Family Attitudes Toward the Deinstitutionalization of Individuals with Developmental Disabilities in Ontario: A Quality of Life Analysis

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Abstract

The deinstitutionalization of individuals with developmental disabilities to community-based residential services is a pervasive international trend. Although controversial, the remaining three institutions in Ontario were closed in March of 2009. Since these closures, there has been limited research on the effects of deinstitutionalization. The following retrospective study evaluated family perceptions of the impact of deinstitutionalization on the quality of life of fifty-five former residents one year post-closure utilizing a survey design and conceptual quality of life framework. The methods used to analyze the survey results included descriptive statistical analyses and thematic analyses. Overall, the results suggest that most family members are satisfied with community placement and supports, and report an improved quality of life for their family member with a developmental disability. These findings were consistent with previously published studies demonstrating the short-term and long-term benefits of community living for most individuals with developmental disabilities and their families.
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To my daughter Olivia: I hope that my personal passions and experiences will inspire you to always value education as a limitless journey and to always tread paths known, unknown and beyond my own.
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Family Attitudes Toward the Deinstitutionalization of Individuals with Developmental Disabilities in Ontario: A Quality of Life Analysis

Deinstitutionalization, the complete replacement of institutions by community services for individuals with developmental disabilities (DD), has become an indelible social and legislative imperative in Ontario and across the Western world (Lemay, 2009). Currently, Ontario is one of the few Canadian provinces that has closed its institutions for persons with DD. Each country that has undergone the deinstitutionalization process has embraced the systemic, sociopolitical and ideological progression afforded by successful community integration (Kozma, Mansell, & Beadle-Brown, 2009). Although deinstitutionalization has been considered controversial, challenging and complex in process and application, it has afforded individuals with DD a chance to enhance the quality of their lives in meaningful, functional ways and has provided family members the tools to advocate for and appreciate the value of habilitation, community living and the Socratic “good life” for all individuals (Mansell, 2005). However, there are many factors involved in the experience of family members before, during, and after deinstitutionalization and many spheres of influence that can offer a smooth or hard road to community placements and adaptation. The significance of such factors was explored in this retrospective research study examining post-deinstitutionalization family attitudes in Ontario in accordance with the quality of life of individuals with DD in the community.

Deinstitutionalization: An International Perspective

Deinstitutionalization has become a pervasive trend amongst Western countries (Kugel & Wolfensberger, 1969). The advancement of community living and integration as ideals and galvanizing principles for individuals with DD originated in the 1950s but were not fully espoused as a governmental and professional practice policies until several years later in the late 1960s and early 1970s (Bruininks, Kudla, Hauber, Hill, & Wieck, 1981; Kugel & Wolfensberger, 1969; Mansell, 2005). According to Mansell (2005), some of the earliest, successful attempts at the
The deinstitutionalization process began with an experimental study by Tizard (1960) in the United Kingdom, followed by pilot projects in Sweden (Grunewald, 1974) and the United States (Casey, McGee, Stark & Menolascino, 1985). In the United Kingdom, North America, Australasia and Scandinavia, deinstitutionalization is recognized as “probably the most important change in policy and the pattern of service provision in learning disability in the last 50 years” (Mansell, 2005, p.22). It has become the prevailing opinion, national trend and standard of care for most countries. Scandinavian countries (i.e., Sweden and Norway) were considered the progenitors in preserving the legal right to community living and services for individuals with DD (Ericsson, 2002; Mansell, 2005; Tøssebro, 2004). Currently, several Northern European (e.g., Netherlands, Germany, Belgium) and Mediterranean (e.g., Greece and Spain) countries have developed rudimentary community-based services while countries such as Russia and former Soviet satellite countries are beginning to trend towards community care (Mansell, 2005; Mansell, Beadle-Brown & Clegg, 2004).

The majority of research studies exploring the impact of deinstitutionalization on individuals with DD in North America, the United Kingdom, Australia, and Scandinavia suggest that community living provides an overall enhancement and improvement in quality of life (Lemay, 2009). Outcome studies demonstrate that deinstitutionalization is correlated with improvements across several dimensions including adaptive behaviours, greater opportunities for choice, more frequent contacts with family and friends, better overall standard of living, and acceptance by the community (Emerson, 2004; Emerson & Hatton, 1996; Larson & Lakin, 1989; Lemay, 2009; Young, Sigafoos, Suttie, Ashman & Grevell, 1998). These dimensions may also be described as synergistic given that improvements in one dimension may potentiate improvements in another. Although deinstitutionalization remains controversial (Parish, 2005), the overall pattern of results suggests that it is beneficial for individuals with a developmental disability, their families and society as a whole (Lemay, 2009). Indeed, community living and integration have become the
hallmark of best-practice for the social inclusion of individuals with DD. There is a vast body of international research, summarized in several reviews, demonstrating emblematic results in favour of deinstitutionalization (Emerson & Hatton, 1996; Ericsson, 1996; Kozma, Mansell and Beadle-Brown, 2009; Larson & Lakin, 1989; Mansell, 2005; Tøssebro, 1998; Tøssebro & Lundeby, 2006; Young et al., 1998).

In the United States, Larson and Lakin (1989) reviewed 18 research studies on the impact of deinstitutionalization on 1358 participants with DD across several domains including adaptive functioning and behaviour, quality of life, independence and self-help. The results demonstrated significant gains in most if not all domains, especially for those individuals residing in smaller community residences (Larson & Lakin, 1989). In a subsequent meta-analysis of American studies between 1980 and 1999, Kim, Larson and Lakin (2001) compared 29 longitudinal studies and concluded that “in 19 of 21 studies reporting statistically significant changes in adaptive behavior, statistically significant improvements in adaptive behavior were found to be associated with movement to community settings” (p. 44).

In a study by Emerson and Hatton (1996) examining 71 peer-reviewed research studies on deinstitutionalization and the quality of life of individuals with DD in the United Kingdom and Ireland, results suggested similar findings to studies conducted in North America (Larson & Lakin, 1996). Specifically, a move to community-based residential services is associated with fewer behavioural challenges, more adaptive behaviours and choice, increased contact with family and friends, and better standards of living (Emerson & Hatton, 1996). In a subsequent review study conducted by Emerson (2004) examining the process of deinstitutionalization in England, the author concluded that the process offered greater benefits for individuals living in the community and that, while the individuals demonstrated quality of life gains, levels of challenging behaviour remained relatively the same.
In a meta-analysis conducted by Young, Sigafoos, Suttie, Ashman, and Grevell (1998) pertaining to the transition of individuals with DD from institutions to the community in Australia, results suggested positive outcomes in adaptive behaviour, daily living, communication, social inclusion and quality of life. However, the findings were inconsistent regarding problem behaviours such as aggression, self-injury and property destruction. Most of the studies in the review concluded that relocation produced beneficial outcomes (Young et al., 1998).

Scandinavian studies regarding deinstitutionalization and relocation, based on data gathered from the Scandinavian Welfare State in Norway, suggest that family attitudes change after relocation with satisfaction and support for relocation increasing overall (Tøssebro, 1998). Predictors of such attitudinal change did not seem to be related to individuals’ and family members’ personal needs and profile nor to the previous and new professional services (Tøssebro, 1998). However, the positive effects of deinstitutionalization and changes in family attitudes supporting community living seem to maintain over the long-term (Tøssebro & Lundeby, 2006). The endurance of family members’ support is considered to be a key factor in the evolution of community living models for individuals with DD.

Concomitant with these and other studies, Kozma, Mansell, and Beadle-Brown (2009) reviewed 67 research papers published between 1997 and 2007 that examined the effects of deinstitutionalization across different phases (e.g., complete community living versus interim community living practices) to determine whether newer studies continue to report the benefits of community living, whether countries new to the deinstitutionalization process can benefit from the policies of countries that have undergone the deinstitutionalization process, whether a greater number of individuals with varying disabilities transitioned into the community in the last decade impacted the results of more recent studies, and whether newer community living models provide similar or different outcomes. The studies were coded by Kozma and colleagues (2009) across 10 key domains: community presence and participation, social networks and friendships, family
contact, self-determination and choice, quality of life, adaptive behaviour, user and family views and satisfaction. “In 7 of 10 domains, the majority of studies show that community-based services are superior to congregate arrangements” (Kozma, Mansell, & Beadle-Brown, 2009, p. 193).

Although most studies suggest that deinstitutionalization improves the quality of life of individuals with DD and family members are satisfied with community supports after the fact, there are studies that report marked variations in results comparing institutions to residential homes (Mansell, 2005). In Emerson and Hatton’s (1994) study reviewing 46 British studies encompassing 2350 people, the researchers found variability and inconsistency in performance scores comparing the quality of care across large institutions, smaller institutions or community homes. This variation in scores is partly based on resident characteristics (e.g., their adaptive behaviour and level of care needs), service provision models and staff performance (Emerson & Hatton, 1994; Mansell, 2005). The variations in the aforementioned results have been interpreted to mean that smaller community homes tend to contextually and philosophically translate the institutional model on a smaller scale (Ericsson, 1996), that community services inadequately execute a community-based model (Emerson & Hatton, 1994) and that community staff lack the training to realize the full potential of the community living model (Larson et al., 1998). However, on average, the researchers concluded that supported housing achieves better results over institutions (Emerson & Hatton, 1994; Mansell, 2005). The pervasive benefits of community living are well documented. Thus, it is prudent to suggest that deinstitutionalization affords constructive and lasting change for the betterment of individuals with DD. As Lemay (2009) noted:

Very simply, the institution cannot replace the community in providing individuals—including those with developmental and serious psychiatric disabilities—with the opportunities for the good life. There are no compelling client-related arguments left for keeping people with cognitive limitations, and possibly people with psychiatric disabilities, away from their families and communities (p. 190-191).
In the United Kingdom, North America, Australasia and Scandinavia where deinstitutionalization and community living services have progressed well, three unambiguous changes to service development have taken place. According to Mansell (2005), these include an emphasis on free-market competition and decentralization (i.e., resource allocation and emphasis on results); the promulgation of the social model of disability (which concentrates on the rights, choices and empowerment of individuals with DD while de-emphasizing specific and sometimes inherent disability challenges); and the implementation of generic policies and nomothetic practices (i.e., one-size-fits-all) by government agencies, or what Sandvin (1996) referred to as "de-differentiation", at the expense of individualized needs and specialized services. As Mansell and Ericsson (1996) specifically noted about Sandvin (1996) and his notion of "de-differentiation":

Sandvin draws attention to an important aspect of recent Norwegian, Swedish and British reforms, which is the transfer of responsibility for services from central to local government agencies. He argues that one of the processes at work is 'de-differentiation', through which people with intellectual disabilities get the benefits and drawbacks on being considered like other people receiving local services (p.25).

Sandvin's notion of 'de-differentiation' and its impact are likely to provide a better conclusion on the quality of community services and staff performance and how family members are likely to further comment about community living services and the quality of life of individuals with DD in the community (Mansell, 2005).

**Deinstitutionalization in Ontario: Historical Roots and Principles**

International and national trends in recent decades towards normalization, community living, inclusion and person-centered planning for individuals with DD have been widely adopted in Ontario (Brown & Percy, 2003; Radford & Park, 2003). These trends have paved the way for individuals with DD to benefit from deinstitutionalization and community living (Lemay, 2009).
The "normalization principle" (Nirje, 1969; Wolfensberger, 1972), the idea that the lives of individuals with DD should be as normal as possible, took root in Canada in the 1970s. This concept galvanized the deinstitutionalization movement in Ontario and informed sociopolitical policy decisions towards supported community living for children and adults with DD with the publication of the Ministry of Health’s *Community Living for the Mentally Retarded in Ontario: A New Policy Focus* (Welsh, 1973). The principal challenge of transitioning people from institutions to community living residence was to ensure that individuals led a happier, dignified and fulfilling life in the community.

Community living for individuals with DD meant that they were included in the social life of the community as respected members of society (Brown & Percy, 2003; Radford & Park, 2003). The goal of social inclusion, as a principle of community living and conduct, was to ensure that people with DD are accepted, valued and afforded similar educational, vocational, and leisure choices and opportunities to those that are available to individuals without a disability (Brown & Percy, 2003; Radford & Park, 2003). Community living organizations, as a result of assisting individuals live a life of quality, adopted individualized or person-centered planning initiatives based on the goals and aspirations of the individual (Brown & Percy, 2003; Radford & Park, 2003).

Person-centered approaches refer to methods to support individuals with DD and family members to control and meet their own wants, needs and goals versus those outlined for them by support systems (Brown & Percy, 2003; Radford & Park, 2003). Essentially, the goal of such person-centered approaches is to improve the quality of life and self-determination of individuals with DD by tailoring community resources to help fulfill measurable and meaningful goals (Brown & Percy, 2003). Person-centered approaches not only empower individuals with a DD to make decisions about their own lives, they also give family members greater responsibility and roles in the lives of their relative with DD (Brown & Percy, 2003; Radford & Park, 2003).
The closing of the last institution in Ontario on March 31st, 2009 validated the commitment by the Ontario government to hold steadfast to its commitment to deinstitutionalization and the lifestyle principles of community living, inclusion and person-centered planning that informed the imperative to assist individuals with DD to live a life of dignity and quality.

Outcomes of Deinstitutionalization: Ontario Perspective

Early reports of deinstitutionalization in Ontario by Braddock, Emerson, Felce, and Stancliffe (2001) described a reduction in institutional care from 4340 to 1200 places during the 1990s with a pervasive trend towards the closing of institutions across Canada. Today, there is a paucity of studies documenting the impact of deinstitutionalization and transition of individuals with DD since the closing of the last three institutions in Ontario (Lemay, 2009). However, the overall outcome from previous institutional closures suggests that deinstitutionalization leads to an overall improvement in the quality of life of individuals with intellectual disabilities (Fotheringham et al., 1993; Griffiths-OAMR, 1985).

Griffiths and the Ontario Association for the Mentally Retarded (OAMR) (1985), now known as Community Living Ontario (CLO), conducted a pioneering study evaluating the effects of deinstitutionalization 1 year after the closure of Pine Ridge Centre in Aurora, Ontario. Based on the results of completed family and agency interview questionnaires, the researcher concluded that the repatriation of individuals into the community had a positive impact on their lives. Specifically, former residents enjoyed an improved quality of life, client-centered plans, and increased access to the community and leisure activities (Griffiths-OAMR, 1985). Family members reported increased contact with their sons and daughters and that their loved ones maintained friendships from the institution while also making new friends in the community. Overall, 95% of family respondents reported that their family members were receiving adequate supports and funding for their needs in the community (Griffiths-OAMR, 1985).
In a similar deinstitutionalization study in Ontario, Fotheringham et al. (1993) concluded that two-thirds of the 108 individuals with intellectual disabilities who expressed their opinions about the community transition and their new residence reported that they were happy with their current residence, their vocational and recreational opportunities, and did not wish to return to the institution.

In a more recent deinstitutionalization study in Ontario, Martin and Ashworth (2010) examined the latency of community relocation pertaining to the level of complex needs and specific characteristics of the individuals with DD. The authors used data from census information gathered between 2005 and 2008 by the Ministry of Community and Social Services (MCSS) on all individuals with DD residing in the remaining three Ontario institutions (Martin & Ashworth, 2010). The data were analyzed using the interRAI Intellectual Disability assessment instrument (a standardized tool focusing on the strengths, needs and preferences of individuals with intellectual disabilities conducted annually by the MCSS) (Martin & Ashworth, 2010). The researchers concluded that approximately 40% of individuals who lived in an Ontario institution had their community move date delayed given the complex needs of the individual (e.g., dual diagnosis and behavioural challenges) and a high level of family support and contact. Interestingly, a high level of family support and contact may have delayed the community integration process due to the controversy surrounding deinstitutionalization (Martin & Ashworth, 2010). Alternatively, individuals who had medical problems and were considered older in age were more likely to move into the community sooner. In their discussion, Martin and Ashworth (2010) emphasized that:

In the future, studies should not only examine the individual’s outcomes and quality of life in the community, but also should seek to qualitatively describe the individual’s and family’s participation in the decision-making process and their experiences of the transition. This type of information is invaluable for jurisdictions in which deinstitutionalization is planned or under way (p. 176).
Since the conclusions of the Fotheringham (1993) study and the closing of the last institution in Ontario on March 31st, 2009, there have not been any formal or well-documented studies examining the specific impact of deinstitutionalization on the quality of life of individuals with DD from the perspective of the individual or their family members (Lemay 2009).

Families and Deinstitutionalization: Attitudes, Perceptions and Outcomes

To be successful, deinstitutionalization must be a multifaceted process requiring changes in funding, staffing, service provision and social support models, along with planning with community partnerships and family members (Chenoweth & Dennis, 2000). To better grasp the complexity of family attitudes towards deinstitutionalization, Berry (1995) applied Bronfenbrenner’s (1979) “social ecology model” as a means of systematically contextualizing the experiences of families. Specifically, the “social ecology model” considers the interaction and interconnectedness of the person’s or family’s behaviour with their social environments (microsystem), their interpersonal and community supports (mesosystem), and the intercultural, community, media and organizational influences (macrosystem) on the individual or family behaviour (Bronfenbrenner, 1979). Although this model is helpful in providing a broad context for understanding the many levels and dynamics of family attitudes towards deinstitutionalization, specific practical factors, based on the available research, play a key role in understanding families’ opposition to deinstitutionalization and the success of deinstitutionalization (Parish, 2005; Tabatabainia, 2003).

It is necessary to look at the attitudes, perceptions and reasons why family members chose institutionalization for their family members in the first place to better understand these factors and the outcomes of deinstitutionalization. It is also useful to develop a road map of the reasons for family members’ initial opposition to and subsequent endorsement of deinstitutionalization given positive quality of life outcomes for persons with DD in the community.
Families’ Views on Institutionalization

A family’s decision to seek institutional care for their relative with DD is an emotional and complex issue. Although the reasons for such a decision are personal and differ across families, there are common themes that have emerged across available studies.

In a qualitative, pre-deinstitutionalization study by Tabatabainia (2003) examining the attitudes of 22 families around institutionalization and deinstitutionalization using a semi-structured interview and thematic analysis of interview data, families reported choosing institutional care based on the following concerns: 1) their own death; 2) challenging behaviour; 3) an inability to meet the needs of their relatives at home due to age; 4) health problems; 5) the impact on family members’ own lives; 6) the impact on the lives of their relatives and the community; 7) public perception and external advice. These factors are highly consistent with the literature pertaining to family attitudes towards institutionalization and deinstitutionalization (Allen, 1972; Avis, 1985; Berry, 1995; Black, Molaison & Smull, 1990; Bromely & Blacher, 1991; Cole, 1986; Conroy, 1985; Essex et al., 1997; Freedman, Krauss & Seltzer, 1997; Gorham, 1975; Hardman, Drew, Egan & Wolf, 1993; Heller & Factor, 1993; Mallory & Herrick, 1986; Novak & Amado, 1988; Saenger, 1960; Tabatabainia, 2003). Each of these reasons, based on an overview of this seminal article and related research, requires further exploration to appreciate the impactful nature of the decisions family members make.

Mortality. One of the main concerns family members have for keeping their relatives in an institution and opposing deinstitutionalization revolves around concerns about their own mortality (Novak & Amado, 1988; Mallory & Herrick, 1986). Family members are apprehensive about community living because they are not sure of the quality of care it can provide for their loved ones after they have been died (Tabatabainia, 2003). The prospect of exchanging comfort for the unknown can be a daunting experience for families. Family members want hard evidence and
peace-of-mind assurances that life will be better for their family member with a developmental disability in the community before making final and even irreversible decisions.

**Challenging behaviour and the “stress-coping model”**. The challenging behaviour of the person with a developmental disability is one of the most frequently reported difficulties and reasons for why family members to seek outside assistance and alternative home settings (Tabatabainia, 2003). The ability of family members to cope with the demanding needs and maladaptive behaviours of their loved ones can often diminish over time. Several studies have supported this as one of the factors that contribute to family members seeking to manage behavioural concerns by proffering structured, specialized care outside the home given the lack of community-based behavioural support services (Allen, 1972; Bromely & Blacher, 1991; Freedman, Krauss & Seltzer, 1997; Mallory & Herrick, 1986; Saenger, 1960). Given the contextual nature of most behavioural challenges, it seems to be a logical albeit taxing step for families to seek a different environmental context to manage the behavioural challenges of their family member. Family members may not always be readily equipped with the skills or supports to handle complex, disruptive behaviour on a long-term basis in their own home or community. As Tabatabainia (2003) reported, this pattern is consistent with Cole’s (1986) “stress-coping model” whereby family members, who are lacking in personal coping resources, social involvement and external supports inside the home, choose to seek residential or institutional options of care as a means of handling their stress. This was a common problem that many family members faced in crisis when alternative supports were unavailable (Tabatabainia, 2003).

**Age, health problems and the “postponed launching model”**. Health problems and the aging of family members are also common variables consistently reported in the literature regarding families’ decision to seek institutional care (Tabatabainia, 2003). The prospect of declining health may act as a motivator for family members to get affairs in order. A proactive approach to ensure the best care in the long-term for their family members was also a common narrative reported by
families (Tabatabainia, 2003). According to Tabatabainia (2003), these concerns are consistent with Essex, Seltzer and Krauss’s (1997) “postponed launching model” given that family members expect that their ability to be supportive as they age diminishes and predict that they will be incapable of taking care of their family members in the future and consequently seek supports to secure the future care and well-being of the individual.

**Familial quality of life.** Family members also reported that their own personal and familial quality of life (i.e., social lives, leisure time, shared family time) is affected and limited by the caregiving demands associated with maintaining their family member at home (Tabatabainia, 2003). Family members reported losing friends, having sleeping difficulties and challenges with managing their care-giving roles partly due to the lack of resources and community supports (Hunt, 1989). These challenges have often predisposed families to the consideration and option of institutionalization while simultaneously creating resistance to the prospect of deinstitutionalization and community supports (Black et al., 1990; Mallory & Herrick, 1986; Tabatabainia, 2003). In the current climate of community care, families have more options available for respite care, daycare, preschool programs and adult day programs to cushion some of the impact of the stress they feel while ameliorating some of the factors that may have led families to choose institutionalization (Tabatabainia, 2003). However, most family members reported that they did not have any alternative options at the time other than institutional care (Tabatabainia, 2003).

**Dependence and the “normative launching model”**. Family members also report that the life of the individual with a developmental disability may also be impacted unfavorably by staying at home (Tabatabainia, 2003). Although community supports are more readily available to families in the present day, families often report concerns that living at home decreased chances for their relatives to engage in social and leisure activities in the community afforded by institutional care (Tabatabainia, 2003). Families expressed concerns that home life may well foster dependence rather than independence in self-care, social and financial support and supervision of their family
members with a developmental disability (Essex et al., 1997; Heller & Factor, 1993). As Tabatabainia (2003) noted, this common worry amongst family members is supported by Essex et al.’s (1997) “normative launching model” in that families seek support elsewhere to increase the chances that the individual with a developmental disability will become independent in his/her self-management and self-care skills.

**Sexual vulnerability and abuse.** Family members also report concerns with their relatives’ safety and vulnerability to sexual harassment and abuse in the community as a reason why they consider institutional care and oppose deinstitutionalization (Spreat et al., 1987; Tabatabainia, 2003). Individuals with DD are at risk for sexual abuse with an estimated 83% of females and 32% of men experiencing some form of sexual exploitation and repeated abuse by caregivers and familiar individuals in their lifetimes (Johnson & Sigler, 2000). Such alarming statistics have most likely validated family members’ concerns for their loved ones’ safety, especially when sexual abuse is under-reported by individuals with a developmental disability and sexual abuse skills training may not be readily available in the community (Johnson & Sigler, 2000).

**Professional advice and public perceptions.** Families are also influenced by the advice of professionals, the social zeitgeist related to the nature of disability at the time, and their own anxieties about public perceptions and community safety in seeking placements for their relatives with a developmental disability (Avis, 1985; Berry, 1995; Conroy, 1985; Gorham, 1975; Hardman, Drew, Egan & Wolf, 1993; Tabatabainia, 2003). All of these factors provide the context for family members’ decisions to seek out-of-home care (Conroy, 1985; Hardman, Drew, Egan & Wolf, 1993; Spreat et al., 1987; Tabatabainia, 2003).

**Families’ Views before Deinstitutionalization**

The aforementioned factors for why families consider placing a relative with a developmental disability in an institution also affect and inform families’ considerations around deinstitutionalization (Tabatabainia, 2003). As Tabatabainia (2003) and several other researchers
noted, many families expressed opposition to deinstitutionalization because of the following: 1) the lack of appropriate and adequate community services comparable to the institution and the adverse impact it may have on their family member with a developmental disability and themselves (Conroy, 1985; Hand, Trewby & Reid, 1994; Halliday, 1987; Tøssebro, 1996; Heller, Bond & Braddock, 1988; Larson & Lakin, 1991); 2) the lack of qualified staff and professionals in the community (Epstein, 1994; Ford & Barlow, 1994; Frohboese & Sales, 1980; Heller et al., 1988; Grimes & Vitello, 1990; Keating et al., 1980; Lord & Hearn, 1987; Mallory & Herrick, 1986; Meyer, 1980; Novak Amado, 1988; Payne, 1976; Spreat et al., 1987; Tøssebro, 1996; Wehmeyer & Metzler, 1995); 3) the disbelief in the notion that individuals with DD can lead “normal” and independent lives in the community (Ford & Barlow, 1994; Frohboese & Sales, 1980; Heller et al., 1988; Keating, Conroy & Walker, 1980; Tøssebro, 1996); and 4) contradictory professional advice (Booth, Booth & Simons, 1989; Cummins & Dunt, 1990; Tøssebro, 1998). Each of these factors require further exploration.

**Substandard community services and the “rebound-reversal model”**. Research studies suggest that most families of individuals with a developmental disability living in an institution opposed the prospect of deinstitutionalization before normalization and community relocation took place (Conroy, 1985; Heller, Bond & Braddock, 1988; Larson & Lakin, 1991). Families also expressed concerns over the perceived impermanency, instability and inferiority of community supports and placements pre-deinstitutionalization and the fear that their family members would return home with substandard supports post-deinstitutionalization (Hand, Trewby & Reid, 1994; Tøssebro, 1996; Tabatabainia, 2003). This common finding could be interpreted to support a possible “rebound-reversal” model (the author’s term) in that family members do not want to relive the same experiences they had prior to institutionalization and choose to deter the prospect of deinstitutionalization. Families expressed worries over the lack of comprehensive community services and the possible incompatibility of their relatives living with other residents with DD.
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(Halliday, 1987; Tabatabainia, 2003). This perspective may have been fostered by a lack of information, education, reassurance and funding from government agencies (Tabatabainia, 2003).

**Lack of qualified staff and specialists.** A corollary of families’ perception that the community could not offer satisfactory services to meet the needs of their relatives with DD was their distress over the lack of qualified staff and specialist resources (Epstein, 1994; Grimes & Vitello, 1990). Indeed, these notions were consistent with researchers’ references to family perceptions of high staff turnover rates, better-qualified staff and experts in the institutional setting, and the lack of financial resources as reasons why family members considered community services inadequate (Epstein, 1994; Ford & Barlow, 1994; Mallory & Herrick, 1986; Wehmeyer & Metzler, 1995). Additional reasons why families prefer institutions are because of programming, supervision, security, facility resources, the number of peers for their relatives, supervision, medical care and the happiness of their relatives (Mallory & Herrick, 1986; Novak Amado, 1988; Payne, 1976; Spreat et al., 1987; Tøssebro, 1996). Overall, a majority of families tend to report that they are generally pleased with the quality of programs provided by the institution prior to deinstitutionalization taking place (Ford & Barlow, 1994; Frohboese & Sales, 1980; Heller et al., 1988; Keating et al., 1980; Lord & Hearn, 1987; Meyer, 1980; Spreat et al., 1987). The reasons for such a high satisfaction rate amongst families may have to do with the unease of changing the perceived quality of care, the fear of the unknown regarding community placement, and the psychological reassurance that comes with keeping the status quo (Tabatabainia, 2003).

**Philosophical doubt.** In research outlining families’ attitudes pre-deinstitutionalization, Tabatabainia (2003) outlines several studies demonstrating that families remain unconvinced by the philosophical tenets of deinstitutionalization, namely that individuals with DD can live lives of quality similar to other citizens (i.e., the principle of normalization), and achieve independence in the community (i.e., developmental model) (Ford & Barlow, 1994; Frohboese & Sales, 1980; Heller et al., 1988; Keating, Conroy & Walker, 1980; Tøssebro, 1996). Families are reportedly doubtful
about how compatible these tenets are with quality care. Indeed, families reported that they did not believe that their relatives with DD could ever fully adapt to life in the community nor become independent in community living (Frohboese & Sales, 1980; Heller et al., 1988; Keating, Conroy & Walker, 1980). These attitudes and arguments against deinstitutionalization are self-reinforcing given that family members tend to contrast the experiences before institutionalization only with experiences with the institution. This is understandable given the lack of information, education, comprehensive planning and resources provided by governments in the past (Tabatabainia, 2003).

**Contradictory professional advice.** According to Tabatabainia (2003), families have not only reported disbelief with the viability and ideology of deinstitutionalization and community services prior to deinstitutionalization but also reported a mistrust of governments and anger towards professionals who initially provided “life decisions” advice but later provided the opposite advice. However, the attitudes of family members opposing deinstitutionalization did not change the policies of countries that had already begun the movement towards deinstitutionalization (e.g., the United States and the United Kingdom) or closed all institutions (e.g., Sweden and Norway) (Tabatabainia, 2003). Indeed, families expressed feelings of anger, fear and confusion about this differential advice and the need to be informed before, during, and after deinstitutionalization. “Top-down, well-meant revolution provoked family opposition and anxiety. Evolution would obviously have been a more welcome strategy among families” (Tøssebro, 1998, p.70). A synthesis of the research literature suggests that when families are involved in the entire process from beginning to end, it aids in the chances for the success of the deinstitutionalization movement overall (Booth, Booth & Simons, 1989; Cummins & Dunt, 1990; Tabatabainia, 2003).

**Families’ Views after Deinstitutionalization**

Many families who expressed their opposition to deinstitutionalization changed their views in a positive manner after their relatives with DD adjusted well to community living and led a happy life (Cummins et al., 1990; Grimes & Vitello, 1990; Lord & Hearn, 1987; Tuvesson &
Although many families initially objected to deinstitutionalization, most families changed their views in favour of deinstitutionalization once it was realized (Cummins et al., 1990; Cummins & Dunt, 1990; Emerson & Hatton, 1996; Ericsson, 2002; Grimes & Vitello, 1990; Larson & Lakin, 1991; Lord & Hearn, 1987; Mansell, Beadle-Brown & Clegg, 2004; Tøssebro, 1997; Tøssebro & Lundeby, 2006; Tabatabainia, 2003). This phenomenon was evident throughout studies from many countries, including the United States, the United Kingdom, Australasia, and Scandinavia.

According to a retrospective and longitudinal review of available studies on family attitudes post-deinstitutionalization between 1974 and 1989 in the United States, Larson and Lakin (1991) reported that 83% of parents were satisfied with the institution before community relocation but that 87% of the same parents were satisfied with the community placement once their family members with DD were transitioned into the community. The researchers also reported that 65% of parents observed and endorsed an enhanced quality of life for their family members with a developmental disability since community relocation (Larson & Lakin, 1991).

In a study by Emerson and Hatton (1996) examining the effects of deinstitutionalization across 71 publications arising from 46 studies between 1980 and 1994 via surveys to families, community staff and some individuals with DD in the United Kingdom and Ireland, the authors concluded that in general, community placements increased ongoing activity and use of community facilities, contact with family members and friends, contact with staff, adaptive behaviour, opportunities for choice, acceptance by the community and an overall better standard of living and quality of life for individuals with DD.

In a study by Cummins and Dunt (1990), examining the lifestyle, community contact and family attitudes towards the deinstitutionalization of a large hospital in Australia after relocation, the authors concluded that the residents experienced broader and more varied routines, social activities and greater contact with family members. Family attitudes towards relocation were
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mainly positive regarding the quality of life of the residents (Cummins & Dunt, 1990). In a 4-year follow-up study by Cummins et al. (1990) examining the post-relocation lifestyle of 85 individuals with severe or profound DD, the authors concluded that there was an increase in the residents’ normalized lifestyle routines, social activities and family contact from initial baseline data levels.

Several longitudinal and retrospective studies from Scandinavia, one of the first areas to close institutions, report positive outcomes of deinstitutionalization from family perspectives. A study by Ericsson (2002), regarding the closure of a large institution in Sweden in the 1990s, concluded that 28% of families approved of community relocation prior to the move compared to 78% after relocation. Families strongly endorsed the move into the community. In a similar study by Tøssebro (1997), 57% of families expected deinstitutionalization to lead to inferior services while 73% found the new services better and only 15% preferred the institution after the move. In a more recent study, Tøssebro and Lundeby (2006) examined whether the positive effects of deinstitutionalization reported by families after resettlement are short-term or long-term effects. The method used in this study involved comparing data gathered from Norwegian institutions before deinstitutionalization in 1989/1990, shortly after resettlement in 1994/1995, and 10 years after resettlement in 2001. There were 5222 participants, aged 18-67, before and shortly after resettlement, and 5176 participants, aged 20-67, 10 years after resettlement. The data were gathered from interviews of staff and postal surveys of parents. Only 17% of families favoured community resettlement before it happened, while 73% preferred it shortly afterwards and 76% supported community placement 10 years later.

Based on the available international studies gauging family attitudes after deinstitutionalization, most studies report better outcomes overall and improved quality of care and quality of life for individuals with DD living in the community (Conroy et al., 2003; Cummins & Dunt, 1998; Mansell, Beadle-Brown & Clegg, 2004; Parish, 2005; Spreat & Conroy, 2002; Wolfensberger, 2003; Young & Ashman, 2004). The success of community placement for
individuals with DD largely depends on the involvement of family and friends in the
deinstitutionalization process (Causby & York, 1990).

Quality of Life: Theoretical Model and Measurement

The purpose of the deinstitutionalization movement was to improve the overall quality of
life of individuals with DD and their family members. The interest in quality of life as a concept
has come from several sources. As Shalock (2004) and Keith and Schalock (1996) noted, these
sources include meaningful scientific and technological advances, improved environmental
conditions, personal, familial and societal values, supports and well-being to improve life, the
measurement of the outcomes of community living, and the right to self-determination and
consumer empowerment. The term “Quality of Life” (QOL), according to Schalock (2004, p.205),
has become a sensitizing notion (i.e., the individual as a reference-point), a social construct (i.e., an
“overriding principle” of societal change) and unifying theme (i.e., practical framework) that has
widely impacted the field of DD in a cross-cultural way. It has also become an all-encompassing
term in theory but also an elevated practical value in society.

Quality of Life is an inclusive term used to describe and measure, often through surveys,
many different subjective and objective aspects of a person’s life (Felce, 1997). Specifically, the
term quality of life is multi-dimensional and comprehensively defined by physical, material, social
and emotional well-being, development, inclusion, productivity, security and rights (Felce & Perry,
1995; Verdugo, Schalock, Keith, & Stancliffe, 2005). Quality of life as a concept is complex,
private, subjective and independently defined based on an individual’s level of satisfaction with
his/her own life (Galambos, 1995). There is no agreed upon definition but most definitions
encompass the following components (Galambos, 1995): control and empowerment; independence
and enablement; interdependence and individuality; social justice; physical and psychological well-
being; personal growth and status enhancement. Given the intricacy and subjectivity of defining
quality of life, researchers struggle with measuring it. The process of trying to understand a
person’s quality of life depends largely on self-reports, reports by alternative proxy observers, and the use of interviews and scales (Felce, 1997). However, more recent studies attempt to provide objective measurements about QOL by focusing on behavioural markers such as independence skills, overall health and the level of community access, participation and activities (Young & Ashman, 2004a, Young & Ashman, 2004b; Young & Ashman, 2004c). There is no doubt that the concept of Quality of Life is a complex and sometimes nebulous notion, but its applicability and measurement provide a comparative continuum across several key domains including overall adjustment, happiness and well-being.

To determine whether the community living initiatives in Ontario were fruitful endeavours, the Ministry of Community and Social Services (MCSS) funded the Quality of Life Project in Ontario in the 1990s. The Quality of Life Project was designed to determine, over several years, whether a sample of 504 adults with DD across several organizations benefitted from community living.

The researchers developed and utilized a Quality of Life Questionnaire to determine the outcomes of community involvement based on the degree to which an individual was satisfied with important possibilities and decisions for his or her own life (Brown, Raphael & Renwick, 1997, p.10). Participants rated their answers based on how good the person’s life was for him or her across three main domains: Being, Belonging, and Becoming. These categories were based on a theoretical model of Quality of Life developed by Brown, Raphael and Renwick (1997).
Specifically, Being is subdivided into physical, psychological and spiritual being, values and health and refers to “who one is” overall; Belonging is subdivided into physical, social and community belonging, supports and “connections with one’s environments”; and Becoming is subdivided into practical, leisure and personal growth becoming or activities and refers to “achieving personal goals, hopes and aspirations” (see Figure 1) (Brown, Raphael & Renwick, 1997, pp.10-11). Each of the QOL domains are further described and defined in Table 1.
Table 1

Quality Of Life Model: Domains and Descriptions (Brown, Raphael & Renwick, 1997)

<table>
<thead>
<tr>
<th>Quality of Life (QOL) Domains</th>
<th>Domain Descriptions</th>
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<tbody>
<tr>
<td>Being</td>
<td>• who one is</td>
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<tr>
<td></td>
<td>• body and health</td>
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<td></td>
<td>• beliefs and values</td>
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<td></td>
<td>• thoughts and feelings</td>
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<tr>
<td></td>
<td>• psychological well-being and adjustment</td>
</tr>
<tr>
<td></td>
<td>• physical appearance</td>
</tr>
<tr>
<td>Belonging</td>
<td>• connections and fit with one’s environment</td>
</tr>
<tr>
<td></td>
<td>• places person works and lives</td>
</tr>
<tr>
<td></td>
<td>• the people in the person’s life</td>
</tr>
<tr>
<td></td>
<td>• the person’s resources</td>
</tr>
<tr>
<td>Becoming</td>
<td>• purposeful activities</td>
</tr>
<tr>
<td></td>
<td>• leisure activities</td>
</tr>
<tr>
<td></td>
<td>• things done to cope</td>
</tr>
<tr>
<td></td>
<td>• adjusting to change</td>
</tr>
</tbody>
</table>

The Quality of Life Project was completed in March 1999. The Project assessed the QOL of 504 randomly selected adult men and women with DD from 23 areas throughout counties, regions, cities and districts in Ontario. Participants for the study were randomly selected across ages, severity of developmental disability, variety of community services, variety of activities (e.g., day programs, employment in the community), and settings where they lived (i.e., on their own, family home, group home, Schedule I or II facilities) (Brown, Raphael & Renwick, 1997; Brown, Renwick & Raphael, 1999). The results, based on the Quality of Life Questionnaire, supported the notion that the quality of life of individuals with DD in the community was not as good as that of the general population. However, those individuals who engaged in more independent living in their community and developed greater community living skills had higher quality of life scores than those who did not (Brown, Raphael & Renwick, 1997; Brown, Renwick & Raphael, 1999).

Several studies have utilized similar survey methods to capture and document QOL ratings after deinstitutionalization that demonstrated positive results overall for the mover (Griffiths-
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OAMR, 1985; Felce et al., 2000; Robertson et al., 2004; Young et al., 2001). However, such measures and surveys rely greatly on the feedback of caregivers, parents and support providers given the communication challenges of individuals with DD (Felce, 1997; Felce & Perry, 1995). In a long-term study conducted by Young and Ashman (2004b) measuring the quality of life of individuals with DD since their relocation from an Australian institution, the overall results suggested increases in the quality of life for all community residents regardless of age, geography, professional services, or level of intellectual disability. O’Brien et al. (2001) used Likert-type scales to measure the perceptions of parents and staff in rating the QOL of deinstitutionalized individuals in New Zealand across several domains including emotional well-being, safety, health, productivity, community involvement, and other factors. The authors concluded that there was a significantly higher quality of life for the individuals with DD since their move into the community.

Nottestad and Linaker (1999) and Nottestad, Stromgren, and Linaker (2001) reported significant improvements in the living conditions of 109 residents since deinstitutionalization. In a longitudinal study of older individuals with DD, Dagan et al. (1998) found consistent progress in quality of life of older individuals with intellectual disabilities over a 41-month period. Cullen et al. (1995) found similar results in favour of community living when comparing the quality of life and quality of the physical environment for individuals with learning disabilities who stayed in the institution versus those who moved into the community. Furthermore, O’Neill et al., (1990) demonstrated that naturalized, residential living environments resulted in gains in overall QOL, activity and cost-effectiveness unrelated to the degree of disability. Similarly, Griffiths-OAMR (1985) found that deinstitutionalization resulted in enhanced overall quality of life of the individuals with a developmental disability and increased family contact and involvement.

Overall, several studies that surveyed families and community staff from across the globe indicate better quality of life outcomes for individuals with DD since their relocation to the community from the institution (Brown, Raphael & Renwick, 1997; Brown, Renwick & Raphael,
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1999; Cullen et al., 1995; Griffiths, 1985; Dagan et al., 1998; Nottestad & Linaker, 1999; Nottestad, Stromgren & Linaker, 2001; O’Brien et al., 2001; O’Neill et al., 1990; Young & Ashman, 2004a; Young & Ashman, 2004b). Furthermore, the impact of deinstitutionalization on the quality of life of individuals with DD and their families is a key indicator of the success of community relocation (Felce, 1997; Nottestad & Linaker, 1999; Nottestad, Stromgren & Linaker, 2001).

Summary of Findings and Significance of Study

Since the Fotheringham et al. (1993) study, the conclusion of the Quality of Life Project in Ontario in 1999 (Brown, Renwick & Raphael, 1999), and the Martin and Ashworth (2010) study examining the process of deinstitutionalization, there have been no published studies on the impact of deinstitutionalization on the quality of life of individuals with DD in Ontario since the closing of the last institution in Ontario in March 31st, 2009 (Lemay, 2009). Further, there have not been any formal or well-documented studies examining the specific impact on the Quality of Life (QOL) of individuals with DD from the perspective of family members in Ontario (Lemay 2009; Martin & Ashworth, 2010).

Quality of Life as a concept, social theory and construct, has widely impacted the field of DD (Brown, Renwick & Raphael, 1999; Lemay, 2009). It is an inclusive term used to describe and measure, often through surveys, many different subjective and objective aspects of a person’s life (Felce, 1997). Although there is no agreed upon definition about what it constitutes, most definitions encompass a variety of components (Galambos, 1995). Quality of Life may be viewed as the degree to which a person enjoys or is satisfied with the important possibilities of his or her life (when talking about the individual with a developmental disability) or by asking the question: “How good is his or her life for him or her?” (Brown, Raphael, Renwick, 1997, p.10). Brown et al. (1997) developed a Quality of Life Model based on this definition and survey questions based on three main categories: Being, Belonging, and Becoming, as part of the Quality of Life Project in Ontario in the 1990s. This theoretical model was utilized to measure the quality of life for
individuals with DD similar to and consistent with the varying degrees of importance and satisfaction related to all aspects of life for all people and the interconnectedness of people with the environments in which they live (Brown, Raphael & Renwick, 1999).

There is an abundance of research on the process of deinstitutionalization and family attitudes about deinstitutionalization in the United States, across the Commonwealth (i.e., the UK, Ireland, Australia, New Zealand) and Scandinavia but very little research in Canada given the recent closure of the last 3 of 16 institutions in Ontario (Lemay, 2009). Although a common result from surveys across studies is that parents are initially against deinstitutionalization (Grimes & Vitello, 1990; O’Brien et al., 2001; Spreat & Conroy, 2002; Tøssebro, 1998), the after-the-fact support for community living generally increases and the frequency of contacts by family members also increases after deinstitutionalization and sometimes remains higher several years later in the community (Spreat & Conroy, 2002). Overall, study surveys suggest that the initial negative attitudes of parents towards deinstitutionalization change and dissipate considerably after the process and are replaced with more positive perspectives and even enthusiasm for community living (Griffiths-OAMR, 1985; Grimes & Vielleo, 1990; Heller, Bond & Braddock, 1988; Larson and Latib, 1991; Lemay, 2009; Tøssebro, 1998; Tuveson & Ericsson, 1996). It is also apparent that these positive effects and attitudes maintain over the long-term (Tøssebro & Lundeby, 2006).

Family members of individuals with DD who have transitioned from institutions to community residences play a key role in the success of relocation (Parish, 2005). Indeed, the level of family contact and family involvement during and after deinstitutionalization is associated with positive attitudes towards the deinstitutionalization (Conroy et al., 2003; Cummins & Dunt, 1998). Consistent and enduring family involvement is necessary for the successful maintenance of quality of life gains in the community (Tabatabainia, 2003) and an overall safeguard of the quality of services and the safety of residents in the community (Spreat & Conroy, 2002; Wolfensberger, 2003; Young & Ashman, 2004). Overall, the research, based on families and staff surveyed,
suggests that individuals with DD have an improved quality of life after deinstitutionalization and that family members are generally satisfied with community relocation (Brown, Raphael & Renwick, 1997; Brown, Renwick & Raphael, 1999; Cullen et al., 1995; Dagan et al., 1998; Griffiths, 1985; Nottestad & Linaker, 1999; Nottestad, Stromgren & Linaker, 2001; O’Brien et al., 2001; O’Neill et al., 1990; Young and Ashman, 2004).

Research Questions

This retrospective study was designed to answer the following research questions based on the Quality of Life Model (Brown, Raphael & Renwick, 1997):

1) What do family members report about how well the individual with DD adapted to the community post-deinstitutionalization (i.e., Being Domain)?

2) What do family members report about their satisfaction with community placement and resources after deinstitutionalization (i.e., Belonging Domain)?

3) What do family members report about the amount of time they interact with their family members with DD after community relocation (i.e., Belonging Domain)?

4) What do family members report about the overall quality of life of the individual with DD after deinstitutionalization (i.e., Becoming Domain)?

5) What do family members report about their overall experiences and outcomes of deinstitutionalization and the factors that enhanced the quality of life of family members with DD? (Being, Belonging, and Becoming Domains).

Method

The current study is part of one of four studies commissioned by the Ministry of Community and Social Services of Ontario to evaluate the Facility Initiative that closed the remaining three facilities. This study represents a family survey sampling from a Family and Agency Survey study and is a partial analysis of family surveys that had been received by the date of analysis required for this evaluation. The agency surveys will be analyzed in another evaluation study.
Family Attitudes Towards Deinstitutionalization In Ontario

The current study adds to the existing literature by specifically exploring family involvement and attitudes on the quality of life of their family members with DD post-deinstitutionalization. This study utilized Brown and colleagues’ theoretical model of Quality Of Life (Brown, Raphael & Renwick, 1997) to determine quality of life outcomes from family members’ perspectives and a means to compare these results with similar studies completed outside Canada.

Participants

After the Ontario government’s announcement of the Facilities Initiative, a total of 941 individuals with DD were relocated into the community. Several of these individuals had lived in a facility for over 40 years with little to no family involvement. Based on a Ministry of Community and Social Services’ (MCSS) report by Martin, Hirdes, Fries and James (2007) of residents across the three facilities, it was estimated that 10.7% of these individuals had an identified informal assistant (e.g., guardian), 17.8% had visited with family in the previous month with 2.3% having an overnight stay, and 10.6% of individuals had had some correspondence with family by either phone, email or letter. Given these statistics, and factors such as age of the resident, lack of family contact and the latency of placement, it is understandable that the family survey produced an expected low 60 respondents (55 at the 1 year mark after the last facility closure) with a reasonable return rate of 6.4%.

It should be noted that the MCSS had sent an introductory letter and general consent form to host community agencies to distribute to all families involved in the Facilities Initiative to promote their participation in the study. The family surveys were mailed to all families for whom there was general consent for the researchers to be involved following an invitation from the Ministry of Community and Social Services (MCSS). All agencies that received individuals into their program were emailed the surveys and consents and called to further request their support in soliciting the participation of families.
At the time of this analysis, 55 families had responded to the invitation and had completed the survey. The participants (N=55) included family members who had relatives with DD transitioned into the community for at least a year since the closure of the last institution in Ontario (March 31, 2009). Inclusion criteria for the sample included family members of individuals who may or may not have had challenges transitioning into the community and represents a cross-section of individuals across varying demographics such as age, gender and client-specific challenges such as biomedical, behavioural and support challenges.

**Family Survey**

*Development of the family survey.* The methodology used for this study included a questionnaire developed for families of individuals with DD and constructed according to the guidelines identified by Hessler (1992). Specifically, the Family Survey about individuals transitioned during the Facilities Initiative in Ontario was developed to examine several aspects of transition challenges, family perspectives and attitudes towards relocation (see Appendix A).

The survey, developed by Dr. Dorothy Griffiths (Project Co-Principal Investigator) in 2010, includes several operationally defined domains including environmental adaptations, frequency and quality of professional supports, frequency of family visits and overall family attitudes concerning quality of life change, satisfaction with new setting and ease of transition (see Appendix A). The questionnaire included open-ended and closed-ended questions. The closed-ended questions were based on a yes/no response or a rating on a Likert-type scale to ensure a response, either way, to the question. The open-ended questions allowed for greater expression of the family members’ personal experiences. The questionnaire was sent to families by mail and available as an online survey.

*Finalization and distribution of the family survey.* The family survey was compared with the preliminary data from the Focus Group study, modified based on themes and concepts garnered from the study, and then pretested using a sample of individuals in the field.
After receiving clearance from Brock University's Research Ethics Board, the survey was first distributed to families approximately one year following the closure of the last facility (i.e., March 31st, 2010). This time frame was selected for several reasons: 1) to decrease the chances of any honeymoon effect (i.e., initial harmonious and positive outcomes); 2) to ensure that community agencies had enough time to implement plans and observe the outcomes; 3) and to ensure that families had enough time and opportunity to observe the outcomes of their family member residing within their new setting.

The family surveys identified demographics (i.e., region and facility) and included an information/instruction letter and informed consent form to include their data in the data set. Informed consent was obtained from families ensuring that all participants understood the purpose of the proposed study along with the voluntary and confidential nature of the study (Please see Appendix A for a copy of the information sheet, consent form and family survey). To obtain a representative sample of families involved in the Facility Initiative at an efficient and prompt return rate, numerous methods were utilized: 1) secure internet access to complete the survey online; 2) follow-up phone calls and email correspondences; 3) the assurance of the confidentiality of responses; 4) and the offer to provide a summary of survey results when they became available.

To ensure anonymity, the family survey data were coded with non-descriptive identifiers (i.e., region, facility, family members) to discover significant and collective issues of process, support and outcomes across these variables while considering significant differences across these variables to avoid the possibility of confounding effects. Quotes provided by family members in the Results sections are coded with numbers representing the completed surveys as an additional means of ensuring anonymity and confidentiality.

**Quantitative and Qualitative Data Analyses**

The main quantitative data analysis method used to answer the research questions for this study was descriptive statistics. Variables such as demographic descriptors of the individuals with a
developmental disability, their families, the institution and new services were considered to study the variation in family attitudes towards the quality of life of family members with intellectual disabilities since community integration. Each of the 21 separate items in the questionnaire was assigned across the Being, Belonging and Becoming categories of the Quality of Life model (Brown, Raphael & Renwick, 1997) by the author and thesis supervisor independently and then reviewed to ensure consensus to address the research questions. Response rates and percent endorsement across the categories were reported for individual demographic questions and distinct questions while considering correlations across categories. Statistical frequency distributions were also employed to provide a visual representation of the data sets and comparative analyses.

The main qualitative data analysis method used to evaluate common themes across narratives provided by family members in the family survey was a thematic analysis (Boyatzis, 1998; Braun & Clarke, 2006). A thematic analysis provides an inductive analysis of the voice and the emotional tone of the participants' narratives across common themes and subthemes present in the narratives (Boyatzis, 1998; Braun & Clarke, 2006). A thematic analysis was performed using Braun and Clarke’s (2006) criteria: familiarizing yourself with the data; generating initial codes; searching for themes; reviewing themes; defining and naming themes; and producing the report.

Table 2 provides a summary of the family survey questions that correspond to the research questions across the QOL domains along with the type of data analysis performed across the research questions. Specifically, family survey questions 5, 6 and 8 correspond to research question 1 (transition and adaptation) and the Being QOL domain; family survey questions 4, 9, 10, 11, 13a, 13b, and 13c correspond to research question 2 (satisfaction with community placement and supports) and the Belonging QOL domain. Family survey questions 15 and 16 correspond to research question 3 (family contact) and the Belonging QOL domain; family survey question 17 corresponded to research question 4 (quality of life ratings) and the Becoming QOL domain. Family survey questions 4, 5, 9, 10, 11, 13, 17 and 18 have a comment component corresponding to
research question 5 (themes related to family member’s comments) and include the Being, Belonging, and Becoming Domains. Descriptive statistical analyses of the quantitative data were used to answer research questions 1, 2, 3, and 4 while a thematic analysis was used to answer research question 5 to garner specific themes and trends from family members’ quotes related the QOL domains.

Table 2

Quality Of Life Domains and Data Analyses Corresponding to Research Questions and Family Survey Questions

<table>
<thead>
<tr>
<th>Quality of Life Domains</th>
<th>Research Questions (RQ)</th>
<th>Family Survey Questions</th>
<th>Data Analysis Methods</th>
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<tr>
<td>BEING</td>
<td>RQ1</td>
<td>Q5</td>
<td></td>
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<tr>
<td></td>
<td>Transition &amp;</td>
<td>Q6</td>
<td>Quantitative</td>
</tr>
<tr>
<td></td>
<td>Adaptation</td>
<td>Q8</td>
<td>(Descriptive Statistics)</td>
</tr>
<tr>
<td></td>
<td>RQ2</td>
<td>Q4</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Family Satisfaction</td>
<td>Q9</td>
<td></td>
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<tr>
<td>BELONGING</td>
<td>RQ1</td>
<td>Q5</td>
<td></td>
</tr>
<tr>
<td></td>
<td>With Community</td>
<td>Q10</td>
<td>Quantitative</td>
</tr>
<tr>
<td></td>
<td>Placement &amp;</td>
<td>Q11</td>
<td>(Descriptive Statistics)</td>
</tr>
<tr>
<td></td>
<td>Supports</td>
<td>Q13a</td>
<td></td>
</tr>
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<td></td>
<td></td>
<td>Q13b</td>
<td></td>
</tr>
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<td></td>
<td></td>
<td>Q13c</td>
<td></td>
</tr>
</tbody>
</table>
RQ3 BECOMING Family Contact Q15
RQ4 Q16
QOL Ratings Quantitative (Descriptive Statistics)

ALL DOMAINS RQ5 Q4, Q5, Q9, Q10, Qualitative (Thematic Analysis)
Narratives & Q11, Q13, Q17,
Themes Q18

Note: Each of the 21 separate items in the Family Survey was assigned across the Being, Belonging and Becoming categories of the Quality of Life model (Brown, Raphael & Renwick, 1997) by the author and thesis supervisor independently and then reviewed to ensure consensus to address the research questions.

Results

The results of the family surveys are initially presented on the quantitative questions using descriptive statistical methods and then themes gained from the qualitative commentary were garnered and reported using a thematic analysis (Boyatzis, 1998; Braun & Clarke, 2006). Both forms of data analyses were performed to answer the research questions based on the family survey results and the theoretical framework of the Quality of Life Model Domains of Being, Belonging, and Becoming (Brown, Raphael & Renwick, 1997). Quotes provided by family members were coded with numbers representing the surveys to ensure anonymity and confidentiality.

Descriptive Statistical Analyses of Family Survey Results

Demographics. There were 55 family surveys returned. Of the family surveys, the following percentages indicate where the individuals had been previously placed: Facility A (53%), Facility B (31%), and Facility C (16%). The individual placements occurred in the following regions: Central (29), Southwest (16), and East (9). The family surveys were filled out by mothers (17), fathers (5), mothers and fathers (2), sisters (18), brothers (11), and other (2), which included a
cousin and sister-in-law. See Figure 2 for a visual graph of each participant who completed the survey.

![Pie chart showing family members who completed the survey](image)

**Figure 2:** Family Members Who Completed The Family Surveys (N=55).

**Transition and Adaptation from the Facility to the Community**

Several questions from the family survey (q5, q6 and q8) asked how well family members with DD were transitioned from the facility and how well they had adapted to their smaller, community settings according to their families (research question 1). Families reported that their family members’ transition from the community was generally excellent (73%) to good (24%) (question 8). Most families were very pleased with the transition and how well their family members adapted to their new setting (see Figure 3). A few family members reported that the transition required improvement (3%). Specifically, they were concerned that the individuals were less involved in activities (12%) and that they did not have the proper level of support (13%) by the end of the first year post-deinstitutionalization.

Families also reported that their family members have generally adapted well to the community (questions 5 & 6) and to living in a new physical environment (96%) and a smaller setting (96%) (See Figure 4).
Families also reported that their family members have generally adapted well to the community (questions 5 & 6) and to living in a new physical environment (96%) and a smaller setting (96%) (See Figure 4).

![Figure 4: Percentage of Families Who Reported That Their Family Member Adapted Well To The New Physical Setting and a Smaller Setting (N=55).](image)

**Family Satisfaction with Community Placement and Supports**

Several questions from the family survey (q4, q9, q10, q11, q13a, q13b, q13c) tapped into family members' overall satisfaction with aspects and appropriateness of the community placement and the quality, staffing arrangements and the amount and access to professional / medical supports (research question 2). Families reported that they were very satisfied with the placement, staffing arrangements and the professional / medical supports of their family member with a developmental disability. Overall, family members were satisfied with the present placement, the level of staff
support provided, the compatibility of the layout and design of the current location to the individual's needs, and the quality, amount and access to professional and medical supports in the community. See Table 3 and Figure 5 for results.

Table 3

*Family Members' Satisfaction Ratings of Placement & Professional / Medical Supports (N=55)*

<table>
<thead>
<tr>
<th>Satisfaction Rating on…</th>
<th>Yes Satisfied</th>
<th>No Not Satisfied</th>
</tr>
</thead>
<tbody>
<tr>
<td>Their family member's present placement (question 4).</td>
<td>96%</td>
<td>4%</td>
</tr>
<tr>
<td>The current staff support provided for their family member (question 9).</td>
<td>96%</td>
<td>4%</td>
</tr>
<tr>
<td>The current location and its goodness of fit for their family member (question 10).</td>
<td>98%</td>
<td>2%</td>
</tr>
<tr>
<td>The layout/design of the current home as appropriate for their family member (question 11).</td>
<td>98%</td>
<td>2%</td>
</tr>
<tr>
<td>The quality of the professional/medical supports received by their family member (question 13a).</td>
<td>96%</td>
<td>4%</td>
</tr>
<tr>
<td>The amount of professional/medical supports received by their family member (question 13b).</td>
<td>96%</td>
<td>4%</td>
</tr>
<tr>
<td>The family member's access to needed professional and medical supports (question 13c).</td>
<td>96%</td>
<td>4%</td>
</tr>
</tbody>
</table>
A minority of family respondents (2-4%) reported that their family members’ support needs were not being met in the community (132, 144). However, a vast majority of family members (96-98%) expressed great satisfaction with the community residence, staffing, and professional / medical supports.

![Graph showing family satisfaction across different aspects](image)

**Figure 5**: Percentage of Family Members’ Satisfaction Ratings across Setting, Staffing & Professional / Medical Supports (N=55).

**Family Contact**

Several questions from the family survey (q15, q16a, q16b, q16c) asked family members to comment about the geographic distance of the community placement and to rate the amount of contact they had with the family member in his/her new home (research question 3). Eighty two percent (82%) of families reported that they now live geographically closer to their family member (q15). Families further reported that they were more likely now to visit more often (82%) and call
more often (82%), but fewer reported that their family member visits them more often (64%). See Figure 6.

![Graph showing family contact]

**Figure 6**: Percentage of Family Contact (Visits to the Residence, Phone Calls to the Residence & Visits to the Family Home) (N=55).

**Quality of Life**

One question on the family survey (q17) specifically addressed quality of life with a rating system (excellent, good, adequate, needs improvement, poor) with the ability to comment further about the rating (research question 4). Families reported that their family member had an excellent (64%) to good (27%) quality of life in the community (Total = 91%). Some family members (9%) reported an adequate quality of life (4%) or that needs improvement (5%) given inadequate supports in the setting and community to meet the overall social (e.g., outings and activities) and biomedical needs (i.e., complex medical care) of their family members. No family members reported that their family member had a poor quality of life since relocation. See Figure 7.
Examples of “excellent” or “good” quality of life for individuals with DD include the following narratives provided by family members:

- “I really don't think that there is much more that they can do to improve her quality of life” (102).

- “[He] has changed from a very 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 also open to learning various modes of communication and spends for less time in self harmful behaviours as a result. We anticipated anything but positive change and are pleasantly surprised” (105).

- “1. They are happier - more choice, more control. 2. [He] has never fed himself before - he does now. So he controls how much and how fast he eats. Wow! 3. Both were prone to pneumonia which can easily become life threatening - better now...4. I thought the move
would kill them (literally). Instead they are healthier, happier and doing better than I ever dreamed!” (110).

- "[Her] quality of life is excellent - if we mean she is enjoying top care, good food and loving and patient attention, but her abilities and participation is limited, so the qualities of a happy, fulfilling life are sometimes absent” (129).

- “I was very much against [my son] being moved away from where he had been most of his life. I thought it would be very disrespectful for him to change living arrangements at this stage of his life. The other members of my family felt it would be good for him. I have changed my views completely now that he has moved for almost 2 years. There was an adjustment period at the beginning, he had more seizures, but this also calmed down and he is a very happy person. He is extremely well cared for and his life is very good” (148).

- “Quality of life keeps on improving. It is soon 5 years since his relocation. There has (and is) noticeable improvement each and every year” (154).

The majority of families who endorsed an enhanced quality of life (91%) reported positive changes in mood, health and community support for their relatives with a DD along with positive changes in their own attitudes towards community location. However, some families (9%) reported an adequate or inadequate improvement in their family members’ quality of life given safety concerns with the community placement and unsatisfactory expert supports for biomedical and behavioural challenges. Examples of “adequate” or “needs improvement” quality of life for individuals with DD include the following narratives provided by family members:

- “[She] had the freedom to go to the canteen on her own, visit the ceramics class and craft room on her own when others were present. Here she is limited because of safety issues. The home can be quite noisy because of some roommates, and there is no place to go if there is frustration because of the noise. Aggressive behaviour sometimes results, then staff use...restraints which isn't pleasant” (122).
Family Attitudes Towards Deinstitutionalization In Ontario

- "Staff not enough experience to understand or meet her special needs - doesn't recognize serious medical situations" (132).

**Thematic Analysis of Family Members’ Narratives**

The comments provided by family members in the survey produced information corresponding to the three overarching themes of Being, Belonging, and Becoming in Brown, Raphael and Renwick’s (1997) Quality of Life Model (Please see Table 1). Specifically, family members were asked to provide their own narrative and experiences of the deinstitutionalization process for the purposes of a thematic analysis of the qualitative data. The qualitative data (i.e., narratives / quotes) were categorized across these three main themes and further analyzed to determine subthemes from the family survey questions that offered possible narratives for family members (i.e., question 4, 5, 9, 10, 11, 13, 17 and 18) (See Appendix C for a summary of quotes supporting the themes and subthemes). This information, along with the quantitative results, provided an overall quality of life analysis (research question 5).

One particular quote from a family member commenting about unanticipated changes since the transition into the community in question 18 of the survey wholeheartedly described the fear and concerns family members felt about the deinstitutionalization process and the transition into the community along with the subsequently reported attitudinal changes, positive effects of community living and the enhanced quality of life of individuals with DD maintained by a majority of family members at least 1 year post-deinstitutionalization:

As mentioned previously, we had worried about the transition. After all, [she] had lived in the institution for more than 40 yrs. And we had been very pleased with her care and activities. We worried that she would miss many of her friends, familiar surroundings, and might become disoriented and withdraw or ‘act out’. We worried that there may not be enough staff in her new location and that [she] may 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 ‘1 size group’ – ‘fits all.’ Thankfully, all of our fears were ill founded when [she] arrived at [community placement]. Care was taken to accommodate [her] with her long time male companion and she has made many new friends” (q18, 103).

This particular quote provided a nice summary of the thematic analysis data results across the three main Quality Of Life Model themes of Being, Belonging, and Becoming and the subthemes that emerged from the comments provided by family members. Please see Figure 8.

![Figure 8: Thematic Analysis of Narratives Provided by Family Members Via The Family Survey.](image-url)
Being

According to Brown et al.'s (1997, pp.10-11) Quality of Life Model, Being refers to “who one is” and how well one physically adapts (i.e., health and physical appearance) and psychologically adapts (i.e., overall well-being, happiness, comfort) to changes in his/her life.

Adaptation. A majority of members cited their family members’ happiness and comfort in their new settings along with the safety, security, and quality of care provided by the community setting as signs of their adaptation.

Examples of the subtheme of “adaptation” include the following:

- “She made the transition to her new home much easier than we had anticipated and has adapted to her new environment very well” (145).
- “She is happier in her new home!” (102).
- “She seems to be happy and content with her current location” (145).
- “It is a comfortable and safe environment” (131).
- “Seems happy, always smiling, looks well!!” (140).

One particular family member commented about how helpful it was for families to have a specialist from the Ontario government assist with transition counselling and to have information sessions on the process of deinstitutionalization:

“One of the most important policy/program aspects of the move was the assignment by the Ministry of a specialist to counsel and assist in the transition. She worked with us ([her] siblings) to identify possible locations, visit them, arrange for a test visit by [her], 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. Another useful program element was a "fair" held in Ottawa by all the care providers in the region about 8 months before [her] move…” (123).
Belonging

According to Brown et al's (1997, pp.10-11) Quality of Life Model, Belonging refers to the goodness-of-fit with one’s environment or “connections with one’s environments” (i.e., location and place the person lives and works, people in the person’s life, contact with family and friends, person’s resources and supports). Based on family members’ comments, several subthemes related to the appropriateness and quality of the community placement and supports became evident:

- Environmental Goodness-Of-Fit
- Quality Staffing Supports
- Quality Professional & Medical Supports

Environmental goodness-of-fit. Family members reported that the design and location of the community home was appropriate and a good fit to meet the needs of their family member with a developmental disability. The change in location also offered greater contact with their family member. Families provided narratives that support their overall ratings across specific areas identified in Table 3 and Figure 4 including the match or goodness-of-fit with the individual, the appropriateness of the placement and the physical layout and design of the new setting. Examples of the family members’ satisfaction with the appropriateness of placement include:

- “The location, staff, programs and living conditions are very well suited to [her] needs. Communication with his family (5 siblings) is excellent” (123).
- “Lovely new home, she has her own room, caring staff and home like atmosphere” (101).
- “1. It was so close to the family 2. We are pleased that she moved in with friends from other home. 3. She seems happy with everyone” (113).

Examples of family members’ satisfaction with the location being a good fit or match for their family members with a developmental disability along with their satisfaction with the
residence being closer to their own homes for easier access and contact with their family members include:

- “Family able to visit more frequently” (122).
- “After driving for an hour to reach the [facility] for previous visit imagine my present gratitude for a lovely, brand new, group home, three blocks from my residence! She is near a shopping mall, a theatre, a beautiful marina, beach and picnic area. So outings are now very frequent and appreciated” (129).
- “It allows more frequent visits, summer, winter. If there is a concern, event, we are able to attend to more easily. Proximity allows for more involvement and care. Also my brother can visit us (mom & dad). This reciprocity was unthinkable before” (147).
- “He is located about 30 minutes from most of his family. We are able to spend much more time with him than before” (148).
- “Very good fit” (154).

Examples of the families’ satisfaction with the physical layout of the new setting include:

- “[She] is able to physically access all levels and her group home is fortunate enough to have an additional ‘craft room’. Also, accommodation has already been made to provide help with the stairs if that becomes an issue in the future (103).
- “Many steps have been taken to make the home user friendly for [him]. He is very comfortable and relaxed with every room and their setups” (105).
- “...The home had been renovated to address their needs - elevator, fenced in yard, shield on deck, downstairs recreation room, secure kitchen, no carpets in house, lift for bath” (110).
• "The facility is new - built as a group home, not a converted residence. It has an elevator and handicap-equipped washrooms. He will never have to be transferred to a nursing home as he ages" (146).

• "This facility has latest new upgrades (safety, etc.)" (149).

**Quality staffing support.** Family members also commented about the quality of current staffing supports to meet the needs of their family members in the community. The majority of family members reported that they were satisfied with the current level of supports. Examples of the family's satisfaction with the level of staffing include:

• "Very good staffing" (102).

• "Excellent attention to his personal needs. Very friendly rapport" (108).

• "I am very satisfied with the current staff support. They call when they have issues or questions, or just call me if my brother wants to talk to me..." (114).

• "Staff support is caring, loving. Competent and professional. [He] is extremely well loved and all his many needs are met. [He] feels happy, safe and content" (128).

• "They are very attentive to a variety of medical problems and take a positive approach in providing interesting activities" (131).

**Quality professional and medical support.** Family members reported that they were pleased with the access, amount and quality of professional and medical supports in the community since their family members' move into the community. Given that many of the individuals with a developmental disability in the sample required biomedical and other professional supports, the need for accessible and quality supports was paramount.

Examples of the families' satisfaction with the quality, amount and access to professional and medical support include:
“[He] has many health issues. He has had to see several different specialists and has been in Emergency several times. This is always done promptly and efficiently” (105).

“A is taken regularly to doctor and dentist appointments... Our small local hospital is only a few blocks from her group home - swiftly accessible” (129).

“Services are available and planned visits are part of his plan” (133).

“All medical services are local in her area” (149).

“Whenever a situation arose where medical requirements were needed, it was there (153).

**Becoming**

According to Brown et al’s (1997, pp.10-11) Quality of Life Model, Becoming refers to practical, leisure and personal growth activities, community access and “achieving personal goals, hopes and aspirations”. Based on family members’ narratives about the individuals’ overall, enhanced quality of life and coping with community living, a few subthemes became evident:

- **Choice and Control**
- **Meaningful Activities**

*Choice and control.* Family members reported that their family member’s quality of life had improved because they had greater choice and control over their lives and their day. Specifically, family members provided the following narratives as examples of the “choice and control” subtheme.

1. They are happier - more choice, more control. 2. [He] has never fed himself before - he does now. So he controls how much and how fast he eats. Wow! 3. Both were prone to pneumonia which can easily become life threatening - better now...4. I thought the move would kill them (literally). Instead they are healthier, happier and doing better than I ever dreamed!” (110).
• “She had never been on a trip taken a flight. Even I got to accompany her last yr. to Winnipeg along with her primary councilor. The trip was to visit a staff member who had moved back home. [She] loves flying and has already been on 3 trips involving flying…” (111).

• “[They] have more control about 1. what they do, 2. when they eat, 3. When they rest/relax, 4. where in home they relax (own bedroom, living area or outside, 5. Have own bedroom vs. sleeping in dorm, 6. more personal time with staff as fewer residents” (110).

• “She has more freedom of choice!” (152).

Meaningful activities. Since the move into the community, family members reported that the community offered a number of possible and accessible meaningful activities that family members wanted to participate in as part of their own goals and aspirations. The following examples are symbolic of the “meaningful activities subtheme”:

• “[He] has been placed in a warm, caring, supportive, ‘home-like’ group, has a wonderful day program to attend and many stimulating field trips and extra-curricular activities (138).

• “She has much more available to her as far as things to do and outings. She also has more one on one care - better ratio of client/staff” (111)

• “[He] is now exposed to a large variety of adventures in the public. He cannot verbalize but does appear happy agreeable when out” (131).

• “There are lots of activities. He loves puzzles, bowling, swimming” (136).

• “[She] has access to events, social functions and interactions with others that he did not before” (153).

Summary of Results

Overall, a vast majority of family members were satisfied with the outcomes of deinstitutionalization across several areas based on ratings and narratives analyzed from the family surveys. Tables 4 and 5 in Appendix B provide a summary of the descriptive statistical analysis and
thematic analysis with representative exemplars of the family survey results. Given the trends in the quantitative data analysis demonstrating overwhelming satisfaction with the deinstitutionalization process and community reintegration at least 1 year post-closure, the qualitative data (i.e., quotes provided by family members) were separated into common themes as depicted in Figure 7. A summary of narratives provided by families is included in Appendix C.

Discussion

Research Questions and Study Results

The results of the descriptive statistical (i.e., quantitative data) analysis of ratings and the thematic analysis (i.e., qualitative data) of the narratives garnered from the family survey produced an overall quality of life analysis of the lives of 55 individuals transitioned at least one year post-deinstitutionalization from three different facilities into community settings across several regions in the province of Ontario. A vast majority of family members reported satisfaction with their family members’ move to the community. Specifically, family members were satisfied with their relatives’ adaptation to community living and their new home (research question 1), the level of staffing, and the availability of professional and medical supports (research question 2). They were also satisfied with the level of family contact and the individuals’ access to and choices of meaningful activities (research question 3). They also reported satisfaction with the individuals’ overall quality of life (research question 4) and quality of life enhancements as it related to their experiences and the outcomes of the facility-to-community transition at least 1 year post-closure (research question 5) (Please see Table 4 and 5 in Appendix B for a summary of results).

When family members were asked about the degree to which their family members enjoyed the important possibilities of his or her life or how good his or her life was for him or her since the move to the community, 91% of family members reported that their family member had an excellent (64%) to good (27%) quality of life since the move into the community. A minority of family members (9%) deemed the quality of life of their family member as adequate (4%) or
needing improvement (5%). These family members reported feeling displeased with how the government and community had supported the challenges of meeting the needs of certain individuals with complex needs (e.g., 1:1 support; medical problems; available supports and resources). Overall, these results were highly consistent with the ratings and narratives across all survey questions and Quality of Life Domains of Being, Belonging and Becoming (Brown, Raphael & Renwick, 1997).

Contributions to the Research

Although there is a plethora of research on the process of deinstitutionalization and family attitudes about deinstitutionalization in the United States, across the Commonwealth (i.e., UK, Ireland, Australia, New Zealand) and Scandinavia, there has been very little research in Canada given the recent closure of the last 3 of 16 institutions in Ontario (Lemay, 2009). The aftermath of the Ontario deinstitutionalization project (i.e., Facility Initiative) has not been thoroughly documented across several important outcome imperatives including parental perspectives and evaluations on the overall benefits and quality of life of individuals with DD and family members since their relocation to the community (Lemay, 2009; Martin & Ashworth, 2010. This particular study adds to the existing compendia of related research on family attitudes and quality of life while distinctly contributing to the much needed research on deinstitutionalization in Ontario (Lemay 2009; Martin & Ashworth, 2010).

The outcomes of this study echo many of the results and discussions garnered from the international body of research on family attitudes post-deinstitutionalization. A common result from surveys across studies is that parents are initially against deinstitutionalization (Grimes & Vitello, 1990; O’Brien et al., 2001; Spreat & Conroy, 2002; Tøssebro, 1998). An equally important result is that the support for community living generally increases as the frequency of contacts by family members also increases after deinstitutionalization (Spreat & Conroy, 2002). Also, family members’ support for community living sometimes increases several years later (Spreat & Conroy,
Overall, study surveys suggest that the initial negative attitudes of parents towards deinstitutionalization dissipate considerably after the process and are replaced with more positive perspectives and even enthusiasm for community living (Grimes & Vielleo, 1990, Griffiths-OAMR, 1985; Heller, Bond & Braddock, 1988; Larson and Latib, 1991; Lemay, 2009; Tuvesson & Ericson, 1996; Tøssebro, 1998). This is consistent with the results of this study.

Many previous studies found that family members play a vital role in the realization and success of relocation (Parish, 2005). Indeed, the level of family contact and involvement during and after deinstitutionalization is associated with positive attitudes towards the deinstitutionalization process (Conroy et al., 2003; Cummins & Dunt, 1998). Steadfast and durable family involvement are necessary for the successful maintenance of quality of life gains in the community (Tabatabainia, 2003) and the overall security of the quality of services and safety of residents in the community (Spreat & Conroy, 2002; Wolfensberger, 2003; Young & Ashman, 2004). Overall, the research, based on families and staff surveyed, suggests that individuals with DD have an improved quality of life after deinstitutionalization and that family members are generally satisfied with community relocation (Brown, Raphael & Renwick, 1997; Brown, Renwick & Raphael, 1999; Cullen et al., 1995; Dagan et al, 1998; Griffiths, 1985; Nottestad & Linaker, 1999; Nottestad, Stromgren & Linaker, 2001; O’Brien et al., 2001; O’Neill et al., 1990; Young & Ashman, 2004a; Young & Ashman, 2004b). This study corroborates these findings. Specifically, the families in this study were involved in the deinstitutionalization process from the beginning in Ontario (i.e., education, process, facilitation, follow-up), which seemed to have helped most families with the anxiety of the move and the transition of loved ones to the community.

Limitations of the Study

There are a few methodological limitations to this study that require attention. The first involves sampling and sample size. Although the sample for this study is representative across the three facilities, one particular facility (Facility A) provided the majority of the data (53%). This is a
point for consideration. However, given the uniformity of results across facilities and family members, this may not have had a great impact on the outcomes of the study overall. The study also used a relatively moderate sample size (N=55), thus lessening the possibility of analyses for statistical significance.

The second limitation involves the use of a retrospective study and the lack of a pre-measure to compare the results before and after deinstitutionalization. Although retrospective studies have the advantage of making use of data collected after-the-fact for quick analyses, the major disadvantage of retrospective studies is that the baseline state, intervention and outcomes are obtained from existing information versus the determination of baseline and controlled intervention comparison as in prospective studies (Gravetter & Forzano, 2005). Also, the effects of confounding variables become less sensitive and obvious in retrospective studies. A baseline measure would have offered greater flexibility to the study for effect size analyses and a deeper thematic analysis of any concerns and controversy expressed by families regarding deinstitutionalization. Indeed, a pre-measure would have also offered a salient analysis of the changes and full impact of deinstitutionalization from family members’ perspectives and an even greater understanding of the many attitudinal issues that may lead to better and more successful implementation of the deinstitutionalization process for individuals with DD. Further, it would have enlightened the process of deinstitutionalization to a greater extent for policy-making purposes and the elucidation of key ingredients for successful integration such as clarification of the process, planning, reassurances, education and funding (Tabatabainia, 2003).

The third limitation involves the use of a survey methodology in research. Survey methods have numerous advantages given that they are relatively inexpensive on resources, easy to deliver and administer from remote locations (i.e., mail, email, telephone), useful in describing the characteristics of larger populations, the possibility of large sample sizes for statistically significant results with multiple variables and the flexibility of offering many questions for research analysis
(Alreck & Settle, 1995; Babbie, 1995, Gravetter & Forzano, 2005). Surveys also have several disadvantages including the possibility of missing crucial information that is most appropriate to many respondents, the inability to change the research design through the data collection process, the uncertainty that a large number of the sample will reply, and the impracticality of participants recalling certain information or telling the truth about a controversial topic (Babbie, 1995; Alreck & Settle, 1995; Gravetter & Forzano, 2005). Although the use of a survey methodology has been widely used in several, similar studies (Conroy et al., 2003; Cummins & Dunt, 1998; Mansell, Beadle-Brown & Clegg, 2004; Parish, 2005; Spreat & Conroy, 2002; Wolfensberger, 2003; Young & Ashman, 2004), and is warranted given the nature of the research questions evaluating the longitudinal impact of deinstitutionalization on the quality of life of individuals with DD from family members’ perspectives, surveys may not provide quick turnarounds or personal contact with the persons completing the surveys. Also, the chance of non-respondents or unanswered questions will differ from respondent to respondent. To improve response rates and to decrease the chance of any measurement errors, contacting the respondents as a follow-up strategy would be prudent in the future.

Future Directions

Given that there are several international studies that have delved into family perspectives on the deinstitutionalization process, this Ontario study is timely in that it is a current and comprehensive study of the quality of life outcomes of individuals with DD since the last facility closure in Ontario. The results of this study are also congruent with the results of similar studies. However, there are several unanswered questions and future directions that research can take to examine the impact of community integration and living on the quality of life of individuals with DD.

The first direction would involve further analysis of family surveys with a larger sample size to get an even richer sense of information that would be fruitful for the deinstitutionalization
process and community living resources based on the needs of individuals with DD and their families. This would also help identify other gaps in services that would be helpful for the individual with a developmental disability, family members, professionals and agencies.

The second direction would involve a 5-year and 10-year post-deinstitutionalization study examining the long-term effects of community integration on the quality of life of individuals with DD. This would allow researchers the opportunity to investigate whether the positive effects of deinstitutionalization reported by families after resettlement are short-term or long-term. This would compliment a more recent study by Tøssebro and Lundeby (2006) that found that the positive effects and attitudes of family members maintain over the long-term. Specifically, only 17% of families preferred community resettlement before it happened, while 73% preferred it shortly afterwards and 76% preferred community placement 10 years later based on data gathered from interviews of staff and postal surveys of family members.

The third direction involves giving a voice to those individuals with a developmental disability who have already transitioned into the community. This could potentially add to the findings of the Fotheringham et al. (1993) Ontario study reviewed previously. The results of such a potential study can be juxtaposed and critiqued against studies that tap into the perspectives of family members around the quality of life of individuals with DD.

The fourth direction involves the lessons learned from the deinstitutionalization process in Ontario and their applicability to other provinces in Canada and other countries. Specifically, the feedback from family members and their involvement in the process is very valuable and can make or break the deinstitutionalization initiative. Further, the community support needs of individuals with DD and the implementation of the resource infrastructure (i.e., meaningful activities, quality staffing care, access to professional and medical services) required to support these needs prior to deinstitutionalization is paramount. This requires government funded resources (i.e., government liaison, transition consultation and education) and policies that safeguard the essential nature of
quality services for individuals with DD in the community. Given the recent Services and Supports to Promote the Social Inclusion of Persons with DD Act (2008) (Ontario Regulation 299/10) (http://www.e-laws.gov.on.ca/html/source/regs/english/2010/elaws_src_regs_r10299_e.htm), the Ontario government is enacting compliance initiatives with quality assurance measures outlined in the Act for approximately 385 agencies that provide services for persons with DD and receive funding from the Ministry of Community and Social Services (MCSS). These quality assurance measures include training on residential service requirements, behavioural support training, and abuse awareness and prevention training. The impact of this Ontario government initiative on the quality of life of individuals with DD in the community would provide fertile ground for future studies.

**Conclusion**

“The institutions are dying. This is what has sparked current controversies over institutionalization...

...As the institutions continue to die, however, so will the controversies” (Taylor, 2005, p.103).

As Taylor (2005) eloquently prophesized, institutional care and the controversy over deinstitutionalization for individuals with DD are fast becoming footnotes to history across the globe. Rhetoric subsides in the face of reality. Although the closing of the last institutions in Ontario has created debate as to the benefits and costs of deinstitutionalization for families and for individuals with a DD, the broad consensus of family members who participated and were surveyed in this retrospective research study was that their family members enjoyed an enhanced quality of life in the community at least one year post-deinstitutionalization. Specifically, family members were predominantly satisfied with their family members’ adaptation to community living and their new home, with staffing, professional and medical supports, the level of contact with their loved ones, the level of access to and choice of meaningful activities, and their family members’ overall quality of life. These results are consistent with available international studies gauging family attitudes after deinstitutionalization that have reported better outcomes overall and an improved
References


Grimes, S.K., & Vitello, S.J. (1990). Follow-up study of family attitudes toward


Footnotes

1 A team of researchers at Brock University under principal investigators Dr. Rosemary Condillac and Dr. Dorothy Griffiths have been commissioned to carry out studies examining the impact of de-institutionalization on individuals with DD in Ontario. The Facilities Initiative Study is a multi-method study, and these data were collected as part of the Family/Agency Survey portion of the study.
Appendix A

Survey Study: Facilities Initiative Research Evaluation

Lead Investigator and Contact Person for the Survey Study: Dr. Dorothy Griffiths
Principal Investigators: Drs. Rosemary Condillac and Dorothy Griffiths
Co-Investigators: Drs. Maurice Feldman, Frances Owen, Jan Frijters
Centre for Applied Disability Surveys
Brock University
Tel: 905-688-5550

Research Coordinator: Leanne Gosse or Jennifer Robinson

Purpose of the Research

The purpose of the survey study is to contribute to an evaluation of the impact of the facility initiative in Ontario by gathering information from people who are living through this experience. We will send surveys to family members and community agencies who received the residents from the facilities.

Introduction

Before you agree to participate in this research study, it is important that you read and understand the following explanation of the study. It describes the purpose, procedures, benefits, and risks associated with the study. All research is voluntary. You are free to withdraw at any time without penalty. If you have questions after you read through this form please contact us. You should not sign this form until you are sure you understand everything on it.

Description of the Research

If you agree to participate in this study, we will ask you to complete a survey about your family member. If you cannot complete the survey but would like to tell us your story you may have a phone interview.

The survey will take approximately ½ hour to complete, depending on the detail you wish to supply. You will be asked to answer questions about your family member’s quality of life, use of services, need for services, and other related information. If you are uncomfortable with any question, you can skip that question.

Potential Harms (Injury, Discomforts or Inconvenience):

Some questions may make you feel uncomfortable. You can skip any question you don’t want to answer. There is potential risk to you if the confidentiality of the information you give us were to be lost. To protect your confidentiality, your information will be kept on a coded form that does not have your name or other identifying information. We will keep your name and that of your family member and other identifying information (such as name and date of birth) on a separate form. All information you give us will be kept in a secure research office, and only authorized research staff will have access to the information.
Potential Benefits:

There are no immediate benefits to you to participating in this study. You will not be paid for participating in this study. The benefits will come from sharing what we learn from you and from other participants that may help others who are involved in facilities closures around the world.

Confidentiality and Privacy:

Confidentiality will be respected and no information that discloses your identity will be released or published without consent, unless required by law.

All information that identifies your family member will be kept confidential and stored and locked in a secure place that only study personnel will have access to. In addition, electronic files that include identification information will be stored on a secure institutional network and will be password protected. It is important to understand that despite these protections being in place, experience in similar surveys indicates that there is the risk of unintentional release of information. The principal investigators will protect your records and keep all the information in your study file confidential to the greatest extent possible. The chance that this information will accidentally be given to someone else is small.

Publication of Results:

In the event that the results of this study are published or presented at conferences, seminars or other public forums, no individual information or identifying information will be released. We will send you a copy after it is over if you tell us you want one. The results will be published both by the Ministry of Community and Social Services and the Investigators of this research.

Reimbursement:

You will not be paid for participating in this study.

Participation and Withdrawal:

Participation in research is voluntary. If you choose not to participate, you will not be affected in any way. Your decision to participate or not participate in this research study will have no effect on the housing, the welfare or the services your family member receives. If you would like to withdraw from the study, you can do so at any time by contacting us by phone.

Study Contact Information:

If you have any questions about this research study, you may contact Dr. Dorothy Griffiths (905-688-5550 ext 4069, e-mail dgirffiths@brocku.ca) or Dr. Rosemary Condillac (905-688-5550 ext. 5671, e-mail: rcondillac@brocku.ca) (collect calls accepted).

Research Ethics Board Contact:

The Research Ethics Board at Brock University may need to review records for monitoring purposes. As part of this review, someone may contact you from the Research Ethics Board to discuss your experience in the research study.

This study has been reviewed and approved by the Brock Research Ethics Board. (File # 08-25) If you have questions or concerns about this study you may call the investigators listed above or the Brock University Research Ethics Officer in the Office of Research Services at 905-688-5550 ext. 3035, email: reb@brocku.ca.
Consent to Participate in a Research Study:

I acknowledge that the research study described above has been explained to me and that any questions that I have asked have been answered to my satisfaction. I have been informed of my right to choose to not participate in the study. As well, the potential risks, harms and discomforts have been explained to me and I also understand the benefits of participating in the research study. I understand that I have not waived my legal rights and those of my family member nor released the investigators, sponsors, or involved institutions from their legal and professional duties. I know that I may ask now or in the future any questions I have about the study or the research procedures. I have been assured that records relating to my family member will be kept confidential and that no information will be released or printed that would disclose my personal identity without my permission unless required by law. I have been given sufficient time to read and understand the above information.

By signing this consent, I agree to allow the agency that is supporting my family to participate in this survey study. I agree to allow the research team to contact the Community Agency that supports my family member to request their completion of a survey about the welfare, quality of life and adaptation of my family member since moving to the community. The data collected will remain anonymous and be coded as described above.

I will retain a copy of this consent form for my records.

Name and Date of Birth of family member for whom I am giving consent to participate in this study:

(Name) Date of Birth

X

Signature of Consent Source Name (printed)

Date

( ) I would like a copy of the survey summary sent to me at the following address when it is completed.

Address:
FAMILY QUESTIONNAIRE ABOUT INDIVIDUALS TRANSITIONED DURING THE FACILITY INITIATIVE

Dear Family member

Please answer the questions below as fully as you can. We are very interested in understanding how your family member is doing since leaving the facility. Your information will be kept totally confidential unless on the last page you identify a concern that you wish us to raise with the Ministry. Otherwise all information will be used as part of the data we collect from everyone who completes questionnaires. A summary of our data will be available if you request it.

Dr. Dorothy Griffiths, Project Lead

Name of family member who left the facility: _______________________ (optional)

1. What facility did s/he live in prior to this placement?

2. To what Agency did your family member move?

3. What is your relationship to this individual? (circle one)
   a) Mother
   b) Father
   c) Brother
   d) Sister
   e) Other (please explain) ____________________________

4. Are you pleased with the present placement? (circle one)  Yes  No
   Please explain:
   _______________________________________________________
   _______________________________________________________

5. Has your family member adapted well to the new physical environment? (circle one)
   Yes  No
   Please explain:
   _______________________________________________________
   _______________________________________________________
6. Has your family member adapted well to living in a smaller setting? (circle one)  Yes  No

7. Has your family member developed positive relationships with the new staff? (circle one)  Yes  No

8. Overall, how would you rate your family member’s transition from the facility to the community? (circle one)
   a) Excellent
   b) Good
   c) Adequate
   d) Needs Improvement
   e) Poor

9. Is the current location a good fit for your family member? (circle one)  Yes  No
   Please explain:

   __________________________________________________________

10. Are you satisfied that the design of the current home is appropriate for your family member? (circle one)  Yes  No
    Comments:

11. Are you satisfied with the current residential staffing arrangements for your family member? (circle one)  Yes  No
    Please explain:

   __________________________________________________________

12. Does your family member have the type of professional/medical supports that were recommended when he/she left the facility? (circle one)
    a) more than recommended
    b) same as recommended
    c) less than recommended
    Please explain:

   __________________________________________________________
13. a) Are you pleased with the type of professional/medical supports your family member is receiving? at were recommended when s/she left the facility? (circle one) Yes No

b) Are you pleased with the amount of professional/medical supports received by your family member? (circle one) Yes No

c) Are you pleased with your family member’s access to needed professional/medical supports (circle one) Yes No

Please explain:

____________________________________________________

____________________________________________________

14. Please describe the communication between family and the new Agency? (circle one)
   a) good communication
   b) adequate communication
   c) poor communication

Please explain:

____________________________________________________

____________________________________________________

15. Are you geographically closer to your family member than when he/she lived in the facility? (circle one) Yes No

16. Are you able to:
   a) Visit more often? (circle one) Yes No Same
   b) Call more often? (circle one) Yes No Same
   c) Have them visit more often? (circle one) Yes No Same

17. Quality of life is the degree to which a person enjoys the important possibilities of his life or when we are talking about your family member “How good is his or her life for him or her?”

---

1 Brown, Raphael, Renwick (1997). Quality of Life-Dream or Reality?, Centre for Health Promotion, Toronto (p.10).
How would you rate the quality of life of your family member now? (circle one)

a) Excellent
b) Good
c) Adequate
d) Needs Improvement
e) Poor

Please explain:

__________________________________________________________________________

__________________________________________________________________________

18. Has your family member’s move to the community produced changes that you had not anticipated before he/she left the facility? (circle one) Yes No
Please explain (write on the back if more space required):

__________________________________________________________________________

__________________________________________________________________________

Comment:

Thank you for your time in completing this questionnaire. Please feel free to share any other details of the story of your family member below.
### Summary of Descriptive Statistical Analysis of Family Survey Rating Results Across Research Questions and Quality of Life Domains.

<table>
<thead>
<tr>
<th>Quality of Life Domains &amp; Themes</th>
<th>Research Questions (RQ)</th>
<th>Family Survey Questions</th>
<th>Descriptive Statistical Analysis Results</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>BEING</strong></td>
<td>RQ1</td>
<td>Q5</td>
<td>Adapted well to physical environment = 96%</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td><strong>Transition &amp; Adaptation</strong></td>
</tr>
<tr>
<td></td>
<td></td>
<td>Q6</td>
<td>Adapted well to smaller setting = 96%</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Q8</td>
<td>Transition into the community</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td>Excellent = 73%</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td>Good = 24%</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td>Adequate = 0%</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td>Needs Improvement = 3%</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td>Poor = 0%</td>
</tr>
<tr>
<td><strong>BELONGING</strong></td>
<td>RQ2</td>
<td>Q4</td>
<td>Satisfaction with the following:</td>
</tr>
<tr>
<td>Family Satisfaction</td>
<td>Q9</td>
<td></td>
<td>Current placement = 96%</td>
</tr>
<tr>
<td>with Community</td>
<td>Q10</td>
<td></td>
<td>Goodness-of-fit of location = 98%</td>
</tr>
<tr>
<td></td>
<td>Q11</td>
<td></td>
<td>Layout / design appropriate of location = 98%</td>
</tr>
<tr>
<td></td>
<td>Q13a</td>
<td>Staffing supports = 96%</td>
<td></td>
</tr>
<tr>
<td>Placement &amp; Supports</td>
<td>Q13b</td>
<td>Quality of professional / medical support = 96%</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Q13c</td>
<td>Amount of professional / medical support = 96%</td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td>Access to professional / medical support = 96%</td>
<td></td>
</tr>
</tbody>
</table>
RQ3
Family Geographically closer to family member = 82%
Contact Visit more often = 82%
Call family member more often = 82%
Family member visiting family home more = 64%

BECOMING
RQ4
Q17
Quality of life ratings:
QOL Ratings
Excellent = 64%
Good = 27%
Adequate = 4%
Needs Improvement = 5%
Poor = 0%

Table 5

Summary of Thematic Analysis of Family Survey Narrative Results Across Research Questions and Quality of Life Domains.

<table>
<thead>
<tr>
<th>Quality of Life Themes</th>
<th>Quality Of Life Subthemes</th>
<th>Research Questions</th>
<th>Family Survey Questions</th>
<th>Representative Narrative Exemplars</th>
</tr>
</thead>
<tbody>
<tr>
<td>Being Adaptation</td>
<td>RQ1</td>
<td>Q5</td>
<td>“She made the transition to her new home much easier than we had anticipated and has adapted to her new environment very well” (145).</td>
<td></td>
</tr>
<tr>
<td>Environmental Belonging Goodness of Fit</td>
<td>RQ2</td>
<td>Q4</td>
<td>“The location, staff, programs and living conditions are very well suited to [her] needs.”</td>
<td></td>
</tr>
<tr>
<td>Quality of Staffing Support</td>
<td>Family Satisfaction</td>
<td>Q9</td>
<td>Communication with his family (5 siblings) are excellent” (123).</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Community Placement &amp; Quality of Supports</td>
<td>Q10</td>
<td>“Staff support is caring, loving. Competent and professional. [He] is extremely well loved and all his many needs are met. [He] feels happy, safe and content” (128).</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Professional &amp; Medical Support</td>
<td>Q11</td>
<td>“Because of the close proximity of the medical facilities he is well taken care of” (142).</td>
<td></td>
</tr>
<tr>
<td>Becoming Choice &amp; Control</td>
<td>RQ4</td>
<td>Q17</td>
<td>“[They] have more control about 1. what they do, 2. when they eat, 3. When they rest/relax, 4. where in home they relax (own bedroom, living area or outside, 5. Have own bedroom vs. sleeping in dorm, 6. more personal time with staff as fewer”</td>
<td></td>
</tr>
</tbody>
</table>
residents” (110).

“She has access to events, social functions and interactions with others that he did not before” (153).

“I really don't think that there is much more that they can do to improve her quality of life” (102).
Appendix C

Summary of Family Member Narratives across Themes and Subthemes Supporting the Thematic Analysis Results for the Overall Quality of Life Analysis.

**Overall Theme: Quality Of Life**

Some examples of narratives supporting enhanced “Quality Of Life” for the individual with a developmental disability include:

- “I really don’t think that there is much more that they can do to improve her quality of life” (102).
- “1. They are happier - more choice, more control. 2. [He] has never fed himself before - he does now. So he controls how much and how fast he eats. Wow! 3. Both were prone to pneumonia which can easily become life threatening - better now…4. I thought the move would kill them (literally). Instead they are healthier, happier and doing better than I ever dreamed!” (110).
- “A’s quality of life is excellent - if we mean she is enjoying top care, good food and loving and patient attention, but her abilities and participation is limited, so the qualities of a happy, fulfilling life are sometimes absent” (129).
- “I was very much against [him] being moved away from where he had been most of his life. I thought it would be very disrespectful for him to change living arrangements at this stage of his life. The other members of my family felt it would be good for him. I have changed my views completely now that he has moved for almost 2 years. There was an adjustment period at the beginning, he had more seizures, but this also calmed down and he is a very happy person. He is extremely well cared for and his life is very good” (148).
- “Quality of life keeps on improving. It is soon 5 years since his relocation. There has (and is) noticeable improvement each and every year” (154).
• “As mentioned previously, we had worried about the transition. After all, [she] had lived in the institution for more than 40 yrs. And we had been very pleased with her care and activities. We worried that she would miss many of her friends, familiar surroundings, and might become disoriented and withdraw or ‘act out’. We worried that there may not be enough staff in her new location and that [she] may 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 ‘1 size group’ – ‘fits all’. Thankfully, all of our fears were ill founded when [she] arrived at [community placement]. Care was taken to accommodate [her] with her long time male companion and she has made many new friends” (103).

• “We were initially extremely upset at the thought of such a disruption for [him]. The results have been so gratifying as we watch [him] benefit day by day from his new setting that we give thanks for this tremendously successful move. We are thankful to all who were involved in this very difficult and time consuming process and look forward to the days ahead for [him] now that he is in his new home and is so happy there” (105).

• “[She] had the freedom to go to the canteen on her own, visit the ceramics class and craft room on her own when others were present. Here she is limited because of safety issues. The home can be quite noisy because of some roommates, and there is no place to go if there is frustration because of the noise. Aggressive behaviour sometimes results, then staff use... restraints which isn't pleasant” (122).
• Staff not enough experience to understand or meet her special needs - Doesn't recognize serious medical situations” (132).

**Theme: Being**

**Subtheme: Adaptation**

Examples of the subtheme of ‘adaptation’ (i.e., happiness and comfort in their new settings along with the safety, security, and quality of care provided by the community setting as signs of their adaptation) for the Quality of Life domain theme of Being included the following:

• “The transition was much easier than expected” (101).

• “She is happier in her new home!” (102).

• “...felt immediately comfortable in the day program and has felt very much at home in the caring atmosphere of her group home. Staff have done an amazing job of facilitating a smooth transition for her” (103).

• “...neither has any vision or hearing. He was initially exhibiting symptoms of discomfort but soon grew to be a relaxed and happy camper” (105).

• “…we were worried about the adjustment. But he adapted very soon after the more thanks to the great care...” (106).

• “He is enjoying his individual house setting with only 3 other residents” (108).

• “Staff have been exemplary. They care about [them] and it shows. It's like [they] are a member of the larger...family. Staff came to know, understand and interpret actions of both very quickly...” (110).

• “She has the possibility to do arts and crafts and is within wheeling distance of restaurants and stores and is taken out more often” (111).

• “...had adapted well to his new environment. He talks more and always wants to hug and kiss you more, and he allows people to touch his stroked hand and arm (right side). [He] never allowed anyone to touch that side of his arm and hand...” (114).
• “He seems to be very happy there. I talk with him once a week...have just returned from a week with him - he seems happy but their approach is totally different...” (115).

• “I have been told there are no problems” (120).

• “He is participating in activities in his [house] where there are only 6 residents” (123).

• “She seems happy, enjoys her care workers and loves getting out into the community” (124).

• “He enjoys living conditions and living in his own place” (125).

• “More activities, excellent supervision, more outings” (126).

• “She appears very comfortable there, seems very happy with the staff and her friends who live with her” (127).

• “… has adapted very well to physical environment. Was happy and smiling when he first got off the bus after arriving...” (128).

• “It is a comfortable and safe environment” (131).

• “Has become more out-going, more stimulated nice programme variety, staff attention/sensitivity” (133).

• “He likes having his own space. He is neat and tidy, and is happy having his own room” (136).

• “… felt immediately comfortable in the day program and has felt very much at home in the caring atmosphere of her group home. Staff have done an amazing job of facilitating a smooth transition for her” (138).

• “Seems happy, always smiling, looks well!!” (140).

• “Very pleased with the service” (141).

• “He has friends here. He seems more peaceful and happier” (142)

• “Quieter - Fewer residents so roomier, wide hallways, lots of windows, brighter all contributing to a more relaxed...” (144).
• “She made the transition to her new home much easier than we had anticipated and has adapted to her new environment very well” (145).
• “He is happier, he has advanced in communication skills and he gives hugs to staff (with a big smile) - which he never did previously” (146)
• “The home setting appears to be very comforting to…” (153).

Theme: Belonging

Subtheme 1: Environmental Goodness-Of-Fit

Examples of the subtheme of ‘Environmental Goodness-Of-Fit’ (i.e., appropriateness of placement; the design and location of the community home to meet the needs of their family member with a developmental disability; greater contact with their family member) for the Quality of Life domain theme of Belonging (i.e., “connections with one’s environments”) include the following:

A. Appropriateness of Placement

• “Lovely new home, she has her own room, caring staff and home like atmosphere” (101).
• “She is well suited for her home, and I can visit her every week and she comes to visit me if I am not feeling well” (102).
• “P has been placed in a warm, caring, supportive, ‘home-like’ group home, has a wonderful day program to attend and many stimulating field trips and extra-curricular activities” (103).
• “For the first time in many years [he] is being treated as 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” (105).
• ”[He] is in a very nice home. He gets excellent care there and we are very pleased” (106).
• “We are very pleased with personal attention to [his] needs - he has significant medical problems and the staff are very caring and competent in this regard” (108)
• “Caring staff, location, involvement in activities” (109).

• 1. Facility staff update me regularly. 2. Care is exemplary -Staff cares about them, they are trained. They like working for [agency]. 3. Meaningful annual planning meetings are held. My input is valued. 4. I am consulted about financial decisions on how their $ are spent. 5. The residence is a home not an institution” (110).

• “1. It was so close to the family 2. We are pleased that she moved in with friends from other home. 3. She seems happy with everyone” (113).

• “I am pleased with the present placement. WHY: My brother is more in a more positive energy environment has younger care worker with lots of energy and they trained as personal health care staff. [He] receives lots of individual care. He seems to be happy with the transition. I believe he is not as depressed as much as he was in the last 5 years at [facility]. [He] is bipolar, so he does have lows . . . but I believe not as many as he had at the... facility” (114).

• "As pleased as I can be considering my son’s age and years at one facility. I am 94 yrs old and of the "old school." I have 4 sons and family is very important to me when my some was 6 yrs old, there was nothing in the community-schools etc. The so called experts - physicians, psychologists - social workers. All abusive institutions. I am one of the parents in Toronto to form Assoc. for Retarded - now called community living. Against my wishes [he] was placed at Rideau Regional = this facility was built to appease many distraught parents...His new home is so different” (115).

• “[He] seems healthy and happy in his new home. The other men there are all easy going. A good atmosphere for [him]” (118).

• “I am 15 minutes away from her so it’s easy to attend all her meetings etc. The staff are very good with the clients, it’s a home like setting, so they have a lot more privacy. My daughter has had great medical attention from the local Drs.” (119).
• "New home good people running and I could eat off the floor!" (120).

• "Has her own room. Fear of things being taken decreased. Closer for more visits. Staff take her shopping and have arranged for crafts that can be used in the facility. [She] is encouraged to participate in some chores" (122).

• "The location, staff, programs and living conditions are very well suited to [his] needs. Communication with his family (5 siblings) are excellent" (123).

• "Although I did not see [her] as often when she was in [the facility], it seems to me that she now has a fuller life...she is treated much more like a normal person" (124).

• "[He] is living in conditions as a real person with freedom and fun once enjoying his life normal! Not in an institution" (125).

• "Excellent security, and better home" (126).

• "The home is beautiful. The staff are excellent and the ladies she glances the residents with are a good mix that I think has led to a lot of positive changes in [her] life" (127).

• "Very pleased with placement - did not find [residence] until nearly time for move to take place due to difficulties encountered with staff at MCSS who did not care where [he] was placed, whether it met his needs or not" (128).

• "[She] was first placed in a Group Home in Windsor where she was very happy. However, I found driving into the city an increasing problem, so when a Group Home was available in Seamington - where I live - she was moved and I am able to visit more often. She also has two brothers living in the area, which is a support for me, as well" (129).

• "[She] is very happy and content in her new home and we are now able to visit her once weekly and its only a 15 min drive from our home" (130).

• "Outstanding philosophy, facility and staff!" (133).

• "He is happy there" (135).
“Very pleased. He seems to be very happy there. He has own room, and gets along well with everybody” (136).

“He was unable to communicate in his previous placement. I’m happy now that [he] is able to communicate in sign language – ASL” (137).

“[She] has been placed in a warm, caring, supportive, ‘home-like’ group, has a wonderful day program to attend and many stimulating field trips and extra-curricular activities (138).

“I think she gets more personal care, all the staff love her!!” (139).

“Better her then she’s ever been” (140).

“My brother is very happy to be there” (144).

“More personal-hands on-attention. [He] seems happier. Closer to family members” (142)

“Well taken care; well loved; client happy” (143).

“[She] lives in a modern, 7-bedroom home in a country - setting with six other residents. She is well cared for and seems to be content” (145).

“More attentive to his needs, more stimulated with respect to physical and mental activities. More emotional support” (147).

“[He] seems much happier and at ease” (146).

“He is very well cared for in a home setting, which is a much more natural setting than the institution ever was” (148).

“There is a lot more staff to patient interaction in all phases” (149)

“We have seen a marked improvement in [his] physical and mental status” (153).

B. Placement a Good Match / Greater Access and Contact with their Family Member:

“Smaller setting, close to Tim Hortons - parks nearby, closer to family” (101).

“The staff are very good to [her] and she is close to me as I live within 10 mins of her” (102).
• “[She] lives close to us and we are able to see her often. She is able to access many community activities” (103).

• “Kitchener is only an hour from my home. This makes it very accessible for visits, doctors' visits, etc. This was very difficult in his previous location” (105).

• “He is able to be with either house members when he feels well, but they also can place him in his private room if he needs to be quiet” (106).

• “They are in a ‘home’ vs. institutional setting. Their residence is beautiful, on a quiet street with a secure yard and deck. They can enjoy outdoors while being secure (yard fenced, high plastic shield on deck). House incorporates a ‘snoezlen’ room which is perfect to soothe and relax [him]” (110).

• “She is within a 30 minute drive and can receive visitors any time. She has access to Para Transport and can also visit us” (111).

• “Since [her] move, [her] other sister...who lives in Cambridge can now visit regularly. [Mother] and I live in Toronto. It only takes 1 1/2 to visit [her] in New Hamburg. There are times when all 3 family members visit on the same day” (114).

• “Location is in a great small town. 15 minutes from my home. His sister and brothers also live close” (1995).

• “Family able to visit more frequently” (122).

• “He has adapted very well. He can take walks go for coffee enjoys the scenery of his walk” (125).

• “She is close to all her medical needs, has an abundance of social and entertainment that have contributed to a much happier lady” (127).

• “The new location is an excellent fit for [him]. He has gone on lots of outings, movies, shopping etc...” (128).
• “After driving for an hour to reach the [facility] for previous visit imagine my present gratitude for a lovely, brand new, group home, three blocks from my residence! She is near a shopping mall, a theatre, a beautiful marina, beach and picnic area. So outings are now very frequent and appreciated” (129).
• Only 15 minute drive to our home (130).
• “The staff to resident ratio is very good the location has access to a great network of program services to Ottawa” (133).
• “[She] lives close to us and we are able to see her often. She is able to access many community activities” (138).
• “It’s closer for visiting especially on the holidays - Christmas, Easter, Birthdays etc.” (142).
• “She seems to be happy and content with her current location” (145).
• “It allows more frequent visits, summer, winter. If there is a concern, event, we are able to attend to more easily. Proximity allows for more involvement and care. Also my brother can visit us (mom & dad). This reciprocity was unthinkable before” (147).
• “He is located about 30 minutes from most of his family. We are able to spend much more time with him than before” (148).
• “Very good fit” (154).

C. Physical Layout and Design of New Setting:
• “[She] is able to physically access all levels and her group home is fortunate enough to have an additional ‘craft room’. Also, accommodation has already been made to provide help with the stairs if that becomes an issue in the future” (103).
• “Many steps have been taken to make the home user friendly for [him]. He is very comfortable and relaxed with every room and their setups” (105).
• “Yes. It’s a very nice home with obvious support equipment in bath and in an elevator...” (106).
• “...The home had been renovated to address their needs - elevator, fenced in yard, shield on deck, downstairs recreation room, secure kitchen, no carpets in house, lift for bath” (110).

• “She has her own room and there are 3 toilets accessible for the 5 residents and staff. One is fitted with a higher seat especially for her” (111).

• “She has her own room” (113).

• “[He] has a huge wall of windows in his private room ([he] has NEVER in 67+ years had a private room). He now has the equipment built into the room to lift his handicapped body out of bed into the wheelchair, or into the bath. [He] has he has his own TV, and stereo set. The family can take him out for wheelchair rides... all year round...” (114).

• “She has everything she needs” (120).

• “It has a more home atmosphere. There is enough room outside to take [him] for walks or sit on chairs outside to enjoy the weather and great times” (122).

• “He has adjusted so well!!” (125).

• “The home is new; the layout of the entire home inside and out is designed in a way to accommodate the needs of both residents and staff...” (127).

• “The current home is brand new all on one floor open concept and bright with a deck and lots of windows where he can watch the birds at the feeder and the cars go by. Surrounded by lots of trees and greenery. He has his own room” (128).

• “A moved from a crowded living and sleeping wards at the Regional Centre to a home-setting, with an uncrowded living and dining room, as well as a private, quiet room of her own!” (129).

• “Excellent outdoor spaces - exterior design is spacious, well thought out” (133).

• “At least, he's in a home now” (137).
• “Since 6 yrs old - First "HOME", private bedroom, exposure to a kitchen, a backyard, neighbours” (144).

• “Her home is in a country setting, is modern and spacious and she has her own bedroom with easy access to a bathroom” (145).

• “The facility is new - built as a group home, not a converted residence. It has an elevator and handicap-equipped washrooms. He will never have to be transferred to a nursing home as he ages” (146).

• “This facility has latest new upgrades (safety, etc.)” (149).

• “[He] has privacy in his own room” (153).

• “More than expected. Being blind can be difficult (154).

Theme: Belonging

Subtheme 2: Quality Staffing Support

Examples of the subtheme of ‘Quality Staffing Support’ (i.e., quality and level of staffing supports for the individual with a developmental disability) for the Quality of Life domain theme of Belonging include the following:

• “We talk on a regular basis and communication is excellent” (101).

• “Very good staffing” (102).

• “The current staff support is outstanding. The staff are friendly, caring and fair and firm when necessary. They consider [her] like/dislikes and help her make appropriate decisions in a safe supportive atmosphere. The staff have been patient with her, have helped her with her assertiveness and social interaction and have responded individually to her needs and requests. All staff have treated her with dignity, respect, care and affection. With staff support, [she] is now talking more than she has in years” (103).
• “We are overcome by the kindness and warmth with which all the staff treat [him]. They keep us notified about all the goings on and they constantly make themselves aware of his needs and do their best to fulfill them” (105).

• “Excellent attention to his personal needs. Very friendly rapport” (108).

• “Extra staff in to provide extra hands for bathing and personal care during the day. Lots of add’l resources - nursing, nutrition, dental, eating clinic, psychologist, heart specialist, etc.” (110).

• “The staff are great and they get extra help with students who are entering this service field. We are consulted when there is a need and kept appraised of everything” (111).

• “I am very satisfied with the current staff support. They call when they have issues or questions, or just call me if my brother wants to talk to me…” (114).

• “I have always been able to get her daily updates. She’s had lots of surgeries and the staff have done a great job of caring for her upon her return…” (119).

• “Her caregiver... very nice lady keeps my mother informed of what is going on in [her] life” (120).

• “Each resident has two full time staff assigned - work is always one on one or in small groups” (123).

• “Excellent. Very knowledgeable” (126).

• “The staff are excellent. Attend to the needs of [my son]. And keep me informed on a regular basis of everything happening in [his] life” (127).

• “Staff support is caring, loving. Competent and professional. [He] is extremely well loved and all his many needs are met. C feels happy, safe and content” (128).

• "They are very attentive to a variety of medical problems and take a positive approach in providing interesting activities” (131).
• “Everyone ‘gets it’ when it comes to daily living with the residents - respect their strengths and weaknesses - very professional and human touches” (133).

• “I am well informed and receive regular information” (135).

• “The current staff support is outstanding. The staff are friendly, caring and fair and firm when necessary. They consider [her] likes/dislikes and help her make appropriate decisions in a safe, supportive atmosphere. The staff have been patient with her, have helped her with her assertiveness and social interaction and have responded individually to her needs and requests. All staff have treated her with dignity respect care and affection (138).

• “All the staff are great” (140).

• “They are friendly and cooperative” (142).

• “24 hour awake staff, use of kitchen relative to ability could access fenced in yard herself - when hospitalized staff provided personal care, and assisted nurses and doctors. Staff were like angels” (144).

• “Her care-givers are very supportive and caring and they try to keep her active and involved” (145).

• “Seems physically and mentally supported and understood” (147).

• “I meet with them regularly and receive regular reports. I know most of the staff and am very satisfied with their work” (146).

• “They are always very friendly and willing to answer any questions we may have concerning [his] care. He is able to have more one-to-one attention from workers” (148).

• “Staff show genuine affection...” (153).

• “Staff support could not be better. 24 hour care provides total peace of mind” (154).
Theme: Belonging

Subtheme 3: Quality Professional and Medical Supports

Examples of the subtheme of ‘Quality Professional and Medical Supports’ (i.e., the access, amount and quality of professional and medical supports in the community since their family member’s move into the community) for the Quality of Life domain theme of Belonging (i.e., ‘connections with one’s environments’) include the following:

- “They [staff] followed up with the lump on her breast” (102).
- “[He] has many health issues. He has had to see several different specialists and has been in Emergency several times. This is always done promptly and efficiently” (105).
- “[He] has cancer, has required radical surgery in London on several occasions. Staff are very good at transporting him (108).
- “She is seeing a dentist at the hospital and I got a call from them just last week” (111).
- “She has to be hospitalized to do her dental cleaning because she won’t stop talking or hold her mouth open. They do this about every 1 1/2 yrs because its been hard to schedule around all her other procedures. The staff at our hospital know her by sight and name and she has come to trust many of them. This makes it easier to get the IB in and all the other parts of the procedures. She now will walk to surgery with the hospital staff” (119).
- “I have no problem with her treatment” (120).
- “We are pleased with what is being done but problems seem to be very complex and program is not a simple matter” (122).
- “The staff have good judgment and know when to call in the experts” (124).
- “[She] is monitored very closely by staff and all her medical needs are dealt with immediately and I am kept up to date on all the medical care she is receiving” (127).
- “All aspects of medical supports are excellent. Hospital is nearby” (128).
• “[She] is taken regularly to doctor and dentist appointments... Our small local hospital is only a few blocks from her group home - swiftly accessible” (129).

• “Services are available and planned visits are part of his plan” (133).

• “Everything is looked after” (136).

• “Because of the close proximity of the medical facilities he is well taken care of” (142).

• “‘Yes’ because medical professionals do their best at present. ‘No’ because the health care decisions makers (ministers, politicians etc.) are not pro-active with timely changes for improvement” (144).

• “A physician visits her home on a regular basis to monitor her health and recommends specialists as necessary” (145).

• “All medical services are local in her area” (149).

• “Whenever a situation arose where medical requirements were needed, it was there” (153).

Theme: Becoming

Subtheme 1: Choice and Control

Examples of the subtheme of ‘Choice and Control’ (i.e., greater choice and control for the individual with a developmental disability in their daily home and community life) for the Quality of Life domain theme of Belonging (i.e., practical, leisure and personal growth activities, community access and achieving goals and aspirations) include the following:

• “She is being given regular food, not pureed and loves it, it was formerly recommended, blended food due to choking possibility which has not happened - she does not use tunnel restraint since moving to community - she does not sit apart from others in a chair with restraint - she is able to go to restaurants and van rides - swearing and inappropriate language has lessened - she picks her own clothes - her toys are not under lock and key - she watches t.v. with staff - she is able to go outside on the deck and just sit in a swing - she is learning to help with her own washing” (101).
• “1. They are happier - more choice, more control. 2. [He] has never fed himself before - he does now. So he controls how much and how fast he eats. Wow! 3. Both were prone to pneumonia which can easily become life threatening - better now...4. I thought the move would kill them (literally). Instead they are healthier, happier and doing better than I ever dreamed!” (110).

• “She had never been on a trip taken a flight. Even I got to accompany her last yr. to Winnipeg along with her primary councilor. The trip was to visit a staff member who had moved back home. [She] loves flying and has already been on 3 trips involving flying...” (111).

• “[They] have more control about 1. what they do, 2. when they eat, 3. When they rest/relax, 4. where in home they relax (own bedroom, living area or outside, 5. Have own bedroom vs. sleeping in dorm, 6. more personal time with staff as fewer residents” (110).

• “She has more freedom of choice!” (152).

Theme: Becoming

Subtheme 2: Meaningful Activities

Examples of the subtheme of ‘Meaningful Activities’ (i.e., community offered a number of possible and accessible community activities that family members wanted to participate in as part of their own goals and aspirations) for the Quality of Life domain theme of Belonging (i.e., practical, leisure and personal growth activities, community access and achieving personal goals and aspirations) include the following:

• ”[She] feels valued and very comfortable in her new community setting. She is surrounded by wonderful, caring staff and friends, and participates in stimulating activities and events both at community living Cambridge and in the community” (103)

• “She has much more available to her as far as things to do and outings. She also has more one on one care - better ratio of client/staff” (111)
• “She gets out to day program - she goes to dances, shopping all the ‘normal’ things” (113).

• “The staff in…are always trying to find things for him to do and enjoy. Music, swimming, attending festivals, books on tape” (118).

• “[He] is now exposed to a large variety of adventures in the public. He cannot verbalize but does appear happy agreeable when out” (131).

• “There are lots of activities. He loves puzzles, bowling, swimming” (136).

• “[She] feels valued and very comfortable in her new community setting. She is surrounded by wonderful, caring staff and friends, and participates in stimulating activities and events both at [community living residence] and in the community” (138).

• “[He] has access to events, social functions and interactions with others that he did not before” (153).

• “She has become more open and talkative. She gets to go shopping every week. She has gone on vacation at Disney Land. She never would have been able to do these things when she was at the center” (102).

• “[She] is a much happier more contented individual in the smaller more intimate atmosphere of a group home. The combined staff are her ‘Family’. She responds to each member as well as the other residents. A smiles more often and laughs out loud in response to others. She is out - in her wheel chair or in the house van very often. There is a greater amount of stimulation in her life” (129).

• “She gets out every day. I believe either for a car ride or walk (when they are short-handed they might not). She bowls! And sometimes goes shopping. She seems to understand more of what is said for her even though she doesn't talk!” (152).

• “[He] is happier in his own home than in the [residence]. He gets to do things and go places in his new community much more than before. He has a more routine life, banking, getting groceries, etc. He has extended vacations and attends events he really enjoys whenever he
wants. He has the same staff present on a daily basis and has only 2 roommates instead of many more on a unit" (153).