

The Ontario Facilities Initiative: Perceptions of the Deinstitutionalization Process

Abstract¹

This paper reports findings from two of four studies conducted as part of the Ontario Facilities Initiative that focused on the outcomes of the closure in 2009 of the last three provincially operated facilities for persons with intellectual disabilities. As a companion to the outcome studies (Griffiths, Owen, & Condillac, 2015a, 2015b) that report positive results for individuals following transition to the community, this paper explores the nature of the deinstitutionalization process from the perspectives of family members of former facility residents, community agency staff, former facility staff, planners, and behaviour consultants.

Participants emphasized the importance of a focus on individualized and well coordinated cross-constituency information sharing and planning to ensure that appropriate community services are matched to authentic individual needs and preferences. Recommendations for other jurisdictions undertaking a similar initiative included the need to inform family members of the impending closure early in the process to ensure that they are aware of time frames and the range of community services available. The central role played by planners was identified and recommendations were made for the training and support needed to facilitate their work.

The improvement in quality of life through the movement from large group living to small group or family living is generally accepted in the field of disability research (Bock & Joiner, 1982; Doody, 2011; Emerson & Hatton, 1994; Lemay, 2009; Mansell, 2006). However successful deinstitutionalization requires coordination of a complex process that includes involvement of families (Doody, 2011; Larson & Lakin, 1989; Tabatabainia, 2003), funding, service delivery models matched to needs, and models of intervention and staffing supports (Bradley, Ashbaugh, & Blaney, 1994). It requires careful and thoroughly coordinated planning at all levels

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involving individuals who are leaving institutions, their families and advocates, government departments, and community-based developmental service agencies, as well as other services providing both generic and specialized supports in the community.

Early deinstitutionalization tended to focus on systems-planning with individuals being placed in community residential spaces that were available. In contrast, current processes are more likely to follow an individualized lifestyle planning or person-centred planning approach to achieve individualization of supports to improve the quality of life of former facility residents (Holburn, Jacobson, Schwartz, Flory, & Vietze 2004). However, as Young, Sigafos, Suttie, Ashman, and Grevell (1998) suggested, the mere fact of community placement is not necessarily sufficient to achieve positive outcomes for individuals; these successes may rely on the interaction among the characteristics of former residents, their care providers, and the nature of community services. Factors that may impede positive outcomes include the adoption of an institutional philosophy in the community setting (Ericsson, 1996), the skill and attitude of the staff (Larson, Lakin, & Bruininks, 1998) and poorly implemented community services (Emerson & Hatton, 1994). International economic pressures and shifting policy foci have added to the complexity of this service implementation.

Simpson and Price (2009) examined the United Kingdom's implementation of the *Valuing People* policy revealing "unintended consequences" (p. 180) of deinstitutionalization related to increased reliance on families as care providers and a lack of supports to provide a full range of services, especially for those who are most vulnerable. These authors warned of the dangers of deinstitutionalization as a neoliberal tool for cost saving without reinvestment in appropriate community supports. Similar gaps between the policy and implementation of deinstitutionalization have been seen elsewhere. In Finland, Miettinen and Teittinen (2014) also described the deinstitutionalization process in the context of a cost saving agenda. They identified a resulting lack of personnel, lack of staff training, lack of service matching to individual needs, and "questionable solutions in the design of the constructed environment for people with intellectual disabilities" (p. 70) as some of the factors compromising the quality of community

services. These findings underscore the need to ensure that developmental and specialized services in the community have adequate resources to meet the needs of former facility residents.

Various family concerns can also present barriers to deinstitutionalization. Family resistance to community repatriation has been linked to satisfaction with existing institutional care, fear that their family member may receive inadequate care in the community and may experience negative outcomes following deinstitutionalization, and concern that the move may result in negative impacts on family life (Tabatabainia, 2003). For some family members, the announcement of impending facility closure prompts reliving and perhaps re-grieving the original placement in the facility so many years ago (Mirfin-Veitch, Bray, & Ross, 2003), and this may act to delay institutional closure (Martin & Ashworth, 2010). However, while families in a study by Tøssebro and Lundebj (2006) opposed deinstitutionalization when the plans were announced, the majority supported the shift to the community after the move. Similar results were reported in earlier investigations by Heller, Bond, and Braddock (1988) and also by Larson and Lakin (1989) in their review of 27 studies of the perceptions of parents of persons who were current or previous institutional residents. Larson and Lakin found that "prior general satisfaction with institutional care and reservations about community care in time turns into overwhelming satisfaction with community settings" (p. 4), suggesting that families should be provided with information about community settings to help reduce their stress and resistance to deinstitutionalization. It is also important for families to be involved actively in the deinstitutionalization process (Doody, 2011). They need information about the rationale for the initiative, the nature of available community supports and services that can support individuals outside their family home, and the process to be used in moving individuals out of facilities (Tabatabainia, 2003). Tabatabainia also emphasized the need for adequate funding to address the service concerns expressed by families. Still, while the ultimate outcomes of deinstitutionalization may be positive for most individuals and families, the process itself can be challenging. These findings highlight the need to examine not just the facts and outcomes of deinstitutionalization, but also the complex multi-constituency process required for its successful implementation.

Four Facilities Initiative studies, two of which are reported in this paper, examined the outcomes of the closure in 2009 of the last three government operated facilities in Ontario, Canada. The studies examined personal outcomes for former facilities residents and their families, and also the perceptions of family members, placement planners, community and former facility staff concerning the nature of the deinstitutionalization process itself. This paper aggregates key findings related to the process and recommendations for other jurisdictions undertaking similar initiatives.

Methodology

The Ontario Facilities Initiative Focus Group and Interview Study, and the Family and Agency Survey Study were conducted within two years following the closure of the last facilities for persons with intellectual disabilities in Ontario in 2009. They included focus groups and interviews with family members, planners, and care providers of former facilities residents, as well as surveys with family members and community agency staff.

Focus Group and Interview Study

Participants

A total of 40 people participated in 7 focus groups and 17 interviews. Ten parents and siblings participated in interviews or in the Central or Southwest Ontario focus groups. (The adult children of two of the parent participants were involved in a previous depopulation initiative.) All family members who were involved in the Focus Group and Interview Study were also sent a copy of the Facilities Initiative Survey to give them an alternative method of participating in the study. Ten Planners (former Regional Placement Facilitators and a Planning Coordinator Assistant), one former facility staff member, and three behaviour consultants also participated. Sixteen community agency staff participated in four community staff focus groups (3 in Eastern Ontario, 1 in Central Ontario). Although participants are identified by one role, some participants had a variety of experience in the field including, for example, community agency staff who had experience as former facilities staff.

Recruitment

Recruitment was conducted between July 2009 and November 2010 with focus groups and interviews conducted between December 2009 and January 2011. Invitation letters for the Facilities Initiative Study were sent to family members through community agencies that supported their family member. Community agency staff members were recruited through invitation materials distributed through their agencies. Former Regional Placement Facilitators and former facilities staff members were recruited through the Ministry of Community and Social Services. The Ministry also provided the researchers with contact information for these groups to facilitate direct follow-up recruitment. The Networks of Specialized Care and Behaviour Consultation Programs were provided with invitation materials and contacted by study researchers.

In addition to this formal recruitment, a variation of snowball recruitment (Sadler, Lee, Lim, & Fullerton, 2010) was used in response to participant concern that people known to them may not have been made aware of the study. This involved Regional Placement Facilitators, professionals in the Networks of Specialized Care, and Behaviour Consultants sharing information about the study with their colleagues whom they believed would be interested, and it was left to these individuals to choose whether they wished to contact the researchers to volunteer for the study.

Given the variety of recruitment methods used to ensure the widest possible dissemination of participation invitations, the total number of people who received recruitment information is not known to the researchers. As a result, the researchers can make no claim that the final group of participants is representative of all who were involved in the Facilities Initiative.

Procedures

Semi-structured questions for the focus groups were developed, based in part on the method of Mitchell, Clegg, and Furniss (2006; see also Cambridge & McCarthy, 2001). The same questions guided the interviews, with most interviews covering all questions. The questions included items that asked participants to describe the process of the move from the facili-

ty to the community, who was involved in making placement decisions, and what advice participants would give to people in other jurisdictions undertaking similar deinstitutionalization initiatives. For each focus group and interview, a researcher or research associate asked questions and a research assistant took notes and audio-recorded the sessions for later transcription.

The focus groups and interviews were conducted in person, through videoconferencing and on the telephone to make study participation accessible to participants in various geographic locations and with various mobility concerns.

Analysis

A descriptive content analysis was used, including a hybrid inductive and deductive approach to thematic analysis (Braun & Clarke, 2006; Fereday & Muir-Cochrane, 2006). Interview and focus group transcripts, and notes from one interview, were coded by the researcher and research associate who conducted all but one of the interviews and all of the focus groups and were, therefore, most familiar with the data. Coding was shared between these researchers who agreed on the codes that were used (Corbin & Strauss, 2008). The initial coding related to the research questions: the placement process and changes or outcomes for the former facilities residents. Specific codes related to these questions were generated in the within-group coding of transcriptions of all family interviews and focus groups, the first four planners, the first behaviour consultant and the first two community staff focus groups. These codes formed the foundation for the first step in coding of the entire data set. The second step in coding was the development of secondary and tertiary codes. The goal of these levels of coding was to reflect the full range of positive and negative process and outcome experiences described by participants. The third step in the analysis was the conceptual grouping of codes across participant groups to develop broader themes and related sub-themes.

Family and Agency Survey Study

The surveys for families and recipient agencies were constructed according to the guidelines identified by Hessler (1992), starting with a liter-

ature review from which key concepts emerged and evolved into a conceptual map that identified the key elements to be examined in the questioning. These key areas included quality of life, functioning changes, access to supports, inclusion in the community, and others. Each concept in the survey was defined operationally, and each question was then developed to elicit the information that was deemed important in the study.

Development of the Agency Survey

The Agency 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.

In the agency survey, each concept was introduced in more than one way to reduce the potential of bias. The survey included a combination of open- and closed-ended questions. The closed-ended questions ensured that the respondent made a definitive statement about the concept; this may include yes and no statements or ratings on a Likert-type scale. The open-ended questions allowed the respondent to give a response expressing richer exemplars and sentiments. The latter allowed the respondent to provide fuller explanation of the responses given in the closed-ended questions and led to a greater understanding of the nature of the rating.

The survey was 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, 2009; Hamelin, Frijters, Griffiths, Condillac, & Owen, 2011). No changes were made following the field-testing.

Development of the Family Survey

The family survey was based on an earlier survey developed to evaluate the outcomes of the Five Year Plan closure of Pine Ridge,

an institution in Aurora, Ontario (Griffiths, 1985). This questionnaire included a combination of 18 open and closed-ended questions. The closed-ended questions ensured that the respondent made a definitive statement about the concept (e.g., *Has your family member adapted well to the new physical environment?* to which they were asked to respond *Yes or No* and then to *explain* their response. Or, *How would you rate the quality of life of your family member now?* to which they were asked to respond on a five-point Likert-type scale, ranging from excellent to poor, with a request to explain their choice.)

The open-ended questions allowed the respondent to give a response expressing richer exemplars and sentiments. The family survey was compared against the preliminary data from the Focus Group and Interview Study (Owen, Griffiths & Condillac, 2010) and pre-tested using a small sample of families from previous transitions; no modifications were made.

Survey Distribution

Surveys were distributed to families and recipient agencies one year following the closure of the last facility. The Ministry of Community and Social Services (MCSS) invited all families and agencies 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 and agencies that responded. Follow-up emails and calls were made to the 80 community support agencies for individuals being repatriated to invite participation from families and agencies who did not respond to the MCSS invitation. Additional invitations to participate were forwarded through networking channels available through Community Living Ontario and the provincial Networks of Specialized Care.

Families and agencies submitted their responses electronically or by mail. Follow-up emails and calls were used to increase the possibility of a return rate that was representative. There were 941 individuals who were repatriated to the community following the announcement of the Facilities Initiative. Each completed survey returned represents an individual who transitioned to the community during the Facilities Initiative. The family survey yielded 61 respondents or a return rate of 6.5%; the agency sur-

vey yielded 114 completed surveys for a return rate of 12% of the individuals who were transitioned to the community during the Facilities Initiative. While these rates of return appear to be low, it is important to note that family contact information was not available for many of the former facility residents. In addition, considerable time had elapsed between facility closure and the initiation of the study that may have reduced interest in participating in these retrospective studies.

Triangulation

To optimize the advantages of the triangulation that was built into the design of the Facilities Initiative Study (Quinn Patton, 2002), the results of the Focus Group and Interview Study and the Family and Agency Survey Study are reported together with a specific focus on themes from these studies that related to the process of planning and implementing the community moves during the Ontario Facilities Initiative.

Results

The reported outcomes of the Facilities Initiative for former facilities residents are strikingly positive. Participants in the Focus Group and Interview Study described important changes in quality of life of former facility residents, including factors such as: increased contact with family members and involvement in family activities, expanded involvement in community activities, and increased privacy, self-determination, and self-expression. In particular, planners, behaviour consultants, and community agency staff members described reduction in the use of restraints and medications for behavioural concerns following community placement. In some cases, these changes occurred very soon after leaving the facilities and represented a dramatic change in behaviour for the individuals involved. For a detailed analysis of these outcomes for individuals see the reports of the Family (Griffiths, Owen, & Condillac, 2015a) and Agency Survey Studies (Griffiths, Owen, & Condillac, 2015b) in this issue.

Key themes related to the process of planning and implementing the Facilities Initiative included family reactions to the announcement of the Facilities Initiative, the amount of time

needed to undertake the process, the nature of the multi-constituency integrated planning process, and the need to prepare communities to welcome and support former facility residents. Each is described below, followed by recommendations for other jurisdictions undertaking deinstitutionalization initiatives.

Family Reaction to the Announcement: Grieving and New Beginnings

Among family members, the process of moving to the community was emotionally charged. Some grieved the loss of relationships that facility residents had with other residents and with facility staff, relationships that represented home for the residents. Some family members also grieved the loss of their relationships with residents and facility staff that had become a way life for them over the years of visiting.

The fear experienced by some family members also related to not knowing what would await them in the community. As a brother reported in the Survey Study:

Prior to his move from [the facility], we were very concerned for his well-being and safety in the outside community. He had spent his whole life at [the facility] and we presumed it was as safe and secure as anything available elsewhere. We feel that the Ministry failed badly in not providing constructive information on the kind and quality of care from agencies. We simply did not know what was in store for his future. The result was we had to sue the government to get control of the placement of all individuals from this facility.

Alternatively, some of the families were eager for the Facilities Initiative and felt it was overdue. One mother noted that the facility provided:

Custodial care only, and in the time [my daughter] was there (1975-2008) I saw and [was] witness to many cases of abuse, neglect, and 100-year-old thinking. One had to make a lot of noise to get something done. All in all, this move is the best thing that could have happened.

One sister noted in her Survey response that she had been convinced by the facility staff that her family member could never be supported in the community because of extremely high

needs; these predicted needs were not apparent or problematic after the transfer to the community. In the absence of detailed background information about this particular individual, it is difficult to interpret whether this difference was the result of the change in setting factors or a reflection of the perspective of the facility staff. One planner described this as "...the institutional culture of health and safety come before desires and what's important to people."

In the Focus Group and Interview Study, even those family members who were not supportive of the closures reported some positive outcomes for their family members. These included increased involvement in family activities, access to new experiences such as travel, involvement in outings, and improved physical and mental health.

In the planning process, families needed to know that they had choices and could visit possible placement sites with or without a government-assigned planner. While families were granted the legal right to the final decision about placement, a number of families in the Survey Study spoke about the practical lack of choice when it came to placement options. They said they accepted the best from what was offered, but indicated they had to "settle" and in some cases had only one available option at the time.

Among all groups of participants in the Focus Group and Interview Study there was general consensus that families should have been involved in the planning process earlier, and should have been provided with more information about the reasons for the closures, the time frame within which they would happen for their family members, and the nature of the services available to their family members in the community. As one family member explained, "... number one, getting a letter is very, very hard. I think that there should be a phone call before the letter goes out to the parents because getting a letter telling you that an institution of 50 years is being closed and you have to move your family member is so daunting and so devastating for everybody."

Time to Complete the Process

Community staff in the Focus Group and Interview Study expressed concern about the time available for planning the placements.

A staff member reflected on how there had been sufficient time for person-centred planning when the process began but, as the end of the Facilities Initiative approached, the process became more rushed. In its later stages the process became more complicated due to limitations in housing options caused by group homes not being ready to receive former residents. Notions of what constitutes adequate planning time varied. A behaviour consultant recommended a minimum of three months of preparation to gather information, conduct observations and assist the resident through the transition process with visits before the final move. In contrast, a former planner suggested the need to begin planning two years in advance of facility closure.

A similar concern was raised regarding the time for post placement follow-up. A planner recommended six rather than the three months of post placement monitoring by planners that was built into the Facilities Initiative. Community staff also suggested a six-month post placement review of service needs to facilitate planning in response to needs that may have changed following initial adjustment.

Integrated Service Planning

The nature and success of the planning process for agencies were largely dependent on the quality of the Essential Plans created for each person who left the facilities. These individual service plans were developed by the Regional Facility planners through a process that involved file reviews, observations, and interviews with staff in the facility, the family, and the individual (if possible). The purpose of the plan was to provide a comprehensive snapshot of the person and the transitional placement needs on which agencies could develop a Transitional Plan. Agency Survey respondents noted that these Essential Plans were very relevant in only 28% of the cases, and only somewhat relevant in 59% of the cases. Thirteen percent of the respondents found the Essential Plans to be not at all relevant.

Participants in the Focus Group and Interview Study discussed the importance of an integrated, open, and flexible team approach to planning that involved all partners in the process including families and all service providers.

Some community agency participants discussed the need for the planning process to be truly individualized, including moving beyond group home placements to find individual supports for people. As a planner emphasized, this was important to ensure "... that everybody who is going to be supporting these persons is grounded in person-centred thinking."

Sharing information between facility and community staff. A key feature in the planning process was sharing information between facility and community staff members. Participants gave varying reports about the ease with which important information was shared. Among some informants in the Focus Group and Interview Study there was a sense of shared vision with facilities staff in facilitating the transition process. A community staff participant reported that "there was lots of teamwork and very good communication and it was a lot of work to see that happen." The days spent at the facility by community staff prior to placement were identified as being very important despite the fact that it was recognized that this could put a strain on small agencies. Sharing included "job shadowing," visiting the individual and staff in the facility, pre-placement meetings or placement visits with the facility staff, post-telephone contact with the facility staff, and a commitment to maintain consistent staff throughout the transition process.

However, some agencies in the Survey raised concerns that pointed to inconsistencies in the process across agencies or facilities, including timeline challenges and lack of information sharing. Community staff reported that they were not always provided with sufficient time to gather the required information during shadowing, or that the accuracy of the information appeared questionable. Pre-placement preparation for the transition was in some cases rushed to meet Ministry of Community and Social Services' deadlines.

Role of planners. Planners were identified by the stakeholder groups as the key link for successful transitional planning and implementation. However, there were families in the Survey Study who experienced the process as a struggle with the Ministry staff and expressed their feeling that the Regional Facility planners did not care where the family member was

placed or if the individual's needs were met. In sharp contrast, other families described the role of the Regional Facility planners as being critical to a positive planning process and as an invaluable link in the chain of events. Family participants in the Focus Group and Interview Study discussed the central role that planners played in guiding them through the deinstitutionalization process. For example, in the Survey Study one brother stated that:

The most important policy/program aspect of the move was the assignment by the Ministry of a specialist to council and assist in the transition. She worked with us... to identify possible locations, visit them, arrange for a test visit... and to follow up with us and the facility. This very professional and dedicated person helped immensely to ease anxiety and facilitate a positive process.

Planners described the complexity of their roles and their need for training and ongoing consultation. However, they also described feeling elation and a life changing impact from the long process of contacting families, developing relationships, negotiating, and achieving community placements. One planner commented with pride on the speed with which the closures occurred given the complexity of the process: "You know when you... think about it... with all the parameters and the elements that you had... to see it completed in four years, to me, it's amazing."

Support for behavioural concerns. Planning for former facility residents with behavioural concerns was identified as being especially important. A planner in the Focus Group and Interview Study described the need to have access to documentation about the behavioural needs of the former facility residents early in the placement process. A behavioural consultant described variable experiences in coordinating services with planners and community staff ranging from complete collaboration on program development to being functionally left out of the placement process.

Community Awareness

Community staff in the Focus Group and Interview Study suggested the utility of newspaper articles, as one staff member explained, "to eliminate that whole stigma that comes with supporting a person with intellectual disability." This participant emphasized the

importance of informing the community about the rights of persons with intellectual disabilities and debunking myths about behavioural concerns. Part of the suggested community preparation was education early in the deinstitutionalization process for medical and other community resources "so that they can be more supportive and understanding, and also understand their responsibility to the process, not only for people moving out of the facility, but every community member ..."

Recommendations for Future Deinstitutionalization

Involving Families Actively and Early in the Process

Before public deinstitutionalization announcements are made, families need to be the first to be informed, in a personal manner, that their family member will be leaving the institution. Families need to know why deinstitutionalization is being undertaken, what the specific time frames for moving their family member will be, how they will be involved in planning, what rights they have, and what resources are available in the community to meet the needs of their family member.

Knowing the Individual and Person-Centred Planning

Family, behaviour consultants and planner participants need to discuss their knowledge of the individual who is leaving the facility, respond to his/her preferences and needs, and provide as much freedom of choice as possible given the limits of safety. Related to this is the need to ensure that facility residents are provided with clear and meaningful explanations of the fact that they are moving because the facilities are closing and not because they are being sent away from their home.

Having More Time for the Process

The time needed to plan placements varied depending on the role of the participant. For comprehensive planning, such as that undertaken by the placement planners, two years may be necessary while specialists may need

three months pre-placement to become familiar with the individual and to review files.

At least six months of post-placement follow-up is necessary to monitor and respond to changing needs following individuals' initial placement adjustment.

Training and Support for Planners

Planners need training in conflict resolution, negotiation skills and person-centred planning. They also need consultation with other planners to discuss strategies and consultation with social workers especially regarding support for families who are experiencing grieving during the deinstitutionalization process.

Preparing the Community

Communities to which former facility residents are moving should be prepared using traditional and social media awareness campaigns to inform them about the rights of the former residents, to dispel myths and to increase the likelihood that community services, including medical and other services, will be prepared to meet their needs.

Discussion

The cross constituency themes from this study generally mirror key family, planning, and coordination process issues discussed in the international literature on deinstitutionalization. The transition process tends to present emotional challenges for families that should be taken into account when planning deinstitutionalization processes and supports (Mirfin-Veitch, Bray, & Ross, 2003). In addition to valued facility relationships, some family members perceived a loss in specialist resources, such as immediate access to facility medical care and, similar to the findings of Tabatabainia (2003), uncertainty about what would be available in the community. This makes provision of information about available community resources especially important in order to reassure families who may envision supports as they were when their family member was placed in the facility.

As Tøssebro and Lundebj (2006) suggested, the initial family discomfort with facility closure tends to be followed by later acceptance. This appeared to be the case for most of the

participants in these studies, although a small number continued to express discomfort with the move. There was expression of concern by some planners about the lack of time available for longer post placement follow-up with families following the move.

The central importance of individualized service planning for the former facilities residents was obvious in the studies. Participants in the studies emphasized the importance of teamwork and communication of information about the needs of former residents including the need for families to be involved in placement planning very early in the process. This relationship among families, former facility residents, planners, facility and community staff was described with an emphasis on the importance of respect, trust and clear communication.

It is not possible to determine the degree to which the results of these two studies are reflective of the full population of families and professionals who were involved with and impacted by the Facilities Initiative. Nine hundred and forty-one people left the final three institutions that were closed over a period of five years between 2004 and 2009 and moved to areas around Ontario. The studies reported here were not initiated until after all these moves had occurred so it is likely that for some people, especially those who were involved with the first people to leave the institutions, the questions examined in these studies were no longer of relevance to them. Many people were well settled into their new homes and their former staff had either dispersed after the facilities closed or had taken new roles in the community.

Future research studies should gather pre-deinstitutionalization data from all stakeholders, periodic update data throughout the placement process, and adjustment data six months following the placement. This would allow for the development of a more dynamic picture of the planning process over time and the differences in individual strengths and needs in the institutional and community settings.

Deinstitutionalization, and all it involves is a complex multi-constituency process that requires skilled planners to support and engage families who are grieving the loss of a familiar service system, and to ensure the development and enactment of a meaningful person-centred plan based on accurate information shared by all

stakeholders. However, despite the challenges, the reports of improved quality of life of former facility residents fuel commitment to the process.

Key Messages From This Article

People with disabilities: Moving from institutions to the community improves people's quality of life. You and your family have a right to be involved in your own deinstitutionalization plan so you can make choices that are best for you as an individual.

Professionals: Person-centred planning is important for success. This must involve individuals and families, facility and community agency staff, and specialists including behavioural and medical professionals in the community.

Policymakers: Families must be involved actively early and at all stages. Professional planners are important to co-ordinate the process. Enough post-placement follow-up (3 and 6 months) must be provided to change placement supports based on changing needs.

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