

Family Feedback on the Closure of Institutions for Persons with Intellectual Disabilities in Ontario

Abstract

On September 9, 2004 the government of the province of Ontario, Canada announced that it would close the last three remaining large, government-run residential facilities for adults with intellectual disabilities. This final phase of the Ontario deinstitutionalization process became known as the Facilities Initiative and was completed on March 31, 2009. Four studies were undertaken to evaluate the Facilities Initiative implemented by the Ontario Ministry of Community and Social Services. The current study reports on the findings from a survey that recorded the perceptions of 61 family members of former facilities residents. The surveys were distributed to families beginning one year following the final closure of the three facilities.

The survey results indicated that families perceived that the vast majority of individuals who were placed in the community as a result of the Facilities Initiative have excellent or good quality of life. Families reported that the transfer to the community and the subsequent adjustment were generally good to excellent, and they indicated an overall satisfaction with the present placement and with the supports and services provided. Although "counter-stories" were evident and of note, the overall results revealed that of the families who participated in this study, most families, even those who were initially concerned, were pleased with the outcomes of the Facilities Initiative.

The Facilities Initiative was the final stage of deinstitutionalization for persons with intellectual disabilities in the province of Ontario, Canada that witnessed the closure of the last three government operated institutions and the repatriation of 941 residents to the community. The Facilities Initiative was completed on March 31, 2009.

Deinstitutionalization emerged fully in the early 1970s as a result of the philosophical shift towards normalization and the concurrent development of the community living movement. The Ontario experience, to a large extent, reflects the path that emerged throughout Scandinavia, and later the United States, the United Kingdom, Australia and elsewhere (Tabatabainia, 2003). The shift was not a universally welcomed change for all families, and in many cases resistance was mounted to stay the path of deinstitutionalization (e.g., Latib, Conroy, & Hess, 1984).

Authors

Dorothy M. Griffiths,¹
Frances Owen,¹
Rosemary Condillac²

¹ Department of Child
and Youth Studies,
Brock University,
St. Catharines, ON

² Centre for Applied
Disability Studies,
Brock University,
St. Catharines, ON

Correspondence

dgriffiths@brocku.ca

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¹ Nelson (1995) referred to "counter-stories" that represent the stories of the real life experiences that can offer alternative understanding of the overall findings from the data.

A large body of scholarly writing on deinstitutionalization has evolved over the past forty years. The research literature provides convincing evidence regarding the positive outcomes of deinstitutionalization across studies and countries (Brown, Raphael, & Renwick, 1999; Emerson & Hatton, 1996; Hamelin, Frijters, Griffiths, Condillac, & Owen, 2011; Larson & Lakin, 1989; Young, Sigafos, Suttie, Ashman, & Grevell, 1998). Although results vary, the research generally reports improvements associated with community rather than institutional living in adaptive functioning, quality of life, family and friend contact, and increased independence and choice-making, but not always in challenging behaviour.

Although family attitudes towards deinstitutionalization are typically negative prior to the transition (Conroy, 1985; Heller, Bond, & Braddock, 1988), and often result in litigation to sustain the status quo (Latib, Conroy, & Hess, 1984), positive change in family attitudes towards deinstitutionalization following placement is consistently noted in the literature (Emerson & Hatton, 1996; Larson & Lakin, 1991; Tabatabainia, 2003). In the case of the Facilities Initiative, litigation to halt the closures was initiated by the families because of concern that the community could not provide the type of care that was provided in the facilities. Although the closures were allowed to proceed, families gained the right in this legal case to make the final decision regarding placement. Thus, following the transition, the perspective of the families with regard to the outcomes for their relatives was a critical area of study.

Methodology

The family survey was based upon an earlier study conducted following the closure of one facility (Pine Ridge, Aurora) that was part of Ontario's Five Year Plan for deinstitutionalization in the 1980s (Griffiths, 1985). Modifications were made based upon the feedback received from the Focus Group and Interview Study of the Facilities Initiative (Owen, Griffiths, & Condillac, 2010), and field-testing prior to dissemination. The survey consisted of closed-ended questions (as noted in Table 1) and open-ended requests for comments in order to provide both quantitative and qualitative responses.

The family survey gathered data on areas related to the experiences of those who left the facilities, including the outcome of the transition to the community, change in their relative following community placement and over time in the community, and access to formal services and informal supports as specified in their personal and support plans.

Survey Participants

The Ontario Ministry of Community and Social Services (MCSS) invited all families involved in the Facilities Initiative to participate in this study, using an introductory letter and general consent form. Surveys were sent directly to all families that responded and were circulated to others through the agencies that were supporting the persons who had moved from the facilities.

There were 941 individuals who were repatriated to the community following the announcement of the Facilities Initiative. The individuals in the facilities were on average 51.7 years of age, nonverbal (69.6%), and had severe or very severe cognitive challenges (73.5%) (Condillac, Frijters, & Martin, 2012). The family survey yielded 61 respondents or a return rate of 6.5% of the individuals who were transitioned to the community during the Facilities Initiative. Although this return rate appears very low, it is important to note that in 2006 a report to the MCSS indicated that only 10.7% of the residents from the three facilities had a family member identified (Hirdes, Martin, Fries, & James, 2006). Many of the individuals who transitioned through the Facilities Initiative had lived in the facilities for more than 40 years. Because of the advanced age of the individuals who were transitioned to the community, the lack of family involvement for many of the individuals, and the latency between placement and evaluation, the rate of return for these families may not be unusually low.

The family surveys were filled out by the following family members of persons who were transitioned during the Facilities Initiative: sisters (32%), mothers (32%), brothers (20%), fathers (10%), both parents (3%), and other (e.g., sisters-in-law and cousins; 3%). The response rate by the three facilities that were closed was Rideau Regional Centre (49.2%), Huronia Regional Centre (18.6%), Southwestern Regional Centre (28.8%), and unspecified (3.4%).

Table 1. Family Survey Quantitative Questions and Response Rates

<i>Questions</i>	<i>Responses</i>
Satisfaction of the transition	
Overall, how would you rate your family member's transition from the facility to the community?	Excellent..... 67% Good..... 24% Adequate..... 2% Needs Improvement..... 5% Poor..... 2%
Satisfaction with community placement	
Has your family member adapted well to the new physical environment?	Yes.....93% No5% No response..... 2%
Has your family member adapted well to living in a smaller setting?	Yes.....93% No7%
Are you pleased with your family member's present placement?	Yes.....93% No5% No response..... 2%
Are you satisfied with the current staff support provided for your family member?	Yes.....92% No8%
Is the current location a good fit for your family member?	Yes.....97% No3%
Are you satisfied that the layout/setting of the current home is appropriate for your family member?	Yes.....95% No5%
Professional/medical supports include specialists that your family member may need (including dentist/ physician/ psychologist/ behaviour analyst/ neurologist etc.).	
a. Are you pleased with the quality of professional/medical supports your family member is receiving?	Yes.....93% No5% No response...2%
b. Are you pleased with the amount of professional/medical supports received by your family member?	Yes.....90% No7% No response...3%
c. Are you pleased with your family member's access to needed professional/medical supports?	Yes.....86% No9% No response...5%
Alignment with essential plan	
Does your family member have the amount of professional/medical supports that were recommended when he/she left the facility?	Yes.....88% No8% Other.....4% (Supports were not needed after the move)

Table 1. Family Survey Quantitative Questions and Response Rates (continued)

Questions	Responses
Communication with staff	
How would you rate the nature of the relationships between the individual and the staff?	Positive, strong individual relationships..... 88% Neutral or limited individual relationships..... 8% Weak or negative relationships..... 4%
Describe the communication between your family and the new agency.	Good79% Adequate.....16% Poor.....5%
Outcomes for former facility residents	
Has your family member's move to the community produced changes that you had not anticipated before he/she left the facility?	Yes.....69% No31%
Quality of life	
Quality of life is the degree to which a person enjoys the important possibilities of his life. When we are talking about your family member, we might ask, "How good is his or her life for him or her?" How would you rate the quality of life of your family member now?	Excellent.....56% Good.....31% Adequate.....3% Needs Improvement8% Poor.....2%
Family involvement	
Are you geographically closer to your family member than when he/she lived in the facility?	Yes.....81% No19%
Are you able to:	
a. Visit more often?	Yes.....81% No14% Same5%
b. Call more often?	Yes.....76% No8% Same16%
c. Have your family member visit more often?	Yes.....53% No24%* Same24%*
* Totals may not equal 100% due to rounding.	

Results

The results below represent a summary of the quantitative questions as depicted in Table 1: Family survey questions and quantitative responses. Selected qualitative comments are included throughout to provide additional illustration of the key points. The responses are categorized in terms of satisfaction with the transition, satisfaction with community placement, alignment with Essential Plans, communication

with staff, outcomes for former facility residents, quality of life, and family involvement.

Satisfaction with the Transition

Following transition to the community, 91% of the families rated their satisfaction with the transition as excellent (67%) or good (24%). Adequate (2%), needs improvement (5%), and poor (2%) ratings were reported by nine percent of the families.

Families reported enormous pre-placement worry but expressed surprise and relief at the unanticipated ease with which most individuals transitioned into the community settings. They were appreciative of the staff of the community agencies for their dedicated work in making the relocation experience comfortable for their family members and welcoming them to their new homes. The response of one family provides the best summary of the fears and apprehension that families expressed about the transition and their reactions following the placement in the community:

We had worried about the transition. After all, [she] had lived in the institution for more than 40 years. And we had been very pleased with her care and activities. We worried that she would miss many of her friends and familiar surroundings, and might become disoriented and withdraw or "act out." We worried that there might not be enough staff in her new location and that [she] might be pushed aside and simply placated. We worried about a high staff turnover rate. We worried about decreased access to activities and programs. We worried about poor tolerance and non-acceptance in the community. We worried about her physical care, too – cleanliness, quality of her meals, decreased exercise, etc. We worried about how much access we would have to her and how that would be arranged. We worried that she would not have stimulating activities to do and that her preferences might be disregarded and she would simply be placed in a "one-size fits all." Thankfully, all of our fears were ill-founded when she arrived at [her group home]. (Response from sister-in-law)

An overarching theme from families was that the announcement of closure was traumatizing. They feared the worst, but in the end they were relieved that the process went well and were surprised by the positive changes.

Since [he] had been at [the facility] for 50 years, I thought it was almost cruel to change his environment, especially when he is non-verbal and he cannot explain things to them. However, I have been very pleasantly surprised. I have now come to believe that an institutional setting is cold and not "loving" and that a group home can be warm and caring, and that we all respond well to love and caring. People at his church... assure me that he is much happier and much more demonstrative about his own love and affection for care workers whom he has come to know and love. (Response from parents)

Satisfaction with Community Placement

Ninety-three percent of the families reported that their family members had both adapted well to the community setting and to living in a smaller environment. Positive change in the demeanour of former facility residents was reported by families who noted that their family members seemed much happier and less anxious since the move to the community. Improvement in health and physical/mental status was also reported by family members.

Families reported overall satisfaction with the present placement of their family member (93%), the staff (92%), the location and goodness of fit (97%), the layout/setting of the home (95%), the quality of medical/professional supports (93%), the amount of medical/professional support (90%), and family access to medical/professional support (86%).

Families expressed satisfaction with the community setting with regard to philosophy; the home-like, yet secure, nature of the settings; the care and approach of trained staff; and the inclusion in activities in the community. With regard to philosophy one family wrote:

For the first time in many years he is being treated and given the same privileges as a "normal" human being. His needs and his desires are being taken into consideration by kind, knowledgeable and caring people. (Response from a sister)

However, one mother was concerned about the agency's philosophy of person-directed care. She reported that the agency in which her son lives was not providing appropriate care because staff were following what they deemed was his right to choose. He was resisting certain personal care procedures, and she believed that failure to provide these was neglectful.

Additionally, although families in the Facilities Initiative had gained, through the litigation, the right to make the final decision about the location of the placement, one family noted that near the end of the process there was a lack of real options for community placements such that their family felt forced to settle for the only available setting.

Alignment with Essential Plan

Eighty-eight percent of the families reported that the amount of professional/medical support that was received by their family members was consistent with or more than that recommended in the Essential Plan that was designed to guide deinstitutionalization planning for each individual. Of the families who reported that the recommended professional or medical supports were less than recommended, two families indicated it was because the individual did not need the services that had been recommended. However, four family members indicated that the medical treatment that their family member was receiving was less than recommended and of concern. They noted the quality and expertise of the presiding physician and delays in evaluation and treatment were the foundation for their concern. Some concerns were related to the responsiveness of the community agency with regard to gaining medical care and the training of the community support staff. Other concerns were directed more towards the Ontario health care system.

Communication with Staff

Families generally (88%) rated the nature of the relationships between their family members and the community staff who support them as positive and strong. Families further noted that their communication with the new agency, regarding their family members, was generally good (79%), while 16% reported an adequate level of communication and 5% reported the communication as poor. Of the five percent ($n = 3$) of the families who reported concern regarding the communication, the concern was attributed to one of three reasons: perceived agency or individual staff obstruction of family involvement, reliance on part-time staff with high staff turn-over, or training of staff.

Outcomes for Former Facility Residents

Sixty-nine percent of the family respondents reported that the move to the community had produced unanticipated positive outcomes for their family members. Thirty-one percent of the families did not feel there were unanticipated changes or were uncertain. The following is

a strong illustration of the changes that were described:

[My sister] spent 40 years of her life in [the institution]. [Her] move almost 5 years ago now to [the group home] has been the most incredible experience for [her] and our whole family...finally being able to reintegrate back into the community in such a family atmosphere with such incredible love and support has been truly amazing. It has been nothing but positive from day one – she opened up her first bank account in the first year there, she went to a movie for the first time in her life, she has gone on trips every year, one to Aruba to attend a wedding of one of the former staff members. The staff has shown her respect and dignity – an experience she was not used to – she is valued for her opinions, and is treated as one of the members of the community in the house. To answer your question, yes, the move has produced changes but every change has been a positive one for [my sister] and the family. (Response from a sister)

The comments regarding outcomes primarily focused on areas of well-being and socialization, self-care and independence, activities, health and behaviour. Examples are provided below.

- **Well-being and socialization.** Increased comfort and happiness was a common theme among the family members who noted positive changes. As one sibling noted:

[He] has changed from a distraught nervous and unhappy man to a very calm, trusting and usually happy individual. We did not anticipate such a metamorphosis. He has become accepting of familiar and friendly touch, something he withdrew from most of his life. He is open to learning various modes of communication and spends far less time in self-harmful behaviours as a result. We anticipated anything but positive change and are pleasantly surprised.

- **Self-care and independence.** Improvement in their family members' self-care skills (such as feeding oneself or eating solid food) and choice-making (choosing clothes) were identified by respondents. As one sister wrote:

Since her move to the new setting, we found out lots of the things she was having problems with

(e.g., bathing, scared of water) were false. She did not need as much care as I was told.

- **Activities.** Families noted the variety of activities that their family members engaged in, from daily routines such as grocery shopping, to extended vacations and special activities in the community and in the home. One mother wrote:

It is hard to describe the changes which offered more peaceful surroundings, regular routines of shopping, bowling, swimming, and walking programs for exercise and fresh air. Most important for my son is his enjoyment of music. Also, a special walkway has been erected in the backyard with a railing for outdoor exercise.

- **Health.** Families indicated that the medical needs of their family members were being addressed through regular monitoring and medical visits. Reduced medication and better nutrition were also noted. One mother who had two children involved in the Facilities Initiative wrote:

Both (my sons) were prone to pneumonia which can easily become life threatening. [It is] better now. They have lived at [the group home] for over 2 years. I thought the move would kill them, literally. Instead they are healthier, happier, and doing better than I ever dreamed.

She noted that her sons had had pneumonia only once since they had been transitioned, compared to a rate of four times per year when in the facility.

- **Behaviour.** Comments about behaviour changes varied, with some families noting remarkable changes such as the elimination of outbursts and self-injury and discontinuation of the use of restraints, while others noted no change, variable change or an elevation in problem behaviour.

Quality of Life

Quality of life is an indicator of “the degree to which a person enjoys the important possibilities of life” (Brown, Raphael, & Renwick, 1997, p. 10). A large majority of families (87%) rated the quality of life of their family members as good to excellent including caring staff, access to a range of activities, nourishing meals, a

homelike atmosphere, and the overall contentment or happiness they witnessed in family members.

Although statistically these data demonstrate an overall positive outcome for most individuals, the counter-stories of those families who rated their family members’ quality of life as either needing improvement (8%) or poor (2%) represent 10% of the families who responded. Their concerns provided important information regarding the community placements. Families who considered the quality of life of their family members to be poor or needing improvement focused on the approach and management of the agency and the quality of staff training. Medical issues and concern for too much autonomy were often noted as being contentious.

Family Involvement

The majority of families reported increased contact, such as visits to (81%), calls to (76%), and visits from (53%) their family member following the transition. The following quote from a sibling describes this change:

We now see [him] approximately once a month. A caregiver brings him out to my siblings’ and my homes. He is calm and enjoys being with us. He is always well groomed and we have been able to get to know our brother as we have never [been] able to do before. We can now see so many family similarities that we hadn’t known we shared. This move has been the best thing to happen to [him]. My entire family agrees.

Families acknowledged the importance to the individual and their family of again having their family member in close proximity to home and family. This has allowed for family involvement in meetings and appointments for their family member as well as the individual’s participation in important family functions. One elderly parent spoke of her appreciation that her daughter could now visit her when she is not well.

One family, however, noted that her family member was placed in a group home some distance from the family and, although she was happy, they found “driving into the city an increasing problem.” This family requested that their family member be moved to a loca-

tion closer to the family; however, this required yet a second relocation and consequent adjustment for the individual.

The overall results from this study were very positive. Still, the counter-stories of some families regarding both their experiences of the deinstitutionalization process and the outcomes they perceived as poor or needing improvement provided a valuable lesson regarding the approach taken to enlist family involvement prior to and following the announcement of closure.

Discussion

Families who participated in this study of the Facilities Initiative reported a range of positive changes in adaptive and maladaptive behaviour, socialization, communication, family contact, health status, community inclusion, and choice-making. Of special note by families was the change in perceived security and happiness of their family members. One family noted that positive changes were ongoing and had continued each year for the five years that the person had been in the community. The findings of improved quality of life are also consistent with the literature reports that families are pleased with the quality of life changes for their family members after deinstitutionalization (e.g., Emerson & Hatton, 1996; Larson & Lakin, 1991; Tabatabainia, 2003).

The study did, however, identify factors that were related to individual differences within the sample. The variations from the majority were also consistent with the literature. Examples that contradict the overall story are provided through counter-stories. Some common characteristics in the counter-stories included the structure and size of the community placement, location and the lack of accommodation for personal expression or individual differences.

One of the most important factors for families was the improved geographical proximity to their family members and the enhanced ability to have increased contact with them since the transition to the community. Many of the families relayed touching stories of how the transition had allowed them to reintegrate their family members into family celebrations. Families were also more involved in the lives

of their family members regarding their practical needs, communication, decision-making, emotional support, and advocacy. Variations in parental involvement related to the age and health of the family members, although many siblings and even cousins had become more actively involved. These findings are similar to other studies that have reported an increase in family contact following deinstitutionalization (e.g., Cummins & Dunt, 1988; Emerson & Hatton, 1994; Spreat & Conway, 2002).

The results from this study far exceed expectations based on an earlier study in Ontario where only 50% of the families reported increased contact following deinstitutionalization (Griffiths, 1985). Moreover, the compelling descriptions of the positive changes in family contact and reunions of family members were not strongly predicted from the available literature; the families in this study elaborated in great detail on this important change in their lives. Their elaborations provide an impressive illustration of the improved quality of life and enhanced level of well-being that families perceived following the transition of their family member to the community.

For jurisdictions undertaking a deinstitutionalization initiative of this kind, a greater emphasis on the planning process with families and for individuals may have a positive impact on the challenges that some families in this study experienced with deadlines and a lack of available options. Such increased family involvement in planning from the earliest stages in the process may also help to reduce family stress and resistance. Perhaps the most noteworthy recommendation that emerged from this survey was that future deinstitutionalization initiatives focus on creating strong family alliances with the Facility Planners as a basis for providing consistent and accurate information about the process, planning, and potential placement options. This alliance should be based on a systematic approach developed through the distribution of brochures and videos and through holding information sessions, as well as personal contacts, to ensure families are accurately informed of the experiences and research regarding previous deinstitutionalizations. A proactive approach to parental involvement would provide a basis for informed decision-making and a counterbalance to the apprehension and misinformation

that they may have heard or hear from other sources regarding community placement. Some families may have experienced or may have heard about community placements that were not successful. They may not be aware of the development of community support services that has emerged since the original institutional placement of their family member and the early stages of deinstitutionalization that took place years ago. In addition, the family affiliation with staff in the facility may be strong and as such they may be inclined to align with the attitudes held by the facility staff members that too may be built on previous experiences and a lack of direct knowledge of the current community conditions. As one family member conveyed, she would have moved her family member earlier had she not been convinced by the facility staff that her brother would be at risk in the community. A focus on family alliance may provide a means not only to reduce family stress but also may aid to channel transitional stress from resistance to collective planning.

Key Messages From This Article

People with disabilities: The last three institutions run by the Ontario government were closed in 2009. Family members say the last people to move out are doing well living in the community.

Professionals: The supports and services recommended for the individuals moving to community living after the closure of the last three institutions in Ontario were available, and the adjustment to community living has been very successful from family members' perspectives.

Policymakers: Family members of residents who were moved to community living after the closure of the final three government-run institutions in Ontario, even those who were initially concerned, were generally pleased with the outcomes of deinstitutionalization.

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