

Changes Before the Transition to the Community: Experiences of Persons in Ontario's Closing Institutions

Abstract

There exists a wide body of research showing that deinstitutionalization results in significant improvements in quality of life and functioning, and this has helped to sustain government policies related to deinstitutionalization. However, far less work has considered the changes that occur in the status of individuals in the time preceding their transition to the community. This study examines the changes in functional abilities, physical health, mood, behaviour, and family involvement among persons who remain in one of Ontario's three remaining specialized institutions after the first year of deinstitutionalization. Analyses are based on information from the interRAI Intellectual Disability (interRAI ID) instrument, which has been used to assess all residents on an annual basis since 2005. Specifically, analyses are based on 826 individuals who have both a baseline (2005) and follow-up (2006) assessment. The results indicate that significant changes in functional abilities, health, and behaviour occurred over the course of one year, and that many of these differed according to the person's age and level of cognitive impairment. Implications of findings for individual-level transition planning are discussed, as is the role of the interRAI ID in the evaluation of transitions to the community.

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In Ontario, responsibility for services to persons with intellectual disabilities (ID) shifted from the Ministry of Health and Long-term Care (MOHLTC) to the Ministry of Community and Social Services (MCSS) in the early 1970s (Lunsky, et al., 2003). As part of its on-going efforts to improve the quality of life and the level of independence of persons with ID in Ontario, the MCSS announced its intention to close the three remaining large scale specialized institutions in the province: Huronia Regional Centre (Orillia), Rideau Regional Centre (Smiths Falls), and Southwest Regional Centre (Blenheim).

These institutions will be phased out in a multi-year process that began in 2005 and will end on March 31, 2009 (Ministry of Community and Social Services, 2004).

Though some have expressed fear that disruption to routine and to relationships as a result of deinstitutionalization may cause both physical and mental stress to individuals (Stancliffe and Hayden, 1998), there exists a wide body of research showing it results in significant improvements in quality of life and functioning (see review by Kim, Larson, and Lakin, 2001). Such findings have in fact sustained government policies and commitment to deinstitutionalization (Mansell, 2006).

As most work tends to focus on evaluation of the outcomes of deinstitutionalization (i.e., the person's status after the move to the community), far less information is available on the changes that occur in the status of individuals in the time preceding their transition to the community. For example, little attention has been paid to the individual changes that occur in areas such as functional abilities, physical health, mood, behaviour, and social relationships throughout the process of deinstitutionalization, though this information would be extremely useful in planning for the transition to the community. In fact, an important first step to ensuring a successful transition is a better understanding of both current needs in all life domains and changes in those needs over time so that appropriate supports may be in place in the community prior to the person's move.

This study examines the changes in functional abilities, physical health, mood, behaviour, and family involvement that have occurred over the course of one year among persons remaining in Ontario institutions after the first year of deinstitutionalization.

Methodology

Participants

In February 2005, the Developmental Services Branch (DSB) of the MCSS contracted the *ideas for Health* research team at the University of Waterloo to assess all residents in each of the three Regional Centres (i.e., Huronia, Rideau, and Southwest) get a population-level view of needs as they plan for transitions to the community. Approximately 1014 individuals were assessed in the summer of 2005 (baseline), and 826 persons remained in the institutions at the time of annual reassessment in 2006. Consequently, analyses are based on those 826 persons with both a baseline and a follow-up assessment.

Process

In 2005, the DSB-MCSS introduced the interRAI ID to staff in the Regional Centres, and requested that it be used as part of regular assessment practices for the duration of closure. The project received full ethics clearance from the Office of Research Ethics at the University of Waterloo.

In the spring of 2005, designated staff assessors from each facility received two full days of training from the research team's Educator on the completion of the interRAI ID assessment instrument (described below). The first day focussed on the individual items in the interRAI ID—the intent and definition for each item was explained, as was the process to obtain and code the information. For example, the importance of using all sources of information available was stressed, including: the assessor's own knowledge or observations of the person, consultation with the individual, consultation with other professionals involved in supporting the individual, family members and friends, as well as other available documentation

or records. On the second day of training, staff completed a practice assessment on a resident with whom they were very familiar. Once finished, staff were asked to comment on their experience, and all questions, issues, or concerns that arose were addressed. The Educator also reviewed each assessor's first assessment and provided both individual and general feedback (e.g., common coding issues). Approximately two weeks after the training, the research team again met with staff, this time to provide more in-depth information about the embedded scales within the interRAI ID, and the instrument's relevance to individual-level planning.

In the spring of 2006, the research team returned to provide a brief 'refresher' training session (5-6 hours), and staff were given the opportunity to request additional review in the areas they felt they needed more information. At the end of the session, details related to the planning applications of the interRAI ID assessment were again presented.

Measures

The interRAI Intellectual Disability (interRAI ID) is a standardized, comprehensive instrument that evaluates the strengths, preferences, and needs of adults with ID, regardless of level of cognitive impairment and residential setting. The interRAI ID was designed to be compatible with other instruments developed by the interRAI organization (www.interrai.org) that have been mandated by the MOHLTC for home care (RAI-Home Care), long-term care (RAI 2.0), and inpatient psychiatry (RAI-Mental Health). Martin, Hirdes, Fries, and Smith (2007) have provided evidence of the psychometric properties of the interRAI ID instrument; embedded measures related to functioning, physical health, and psychopathology are briefly described here.

Scales Measuring Functioning

The *Cognitive Performance Scale* (CPS) describes the individual's current cognitive status using a predictive algorithm based on memory, decision-making, expression, and self-performance in eating. Scores range from intact (0) to very severely impaired (6) (Hartmaier, Sloane, Guess, and Koch, 1995; Morris, Fries, Mehr, Hawes, Phillips, Mor, et al, 1994). While the CPS does not replace the documented level of ID severity based on the person's IQ score (i.e., mild, moderate, severe, profound), it is significantly correlated to the former, and could be used as a proxy measure for severity of cognitive impairment if no IQ score is available ($r=0.55$, $p<.0001$ in the current study population and $r=0.79$, $p<.0001$ in a sample of community-dwelling adults – see Martin et al., 2007). The *Activities of Daily Living (ADL) Hierarchy* measures self-performance of ADLs, classifying them according to the stages at which they can no longer be performed to reflect the disablement process. Items indicative of early loss (i.e., personal hygiene) are given lesser scores than those associated with later loss (middle loss=toilet use and mobility; late loss=eating). These items are combined in an algorithm that yields a scale ranging from independent (0) to full dependence (6). The *Instrumental Activities of Daily Living (IADL) Performance Scale* and *Capacity Scale* inform on the person's ability to perform IADLs (performance) and the staff's perception of the person's ability to perform IADLs (capacity) to carry out the following eight activities: meal preparation, ordinary housework, managing finances and medications, transportation, shopping, phone use, and work. Each IADL is scored from independent (0) to totally dependent (6). Summary scores range from 0 to 48, where higher scores reflect a higher actual (performance) or perceived (capacity) need for support with IADLs. Excellent internal

consistency in the study population is reported for the ADL Hierarchy, IADL Performance Scale, and IADL Capacity Scale (standardized Cronbach's $\alpha=0.88$, 0.87 , and 0.78 , respectively). Since the CPS is based on a predictive algorithm where non-parallel items measuring different aspects of cognition contribute differently to the total score, internal consistency may not be calculated.

Scale Measuring Physical Health

The *Pain Scale* uses two items on pain frequency and intensity to create a score that ranges from no pain (0) to severe daily pain (3), and is highly internally consistent in the study population (standardized Cronbach's $\alpha=0.90$).

Scales Measuring Mood and Behaviour

The *Aggressive Behaviour Scale* (ABS) indicates aggression exhibited within the last three days, based on verbal and physical abuse, socially inappropriate or disruptive behaviour, and resisting care; summary scores range from 0 to 12 and higher scores indicate more problems with aggression. The *Depression Rating Scale* (DRS) points to possible clinical depression based on the presence of negative statements, persistent anger, expressions of unrealistic fears, repetitive health complaints, repetitive anxious complaints, facial expression, and crying or tearfulness over the last three days. Summary scores range from 0 to 14,

where a score of 3 or more warrants further investigation into possible depression (Burrows, Morris, Simon, Hirdes, and Phillips, 2000). Acceptable values of internal consistency were reported for both the ABS and DRS in the study population (standardized Cronbach's $\alpha=0.68$ and 0.69 , respectively).

Individual Items

In addition to the above scales, individual items in the interRAI ID will also be used to assess function (i.e., expressive and receptive communication, recent cognitive and functional decline), physical health (i.e., sensory impairment, falls, bladder and bowel continence), behaviour (i.e., uneasy adjustment to changes in routine, destructive behaviour, inappropriate public sexual behaviour or disrobing,

Table 1. *Personal Characteristics*

Characteristics	% All residents (N=826)
Average age (SD)	51.7 (9.6)
18-44 years	25.7%
45-54 years	45.1%
55+ years	29.2%
Sex	
Male	62.7%
Female	37.3%
Nature of intellectual impairment	
Cause unspecified	38.3%
Down syndrome	9.9%
Other genetic syndrome	48.5%
Autism or autistic spectrum disorder	3.3%
Level of severity of intellectual impairment	
Borderline	0.6%
Mild	2.1%
Moderate	8.2%
Severe	16.8%
Profound	52.7%
Not documented	19.6%
Average age (SD) at which left family home	12.4 (18.6)
Average number of years (SD) spent in an institutional setting in lifetime	42.0 (10.7)

Table 2. *Change in Functional, Clinical, and Social Characteristics Over One Year*

	% (N=826)	
	Baseline (2005)	Follow-up (2006)
Functioning		
Cognition		
Mild to moderate impairment (CPS=0,1,2,3,4)	27.2%	29.3%
Severe cognitive impairment (CPS=5,6)	72.9%	70.7%
Communication		
Severely impaired expressive communication*	47.5%	43.5%
Severely impaired receptive communication	26.2%	24.3%
Activities of Daily Living (ADL) Performance*		
Average ADL Hierarchy score (SD)	3.6 (1.7)	3.8 (1.7)
Recent decline in function (last 90 days)		
ADLs*	2.6%	4.7%
Cognition	2.9%	2.5%
Both ADLs and cognition	1.7%	1.2%
Instrumental Activities of Daily Living (IADLs)		
Average score for IADL Performance (SD)*	47.3 (2.5)	33.4 (14.3)
Average score for IADL Capacity (SD)*	47.1 (2.6)	45.4 (4.3)
Physical Health		
Any pain (Pain scale=1+)	22.5%	23.9%
Sensory impairment		
Any impairment in vision	44.3%	46.6%
Any impairment in hearing	29.4%	31.2%
Falls		
Fall within the last 30 days	8.0%	7.1%
No fall in the last 30 days, but fell 31-90 days ago	4.1%	5.6%
Incontinence in last 3 days		
Bladder*	57.9%	62.1%
Bowel*	50.7%	55.5%
Seizure in last 3 days	2.3%	3.4%
Mood and Behaviour		
Possible depression (DRS=3+)	11.9%	13.3%
Aggression		
None (ABS=0)	41.8%	36.9%
Mild to moderate (ABS=1-4)	45.2%	52.3%
Severe (ABS=5+)	13.1%	10.8%
Challenging behaviours in last 3 days		
Uneasy adjustment to changes in routine*	57.3%	46.7%
Destructive behaviour	7.6%	5.8%
Inappropriate public sexual behaviour or disrobing	7.1%	7.1%
Self-injurious behaviour	14.8%	13.0%
Pica	8.4%	7.1%
Family involvement		
Contact with family/friends in last 30 days	22.1%	24.3%
Receipt of any informal help in the last 3 days*	0.7%	4.1%

self-injurious behaviour, and pica), and family involvement (i.e., contact with family/friends, receipt of informal help).

Results

Population Characteristics

Table 1 presents demographic and personal information on the 826 individuals comprising the study population.

On average, persons were in their early fifties; male; had intellectual impairment due to either a genetic syndrome (other than Down syndrome) or an unspecified cause; had profound ID; had left their family home at about 12 years of age; and had spent approximately 42 years in an institutional setting.

Change Over Time

Table 2, on page 131, presents information on functioning, physical health, mood, behaviour, and family involvement for all residents on both the baseline and the follow-up interRAI ID assessments; it also informs on the significance of observed change using the appropriate statistical techniques (i.e., McNemar's chi-square test for categorical variables; Wilcoxon's matched-pairs test for ordinal variables; Paired t-tests for continuous variables).

The results indicate that over the course of one year significant change had occurred in expressive communication ($z=3548.5$; $p=.0069$), performance of ADLs ($t=-4.34$; $df=824$; $p<.0001$), recent change in ADL function ($\chi^2\text{McNemar}=6.15$; $df=1$; $p=.0131$), both performance ($t=5.97$;

Table 3. Direction of Change Over One Year

	Direction of Change %		
	Same	Improvement	Decline
Functioning			
Expressive communication	81.2%	11.4%	7.4%
ADL Performance	60.9%	15.0%	24.1%
Recent change in ADL function	92.9%	2.2%	4.8%
IADLs			
Performance	7.9%	91.5%	0.6%
Capacity	55.0%	40.7%	4.4%
Physical Health			
Continence			
Bladder	71.1%	10.1%	18.9%
Bowel	71.1%	10.1%	18.9%
Mood and Behaviour			
Uneasy adjustment to changes in routine	67.5%	21.4%	11.1%
Family involvement			
Receipt of any informal help in the last 3 days	95.2%	4.4%	0.5%

$df=136$; $p<.0001$) and capacity ($t=14.37$; $df=794$; $p<.0001$) for performance of IADLs, bladder ($\chi^2\text{McNemar}=9.96$; $df=1$; $p=.0016$) and bowel ($\chi^2\text{McNemar}=15.38$; $df=1$; $p<.0001$) continence, uneasy adjustment to changes in routine ($\chi^2\text{McNemar}=22.61$; $df=1$; $p<.0001$), and receipt of informal help ($\chi^2\text{McNemar}=20.83$; $df=1$; $p<.0001$).

Table 3 presents more detailed information on the direction of change experienced by residents (for significant variables only). Note that based on coding in the interRAI ID, "improvement" is characterised by a reduction in the person's score over time, while "decline" refers to instances where the person's score increased over time.

While the majority of individuals experienced relative stability in each area, the results show that there was more improvement than decline experienced in expressive communication skills, IADL performance and capacity, uneasy adjustment to changes in routine, and receipt of informal help from

Table 4. Direction of Change over One Year by Age and Level of Cognitive Impairment

	% Age group (years)			% Level of cognitive impairment	
	18-44 (n=163)	45-54 (n=384)	55+ (n=279)	Mild to Moderate (n=242)	Severe (n=584)
Functioning					
Expressive communication ^{1,2}					
No change	83.2%	79.7%	81.8%	91.1%	77.7%
Improvement	10.1%	13.2%	9.8%	4.0%	14.1%
Decline	6.7%	7.1%	8.5%	4.9%	8.2%
ADL Performance ¹					
No change	68.8%	62.7%	52.5%	46.9%	66.1%
Improvement	13.5%	14.8%	16.5%	19.2%	13.5%
Decline	17.8%	22.5%	30.9%	33.9%	20.5%
IADL Performance					
No change	9.1%	6.0%	8.9%	5.8%	8.5%
Improvement	89.4%	93.7%	90.7%	92.9%	91.2%
Decline	1.4%	0.3%	0.4%	1.3%	0.3%
IADL Capacity					
No change	53.9%	55.1%	55.9%	23.7%	66.6%
Improvement	42.8%	40.0%	39.4%	63.8%	32.1%
Decline	3.4%	4.9%	4.7%	12.5%	1.3%
Physical Health					
Bladder continence ^{1,2}					
No change	76.4%	71.8%	65.7%	64.7%	73.4%
Improvement	10.1%	10.4%	8.9%	12.1%	9.3%
Decline	13.5%	17.8%	25.4%	23.2%	17.3%
Bowel continence ¹					
No change	76.4%	71.8%	65.7%	64.7%	73.4%
Improvement	10.1%	10.4%	8.9%	12.1%	9.3%
Decline	13.5%	17.8%	25.4%	23.2%	17.3%
Mood and Behaviour					
Adjustment to changes in routine					
No change	57.7%	54.0%	57.6%	53.6%	56.9%
Improvement	34.6%	35.6%	33.5%	39.7%	33.0%
Decline	7.7%	10.4%	8.9%	6.7%	10.2%

¹ $p < .05$ Age category; ² $p < .05$ Level of cognitive impairment

family and friends. However, greater decline was experienced in ADL performance and bladder and bowel continence. Further, more persons had experienced recent decline in ADLs at the time of follow-up compared to baseline.

Impact of Age and Level of Cognitive Impairment on Change

For characteristics in which statistically significant change was noted over time, stratified analyses were conducted to determine whether change differed by age and level of cognitive impairment. Individuals were grouped according to the following age categories: 18 to 44 years ($n=163$), 45 to 54 years ($n=384$), and 55 years or more ($n=279$). These categories

were chosen as they represented both clinically and scientifically meaningful categories—specifically, the groups could be expected to differ on a number of clinical characteristics, and each group comprised a sufficient number of individuals for statistical analysis. As the IQ score was not documented for 19.6% of individuals, the level of cognitive impairment is based on the Cognitive Performance Scale (CPS) score. Residents were grouped into two categories: mild to moderate impairment (CPS=0 to 4; $n=242$) and severe impairment (CPS=5 or 6; $n=584$). This classification allowed for a clinical differentiation of groups that had adequate statistical power. Note that insufficient power existed to conduct stratified analyses on recent change in ADL function and receipt of informal help. Table 4 shows the direction of change experienced by age and level of cognitive impairment [see page 133].

The results indicate that change in status differed according to age for expressive communication, ADL performance, and bladder and bowel continence. Both, persons aged 18-44 years ($z=404.5$; $p=.0046$) and those aged 45-54 years ($z=835$; $p=.03$), experienced significantly more improvement than decline in expressive communication over the last year. Persons aged 45-54 also experienced worsening of ADL performance ($t=-2.21$; $df=364$; $p=.0275$), and bowel continence ($\chi^2\text{McNemar}=4.08$; $df=1$; $p=.0433$). Persons aged 55+ years experienced significantly more decline in ADL performance ($t=-3.38$; $df=235$; $p=.0009$), and bladder ($\chi^2\text{McNemar}=8.80$; $df=1$; $p=.003$) and bowel ($\chi^2\text{McNemar}=8.53$; $df=1$; $p=.0035$) continence, over the last year. All age groups experienced significant improvements in terms of IADL performance and capacity, as well as adjustment to changes in routine.

Change in status also differed according to the person's level of cognitive impairment

for expressive communication and bladder continence, where persons with severe cognitive impairment experienced more decline than improvement in each domain (expressive communication: $z=1958.5$; $p=.0042$; bladder continence: $\chi^2\text{McNemar}=7.86$; $df=1$; $p=.0051$). Both groups experienced significant decline in ADL performance, bowel continence, and improvement in IADL performance and capacity, and adjustment to changes in routine.

Discussion

Residents of Ontario's remaining institutions tended to be in their early fifties, where almost half were 55 years of age or more. Approximately half of the residents had severe intellectual impairment (according to their IQ scores) and a genetic syndrome (other than Down syndrome) documented as the cause of the ID. The cause of the ID was unknown or unspecified for approximately 40% of residents, and the level of severity was not documented in about 20% of records. The majority of individuals had resided in the institution for over forty years.

In this study, we found that residents' status in a number of domains changed over the course of one year (i.e., between baseline and follow-up assessments). In particular, there was an overall *improvement* in scores for expressive communication, instrumental activities of daily living, and adjustment to changes in routine. Over the course of the last year, a number of changes have happened within the institutions. For example, as a result of people leaving the institution some units have closed necessitating within-institution moves for some residents. Consequently, residents are getting used to living in a new area, and with new people. This may have contributed to the improvements noted in expressive communication, in that the person cannot rely on the availability of familiar staff

to anticipate their needs. Improvement in performance of IADLs may be a result of the expectation of staff members from other units in the institution (for example, units where there was higher expectations for independence), from staff encouraging independence to prepare individuals for their transition to the community, or simply from a decreasing number of staff (resulting in residents having to do more for themselves). Improvements seen in assessment of the capacity for IADLs could then be a result of an increase in actual independence in IADL performance. Staff may have realized that residents could be capable of even more independence over time, and with the appropriate support. The combination of moves within the institution and changing staff may also have contributed to the increase in the resident's ability to adjust to changes in routine, and could further ease the transition into the community.

However, an overall *decline* was observed for ADL performance and bladder and bowel continence. ADL decline and bowel incontinence was more common among older adults, while persons with severe cognitive impairment experienced higher rates of decline in bladder continence only. These findings are not surprising as incontinence and decline in functional abilities are known to be more common among older, institutionalized, and chronically ill individuals. Given that personal care activities and toileting are among the very basic activities of everyday living, and depending on the person's baseline status, even the slightest increase in dependence could mean the need for substantially more support. For example, someone who at baseline needed assistance from one person for toileting who now requires full support from two or more persons for that same activity. The implications for staffing in both the institution and community are deserving of thoughtful consideration given that

more than half of residents are currently over 50 years of age.

Though not examined in-depth due to lack of power, more residents had received assistance from an informal helper (i.e., family member or friend) at the time of the follow-up assessment compared to their baseline assessment. Increases in the receipt of informal help may result from staff having contacted and engaged family members in the planning process. The increase in family involvement is hopefully a trend that will continue throughout the individual's transition to the community, and beyond.

There were limitations to the current analyses. The use of secondary data limited our ability to study certain individual-level (e.g., number of moves within the facility, person's feelings about the move to the community) and facility-level (e.g., staffing ratio, overall number of units closed) characteristics that may have helped to better understand the change in residents' status. Also, a lack of power prevented more in-depth analyses of certain variables – namely, receipt of informal help and recent functional decline. Such analyses may become possible over the remainder of the project (which will end upon full closure of institutions in March 2009), if family involvement continues to increase, and should residents continue to experience declines in physical functioning.

It is hoped that the information learned regarding individual-level change will help staff to better understand what supports are needed in the community. In addition to using the person's latest interRAI ID assessment to get an overall sense of his/her current status, the individual's trajectory of change should also be taken into account. For example, staff should consider areas in which the person has experienced improvement, e.g., IADL performance, and plan for community supports that

will further enhance that improvement. Similarly, areas in which the person has declined, e.g., ADL performance, should also be taken into account. Here, supports that will help to either reverse or minimize the impact of that decline on the person's overall quality of life should be in place.

Conclusion

With the use of the interRAI ID, the DSB-MCSS has standardized, comprehensive information on the status of all persons residing in Ontario's remaining institutions. The information from the interRAI ID, along with other available information in the person's records, is extremely useful in planning for the transition to the community, as individual areas of strengths, preferences, and needs are highlighted. However, even more useful is the availability of information on the change in the person's status over time. Planning, therefore, should take into account not only the person's current status and needs, but also the change that has occurred in his/her status, as well as the change that is likely to occur based on his/her age and level of cognitive impairment. Consequently, it is hoped that this project will not only help the DSB-MCSS pre-plan for the successful transition of individuals, but will also provide a framework through which quality of life and outcomes in the community may be understood. The use of the interRAI ID to evaluate community placements would enable the DSB-MCSS to directly compare the person's status in the institution to that in the community.

As a result of the MCSS having increased its emphasis on community integration, the ability of community agencies to provide adequate residential, vocational, recreational, and social supports for persons with ID has improved dramatically over the last few decades. The formal health care system, however, has been somewhat slower in developing expertise in ID (King-

Andrews and Farrell, 2006). The problems in coordinating services to persons with ID provided by two Ministries (i.e., MCSS and MOHLTC) represent a major challenge that further complicates the delivery of adequate health care services to persons with ID. As the interRAI ID is compatible with systems mandated by the MOHLTC in home care, long-term care, and inpatient psychiatric settings, its continued use in the developmental sector would facilitate communication between providers in those different settings/sectors through the use of a common assessment language. Further, it would allow for a more integrated health and social service system.

To the extent that persons with ID access home care, long-term care, and inpatient psychiatric services in Ontario they are already being assessed with an interRAI instrument. Future work, therefore, should compare the needs of persons moving from the institutions to those of persons currently receiving health care services. This information could help us to better understand the needs, service utilization, and outcomes of persons with ID who currently receive health care services. It could also provide the evidence base to inform decisions around improving current services and developing new services that will improve the overall quality of life of persons with ID in the community.

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