


Article

Examining the Changes in Problem Behaviours and Communication of Persons with Intellectual and Developmental Disabilities after Transitioning from an Institutional Setting to the Community

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Abstract: Worldwide, the community transition process away from institutions has increased in the past 30–50 years among persons with severe intellectual and developmental disabilities. This process, also known as “deinstitutionalization”, could potentially impact problem behaviors and communication. This study examined the impacts of community transitions on behavioural and communication outcomes in Canadians with intellectual and developmental disabilities. Data were collected using the Comprehensive Health Assessment Program and medical chart reviews. Descriptive, aggregate-level, and individual-level analyses were conducted for 32 adults who transitioned to community living. Descriptive analyses and the McNemar Chi-Square Test were conducted. Following community transitions, the study group experienced a significant decrease in problem behaviours and changes in communication. The study findings suggest that deinstitutionalization could provide effective strategies for addressing problem behaviors and fostering improvements in communication, promoting the well-being and quality of life of persons with intellectual and developmental disabilities.

Keywords: intellectual and developmental disabilities; community living; community transitions; challenging behaviours; deinstitutionalization; adult



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1. Introduction

There have been significant improvements in services for persons with intellectual and developmental disabilities over the last several decades [1,2]. Transitions to community living after long-term institutional admissions are commonly referred to as community transitions (i.e., deinstitutionalization) and have been part of a progressive movement in the standards of care and services for persons with intellectual and developmental disabilities. Human and legal rights advancements for persons with intellectual and developmental disabilities in support of community transitions promote opportunities for improved functioning and community participation [3–6].

The overarching goals of moving persons with intellectual and developmental disabilities from institutions into community homes are to promote their health and quality of life. Deinstitutionalization has resulted in beneficial changes to the daily lives of persons with disabilities that are often associated with improved quality of life [3,7–10]. There is evidence of improved community inclusion, decision-making, and adaptive skills [3–5,9,11,12]. However, some researchers have documented that transitioning to a community home does not always have positive outcomes [13,14]. For example, some individuals may experience decreased communication with family or no new social connections after their community transitions [13]. Others have reported difficulty with the transition process [14], limited

social inclusion [15,16], or experiencing inadequate healthcare [15,16]. Limited opportunities to communicate or engage with others may have a negative impact on the overall quality of life and well-being of individuals with IDD. Notably, the Canadian Consensus Guidelines for the Primary Care of Adults with IDD [17], developed to promote health outcomes and well-being among these individuals, include recommendations to promote friendships and social networks.

As deinstitutionalization continues throughout Canada and beyond, persons with intellectual and developmental disabilities are experiencing a higher standard of living in their communities [2,3], such as greater social inclusion, social engagement, and participation, but it is also important to better understand other outcomes of these community transitions, for example in relation to individuals' behaviours and modes of communication.

To our knowledge, no previous longitudinal research in Canada has examined changes in problem behaviours and modes of communication in persons with intellectual and developmental disabilities following their move from an institutional setting to a community home.

Problem behaviours can be defined as disruptive behaviours that do not largely impact the functioning of an individual [18]. Problem behaviours are common and frequent in persons with intellectual and developmental disabilities [19–21]. For example, 62% of adults with intellectual disabilities were found to engage in problem behaviours [19]. Moving from an institution to a community home may be a difficult transition for some individuals with intellectual and developmental disabilities and the changes in settings, routines, and staff may result in worsening of behavioural outcomes [11,15]. In a review of 34 years of community transitions research (1977–2011) that examined behavioural outcomes, most studies reported improvements in adaptive behaviours, and mixed results with regards to challenging behaviours in the study groups [11].

Another important aspect that might be affected by changes in living arrangements of persons with intellectual and developmental disabilities is their way of communication. Persons with intellectual disabilities experience difficulties with communication more frequently [22], and their ability to communicate, either expressively or receptively, varies. Expressive communication involves communicating through speech, while receptive communication involves language demonstrating understanding of information being received [23,24]. Receptive communication skills are often more advanced than expressive communication skills among persons with intellectual disabilities [25]. Communication devices are often used to assist with communication among persons with intellectual and developmental disabilities.

The purpose of this study was to examine the impact of community transitions on behavioural and communication outcomes of persons with intellectual and developmental disabilities who moved from an institutional setting into shift-staffed homes in the community, using data collected in a longitudinal study. This study was one component of a larger multi-phase longitudinal mixed-methods research project aimed at evaluating the process and outcomes of community transitions implemented by one organization, St. Amant, in the Canadian province of Manitoba. Our research sought to determine what changes in problem behaviours and communication methods occur, following community transitions from Health and Transition Services of St. Amant, among persons with severe intellectual and developmental disabilities in Manitoba, Canada.

2. Materials and Methods

2.1. Study Design

As part of the larger longitudinal study, we analyzed individual-level pre- and post-transition data to examine changes in problem behaviours and communication methods following community transitions for our study cohort.

2.2. Setting

This study was conducted in the Canadian province of Manitoba, which has a population of 1,390,000 [26]. Approximately 9000 adults with intellectual and developmental

disabilities live in Manitoba [27]. The majority of these individuals are supported by service agencies for community living [28]. St.Amant, one of the largest not-for-profit organizations supporting persons with intellectual and developmental disabilities in Manitoba, is located in the city of Winnipeg, and offers a wide range of community-based and specialized services to this population and their families [29]. As part of the organization's 2013–2018 strategic plan, more community living options were offered to people who lived at their long-term complex care facility. Persons with intellectual and developmental disabilities moved out of St.Amant's complex care facility and now reside in a variety of community homes including shift-staff group homes, foster homes, and family homes throughout Manitoba. The shift-staff group homes where former St.Amant residents are currently living are managed by St.Amant and nine other agencies.

2.3. Study Cohort

Between July 2014 and December 2019, a total of 55 adults with severe intellectual and developmental disabilities transitioned from St.Amant's Health and Transition Services into community-based residences. St.Amant's Health and Transition Services is a complex care facility of St.Amant. Formerly River Road Place, which was for long-term admission, it was changed to Health and Transitions Services and no longer admits persons with intellectual and developmental disabilities for long-term residential support. Of the 55 people who experienced community transitions, consent for research participation in this study was obtained from the appropriate Substitute Decision Makers for 36 individuals. The results presented in this paper are based on data from the 32 persons with severe intellectual and developmental disabilities for whom we had complete pre- and post-transition health data. All 32 individuals whose data were used in the analysis presented in this paper were living in shift-staff group homes at the time of data collection. The cause of intellectual and developmental disabilities was known for 22 (68.8%) of these individuals, and among those with known causes, the most common cause was reported as being cerebral palsy ($n = 9$). The sociodemographic characteristics of the study cohort are summarized in Table 1.

Figure 1 represents the distribution of the year of discharge from St.Amant.

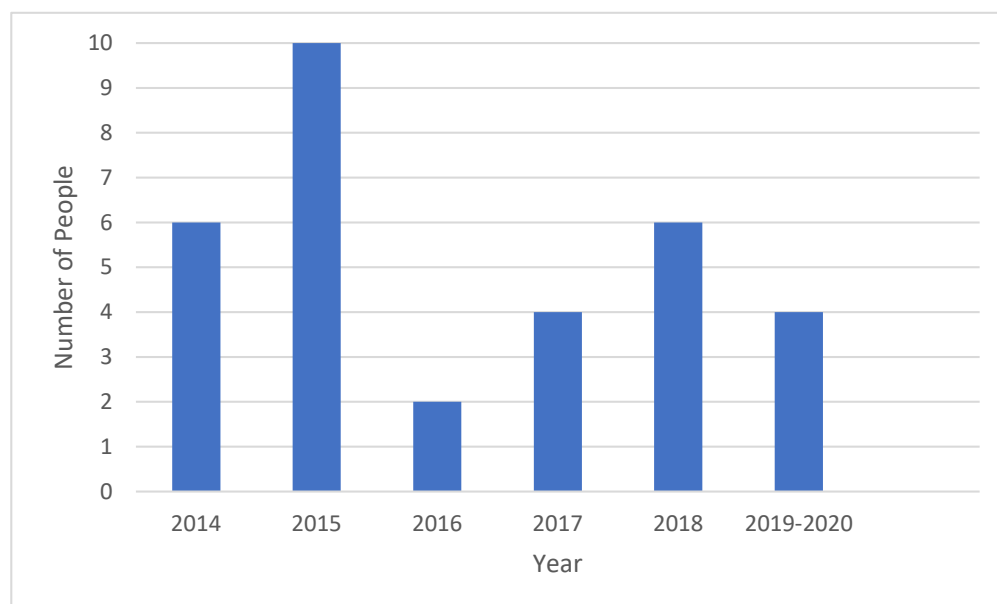


Figure 1. Distribution of year of discharge, i.e., the year participants moved.

Table 1. Characteristics of the Study Cohort.

		<i>n</i>	%
Age at time of discharge (Years)	<50	25	78.1
	≥50	7	21.9
Sex	Female	15	46.90
	Male	17	53.10
Length of stay at H & T (Years)	<10	4	12.5
	10–19	4	12.5
	20–29	4	12.5
	30–39	12	37.5
	≥40	8	25

Note: H & T = St. Amant Health and Transition Services.

2.4. Materials

The Comprehensive Health Assessment Program (CHAP) and medical charts were used to collect data on the health of study participants both pre- and post-transition. The CHAP is an effective health assessment tool for promoting access to primary care for persons with intellectual disabilities, which was developed and validated by Dr. Nick Lennox and colleagues from the Queensland Centre for Intellectual and Developmental Disability in Australia [30,31]. The CHAP consists of two parts: (A) a questionnaire on the history of the person with intellectual and developmental disabilities to be completed by the person with intellectual and developmental disabilities, their family, and/or their caregiver who knows them well (i.e., proxy), and (B) a questionnaire on the history of the person with intellectual and developmental disabilities completed by the primary care provider (e.g., general practitioner) of the person with intellectual and developmental disabilities [30,32]. The 2016 version of the CHAP was used in this longitudinal study. A Supplementary Form was created and completed by a nurse practitioner to collect additional health-related data for our study participants, including dietary patterns, communication methods, day programming, and the study participant's personal preferences and dislikes. This paper is part of a broader longitudinal study, and therefore, selected variables were chosen from the CHAP and the Supplementary Form to focus on problem behaviours and communication. See Appendix A for the list of specific measures used in this study and their source (Part A or Part B of the CHAP, or the Supplementary Form).

2.5. Data Collection Procedures

Individual-level health data were collected prior to transition (pre-transition) and after transition to community homes (post-transition) for each member of our study cohort. Pre-transition health data were collected by reviewing individuals' medical charts as well as completing Part A of the CHAP. Post-transition health data were collected by completing the CHAP and the Supplementary Form. Health assessments were completed by proxy for all 32 study participants in our study cohort, as none of them had sufficient cognitive and/or communication skills to answer the questions on the CHAP or the Supplementary Form by themselves.

A graduate research assistant facilitated completion of post-transition health assessments. The research assistant contacted staff of community agencies (e.g., team leaders) supporting persons with disabilities in their new homes in the community by phone to complete a CHAP for each participant. Hard copies of CHAPs were mailed to the participants' homes with a postage-paid return envelope for staff to complete at their earliest convenience. Staff members either completed Part A independently, forwarded the CHAP to a more knowledgeable caregiver, or scheduled a phone appointment to complete the CHAP with support from the research assistant. Part B of the CHAPs was completed by the study participants' primary care providers. After completing Part A of the CHAP, the community agency staff scheduled appointments with the regular primary care providers of our study

participants to have them complete Part B of the CHAP. Approximately weekly follow-up phone calls and/or emails were made to help facilitate this process. Upon completion of Part B of the CHAP by the primary care providers, the community agency staff returned a copy of the completed assessment form to the research assistant via a postage-paid return envelope. For each study participant, pre-and post-transition comprehensive health data were entered into a SPSS database and analyzed to examine patterns of change, or stability from pre- to post-transition. Pre-transition data were collected in 2018. Post-transition data were collected between 2019 and 2021, which was at least six months after the transition date. The time lag between pre- and post-transition data collection for the 32 individuals in our study cohort ranged from 6 to 48 months.

2.6. Data Analysis

Descriptive analyses were conducted to describe the characteristics of the study cohort. Within-subject repeated measures were used to examine changes in problem behaviours and communication methods from pre- to post-transition. To test if the observed differences in pre- to post-transition outcomes were statistically significant for aggregate variables, the McNemar Chi-Square test was used. For variables where there was at least 5% missing data, we defined “missing” as one category and included them on those variables in the analysis. If there was less than 5% missing data on a variable, we excluded individuals with missing data on those variables from the analysis.

Data were analyzed both at the aggregate and individual levels. With aggregate-level analyses, data were analyzed as a group to compare changes from pre- to post-transition. For individual-level analyses, we created new variables to indicate change or stability in the study outcomes from pre- to post-transition for each study participant. The purpose of analyzing at the aggregate level was to assess changes at the group level, whereas individual-level analyses allowed us to assess the specific changes each study participant experienced following community transition, such as whether they started showing problem behaviours or their problem behaviours ceased. We were then able to describe patterns of stability or change (positive or negative). These patterns were further categorized by study participants’ age, sex, and length of stay in the institution.

Two qualitative questions were coded into main categories by two research assistants. The questions were ‘Describe the problem behaviours’ and ‘Comments regarding communication’. Furthermore, we examined the association between communication methods and problem behaviours. Data were analyzed using Statistical Package for the Social Sciences (IBM SPSS) version 28.

3. Results

3.1. Problem Behaviours

3.1.1. Aggregate-Level Analyses

Of the 32 persons with severe intellectual and developmental disabilities in our study cohort, 26 (81%) engaged in problem behaviours while living at St. Amant Health and Transition Services (pre-transition). Post-transition, caregivers reported that 18 participants (58%) engaged in problem behaviours. Problem behaviours among our study cohort decreased when living in the community compared to living in an institutional setting, and this change was statistically significant ($p = 0.016$). Table 2 summarizes the type of problem behaviour and related interventions at both times, pre- and post-transition, respectively. The most common types of problem behaviour reportedly exhibited by participants pre-transition were self-harm ($n = 19$, 59.4%), noise-making ($n = 17$, 53.1%), and aggression towards others ($n = 16$, 50%). Post-transition, self-harm ($n = 9$, 29%), aggression towards others ($n = 7$, 22.6%), and noise-making ($n = 4$, 12.9%), remained the most common types of reported problem behaviours but were less prevalent.

Table 2. Pre- and post-transition problem behaviours and related interventions.

Problem Behaviour	Pre-Transition						Post-Transition					
	Yes		No		Missing/ Unknown		Yes		No		Missing/ Unknown	
	<i>n</i>	%	<i>n</i>	%	<i>n</i>	%	<i>n</i>	%	<i>n</i>	%	<i>n</i>	%
Does the person engage in problem behaviours	26	81.3	6	18.8	0	0	18	58.1	13	41.9	1	3.1
Is noise-making a problem behaviour	17	53.1	15	46.9	0	0	4	12.9	27	87.1	1	3.1
Is self-harm a problem behaviour	19	59.4	13	40.6	0	0	9	29	22	71	1	3.1
Is harm to others a problem behaviour	16	50	16	50	0	0	7	22.6	24	77.4	1	3.1
Is non-compliance a problem behaviour	1	3.1	31	96.9	0	0	2	6.3	28	87.5	2	6.3
Is wandering/running away a problem behaviour	6	18.8	26	81.3	0	0	1	3.2	30	96.8	1	3.1
Is diaper shredding/fecal smearing/throwing/ingestion a problem behaviour	6	18.8	26	81.3	0	0	0	0	31	100	1	3.1
Is property destruction a problem behaviour	8	25	24	75	0	0	1	3.2	30	96.8	1	3.1
Has the person received help for problem behaviours	25	78.1	7	22	0	0	9	29	22	71	1	3.1
Does the person wear a special vest	3	9.4	29	90.6	0	0	1	3.2	30	96.8	1	3.1
Is redirection used	21	65.6	11	34.4	0	0	4	12.9	27	87.1	1	3.1
Is waiting behaviours out used	7	21.9	25	78.1	0	0	3	9.7	28	90.3	1	3.1
Is a crisis beeper used	1	3.1	31	96.9	0	0	0	0	31	100	1	3.1
Is a padded room used	0	0	32	100	0	0	0	0	31	100	1	3.1
Are physical restraints used	8	25.8	23	74.2	1	3.1	2	6.5	29	93.5	1	3.1
Is avoid eye contact used	2	6.3	30	93.8	0	0	0	0	31	100	1	3.1
Is pharmacological intervention used	10	31.3	22	68.8	0	0	4	12.9	27	87.1	1	3.1

Note: Variables following “Does the person engage in problem behaviours” were from the variable “Describe the problem behaviours” and coded into groups.

3.1.2. Individual-Level Analyses

Of the participants, 24 experienced no changes in their status with regards to problem behaviours from pre- to post-transition, while 18 (58.1%) participants reportedly continued to engage in problem behaviours, and 6 (19.4%) participants reportedly remained without problem behaviours from pre- to post-transition. Seven participants (22.6%) with a history of engaging in problem behaviours stopped exhibiting problem behaviours after moving to the community. No study participants reportedly initiated problem behaviours after moving to the community.

Some CHAP respondents ($n = 19$) provided detailed comments to describe the reported problem behaviours. During post-transition, five main categories of reported problem behaviours were identified: (1) self-injurious behaviours ($n = 8$), (2) harm to others ($n = 5$), (3) non-compliance ($n = 4$), (4) mental disorder indicator ($n = 4$), and (5) personal qualities or behaviours that were reported to be problem behaviours ($n = 7$), such as, for example, being described as stubborn or a picky eater.

3.2. Communication Methods

3.2.1. Aggregate-Level Analyses

Table 3 summarizes the patterns of stability and change in communication methods from pre- to post-transition used by our study cohort. A reduction in the use of a communication device and the use of communication with symbols was reported after moving into community homes, and these changes were statistically significant. Reported expressive and receptive communication was not significantly different between an institution and community home after moving. Some methods of communication slightly decreased

after transitioning to community living, namely using sounds for expressive communication, using simple questions for expressive communication, and communicating with a communication board. Responding to voice for receptive communication did not change following community transitions. There was a slight increase (<3 persons) in the following communication methods: (1) using expressive communication, (2) using eye contact for receptive communication, (3) following instructions for receptive communication, and (4) communicating with sign language. There was an increase by eight persons in using imitation for expressive communication after community transition.

Table 3. Pre- and post-transition communication methods used by the study cohort.

		Pre-Transition						Post-Transition					
		Yes		No		Missing/ Unknown		Yes		No		Missing/ Unknown	
		<i>n</i>	%	<i>n</i>	%	<i>n</i>	%	<i>n</i>	%	<i>n</i>	%	<i>n</i>	%
Expressive Communication	Does the person use expressive communication?	28	87.5	1	3.1	3	9.4	30	96.8	1	3.2	1	3.1
	Does the person use sounds for expressive communication?	27	84.4	2	6.3	3	9.4	25	80.6	6	19.4	1	3.1
	Does the person use simple questions for expressive communication?	4	12.5	26	81.3	2	6.3	3	9.4	27	84.4	2	6.3
	Does the person use imitation for expressive communication?	0	0	10	31.3	22	68.8	8	25.8	23	74.2	1	3.1
Receptive Communication	Does the person use receptive communication?	29	90.6	1	3.1	2	6.3	30	96.8	1	3.2	1	3.1
	Does the person use eye contact for receptive communication?	22	68.8	8	25	2	6.3	23	74.2	8	25.8	1	3.1
	Does the person respond to voice for receptive communication?	29	90.6	1	3.1	2	6.3	29	93.5	2	6.5	1	3.1
	Does the person follow instructions for receptive communication?	23	71.9	5	15.6	4	12.5	24	77.4	7	22.6	1	3.1
Communication Device	Does the person use a communication device? *	15	46.9	15	46.9	2	6.3	6	19.4	25	80.6	1	3.1
	Does the person communicate with sign language?	4	12.5	26	81.3	2	6.3	5	16.1	26	83.9	1	3.1
	Does the person communicate with symbols? *	7	21.9	23	71.9	2	6.3	1	3.2	30	93.8	1	3.1
	Does the person communicate with a communication board?	1	3.1	9	28.1	22	68.8	0	0	31	100	1	3.1

Note: Alpha = 0.05. * denotes statistical significance.

3.2.2. Individual-Level Analyses

As summarized in Table 4, communication methods used by our study participants both stayed the same and changed following moving into community homes. There was a reported increase in using only expressive and receptive communication and a reported decrease in using expressive, receptive, and communication devices in community homes compared to an institution. In addition, there were some communication types that had no changes.

Table 4. Pre- and post-transition communication types.

Communication Types	Pre-Transition		Post-Transition	
	<i>n</i>	%	<i>n</i>	%
Only expressive	1	3.1	1	3.2
Only receptive	0	0	0	0
Only communication device	0	0	0	0
Expressive and receptive	14	43.8	24	77.4
Expressive and communication device	0	0	0	0
Receptive and communication device	1	3.1	1	3.2
Expressive, receptive, and communication device	13	40.6	5	16.1
Missing/Unknown	3	9.4	1	3.1

Note: Missing/unknown data <5% were excluded from the analyses.

Various comments were received from the nurse practitioners regarding communication. In pre-transition, there were missing data for all participants; however, two (6.3%) had the comment “button switch”. During post-transition, we categorized comments into four main categories for 12 people: (1) had gestures ($n = 2$), (2) had music/singing involved ($n = 2$), (3) were verbal ($n = 4$), and (4) were non-verbal ($n = 2+$).

3.3. Sub-Analyses

All ages experienced a decrease in reported problem behaviours at a similar percentage. Males reportedly experienced more problem behaviours than females at both pre- and post-transition. Those who stayed in an institution for less than 30 years had fewer reported problem behaviours than those who stayed for over 30 years. Those below 45 years of age reportedly experienced a decrease in communication, whereas those above 45 years of age reportedly experienced an increase in expressive communication after moving to the community. Females reportedly experienced no change in expressive communications, whereas males reportedly experienced a slight increase in expressive communication. Those who resided in the institution for less than 30 years had a reported decrease in expressive communication after moving to the community, whereas an increase was reported for those above 30 years. All ages reportedly experienced an increase in receptive communication. Sex differences were observed. Females had a reported increase in receptive communication, whereas males had a reported decrease in receptive communication from community transitions. No changes were observed in receptive communication by length of stay at Health and Transition Services. All ages, sexes, and lengths of stay were associated with a decrease in using a communication device. Details are presented in Table 5.

Table 5. Problem behaviour and communication sub-analyses by age, sex, and length of stay at Health and Transition Services.

		Pre-Transition						Post-Transition					
		Yes		No		Missing/ Unknown		Yes		No		Missing/ Unknown	
		<i>n</i>	%	<i>n</i>	%	<i>n</i>	%	<i>n</i>	%	<i>n</i>	%	<i>n</i>	%
Does the person have problem behaviours													
Age at time of discharge (Years)	<45	15	83.3	3	16.7	0	0	10	58.8	7	41.2	1	5.6
	≥45	11	78.6	3	21.4	0	0	8	57.1	6	42.9	0	0

Table 5. Cont.

		Pre-Transition						Post-Transition					
		Yes		No		Missing/ Unknown		Yes		No		Missing/ Unknown	
		<i>n</i>	%	<i>n</i>	%	<i>n</i>	%	<i>n</i>	%	<i>n</i>	%	<i>n</i>	%
Sex	Female	10	66.7	5	33.3	0	0	5	35.7	9	64.3	1	6.7
	Male	16	94.1	1	5.9	0	0	13	76.5	4	23.5	0	0
Length of stay at H & T (years)	<30	11	91.7	1	8.3	0	0	7	58.3	5	41.7	0	0
	≥30	15	75	5	25	0	0	11	57.9	8	42.1	1	5
Does the person use expressive communication													
Age at time of discharge (Years)	<45	18	100	0	0	0	0	16	94.1	1	5.9	1	5.6
	≥ 45	10	71.4	1	7.1	3	21.4	14	100	0	0	0	0
Sex	Female	13	92.9	1	7.1	1	6.7	13	92.9	1	7.1	1	6.7
	Male	15	88.2	0	0	2	11.8	17	100	0	0	0	0
Length of stay at H & T (Years)	<30	12	100	0	0	0	0	11	91.7	1	8.3	0	0
	≥30	16	80	1	5	3	15	19	100	0	0	1	5
Does the person use receptive communication													
Age at time of discharge (Years)	<45	17	94.4	1	5.6	0	0	17	100	0	0	1	5.6
	≥45	12	85.7	0	0	2	14.3	13	92.9	1	7.1	0	0
Sex	Female	13	92.9	1	7.1	1	6.7	14	100	0	0	1	6.7
	Male	16	100	0	0	1	5.9	16	94.1	1	5.9	0	0
Length of stay at H & T (Years)	<30	11	91.7	1	8.3	0	0	11	91.7	1	8.3	0	0
	≥30	18	90	0	0	2	10	19	100	0	0	1	5
Does the person use a communication device													
Age (Years)	<45	9	50	9	50	0	0	3	17.6	14	82.4	1	5.6
	≥45	6	42.9	6	42.9	2	14.3	3	21.4	11	78.6	0	0
Sex	Female	6	42.9	8	57.1	1	6.7	3	21.4	11	78.6	1	6.7
	Male	9	56.3	7	43.8	1	5.9	3	17.6	14	82.4	0	0
Length of stay at H & T (Years)	<30	6	50	6	50	0	0	4	33.3	8	66.7	0	0
	≥30	9	45	9	45	2	10	2	10.5	17	89.5	1	5

Note: H & T = St.Amant Health and Transition Services.

4. Discussion

The purpose of this study was to examine patterns of change or stability in reported problem behaviours and communication methods for a cohort of persons with severe intellectual and developmental disabilities who transitioned from an institutional setting to community homes. We observed a statistically significant decrease in the proportion of persons who reportedly engaged in problem behaviours while living in the community as compared to while living in an institutional setting (pre-transition). Males experienced more problem behaviours than females. There was a significant decrease in the reported use of a communication device after transitioning into community living. There were minimal changes in reported expressive and receptive communication methods after community transitions. Overall, the observed changes were in desirable directions and, thus, our results contribute to the body of evidence in favour of community living for persons with severe intellectual and developmental disabilities. However, some findings warrant further investigation, particularly regarding the decrease in using a communication device and symbols after moving into the community.

Despite some previously published evidence that outcomes of persons with disabilities declined after deinstitutionalization (e.g., [7]), we observed improvements in reported problem behaviours and communication in our study participants after they moved to the community. Implications for reduced problem behaviours (i.e., less time engaging in problem behaviours) could mean that more time is spent engaging in preferred activities, participating in the community, and decreasing injury to self and others, which in itself may have staff and organizational implications with regard to sick time and staff turnover. In addition, all reported problem-behavioural interventions decreased in frequency after moving into community living. For example, a decrease in pharmacological interventions to address behaviour perceived as problematic was observed, which may also impact an individual's overall long-term health. Some participants had been living in the community already for a number of years; therefore, the reported decreased use of pharmacological interventions to address reported problem behaviours was maintained over time. The lower staff-to-client ratios in the community living setting compared to an institution may have impacted our findings. This is an important consideration, as it relates to how well a care provider knows the person they are serving. In addition, while a lower number of persons reportedly received help for problem behaviours after moving into the community, it is possible that the reported problem behaviours were either too infrequent or not perceived as significant enough by the care provider to warrant intervention support. It is also possible that individuals living in the community may not have had readily available access to intervention services.

A notable strength of this project is its contribution to deinstitutionalization research by examining a group of persons with severe intellectual and developmental disabilities, which is a subset of the population not commonly included in research. Furthermore, this research study addresses the existing knowledge gap for deinstitutionalization research in Canada. Our study helps to clarify some of the mixed evidence regarding deinstitutionalization and contributes current data on community transitions to this body of knowledge. Finally, another strength of our study is its longitudinal design, involving the collection of multiple datapoints from the same group of individuals. The present study is the first comprehensive examination of problem behaviours and communication outcomes in Manitoba, Canada and longitudinal evaluation. Replicating our study is recommended to further understand mixed findings regarding deinstitutionalization in other geographic locations. Additionally, examining outcomes for a larger cohort is also recommended, whenever possible.

Some limitations were unavoidable in this study. In spite of all our efforts, data on some of the study variables was missing for a large number of study participants, which limited our ability to report on those aspects related to problem behaviours or methods of communication. It is possible that alternative interpretations may have resulted if complete data on those study variables were available for all, or the majority, of our study participants. Different data sources were used to collect pre-transition data, which was another limitation of our study. More specifically, some participants had already transitioned into the community when we started pre-transition data collection, and therefore we were not able to assess their health based on data from a completed CHAP. For these individuals, medical charts were reviewed to extract the data which were needed if they had gone through a comprehensive health assessment using the CHAP. In addition, for those whose pre- and post-transition health data were collected using the CHAP, different staff completed the pre- and post-transition CHAP, and there could be potential bias and subjectivity by the caregivers about what constitutes a problematic behaviour. Variations in the length of stay within the institutional setting and the time lag between data collection periods before and after the transition could have impacted the results of the study as well. Finally, there was a lack of data reported on frequency and duration of communication.

The movement towards deinstitutionalization without adequate community support may induce great anxiety among individuals with intellectual and developmental disabilities and their families. Ensuring the existence of adequate and high-quality support in the community is necessary to maximize the positive outcomes for individuals transitioning

from an institutional setting to community living. As adaptive behaviours were not examined in this study, future research may examine both problem and adaptive behaviours in order to have a better understanding of the whole person and impact of community living. As deinstitutionalization may also occur in other environments, such as in hospitals and prisons, it may be beneficial to examine the behavioural and communication changes of individuals transitioning from these settings as well. It is possible that problem behaviours and communication may have interplayed throughout the process of deinstitutionalization. Future research should look at the interplay or association of problem behaviours and communication broadly amongst additional social determinants of health variables. Furthermore, future research is recommended in other provinces and territories in Canada to explore whether these same benefits are observed in different regions.

5. Conclusions

Our study extends previous research in support of community living for persons with intellectual and developmental disabilities. Reported problem behaviours significantly decreased after transition into the community. Various communication methods changed between living environments. Knowing how to identify disparities in those that do not communicate verbally is important when supporting persons with intellectual and developmental disabilities, to ensure the best possible health and well-being outcomes when caring for them. Our findings suggest the need for improved person-centred service and relationships between individuals with intellectual and developmental disabilities and their care providers while living in the community. Our findings demonstrate the benefits of community transitions for Manitobans with intellectual and developmental disabilities, suggesting that other Canadian provinces may consider facilitating the process of deinstitutionalization to help other people with intellectual and developmental disabilities obtain similar benefits.

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Appendix A

Table A1. Study Measures.

Measure	Section	Label
Age	Medical Charts/CHAP	Age at Health and Transition Services discharge
Year of Discharge	Medical Charts/CHAP	Date of discharge from St.Amant
Years in Institution	Medical Charts/CHAP	Total number of years supported residentially at St.Amant
Sex	Medical Charts/CHAP	What is the client’s sex?

Table A1. Cont.

Measure	Section	Label
Etiology	CHAP Part B	Is the cause of intellectual disability known?
Etiology	CHAP Part B	If ODKC_A0 = 2 then; What is the cause of intellectual and developmental disabilities?
Problem Behaviour	CHAP Part A	Does the person have problem behaviours?
Problem Behaviour	CHAP Part A	Describe the problem behaviours
Communication	Supplementary Form	Does the person use expressive communication?
Communication	Supplementary Form	Does the person use sounds for expressive communication?
Communication	Supplementary Form	Does the person use simple questions for expressive communication?
Communication	Supplementary Form	Does the person use imitation for expressive communication?
Communication	Supplementary Form	Does the person use receptive communication?
Communication	Supplementary Form	Does the person use eye contact for receptive communication?
Communication	Supplementary Form	Does the person respond to voice for receptive communication?
Communication	Supplementary Form	Does the person follow instructions for receptive communication?
Communication	Supplementary Form	Does the person use a communication device?
Communication	Supplementary Form	Does the person communicate with sign language?
Communication	Supplementary Form	Does the person communicate with symbols?
Communication	Supplementary Form	Does the person communicate with a communication board?
Communication	Supplementary Form	Comments regarding communication

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