarly aged members of society (Buell, 1995). Up until 35 years ago, many persons with an intellectual disability living in Canada were housed in institutions where many of their social, education and health care needs were looked after. Primary care was readily available and provided by in-house physicians and nurses who understood the health needs of this population (Hennen, 2005). This system of services functioned independently of services provided for the general population and was consistent with the philosophy of the time which understood intellectual disability as a primarily medical problem (Buell, 1995; Macdonald, 2002). Unlike this medical understanding of disability, the social model of disability points to material constraints and barriers within society as the source of disability rather than a person’s impairment (Stalker et al., 1999). While not entirely compatible in their conceptualization of disability, the principle of normalization and the social model of disability are consistent in their emphasis away from the view of disability as disease.

Deinstitutionalization has been credited with improving the quality of life of persons with an intellectual disability (Macdonald, 2002); however, it has also meant that the many specialized health care needs of this population would need to be looked after by
community based health care services that were not necessarily well prepared through training or financial support (Lennox, 2002). In a study contrasting the quality of life of persons with an intellectual disability in the mid-western United States who moved from an institution to community living settings, improvements post deinstitutionalization were noted for all categories measured except access to health professionals (Conroy et al., 2003). Post deinstitutionalization, study participants reported greater difficulty in obtaining medical services and the study found a corresponding decrease in frequency of physician visits. A similar pattern was described in a study from Norway where visit frequency to general practitioners, psychiatrists, and psychologists decreased after deinstitutionalization despite increases in behaviour disturbances (Nottestad & Linaker, 1999).

In countries where deinstitutionalization has taken place, there have been ongoing debates about the best way to organize health services for persons with an intellectual disability (Alexander et al., 2002; Aspray et al., 1999; Hassiotis et al., 2000; O'Hara, 2000). In England, Community Learning Disability Teams were created to provide a diverse range of clinical services to meet, in a comprehensive way, the mental and physical health needs of persons with an intellectual disability (O'Hara, 2000). These have been criticized for frequently bypassing mainstream primary care services. Other jurisdictions relied more on the mainstream health care system but questions have been raised as to its adequacy (Lennox, 2002).
Canada and Australia, for example, are countries with comparable universal publicly funded health insurance who have relied on their mainstream health care system (Lennox et al., 1997; Sullivan et al., 2006). The assumption is that the universally accessible physician and hospital care made available without financial barriers to all Canadians and Australians should be adequate to meet the sometimes complex needs of persons with an intellectual disability living in the community. Research from Australia, however, has shown this not to be the case: An often quoted study from northern Sydney took a random sample of persons with an intellectual disability and found an increased number of chronic diseases that were frequently not recognized or, when diagnosed, not properly treated (Beange et al., 1995). In response local programs have been initiated that provide specialist consultation to support the mainstream health care services. For example, the Centre for Developmental Disability Health Victoria in Melbourne, Australia provides health care services support through general practice and psychiatry clinics and, in Toronto Canada, the Surrey Place Centre provides physician consultations in family medicine, paediatrics, neurology and psychiatry (Centre for Developmental Disability Health Victoria, 2007; Surrey Place Centre, 2009). It must be emphasized, however, that these programs are located in large cities and have not evolved to provide services beyond their jurisdictions.

1.7 Primary care and ambulatory care sensitive conditions

Although frequently used interchangeably, some health services researchers make distinctions between ‘primary health care’ and ‘primary care’ (Institute for Clinical Evaluative Sciences, 2006). They both represent different aspects of the development
and expression of the first point of entry into the health system (Saltman et al., 2006). Primary health care has a broader meaning that incorporates personal care with health promotion, the prevention of illness and community development (World Health Organization, 1978). Primary health care includes the principles of equity, access, empowerment, community self-determination and inter-sectoral collaboration. It encompasses an understanding of the social, economic, cultural and political determinants of health. Primary care is more clinically focused and can be seen as a component of the broader primary health care system (Institute for Clinical Evaluative Sciences, 2006). According to the Institute of Medicine (Institute of Medicine, 1996) primary care is the “provision of integrated, accessible health care services by clinicians who are accountable for addressing a large majority of personal health care needs, developing a sustained partnership with patients and practicing in the context of family and community” (p. 1).

Reviews have been conducted of studies that examine the adequacy of primary care among persons with an intellectual disability (Alborz et al., 2005; Larson et al., 2005; Lennox & Kerr, 1997). None of the included studies were from Canada. The reviews concluded that community dwelling persons with an intellectual disability have untreated, yet treatable, medical conditions despite receiving primary care. Studies from the United Kingdom, Australia and the United States reported frequently undiagnosed or untreated conditions that require ongoing management such as hypertension, diabetes, vision and hearing impairment, endocrine disease, skin disease, mental health disorders, seizure disorders, diseases of the teeth and gums, and many others (Alborz et al., 2005; Beange et
al., 1995; Janicki et al., 2002; Larson et al., 2005; Lennox & Kerr, 1997). Research has consistently found that persons with an intellectual disability experience lower rates of preventive and health promotion practices compared to the general population. For example, compared to groups without an intellectual disability, there is evidence of low utilization of cervical, breast, and prostate cancer screening; less uptake of immunization initiatives; and less frequent exercise (Durvasula et al., 2002; Havercamp et al., 2006; Larson et al., 2005). Tudor Hart’s inverse care law seems to apply: Those in most need of health promotion are least likely to receive it (Hart, 1971). Some authors have argued that the considerable challenges faced by providers when dealing with a presenting condition may mean that opportunities to undertake preventive care are being missed (Alborz et al., 2005; Lennox et al., 2000).

Research regarding frequency of visits by persons with an intellectual disability to a primary care provider is inconsistent. One review cited studies from the United States, Australia, and Wales and found that persons with an intellectual disability visit their primary care provider with at least the same regularity as the general population (Lennox & Kerr, 1997). Using studies from the United Kingdom, a more recent review concluded that, overall, persons with an intellectual disability accessed primary care providers less frequently than the general population (Alborz et al., 2005). The inconsistencies stress the importance of context specific research to identify needs among persons with an intellectual disability to help guide health care service planning.
The primary focus of this thesis is ambulatory care sensitive (ACS) conditions. Hospitalizations for ACS conditions are considered to be a measure of access to, and the quality of, primary care (Billings et al., 1993; Porter et al., 2007). Examples of ACS conditions include asthma, otitis media, congestive heart failure, and angina pectoris. The rationale is that proper primary care for certain conditions should delay the progression of the disease or prevent serious complications and thus prevent hospitalization. Not all hospitalizations for ACS conditions are avoidable but it is assumed that appropriate ambulatory care could prevent the onset of this type of illness or condition, control an acute episode, or manage a chronic disease or condition (Billings et al., 1993). Research has shown a relationship between high rates of ACS hospitalizations and problems with access to primary care (Caminal et al., 2004). Measuring primary care using ACS condition hospitalization rates has been applied to vulnerable populations (Armour et al., 2009; Carter & Porell, 2005; Epstein, 2001; Li et al., 2008) and may prove useful when making health service planning decisions for persons with an intellectual disability living in Canada.

1.7.1 Ambulatory care sensitive conditions and intellectual disability

A study from the Canadian province of Ontario found that persons with an intellectual disability were hospitalized for ACS conditions at higher rates than the general population (Balogh et al., 2005). Using a list of ACS conditions commonly applied for the general population, the study from Ontario found rates of hospitalization to be almost 3 times higher for persons with an intellectual disability compared to the general population. A recent study based in Montreal, Canada found no differences in ACS
condition hospitalizations between a sample of children with developmental delays (n=107) and a control group (Nachshen et al., 2009). The study from Montreal had a smaller sample size and included a heterogeneous group of children with disabilities which may account for the differences in results. No other study reporting on ACS conditions for persons with an intellectual disability could be found.

Other research has reported higher rates of ACS condition hospitalizations among other vulnerable populations such as persons with physical disabilities and mental illnesses (Armour et al., 2009; Li et al., 2008; Carter & Porell, 2005). A study from the United States analyzed data from people covered by employer-sponsored health insurance to compare rates of urinary tract infection between persons with spina bifida to those without (Armour et al., 2009). Hospitalizations for urinary tract infections were considered ambulatory care sensitive. There were 22.8 hospitalizations per 1000 persons with spina bifida over three years compared to only 0.44 hospitalizations per 1000 persons without spina bifida. No test statistic was provided. The authors identified many possible explanations for the large difference including underuse of preventive care; poor quality of ambulatory care; and overcautious admitting practices. The authors strongly endorsed the creation of practice guidelines to guide primary care clinicians. Another study found that nursing home residents with Alzheimer’s disease and related dementias were less likely to be hospitalized for an ACS condition in living situations with increased registered nurse staffing levels (p<0.0001) and where an on-site nurse practitioner was used (p<0.0001) (Carter & Porell, 2005). Lastly, a study from New York compared ACS condition hospitalizations between persons with and without mental
disorders (Li et al., 2008). After adjusting for other variables, persons with a mental illness were 2.3 (95% CI: 2.2, 2.4) times more likely to be hospitalized for an ACS condition than were persons without a mental illness. Similar to what would be recommended for persons with an intellectual disability, the authors of this study stressed the importance of better understanding and addressing the behavioural, attitudinal, financial and social barriers faced by these patients during outpatient care.

Studies from Taiwan and Australia have evaluated hospital utilization among persons with an intellectual disability. A study by Lin et al. used a cross-sectional survey among 1390 persons with an intellectual disability receiving services from day care centres in Taiwan (Lin et al., 2004). The authors found that persons less than 6 years of age, with an existing illness, and requiring rehabilitation were more likely to be hospitalized. Loh et al. studied persons with an intellectual disability cared for at a large disability institution in Taipei (Loh et al., 2007). Low income, living in the institution, having cerebral palsy, and high use of outpatient services were all associated with greater risk for hospitalization. A study from Western Australia reported a higher risk of hospitalization for children with an intellectual disability compared to non-affected individuals (Williams et al., 2005). The need for more research on the medical and social needs of this population was emphasized.

1.8 Objectives and rationale

1) To identify ambulatory care sensitive conditions that are applicable to persons with an intellectual disability living in Canada.
2) To compare hospitalization rates for ambulatory care sensitive conditions between persons with and without an intellectual disability in a publicly insured province of Canada.

3) To identify factors associated with hospitalizations for ambulatory care sensitive conditions among adults with an intellectual disability living in a publicly insured province of Canada.

The quality of health services and the health status of persons with an intellectual disability living in developed countries are summarized well in a report by the United States Secretary of Health and Human Services: Compared with the general population, adults with an intellectual disability experience poorer health and more difficulty in finding, getting to, and paying for appropriate health care (United States Public Health Service, 2001). A range of factors have been identified as possible barriers to effective primary care. Client level barriers include communication, behaviour and mobility problems; community level barriers include lack of physically accessible buildings, lack of transportation, and distance to health services; health care provider barriers include inadequate training and experience dealing with persons with an intellectual disability, unsupportive attitudes, inadequate number of providers, insufficient remuneration, and lack of time (Baxter & Kerr, 2002).

Problems with communication have been identified as one of the most significant barriers to primary care provision for persons with an intellectual disability (Lennox & Kerr, 1997). To varying degrees, almost all persons with an intellectual disability experience problems with communication which influences the process of assessment, diagnosis and management in primary care. A complete history is considered key to a consultation and,
according to a survey of general practitioners in Australia, difficulties in obtaining such a history significantly affected the quality of care provided to persons with an intellectual disability (Lennox et al., 1997). Partly because of communication problems, persons with an intellectual disability are reliant on others (e.g. family or service workers) to facilitate their health care; unfortunately, workers or family members may find it difficult to identify health problems. Difficulties in identifying symptoms early in the disease process may mean that opportunities for early management or prevention may be missed leading to potentially avoidable health service use including hospitalizations.

A Canadian review of research on disparities in health and health services has been published but was based almost exclusively on results from international findings (Ouellette-Kuntz et al., 2005). In an editorial for the Canadian Family Physician, Lennox describes how, unlike other groups with significant unmet health care needs, the situation of persons with an intellectual disability receives virtually no attention in the medical literature (Lennox, 2006). There is a need for Canadian based research on the adequacy of primary care for persons with an intellectual disability. This will make it possible for governments, health care administrators, primary care providers and service users to make decisions based on evidence from a Canadian context.

The overall objective of this thesis was to describe rates of hospitalizations for ACS conditions applicable to persons with an intellectual disability living in Manitoba. Evidence of a higher ACS condition hospitalization rate among persons with an intellectual disability in the province of Manitoba should be cause for concern for policy
makers, health care administrators and providers. The results provide important
information on the adequacy of health services for persons with an intellectual disability
living in Canada and provide insight on whether this population is receiving the health
care they are entitled to.

1.9 Thesis organization

This thesis uses the manuscript format consistent with requirements of the Graduate
Department of Rehabilitation Science and the School of Graduate Studies at the
University of Toronto. Chapters 2, 3, and 4 of the thesis address each of the objectives
and stand alone as manuscripts that are about to be submitted for journal publication.
Given this organization, the reader will find instances of repetition and differences in
formatting between chapters.

Chapter 2: A version of this first manuscript is being prepared for possible publication
in the Journal of Applied Research in Intellectual Disabilities. It addresses the first
objective and provides the introduction, method, results and discussion of an online
survey questionnaire distributed to primary care providers.

Chapter 3: Using the list of ACS conditions developed in Chapter 2, this second
manuscript deals with the second objective. It is also being prepared for submission to
the Journal of Applied Research in Intellectual Disabilities. It compares rates of ACS
condition hospitalizations between persons with and without an intellectual disability.
The manuscript describes in detail the methods used to obtain data on Manitobans with
an intellectual disability from administrative databases maintained at the University of Manitoba.

**Chapter 4:** Again using the list from Chapter 2, this last manuscript identifies factors associated with ACS condition hospitalizations among persons with an intellectual disability living in Manitoba (objective 3). Unlike chapter 3, this manuscript includes data from adults only. A version of this manuscript will be submitted to the Journal of Intellectual Disability Research.

**Chapter 5:** The last chapter of the thesis provides a summary of results and a general discussion.
Chapter 2: Ambulatory care sensitive conditions in persons with an intellectual disability – Development of a consensus

This chapter is a longer version of a manuscript that will be submitted for publication to the Journal of Applied Research in Intellectual Disabilities:

2.1 Abstract

Objective: To identify ambulatory care sensitive conditions that are applicable to persons with an intellectual disability living in Canada.

Design: Modified Delphi process using a web based questionnaire survey

Setting: Primarily Canada

Participants: 11 participants out of a potential 19. The participants were clinicians with experience in primary care for persons with an intellectual disability

Main Outcome Measures: Potential ambulatory care sensitive conditions were evaluated based on three criteria. To be included in the final list of ambulatory care sensitive conditions applicable to persons with an intellectual disability, a condition needed to be: 1) frequent (at least 1 out of every 10 000 hospitalizations), 2) clearly defined, and 3) have face validity as evaluated by the study participants.

Results: All the conditions that were considered ambulatory care sensitive for the general population met the three inclusion criteria. Study participants suggested five other conditions of which four met the criteria: constipation, gastroesophageal reflux, epilepsy, and schizophrenic disorders. Consensus was achieved after only one round of the Delphi process.

Conclusions: There is a very high degree of agreement as to what constitutes an ambulatory care sensitive condition for persons with an intellectual disability in Canada. The final list has the potential to be used with other populations with cognitive disabilities and in countries other than Canada.


2.2 Introduction

Hospitalization rates for ambulatory care sensitive (ACS) conditions are considered to be a measure of access to, and quality of, primary care in a given community or for a given group of patients (Porter et al., 2007). Examples of ACS conditions include asthma, congestive heart failure, epilepsy and diabetes. The rationale is that proper primary care for such conditions should delay the progression of the disease or prevent serious complications and thus prevent hospitalization. Not all hospitalizations for ACS conditions are avoidable but it is assumed that appropriate primary care could prevent the onset of this type of illness or condition, control an acute episode, or manage a chronic disease or condition (Billings et al., 1993). Research from Europe and the United States has shown a relationship between high rates of ACS condition hospitalizations and problems with access to primary care (Caminal et al., 2004; Ansari et al., 2006; Bindman et al., 1995). Measuring primary care access using ACS condition hospitalization rates has been applied to vulnerable populations (Armour et al., 2009; Carter & Porell, 2005; Li et al., 2008) and may prove useful when making health service planning decisions for persons with an intellectual disability living in Canada.

Intellectual disability originates before age 18 and is characterized by significant limitations in intellectual functioning and adaptive behaviour (American Association on Intellectual and Developmental Disabilities, 2009). Approximately 1% of the Canadian population has an intellectual disability (Ouellette-Kuntz & Paquette, 2001; Bradley et al., 2002). The United States Secretary of Health and Human Services has concluded that, compared with the general population, adults with an intellectual disability experience
poorer health and more difficulty in finding, getting to, and paying for appropriate health care (United States Public Health Service, 2001). There is very little Canadian research in the area. One Ontario based study found that persons with an intellectual disability were hospitalized for an ACS condition at a rate of 1018 per 100 000 population or almost three times higher than the rate for the general population (Balogh et al., 2005). This study used a definition of ACS conditions provided by the Canadian Institute for Health Information (Canadian Institute for Health Information, 2001); however, it is unknown which, if any, ACS conditions used for the general population are applicable to persons with an intellectual disability.

Brown (Brown, 2001) advocates for the development of ACS conditions that are specific to persons with disabilities. Prior to this research, such a list did not exist for persons with an intellectual disability. The list could be used by researchers and health care planners to evaluate the adequacy of primary care access for this population in various jurisdictions across the country. Before using ACS conditions for such purposes, past research has considered the selection of appropriate conditions one of the most important parts of the methodology and recommended that a list of ACS conditions be adapted to the context of each study population (Caminal et al., 2004).

The primary objective of this study was to identify ACS conditions that are applicable to persons with an intellectual disability living in Canada.
2.3 Methods

This study employed a modified Delphi consensus process to distribute a survey questionnaire with both closed and open ended questions. An original list of ACS conditions, deemed potentially applicable to persons with an intellectual disability living in Canada, was put together from health literature dealing with the general population. A group of experts in the field of primary care for persons with an intellectual disability was recruited to make judgments on the suitability of the identified ACS conditions and to suggest additional conditions. The process consisted of responses to two rounds of an online questionnaire. A final list of ACS conditions was selected based on the results from the consensus process and the application of three criteria: frequency, clarity and face validity. Approval to conduct this study was obtained from the Research Ethics Board at the University of Toronto.

2.3.1 Participants and Recruitment

The experts were identified through contacts made at international conferences and meetings on health care for persons with an intellectual disability and a colloquium held in Toronto in November 2005. The colloquium brought together academics, clinicians and administrators recognized for their expertise and experience in health care for persons with an intellectual disability (Sullivan et al., 2006). An e-mail was sent to 19 potential participants describing the intent of the study and included a link to the online questionnaire (see appendix A). All potential participants were clinicians with primary care experience working with persons with an intellectual disability.
If there was no response after one week, the potential participant was sent a follow up e-mail to encourage participation (see appendix B). No further contact was attempted after this second e-mail. Responses to the first round of the questionnaire were summarized and hard copies of the results were sent to the participants. Six weeks after the initial recruitment, invitations to fill out the second round version of the online questionnaire were sent out (see appendix C). After a week, a reminder e-mail was sent to persons who did not respond to the second round questionnaire. The questionnaire was created and the responses were collected using survey monkey, an online survey tool.

2.3.2 Questionnaire Development and Analysis

Most of the ACS conditions used in the questionnaire came from a list developed and validated for the Canadian population in a study by Brown et al. (Brown et al., 2001). Conditions from other Canadian sources and judged potentially appropriate to persons with an intellectual disability were also included (Statistics Canada, 2004; Manitoba Centre for Health Policy, 2005). The original list included: asthma, angina pectoris, congestive heart failure, gastrointestinal ulcer, immunization preventable infection, malignant hypertension, otitis media, neurotic depressive disorders, dental conditions, diabetes mellitus, and pelvic inflammatory disease.

Appendicitis was also included in this list as a validity check since it is considered an example of a condition for which hospitalization is unavoidable. The provision of timely and effective primary care for this condition is likely to have little impact on the need for hospitalization and there is substantial agreement among practitioners on the clinical
criteria for admission (Billings et al., 1993; Bindman et al., 1995). The inclusion of appendicitis played a dual role: It helped to avoid the tendency of participants to answer questions by rote and can be used as an indicator of access to nondiscretionary health care.

The questionnaire content was based on examples used by Brown et al. (Brown, 2001) and Caminal et al. (Caminal et al., 2004) and was piloted by four researchers with survey experience. The questionnaire for round 1 (see appendix D) consisted of a series of questions repeated for each one of the 12 conditions from the original list of ACS conditions. Query 4 from the questionnaire was open ended and asked the participants ‘what other condition(s) could primary care help to avoid a hospitalization in persons with an intellectual disability?’ Responses to this question were used in the round 2 questionnaire (see appendix E) which is almost identical in form and format to the round 1 questionnaire.

### 2.3.3 Criteria for inclusion

To be included in the final ACS list the following three criteria, based on prior research, were applied to each condition (Caminal et al., 2004; Solberg et al., 1990; Weissman et al., 1992):

1) Frequency: The hospitalization rate was at least 1/10 000

2) Clarity: The coding using the International Classification of Diseases, 9th Revision (ICD-9) was clear (World Health Organization, 1977)
3) Face validity: A hospitalization was potentially avoidable through primary care

Criterion 1 was determined using data from the Manitoba Centre for Health Policy (MCHP). This is the only known source in Canada for population level data on hospitalizations among persons with an intellectual disability. MCHP provided hospitalization rates for each ACS condition per 10,000 total hospitalizations among persons with an intellectual disability living in Manitoba from 1999 to 2003. Criterion 2 was evaluated by the study authors. Criterion 3 was evaluated by the study participants. To meet this criterion, for a given condition, at least 80% of participants were required to respond in the affirmative that primary care plays a role in preventing a hospitalization.

2.3.4 Other questions

Variation in rates of hospitalization for ACS conditions may be due to differences in clinical practice rather than access to or quality of primary care; therefore, using Brown et al.’s (Brown, 2001) example, both rounds of the questionnaire included a question evaluating the perceived agreement on clinical criteria for admission to a hospital. A Rating Average is calculated for each row of the tables produced by answers to the perceived agreement items. The Rating Average is a weighted average calculated by assigning weights from 1 to 5 to the columns of the tables. This means that any Rating Average greater than 3 falls to the right of neutral and closer to the options of increased agreement.
2.4 Results

2.4.1 Response rate and participant characteristics

Of the 19 potential participants, 12 filled out the first round of the questionnaire (63% response rate); of the 12, 11 also filled out the second round. The data for the 11 participants who filled out both questionnaires were analyzed.

The 11 participants included six primary care and/or family physicians, one general practitioner/academic, one paediatrician, two nurses, and one psychiatrist. The nationality breakdown was: 9 Canadians, 1 Welsh, and 1 Australian.

2.4.2 Conditions meeting criteria

All the conditions in the original list of 12 met the frequency and clarity criteria and there was near unanimity for the face validity criteria (table 2.1). There was 100% agreement that primary care helps to avoid hospitalizations for 10 of the 12 conditions. Dental conditions achieved 82% (9/11) agreement and appendicitis 36% (4/11). The high degree of agreement meant that it was unnecessary to undertake follow up rounds of consensus building usually required in a Delphi exercise. The international participants agreed with their Canadian counterparts as to which conditions should be included in the final list of ACS conditions.
Table 2.1. Original list of ambulatory care sensitive conditions and inclusion criteria values after round 1 of the questionnaire

<table>
<thead>
<tr>
<th>Ambulatory Care Sensitive Conditions</th>
<th>ICD-9 code</th>
<th>Criterion 1: Frequency *</th>
<th>Criterion 2: Clarity</th>
<th>Criterion 3: Face validity **</th>
</tr>
</thead>
<tbody>
<tr>
<td>asthma</td>
<td>493</td>
<td>107</td>
<td>Yes</td>
<td>100% (11/11)</td>
</tr>
<tr>
<td>angina pectoris</td>
<td>413</td>
<td>6</td>
<td>Yes</td>
<td>100% (11/11)</td>
</tr>
<tr>
<td>congestive heart failure</td>
<td>428</td>
<td>61</td>
<td>Yes</td>
<td>100% (11/11)</td>
</tr>
<tr>
<td>gastrointestinal ulcer</td>
<td>531, 532, 533, 534</td>
<td>8</td>
<td>Yes</td>
<td>100% (11/11)</td>
</tr>
<tr>
<td>immunization preventable infection</td>
<td>032, 033, 037, 055, 072</td>
<td>2</td>
<td>Yes</td>
<td>100% (11/11)</td>
</tr>
<tr>
<td>malignant hypertension</td>
<td>401.0, 402.0, 403.0, 404.0</td>
<td>1</td>
<td>Yes</td>
<td>100% (11/11)</td>
</tr>
<tr>
<td>otitis media</td>
<td>382</td>
<td>18</td>
<td>Yes</td>
<td>100% (11/11)</td>
</tr>
<tr>
<td>neurotic depressive disorders</td>
<td>300</td>
<td>85</td>
<td>Yes</td>
<td>100% (11/11)</td>
</tr>
<tr>
<td>dental conditions</td>
<td>521, 522, 523, 525, 528</td>
<td>38</td>
<td>Yes</td>
<td>82% (9/11)</td>
</tr>
<tr>
<td>diabetes mellitus</td>
<td>250</td>
<td>129</td>
<td>Yes</td>
<td>100% (11/11)</td>
</tr>
<tr>
<td>pelvic inflammatory disease</td>
<td>614, 615</td>
<td>8</td>
<td>Yes</td>
<td>100% (11/11)</td>
</tr>
<tr>
<td>appendicitis (non-ACS condition)</td>
<td>540.9, 541, 542</td>
<td>25</td>
<td>Yes</td>
<td>36% (4/11)</td>
</tr>
</tbody>
</table>

*Number of hospitalizations for specific condition per 10 000 total hospitalization. Must be > or = 1 to meet criteria

** Percentage of participants who responded that primary care plays a role in preventing a hospitalization. Must be > or = 80% to meet criteria.
In question 4 (questionnaire round 1), participants suggested several other conditions that might meet the criteria for inclusion as an ACS condition. The five most common responses were: constipation (55% of participants), mental illnesses (45% of participants), epilepsy/seizures (36% of participants), fractures/osteoporosis (27% of participants), and gastroesophageal reflux disease (27% of participants). The inclusion criteria were applied to this second list of conditions during the second round of the questionnaire. In order to be consistent with ICD-9 taxonomy, schizophrenic disorders were used to represent mental illness (i.e. simple, disorganized, catatonic, paranoid, residual, latent, schizophreniform disorder, schizoaffective disorder and other specified and unspecified types of schizophrenia).

All conditions on the second list met the frequency criteria (table 2.2) and there was near unanimity that primary care plays a role in avoiding hospitalizations. Only osteoporosis reached less than 100% agreement (90.9%). In addition, osteoporosis did not meet the clarity criteria necessary to be included in the final list of ACS conditions. Osteoporosis is considered a silent condition with no symptoms felt by the affected individual until it results in a fracture (Hawker, 1998). Persons are usually hospitalized for fractures secondary to osteoporosis and rarely for osteoporosis alone. As a result, osteoporosis is sometimes not included as the primary diagnosis for admission which is the usual way for identifying ACS hospitalizations in databases. Osteoporosis was therefore left out of the final list of ACS conditions.
Table 2.2. List of ambulatory care sensitive conditions suggested by participants and inclusion criteria values after the round 2 questionnaire

<table>
<thead>
<tr>
<th>Ambulatory Care Sensitive Conditions</th>
<th>ICD-9 code</th>
<th>Criterion 1: Frequency *</th>
<th>Criterion 2: Clarity</th>
<th>Criterion 3: Face validity **</th>
</tr>
</thead>
<tbody>
<tr>
<td>constipation</td>
<td>564.0</td>
<td>37</td>
<td>Yes</td>
<td>100% (11/11)</td>
</tr>
<tr>
<td>gastroesophageal reflux</td>
<td>530.81</td>
<td>41</td>
<td>Yes</td>
<td>100% (11/11)</td>
</tr>
<tr>
<td>epilepsy</td>
<td>345</td>
<td>258</td>
<td>Yes</td>
<td>100% (11/11)</td>
</tr>
<tr>
<td>schizophrenic disorders</td>
<td>295</td>
<td>243</td>
<td>Yes</td>
<td>100% (11/11)</td>
</tr>
<tr>
<td>osteoporosis</td>
<td>733.0</td>
<td>1</td>
<td>No</td>
<td>90.9% (10/11)</td>
</tr>
</tbody>
</table>

* Number of hospitalizations for specific condition per 10,000 total hospitalizations. Must be > or = 1 to meet criteria.
** Percentage of participants who responded that primary care plays a role in preventing a hospitalization. Must be > or = 80% to meet criteria.
2.4.3 Responses to other questions

The participants perceived that there is agreement on clinical criteria for hospital admissions for all conditions except neurotic depressive disorders (table 2.3). The Rating Average for neurotic depressive disorders was 3, corresponding to a perceived agreement between 25 and 50%.
Table 2.3. Perceived agreement on clinical criteria for hospital admissions (Results from round 1 and 2 of questionnaire)

For patients with similar medical and social circumstances, how much do you think primary care providers are likely to agree on the clinical criteria for admission for the following conditions?

<table>
<thead>
<tr>
<th>Condition</th>
<th>Round 1 conditions</th>
<th>Round 2 conditions</th>
<th>No agreement</th>
<th>1-25% agreement</th>
<th>26-50% agreement</th>
<th>51-75% agreement</th>
<th>76-100% agreement</th>
<th>Don’t Know</th>
<th>Rating Average</th>
<th>Count</th>
</tr>
</thead>
<tbody>
<tr>
<td>Asthma</td>
<td>0.0 (0)</td>
<td>18.2 (2)</td>
<td>9.1 (1)</td>
<td>45.5 (5)</td>
<td>18.2 (2)</td>
<td>9.1 (1)</td>
<td>3.70</td>
<td>11</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Angina pectoris</td>
<td>0.0 (0)</td>
<td>9.1 (1)</td>
<td>9.1 (1)</td>
<td>27.3 (3)</td>
<td>45.5 (5)</td>
<td>9.1 (1)</td>
<td>4.20</td>
<td>11</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Congestive Heart Failure</td>
<td>0.0 (0)</td>
<td>9.1 (1)</td>
<td>9.1 (1)</td>
<td>54.5 (6)</td>
<td>18.2 (2)</td>
<td>9.1 (1)</td>
<td>3.90</td>
<td>11</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Gastrointestinal Ulcer</td>
<td>0.0 (0)</td>
<td>27.3 (3)</td>
<td>18.2 (2)</td>
<td>36.4 (4)</td>
<td>9.1 (1)</td>
<td>9.1 (1)</td>
<td>3.30</td>
<td>11</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Immunization preventable Infections</td>
<td>0.0 (0)</td>
<td>18.2 (2)</td>
<td>9.1 (1)</td>
<td>36.4 (4)</td>
<td>18.2 (2)</td>
<td>18.2 (2)</td>
<td>3.67</td>
<td>11</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Malignant Hypertension</td>
<td>0.0 (0)</td>
<td>18.2 (2)</td>
<td>0.0 (0)</td>
<td>27.3 (3)</td>
<td>45.5 (5)</td>
<td>9.1 (1)</td>
<td>4.10</td>
<td>11</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Otitis media</td>
<td>9.1 (1)</td>
<td>18.2 (2)</td>
<td>9.1 (1)</td>
<td>0.0 (0)</td>
<td>36.4 (4)</td>
<td>27.3 (3)</td>
<td>3.50</td>
<td>11</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Neurotic Depressive Disorders</td>
<td>0.0 (0)</td>
<td>27.3 (3)</td>
<td>36.4 (4)</td>
<td>27.3 (3)</td>
<td>0.0 (0)</td>
<td>9.1 (1)</td>
<td>3.00</td>
<td>11</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Dental Conditions</td>
<td>9.1 (1)</td>
<td>9.1 (1)</td>
<td>9.1 (1)</td>
<td>27.3 (3)</td>
<td>9.1 (1)</td>
<td>36.4 (4)</td>
<td>3.29</td>
<td>11</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Diabetes Mellitus</td>
<td>0.0 (0)</td>
<td>18.2 (2)</td>
<td>27.3 (3)</td>
<td>36.4 (4)</td>
<td>9.1 (1)</td>
<td>9.1 (1)</td>
<td>3.40</td>
<td>11</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Pelvic Inflammatory Disease</td>
<td>0.0 (0)</td>
<td>18.2 (2)</td>
<td>27.3 (3)</td>
<td>27.3 (3)</td>
<td>9.1 (1)</td>
<td>18.2 (2)</td>
<td>3.33</td>
<td>11</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Appendicitis</td>
<td>0.0 (0)</td>
<td>0.0 (0)</td>
<td>9.1 (1)</td>
<td>9.1 (1)</td>
<td>63.6 (7)</td>
<td>18.2 (2)</td>
<td>4.67</td>
<td>11</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Constipation</td>
<td>0.0 (0)</td>
<td>18.2 (2)</td>
<td>36.4 (4)</td>
<td>18.2 (2)</td>
<td>18.2 (2)</td>
<td>9.1 (1)</td>
<td>3.40</td>
<td>11</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Osteoporosis</td>
<td>0.0 (0)</td>
<td>27.3 (3)</td>
<td>18.2 (2)</td>
<td>27.3 (3)</td>
<td>9.1 (1)</td>
<td>18.2 (2)</td>
<td>3.22</td>
<td>11</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Gastro-esophageal reflux disease</td>
<td>0.0 (0)</td>
<td>27.3 (3)</td>
<td>0.0 (0)</td>
<td>45.5 (5)</td>
<td>18.2 (2)</td>
<td>9.1 (1)</td>
<td>3.60</td>
<td>11</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Epilepsy</td>
<td>0.0 (0)</td>
<td>9.1 (1)</td>
<td>18.2 (2)</td>
<td>36.4 (4)</td>
<td>27.3 (3)</td>
<td>9.1 (1)</td>
<td>3.90</td>
<td>11</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Schizophrenic disorders</td>
<td>0.0 (0)</td>
<td>9.1 (1)</td>
<td>27.3 (3)</td>
<td>27.3 (3)</td>
<td>27.3 (3)</td>
<td>9.1 (1)</td>
<td>3.80</td>
<td>11</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>
Using the criteria set out in this and previous sections, table 2.4 lists the final and admission criteria restricted list of ACS conditions.

Table 2.4. Final and admission criteria restricted list of ambulatory care sensitive conditions

<table>
<thead>
<tr>
<th>Original list of Ambulatory Care Sensitive Conditions</th>
<th>ICD-9 code</th>
<th>Final list</th>
<th>Admission criteria restricted list</th>
</tr>
</thead>
<tbody>
<tr>
<td>asthma</td>
<td>493</td>
<td>Yes</td>
<td>Yes</td>
</tr>
<tr>
<td>angina pectoris</td>
<td>413</td>
<td>Yes</td>
<td>Yes</td>
</tr>
<tr>
<td>congestive heart failure</td>
<td>428</td>
<td>Yes</td>
<td>Yes</td>
</tr>
<tr>
<td>gastrointestinal ulcer</td>
<td>531, 532, 533, 534</td>
<td>Yes</td>
<td>Yes</td>
</tr>
<tr>
<td>immunization preventable infection</td>
<td>032, 033, 037, 055, 072</td>
<td>Yes</td>
<td>Yes</td>
</tr>
<tr>
<td>malignant hypertension</td>
<td>401.0, 402.0, 403.0, 404.0</td>
<td>Yes</td>
<td>Yes</td>
</tr>
<tr>
<td>otitis media</td>
<td>382</td>
<td>Yes</td>
<td>Yes</td>
</tr>
<tr>
<td>neurotic depressive disorders</td>
<td>300</td>
<td>Yes</td>
<td>No</td>
</tr>
<tr>
<td>dental conditions</td>
<td>521, 522, 523, 525, 528</td>
<td>Yes</td>
<td>Yes</td>
</tr>
<tr>
<td>diabetes mellitus</td>
<td>250</td>
<td>Yes</td>
<td>Yes</td>
</tr>
<tr>
<td>pelvic inflammatory disease</td>
<td>614, 615</td>
<td>Yes</td>
<td>Yes</td>
</tr>
<tr>
<td>constipation</td>
<td>564.0</td>
<td>Yes</td>
<td>Yes</td>
</tr>
<tr>
<td>gastroesophageal reflux</td>
<td>530.81</td>
<td>Yes</td>
<td>Yes</td>
</tr>
<tr>
<td>epilepsy</td>
<td>345</td>
<td>Yes</td>
<td>Yes</td>
</tr>
<tr>
<td>schizophrenic disorders</td>
<td>295</td>
<td>Yes</td>
<td>Yes</td>
</tr>
<tr>
<td>osteoporosis</td>
<td>733.0</td>
<td>No</td>
<td>No</td>
</tr>
</tbody>
</table>
2.5 Discussion

This is the first study examining the relevance of designating conditions as ambulatory care sensitive for persons with an intellectual disability. Fifteen ACS conditions were identified that are applicable to persons with an intellectual disability living in Canada. Eleven of the conditions are commonly applied in research dealing with the general population and four are unique to this population. Only neurotic depressive disorders reached a low rating for agreement on clinical criteria for hospital admissions.

A recent review by Purdy et al. (Purdy et al., 2009) identified 36 conditions that were described as ambulatory care sensitive in prior research. The National Health Service in England commonly uses a subset of only 19 conditions while the Canadian Institute of Health Information currently uses a list of 9 conditions (Purdy et al., 2009; Sanchez et al., 2008). The current study suggests that 15 conditions are specifically applicable to persons with an intellectual disability living in Canada and, consistent with the suggestions of the review paper, a detailed specification of the conditions and codes is provided.

Similar to the current study, Walker et al. (Walker et al., 2009) evaluated the applicability of ACS conditions for a subset of the general Canadian population with higher health needs. They convened a panel of 9 experts that reached consensus on 18 conditions judged applicable to residents in Canadian long term care facilities. Consistent with the current paper, the panel from Walker et al. included conditions in their list that were specifically applicable to the health situation of the population under study.
Future researchers that consider using our proposed list of ACS conditions may decide to exclude neurotic depressive disorders. It produced the lowest rating for agreement on clinical criteria for hospital admissions. As for many other psychiatric disorders, criteria for hospitalization are more discretionary and depend on a physician’s evaluation of level of distress, social support, disability, and threat of harm to self or others (Pasic & Zarkowski, 2008).

2.5.1 Strengths

The response rate to the survey was high with 63% responding to the first round questions, which is much higher than the overall response rate to the 2004 National Physician Survey (36% among primary care physicians) (Canadian Institute for Health Information, 2004). The successful recruitment of participants is probably due to the specific interest they have in the topic since many of them were identified through conferences dealing with the management of health issues in persons with intellectual disability.

The questionnaire was administered with the aim of obtaining a Canadian perspective on ACS conditions for persons with an intellectual disability. The majority of participants were Canadian, but the responses from the two international participants were not different from those of their Canadian counterparts. It is likely that the ACS conditions identified in this study are suited to research outside of Canada. Furthermore, the ACS conditions identified by this study are likely applicable to persons with cognitive
problems resulting from acquired brain injuries or other neurological conditions occurring later in life. These assertions should be confirmed before pursuing.

The participants were from a range of professions that practice primary care which is suitable for a study of ACS conditions. Brown et al. (Brown, 2001) state that failure to involve clinicians in the development of ACS or other similar indicators would reduce their credibility. This applies to dental professionals since dental conditions were included as an ACS condition. Dentists and dental hygienists are commonly used by the Canadian population for their primary dental health care issues (Millar, 2004). They were not recruited for the study and should be used in the future to evaluate the appropriateness of dental conditions as an ACS condition.

A modified Delphi process was used for this study. It works under the assumption that the views of a group have greater validity and reliability than the judgement of an individual (De Villiers et al., 2005; Raine et al., 2005). Consensus methods provide a means of synthesizing information where published information is inadequate and a way of harnessing the insights of experts to enable decisions to be made (De Villiers et al., 2005; Jones & Hunter, 1995). Since the Delphi process participants are not known to each other, it encourages honest opinion, free from peer group pressure (Frances et al., 1998; Hutchings & Raine, 2006; Keeney et al., 2001; Williams & Webb, 1994). Using a web based survey made the process inexpensive and allowed for the involvement of geographically dispersed participants.
Some researchers have advocated the measurement of the natural state of consensus over the traditional Delphi process which attempts to ‘force’ agreement (Frances et al., 1998; Unwin & Deb, 2008). While we set out to use a traditional Delphi exercise (Hutchings & Raine, 2006; Jones & Hunter, 1995; Raine et al., 2005), our process was modified after observing that at least 80% of the participants agreed after being asked only once. As such we measured the level of consensus that naturally exists and used two rounds of questionnaires to evaluate two different lists of conditions.

2.5.2 Limitations

The limitations of this study stem from the use of the Delphi process which has been critiqued. The definition of consensus is considered one of the more contentious components of the method (Crisp et al., 1997). There is no agreement in the literature on specific criteria to use to decide when consensus has been achieved – in other words, when the Delphi process can stop (Holey et al., 2007). The current study chose 80% as threshold for accepting consensus at the onset of the study. This is considered a conservative cut off and used by similar studies (Caplin et al., 2006; Haggerty et al., 2007; Marshall et al., 2006). Williams et al. (Williams & Webb, 1994) advocated this method over the attempt of many researchers to set an arbitrary value after the data have been analyzed.

There is little agreement about how many and who should be included as members of the expert group (Crisp et al., 1997; Jones & Hunter, 1995; Keeney et al., 2001). It is suggested that the size and heterogeneity of the group is dependent on the purpose of the
project (Keeney et al., 2001). Participant numbers from prior studies on ACS conditions using the Delphi process ranged from 6 to 20 (Billings et al., 1993; Caminal et al., 2004). The current study recruited 11 participants which is a high number considering the low number of primary care providers with experience working with persons with an intellectual disability. The current study includes participants from both sexes and a mix of professions from Canada and abroad ensuring that a wide spectrum of opinion is determined. Although there are no stringent rules about how many and who to include in expert groups, the current study used methods consistent with prior studies (Brown et al., 2001; Caminal et al., 2004; Weissman et al., 1992).

Other authors have questioned the reliability and validity of the Delphi process (Crisp et al., 1997; Sackman, 1974; Williams & Webb, 1994). In their review of the method, however, Keeney et al. (Keeney et al., 2001) referred to a study (Ono & Wedemeyer, 1994) that was able to replicate the results between groups over time. Since the current study met the 80% criteria for inclusion in the final list after only the first round of the questionnaire, it must be assumed that most primary care practitioners with experience working with persons with an intellectual disability would agree with the results of this study. As for the validity of the method, Jones and Hunter (Jones & Hunter, 1995) caution that unless findings can be tested against observed data, researchers can never be sure the process has produced the ‘correct’ answer. Evidence from more objective data come from studies that have shown that communities with higher rates of hospitalizations for ACS conditions also have poorer self rated access to health care (Ansari et al., 2006; Bindman et al., 1995; Parchman & Culler, 1999)
2.6 Conclusion

The participants in the current study overwhelmingly agreed on a list of ACS conditions applicable to persons with an intellectual disability. The list of conditions is potentially applicable to persons with disabilities similar to intellectual disability and to countries other than Canada. The results are of relevance to researchers of health care for persons with an intellectual disability and Canadian regional health administrators. Using the study’s list of ACS conditions, authorities can perform comparisons of preventable hospitalizations between different regions or between persons with an intellectual disability and a control population.
Chapter 3: Hospitalization rates for ambulatory care sensitive conditions for persons with and without an intellectual disability-a population perspective

This chapter is a longer version of a manuscript that will be submitted for publication to the Journal of Applied Research in Intellectual Disabilities:

3.1 Abstract

**Background:** Persons with an intellectual disability represent between 1 and 3% of the population. They experience higher rates of disease than the general population. There is also evidence they face barriers to primary care; however, this has not been extensively studied at the population level. Rates of hospitalization for ambulatory care sensitive conditions are used as an indicator of access to, and quality of, primary care.

**Objective:** To compare hospitalization rates for ambulatory care sensitive conditions between persons with and without an intellectual disability in a publicly insured population.

**Methods:** Persons with an intellectual disability were identified among the general population of a Canadian province between 1999 and 2003. Using a list of conditions applicable to persons with an intellectual disability, rates of hospitalizations for ambulatory care sensitive conditions for persons with and without an intellectual disability were calculated and compared. Regression models were used to adjust for age, sex, and place of residence. Hospitalization rates for specific conditions were also compared, controlling for differences in disease prevalence where possible.

**Results:** Persons with an intellectual disability (n=8106) were consistently hospitalized for ambulatory care sensitive conditions at a higher rate than persons without an intellectual disability (n=1 189 638). Between 1999 and 2003 the adjusted rate ratio (RR) was 6.1 (95% CI= 5.6, 6.7). Rate ratios were highest when comparing persons with, to persons without, an intellectual disability between the ages of 30-39 (RR 13.1; 95% CI= 10.6, 16.2) and among urban area dwellers (RR 7.0; 95% CI= 6.2, 7.9). Hospitalization rates for epilepsy and schizophrenic disorders were respectively 54 and 15 times higher for persons with an intellectual disability than for persons without an intellectual disability. Taking into account the prevalence of disease for the populations changed the estimated rate ratios for diabetes but not asthma.

**Conclusions:** The large discrepancy in rates of hospitalization between persons with and without an intellectual disability is an indicator of inadequate primary care for this vulnerable population. Decreasing the number of ambulatory care sensitive condition hospitalizations through specialized outpatient programs for persons with an intellectual disability would potentially lead to better health, improved quality of life and cost savings. Future research should include potentially important factors such as disease severity, socioeconomic variables, and measures of health service organization in the analysis. International comparisons of ambulatory care sensitive condition hospitalization rates could point to the benefits and limitations of the health service policy directions adopted by different countries.
3.2 Introduction

Intellectual disability can be defined as a disability originating before age 18 characterized by significant limitations both in intellectual functioning and in adaptive behaviour as expressed in conceptual, social, and practical adaptive skills (American Association on Intellectual and Developmental Disabilities, 2009). An intelligence quotient score of 70 or below is commonly used as the criterion for intellectual functioning. Limitations in adaptive behaviour impact a person’s daily life and affect the ability to respond to particular situations or the environment. The different terms used by some jurisdictions to identify this population include ‘developmental disability’, ‘learning disability’, and ‘mental retardation’ (Ouellette-Kuntz et al., 2005). Between 1-3% of the world’s population has an intellectual disability (World Health Organization, 2001b). Common causes include genetic abnormalities, pre, peri and post natal injuries, exposure to toxins, central nervous system abnormalities, and metabolic/endocrine abnormalities (Curry et al., 1997; Percy & Brown, 2003).

Persons with an intellectual disability experience higher rates of morbidity than the general population. A case-control study from the Netherlands compared morbidity in a group of persons with an intellectual disability to age and sex matched controls that made visits to primary care practitioners (Van Schrojenstein Lantman-de Valk et al., 2004). Persons with an intellectual disability had significantly more psychological, digestive, ear, neurological, and other less clearly defined problems than controls. Only some of the increased morbidity can be attributed to syndrome specific conditions such as the increased risk of thyroid disease in people with Down syndrome (McElduff, 2002). The
life expectancy of this population has increased over the years and like the general population, adults with intellectual disabilities are increasingly experiencing age-related health concerns (Kapell et al., 1998).

In many developed countries, there has been a move to deinstitutionalize persons with a disability. In Canada, for instance, policy changes by Canadian provincial governments in the 1970s and 1980s led to a shift from institutional residences for persons with an intellectual disability to community based homes (Macdonald, 2002). With these policy changes, it became necessary for community health services to accommodate this population that formerly received many health services within the institutions where they lived (Hennen, 2005). In a study contrasting the quality of life of persons with an intellectual disability in the mid-western United States who moved from an institution to community living settings, improvements post deinstitutionalization were noted for all categories measured except access to health professionals (Conroy et al., 2003). Post deinstitutionalization, study participants reported greater difficulty in obtaining medical services and the study found a corresponding decrease in frequency in physician visits. A similar pattern was described in a study from Norway where visit frequency to general practitioners, psychiatrists, and psychologists decreased after deinstitutionalization despite increases in behaviour disturbances (Nottestad & Linaker, 1999). It is frequently suggested that community health care is to this day inadequate for this population (Beange et al., 1995; Hennen, 2005; Morgan et al., 2000; Sullivan et al., 2006; Lennox, 2002; Criscione et al., 1995).
The quality of health services and the health status of persons with an intellectual disability living in developed countries are summarized well in a report by the United States Secretary of Health and Human Services which concluded that compared with the general population, adults with an intellectual disability experience poorer health and more difficulty in finding, getting to, and paying for appropriate health care (United States Public Health Service, 2001). Payment for health care may not be as problematic for persons with an intellectual disability living in countries with universal publicly financed health insurance plans; nevertheless, a review of research from the United Kingdom showed that persons with an intellectual disability access primary care less frequently than the general population or other vulnerable groups (Alborz et al., 2005). A range of factors have been identified as possible barriers to effective care. Client level barriers include communication, behaviour and mobility problems; community level barriers include lack of physically accessible buildings, lack of transportation, and distance to health services; health care provider barriers include inadequate training and experience dealing with persons with an intellectual disability, unsupportive attitudes, inadequate number of providers, insufficient remuneration, and lack of time (Baxter & Kerr, 2002).

The role of primary care in providing access to a variety of health services suggests that it is an area that warrants specific investigation in relation to understanding disparities in health experienced by persons with intellectual disabilities. Primary care is the health care provided by a health professional (typically a physician or nurse practitioner) that is a patient’s first point of entry into the health system (Institute for Clinical Evaluative
Sciences, 2006). The Institute of Medicine defines primary care as “the provision of integrated, accessible health care services by clinicians who are accountable for addressing a large majority of personal health care needs, developing a sustained partnership with patients and practicing in the context of family and community” (Institute of Medicine, 1996)p. 1). Researchers have identified deficiencies in primary care for persons with an intellectual disability, leading to the denial of basic health services that are recommended for everyone (Cameron, 2005; Havercamp et al., 2006; Lennox & Kerr, 1997; Lewis et al., 2002). These include inadequate uptake of health promotion and disease prevention, insufficient access to care, and lack of care coordination. A lack of recognition of the specific special needs of the population has also been reported (Lennox et al., 1997).

In countries where deinstitutionalization has taken place, there have been ongoing debates about the best way to organize primary care services for persons with an intellectual disability (Alexander et al., 2002; Aspray et al., 1999; Hassiotis et al., 2000; O'Hara, 2000). In England, Community Learning Disability Teams were created to support mainstream primary care providers by offering a range of clinical services to meet, in a comprehensive way, the mental and physical needs of persons with an intellectual disability (Slevin et al., 2008; O'Hara, 2000). Canada and Australia, countries with comparable universal publicly funded health insurance, have relied more on the mainstream health care system (Lennox et al., 1997; Sullivan et al., 2006). The assumption is that the universally accessible primary care made available without financial barriers to all Canadians and Australians should be adequate to meet the
sometimes complex needs of persons with an intellectual disability living in the community. Research from Australia has shown this not to be the case. A seminal study from northern Sydney took a random sample of persons with an intellectual disability and found an increased number of chronic diseases that were frequently not recognized or, when diagnosed, not properly treated (Beange et al, 1995). In response, programs have been introduced in some cities to provide specialist consultation to support the mainstream health care services. For example the Centre for Developmental Disability Health Victoria in Melbourne, Australia provides health care services support through general practice and psychiatry clinics and in Toronto, Canada the Surrey Place Centre provides physician consultations in family medicine, paediatrics, neurology and psychiatry (Centre for Developmental Disability Health Victoria, 2007; Surrey Place Centre, 2009); it should be emphasized, however, that these programs are local initiatives based in large urban centres and have not been organized to provide country-wide services like in England.

The impetus for the current study came from a Canadian based investigation into hospital admissions among persons with an intellectual disability (Balogh et al., 2005). The study found high rates of ambulatory care sensitive (ACS) conditions among persons with an intellectual disability living in the province of Ontario. Rates of hospitalization for ACS conditions are considered to be a measure of access to, and quality of, primary care in a given community or for a given group of patients (Porter et al., 2007). Examples of ACS conditions include asthma, otitis media, congestive heart failure, and angina pectoris. The rationale for including these conditions is that proper primary care for such
conditions should delay the progression of the disease or prevent serious complications and thus prevent hospitalization. Not all hospitalizations for ACS conditions are avoidable but it is assumed that appropriate primary care can prevent the onset of this type of illness or condition, control an acute episode, or manage a chronic disease or condition (Billings et al., 1993). Research from Europe and the United States has shown a relationship between high rates of ACS condition hospitalizations and problems with access to primary care (Caminal et al., 2004). Measuring the adequacy of primary care using ACS condition hospitalization rates has been applied to vulnerable populations and used to identify disparities with the general population (Epstein, 2001; Gunraj et al., 2003; Laditka, 2003). This method may prove useful as a surveillance tool to identify problems with primary care in certain regions or among populations at risk, like persons with an intellectual disability.

This study is the first population based study that compares hospitalization rates for ACS conditions between persons with and without an intellectual disability.

3.3 Methods

3.3.1 Study design

This open cohort study compares rates of ACS condition hospitalizations for persons with and without an intellectual disability according to person, place, and time.

3.3.2 Data source and management

The data for this analysis were accessed at the Manitoba Centre for Health Policy (MCHP) at the University of Manitoba's Faculty of Medicine. MCHP houses a data
system called the Population Health Research Data Repository (Repository) (Roos et al., 2003). The Repository contains a collection of administrative databases that hold anonymized records of all contacts Manitoba (population=1,169,667) (Manitoba Health, 2004) residents have with the health care, social services, and education systems (see appendix F). The Repository also contains a population-based registry, which includes all Manitobans registered to receive health care, making it possible to track moves into, out of, and around the province (including births and deaths) (Roos & Nicol, 1999). The entire population of the province is covered by the Manitoba Health Services Insurance Plan (Roos et al., 2005b). The plan covers all physician visits and hospital stays. There is minimal non-participation since residents are not obliged to pay premiums to register for insured benefits. Each individual represented in the various databases contained in the Repository is assigned a scrambled unique numeric identifier. Using the identifier, information on the same person from two or more databases can be merged into one database (Manitoba Centre for Health Policy, 2009e). The validity and utility of the information in the Repository have been well documented (Brownell et al., 2001; Roos & Nicol, 1999).

Persons with an intellectual disability living in Manitoba were identified using information from four databases: medical services (i.e. physician claims), hospital records, family services, and education enrolment. The unique identifier was used to track any persons identified with an intellectual disability from any of these databases from 1984 to 2007. This was necessary since persons with an intellectual disability are not consistently identified in administrative databases (Balogh et al., 2005). From this
larger pool of persons with an intellectual disability, only those living in Manitoba at any
time between 1999 and 2003, identified using the population-based registry, were
included in the analysis.

3.3.3 Study population

The method used to identify a person with an intellectual disability from the various
databases contained in the Repository follows:

Medical services: Physicians submit claims to the Manitoba government for
services they provide (Manitoba Centre for Health Policy, 2009c). The claim
includes space for a single diagnosis. Persons with an intellectual disability
seeking physician services were identified using codes from the International
Classification of Diseases, 9th revision (ICD-9), for mental retardation (317, 318,
319) and codes for chromosomal and congenital anomalies (758, 759) (World
Health Organization, 1977). Appendix G provides a full list of the codes used.

Hospital records: When an individual is discharged from a hospital, a
computerized record is created using information taken from the person’s medical
chart (Manitoba Centre for Health Policy, 2009b). The record contains up to 16
diagnoses related to the hospitalization and is coded using ICD-9. Persons with
an intellectual disability were identified if any of the codes for mental retardation,
chromosomal and congenital anomalies were included as a diagnosis (see
appendix G).

Family services: Intellectual disability was identified if a person received
income assistance for reasons of mental retardation.
**Education enrollment:** A person was identified if they received special funding for multiple handicaps. The Department of Education in Manitoba uses the term multiple handicaps almost exclusively for persons with an intellectual disability (T. Thorne, personal communication, March 6, 2008). ‘Multiple’ refers to the fact that an identified person has an IQ lower than 70 and an associated deficit in adaptive functioning.

The study included persons of all ages with and without an intellectual disability living in Manitoba between 1999 and 2003. Information from the registry was used to ensure that persons included in the study were living in Manitoba at some point between 1999 and 2003. The registry also provided information on age, sex, and area of residence for all Manitobans including those without an intellectual disability who acted as a comparison group.

### 3.3.4 Analysis

#### 3.3.4.1 Age, gender distribution

The age and gender distributions of Manitobans with and without an intellectual disability were compared using population pyramids.

#### 3.3.4.2 Hospitalization rates and rate ratios

Rates for ACS condition hospitalizations between persons with and persons without an intellectual disability were calculated and compared. The numerator for the rates included all hospitalizations to acute care hospitals for ACS conditions with admission
dates between January 1, 1999 and December 31, 2003. The ACS conditions were those established by consensus building (see chapter 2 or (Balogh R.S. et al., 2010b)) and included: asthma, angina pectoris, congestive heart failure, gastrointestinal ulcer, immunization preventable infection, malignant hypertension, otitis media, neurotic depressive disorders, dental conditions, diabetes mellitus, constipation, gastroesophageal reflux, epilepsy, and schizophrenic disorders (Appendix H shows the full list and corresponding ICD-9 codes). Cases of angina pectoris, congestive heart failure, and constipation were excluded if a surgical procedure occurred during the hospitalization since these conditions are occasionally due to secondary effects of surgery (Manitoba Centre for Health Policy, 2005). Readmissions, defined as an admission to the same or different hospital within 30 days following discharge from a hospital, were excluded from the numerator (Manitoba Centre for Health Policy, 2007b). The denominator represents person-years, calculated from the duration a person has been registered for health insurance benefits during the study period, as identified in the registry. Crude and adjusted rate ratios with 95% confidence intervals and corresponding p-values were calculated. Hospitalization distributions are presented by year (1999 to 2003), age groups (0-9 to 70+) and area of residence (urban or rural). Consistent with other research from Manitoba, urban was defined as any residence with a postal code from Winnipeg (population=663 443 in 2004) or Brandon (population=48 612 in 2004), and rural was defined as any other postal code (Manitoba Centre for Health Policy, 2008; Manitoba Health, 2004).
3.3.4.3 Hospitalization rates and rate ratios for specific conditions

Some conditions were included for separate analysis. These were chosen for the following reasons: Epilepsy, schizophrenic disorders, asthma, diabetes and constipation were among the most common conditions for which a hospitalization occurred; pelvic inflammatory disease can only be analyzed among females; and appendicitis is a condition for which hospitalization is considered unavoidable and is sometimes referred to as a nonambulatory care sensitive condition (Bindman et al., 2005). Appendicitis is useful in comparison to the other conditions in this analysis, because it requires admission to hospital for effective treatment and admission would not be expected to vary with differing access to primary care (Public Health Division, 2001). Rates and rate ratios for the specific conditions were calculated like those described in the previous section.

Differences in rates of ACS condition hospitalizations between persons with and without an intellectual disability may be due to differences in disease prevalence rather than issues with the quality or quantity of primary care (Laditka et al., 2003; Oster & Bindman, 2003; Shwartz et al., 2005). For asthma and diabetes it was possible to control for this issue by estimating the prevalence of these diseases using algorithms developed by MCHP (Lix et al., 2006). Diabetes cases were identified if 1 or more hospitalizations, or 2 or more physician claims for diabetes occurred over a two–year period prior to 1999 (positive predictive value (PPV) 87.9%, negative predictive value (NPV) 98.7%). For asthma the algorithm was 2 or more physician claims over two years prior to the start of the study (PPV 70%, NPV 94.6%). These algorithms were chosen because of their high
NPV, relatively high PPV and consistency with recognized definitions (Public Health Agency of Canada, 2008; Blanchard et al., 1996).

3.3.4.4 Statistical models

Multiple regression analysis using the GENMOD procedure in SAS® software was used to calculate adjusted rate ratios (SAS Institute, 1999). The dependent variable was the rate of acute care hospitalizations for ACS conditions (or a single condition) and the primary independent variable was whether or not someone had an intellectual disability. Variables for sex, 10-year age groups, and area of residence (urban or rural) were included in statistical models to control for their influence.

Using GENMOD the outcome was specified by providing a count representing the number of hospitalizations. An offset term was included so the outcome could be interpreted as a rate rather than a count, thus adjusting for differences in group size. All independent variables were specified as categorical and included in the CLASS statement. A negative binomial distribution was used instead of poisson in order to control for evidence of over-dispersion.

3.3.4.5 Sample size

The Epi Info™ software package was used for sample size calculations (Centers for Disease Control and Prevention, 2004). Using a 4:1 sampling ratio, 8752 persons without and 2188 persons with an intellectual disability would be required to find a significant difference in hospitalization rates for ACS conditions. This is based on reported rates for
ACS conditions in the general population (345/100 000 population) and persons with an intellectual disability (1020/100 000 population) and a confidence level of 95% and power of 80% (Balogh et al., 2005). These results are based on the ACS conditions as described by the Canadian Institute for Health Information which are fewer than the conditions used for this paper; as such, the sample size calculation represents a conservative estimate. According to the Manitoba Health Population Report, the population of Manitoba was 1 169 667 in 2004 (Manitoba Health, 2004). Among these approximately 6667 persons have an intellectual disability (using a .57% prevalence rate) (Ouellette-Kuntz & Paquette, 2001). This provides the study with ample power to find significant results for the stated objective.

3.4 Results

3.4.1 Age, sex distribution

Figures 3.1 and 3.2 show the age and gender distribution of Manitoba residents with and without an intellectual disability for the years 1999 and 2003. More than a third of persons identified with an intellectual disability in Manitoba are between the ages of 0 and 24. Among persons with an intellectual disability 57.4% were male in 1999 and 57.7% were male in 2003. This is higher than the percentages for persons without an intellectual disability (49.4% male in 1999 and 2003). The tables with the values used to produce the figures are found in appendix I.
Figure 3.1. Age and gender distribution of population of Manitoba with and without an intellectual disability, 1999
Figure 3.2. Age and gender distribution of population of Manitoba with and without an intellectual disability, 2003
3.4.2 Hospitalization rates by year

Table 3.1 shows the hospitalization rates and ratios for ACS conditions by year, from 1999 to 2003, for Manitobans with and without an intellectual disability. The adjusted rate ratios range between 5.31 and 6.65 and the combined rate ratio for all five years is 6.12 (5.58, 6.72). The hospitalization rates among persons without an intellectual disability decreased every year between 1999 and 2003; this trend was less consistent among persons with an intellectual disability.
Table 3.1. Rate comparisons for ambulatory care sensitive condition hospitalizations between persons with and without an intellectual disability, by calendar year (1999-2003), Manitoba

<table>
<thead>
<tr>
<th>Year, Population</th>
<th>Number of ACS condition hospitalizations</th>
<th>Number of person-years</th>
<th>Crude rate per person-year (x 1000)</th>
<th>Crude Rate Ratio</th>
<th>Rate Ratio adjusted for age-sex-region</th>
<th>95% Confidence interval (p-value)</th>
</tr>
</thead>
<tbody>
<tr>
<td>1999, with an ID</td>
<td>278</td>
<td>8100</td>
<td>34.3</td>
<td>4.81</td>
<td>6.29</td>
<td>5.22, 7.58 (p&lt;0.0001)</td>
</tr>
<tr>
<td>1999, without an ID</td>
<td>8290</td>
<td>1 162 624</td>
<td>7.13</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>2000, with an ID</td>
<td>240</td>
<td>8203</td>
<td>29.3</td>
<td>4.38</td>
<td>6.14</td>
<td>5.01, 7.54 (p&lt;0.0001)</td>
</tr>
<tr>
<td>2000, without an ID</td>
<td>7829</td>
<td>1 171 301</td>
<td>6.68</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>2001, with an ID</td>
<td>250</td>
<td>8245</td>
<td>30.3</td>
<td>4.71</td>
<td>6.65</td>
<td>5.48, 8.09 (p&lt;0.0001)</td>
</tr>
<tr>
<td>2001, without an ID</td>
<td>7592</td>
<td>1 178 266</td>
<td>6.44</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>2002, with an ID</td>
<td>199</td>
<td>8247</td>
<td>24.1</td>
<td>3.89</td>
<td>5.31</td>
<td>4.37, 6.46 (p&lt;0.0001)</td>
</tr>
<tr>
<td>2002, without an ID</td>
<td>7353</td>
<td>1 184 329</td>
<td>6.21</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>2003, with an ID</td>
<td>208</td>
<td>8218</td>
<td>25.3</td>
<td>4.26</td>
<td>5.99</td>
<td>4.76, 7.55 (p&lt;0.0001)</td>
</tr>
<tr>
<td>2003, without an ID</td>
<td>7082</td>
<td>1 192 256</td>
<td>5.94</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>5-year rate, with an ID</td>
<td>1175</td>
<td>41013</td>
<td>28.6</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>5-year rate, without an ID</td>
<td>38 146</td>
<td>5 888 776</td>
<td>6.48</td>
<td>4.42</td>
<td>6.12</td>
<td>5.58, 6.72 (p&lt;0.0001)</td>
</tr>
</tbody>
</table>

ID=intellectual disability

When interaction terms were included in the full statistical model, the association between intellectual disability status and ACS condition hospitalization rates differed according to age group (p<0.0001), region (p<0.0003), but not by sex (p=0.08) nor year (p=0.4). This means that the rate ratios between sexes and between years show homogeneity of effect.

3.4.3 Hospitalization rates by age groups

Table 3.2 compares rates of hospitalizations for ACS conditions between persons with and without an intellectual disability, by age group. The highest rate ratios were for the 20-29 age group (11.5; CI= 9.2, 14.3) and the 30-39 age group (13.1; CI=10.6, 16.3).

The ratio of rates between the two populations in the oldest age group was not significant (1.2; CI=0.93, 1.64). Appendix J has a break down of these results by year.
Table 3.2. Rate comparisons for ambulatory care sensitive condition hospitalizations between persons with and without an intellectual disability, by age, Manitoba

<table>
<thead>
<tr>
<th>Year</th>
<th>Age group in years, population</th>
<th>Crude rate values a</th>
<th>Crude rate per person-year (x 1000)</th>
<th>Crude rate ratio</th>
<th>Rate ratio adjusted for sex-region</th>
<th>95% CI (p-value)</th>
</tr>
</thead>
<tbody>
<tr>
<td>1999 to 2003</td>
<td>0-9, with ID</td>
<td>315/10 941</td>
<td>28.79</td>
<td>6.44</td>
<td>6.38</td>
<td>5.30, 7.67 (&lt;.0001)</td>
</tr>
<tr>
<td></td>
<td>0-9, without ID</td>
<td>3461/774 630</td>
<td>4.47</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>10-19, with ID</td>
<td>194/10 799</td>
<td>17.96</td>
<td>8.25</td>
<td>8.47</td>
<td>6.89, 10.42 (&lt;.0001)</td>
</tr>
<tr>
<td></td>
<td>10-19, without ID</td>
<td>1810/831 633</td>
<td>2.18</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>20-29, with ID</td>
<td>145/4782</td>
<td>30.32</td>
<td>11.3</td>
<td>11.46</td>
<td>9.20, 14.29 (&lt;.0001)</td>
</tr>
<tr>
<td></td>
<td>20-29, without ID</td>
<td>2096/781 741</td>
<td>2.68</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>30-39, with ID</td>
<td>163/4079</td>
<td>39.96</td>
<td>12.8</td>
<td>13.09</td>
<td>10.59, 16.19 (&lt;.0001)</td>
</tr>
<tr>
<td></td>
<td>30-39, without ID</td>
<td>2642/849 311</td>
<td>3.11</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>40-49, with ID</td>
<td>124/4040</td>
<td>30.69</td>
<td>8.28</td>
<td>8.38</td>
<td>6.66, 10.53 (&lt;.0001)</td>
</tr>
<tr>
<td></td>
<td>40-49, without ID</td>
<td>3348/902 999</td>
<td>3.71</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>50-59, with ID</td>
<td>119/2927</td>
<td>40.66</td>
<td>7.01</td>
<td>7.18</td>
<td>5.70, 9.05 (&lt;.0001)</td>
</tr>
<tr>
<td></td>
<td>50-59, without ID</td>
<td>3936/67 824</td>
<td>5.80</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>60-69, with ID</td>
<td>60/1775</td>
<td>33.80</td>
<td>3.23</td>
<td>3.36</td>
<td>2.51, 4.49 (&lt;.0001)</td>
</tr>
<tr>
<td></td>
<td>60-69, without ID</td>
<td>4660/445 260</td>
<td>10.47</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>70 years +, with ID</td>
<td>55/1670</td>
<td>32.93</td>
<td>1.27</td>
<td>1.23</td>
<td>0.93, 1.64 (0.151)</td>
</tr>
<tr>
<td></td>
<td>70 years +, without ID</td>
<td>16193/624 918</td>
<td>25.91</td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

ID=intellectual disability

a: Rate = number of hospitalizations / number of person years
3.4.4 Hospitalization rates by urban/rural regions

Table 3.3 compares hospitalization rates for ACS conditions for Manitobans with and without an intellectual disability living in rural and urban areas over five calendar years (1999-2003). While significant in both urban and rural areas, the difference was more pronounced in the urban areas. Appendix K has a break down of these results by year.

Table 3.3. Rate comparisons for ambulatory care sensitive condition hospitalizations between persons with and without an intellectual disability, by urban/rural region, Manitoba

<table>
<thead>
<tr>
<th>Year</th>
<th>Urban(^a) or rural(^b) residence, population</th>
<th>Crude rate values(^c)</th>
<th>Crude rate per person-year (x 1000)</th>
<th>Crude rate ratio</th>
<th>Rate ratio adjusted for age-sex</th>
<th>95% C (p-value)</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Urban, without ID 17 257/3 590 802</td>
<td>4.81</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>Rural, with ID 539/16 368</td>
<td>32.93</td>
<td>3.62</td>
<td>5.29</td>
<td>4.63, 6.05 (&lt;.0001)</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Rural, without ID 20 889/2 297 974</td>
<td>9.09</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

ID=intellectual disability
a: Urban: Winnipeg and Brandon
b: Rural: All other regions of Manitoba
c: Rate = number of hospitalizations / number of person years
### 3.4.5 Most common hospitalizations

Table 3.4 shows the ACS conditions for which a hospitalization most commonly occurred. For persons with an intellectual disability, almost half (48.5%) of ACS hospitalizations were for epilepsy and schizophrenic disorders. These two conditions made up only 10.6% of ACS hospitalizations for persons without an intellectual disability. The most common reason for hospitalization among persons without an intellectual disability was congestive heart failure (25.1%) corresponding to only 6.0% for persons with an intellectual disability.

Table 3.4. Most common ambulatory care sensitive condition hospitalizations, among persons with and without an intellectual disability, Manitoba, 5 calendar years (1999-2003)

<table>
<thead>
<tr>
<th>Specific ACS conditions and appendicitis</th>
<th>ACS hospitalizations among persons with ID</th>
<th>ACS hospitalizations among persons without ID</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>n</td>
<td>% (col)</td>
</tr>
<tr>
<td>1) Epilepsy</td>
<td>329</td>
<td>27.26</td>
</tr>
<tr>
<td>2) Schizophrenic disorders</td>
<td>256</td>
<td>21.21</td>
</tr>
<tr>
<td>3) Asthma</td>
<td>119</td>
<td>9.86</td>
</tr>
<tr>
<td>4) Diabetes</td>
<td>104</td>
<td>8.62</td>
</tr>
<tr>
<td>5) Anxiety, dissociative and somatoform disorders</td>
<td>97</td>
<td>8.04</td>
</tr>
<tr>
<td>6) Congestive heart failure</td>
<td>72</td>
<td>5.97</td>
</tr>
<tr>
<td>7) Gastroesophageal reflux</td>
<td>57</td>
<td>4.72</td>
</tr>
<tr>
<td>8) Dental conditions</td>
<td>50</td>
<td>4.14</td>
</tr>
<tr>
<td>9) Constipation</td>
<td>50</td>
<td>4.14</td>
</tr>
<tr>
<td>10) other</td>
<td>73</td>
<td>6.04</td>
</tr>
<tr>
<td>Total</td>
<td>1207</td>
<td>100</td>
</tr>
</tbody>
</table>

ID=intellectual disability
3.4.6 Hospitalization rates for specific conditions

Table 3.5 compares hospitalization rates for specific ACS conditions between persons with and without an intellectual disability for the years 1999 to 2003. The highest rate ratios were for epilepsy (54.1; CI=43.1, 67.9) and schizophrenic disorders (14.8; CI=11.5, 18.9). The rate ratios for appendicitis (0.81; CI=0.53, 1.21) and pelvic inflammatory disease (1.84; CI=0.92, 3.70) hospitalizations were not statistically significant.
Table 3.5. Hospitalization rate comparisons for specific ambulatory care sensitive conditions between persons with and without an intellectual disability, Manitoba, 5 calendar years (1999-2003)

<table>
<thead>
<tr>
<th>Specific ACSC and appendicitis</th>
<th>Population</th>
<th>Crude rate(^a) (per person-year (x\ 1000))</th>
<th>Crude rate ratio</th>
<th>Rate ratio (Adjusted for age-sex-region)</th>
<th>95% CI (p-value)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Epilepsy</td>
<td>Persons with ID</td>
<td>329/41 013</td>
<td>8.02</td>
<td>54.93</td>
<td>54.13</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td>43.14, 67.92</td>
</tr>
<tr>
<td></td>
<td>Persons without ID</td>
<td>860/5 888 776</td>
<td>0.15</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Schizophrenic disorders</td>
<td>Persons with ID</td>
<td>256/41 013</td>
<td>6.24</td>
<td>9.98</td>
<td>14.75</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td>11.49, 18.94</td>
</tr>
<tr>
<td></td>
<td>Persons without ID</td>
<td>3683/5 888 776</td>
<td>0.63</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Asthma(^b)</td>
<td>Persons with ID</td>
<td>26/25 644</td>
<td>1.01</td>
<td>2.08</td>
<td>2.05</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td>1.35, 3.11</td>
</tr>
<tr>
<td></td>
<td>Persons without ID</td>
<td>2105/4 320 017</td>
<td>0.49</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Diabetes(^c)</td>
<td>Persons with ID</td>
<td>61/15 828</td>
<td>3.87</td>
<td>4.25</td>
<td>4.72</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td>3.50, 6.36</td>
</tr>
<tr>
<td></td>
<td>Persons without ID</td>
<td>2922/3 212 335</td>
<td>0.91</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Pelvic inflammatory disease(^d)</td>
<td>Persons with ID</td>
<td>8/17 365</td>
<td>0.46</td>
<td>1.67</td>
<td>1.84</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td>0.92, 3.70</td>
</tr>
<tr>
<td></td>
<td>Persons without ID</td>
<td>820/2 980 990</td>
<td>0.28</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Constipation</td>
<td>Persons with ID</td>
<td>50/41 013</td>
<td>1.22</td>
<td>7.13</td>
<td>7.89</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td>4.40, 14.18</td>
</tr>
<tr>
<td></td>
<td>Persons without ID</td>
<td>1007/5 888 776</td>
<td>0.17</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Appendicitis</td>
<td>Persons with ID</td>
<td>24/41 013</td>
<td>0.59</td>
<td>0.91</td>
<td>0.81</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td>0.53, 1.21</td>
</tr>
<tr>
<td></td>
<td>Persons without ID</td>
<td>3805/5 888 776</td>
<td>0.65</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

ID=intellectual disability

\(^a\): Rate = number of hospitalizations / number of person years

\(^b\): Calculated among persons greater than 11 and less than 70 years of age

\(^c\): Calculated among persons greater than 19 and less than 60

\(^d\): Calculated among females only
3.4.7 Rate ratios adjusted for disease prevalence

Table 3.6 shows rate ratios comparing persons with and without an intellectual disability, adjusting for disease prevalence. The prevalence of asthma and diabetes is higher among persons with an intellectual disability. The adjusted rate ratio did not change appreciably for asthma when comparing results from table 3.5 to table 3.6; however, for diabetes there is a 20% decrease in the rate ratio adjusted for prevalence.

Table 3.6. Rate ratios for asthma and diabetes adjusted for prevalence of disease between persons with and without an intellectual disability, Manitoba, 5 calendar years (1999-2003)

<table>
<thead>
<tr>
<th>Disease</th>
<th>Population</th>
<th>Crude prevalence of disease values (1999)&lt;sup&gt;a&lt;/sup&gt;</th>
<th>Prevalence (%)</th>
<th>Rate ratio (Adjusted for age-sex-region-disease prevalence)</th>
<th>95% CI (p-value)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Asthma</td>
<td>Persons with ID</td>
<td>220/4680</td>
<td>4.70</td>
<td>2.10</td>
<td>(1.39, 3.16) p&lt;0.0004</td>
</tr>
<tr>
<td></td>
<td>Persons without ID</td>
<td>37 219/847 194</td>
<td>4.39</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Diabetes</td>
<td>Persons with ID</td>
<td>156/3016</td>
<td>5.17</td>
<td>3.73</td>
<td>(2.63, 5.29) p&lt;0.0001</td>
</tr>
<tr>
<td></td>
<td>Persons without ID</td>
<td>16 287/630 821</td>
<td>2.58</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

ID=intellectual disability

<sup>a</sup>: Prevalence of disease=number of persons diagnosed with disease using algorithm described in method section/population of Manitoba estimate for 1999. Persons greater than 19 and less than 60 for diabetes, persons greater than 11 and less than 70 years for asthma.
3.5 Discussion

3.5.1 Summary of main results

Persons with an intellectual disability living in Manitoba were consistently hospitalized for ACS conditions at a higher rate than persons without an intellectual disability. Rate ratios significantly higher than one were calculated across time, age groups, and regions. Age group and region modified the risk intellectual disability had on being hospitalized for an ACS condition. Hospitalization rates for epilepsy and schizophrenic disorders were respectively 54 and 15 times higher for persons with an intellectual disability than for persons without an intellectual disability. Taking into account the prevalence of disease for the populations changed the estimated rate ratios for diabetes but not asthma.

3.5.2 Interpretation of results in context of prior research

Among persons with an intellectual disability included for analysis, males made up a larger proportion than females (57.7% vs. 42.3% in 2003). This is consistent with prior research and is possibly due to a large number of genes concerned with mental functions found on the X chromosome (Percy, 2007). Males have only one X chromosome and therefore mutations to this chromosome will affect males more than females.

The current study arose from the results of prior research from Ontario published in 2005 (Balogh et al., 2005). Similar to the current study, Balogh et al. found that persons with an intellectual disability were hospitalized for ACS conditions at higher rates than the general population. The study from Ontario found rates of hospitalization to be almost 3 times higher for persons with an intellectual disability compared to the general
population; a corresponding rate ratio of 6 was obtained from the current study. The results from the two studies are not directly comparable since they used different ACS condition lists. In particular, the current list included conditions deemed, by experts in the field of intellectual disabilities, to have potentially better outcomes when properly managed by primary care (e.g. constipation) (see chapter 2 or (Balogh R.S. et al., 2010b)).

A recent study based in Montreal, Canada found no differences in ACS condition hospitalizations between a sample of children with developmental delays (n=107) and a control group (Nachshen et al., 2009). The study from Montreal had a smaller sample size and included a heterogeneous group of children with disabilities which may account for the differences in results. No other studies reporting on ACS conditions for persons with an intellectual disability could be found; however, higher rates have been reported for other vulnerable populations such as persons with physical disabilities and mental illnesses (Armour et al., 2009; Li et al., 2008). A study from the state of New York found that the odds of an ACS hospitalization among persons with mental illnesses was up to 4 times higher than for persons without mental illnesses (Li et al., 2008). For a group of privately insured persons in the United States, higher rates of hospitalizations for urinary tract infections were found among persons with spina bifida when compared to persons without this physical disability (Armour et al., 2009).

In this study, rate ratios comparing persons with and without an intellectual disability were lowest among the older populations. Among the 70+ years category, the rate ratio was not significantly different from 1 (RR 1.2; 95% CI=0.93, 1.64). This was not due to
a decrease in the rate among persons with an intellectual disability but rather an increase in the rate in the comparison population. The increased rate of hospitalization for ACS conditions among older age groups in the general population has been reported elsewhere (Kozak et al., 2001). Kozak et al. reported a rate of hospitalization for Americans in 1998 that was twice as high for persons between the ages of 75-84 compared to persons in the 65-74 age-group. This suggests that, as persons without an intellectual disability age, their health care needs and/or primary care’s ability to manage them become more similar to those of persons with an intellectual disability. Other studies have found that in later life there is a convergence in terms of health, health care, and social care needs between people with and without an intellectual disability (Holland, 2000). This has been attributed to the ‘healthy survivor’ effect whereby persons with an intellectual disability associated with more severe disease die at a younger age leaving a relatively healthier group in older age. Some etiologies for intellectual disability (e.g. Down syndrome) are associated with premature aging (Bigby, 2007). This may explain in part why rates of hospitalization are high among persons with an intellectual disability, even for relatively younger age groups.

Consistent with other published reports, this research found lower rates of hospitalization for ACS conditions among urban residents (Ansari, 2007; Public Health Division, 2001); however, among the urban population, persons with an intellectual disability are hospitalized at a higher rate than their counterparts without an intellectual disability (RR 7.0; 95% CI=6.2, 8.0). This contrast exists in rural areas also, but to a lesser extent (RR 5.3; 95% CI=4.6, 6.1). This might be because differences in health status between
persons with and without an intellectual disability are more drastic in urban areas. Another possibility is that the proximity of primary care in urban areas has a greater impact on persons without an intellectual disability.

The rate ratios for epilepsy (54.1; CI 95% 43.1, 67.9) and schizophrenic disorders (14.8; CI 95% 11.5, 18.9) were surprisingly high. These two conditions were the most common conditions for which persons with an intellectual disability were hospitalized: They represented 27 and 21% of all ACS condition hospitalizations respectively. These were considerably higher percentages than those found for persons without an intellectual disability (2% for epilepsy, 9% for schizophrenic disorders). Differences in rates between the two populations may be partly explained by differences in disease prevalence. Although results vary according to methodology, studies have found that 4.4% of adults with an intellectual disability also experience a psychotic disorder compared to only .5% in the general population (Cooper et al., 2007; Public Health Division, 2001; Singleton et al., 2000). Similarly, the prevalence of epilepsy among persons with an intellectual disability is between 14 and 44%, considerably higher than estimates for the general population (0.3-0.8 %) (Bowley & Kerr, 2000; Forsgren et al., 2005).

The current study found no significant difference in rates of hospitalization for appendicitis between persons with and without an intellectual disability (0.8; CI 95% 0.5, 1.2). Past research has not investigated hospitalization rates for this condition among persons with an intellectual disability. Appendicitis is considered a nonambulatory care
sensitive condition because there are no primary care based strategies for preventing a hospitalization for this condition (Bindman et al., 2005). Hospitalization rates for appendicitis are useful as an indicator of access to emergency operative care because the condition is characterized by a definitive need for hospitalization for treatment, a hospitalization rate that is relatively consistent over time and across populations, and no known biological predisposition by race or ethnic group (Krajewski et al., 2009; Saha et al., 2007). The non-significant rate ratio found in the current study indicates that there is no evidence of disparity in access to emergency operative care between persons with and without an intellectual disability.

Whether research on ACS condition hospitalization rates should control for the prevalence of disease depends on assumptions about how effective the health care system is at addressing challenges to population health (Ansari, 2007). Some authors contend that successful primary care can limit ACS condition hospitalizations even when disease prevalence is high (Ansari, 2007). This study takes a conservative approach and assumes that even the most successful health care cannot overcome all levels of population disease burden. It was possible for asthma and diabetes, to test how much disease prevalence influenced rate ratio results. Using the algorithms that identify disease prevalence in populations using administrative databases, the current study found higher rates of asthma and diabetes among persons with an intellectual disability. These measures are useful by themselves, since asthma and diabetes estimates are not well researched for this population (Rey-Conde & Lennox, 2007; Schieve et al., 2009). Adjusting for prevalence had very little impact on the rate ratio for asthma (2.05 to 2.10) but had the effect of
decreasing the estimate for diabetes (4.72 to 3.73). Higher disease prevalence appears to act as a confounder of the association between ACS condition hospitalizations for diabetes and intellectual disability status. This may not be translatable to other diseases investigated in the study. Other research has found little influence by prevalence on ACS admission rates. Laditka et al. compared ACS admission rates between African-Americans and Hispanics to non-Hispanic whites and found that significant relative risks persisted despite adjustment for prevalence of disease (Laditka et al., 2003). An Australian study by Ansari et al. found that disease prevalence was not a significant predictor of ACS hospitalization in a multivariate regression model (Ansari et al., 2006).

3.5.3 Alternative reasons for findings
This study makes the assumption that the higher level of hospitalization for ACS conditions among persons with an intellectual disability is inappropriate. It could be that in some cases hospitalization is necessary to minimize risk to the person with an intellectual disability. Physicians may err on the side of caution or rely on the increased support available from a hospital setting as opposed to a community outpatient setting to care for, or perform procedures on, persons with intellectual disabilities. For example, persons with an intellectual disability are sometimes hospitalized for simple dental procedures that are usually done in community dental clinics (Balogh et al., 2004).

Several other factors have been identified in the literature that could potentially explain the differences in ACS admission rates between persons with and without an intellectual disability. A review of research using ACS conditions provides a summary of the impact
of factors such as severity of illness, socioeconomic status, health system organization, lifestyle, environment, and propensity to seek care (Ansari, 2007). At least three of these factors (severity of disease, socioeconomic status, health system organization) may noticeably influence the association found between intellectual disability status and the risk of ACS condition hospitalization.

Severity of illness is considered a strong predictor for ACS condition hospitalization. Disease severity is sometimes measured by grouping comorbidities for a given illness (also known as disease staging) (Yuen, 2004). Since persons with an intellectual disability are known to experience higher rates of morbidity than the general population they may also experience more severe forms of a disease, thus requiring more hospitalizations for ACS conditions.

Socioeconomic status and health system organization are modifiable factors that could potentially be influenced using social or health interventions. Most studies have found that measures of socioeconomic status like income were strong predictors of ACS hospitalization (Ansari, 2007). Studies have also consistently identified a link between better access to primary care (measured by physician supply or access to subsidized outpatient care) and ACS condition hospitalization rates (Ansari, 2007). Many of these studies, however, come from the United States, which is different than Canada and many other developed countries in two relevant areas: The United States experiences greater inequalities in wealth distribution and it does not publicly fund universal access to
physician and hospital services for large segments of its under 65 population (United Nations Development Programme, 2007; Szick et al., 1999).

3.5.4 Strengths and limitations

This research was a secondary analysis of administrative data and experienced the limitations typical of such a design. While the data from health services have been tested for their validity and reliability, the data from the family services and education enrollment have only recently been made available for analysis and have not undergone the same quality evaluation. It is possible that some persons with an intellectual disability living in Manitoba during the study period were not identified in any of the databases used and these are likely persons with a mild form of intellectual disability. Research from other jurisdictions has also reported that using data from administrative databases probably underrepresents this population (Iezzoni, 2002). This study is, however, an improvement on the other Canadian-based study (Balogh et al., 2005) that relied solely on a hospital admissions database for identification and found that at least 50% of those records did not consistently identify persons with an intellectual disability. Using multiple databases maintained at the Manitoba Centre for Health Policy, the current study identified 8106 Manitobans with an intellectual disability for the year 2003. This represents .7% of the Manitoba population, which is close to estimates made by Canadian based prevalence studies (Ouellette-Kuntz & Paquette, 2001).

Another limitation of the current study is a reliance on routinely collected hospital admissions data to identify instances of hospitalization for ACS conditions. These data
are not primarily collected for research purposes and require evaluations for quality in order to validate their use as a source of information for health related research. Two common approaches to evaluate data quality are record linkage and re-abstraction (Manitoba Centre for Health Policy, 2009d). Record linkage joins two or more separate sources of information on a specific individual. The degree of agreement between items on both records provides a measure of reliability. Re-abstraction focuses on how reliably information from hospital charts moves into computerized form. Reviews have summarized the results from studies assessing the quality of available administrative data in Canada (Roos et al., 2005a; Williams & Young, 1996). Data from administrative databases for demographic characteristics (sex, age) and mortality are complete and reliable with discrepancies between datasets reaching only 2% (Roos et al., 1993; Roos & Nicol, 1999; Williams & Young, 1996). Although some authors report reliable information for place of residence others stated that this is an area that needs more exploration (Roos et al., 2005a; Williams & Young, 1996). It is estimated that 12% of Manitobans move across postal codes annually and there is a lag between the move and when corresponding changes are made to the registry (Roos et al., 2005a). It appears, however, that almost all moves are noted within two years (Roos & Nicol, 1999).

The reliability of diagnoses found in administrative databases depends on the diagnosis. For example, a comparison between abstracted data and chart information from hospitalizations in Saskatchewan for acute myocardial infarction showed exact agreement in 97% of cases but only in 58% for depressive disorder (Rawson & Malcolm, 1995; Rawson et al., 1997). The reliability of coding has been evaluated for only a few ACS
conditions included in the current study. A study using hospitalization records from Quebec found an agreement level of 95% for asthma (Delfino et al., 1993). In Saskatchewan, the diagnosis concordance between computerized data and medical charts was good for schizophrenia (94%) (Rawson et al., 1997). It should be noted that 3-digit codes were used in the current study to identify most ACS conditions. This has been shown to give more accurate re-abstracting results than coding using 4 or 5 digit codes (Fisher et al., 1992; Henderson et al., 2006).

3.6 Conclusions

3.6.1 Policy implications

Analysis using ACS conditions can contribute to improving the effectiveness and efficiency of the health system by identifying less expensive models of care (Ansari, 2007). Organising health services differently has been suggested as one way to decrease the number of hospitalizations for ACS conditions among persons with an intellectual disability (Balogh et al., 2008). Decreasing the number of ACS condition hospitalizations would lead to potentially better health and significant cost savings, if it could be shown that hospitalizations for ACS conditions are more costly than appropriate community management of the conditions.

This study identified three groups among persons with an intellectual disability that could potentially benefit most from health service reorganisation. These are persons with an intellectual disability who are also diagnosed with epilepsy and/or schizophrenia and persons with an intellectual disability who are transitioning from child to adult health
related services. Young people with an intellectual disability face many challenges as they reach adulthood and attempt to transition out of school and out of health services provided for children. As persons with an intellectual disability grow into adulthood many find it difficult to find meaningful occupations which can lead to negative consequences for their physical and mental health (Law et al., 1998; Whiteford, 2000). In most developed countries, it is also necessary for persons with an intellectual disability to break links with specialized and integrated care established during childhood because they become ineligible for paediatric health care services usually after age 18 (young 2006). The problems persons with disabilities face as they reach adulthood and attempt to use fragmented health services that are not focused on their needs has been well documented (Knapp et al., 2008; Lotstein et al., 2009; Morris, 1999; Young et al., 2006). This may in part explain why the current study found that rate ratios for ACS condition hospitalizations increased from 8.5 for the 10-19 age group to 11.5 for the 20-29 age group. Some researchers have suggested that transition health teams or the use of medical homes may help to overcome the challenges (Kelly et al., 2008; Lotstein et al., 2009; Morris, 1999).

In Toronto, Canada, the Surrey Place Centre provides physician consultations in family medicine, paediatrics, neurology and psychiatry to support professionals in mainstream health care who provide services to persons with an intellectual disability. The programs provided by this local initiative may have a significant impact on the health of persons with an intellectual disability since it includes support to specialists who specifically train to care for persons with seizure disorders (neurologists) and mental health problems
(psychiatrists). Presumably, the Centre is also able to facilitate the transition from paediatric to adult care since the two specialties are administered by the same organization. Unfortunately there is no research to support these hypotheses which may be one reason the Centre’s model has not evolved beyond its Toronto jurisdiction.

Research has shown that there are can be benefits to reorganising health services. Randomized trials from England and the Netherlands have shown that multidisciplinary outpatient teams were able to effectively decrease hospitalizations for persons with an intellectual disability and a comorbid mental health condition (Hassiotis et al., 2001; Van Minnen et al., 1997). Both studies found significant costs savings for the group receiving care from the multidisciplinary outpatient teams compared to standard treatment. Preventing hospitalizations has benefits beyond costs. These include the decreased risk of hospital acquired infections and improved quality of life, through reduced disruptions of everyday occupations, for individuals and caregivers.

Hospitalization rates for ACS conditions could be used as a tool to continuously monitor primary care as part of a surveillance system (Ansari, 2007). Monitoring could take place over time and between regions to identify potential gaps in primary care allowing health planners and policy makers to implement interventions where and when warranted.

3.6.2 Research implications
The current research compared rates of ACS hospitalizations between persons with and without an intellectual disability. Demographic variables and disease prevalence (where
possible) were included as control variables in the statistical models. Future research should include other potentially important risk factors such as disease severity, socioeconomic variables, and measures of health system organization. Including measures of barriers to primary care in the analysis may point to potential health system or public health interventions with health benefits for persons with an intellectual disability.

The very high rate ratio results for epilepsy and schizophrenic disorders should be investigated further. One way to control for the possible influence of different disease prevalence between persons with and without an intellectual disability would be to compare rates of hospital readmissions for these conditions.

International comparisons in rates of ACS condition hospitalizations would provide insight on the different approaches to health services for persons with an intellectual disability that have evolved since deinstitutionalization. For instance, ACS condition hospitalization rates in countries without specialty health services for persons with an intellectual disability could be compared to those in countries like the United Kingdom or the Netherlands. This would provide evidence for, or against, the use of specialty health teams.
Chapter 4: Factors associated with hospitalizations for ambulatory care sensitive conditions among persons with an intellectual disability-a publicly insured population perspective

This chapter is a longer version of a manuscript that will be submitted for publication to the Journal of Intellectual Disability Research:

4.1 Abstract

Background: Persons with an intellectual disability represent between 1 and 3% of the population. They experience higher rates of disease than the general population and face barriers to primary care. Hospitalizations for ambulatory care sensitive conditions are used as an indicator of access to, and the quality of, primary care. Little research on health service utilization among persons with an intellectual disability comes from Canada.

Objective: The objective is to identify factors associated with hospitalizations for ambulatory care sensitive conditions among adults with an intellectual disability living in a publicly insured province of Canada.

Methods: Adults with an intellectual disability living in a Canadian province between 1999 and 2003 were identified from administrative databases. Observations over 5 years among persons who were hospitalized for ambulatory care sensitive conditions were compared to persons who were not. Using a conceptual model, independent variables were selected and an analysis performed to identify which were associated with hospitalizations for ambulatory care sensitive conditions. Appropriate statistical analyses were utilized to account for the correlated nature of the observations.

Results: In the multivariate regression analysis, four variables remained significantly associated with the likelihood of being hospitalized for an ambulatory care sensitive condition. Living in a rural area (odds ratio 1.3; 95% CI=1.0, 1.8), living in an area with a high proportion of First Nations people (odds ratio 2.3; 95% CI=1.3, 4.1), and experiencing higher levels of comorbidity (odds ratio 25.2; 95% CI=11.9, 53.0) were all associated with a higher likelihood of being hospitalized for an ambulatory care sensitive condition. Dwelling in higher income areas had a protective effect (odds ratio 0.56; CI=0.37, 0.85). None of the health service resource variables showed statistically significant associations.

Conclusions: Persons with an intellectual disability experience inequity in hospitalizations for ambulatory care sensitive conditions according to rurality, income, and proportion who are First Nations in a geographic area. This suggests that addressing the socioeconomic problems of poorer areas and specifically areas densely populated by First Nations people may have an impact on the number of hospitalizations for ACS conditions. Study strengths and limitations and areas for potential future research are discussed.
4.2 Introduction

Intellectual disability originates before age 18 and is characterized by significant limitations in intellectual functioning and adaptive behaviour (American Association on Intellectual and Developmental Disabilities, 2009). Limitations in adaptive behaviour influence many everyday social and practical skills and are measured with standardized tests. An IQ test score of 70 or below is generally used as the intelligence criterion. Other terms used to refer to this population include ‘developmental disability’, ‘learning disability’, and ‘mental retardation’ (Ouellette-Kuntz et al., 2005). The World Health Organization estimates that the prevalence of intellectual disability is between 1% and 3% (World Health Organization, 2001b).

Since the 1970s many developed countries have enacted legislation that led to the deinstitutionalization of persons with an intellectual disability (Mansell, 2005). Deinstitutionalization is the process of closing institutional facilities and placing their residents in more community based housing. Deinstitutionalization has led to improved quality of life; however, research has shown that primary care for persons with an intellectual disability has been inadequate (Conroy et al., 2003; Havercamp et al., 2006; Lennox & Kerr, 1997). The majority of research on the health status of persons with an intellectual disability and their utilization of health services comes from the United States, the United Kingdom, the Netherlands, Australia, and New Zealand, countries that have all found that, compared to the general population, persons with an intellectual disability experience lower health status, higher morbidity and premature mortality (Ouellette-
Kuntz et al., 2005); there is consensus that these health concerns can be partly attributed to health services and in particular, primary care (Ouellette-Kuntz, 2005).

Similar conclusions were made by government commissioned papers. In the United Kingdom “Valuing People” was presented to Parliament in 2001 (Department of Health, 2001). It stated that many persons with an intellectual disability found encounters with primary care frustrating and difficult. In the United States ‘Closing the Gap’ was published as a blueprint to improve the health of persons with an intellectual disability (United States Public Health Service, 2001). It reported that health care providers missed opportunities to educate clients with an intellectual disability and their families concerning a range of primary care and prevention topics. The paper identified shortages of appropriately trained and experienced providers at all points of contact in the health care system including primary care. It concludes that compared with other populations persons with an intellectual disability of all age groups “experience poorer health and more difficulty in finding, getting to, and paying for appropriate health care” (United States Public Health Service, 2001) p. xii).

Ambulatory care sensitive (ACS) conditions are defined as conditions where appropriate primary care may prevent or reduce the need for hospitalization (Canadian Institute for Health Information, 2009b). Preventing the need for a hospitalization is of interest to health care consumers and health policy makers since it should decrease the costs of providing care (Shi et al., 1999). Not all hospitalizations are avoidable; however, timely and effective primary care in the community could prevent the onset of this type of
condition, control an acute illness or manage a chronic condition (Billings et al., 1993). Asthma, diabetes and congestive heart failure are, for example, commonly considered ambulatory care sensitive. High rates of ACS condition hospitalizations have been used by several countries as an indirect measure of problems with access to, and quality of, primary care (Caminal et al., 2004; Canadian Institute for Health Information, 2009b; Public Health Division, 2001; Porter et al., 2007). Rates for these conditions have the potential to be used as a tool to regularly monitor health services by including them in surveillance systems of acute and chronic conditions (Ansari, 2007). Analyses of ACS conditions have also been used to identify and measure the impact of barriers to primary care in the general population.

In a review of ACS conditions, Ansari et al. identified ten categories of factors that affect variation in ACS condition hospitalizations (Ansari, 2007):

1) Demographics (e.g. sex and age),
2) Socioeconomic status (e.g. income),
3) Rurality,
4) Health system factors (e.g. primary care physician supply),
5) Prevalence of ACS conditions between comparison groups,
6) Lifestyle factors (e.g. smoking and alcohol consumption),
7) Environment (e.g. air pollution),
8) Adherence to medication,
9) Severity of illness, and
10) Propensity to seek care.

Very few studies exist that investigated ACS conditions among persons with an intellectual disability. A recent study based in Montreal, Canada examined a sample of children with developmental delays (n=107) including at least six persons with an intellectual disability (Nachshen et al., 2009). Compared to a control group experiencing
no delays, no differences in ACS hospitalizations were found. An Ontario based study on
the other hand found that adults with a developmental disability (including intellectual
disability, autism and fetal alcohol syndrome) were admitted 1018 per 100 000
population for an ACS condition (Balogh et al., 2005). This is close to three times higher
than the rate reported by the Canadian Institute for Health Information for the general
population of Ontario in the same year (345 per 100 000 population) (Canadian Institute
for Health Information, 2009a). Differences in results have been attributed to the
different age groups used in the comparisons (Nachshen et al., 2009); while this may be
the case, the disabilities included in the study populations from the two studies were also
considerably different.

The objective is to identify factors associated with hospitalizations for ACS conditions
among adults with an intellectual disability living in a publicly insured province of
Canada.

4.3 Methods

4.3.1 Study design

This is a population based cohort study of ACS hospitalizations using retrospective data.
It is retrospective in the sense that all the data for the exposure and outcome variables
were collected in an administrative database prior to the initiation of the study. No
predominant focal relationship between an independent and dependent variable is offered.
Instead, potential independent variables are identified using a conceptual model and an
expected direction for each association is hypothesized.
4.3.2 Study population

The study population were adults with an intellectual disability, 19 years and over, and residing in the province of Manitoba between 1999 and 2003.

4.3.3 Data source and management

The data for this objective were accessed at the Manitoba Centre for Health Policy (MCHP) at the University of Manitoba's Faculty of Medicine. The centre conducts research concerning the health of Manitobans by examining patterns of illness in the population and use of health care services (Roos et al., 1999). MCHP houses a data system called the Population Health Research Data Repository (Repository) (Roos et al., 2003). The Repository contains a collection of administrative databases that hold anonymized records of Manitobans' contacts with the health care, social services, and education systems (see appendix F). The Repository also contains a population-based registry, which includes all Manitobans registered to receive health care, making it possible to track moves into, out of, and around the province (including births and deaths) (Roos & Nicol, 1999). The entire population of the province is covered by the Manitoba Health Services Insurance Plan (Roos et al., 2005b). The validity and utility of the information in the Repository have been well documented (Brownell et al., 2001; Roos & Nicol, 1999).

Each individual represented in the various databases contained in the Repository is assigned a scrambled unique numeric identifier. Using the identifier, information on the
same person from two or more databases can be merged into one database (Manitoba Centre for Health Policy, 2009e). Persons with an intellectual disability living in Manitoba were identified using information from five databases: the population based registry, hospital records, medical services, family services, and education enrolment. Details on how persons with an intellectual disability were identified in each of the databases were described earlier (see section 3.3.3 or Balogh R.S. et al., 2010a). The unique identifier was used to track any persons identified with an intellectual disability from any of these databases from 1984 to 2007. This was necessary since persons with an intellectual disability are not consistently identified in administrative databases (Balogh et al., 2005). From this larger pool of persons with an intellectual disability, only those living in Manitoba of 19 years of age or over at any time between 1999 and 2003 were included for analysis.

4.3.4 Dependent variable

The dependent variable was specified as a binary response. Occurrences of hospitalization for an ACS condition were coded 1 and instances when such a hospitalization did not occur were coded 0. The list of ACS conditions and corresponding international classification of disease codes can be found in appendix H (World Health Organization, 1977). The list is based on ACS conditions relevant to persons with an intellectual disability developed in chapter 2 (or see Balogh R.S. et al., 2010b). Admissions for ACS hospitalizations that occurred within 30 days of a discharge for the same condition were not included.
4.3.5 Independent variables

The Andersen Behavioral Model of Health Service Utilization was used as a framework to conceptualize the outcome and related independent variables (Andersen, 1995). The Andersen model’s conceptual categories were used to select and group independent variables potentially associated with the likelihood of being hospitalized for an ACS condition among persons with an intellectual disability. The conceptual categories are predisposing characteristics (social and demographic characteristics and health-related attitudes that exist prior to an illness episode), enabling resources (the organization of health care, quality of social relationships and economic situation are all factors that can facilitate or impede service use), need variables (characterized by the illness or impairment for which services are sought) and health care system resources (variables such as the number of hospital beds or specialists available in a region). A list of the variables available from the Manitoba repository is provided in appendix L.

4.3.5.1 Predisposing

There were four variables describing predisposing characteristics. Age was categorized into age groups consistent with phases of life and prior research: adulthood (19-50) and older adults (51+) (Stamp et al., 1998; Laditka et al., 2005; Connolly, 2001). The 51+ age group was used for reference. Higher rates of ACS condition hospitalizations have been found among older age groups (Ansari, 2007; Laditka et al., 2005). Sex was included as an independent variable with females used as the reference group. Some studies have found higher rates of ACS hospitalizations among females (Ansari, 2007; Kozak et al., 2001). Place of residence was categorized as rural or urban. Urban
(reference) was defined as any residence with a postal code from Winnipeg (population=663,443 in 2004) or Brandon (population=48,612 in 2004), and rural was defined as any other postal code (Manitoba Centre for Health Policy, 2008; Manitoba Health, 2004). Living in a rural area is associated with a higher rate of ACS hospitalization (Shi et al., 1999). Information on the proportion of First Nations people living in a dissemination area was obtained from Census Canada (Manitoba Centre for Health Policy, 2009a). This continuous variable was grouped into four categories in order to facilitate interpretation. The rationale for including this variable is based on results from the province of Ontario’s aboriginal population that have shown increased rates of hospitalizations for ACS conditions that could not be explained by the geographic isolation and low socioeconomic status frequently experienced by this population (Shah et al., 2003).

4.3.5.2 Enabling

Enabling resources describe the means individuals have available to them for the use of services (Andersen, 1995). Income and health insurance can play an important role. Mean household income data from Census Canada were used to rank the poorest to the wealthiest dissemination areas of Manitoba and group them into quintiles (poorest=1 and wealthiest=5) (Manitoba Centre for Health Policy, 2009a). Since income distributions in rural and urban areas are different, quintiles were first calculated for rural and urban regions separately and then combined (Manitoba Centre for Health Policy, 2008).

According to the Census, income is the sum of incomes of all persons in the household,

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A dissemination area is the smallest geographic area for which all Census Canada data are published. It is composed of one or more neighbouring blocks with a population of 400 to 700 persons (Statistics Canada, 2009)
where “household” refers to all persons who live within the same dwelling, regardless of their relationship to each other (Statistics Canada, 2008). Studies from the United States have consistently found strong associations between measures of socioeconomic status and ACS condition hospitalizations (Ansari, 2007). This may be less evident in Canadian provinces like Manitoba which administer health insurance plans that provide universal and comprehensive coverage for medically necessary hospital and medical practitioner care. The objective of the government administered health plan is to provide reasonable access to health services to all Manitobans without financial or other barriers (Health Canada, 2004). Indeed, a study on children from Spain, which has universal finance for health care, found no association between income and ACS condition hospitalizations (Casanova et al., 1996).

Andersen sees the extent and quality of social relationship as an enabling resource that is an important predictor of health service use (Andersen, 1995). Marital status (not-married versus married) was used as a measure of the presence of a significant social relationship among adults with an intellectual disability. Being married can also be used to identify persons with higher communication and intellectual abilities. Being married has been shown to be associated with better health outcomes and presumably fewer ACS condition hospitalizations (Liu & Umberson, 2009).

Visits made to a primary care physician were included as an enabling variable. This variable was updated each year a person contributed to the risk set. A one year time lag was applied thus ensuring that the presence or absence of a visit for each observation
occurred prior to a potential hospitalization. This avoids the possibility that visits to a primary care physician were follow up visits after a hospitalization for a serious illness. The variable was coded as ‘0’ (reference) if there was no visit and ‘1’ if one or more visits occurred to a family physician or general practitioner. After controlling for other independent variables, persons who have visited a primary care physician should have a decreased probability of being hospitalized for an ACS condition. ACS condition hospitalizations have been proposed as an indicator of access to, and the quality of, primary care (Porter et al., 2007). Some research has shown that increased primary care physician supply or having a regular source of care decreases the risk of being hospitalized with an ACS condition (Ansari, 2007). In contrast, a study from Manitoba reported that higher use of primary care among urban poor and wealthy residents was associated with more hospitalizations for ACS conditions (Roos et al., 2005b).

4.3.5.3 Need

Need variables refer to illness level which may be either perceived by the individual or evaluated by the health delivery system (Aday & Andersen, 1974). According to Andersen evaluated need “represents professional judgment about people’s health status and their need for medical care” (Andersen, 1995) 3). Consistent with a study by Laditka on ACS hospitalizations, this study used comorbidities to represent evaluated need (Laditka, 2004). Greater numbers and more serious comorbidities indicate greater need and should be associated with a higher risk for an ACS hospitalization.
Comorbidities were measured using the Adjusted Clinical Group system developed by the Johns Hopkins University School of Hygiene and Public Health in Baltimore (Manitoba Centre for Health Policy, 2007a; The Johns Hopkins University Bloomberg School of Public Health, 2003). The system was validated for use using data from Manitoba in research by Reid et al. (Reid et al., 1999). The system groups individuals based on their age, gender, and all known medical diagnoses in hospital and physician claims over one year. Each individual is assigned an Adjusted Clinical Group value which is a measure of that person’s comorbidity level representing expected or actual consumption of health services. For this study, the Adjusted Clinical Group reflects a person’s comorbidity level in the year prior to being potentially hospitalized. There are a total of 106 Adjusted Clinical Group values that range from 0 to 5070. Each Adjusted Clinical Group value includes individuals with similar pattern of comorbidity and similar expected resource use. At one extreme a value of 0 represents a group of individuals who did not use health services, are assumed to have no comorbidities requiring health care attention, and who are therefore least likely to require health services in the following year; at the other extreme, a value of 5070 would be given to a group of individuals with multiple (10 or more) comorbidities and who are most likely to require further care from health services. When the Adjusted Clinical Group variable was treated as continuous, it showed evidence of a non-linear relationship with hospitalizations for ACS conditions; four categories were therefore created to represent groups with the highest (4220-5070), high (3500-4210), low (900-3400), and lowest (0-800) Adjusted Clinical Group values (Frohlich et al., 2006).
4.3.5.4 Health care system resources

Health care system resources were included as independent variables to recognize the distribution and organization of resources in the health care system as important determinants of the population’s use of services (Andersen, 1995). Two continuous variables updated every year of the study were included in this category: Regional Health Authority beds per 100 population and Regional Health Authority primary care physician supply. In Manitoba, a Regional Health Authority is a governance structure set up by the province to be responsible for the delivery and administration of health services for a specific region (Manitoba Centre for Health Policy, 2006). There are 11 Regional Health Authorities: Winnipeg, Brandon, South Eastman, Assiniboine, Central, Parkland, North Eastman, Interlake, Burntwood, Norman, and Churchill. A map of the regions is provided in appendix M.

Regional Health Authority beds per 100 population was calculated by dividing the number of staffed nursing home and acute care beds by the number of persons in the general population living in the Regional Health Authority. In a study by Zhan et al, higher supply of hospital beds was associated with higher rates of ACS condition hospitalizations even after adjustment for other variables (Zhan et al., 2004). For each Regional Health Authority, primary care physician visit supply was calculated by dividing the number of visits to a primary care physician (general practitioner or family physician) by persons with an intellectual disability by the number of people with an intellectual disability living in a region. Higher values for primary care physician visit supply should be associated with a decreased likelihood of ACS hospitalization. Ansari’s
review of ACS conditions found that most studies that included a measure of physician supply reported a significant negative association; that is, the higher the physician supply the lower the risk of ACS condition hospitalization (Ansari, 2007).

4.3.6 Exclusions

Excluded were the observations from persons who were wards of the Public Trustee of Manitoba (21,055 observations, 1,091 persons). These individuals live throughout Manitoba but their location cannot be confirmed. They were not included in the analysis since many of the independent variables are reliant on the use of valid postal codes. Observations for people with missing census values for a dissemination area were also excluded (501 observations, 15 persons). This represented less than 1% of all observations.

4.3.7 Analysis

Using methods described by Allison, each individual’s time spent living in Manitoba was broken down into a set of 90-day units that were treated as distinct observations (Allison, 1995). The study period lasted 5 years, meaning individuals could contribute up to 20 observations each. If a person died or left the province during the study period, they would cease contributing to the risk set. The use of 90-day intervals is consistent with prior research applying regression analysis with ACS conditions as an outcome; it leads to increased power and allows for time varying variables to be included in the analysis (Laditka, 2004; Allison, 1995). The dataset was prepared for analysis by developing a ‘person-period’ layout of the data where each person has multiple records (one for each
90-day measurement occasion). For each 90-day period, the value for each independent variable was updated. Independent variables could be fixed over the entire 5-year period (e.g. sex), or potentially changed during a 90-day period or year (e.g. age, rural/urban). Observation periods were pooled and a multivariate regression model created to predict whether an event (i.e. an ACS condition hospitalization) did or did not occur in each time unit.

Logistic regression is the standard model used to analyze data where the dependent variable is binary. Logistic regression assumes that observations are independent of each other and violations of this assumption lead to invalid statistical inferences (Kuss, 2002). The current study analyzed a dataset of repeated observations of the same persons over time. These are likely to be correlated and the repeated observations are said to be clustered within the subject. The GENMOD procedure in SAS was therefore used to fit logistic regression models and to control for the correlated nature of data by invoking the method of Generalized Estimating Equations (GEE). GEE corrects for dependency between observations by adding a within-subject correlation structure or matrix (Twisk, 2003). The correlation matrix can take on different forms and must be specified when invoking GEE. An ‘exchangeable’ or ‘autoregressive’ structure is recommended when there are several time points (Allison, 2001).

The Quasilikelihood under the Independence model Criterion (QIC) statistic proposed by Pan was used to compare model fit (Pan, 2001). The more familiar Akaike’s Information Criterion (AIC) statistic is not available for models using GEE (SAS Institute, 2009).
QIC can be used to find an acceptable correlation structure by comparing and selecting the model that generates the smaller statistic.

Three steps were used to come to a final multivariate regression model with effect estimates for relevant independent variables. First the independent variables selected using the Andersen model were described using univariate statistics (numbers and percentages for count data and means and standard deviations for continuous variables). Secondly, the bivariate association between each independent variable and the outcome was evaluated. Thirdly, the independent variables with a score test p-value of .2 or less in the bivariate analysis were included in a multivariate regression analysis. The second and third steps analyzed data using the GEE method described above. The QIC statistic was used to evaluate model fit. Tests for possibly redundant or spurious associations were pursued where relevant.

4.4 Results

4.4.1 Descriptive statistics and bivariate results

For the 5-year period of the study, 3326 adults with an intellectual disability were included contributing a total of 55 449 observations (90-day periods). There were 519 hospitalizations for ACS conditions of which 212 were repeat admissions.

Table 4.1 shows the results of the univariate and bivariate analyses. Results of the univariate analysis showed that a majority of observations were from individuals who were between ages 19 and 50 (76%), male (51%), urban dwellers (56%), not married (66%), and from areas where less than 41% of the population was First Nations (88%).
Over the five years of the study, the rate of visits to a primary care physician was 86%. Keeping household income as a continuous variable, the median income was $41,930. Among the Regional Health Authorities, there were yearly averages of 0.4 beds per 100 population and 5 visits to a primary care physician per person with an intellectual disability. During the bivariate analysis, three of the variables did not reach a significance level high enough to be included in the multivariate analysis. The p-value from the score test statistic for sex, the number of hospital beds per 100 in a Regional Health Authority, and primary care physician supply were all greater than 0.2.
Table 4.1. Descriptive statistics and bivariate results for variables in relation to ambulatory care sensitive condition hospitalizations, person-90-day periods of adults with an intellectual disability living in Manitoba, 1999-2003 (n=55 449)

<table>
<thead>
<tr>
<th>Characteristic</th>
<th>Total person-90-day periods n=55 449 n (% col) or mean (SD)</th>
<th>ACS condition hospitalization n=519 n (% col) or mean (SD)</th>
<th>No ACS condition hospitalization n=54 930 n (% col) or mean (SD)</th>
<th>Crude odds ratio (adjusted for repeat observations only) (95% CI)</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Predisposing</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Age in years, by category *</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>19 to 50</td>
<td>42 176 (76.1)</td>
<td>376 (72.5)</td>
<td>41 800 (76.1)</td>
<td>0.82 (0.63, 1.08)</td>
</tr>
<tr>
<td>51+</td>
<td>13 273 (23.9)</td>
<td>143 (27.6)</td>
<td>13 130 (23.9)</td>
<td>1 (reference)</td>
</tr>
<tr>
<td>Sex</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Male</td>
<td>28 277 (51.0)</td>
<td>268 (51.6)</td>
<td>28 009 (51.0)</td>
<td>1.02 (0.78, 1.33)</td>
</tr>
<tr>
<td>Female</td>
<td>27 172 (49.0)</td>
<td>251 (48.4)</td>
<td>26 921 (49.0)</td>
<td>1 (reference)</td>
</tr>
<tr>
<td>Region *</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Rural</td>
<td>24 436 (44.1)</td>
<td>261 (50.3)</td>
<td>24 175 (44.0)</td>
<td>1.29 (0.99, 1.69)</td>
</tr>
<tr>
<td>Urban</td>
<td>31 013 (55.9)</td>
<td>258 (49.7)</td>
<td>30 755 (56.0)</td>
<td>1 (reference)</td>
</tr>
<tr>
<td>Proportion First Nations in dissemination area, by category*</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>71-100%</td>
<td>2428 (4.4)</td>
<td>56 (10.8)</td>
<td>2372 (4.3)</td>
<td>2.98 (1.80, 4.93)</td>
</tr>
<tr>
<td>41-70%</td>
<td>4514 (8.1)</td>
<td>65 (12.5)</td>
<td>4449 (8.1)</td>
<td>1.83 (1.23, 2.74)</td>
</tr>
<tr>
<td>11-40%</td>
<td>26 167 (47.2)</td>
<td>223 (43.0)</td>
<td>25 944 (47.2)</td>
<td>1.07 (0.80, 1.43)</td>
</tr>
<tr>
<td>0-10%</td>
<td>22 340 (40.3)</td>
<td>175 (33.7)</td>
<td>22 165 (40.4)</td>
<td>1 (reference)</td>
</tr>
<tr>
<td><strong>Enabling</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Marital status *</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>not married</td>
<td>36 718 (66.2)</td>
<td>370 (71.3)</td>
<td>36 348 (66.2)</td>
<td>1.26 (0.95, 1.68)</td>
</tr>
<tr>
<td>married</td>
<td>18 731 (33.8)</td>
<td>149 (28.7)</td>
<td>18 582 (33.8)</td>
<td>1 (reference)</td>
</tr>
<tr>
<td>Income, quintiles*</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>5th high</td>
<td>10 428 (18.8)</td>
<td>79 (15.2)</td>
<td>10 349 (18.8)</td>
<td>0.60 (0.39, 0.90)</td>
</tr>
<tr>
<td>4th</td>
<td>11 831 (21.3)</td>
<td>66 (12.7)</td>
<td>11 765 (21.4)</td>
<td>0.44 (0.30, 0.65)</td>
</tr>
<tr>
<td>3rd</td>
<td>11 345 (20.5)</td>
<td>121 (23.3)</td>
<td>11 224 (20.4)</td>
<td>0.83 (0.57, 1.21)</td>
</tr>
<tr>
<td>2nd</td>
<td>11 099 (20.0)</td>
<td>116 (22.4)</td>
<td>10 983 (20.0)</td>
<td>0.82 (0.57, 1.16)</td>
</tr>
<tr>
<td>1st low</td>
<td>10 746 (19.4 )</td>
<td>137 (26.4)</td>
<td>10 609 (19.3)</td>
<td>1 (reference)</td>
</tr>
<tr>
<td>Visit(s) to a primary care physician*</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>yes</td>
<td>47 853 (86.3)</td>
<td>473 (91.14)</td>
<td>47 380 (86.3)</td>
<td>1.61 (1.09, 2.38)</td>
</tr>
<tr>
<td>no</td>
<td>7596 (13.7)</td>
<td>46 (8.9)</td>
<td>7550 (13.7)</td>
<td>1 (reference)</td>
</tr>
<tr>
<td><strong>Need</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Adjusted Clinical Group, by category*</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>high (4220-5070)</td>
<td>18 157 (32.7)</td>
<td>377 (72.6)</td>
<td>17 780 (32.4)</td>
<td>22.71 (11.09,46.47)</td>
</tr>
<tr>
<td>(3500-4210)</td>
<td>11 591 (20.9)</td>
<td>90 (17.3)</td>
<td>11 501 (20.9)</td>
<td>8.71 (4.24, 17.92)</td>
</tr>
<tr>
<td>(900-3400)</td>
<td>11 570 (20.9)</td>
<td>40 (7.7)</td>
<td>11 530 (21.0)</td>
<td>3.96 (1.78, 8.85)</td>
</tr>
<tr>
<td>low (0-800)</td>
<td>14 131 (25.5)</td>
<td>12 (2.3)</td>
<td>14 119 (25.7)</td>
<td>1 (reference)</td>
</tr>
<tr>
<td><strong>Health care system resources</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Regional Health Authority beds per 100 population b</td>
<td>0.40 (0.12)</td>
<td>0.41 (0.15)</td>
<td>0.40 (0.12)</td>
<td>1.52 (0.71, 3.26)</td>
</tr>
<tr>
<td>Primary care physician supply b,c</td>
<td>4.96 (1.08)</td>
<td>4.98 (1.13)</td>
<td>4.97 (1.08)</td>
<td>1.02 (0.89, 1.16)</td>
</tr>
</tbody>
</table>

* Overall Score statistic p-value <0.2
a: Adjusted Clinical Group: A measure of an individual’s expected consumption of health services. Higher values represent higher consumption.
b: Interpretation of continuous variable odds ratio: For every one unit increase in the variable, there is a 100(odds ratio-1) percentage change in the odds.
c: Visits to a primary care physician per person with an intellectual disability living in a Regional Health Authority
4.4.2 Multivariate regression analysis

Table 4.2 describes the results of the multivariate regression using longitudinal data of adults with an intellectual disability living in Manitoba between 1999 and 2003. Only independent variables that were significant at p<0.2 in the bivariate analysis were included in this step. Four of the variables remained significantly associated with the likelihood of being hospitalized for an ACS condition. Compared to urban residents, living in a rural area of Manitoba was associated with a 34% higher likelihood of being hospitalized for an ACS condition. Persons living in dissemination areas with a high proportion of First Nations people experienced higher odds of being hospitalized: Compared to areas with the lowest proportion of First Nations people, persons living in areas with 71-100% and 41-70% were 2.32 times and 1.52 times more likely to be hospitalized. Persons with an intellectual disability living in a dissemination area with the fourth highest household income experienced a protective effect: They were 44% less likely to be hospitalized for an ACS condition compared to the lowest income areas. The need variable measured using Adjusted Clinical Group was the independent variable with the strongest association with ACS condition hospitalization. In high to low sequence, persons in ACG categories were 25 (p<0.0001), 10 (p<0.0001) and 4 (p<0.001) times more likely to be hospitalized for an ACS condition when compared to the lowest Adjusted Clinical Group category.
Table 4.2. Multivariate regression model of the odds of being hospitalized for an ambulatory care sensitive condition: Adults with an intellectual disability, Manitoba, 1999-2003 (n=55 449).

<table>
<thead>
<tr>
<th>Characteristic</th>
<th>Odds ratio (95% CI)</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Predisposing</strong></td>
<td></td>
</tr>
<tr>
<td>Age category, years</td>
<td></td>
</tr>
<tr>
<td>19 to 50</td>
<td>1.07 (0.81, 1.41)</td>
</tr>
<tr>
<td>51+</td>
<td>1.00 (reference)</td>
</tr>
<tr>
<td>Region</td>
<td></td>
</tr>
<tr>
<td>Rural</td>
<td>1.34 (1.03, 1.75)*</td>
</tr>
<tr>
<td>Urban</td>
<td>1.00 (reference)</td>
</tr>
<tr>
<td>Proportion First Nations in dissemination area, by category</td>
<td></td>
</tr>
<tr>
<td>71-100%</td>
<td>2.32 (1.30, 4.13)*</td>
</tr>
<tr>
<td>41-70%</td>
<td>1.52 (1.01, 2.30)*</td>
</tr>
<tr>
<td>11-40%</td>
<td>0.91 (0.68, 1.22)</td>
</tr>
<tr>
<td>0-10%</td>
<td>1.00 (reference)</td>
</tr>
<tr>
<td><strong>Enabling</strong></td>
<td></td>
</tr>
<tr>
<td>Marital status</td>
<td></td>
</tr>
<tr>
<td>Not married</td>
<td>1.18 (0.89, 1.56)</td>
</tr>
<tr>
<td>Married</td>
<td>1.00 (reference)</td>
</tr>
<tr>
<td>Income, quintiles</td>
<td></td>
</tr>
<tr>
<td>5th high</td>
<td>0.89 (0.58, 1.37)</td>
</tr>
<tr>
<td>4th</td>
<td>0.56 (0.37, 0.85)*</td>
</tr>
<tr>
<td>3rd</td>
<td>1.04 (0.70, 1.54)</td>
</tr>
<tr>
<td>2nd</td>
<td>0.92 (0.65, 1.30)</td>
</tr>
<tr>
<td>1st low</td>
<td>1.00 (reference)</td>
</tr>
<tr>
<td>Visit(s) to a primary care physician</td>
<td></td>
</tr>
<tr>
<td>yes</td>
<td>1.22 (0.80, 1.86)</td>
</tr>
<tr>
<td>no</td>
<td>1.00 (reference)</td>
</tr>
<tr>
<td><strong>Need</strong></td>
<td></td>
</tr>
<tr>
<td>Adjusted Clinical Group a</td>
<td></td>
</tr>
<tr>
<td>high (4220-5070)</td>
<td>25.15 (11.94, 53.0)**</td>
</tr>
<tr>
<td>(3500-4210)</td>
<td>9.70 (4.61, 20.41)***</td>
</tr>
<tr>
<td>(900-3400)</td>
<td>4.22 (1.85, 9.61)**</td>
</tr>
<tr>
<td>low (0-800)</td>
<td>1.00 (reference)</td>
</tr>
</tbody>
</table>

*p<0.05  
**p<0.001  
***p<0.0001

a: Adjusted Clinical Group: A measure of an individual’s expected consumption of health services. Higher values represent higher consumption.
4.4.2 Evaluation of spuriousness

In the results from table 4.1, visits to a primary care physician appear to be associated with an increased likelihood of being hospitalized for an ACS condition. The direction of the association is opposite than what was hypothesized based on prior research (Ansari, 2007). Using methods described by Aneshensel, the possibility that there was a spurious association between this variable and hospitalizations for ACS conditions was evaluated (Aneshensel, 2002). To do this Adjusted Clinical Group was evaluated as a possible common causal confounder of the association between visits to a primary care physician and ACS condition hospitalization. Visits to a primary care physician and Adjusted Clinical Group were analyzed together as independent variables using the ACS hospitalizations as the outcome. In this model the levels representing Adjusted Clinical Group did not change in terms of magnitude or level of significance (p<0.0001); however, visits to a primary care physician became non significant (OR 1.26, p=0.31). This is consistent with a spurious positive association between visits to a primary care physician and the outcome variable (Aneshensel, 2002).

4.5 Discussion

4.5.1 Summary of main results

This is the first study identifying factors associated with ACS condition hospitalizations among persons with an intellectual disability using a population based database. Multivariate regression analyses were used to estimate the strength of association between ACS condition hospitalizations and predisposing, enabling, need, and health care system variables. Rurality, the proportion of First Nations people living in a dissemination area, household income, and level of Adjusted Clinical Group remained
significant after controlling for other independent variables. None of the variables measuring aspects of health care system resources were significant.

4.5.2 Interpretation of results in context of prior research

There is very little research on ACS condition hospitalizations among persons with an intellectual disability. The few studies that exist attempted to compare ACS hospitalizations between geographic regions or between populations of persons with and without a disability (Balogh et al., 2005; Nachshen et al., 2009). The purpose of such studies is to identify difference in ACS condition hospitalizations between groups, rather than recognize reasons for the discrepancies.

The current study adds to the literature by using five years of population based data of persons with an intellectual disability maintained by the Manitoba Centre for Health Policy. To study persons with an intellectual disability, research commonly uses the general population or persons without an intellectual disability as a comparison group. Using only persons with an intellectual disability, the current study made the study populations more comparable thereby reducing the possibility that important unknown or unmeasured variables were left out.

Some of the results from the univariate analysis can be compared to values from the general population. The median household income in the study group was $41,930, slightly higher than the median reported for all Manitoba households for the 2001 census year ($41,661) (Statistics Canada, 2007). One third of the observations had an Adjusted
Clinical Group value of 4220 or higher, substantially higher than the value recorded for the general population (15%) (Reid et al., 1999). Among the Regional Health Authorities there were on average 5 visits to a primary care physician per year which is higher than the average 3.8 visits obtained from recent data on the general population of Manitoba (Fransoo et al., 2009). Using data from fiscal 1991, a study reported that 76% of all Manitobans had visited a primary care physician, compared to a rate of 86% over five years for the current study (Tataryn et al., 1995).

The proportion of First Nations persons living in a dissemination area was positively associated with the likelihood of an ACS condition hospitalization. That is, the higher the proportion of First Nations persons living in an area the higher the risk of an ACS hospitalization. This variable stayed significant after controlling for income and rurality. This is consistent with a study by Shah et al. in Ontario which found rates of ACS condition hospitalizations significantly higher for First Nations persons than for the general population and of higher magnitude than geographic and socioeconomic control groups (Shah et al., 2003).

Controlling for all other variables, lower household income remained significantly associated with a higher likelihood of being hospitalized. This association would be expected in environments where financial barriers to physician or hospital care exist. This has been confirmed by many studies from the United States (Billings et al., 1993; Bindman et al., 1995; Ricketts et al., 2001; Shi et al., 1999). But the association persists in countries like Canada which has government funded universal health care for
physician and hospital care. A study among children from Ontario by Agha et al. found a large positive association between socioeconomic disadvantage and ACS condition hospitalizations that was consistent across conditions and remained stable over time (Agha et al., 2007). In a study from Manitoba, Roos et al., found that residents from the lowest income neighbourhoods have more visits to ambulatory care and more hospitalizations than their counterparts from higher income areas (Roos et al., 2005b). Roos et al. concluded that increasing physician supply to deal with apparent shortages is unlikely to change the socioeconomic factors associated with hospitalizations; supporting this view, the current study found no association between primary care physician supply and risk of hospitalization.

The current study found that living in a rural area increased the likelihood of being hospitalized for an ACS condition. Statistically significant risk ratios of 1.07 and 1.20 (rural vs. urban) were also reported in prior research using multivariate analyses (Laditka, 2003; Shi et al., 1999). Reasons that may explain this difference include evidence of high turnover rates among primary care providers in rural areas leading to poor continuity of care, fewer available specialists, and longer distances required to get to primary care services (Tataryn et al., 1995; Tepper et al., 2005). It is also possible that rural health providers use a lower clinical threshold to decide who should be admitted to hospital (Silver et al., 1997). A lower admission threshold may be appropriate for geographically isolated patients. Patients and their caregivers from isolated areas invest time and money to travel long distances to get to a hospital. In such situations admitting physicians may
be more inclined to admit someone that under usual circumstances would be sent back home.

There was evidence of spuriousness between the variable ‘visits to a primary care physician’ and hospitalizations for an ACS condition. Other studies have found unexpected positive relationships between measures of physician accessibility and ACS condition hospitalizations (Basu & Cooper, 2000; Roos et al., 2005b; Schreiber & Zielinski, 1997). A study by van Walraven et al. unexpectedly found that patients with a regular family physician had a higher risk of hospitalization (van Walraven et al., 2002). They concluded that having a regular physician acted as marker for chronic illness and comorbidity; the current study found that visits to a primary care physician played a similar role.

4.5.3 Strengths and limitations

Past research has stressed the importance of selecting ACS conditions that are appropriate to the study population (Brown, 2001; Caminal et al., 2004). The current study, therefore, used a list of ACS conditions deemed applicable to persons with an intellectual disability by a panel of primary care providers with experience working with this population (see chapter 2 or (Balogh R.S. et al., 2010b)). The present study used multi-level analysis to take into account the correlated nature of the repeated observations of the same persons over time. The repeated observations are said to be clustered within the subject structuring the data into two levels. During early analyses a three-level approach was carried out that took into account the possibility that individuals were clustered into
geographic regions. This method confirmed that there was very little variation due to clustering at the regional level and therefore it was deemed unnecessary to pursue the analysis using three-levles.

The limitations of this study are primarily those associated with the use of administrative databases. Of primary concern is the identification of persons with an intellectual disability and specifically persons with mild intellectual disability. In Canada, province wide registries of persons with an intellectual disability do not exist. To do research, Canadians have had to use registries of persons with an intellectual disability from smaller geographic areas (Cleaver et al., 2009); however, this has restricted the sample size of the study. Another option has been the use of hospitalization records which include primary and secondary diagnostic codes which are responsible for the hospital admission (Balogh et al., 2005); this method, however, leads to underreporting of the number of persons with an intellectual disability particularly those with a mild form. Similarly, research from the United States used data from Medicaid and Medicare to identify persons with an intellectual disability but pointed out that this condition is not always coded for, possibly because few health interventions target intellectual disability directly (Iezzoni, 2002). Using multiple databases maintained at the Manitoba Centre for Health Policy, the current study used data from 3326 adults with an intellectual disability for the year 2003. This represents approximately .4% of the adult Manitoba population, which is close to estimates made by Canadian based prevalence studies (Ouellette-Kuntz & Paquette, 2001). It should be noted, nevertheless, that while the data from medical and hospital records have been tested for their validity and reliability, the data from the
family services and education enrollment have only recently been made available for analysis and have not undergone the same quality evaluation.

Administrative databases contain routinely collected data that are not primarily used for research purposes. For this reason not all variables that are suggested by the Andersen behavioural model of health service use could be evaluated. For instance the model by Andersen includes the extent and quality of social relationships as an enabling resource that can facilitate or impede health services use (Andersen, 1995). Although marital status is included, it does not provide a complete measure of social relationships. Another example is the lack of variables describing living situations which may affect decisions regarding hospitalizations. Persons with an intellectual disability may be living in institutions, group homes, foster homes, or their family home, and some even experience homelessness (Oakes & Davies, 2008). Persons who are homeless may, for instance, be hospitalized for reasons of benevolence. A measure of the supply of rehabilitation services might also be instructive as a health care system resource variable. A study from Taiwan found that need for rehabilitation among persons with an intellectual disability was associated with an increased risk of inpatient hospitalization (Lin et al., 2003).

Some of the independent variables used in the analyses were aggregates of attributes measured at the individual level. For example, as is commonly done, income was measured at the dissemination area level and attributed to an individual (Agha et al., 2007; Roos et al., 2005b). This leads to the possibility of an ecologic fallacy where one
concludes incorrectly that an association found at the aggregate level also applies at the individual level (Young, 2005); yet, census based attribution like this has been shown to closely represent individual level socioeconomic status (Krieger, 1992; Subramanian et al., 2006; Mustard et al., 1999). The proportion of First Nations persons living in a dissemination area, and physician and bed supply are other examples of variables that were measured at the level of a geographic area. Not many studies have included variables representing First Nations people perhaps due to difficulties obtaining person level data. Using dissemination area data from Census Canada made it possible to represent this frequently disadvantaged group in the analysis. Physician and bed supply are used to assess persons’ access to care and are generally considered appropriate (Laditka, 2004; Roos et al., 2005b). The concern that is expressed about these variables is that they may not generate enough variation making it difficult to detect any effect (Blakely & Woodward, 2000). The lack of variation may also be considered an accurate portrayal of the relative equity in service distribution in Manitoba.

4.6 Conclusions

4.6.1 Policy and research implications

Equity in health services has been said to exist when they are distributed on the basis of people’s need for them. When, for example, one’s race or income is a predictor of health system use, there is said to be inequity (Andersen et al., 1983). The results of this study show evidence of inequity in hospitalizations for ACS conditions among adults with an intellectual disability according to rurality, income, and proportion who are First Nations in a dissemination area. This suggests that addressing the socioeconomic problems of
poorer areas and specifically areas densely populated by First Nations people would have a larger impact on hospitalizations for ACS conditions than would specific policies to increase the supply of primary care.

Health care improvements have had a big impact on life expectancy in persons with an intellectual disability. This is seen dramatically in population based research from the United States, where the median age at death for persons with Down syndrome increased from 26 years in 1983 to 49 years in 1997, while in the general population the median age increased from 73 years to 76 years (Yang et al., 2002). Congenital heart defects are very common among persons with Down syndrome and their increased life expectancy is in large part attributed to improvements in early diagnostic and surgical techniques for these conditions (Frid et al., 1999). Examples like this have led to the assumption that health care broadly has a greater impact on the mortality and morbidity of this population compared to the general population (Krahn et al., 2006; McGinnis et al., 2002). The results of the current study, however, suggest that, like the general population, social policy initiatives may be more relevant than the amount of primary care provision when the goal is to decrease the number of potentially preventable hospitalizations (Ricketts et al., 2001; Roos et al., 2005b; Roos & Mustard, 1997).

A change in policies related to employment is one area adults with an intellectual disability may benefit from. Persons with an intellectual disability are underrepresented in the labour market with a reported unemployment rate between 70-90% (Burge et al., 2007). Like other persons with disabilities, they face disincentives to work in order to
avoid loss of benefits including for example funding for medication (Kirsh et al., 2009). Removing such barriers could lead to more employment and possibly a positive impact on health through involvement with meaningful occupation.

The objective of the current study was to identify factors associated with hospitalizations for ACS conditions among adults with an intellectual disability. Future research should consider using the results of this study to investigate causal relationships for instance through the use of path analysis and structural equation modeling.

ACS condition hospitalizations are considered an indicator of two separate effects: First, realizing access to primary care, and second, the quality of that care once access is realized. Failure on either of these may account for higher rates. The current study measured aspects of the first effect. Future research should include health system variables that measure the quality of primary care. For example among the elderly in Manitoba, continuity of care has been shown to decrease hospitalizations for ACS conditions (Roos et al., 2005b). The Health Council of Canada has said that health care policy makers, managers and providers should invest in health service strategies that require a shift from a ‘find it and fix it’ culture to a ‘prevent it, find it, manage it’ mentality (Health Council of Canada, 2009). The Council stresses that the focus of these strategies should be particularly on patients with multiple chronic conditions, a group which obviously includes persons with an intellectual disability.
The provision of care through multidisciplinary teams has shown promise to improve health outcomes, especially for persons with an intellectual disability and a co-occurring mental health problem (Balogh et al., 2008). Some countries have introduced specialized health care teams for persons with an intellectual disability to support, or in some cases to take the role of, existing community mainstream primary care (e.g. United Kingdom and the Netherlands). A comparison of population level primary care outcomes between countries that have, versus those that have not, introduced health team strategies could shed light on how to best provide services for this population.
Chapter 5: Summary and general discussion

5.1 Introduction

This thesis followed a logical process to describe hospitalizations for ambulatory care sensitive (ACS) conditions among persons with an intellectual disability living in Manitoba. The first chapter introduced important terms and concepts and reviewed the literature on ACS condition hospitalizations among persons with disabilities. In the second chapter, a list of ACS conditions deemed applicable to persons with an intellectual disability was developed. The list was then used in chapter 3 to identify disparities in ACS hospitalizations between persons with and without an intellectual disability. Finally, in chapter 4, factors were identified which were associated with ACS hospitalizations among adults with an intellectual disability.

The following chapter will summarize the results of chapters 2 to 4 and discuss contributions and general issues dealing with the use of hospitalizations for ACS conditions.

5.2 Summary of results

The chapter 2 manuscript dealt with the first objective: To identify ambulatory care sensitive conditions that are applicable to persons with an intellectual disability living in Canada. Using a modified Delphi process 11 participants responded to two rounds of a web based questionnaire survey. The 9 Canadian and two international participants all had experience in primary care for persons with an intellectual disability. Fifteen ACS conditions were judged applicable to persons with an intellectual disability living in
Canada. Eleven of the conditions are commonly applied in research dealing with the
general population (asthma, angina pectoris, congestive heart failure, gastrointestinal
ulcer, immunization preventable infection, malignant hypertension, otitis media, neurotic
depressive disorders, dental conditions, diabetes mellitus, pelvic inflammatory disease)
and four are unique to this population (constipation, gastroesophageal reflux, epilepsy,
and schizophrenic disorders).

The manuscript from chapter 3 dealt with the second thesis objective: To compare
hospitalization rates for ambulatory care sensitive conditions between persons with and
without an intellectual disability in a publicly insured province of Canada. Using
administrative databases, persons with an intellectual disability were identified among the
general population of Manitoba between 1999 and 2003. Rates of hospitalization for
ACS conditions between persons with and without an intellectual disability were
compared. Adjusting for age, sex, and place of residence, the rate of hospitalization for
all ACS conditions among persons with an intellectual disability was 6 times higher.
Hospitalization rates for epilepsy and schizophrenic disorders were respectively 54 and
15 times higher.

Chapter 4, the third manuscript, dealt with the final objective: To identify factors
associated with hospitalizations for ambulatory care sensitive conditions among adults
with an intellectual disability living in a publicly insured province of Canada.
Appropriate, regression analyses were used to estimate the strength of association
between ACS condition hospitalizations and predisposing, enabling, need, and health
care system variables. Rurality (odds ratio 1.3; 95% CI=1.0, 1.8), household income (odds ratio 0.56; CI=0.37, 0.85), the proportion of First Nations people living in a dissemination area (odds ratio 2.3; 95% CI=1.3, 4.1), and level of comorbidity (odds ratio 25.2; 95% CI=11.9, 53.0) remained significant after controlling for other independent variables. Measures of primary care supply were not significantly associated with the likelihood of an ACS condition hospitalization.

5.3 Contributions

5.3.1 A Canadian perspective

One of the more significant contributions of this thesis is that it gives a Canadian perspective on health and health service use among persons with an intellectual disability. Very little research on the health status of persons with an intellectual disability and their utilization of health services comes from Canada. For too long Canadians concerned with the health of persons with an intellectual disability have used research from other countries for reference assuming that what is happening in other developed countries is also happening at home. The process of deinstitutionalization of persons with an intellectual disability has been ongoing for 3 decades in this country, yet there is little research focusing on how well this population has been coping in the community. This is possibly due to the impression that with the Canadian provinces’ universal coverage of physician and hospital care, persons with an intellectual disability would fare well. Persons with an intellectual disability have gone from living in institutions where their medical needs were overemphasized to a situation where they live in the community but where their health care needs may be neglected.
5.3.2 Theoretical considerations

One possible reason for the lack of research regarding health and health care for this population is the concern expressed by some that policy and practice may become dominated (again) by the medical model of disability (Switzky & Greenspan, 2006). This model equates disability with chronic illness, ascribes a sick role to the individual and focuses on ‘dysfunction’ (Stalker et al., 1999). This way of thinking has had negative implications for persons with disabilities in general, including, in extreme cases, its use to justify eugenic practices such as forced sterilization programs. A social model perspective of intellectual disability is offered instead: Intellectual disability is not “something you have, like blue eyes or a bad heart. Nor is it something you are, like being short or thin. It is not a medical disorder, although it may be coded in a medical classification of disease…intellectual disability refers to a particular state of functioning that begins in childhood, is multidimensional, and is affected positively by individualized supports” (Luckasson et al., 2002)p. 48). Unlike the medical model, the social model points to material constraints and barriers within society as the source of disability (Stalker et al., 1999). Surely, full participation of persons with an intellectual disability in society must include getting to and using health services. And if there are constraints and barriers to achieving this role then they should be identified and remediated where possible. This thesis makes use of aspects of both the medical and social models of disability. For example, persons with an intellectual disability were identified in hospital databases using disease codes: This is consistent with a medical view of disability. On the other hand, the identification of the social variables associated with hospitalizations for ACS conditions borrows from a more social interpretation of disability.
5.3.3 The use of administrative databases

Other explanations for the lack of research include lack of funding, lack of advocacy, or lack of interest from decision makers. Fortunately, the situation may be changing at least in some areas of Canada. The research from this thesis was conducted in Manitoba where a database of persons with an intellectual disability is available and linkable to health service utilization data. The province of Manitoba is one of the only jurisdictions in Canada that makes it possible for independent researchers to do population level health research on vulnerable populations such as persons with an intellectual disability. This is due to the forward thinking of succeeding governments and the work of leaders at the Manitoba Centre for Health Policy.

The use of existing databases to study hospitalizations for persons with an intellectual disability is constrained by the privacy and confidentiality concerns of the institutions which administer the databases. For example, in some jurisdictions it is only possible to use hospitalization and physician visit records to identify persons with an intellectual disability. This can drastically decrease the number of persons available for inclusion (Balogh et al., 2005). Like the many studies on the general populations using administrative databases, the current study was conducted under very strict conditions in order to preserve the privacy and confidentiality of the person level data. The value of the results from this study is undeniable and the restrictions put in place make the risk negligible. This should encourage other provinces to make anonymized data available for health services research in an effort to understand and improve the health and health care services of populations at risk, like persons with an intellectual disability.
Countries such as Australia, Ireland, Wales, the Netherlands, Finland and Taiwan have used administrative databases or registries to study health issues among persons with an intellectual disability (Kelly et al., 2007; Lin et al., 2003; Morgan et al., 2003; Morgan et al., 2000; Sullivan et al., 2003; Westerinen et al., 2007; Wullink et al., 2007); but, this thesis is one of few that have examined a primary care indicator at a population level. Registries of persons with an intellectual disability are maintained in Western Australia and Ireland and have been used to evaluate breast cancer screening uptake, living situations and social service needs (Kelly et al., 2007; Sullivan et al., 2003). In Finland, the Netherlands, and Wales administrative databases were used to identify persons with an intellectual disability and conduct studies on prevalence and morbidity (Morgan et al., 2003; Morgan et al., 2000; Westerinen et al., 2007; Wullink et al., 2007). A database of institutions for persons with an intellectual disability is kept by the Republic of China and was used to evaluate outpatient and inpatient health care in Taiwan (Lin et al., 2003; Lin et al., 2004). Researchers have used administrative databases to help determine when, where and how health care might be improved for persons with an intellectual disability. The same is now possible in Manitoba.

5.3.4 First Nations people and advocacy efforts

This thesis is one of very few studies on persons with an intellectual disability that includes an indicator for First Nations people in Canada. A publication from 1985 studied institutionalized First Nations children with a severe or profound intellectual disability in Manitoba (Evans et al., 1985). The authors found that the First Nations children commonly had histories including low socioeconomic status, illegitimacy, high
birth order, poor maternal reproductive history and increased consanguinity. Fetal alcohol syndrome, a condition which leads to intellectual disability in approximately 19% of cases, is commonly studied among First Nations people due to the high prevalence in that population (Burd & Moffat, 1994; Nulman et al., 2007).

The health and social problems faced by First Nations people are well documented (Adelson, 2005). A report from Manitoba showed that First Nations people experienced disparities in preventive care and health care use when compared to the general population (Martens et al., 2002): First Nations children were far less likely to have their complete set of immunizations, First Nations women had half the uptake for breast screening, and hospitalizations rates were 2.2 times higher among registered First Nations persons. The disparities persisted when measuring determinants of health such as income, unemployment and housing. The last manuscript of this thesis found high rates of ACS hospitalizations for persons with an intellectual disability living in dissemination areas with higher First Nations population density. Since this result is not based on person level data, firm conclusions about outcomes for persons with an intellectual disability who are First Nations cannot be made.

Using findings from other research, it is likely that First Nations persons with an intellectual disability in Canada are being exposed to risk factors associated with poorer health from two population groups that do very poorly when evaluated alone (Adelson, 2005; Ouellette-Kuntz et al., 2005). Having First Nations heritage or acquiring an
intellectual disability is not a choice and, unfortunately, these two populations begin life with unfair disadvantages. In Canada not enough is being done to fix this. The living conditions of First Nations people living in Canada have been compared to that found in developing countries (Assembly of First Nations, 2004). In an effort to address the challenges facing this population, in 2005 the Canadian Government reached a consensus with the provinces, territories, First Nations, Métis and Inuit people which came to be known as the Kelowna Accord (Canadian Broadcasting Corporation, 2006). The goal of the Accord was to eliminate gaps between Aboriginal and non-Aboriginal Canadians in the areas of health, education, housing and economic opportunity. Unfortunately the Government that participated in the Accord was defeated in a federal election soon after it was signed. First Nations issues were not a priority for the new Canadian Government and the Accord was never enacted.

Comparing the living situation of First Nations people to that of a developing country may sound sensationalist; unfortunately, this is sometimes the only way to alert decision makers to real problems. The most drastic results from the current thesis are those showing hospitalization rates for epilepsy and schizophrenic disorders that were respectively 54 and 15 times higher for persons with an intellectual disability than for persons without an intellectual disability. Such large differences may make some policy makers take notice. In the United Kingdom a report on avoidable deaths has led to action from the government. Mencap, an advocacy organization for persons with an intellectual disability in the United Kingdom, published a report titled ‘Death by indifference’ (Mencap, 2006). The report told the stories of six individuals with an intellectual
disability who Mencap believed died unnecessarily while under the care of the 
government funded health system. In response to the report, an independent inquiry was 
ordered which found some good practices but also ‘appalling examples of discrimination, 
abuse and neglect across the range of health services’ (Michael, 2008)p. 7). The report 
specifically identifies the striking lack of awareness of the health needs of people with 
intellectual disability among primary care providers. The report goes on to recommend 
that primary care providers should make reasonable adjustments for persons with an 
intellectual to accommodate their disability; primary care services should be enhanced by 
including regular health checks; liaison staff should be hired to coordinate health services 
across the spectrum of care; and data should be collected to allow persons with an 
intellectual disability to be indentified and their pathways of care tracked. It is 
unacceptable that the lives of such vulnerable people need to be put at risk before action 
is taken.

5.3.5 Relevance to rehabilitation

Rehabilitation science is broad in nature and researchers have attempted to identify fields 
of research within the science. This thesis fits well in the social and cognitive 
rehabilitation sciences, a field concerned with lost or altered cognitive and social function 
with the aim of enhancing functional competence in real-world situations (Graduate 
Department of Rehabilitation Science, 2008). Persons with an intellectual disability by 
definition have problems with cognitive function and many of the independent variables 
included in the chapter 4 manuscript included socially relevant measures. The thesis was
concerned with the real world situation of participation in primary care as measured by hospitalizations for ACS conditions.

As described in the introductory chapter, barriers to effective primary care include the communication, behaviour and mobility problems experienced by persons with an intellectual disability (Baxter & Kerr, 2002). All of these are areas of specific professional interest for occupational, physical and speech language therapists. It is not surprising, therefore, that a study by Lin et al. found that one of the strongest predictors of hospitalization among persons with an intellectual disability, was a need for rehabilitation services (Lin et al., 2004). The original intent for the manuscript in chapter 4 was to evaluate measures of home care and rehabilitation personnel supply as independent variables potentially associated with hospitalizations for ACS conditions; however, these variables were either unavailable or occurred too infrequently leading to cells with low counts and unstable statistical results. Only data on inpatient hospital rehabilitation services are currently available from administrative databases. Research institutes like the Manitoba Centre for Health Policy and the Institute for Clinical and Evaluative Sciences should consider the inclusion of more health service data beyond hospitalization and physician information. Data from a provincially funded entity like children’s rehabilitation centres would, for example, be an important source to consider. In the province of Québec, 23 ‘Centre de Réadaptation en Déficience Intellectuelle et en Troubles Envaissants du Développement’ have been collecting data for 10 years on persons with intellectual and developmental disabilities. This source has the potential to
be used to identify persons with an intellectual disability in larger datasets and to evaluate the association between rehabilitation services, health and social factors.

Several of the ACS conditions used in this thesis can also be considered rehabilitation sensitive. For example, the work done by psychologists and occupational therapists in outpatient settings with persons with a dual diagnosis of intellectual disability and mental health problems may have an impact on hospitalization rates for specific conditions. In the future, researchers may consider using the same methods from the manuscript in chapter 2 to develop a list of ACS conditions that are more specifically ‘sensitive’ to the rehabilitation disciplines.

5.3.5 Future research

The thesis results are descriptive and cannot give definitive answers as to what policy initiatives or health interventions should be pursued to improve the lives of persons with an intellectual disability; but, the work offers clear direction for future research. Persons with an intellectual disability are much more frequently hospitalized for epilepsy and schizophrenic disorders than the general population. A study which investigates the effectiveness of interventions that target these two conditions in outpatient settings should be considered to see if the burden of these illnesses can be decreased. A study comparing primary care outcomes between countries with different approaches to health services for persons with an intellectual disability would be an instructive next step. This thesis did not include an evaluation of the costs that could be saved by decreasing hospitalizations. Such an analysis might hold more sway among policy makers. The
results from chapter 4, which found that socioeconomic factors are more strongly associated with hospitalizations than measures of the quantity of health services, should be further pursued. Examples include a study that looks more specifically at the causal relationships between factors or a study that investigates factors such as the quality of primary care.

The thesis results are encouraging for researchers from other provinces who are considering similar projects. An example from Québec has already been described. In Ontario, a continuing education project is training primary care providers to help improve the health care provided to persons with an intellectual disability. The training is part of a process that started with the publication of primary care guidelines which were developed with input from health professionals (including input from rehabilitation), academics and administrators (Sullivan et al., 2006). The analysis of indicators related to primary care using administrative databases is being considered as one way to evaluate the outcomes of the project. Unfortunately the initiative has been slowed by representatives from different Ministries who are hesitant to share data across jurisdiction for bureaucratic reasons.

5.4 Ambulatory care sensitive conditions

The focus of much of this thesis has been on ambulatory care sensitive conditions as an indicator for access to, and the quality of, primary care. The underlying premise is that hospital admissions data for selected conditions can be used to identify possible deficiencies in primary care services (Billings et al., 1993; Porter et al., 2007). There are
several scenarios that describe why an admission for an ACS may occur. For instance, an ACS condition admission may occur when demand for primary care exceeds its supply; when the quality of the primary care is inadequate to meet needs; or when geographic, cultural or social barriers impede the use of primary care services (Ansari, 2007). Proponents of ACS condition hospitalizations as a primary care indicator have described potential policy implications (Ansari, 2007): 1) ACS condition admission rates could be used for continuous monitoring of health services. Changes in ACS condition rates over time or in specific regions could identify gaps in the health system in need of support; 2) ACS condition hospitalization rates could be included as an outcome measure for in depth analyses to identify specific barriers to primary care; 3) Vulnerable populations could be specifically evaluated to identify disparities in health outcomes.

The conception of ACS condition hospitalizations as an indicator for access to, and quality of, primary care has been criticized. In an editorial, Steiner suggested that assumptions about the role of ACS condition hospitalizations in health service research should be reconsidered (Steiner, 2007). In his estimation, the premise underlying conditions selected as ambulatory care sensitive has been too readily accepted. A measure should not be considered as meaningful simply because it has face validity and because it is easy to obtain. The concern stems from some studies that found, paradoxically, that actions to increase access to primary care were associated with increased rates of hospitalization for ACS conditions (Flores et al., 2003; Saha et al., 2007; Weinberger et al., 1996). For the most part the inconsistent results can be explained by the inadequate inclusion of control variables that measure important
variables beyond the control of health care services such as air pollution, poor housing, poverty, and social relationships (Andersen, 1995; Schreiber & Zielinski, 1997). The fourth chapter of this thesis includes a combination of predisposing, enabling and need variables in recognition of this issue and makes a significant methodological contribution for future research.

Another criticism is that ACS condition hospitalization rates are not specific as to what aspect of primary care they measure. High ACS admissions may be due to problems with service supply shortages or the quality of primary care services. Since it is an imperfect measure, some authors have suggested that ACS hospitalization rates should be used more as a screening tool to evaluate primary care system needs (Garg et al., 2003).

To deal with the criticisms, the use of different data sources and qualitative research methods have been proposed as a way to clarify how social inequalities, access and the quality of health care affect hospitalization rates (Steiner, 2007). A study by Flores et al. included a survey of parents, primary care physicians and inpatient attending physicians in an analysis of pediatric hospitalizations for ambulatory care sensitive conditions (Flores et al., 2003). The results of the survey showed that, depending on the source, only between 13 and 46% of hospitalizations were judged to be avoidable. For this reason, the authors state that caution should be exercised when analyzing ACS hospitalizations using administrative databases. To what degree the survey accurately measures avoidable hospitalizations is not discussed by the authors; it is, however, reasonable to assume that a parent or primary care physician might be reluctant to admit
that they could have done more to prevent a hospitalization. The authors went on to identify reasons for the avoidable hospitalizations. Medication–related problems, inadequate preventive measures, and delay or lack of follow up care were identified as reasons the hospitalization was preventable. Conspicuously, no socioeconomic reasons were suggested by any of the sources. There is no denying that qualitative research can uncover details not possible with quantitative methods; however, the reasons given for an avoidable hospitalization in the study by Flores et al. are related either to the quality or quantity of primary care and, in the opinion of the thesis author, as the quality and content of administrative databases improve, so will their ability to assess health service indicators.

5.5 Concluding Remarks

Manitobans with an intellectual disability are hospitalized for ACS conditions at a higher rate than persons without an intellectual disability. Among adult persons with an intellectual disability, living in a rural or socioeconomically disadvantaged area is associated with a higher likelihood of being hospitalized for an ACS condition. Future research should investigate whether the quality of primary care or different types of care organization have an impact on admissions. Research using administrative databases makes it possible to obtain descriptive information on the health status of persons with an intellectual disability and the health services they receive.
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Appendix A: Introductory email, internet survey information, and consent e-mail for potential participants
Hello XXXXX,

I am a PhD student at the University of Toronto.

As part of my thesis I am conducting an online survey of clinicians with experience working with persons with an intellectual disability. I am trying to validate a list of "ambulatory care sensitive conditions" for persons with an intellectual disability. These are conditions like asthma and diabetes that are used as indicators for problems with access to primary care. If a region has a high rate of hospitalizations for these conditions then it may be due to problems with primary care access.

Please find below further information on the survey and a link that will bring you to the online survey website.

I would be grateful for your help.

Kind regards,

Robert Balogh

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From: Robert Balogh  
Subject: Survey on primary care for persons with an intellectual disability living in Canada

Hello,

My name is Robert Balogh, a PhD student at the University of Toronto supervised by Angela Colantonio (University of Toronto), Hélène Ouellette-Kuntz (Queen’s University), and Marni Brownell (University of Manitoba). I am seeking your help with a survey on the topic of ambulatory care sensitive conditions among people with an intellectual disability living in Canada.

Examples of ambulatory care sensitive conditions include asthma, otitis media, congestive heart failure, and angina pectoris. Hospitalization for an ambulatory care sensitive condition is considered to be a measure of access to appropriate medical care. The rationale is that proper primary care for certain conditions should delay the progression of the disease or prevent serious complications and thus prevent hospitalization. Research has shown a relationship between high rates of ambulatory care sensitive hospitalizations and problems with access to primary care. Measuring primary
care using ambulatory care sensitive condition hospitalization rates may prove useful when making health service planning decisions for persons with an intellectual disability living in Canada.

Using a consensus building process, lists of ambulatory care sensitive conditions have been developed for the general population in Europe, the United States and Canada. We wish to substantiate a list of ambulatory care sensitive conditions that is specific to the situation of persons with an intellectual disability living in Canada.

You have been identified as a person with expertise in the area of primary care among persons with an intellectual disability and we wish to invite you to participate in this internet based consensus building process. Your participation is strictly voluntary. You may refuse to participate or withdraw at any time without penalty. You’re welcome to contact our office at any time if you have questions about the survey (416-389-2522 or robert.balogh@utoronto.ca).

Any and all information we receive will be kept strictly confidential and will only be seen by authorized persons. Data gathered from the survey will be summarized in the aggregate, excluding all references to any individual responses. The aggregated results of our analysis will be used in my PhD dissertation and hopefully published in a peer reviewed journal. All data will be deleted once analyzed and after the results are published.

There will be two rounds of the online survey which will take only about 30 minutes each time. Once you complete them, we will send you a $30 Indigo/Chapters bookstore voucher. Our goal is to receive surveys from the first round by October 26.

Thank you for taking the time to help us with this important project.

If you have questions about your rights as a research participant, please contact Jill Parsons, Health Sciences Ethics Review Officer, Ethics Review Office, University of Toronto, at telephone 416-946-5806 or by email: jc.parsons@utoronto.ca.

To begin participating in this research, click on http://www.surveymonkey.com/s.aspx?sm=iUq3aspDrcR7ObAo7COKXw_3d_3d

Sincerely,

Rob Balogh PhD (c)

Phone number: 416-389-2522

e-mail address: robert.balogh@utoronto.ca
Appendix B: Follow up e-mail for non-responders
Hello XXXXXX,

One week ago I sent an e-mail message asking you to assist us in evaluating a list of 'ambulatory care sensitive conditions' for persons with an intellectual disability. The success of the research project depends on responses from people like you who have experience working with this population.

I hope you will take the few minutes to read the message below and complete the survey. On average, it has taken clinicians 15 minutes to fill out. Your participation in this project would really help us out.

To start the survey right away, click on:  http://www.surveymonkey.com/s.aspx?sm=iUq3aspDrcR7ObAo7COKXw_3d_3d

I look forward to sharing the results with you in the future.

Sincerely,

Rob Balogh
Appendix C: Invitation to second round version of questionnaire
Hello XXXXXXX,

As you know I am conducting online surveys on ‘ambulatory care sensitive conditions’ for persons with an intellectual disability. These are conditions for which proper primary care should help to delay the progression of the disease or prevent serious complications, thus preventing a hospitalization.

By now you should have received an envelope in the mail containing a ‘thank you’ letter, a hard copy of the initial survey results, and a $30 gift certificate. Please let me know if this is not the case.

Your answers to the initial survey helped to substantiate a list of ambulatory care sensitive conditions for persons with an intellectual disability that was originally conceived for the general population. You and your colleagues’ suggested a new list of five conditions that might be specifically applicable to persons with an intellectual disability. The purpose of the following survey is to confirm that outcomes for this new list of conditions are influenced by primary care.

Like the initial survey, any and all information we receive will be kept strictly confidential and will only be seen by authorized persons. Data gathered from the survey will be summarized in the aggregate. The results of our analysis will be used in my PhD dissertation and hopefully published in a peer reviewed journal. All data will be deleted once analyzed and after the results are published. You’re welcome to contact our office at any time if you have questions about the survey (416-389-2522 or robert.balogh@utoronto.ca).

There are only 5 conditions in this final round of the survey. In my estimation it will take a maximum of 10 minutes to complete.

On behalf of my thesis committee and myself I’d like to thank you again for participating in this process. We look forward to sharing the results with you once the survey is complete.

To begin the survey click on:  http://www.surveymonkey.com/s.aspx?sm=5meL_2bP0sGTLJfe8yF07UDg_3d_3d

Sincerely,

Rob Balogh PhD (c)
robert.balogh@utoronto.ca
Phone: 416-389-2522

Thesis committee:
Dr. Angela Colantonio
Appendix D: Blank questionnaire (round 1)
Navigating the survey and participant information

Thank you for taking the time to complete this survey.

In order to progress through this survey, please use the following navigation links:
- Click the Next >> button to continue to the next page.
- Click the Previous << button to return to the previous page.
- Click the Done >> button to submit your survey.

If you wish, it is possible to exit the survey and return at a later time. Simply Click the Exit the Survey Early >> button. To return to the survey, click on the link sent to you in the original e-mail.

1. Please provide the information requested below, so we can identify you from the other participants and send you the bookstore voucher.

   Name (required): 
   Address: 
   City/Town: 
   State/Province: 
   ZIP/Postal Code: 

2. Please indicate your profession and specialty area (if relevant). This is a required item.
Access to primary care for persons with an intellectual disability (round 1)

Ambulatory care sensitive conditions, primary care, and hospitalization

Timely and effective primary care can help to reduce the risk of hospitalization for an ambulatory care sensitive condition. For example, primary care can prevent the onset of an illness or condition, control an acute episodic illness or condition, or manage a chronic disease or condition.

The overall aim of this question is to determine if a list of ambulatory care sensitive conditions is applicable for persons with an intellectual disability.

3. In your opinion, in what way(s) does primary care help to avoid a hospitalization for the following list of conditions? Consider patients with an intellectual disability when answering.
   (check all that apply for each condition)

<table>
<thead>
<tr>
<th>Condition</th>
<th>It provides primary prevention</th>
<th>It provides early diagnosis and treatment of the condition or its precursor</th>
<th>It provides good ongoing management during chronic stages of the disease</th>
<th>It provides control for an acute episode of the condition</th>
<th>There is little or no role for primary care to avoid a hospitalization</th>
</tr>
</thead>
<tbody>
<tr>
<td>asthma</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>angina pectoris</td>
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<tr>
<td>congestive heart failure</td>
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<tr>
<td>gastrointestinal ulcer</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>immunization preventable infections</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>malignant hypertension</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>otitis media</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>neurotic depressive disorders</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>dental conditions</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>diabetes mellitus</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>pelvic inflammatory disease</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>appendicitis</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

Comments are welcome
Access to primary care for persons with an intellectual disability (round 1)

<table>
<thead>
<tr>
<th>1</th>
<th>includes gastric ulcer, duodenal ulcer, peptic ulcer, gastrojejunal ulcer</th>
</tr>
</thead>
<tbody>
<tr>
<td>2</td>
<td>includes diphtheria, whooping cough, tetanus, measles, mumps</td>
</tr>
<tr>
<td>3</td>
<td>includes malignant essential hypertension, malignant hypertensive heart disease, malignant hypertensive kidney disease, malignant hypertensive heart and kidney disease</td>
</tr>
<tr>
<td>4</td>
<td>includes anxiety, dissociative and somatoform disorders</td>
</tr>
<tr>
<td>5</td>
<td>includes diseases of the hard tissues of the teeth, diseases of pulp and periodontal tissues, gingival and periodontal diseases, other diseases and conditions of the teeth and supporting structures</td>
</tr>
<tr>
<td>6</td>
<td>includes inflammatory diseases of ovary, fallopian tube, pelvic cellular tissue, and peritoneum; and inflammatory diseases of uterus, except cervix</td>
</tr>
</tbody>
</table>

Suggest other conditions (optional)

4. In your opinion, for what other condition(s) could primary care help to avoid a hospitalization in persons with an intellectual disability?
Access to primary care for persons with an Intellectual disability (round 1)

**agreement on clinical criteria for admission**

This question evaluates the degree to which there is perceived agreement on clinical criteria for admission for a list of conditions. The context is among **persons with an intellectual disability**.

5. **For patients with similar medical and social circumstances, how much do you think primary care providers are likely to agree on the clinical criteria for admission for the following conditions?**

<table>
<thead>
<tr>
<th>Condition</th>
<th>No agreement</th>
<th>1-25% agreement</th>
<th>26-50% agreement</th>
<th>51-75% agreement</th>
<th>76-100% agreement</th>
<th>Don't know</th>
</tr>
</thead>
<tbody>
<tr>
<td>asthma</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>angina pectoris</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>congestive heart failure</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>gastrointestinal ulcer</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>immunization preventable infections</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>malignant hypertension</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>obstetric media</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>neurotic depressive disorders</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>dental conditions</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>diabetes mellitus</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>pelvic inflammatory disease</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>appendicitis</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

**comment**

Thank you for taking the time to fill out this survey. Once we analyze the data received from you and other participants, we will send back the results to you. In order to build a consensus, you will then have an opportunity to modify your responses.

Sincerely,

Roh Balogh
Appendix E: Blank questionnaire (round 2)
Navigating the survey and participant information

Thank you for taking the time to complete this survey.

In order to progress through this survey, please use the following navigation links:
- Click the Next >> button to continue to the next page.
- Click the Previous << button to return to the previous page.
- Click the Done >> button to submit your survey.

If you wish, it is possible to exit the survey and return at a later time. Simply click the Exit the Survey Early >> button. To return to the survey, click on the link sent to you in the original e-mail.

1. Please provide your name so we can link your responses with those from the first round of the survey.

Name (required):
Ambulatory care sensitive conditions, primary care, and hospitalization

Timely and effective primary care can help to reduce the risk of hospitalization for an ambulatory care sensitive condition. For example, primary care can prevent the onset of an illness or condition, control an acute episodic illness or condition, or manage a chronic disease or condition.

The overall aim of this question is to determine if a list of ambulatory care sensitive conditions is applicable for persons with an intellectual disability. The list of conditions is based on the responses that you and other participants offered during the first round of the survey.

2. In your opinion, in what way(s) does primary care help to avoid a hospitalization for the following list of conditions? Consider patients with an intellectual disability when answering.
(check all that apply for each condition)

<table>
<thead>
<tr>
<th>Condition</th>
<th>It provides primary prevention</th>
<th>It provides early diagnosis and treatment of the condition or its precursor</th>
<th>It provides good ongoing management during chronic stages of the disease</th>
<th>It provides control for an acute episode of the condition</th>
<th>There is little or no role for primary care to avoid a hospitalization</th>
</tr>
</thead>
<tbody>
<tr>
<td>constipation</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>osteoporosis</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>gastroesophageal reflux disease</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>epilepsy&lt;sup&gt;1&lt;/sup&gt;</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>schizophrenic disorders&lt;sup&gt;2&lt;/sup&gt;</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

Comments are welcome

---

<sup>1</sup> Includes focal and generalized seizures

<sup>2</sup> Includes the following types of schizophrenia: simple, disorganized, catatonic, paranoid, residual, latent, schizophreniform disorder, schizoaffective disorder and other specified and unspecified types of schizophrenia
agreement on clinical criteria for admission

This question evaluates the degree to which there is perceived agreement on clinical criteria for admission for a list of conditions. The context is among persons with an intellectual disability.

3. For patients with similar medical and social circumstances, how much do you think primary care providers are likely to agree on the clinical criteria for admission for the following conditions?

<table>
<thead>
<tr>
<th>Condition</th>
<th>No agreement</th>
<th>1-25% agreement</th>
<th>26-50% agreement</th>
<th>51-75% agreement</th>
<th>76-100% agreement</th>
<th>don't know</th>
</tr>
</thead>
<tbody>
<tr>
<td>constipation</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>osteoporosis</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>gastroesophageal reflux disease</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>epilepsy</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>schizophrenic disorders</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

comment

Thank you for taking the time to fill out this survey. Once we analyze the data received from you and other participants, we will send back the results to you.

Sincerely,

Rob Balegh
Appendix F: Manitoba population health research data repository
Appendix G: List of ICD-9 codes used to identify persons with an intellectual disability from hospital and physician records
<table>
<thead>
<tr>
<th>ICD-9 Diagnostic Code (World Health Organization, 1977)</th>
<th>Specific disorders / syndromes</th>
</tr>
</thead>
<tbody>
<tr>
<td>317-317.99 318-318.99</td>
<td>Mild, moderate, severe, and profound mental retardation</td>
</tr>
<tr>
<td>319-319.99</td>
<td>Unspecified mental retardation</td>
</tr>
</tbody>
</table>
| 758.0 758.1 758.2 758.3                               | Chromosomal anomalies:  
  • Down syndrome  
  • Patau’s syndrome  
  • Edwards’ syndrome  
  • Autosomal deletions (e.g. cri-du-chat) |
| 759.81 759.83 759.89                                   | Other and unspecified congenital anomalies:  
  • Prader Willi Syndrome  
  • Fragile X Syndrome  
  • other (e.g. Laurence-moon-Biedl syndrome) |
Appendix H: List of included ambulatory care sensitive conditions
<table>
<thead>
<tr>
<th>Generic diagnosis</th>
<th>ICD-9 Code (s)</th>
<th>Comment</th>
</tr>
</thead>
<tbody>
<tr>
<td>Asthma</td>
<td>493</td>
<td></td>
</tr>
<tr>
<td>Angina pectoris</td>
<td>413</td>
<td>Exclude cases with surgical procedure</td>
</tr>
<tr>
<td>Congestive heart failure</td>
<td>428</td>
<td>Exclude cases with surgical procedure</td>
</tr>
<tr>
<td>Gastrointestinal ulcer</td>
<td>531, 532, 533, 534</td>
<td></td>
</tr>
<tr>
<td>Immunization preventable infection</td>
<td>032, 033, 037, 055, 072</td>
<td></td>
</tr>
<tr>
<td>Malignant hypertension</td>
<td>401.0, 402.0, 403.0, 404.0</td>
<td></td>
</tr>
<tr>
<td>Otitis media</td>
<td>382</td>
<td></td>
</tr>
<tr>
<td>Anxiety, dissociative and somatoform disorders</td>
<td>300</td>
<td></td>
</tr>
<tr>
<td>Dental conditions</td>
<td>521, 522, 523, 525, 528</td>
<td></td>
</tr>
<tr>
<td>Diabetes mellitus</td>
<td>250</td>
<td></td>
</tr>
<tr>
<td>Pelvic inflammatory disease*</td>
<td>614, 615</td>
<td>Exclude cases with hysterectomy procedure</td>
</tr>
<tr>
<td>Constipation</td>
<td>564.0</td>
<td>Exclude cases with surgical procedure</td>
</tr>
<tr>
<td>Gastroesophageal reflux</td>
<td>530.81</td>
<td></td>
</tr>
<tr>
<td>Epilepsy</td>
<td>345</td>
<td></td>
</tr>
<tr>
<td>Schizophrenic disorders</td>
<td>295</td>
<td></td>
</tr>
<tr>
<td>Appendicitis* (marker condition: non-ACSC)</td>
<td>540.9, 541, 542</td>
<td>Without mention of perforation, peritonitis, or rupture With appendectomy (47.0)</td>
</tr>
</tbody>
</table>

* Only included in table 3.4
Appendix I: Age and gender distribution of Manitobans, 1999 and 2003
### Age and gender distribution of population of Manitoba with and without an intellectual disability, 1999

<table>
<thead>
<tr>
<th>Age in years</th>
<th>Persons with an intellectual disability</th>
<th>General population with no intellectual disability</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Male n</td>
<td>Female n</td>
</tr>
<tr>
<td>0-4</td>
<td>680</td>
<td>14.7</td>
</tr>
<tr>
<td>5-9</td>
<td>900</td>
<td>19.5</td>
</tr>
<tr>
<td>10-14</td>
<td>694</td>
<td>15</td>
</tr>
<tr>
<td>15-19</td>
<td>446</td>
<td>9.6</td>
</tr>
<tr>
<td>20-24</td>
<td>257</td>
<td>5.56</td>
</tr>
<tr>
<td>25-29</td>
<td>199</td>
<td>4.31</td>
</tr>
<tr>
<td>30-34</td>
<td>192</td>
<td>4.15</td>
</tr>
<tr>
<td>35-39</td>
<td>220</td>
<td>4.57</td>
</tr>
<tr>
<td>40-44</td>
<td>195</td>
<td>4.22</td>
</tr>
<tr>
<td>45-49</td>
<td>204</td>
<td>4.41</td>
</tr>
<tr>
<td>50-54</td>
<td>147</td>
<td>3.18</td>
</tr>
<tr>
<td>55-59</td>
<td>138</td>
<td>2.99</td>
</tr>
<tr>
<td>60-64</td>
<td>93</td>
<td>2.01</td>
</tr>
<tr>
<td>65-69</td>
<td>85</td>
<td>1.84</td>
</tr>
<tr>
<td>70-74</td>
<td>73</td>
<td>1.58</td>
</tr>
<tr>
<td>75-79</td>
<td>53</td>
<td>1.15</td>
</tr>
<tr>
<td>80+</td>
<td>46</td>
<td>1</td>
</tr>
<tr>
<td>Total</td>
<td>4622</td>
<td>100</td>
</tr>
</tbody>
</table>

### Age and gender distribution of population of Manitoba with and without an intellectual disability, 2003

<table>
<thead>
<tr>
<th>Age in years</th>
<th>Persons with an intellectual disability</th>
<th>General population with no intellectual disability</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Male n</td>
<td>Female n</td>
</tr>
<tr>
<td>0-4</td>
<td>296</td>
<td>6.32</td>
</tr>
<tr>
<td>5-9</td>
<td>817</td>
<td>17.4</td>
</tr>
<tr>
<td>10-14</td>
<td>884</td>
<td>18.9</td>
</tr>
<tr>
<td>15-19</td>
<td>638</td>
<td>13.6</td>
</tr>
<tr>
<td>20-24</td>
<td>392</td>
<td>8.37</td>
</tr>
<tr>
<td>25-29</td>
<td>230</td>
<td>4.91</td>
</tr>
<tr>
<td>30-34</td>
<td>177</td>
<td>3.78</td>
</tr>
<tr>
<td>35-39</td>
<td>205</td>
<td>4.38</td>
</tr>
<tr>
<td>40-44</td>
<td>213</td>
<td>4.55</td>
</tr>
<tr>
<td>45-49</td>
<td>192</td>
<td>4.1</td>
</tr>
<tr>
<td>50-54</td>
<td>173</td>
<td>3.69</td>
</tr>
<tr>
<td>55-59</td>
<td>125</td>
<td>2.67</td>
</tr>
<tr>
<td>60-64</td>
<td>99</td>
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<tr>
<td>65-69</td>
<td>81</td>
<td>1.73</td>
</tr>
<tr>
<td>70-74</td>
<td>68</td>
<td>1.45</td>
</tr>
<tr>
<td>75-79</td>
<td>48</td>
<td>1.02</td>
</tr>
<tr>
<td>80+</td>
<td>46</td>
<td>0.98</td>
</tr>
<tr>
<td>Total</td>
<td>4684</td>
<td>100</td>
</tr>
</tbody>
</table>
Appendix J: Hospitalization rate comparisons by year and age group
Rate comparisons for ACSC hospitalizations between persons with and without an intellectual disability, by age and year, Manitoba

<table>
<thead>
<tr>
<th>Year</th>
<th>Age group in years, population</th>
<th>Crude rate values $^a$</th>
<th>Crude rate per person-year (x 1000)</th>
<th>Crude rate ratio</th>
<th>Rate ratio adjusted for sex-region</th>
<th>95% CI (p-value)</th>
</tr>
</thead>
<tbody>
<tr>
<td>1999</td>
<td>0-9, with ID 95/2524 37.64</td>
<td>7.17</td>
<td>6.99</td>
<td>4.96, 9.86</td>
<td>(&lt;.0001)</td>
<td></td>
</tr>
<tr>
<td></td>
<td>0-9, without ID 832/158585 5.25</td>
<td>12</td>
<td>11.90</td>
<td>7.98, 17.74</td>
<td>(&lt;.0001)</td>
<td></td>
</tr>
<tr>
<td></td>
<td>10-19, with ID 51/1856 27.48</td>
<td>8.4</td>
<td>8.51</td>
<td>5.00, 14.47</td>
<td>(&lt;.0001)</td>
<td></td>
</tr>
<tr>
<td></td>
<td>10-19, without ID 371/162518 2.28</td>
<td>12</td>
<td>12.79</td>
<td>8.28, 19.77</td>
<td>(&lt;.0001)</td>
<td></td>
</tr>
<tr>
<td></td>
<td>20-29, with ID 19/838 22.67</td>
<td>8.39</td>
<td>8.71</td>
<td>5.55, 13.67</td>
<td>(&lt;.0001)</td>
<td></td>
</tr>
<tr>
<td></td>
<td>20-29, without ID 418/154785 2.70</td>
<td>2.83</td>
<td>2.99</td>
<td>1.59, 5.59</td>
<td>(0.0006)</td>
<td></td>
</tr>
<tr>
<td>2000</td>
<td>30-39, with ID 34/847 22.67</td>
<td>11.7</td>
<td>11.92</td>
<td>7.33, 19.41</td>
<td>(&lt;.0001)</td>
<td></td>
</tr>
<tr>
<td></td>
<td>40-49, with ID 19/779 24.39</td>
<td>5.9</td>
<td>6.04</td>
<td>3.57, 10.24</td>
<td>(&lt;.0001)</td>
<td></td>
</tr>
<tr>
<td></td>
<td>40-49, without ID 719/173949 4.13</td>
<td>8.39</td>
<td>8.71</td>
<td>5.55, 13.67</td>
<td>(&lt;.0001)</td>
<td></td>
</tr>
<tr>
<td></td>
<td>50-59, with ID 30/569 52.72</td>
<td>8.39</td>
<td>8.71</td>
<td>5.55, 13.67</td>
<td>(&lt;.0001)</td>
<td></td>
</tr>
<tr>
<td></td>
<td>50-59, without ID 792/126004 6.29</td>
<td>11.7</td>
<td>11.92</td>
<td>7.33, 19.41</td>
<td>(&lt;.0001)</td>
<td></td>
</tr>
<tr>
<td></td>
<td>60-69, with ID 12/348 34.48</td>
<td>12.17</td>
<td>12.79</td>
<td>8.28, 19.77</td>
<td>(&lt;.0001)</td>
<td></td>
</tr>
<tr>
<td></td>
<td>60-69, without ID 1063/87328 12.17</td>
<td>14</td>
<td>14.22</td>
<td>9.17, 22.07</td>
<td>(&lt;.0001)</td>
<td></td>
</tr>
<tr>
<td></td>
<td>70 years +, with ID 18/339 53.10</td>
<td>1.85</td>
<td>1.81</td>
<td>1.09, 2.98</td>
<td>(0.0213)</td>
<td></td>
</tr>
<tr>
<td></td>
<td>70 years +, without ID 3532/122988 28.72</td>
<td>1.85</td>
<td>1.81</td>
<td>1.09, 2.98</td>
<td>(0.0213)</td>
<td></td>
</tr>
<tr>
<td>2001</td>
<td>0-9, with ID 61/2385 25.58</td>
<td>5.47</td>
<td>5.58</td>
<td>3.76, 8.29</td>
<td>(&lt;.0001)</td>
<td></td>
</tr>
<tr>
<td></td>
<td>0-9, without ID 733/156799 4.68</td>
<td>8.14</td>
<td>8.07</td>
<td>5.16, 12.62</td>
<td>(&lt;.0001)</td>
<td></td>
</tr>
<tr>
<td></td>
<td>10-19, with ID 38/2020 18.81</td>
<td>2.23</td>
<td>2.51</td>
<td>1.26, 4.99</td>
<td>(0.0089)</td>
<td></td>
</tr>
<tr>
<td></td>
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<td>Year</td>
<td>Age group in years, population</td>
<td>Crude rate values</td>
<td>Crude rate per person-year (x 1000)</td>
<td>Crude rate ratio</td>
<td>Rate ratio adjusted for sex-region</td>
<td>95% CI (p-value)</td>
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<tr>
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<td>8.24</td>
<td>5.16, 13.16</td>
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<td>33/853</td>
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<td>10.81</td>
<td>6.73, 17.37</td>
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<td>667/186043</td>
<td>3.59</td>
<td>10.81</td>
<td>6.73</td>
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<td>X</td>
<td>X</td>
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ID=intellectual disability
X: suppressed due to low cell count or to prevent inference of cell count
a: Rate=number of hospitalizations/number of person years
Appendix K: Hospitalization rate comparisons by year and region
Rate comparisons for ACSC hospitalizations between persons with and without an intellectual disability, by urban/rural region and year, Manitoba

<table>
<thead>
<tr>
<th>Year</th>
<th>Urbana or ruralb residence, population</th>
<th>Crude rate valuesc</th>
<th>Crude rate per person-year (x 1000)</th>
<th>Crude rate ratio</th>
<th>Rate ratio adjusted for age-sex</th>
<th>95% C (p-value)</th>
</tr>
</thead>
<tbody>
<tr>
<td>1999</td>
<td>Urban, with ID 137/4877 28.09</td>
<td>5.54</td>
<td>6.82</td>
<td>5.28</td>
<td>8.82 (&lt;.0001)</td>
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<tr>
<td></td>
<td>Urban, without ID 3585/707279 5.07</td>
<td>4.23</td>
<td>5.78</td>
<td>4.44</td>
<td>7.53 (&lt;.0001)</td>
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<tr>
<td></td>
<td>Rural, with ID 141/3223 43.75</td>
<td>10.33</td>
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<td></td>
<td></td>
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<tr>
<td></td>
<td>Rural, without ID 4705/455345</td>
<td>3.48</td>
<td>5.23</td>
<td>3.90</td>
<td>7.02 (&lt;.0001)</td>
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<td>2000</td>
<td>Urban, with ID 132/4932 26.76</td>
<td>5.48</td>
<td>7.10</td>
<td>5.40</td>
<td>9.35 (&lt;.0001)</td>
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<td></td>
<td>Urban, without ID 3488/713651 4.89</td>
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<td></td>
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<tr>
<td></td>
<td>Rural, with ID 108/3271 33.02</td>
<td>33.02</td>
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<td>9.49</td>
<td></td>
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<tr>
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<td>Urban, with ID 140/4935 28.37</td>
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<td>7.81</td>
<td>6.03</td>
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<td></td>
<td>Urban, without ID 3445/718661 4.79</td>
<td>4.7</td>
<td>5.57</td>
<td>4.21</td>
<td>7.36 (&lt;.0001)</td>
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<td>Rural, with ID 110/3310 33.23</td>
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<tr>
<td></td>
<td>Rural, without ID 4147/459605</td>
<td>9.02</td>
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<td>2002</td>
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<td>4.68</td>
<td>7.89 (&lt;.0001)</td>
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<td>Urban, without ID 3436/723164 4.75</td>
<td>4.75</td>
<td>6.33</td>
<td>4.62</td>
<td>6.99 (&lt;.0001)</td>
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<td>Rural, without ID 3917/461165 8.49</td>
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<td>2003</td>
<td>Urban, with ID 116/4949 23.44</td>
<td>5.17</td>
<td>6.96</td>
<td>5.12</td>
<td>9.47 (&lt;.0001)</td>
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<td>Urban, without ID 3303/728047 4.54</td>
<td>4.54</td>
<td>6.66</td>
<td>4.49</td>
<td>6.46 (&lt;.0001)</td>
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<tr>
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<td>Rural, with ID 92/3269 28.14</td>
<td>3.46</td>
<td>5.08</td>
<td>3.65</td>
<td>7.07 (&lt;.0001)</td>
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<td>Rural, without ID 3779/464209 8.14</td>
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<td>All years</td>
<td>Urban, with ID 636/24645 25.81</td>
<td>5.37</td>
<td>6.99</td>
<td>6.17</td>
<td>7.93 (&lt;.0001)</td>
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<td>Urban, without ID 17257/3590802 4.81</td>
<td>4.81</td>
<td>6.68</td>
<td>4.69</td>
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<td>5.29</td>
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<td>Rural, without ID 20889/2297974 9.09</td>
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ID=intellectual disability
a: Urban: Winnipeg and Brandon
b: Rural: All other regions of Manitoba
c: Rate: number of hospitalizations/number of person years
Appendix L: Summary of variables using Andersen Behavioural Model of Health Service Use
<table>
<thead>
<tr>
<th>Andersen Model</th>
<th>Database source</th>
<th>Definitions</th>
<th>Hypothesized direction of effect (– or +)</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>1) Predisposing</strong></td>
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</tbody>
</table>
| Age | Registry | 19 to 50 vs. 51+  
- Time varying: updated during a 90-day period | 21<=Age<=50  
(–) |
| Sex | Registry | Male vs. female  
- Fixed | Males  
(–) |
| Proportion First Nation | Census Canada 2001 | Four categories:  
70-100%  
41-70%  
11-40%  
0-10% (reference)  
- Fixed | Higher proportion  
(+) |
| Region | Registry | Rural (rest of Manitoba) vs. urban (Winnipeg and Brandon)  
- Time varying: updated every year | Rural  
(+) |
| **2) Enabling** | | | |
| Marital status | Registry | Not-married vs. married  
- Time varying: updated every year | Not-married  
(+) |
| Income | Census Canada 2001 | Quintiles:  
5th high  
4th  
3rd  
2nd  
1st low (reference)  
- Fixed | high income  
(–) |
| Visit(s) to a primary care physician | Medical Claims Database | Visited vs. did not visit a primary care physician  
- Time varying: updated every year | Visit  
(–) |
| **3) Need** | Adjusted Clinical Group (ACG) | ACG quantifies morbidity or resource burden by grouping individuals based on age, gender and all known medical diagnoses  
- Four groups created based on ACG values for each person:  
  high (4220-5070)  
  (3500-4210)  
  (900-3400)  
  low (0-800) (reference)  
- Time varying, updated every year | higher ACG  
(+) |
<table>
<thead>
<tr>
<th><strong>4) Health care system resources</strong></th>
<th><strong>Manitoba Health and Registry</strong></th>
<th><strong>Medical Claims Database and Registry</strong></th>
<th><strong>Higher number of beds (++)</strong></th>
<th><strong>Higher supply (–)</strong></th>
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<tbody>
<tr>
<td>Regional Health Authority beds per 100 population</td>
<td>The number of staffed nursing home and acute care beds on March 31st of each year divided by the number of persons in the general population living in the Regional Health Authority x 100</td>
<td>The number of visits to a primary care physician (general practitioner or family physician) in a Regional Health Authority divided by number of people with an intellectual disability living in that region</td>
<td>Time varying; updated every year</td>
<td>Continuous</td>
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Appendix M: Map of regional health authorities of Manitoba
(Manitoba Centre for Health Policy, 2003)