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The Facilities Initiative in Ontario: A Survey of Community Agencies

Abstract

*On March 31, 2009 the last three remaining government oper-
ated facilities for persons with intellectual disabilities closed
in Ontario, ending the Ministry of Community and Social
Services' Facility Initiative and more than 30 years of dein-
stitutionalization. Following the closures, four studies were
undertaken as part of the Facilities Initiative evaluation. This
summary report provides the results of an agency survey con-
cerning outcomes for each individual who moved to community
living. Surveys were sent to all community agencies that par-
ticipated in the Initiative. Responses were received for 114 of
the 941 persons who were repatriated.*

*Responses from the agency surveys indicated that the vast
majority of individuals who were placed in the community as a
result of the Facilities Initiative were perceived to have excellent
or good quality of life. Agency respondents reported that the
transfer to the community and the subsequent adjustment were
generally good to excellent, with respondents reporting that
most individuals adjusted in less than three months. The study
results do note, however, that there were individual differences
within the sample. Overall, the study supports the view that
community living is associated with more positive life values
than institutional living.*

Research on deinstitutionalization generally demonstrates
improvement in both the quality and standard of life of indi-
viduals who move from facilities to community settings. In
Ontario, one study reported increased quality of life scores
for adults who moved from institutional to community liv-
ing (Brown, Renwick, & Raphael, 1999). Results of large dein-
stitutionalization projects in Australia, the United Kingdom,
and the United States have produced similar results (e.g.,
Dunt & Cummins, 1990; Emerson & Hatton, 1996; & Larson
& Lakin, 1989, respectively). They demonstrate increased
adaptive behaviour and autonomy in areas such as self-care,
domestic skills, community activities, leisure skills, and
choice-making. In spite of various measures being used to
evaluate such changes, researchers generally report positive
results; individuals exhibit early positive changes followed
by a levelling off or decline in some measures (e.g., Cullen et
al., 1995; Dagnan, Ruddick, & Jones, 1998). In some cases, the
levelling off is hypothesized to be the result of a ceiling effect
(persons meeting their potential); in other cases, the decline
is hypothesized to be the result of inconsistent maintenance
(Dagnan et al., 1998). In addition, research shows overall that
the amount and quality of interaction with staff, family, and
friends increases when people with intellectual disabilities

are residing in community settings. Moreover, problem behaviours such as aggression, self-injury, and property destruction are reported to decrease in some cases, although this finding is inconsistent (Young, Sigafoos, Suttie, Ashman, & Grevell, 1998). At an individual level, positive outcomes are reported for most, but not all, individuals. This led Young et al. (1998) to suggest that community placement is therefore not a panacea, but rather that its success depends upon an interaction of the individual's characteristics with the environment including staff and setting characteristics.

In summary, there is considerable literature on the outcomes of deinstitutionalization. Overall, the research on the change from institutional to community living provides evidence of improvement in adaptive behaviour (Conroy, Efthimiou, & Lemanowicz, 1982; Hamelin, Frijters, Griffiths, Condillac, & Owen, 2011). Even individuals who have been labelled as "unlikely to succeed" have been able to adjust to community living (Bogdan & Biklen, 1982). Deinstitutionalization has been shown to be associated with a number of benefits for persons with intellectual disabilities, including "increased satisfaction, social inclusion, engagement, and support," although it has little impact on levels of challenging behaviour (Emerson, 2004, p. 79).

Deinstitutionalization of people with intellectual and developmental disabilities has been an international trend over the past 30 years and was systematically carried out in Ontario during that time period. According to Radford (2011), "At the height of the [institutional] era, about 1970, Ontario had 20 institutions, almost half the number that existed in Canada" (p. 29). These were gradually downsized, then closed, as residents were moved to community living settings. On March 31, 2009, the last three remaining government operated facilities closed in Ontario. The Ontario government's Ministry of Community and Social Services set up a Facilities Initiative in 2004 to "complete a long-standing journey from an institution-based service system for people with developmental disabilities to a community-based system that promotes inclusion, independence and choice" (Mackie & Philp, 2004, p. 8).

The Facilities Initiative was evaluated in a series of four studies. The Facilities Initiative Agency Survey Study, the subject of this report, was one of the four studies, and was undertaken to garner feedback on individual outcomes and satisfaction ratings from community agencies that received residents from the last three remaining institutions as part of the Facilities Initiative.

Method

Following the closure of the final three institutions in Ontario, four studies were undertaken as part of an evaluation of the Facilities Initiative. In the study involved in this paper, an invitation was sent to all community agencies that participated in the Facilities Initiative to complete the Facilities Initiative Agency Survey on each individual who had moved from an institution to their agencies. In each agency, the person who had the most direct contact with, and had greatest knowledge of, the individual was asked to complete the survey. Responses were received for 114 of the 941 persons who were repatriated to community agencies, a return rate of 12%. The low rate of return, although not inconsistent with the return rate of other published research, may be attributable to the latency between the closure and the study and the competing demands on staff time.

The survey for recipient agencies was constructed according to the guidelines identified by Hessler (1992). A conceptual map of key concepts was created based upon a review of the literature. The key concepts that emerged were synthesized into six distinct categories. The resulting survey contained 69 qualitative and quantitative questions related to the effectiveness and impact of deinstitutionalization including adaptation, quality of life, family relationships, engagement in activities and community, access to specialized services, changes in independence, health and behaviour, as well as demographic information regarding location and staffing. Questions were posed quantitatively, requesting a yes or no response, or a rating on a 5 point Likert-type scale, such as from excellent to poor, then followed with opportunity for qualitative expansion or exploration. The agency survey was then field-tested with 23 individuals who were deinstitutionalized from a psychiatric facility and compared against a meta-analysis of factors evaluated in the literature of indicators of effective outcomes (Hamelin et al., 2011); no modifications were made following the field-testing.

The survey data were aggregated and analyzed descriptively for trends and outliers. For the purpose of this brief report selected quantitative data have been presented descriptively to demonstrate the overall trends. For complete results and qualitative summaries, readers are referred to Griffiths, Owen, & Condillac (in press).

Results

The results from the Survey are summarized in Table 1 and described on pages 41 and 42.

Living Location and Resources

Ninety-two percent of the 114 individuals who were transitioned to the community were relocated to group home settings. The majority of individuals (90%) resided in settings with seven or fewer individuals; however, the settings ranged from groupings of 1 to 120 persons. The ideal of 5 or fewer individuals in a group home was a reality for 60% of the sample. Ten percent of the individuals were living in settings of more than 13 persons. Most individuals (92%) had their own rooms. Agency respondents reported that the majority of the individuals were placed in appropriate environments that were rated as excellent (55%) or good (30%) relative to their needs. Those agency respondents who reported excellent or good ratings described more individual supports; a personalized or "home" setting; and increased interactions with staff, the community, and families. However, 14% of the individuals were in environments that were rated as only adequate and 1% resided in a setting that the agency respondent rated as poor. Agency respondents who identified the setting as being only adequate described limited resources, too many people in the setting, overcrowding, a lack of opportunity for community engagement, a lack of activities, and a lack of space within a community home in comparison to the facilities.

Adjustment and Relationships

Ninety-seven percent of the 114 individuals surveyed adjusted to the transition from the facilities to the community. Adjustment was reported to take place immediately or within the first 3 months for 70%, and within 6 months for 13% of the individuals. Only 3% of the individuals were identified as having not

adjusted to the new environment by the end of the first year. The degree of adjustment varied: 45% of the individuals adapted extremely well to the placement, and 26% required little adjustment, while 29% demonstrated moderate (20%) to significant (9%) challenges for a period of time. These challenges included yelling, swearing, name calling, banging dresser drawers in rooms, hitting the walls of a room, and exhibiting daily agitation. Increased medication was often provided for some individuals. Behaviours such as these often interfered with the individual's participation in the community.

One of the key variables related to positive transitions was the development of positive staff and peer relationships in the new setting. Eighty-one percent of the agency respondents noted that the individual had developed positive and strong relationships with staff and no respondent reported negative relationships with staff. However, 60% of the respondents reported that the person's relationships with peers were more likely to be neutral or limited; only 33% of the individuals had developed positive and strong peer relationships. Additionally, 7% had negative, weak, or mixed relationships with peers.

Quality of Life

Following transition to the community, agency respondents rated their impression of the quality of life of the majority (91%) of individuals as being good (53%) to excellent (38%). Only 1% of the respondents rated the quality of life of an individual as poor, although an additional 5% were rated as only adequate or needing improvement. Three percent rated the overall quality of life as mixed, noting that some aspects of life quality were better than others. Positive ratings of quality of life primarily focused on increased happiness and decreased distress. "Excellent" ratings included reference to improved communication skills and health, positive environments, and new or renewed opportunities for community and family connections. "Good" ratings were accompanied by themes of involvement and choice. The agency respondents attributed the positive quality of life changes to the quality and consistency of staffing, promotion of personal choice, participation of individuals in activities in the home and the community, and the nature of the home environment itself.

Table 1. Quantitative Responses to Major Agency Survey Questions

Question	Response	
Living Location and Resources		
Type of setting	Group home	92%
	Apartment	4%
	Family home	1%
	Other	3%
Number of persons with ID in setting	Less than 3	31%
	3–7	59%
	More than 13	10%
Appropriateness of environment	Excellent	55%
	Good	30%
	Adequate	14%
	Poor	1%
Adjustment and Relationships		
Length of time for adjustment to occur	Immediate or within the First 3 months	70%
	By 6 months	83%
	By 12 months	97%
Degree of adjustment	Extremely well	45%
	Little adjustment needed	26%
	Moderate adjustment	20%
	Significant adjustment required	9%
Relationships with staff	Positive & strong	81%
	Neutral	19%
	Negative or weak	0%
Relationships with peers	Positive & strong	33%
	Neutral	60%
	Negative or weak	6%
	Mixed	1%
Quality of Life		
Rating of quality of life	Excellent	38%
	Good	53%
	Adequate	4%
	Needs improvement	1%
	Poor	1%
	Mixed	3%
Community Staff and Professional Services		
Community staff satisfaction with:	Ratios	84%
	Specialized training received	90%
	Sufficiency of training received	86%
Professional support services:	Availability	91%
	Consistent with Essential Plan recommendations	94%
	Of sufficient quality	98%
Engagement in Activities		
Access to activities that:	Give the person pleasure	93%
	Were previous interests	73%
	Are new interests	82%
Access to exercise	Daily	54%
	Several times a week	20%
	Weekly	12%

Table 1. Quantitative Responses to Major Agency Survey Questions (continued)

Question	Response	
Engagement in Activities (continued)		
Engagement in day programming	Engaged in a day program	40%
	(52% of these were out-of-home)	
Type of day programming	Group activities	54%
	Individualized activities	31%
	Mixed program	13%
Appropriateness of day programming	Excellent	22%
	Very good	38%
	Adequate	29%
	In need of improvement or change	6%
	Poor	5%
Engagement in the community	Actively included in the community	81%
	Reported to be positive	92%
Type of community activities	*Frequent:*	
	To the park or for walks	91%
	Shopping	79%
	Restaurants	76%
	Haircuts	72%
	Less frequent:	
	Plays or concerts	79%
	Movies	78%
	Vacation	72%
	Social clubs	69%
	Sporting events	64%
	Place of worship	54%
Family Relationships		
Change in family relationships	Changed	69%
	(89% of these increased)	
	Unchanged	30%
	Unknown	1%
Roles families play	Advocacy	64%
	Emotional support	53%
	Advice	42%
	Practical help	39%
Change in Independence, Health, and Behaviour		
Independence	More independent	66%
	(89% of whom are making choices in daily life)	
Health	Changes in:	
	- medical status	52%
	- mental health	22%
Behaviour and adaptive functioning	Less challenging than in facility	51%
	Unchanged	31%
	Increased challenges	17%
	Unknown	1%
	Positive changes in:	
	- Interests	54%
	- Adaptive skills	45%
	- Self-care skills	36%
	- Social skills	48%
	- Communication skills	53%

Community Staffing and Specialized Services

Agency respondents reported that they were generally satisfied with both the staffing ratio and the supports that individuals were receiving, with satisfaction ratings from 84% to 98% in all areas: sufficient staffing ratio to meet the needs of the individuals (84%), appropriate staffing patterns (94%), and staff training that was sufficient (86%), appropriate (93%), and specialized to the needs of the individuals (90%). The support services that had been recommended in the Essential Elements Plans[1] were available in 94% of the cases; these supports were rated by agencies as being both sufficient (91%) and of sufficient quality (98%) to meet the needs of the individuals.

Agency respondents reported that individuals were receiving a range of medical and professional services. All individuals had a presiding physician, and regular dental care was being provided for 96% of the individuals. Agency respondents explained that individuals who previously had all their teeth removed were receiving in-home gum care. Agency respondents reported that all other services were being provided at a rate consistent with or in excess of the rate recommended in the Essential Elements Plans. It was noted that availability of specialized services, such as physiotherapy, was an issue in several cases where individuals were on wait lists. Although the need for and use of professional and medical services overall exceeded recommendations, for participants for whom behaviour therapy was recommended in the Essential Elementals plan, the need for these services after transition to the community was not required for as long a period of time or to the extent that had been anticipated. Additional services received by individuals were cardiology, optometry, nursing, orthotics, dietician services, and consultation from ear, nose, and throat specialists.

Engagement in Activities

Ninety-three percent of the individuals were engaged in activities of daily life that gave them pleasure. Seventy-three percent of the respondents indicated that the activities that individuals engaged in reflected previous interests; however, 82% were reported to engage in activities that reflected new interests. When asked about the availability of all of the activities recommended in the Essential Elements Plan, it was reported that some activities that had been recommended in the Plan were either unavailable (18%) or inaccessible (14%). For example, specialized sensory stimulation programs that had been recommended were noted to be unavailable in most areas.

Most individuals received regular exercise on a daily basis (54%), several times a week (20%), or weekly (12%). Fifty percent of the individuals participated in daily household activities. Some of the common daily activities that were listed as giving the individuals pleasure were walking, recreation activities, sports, television/music/media, and socializing. For some, lack of participation was reported to be the result of physical limitations of individuals or their lack of interest.

Forty percent of the individuals were reported to be engaged in a day program. Of those responding that the individual was attending a day program, only 52% were doing so out-of-home. Of those engaged in day programming, 54% participated in group activities, 31% received individualized programming, and 13% received a mixed program of individual and group activities. Two percent chose not to participate in day programming activities. The appropriateness of the day programming to the wishes of the individuals varied. Sixty percent reported that those involved in day activity programs were matched at a level that was very good (38%) to excellent (22%). However, 40% of those in day programs were in programs rated as adequate (29%), in need of improvement or change (6%), or poor (5%). The day programmes described were primarily community and recreational activities.

Eighty-one percent of the individuals were reported to be actively included in the community. Of those, community contacts had been positive for 92%. Some of the activities that were frequently engaged in include: going to the park or for walks (91%), shopping (79%), going to restaurants (76%), and getting haircuts (72%). Although reported to be less frequent, 79% of the individuals attended plays or concerts, 78% went to the

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1   Essential Element Plans were the transitional plans designed to identify the needs for the individual to be appropriately supported in the community,

movies, 72% spent time on vacation, 69% attended a social club, 64% attended sporting events, and 54% participated in places of worship.

Family Relationships

Agency respondents reported that family relationships had changed for 69% of the individuals since moving to their new homes in the community and 30% remained unchanged, noting that many individuals did not have family or family contact. One percent was rated as unknown. Of those reporting a change, 89% reported that family contact had increased, and 86% reported an increase in contact with friends. Increased family and friend contacts both included renewals of past relationships.

Thirty-three percent of the individuals had frequent visits from family members, 17% frequently visited family members, and 31% had frequent family telephone contact. Twenty-eight percent of the individuals had frequent visits from friends from outside the home and 34% visited friends frequently, but only 6% had frequent telephone contact. Most often, the individuals (72%) socialized with peers in their home or programs.

Family members served as advocates (64%), and provided emotional support (53%), advice (42%), and practical help (39%). To a lesser extent, friends provided advocacy (11%), practical help (14%), advice (10%), and emotional support (22%).

Changes in Independence, Health, and Behaviour

The most common changes reported in individuals since transition to the community were in the areas of choice-making, medical status, behaviour, and adaptive functioning. Agency respondents reported that 66% of the individuals who transitioned from the facilities were more independent and 89% of the individuals were now able to make choices regarding their daily routines. Eighty-five percent of the agency respondents reported that the individuals had shown an increase in choice-making since leaving the facility. The degree of independence in choice-making varied from relatively independent (20%), to choice-making in some areas (49%), and choice-making that required staff facilitation (31%).

Medical changes had occurred in fifty-two percent of the individuals. Change was generally described as improved health and medication reduction. Twenty-two percent reported changes in the mental health of the individuals since moving to the community; there had been a change in diagnoses for 6% of the individuals. Thirty percent of the individuals had experienced some form of hospitalization since moving to the community.

Many of the agency respondents reported positive changes in skill areas including adaptive skills (45%), self-care skills (36%), social skills (48%), and communication skills (53%) of the individuals transitioned from the facilities. Respondents noted that 49% of the individuals had experienced behaviour problems since leaving the facility. Of those, the behaviour problems were described as being less than in the facility for 51% of the individuals, and as being at the same rate as in the institution for 31%. As noted in the description of specialist services above, it was reported that generally individuals required less behaviour therapy than initially recommended. Only 17% of the individuals experienced an increase in behaviour problems following the transition. One individual was rated as unknown. Only 2% of the individuals had experienced contact with the police, security services, or other law enforcement services.

Discussion

In general, agency respondents reported satisfaction with the outcomes and the supports that were put in place for the individuals who were transitioned to the community through the Facilities Initiative. In this sample, almost all the individuals who were transitioned moved into group home settings, the exception being one person who moved into a long-term care facility. A large number of the settings were described as group homes, yet they exceeded the number of residents identified to meet the accepted definition of a group home. As a result, some agency staff reported that the quality of care provided to the former facility residents, in some cases, was reduced because of the large number of individuals in the home and the resulting overcrowding. However, overall, individuals were reported to have received

the type of supports that had been recommended in their Essential Elements Plans and that these supports were generally rated as being adequate and sufficient. The inconsistency in these messages speaks to a lack of specificity in the planning process that did not identify the definition of a group home to be four to six individuals (Clement & Bigby, 2010).

Agency respondents reported a range of positive changes in adaptive and maladaptive behaviour, socialization, communication, family contact, health status, community inclusion, and choice-making. These findings are consistent with those found in the literature (Dunt & Cummins, 1990; Emerson & Hatton, 1996; Hamelin et al., 2011; & Larson & Lakin, 1989).

Adjustment to the community was immediate in some cases, and for most individuals adjustment to the transition took less than three months. Some individuals were reportedly still showing challenges with adjustment, but very few respondents reported regression in behaviour after moving from the facility. This finding was consistent with the variation in challenging behaviour noted by Young et al. (1998).

Noteworthy in this study is that once some individuals moved to the community, the level of support identified in their Essential Elements Plans based on their functioning in the facilities was not required or not required to the degree that had been anticipated. For some individuals, the supports anticipated during the planning process were not needed at all. This was not the case, though, for all people who moved to communities, so it may be that some pre-placement planning processes were more accurate than others. It may also be that some Essential Element Plans were prepared to respond to the worst possible outcome, and when it did not materialize the expected resources were unnecessary. Or it may be that there were real changes in the functioning of the individuals once they began living in their communities, and this resulted in reduced resource needs. The overall positive outcomes reported give credence to this last hypothesis.

Most agency respondents reported satisfaction with the level of professional and medical supports that were available in the community, and use of these was higher than anticipated. For the most part, the resources that had been identified in the planning process were present, although there was inconsistent access to some resources across the province. In some cases, however, in order compensate for these deficiencies creative options for online consultation were accessed through the Networks of Specialized Care (a resource available throughout Ontario that provides training and resources often through satellite communication facilities).

Although generally positive, the current community-support system presented a "mixed picture" (Mansell, 2006, p. 70) that speaks to the need for increased quality assurance to ensure greater consistency of staffing expectations and service provision throughout the deinstitutionalization process. The data indicated that most individuals were participating in the community but the frequency and degree of social inclusion remained problematic for many individuals. Some agencies reported that additional resources would be required for achievement of optimal social inclusion and quality of life. The above findings were similar to those noted by Emerson and Hatton (1996) who concluded that community integration has been largely superficial and infrequent.

One important area that appeared to be largely unavailable and not planned for was access to consistent out-of-home day programming. Although most agencies reported that individuals were engaged in some community activities and out-of-home activities on a regular basis, albeit at different frequencies, the degree to which this represented real inclusion or access to personally valued activities was unknown. Day programming was a major area of planning that was not fully addressed in most of the transitional plans. Where day programming options were available, they were often provided in the home. Day programming activities were typically recreational or leisure. The lack of meaningful day programming outside of the home represents a significant gap in the planning process and contrasts with an earlier deinstitutionalization study in Ontario that found that 81% of the individuals were involved in appropriate day programming post transition (Griffiths, 1985). This contrast is likely a reflection of the community trend away from congregated day programming, but the implication is that alternative day programming has not been introduced to fill the void.

The survey data showed that, overall, individuals experienced a relatively positive transition to the new settings and adjusted well within these settings. The surveys also provided rich information about both the planning process and the implementation phase that contributes to the available knowledge about deinstitutionalization and that can inform the development of an enhanced deinstitutionalization process in jurisdictions that may be initiating the process. For those undertaking deinstitutionalization, the survey results suggest several positive elements that were responsible for the promotion of a successful process and other elements that proved to be counterproductive. Elements associated with positive outcomes were reported to be:

- The development of a strong relationship with the families and the planners

- Community agencies that were welcoming and had well-trained staff who possessed a person-centred and human-rights based philosophy of care

- The provision of adequate supports and services

- The delivery of appropriate staff training and orientation prior to placement

- Strong communication with families and positive relationships with the individual

- Commitment

Less than positive outcomes in some cases reflected:

- Conditions of restricted access to the community

- Locations that did not facilitate inclusion

- Overcrowding

- A high number of persons with disabilities in one setting

The agencies, where these less favourable conditions were reported, were also noted to have adopted an institutional approach within the community settings, rather than the person-centred approach that typified the majority of the homes that were described as individualized, home-like, and respectful (cf., Ericsson, 1996).

The main recommendations for improvement from agency respondents included more day programming, additional staffing, increased professional supports and funding, and fewer people living in each residence. Lack of funding was the consistent reason given to explain why ideas to further improve the quality of life of the individuals who were being supported in the community were not being pursued.

A noteworthy limitation to the current study was that the sample included only those agencies that elected to respond. Although the data were similar to those reported in other studies, outcomes may not have been the same in the agencies that elected to not participate in the research.

The Agency Survey results provide strong support for the overall benefits for most individuals who moved to community settings through the Facilities Initiative. The results support research literature regarding the positive outcomes of deinstitutionalization. Although the overall outcomes of the Facilities Initiative are generally very positive, the Ontario experience does point out some exceptions that can provide valuable lessons. These counter-stories identify some key factors that can threaten the integrity of the deinstitutionalization process and its outcomes.

Key Messages From This Article

People with disabilities: The last institutions in Ontario were closed in 2009. The last people to move out of the institutions are doing well living in the community.

Professionals: Former residents of institutions are, for the most part, adjusting well to community living. Appropriate services for individuals with intellectual disabilities – especially those with a person-centred, right-based approach – are not tied only to location, but also to the attitudes, staff expertise, and the nature of supports provided.

Policymakers: Through an individualized planning process, the remaining government operated facilities in Ontario were closed with generally successful outcomes. With appropriate planning and supports, individuals with intellectual disabilities can be transitioned to a community life that is as good as or better than what they experienced in the institutions.

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