

## Health and Health Care Utilization of Manitoba Children in Care With and Without Developmental Disabilities: A Population-Based Comparative Study

### Abstract

#### Background

*This study examined health disparities between children with and without developmental disabilities (DD) living in child protective care. We conducted a population-based study of children in care in Manitoba, Canada; 11% were identified with DD.*

#### Method

*Using administrative health data, we compared the health status and health services utilization of children in care with ( $n = 1,212$ ) and without ( $n = 2,424$ ) DD, matched by age, sex, and region of residence, using Generalized Estimating Equation (GEE) regression modelling.*

#### Results

*Among children in care, those 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, and made more ambulatory physician visits compared to those without DD.*

#### Conclusions

*Compared to their counterparts in care, those with DD are more likely to have health problems and use health services. Recommendations are made for further research.*

Children with developmental disabilities (DD) are at great risk of being removed from their biological family of origin and placed *in care* of another family (e.g., foster care) or alternative living arrangement (Shooshtari et al., 2016). Manitoba has the highest rate of children *in care* in Canada (Canadian Child Welfare Research Portal, 2011). Children are often placed in care because of concerns related to abuse, family death or conflict, or emotional problems (Brownell et al., 2011). Those with DD are overrepresented in the in-care population (Brownell et al., 2015). To date, however, children with DD and children in care have typically been studied as non-overlapping groups, with the result that little is known about the health status and health care utilization specifically of *children in care with developmental disabilities*. The primary goal of the present population-based study was to examine health and health care use of children in care with DD to determine whether health disparities are more pronounced for those with DD compared to their counterparts without DD.

As a group, children in care are more likely to have impairments and chronic illnesses that require specialized services (see Christian & Schwarz, 2011), psychosocial problems

#### Authors

Dustin Heinrichs,<sup>1</sup>  
Shahin Shooshtari,<sup>2</sup>  
Marni Brownell,<sup>2</sup>  
Rosemary Mills,<sup>2</sup>  
Brenda Stoesz<sup>3</sup>

<sup>1</sup> Department of Family Social Sciences,  
University of Manitoba,  
Winnipeg MB

<sup>2</sup> Department of Community Health Sciences,  
Max Rady College of Medicine,  
University of Manitoba;  
St. Amant Research Centre, Winnipeg MB

<sup>3</sup> Department of Psychology,  
University of Manitoba,  
Winnipeg MB

#### Correspondence

shahin.shooshtari  
@umanitoba.ca

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(Altshuler & Poertner, 2003; Simms, 1989), and respiratory illnesses leading to hospitalizations (Brownell et al., 2011) than those not in care. Children in care are also more likely to be overweight and obese (Hadfield & Preece, 2008), putting them at greater risk for developing diabetes (Altshuler & Poertner, 2003) compared to the general population of children. Children in care also lack preventative dental care, increasing the likelihood of hospital-based dental treatment (Kling, Vinnerljung, & Hjern, 2016; Melbye, Chi, Milgrom, Huebner, & Grembowski, 2014). Children with DD (Shooshtari et al., 2014) and children in care (Brownell et al., 2011) are also at high risk for injury. Despite the high number of physician visits and hospital admissions, children with DD (Shooshtari et al., 2016) and children in care (DiGiuseppe & Christakis, 2003) lack continuity of care.

Children with DD are also an at-risk group; they are more likely to be diagnosed with respiratory illnesses and depression, to be hospitalized due to injury (Shooshtari et al., 2014, 2016), and to be obese and have diabetes (Rimmer, Yamaki, Lowry, Wang, & Vogel, 2010) than those without DD. Children with DD have more ambulatory physician visits (Lee & Chen, 2012), and are more likely to be admitted to hospital on more occasions, for longer durations, and for a broader range of clinical diagnoses (Gallaher, Christakis, & Connell, 2002; Williams et al., 2005), and to be seen by specialists (Schieve et al., 2012) than children without DD. Children with DD are less likely than those without DD to receive preventative dental care (Chi, Momany, Kuthy, Chalmers, & Damiano, 2010), and more likely to be admitted to hospital for dental treatment (Slack-Smith et al., 2009). Children with DD are also at high risk for injury (Shooshtari et al., 2014). Moreover, despite the high number of physician visits and hospital admissions, children with DD lack continuity of care (Shooshtari et al., 2016). Factors contributing to health disparities in people with DD include health-damaging behaviours, inadequate access to health services, and motor impairments (Ouellette-Kuntz, Garcin, Lewis, Martin, & Holden, 2005); other factors may include out-of-home placement and vulnerability to maltreatment (see Sullivan & Knutson, 2000). Thus, being placed in care may compound the health disparities experienced by children with DD, making children with DD

a particularly vulnerable subgroup of those in care. The purpose of the present study was to determine whether health disparities are greater for this subgroup.

Toward this end, the aim of the present study was to examine differences in health status and health services utilization of Manitoba children in care with DD and without DD. The objectives were to (1) describe the demographic and socioeconomic characteristics of the two groups, and compare the two groups with respect to (2) physical and mental health status, and (3) health care utilization patterns. An enhanced understanding of disparities in health and access to health services experienced by children in care with DD may help program providers and planners better meet the needs of these children.

## Methods

### Study Design and Setting

A retrospective cohort study was conducted using multiple years of administrative health data collected in Manitoba, a province of Canada with a population of 1.2 million (Statistics Canada, 2012). Manitoba provides publicly funded universal health care to its residents via five regional health authorities (RHAs). Region of residence was considered in this study as prior research shows regional variations in access to health services (Brownell et al., 2015).

### Data Sources

Data were obtained from databases contained in the Manitoba Population Research Data Repository maintained by the Manitoba Centre for Health Policy (MCHP). Each person registered with the provincial health department is assigned a nine-digit Personal Health Identification Number (PHIN). We used de-identified and scrambled PHINs for data linkage to protect confidentiality without losing track of individuals over time and across various databases in this study. Eighteen years of health and non-health administrative data (1995–2012) were linked to identify the study cohort. The databases used for the present study were: (1) Hospital discharge abstracts; (2) Physician claims; (3) Drug Program Information Network

file; (4) Enrolment data from Manitoba Education and Training; (5) Manitoba Fetal Alcohol Spectrum Disorder (FASD) Centre; (6) Manitoba Population Registry (2012); and (7) Child and Family Services Information System (CFSIS) data set. Canadian Census data (2011) were used to determine neighbourhood income quintiles. Three years of data (2009–2012) from the health databases were used to examine health status and access to health care services.

## Study Population

The study population consisted of children (aged 0–17 years in 2012) in care. Children “in care” were those who had been removed from the care of their original families because of a situation where authorities have deemed their family unable or unfit to look after them properly (Brownell et al., 2011). In this study, children “in care” were identified based on the Child and Family Services Information System (CFSIS) data set from Manitoba Department of Family Services. The study population (i.e., children in care) was then divided into two groups: those in care with a DD and those in care without a DD.

The cohort of children in care with DD consisted of those who met at least one of the following criteria: (1) received special education funding due to multiple handicaps or autism spectrum disorder based on information obtained from the enrolment data; (2) presence of a diagnostic code for DD in the hospital discharge abstracts or physician claims; or (3) presence of a diagnostic code for an alcohol-related disorder in the Manitoba FASD Centre database (as per Shooshtari, Martens, Burchill, Dik, & Naghipur, 2011). The comparison group consisted of children in care who did not meet the criteria for DD. Each child with a DD was matched with two children of the same age, sex, and region of residence in the comparison group, which allowed minimization of the influences of these factors as potential confounders (see Fransoo et al., 2013; Shooshtari et al., 2014). Of the 1,212 children with DD in care, 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, sex, and region of residence. As it was not possible to match the remaining 10 children with DD in care with children on the same exact birth year,

they were matched as closely as possible on birth year plus or minus one year, but the exact match on sex and place of residence.

## Study Measures

**Characteristics of children in care with and without DD.** The two study groups were compared with respect to several personal and in-care characteristics: (1) *Child age and sex*, with age defined as time in years from birth to 2012 and sex as biological male or female status; (2) *Child socioeconomic status (SES)*, measured using 2011 Canada Census neighbourhood income data and calculated by dividing the total population into income quintiles based on mean household income, with higher values reflecting higher incomes (Fransoo et al., 2009); (3) *Child place of residence*, described as the health region in which the child resided; and (4) *In-care characteristics*: the number of episodes and the duration of children’s placement in care, using 18 years of data (1995–2012) from the CFSIS dataset. The number of episodes in care was defined as the number of times that a child entered or re-entered into care over their time. Children placed in care for fewer than seven days were excluded from the analyses. Duration of care was examined in years.

**Physical and mental health status.** Three measures of child health were obtained: (1) *Total Respiratory Morbidity (TRM)*, defined as the proportion of population in each study group that had a respiratory illness (Fransoo et al., 2009); (2) *Diabetes*, defined as at least one hospitalization with a diabetes diagnosis, or at least two physician visits with a diabetes code, or filled two or more prescriptions for diabetes medication; (3) *Mood or anxiety disorders*, defined as meeting at least one of the following criteria: (a) one or more hospitalizations with a diagnosis of depressive disorder, affective psychosis, neurotic depression, or adjustment reaction; (b) one or more hospitalizations with a diagnosis for anxiety disorders AND one or more prescriptions for an antidepressant or mood stabilizer; (c) at least one physician visit with a diagnosis for depressive disorder, affective psychosis, or adjustment reaction; or (d) one or more physician visits with a diagnosis for anxiety disorders AND one or more prescriptions for an antidepressant or mood stabilizer (Fransoo et al., 2009; Martens et al., 2010).

**Health service utilization.** Children's use of health care services was assessed by four measures: (1) *Continuity of care*, assessed for children with at least three physician visits over a specified period (2009–2012). Children who visited the same physician for more than 50% of visits were classified as having continuity of care, whereas those who visited the same physician for 50% or less of their visits to physicians were classified as not having continuity of care. (2) *Total ambulatory physician visits*, assessed as the number of ambulatory visits to general practitioners and specialists, including visits in offices and walk-in clinics, homes, personal care homes, and outpatient departments over three years (2009–2012). (3) *Injury-related hospitalizations*, measured as admissions of more than one day coded in the hospital abstract records over three years (2009–2012). (4) *Hospital-based dental care*, indicated by a diagnostic code for procedures that took place in a hospital. Children with dental cavities and periapical abscess without sinus, and with an identified surgical procedure such as tooth restoration were classified as those who received hospital-based dental care. A list of ICD codes used to define the above listed measures is provided in Appendix A.

## Data Analysis

The proportion of children with TRM, diabetes, and mood and anxiety disorders were computed to estimate prevalence at the population level. We also estimated the rates of hospitalized dental care, continuity of care, and injuries. The estimates for the two study groups were compared using Generalized Estimating Equation regression modelling, taking matching into consideration. We used the relative risk (RR) and 95% confidence intervals to determine if the observed differences in prevalence estimates were statistically significant. Comparisons between the study groups were conducted using paired *t*-tests for number of episodes and duration in care, and total ambulatory physician visits. Data analyses were performed using SAS software, version 9.1 (SAS Institute Inc., 2004).

## Ethics

This research was approved by the University of Manitoba Research Ethics Board.

## Results

### Characteristics of Children in Care With and Without DD

As Table 1 shows of the 8,830 children living in care in 2012 for more than 7 days, 13.73% (1,212) had DD. The mean age of children with DD was 10.57 years ( $SD = 4.44$ ), and that of the comparison group was 10.56 years ( $SD = 4.41$ ). Table 1 shows the distribution of the study groups by age, sex, place of residence, and income quintile. Due to matching, age, sex, and regional distribution of the two study groups are similar. However, as shown in Table 1, a smaller proportion of children in care with DD than those in care without DD were living in neighbourhoods with higher income. Overall, the two groups differed in terms of their neighbourhood income level [ $\chi^2 = 69.93$ ,  $df = 5$ ,  $p < .0001$ ].

As summarized in Table 2 (see page 10), children with DD were in care for more days than children in the comparison group [ $t(2,217.1) = -12.59$ ,  $p < .0001$ ]; however, the average number of episodes was similar between groups [ $t(2,356.5) = 0.38$ ,  $p = .71$ ].

### Physical and Mental Health Status of Children in Care With and Without DD

Three indicators were used to measure and compare physical and mental health status between the study cohort and the matched comparison group. As summarized in Table 3, children in care with DD had a higher risk of respiratory illnesses (RR = 1.20, 95% CI: 1.05, 1.37,  $p = 0.0082$ ), diabetes (RR = 2.13, 95% CI: 1.21, 3.75,  $p = .0092$ ), and mood or anxiety disorders (RR = 1.88, 95% CI: 1.42, 2.49,  $p < .0001$ ) than did the children in the comparison group.

### Health Service Utilization by Children in Care With and Without DD

As shown in Table 3 (see page 11), the average number of ambulatory physician visits for children with DD ( $M = 36.90$ ,  $SD = 47.73$ ) was significantly higher than that found for the comparison group [ $M = 23.20$ ,  $SD = 17.28$ ;  $t(1,285.2) = 9.23$ ,  $p < .0001$ ]. Children with DD were significantly more likely than those in the comparison group

Table 1. Distribution of Study Populations by Age, Sex, Health Region of Residence, and Income Quintile

Characteristics	Children in Care With Developmental Disability (N = 1, 212)		Children in Care Without Developmental Disability (N = 2,424)	
	n	%	n	%
<b>Sex</b>				
Male	760	62.71	1,520	62.71
Female	452	37.29	904	37.29
<b>Age</b>				
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
<b>Health region of residence</b>				
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
<b>Income quintile</b>				
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

Note: NF = data "Not Found" could be due to multiple reasons; the most likely reason in this study is that the postal code is associated with the Child and Family Services (CFS) Office.

to have a history of injury-related hospitalization (RR = 2.36; 95% CI: 1.38, 4.03,  $p = .0016$ ) and hospital-based dental care (RR = 1.74; 95% CI: 1.28, 2.38,  $p = .0004$ ); however, the two study groups had comparable rates of continuity of care (OR = 0.89, 95% CI: 0.75, 1.05,  $p = .1726$ ).

## Discussion

The present study had three objectives. These objectives were met by examining retrospective

linked health and non-health administrative data for a population-based cohort of Manitoba children in care with and without DD. The first objective was to describe demographic and socioeconomic characteristics of children in care with and without DD. More than 3% of all Manitoba children were identified as being in care for more than seven days in 2012, and nearly 14% of these children in care were identified with DD. Manitoba has one of the highest rates of children in care among Canadian pro-

Table 2. Distribution of Duration In Care and Number of In Care Episodes

<i>Characteristic</i>	<i>Children in Care With Developmental Disability</i>		<i>Children in Care Without Developmental Disability</i>	
	<i>n</i>	<i>%</i>	<i>n</i>	<i>%</i>
<b>Duration in care (years)</b>				
< 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%
<b>Average number of days in care</b>	2,789.46 ( <i>SD</i> = 1,628.27)		2,090.83 ( <i>SD</i> = 1,472.18)	
<b>Number of episodes</b>				
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%
<b>Average number of episodes in care</b>	2.06 ( <i>SD</i> = 1.32)		2.07 ( <i>SD</i> = 1.28)	

inces and territories (Canadian Child Welfare Research Portal, 2011). Compared to children without DD, children with DD were in care significantly longer per episode, suggesting that they either enter care earlier, or less likely to return to their family of origin than children without DD. Nearly one third of all children in care were residing in the lowest income neighbourhoods. Living in poverty increases the risk for a number of health problems and adverse life events, particularly for children with DD (Emerson, 2007, 2015).

The second objective was to examine the health status of children in care with and without DD. Children in care with DD had significantly higher rates of respiratory morbidity, diabetes, and mood or anxiety disorders than those without DD. Higher respiratory morbidity in children with DD may be attributed to

greater susceptibility to respiratory infections because they often have physical abnormalities, immune dysfunction, and/or gastro-esophageal results that increase susceptibility to infections (Doull, 2001; Ram & Chinen, 2011). Higher prevalence of diabetes among children in care with DD than without DD is consistent with previous research indicating that children with DD have an increased risk of diabetes (Beange, Lennox, & Parmenter, 1999; Fujiura, Fitzsimons, Marks, & Chicoine, 1997; Rimmer, Braddock, & Fujiura, 1994).

Similar to previous findings for adults with DD (see Cooper et al., 1996), children in care with DD were more likely to have a history of mood or anxiety disorders than those in the comparison group. Depression is linked to a variety of adverse outcomes including self-injurious behaviours in children with DD (Cooper et

Table 3. Health Indicators by Study Group

Health Indicator	Children With Developmental Disability (%)	Matched Comparison Group (%)	Odds Ratio (95% CI)	p-value
Total respiratory morbidity (TRM)	45.54	41.17	1.05 (1.05–1.37)	.0082
Diabetes	1.40	0.66	2.13 (1.21–3.75)	.0092
Mood and anxiety disorders*	19.76	11.21	1.88 (1.42–2.49)	< .0001
Continuity of care	37.92	40.75	0.89 (0.75–1.05)	.1726
Injury related hospitalizations	1.90	0.83	2.36 (1.38–4.03)	.0016
Hospital-based dental care	7.51	4.13	1.74 (1.28–2.38)	.0004

Note: \*Consistent with the Manitoba Centre for Health Policy (MCHP) definition of mood and anxiety disorders, only children over the age of 10 were included in the analyses.

al., 2009; Hardan & Sahl, 1999). Psychotropic medications have been prescribed to manage self-injury and other challenging behaviours in this population; however, little is known about the effectiveness of these medications for this purpose (Matson & Neal, 2009), which may increase risk for adverse side effects. In addition, studies in other jurisdictions found that although children whose placements change while in care, or leave and then re-enter care have a higher rate of mental health services utilization, they are not receiving appropriate treatment (Leslie, Hurlburt, Landsverk, Barth, & Slymen, 2004; Simms, Dubowitz, & Szilagyi, 2000). Examining placement change, and reviewing the level of family support and personal coping skills of children in care with DD is necessary, as these factors may mitigate symptoms associated with mood or anxiety disorders (Essau, Conradt, Sasagawa, & Ollendick, 2012; Kochenderfer-Ladd & Skinner, 2002; Weiss, 2002).

The third objective was to examine the utilization of health services in the study population. There were significant disparities in physician visits and injury-related hospitalizations for children with DD compared to those without DD, but no differences with respect to continuity of care. Poor health outcomes for children

in care are often attributed to previous exposure to parental substance abuse and mental illness, poverty, and family and neighbourhood violence (see Curtis, 1999), and the trauma of separation from their families (see Christian & Schwarz, 2011; Clausen, Landsverk, Ganger, Chadwick, & Litrownik, 1998), and the unmet health care needs of may continue to go unaddressed even after placement (Deutsch & Fortin, 2015; Simms et al., 2000; Takayama, Wolfe, & Coulter, 1998). This may be particularly true for children in care with DD. Despite high utilization of physician services, the complex health care needs of children with DD often remain unmet (Leslie et al., 2003) because of placement instability and the fragmented health systems (Simms et al., 2000), and contribute to a lower rate of primary preventive care (Kortenkamp & Ehrle, 2002).

The finding of more hospital-based dental care among children in care with DD also is consistent with previous research (e.g., Shooshtari et al., 2015). Hospital settings are often the preferred or necessary location for treating oral health issues in children with DD because they exhibit more behavioural problems or have more advanced tooth destruction (Balogh, Hunter, & Ouellette-Kuntz, 2005; Enever, Nunn, & Sheehan, 2000; Melbye, Huebner, Chi,

Hinderberger, & Milgrom, 2013; Schneiderman, Smith, & Palinkas, 2012; Shooshtari et al., 2015). Future studies should explore reasons for unmet dental needs in persons with DD.

The present study is the first population-based study of health and health care utilization patterns of Manitoba children in care with DD using information that cannot be obtained from other provincial or national sources. However, the data lack information on several personal (e.g., health-related behaviours) and environmental (e.g., family dynamics) factors that may provide insight into children's overall health and well-being and longer-term health outcomes. Although we did control for the effects of age, sex, and place of residence in our analyses, we did not control for the effects of neighbourhood income level. Given the fact that a smaller proportion of children with DD than those without DD were living in neighbourhoods with higher income, this factor might have helped to explain some of the disparities in health and utilization of health services observed between the two study groups. Another limitation of the study relates to the diagnostic codes used to identify the selected health conditions and outcomes. The ICD codes present are not definitive clinical diagnoses; rather they are indicators that services for particular issues were utilized. In spite of these limitations, our study findings can be used by those involved in planning and provision of health and social services to children in care in Manitoba and in other jurisdictions to improve the health and the quality of care that the children in care with and without DD receive.

## Key Messages From This Article

**People with disabilities.** You deserve to be healthy and have access to healthcare that you need, even if you are not cared for by your own family.

**Professionals.** Children in care with developmental disabilities are at a greater risk for a number of health conditions and injuries compared to other children in care. You need to be aware of specific needs of children in care with developmental disabilities.

**Policy makers** Policy to ensure health and safety of children in care with developmental dis-

abilities is necessary to prevent negative health outcomes such as mental illness and unnecessary use of health services.

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## Appendix A: ICD Codes

Total Respiratory Morbidity (TRM): ICD-9-CM codes 466, 490, 491, 492, 493, 496; ICD-10-CA codes J20, J21 or J40-J45

Diabetes: ICD-9-CM code 250; ICD-10-CA codes A10 (Anatomical Therapeutic Chemical [ATC]) and E10-E14

Mood or anxiety disorders. ICD-9-CM codes 296, 309, 311 (depressive disorder, affective psychoses, or adjustment reaction); ICD-9-CM code 300 (anxiety disorder) AND ATC codes N03AB02, N03AB52, N03AF01, N05AN01, N06A; 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 (depressive disorder, affective psychosis, neurotic depression, or adjustment reaction); ICD-10-CA codes F32.0, F34.1, F40, F41, F42, F44, F45.0, F45.1, F45.2, F48, F68.0, F99 (anxiety disorders) AND ATC codes N03AB02, N03AB52, N03AF01, N05AN01, N06A (anti-depressant or mood stabilizer)

Injury-related hospitalizations. 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. ICD-10-CA codes of K02 (dental cavities) and K04.7 (periapical abscess without sinus), and 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).