JoDD

Journal on Developmental Disabilities
Volume 25 Number 2, 2020
On-Line First

Health of Persons with Intellectual and Developmental Disabilities Transitioning into Community Homes from a Complex Care Residence in Canada

La santé des personnes ayant une déficience intellectuelle ou un trouble du développement lors de leur transition entre des milieux de vie résidentiels spécialisés et des milieux de vie communautaires au Canada

Author Information

Katherine Chimney,[1]
Soroush Kian,[2]
Margherita Cameranesi [3]
Lindsay McCombe,[4]
Shahin Shooshtari [2]

[1]Faculty of Science, University of Manitoba, Winnipeg MB
[2]Dept. of Community Health Sciences, Rady Faculty of Health Sciences, University of Manitoba, Winnipeg, MB
[3]Applied Health Sciences Program, University of Manitoba, Winnipeg MB
[4]St.Amant Research Centre, Winnipeg, MB

Correspondence:

shahin.shooshtari@umanitoba.ca

Keywords

baseline health,
community living,
community transition,
healthcare,
retrospective review

Abstract

Health of Persons with Intellectual and Developmental Disabilities Transitioning into Community Homes from a Complex Care Residence in Canada
Community living of persons with intellectual and developmental disabilities (IDD) has been encouraged to reduce health disparities experienced by this population. This study aims to assess health and access to healthcare of 45 persons with IDD prior to their transition into community homes. Data were collected retrospectively by reviewing individual medical charts of persons with IDD. Selected health measures were based on the Comprehensive Health Assessment Program and the recently updated Canadian consensus health guidelines to provide a description of the pre-transition health of the study group. The health and healthcare use of the study population mostly met the current healthcare recommendations. There were limited data for several areas that we recommend being collected as part of routine practice. We also recommend routine use of standard tools available. This was the pre-transition phase of a longitudinal study. Similar data will be collected post-transition to explore changes in health status.

Résumé

La possibilité de pouvoir maintenir un milieu de vie dans la communauté a été identifiée comme moyen d'atténuer les disparités sur le plan de la santé qu'éprouvent les personnes ayant une déficience intellectuelle (DI) ou un trouble du développement (TD). La présente étude vise à évaluer l'état de santé et l'accès aux soins de santé chez 45 personnes ayant une DI ou un TD avant leur transition depuis un milieu de vie spécialisé à un milieu de vie dans la communauté. La collecte de données fut effectuée rétrospectivement grâce à une analyse de leurs dossiers médicaux selon des indicateurs basés sur le *Comprehensive Health Assessment Program* et les récentes orientations canadiennes en matière de santé. L'état de santé et l'utilisation des soins de santé des participants de l'étude répondaient majoritairement aux recommandations actuelles. Cependant, peu d'informations ont été retrouvées pour plusieurs domaines qui devraient être évalués de façon routinière. Nous recommandons également l'intégration des outils standardisés disponibles dans ce domaine dans les pratiques courantes. Cet article expose les données d'un premier temps de mesure d'une étude longitudinale concernant l'état de santé des personnes lors de leur transition de milieu de vie. Des données semblables seront recueillies après cette transition.

Mots-clés : niveau de santé de base, intégration communautaire, transition communautaire, soins de santé, étude rétrospective

Introduction

Persons with intellectual and developmental disabilities (PwIDD) experience significant health disparities compared to the general population (Krahn, Hammond, & Turner, 2006; Ouellette-Kuntz et al., 2005; Shooshtari et al., 2016), and have fewer opportunities to engage in health-promoting activities (Krahn, Fox, Campbell, Ramon, & Jesien, 2010; Lennox, Ware, Bain, Taylor Gomez, & Cooper, 2011). Consequently, preventable mortalities and comorbidities are more common among PwIDD compared to persons without IDD (McCarron, Carroll, Kelly, & McCallion, 2015; Mencap, 2007; Ouellette-Kuntz, Shooshtari, Balogh, & Martens, 2015). Despite poorer health and higher healthcare needs, PwIDD experience more difficulty in accessing primary healthcare than the general population (Lunsky, Klein-Geltink, & Yates, 2013; Robertson, Roberts, Emerson, Turner, & Greig, 2011). They are also more likely than persons without IDD, or even those with other types of disabilities to report unmet healthcare and social service needs (Cooper, Melville, & Morrison, 2004; Shooshtari, Naghipur, & Zhang, 2012). The combination of these two issues represents a "double whammy" for PwIDD who not only suffer from significant health issues but also encounter barriers accessing primary healthcare services they need. Consequently, PwIDD experience poorer health and quality of life than persons without IDD (Lennox et al., 2011; Lunsky et al., 2013; Ouellette-Kuntz et al., 2015).

Changes in living arrangement as result of deinstitutionalization also impacts the health status of PwIDD (e.g., Martínez-Leal et al., 2011). Deinstitutionalization refers to the movement of PwIDD from large institutions into smaller, community-based settings. This process has represented a progressive shift in the standard of care in service provision for PwIDD (Hamelin Frijters, Griffiths, Condillac, & Owen, 2011). In some countries, such as Sweden and Norway, the large residential institutions for PwIDD have been completely closed for many years now,

while in other European countries such as Greece and Spain, there are still PwIDD living in large institutions (Beadle-Brown, Mansell, & Kozma, 2007).

Canada aligns with the United Nations Policy on Deinstitutionalization adopting full integration into the community for PwIDD in several provinces (Canadian Heritage, 2014). However, in Canada, health and social services are provincial responsibilities, with each province responsible for developing its own unique system of providing care to PwIDD (Lemay, 2009). The provinces of British Columbia and Ontario have closed all institutions for PwIDD. In the province of Manitoba, two residential centres for PwIDD still exist, St.Amant, which is located in the city of Winnipeg, and the Manitoba Developmental Centre, which is located in Portage la Prairie.

St.Amant is a not-for-profit organization that offers a wide range of programs and services to support Manitobans with IDD and autism and their families. St.Amant provides comprehensive resources and programs including a large residence for complex-care, Health and Transition Services (H&TS). In 2013, St.Amant initiated a strategic plan to offer community living options for PwIDD who were living at this residential centre. Health service changes for these persons are anticipated as they transition from the long-term care facility H&TS, that provides specialized healthcare on-site, to community homes in which they will access community-based mainstream healthcare services.

As the shift from specialized to mainstream care has been criticized for not adequately meeting the special care needs of this population (Brown, MacArthur, McKechanie, Hayes, & Fletcher, 2010; Meijer, Carpenter, & Scholte, 2004), a longitudinal research study was designed to evaluate the impact that transitioning individuals from the complex-care facility H&TS of St.Amant has on their health and access to healthcare. As part of this longitudinal study, we reviewed health records of 45 PwIDD to describe their health status and healthcare use prior to their transition into community-based homes. In this paper, we describe the health status and healthcare use of these persons while living at St.Amant's long-term care facility H&TS, before their transition into community homes. In the subsequent phase of this study, we will collect similar data on health and access to healthcare for the same individuals while living in community homes (post-transition). This comparison of pre-and post-transition data will demonstrate the impact of community transitions.

Materials and Methods

Study Design

This phase of the study was a retrospective cohort study based on data obtained from individuals' medical records. The study was approved by the University of Manitoba Health Research Ethics Board (HREB) and St.Amant Research Access Review Committee.

Data Source

Data were collected by reviewing individual medical charts of study participants stored in the Health Information Services and Privacy office at St.Amant. Data were gathered from various forms in the individuals' medical records. Data were extracted, coded, and entered into an Excel file by two research trainees following a set of established rules and procedures. Missing data, and any inconsistency in coding were discussed with the lead investigator before data were

exported into SPSS for analysis. A data codebook was created to document the coding, and labelling of the variables in the database. Data collection and data entry were conducted between May and August of 2018. At the time of data collection, all study participants had already been transitioned to community homes.

Study Population

Our study population consisted of 45 PwIDD who had been transitioned from St.Amant long-term care facility H&TS to community-based residences between July of 2014 and July of 2018.

Study Measures

Health-related measures Data on each study participant's health and access to care were collected in eight domains including physical health, mental health, functional health, oral health, women's health, men's health, immunization status, and health-related behaviors. The health indictors used were selected based on the Comprehensive Health Assessment Program (CHAP; Lennox, Green, Diggens, & Ugoni, 2001) and the Canadian Consensus Guidelines for Primary Care of Adults with IDD (Sullivan et al., 2018). The CHAP is a tool developed by Lennox and colleagues (2001) in Australia to promote access to primary healthcare for PwIDD. The 2018 aforementioned Canadian guidelines are based on the consensus among active experts and clinicians in the field, and emphasize the importance of periodic comprehensive health reviews with adapted clinical tools to aid primary care providers in their assessments. The individual health indicators examined are listed in Tables 2-6.

Socio-demographic characteristics The socio-demographic profile of the study population was described using a number of measures including age, length of residency at the residential centre before the transition to community, etiology of IDD, sex, Indigenous status, type of delivery, weight at birth, first-born child in the family, enrolment at St.Amant School within 5 years prior to their transition, and Public Guardian and Trustee Substitute Decision Maker (see Table 1).

Data Analysis

Secondary data analysis was performed using SPSS version 25. Descriptive statistics, including frequencies, were run to describe socio-demographic and health-related characteristics of the study population. Variables were recorded following a procedure that protected the confidentiality of all persons involved in the study.

Results

Description of the Study Population

Detailed information on socio-demographic characteristics of the study population is presented in Table 1. Our study population included 45 PwIDD, who were almost evenly divided between sexes (51% males and 49% females). Twenty percent of the study population were of known Indigenous status, and 42% were between the ages of 35 and 44 years at the time of their transition. Age at admission to the residential centre ranged from 1 year to 47 years (M = 13

years) and 40% of the study population had resided at the residential centre for 29 to 38 years at the time of discharge from H&TS. Persons supported at the long-term care facility H&TS transitioned to a variety of community-based settings such as group homes, foster homes, residential and community living services, and family managed shift staffed homes.

The etiology of IDD was known for 76% of the study population (see Table 2). Diagnoses included genetic disorders such as Down syndrome, fragile X, phenylketonuria, Cornelia de Lange syndrome, William syndrome, pyruvate carboxylase deficiency, tuberous sclerosis, Noonan syndrome, and other structural chromosomal abnormalities. Additionally, structural brain abnormalities such as agenesis of the corpus callosum, as well as other conditions such as cerebral palsy were present. However, IDD etiology was unknown for 24% of the study population, and no referrals for genetic assessment or reassessment were arranged in these cases.

Maternal and prenatal history Advanced maternal age is a risk factor for autism (Durkin et al., 2008) and other causes of IDD such as Down syndrome (Tearne, 2015). A small proportion of mothers (11%) were over the age of 35 at the time of birth of the study population. Minimal information on maternal and prenatal history were recorded in the medical charts that were reviewed. Therefore, we were unable to collect data on infectious disease or medications taken during pregnancy, sibling history, or the nature of the delivery at birth.

Table 1 - *Socio-Demographic Characteristics of the Study Population*

Socio-demographic characteristics		*N*	%
Age at discharge (in years)	<25	6	13
	25-34	6	13
	35-44	19	43
	45-50	8	18
	>50	6	13
Length of residency at <name of organization> (in years)	0-8	10	22
	9-18	5	11
	19-28	5	11
	29-38	18	40
	39-48	7	16
Sex	Male	23	51
	Female	22	49
Indigenous status	Yes	9	20
	No	14	31
	Missing data	22	49
Length of pregnancy	Full-term	26	58
	Pre-term	10	22
	Missing data	9	20

Type of delivery	Natural	23	51
	Other[a]	9	20
	Unknown	13	29
Weight at birth	Normal[b]	21	47
	Abnormal[c]	12	27
	Missing data	12	27
First-born child in family	Yes	15	33
	No	22	49
	Unknown	8	18
<name of organization> School enrolment within 5 years of discharge	Yes	16	36
	No	29	64
Substitute Decision Maker is Public Guardian and Trustee	Yes	30	67
	No	15	33

Note. [a]Other type of delivery includes C-section, induced, and forceps. [b]Normal birth weight is between 2,500 grams and 4,000 grams. [c]Abnormal birth weight includes low weight (1,500-2,499 grams), very low weight (<1,500 grams), and fetal macrosomia (weight>4,000 grams).

Table 2 - *Physical Health Status of the Study Population*

Physical health indicators		*N*	%
Etiology of intellectual/ developmental disability	Cerebral palsy	15	33
	Other etiology	13	29
	Down syndrome	6	13
	Missing data	11	25
Family history of intellectual/ developmental disabilities	Yes	10	22
	No/Unknown	35	78
Number of medications	2-3	6	13
	4-5	14	31
	6-8	17	38
	>9	8	18
Number of PRN medications	1-2	5	11
	3-4	28	62
	>5	12	27
History of seizures	Yes	30	67
	No	15	33
Epilepsy	Yes	23	51
	No	22	49

Problems with sleep	Yes	8	18
	No	37	82
Autism spectrum disorder	Yes	8	18
	No	37	82
Other ongoing neurological disorder	Yes	7	16
	No	38	84
History of other neurological disorder	Yes	5	11
	No	40	89
Vision problems	Yes	30	67
	No	15	33
Wearing glasses	Yes	7	16
	No	17	38
	N/A	21	47
Other ongoing eye disorder	Yes	13	29
	No	32	71
History of otitis media	Yes	9	20
	No	36	80
History of cardiovascular disorder	Yes	6	13
	No	39	87
Other ongoing blood disorder	Yes	6	13
	No	39	87
History of anemia	Yes	15	33
	No	30	67
History of recurrent upper respiratory tract infection	Yes	5	11
	No	40	89
History of lower respiratory tract infection or pneumonia	Yes	8	18
	No	37	82
Regurgitation/vomiting	Yes	6	13
	No	39	87
Ongoing dysphagia	Yes	6	13
	No	37	87
Chronic constipation	Yes	32	71
	No	13	29
Bowel incontinence	Yes	23	51
	No	22	49

History of gastroesophageal reflux disease	Yes	11	24
	No	34	76
History of hernia	Yes	8	18
	No	37	82
History of bowel obstruction	Yes	5	11
	No	40	89
History of other gastrointestinal disorder	Yes	10	22
	No	35	78
Urinary incontinence	Yes	30	67
	No	15	33
History of urinary tract infection	Yes	16	36
	No	29	64
Pressure sore risk[a]	Little or no risk	25	56
	At risk	10	22
	Moderate risk	5	11
	Missing data	5	11
Ongoing dry skin	Yes	11	24
	No	34	76
Ongoing acne	Yes	8	18
	No	37	82
Ongoing dermatitis	Yes	5	11
	No	40	89
Other ongoing skin disorder	Yes	13	29
	No	32	71
History of eczema	Yes	10	22
	No	35	78
History of other skin disorder	Yes	7	16
	No	38	84
History of fracture	Yes	8	18
	No	37	82
Ongoing spastic plegia	Yes	17	38
	No	28	62

Ongoing spinal curvature disorder	Yes	15	33
	No	30	67
BMI interpretation[b]	Normal weight	35	78
	Abnormal weight	10	22
Recently lost weight	Yes	8	18
	No	37	82
Diabetes	Yes	-	-
	No	45	100
Ongoing dyslipidemia	Yes	7	16
	No	38	84
Ongoing hypothyroidism	Yes	6	13
	No	39	87
History of other metabolic/endocrine disorder	Yes	6	13
	No	39	87
Known allergies	Yes, to medication	19	42
	Yes, to other	9	20
	None known	25	56
Known food intolerance	Yes	9	20
	No	36	80

Note. PRN = pro re nata (i.e., as needed). BMI = Body Mass Index. [a]Pressure sore risk defined by Braden Pressure Ulcer Risk Assessment. [b]Underweight if BMI < 18.5, normal weight if 18.5 < BMI < 24.9, overweight if 25 < BMI < 29.9, and obese if BMI > 30.

Physical health status Detailed information on individuals' physical health status is presented in Table 2. The vast majority of study participants used more than 3 prescription medications (87%), experienced chronic constipation (71%), and had at least one known vision problem (67%) at the time of discharge from St.Amant's H&TS. Most participants had a Body Mass Index within normal range (78%), and none of the individuals in this study had been diagnosed with diabetes.

A vast proportion of study participants (67%) had a history of epileptic seizures of various types, durations (from a few seconds to more than 5 minutes), and frequencies (from less than one per year to more than one per day). Seizure medication was reviewed within a month prior to discharge, as per the medication administration record files in each chart.

Many individuals in the study group had some type of vision problem (67%) such as cataracts, nearsightedness or myopia, cortical blindness, farsightedness or hyperopia, keratoconus, blindness due to retrolental fibroplasia, retinal detachment, or optic atrophy, and in multiple cases a combination of two of the above. Despite this, only 16% of the study population wore glasses regularly. It was common for individuals to be prescribed glasses but refuse to wear them. Specifically, only 35% of those with prescribed glasses actually wore them. Hearing

problems were infrequent in the study population and included mild conductive and sensorineural hearing loss.

Other documented ongoing medical problems not entered in Table 2 included neurological disorders such as fetal alcohol spectrum disorder (FASD), attention-deficit hyperactivity disorder (ADHD), Tourette syndrome, verbal apraxia, chronic dizziness, congenital porencephalic cyst, Lennox-Gastaut syndrome, and stereotypic movement disorder. Sixteen percent of the study population had at least one of these ongoing neurological disorders at the time of their transition to the community. Recorded bone density test results (47%) indicated that 16% of the study participants had low bone density and 29% were classified as osteoporotic.

Aortic root dilation and pulmonary stenosis were the only specified ongoing cardiovascular disorders recorded in the individual medical charts. However, our review identified a number of ongoing blood disorders (13%) including neutropenia, thrombocytopenia, pancytopenia, autoimmune hemolytic anemia, normocytic anemia, and bleeding disorder. Our chart reviews also identified two ongoing gastrointestinal or hepatic disorders (hepatitis C and cholelithiasis), and two ongoing urogenital disorders (overt nephropathy and renal cyst). Furthermore, some study participants had been diagnosed with ongoing musculoskeletal disorders, while others had been diagnosed with metabolic and endocrine disorders including congenital lactic acidosis and hyperprolactinemia. No ongoing respiratory disorders were recorded in any individual medical chart we reviewed.

Mental health status Information on participants' mental health status and challenging behaviours is summarized in Table 3. As presented in the table, 78% of the study participants exhibited at least one type of challenging behaviour. Management for these behaviours included the wearing of special clothing, redirection, waiting for the behaviour to terminate, increasing supervision, using a crisis beeper, using a padded room, using physical restraints, avoiding eye contact with the person, and pharmacological intervention. Triggers for the challenging behaviours, if known, were indicated as other people, loud and stimulating environments, boredom, and pain.

For confidentiality reasons, we present data only on anxiety disorders, which had been diagnosed in five study participants by the time of their transition. Due to the small number of cases, other psychiatric disorders reported in the medical charts including mood disorders, psychotic disorders, obsessive-compulsive disorder, pica, trichotillomania, and impulse control disorder were combined into the "other psychiatric disorders" category.

Table 3 - *Mental Health Status and Challenging Behaviours of the Study Population*

Mental health indicators		*N*	%
Number of psychiatric disorders	0	13	29
	1	24	53
	>2	8	18
Anxiety disorders	Yes	5	11
	No	40	89
Other psychiatric disorder(s)	Yes	10	22
	No	35	78

Current approved restraint plan	Yes	30	67
	No	15	33
Family history of psychiatric disorders	Yes	16	36
	No/Unknown	29	64
Challenging behaviour	Yes	35	78
	No	10	22
Type of challenging behaviour[a]	Noise-making	24	53
	Harmful towards self	25	56
	Harmful towards others	25	56
	Wandering/running away	7	16
	Fecal smearing	11	24
	Destruction of property	14	31
	No challenging behaviour	10	22
Frequency of challenging behaviour	Never	10	22
	Less than daily	13	29
	Daily/on a consistent basis	14	31
	Unknown	8	18
PRN medication for challenging behaviour	Yes	14	31
	No	31	69

Note. [a]More than one type of challenging behaviour was possible for each individual. PRN = pro re nata (i.e., as needed).

Table 4 – *Functional Health Status of the Study Population*

Indicators		*N*	%
Communication method[a]	Facial expressions	37	82
	Vocalizations	32	71
	Gestures	31	69
	Assistive-communication device	21	47
	Symbols	14	31
	Verbal	12	27
	Sign language	6	13
Makes eye contact	Yes	39	87
	No	5	11
Independent ambulation	Yes	22	49
	No	23	21
Wheelchair use	Yes	27	60
	No	18	40

Ability of wheelchair use	Independent use	12	27
	Use with assistance	15	33
	N/A	18	40
Walker use	Yes	18	40
	No	27	60
Ability with stairs	Independent use	16	35
	Use with assistance	8	18
	Unable	21	47
Use of orthotics	Yes	17	38
	No	27	60
Recent decline in mobility	Yes	6	13
	No	39	87
Fall risk	Low risk	19	42
	Moderate risk	19	42
	High risk	5	11
Fall history	None in past year	32	71
	Recurrent falls	8	18
Fine motor skills	Functional use of both hands	25	56
	Other	6	13
	Missing data	14	31
Use of computer or tablet electronics	Yes	18	40
	No	12	27
	Unknown	15	33
Feeding ability	Feeds self independently	27	60
	Feeds self with assistance	8	18
	Fully assisted by staff or tube fed	10	22
Abnormal eating behaviour	Food or liquid refusal	11	24
	Choking, regurgitation, or ingestion of inedible objects	11	24
	No abnormal eating behaviours	23	52
Personal care assistance	Partial assistance	17	38
	Total assistance	28	62

Functional health status Several indicators were used to measure the study participants' functional health status (see Table 4). Assistive communication devices were utilized by approximately half of the study population, with the most common device being a speech-generating device (33%). Methods such as individual symbols, Eye Transfer (E-Tran) boards, and sequencers were also utilized. An E-Tran is a communication support tool that enables individuals to select letters with their eyes. There are various sequencing devices to help with

communication of persons with disabilities. For example, icon sequencing is a system utilized in various devices, where sequences of icons are combined in order to create a word or a phrase.

All individual medical charts reviewed included some information on participants' personal care assistance needs; however, our review revealed some heterogeneity in the ways this information was originally recorded and interpreted among study participants. Almost two-fifths (38%) of our study population required partial assistance for personal care activities. Full support was needed for self-care practices such as bathing, hair brushing, and tooth brushing for 62% of the study population.

Oral health status Oral health was assessed based on data collected from the dental records. Overall, the majority of individuals had fair or poor oral hygiene. Reported oral health pathologies included inflammation, severe periodontal disease, and wear due to grinding of teeth. Further, dental fillings and extractions were performed frequently.

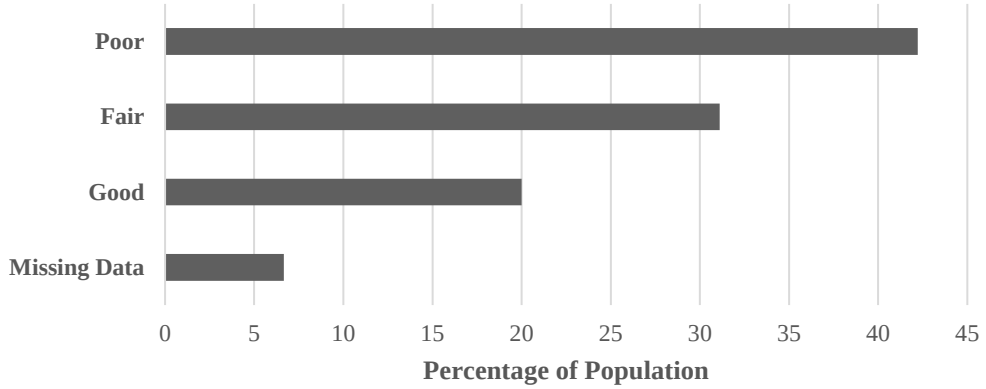

Figure 1. Oral hygiene state of the study population.

Women's health status Women's health status was assessed based on the presence or absence of symptoms such as amenorrhea, pre-menstrual syndrome, painful periods or dysmenorrhea, and menopausal symptoms. The mean age of the women included in this study was 39 years, and the majority of these women had menstrual periods. Studies have suggested that painful periods are more prevalent among women with IDD and may negatively impact their daily functioning more than women in the general population (Kennedy, O'Higgings, Sarma, Willig, & McGuire, 2014). Therefore, the 2018 Canadian guidelines recommend that concerns and symptoms related to menstruation should be monitored regularly and that education regarding options for menstrual pain management should be provided to women with IDD (Sullivan et al., 2018).

Additionally, the use of hormonal contraceptives or menstrual regulators such as oral contraceptive pills or Depo Provera was examined, and it was found that 27% of women were using one of these medications at the time of their transition to the community. Little to no data were identified for history of mammograms or Pap tests, although the majority of women had received a breast check by a general practitioner during their last physical exam.

Men's health status Men's health status was determined by whether or not the men in our study population had been checked for undescended testes (cryptorchidism), which is associated with a threefold increase in risk for testicular cancer if not surgically managed via pre-pubertal

orchidopexy, or orchiectomy if the individual is over the age of 12 (Haire, Flavill, Groom, & Dhandapani, 2015; Wilson et al., 2018). Cryptorchidism is not strictly a neonatal condition, as older men have acquired undescended testes due to muscle spasticity leading to pathological retraction of one or both testes, especially in cases of cerebral palsy (Haire et al., 2015). Additionally, studies have found that IDD is an independent risk factor for cryptorchidism, further suggesting the importance of physical examination in this population (Haire et al., 2015). All men participating in our study had been checked for undescended testes at the time of their transition.

Table 5 - *Sex-Specific Health Status of the Study Population*

Health indicators		*N*	%
WOMEN (*N* = 22)			
Hormonal contraceptive or menstrual regulator use	Yes	6	27
	No	16	73
Had pre-menstrual syndrome	Yes	7	32
	No	15	68
Had painful periods	Yes	16	73
	No	6	27
MEN (*N* = 23)			
Checked for undescended testes	Yes	23	100
	No	-	-

Immunization status As Figure 2 shows, the majority of study participants had received immunization for TDP (tetanus, diphtheria, and pertussis), Td (tetanus and diphtheria), pneumococcus, and MMR (measles, mumps, and rubella). Furthermore, the vast majority of study participants had received annual immunization for influenza. However, according to the 2018 Canadian guidelines (Sullivan et al., 2018), both hepatitis A and hepatitis B immunizations are also recommended for individuals living in group settings. Despite this, there was minimal documentation on hepatitis A immunization and only 53% of study participants had been immunized for hepatitis B at the time of discharge. The rate for HPV (human papilloma virus) vaccinations was also very low. Some reasons for clients remaining unvaccinated included previous naturally acquired immunity, allergy to vaccine, and lack of consent by their substitute decision maker.

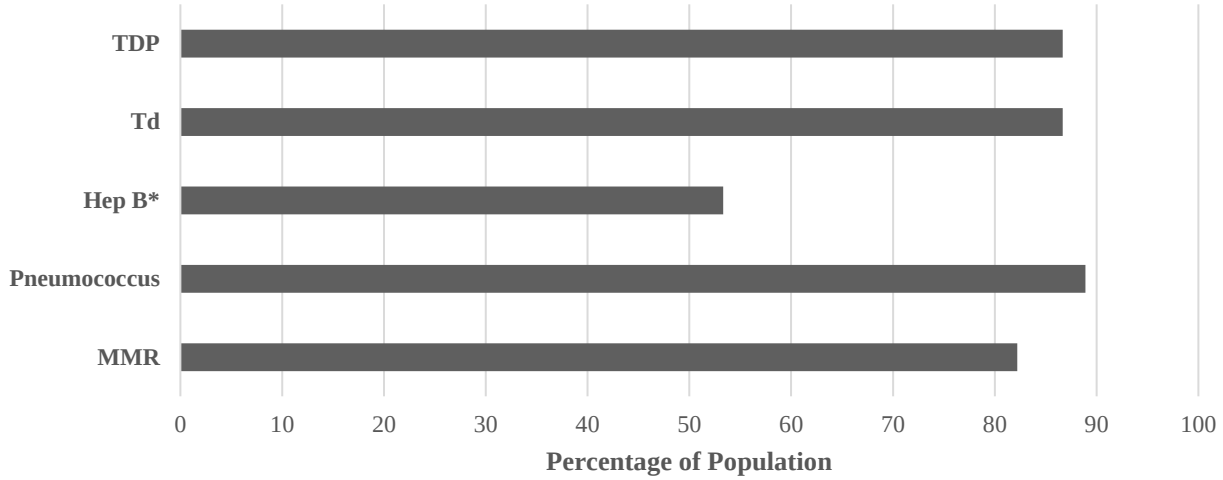

Figure 2. Immunization status of the study population. TDP = tetanus, diphtheria, and pertussis, Td = tetanus and diphtheria, Hep B = hepatitis B, MMR = measles, mumps, and rubella. *Recommended for those who live in group settings (Sullivan et al., 2018).

Health-related behaviours We identified very limited information on health-related behaviours of our study population. The only available data were on bicycle or tricycle use and swimming, which were both utilized by approximately 84% of the study population. However, no data were available on frequency or intensity of these activities.

Table 6 - *Study Populations' Access to Healthcare*[a]

Indicators		*N*	%
Medications reviewed in last 3 months[b]	Yes	45	100
	No	-	-
Dental review in past 6 months[c]	Yes	31	69
	No	14	31
Optometry assessment in past 2 years (if over 40 years of age)[b]	Yes	15	33
	No/Unknown	6	13
	N/A	24	53
Audiology assessment in past 5 years (if over 45 years of age)[b]	Yes	-	-
	No/Unknown	13	29
	N/A	32	71
Osteoporosis risk assessed prior to age 40[d]	Yes	15	33
	No/Unknown	30	67

Assessed for dysphagia or GERD[c]	Yes	13	29
	No/Unknown	32	71
Blood glucose test performed prior to age 40[b]	Yes	21	47
	No/Unknown	24	53
Thyroid function test in past 5 years or in past 12 months if elevated risk (Down syndrome, patients taking lithium, atypical or 2nd generation antipsychotics or seizure medication)[b,e]	Yes	31	69
	No/Unknown	14	31
Vitamin D test performed[c]	Yes	5	11
	No/Unknown	40	89
History of physiotherapy in past 5 years[f]	Yes	38	84
	No	7	16
History of occupational therapy in past 5 years[f]	Yes	45	100
	No	-	-
Speech language pathology services use in past 5 years[f]		37	82
		8	18
History of psychological services use in past 5 years[f]	Yes	5	11
	No	40	89
History of music therapy in past 5 years[f]	Yes	21	47
	No	24	53

Note. [a]Individuals eligible based on the criteria used to define the indicators. [b]Recommended by the 2018 Canadian guidelines (Sullivan et al., 2018). [c]Recommended by the CHAP (Lennox et al., 2001). [d]Recommended by Balogh and colleagues (2017). [e]Recommended by the 2011 Canadian guidelines (Sullivan et al., 2011). [f]Services provided within long-term care facility. GERD = gastroesophageal reflux disease.

Baseline healthcare utilization Table 6 presents data on healthcare use by our study participants. This includes healthcare services accessed within the long-term care facility H&TS (such as medication reviews), as well as in the community (such as optometry/ophthalmology assessments) that were recorded in individual medical charts. Seventy-five percent of men over the age of 40 and women over the age of 50 in our study population received a lipid screen at the time of transitioning, which is recommended for PwIDD of these ages (Allan et al., 2015; Sullivan et al., 2011). Only a small proportion of the study population had undergone colorectal cancer screening at the time of discharge, likely due to the young age of persons in this study, as well as to the limited available information on the oncologic medical history of participants' family members. Sullivan and colleagues (2011) recommend screening for colorectal cancer for all PwIDD over the age of 50.

Discussion

This study describes health status and access to healthcare for 45 PwIDD prior to their transition from a local residential centre into various community homes. Overall, we found that, for the

most part, the study population met the recommendations set by the 2018 Canadian guidelines for Primary Care of Adults with IDD (Sullivan et al., 2018). For example, we found that the majority of the study population had a confirmed diagnostic etiology of IDD (74%), and that immunization rates were generally high with 80-90% of study participants receiving immunizations for tetanus, diphtheria, pertussis, pneumococcus, measles, mumps, and rubella. Recommendations for dental reviews and thyroid function tests were met in the majority of cases, with 69% of the study participants who received the appropriate tests and examinations in both cases. Furthermore, all men had received examinations for undescended testes. Interestingly, no one in the study population had a diagnosis of diabetes and only a small proportion of the study participants were overweight or obese. The entire study population had their medications reviewed within the last 3 months before their discharge.

A large volume of data recorded in participants' medical charts were reviewed and extracted to report on the wide range of health status and healthcare access indicators summarized in this study. However, our review of the medical charts also revealed a number of gaps in the data. Three indicators of interest based on the 2018 Canadian guidelines (Sullivan et al., 2018) relate to family medical history, screening for dementia, and recommendations for clients with unknown etiologies of IDD. According to Sullivan and colleagues (2018), family medical history is considered to be important for informing cancer screening intervals; however, this information was very rarely reported in participants' medical charts. Screening for dementia in this population is critical because of a three-fold increased risk of developing dementia and an earlier onset among individuals with IDD compared to the general population (Shooshtari et al., 2017; Sullivan et al., 2018), Unfortunately, no information regarding dementia screening was identified in the medical charts we reviewed, despite the availability of a screening tool for PwIDD developed by Esralew and colleagues in 2013, the National Task Group Early Detection Screen for Dementia (NTG-EDS). Finally, Sullivan and colleagues (2018) acknowledge the importance of identifying disability etiologies in their guidelines. An established cause can inform preventative care, support, and decisions regarding treatment. In almost 25% of the medical charts we reviewed, the etiology of the disabilities experienced by study participants was unknown. Furthermore, we did not identify any recently documented genetic assessments or referrals for genetic testing (e.g., at a genetics centre) in the medical charts we reviewed. It is important to note that the diagnostic yield (i.e., percentage of patients who receive a conclusive molecular diagnosis for their condition in cases of IDD) has increased greatly in recent years, rising from 20% in the 1990s to over 60% in 2015 (Vissers, Gilissen, & Veltman, 2016). Therefore, it is recommended that individuals with unknown etiology of IDD continue to be assessed periodically as it is reasonable to expect that new developments in the field of genetics could reveal an etiology that would potentially benefit the overall provision of healthcare.

In addition, we identified very limited information on participants' typical level of physical activity recorded in their medical charts. Sullivan and colleagues (2018) have recommended promoting mobility and regular physical activity for PwIDD by addressing modifiable risk factors such as barriers to physical activity and referring individuals that are not meeting physical activity targets to interprofessional health promotion resources. Therefore, we recommend a standard practice of documenting participation in physical activities in the medical charts of all PwIDD supported at H&TS, including the frequency, duration, and intensity of the physical activities they usually engage in.

Limitations identified in our study include a lack of data on quality of dietary intake, such as quantity of fruits and vegetables, as well as a lack of data on types and severity of injuries due to challenging behaviours. Additionally, for confidentiality reasons due to our small population size, many health variables had to be grouped together for presentation purposes. This limited our ability to show the diverse types of intellectual and developmental disabilities as well as the concurrent conditions experienced in this sample. Small population size also prevented us from examining healthcare use by heath conditions, for example use of psychological services by challenging behaviours. The comprehensive health data that we are planning to collect in post-transition phase of the study will help us to overcome many of these data gaps.

Key Messages

People with disabilities: You are entitled to accessible healthcare provided by knowledgeable care providers who understand the health risks associated with IDD, regardless of whether you live in a home in the community or in a large facility.

Professionals: It is vital that you possess the knowledge and professional skills needed to provide accessible services that benefit the health of the PwIDD you care for.

Policymakers: Professionals need to be educated about the importance of routine and appropriate comprehensive health reviews for PwIDD.

Messages clés de cet article

Personne avec une incapacité : Vous méritez des soins de santé accessibles offerts par des professionnels compétents qui comprennent les risques pour la santé associés aux DI et aux TD, peu importe où vous vivez.

Professionnels : Il est important de posséder les connaissances et compétences professionnelles afin d'offrir des soins qui contribuent à la santé des personnes ayant une DI ou un TD dont vous êtes responsables.

Décideurs : Les professionnels doivent être informés de l'importance d'adopter des pratiques d'évaluation exhaustives de la santé des personnes ayant une DI ou un TD.

Acknowledgements

We wish to thank the members of the Community Transitions research team, and in particular, the members of the project working group including Sheila Chatyrbok, Joanne van Dyck, Peter Duff, Kerry Heather, and Janice Ranson for their invaluable feedback and input. We also acknowledge and thank all St.Amant management and staff who have played a critical role by facilitating data access. The study was funded by The Winnipeg Foundation (2015-2019) and a Mitacs Award (2016-2020).

References

Allan, G., Lindblad, A., Comeau, A., Coppola, J., Hudson, B., Mannarino, M., … Kolber, M. (2015). Simplified lipid guidelines: Prevention and management of cardiovascular disease in primary care. *Canadian Family Physician, 61*, 857-867.

Balogh, R., Wood, J., Dobranowski, K., Lin, E., Wilton, A., Jaglal, S. B., … Lunsky, Y. (2017). Low-trauma fractures and bone mineral density testing in adults with and without intellectual and developmental disabilities: A population study. *Osteoporosis International, 28*(2), 727-732. doi: 10.1007/s00198-016-3740-2

Beadle-Brown, J., Mansell, J., & Kozma, A. (2007). Deinstitutionalization in intellectual disabilities. *Current Opinion In Psychiatry, 20*(5), 437-442.

Brown, M., MacArthur, J., McKechanie, A., Hayes, M., & Fletcher, J. (2010). Equality and access to general health care for people with learning disabilities: Reality or rhetoric? *Journal of Research in Nursing, 15*(4), 351-361. doi: 10.1177/1744987110370019

Canadian Heritage. (2014). *Convention on the rights of persons with disabilities: First report of Canada.* (Catalogue No. CH37-4/19-2013E-PDF). Retrieved from the Government of Canada Publications website: http://publications.gc.ca/pub?id=9.696822&sl=0

Cooper, S. A., Melville, C., & Morrison, J. (2004). People with intellectual disabilities. *British Medical Journal, 329*(7463), 414-415.

Durkin, M. S., Maenner, M. J., Newschaffer, C. J., Lee, L., Cunniff, C. M., Daniels, J. L., …, Schieve, L. A. (2008). Advanced parental age and the risk of autism spectrum disorder. *American Journal of Epidemiology, 168*(11), 1268-1276.

Esralew, L., Janicki, M. P., DiSipio, M., Jokinen, N., Keller, S. M., & Members of the National Task Group Section on Early Detection and Screening. (2013). *National task group early detection screen for dementia: Manual*. Retrieved from http://www.aadmd.org/ntg/screening

Haire, A. R., Flavill, J., Groom, W. D., & Dhandapani, B. (2015). Unidentified undescended testes in teenage boys with severe learning disabilities. *Archives of Disease in Childhood, 100*(5), 479-480.

Hamelin, J. P., Frijters, J., Griffiths, D., Condillac, R., & Owen, F. (2011). Meta-analysis of deinstitutionalization adaptive behavior outcomes: Research and clinical implications. *Journal of Intellectual & Developmental Disability, 36*(1), 61-72. doi:10.3109/13668250.2010.544034

Kennedy, S., O'Higgins, S., Sarma, K., Willig, C., & McGuire, B. E. (2014). Evaluation of a group based cognitive behavioural therapy programme for menstrual pain management in young women with intellectual disabilities: Protocol for a mixed methods controlled clinical trial. *BMC Women's Health, 14*(1), 1-10.

Krahn, G., Fox, M. H., Campbell, V. A., Ramon, I., & Jesien, G. (2010). Developing a health surveillance system for people with intellectual disabilities in the United States. *Journal of Policy and Practice in Intellectual Disabilities, 7*(3), 155–166. doi: 10.1111/j.1741-1130.2010.00260.x

Krahn, L. G., Hammond, L., & Turner, A. (2006). A cascade of disparities: Health and health care access for people with intellectual disabilities. *Mental Retardation and Developmental Disabilities Research Reviews, 12*, 70-82.

Lemay, R. A. (2009). Deinstitutionalization of people with developmental disabilities: A review of the literature. *Canadian Journal of Community Mental Health, 28*(1), 181-194. doi: 10.7870/cjcmh-2009-0014

Lennox, N. G., Green, M., Diggens, J., & Ugoni, A. (2001). Audit and comprehensive health assessment programme in the primary healthcare of adults with intellectual disability: A pilot study. *Journal of Intellectual Disability Research, 45*, 226-232. doi: 10.1046/j.1365-2788.2001.00303.x

Lennox, N., Ware, R., Bain, C., Taylor Gomez, M., & Cooper, S. A. (2011). Effects of health screening for adults with intellectual disability: A pooled analysis. *British Journal of General Practice 61*, 193-196.

Lunsky, Y., Klein-Geltink, J. E., & Yates, E. A. (2013). *Atlas on the primary care of adults with developmental disabilities in Ontario.* Toronto, ON: Institute for Clinical Evaluative Sciences and Centre for Addiction and Mental Health.

Martínez-Leal, R., Salvador-Carulla, L., Linehan, C., Walsh, P., Weber, G., Van Hove, G., … Kerr, M. (2011). The impact of living arrangements and deinstitutionalisation in the health status of persons with intellectual disability in Europe. *Journal of Intellectual Disability Research, 55*, 858-872. doi: 10.1111/j.1365-2788.2011.01439.x

McCarron, M., Carroll, R., Kelly, C., & McCallion, P. (2015). Mortality rates in the general Irish population compared to those with an intellectual disability from 2003 to 2012. *Journal of Applied Research in Intellectual Disabilities, 28*(5), 406-413.

Meijer, M., Carpenter, S., & Scholte, F. A. (2004). European manifesto on basic standards of health care for people with intellectual disabilities. *Journal of Policy and Practice in Intellectual Disabilities, 1*, 10-15.

Mencap. (2007). *Death by indifference*. Retrieved from https://www.mencap.org.uk/death-by-indifference

Ouellette-Kuntz, H., Garcin, N., Lewis, M. E., Minnes, P., Martin, C., & Holden, J. J. (2005). Addressing health disparities through promoting equity for individuals with intellectual disabilities. *Canadian Journal of Public Health, 96*(Suppl 2), S8-S22.

Ouellette-Kuntz, H., Shooshtari, S., Balogh, R., & Martens, P. (2015). Understanding information about mortality among people with intellectual and developmental disabilities in Canada. *Journal of Applied Research in Intellectual Disabilities, 28*(5), 423-435.

Robertson, J., Roberts, H., Emerson, E., Turner, S., & Greig, R. (2011). The impact of health checks for people with intellectual disabilities: A systematic review of evidence. *Journal of Intellectual Disability Research, 55*(11), 1009-1019. doi:10.1111/j.1365-2788.2011.01436.x

Shooshtari, S., Brownell, M., Mills, R. S. L., Dik, N., Yu, D. C.T., Chateau, D., . . . Wetzel, M. (2016). Comparing health status, health trajectories and use of health and social services

between children with and without developmental disabilities: A population-based longitudinal study in Manitoba. *Journal of Applied Research in Intellectual Disabilities, 30*(4), 584-601.

Shooshtari, S., Naghipur, S., & Zhang, J. (2012). Unmet health care and social services needs of older adults living with a developmental disability in Canada. *Journal of Policy and Practice in Intellectual Disabilities, 9*(2), 81-91. doi: 10.1111/j.1741-1130.2012.00346.x

Shooshtari, S., Stoesz, B. M., Udell, L., Fenez, L., Dik, N., Burchill, C., … Menec, V. (2017). Aging with intellectual and developmental disabilities and dementia in Manitoba. *Advances in Mental Health and Intellectual Disabilities, 11*(4), 134-144. doi: 10.1108/AMHID-03-2017-0007

Sullivan, W., Berg, J., Bradley, E., Cheetham, T., Denton, R., Heng, J., … McMillan, S. (2011). Primary care of adults with developmental disabilities: Canadian consensus guidelines. *Canadian Family Physician, 57*, 541-553.

Sullivan, W., Diepstra, H., Heng, J., Ally, S., Bradley, E., Casson, I., … Witherbee, S. (2018). Primary care of adults with intellectual and developmental disabilities: Canadian consensus guidelines. *Canadian Family Physician, 64*(4), 254-279.

Tearne, J. (2015). Older maternal age and child behavioral and cognitive outcomes: A review of the literature. *Fertility and Sterility, 103*(6), 1381-1391.

Vissers, L., Gilissen, C., & Veltman, J. (2015). Genetic studies in intellectual disability and related disorders. *Nature Reviews Genetics, 17*(1), 9-18.

Wilson, J., Adeline, P., Bungaroo, D., Khadra, A., White, S., Bradley, E., Lodge, K-M., & The Baroness Hollins, S. (2018). Promoting testicular self-examination and awareness amongst young men with Intellectual Disabilities: A parallel intervention randomized study. *Journal on Developmental Disabilities, 23*(3), 57-70.