

**A Population-based Comparative Study of Health and Health Care Utilization of Manitoba  
Children in Care with and without Developmental Disabilities**

Dustin Joel Charette Heinrichs

A Thesis submitted to the Faculty of Graduate Studies of  
The University of Manitoba  
in partial fulfillment of the requirements of the degree of

MASTER OF SCIENCE

Department of Family Social Sciences  
University of Manitoba  
Winnipeg, Manitoba

Copyright © 2015 by Dustin Heinrichs

## Contents

<b>Contents .....</b>	<b>i</b>
<b>Table of Figures.....</b>	<b>v</b>
<b>Table of Tables .....</b>	<b>vi</b>
<b>Abbreviations .....</b>	<b>vii</b>
<b>Abstract.....</b>	<b>viii</b>
<b>Acknowledgements .....</b>	<b>ix</b>
<b>Dedication .....</b>	<b>x</b>
<b>Disclaimer .....</b>	<b>xi</b>
<b>Chapter 1: Introduction .....</b>	<b>1</b>
<b>The Present Study .....</b>	<b>5</b>
<i>Research Objectives.</i> .....	<b>6</b>
<i>Theoretical/conceptual framework.</i> .....	<b>6</b>
<b>Chapter 2: Review of the Literature .....</b>	<b>11</b>
<b>Canadian Children in Care.....</b>	<b>11</b>
<b>Health Disparities between Children in Care with and without DD.....</b>	<b>13</b>
(a) <i>Physical health disparities.</i> .....	<b>13</b>
(i) <i>Respiratory illness.....</i>	<b>14</b>
(ii) <i>Diabetes. ....</i>	<b>15</b>
(b) <i>Mental Health Disparities.....</i>	<b>17</b>
<i>Mood and anxiety disorders.....</i>	<b>17</b>
<b>Health Care Utilization.....</b>	<b>20</b>
(i) <i>Continuity of care.....</i>	<b>20</b>
(ii) <i>Injury-related hospitalizations.....</i>	<b>22</b>
(iii) <i>Oral health.....</i>	<b>22</b>
<b>Chapter 3: Methods .....</b>	<b>25</b>
<b>Population and Data Sources.....</b>	<b>25</b>
<i>Study design.....</i>	<b>25</b>
<i>Data sources. ....</i>	<b>25</b>
<i>Data linkages.....</i>	<b>26</b>
<i>Study population. ....</i>	<b>27</b>

<i>Study group</i> .....	27
<i>Matched comparison group</i> .....	28
<b>Study Measures .....</b>	<b>28</b>
<b><i>Demographic characteristics</i></b> .....	<b>28</b>
<i>Age</i> .....	28
<i>Sex</i> .....	28
<i>Socioeconomic status</i> .....	28
<i>Place of residence</i> .....	29
<b><i>In-care characteristics</i></b> .....	<b>29</b>
<i>Children in care</i> .....	29
<i>Duration in care</i> .....	29
<i>Number of episodes in care</i> .....	29
<b><i>Developmental disability</i></b> .....	<b>29</b>
<b><i>Health measures</i></b> .....	<b>31</b>
<i>Total Respiratory Morbidity</i> .....	32
<i>Diabetes</i> .....	32
<i>Mood and anxiety disorders</i> .....	32
<b><i>Health care utilization</i></b> .....	<b>33</b>
<i>Continuity of care</i> .....	33
<i>Total physician visits</i> .....	34
<i>Injury-related Hospitalizations</i> .....	34
<i>Hospital-based dental care</i> .....	34
<b><i>Timeframe</i></b> .....	<b>35</b>
<b>Data Analysis</b> .....	<b>35</b>
<b>Ethical Considerations</b> .....	<b>36</b>
<b>Chapter 4: Results</b> .....	<b>37</b>
<b>Demographic and Socioeconomic Characteristics of Manitoba Children and Manitoba Children in Care, 2012</b> .....	<b>37</b>
<b>Manitoba Children in Care with DD</b> .....	<b>41</b>
<b>Demographic, Socioeconomic, and in Care Characteristics of Children in Care with and without DD in Manitoba</b> .....	<b>42</b>

<i>Age</i> .....	43
<i>Sex</i> .....	43
<i>Health Region</i> .....	44
<i>Socioeconomic status</i> .....	44
<i>Days in care</i> .....	45
<i>Episodes of care</i> . ....	46
<b>Health Status of Manitoba Children in Care with and without DD .....</b>	<b>47</b>
<i>Total respiratory morbidity</i> .....	47
<i>Diabetes</i> .....	48
<i>Mood and anxiety disorders</i> .....	49
<b>Health Care Utilization Patterns of Children in Care with and without DD.....</b>	<b>49</b>
<i>Total ambulatory physician visits</i> .....	50
<i>Continuity of care</i> .....	50
<i>Injury-related hospitalizations</i> .....	51
<i>Hospital-based dental care</i> .....	52
<b>Chapter 5: Discussion .....</b>	<b>54</b>
<b>Demographic and Socioeconomic Status .....</b>	<b>54</b>
<i>Sex</i> .....	55
<i>Place of residence</i> .....	55
<i>Socioeconomic status</i> .....	55
<b>Health Status .....</b>	<b>56</b>
<i>Total respiratory morbidity</i> .....	56
<i>Diabetes</i> .....	57
<i>Mood and anxiety disorders</i> .....	57
<b>Health Care Utilization.....</b>	<b>58</b>
<i>Continuity of care</i> .....	58
<i>Injury-related hospitalizations</i> .....	58
<i>Hospital-based dental care</i> .....	59
<b>Study Strengths and Limitations .....</b>	<b>60</b>
<b>Implications and Future Directions for Research.....</b>	<b>62</b>
<i>Policy Implications</i> .....	62

<b>References .....</b>	<b>65</b>
-------------------------	-----------

## **Table of Figures**

Figure 1. ICF Model of Health. Source: World Health Organization, 2002, p. 9. .... 9

## **Table of Tables**

Table 1. Rate of children in care by province/territory of Canada, 2007-2008.....	11
Table 2. Hospital Discharge Abstract Data ICD-10-CA codes to identify DD.....	30
Table 3. Age distribution of all Manitoba children and Manitoba children in care in 2012. ....	37
Table 4. RHA distribution of all children in Manitoba and children in care in 2012.....	38
Table 5. Distribution of children in care by income quintiles. ....	39
Table 6. Duration in care for Manitoba children in care in 2012. ....	40
Table 7. Number of episodes in care for all Manitoba children in care in 2012. ....	41
Table 8. Distribution of Manitoba Children in Care with DD by Source of DD Identification..	42
Table 9. Age distribution of the two study groups.....	43
Table 10. Sex distribution of the two study groups. ....	43
Table 11. Distribution of the two study groups by health region of residence. ....	44
Table 12. Distribution of the two study groups by neighbourhood income quintiles.....	45
Table 13. Distribution of duration in care between both study groups.....	46
Table 14. Number of episodes in care by study group. ....	47
Table 15. Total Respiratory Morbidity (TRM) by Study Group. ....	48
Table 16. Diabetes by Study Group.....	48
Table 17. Prevalence of mood and anxiety disorders by study group of children over the age of 10.....	49
Table 18. Distribution comparing total physician visits between the study groups. ....	50
Table 19. Continuity of care by study group. ....	51
Table 20. Injury-related hospitalizations by study group. ....	52
Table 21. Hospital-based dental care by study group. ....	52

## **Abbreviations**

ASD	Autism Spectrum Disorder
CFS	Child and Family Services
CFSIS	Child and Family Services Information System
DD	Developmental Disability
DPIN	Drug Program Information Network
FASD	Fetal Alcohol Spectrum Disorder
ICD-9-CM	International Classification of Diseases, Ninth Revision, Clinical Modification
ICD-10-CA	International Classification of Diseases, Tenth Revision, Canada
ICF	International Classification of Functioning, disability and health
ID	Intellectual Disability
IDD	Intellectual and Developmental Disability
MCHP	Manitoba Centre for Health Policy
PHIN	Personal Health Identification Number
RHA	Regional Health Authority
SIB	Self-Injurious Behaviour

## **Abstract**

There is a lack of information on the health status of children with developmental disability (DD) living “in care” and their utilization of health services. This study addresses this gap in knowledge by examining population-based data and comparing the health status and access to health services between groups of children with and without DD in care in Manitoba. Data from several data sets were used to identify a cohort of children with DD among those in care in 2012 ( $n = 1,212$ ) contained in the Manitoba Population Health Research Data Repository housed and maintained by the Manitoba Centre for Health Policy (MCHP). Each child in the study cohort was matched with two children without DD ( $n = 2,424$ ) of the same age, sex, and from the same region of residence. Generalized Estimating Equation (GEE) Modeling was used to compare the two study groups on a number of measures, including total respiratory morbidity, diabetes, mood and anxiety disorders, continuity of care, injury-related hospitalizations, hospital-based dental care, and total number of ambulatory physician visits. Findings revealed that children in care with DD were significantly more likely to have a history of mood and anxiety disorders, respiratory illnesses, diabetes, hospital-based dental care, and injury-related hospitalizations compared to the children in the matched comparison group. Children in care with DD also had significantly higher number of visits to physicians. In terms of their continuity of care, there was no significant difference between children in care with and without DD. The knowledge gained from this study will inform those who support children in care so they can plan more appropriate care placements for children with DD. There is a great need for prospective longitudinal studies examining health and health services utilization of children in care with DD as they grow older into their adolescence and adulthood.

## **Acknowledgements**

I would like to thank my family and friends for their support and encouragement throughout this journey, without them, this would not have been possible. To my wife Melissa and son Felix, who have been more than understanding when I have needed time to focus and work on this project.

I would like to give a special thank you to my advisor, Dr. Shahin Shooshtari, who I admire for her endless patience with me, logical approach to this project and her ability to convey information in a clear and concise manner.

I would like to thank my committee members Dr. Marni Brownell and Dr. Rosemary Mills, for sharing their wisdom, expertise, and knowledge, and for the time they took to be members on my thesis committee. It was a wonderful experience working with these women.

I greatly appreciate being able to access data from at the Manitoba Centre for Health Policy (MCHP). I want to especially thank Charles Burchill, Associate Director for Data Access and Use at MCHP. He was always quick to respond to my questions about datasets, SAS programming, and computer problems. He was very patient and always willing to assist in these areas as well as facilitate numerous versions of vetted output.

I would like to thank Dr. Brenda Stoesz, for all your guidance, advice, support, and assistance along the way.

Finally, I would like to thank the St. Amant Foundation for providing the funding to access the data required for completion of this research project.

## **Dedication**

I dedicate this project, the work, and time it took to complete my thesis, to my family. To my wife Melissa and son Felix, thank you for all of your love, support and understanding through this process.

## **Disclaimer**

The authors acknowledge the Manitoba Centre for Health Policy for use of data contained in the Population Health Research Data Repository under project #2014 - 020 (HIPC# 2013/2014 - 59). The results and conclusions are those of the authors and no official endorsement by the Manitoba Centre for Health Policy, Manitoba Health, Healthy Living & Seniors, or other data providers is intended or should be inferred. Data used in this study are from the Population Health Research Data Repository housed at the Manitoba Centre for Health Policy, University of Manitoba and were derived from data provided by Manitoba Health, Healthy Living & Seniors, Manitoba Education and Advanced Learning, Manitoba Family Services, and the Winnipeg Regional Health Authority.

## **Chapter 1: Introduction**

Developmental Disabilities (DD) are “severe chronic disabilities that can be cognitive or physical or both, that appear before the age of 22 [years] and are likely to be lifelong” (American Association for Intellectual and Developmental Disabilities, n.d.). Globally, it is estimated that 1-3% of the population has a DD (World Health Organization, 2001). The prevalence estimates vary by country due to varying criteria used to identify persons with DD and methods used to collect this information. DD prevalence varies greatly by average country income, and is higher in adolescents in comparison to the adult population (Maulik, Mascarenhas, Mathers, Dua, & Saxena, 2011). Some studies have examined prevalence of DD, some intellectual disability (ID), and others mental retardation. In research on developmental and intellectual disabilities (IDD), there has been confusion in using such terms. DD may or not include ID in which the individual has had a physical and/or mental impairment from an early age that is likely to continue indefinitely, and has significant functional limitations in at least three major areas of daily living (Schalock, et al., 2010). By contrast, ID is defined as a condition in which there are “significant limitations in cognitive functioning as well as in adaptive behavior which occurs prior to the age of 18” (Schalock, et al., 2010). The terms DD and ID have typically been used as synonyms in both research and practice (Developmental Disabilities Association; L’Arche International). For the purpose of this study, the term DD includes the conditions ID, Mental Retardation, Fetal Alcohol Spectrum Disorders (FASD), and Autism Spectrum Disorders (ASD).

Few studies have estimated the prevalence of DD among Canadians, and those that have, report prevalence of at least 5.6 per 1,000. Specifically, a report from the National Health & Welfare estimated a prevalence rate for mental retardation across Canada of 8 per 1,000 individuals (Health & Welfare Canada, 1988). Some studies have focused on specific provinces

of Canada. Several studies of DD focusing on the population of Ontario provide prevalence estimates between 5.6 and 9.0 per 1,000 (Bradley, Thompson, & Bryson, 2002; Nguyen, 1996; Ouellette-Kuntz & Paquette, 2001). In Manitoba, Ouellette-Kuntz and colleagues (2010) estimated that 0.47% of the population had a DD. Further, of those with a diagnosis of DD, over 57% ( $n = 3,096$ ) were under the age of 20 years, and of those 3,096 individuals, 10.9% were between the ages of 5 and 9 years and 11.1% were between the ages of 10 and 14 years (Ouellette-Kuntz, et al., 2010). As seen from these studies, there are higher proportions of children and adolescents with DD than adults with DD.

Persons with DD have other conditions that affect their daily functioning, including decreased mobility, bone fractures (Beange & Lennox, 1998; Center, Beange, & McElduf, 1998), and hearing and vision loss (Evenhuis, Theunissen, Denkers, Verschuur, & Kemme, 2001). Poor communication skills (Keane, 1972) and motor impairments (Evenhuis, Henderson, Beange, Lennox, & Chicoine, 2001), social factors such as poverty (Martin, Roy, & Well, 1997), and low levels of literacy (Saint-Laurent, Giasson, & Couture, 1998) are also associated with DD, all of which affect the health and well-being of persons with DD and their ability to perform their activities of daily living. Many research studies have identified challenging behaviours as a major concern for these children. For example, in a systematic review, Montgomery and colleagues (2014) reported that the most studied, commonly found categories of problem behaviours in children with DD were stereotyped, repetitive, and self-stimulatory behaviour, physical and verbal aggression and property destruction, self-injurious behaviour, and disruption. These behaviours affect their families and caregivers negatively. For example, parents of a child with a DD experience increased stress (Hastings, 2002; Schieve, Blumberg, Rice, Visser, & Boyle, 2007), mental health problems (Weiss, 1991), self-blame and devaluation (Holroyd,

Brown, Wikler, & Simmons, 1975), impaired physical functioning, and exhaustion (Emerson, 2003a; Emerson, 2003b; Hedov, Anneren, & Wikiblad, 2000). Some of these conditions can improve if social supports are in place and parents and the child are using appropriate coping strategies, which vary depending upon the characteristics of the parent and the child (Raina, et al., 2004; Vitaliano, Zhang, & Scanlan, 2003). These conditions contribute to the level of functioning of the individual as well as their family unit.

Research also shows significant physical and mental health disparities between persons with and without DD (Ouellette-Kuntz, et al., 2005). Health disparities have been defined as “potentially avoidable differences in health between groups of people who are more and less advantaged socially; these differences place socially disadvantaged groups at further disadvantage on health” (Braveman, 2006, p.180). Oullette-Kuntz and colleagues (2005) identified various factors that contribute to these health disparities such as having health-damaging behaviours and poor health related behaviours, exposure to unhealthy, stressful environments, health related mobility, inadequate access to essential health services and other basic services due to communication difficulties, motor impairments and poor accessibility, and the knowledge and attitudes of health-care providers. Many negative health problems have been attributed to a lack of attention to the person’s care needs, poor health-promoting behaviours, and poor accessibility to quality health care services for people with DD (Krahn, Hammond, & Turner, 2006). Persons with DD, compared to the general population, have a shorter lifespan (Bittles, Petterson, Sullivan, Hussain, & Glasson, 2002; Cooper, Melville, & Morrison, 2004), more cardiovascular diseases and infections that lead to premature death (Eyman, Grossman, Chaney, & Call, 1990; Patja, Livanainen, Vesala, Oksanen, & Ruoppila, 2000), a rate of obesity double that of the general population (Pitetti, Rimmer, & Fernhall, 1993; Stewart, Beange, &

Mackerras, 1994), greater risk of having a psychiatric disorder (Bongiorno, 1996; Borthwick-Duffy & Eyman, 1990), and poorer oral health (Gizani, et al., 1997). Although much of the research pointing to health disparities in persons with DD focuses on the adult years (Haveman, et al., 2010; Krahn et al., 2006; Perkins & Moran, 2010), but disparities are also apparent in the early years. There is limited information on physical or mental health disparities among children with DD based on well-designed population-based studies, or studies with representative samples of children. In one such study, Shooshtari, Brownell, and Dik (2011) compared prevalence of diabetes and depression between children with and without IDD, matched by age, sex, and region of residence and found that the risk of these chronic health conditions in children with IDD was significantly higher than that of the matched comparison group [Diabetes: RR = 3.93, 95% CIs (1.82, 8.52); Depression: RR = 1.85, 95% CIs (1.69, 2.03)]. The authors also found that children with IDD had a significantly higher risk of injury-related hospitalizations compared to children in the matched comparison group [RR = 2.18, 95% CIs (1.37 – 3.46)]. Jansen, Krol, Groothoff, and Post (2004) in a review of comparative studies found that the majority of the comparative research of people with DD reports higher prevalence rates of epilepsy, diseases of the skin, sensory loss and increased risk of fractures compared to people without DD. In their cohort study of children under five years of age in Western Australia, Williams and colleagues (2005) found that children with DD were more likely to be admitted to hospital, on more occasions, for longer durations, and for a larger range of clinical diagnoses, than their non-DD peers. Although limited, the research on the health and well-being of children with DD shows that children with DD have poorer health status compared to their non-DD counterparts (Jansen, Krol, Groothoff, & Post, 2004; Shooshtari et al., 2014; Williams, Tursan d'Espagnet, Colvin, Slack-Smith, & Stanley, 2005).

Prior research shows that children with disability, in particular those with a DD, are overrepresented among children in care. The term “in care” refers to children who have been removed from their biological family of origin and placed in the care of another family or alternative living arrangement (Government of Manitoba, 1996). According to the Canadian Child Welfare Research Portal, in 2007, Manitoba had the highest rate of children in care among all Canadian provinces (Canadian Child Welfare Research Portal, n.d.). For example, Lightfoot, Hill, and La Liberte (2011) reported that, in Minnesota, children with disabilities identified as having an emotional disturbance, DD, ID, or learning disorder were 1.87 times more likely to be living in care than children without disabilities. In Manitoba, Fuchs, Burnside, Marchenski, and Mudry (2005) found that of children in care, one third had a disability, and of those three quarters were identified as having a DD. A more recent study from Manitoba found that a significantly greater proportion of children with DD were placed in care than children in a matched comparison group (Shooshtari, et al., 2011). More specifically, children with DD were at least five times more likely to be placed in care than children in a matched comparison group (Shooshtari et al., 2011). In addition, there has been a significant increase of 8% in the prevalence of children in care in Manitoba over time (2000/01 – 2002/03 to 2006/07 – 2008/09 (Brownell et al., 2012). Brownell and colleagues (2012) noted that these figures most likely underrepresented the true prevalence of children in care due, in large part, to incomplete numbers reported for children in services governed by Aboriginal Agencies in Manitoba.

### **The Present Study**

As described above, prior research shows that children in care are at a higher risk for a number of physical and mental health problems than children living in other settings (Bass, Shields, & Behrman, 2004). Although there has been some research on physical and mental

health and access to services for children in care, there is relatively little information about children with DD living in care (Lightfoot, Hill, & LaLiberte, 2011). Moreover, because of the high rate and recent increases in the number of children in care in Manitoba, data from this province was selected for this study. The unique, population based data from multiple services, through the Manitoba Centre for Health Policy, allowed for study of the Manitoba population of children in care with DD that could not be explored by any other provincial or national survey. The **main goal** of the present study was to use population-based data from several sources to examine the differences in the health status and access to health services between a cohort of Manitoba children with DD in care and a matched comparison group of children without DD in care. An enhanced understanding of disparities in health and access to health services experienced by children with DD could help those involved in provision of care and planning of programs and services to this population to plan accordingly to meet the specific needs of these children.

**Research Objectives.** The specific objectives of the study were to:

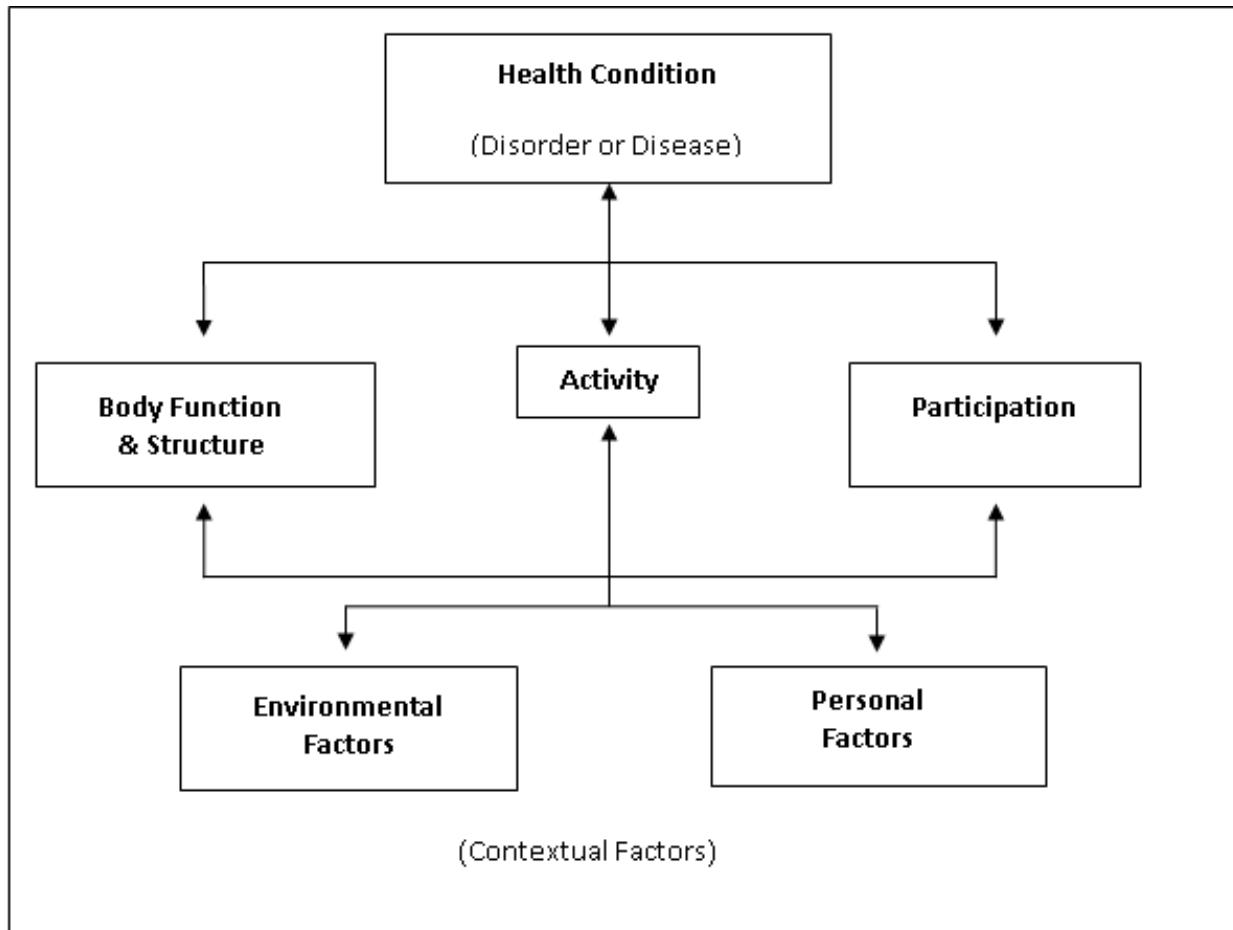
1. Determine the number and proportion of Manitoba children in care with DD.
2. Describe the demographic and socioeconomic characteristics of children in care in Manitoba with and without DD who are of the same age, sex, and place of residence (region).
3. Describe the health status of children in care with DD and compare it to the health status of children in care without DD who are of the same age, sex, and place of residence (region).
4. Describe the health care utilization patterns of children in care with DD and compare their utilization patterns to that of children in care without DD who are of the same age, sex, and place of residence.

**Theoretical/conceptual framework.** This study is focused on children in care with DD,

and understanding the differences in health and health service utilization that exist between them and children in care of the same age, sex, and from the same place of residence, but without DD. Over time, different models have been developed to understand disability and guide research and clinical practice in the area. Two of the most common models of disability used were the medical model of disability and the social model of disability. The *medical model of disability* focuses on disability as a characteristic of the individual, directly caused by disease, trauma or health condition. In this model, “fixing” disability can only be achieved through medical treatments or interventions by trained medical professionals. This model is limited in examining health of children in care with DD because it does not take into account the child’s past or current physical environment, social environmental, or their biological or psychological histories. On the other hand, the *social model of disability* views disability as a problem resulting from the individual’s social environment not being able to accommodate the physical and/or developmental needs of the person. In the case of children with DD, this conceptual model limits the examination to the type of the conditions that children have because it does not take into account the severity of the DD, or the level of participation and activity that the children are able to engage in.

Given the limitations of these two models of disability, the present study was guided by a more recent model, the *International Classification of Functioning, Disability, and Health* (ICF; World Health Organization, 2002). This conceptual model merges the social and medical perspectives of disability, and allows one to examine the interactions of an individual’s health and their contextual factors (environmental and personal) in describing their overall health and functioning. This conceptual framework emphasizes individuals’ level of functioning and participation rather than focusing only on their disability and impairments or their social

environment (World Health Organization, 2002). In the ICF model, individuals' level of disability and functioning is conceptualized as the outcomes of interactions between individuals' health conditions (i.e., the diseases, disorders, and injuries that the individuals have) and their environment (i.e., physical, social, and attitudinal environments that individuals live in) and personal characteristics (e.g., their age, sex, level of education, behaviour pattern, coping skills) (see Figure 1). For example, a child with poor coping skills living in an abusive environment may develop increased rates of mood or anxiety disorders over time. This model differentiates among three levels of functioning: functioning at the level of body part, the person's overall level of functioning in daily activities, and individuals' participation and degree of involvement in their social life. Disability is conceptualized as a continuum, from impairments only (i.e., dysfunction at the level of body part), to activity limitations, to participation restrictions.



**Figure 1. ICF Model of Health.** Source: World Health Organization, 2002, p. 9.

The ICF model of disability and functioning guided the present study by suggesting which factors to study in examining disparities in health and access to health care for children in care with DD. In this study, comparisons were made between two groups of children, both of which were in care of Manitoba Child and Family Services. Furthermore, we matched children in care with DD with children in care without DD based on their age, sex, and region of residence. The decision to compare children in care with DD to children in care without DD from the same region of residence was to control for the children's living environment, which might be associated with their health or access to health services. The matching of these two

groups of children based on their age, and sex was to control for the potential influence of individuals' personal characteristics on their health or access to health services. Children's health status was examined using a number of health indicators measured at the population-level including total respiratory morbidity, diabetes, and mood and other mood disorders. The ICF does not help to understand the patterns of health services use. However, in this study, continuity of care, injury-related hospitalizations, and hospitalized dental care were used as indicators of health services use, related to individuals' level of health, with those being healthier, experiencing better continuity of care, and less frequent injury-related hospitalizations, and hospital based dental care. All of the health indicators used can, on some level, be attributed to individuals' personal and/or environmental factors. For example, mood and anxiety disorders may be attributed to the children's genetic characteristics, but also a lack of attachment to the care provider(s), maltreatment, substance abuse, and lack of parenting skills. Diabetes could be attributed to children's genetic characteristics, and/or their nutritional and health-related behaviours. The use of the ICF conceptual framework emphasized the fact that understanding health disparities that are experienced by children in care with DD compared to children in care without DD requires examination of a wide range of contextual factors including both personal and environmental factors. By using multiple sources of data, it was possible to consider a number of potential contributing factors.

## **Chapter 2: Review of the Literature**

This literature review chapter is organized into three sections: (1) Canadian children in care; (2) physical and mental health disparities experienced by children in care with DD; and (3) health services utilization patterns for children in care with DD.

### **Canadian Children in Care**

The terminology used to describe children placed outside of their biological family of origin varies greatly, leading to difficulties in describing this population. A variety of terms are used including “out-of-home care,” “in care,” “foster care,” and “looked after children.” For the purposes of this study, I used the term “in care”, inclusive of all the various terms used in the literature. In 2011, there were 47,885 children between the ages of 0-18 years living in care in Canada (Statistics Canada, 2012). The prevalence of children in care in 2007-2008 varied greatly by region of residence (see Table 1). Manitoba has the highest rate of children in care per 1,000 children among the provinces and third highest in all provinces and territories.

**Table 1. Rate of children in care by province/territory of Canada, 2007-2008.**

Province/Territory	Rate per 1,000 children in care
North West Territories	30.8
Yukon Territory	24.7
Manitoba	24.4
Saskatchewan	21.7
Nunavut Territory	15.3
Quebec	13.2
Alberta	10.6
British Columbia	10.1

New Brunswick	9.0
Nova Scotia	8.8
Newfoundland and Labrador	7.5
Ontario	7.5
Prince Edward Island	5.2

---

**Sources:** (Canadian Child Welfare Research Portal; Ontario Association of Children's Aid Societies, 2008).

The health of children living in care is affected not only by medical and social factors but also by changing living conditions. Research shows that children in care experience higher rates of acute and chronic health conditions, mental health problems, and developmental delays than that of their peers in the general population (Chernoff, Combs-Ome, Risley-Curtiss, & Heisler, 1994; Hochstadt, Jaudes, Zimo, & Schachter, 1987; Simms, 1989). Research has found that the health needs of these children continue to be unmet and neglected after they enter into care (Halfon, Mendonca, & Berkowitz, 1995; Moffat, Peddie, Stulginskas, Pless, & Steinmetz, 1985; Takayama, Bergman, & Connell, 1994). Contrary to this finding, however, Katz and colleagues (2011) report that rates of hospital admissions and physician visits decreased after a child entered into care.

Although there has been some research on health and access to services for children in care, there is relatively little information about children in care with DD (Lightfoot, Hill, & LaLiberte, 2011). One of the challenges is the clear identification of children with DD given the various definitions of disability that exist. For example, in the United States, each state has different requirements for identifying children with disabilities, and only 39 states collect information regarding disabilities. States that collect information on children with disability have reported varying estimates of the proportion of children with disability in care. The estimates of children with disabilities in care range drastically, from less than 0.06% in Florida,

to 0.7% in Kansas, to 46.7% in North Dakota (Rosenberg & Robinson, 2004). Some researchers found that children with DD are underrepresented among children in care (Schilling, Kirkham, & Schinke, 1986; West, Richardson, LeConte, Crimi, & Stuart, 1992), whereas other researchers claimed that children with DD are over-represented among children in care. For example, Lightfoot and colleagues (2011) reported that children with disabilities, identified as having an emotional disturbance, DD, ID, or learning disorder, were 1.87 times more likely to be living in care than children without disabilities.

The following conditions were found to be the most common problems in children with disabilities that were placed in care: emotional disturbances (37.5%), IDD (10.7%), and multiple disabilities (9.5%) (Lightfoot, Hill, & LaLiberte, 2011). Children with DD tend to live in institutional or other restrictive settings, whereas children without DD are more often placed into the care of a biological relative (Eyman & Call, 1977; Hill & Bruininks, 1984; Jacobson, 1982). Using the American, federally mandated, administrative datasets, Adoption and Foster Care Analysis and Reporting System (AFCARS), Rosenberg and Robinson (2004) found that young children (aged 0-3 years) with developmental or health conditions were more likely to be placed in care, had longer stays in foster homes, and were less likely to return to their parental homes.

### **Health Disparities between Children in Care with and without DD**

A comprehensive review of the published literature was conducted to identify disparities in health between children with DD compared to children without DD among those in care. The health disparities were divided into two categories: (a) physical health disparities; and (b) mental health disparities, and are discussed below.

**(a) Physical health disparities.** Of the studies that focused on health disparities between children with and without DD, a vast majority focused on physical health disparities using

various health indicators. For the purpose of this study, the literature review on physical health disparities was limited to the specific conditions of interest, including: (i) respiratory illness, and (ii) diabetes.

(i) **Respiratory illness.** A consistent finding in the academic literature is that children with DD are at a higher risk for respiratory illness than their non-DD peers. For example, in the United States, preschool aged children (0-5 years) with DD are one and a half to two times more likely than their non-DD peers to have respiratory illness (Gallaher et al., 2002). Other studies have consistently shown that respiratory illnesses are the most common cause of death in people with DD (e.g., Beange, Lennox, & Parmenter, 1999; Blisard, Martin, Brown, Smialek, Davis, & McFeeley, 1988; Chaney & Eyman, 2000; Cooper, Melville, & Morrison, 2004; Hollins, Attard, von Fraunhofer, McGuigan, & Sedgwick, 1998; Janicki, Dalton, Henderson, & Davidson, 1999; Strauss, Anderson, Shavelle, Sheridan, & Trenkle, 1998), particularly among those with severe DD (e.g., Durvasula, Beange, & Baker, 2002; Patja, Livanainen, Vesala, Oksanen, & Ruoppila, 2000; Tuffrey-Wijne, Hogg, & Curfs, 2007). For example, Durvasula and colleagues (2002) found that death occurred in 35% of their sample of persons with ID ( $n = 14$ ) from respiratory illness and was the main cause of death. Research from Manitoba showed that respiratory illnesses are highly overrepresented in children who live in care compared to those who do not, and between 1998/99-1999/2000 respiratory illnesses were the leading cause of hospitalizations for children under 18 living in care (25% of all hospitalizations) (Brownell, et al., 2008). Respiratory illness is associated with a high risk of death within the DD population (Cooper, Melville, & Morrison, 2004; Durvasula, Beange, & Baker, 2002).

In the current study, TRM was used to estimate and compare prevalence of respiratory illnesses among children in care with and without DD. This examination is important given the

suggested strong link between respiratory illnesses and increased risk of death in children with DD. Prior research has found a strong association between respiratory infection and poor housing conditions (Bailie, Stevens, McDonald, Brewster, & Guthridge, 2010). For this reason, TRM is considered an indicator of health, reflecting on the children's living conditions and environment.

Respiratory illnesses are among the more frequently reported health problems in children in care. In a national-level longitudinal study in the United States, Ringeisen, Casanueva, Urato, and Cross (2008) found that children in care were significantly more likely than their peers, who were not in care, to have asthma. Similarly, Takayama, Wolfe, and Coulter (1998) found that the most common chronic conditions that children in care had were illnesses of the upper respiratory system and conditions such as tuberculosis. In a qualitative study, Schneiderman, Smith, and Palinkas (2012) found that 84% of caregivers of children in care were concerned about conditions such as asthma, diabetes, behavioural problems as well as DD. Studies that compared children in care with children living with their biological families found that acute bronchitis was more prevalent among children who were in care of others and not living with their biological families (41.5% vs. 17.8%) (Marinkovic, Backovic, & Kocijancic, 2004).

To my knowledge there have not been any population-based studies to compare rates of respiratory illnesses between children in care with and without DD. Such an examination is important as it would provide useful information that could help with the planning of the prevention programs and initiatives, but also the training of the parents including foster parents.

*(ii) Diabetes.* Diabetes is a major health concern for children with DD. Although genetic factors contribute to the development of diabetes, several other factors and health conditions, such as being overweight and obesity, play a major role in the development of diabetes (Yamaki,

Rimmer, Lowry, & Vogel, 2011; Oesenburg, Jansen, Dijkstra, Groothoff, & Reijneveld, 2010). .

In fact, being overweight or obese accounts for 80% of all type 2 diabetes diagnoses in adults (Tsigos, 2008). Prior research has found high rates of obesity and being overweight among persons with disability (Denny-Wilson, Hardy, Dobbins, Okely, & Baur, 2008; Lloyd, Temple, & Foley, 2012). For example, in a study on children with DD (aged 12-18 years), children with autism were 2 to 3 times more likely to be obese than the general population of adolescents (24.6% vs. 13% obese). Overweight adolescents with cognitive disabilities are also more likely than healthy weight adolescents with cognitive disabilities to have diabetes (6.5% vs. 1.4%; Rimmer, Yamaki, Lowry, Wang & Vogal, 2010). A number of modifiable factors contribute to overweight or obesity problems in children in general, and among those with disability specifically. For example, overweight and obese children with DD have an increased risk of diabetes due to a sedentary lifestyle in many residential settings (Beange, McElduff, & Baker, 1995; Fujiura, Fitzsimmons, Marks, & Chicoine, 1997; Rimmer, Braddock, & Fujiara, 1994). Altshuler and Poertner (2003) compared children who were living in a non-relative foster care to a matched group of children not in care. Children in care were almost three times more likely to have unstable chronic health conditions, which the researchers identified as heart disease, diabetes or sickle-cell anemia, than children in the comparison group (14% vs. 4.8%).

As administrative data sets lack information on children's health-related behaviours, such as nutrition and level of physical activity, prevalence of diabetes is used as a proxy indicator to provide further insight to children's lives and living conditions as well as their potential genetic predispositions. Childhood obesity is a major health concern as it has been found that 70% of adolescents with obesity will remain obese later into adulthood (Dehghan, Akhtar-Danesh, & Merchant, 2005), and those who are overweight/obese are at an increased risk of developing

diabetes later in life (Daniels, 2006; Goran, Ball, & Cruz, 2003; Mayer-Davis, 2008; Ogden, Flegal, Carroll, & Johnson, 2002; Sinha, Fisch, Teague, Tamborlane, Banyas, & Allen, 2002).

**(b) Mental Health Disparities.** Disparities in mental health for children with DD compared to children without DD was a consistent finding in the literature. The most reported disparities in mental health was for mood and other mood disorders; for this reason, prevalence of mood and other mood disorders were used in the current study to measure and examine mental disparities between children in care with and without DD. Research shows that regardless of their level of (dis)ability, children placed in care might develop attachment problems, which in turn leads to various developmental and mental health problems (Fonagy, 2003). Attachment problems have been associated with being placed in alternative living arrangements from the family of origin (Marcus, 1991). Children in care with DD have a more complex set of problems than children in care without DD as these children experience additional barriers to health, for example, they are more likely to lack social/communication skills (Margalit, 1991; Roberts & Zubrick, 1992) or adaptive behaviours, or have behavioural problems (Allen & Burns, 1998; Hunt & Goetz, 1997). For example, Bhaumik and colleagues (2011) conducted a UK study of teenagers with DD living in care, and found that 59% had some form of physical problem, 20.3% had a mental health problem, 46.8% had behavioral problems, and 51.9% of the sample had both mental health and behavioral problems (Bhaumik, et al., 2011). This shows the degree of complex problems faced by children in care with DD.

***Mood and anxiety disorders.*** The increased risk of mood and anxiety disorders in persons with DD compared to the general population is a consistent finding in the scientific published literature (Cooper, 1997; Hardan, & Sahl, 1997; Menis, 1993). It is reported that 10% (Lowry, 1998) to 20% (Cooper, 1996) of the population with DD experience depression at some

point in their lifetime. The majority of the estimates are based on small and non-representative samples of adults with DD. There have been few population-based studies comparing rates of mood and other mood disorders in children with DD. A recent population-based study of children 10 years of age or older in Manitoba, found that the prevalence of depression was almost twice as high in adolescents with DD compared to the matched comparison group of adolescents [RR = 2.13 (95% CI: 1.94, 2.33, p < 0.001)] (Shooshtari et al., 2014).

In studies examining the role of life events in people with DD, it has been found that changes due to recent and important life events are major risk factors for depression (Cooper, Smiley, Morrison, Williamson, & Allen, 2007; Myers & Pueschel, 1995). Some of the life events identified in these studies included parental separation, deaths in the family, and divorce. These life events most likely contribute to feelings of loneliness, social isolation, self-hatred, and social withdrawal, which can all contribute to increased risk of depression (Ailey, Miller, Heller, & Smith, 2006).

Depression can be a contributing cause to various health concerns, and has been associated with suicide and suicidal behaviour, where suicide is the third leading cause of death for 15-24-year-olds, and account for 20% of all deaths in this age group (Lewinsohn, Rohde, Seeley, 1998; Patja, Livanainen, Raitasuo, Raitasuo, & Lonnqvist, 2001; Centers for Disease Control and Prevention, n.d.). A United States study on children with ID, ages 4-18 years, revealed that 30% of suicidal children had a depressive disorder (Kemp & Krause, 1999). Patja and colleagues (2001) found that adolescents with DD have a rate of suicide that is one-third of the rate of the general population. Other factors associated with depression are self-injurious behaviours (SIB). In a Scottish study of adolescents and adults (older than 16 years) with ID, over a three-month period, Cooper and colleagues (2009) found an incidence of 4.9% and 25%

prevalence rate of SIB. Importantly, out-of-home placement was significantly associated with SIB (Cooper et al., 2009). In their study on Manitoba children and adolescents in care, Katz and colleagues (2011) found that children in care had higher rates than a comparison group for suicide [RR 3.54, 95% CI 2.11-5.95] and attempted suicide [RR 2.11, 95% CI 1.84-2.43], but the rates of attempted suicide decreased after entry into care (Katz et al., 2011).

Mental health, in particular mood and anxiety disorders, is an important factor in the development and quality of life for all children in care, and is of increased concern for children with DD. Children in care have more mental health problems than that of the general population (Bilaver, Jaudes, Koepke, & Goerge, 1999; Farmer et al., 2001; Simms, Freundlich, Battistelli, & Kaufman, 1999). The children who need to be placed in care do so with more mental health conditions than other children, and do not receive the health supports they need while in care (Leslie, Hurlbert, Landsverk, Barth, & Slymen, 2004; Simms, Dubowitz, and Szilagyi, 2000). Children whose placements change while in care, or have left care and re-entered care at a later time, have a higher percentage of mental health services utilization, which increases in frequency as the child becomes older (Leslie et al., 2000; Rubin, Alessandrini, Feudtner, Mandell, Localio, & Hadley, 2004). Pharmacology is often used to treat many mental health conditions, but research shows that children in care may actually be over prescribed. For example, in a national sample of children in care in the United States, Raghaven and colleagues (2005) found that 13.5% of all children in care were receiving psychotropic medications, which is two to three times more often than children in the general population. In their 2002 report, the Committee on Early Childhood, Adoption, and Dependent Care acknowledged these concerns and recommended that children in care should receive a mental health assessment, be referred to appropriate mental health services, have more frequent monitoring of their mental health status,

and have the results of the mental health assessment shared across services at each health visit (within one month of placement).

## **Health Care Utilization**

Researchers have measured health service utilization in a variety of ways including examining the number of hospital visits (Lee & Chen, 2012), length of stay in hospitals, number of visits to a physician (Newacheck & Halfon, 1998), and number of visits to medical specialists (Krauss, Gully, Sciegaj, & Wells, 2003; Schieve, et al., 2012). In the present study, utilization of health services was examined using three indicators: (i) continuity of care, (ii) injury-related hospitalizations for children in care with DD, and (iii) oral health.

**(i) Continuity of care.** There have been many documented barriers that adults and children with DD face when they need to access primary health care (Betz, et al., 2004) or more specialized medical care (Krauss, Gully, Sciegaj, & Wells, 2003). The research suggests that this issue becomes more complex for children with a dual diagnosis (i.e., coexisting DD and a mental health condition such as ADHD, depression, anxiety, and emotional problems) (Nageswaran, Parish, Rose, & Grady, 2011). Due to the lack of access to appropriate and timely primary healthcare, children with DD utilize some types of health services more frequently than children without these conditions. For example, children with DD have more hospital visits per capita than their non-DD counter parts (108.4 vs. 51.5,  $p < 0.001$ ) (Lee & Chen, 2012). Using data from the American National Health Interview Survey, Newacheck and Halfon (1998) found that children with DD had contact with their physicians at a rate which was three times higher than that of children without DD. Children in care have been found to utilize pediatric services more frequently than their peers not in care, but even with their high rate of using of services, their complex needs still remain unmet (Leslie et al., 2003; Sphere Institute, 2003). Schieve and

colleagues (2012) found that children with DD were significantly more likely to have seen a medical specialist, having on average of more than 9 medical visits in the past year, compared to non-DD children. This is not consistent with the findings of studies that reported more limited access to specialized care by children with DD compared to those without DD (Betz et al., 2004; Krauss, et al., 2003).

In the general population, however, children in care often receive inconsistent care and do not have continuity of care (Kortenkamp & Ehrle, 2002). A United States General Accounting Office publication reported that 34% of children in care did not receive any immunizations, 12% of children in care did not receive routine medical care, and only 10% received services for developmental delays (U.S. General Accounting Office, 1995). Placement instability is likely a large contributor to lack of continuity of care for children in care (U.S. General Accounting Office, 1995). Not only is an inadequate level of care provided to these children, but they often use more acute health services and less primary care services inappropriately than their peers in the general population (Rublin, Alessandrini, Feudtner, Localio, & Hadley, 2004). However, it has been noted that they receive the wrong types of services due to the child's caregiver receiving incomplete information regarding the child's medical records, which may be contributing to the fragmentation of health services being provided to them (Simms et al., 1999; Sobel & Healy, 2001).

Although research has made little connection between children in care with DD and their health utilization, examining each group (i.e., children with DD and children in care) on its own reveals a very complex health service utilization pattern. It is difficult to determine in the literature if these two non-mutually exclusive groups of children compounds or minimizes the problems associated with health care utilization.

**(ii) Injury-related hospitalizations.** Children with DD have been identified as having an even higher risk of accidents or injuries that are in need of hospitalization than children without DD (Xiang, Stallones, Chen, Hostetler, & Kelleher, 2005). Increased injury risk in children with DD is often understood to be a factor of the individual's limitations in not knowing or understanding the dangers of the situation and in coping with changes in the environment (Davidson, 1987; Dunne, Asher, & Rivara, 1993; Konarski, Sutton, & Huffman, 1997; Mellinger & Manheimer, 1967; Rivara, 1995). A recent study found that children aged 3-5 years who had some type of psycho-developmental, or behavioural problems were between 2 and 3 times more likely to experience injuries that were in need of medical attention than children of the same age, but without those conditions [autism (2.15 times; 95%CI: 1.00–4.60), ADD/ADHD (2.74 times; 95% CI: 1.63–4.59), and other psychopathology (2.06 times; 95% CI: 1.24–3.42)] (Lee, Harrington, Chang, & Connors, 2008). In an epidemiologic study, people with DD (age 5-29 years) were twice as likely as the general population to experience injury-related hospitalizations (Sherrard, Tongue, & Ozanne-Smith, 2001). In addition, falls were the most common cause of injury, and the injuries experienced by people with DD were more similar to injuries seen by younger children than injuries incurred by their same-age peers in the general population (Sherrard, Tongue, & Ozanne-Smith, 2001). Altshuler and Poertner (2003) compared children living in non-related foster care to children in a comparison group of children not in care. Children living in care reported more broken bones, head injuries, gunshot or stab wounds (26% vs. 13.1%), and more minor adverse effects from injuries (62.0% vs. 46.1%; Altshuler & Poertner, 2003). Previous research on both children with DD and studies on children in care show that both populations of children have higher rates of hospitalizations due to injuries.

**(iii) Oral health.** A comprehensive review of the literature revealed that there is very

limited information on issues related to oral health for children in care with DD. When examining the literature on oral health in children with DD in general, the main finding is that children with DD receive less preventative dental care compared to their non-DD counter parts (Chi, Momant, Kuthy, Chalmers, & Damiano, 2010). The lack of preventative oral care often leads to extensive oral health problems resulting in children with DD being admitted to hospitals in order to care for their oral health needs. The most common oral health problems that children with DD seek medical help for is gingivitis and dental caries (Albino, Schwartz, Goldberg, & Stern, 1979; Slack-Smith, Colvin, Leonard, Kilpatrick, & Bower, 2009). Williams and colleagues (2005) found that while examining hospital admissions for dental problems in children with and without DD, children with DD were more likely to present at a hospital for health matters relating to their dental problems. Slack-Smith and colleagues (2009) found that children with a DD were almost twice [OR = 1.92; (95% CIs: 1.63, 2.27)] as likely to have an admission to a hospital for dental work and almost four times increased odds [OR = 3.7; (95% CIs: 1.7, 8.2)] of being admitted for gingival and periodontal diseases compared to their non-DD counterparts. This may be due to children with DD exhibiting more behavioural problems and/or more advanced tooth destruction, which may make a hospital setting the preferred and/or necessary location to perform oral health treatments (Enever, Nunn, & Sheehan, 2000).

Studies which have focused on children (in general) entering into care report that a large proportion of children have health problems associated with a lack of dental care (Oliván, 1999). Using data from the US National Survey of America's Families, Leslie and colleagues (2003) found that depending on the state, 20 - 40% of children in care received no preventative health or dental care. A qualitative study of caregivers of children in care reported caregiver's feelings of frustration with access and Medicaid authorization for dental care, such as filling cavities and

braces, to be performed. One respondent stated that they had to go to five or six dentists before they were able to find a dentist willing to provide services to the child in care, and eventually had to seek services from a University School of Dentistry clinic (Scheiderman et al., 2012). To date, no study has examined oral health or dental care in children in care with DD, however, the research summarized above suggests that this particular group likely experiences even higher utilization of hospital- rather than community-based dental services, which may demonstrate lack of access to preventive health care.

The present study described the health status and health care utilization patterns of children in care with DD, compared to the health and health care utilization patterns of children in care without DD. This was done by examining TRM, diabetes, and mood and other mood disorders as indicators of the health condition of children in care, both with and without DD. Health care utilization indicators consisted of continuity of care, injury-related hospitalizations, and hospital based dental care to determine whether children in care with DD have the same level of access to healthcare services as children in care without DD. Placement in care determines children's living environment, which is a factor of interest in this study. Because environmental factors contribute to children's health, focusing on children in care helps to ensure the environmental factors in this study are comparable for the two study groups to allow a fairer comparison. Additionally, the two study groups were matched on age, sex, and place of residence, which allow for more similar environmental and personal characteristics between the two study groups.

## Chapter 3: Methods

The study methodology is described in five sections: population and data sources (study design, data sources, data linkages, study population), study measures (demographic characteristics, children in care, DD, health measures, health care utilization), timeframe of the data, data analysis overview, and ethical considerations.

### Population and Data Sources

**Study design.** The purpose of the study was to describe health status and health care utilization patterns of children in care with DD and compare that to the health status of children in care without DD. To this end, the study used a matched cohort design, involving multiple years of population-based administrative data, to estimate the number and describe the demographic and socioeconomic characteristics of children in care with and without DD in Manitoba.

**Data sources.** Data were obtained from several data sets contained in the Manitoba Population Health Research Data repository housed and maintained by the Manitoba Centre for Health Policy (MCHP). The specific data files used were:

- Health databases (hospital discharge abstracts, drug database, and physician claims).
  - Hospital discharge abstracts (1995-2012 calendar years) to identify children with DD, TRM, diabetes, depression, hospitalizations due to injury, and dental extractions.
  - Medical services databases (1995-2012 calendar years) to identify children with DD, TRM, diabetes, depression, and continuity of care.
- Drug database
  - Drug Program Information Network (DPIN) file (2009-2012 calendar years)
    - Identify medications used as indicators of diabetes and mood and anxiety

disorders.

- Education database
  - Manitoba Education and Advanced Learning enrolment file (1995-2012 calendar years)
    - identify children with DD and/or autism who are receiving categorical funding in the education system
- FASD database
  - Manitoba Fetal Alcohol Spectrum Disorder Centre database (1999-2012 calendar years)
    - Identify children with FASD
- Population Registry
  - Manitoba Population Registry (2012)
    - Residence location (RHA)
    - Age
    - Sex
- Family Services Data
  - Child and Family Services Information System (CFSIS) data set from Manitoba Family Services (1995-2012 calendar years)
    - Identify children in care
- Canadian Census data
  - 2011 Canadian Census (2011)
    - Income data associated with residence location

**Data linkages.** Each individual registered in the Manitoba health care program is assigned a nine digit Personal Health Identification Number (PHIN). To protect confidentiality of individuals while still allowing researchers to use of the information stored in the databases,

the MCHP data repository contains non-identifying scrambled PHINs, which are consistent from one database to another. The scrambled PHINs were used to link the data across time and data sets for each child in the two study groups.

The data from MCHP are stored on secured computers, and were accessed from one of the MCHP remote terminals located in Room 212 Human Ecology Building of the University of Manitoba. The data were analysed using the Statistical Analysis System (SAS 9.4) software provided by the University of Manitoba.

**Study population.** The study population consisted of children who were (a) residing in the province of Manitoba in 2012; (b) under the age of 18 (i.e., aged 1-17); and (c) classified as “Children in Care in 2012”. Children in Care (CIC) are those “children who are removed from their families of origin and placed in the care of another adult(s) (not a parent or guardian) due to concerns about the proper provision of care in the family of origin. There are situations where a family is unable or unfit to properly look after their child(ren) and in these cases the child(ren) may be placed into foster care. Children can come into care for a variety of reasons including abuse and neglect, illness, death, conflict in their family, disability, or emotional problems. Children can be placed in foster care through voluntary placement, voluntary surrender of guardianship, apprehension, or order of guardianship. CIC does not include children who remain with or are returned to a parent or guardian under an order of supervision” (Manitoba Centre for Health Policy). Children “in care” were identified in the CFSIS database. For the purpose of this study, the study population was divided into two groups:

**Study group.** The study group consisted of children in the study population who met at least one of the following three criteria for DD: 1) applied to receive funding for special needs in support of their education between 1995-2012; 2) had a diagnosis code for DD in their hospital

discharge abstracts or Physician Claims between 1995-2012; and 3) had a diagnostic code of FASD in the Manitoba FASD dataset between 1999-2012. A complete list of ICD-9-CM and ICD-10 diagnostic codes of DD along with other identifying criteria is presented in the study measures section in this chapter.

***Matched comparison group.*** The matched comparison group consisted of children in the study population, who did not meet any of the three specified criteria for DD. Each child in the case group was matched with two children of the same age, sex, and place of residence in the comparison group, which allowed minimization of the influences of these factors as potential confounders. These potential confounding factors were made due to children with DD having previously been found to be of younger age, and consist of a higher proportion of males, than in the general population (Shooshtari et al., 2014). In addition, the various place of residence (RHA) have different levels of services available for them to access between remote and urban regions of Manitoba. For 10 children in care with DD (0.08%) it was not possible to match with children in care without DD on the exact birth year. For these children, they were matched as closely as possible on birth year plus or minus 1 year with an exact match on sex and place of residence.

## **Study Measures**

### **Demographic characteristics.**

***Age.*** Age of individuals in this study is described as the time in years from birth.

***Sex.*** In this study, sex is described as the individual's biological male or female status.

***Socioeconomic status.*** Socioeconomic status can be measured in different ways using MCHP data. In this study, socioeconomic status was measured using area-level data by ranking the total population into five income groups called income quintiles, from lowest to highest.

These quintiles are equally divided with 20% increments from 1 (poorest) to 5 (wealthiest) based upon mean household income from Statistics Canada census files (Fransoo et al., 2009)

**Place of residence.** In Manitoba, the province is divided into 5 geographical health regions or RHAs, where health services are provided to the residence of that region. Place of residence is the RHA in which an individual lives based on the postal codes associated for that location.

### **In-care characteristics**

**Children in care.** The 18 years of data (1995-2012) from the CFSIS dataset was used to determine a child's in care characteristics in children who were in care in 2012. Age of the child in years, the number of times a child re-entered into care, and the total duration the child was in care were calculated based on the CFSIS dataset.

**Duration in care.** For children in care in 2012, the CFSIS data from the 18 years (1995-2012) was used to calculate duration in care. The number of days in care during multiple episodes were added together to provide a total duration that an individual had been in care over their life. Duration of care was examined in yearly intervals. After a child was in care for more than nine years, the duration in care was reported as having spent more than nine years in care.

**Number of episodes in care.** For children in care in 2012, the CFSIS data from the 18 years of data (1995-2012) were used to determine the number of episodes that a child had been in care for. Some children in care are placed into temporary care and returned to their biological families after some time. Some children may again re-enter into care at a later point in life. The number of episodes is the number of times that a child enters into care over their life.

**Developmental disability.** To define developmental disability, the use of an operational definition, developed by Shooshtari and colleagues (2011) based on administrative data from

multiple data sets in the MCHP Data Repository was used. Children with DD were defined as those who met at least one of the following criteria from the 18 years of data used (1995-2012), with the exception of the Manitoba FASD dataset, where data from 1999-2012 were used:

- 1) Received funding for special needs – This information was obtained from the Manitoba Education Enrollment, Marks, and Assessments database. Children with a categorization of “Multiple Handicaps” (“MH”) or “Autism Spectrum Disorder” (ASD) within the CATEGORYN variable were selected. CATEGORYN is a variable that identifies if a student has an application to receive special (categorical) funding for special needs. The Manitoba Education data from 1995-2012 was examined. This study examined only children that were 18 and younger during this timeframe.
- 2) Have a diagnosis of DD in the hospital discharge abstracts – The most recent year of Hospital Discharge Abstract Data was used, where at least one of the following ICD-10-CA codes shown in Table 2.

**Table 2. Hospital Discharge Abstract Data ICD-10-CA codes to identify DD.**

<i>ICD-10-CA codes</i>	<i>Description</i>
F70.0, F70.1, F70.8, F70.9	Mild mental retardation
F71.0, F71.1, F71.8, F71.9	Moderate mental retardation
F72.0, F72.1, F72.8, F72.9	Severe mental retardation
F73.0, F73.1, F73.8, F73.9	Profound mental retardation
F78.0, F78.1, F78.8, F78.9	Other mental retardation
F79.0, F79.1, F79.8, F79.9	Unspecified mental retardation
F84.0, F84.1, F84.3, F84.4, F84.5, F84.8, F84.9	Pervasive developmental disorders

P04.3	Fetus and newborn affected by maternal use of alcohol
Q86.0, Q86.1, Q86.2, Q86.8	Congenital malformation syndromes due to known exogenous causes, not elsewhere classified
Q87.0, Q87.1, Q87.2, Q87.3, Q87.5,	Other specified congenital malformation
Q87.8	Syndromes affecting multiple systems
Q89.8	Other congenital malformations
Q90.0, Q90.1, Q90.2, Q90.9	Down's syndrome
Q91.0, Q91.1, Q91.2, Q91.3, Q91.4, Q91.5, Q91.6, Q91.7	Edward's syndrome and Patau's syndrome
Q93.0, Q93.1, Q93.2, Q93.3, Q93.4, Q93.5, Q93.6, Q93.7, Q93.8, Q93.9	Monosomies and deletions from the autosomes, not elsewhere classified
Q99.2	Fragile X chromosome

---

- 3) Have a diagnosis of DD in the Physician Claims data set – The 18 years of data (1995-2012) were used from the Physician Claims data set, searching for an ICD-9-CM code of 317 (Mild Mental Retardation [MR]), 318 (other MR), 319 (unspecified MR), and 299 (Autism and other psychoses with origin specific to childhood).
- 4) Have a diagnostic code of ARND (Alcohol Related Neurological Disorder), ARND/ARBD (both Alcohol Related Behavioral Disorder and Alcohol Related Neurological Disorder), FAS (Fetal Alcohol Syndrome), FAS/ARBD (both Fetal Alcohol Syndrome and Alcohol Related Behavioral Disorder), and Partial FAS (Partial Fetal Alcohol Syndrome).

**Health measures.**

**Total Respiratory Morbidity.** Consistent with previous research based on MCHP data, TRM was derived based on all types of respiratory illnesses (Fransoo, Martens, Burland, The Need to Know Team, Prior, & Burchill, 2009). The illnesses that TRM covers are asthma, chronic or acute bronchitis, emphysema, chronic airway obstruction or chronic obstructive pulmonary disease (COPD). The data on TRM were obtained from both the hospital abstract data, as well as the physician claims from the most recent three years (2009-2012). Those with a respiratory illness were defined as those who have; 1) one of the following ICD-10-CA codes in hospital discharge abstracts J20, J21 or J40 – J45, or; 2) one or more physician visits with an ICD-9-CM code of 466, 490, 491, 492, 493, or 496.

**Diabetes.** For the purpose of this study, diabetes was defined as having either type 1 or type 2 diabetes. This was done as it was not possible to differentiate between type 1 and type 2 diabetes due to the multiple sources of data used where some data sources do not allow for a distinction between the types of diabetes. Data from Physician claims, hospital discharge abstracts and the Pharmaceutical Drug Program Information Network (DPIN) data file were used to estimate prevalence of diabetes as estimated in previous research focusing on children (Brownell, et al., 2008; Brownell, et al., 2012). This measure indicates proportion of population in each study group, which had a diagnosis of diabetes in the most recent three-year time period (2009-2012). A diagnosis of diabetes was determined based on at least one hospitalization with a diabetes diagnosis (ICD-10-CA of E10-E14), or at least 2 physician visits with ICD-9-CM diagnostic code of 250, or filled two or more prescription for a diabetes medication with an Anatomical Therapeutic Chemical (ATC) code A10 (drugs used in diabetes) in the most recent 3-year time period (2009-2012).

**Mood and anxiety disorders.** A measure of mood and anxiety disorders was defined

consistent with previous MCHP research (Chartier et al., 2012; Fransoo et al., 2009; Martens et al., 2010). This indicator was computed for children 10 years of age and older, as it is difficult to accurately diagnose mood or anxiety disorders under the age of 10 (Martens, et al., 2004).

Individuals who met at least one of the following criteria were identified as having mood and anxiety disorders within the three years studied (2009-2012):

1. One or more hospitalizations with a diagnosis of depressive disorder, affective psychosis, neurotic depression, or adjustment reaction (ICD-10-CA codes F31, F32, F33, F34.1, F38.0, F38.1, F41.2, F43.1, F43.2, F43.8, F53.0, F93.0).
2. One or more hospitalizations with a diagnosis for anxiety disorders (ICD-10-CA codes F32.0, F34.1, F40, F41, F42, F44, F45.0, F45.1, F45.2, F48, F68.0, F99) AND one or more prescriptions for an antidepressant or mood stabilizer with ATC codes of N03AB02, N03AB52, N03AF01, N05AN01, N06A.
3. At least one physician visit with a diagnosis for depressive disorder, affective psychoses, or adjustment reaction (ICD-9-CM codes 296, 309, or 311).
4. One or more physician visit with a diagnosis for anxiety disorders (ICD-9-CM code 300) AND one or more prescriptions for an antidepressant or mood stabilizer, ATC codes N03AB02, N03AB52, N03AF01, N05AN01, N06A.

### **Health care utilization.**

***Continuity of care.*** Continuity of care is measured in children with at least three physician visits where the proportion of visits to a single physician is greater than 50% of all physician visits over a specified period (2009-2012). This measure can range from a score of zero to one, with children receiving a score of greater than 0.5, considered to have continuity of care.

**Total physician visits.** The total ambulatory physician visits was determined as the total number of visits from physician contacts including contacts with general practitioner and specialists; this includes office visits, walk-in clinics, home visits, personal care home and nursing home visits and visits to outpatient departments over the three years of data (2009-2012).

**Injury-related Hospitalizations.** Injuries requiring hospitalization is an important measure to examine as this measure could indicate a lack of preventive care for a child, an increase in challenging behaviour in a child, or not receiving reliable care from their caregiver.

Hospitalizations due to injury are measured as admissions of more than one day coded in the hospital abstract records within the most recent three years of data (2009-2012), with ICD-10-CA codes within the categories of transportation accidents (V01-V79), falls (W00-W19), exposure to mechanical forces (W20-W64), accidental drowning and submersion (W65-W74), other accidental threats to breathing (W75-W84), exposure to electric current, radiation and extreme ambient air temperature or pressure (W85-W99), exposure to smoke, fire and flames (X00-X09), contact with heat and hot substances (X10--X19), contact with venomous plants and animals (X20-X29), exposure to forces of nature (X30-X39), accidental poisoning and exposure to noxious substances (X40-X49), overexertion, travel and privation (X50-X57), exposure to other and unspecified accidental factors (X58,X59), intentional self-harm (X60-X84), assault, including neglect and abandonment and other maltreatment syndromes (X85-Y09), event of undetermined intent (Y10-Y34), legal intervention and operations of war (Y35 and Y36).

**Hospital-based dental care.** A child receiving dental care in a hospital is seen as a demonstration of a lack of preventative care in the community. Oral care was chosen as an indicator as it is a very preventable condition that can lead to serious health conditions if left untreated (Mouradian, Wehr, & Crall, 2000). The data for dental care are limited only to those

procedures that take place in a hospital, and were examined from the hospital abstract data from the most recent three years of data (2009-2012). Children with ICD-10 CA codes of K02 (dental cavities) and K04.7 (periapical abscess without sinus), or with an identified surgical procedure (Canadian Classification of Health Interventions (CCI) codes of 1.FE.57.JA (tooth extraction), 1.FF.56 (removal of foreign body, root of tooth), 1.FF.89 (excision total, root of tooth), 1.FE.89 (excision total, tooth), 1.FE.29 (tooth restoration), 1.FE.53.JA-RV (implantation of internal device, tooth), 1.FF.59.JA (destruction, root of tooth), 1.FD.52 (gingival drainage), 1.FE.87.JA-H (excision partial, tooth), 1.FF.53 (implantation of internal device, root of tooth), 1.FF.80 (repair, root of tooth), and 1.FF.87 (excision partial, root of tooth) were examined for 2009-2012.

**Timeframe.** The data used in this study encompassed multiple years. Data for neighbourhood income levels were obtained from the Manitoba Population Registry file, which was derived from the 2011 Canadian Census data. The most recent 18 years (1995-2012) of data from the CFSIS database was used to identify children in care, their age that they entered into care, the duration that they have been in care and to ensure that children living in care have been in this place of residency for a minimum of seven days. The 18 years of data (1995-2012) were used for the Health databases and Educational databases and the years 1999-2012 were examined for the Manitoba FASD dataset. For TRM, injury-related hospitalizations, hospitalized dental care and diabetes the most recent three years (2009-2012) of data were used.

## **Data Analysis**

The two study groups were compared on their health and health care utilization measures in various ways. The health statuses and health care utilization of children in care were described by computing prevalence for TRM, diabetes, and mood and anxiety disorders, rates of

hospitalized dental care, and continuity of care. The computed prevalence estimates were compared between children in care, with and without DD, using Generalized Estimating Equation (GEE) modeling. Health care utilization indicators were analyzed using two different methods. Differences in neighbourhood income quintiles were analyzed between the two study groups by means of a chi-square test. Comparisons between the two study groups were conducted with the use of paired *t*-tests for duration in care, episodes in care, and total ambulatory physician visits.

### **Ethical Considerations**

This research proposal was approved by Heath Information and Privacy Committee (HIPC), the Health Research Ethics Board (HREB), as well as by Manitoba Family Services, the Winnipeg Regional Health Authority (WRHA), and Manitoba Education and Advanced Learning.

## Chapter 4: Results

This chapter is organized into five sections. In the first section, the demographic and socioeconomic profiles of Manitoba children in 2012 and Manitoba children in care in 2012 are described. The second section provides descriptive information on children in care with DD. In the third section, the demographic and socioeconomic characteristics of Manitoba children in care with and without DD of the same age, sex, and from the same place of residence (RHA) are compared. In the fourth section, the health status of children in care with DD of the same age, sex, and from the same place of residence (RHA) is compared to children in care without DD. In the fifth section, the health care utilization patterns of children in care with and without DD of the same age, sex, and from the same place of residence (RHA) are compared.

### **Demographic and Socioeconomic Characteristics of Manitoba Children and Manitoba Children in Care, 2012**

There were 272,814 children under the age of 18 years residing in Manitoba in 2012. Approximately 49% (or 132,905 children) were female. The sex distribution for Manitoba children in care in 2012 was similar to that of the general population, with 49.89% ( $n = 4,405$ ) female.

The age distribution of these children is shown in Table 3. As the table shows, of all Manitoba children in 2012, a total of 8,830 (3.23%) were in care and the age distribution of these children is similar to that of the general population of Manitoba children.

**Table 3. Age distribution of all Manitoba children and Manitoba children in care in 2012.**

Age	<i>N</i>	% of all Manitoba Children	Manitoba children in care in 2012	
			<i>n</i>	% of all Manitoba children in care

0-2	44,185	16.20%	1,196	13.54%
3-5	48,810	17.89%	1,673	18.95%
6-8	46,099	16.90%	1,528	17.30%
9-11	46,692	17.11%	1,413	16.00%
12-14	48,404	17.75%	1,609	18.22%
15-17	38,624	14.16%	1,411	15.98%
Totals	272,814	100%	8,830	100%

As Table 4 shows the majority (71%) of Manitoba children in care resided in the Winnipeg health region. The proportion of children in care was lower in the Southern and Prairie Mountain health regions compared to all Manitoba children in 2012.

**Table 4. RHA distribution of all children in Manitoba and children in care in 2012.**

RHA	All Manitoba children in 2012		Manitoba children in care in 2012	
	N	%	n	%
Interlake-Eastern (IE)	26,010	9.53%	700	7.93%
Northern (NO)	24,637	9.03%	648	7.34%
Southern (SO)	48,028	17.60%	508	5.75%
Prairie Mountain Health	34,690	12.72%	703	7.96%
Winnipeg	139,449	51.11%	6,271	71.02%
Totals	272,814	100%	8,830	100%

The distribution of children in care in 2012 by income quintiles is shown in Table 5.

There are disproportionate numbers of children in care residing in neighbourhoods with the lowest income or where income data were not found. These two income groupings accounted for three quarters (73%) of children in care. There were less than 2% of all Manitoba children from neighbourhoods where information was not available. For all Manitoba children in 2012, there was a fairly equal distribution across all income quintiles.

**Table 5. Distribution of children in care by income quintiles.**

Income Quintile	All Manitoba children in 2012		Manitoba children in care in 2012	
	N	% of all Manitoba children	n	% of all Manitoba children in care
NF	3,890	1.43%	3,034	34.36%
lowest quintile Q1	60,343	22.12%	3,442	38.98%
Q2	49,422	18.12%	1,156	13.09%
Q3	50,129	18.37%	578	6.55%
Q4	54,572	20.00%	477	5.40%
highest quintile Q5	54,458	19.96%	173	1.96%
Totals	272,814	100%	8,830	100%

Notes: NF = Income data “Not Found” for neighbourhood level, could be due to multiple reasons. The most likely reason for a child to be placed in the “NF” group in this study is that the postal code is associated with a Public Trustee Office, or a Child and Family Services (CFS) Office.

Of the 8,830 children in care, about one quarter (24%) were in care for less than two

years. Table 6 shows the distribution of children in care in 2012. The average number of days for children in care was 1869.09 days or about 5.1 years. Almost one-fifth (17%) of children in care in 2012 were in care for more than nine years.

**Table 6. Duration in care for Manitoba children in care in 2012.**

Duration in care	Manitoba children in care in 2012	
	N	%
< 1 year	577	6.53%
1 year	1,464	16.58%
2 years	1,247	14.12%
3 years	1,166	13.20%
4 years	895	10.14%
5 years	640	7.25%
6 years	506	5.73%
7 years	507	5.74%
8 years	365	4.13%
> 9 years	1,463	16.57%
Totals	8,830	100%

The next characteristic examined was the “number of times a child enters into care.” The number of episodes is the number of times that a child enters into care. Table 7 shows the number of episodes in care for children in care in 2012. Of the 8,830 children in care in 2012, 4,110 (47%) children had only one episode in care. The average number of episodes in care was

1.93 ( $SD = 1.23$ ).

**Table 7. Number of episodes in care for all Manitoba children in care in 2012.**

Manitoba children in care in 2012		
Number of in care episodes	n	%
1	4,110	46.55%
2	2,837	32.13%
3	1,037	11.74%
4	458	5.19%
5 or more	388	4.39%
Totals	8,830	100%

### **Manitoba Children in Care with DD**

Table 8 shows the sources of data that were used to identify children with DD, by percent of children identified by each source. Of the 8,830 Manitoba children who were in care in 2012, a total of 1,212 children (13.73%) had an indication of DD based on all the data sources used in this study. As shown in Table 7, of the 1,212 children in care identified as having DD, 877 children (72.36%) were identified by only one source, demonstrating the importance of linking data across multiple databases. Two hundred and forty-five children (20.21%) met criteria for DD based on two sources, and 90 (or 7.43%) were identified based on three or more data sources.

Of the 1,212 children in care with DD, a total of 1,202 (99.2%) were matched on a ratio of 1:2 (two children in care without DD for every child in care with DD) based on exact year of birth, but also sex and region of residence. As it was not possible to match the remaining 10

children in care with DD with children on the same exact birth year, we matched them, to two matches, as closely as possible on birth year plus or minus one year.

**Table 8. Distribution of Manitoba Children in Care with DD by Source of DD**

**Identification.**

Source of Data	n	%
Medical Claims	61	5.03%
Hospital Abstracts	232	19.14%
FASD	368	30.36%
Education	216	17.82%
Medical Claims & Hospital Abstracts	12	0.99%
FASD & Medical Claims or Hospital Abstracts	45	3.71%
Education & Medical Claims	68	5.61%
Education & Hospital Abstracts	58	4.79%
Education & FASD	62	5.12%
Three or more sources	90	7.43%
Totals	1,212	100%

**Note:** Due to small sizes, it was not possible to report number of cases for FASD & Medical Claims, FASD & Hospital Abstracts, or combinations of three or more sources separately and thus these were combined.

**Demographic, Socioeconomic, and in Care Characteristics of Children in Care with and without DD in Manitoba**

The demographic characteristics (i.e., age, sex, and region of residence) were described for both study groups. The socioeconomic characteristic (i.e., income quintiles) was compared using chi squared test. The in care characteristics (i.e., duration in care, and number of care episodes) of the two study groups, the means were compared using paired t-tests. Due to the matching, the two study groups had similar sociodemographic profiles in age, sex, and regional

distribution.

**Age.** Age distribution of children in care with DD compared with the matched comparison group is shown in Table 8. The mean age of children in care with DD was 10.57 ( $SD = 4.44$ ) years. The mean age of the matched study group was 10.56 ( $SD = 4.41$ ) years. As shown in Table 9, a small proportion of children in both groups were in the 0-2 age groups (4.54% in each group).

**Table 9. Age distribution of the two study groups.**

Age	Children in care with DD		Matched Study group of children in care without DD	
	n	%	N	%
0-2	55	4.54%	110	4.54%
3-5	151	12.46%	296	12.21%
6-8	185	15.26%	373	15.39%
9-11	216	17.82%	456	18.81%
12-14	314	25.91%	633	26.11%
15-17	291	24.01%	556	22.94%
Totals	1,212	100%	2,424	100%

**Sex.** Table 10 shows the sex distribution of the two study groups. As shown in the table, 37% of children in both study groups were female.

**Table 10. Sex distribution of the two study groups.**

	Children in care with DD	Matched Study group of children in care without DD

Sex	<i>n</i>	%	<i>N</i>	%
Male	760	62.71%	1,520	62.71%
Female	452	37.29%	904	37.29%
Totals	1,212	100%	2,424	100%

**Health Region.** Table 11 shows the distribution of children in the two study groups by health region of residence. The majority, 77%, of the children in both study groups resided in the Winnipeg region.

**Table 11. Distribution of the two study groups by health region of residence.**

RHA	Children in care with DD		Matched study group of children in care without DD	
	<i>n</i>	%	<i>N</i>	%
Interlake-Eastern	92	7.59%	184	7.59%
Northern	63	5.20%	126	5.20%
Southern	53	4.37%	106	4.37%
Prairie Mountain	61	5.03%	122	5.03%
Winnipeg	943	77.81%	1,886	77.81%
Totals	1,212	100%	2,424	100%

**Socioeconomic status.** Comparison of income quintiles for the study groups is shown in Table 12. Children in care with DD were more likely to be living in neighbourhoods categorized by “NF” than their matched study group (54% vs. 40%). Children in care with DD were less likely to be living in the neighbourhoods falling into the lowest 20% income quintile as compared to their matched study group of children in care without DD (27% vs. 37%). A chi-squared test was performed to examine if there was a statistically significant difference between

the two study groups in terms of their neighborhood income level. Results showed that the observed difference was statistically significant,  $\chi^2 = 69.93$ , df = 5,  $p = <0.0001$ .

**Table 12. Distribution of the two study groups by neighbourhood income quintiles.**

RHA	Children in care with DD		Matched study group of children in care without DD	
	n	%	N	%
NF	659	54.37%	959	39.98%
Lowest quintile Q1	327	26.98%	897	37.00%
Q2	106	8.75%	270	11.14%
Q3	62	5.12%	135	5.57%
Q4	46	3.80%	127	5.24%
Highest quintile Q5	12	0.99%	26	1.07%
Totals	1,212	100%	2,424	100%

Notes: NF = Income data “Not Found” for neighbourhood level, could be due to multiple reasons, most likely reason in this study is that the postal code is associated with a Public Trustee Office, or a Child and Family Services (CFS) Office.

**Days in care.** The total number of days in care for children with DD was collapsed into 1 year intervals. The distribution of the two study groups by total number of days in care is shown in Table 13. For children in care with DD, 2.39% were in care for less than one year. Of the children in the matched group, a higher proportion (5.65%) was in care for less than one year. The average number of days in care for children with DD was 2,789.46 ( $SD = 1,628.27$ ), or around 7.6 years. The average number of days in care for children in the matched comparison group was less than that of the children in care with DD at 2,090.83 ( $SD = 1,472.18$ ) days, or around 5.7 years. Results of the paired *t*-test showed that there is a statistically significant

difference between the two study groups in terms of days in care,  $t(2217.1) = -12.59, p < 0.0001$ .

**Table 13. Distribution of duration in care between both study groups.**

Duration in care (year)	Children in care with DD		Matched study group of children in care without DD	
	n	%	n	%
< 1	29	2.39%	137	5.65%
1	84	6.93%	322	13.28%
2	89	7.34%	283	11.67%
3	102	8.42%	279	11.51%
4	111	9.16%	246	10.15%
5	98	8.09%	213	8.79%
6	81	6.68%	173	7.14%
7	91	7.51%	168	6.93%
8	81	6.68%	107	4.41%
> 9	446	36.80%	496	20.46%
Totals	1,212	100%	2,424	100%

**Episodes of care.** The number of episodes in care for the two study groups is shown in Table 14. Children in care with DD were slightly less likely than children in the matched comparison group to have only one episode of care (38.45% vs. 40.26%). The average number of episodes for the DD group was 2.06 ( $SD = 1.32$ ). The average number of episodes for children in the matched comparison group was 2.07 ( $SD = 1.28$ ). The results of the paired t-test showed that the observed difference in number of care episodes between the two study groups was not statistically significant,  $t(2356.5) = 0.38, p = 0.71$ .

**Table 14. Number of episodes in care by study group.**

Number of episodes	Children in care with DD		Matched study group of children in care without DD	
	n	%	n	%
1	466	38.45%	976	41.26%
2	468	38.61%	801	33.04%
3	147	12.13%	357	14.73%
4	67	5.53%	167	6.89%
5 or more	64	5.28%	123	5.07%
Totals	1,212	100%	2,424	100%

The majority of children in care with DD lived in Winnipeg (78%), and from neighbourhoods not associated with a postal code (54%), or in the lowest income quintile (27%). Children in care with DD had similar number of episodes in care, but were in care longer than the matched comparison group.

### **Health Status of Manitoba Children in Care with and without DD**

The health status of Manitoba children in care with and without DD was compared on health indicators of TRM, diabetes and mood and anxiety disorders. Analysis was completed to compare the two study groups using a GEE.

**Total respiratory morbidity.** Children in care with and without DD who had an indication of respiratory morbidity in their medical records over a three-year time period (2009 – 2012) were identified. As shown in Table 15, of all Manitoba children in care with DD, 45% had an indication of respiratory morbidity in their medical records whereas only 41% of children in care in the non-DD matched comparison group had this indication. Results of the GEE showed that the observed difference in the rates of TRM between the two study groups was

statistically significant [OR = 1.20; (95% CI: 1.05, 1.37,  $p = 0.0082$ )].

**Table 15. Total Respiratory Morbidity (TRM) by Study Group.**

Total Respiratory Morbidity	Children in care with DD		Matched study group of children in care without DD	
	n	%	n	%
Yes	552	45.54%	998	41.17%
No	660	54.46%	1,426	58.83%
Total	1,212	100%	2,424	100%

**Diabetes.** Children in care with and without DD with an indication of diabetes in their medical records are shown in Table 16. Results of the GEE showed that children in care with DD were two times the odds of having diabetes than the matched comparison group [OR = 2.13; (95% CI: 1.21, 3.75,  $p = 0.0092$ )].

**Table 16. Diabetes by Study Group.**

Diabetes	Children in care with DD		Matched study group of children in care without DD	
	n	%	n	%
Yes	17	1.40%	16	0.66%
No	1,195	98.60%	2,408	99.34%
Total	1,212	100%	2,424	100%

**Mood and anxiety disorders.** The number and proportion of each study group that had a mood and/or anxiety disorder are shown in Table 17. Children in care with DD were almost two times more likely to have mood/anxiety disorders compared to children in care without DD (20% vs. 11%). Results of the GEE showed that children in care with DD were almost 1.9 times the odds of having mood or anxiety disorders compared to the matched comparison group. The observed difference was statistically significant [OR = 1.88; (95% CI: 1.42, 2.49,  $p < 0.0001$ )].

**Table 17. Prevalence of mood and anxiety disorders by study group of children over the age of 10.**

Mood and anxiety disorders	Children in care with DD		Matched Study group of children in care without DD	
	n	%	N	%
Yes	147	19.76%	168	11.21%
No	597	80.24%	1,331	88.79%
Total	744	100%	1,499	100%

**Note:** Consistent with the MCHP definition of mood and anxiety disorders, only children over the age of 10 were included in the analyses.

The results of the health status of children in care with DD show higher prevalence of all measures, TRM, diabetes and mood and anxiety disorders than the matched comparison group with all analyses being statistically significant.

### **Health Care Utilization Patterns of Children in Care with and without DD**

The health care utilization patterns of children in care with and without DD were compared on, total ambulatory physician visits, continuity of care, injury-related hospitalizations and hospital-based dental care. Analysis was completed using both paired *t*-tests and GEE

modeling.

**Total ambulatory physician visits.** Table 18 shows the distribution of total ambulatory physician visits, in both study groups between 2009 and 2012. Children in care with DD have a smaller proportion of fewer than three visits (8.17% versus 21.74%), but almost double the proportion (38% vs. 18%) of having over 30 physician visits over the three-year study period (2009-2012) than the matched study group. The average number of physician visits was 36.90 ( $SD = 47.73$ ) for children in care with DD, which was higher than the mean 23.20 ( $SD = 17.28$ ) for the matched comparison group. The results of the paired *t*-test showed that the observed difference in the total number physician visits between the two study groups was statistically significant,  $t(1285.2) = -9.23$ ,  $p < 0.0001$ .

**Table 18. Distribution comparing total physician visits between the study groups.**

	Matched study group of children in care without DD			
	Children in care with DD		care without DD	
	n	%	N	%
< 3	99	8.17%	527	21.74%
3-5	19	1.57%	76	3.14%
6-10	85	7.01%	293	12.09%
11-15	146	12.05%	338	13.94%
16-20	174	14.36%	335	13.82%
21-25	116	9.57%	235	9.69%
26-30	118	9.74%	192	7.92%
>30	455	37.54%	428	17.66%
Total	1,212	100%	2,424	100%

**Continuity of care.** The proportion of children with more than three physician visits

with more than 50% of visits to a single physician, was used as an indicator of continuity of care (i.e., a child has been followed consistently by a primary physician). Table 19 shows the continuity of care over a three-year period (2009-2012) by study group. The proportion of children in each study group who had continuity of care was lower for children in care with DD than in the matched comparison group (38% vs. 41%). Results of the GEE test showed that the observed difference in proportion of population in each study group which had continuity of care was not statistically significant [OR = 0.89; (95% CI: 0.75, 1.05,  $p = 0.1726$ )].

**Table 19. Continuity of care by study group.**

Continuity of care	Children in care with DD		Matched Study group of children in care without DD	
	n	%	N	%
Yes	422	37.92%	773	40.75%
No	691	62.08%	1,124	59.25%
Total	1,113	100%	1,897	100%

**Injury-related hospitalizations.** The number and proportion of children in each study group who had at least one injury-related hospitalization are shown in Table 20. The proportion of children in care with DD, who had such a history in their medical records, was twice that of the matched comparison group (2% vs. 1%). Results of the GEE analysis showed that the observed difference in the two study groups was statistically significant [OR = 2.36; (95% CI: 1.38, 4.03,  $p = 0.0016$ )].

**Table 20. Injury-related hospitalizations by study group.**

Injury-related hospitalizations	Children in care with DD		Matched Study group of children in care without DD	
	n	%	n	%
Yes	23	1.90%	20	0.83%
No	1,189	98.10%	2,404	99.17%
Total	1,212	100%	2,424	100%

**Hospital-based dental care.** The number and proportion of children hospitalized for dental care is shown in Table 21. Children in care with DD were slightly more likely than children in the matched comparison group to having had a hospital-based dental care in a hospital setting compared to the matched comparison group (8% vs. 4%). Results of the GEE testing showed that the observed difference between the two study groups in terms of hospital-based dental care was statistically significant [OR = 1.74; (95% CI: 1.28, 2.38,  $p = 0.0004$ )].

**Table 21. Hospital-based dental care by study group.**

Hospitalized dental care	Children in care with DD		Matched Study group of children in care without DD	
	n	%	n	%
Yes	91	7.51%	100	4.13%
No	1,121	92.49%	2,324	95.87%
Total	1,212	100%	2,424	100%

Results of the health care utilization patterns showed that children in care with DD had similar rates of continuity of care, although they had significantly higher rates of total ambulatory

physician visits. Children in care with DD had significantly higher rates of injury-related hospitalizations and hospital-based dental care.

## **Chapter 5: Discussion**

The objectives of this study were to describe: 1) the number and proportion of children with DD among Manitoba children in care, 2) the demographic and socioeconomic characteristics of children in care with and without DD who are of the same age, sex, and live in the same region of residence (RHA), 3) the health status of children in care with DD and compare it to the health status of children in care without DD who are of the same age, sex, and live in the same region of residence (RHA), and 4) the health care utilization patterns of children in care with DD and compare their utilization patterns to that of the children in care without DD who are of the same age, sex, and live in the same region of residence (RHA). A number of measures were used to compare health status and utilization patterns of children in the study cohort with the matched comparison group. These measures included prevalence of TRM, prevalence of diabetes, prevalence of mood and anxiety disorders, continuity of care, injury-related hospitalizations, hospital-based dental care, and total number of ambulatory physician visits. GEE Modeling was used to compare the selected measures between children in care, with and without DD. Findings of the study revealed that children in care with DD were significantly more likely to have mood and anxiety disorders, respiratory illnesses, diabetes, hospital-based dental care, and injury-related hospitalizations compared to the children in the matched comparison group. They also had significantly higher number of visits to physicians. However, there was no statistically significant difference between children in care with and without DD in terms of their continuity of care.

### **Demographic and Socioeconomic Status**

This study found that as the age of children increased, so does the proportion of children in care, with a slight decrease in the oldest age category. It is unclear from this study why there

were higher proportions of older children in care. It is possible that as children age agencies, like family services, have had more time to intervene and place them into care. It is unknown from this study as to why children in the oldest age categories decreased compared to other age groups. One possible explanation was that children in the oldest age groups are leaving care prior to the age of 18, the age that most children leave care.

**Sex.** The findings of this study found that there were a disproportionate number of males in care with DD compared to all children in care in the study cohort. In this study, almost 63% of children in care with DD were male, which is consistent with results from previous studies on children with DD (Fuchs et al., 2005). Shooshtari and colleagues in their population study on Manitobans with DD found that 64.15% of the population with DD was male (Shooshtari et al., 2011). Some possible explanations for future research to explore would be to determine if these differences are due to biological factors, or are boys with DD who end up in care more difficult to handle and exhibit more challenging behaviors than girls with DD, leading to fewer girls in care.

**Place of residence.** Children in the study groups were increasingly found to be living in the Winnipeg RHA (77.81%). This is a larger proportion than is seen in all Manitoba children in care in 2012 (63%). This may be an indication of a greater number of specialists who can provide diagnoses of DD than in rural areas, or may be due to increased specialized services located in Winnipeg to address the needs of children in care with DD.

**Socioeconomic status.** There were a higher proportion of children in care with DD in the “Not Found” income quintile category, but fewer in the lowest 20% income quintile, than the matched comparison group. Children in the matched comparison group were similar to that of all Manitoba children in care in 2012. This indicates that more children in care with DD have

addresses where their average income is suppressed, which occurs when 90% of population is institutionalized (i.e. personal care home, prison, Public Trustee Office postal box or a Child and Family Services office) and are less likely to be in the lowest income neighborhoods than children in care without DD. Children in care in the study groups were less likely to be living in neighborhoods with higher income. Only 10% of children in care with DD and 12% of the matched comparison group were living in the highest three neighborhood income quintiles. Living in lower income neighborhoods may be a contributing factor to their poorer health conditions.

**In-care characteristics.** The number of episodes in care was similar across both study groups and there were a high proportion of children in both study groups with multiple episodes in care. Previous studies of children in care have found the rate of children who have more than one episode in care ranges from 20% to 40% (Courtney, 1995; Sullivan, & van Zyl, 2008; Terling, 1999). This paired with the distribution of duration of care shows that children with DD have a similar number of episodes, but have much longer durations in care per episode on average. This finding indicates that children in care with DD are less likely to leave care and returned to their family of origin than children in care without DD.

## **Health Status**

In comparing the multiple health indicators, it was found that children in care with DD have higher rates of health conditions, for all of the health indicators (total respiratory morbidity, diabetes, and mood and anxiety disorders) used in this study.

**Total respiratory morbidity.** This study found that children in care with DD have a higher rate of having TRM than their matched study group. It is unclear from this study if this health condition was identified more in children with DD because they have more contacts with

their family physician, increased access to services, or is related to having more chronic respiratory conditions. This study did not distinguish between different DD diagnoses, but the rate of TRM may be associated to factors resulting from the conditions of the DD.

**Diabetes.** Children in care with DD in Manitoba were more likely to have diabetes than the matched comparison group. Although research on diabetes and children in care with DD was not found, there is previous research on children with DD and diabetes. Prior research has found that overweight and obese children with DD have an increased risk of diabetes due to a sedentary lifestyle (Beange, McElduff, & Baker, 1995; Fujiura, Fitzsimmons, Marks, & Chicoine, 1997; Rimmer, Braddock, & Fujiara, 1994). Using administrative data to examine diabetes prevalence in children in care with DD did not allow for the examination of an individual's level of activity and participation as contributory to health conditions. Future research to explore these factors, possibly by surveying caregivers and children about their activity levels, family history of diabetes, and dietary histories would greatly add to the knowledge of diabetes in children in care with DD. Further information regarding type of diabetes, genetic factors, and health-related behaviours would greatly improve our understanding of the results found in this study, and should be included in future research.

**Mood and anxiety disorders.** The proportion of mood and anxiety disorders found in this study for children in care with DD falls within the range previously reported for adults with DD (Cooper, 1996); nearly twice the proportion found in the matched comparison group. Although not described in the present study, others have found that 13.5% of children in care were being treated for depression with medication (Raghavan, et al., 2005). Previous research has found that multiple psychotropic medications, usually used to treat depression, have also been prescribed to manage challenging behaviours in people with DD, with little research on the

effectiveness of the medications to address challenging behaviours (Matson & Neal, 2009). It is unclear from this study, of, or to what the extent, this practice is occurring. Future research should examine the level of family supports and personal coping skills that children in care with DD have, as these factors are known to mitigate mood and anxiety disorders (Essau, Condradt, Sasagawa, & Ollendick, 2012; Kochenderfer-Ladd & Skinner, 2002; Weiss, 2002).

## **Health Care Utilization**

**Continuity of care.** Children in care with DD had a higher proportion, compared to the matched study group, of having more total ambulatory physician visits. Furthermore, more of the children in care with DD had more than 30 ambulatory physician visits than that in the matched study group (34% vs. 18%). The difference in the average number of ambulatory physician visits per year showed that children in care with DD had approximately four more visits per year than the matched study group. This finding is greater than found in previous research on children with DD, which found that children with DD had 1.5 more physician visits than non-DD peers (Boyle, Decoufle, & Yeargin-Allsopp, 1994). Although children in care with DD had higher proportions of total ambulatory physician visits, this study found no statistically significant difference in continuity of care compared to the matched comparison group. It is possible that these results are due to children in care with DD needing and receiving more ambulatory physician visits to address the medical needs of their diagnosis, or other chronic health concerns, compared to children in care without DD.

**Injury-related hospitalizations.** This study found that children in care with DD were more likely to have an injury-related hospitalization compared to the matched comparison group. Previous research has similar findings in that children with DD are twice as likely to experience injuries needing hospitalizations (Altshuler & Poertner, 2003; Sherrard, Tongue, & Ozanne-

Smith, 2001). Future research should explore the various types of injuries experienced by children in care with DD, and the limitations of the DD that may be contributing to these injuries. The limitations of a child's DD was not able to be determined through the use of administrative data, but may be a contributing factor to the increased proportion of injuries requiring hospitalization.

**Hospital-based dental care.** Differences between study groups in hospital-based dental care were found to be statistically significant, where children in care with DD are more likely to have hospitalized dental care than the matched comparison group. Previous studies have explored possible reasons that higher proportions of children with DD receive hospital-based dental care. These studies found that children with DD have high rates of day-surgeries for dental procedures due to exhibiting more behavioural problems and had more advanced tooth destruction, which make a hospital settings the preferred and/or necessary location to perform oral health treatments, (Balogh, Hunter, & Oullette-Kuntz, 2005; Enever, Nunn, & Sheehan, 2000). The differences in hospitalized dental care could be further explained if future research explores the severity of the DD, level of activity and participation that is required to perform preventative dental care. Unfortunately, this type of information was not available for this study.

The findings of this study showed both significant and non-significant results. Significant findings in this research show a higher prevalence of number of total days in care, total number of ambulatory physician visits, mood and anxiety disorders, total respiratory morbidity, diabetes, hospital-based dental care, and hospitalizations due to injury for children in care with DD compared to a matched comparison group by age, sex, and place of residence. Significant differences between the two study groups were not found for the number of episodes in care and continuity of care. Due to the nature of conducting research with secondary data,

there are limitations associated with using this type of data. By examining administrative data, we are unable to determine differences between an individual's body structure and the activity level that a child has to complete tasks in their life. To gain a better understanding of children in care with DD and their health and health care utilization patterns, future research should build upon this research by also exploring the activity and participation levels of these children. This would allow for a more encompassing picture of the health and health care utilization of children in care with DD. Further studies should also explore a larger sample of children in care and health records to allow for a larger sample of children in care with DD, as well as its impact on more health care indicators.

### **Study Strengths and Limitations**

This study is the first population-based study of Manitoba children in care with DD. This study utilized the unique population based information from multiple databases. First, the Manitoba population registry was used to identify all children living in the province. Second, data from Manitoba Family Services were used to identify all Manitoba children who were in care in 2012 and at any time prior to that. Availability of a unique identifier (scrambled PHIN) made it possible to link data from several health data sets including hospital discharge abstracts, physician's claims and the DPIN data sets with the data from Family Services. In addition, by linking data from health, Family Services and education data sets it was possible to identify children with an indication of DD among Manitoba children in care. Through the use of the unique identifier, a large number of children with DD were able to be identified based on different datasets using multiple years of data, without duplication.

The present study is comparative and involved examination of retrospective health records for a population-based cohort of children in care with DD, matched with children in care

of the same age, sex, and region of residence, but without DD to prevent confounding by these factors.

The availability of multiple years of health data made it possible to examine the health status and patterns of health services use for the study cohort and the matched comparison group reliably. The completeness and accuracy of the data from MCHP has been used for many population based research due to its high evaluation of its quality (Robinson & Tataryn, 1997; Roos, Nicol, & Cageorge, 1987; Roos & Nicol, 1999; Roos & Shapiro, 1999). This allowed multiple sources to estimate prevalence of health conditions and rates of health services utilization. The use of administrative data through MCHP has many advantages when conducting research. For example, data from MCHP has allowed a wide range of health status, and health and social services utilization indicators to be used for this study. Currently it is not possible to obtain such information from any of the other provincial or national sources.

The limitations of this study are related to the use of administrative data, which was not collected for the purpose of research, and only identifies children who accessed health services and does not necessarily identify children with the particular condition, disease or illnesses that they sought services for. The administrative data is not a clinical diagnosis and could vary from one service provider to another on the interpretation of child's presentation at time of assessment. It is unknown how many children are not accounted for, both with a diagnosis of DD, as well as for any of the health conditions studied, as a result of these individuals not accessing services.

The findings show a low agreement among the databases used to identify children with DD. For example, if this study used only the education database as the source to identify DD, approximately 60% of children identified by other sources would have been missed. The

administrative data only identifies children who have accessed services during the study period examined and does not reflect previous indicators of health conditions. Although the linkage of data from several sources allowed for a wide range of health information, the data lacked information on many important personal factors that might have been helpful to explain some of the differences observed in the health and health service utilization patterns between children in care with and without DD. For example, none of the databases used provide information on individuals' coping skills, IQ level, physical impairments, severity of disability, level of functioning, family histories, and health-related behaviours.

Additionally, these data sets are lacking information on environmental characteristics that might have any influence on our results. Some environmental factors that were unable to be examined were the quality of care a child is receiving and the type and dynamics of the family that is providing care for the child. Knowledge on these and other health-related factors is critical to gain a broad understanding of the children's experiences and their overall health and well-being.

### **Implications and Future Directions for Research**

**Policy Implications.** Through the completion of this research there have been a few areas where changes in practice and policy would benefit future research. This project utilized data collected from various organizations and was linked to allow multiple databases from different organizations to be examined. More consistency is needed at the organizational level in identifying and recording of data to maximize the reliability of the data. For example, when looking at the sources used to identify DD in this study, there were inconsistencies from one dataset to another. This was demonstrated when the vast majority of children in this study had an indication of a DD from only one source. By gaining a better understanding and knowledge of

the health and health care utilization patterns of children with DD, agencies like CFS would be better equipped and able to provide a more informed and appropriate care placements for children with DD. This could be done by increasing both the training and knowledge of prospective foster parents on the health conditions and health care utilization of children in care with DD.

Currently, the Province of Manitoba has a number of initiatives in place for people with disabilities. These initiatives have tended to focus on the broad understanding of disability, or used terminology such as disability to refer to people with physical disabilities. The initiatives that follow were created to ensure the rights and freedoms of adults living with disabilities with little to no attention of children living with DD. The Vulnerable Persons Living with a Mental Disability Act has led to increased reporting and promotion of disability related research. This act has been instrumental in providing the right to protection from abuse and neglect as the target population is identified as a population of vulnerable persons (Government of Manitoba, 1996).

In addition to a generalized approach of the government's initiatives on disability, the province of Manitoba has some initiatives that are more disability specific such as FASD (Government of Manitoba, 2008a; Government of Manitoba, 2008b; Government of Manitoba, 2010), which has contributed to the establishment of the Manitoba FASD centre.

**Research Implications.** This study was a retrospective cohort study and is a starting point to begin addressing the gaps found in the existing literature. Based on the findings of this research, future research should build upon the key findings of this study to try and determine reasons that children in care with DD experience these health conditions and health utilization patterns at a higher rate than their non-DD peers. This could include studies that compare the changes in health and health care utilization patterns before and after children enter into care for

the first time. The need for longitudinal studies addressing incidence rates of health conditions as well as, how duration in care affects the health and health care utilization patterns of children in care with DD is needed. These future studies would greatly increase the understanding of the health and health care utilization patterns within this population and would further inform future research and policy in the area.

## References

- Albino, J., Schwartz, B., Goldberg, H., & Stern, M. (1979). Results of an oral hygiene program for severly retarded children. *ASDC Journal of Dentistry for Children*, 46(1), 25-28.
- Ailey, S. H., Miller, A. M., Heller, T., & Smith, E. V., Jr. (2006). Evaluating an Interpersonal Model of Depression among adults with Down syndrome. *Research and Theory for Nursing Practice*, 20, 229–246.
- Allen J. D. & Burns J. P. (1998) Managing inclusive classrooms. *Kappa Delta Pi Record* 35, 28-30.
- Altshuler, S. J., & Poertner, J. (2003). Assessing child well-being in non-relative foster care with a new outcome measurement tool. *Journal of Family Social Work*, 7(2), 73–85.
- American Academy of Pediatrics: Committee on Child Abuse and Neglect and Committee on Children with Disabilities. (2001). Assessment of maltreatment of children with disabilities. *Pediatrics*, 108(2), 508-512.
- American Association on Intellectual and Developmental Disabilities. (n.d.). *Definition of Intellectual Disability*. Retrieved February 11, 2012, from American Association on Intellectual and Developmental Disabilities: <http://www.aaidd.org>
- American Association on Intellectual and Developmental Disabilities. (n.d.). *Intellectual Disability*. Retrieved March 29, 2013, from American Association on Intellectual and Developmental Disabilities: [www.aaidd.org](http://www.aaidd.org)
- Bailie, R., Stevens, M., McDonald, E., Brewster, D., & Guthridge, S. (2010). Exploring cross-sectional associations between common childhood illness, housing and social conditions in remote Australian Aboriginal communities. *BMC Public Health*, 10 (147).
- Balogh, R. S., Hunter, D., & Ouellette-Kuntz, H. (2005). Hospital utilization among persons with

- an intellectual disability, Ontario, Canada, 1995–2001. *Journal of Applied Research in Intellectual Disabilities, 18*(2), 181-190.
- Barth, R. P. (1997). Effects of age and race on the odds of adoption versus remaining in long-term out-of-home care. *Child Welfare, 76*(2), 285.
- Bass, S., Shields, M. K., & Behrman, R. E. (2004). Children, families, and foster care: Analysis and Recommendations. *Children, families, and foster care, 14*(1), 5-29.
- Beange, H., & Lennox, N. (1998). Physical aspects of health in the learning disabled. *Current Opinions in Psychiatry, 11*, 531-534.
- Beange, H., Lennox, N., & Parmenter, T. R. (1999). Health targets for people with an intellectual disability. *Journal of Intellectual & Developmental Disability, 24*(4), 283-297.
- Beange, H., McElduff, A., & Baker, W. (1995). Medical disorders of adults with mental retardation: A population study. *American Journal of Mental Retardation, 99*, 595-604.
- Betz, C. L., Baer, M. T., Poulsen, M., Vahanavaty, U., Bare, M., Haddad, Y., & Nwachukwu, G. (2004). Secondary analysis of primary and preventive services accessed and perceived service barriers by children with developmental disabilities and their families. *Issues in Comprehensive Pediatric Nursing, 27*(2), 83-106.
- Bhaumik, S., Watson, J., Barret, M., Raju, B., Burton, T., & Forte, J. (2011). Transition for teenagers with intellectual disability: Carers' perspectives. *Journal of Policy and Practice in Intellectual Disabilities, 8*(1), 53-61.
- Bilaver, L. A., Jaudes, P. K., Koepke, D., & Goerge, R. M. (1999). The health of children in foster care. *Social Service Review, 73*(3), 401–418.

- Bittles, A. H., Petterson, B. A., Sullivan, S. G., Hussain, R., & Glasson, E. J. (2002). The influence of intellectual disability of life expectancy. *Journal of Gerontology and Biological Science Medicine*, 57, M470-472.
- Blisard, K. S., Martin, C., Brown, G. W., Smialek, J. E., Davis, L. E., & McFeeley, P. J. (1988). Causes of death of patients in an institution for the developmentally disabled. *Journal of Forensic Sciences*, 33, 1457-1462.
- Bongiorno, F. P. (1996). Dual diagnosis: Developmental disability complicated by mental illness. *Southern Medical Journal*, 89, 1142-1146.
- Borthwick-Duffy, S. A., & Eyman, R. K. (1990). Who are the dually diagnosed? *American Journal of Mental Retardation*, 94, 586-595.
- Boyle, C., Decouflé, P., & Yeargin-Allsopp, M. (1994). Prevalence and health impact of developmental disabilities in US children. *Pediatrics*, 93(3), 399–403.
- Bradley, E. A., Thompson, A., & Bryson, S. E. (2002). Mental retardation in teenagers: prevalence data from the Niagara region, Ontario. *Canadian Journal of Psychiatry*, 47, 652–659.
- Braveman, P. (2006). Health disparities and health equity: concepts and measurement. *Annual Review of Public Health*, 27, 167-194.
- Brownell, M., Chartier, M., Au, W., & Schultz, J. (November 2010). *Evaluation of the Healthy Baby Program*. Winnipeg, MB: Manitoba Centre for Health Policy.
- Brownell, M., Chartier, M., Santos, R., Ekuma, O., Au, W., Sarkar, J., . . . Guenette, W. (October 2012). *How Are Manitoba's Children Doing?* Winnipeg, MB: Manitoba Centre for Health Policy.

- Brownell, M., De Coster, C., Penfold, R., Derksen, S., Au, W., Schultz, J., & Dahl, M. (November 2008). *Manitoba Child Health Atlas Update*. Winnipeg, MB: Manitoba Centre for Health Policy.
- Brownell, M., Ouellette-Kuntz, H., & Colantonio, A. (2010). Hospitalisation rates for ambulatory care sensitive conditions for persons with and without an intellectual disability - a population perspective. *Journal of Intellectual Disability Research*, 54, 820-832.
- Canadian Child Welfare Research Portal. (n.d.). *Child Welfare Across Canada*. Retrieved 2013 from Canadian Child Welfare Research Portal: <http://cwrp.ca/>
- Center, J., Beange, H., & McElduf, A. (1998). People with mental retardation have an increased prevalence of osteoporosis: A population study. *American Journal of Mental Retardation*, 103, 19-28.
- Centers for Disease Control and Prevention. (2010, September). *The ICF: An overview*. Retrieved from Centers for Disease Control and Prevention: [http://www.cdc.gov/nchs/data/icd9/ICFOverview\\_FINALforWHO10Sept.pdf](http://www.cdc.gov/nchs/data/icd9/ICFOverview_FINALforWHO10Sept.pdf)
- Centers for Disease Control and Prevention, National Center for Injury Prevention and Control. (2010). Web-based Injury Statistics Query and Reporting System (WISQARS) [online]. Available from [www.cdc.gov/injury/wisqars/index.html](http://www.cdc.gov/injury/wisqars/index.html).
- Chaney, R. H., & Eyman, R. K. (2000). Patterns in mortality over 60 years among persons with mental retardation in a residential facility. *Mental Retardation*, 38, 289-293.
- Chartier, M., Finlayson, G., Prior, H., McGowan, K., Chen, H., de Rocquigny, J., Walld, R., & Gousseau, M. (2012). *Health and Healthcare Utilization of Francophones in Manitoba*.

- Winnipeg, MB: Manitoba Centre for Health Policy.
- Chernoff, R., Combs-Ome, T., Risley-Curtiss, C., & Heisler, A. (1994). Assessing the health status of children entering foster care. *Pediatrics*, 93, 594-601.
- Chi, D. L., Momant, E. T., Kuthy, R. A., Chalmers, J. M., & Damiano, P. C. (2010). Preventive dental utilization for Medicaid-enrolled children in Iowa identified with intellectual and/or developmental disability. *Journal of Public Health Dentistry*, 70, 35-44.
- Committee on Early Childhood, Adoption, and Dependent Care (2002). Health Care of Young Children in Foster Care. *American Academy of Pediatrics*. 109 (3), 536-541.
- Cooper, S. (1996). Depressive episodes in adults with learning disability. *Irish Journal of psychological medicine*, 13, 105-113.
- Cooper, S. (1997). Epidemiology of psychiatric disorders in elderly compared with younger adults with learning disabilities. *British Journal of Psychiatry*, 170, 375-380.
- Cooper, S. A., Melville, C., & Morrison, J. (2004). People with intellectual disabilities: Their health needs differ and need to be recognised and met. *BMJ*, 329(7463), 414-415.
- Cooper SA, Smiley E, Jackson, A., Finayson, J., Allan L., Mantry, D., & Morrison, J. (2009). Adults with intellectual disabilities: prevalence, incidence and remission of self-injurious behaviour, and related factors. *Journal of Intellectual Disability Research*. 53(3), 217-232.
- Cooper, S. A., Smiley, E., Morrison, J., Williamson, A., & Allan, L. (2007). An epidemiological investigation of affective disorders with a population-based cohort of 1023 adults with intellectual disabilities. *Psychological Medicine*, 37, 873–882.
- Courtney, M. E. (1995). Re-entry to foster care of children returned to their families. *Social*

- Service Review, 69(2), 226-241.*
- Daniels, S. R. (2006). The consequences of childhood overweight and obesity. *Future Child, 16(1), 47-67.*
- Davidson, L. (1987). Hyperactivity, antisocial behaviour, and childhood injury: A critical analysis of the literature. *Journal of Developmental Behavioral Pediatrics, 8, 335-340.*
- Dehghan, M., Akhtar-Danesh, N., & Merchant, A. T. (2005). Childhood obesity, prevalence and prevention. *Nutrition Journal, 4, 24.*
- Denny-Wilson, E., Hardy, L., Dobbins, T., Okely, A., & Baur, L. A. (2008). Body mass index, waist circumference and chronic disease risk adolescents. *Archives of Pediatric Adolescent Medicine, 162(6), 566-573.*
- Developmental Disabilities Association. (n.d.). *What is a Developmental Disabilities?* Retrieved September 18, 2013, from Developmental Disabilities Association:  
<http://www.develop.bc.ca/about/development-disabilities.html>
- Dunne, R., Asher, K., & Rivara, F. (1993). Injuries in young people with developmental disabilities: Comparative investigation from the 1988 National Health Interview Survey. *Mental Retardation, 31, 83-88.*
- Durvasula, S., Beange, H., & Baker, W. (2002). Mortality of people with intellectual disability in northern Sydney. *Journal of Intellectual & Developmental Disability, 27(4), 255-264.*
- Emerson, E. (2003a). Prevalence of psychiatric disorders in children and adolescents with and without intellectual disability. *Journal of Intellectual Disability Research, 47, 51-58.*
- Emerson, E. (2003b). Mothers of children and adolescents with intellectual disability: social and

- economic situation, mental health status, and the self-assessed social and psychological impact of the child's difficulties. *Journal of Intellectual Disability Research*, 47, 385-399.
- Enever, G., Nunn, J., & Sheehan, J. (2000). A comparision of post-operative morbidity following outpatient dental care under general anaesthesia in paediatric patients with and without disabilities. *International Journal of Paediatric Dentistry*, 10, 120-125.
- Essau, C. A., Conradt, J., Sasagawa, S., & Ollendick, T. H. (2012). Prevention of anxiety symptoms in children: Results from a universal school-based trial. *Behavior Therapy*, 43 (2), pg 450-464.
- Evenhuis, H. M., Theunissen, M., Denkers, I., Verschuur, H., & Kemme, H. (2001). Prevalence of visual and hearing impairment in a Dutch institutionalized population with intellectual disability. *Journal of Intellectual Disability Research*, 45(5), 457-464.
- Evenhuis, H., Henderson, C. M., Beange, H., Lennox, N., & Chicoine, B. (2001). Healthy ageing - adults with intellectual disabilities: Physical health issues. *Journal of Applied Research in Intellectual Disabilities*, 14(3), 175-194.
- Eyman, R. K., & Call, T. (1977). Maladaptive behaviour and community placement of mentally retarded persons. *American Journal of Mental Deficiency*, 82, 137-144.
- Eyman, R. K., Grossman, H. J., Chaney, R. H., & Call, T. L. (1990). Life expectancy of profoundly handicapped people with mental retardation. *New England Journal of Medicine*, 323, 584-589.
- Farmer, E.M. Z., Burns, B. J., Chapman, M. V., Phillips, S. D., Angold, A., & Costello, E. J. (2001). Use of mental health services by youth in contact with social services. *Social*

- Service Review*, 75(4), 605–625.
- Farris-Manning, C., & Zandstra, M. (2003). *Children in Care in Canada: A summary of current issues and trends with recommendations for future research*. Child Welfare League of Canada.
- Fonagy, P. (2003). The development of psychopathology from infancy to adulthood: The mysterious unfolding of disturbance in time. *Infant Mental Health Journal*, 24(3), 212-239.
- Fransoo, R., Martens, P., Burland, E., & The Need to Know Team, Prior, H., & Burchill, C. (2009). *Manitoba RHA Indicators Atlass 2009*. Winnipeg, MB: Manitoba Centre for Health Policy.
- Fuchs, D., Burnside, L., Marchenski, S., & Mudry, A. (2005). *Children with disabilities: Receiving services from Child Welfare Agencies in Manitoba*. Winnipeg.
- Fujiura, G., Fitzsimmons, N., Marks, B., & Chicoine, B. (1997). Predictors of BMI among adults with Down syndrome: The social context of health promotion. *Research in Developmental Disabilities*, 18, 261-274.
- Gallaher, M. M., Christakis, D. A., & Connell, F. A. (2002). Health care use by children diagnosed as having developmental delay. *Archives of pediatrics & adolescent medicine*, 156(3), 246-251.
- Gizani, S., Declerck, D., Vinckier, F., Martens, L., Marks, L., & Goffin, G. (1997). Oral health condition of 12-year-old handicapped children in Flanders (Belgium). *Community Dentistry and Oral Epidemiology*, 25, 352-357.

Goran, M. I., Ball, G. D., & Cruz, M. (2003). Obesity and risk of type 2 diabetes and cardiovascular disease in children and adolescents. *Journal of Endocrinology and Metabolism*, 88(4), 1417-1427.

Government of Manitoba. (1996). *What is the Vulnerable Persons Act?* Retrieved from Department of Family Services and Consumer Affairs, Office of the Vulnerable Persons' Commissioner: <http://www.gov.mb.ca/fs/vpco/about/vpa.html>

Government of Manitoba. (2001). *Full Citizenship: Manitoba Provincial Strategy on Disability.* Retrieved from Minister Responsible for Persons with Disabilities:  
[http://www.gov.mb.ca/dio/pdf/full\\_citizenship.pdf](http://www.gov.mb.ca/dio/pdf/full_citizenship.pdf)

Government of Manitoba. (2008a). *Manitoba's FASD Strategy.* Retrieved from Healthy Child Manitoba: <http://www.gov.mb.ca/healthychild/fasd/index.html>

Government of Manitoba. (2008b). *Province launches spectrum connections, a first-in-Canada mobile support team for people with FASD.* Retrieved from News Release:  
<http://news.gov.mb.ca/news/?archive=today&item=4385>

Government of Manitoba. (2010). *Province announces expanded fetal alcohol spectrum disorder strategy on International FASD Awareness Day.* Retrieved from News Release:  
<http://news.gov.mb.ca/news/index.html?archive=2010-09-01&item=9620>

Government of Manitoba. (n.d.). *Manitoba Family Services and Labour.* Retrieved 2013 ыйл 25-July from Foster Care: [http://www.gov.mb.ca/fs/childfam/fostercare\\_faq.html#foster](http://www.gov.mb.ca/fs/childfam/fostercare_faq.html#foster)

Halfon, N., Mendonca, A., & Berkowitz, G. (1995). Health status of children in foster care. *Archives of Pediatric and Adolescent Medicine*, 149, 386-392.

- Hardan, A., & Sahl, R. (1997). Psychopathology in children and adolescents with developmental disorders. *Research in Developmental Disabilities, 18*, 369-382.
- Hardan, A., & Sahl, R. (1999). Suicidal behavior in children and adolescents with developmental disorders. *Research in Developmental Disabilities, 20*, 287-296.
- Hastings, R. P. (2002). Parental stress and behaviour problems of children with developmental disability. *Journal of Intellectual and Developmental Disability, 27*(3), 149-160.
- Haveman, M., Heller, T., Lee, L., Maaskant, M., Shooshtari, S., & Strydom, A. (2010). Major health risks in aging persons with intellectual disabilities: An overview of recent studies. *Journal of Policy and Practice in Intellectual Disabilities, 7*(1), 59-69.
- Health and Welfare Canada (1988). The epidemiology of mental retardation. Report of the working group. Ottawa: Author.
- Hedov, G., Anneren, G., & Wikblad, K. (2000). Self-perceived health in Swedish parents of children with Down's syndrome. *Quality of Life Research, 9*, 415-422.
- Hill, B. K., & Bruininks, R. H. (1984). Maladaptive behavior of mentally retarded individuals in residential facilities. *American Journal of Mental Deficiency, 88*, 380-387.
- Hochstadt, N. J., Jaudes, P. K., Zimo, D. A., & Schachter, J. (1987). The medical and psychosocial needs of children entering foster care. *Child Abuse & Neglect, 11*, 53-62.
- Hollins, S., Attard, M. T., von Fraunhofer, N., McGuigan, S., & Sedgwick, P. (1998). Mortality in people with learning disability: Risks, causes, and death certification findings in London. *Developmental Medicine and Child Neurology, 40*, 50-56.
- Holroyd, J., Brown, N., Wikler, L., & Simmons, J. Q. (1975). Stress in families of institutionalized and non-institutionalized autistic children. *Journal of Community Psychology, 3*, 26-31.

- Hunt P. & Goetz L. (1997) Research on inclusive educational programs, practices, and outcomes for students with severe disabilities. *Journal of Special Education* 31, 3-29.
- Jacobson, J. W. (1982). Problem behavior and psychiatric impairment in a developmentally disabled population I: behavior frequency. *Applied Research in Mental Retardation*, 3, 121-139.
- Janicki, M. P., Dalton, A. J., Henderson, C. M., & Davidson, P. W. (1999). Mortality and morbidity among older adults with intellectual disability: Health services considerations. *Disability and Rehabilitation*, 21, 284-294.
- Jansen, D., Krol, B., Groothoff, J., & Post, D. (2004). People with intellectual disabilities and their health problems: A review of comparative studies. *Journal of Intellectual Disability Research*, 48, 93-102.
- Katz, L., Au, W., Singal, D., Brownell, M., Roos, N., Martens, P.J., Chateau, D., Enns, M. W., Kozrskyj, Al. L., & Sareen, J. (2011). Suicide and suicide attempts in children and adolescents in the child welfare system. *Canadian Medical Association Journal*, 183(17), 1977-1981.
- Keane, V. E. (1972). The incidence of speech and language problems in the mentally retarded. *Mental Retardation*, 10, 3-8.
- Kemp BJ, & Krause JS. Depression and life satisfaction among people ageing with post-polio and spinal cord injury. *Disability and Rehabilitation*. 1999; 21:241-249.
- Kochenderfer-Ladd, B., & Skinner, K. (2002). Children's coping strategies: moderators of the effects of peer victimization?. *Developmental psychology*, 38(2), 267.
- Konarski, E., Sutton, K., & Huffman, A. (1997). Personal characteristics associated with

- episodes of injury in a residential facility. *American Journal of Mental Retardation, 102*, 37-44.
- Kortenkamp, K., & Ehrle, J. (2002). The well-being of children involved with the child welfare system: A national overview. *The Urban Institute, Series B(B-43)*, 1-8.
- Krahn, G. L., Hammond, L., & Turner, A. (2006). A cascade of disparities: Health and health care access for people with intellectual disabilities. *Mental Retardation and Developmental Disability Research Reviews, 12*(1), 70-82.
- Krauss, M. W., Gully, S., Sciegaj, M., & Wells, N. (2003). Access to specialty medical care for children with mental retardation, autism, and other special health care needs. *Mental Retardation, 41*(5), 329-339.
- L'Arche International. (n.d.). *What does :intellectual disability" mean?* Retrieved September 18, 2013, from L'Arche International: <http://www.larche.org/faq-who-we-are.en-gb.25.0.news.htm>
- Lee, L.-C., Harrington, R. A., Chang, J. J., & Connors, S. L. (2008). Increased risk of injury in children with developmental disabilities. *Research in Developmental Disabilities, 29*(3), 247-255.
- Lee, W.-C., & Chen, T.-J. (2012). Quantifying morbidity burdens and medical utilization of children with intellectual disabilities in Taiwan: A nationwide study using the ACG case-mix adjustment system. *Research in Developmental Disabilities, 33*, 1270-1278.
- Leslie, L. K., Hurlburt, M. S., Landsverk, J., Barth, R. P., & Slymen, D. J. (2004). Outpatient mental health services for children in foster care: A national perspective. *Child Abuse*

- and Neglect, 28, 697–712.
- Leslie, L. K., Hurlburt, M. S., Landsverk, J., Rolls, J. A., Wood, P. A., & Kelleher, K. J. (2003). Comprehensive assessments for children entering foster care: A national perspective. *Pediatrics*, 112(1), 134–142.
- Lewinsohn P. M., Rohde P., & Seeley J. R. (1998). Major depressive disorder in older adolescents: Prevalence, risk factors, and clinical implications. *Clinical Psychology Review*. 18(7), 765-794.
- Lightfoot, E., Hill, K., & LaLiberte, T. (2011). Prevalence of children with disabilities in the child welfare system and out of home placement: An examination of administrative records. *Children and Youth Services Review*, 33, 2069-2075.
- Lloyd, M., Temple, V. A., & Foley, J. (2012). International BMI comparison of children and youth with intellectual disabilities participating in Special Olympics. *Research in Developmental Disabilities*, 33(6), 1708-1714.
- Lowry, M. (1998). Assessment and treatment of mod disorders in persons with developmental disabilities. *Journal of Developmental and Physical Disabilities*, 10, 287-406.
- Manitoba Centre for Health Policy. (n.d.). *Glossary and concept dictionary: Children in care*. Retrieved from Manitoba Centre for Health Policy: <http://mchp-appserv.cpe.umanitoba.ca/viewDefinition.php?definitionID=103824>
- Marcus, R. F. (1991). The attachments of children in foster care. *Genetic, Social, and General Psychology Monographs*, 117(4), 365-394.
- Margalit M. (1991). Promoting classroom adjustment and social skills for students with mental retardation within an experimental and control group design. *Exceptionality*, 2, 195 –

204.

Marinković J., Backović D., & Kocijancić R. (2004). Health status of adolescents deprived of parental care. *Medicinski pregled*. 57(11-12), 588-591.

Martens, P. J., Bartlett, J., Burland, E., Prior, H., Burchill, C., Huq, S., Romphf, L., Sanguins, J., Carter, S., & Bailly, A. (2010). *Profile of Métis Health Status and Healthcare Utilization in Manitoba: A Population-Based Study*. Winnipeg, MB: Manitoba Centre for Health Policy.

Martens, P. J., Fransoo, R., McKeen, N., The Need to Know Team, Burland, E., Jebamani, L., Burchill, C., De Coster, C., Ekuma, O., Prior, H., Chateau, D., Robinson, R., & Metge, C. (2004). *Patterns of Regional Mental Illness Disorder Diagnoses and Service Use in Manitoba: A Population-Based Study*. Winnipeg, MB: Manitoba Centre for Health Policy.

Martin, D. M., Roy, A., & Well, M. B. (1997). Health gain through health checks: Improving access to primary care for people with intellectual disability. *Journal of Intellectual Disability Research*, 41(5), 401-408.

Matson, J. L., & Neal, D. (2009). Psychotropic medication use for challenging behaviors in persons with intellectual disabilities: An overview. *Research in developmental disabilities*, 30(3), 572-586.

Maulik, P. K., Mascarenhas, M. N., Mathers, C. D., Dua, T., & Saxena, S. (2011). Prevalence of intellectual disability: A meta-analysis of population-based studies. *Research in Developmental Disabilities*, 32(2), 419-436.

- Mayer-Davis, E. J. (2008). Type 2 diabetes in youth. *Epidemiology and Current Research toward Prevention and Treatment*, 108(4), s45-s51.
- Mellinger, G., & Manheimer, D. (1967). An exposure-coping model of accident liability among children. *Journal of Health and Social Behavior*, 8, 96-106.
- Menis, W. (1993). Prevalence and risk factors for depressive disorders in adults with intellectual disabilities. *Australasian and New Zealand Journal of Developmental Disabilities*, 18, 147-156.
- Moffat, M. E. K., Peddie, M., Stulginskas, J., Pless, I. B., & Steinmetz, N. (1985). Health care delivery to foster children: A study *Health and Social Work*, 10, 129-137.
- Montgomery, J., Martin, T., Shooshtari, S., Stoesz, B. M., Heinrichs, D. J., North, S., Dodson, L., Senkow, Q., & Douglas, J. (2014) Interventions for Challenging Behaviours of Students with Autism Spectrum Disorders and Developmental Disabilities: A Synthesis Paper. *Exceptionality Education International*, 23, 2-21.
- Mouradian, W. E., Wehr, E., & Crall, J. J. (2000). Disparities in children's oral health and access to dental care. *The Journal of the American Medical Association*, 284(20), 2625-2631.
- Myers, B. A., & Pueschel, S. M. (1995). Major depression in a small group of adults with Down syndrome. *Research in Developmental Disabilities*, 16, 285-299.
- Nageswaran, S., Parish, S. L., Rose, R. A., & Grady, M. D. (2011). Do children with developmental disabilities and mental health conditions have greater difficulty using health services than children with physical disorders? *Maternal and Child Health Journal*, 15, 634-641.
- Newacheck, P. W., & Halfon, N. (1998). Prevalence and impact of disabling chronic conditions

- in childhood. *American Journal of Public Health, 88*, 610-617.
- Nuyen, M. (1996). What is the prevalence of Ontarians labeled as having a “developmental disability”? Toronto, ON: Developmental Services Branch, Ministry of Community and Social Services.
- Oeseburg, B., Jansen, D. E., Dijkstra, G. J., Groothoff, J. W., & Reijneveld, S. A. (2010). Prevalence of chronic diseases in adolescents with intellectual disability. *Research in Developmental Disabilities, 31*(3), 698-704.
- Ogden, C. L., Flegal, K. M., Carroll, M. D., & Johnson, C. L. (2002). Prevalence and trends in overweight among US children and adolescents 1999 - 2000. *The Journal of the American Medical Association, 288*(14), 1728-1732.
- Oliván Gonzalvo G. (1999). Social characteristics and health status of children entering foster care centers. *Anales Espanoles de Pediatría, 50*(2), 151-155.
- Ontario Association of Children's Aid Societies. (2008). *Report on Children in Care Across Ontario*. From <http://www.cashn.on.ca/index.php/2008/10/14/report-on-children-in-care-across-ontario/>
- Ouellette-Kuntz, H., Garcin, N., Lewis, S., Minnes, P., Martin, C., & Holden, J. (2005). Addressing health disparities through promoting equity for individuals with intellectual disability. *Candian Journal of Public Health, 96*(2), S8-S22.
- Ouellette-Kuntz, H., & Paquette, D. (2001). The prevalence of developmental disabilities in Lanark County, Ontario. *Journal on Developmental Disabilities, 8*, 1–16.
- Ouellette-Kuntz, H., Shooshtari, S., Temple, B., Brownell, M., Burchill, C., Yu, C., Holden, J., & Hennen, B. (2010). Estimating administrative prevalence of intellectual disabilities in

- Manitoba. *Journal on Developmental Disabilities*, 15(3), 69-80.
- Patja K., Livanainen M., Raitasuo M., Raitasuo, S., & Lonnqvist, J. (2001). Suicide mortality in mental retardation. A 35-year follow-up study. *Acta Psychiatrica Scandinavica*. 103(4), 307-311.
- Patja, K., Livanainen, M., Vesala, H., Oksanen, H., & Ruoppila, I. (2000). Life expectancy of people with intellectual disability: A 35-year follow-up study. *Journal of Intellectual Disability Research*. 40(5), 591-599.
- Perkins, E. A., & Moran, J. A. (2010). Aging adults with intellectual disabilities. *The Journal of the American Medical Association*, 304(1), 91-92.
- Pitetti, K. H., Rimmer, J. H., & Fernhall, B. (1993). Physical fitness and adults with mental retardation. An overview of current research and future directions. *Sports Medicine*, 16, 23-56.
- Raghavan, R., Zima, B. T., Andersen, R. M., Leibowitz, A. A., Schuster, M. A., & Landsverk, J. (2005). Psychotropic medication use in a national probability sample of children in the child welfare system. *Journal of Child and Adolescent Psychopharmacology*, 15(1), 97–106.
- Raina, P., O'Donnell, M., Schwellnus, H., Rosenbaum, P., King, G., Brehaut, J., Russell, D., Swinton, M., King, S., Wong, M., Walter, S. D., & Wood, E. (2004). Care giving process and caregiver burden: conceptual models to guide research and practice. *BMC Pediatrics*, 4(1), 1.
- Redding, R. E., Fried, C., & Britner, P. A. (2000). Predictors of placement outcomes in treatment foster care: Implications for foster parent selection and service delivery. *Journal of Child*

- and Family Studies*, 9(4), 425-447.
- Rimmer, J. H., Braddock, D., & Fujiara, G. (1994). Cardiovascular risk factors in adults with mental retardation. *American Journal on Mental Retardation*, 98, 510-518.
- Rimmer, J. H., Yamaki, K., Davis Lowry, B. M., Wang, E., & Vogal, L. C. (2010). Obesity and obesity-related secondary conditions in adolescents with intellectual/developmental disabilities. *Journal of Intellectual Disability Research*, 54(9), 787-794.
- Ringiesen, H., Casanueva, C., Urato, M., & Cross, T. (2008). Special health care needs among children in the child welfare system. *Pediatrics*, 122(1), e232–e241.
- Rivara, F. (1995). Developmental and behavioral issues in childhood injury prevention. *Journal of Developmental Behavioral Pediatrics*, 16, 362-370.
- Roberts C. & Zubrick S. (1992) Factors influencing the social status of children with mild academic disabilities in regular classrooms. *Exceptional Children* 59, 192-202.
- Robinson, J. R., & Tataryn, D. J. (1997). Reliability of the Manitoba Mental Health Management Information System for Research. *Canadian Journal of Psychiatry. Revue Canadienne de Psychiatrie*, 42(7), 744–9.
- Roos, L. L., & Nicol, J. P. (1999). A research registry: uses, development, and accuracy. *Journal of Clinical Epidemiology*, 52(1), 39–47.
- Roos, L. L., Nicol, J. P., & Cageorge, S. M. (1987). Using administrative data for longitudinal research: comparisons with primary data collection. *Journal of Chronic Diseases*, 40(1), 41–9.
- Roos, N. P., & Shapiro, E. (1999). Revisiting the Manitoba Centre for Health Policy and Evaluation and its population-based health information system. *Medical Care*, 37(6 Suppl), JS10–4.

- Rosenberg, S. A., & Robinson, C. C. (2004). Out-of-home placement for young children with developmental and medical conditions. *Children and Youth Services Review*, 26(8), 711-723.
- Rubin, D. M., Alessandrini, E. A., Feudtner, C., Localio, A. R., & Hadley, T. (2004). Placement changes and emergency department visits in the first year of foster care. *Pediatrics*, 114(3), 354–360.
- Rubin, D. M., Alessandrini, E. A., Feudtner, C., Mandell, D. S., Localio, A. R., & Hadley, T. (2004). Placement stability and mental health costs for children in foster care. *Pediatrics*, 113(5), 1136–1341.
- Saint-Laurent, L., Giasson, J., & Couture, C. (1998). Emergent literacy and intellectual disabilities. *Journal of Early Intervention*, 21, 267-281.
- Schalock, R. L., Borthwick-Duffy, S. A., Bradley, V. J., Buntinx, W. H., Coulter, D. L., Craig, E. M., . . . Tassee, M. (2010). *Intellectual Disability: Definition, Classification, and Systems of Supports. Eleventh Edition*. Washington, DC, USA: American Association on Intellectual and Developmental Disabilities.
- Schieve, L. A., Blumberg, S. J., Rice, C., Visser, S. N., & Boyle, C. (2007). The relationship between autism and parenting stress. *Pediatrics*, 119(Supplement 1), S114-S121.
- Schieve, L. A., Gonzalez, V., Boulet, S. L., Visser, S. N., Rice, C. E., Van Naarden Braun, K., & Boyle, C. A. (2012). Concurrent medical conditions and health care use and needs among children with learning and behavioral developmental disabilities, National Health Interview Survey, 2006-2010. *Research in Developmental Disabilities*, 33, 467-476.
- Schilling, R. F., Kirkham, M. A., & Schinke, S. P. (1986). Do child protection services neglect developmentally disabled children? *Education and Training of the Mentally Retarded*, 9,

21-26.

Schneiderman, J. U., Smith, C., & Palinkas, L. A. (2012). The caregiver as gatekeeper for accessing health care for children in foster care: A qualitative study of kinship and unrelated caregivers. *Children and Youth Services, 34*, 2123 -2130.

Sherrard, J., Tongue, B. J., & Ozanne-Smith, J. (2001). Injury in young people with intellectual disability: Descriptive epidemiology. *Injury Prevention, 7*, 56-61.

Shooshtari, S., Brownell, M., & Dik, N. (2011). Trajectories in health and use of health and social services by children with developmental disabilities: A population-based longitudinal study. *A poster presented at Health and Well-being in Developmental Disabilities Conference*. Toronto, Canada.

Shooshtari, S., Brownell, M., Dik, N., Chateau, D., Yu, C.T., Mills, R. S. L., Burchill, C.A., & Wetzel, M. (2014). A Population-based Longitudinal Study of Depression in Children with Developmental Disabilities in Manitoba. *Journal of Mental Health Research in Intellectual Disabilities, 7* (2).

Shooshtari, S., Martens, P. J., Burchill, C. A., Dik, N., & Naghipur, S. (2011). Prevalence of depression and dementia among adults with developmental disabilities in Manitoba, Canada. *International Journal of Family Medicine, 2011*, 9 pages.

Simms, M, (1989). The foster care clinic: A community program to identify treatment needs of children in foster care. *Developmental and Behavioral Pediatrics, 10*, 121-128

Simms, M. D., Dubowitz, H., & Szilagyi, M. A. (2000). Health care needs of children in the foster care system. *Pediatrics, 106*(Supplement 3), 909-918.

- Simms, M. D., Freundlich, M., Battistelli, E. S., & Kaufman, N. D. (1999). Delivering health care and mental health care services to children in family foster care after welfare and health care reform. *Child Welfare*, 78(1), 167–182.
- Sinha, R., Fisch, G., Teague, B., Tamborlane, W. V., Banyas, B., & Allen, K. (2002). Prevalence of impaired glucose tolerance among children and adolescents with marked obesity. *New England Journal of Medicine*, 346(11), 802-810.
- Slack-Smith, L., Colvin, L., Leonard, H., Kilpatrick, N., & Bower, C. B. (2009). Factors associated with dental admissions for children aged under 5 years in Western Australia. *Archives od Disease in Childhood*, 94, 517-523.
- Sobel, A., & Healy, C. (2001). Fostering health in the foster care maze. *Pediatric Nursing*, 27(5), 493–497.
- Sphere Institute (2003). Utilization of Medi-Cal services by current and former foster care children. Retrieved from Sphere Institute website:  
[http://www.sphereinstitute.org/publications%5CUtilization\\_Medi\\_Cal\\_by\\_FC\\_Children\\_FINAL.pdf](http://www.sphereinstitute.org/publications%5CUtilization_Medi_Cal_by_FC_Children_FINAL.pdf)
- Statistics Canada. (2012). Overweight and obesity in children and adolescents. *Health Reports*, 23(3), 1-7.
- Stewart, L., Beange, H., & Mackerras, D. (1994). A survey of dietary problems of adults with learning disabilities in the community. *Mental Handicap Research*, 1994, 41-50.
- Strauss, D., Anderson, T. W., Shavelle, R., Sheridan, F., & Trenkle, S. (1998). Causes of death of persons with developmental disabilities: Comparison of institutional and community residents. *Mental Retardation*, 36, 386-391.

- Sullivan, D. J., & van Zyl, M. A. (2008). The well-being of children in foster care: Exploring physical and mental health needs. *Children and Youth Services Review*. 30, 774-786.
- Takayama, J. I., Bergman, A. B., & Connell, F. A. (1994). Children in foster care in the state of Washington: Health care utilization and expenditures. *Journal of the American Medical Association*, 271, 1850-1855.
- Takayama, J. I., Wolfe, E., & Coulter, K. P. (1998). Relationship between reason for placement and medical findings among children in foster care. *Pediatrics*, 101(2), 201–207.
- Terling, T. (1999). The efficacy of family reunification practices: re-entry rates and correlates of re-entry for abused and neglected children reunited with their families. *Child Abuse and Neglect*, 23(10626617), 1359-1370.
- The Vulnerable Personas Living with a Mental Disability Act, C. C. S. M. c. V90. (2004). *The Vulnerable Personas Living with a Mental Disability Act, C. C. S. M. c. V90*. Retrieved from Manitoba Laws: <http://web2.gov.mb.ca/laws/statutes/ccsm/v090e.php>
- Tsigos, C. (2008). Management of obesity in adults: European clinical practice guidelines. *Obesity Facts*, 1, 106-116.
- Tuffrey-Wijne, I., Hogg, J., & Curfs, L. (2007). End-of-life and palliative care for people with intellectual disabilities who have cancer or other life-limiting illness: A review of the literature and available resources. *Journal of Applied Research in Intellectual Disabilities*, 20, 331-334.
- U.S. General Accounting Office. (1995, May 26). Foster care: Health needs of many children are unknown and unmet. *HEHS-95-114*. Retrieved from <http://www.gao.gov/archive/1995/he95114.pdf>

- Vitaliano, P. P., Zhang, J., & Scanlan, J. M. (2003). Is caregiving hazardous to one's physical health? A meta-analysis. *Psychological Bulletin, 129*(6), 946-72.
- Weiss, M. J., (2002). Hardiness and social supports as predictors of stress in mothers of typical children, children with Autism, and children with mental retardation. *Autism, 6*(1), 115-130.
- Weiss, S. J. (1991). Stressors experienced by family caregivers of children with pervasive developmental disorders. *Child psychiatry and human development, 21*(3), 203-216.
- West, M. A., Richardson, M., LeConte, J., Crimi, C., & Stuart, S. (1992). Identification of developmental disabilities and health problems among individuals under child protective services. *Mental Retardation, 30*(4), 22-225.
- Williams, K., Leonard, H., d'Espaignet, E. T., Colvin, L., Slack-Smith, L., & Stanley, F. (2005). Hospitalisations from birth to 5 years in a population cohort of Western Australian children with intellectual disability. *Archives of disease in childhood, 90*(12), 1243-1248.
- World Health Organization. (2001). *Mental health: New understanding, new hope*. Geneva: World Health Organization.
- World Health Organization. (2002). *Towards a common language for functioning, disability and health: ICF*. Geneva: World Health Organization.
- Xiang, H., Stallones, L., Chen, G., Hostetler, S. G., & Kelleher, K. (2005). Nonfatal injuries among US children with disabling condition. *American Journal of Public Health, 95*, 1970-1975.
- Yamaki, K., Rimmer, J. H., Lowry, D. D., & Vogel, L. C. (2011). Prevalence of obesity-related chronic health conditions in overweight adolescents with disabilities. *Research in*

*Developmental Disabilities, 32,* 280-288.