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**AGING WITH DEMENTIA AND AN INTELLECTUAL DISABILITY
A CASE STUDY OF SUPPORTED EMPOWERMENT
IN A COMMUNITY LIVING HOME**

by

Shehenaz Manji

(Master of Social Work, Wilfrid Laurier University, 1997)

DISSERTATION

**Submitted to the Faculty of Social Work
in partial fulfilment of the requirements for**

Doctor of Philosophy

Wilfrid Laurier University

2008

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**AGING WITH DEMENTIA AND AN INTELLECTUAL DISABILITY
A CASE STUDY OF SUPPORTED EMPOWERMENT
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Doctor of Philosophy 2008

Shehenaz Manji

Faculty of Social Work

Wilfrid Laurier University

Abstract

This case study explores the qualitative experience of 4 consumers with a dual disability living in a home specializing in dementia support. Drawing insights from participant observation, daily living log notes, and interviews with 4 each of family/friend caregivers, direct-care staff, and administrators, the study has 3 main goals: (i) to understand how the onset of dementia in people with an intellectual disability changes their needs, what adjustments have to be made in the support practices, and what service barriers and successes are experienced; (ii) to understand how people with dual disabilities experience living in a home specializing in dementia support and how stakeholders perceive this model of support; and (iii) to identify ways policymakers can better respond to the changing needs of people with dual disabilities.

The findings of the study identify two social processes; one of marginalization and the other of supported empowerment. The process of marginalization depicts how dementia affects people with intellectual disabilities as they incur multiple losses in ability, home, and community. In spite of losses, the data illustrate how these individuals maintain their selfhood with good health support, decision-making, self-agency, and autonomy. Further, a home of choice with an individualized transition process, consistent and person-centered support, and elevated empathy facilitate their freedom of choice. Engaging the self in community, both inside and outside the home, is emphasized. The findings are contrasted with divergent perspectives on support practices and barriers in providing empowering support to consumers living in the home.

The study generates a theory of *supported empowerment* grounded in the data. This theory yields an empowering social model and micro-practices that harness elements of empowerment necessary to support people with dual disabilities. Seven policy considerations that prevent premature placement in nursing homes, enable aging in place, and maintain a participatory life in community are recommended from insights gained. Several research implications are raised by this study, notably, inclusive research methodologies to access the voice of people with a dual disability, caregiver support, inclusive community participation, the benefits of social versus medical models of long-term support, and personhood created in quality of lives.

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Next, I thank Dr. Peter Dunn, my thesis advisor, who brought his unique perspective on disability policies, social housing, poverty issues, gender concerns, and alternative social interventions to my study. He helped to humanize my language, and his research experience with Independent Living Centres helped me critically examine my findings. My dissertation journey was fraught with personal losses and challenges, and Dr. Dunn patiently and persistently supported me to stay the course.

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Dedication

I dedicate this thesis to all people with an intellectual disability, especially the four wonderful individuals who participated in this study. Their vision of an integrated social life free of stigma, oppression, and divisions inspires us all.

I also dedicate this thesis to my recently deceased mother, Daulatkhanu Hussenali Jiwa, who lives on in spirit to gently guide the steps of loved ones she left behind. The textures of her life are embedded in this thesis and compel us to honour the gifts of people no matter their age, ability, gender, and ethnicity.

CHAPTER ONE

Introduction

The number of people with an intellectual disability¹ and dementia² is on the rise (see Alzheimer's Society (UK), 2004; Cooper & Holland, 2007; Janicki & Dalton, 1997; Wisniewski & Lott, 1990). Henceforth, I shall refer to this combined experience as a *dual disability*³. Much of the research in this area has focused on the age of onset for dementia, medical interventions, and treatment to ameliorate this medical condition. Few studies have focused on the experiences of those living with a dual disability. As a result, there is inadequate understanding and knowledge regarding the specific, distinct caregiving and support needs for a person with an intellectual disability who, with dementia, experiences a drop in the quality of life.

One of the aims of this dissertation was to explain the experiences of people living with both an intellectual disability and dementia; and further, to understand how they experienced living in a home specializing in dementia support. I wanted to explore if existing interconnected health infrastructures, including living environments for this

¹ The term *intellectual disability* used in this paper replaces the terms *developmental disabilities*, *developmental handicap*, *mental handicap*, and the term widely used in North American scholarly literature, *mental retardation*. The American Psychiatric Association (2000) describes intellectual disability as sub-average adaptive and intellectual functioning at an IQ score of 70 or below and onset before age 18 years.

² *Dementia* is evidenced by a progressive decline in cognitive function due to damage to the nerve cells in the brain. It may lead to physical decline, affect a person's ability to relate socially, and reduce function in day-to-day activities (Alzheimer's Society (Canada), 2008).

³ The term *dual disability* to describe a condition of intellectual disability and dementia is selected by the author for use in this paper. The terminology in use at Community Living London where this study took place is, "people dually diagnosed with Alzheimer's and Down Syndrome."

population, delivery of support, and the policy and funding systems that support them, were able to address their needs appropriately and effectively. As the focus of this dissertation was people with a dual disability and their unique needs, and as current literature in this area is lacking, my goal was to address this gap by providing a clearer understanding of daily living, specifically as it relates to change in ability, environment, and community. My research questions were threefold:

1. What are the specific needs of individuals with a dual disability, what adjustments have to be made in the support practices, and what service barriers and successes are experienced?
2. How are these needs addressed in their living environment that specializes in dementia support and how do stakeholders involved in their lives perceive this model of support?
3. How can policymakers better respond to the changing needs of people with dual disabilities?

In this qualitative study I have examined the lives of four consumers with a dual disability residing in one living environment, a home specializing in dementia support. Rather than comparing multiple facilities and identifying the best amongst them, I aimed to uncover patterns in the daily living experiences of the consumers with a dual disability. The objective was not to rate the home I examined but to identify practices in the living environment. In order to gather data, I employed participant observation of the consumers as well as one-on-one, in-depth interviews with people involved in their support, including family (or family-like friend) members, direct-care staff, and agency administrators. I also reviewed agency records of the consumers.

While there were no theoretical frameworks by which to comprehensively measure development, implementation, and delivery of supports for this specific population, there was an empowerment model that informed my analysis. Not all the components of this model applied to the experience of the consumers in the study. Therefore, I used only the relevant elements throughout my analysis to develop a more complete theoretical framework. Using my findings, I provide some insights for policy and practices that empower people with a dual disability.

Structure of the Dissertation

This dissertation contains seven chapters. In chapter 1, I provide an overview of the prevalence of dementia in people with an intellectual disability; outline healthcare policies and challenges they experience; describe an innovative response to these challenges, homes specializing in dementia support; outline the purpose of the study; and detail my social location in it.

In chapter 2, I review the literature, beginning with the history of policies and practices for people with a dual disability or dementia. I then present current issues in policy and practice for the dual-disability population and describe medical and social discourses on disability. I conclude by portraying living environments for these individuals, summarizing empowerment theory, and describing research implications for a social model of dementia support.

In chapter 3, I outline the methodology I used in the study, my research aims, and research design. I then describe the research site, characteristics of the participants, and my role as the researcher in the home. Finally, I address the credibility, ethical considerations, and limitations of the study.

In chapter 4, I present the findings of the study and integrate some first level

interpretation to highlight the marginalization of the consumers participating in this study. In chapter 5, I continue to report the findings discussing the social process of empowerment and barriers to supported empowerment.

In chapter 6, I summarize and discuss the findings and how they contribute to empowerment theory. I then propose a model of support which I call, *supported empowerment*, and present a template of practice strategies that empower people with a dual disability. Lastly, in chapter 7, I point out the key findings of the study, discuss the implications of the study for policy development, and recommend areas for further research.

Prevalence of Dementia in the Aging Population

The most common form of dementia is Alzheimer's disease⁴, a deteriorating brain disease with an ultimate prognosis of death (Hill, Forbes, Berthelot, Lindsay, & McDowell, 1996). The main symptoms of clinically diagnosed dementia are progressive memory loss, inability to concentrate, poor sense of time and place; difficulty in communicating, completing self-care and domestic tasks, and solving minor problems; changes in mood and behaviour; incontinence, seizures, impaired mobility, and weight loss (Alzheimer's Society (UK), 2004; Cooper & Holland, 2007; Wisniewski & Lott, 1990).

Each of these symptoms varies according to an individual's baseline functioning and the stage of the disease. In someone with an intellectual disability, these symptoms may go unnoticed or be misinterpreted, because the person may have difficulty communicating any changes in health (Alzheimer's Society (UK), 2004). As a result,

⁴ Alzheimer's disease is a neurodegenerative disorder characterized by plaques and tangles in the brain (Alzheimer's Society (UK), 2004; Wisniewski & Lott, 1990).

some researchers suggest that the insidious and subtle symptoms of dementia are unrecognized in people with an intellectual disability and that the disease is therefore detected at a much later stage (Reisberg et al., 1989).

The presence of dementia has been well documented in the Canadian population. In a 1991 national study, Alzheimer's disease affected nearly two thirds (64%) of Canadians with dementia. The remaining third (36%) had vascular dementia (19%) and other forms of dementia (17%) (Hill et al., 1996). Dementia has been found to be associated with age; it is expected that, by 2031, over 750,000 people in Canada will have dementia due to the growth in the senior population (Alzheimer Society (Canada), 2007). In Ontario, Canada's most populous province, more than 100,000 people are already affected by Alzheimer's disease and related dementias. The Ministry of Health and Long-Term Care (MOHLTC) projects that this number will triple (to over 350,000) by 2031 (MOHLTC, 1999).

Prevalence of Dementia in People with Intellectual Disabilities

The occurrence of intellectual disabilities in the general population varies between 1% and 3% (Pary, 1992). It can thus be estimated that within Canada's population of 31,612,897 (Statistics Canada, 2006), there are between 316,128 and 948,386 people living with an intellectual disability. These individuals are experiencing longer life as a result of improved surgical procedures, medical care, antibiotic therapy, and living conditions (Chaney, Eyman, & Miller, 1985; Cooper & Holland, 2007; Kolata, 1985; Stein & Susser, 1971). Studies report that the mean life expectancy of people with Down Syndrome⁵ (who make up 15% of the population with intellectual disabilities) has

⁵ Down Syndrome is a genetic disorder in which individuals have aberrations, or extra material, on Chromosome 21 (Chicchetti & Beeghly, 1990).

increased from 9 years in the early part of the 20th century to 45 years at present (Baird & Sadovnik, 1987; Holland & Moss, 1997). Marler and Cunningham (1994) report that about 70% of people with Down Syndrome now survive to their third decade, 44% reach 60, and 13% live to 68 years.

As people with intellectual disabilities are living longer, neuroleptic disorders, such as dementia, are becoming more evident among them. Studies report that the prevalence of dementia is four times higher in aging people with an intellectual disability compared to those in the general population; and even higher for those with Down Syndrome (Alzheimer's Society (UK), 2004; Cooper & Holland, 2007; Wisniewski & Lott, 1990). Approximately 9%-25% of those aged 40 and older are affected by Alzheimer's disease (Janicki & Dalton, 1997; Oliver & Holland, 1986; Prasher & Krishnan, 1993).

Further, dementia among people with intellectual disabilities appears earlier than in the general population. Wisniewski and Lott (1990) found that 25% or more of individuals with Down Syndrome over 35 show clinical signs and symptoms of Alzheimer's disease, and that this percentage increases with age varying between 54.5% to 75% in those 60 and over (Lai & Williams, 1989; Janicki & Dalton, 1997; Janicki, McCallion, & Dalton, 2002; Prasher, 1995). In comparison, Alzheimer's disease within the general population peaks in the years 80 and over with a prevalence rate of 35%-40% (Canadian Study of Health and Aging Working Group, 1994; Janicki & Dalton, 1997).

The higher prevalence and earlier onset of dementia in people with intellectual disabilities is compounded by more rapid progression of the disease. It is much faster than in the general population, for whom the estimated survival from onset of dementia

varies between 1 year to 16 years and more (Molsa, Martila, & Rinne, 1986; U. S. Department of Health & Human Services, 1984; Walsh, Welch, & Larson, 1990; Wolfson et al., 2001). Among people with Down Syndrome, survival from onset of dementia ranges from 3 to 10.5 years and in rare instances up to 20 years (Dalton & Wisniewski, 1990; Lai, 1992; Prasher, 2005; Prasher & Krishnan, 1993; Tyler & Shank, 1996).

Health Services for People with Dementia

Policymakers in Ontario have begun planning for the projected rise in the aging population for dementia support. Funding and services for people with dementia come under the Ministry of Health and Long-Term Care (MOHLTC), which released in September 1999 Ontario's Strategy for Alzheimer Disease and Related Dementias – Preparing for Our Future. This plan was developed with input from individuals and community groups at the Ontario Alzheimer Round Table.

In 1998/99, the Ontario government pledged a multiyear increase in investment for long-term care, and to date, health initiatives have focused on reforming long-term care facilities, homecare and community-care services, the Drug Benefit Program, and a property-tax exemption for residences built or modified to accommodate a person with a disability (MOHLTC, 2008). Other strategies in dementia support have included research for a cure, finding effective medical interventions, testing and monitoring by physicians, and providing in-home support through Community Care Access Centres (CCACs).

The CCAC offers one-stop shopping for people to find health and social services based on need. It provides homecare assistance to seniors and those with disability or sickness who are living at home. The organization assesses and monitors the health needs of clients (including people with a dual disability) and makes referrals (e.g., to

physicians, nurses, physiotherapists, occupational therapists, speech language pathologists, dieticians, social workers, personal support workers, and homemakers) as needs change (CCAC, n.d.). When needs increase beyond the resources of the organization, the CCAC co-ordinates the placement in a long-term care facility.

In 2007, 14 Local Health Integration Networks (LHINS) were created to be served by their respective CCACs. At the same time the Ontario Minister of Health, Mr Smitherman, announced an Aging at Home strategy to assist seniors to live independently in their own homes “for the rest of their lives” (MOHLTC, 2007a, 2007b). As part of a three-year \$700 million strategy, the LHINS would receive funds based on their costs and health needs estimated by each individual’s age, diagnosis, and rural and socio-economic status in the respective geographic areas (MOHLTC, 2007b).

The new funding model is expected to enhance home care and community support services with “meals, transportation, homemaking services and caregiver supports, shopping, snow shoveling, friendly home calling, adult day programs, and increased access to mobility aids.” As well, non-traditional partnerships and new preventive and wellness services (e.g., those who deliver care informally, such as “friendly home visits/telephone calls and transportation to appointments”) may be eligible for funding (MOHLTC, 2007a).

Health Services for People with Intellectual Disabilities

Most of the people with intellectual disabilities live in the community, with funding from the Ministry of Community, Family and Children's Services (MCFCS). Community services and supports to these individuals and their families are primarily provided through a network of community-based, board-overseen, nonprofit, transfer-payment agencies. These agencies form the local chapters of the Canadian Association

for Community Living (Community Living Ontario, n.d.).

Services delivered by these nonprofit agencies include respite for family caregivers and specialized supports to help people with intellectual disabilities remain in the community. Programs include residential, vocational, and social supports for integration into community life (MCFCS, 2001). In addition, the Ministry directly delivers Special Services at Home (SSAH), offers respite for family caregivers, provides supervised living and day programs for those who require specialized care, administers income and employment support programs under the Ontario Disability Supports Program, and operates the means-tested Assistance for Children with Severe Disabilities (ACSD) program that covers ongoing extraordinary costs arising from disability (MCFCS, 2001).

Health Services for People with a Dual Disability

As more individuals with intellectual disabilities face dementia, demand for services to address the unique needs of this population is growing (Alzheimer's Society (UK), 2004; Baird & Sadovnik, 1987; Cooper & Holland, 2007; Holland & Moss, 1997; Wisniewski & Lott, 1990). Current policy for supporting people with a dual disability in Ontario assumes that dementia impacts a person with an intellectual disability the same way as seniors in the mainstream. Therefore, when a person with an intellectual disability is diagnosed with dementia, funding and services for this condition fall under the Ministry of Health and Long-Term Care, the same ministry that serves the aging general population. This situation has arisen in part due to a lack of multisystemic, integrated, comprehensive assessment and services to meet the needs of individuals with a dual diagnosis (Dart, Gapen, & Morris, 2002).

Lack of service is linked with the diagnosis of dementia in people with

intellectual disabilities. In spite of advancements in the use of electronic imaging to diagnose dementia, detecting cognitive decline in people with an intellectual disability remains elusive (Lott & Head, 2001). A low mental age and impaired functioning in speech, cognition, visual-spatial ability, and memory can confound the results of tests (Lott & Head, 2001; Moss, Tomoeda, & Bayles, 2000; Powell & Benson, 1990). In addition, other illnesses (such as stroke, depression, thyroid disorders, brain tumours, metabolic imbalances, and neurological disturbances) and maladaptive behaviours mimic the signs of clinical dementia (Burt, Loveland, & Lewis, 1992; Burt et al., 1998; Collacott, Cooper, & Ismail, 1994; Wisniewski & Lott, 1990). The inability to confirm a diagnosis makes it difficult for service providers to obtain funding for dementia-related services.

Due to these diagnostic challenges, people with intellectual disabilities who exhibit dementia-like symptoms receive a clinical diagnosis of this condition with a caveat that it is probably Alzheimer's disease, especially if the person has Down Syndrome. Once a diagnosis is conferred, studies identify challenges in accessing services such as in-home supports and nursing home placements (see Chaput, 2002; Crandall, 1990; Evasuk, 1990; Forbes, Morgan, & Janzen, 2006; Ontario Partnership on Aging and Developmental Disability, [OPADD], 2005). Family caregivers depend heavily on external financial and instrumental resources, such as homecare, to enable their loved one to age in place (Buhr, Kuchibhatla, & Clipp, 2006; Forbes et al., 2006; Smale & Dupuis, 2002). However, since the mid-1980s, researchers have reported that it is the parents, usually mothers, who bear the responsibility for primary care of their children with intellectual disabilities (Roberto, 1993). This is despite the fact that they

themselves are aging (Janicki & Wisniewski, 1985). When parents' health declines a placement outside the family home is predicated.

For those people with a dual disability who are living in supported environments in the community, challenges occur in accessing funding from the health ministry when they are already supported by funding from another ministry. Funding for all community living supports, accommodations, and programs for people with intellectual disabilities in Ontario comes from MCFCS, while additional dollars are needed from MOHLTC to pay for complex care (e.g., nursing support for palliative care and co-existing health complications⁶) when dementia sets in. To put it simply, once a person exhibits symptoms of dementia, their funding comes from two different ministries, forcing service providers to deal with double the bureaucracy. This concern was stated in a letter from the President of the Ontario Association for Community Living on July 9, 1999. The two Ministers⁷ (of MOHLTC and MCFCS) responded that

... people with Down Syndrome who are diagnosed with Alzheimer's Disease, whether living at home or in other situations in the community, should be able to access the services described in the paper, such as: supports provided through the Community Care Access Centres, day programs, [and] secure facility services.

However, in practice, service providers perceive that individuals who receive funding from the MCFCS as well as the MOHLTC are "double-dipping" (Parker & Lawler, 1999). As such, although generic health services exist for people with dementia, people with a dual disability have to negotiate with two ministries and compete for restricted resources.

A further barrier is the lack of skills among healthcare professionals to support

⁶ Generic healthcare (i.e., physician visits, hospital care, and treatments) is funded by the public Ontario Health Insurance Plan.

⁷ Elected politicians responsible for the two ministries.

people with intellectual disabilities. The first point of contact, source of help, and referral agent to health services in Ontario is usually the family physician. How helpful a physician can be depends on the level of information exchange and coordination between this primary care contact and other health and social service structures in the community. Many Canadians report wait times and difficulties getting an appointment as barriers to seeing a specialist, getting diagnostic tests, and undergoing elective surgery (Statistics Canada, 2005).

Moreover, findings from a 25-year-long study of families in North America living with a major disability indicate that two major factors affected the access to healthcare services: (a) the fragmentation of the healthcare system which resulted in uneven access for those with an intellectual disability and (b) healthcare providers being poorly prepared to provide appropriate and effective services (Rowitz, 1988). Burke (1999) states that health professionals have not been knowledgeable about how health issues (such as, Alzheimer's, menopause, mental illness) present in people with an intellectual disability. Therefore, past practices, such as restraining the individual when exhibiting self-injury, have been intrusive, traumatizing, and ignored the emotional difficulties causing the behaviour (1999).

It is apparent that health professionals need education and training about providing medical care to people with an intellectual disability, early detection and management of dementia in this population, and suitable strategies to implement treatment. Plus, people with an intellectual disability rely heavily on their care providers to detect health problems, to alert the medical team for timely treatment, and to manage healthcare problems (Rowitz, 1988; Walsh, 2005).

Consequently, while the intent of the Ontario government is to integrate services for people with a dual disability with those for the general population with dementia, there are access and resource challenges for these individuals. Further, some studies indicate that this group has unique needs: the appropriateness of nursing homes for young (35-50 years old) people with a dual disability, the significance of maintaining familiar routines, and ensuring continued involvement of their current caregivers (Antonangeli, 1995; Janicki & Dalton, 1997; Janicki, Heller, Seltzer, & Hogg, 1996; Manji, 2002; Sparks, Temple, Springer, & Stoddart, 2000; Wisniewski & Lott, 1990). A significant concern for caregivers of individuals with a dual disability is moving to a nursing home due to lack of resources to age in place (Manji, 2002). Moving causes severe transition issues, loss of connections, and serious threats to the desired quality of life.

To address these concerns, the agency participating in this study built a specialized home by restructuring existing funds to continue supporting members at the outset of dementia. The home is barrier free, with features such as step-less entries, widened doorways for wheelchair passage, lowered kitchen counters, lowered light switches, large roll-in showers with grab bars, and other features to ensure safe, comfortable living in the later stages of dementia (Mollica & Jenkins, 2001). Up to six residents share the home and are supported 24 hours a day by trained staff to foster independence of people with intellectual disabilities. They provide support for activities of daily living, home management, and community integration. Additional specialized services (e.g., physiotherapist, psychologist, nurses) and staff training are incorporated into the support package, according to the needs of the residents. Staff members are trained in dementia and palliative care, focusing on behaviour management, bereavement,

grief, and support for family, caregivers and friends (Antonangeli, 1995; Bauer & Shea, 1986; Janicki et al., 1996; Tyler & Shank, 1996).

The Purpose of the Dissertation

While homes specializing in dementia support address the complex needs of people with a dual disability, it is unknown whether these homes are effective environments for people with a dual disability. Moreover, it appears that these homes have been built in reaction to the challenge of dementia and little proactive planning is in place to respond to the long-term care needs of these individuals (Janicki et al., 2000). The aim of this dissertation was to understand the implications of a specialized model of support within community living that had evolved to support individuals with a dual disability. I wanted to understand this experience from the perspectives of consumers and their stakeholders (informal caregivers, direct-care staff, and administrators) who plan and implement their daily support. Accordingly, I highlight elements of good practice that serve the unique needs of people with a dual disability and how these elements are expressed (or not) in a small, community living arrangement specializing in dementia support. Using the findings, I generate a theory and model of *supported empowerment*, grounded in the data, and propose seven policy considerations which can inform families, agencies, and policymakers on support needs and living environments for people with a dual disability.

Social Location of the Researcher

The purpose, design, and interpretation of the findings of this study link to my personal experiences and life influences. These inform my social location as a researcher. My commitment to people with intellectual disabilities began during my employment with an agency mandated to serve them. My various roles as a frontline worker (Family

Support Worker, Integration Specialist, and Residential Counsellor) gave me insight into the lifelong needs and aspirations for community integration of this population, and practices that address these needs and aspirations.

Supporting families gave me first-hand insight into the needs of family members and caregivers seeking services for their loved ones. Primarily, they sought health resources (e.g., medical diagnoses, speech pathology, rehabilitation, assistive devices), respite to ease the intense burden of 24-hour support, and access to specialized as well as integrated programs in the community. Fostering community integration for young adolescents exposed me to the continuing struggle of families trying to plan the transition of their children from full-time school to community participation through volunteering, recreation, and employment. I then learned how as adults, people with intellectual disabilities confront barriers of communication, economic disadvantage, discrimination, exclusion, and access to services. I shared their hope for a better choice of life options, equal respect, dignity, and acceptance into the mainstream community.

I also experienced a shift in my own understanding of the strengths and aspirations of people with intellectual disabilities. Prior to this experience, I had met with some adults living in a mental health institution in England and recalled having difficulty with accepting their fate. I had wondered if the institutional life that had been created for them had, in fact, caused them to acquire behaviours that were termed as pathological. These individuals were in locked wards and primarily sedated with medications.

Therefore, when I commenced working with those supported by a community living philosophy, I felt heartened that they were free to be in the community and enjoying an array of programs to enrich their lives. It seemed like a perfect blend of

opportunities and professional support for people with intellectual disabilities to maintain a humane life in the community. For some, life's pleasures came in simple forms of human interaction. For others, larger goals of independent living and employment were the focus of their efforts. Overall, it was evident that they received pleasure from experiences of community life such as a smile from a community member, a greeting acknowledging their presence, tools to create with their hands, recreation, learning new things, and contributing their gifts through volunteering and employment.

It was also evident to me that the community was not always hospitable to people with intellectual disabilities. Much education with members of the community was required to include people with intellectual disabilities in places of employment, leisure, and recreation. Journeying with these individuals, I incorporated their values of social justice, human rights, and equal participation in all aspects of community life. I also acknowledged that for these values to be incorporated in the resident community, widespread education and system change was an ongoing intentional enterprise.

With regards to system change, people with intellectual disabilities voiced an important value to be considered; that each of them was unique in their needs, interests, and pathways of achieving goals. Thus, their pathways ranged from total immersion in community living as independent people to being supported in group homes and remnant segregated programs. These pathways reflected the opportunities available in community and the aspirations of people with intellectual disabilities.

For instance, there were many people with intellectual disabilities who refused to be in settings where they would be identified as a disability group. At the same time, it was perplexing for me when others were distressed with the closure of their segregated

programs. Like many who were on the path of change I was emphasizing integration. However, I realized that for some people with intellectual disabilities, segregated programs were places of social opportunities and strong peer connections that enabled and empowered them; integrated programs were foreign and uncomfortable.

Irrespective of which pathways were available, it was critical for me to respect the difference and individuality of people with intellectual disabilities using a person-centered approach. I believed that their life forms should take on a personalized design without judgement of their decisions or choice. They should have the power to make day-to-day and future decisions about their living conditions based on informed choice. These decisions may involve an element of risk according to others and may not even concur with the progressive ideas of peers, caregivers, or supporters.

I also acknowledge that people with intellectual disabilities, as all other members of society, influence and are influenced by the perceptions, norms, resources, and opportunities in a community of people. Ideas and decisions about self evolve over time and change according to personal histories and experiences-in-community. I believe that people with intellectual disabilities do use their unique histories and experiences when making decisions about how and where to live. If allowed to live in self-prescribed ways that enable them to participate and contribute in community they create their realities which are same or different from our understanding of “ideal life.”

The onus is on the community around people with intellectual disabilities to create openness, hospitality, and resources to enable them to realize their aspired life. Conditions in community must honour their rights, humanity, and diversity. In my opinion, these values are paramount when people with intellectual disabilities lose their

capacity to advocate for themselves upon the onset of dementia.

As a Residential Counsellor, I supported five aging individuals with dementia in the barrier-free home explored in this study. I was inspired by their zest for life, affection, and daily achievements. Instead of focusing on helping the individuals to live out their lives with a terminal disease, the staff paid attention to how each moment of their lives could be facilitated in a way that they would want to live it. This required adjusting support and services day-to-day and moment-to-moment.

At the same time, agency managers began to see the gaps in services as the individuals progressed through the course of dementia. As a member of an ad hoc committee to address service barriers for people with a dual disability, I became part of a campaign to lobby for governmental support to meet the changing needs of this population. I became aware of the dynamics between caregivers and adult care receivers, the service systems in which the two groups operated, and the role of the state in regulating the service structure.

Concurrent with my professional journey, I embarked on a similar journey in my personal life: caring for my elderly mother, who had complex physical and mental health challenges. As a family caregiver, I witnessed the plethora of experiences with which fragile individuals struggle on a daily basis, as they are manoeuvred within Ontario's social and health systems. I dealt with the issues of transition, access, communication, economic privilege, and personal agency that impacted on a minority senior moving from home to institution, from a South Asian to a European culture. I watched my mother move along a continuum of power from self-agency, to group agency, to total dependency on others.

My mother lived out her last 3 years in three nursing homes. She was bedridden, immobile, and required tube feeding. Her medical diagnoses included dysfunction of the digestive organs, angina, arthritis, anxiety, depression, and dementia. The cause of her death, at 84, was brain haemorrhage from a stroke.

At her last placement, a newly built, attractive institution, she shared a room with one other resident. They were housed in a neighbourhood of 32 residents, within a 160-bed facility for seniors requiring light to heavy support. Her personal and medical care, as well as that of the other 32 residents in her neighbourhood, was managed by one nurse and two personal support workers (three during peak periods) who rotated each shift. My father helped with her daily lunch routine and accompanied her to medical appointments and hospital emergencies.

In addition, my father interpreted her needs, which she expressed nonverbally and verbally in her mother tongue, Gujarati. As a last resort, she would evoke her limited ability to converse in English with medical practitioners and staff. She was able to sit up for a couple of hours at lunchtime, spending the rest of her day in bed. She had no interest in participating in any leisure, recreation, or therapeutic programs offered at the nursing home. My mother looked to me for companionship, and to my father for support as the primary caregiver and decision-maker. We helped my mother by advocating for her, navigating bureaucracies, interpreting medical treatments and her care to her, translating from English to Gujarati, handling the paperwork, and taking part in end-of-life decisions.

These experiences as a family caregiver for my aging mother gave me insights into how an individual must continuously adjust to the health system, as she is confronted

by new care providers and practices in multiple institutions. My mother's experience led me to question whether person-centered philosophies of support were actually being implemented in institutional settings. I came to believe that merely documenting such principles in policy documents is not sufficient to value the person. Even if she is able to command individualized support, elements in the practice of caring for fragile people either maintain or ignore their personhood. This concurrence in professional and personal journeys led me to my dissertation topic of living with a dual disability. In the next chapter, I provide a synopsis of the literature relevant to this topic.

CHAPTER TWO

Literature Review

This chapter provides a brief discussion of the literature on dual disability and an overview of theoretical concepts that frame my research and findings. Relevant theoretical concepts are also elaborated in chapters 6 and 7 where I discuss the findings emerging from a grounded theory approach. In order to familiarize the reader with the issues facing people with a dual disability, first, I give a historical and current overview of the policies and practices for people with intellectual disabilities or dementia. Second, descriptions of the medical and social discourses regarding disability indicate the predominant thought that informs policy and practice, particularly, the saliency of the concepts of citizenship, personhood, and social inclusion in the implementation of practice. Third, a portrayal of the variable living environments for people with an intellectual disability outlines the choice to age in place for those who have dementia. Fourth, a summary of empowerment theory provides a framework for understanding the extent to which living environments are empowering for people with a dual disability. I conclude with research implications for developing a social model of dementia support for people with a dual disability living in community.

Historical Overview of Policy and Practice

The findings of my research provide a foundation for determining an appropriate policy response for people with an intellectual disability, so it is important to first understand the historical experience of those individuals who now live in community. Until the latter part of the nineteenth century, no specific policies existed concerning adults with an intellectual disability. They were cared for at home by their families,

depended on charities such as places of refuge or insane asylums, or ended up in prisons (Radford & Park, 1999; Simmons, 1982).

The late nineteenth century until the middle of the twentieth saw the development of a regional dialogue about the value and role of people with an intellectual disability in mainstream society. This dialogue was infused with a eugenic ideology prevalent at the time together with a pervasive medical ideology rooted in positivistic science. The eugenic ideology, imported from the North American and European states, strongly advocated the care and control of people with intellectual disabilities who were perceived to be mentally defective or feebleminded (Radford & Park, 1999). It was argued that state intervention was required to protect society from this population who could plague it with poverty, prostitution, slums, and other problems (Radford & Park, 1999).

People with intellectual disabilities were regarded as unfit people similar to those who were deviant or mad. Clinical psychiatrists, labelling people with intellectual disabilities as insane and dangerous, attributed them with pathology – possessing the potential to cause harm even when harmful acts had not been manifested (Castel, 1991). Scientists and medical professionals who advanced a perspective of pathology, and whose perspective was perceived as legitimate, influenced the creation of policy that attached professional service to an active treatment program in custodial care.

In 1876, the government of Ontario opened the first institution at Orillia, called the Ontario Asylum for Idiots (Radford & Park, 1999; Simmons, 1982). This action began the asylum era with a significant shift in the role of the state toward the affairs of people with an intellectual disability. For several decades, thereafter, institutional living became the simple, effective, and most economical means of segregating people with an

intellectual disability from the rest of society (Simmons, 1982). Many of these institutions were renamed as hospitals, enumerated as beds, divided into wards, staffed by medical doctors, nurses, psychologists, and other health professionals, and run by health authorities (Radford & Park, 1999). By 1970, Ontario had accrued a patient population of 7,256 individuals housed in 20 institutions – almost double the number of institutions that existed across the rest of Canada (Radford & Park, 1999). These health units became a source of competition for government funding, as Ontario communities invested in medical staffing and services to expand the system.

The rapid growth of institutions led to a series of problems for the government of Ontario. In addition to the rising costs threatening the maintenance of an institutional model of care, the quality of care came under severe criticism, with public scandals, strong complaints voiced by parents about the living conditions of their institutionalized children, and increased pressure from advocacy groups outside the medical profession to change oppressive practices (Simmons, 1982).

In the 1940s, the parents' movement was the first advocacy group to fight endless battles to include their children in the education system (Simmons, 1982). A particular thrust for the parent uprising came from the normalization movement. Normalization was first defined in 1959 by Bank-Mikkelsen, head of the Danish mental retardation service, as "letting the mentally retarded obtain an existence as close to the normal as possible" (as cited in Simmons, 1982, p. 195).

Ten years later, Bengt Nirje, executive director of the Swedish Association for Retarded Children, transported this term from Scandinavia to North America. Serving as a civil servant in Ontario, he focused on the application of normalization to the design

and operation of residential living. He envisioned living environments that went beyond the medical model to incorporate social needs of the person with an intellectual disability

... medical or physical condition which is usually the most visible, but which is increasingly open to medical and other scientific advances ... [plus] the broader environment – the living conditions, daily routines, economic status, and prevailing social attitudes ... [and] the identity of the disabled person, himself or herself, affected by the physical condition certainly, but not in the deterministic way often presented, and comprising self-images that are reflections of the broader environment. (As cited in Radford & Park, 1999, pp. 12-13)

Nirje's application of normalization was broadened by a leading American scholar of mental retardation, Wolf Wolfensberger, to include the "utilization of means which are as culturally normative as possible, in order to establish and/or maintain personal behaviours which are as culturally normative as possible" (as cited in Simmons, 1982, p. 197).

Wolfensberger (as cited in Romney, Brown, & Fry, 1994) renamed the term normalization as *social role valorization* to emphasize that people with an intellectual disability must carry out tasks that are valued by them and others around them.

In the 1950s, the parent consumer group merged into the Ontario Association for Retarded Children (OARC), later renamed Community Living Ontario. Community Living chapters supported normalized living of people with intellectual disabilities in the community as policymakers moved towards deinstitutionalization. With several chapters across the province, Community Living Ontario continues today to advocate for funding, services, and rights of people with an intellectual disability to integrate and participate in community life.

The parent movement was followed by an influx of other consumer movements in the 1960s, 1970s, and 1980s (e.g., the independent living movement, the community mental health movement, the psychiatric consumer/survivor movement, Parents' Council,

Disability Rights) evolving from the broader social and disability movements in North America among marginalized groups such as, African-Americans, women, aboriginals, and people with hearing and visual disabilities (see Denton, 2000; Dunn, 2006; Lord, 2000; Ochoka, Nelson, & Lord, 1999; People First of California, 2007). Likewise, self-advocating people with intellectual disabilities organized in the early 1970s as “People First” to offset constraints on individual freedoms experienced as parents, policymakers, and service providers proceeded with the planning and implementation of restructured programs and services. They continue to raise awareness of their rights by hosting international conferences and sitting on decision-making bodies (People First of California, 2007). Activists from the intellectual disability camp push their agenda in the political arena to eradicate prejudices in the Canadian society.

Hence, politicized consumer movements changed the discourse about intellectual disability. The value of the person with an intellectual disability also changed, from “idiot” to “citizen.” New social theories on disability and an international focus on universal human rights paved the path to community integration and normalization, enabling the shift from living in asylums to living in the community. Advocates and policymakers focused on changing the language used to describe people with an intellectual disability and restructuring education, health, and social services to improve the quality of life for these individuals (see Tindale, Livingstone, & Sharon, 2000).

As well, inclusive policies for community integration were encouraged by the notion of human rights raised in the international agenda for human rights in Canada when the United Nations declared the Year (1981) and Decade of Disabled Persons (1983-1992) (Dunn, 2006). During this decade, the federal government instituted into the

Canadian constitution, in Section 15 of the Canadian Charter of Rights and Freedoms, the “right to equal protection and equal benefit of the law without discrimination, and in particular, without discrimination based on ... mental or physical disability” (Rioux & Frazee, 1999, p. 60). Following this legislation, the federal government undertook several steps to realize the ambitious goals of Section 15. It put into place mechanisms for litigation on equality rights; established a Secretariat and Minister responsible for the Status of Disabled Persons; requested and received several Special Committee reports articulating recommendations toward a “pan Canadian approach to disability issues that builds disability considerations into mainstream policies and programs” (p. 12 in federal government report “The Will to Act” cited in Dunn, 2006); and as part of the National Strategy for the Integration of Persons with Disabilities, based on extensive data collection, provided \$158 million to consumers to facilitate integration and inclusion in the community (Dunn, 2006).

The rights movements in the federal government provided an impetus for the provincial government of Ontario to act. In March 1973, Robert Welch, Minister of Social Development Policy, presented a Green Paper to the Ontario government entitled “Community Living for the Mentally Retarded: A New Policy Focus” (Simmons, 1982). In 1974, the Developmental Services Act gave the responsibility for mental retardation policy to the Ministry of Community and Social Services (now called the Ministry of Community, Family and Children’s Services) (Simmons, 1982). This Ministry passed new and amended legislation in several areas of community life, for example, the Health Care Consent Act, the Substitute Decisions Act, the Ontario Disability Support Program Allowance, the Ontario Works Act, the Disability Tax Credit, the Medical Expense Tax

Credit, the Tenant Protection Act, and the Education Act, all to accommodate people who were being de-institutionalized (Peppin & Baker, 1999).

The primary purpose of these laws was to allow people with intellectual disabilities to live, work, and participate in a wide range of activities within the community, thereby improving the quality of their lives. Community living for people with intellectual disabilities leaving the institutions took the form of segregated housing and participation in community activities. Segregated housing meant group homes or mini-institutions in community neighbourhoods run by professional staff trained to support people with intellectual disabilities. For those living at home with family, assistance was provided for respite with special services at home. Day programs and sheltered workshops were developed where professional staff facilitated recreational and vocational activities. People with intellectual disabilities congregated with each other, segregated from the mainstream.

Since the 1980s, however, a major shift in focus for the support of people with intellectual disabilities, concepts of inclusion, equity, and person-centeredness have been endorsed as integral to the rights of people with intellectual disabilities who are equal citizens in the community. A person-centered philosophy of support places the person rather than the service system, organization, or provider at the center of planning (Galambos, 1999). Such an approach respects individuals as human beings who have rights and privileges to determine services, supports, and respective costs tailored to their individual needs (Galambos, 1999). As such, the aspirations of people with intellectual disabilities were included in the design and delivery of services (Radford & Park, 1999).

During the 1990s, the principle of inclusion, leading to nonsegregated forms of independent living, working, and recreating in the residential community, evolved significantly (Buell & Brown, 1999). Agencies mandated to support people with intellectual disabilities introduced Individualized Program Plans (IPPs), which directed program staff on how to support the individual (Galambos, 1999). Based on the success of these measures, the Ministry introduced individualized funding for people with intellectual disabilities needing complex care. Individualized funding gave control to the individual as a consumer to propose their own plan for independent living by identifying available resources and projecting annual costs for required support (Dunn, 2006). Other innovative pilot projects were the implementation of supportive housing that included personal supports and the development of brokerage associations to ensure people with intellectual disabilities received individualized services and support (Dunn, 2006).

To summarize, the historical overview of policy and practice for people with intellectual disabilities demonstrates the struggle of this population to move from segregated forms of institutional living to integrated forms of independent living. As consumers of services moved towards the direction of community integration, in 2001, the provincial Ministry of Community, Family and Children Services announced a budget of \$197 million to fund a multi-year plan to enhance services and supports for 48,000 children and adults with intellectual disabilities and their families (MCFCS, 2001). The aim of the Ministry was to revitalize agency services, attract quality caregivers, and expand the day and respite programs (MCFCS, 2001). An additional \$67 million would be provided over the next 5 years to build new places to live in the community. However,

these measures fall short for people with a dual disability who are aging and require supports for a further disability, dementia. I will now outline these responses in Ontario.

Current Policy and Practice

As people with intellectual disabilities began to age and some members began to experience the onset of dementia, the Ontario government responded by forming a regional body of the Ontario Partnership on Aging and Developmental Disabilities (OPADD). Developmental services and the long-term care service sector, partnered together as OPADD, to facilitate the exchange of information between experts, researchers, and key informants in these sectors, and to support the direction of policy. The primary intent of this initiative was to identify the issues facing these sectors and to explore ways of partnering to make aging services more responsive to seniors with intellectual disabilities, including those who have dementia (OPADD, n.d.).

An initiative to gather community-wide feedback was triggered by the fact that more than 100,000 people in Ontario are affected by dementia, and 90% of them are above the age of 65 years (MOHLTC, 1999). No separate policy initiatives exist for people with a dual disability whose needs are already funded by one ministry, (the Ministry of Community and Social Services), because of the assumption that their healthcare needs will be assimilated in the planning for aging seniors in the mainstream (MOHLTC, 1999).

The plan for dementia is reflected in a multi-year investment increase in long-term care, announced by the Ontario government in 1999. An injection of \$1.2 billion from the Ministry of Health and Long-Term Care was expected to improve services for all seniors, including those with a dual disability, and provide in-home services, community support, and long-term care in nursing homes (MOHLTC, 1999). Also in

1999, the Ministry of Health and Long-Term Care provided \$68.4 million, to be allocated over five years, to implement the strategies of the proposed action plan for people with dementia. These strategies were intended to assist consumers and healthcare providers to prepare for the impending demand for specialized support from people with dementia (MOHLTC, 1999).

The Ontario plan of action dedicated \$37 million for education and training. This commitment was made mainly for the training of physicians and staff in aging services and the hiring of psychogeriatric consultants to advise long-term care staff on effective ways to work with people with difficult or aggressive behaviour. Thirty-one million dollars were dedicated to caregiver support, to be used for research, tools for caregivers, expansion of volunteer in-home respite programs, and the creation of new adult day programs. The planning of living environments was delegated \$250,000, for the exploration of functional designs of living space, safe and secure environments, best models of support, and appropriate improvements in home environments. Policy reviews received \$100,000 for consulting with key stakeholders about advance directives for care choices, the dissemination of educational materials, and staff training in order to implement these policies consistently.

It is evident that funding of services from the health ministry has been predominantly directed to institutional care such as nursing-home facilities. The literature indicates that the funding is not sufficient to meet the needs of those who are looking for placement in nursing homes or living at home in the community (see Chaput, 2002; OPADD, 2005; Smale & Dupuis, 2002; Tindale et al., 2000). In a transition planning survey to understand the needs of people with an intellectual disability with respect to

aging services, respondents who had requested long-term care placement experienced a minimum 3-month wait to access this service (OPADD, 2005). Similar long wait lists were found across Ontario for out-of-home residential placements such as those offered by associations of community living (Tindale et al., 2000).

In addition, 82% of family caregivers and service providers experienced barriers for services other than long-term care placement (OPADD, 2005). The majority of survey respondents were looking for flexible funding to facilitate the individual needs of people with intellectual disabilities when transitioning to residential and nonresidential services (e.g., continuing with existing community programs, leisure, fitness, educational, personal support, and home help). However, Hennen (as cited in Tindale et al., 2000) found that families providing support to an individual with an intellectual disability at home only received \$2000 - \$3000 per year in Special Services at Home funding compared to \$55,000 a year if the individual lived in a group home. Further, 81% of extra resources required to support transition costs was absorbed by the developmental and long-term care sectors (OPADD, 2005).

Flexibility of funding was integral to planning for choices in a range of living environments for people with intellectual disabilities such as the family home; supportive adult residences and community living group homes; 24-hour supervised residential support facilities; homes for people with Alzheimer's; noncongregate settings; retirement/accessible homes; nursing homes, specialized units in nursing homes; designated beds in long-term care facilities; designated clustered units and CCAC cluster care facilities; and separate specialized facilities operating under different regulations

from long-term care (OPADD, 2005, p. 28). Flexible funding was required to access living environments that were individualized, inclusive, seamless, and ability-focused.

Existing funding issues and barriers to accessing services are compounded when people with an intellectual disability require additional funding to support the health condition of dementia. In Ontario, this funding is integrated into decisions about the provision of health-related services determined by the Ministry of Health and Long-Term Care. Healthcare providers in Ontario are currently dealing with restructuring systems as they are transitioning to the delivery of health-related services through Local Health Integration Networks (LHINs) and the Local Health System Integration Act (MOHLTC, n.d.). The Ministry expects that the LHINs will engage the community to plan and fund a system of healthcare that is integrated and responsive to local needs. The government will continue to direct policy and system standards in the delivery of provincial programs and services (MOHLTC, n.d.).

It appears that the Ontario government is on course with planning for dementia, the aging population, and the delivery of health services in response to local needs. However, for the caregivers and services providers of people with a dual disability, the allocation of funding is not appropriately earmarked. Gaps in services are reported in all living environments and in accessing community amenities (see Buhr et al., 2006; Dart et al., 2002; Forbes et al., 2006; Lott & Head, 2001; OPADD, 2005; Parker & Lawler, 1999; Rowitz, 1988; Statistics Canada, 2005).

In addition, caregivers and service providers question whether services for individuals with a dual disability should be included with those of seniors in the mainstream. They assert that distinct services are required for them due to their unique

needs, such as earlier onset of dementia, challenge of diagnosing dementia, impact of trauma upon moving, and ties with current supported living arrangements (Antonangeli, 1995; Janicki & Dalton, 1997; Janicki et al., 1996; Manji, 2002; Sparks et al., 2000; Wisniewski & Lott, 1990). All these concerns are at the center of caregiver/service provider debates who want to ensure that the rights of equal citizenship and participation achieved by this population from a long history of consumer advocacy are not dissipated upon the onset of dementia.

The Ontario government, recognizing the historical gains made by people with intellectual disabilities, is now careful to include widespread community consultation to develop a strategy for dementia support. It has directed the developmental and long-term care sectors to engage in their own constituent consultation regarding their distinct and common issues. However, to date, despite cooperation between diverse parties in developing government strategy, practical responses to dual disability still hang between two ministries; the Ministry of Community and Social Services and the Ministry of Health and Long-Term Care. Each ministry has infused with funding particular services for people with intellectual disabilities and aging people with dementia respectively, but neither has provided direction on how combined funding is to flow to a person with a dual disability.

In response to this shortcoming, some agencies supporting people with intellectual disabilities have lobbied government ministries to adjust their funding criteria and to modify their models of support so that they can meet the needs of those who are aging with dementia. In May 2006, the Minister of Community and Social Services presented, "Opportunities and Action – Transforming Supports In Ontario For People

Who Have A Developmental Disability.” The Minister intended to promote more consistency in applying policies to meet the needs of people with a dual diagnosis (i.e., people with both an intellectual disability and a mental health problem) and older individuals with an intellectual disability who are moving to long-term care (MCSS, 2006). A recommended action in the document was to develop a protocol with the Ministry of Health and Long-Term Care to facilitate cross-sector planning and develop service partnerships to clarify expectations, roles, responsibilities, and decision-making for transitioning to aging services (MCSS, 2006). It is not clear at this point if the cross-sector planning will support aging in place or the path of assimilating people with a dual disability into the mainstream medical model of long-term care for seniors.

Whichever direction the government takes, it is worth noting the discourses that inform policy. Discourses are important as they reflect the interventions that develop from policy. These interventions may or may not be appropriate for people with a dual disability, depending on the legitimacy of knowledge within discourses. The issue of which discourse is established as legitimate is particularly significant when there is a lack of empirical knowledge to inform policy about effective services for people with a dual disability.

Discourses that Inform Policy on Dual Disability and Practice

The issue of dementia coexisting with an intellectual disability is different from the issue of dementia on its own, but both issues are common to the concept of aging when dementia is viewed as an age-related disorder. It seems that the primary focus in policy has been the sole issue of dementia as an outcome of aging. Critical theorists concur that the tendency in social policy has been to bring the different into the mainstream, a normalizing procedure that then allows neutral standards in policy and

practice to be applied that eliminate unequal standards (Gadacz, 1994). However, this approach does not recognize the distinctness of people with a dual disability and can easily lead to prescriptive practices that are inappropriate or may oppress people who are perceived to be deviant, less than the “other,” and not deserving of the best standards in living. This point is well articulated by Gadacz (1994), who says that

... from the perspective of disabled citizens, applying neutral standards will not eliminate inequality and oppression. A theory of equality must recognize that there really are differences between people and that not everyone is the same. Equality does not mean ‘sameness.’ Factors such as powerlessness, exclusion and disadvantage are the direct consequence of the subordination of certain groups and the domination of others, and the application of neutral standards implies ‘sameness’ or conformity to specific values and ideals. (p. 222)

Policies for people with intellectual disabilities have attempted to honour their distinctness. However, specific values and ideals informing policy have generated different practices wavering between a universal medical and rehabilitation paradigm on the one hand, and an individualized consumer-control, empowerment, and self-help paradigm on the other. The biomedical view has focused on disease and disability, while a social-political view of the individual has emphasized the person as a citizen. An in-depth understanding of these two views reveals how different discourses distinctly shape policy and consequently influence the practice of providing services for people with a dual disability.

Biomedical View

The literature on dementia and dual disability is significantly weighted by interest from the medical science community. It aims to bring to light the new pressures families and caregivers experience as their dependents suffer from loss of memory, personality changes, aggressive behaviour, decline in daily living skills, seizures, changes in

coordination and gait, incontinence, and rapid decline in physical and mental health.

Research shows that these medical issues cause stressors in maintaining in-home care and trigger out-of-home placements (Buhr et al., 2006; Forbes et al., 2006; Tindale et al., 2000; Wisniewski & Lott, 1990). This type of discourse articulates the impact of a debilitating disease and its emphasis provides the basis for practice.

For instance, substantial clinical research on dementia has enabled medical practitioners to offer various drug therapies to control the symptoms of dementia, such as, seizures, repetitive verbalizations, sleep disturbances, and depression (Tyler & Shank, 1996). Such research suggests the combination therapies of various drug regimens may be helpful to arrest or slow down dementia, especially of the Alzheimer's type. However, researchers emphasize that more clinical trials are needed to monitor the effects of these therapies, particularly trials in conjunction with positron emission tomography (PET) scans that can visually display brain abnormalities (Jelic & Nordberg, 2000). Much of the research in the medical aspects of dementia is fuelled by the hope that by approaching treatment of the phases in the neuropathology of this disease through genetics and cell biology, there will be successful outcomes in the future (Selkoe, 1997).

Although new drug therapies are showing some potential in improving the quality of life of people suffering from dementia, empirical evidence reveals that medical interventions for terminal illnesses such as dementia of the Alzheimer type do not have a significant effect on population mortality (Eyman & Borthwick-Duffy, 1994). Since the quality of life for people with dementia is not ameliorated greatly by medical treatment, a biomedical model of care is limited (Bond, 1999; Eyman & Borthwick-Duffy, 1994; Holland, Karlinsky, & Berg, 1993). However, current funding for dementia services in

Ontario has been predominantly directed to establishing a biomedical model of long-term institutional care to accommodate the expected influx of aging people who will no longer be able to live at home because they require 24-hour support (see Ontario's Strategy for Alzheimer Disease and Related Dementias - Preparing for Our Future, MOHLTC, 1999). The literature confirms that the most readily available living option for people with a dual disability is a nursing home, usually in a special care unit for dementia and offering a custodial philosophy of support (see Chaput, 2002; Ostbye & Cross, 1994).

Contrary to a medical model of support, especially in the absence of a medical solution for dementia, some researchers recommend that people with a dual disability continue to live in their existing choices of community living; in other words, to age in place (Antonangeli, 1995; Janicki et al., 1996, Manji, 2002). Researchers have suggested that dementia can be managed with nondrug treatments. Nonaversive interventions have been used successfully for people with intellectual disabilities where applied behaviour analysis identifies the environmental events and factors that influence the person's behaviour and the purpose that behaviour serves for the individual (Bakke, 1997). Positive behavioural interventions design the treatment according to the purpose of the behaviours and minimize the need to use psychoactive drugs and mechanical restraints (Bakke, 1997).

Unfortunately, continuing to live in the community entails planning for extra funding for staffing, dementia training, and adaptive devices for individuals with a dual disability (Antonangeli, 1995). As well, resources for guardian-related responsibilities for care and end-of-life decisions are required (Antonangeli, 1995). As additional resources

are not available in existing funding formulas established by government policy, often the onset of dementia triggers a move to a nursing home.

Lack of resources to support dementia while aging in place raises the question of how the state views its citizens who have a dual disability. The discourse in which dementia is seen as an illness to be managed in custodial care seems to have been a socially constructed one; such a construction seems likely to have influenced the care practices for people with a dual disability. Medical sociologists state that a discourse on illness persists because “illness and disease is a social state of affairs rather than being a narrowly defined biochemical malfunction of the organism” (Turner, 1995, p. 37). The sick role allows a person to legitimately withdraw from social responsibilities and regular activities in society, to require professional care in order to get better, and to take the responsibility of accessing medical care from trained professionals (Parsons, 1951).

Likewise, a biomedical view of dual disability requires the person to occupy a sick role, because the person with a dual disability is abnormally postured against the healthy person without a dual disability. Devlin and Pothier (2006) argue that a biomedical view accords people with disabilities a disabling form of citizenship as they are no longer seen as productive members of society. Productivity is seen as the activity of able-bodied people who by their contribution to society maintain their personhood and gain the privilege to participate fully in all areas of citizen life (Carey, 2001). In this context, people with disabilities are “dis-citizens” (Devlin & Pothier, 2006), powerless over the way they live their day-to-day lives, viewed as people to be handled and treated, subject to decisions made by experts on their behalf, and gradually excluded from the community. An individual with a dual disability who is viewed through a biomedical lens

falls under a medical model of custodial care and is systematically reduced into a state of dis-citizenship.

History has shown how a pathological view of disability resulting in institutionalized care has excluded, oppressed, and further disabled people with an intellectual disability. Similarly, when dementia is understood as a consequence of neuropathological changes leading to cognitive decline, a pathological view of disablement is apparent. However, when the concept of personhood is introduced, by which social identity is manifested and maintained through interaction with others, the environment and the psychosocial interventions can all positively influence the dementia experience and improve the quality of life of the person with a dual disability (Bartlett & O'Connor, 2007; Sabat & Harre, 1992). Literature supports the idea that people with dementia can maintain a sense of self into the late stages of dementia (Cohen-Mansfield, Parpura-Gill, & Golander, 2006)

The tendency to disable people by analyzing dementia in solely medical categories (sick versus non-sick) fosters “othering” where, depending on what is valued, “persons are *manufactured* as disabled” (Devlin & Pothier, 2006, p. 5, italics in text). Rather, what is needed is a new way of defining dual disability that takes into account how social organization (e.g., human interactions, living structures, and social systems) responds to the differential needs of these people in society, which is offered by a social-political perspective.

Social-Political View

Sociological and social-psychological theorists challenge the reductionist tendencies of the biomedical view of disability (Barnes, 1991; Bickenbach, 1993; Oliver, 1996; Rioux, 1996) by arguing that people with disabilities are disabled by discrimination

from others in society who marginalize them because of their different characteristics (Bach, 1999). From the perspective of social constructionists, “handicaps are socially constructed phenomena brought about by attitudes toward people with disabilities, which, once embedded in social practices and institutions, sustain the disadvantageous social condition of people with disabilities” (Bickenbach, 1993, p. 13).

Therefore, disability, rather than being seen as a problem within the individual, is seen as a problem outside the individual. Specifically, this problem is “located within the minds of able-bodied people, whether individually (e.g., prejudice) or collectively, through the manifestation of hostile social attitudes and the enactment of social policies based upon a tragic view of disability” (Oliver, 1990, pp. 82-83).

In addition, a social-construction theory of disability broadens the concept of what it means to be disabled. If “the view of disability centers on where the ‘problem’ is actually located” (Oliver, 1990, pp. 82-83), even society’s failure to recognize disability contributes to the disabling (Abberley, 1993; Crow, 1996; Oliver, 1992). People with disabilities can be at a disadvantage if their special requirements are not recognized (Abberley, 1993) or even linguistically denied, as when referring to disabled people as people with disabilities (Oliver, 1992). Thus, the social-creationist view points to the injustices that flow from the nonrecognition of disability (Abberley, 1993). Therefore, a social model of disability attempts to break down attitudinal, linguistic, economic, and political barriers that have previously prevented people with disabilities from genuinely belonging and participating as equitable citizens in society (Devlin & Pothier, 2006).

One such model that has evolved for people with disabilities is the Independent Living (IL) model (see Appendix A). The IL model views people with disabilities as

experts who can determine how they want to live and what services they require to live comparatively independently. Thus, individuals are viewed as consumers of services and decision-makers in their day-to-day living. Even when professional services are enlisted by the individual, those who provide the services seek guidance from the person with the disability, adopting the stance in their oft-used phrase of “Nothing about us without us” (Hutchison & Pedlar, 1999; National Council on Independent Living, n.d.).

The principles of IL models promote equal rights and opportunity for people with disabilities to be included in all mainstream activities. Efforts towards equal citizenship, inclusion, consumerism, de-institutionalization, and de-medicalization must be supported by people with different types of disabilities so that the collective work benefits all people with disabilities. In addition, IL programs stress self-help, peer support, advocacy, removal of barriers, and consumer control (Dunn, 1999).

The fidelity of IL principles is evident when consumers have the freedom and flexibility to make choices and direct their support, and at least 51% of decision-makers in the organization (e.g., staff, management, board members) are consumers with disabilities. An IL organization, true to its principles, is actively involved in its local community to raise awareness for disability issues, advocate for needed resources, provide information and referral to consumers for independent living, promote peer support, and facilitate independent skills training (Hutchison & Pedlar, 1999; National Council on Independent Living, n.d.).

Studies indicate that few programs are based on IL principles; that is, community-based, run by consumers, or providing support that increases self-determination and minimizes dependence (Carling, 1995; Pedlar & Hutchinson, 2000). The more programs

endure strict controls on funding, standardization, licensing, and specialization, the more they are likely to become analogous to traditional models of institutional care (Frieden, 1980; Lord, 2000). Traditional models increase dependency on professionals, perpetuate stigma, limit consumer control, and segregate individuals from mainstream community (Dunn, 1999). People with disabilities are isolated from the community where people otherwise come together, offer hospitality, and foster participation in places and events (Lord, 2000). Once excluded from community, people with disabilities are denied their rights to citizenship. When they also have dementia, impoverished social contexts defy their personhood.

Social Inclusion, Citizenship, and Personhood

The exclusion of people with intellectual disabilities is compounded when they have a mental illness. Dugan and Kivett (1994) found that older adults with mental health issues who are not integrated (or reintegrated) within their community feel lonely, bored, and socially isolated. They encounter obstacles such as lack of money, time, support, poor health (Pearlin & Skaff, 1995) and underdeveloped community resources to support their needs when they are leaving institutions (Hebblethwaite & Pedlar, 1992).

In response to the social and economic exclusion of vulnerable people the concept of social inclusion has gained momentum (Lord & Hutchinson, 2007). Social inclusion of people with a dual disability began with their integration when they moved from segregated institutions to live in community. It was thought that successful community integration, that created opportunities to integrate the individual rather than expecting the individual to adapt to community, ensured everyone's right to community membership and participation (Carling, 1995; Rousseau, 1993).

Since the 1980s, however, advocates have highlighted the limits of integration stating that those who are “in the community” are not necessarily “of the community” if they are not accepted as full participants and valuable contributors of society (Pedlar, Haworth, Hutchison, Taylor, & Dunn, 1999; Rioux & Valentine, 2006). Scholars state that social inclusion is broader than integration and is measurable as a goal, outcome, and process (Lord & Hutchinson, 2007). In a socially inclusive society

people would feel valued and accepted in all public spaces; people would feel that their differences matter much less than their gifts and strengths; communities would value diversity in the ways they embrace and accommodate differences; communities and organizations within the non-profit sector would create various policies and vehicles for enhancing social inclusion. (Lord & Hutchinson, 2007, p. 12)

The process of social inclusion emphasizes how community groups build pathways to reach the goal of full participation such that individuals are socially and economically included in all aspects of community life (Lord & Hutchinson, 2007).

Pathways to full participation in community are also required for citizenship (Rioux & Valentine, 2006) defined as both a status and a practice by which people are given access to and are allowed to participate in all political, social, and cultural spheres of society (Devlin & Pothier, 2006). Citizenship is not just about individual status and being valued in community but about whether or not individuals belong to the larger community (Devlin & Pothier, 2006; Lord & Pedlar, 1991; Wolfensberger, 1983). In other words, citizenship is about relationship building in welcoming communities where diversity is accepted and all members share a sense of belonging.

Further, inclusive citizenship is expressed in the practice or lived citizenship of the individual (Hall & Williamson, 1999). In the lived experience of individuals is the knowledge of how they negotiate their rights and responsibilities, belong and participate

in a collective, and the way their social contexts, cultural backgrounds and material means affect their citizenship (Hall & Williamson, 1999). Lived citizenship includes intimate and sexual citizenship; the right to choose “what we do with our bodies, our feelings, our identities, our relationships, our genders, our eroticisms and our representations” (Plummer, 1995, p. 7). Intimate citizenship is conceptualized in the public discourse on personal life and has the potential to bridge the personal and the political spheres of community life (Plummer, 2003).

Lived citizenship is evident in the postmodern definition of citizenship; being able “to define one’s own identity and to celebrate this identity in different ways” (Bracken & Thomas, 2005, p. 81). In this context, citizenship is viewed beyond a fixed status with rights and responsibilities accorded to an individual; it is a process that continually narrates the meaning of human experience as celebrated in different identities, sexualities, lifestyles, cultures, and perceptions of individuals (Bauman, 1992; Isin & Turner, 2002).

Researching different human experiences, scholars have identified values inherent in the lived citizenship of globally excluded people. Kabeer (2005) states that despite the different social contexts, struggles of diverse excluded groups in developing countries underpin an understanding of full citizenship. She argues that

their testimonies and actions suggest there are certain values that people associate with the idea of citizenship which cut across the various boundaries that divide them. These values may not be universal but they are widespread enough to suggest that they constitute a significant aspect of the organization of collective life and of the way in which people connect with each other. And because they are being articulated by groups who have experienced exclusion in some form or other, these values also articulate their vision of what a more inclusive society might imply. (p. 3)

The four values of inclusive citizenship emerging in the personal accounts of diverse and internationally placed marginalized groups include: (a) justice – what is fair for one person might be different for another; (b) recognition – the value and respect accorded to individuals; (c) self-determination – individuals having control over their lives; and (d) solidarity – a group united for justice and recognition (Kabeer, 2005). These values underline the practice of citizenship where pluralistic identities are equally respected and recognized within a collective.

People with intellectual disabilities who have dementia have their own pluralistic identities that are embodied in the concept of personhood. Personhood defines the distinctness of the individual: “The state or condition of being a person, especially having those qualities that confer distinct individuality” (Personhood, n.d.). Historically, dementia has been associated with loss of cognitive functions and, therefore, loss of self leading to loss of person (Cohen & Eisdorfer, 1986; Herskovits, 1995). Now, it is accepted that individuals maintain their personhood even after the onset of dementia. Recognition of personhood promotes the continued individuality of people, valuing their experiences and nuances that make them who they are.

Similar to citizenship, personhood is “a standing or status that is bestowed upon one human being, by others, in the context of relationship and social being” (Kitwood, 1997, p. 13). Taken in the social context, personhood is socially constructed by and with people’s interactions with their environments (Bartlett & O’Connor, 2007; Hughes, 2001; Kitwood, 1997; Sabat & Harre, 1992). That is, people with dementia construct their own reality and live by the reality that is constructed for them. Our understanding of personhood indicates, therefore, that decline in dementia is not only due to

neurodegenerative changes but also related to personal histories and the quality of social environments; how interactions with others occur therein and how the person is perceived (O'Connor et al., 2007). Like citizenship, personhood is lost in deprived social contexts of weak interpersonal relations (Davis, 2004; Hughes, 2001).

A fundamental difference between personhood and citizenship is the focus on the issue of power. The discourse on citizenship confronts the lack of power afforded to some citizens and raises the discussion to the realm of politics. People with disabilities have made their personal experiences of discrimination and social inequality political and in the process improved their status and treatment in society (Campbell & Oliver, 1996; Tregaskis, 2002). A limitation of people who have dementia may be that they are dependant on others for the advocacy that makes change happen. Therefore, while they are able to communicate their needs at the interpersonal level, their issues may not be reflected in the socio-political context (Bartlett & O'Connor, 2007).

A political dialogue on the citizenship of people with dementia requires the inclusion of the concept of personhood (Bartlett & O'Connor, 2007). Such a dialogue is apparent in the everyday practice of citizenship through political participation and changed relations at the interpersonal level. For example, when a person with dementia insists on sitting in a particular chair in a care home, this can be viewed as an act of resistance expressed by the power of a citizen rather than idiosyncratic behaviour of a person in cognitive decline (McColgan, 2005). It is in their personal activities that people with dementia move beyond the concept of personhood and take on a political meaning in the act of citizenship.

Hence, to attain social equity, people with a dual disability need affirmation of both their citizenship and personhood, because citizenship assumes that a person will advocate on their own behalf to exercise their rights and responsibilities (Bartlett & O'Connor, 2007). To ensure citizenship, the practice of those who provide service and those who control community decisions should be thoughtful because neither the personhood nor the citizenship of the person with a dual disability can be taken for granted. Citizenship for these individuals means *giving* power to them and highlighting the politics of difference by reworking “images, assumptions and representations that are seen to be exclusive as well as marginalizing” (Stevenson, 2003, p. 18). Service providers, peers, friends, and caregivers can empower people with a dual disability to make change happen in their personal lives at the same time as affecting change at the societal level.

In addition, meaningful citizenship ensures the *dignity* of individuals in a community where they belong in spite of difference and where common humanity is recognized and valued (Morris, 2005; Narayan, 1997). Treating individuals as worthy of respect and appropriate support will advocate a humanistic (rather than a medical) perspective of dementia (Bartlett & O'Connor, 2007). Within a humanistic perspective all people lead textured lives in which they enjoy a variety of activities and mutually caring, permanent human relationships. A textured life is evident

... when people have social and physical variety and richness in their day-to-day experiences. Their days are varied, and although they may have an activity that they routinely engage in at least for part of any day, there is also a sense of choice in what they are involved in from week to week. There is more spontaneity in day-to-day life, and routine activities bring the individual into contact with a wide variety of people and lead to a wide variety of experiences (Pedlar et al., 1999, p. 103).

In other words, people with disabilities engage in the same quality of social life in the community as other people who do not have disabilities (Pedlar et al., 1999). Or, they have the opportunity to create a social life that is empowering and fulfilling in which their citizenship is not merely a relationship with the state but “a more total relationship, inflected by identity, social positioning, cultural assumptions, institutional practices and a sense of belonging” (Werbner & Davis, 1999, p. 4).

It is apparent that the environment, the interactions, and the psychosocial interventions all influence the extent to which people with a dual disability are included in society, treated as people with a sense of self, and are able to exercise their power and freedom to live the participatory life of a citizen. Participatory parity requires a distribution of material resources such that citizens experience equality of opportunity (Fraser, 2003; Krogh & Johnson, 2006). A critical resource for people with a dual disability is an adequate living environment.

Living Options for People with a Dual Disability

Adequate living environments for people with a dual disability take into account physical aspects of privacy, socialization, security, daily-living activities, individual rooms, options to furnish and personalize space, way-finding techniques, elimination of glare and shadows from lighting, wandering paths, and access to outdoors (Calkins 1997; Regnier, 1994). In addition, social aspects of the environment include consideration of staff-to-resident ratios, staff satisfaction with salaries, training in dementia support, shift lengths, staff consistency, programming, and whether the philosophy of support is custodial, medical, functional, or therapeutic (see Chaput, 2002). Creating living options for people with a dual disability must take into account the physical and social aspects of the environment to ensure a good quality of life (Lawton, 1994).

The literature identifies four main living environments for people with a dual disability: supported housing such as cooperatives or apartments, family homes, supportive housing such as group homes or clustered apartments, and nursing homes (Carling, 1995; Chaput, 2002; Forbes et al., 2006; Janicki, McCallion, & Dalton, 2002; Nelson, Lord, & Ochoka, 2001b; Parkinson, Nelson, & Horgan, 1999; Smale & Dupuis, 2002). The type of housing and living environment has both a positive and a negative influence on a person's sense of self-efficacy and on their satisfaction with life (Nelson, Sylvestre, Aubry, George, & Trainor, 2007).

Supported Housing

Supported housing is a form of independent living in the community that is chosen by the individual with a disability (Carling, 1995). In this living environment the individuals have choice and control over where they live, how they live, and the kind of support they will receive. Professional services are replaced by personalized support (Nelson et al., 2007). This type of living option is more empowering as it provides more choice and control to individuals, with support characterized as self-help through natural support mechanisms.

However, while living in supported housing may provide the greatest resident control, individuals may tend to feel lonely and isolated because there is often less access to social support compared to life in supportive housing (Pulice, McCormick, & Dewees, 1995). As well, lack of housing resources, long waitlists, and insufficient income support programs mean that individuals have to accept whatever is available regardless of the neighbourhood or type of home (Nelson et al., 2007).

Family Home

Some people with an intellectual disability continue to live in their family homes. The number of older parents who are providing lifetime care for adult family members with intellectual disabilities is on the rise (Heller & Factor, 1993; Minnes & Woodford, 2004). Minnes, Woodford, and Passey (2007) interviewed 80 parent caregivers over the age of 50 and found that their health and depression was mediated by their perceptions of aging and stress. In addition, their perceived stress significantly mediated the relationship between their level of depression and maladaptive behaviours of their family members with intellectual disabilities. Individuals depend on family and professional supports to maintain living at home.

Support services for individuals with a dual disability who live at home only cater to the short-term needs of those experiencing acute symptoms of dementia rather than delivering long-term support for less acute symptoms (Forbes et al., 2006). Support services involve meal preparation, personal support, adult day-away programs, homemaker services, Alzheimer's support groups, case management, in-home respite services, and home healthcare (Forbes et al., 2006; Smale & Dupuis, 2002). In the absence of long-term service, family caregivers are usually forced into the complex and emotionally draining task of permanency planning in an institution of long-term care once their loved one experiences the onset of dementia. This process requires making difficult decisions around financial security, proper placement, and guardianship (Seltzer, & Seltzer, 1985; Smith & Tobin, 1989).

A move away from home is considered to access more resources for the individual with dementia. In Janicki et al. (2002), specialized staff and specialized environments are considered the best option to cater to the long-term needs of this

population. It is assumed that a move to a specialized facility will ease the stress for the family caregiver. However, caregiver researchers are ambivalent about this assumption. The literature on caregiving indicates that studies focusing on physical stress alone show improvement for family caregivers following a nursing home placement but studies focusing on caregiver health, life satisfaction, and emotional well-being demonstrate little change following placement (McConnell, Lieberman, & Fisher, 2001).

Although some caregiver research indicates that family members feel a sense of freedom from the caregiving role (Aneshensel & Pearlin, 1993) and their quality of family life improves after placement (Pushkar, Gold & Reis, 1995), studies with Alzheimer patients' spouses and family members (i.e., adult offspring, in-laws married to offspring) do not show a significant improvement in health and overall stress levels following placement (Barber, 1993; McConnell et al., 2001). In some cases, caregivers are more distressed upon placement of a family member in a nursing home (Ritchie & Ledesert, 1992), experience loneliness and difficulty in coping with their role change (MacKenzie & MacLean, 1992), and continue to feel depressed (Zarit & Whitlatch, 1992). In addition, female family caregivers show a greater decline in well-being irrespective of whether their family member with dementia is placed or not (McConnell et al., 2001).

For individuals with a dual disability to remain at home they require adaptations in the home for accessibility, home support at the level of need (e.g., support for leisure in the community, personal support, engaging with social links), nursing and palliative care, accessible medical services, respite for family caregivers, dementia training for family caregivers, support workers trained in intellectual disability and dementia support,

transportation, support to participate in textured community activities, and funds for assistive equipment. However, as research shows, the overall lack of supports to meet the complex needs of a person with dementia at home (see Buhr et al., 2006; Forbes et al., 2006; Tindale et al., 2000) warrants placement in an alternative living environment.

The most common reasons cited for out-of-home placements include the need for skilled support, the caregiver's health preventing them from being able to adequately support the individual, the caregiver not being able to handle the dementia-related behaviours, the severity of disability, the lack of finances to provide support in the home, and the caregiver's death (Buhr et al., 2006; Chaput, 2002; Hersen & Van Hasselt, 1998; Olson, 2006). One placement option with additional resources to provide support for dementia-related needs is supportive housing.

Supportive Housing

An alternative living environment with more resources is a smaller group home in the community that is supported by professional staff. Such homes are usually operated by agencies and family support networks (Janicki et al., 2002) and are more economical compared to nursing homes because staff do not require medical expertise on par with nursing qualifications (Chaput, 2002). In addition, unlike nursing homes, supportive housing encourages and facilitates community interaction, day programs, daily outings, and maintaining individually desired lifestyles (Chaput, 2002). Thus, individuals sustain their independence to complete their daily living tasks with help from staff and maintain their prior lifestyle. Staff members cater to individual preferences and emphasize a person-centered approach that fosters the development of a person's needs and strengths (Calkins, 1997).

Antonangeli (1995) has found that supportive housing can be adjusted to provide dementia support by educating family members and professional caregivers who need practical strategies to deal with specific problematic behaviours such as anger, wandering, agitation, or disorientation. These living environments can incorporate knowledge about local resources on dementia, diagnostic evaluations, routine healthcare management (e.g., dental and physical health, nutrition, fluid intake), and specialized approaches to support the person in daily-living activities. Dementia support approaches adjust the communication to match the individual's needs, create individualized home and day programs, maintain the individual's abilities and skills, adapt and modify the physical environment to ensure safety, and teach caregivers new skills to support complex medical or nursing needs when the person is bedridden and inactive (Antonangeli, 1995; Bauer & Shea, 1986; Janicki et al., 1996; Toseland, Derico, & Owen, 1984; Tyler & Shank, 1996).

According to Janicki et al. (2002), creating such a therapeutic environment facilitates aging in place, meaning services and supports are adapted to meet the current and future needs of the individual. Factors influencing the extent to which aging in place can be accomplished include the agency's ability to reassign resources to create a therapeutic home, their commitment to continued support, the needs of people living in the home, the losses experienced by individuals, how well the staff can adapt to changing needs, and what the individuals are able to express and do (Janicki et al., 2002).

Supportive housing for people with a dual disability reduces the onerous physical and mental stress of caregiving, a benefit created when a core team of family and professional caregivers join together in the task of supporting a person with a dual

disability (Manji, 2002). The team that comes together in a small home setting around the support of an individual has the potential to share expertise and enhance professional development, provide multiple (formal and informal) informant sources to clarify the diagnosis of dementia in people with an intellectual disability, and help individuals to maximize their ability during the progression of dementia (Manji, 2002).

One criticism of supportive housing is that the staff members are unable to cater for medically fragile people because residential support workers are not qualified to handle complex medical needs (Chaput, 2002; Coons & Mace, 1996). Residents in the later stages of dementia must often be transferred to a nursing home where medical needs can be better addressed (Coons & Mace, 1996). However, long waitlists and limited options for nursing-home care create new challenges for moving individuals to a facility of their choice at the time when this option is needed (Crandall, 1990; Evasuk, 1990).

A further criticism of supportive housing is that it is a type of institution in which the services are planned by the staff and the funding goes to the program rather than the individual. Many consider this approach as a form of segregated living. Simulating a custodial arrangement found in nursing homes, it may not provide any choices about where and how people want to live (Lord & Pedlar, 1991; Pedlar, Hutchison, Arai, & Dunn, 2000). In addition, a limitation of this type of housing is that it often does not facilitate social integration (O'Brien & O'Brien, 1991), as individuals do not make friends or form supportive networks in the home (Lord & Pedlar, 1991).

Nursing Home

Out of all living options available to people with a dual disability, the most readily available is the mainstream long-term care facility for seniors, a nursing home, also known as a personal care home (Chaput, 2002). Some nursing homes have special

care units, small and separate units within a larger facility, which usually cater to people at an advanced stage of dementia. Larger in size than a private home or group home, the special care unit emphasizes ambulatory care and has security, socialization, and activities to engage the residents daily (Chaput, 2002). Direct-care staff members who work in special care units in Canada are health aides who have a healthcare certificate and are trained to deal with the physical and behavioural problems commonly present in this population (Chaput, 2002).

Flexibility for an individual in this setting is limited because services are planned by the staff, activities are universal and preprogrammed, and all residents are required to follow a rigid routine. In addition, funding is attached to the long-term care program in which support is prioritized by the medical rather than the social needs of the individual. Therefore, the philosophy of support in these special units within institutions is custodial, emphasizing the treatment of disease and the care of dependent people (Parkinson et al., 1999).

In spite of the provision of a highly specialized therapeutic environment, a 10-year longitudinal study (Segal & Kotler, 1993) of 360 residents who had lived in such institutional care in the United States found that these individuals had poorer health, more symptoms, were less independent, and had less social interaction and family contact compared to when they entered the sheltered-care facility. Moreover, the mortality rate for this population was found to be higher than in the general population (Segal & Kotler, 1993). Empirical evidence in the mental health and psychiatric literature also demonstrates that living in nursing home settings increases mortality rates and decreases life expectancy, while living in alternative settings (i.e., supported housing, group homes,

and specialized residential homes) improves life satisfaction and life expectancy (McClendon, Smyth, & Neundorfer, 2006; Nelson, Hall, & Walsh-Bowers, 1998, 1999).

Further, some researchers argue that institutional settings restrict the extent to which residents can exercise choice and control over their decisions, leading them to depression and negative affect (Taylor, Elliott, & Kearns, 1989). Chaput (2002) found that long-term care facilities were particularly detrimental for people who were heavily involved in the community before the onset of dementia; moving to an institutional setting required the individual to give up interactions within the community and familiar activities outdoors. Institutional settings, while providing a high level of specialized care, tend to restrict choice and autonomy for individuals, isolating them from the external community.

Having discussed the various housing options for people with a dual disability it is evident that the living environment is influenced by a medical versus social perspective of dementia. Whether the resulting practice is empowering or disempowering is necessary to understand; in particular, the extent to which people with dementia are able to construct their personhood, citizenship, and community. The theory of empowerment can provide a framework by which to understand this context. A description of its process and elements is given in the next section.

A Process of Empowerment

Empowerment is facilitated in three domains: 1) personal, 2) community, and 3) societal (Lord & Hutchinson, 2007). At the personal level the individual is empowered when his or her ability to influence daily life and participate in community is increased; at the community level empowerment is facilitated through a collective effort of groups influencing a shared experience; and at the societal level empowerment entails access to

resources and strategies enhancing community control (Keiffer, 1984; Presby, Wandersman, Florin, Rich, & Chavis; Labonte as cited in Lord & Hutchinson, 1993).

Keiffer (1984) has described personal empowerment as a developmental process that undergoes four stages: entry, advancement, incorporation, and commitment. The entry stage is motivated by a provocative event that threatens the self or family. It is a life-changing event or condition, such as physical disability, intellectual disability, health disorder, and poverty. The event renders a person powerless with low self-esteem, limited choices, little or no ability to control his or her life or influence others, and to exist in a state of survival rather than living at one's full potential (1984).

In the second stage of advancement (Lord & Hutchinson, 1993, p. 3), the empowerment process matures with the assistance of "a mentoring relationship; supportive peer relationships with a collective organization; and a greater awareness of social and political relations." A greater political consciousness is achieved in the third stage of incorporation. In the final stage of commitment, individuals "apply the new participatory competence to ever expanding areas of their lives" (p. 4).

Consequently, empowerment is both a process and an outcome; the "*processes whereby individuals achieve increasing control of various aspects of their lives and participate in the community with dignity*" constitute empowerment (Lord and Hutchison, 1993, p. 4, italics in text). The goal of empowerment is to help individuals to overcome barriers that obstruct self fulfillment and, in so doing, change conditions to improve their world (Neuman & Kreuger, 2003; Payne, 2005).

Individuals who are empowered gain greater control over their own lives when barriers that limit their power to change are broken down and replaced with confidence

and capacity to effect decisions (Payne, 2005). When people feel empowered, they feel self-confident, have a sense of personal control, are less socially-isolated, participate more actively in the community, have increased social interactions, and take more initiative in changing their lives (Lord & Hutchison, 1993). Empowered individuals feel independent and competent to influence their daily life.

For personal empowerment to occur, opportunities must be created for individuals to express their needs, make choices, and participate in community (Nelson et al., 2001b). The capacity of the individual to make choices is linked to the capacity of the community to engage in the empowerment process. Individuals achieve empowerment when community promotes participation to strengthen their assertive leadership, knowledge and skills, confidence, and self-esteem (Payne, 2005; Sommer, 2001).

An empowerment process at the community level leads to the development of resources, support systems, relationships, and increased participation in the community.

Thus, in this domain empowerment is

an intentional, ongoing process centered in the local community, involving mutual respect, critical reflection, caring and group participation through which people lacking an equal share of valued resources gain greater access to and control over those resources. (Wolff, 1992, p. 3)

Community oriented empowerment focuses on “the practice of activating resources, creating alliances and expanding opportunities for people in groups and communities” (Payne, 2005, p. 302).

Empowerment-in-community is evident when individuals lead lives that have *texture* (Pedlar et al., 1999). Textured lives are secure and rich with a variety of social and physical day-to-day experiences. Fully accepted in community, individuals have daily experiences that are diverse consisting of routine as well as spontaneous activities

of choice. They interact with a wide variety of people from the community and enjoy relationships that are relatively permanent, based on mutual caring and respect.

Empowerment is facilitated by conditions in the community that invoke participation. Further, collective action facilitates access to community resources and increases social support (Mullender & Ward as cited in Payne, 2005). A collective action in the community entails partnering and collaborating with individuals and agencies to facilitate individual and community control over the planning and implementation of solutions to individually and locally experienced problems (Perkins, 1995). Working as partners strengthens the relationship of all the individuals to conquer injustices because people together articulate a “collective narrative that sustains their own personal life story in positive ways” (Rappaport, 1995, p. 796).

However, Boehm and Staples (2002) caution that a one-size-fits-all solution focused on a single narrative is inconsistent with the practice of empowerment; what is or is not empowering depends on the context and meaning assigned across a broad sampling of society (Foster-Fishman, Salem, Chibnall, Legler, & Yapchai, 1998; Rappaport, 1984; Salzer, 1997; Zimmerman, 1995). Foster-Fishman et al. (1998) state that empowerment is a dynamic concept that changes over time and takes on pluralistic forms:

Empowerment takes on different forms for different people. Because personal history emerges from the intersection of demographic characteristics and social opportunities, we should expect individuals with different racial, gender, ethnic, class, and social backgrounds to desire different forms of empowerment. (p. 509)

Empowerment theory then links “individual well being with the larger social and political environment” (Perkins & Zimmerman, 1995, p. 569). Processes which disempower individuals and obstruct self-actualization are found in power differentials between individuals and groups, classism, and oppressed conditions (see Payne, 2005).

Processes of empowerment challenge oppression, transfer power to individuals to identify their own needs, engage them in decision making and planning, and join them with others to organize services according to their fit (Payne, 2005).

At the societal level, empowerment results in changing public consciousness, mobilizing people and resources to increase access to government and community resources, and formally recognizing that power has been transferred to the individuals who were formerly left powerless (Fisher, 1994; Lord & Hutchison, 1993; Nelson et al., 2001b; Perkins & Zimmerman, 1995; Salzer, 1997; Zimmerman, 1995). When helpers transfer power to individuals they acknowledge that all people have skills, understanding, and knowledge; they have a right to be heard, to control their own lives, to participate or not to participate, to define issues, and to take action; and their problems always reflect issues of power and oppression, policy, and economy as well as personal deficits (Mullender & Ward cited in Payne, 2005).

It is evident that empowerment in the three domains of social life (i.e., personal, community, and societal) is interactive; changes in one domain are often reflected in changes in other domains (Nelson et al., 2001b). As well, the level of change is directly related to the level of empowerment in each domain (Perkins & Zimmerman, 1995; Salzer, 1997). A better quality of life and health is achieved for the individual when change occurs in all three domains (Scott, 1999).

People with a dual disability are experiencing significant service gaps that reduce the quality of their lives (see Antonangeli, 1995; Bartlett & O'Connor, 2007; Bauer & Shea, 1986; Janicki et al., 1996; Manji, 2002; Tyler & Shank, 1996). Given the living and support issues facing these individuals, accurate knowledge is required to assist

policymakers in designing and implementing both appropriate interventions and models of living that foster empowerment.

Research Implications for a Social Model of Dementia Support

The search for accurate information to develop a social model of dementia support has thus far met with some challenges as researchers have gained limited knowledge of the specific needs and abilities of people with a dual disability through just a small number of studies. Research on dementia has focused on the disease aspect of the condition. Limitations in conducting studies with people with a dual disability may be in part due to a number of methodological issues.

For instance, a lack of accurate instruments and a lack of standard diagnostic procedures to accurately diagnose dementia in people with intellectual disabilities results in significant differences in the baseline criteria used in studies. Policy guidelines maintain that appropriate tools (diagnostic instruments, reliable measures of performance, assessment strategies) be used to promote healthy aging and support for dementia in people with an intellectual disability. The level of support should be conducive to a choice to live in the desired residence and community, equitable access should be provided to mainstream services and supports, and future needs of people with a dual disability must be considered across all levels of service planning (Wilkinson & Janicki, 2001).

Effectively managing the course of dementia in environments that incorporate the “strengths, capabilities, skills and wishes” of the individual (see Edinburgh Principles, Wilkinson & Janicki, 2001, p. 1) is more likely to ensure better quality of life outcomes for people with a dual disability (Antonangeli, 1995; Bauer & Shea, 1986; Devenny, Krinsky-McHale, Sersen, & Silverman, 2000; Holland, Hon, Huppert, & Stevens, 2000;

Janicki et al., 1996). Nelson, Hall, and Walsh-Bowers (1998) elaborate that a living environment that is individualized, respectful, and has a person-centered approach to support empowers a person to have more control over their decisions, enables active participation in the community, and facilitates an improvement in mental health with a greater sense of life satisfaction.

In summary, some living options for people with a dual disability appear to be more empowering than others. For instance, supported housing offers the most potential for empowered living and supportive housing, enhanced with therapeutic supports, may be more empowering than nursing homes. However, consumers and their families are unable to pursue the more empowering living options because government policy has focused on the provision of aggregated support for people with dementia, primarily in custodial medical settings such as nursing homes (see Chaput 2002).

Despite policy, some researchers assert that small barrier-free therapeutic living options in the community or aging in place can delay or even eliminate institutionalization in nursing homes; more familiar environments allow people with dementia to maintain routines that appear to compensate for the disorientation they experience living with dementia (Antonangeli, 1995; Janicki et al., 1996). Furthermore, these options provide consistency, facilitate access to health and therapeutic interventions, and sustain strong emotional and social ties with family, peers, and community (Antonangeli, 1995; Janicki et al., 1996; Manji, 2002; Sparks et al., 2000).

This study was conducted at one such barrier-free model specializing in dementia support. It is a community living model of supportive living that is largely resourced from reallocation of existing agency resources. Similar to other service providers who

have reassigned their existing group homes to cater for the dementia needs of their members (Janicki et al., 2002), the home studied was purpose-built to house people with a dual disability. I examined the experiences of four consumers who lived in this home. The methodology used to garner these experiences is described next followed by the findings of this study.

CHAPTER THREE

Methodology

This study explores the experiences of people with a dual disability (an intellectual disability and dementia) living in a home specializing in dementia support. While I was directly concerned with the experiences of these consumers living in the home, I could not ignore the perspectives of significant others who are involved in their lives, daily support, and planning. Qualitative research assumes that reality is subjective and multiple; events, experiences, occurrences, and happenings unfold through collective interactions between consumers and those in their circle of support (Creswell, 1998). As well, qualitative research assumes that it is the participants in the study who provide evidence of different perspectives (Creswell, 1998).

Therefore, I applied qualitative methods to observe the interactions of consumers with a dual disability and their family or friend caregivers, direct-care staff, and administrators (hitherto collectively referred to as *stakeholders*). My interest was to explore what it means for people with a dual disability to be in a specialized home setting, “what their lives are like, what’s going on for them, what their meanings are, [and] what the world looks like in that particular setting” (Patton, 1985 as cited in Merriam, 1988). Qualitative research provided an in-depth holistic picture of the living environment and rich descriptions of the experiences of consumers residing in the home (Corbin & Strauss, 2007).

Methodological Approach

In a qualitative approach, data are collected from the standpoint of uncertainty, where no generalizations are made and patterns are only perceived after the study is

completed. This view requires thinking that is open, not rigid or structured, so that outcomes are not preconceived and conclusions are created as knowledge develops. Breaking away from rigid and structured thinking prevents the application of categories such as disabled versus nondisabled and demented versus nondemented. These dichotomies are not value-free or neutral and either empower or disempower research participants. For the researcher, dichotomies generate assumptions and biases that hinder a full understanding of the reality of dementia (Wilson, 2001). Hence, this study explores how stakeholders understand dementia. I recognize that the subjective meaning of dementia is different for each individual as defined by their personal experience of working or living with the condition (Bond & Corner, 2001).

The researcher in the field who uses the qualitative method assumes that the participants' reality is socially constructed, always changing and evolving, complex, not linear, multicausal, contextual, and multidimensional. The inclusion of multiple voices enabled me to probe and corroborate stories and experiences from various angles to address the main research question, "What are the experiences of people with a dual disability living in a home specializing in dementia support?" The answer to this main question involved secondary questions to facilitate a subjective understanding of the consumers' needs and living experiences in this specialized service model. Needs were instrumental, psychological, emotional, and social presented as those things required for basic survival, such as shelter, food, healthcare, security, a strong sense of identity, and validation by others. I applied three secondary questions to probe the main research question:

1. What are the needs of consumers with a dual disability residing in the home?
2. What adjustments have to be made in supporting their needs and what service barriers and successes are experienced?
3. How is the specialized service model perceived by stakeholders (i.e., family or friend caregivers, direct-care staff, and administrators) involved in the support of the consumers participating in the study?

Probing deeper with these questions, I was able to identify how dementia affects people with intellectual disabilities and helpful ways to support them. Plus, the data highlighted success factors and barriers of a specialized service model, precipitating factors that result in people with a dual disability moving from one model of living to another, such as from the family home to a group home, and current policy issues regarding the support of this population.

Ethical Considerations

The main ethical considerations in this study pertained to conducting research with vulnerable participants, who in this case are people living with both intellectual disabilities and dementia. The issue of informed consent arises when involving people with a dual disability in the research environment.

Research with Vulnerable Participants

I invited for this study the participation of people with intellectual disabilities and those who have dementia. Researchers are often challenged by the assumption that people with dementia do not have the capacity to understand what they are consenting to because they do not have a sense of self to express their desires. However, some researchers argue that people with dementia still retain a “private sense of self,” an

argument that has been corroborated by caregivers of people with dementia (Downs, 1997).

Social constructionist theory suggests that in dementia the “self” remains intact despite the loss of cognitive and motor functions (Sabat & Harre, 1992). Empirical evidence shows that people with dementia do express preferences (Kane, 1997) and do interpret their experiences with specific meanings (Brod, Stewart, & Sands, 1999). For example, when people with dementia share conversations that they have had with family, friends, or service providers, whether imagined or real, this is their reality and lived experience. The person with dementia has “good” and “bad” experiences (Lawton et al., 1999) which when influenced provide a better experience of lived life.

Hence, the loss of self may not be threatened by the progress of dementia but rather by the relational behaviour of significant others. The consequence of this relational behaviour is that a person with dementia experiences a loss of autonomy and personhood (Sabat & Harre, 1992). Therefore, it is possible that giving a choice to participate in this study empowered the individuals with a dual disability to exercise their autonomy and express their experiences. Approval for the participation of the consumers and their peers in this study was given by the Wilfrid Laurier University Research Ethics Board (see Appendix B). Further, I developed a guideline based on the experiences of other people such as children who have been deemed to be “incompetent” to participate in research (see Appendix C). There is overlap in social research, especially in establishing sensitive interview practices and also in ensuring informed consent.

Informed Consent

Irrespective of the rights of people with dementia and intellectual disabilities to participate in research, the ability of participants to understand the information presented,

including the consequences of participating or not participating in the study, is an ethical issue. The method of giving information and garnering consent from research participants is based on the assumption that a signed and written form legalizes the participation contract. For those participants in the study who were not deemed to be “incompetent” to give informed consent, we first discussed a written contract of consent that was then signed before commencing the interview process (Appendix D).

To include consumers who have a dual disability in this study, I had to accommodate the fact that people who use alternative communication skills (e.g., verbal, behavioural) are unable to interpret written forms of communication. A person with dementia with different “abilities in communication, memory, language and perception does not experience the ritual of informed consent from the perspective of an equal participant” (Dewing, 2002, p. 159). Therefore, I had to adapt the normal means of communication for giving information and gaining consent to that appropriate for the person with dementia.

In qualitative research, the process of consent is not a single, a priori event but a continual process between the researcher and participant (Kayser-Jones & Koenig, 1994). Therefore, during the consent procedure informed participation is assumed to occur during each research activity, although it is left up to the participant to contest this and to revoke consent. Viewed in this way, I assumed that consumers participating in this study could consent to participate in research through a process of meaning-making when they were present at each research interaction. This would account for times when consumers forgot what they had consented to and needed clarification at each visit. I maintained consent by adapting the method to include multiple times when I explained the research

activity and renegotiating informed consent. For example, during a research interaction with a consumer, the accompanying staff or caregiver who was knowledgeable about the individual's communication, likes, and dislikes, interpreted a behaviour (e.g., consumer leaves the room) as not wanting to participate. In such an instance the research interaction was stopped, future participation reviewed with the staff or caregiver and participant, and renewed assent acquired before engaging in further research interaction.

The issue of consent in this study was thoroughly explored. I regularly obtained feedback from the consumers, their guardians, and primary caregivers and ongoing verification of the consumers' current involvement in decision making processes about their lives such as at person-centered planning meetings or completing service evaluations in the agency. It was important for me to understand how to interpret nonverbal communication in observations, verify this information with other sources (e.g., documentation), involve caregivers or interpreters in interpreting nonverbal communication, and gain verbal/nonverbal assent for each time period or task in which I was engaged with the consumer.

Hence, the data for a particular research task were collected in a manner and timeframe that was comfortable, suitable, and appropriate to the consumers' means of interaction and social exchange, as identified in the planning stage and assessed during the research process. For the process of participant observation, I requested written signed consent from consumers' proxies allowing consumers to be research participants and allowing me access to their documented records for review (Appendix E).

Risks and Benefits

There is a probability of harm when conducting research with vulnerable populations. A balance must be established between the ethical principles of

nonmaleficence (harm) and beneficence (possible benefits from research). When consent is obtained, the implication is that the researcher is identifying a “moral space” (Kitwood, 1990b, p. 99) that must be respected in the research relationship. Consent implies “an ethical imperative to establish mutual trust between researchers and narrator” (Kenyon, 1996, p. 661) and “create[s] a continuous ethical obligation on the part of the researcher to ensure that the research does not harm the participant and that the privileged position of access ... will not be used to the participant’s detriment” (Sankar & Gubrium, 1994, p. 14). To ensure that the participants of this study did not incur any harm, I always gave the participant the option to change the conditions of their participation (e.g., time or place of research, type of research activity, etc.) to the point of being able to withdraw at any time if they felt they were no longer able to participate.

Sensitive information gathered during data collection had the potential to harm the consumer. I therefore developed a protocol (Appendix F) for addressing sensitive information in the event that such information should come to my attention by way of disclosure from participants in the study or during the observation periods. The protocol involved presenting information to multiple internal and external representatives of the consumers I had identified, who could then implement a resolution that would maintain the safety of vulnerable participants in the study.

The researcher who works with people with a dual disability must possess the vigilance and skills to adequately interpret their communication. For example, Clarke and Keady (1996) found that some participants in their study were not aware of their diagnosis and were using phrases such as “memory problems,” which caregivers may have told them, to describe their condition. It may or may not have been misleading for

participants if I did not make it clear that the study was about dementia. To avoid such unintentional harm, during the preliminary phase of the study I discussed with agency administrators whether using the term dementia would cause distress to the consumer, whether the usage of certain terms would be stigmatizing, and whether avoiding these terms would amount to deception. The agency administrators recommended using the term dementia and not incurring deception. They verified that the tools developed for the study did not contain stigmatizing terms. Their responses clarified the concepts, aims, and objectives of the study and ensured that all participants understood, accepted, and were willing to be party to the research as articulated.

The issue of harm was also continuously monitored during those data gathering phases when vulnerable participants consented to participate. Again, the consumers' significant others and support people were asked to be observers and companions during the research interactions so they could interpret consumers' communication and ensure their comfort and safety. As active participants of the research, the consumers and their support people assisted me to overcome the challenges that might lead to harm.

The Researcher as an Insider

A final ethical consideration arose from the fact of my prior employment with the participating agency. This pre-existing relationship helped me gain the trust of the participants, both consumers and stakeholders, and to elicit their experiences. Some of the stakeholders or consumers may have been participating because of prior liaisons with me, which could be seen as a form of coercion, particularly because some I had known before, but there were others with whom I had had no previous contact.

In either case, I emphasized verbally and in writing that participants would experience no adverse consequences as a result of choosing not to participate. I

conducted my research according to the required ethical guidelines emphasizing voluntary participation for all the recruits in the study. The stakeholders knew that the study would be conducted with a clear perception of their and the consumers' sensitivities and vulnerabilities and with all their best interests at the center of research interactions.

Case Study

This project involved an exploratory qualitative case study of people with a dual disability who live in a specialized home modeled as community living for people with an intellectual disability. Yin (2002) describes a case study as an empirical investigation into "a contemporary phenomenon within its real-life context; when the boundaries between phenomenon and context are not clearly evident; and in which multiple sources of evidence are used" (p. 23). A case study approach to data collection allowed for the inclusion of multiple sources and multiple methods. Consumers with a dual disability residing in the home, their family or friends, their peers with intellectual disabilities, their professional caregivers (direct-care staff), their documented histories and records of support, and other stakeholders (e.g., management staff) in the supporting agency were all sources for data.

I limited direct observation to 150.75 hours at the home within a 6-month period. In addition, I conducted one-on-one interviews with other participants in the study and reviewed consumer records. With multiple sources and methods for data collection, I explored the complexities of the living environment, probed critical incidents, investigated the extent to which the specialized model of living responded to the needs of consumers, and, in the end, gained a holistic understanding of the consumers' experiences living in the home.

Case studies can serve different purposes. Creswell (1998) states that “some case studies generate theory, some are simply descriptions of cases, and others are more analytical in nature and display cross-case or inter-site comparisons” (p. 186). This case study is theoretical in nature; the data led me to generate a theory regarding the empowerment of people with a dual disability.

Selection of Site of Research Study

For the site of my research, I chose a home-like setting designed for people with a dual disability in London, Ontario. This home is managed by Community Living London (CLL), a nonprofit agency mandated by the government to support individuals with intellectual disabilities. I was employed by this participating agency from 1995 to 2002 as a support worker and integration specialist. As a result, some participants in this agency were already known to me. These prior relationships facilitated entry into the site of study and assisted in the development of empathy and trust between the researcher and the participants.

Context of the Agency

Community Living London implements various programs and services to support people with an intellectual disability in community living. Their services include residential programs; advocacy; children services (e.g., toy lending, respite, family support, etc.); community access connecting people with intellectual disabilities to leisure, recreation, volunteering, and lifelong learning; supported employment; and person-centered planning to assist people with intellectual disabilities to develop individualized support plans.

A major service of the agency is the operation of residential programs, independent living and group homes such as the home in my study. Many of the 150

individuals supported in the residential programs were at risk of dementia (due to Down Syndrome) or showing early signs of dementia. Four people with a medical diagnosis of dementia were living in the home that opened in 1998.

Location and Design of the Home

The home is situated in a newer and affluent neighbourhood. From the outside the house looks like a large detached family bungalow (see Figure 1) set in a crescent street. The bungalow has five bedrooms for residents, one den for staff to use as an office, two bathrooms (one with a bathtub and one with an accessible shower area), an open-plan living room, kitchen, and foyer, a double garage with ramp, a basement for storage, and a garden with patio. Apart from its extra-wide driveway, it is no different externally from any other home in the street and there is no sign indicating that it is a facility for residential support.

The home is barrier-free, which means it responds to the physical needs of its residents. An open and secure layout accommodates wheelchairs and other equipment needed to support activities of daily living, such as mechanical lifts to transfer people who have lost their mobility, an accessible van, special beds, etc. The interior decor, lighting, and temperature control are designed to keep the person with dementia relaxed and calm. The open concept also allows the individuals to walk freely around the living space on the continuous floor connecting the kitchen, living room, and foyer. A 12-foot opening in one interior wall connects the kitchen to the living room. The kitchen also provides access to the backyard and patio, which extends the internal space into the outdoors.

Residents in the Home

At the time of the study this home had five residents, all of whom had an intellectual with dementia when the home first opened. This resident continues to choose to stay in this home even though her friend has passed on. The four residents with a dual

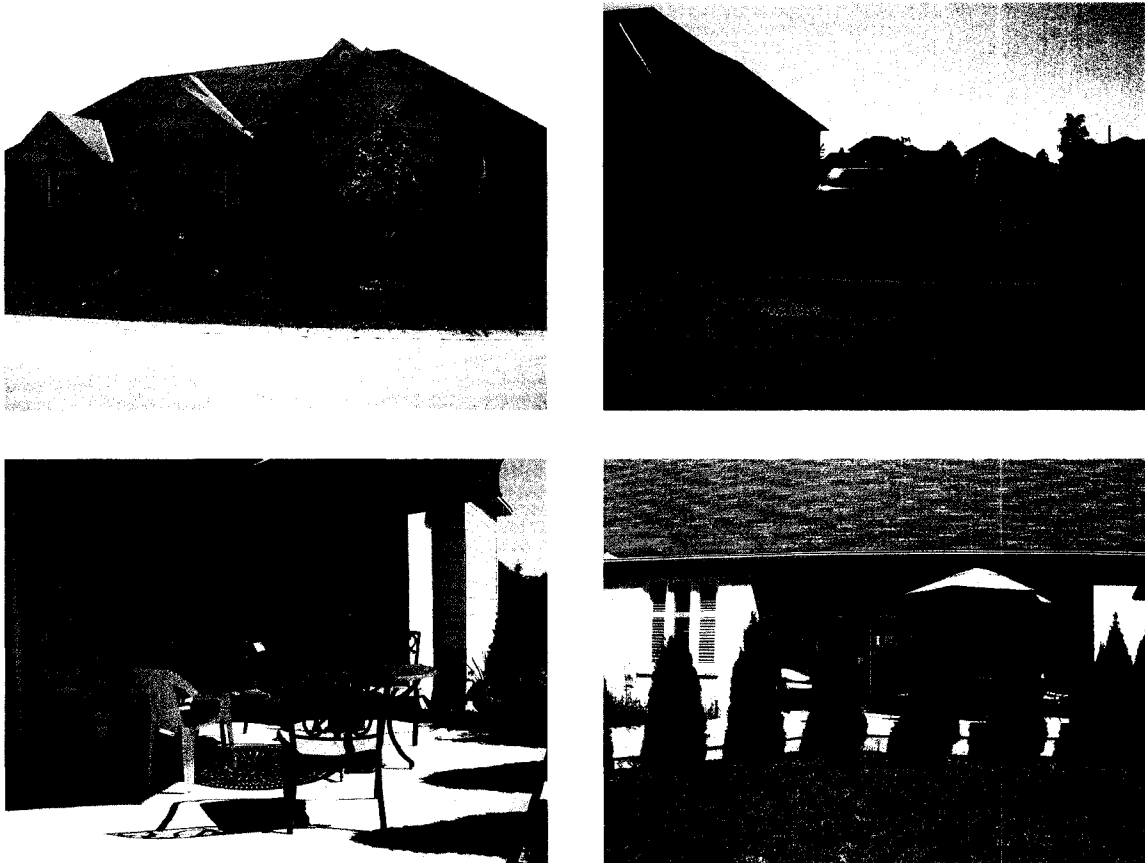


Figure 1. Consumers' home.

disability – the consumers participating in this study – were at various stages of dementia. They were supported by approximately eight staff, both full- and part-time support workers who were providing 24-hour support. The staff rotated in the home according to their shifts; one staff person was awake in the home all night. The home and the staff

were managed by a residential manager who reported to the manager of accommodations in the agency.

Recruitment of Participants

I contacted management of the participating organization and provided them with an information and recruitment letter describing the rationale of this study (Appendix G). During subsequent meetings with the executive director, manager of accommodations, residential manager of the home, and manager of person-centered planning, I gathered basic information about the context of the research environment. Together, we discussed the demographics of people served by the agency, identifying how family and friends would be involved and which direct-care staff and other stakeholders might participate.

In addition, we explored questions about which residents would be participants in my research, the accommodations required to engage these individuals in the research process, including interpreters for peers participating in interviews, and the role of these interpreters. Further, we established procedures for accessing informed consent, introducing the role of the researcher in the unstructured observation setting (e.g., issues of access to the home, privacy, and intrusion while the researcher is in the home) and addressing sensitive information I found during my observations. The collective process of discussing critical information and establishing procedures with key informants, together with the results from piloting the semistructured interview schedules and sampling from my participant observation, assisted me in recruiting the sample of participants, designing the methods and protocols of research, and developing questions to be addressed in the main study.

Participants in the Study

The unit of analysis in this study was the single residential facility or home specializing in dementia support. I obtained data from a nonprobability purposive sample (Powers, Meenaghan, & Toomey, 1985) of stakeholders, including the four people with a dual disability residing in the home, their families or close friends akin to family currently active in their lives, their direct-care staff, agency administrators involved in the operations of the home, and their peers with intellectual disabilities being supported in other residential facilities or independent living by the agency.

A representative cross-section of the above consumers and stakeholders involved a total of 20 participants including four individuals with a dual disability, four family or friend caregivers (hitherto referred to as *family caregivers*), four direct-care staff, four administrators, and four peers with an intellectual disability supported by the agency. These individuals were identified and recruited through the agency by taking into consideration their understanding of the rationale of the study, their understanding of their involvement as participants and that participation was voluntary, and their ability to participate and give consent by themselves or by proxy.

During my consultation with the agency, the management indicated that consumers with a dual disability who would be invited to participate in this study would not be able to participate in an interview that required any measure of cognitive and verbal functioning. Therefore, I sought to better understand their history of living before dementia by interviewing four of their peers with an intellectual disability who had experiences in community living. However, when I analyzed interview transcripts, I realized the themes in the data collected from these peers did not answer the main research question and the three secondary questions of this study. In order to report on

those themes that directly related to the research questions, I decided, in consultation with my dissertation committee, to exclude the peer interview findings from this dissertation.

Table 1 indicates the characteristics of the participants whose data are included in this dissertation and form the basis of the findings of this research study.

Table 1
Characteristics of participants in the study

Participant	Age Range	Gender	Years in Home	Status
Consumer	49 – 59 yrs	25% male; 75% female	1 – 5 yrs	1 lived in supported independent living; 2 in group homes; 1 in family home
Family Caregiver	30 – 80 yrs	25% male; 75% female	N/A	1 parent; 1 sibling; 2 friend
Direct-Care Staff	≥ 18 yrs	100% female	9 mths – 6 yrs	2 full-time; 2 part-time
Administrator	30 – 60 yrs	25% male; 75% female	N/A	1 ED; 1 Mgr; 1 Supv; 1 PCP

Individuals with a Dual Disability

Four consumers with a dual disability were selected for this study. The staff reported that all these consumers were in the early to middle stages of dementia. The consumers, three female and one male, all between 49 and 59 years of age, had been living in this home for no less than one year and no more than five years. Their perspective in this study was critical to understanding their experience of living with dementia in a home specializing in dementia support.

Family Caregivers

Management identified four caregivers as next of kin for each consumer and primary contacts as substitute decision-makers. Three were female and one was male, aged between 30 and 80 years old. Two of the four caregivers were family – a sibling and a parent. The remaining two were significant friends who were akin to family: “she is like my sister. ... My family has just taken in [name of consumer]; she is like our family.” One significant friend who was a volunteer in the agency was invited by the consumer to become her friend and next of kin; the friend said, “We have been seeing each other for years and years on a volunteer basis. ... It’s just truly a friendship and now she is truly part of our family ... I am her next of kin.” The perspective of family caregivers is unique as they have intimate knowledge about individuals with a dual disability that, according to one family caregiver, “comes from the heart [as] I know every move she makes.”

Direct-Care Staff

The four staff that participated in this study, and represented the perspective of direct-care staff were all female and over 18 years old. Two were full-time staff and two were part-time staff, with length of service in the home ranging from 9 months to 6 years. The direct-care staff were developmental service workers hired by the agency to provide support in this home. They had training in providing assistance for daily living and community participation; administering medications, creams, special diets and tube feeding; implementing health protocols (e.g., for seizures); and providing first aid and cardiopulmonary resuscitation (CPR) responses. For health issues, dementia-related or otherwise, the staff sought the assistance of professionals in the community health system. When a resident was hospitalized, staff assisted in the hospital with nursing duties.

The perspective of these staff members was significant as they were intimately involved in the day-to-day support of the consumers in this study. As well, they had supported people with intellectual disabilities prior to the onset of dementia.

Administrators

The four administrators who participated in this study were involved in program development, person-centered planning, management of the home, and supervision of administrative functions and staff. Their involvement with the consumers varied according to their responsibilities; they might be directly involved with the home and its residents as infrequently as a couple of times a year, or more often if required.

Three administrators were female and one was male, all aged between 30 and 60 years. All four administrators had been with the agency for at least 5 years and their perspective was important to understand the influence of funding and policy considerations in the support of people with a dual disability.

Naming and Profile of Consumers in the Study

The results reported in the findings are supported by quotations from participant interviews, field observations, and notes from daily logs kept by the direct-care staff. All quotations are identified by their group source (family, direct-care staff, administrator, observation notes, or documentation). In the case of block quotes, the specific speaker is identified. When referring to consumers who were part of the field observations in this study, pseudonyms have been used. I prescribed these names when writing the draft thesis to protect the identity of the consumers. I recognize that people who are closely connected to the consumers (e.g., family caregivers, direct-care staff) will be able to identify the consumers from their descriptions. However, I felt that the use of pseudonyms was appropriate when reporting the study to a broader public. For the final

draft, family caregivers were given the option of changing these pseudonyms (see “Participant Feedback” form in Appendix H). All these caregivers decided to use my chosen pseudonyms of Donna, Jenny, Jim, and Rose. Following is a brief description of the lives and characteristics of each of the consumers who participated in this study:

Donna. Donna was 56 years old at the time of the study. She began to experience the first symptoms of dementia in her early 50s, and had been living in this home for five years. Donna is an only child and was born with Down Syndrome. Like her peers in her era, she spent her early years at home with her parents and then moved to an institution. Later in life she moved into group living in the community. Donna was described as a very friendly, affectionate, outgoing, and openly loving person.

Before dementia, Donna worked at a sheltered workshop and was said to have a very strong work ethic. She also participated in day programs and integrated community programs for leisure and recreation. Donna liked responsibilities such as cleaning up, making tea, assisting with meal preparation, and grocery shopping. She was particular about her personal hygiene and privacy and was able to take care of herself with little support.

About twenty years ago, Donna asked a volunteer in the agency to become her close friend. This friend became her weekly companion, accompanying her when Donna visited her only relative in Canada, her mother. Donna also had some connection with extended family members who lived abroad, receiving cards from them occasionally. When Donna's mother died, Donna's friend included her into her own family and became her next of kin. According to this caregiver friend, Donna had a big circle of friends

because of all the places she had lived where she had enjoyed socializing, celebrations, music, singing, dancing, movies, watching television, going to the theatre, and travel.

Jenny. Jenny was 50 years old at the time of the study. She began experiencing early signs of dementia in her mid-40s. Jenny was one of two siblings and was diagnosed in her early years as having an intellectual disability. In her childhood, she lived with her paternal family in Europe and came back to Canada when she was 19 years old. Jenny stayed at home with her mother and attended day programs until she turned 26, when she went to live in a group home, as a way for her family to secure her future should her mother and only relative in Canada no longer be able to support her. She moved a couple of times before settling into a bungalow with two ladies with physical disabilities. At the onset of dementia, Jenny moved to her current home. She had been living in this home for about one year at the time of the study.

According to Jenny's caregiver, she had made one friend who had been originally hired to take her out once a month. This person has stayed in touch with her, visiting on special days. As well, Jenny has family friends whom she visits at seasonal gatherings and a sibling and grandmother abroad who are in touch with her.

At the time of the study, Jenny enjoyed music, walks, going for drives, eating at a restaurant, and being helpful in the kitchen washing and drying dishes. She liked arranging closets and folding clothes. Jenny regularly went to the day program she had attended for several years. Jenny communicated mostly by behaviour using nonverbal and limited verbal cues together. She indicated her like of a person or interaction when her face lit up with a smile. She was unable to articulate what it was about it that she

liked. Jenny was pleasant to have around and had always needed assistance with personal support.

Jim. Jim was 49 years old at the time of the study. He was a middle child of three siblings and was born with Down Syndrome. At the age of 14 months Jim became deaf after becoming infected with German measles. When Jim was 8 years old he went to live in an institution. At the age of 14, Jim showed an aptitude to learn and was moved to a smaller facility with an educational component. When Jim turned 18 he moved to an adult residential facility with apartment complexes housing four to six people each. Under the guidance of a counsellor, he learned life skills such as cleaning, cooking, shopping, travel, and sign language in preparation for living in a group home. Jim then resided in group homes and for almost eight years lived on his own in apartments with limited supervision. During this time Jim began working in sheltered workshops for silk screening and making canvas bags. He continued to participate in this workplace at the time of the study.

From the time Jim had moved out of the family home his parents and siblings had maintained regular visits, during which they engaged in ritual family activities such as going to church, dining, and sharing celebrations. According to his caregiver, Jim had an outgoing and pleasant demeanour always keen to learn different things. He “liked to just sit and doodle, copy notes and words to a page.” He liked to collect stacks of paper and flyers and spent hours tearing pieces of paper so he could have little piles to make into notepads. He liked bowling, movies, trips, and social functions, eating out at restaurants, watching hockey and wrestling, and spending holidays with his family.

Jim began to experience early signs of dementia in his late 40s while he lived alone in the community. Concerns for his safety in his apartment and concerns that he might get lost out in the community prompted first a brief stay at a group home and then the move to this home about a year prior to this study.

Rose. Rose was 59 years old at the time of the study. She was an only child born with Down Syndrome. Apart from a few years living in a group home and a convent where she learnt some daily living skills, she spent most of her life at home with her parents. When living with her parents, Rose did not agree to go to day programs, choosing instead to spend her time at home. After Rose's parents died she continued to reside in her home with the family caregiver who had taken care of her father since 1987. Rose became included in the activities of that caregiver's family.

According to that caregiver, Rose could say a few words, write grocery lists and help with chores in the house. She was a "fashionable young lady" and liked everything to be tidy and in its place. Some leisure activities that Rose enjoyed were music, dining at restaurants, going swimming, walking, shopping, socializing at the senior's club, watching board games, being at family gatherings at Christmas, and spending summers at the family cottage. While Rose had an active life, she did not appear to have any friends of her own but friends of her parents and caregiver had become her friends.

Rose began to experience early signs of dementia in her mid-50s. This, together with the aging of her caregiver, prompted planning for aging services. Rose stayed in a nursing home for two months and then moved to this home. She had been living in this home for almost two years at the time of the study.

Role of the Researcher in the Home

My role as researcher was that of both an observer and a participant involved in the central activities of this home (Pretzlik, 1994). I used verbal and written communication to explain my role and the reasons for my presence in the home to the people involved with the home. These individuals were participants in the study or affiliated with the home in their roles as caregivers, service providers, and visitors. The direct-care staff assisted me to explain my role and presence in the home to the consumers in the study depending on the mode of communication they used. I immersed myself with the staff in the home, participating in routine activities such as watching television, preparing and serving meals, conversing with the residents, and accompanying them in the community for individual and group outing. I sought direction from the administrators and staff to limit my involvement in private areas in the home and to determine the hours of my shift.

Research Design

I conducted the study in three phases: (a) planning, (b) gathering data through interviewing or observation of participants recruited for the study, and (c) reviewing records pertaining to the consumers observed. In the preliminary phase of planning, I gathered background information such as the history and mandate of the organization, its programs and services, a description of the specialized model of support, an inventory of consumers and stakeholders involved in the home, and the overall political-economic situation within the agency regarding the support of people with a dual disability.

As well, I adopted a participatory approach by involving key informants in the identification of key issues that were important to research. Participatory research “aims to contribute both to the practical concerns of people in an immediate problematic

situation and to the goals of social science by joint collaboration within a mutually acceptable ethical framework” (Rapoport, 1970, p. 499). I consulted with key informants on the relevant questions for in-depth investigation in the study, who would participate in the project, and the suitability of the methods of data collection. To design appropriate research methods for the inclusion of people with a dual disability, I followed guidelines for inclusive research collated from practical experience and research studies with people with intellectual disabilities and dementia (see Appendix C).

The tools developed in the planning phase were piloted with a sample of the participants, which involved face-to-face interviews with one family member, one direct-care staff member, and one administrator, and an observation session of a consumer in the home. This preresearch phase allowed me to modify the research tools, but also to refine my own interaction with the participants and the data. At this stage, I developed a relationship with the consumers and stakeholders, became aware of some of my own limitations, values, and biases, and through self-reflection, distinguished my perspectives from other possible perspectives when gathering data for the main study.

In the second and third phases of the study, I explored the research aims in greater depth through my participant observer role, observing consumers as they lived day-to-day. I also examined their written records. As well, I interviewed one-on-one those family members most knowledgeable about each individual’s support, professional caregivers involved in hands-on direct support with the consumers, and administrators involved in the operation of the home.

A participatory approach engaged the stakeholders in dialogue with me in a mutual learning exercise. I learned from the people concerned by empathizing with their

problems, needs, and feelings. The data gathered provided a theoretical extension of knowledge about the service experience in a home specializing in dementia support. I analyzed data based on actual working practices and living experiences of the consumers and drew up recommendations to consider in policy and/or interventions addressing the needs and quality of life of people with a dual disability.

Data Collection

Data collection began in February 2005 and ended in December 2006. From February to March 2005, I made contact with the agency, revised my research tools, and recruited the participants. Interviews commenced in April 2005 and concluded in August 2005. This was followed by participant observation of consumers from August 2005 to October 2005, and then analyzing interview transcripts and field notes from participant observation for emerging themes. In December 2006, I returned to the home to review the documented log notes of consumers kept by the direct-care staff. I used this information to corroborate whether the themes identified by the stakeholders in the study and in the observations were present in the documents. All data was collected over a period of 9 months: 5 months for interviews, 3 months for participant observation, and 1 month for document review.

Table 2 lists major sources of data and corresponding data collection dates. Planning meetings with the administrator and person-centered planner took place at the agency's head office. As well, all administrators and one direct-care staff were interviewed at this site in meeting rooms or individual offices. Three other direct-care staff and one family caregiver were interviewed in the office or basement of the home studied. One family caregiver arranged her interview in a meeting room at her workplace and the remaining two family caregivers were interviewed in their own homes.

Data collection during participant observation took place inside and outside the home studied. The consumers were observed in all areas of the home except in private

Table 2

Principal Data Sources and Collection Dates

Date	Data Source
February 11, 2005	Planning meeting with administrators
March 23, 2005	Planning meeting with person centred planner
March 23, 2005	Pilot direct-care staff interview (DCS1)
March 23, 2005	Pilot administrator interview (A1)
April 13, 2005	Pilot friend caregiver interview (FC1)
April 20, 2005	Administrator interview (A2)
May 5, 2005	Administrator interview (A3)
May 18, 2005	Direct-care staff interview (DCS2)
May 25, 2005	Friend caregiver interview (FC2)
June 3, 2005	Family caregiver interview (FC3)
June 4, 2005	Family caregiver interview (FC4)
June 4, 2005	Direct-care staff interview (DCS3)
June 4, 2005	Pilot consumer participant observation
June 28, 2005	Administrator interview (A4)
August 4, 2005	Direct-care staff interview (DCS4)
August 14 – October 18, 2005	Consumers' participant observation
December 2006	Review of log notes

bedrooms and bathrooms. They were also observed when they spent time in the backyard or went out in the community. For instance, I observed Jim and Jenny at their day programs. I also observed all the consumers when they invited me to go with them in the community (e.g., for haircuts, shopping, eating out, going for a ride, family visiting, attending a senior's centre). In addition, reviewing of consumers' log notes was done in their home as these documents could not be taken out of the premises.

Participant Observation

One aim of this study was to include the voices of people with a dual disability. I made a concerted effort to design pluralistic approaches to research methods in order to include consumers in data collection. Documented studies with vulnerable populations and data gathered in the preliminary phase of this study contributed to this design process. In discussions with key informants, we acknowledged that consumers in this study would be unable to participate in a one-on-one interview format of data gathering. For these four consumer participants, my primary method of data collection, therefore, was short-term participant observation (Pretzlik, 1994).

My visits to the home ranged from 3 to 8 hours in length. Using a "Participant Observation Guide" (Appendix H), I conducted unstructured observations of discrete behaviours that occurred in the residential facility, such as the way the social setting was constructed and used, the way people behaved, and the way people interacted in the space (Mulhall, 2002). I also observed the structural and organizational features of the barrier-free home, the routine and daily process of activities in the home, the flow of visitors to the home, and special events such as activities that took consumers out in the community.

I did not have specific questions in mind when I started observing in the home. However, questions about particular situations arose when I was immersed in the

observation. These questions led me to seek out opportunities to collect data regarding these situations. For example, after entering the home I found that some consumers spent more time outside the home than others. To understand this situation I began gathering data on who went out, why they went out, and what places they visited.

The timing of the visits was varied to observe the various aspects of the individual's daily life during morning, afternoon, evening, and night shifts covering each day of the week and special events that were happening at specific times. The amount of time I spent in the home and the frequency of my visits I determined by the impact of the research intervention on the living environment, comfort levels of the residents, and accommodations possible by the staff and management (e.g., ensuring that staff most able to support the consumers during an observation time were present and taking account of the schedule of the consumer).

Interviews

Twelve participants from the sample group of families of the consumers, direct-care staff, and administrators each took part in one in-depth individual interview. Interviews lasted from 1 to 2 hours, to stimulate dialogue and reflection. Using a semistructured interview schedule (Appendix I, "Family Caregiver"; Appendix J, "Direct Care Staff"; and Appendix K, "Administrators"), I explored the experiences and perspectives of these stakeholders. Among other things, the interview schedule probed in depth consumers' experience of past service before moving to the home, the fit of the current service for the consumers, and different options of good practice models for people with a dual disability.

Although I used a semistructured interview schedule, the stakeholders were allowed to determine the pace of the interview and to share what they deemed to be

significant in their experience (Patton, 1990). Many important issues were raised in the preliminary phase of the study, but new ideas also arose in the first few interviews. I incorporated these new ideas in the interview schedule so that subsequent participants interviewed could provide their feedback on these issues. The intent was not to compare the interviews but to generate as many ideas as possible for analysis.

The interviews were audiotaped to ensure that the information gathered was accurately recorded. I coded the transcripts of the tapes according to recurrent patterns and then analyzed them to generate emerging themes. Appropriate protocols were followed for preserving confidentiality of the data collected.

Field Notes

By keeping detailed notes, I created a trail of my participant observations. The field notes clarified my accounts of what was happening in the observation field, my thoughts on being there as a participant observer, and my reflections on personal life experiences that might be influencing the interpretation of the observations (Mulhall, 2002).

In addition to keeping field notes and making audiotapes of the interviews, I also made videotapes and took photographs of the consumers in the home and in the community, having first obtained permission from proxies (Appendix E). These visual media allowed me to capture images of scenes or situations that I thought might be useful in the future to support my observations of the day-to-day living experiences of a person with a dual disability living in this home.

Prior to completing the final draft of the dissertation, the relevant proxies of consumers and their housemate who was not involved in the study were asked if photographs taken during participant observation could be used in the thesis and oral

presentations. Two family caregivers of consumers provided written consent to use selected photographs in publications and oral presentations and one family caregiver consented to their use in oral presentations only. One family caregiver had given verbal consent over the phone with a written consent to follow; a written consent had not been received at the time of writing. One administrator consented to use in publication and oral presentations those photographs that included the housemate. She also consented to the use of the photographs of the home, both in publications and oral presentations.

Upon consents received from proxies, I consulted with my Dissertation Committee members regarding the inclusion of photographs in this thesis. We decided to only include the photographs of the home, and not of the consumers. The committee members felt that the rich descriptions and my interpretations in the thesis were sufficient to illustrate the profiles and living experiences of these individuals.

Documentation

In addition to using my own recording methods, I also reviewed the log notes kept by the direct-care staff at the end of each shift of work in the home. In a separate journal for each consumer, direct-care staff members describe the general well-being of consumers and their participation in daily living and community activities during the shift. In particular, the log notes document any challenges experienced by the individual during a shift, such as poor nourishment, health issues, behaviour issues, etc.

I reviewed daily logs recorded by staff for each consumer for the months of August, September, and October 2005. These logs reflect the period of time during which I conducted short-term participant observations at the home. Since I was only on site for 3 to 8 hours each time, the log notes also captured times when I was not on site. I noted concrete citations that supported the general themes already found in the interviews and

observation data (e.g., activity in the home, activity in the community, number of visitors, contact with peers/friends, relationship with staff, health issues, etc.).

Data Analysis

This study uses an emergent and interpretive methodology to analyze the experience of the consumers and views of the participants (Creswell, 1998). The data I gathered (from a review of consumer log notes, short-term participant observation, and qualitative interviews using a semistructured interview schedule) presented patterns, common themes, and categories from which I could generate theory (Creswell, 1998). The specific experiences of people with a dual disability were not analyzed according to a priori assumptions; instead, the emergent themes revealed general patterns from which I could develop a theoretical framework for understanding the consumers' experience.

To uncover both the unique and the similar themes raised by the participants, I analyzed the data in several steps. After each interview and field observation session, I recorded in a journal my general impressions that arose during the discussion with the participant and the writing of field notes (Creswell, 1998). This journal itemized the major themes that I initially identified and also included reflections on any researcher bias that may have been evoked during the research process.

At the end of the study, I open coded all the transcripts separately, beginning with the interviews of family caregivers who I assumed were closest to the consumer experience. I entered in the margins memos noting themes of significance, and checked the themes across the respective journal entries completed during the research process. Based on the patterns that emerged, I re-examined the data to adjust the coding as appropriate and to remove any redundancies. I then compared the coded themes from each source of the data (i.e., documents, interviews, field notes) to each other to find

evidence of triangulation and divide into units of information (Lincoln & Guba, 1985).

The final organization of the units of information resulted in a number of themes and sub-themes.

The refined coding scheme I developed defined codes according to themes and insights that emerged from all the data. I then organized the data in this coding scheme using the computer software program QSR NVivo 1.3 (QSR International, 2000). This software generated a table of categories, themes, and sub-themes from across the data. The table provided an analytical tool for rendering a list of categories in which appear similar and unique themes inherent in the experiences of people with a dual disability in the context of a specialized model of support.

When analyzing the data it was evident that there were converging themes across all groups (i.e., family caregivers, direct-care staff, and administrators). The validity of these findings was strengthened when triangulated with field and log notes (Lincoln & Guba, 1985) and formed the categorical findings of the study. It was also evident that there were differences between groups (e.g., between the group of family caregivers and the group of administrators or between what stakeholders said and what I observed). Themes that arose from these differences were highlighted as divergent perspectives.

In some cases, unique themes emerged in the divergent perspectives of members of a single group (e.g., among family caregivers). Even though these findings could not be triangulated with multiple sources of the data, they were included in the findings to provide an in-depth understanding of the case. Detailed and descriptive text from the interviews, field notes, and documents drew attention to the similar and unique themes of interest. The theory is illustrated by the findings outlined in chapters 4 and 5.

Credibility of the Study

I undertook several measures to ensure the credibility of this study. For instance, various processes incorporated in the research supported the authenticity of the data: cross-checking at several stages of analysis between journal notes memos, first coding of the themes, and becoming thoroughly familiar with the data by the end of the analysis (Creswell, 1988; Lincoln & Guba, 1985).

Bond and Corner (2001) suggest that participatory methods such as personal experiences of living with or caring for a person with dementia exemplify how a researcher can gain an intimate understanding of the area researched. I believe that, having established a working relationship with CLL as an employee and, specifically, as a residential counsellor in this home, I have brought a useful “insider” perspective into the issues of people with a dual disability. My familiarity with the culture and means of communication of these individuals has made the interpretation of the data more salient.

Nevertheless, to prevent my prior knowledge and experience with the agency from interfering with the data and my interpretations, I continuously debriefed with my thesis supervisor, who acted as a “devil’s advocate” (Lincoln & Guba, 1985). This regular interaction kept me in check so that I could curtail my bias when interpreting the findings. I also checked for bias during data interpretation by verifying my findings with my peers and editors.

In addition, I make my social location explicit in the description of the study so as to further curtail a biased representation of the findings (Merriam, 1988). During data collection, I regularly sought feedback from the staff on site to verify my understanding of the scenes and situations I observed. Their feedback reduced the possibility that I, as

the sole researcher, might be misinformed about an event and misrepresent it (Creswell, 1998), and strengthened the authenticity of the data collected.

Further, the study incorporates the voices of different sources to corroborate my understanding of the consumers' experiences. Lincoln and Guba (1985) state that trustworthiness of research findings is increased in a multiperspective approach in a case study. Triangulating data from different sources verifies the credibility of the major themes that emerge. These attempts to ensure the credibility of this study are combined with in-depth information bounded by local situations gathered in this dissertation. Rich, thick descriptions (quotations and illustrations), assist the reader in determining the authenticity of this study and contemplating the transference of this study's method and findings to other similar settings.

My understanding of the consumers' experiences was also corroborated by member checking with the stakeholders (see Appendix L). In January, 2008, I returned transcripts, findings, and my research conclusions to the stakeholders so that they could check for the accuracy of the findings (Stake, 1995). The stakeholders were asked to comment, modify, or exclude information they felt did not represent their account of the experiences of consumers living in this home. Seven out of twelve stakeholders (three family caregivers, three administrators, and one direct-care staff) provided written feedback on the form provided. One administrator who responded also shared the thesis with a person-centered planner in the agency who was not a participant in this study. This person also provided written feedback. Three stakeholders (a family caregiver, administrator, and direct-care staff each) were unable to provide feedback due to time constraints. Nil response was received from two stakeholders (direct-care staff).

Stakeholder feedback on the findings of this study was primarily positive: “I thoroughly enjoyed all aspects of your thesis;” “It is certainly an accurate reflection of Donna’s condition/situation;” “You did a great job with it;” “[It] does reflect my situation;” “Yes! I agree more financial support is needed.” As well, the person-centered planner who was not a participant said the document provided “a very good description of the unique features of the support setting and care network.”

The stakeholders also offered alternative descriptors to use in this thesis. For instance, I was advised that the term “dual disability” is not consistent with the practice and terminology used at the agency. Instead, the term used is “dually diagnosed with Alzheimer’s and Down Syndrome.” As well, the home studied is not referred to as the “dementia home,” but just as, “the home.” In consultation with the relevant stakeholders who provided feedback and my Dissertation Committee members, the term “dual disability” is retained in this document with a qualifying footnote. Also, the home studied is referred to as “the home” or, when it is necessary to make a distinction, “the home specializing in dementia support.”

Limitations

This study was limited by its methodological approach, the use of a collective theoretical lens as a framework, and the lens of the researcher. Regardless, I submit that it has the potential to transform knowledge.

Methodological Approach

A major methodological limitation of this study was my inability to communicate with the consumers in this study to get an in-depth understanding of their living experiences with dementia and in this home. In the planning phase of the study, key informants provided feedback on the tools that I had already prepared for interviewing

and participant observation. Based on these tools they stated that the consumers could not participate in an interview process that required length of focus (i.e., 1 – 2 hours) and command of speech. It was, therefore, agreed to collect data from consumers using participant observation.

In hindsight, I wonder what knowledge key informants might have provided if I had asked how formal and informal service providers communicated with the consumers. It was evident to me during periods of observation that they did communicate with each other, understand each other, and accomplish tasks together. Therefore, a dialogue on how a researcher could communicate with the consumers might have yielded creative options.

Depending on the suggested method of communication and process of gathering information, it is likely that I would have had to modify the methodology I had proposed to use. For instance, if each individual communicated through a different medium, or if it was necessary to be immersed in the environment for communication to occur, an ethnographic study with one individual might have been appropriate. At the same time, I would have required the time and training to develop my expertise in the communication medium used by the individual before I could commence the study. Nonetheless, the understanding I did gain in this study was deducted from the views of other participants who were witnesses to consumers' experiences and also from those participants' interpretations of what I observed in the home.

Also, I cannot generalize the findings of this study; they are limited to the experience and perceptions of the sixteen participants within the one agency where they worked and lived or with which they were associated. Although common themes raised

by all participants in this study are reported in the findings, the sample of consumers was small. A bigger sample is required to generalize the experiences of the participants in this study to the dual disability population (Lincoln & Guba, 1985).

Theoretical Lens

Another limitation of the study is the interpretation of the data using a collective theoretical lens as a framework. While participant quotes supporting the emergent themes confirmed the interpretation of the data, the multiplicity of lenses, perspectives, and subjective truths about a complex human condition challenge that interpretation. Such an interpretation, therefore, requires the excavation of possibilities within the multiple conditions stemming from an array of interactions that happen in an intricate environment coloured by our imagination.

It is not possible to delineate specifically when, how, and where influences such as social, political, economic, researcher bias, and so forth, have an impact upon the interpretation of people's experience who live with a dual disability. To sufficiently contemplate multiplicity, we need to draw our imagination away from the idea of a continuous and universal history of a "fixed and timeless" human nature (Rajchman, 1985, pp. 3-5). This frees us to excavate pluralities, subjective knowledge, and changing practices and question particular systems of thought. However, this exercise is in itself limited by the lens of the analyst.

The Lens of the Researcher

As an analyst in this study, I am bound by my subjective experience when interpreting the data. The act of deciphering how I have filled my imagination about a certain construct requires an intense mental exercise; my perceptions have become

“caged” within multiple bodies of knowledge. I am compelled to draw my imagination away from my current understanding of a construct and ponder

... this wordless thing in an empty place, a hard shut dry cold black place, where nothing stirs, nothing speaks, and that I listen, and that I seek, like a caged beast born of caged beasts born of caged beasts born of caged beasts born in a cage. (Beckett, 1965, p. 386)

My “cages” are my historical self: an ethnic woman, born and raised in an Eastern culture; a product of colonization; an immigrant to the West though not by choice; a migrant within the West by choice; a holder of cultural heritage including Islamic faith and community traditions; and an inhabitant of three continents who has transitioned through the South Asian, African, European, and North American cultures. These facts of my background present a unique lens for the interpretation of every condition explored in this study, including the concept of dual disability itself.

With this layered persona, I have attempted to interpret the concept of disability as it has evolved in the West. In fact, my very viewpoint of the West is framed by my experiences of colonized life in the Third World, knowledge acquired while living in the West, and experiences gained while navigating between the Eastern and Western cultures. This broader landscape includes my social location (see “Social Location of the Researcher” in chapter 1) on the issue of disability and aging as manifested in recent years in Canada in my work and personal spheres. Hence, this work is limited by at once a diverse and yet a single interpretation that is unique to my life experience.

Foucault, in “What Is An Author?” (1977) acknowledges that an author resides in a “transdiscursive position” (p. 131). The author is “but a vehicle that claims and extends a particular intersection of the thinking of that period” (Chambon, 1999, p. 51). As not only the researcher but also the author of the findings presented here, my transdiscursive

position is influenced by my social location and limits my interpretation of the data in this study.

Transforming Knowledge

While I recognize that my perspective dominates this work as a matter of course, it is by no means an exclusive and permanent view. While the unique view of the researcher is a limitation, it also presents one of many possible perspectives; it attempts to disturb the ground and to create knowledge that could transform thought and contribute to new perspectives. Indeed, this effort is tied to a firm belief by Foucault that transformative knowledge requires the act of disturbing, because

it ruffles the smoothness of our habits, rattles our certainties, disorganizes and reorganizes our understanding, shakes our complacency, unhinges us from secure moorings. It is serious and “dangerous” work. ... The aim is not to destroy but to redefine and reorient what we do and what we know. It is a commitment to transformation (as cited in Chambon, 1999, p. 53).

Hence, to refine and enrich this work, we must engage in a collective and evolving process of radical questioning to understand the social phenomenon of dual disability at a deeper level in all its complexities and all its possibilities. Irving (1999) attests that “transgressive counterdiscourses, an endless questioning of the systems of thought in which we are located ... [open up] realms of freedom accomplished through speaking the truths of the multiplicities that traverse the self” (p. 43). In this manner, I invite the reader to challenge the limitations by which this study is bound by actively engaging, questioning, interpreting, assigning meaning, and transforming the knowledge arrived at within the context of my personal boundaries, life influences, and data that are all embedded in this case study.

Summary

This chapter has explained the methodologies of doing a qualitative case study using a grounded theory approach to data analysis, pointing out the validity of the research collected. Three data collection methods (interviews, observations, and documentation) have allowed for multiple perspectives to inform the research question. A profile of each consumer has shown the uniqueness of their personalities even though they are immersed in the common experience of dementia. Both ethical considerations and the limitations of the study, as well as the measures taken to achieve authenticity and trustworthiness of the research have concluded the chapter. The next two chapters outline the findings of the study that contribute to empowerment theory.

CHAPTER FOUR

Findings: The Social Process of Marginalization

In this study, I sought multiple perspectives to understand the experiences of people with a dual disability living in a home specializing in dementia support: (a) family caregivers, (b) direct-care staff (also called *support workers*), and (c) administrators. All of these perspectives were evident in stakeholder interviews. My perspective is evident in field notes I took on observations of the four consumers with a dual disability living in the home. I also analyzed notes from daily logs kept by support workers to support the themes evident in the data.

In this chapter and the next, I report on similar (or convergent) and divergent themes that emerged from my findings combined with some first level interpretation. The themes are supported by quotations from interviews, field notes, and support workers' log notes. Quotations from observations (or field notes) and documentation (or log notes) are stated as such. When using stakeholders' quotes from interview data, only a general reference is made to the member group in the text of the reporting; a specific source or notation of the speaker is not provided. Rather, quotes represent stakeholders collectively when the majority of them concur on a theme. Individual groups of family caregivers, direct-care staff, and administrators are mentioned when majority members within these groups concur on a theme. Where relevant, I have indicated if all members in a group or only one member of a group supports a theme represented by quotations.

When using block quotations, however, the specific source is provided. The source is identified at the beginning of the quote as FC1-FC4 for family caregivers, DCS1-DCS4 for direct-care staff, A1-A4 for administrators, FN for field notes, and LN

for log notes. As well, I use pseudonyms (accepted by family caregivers) when referring to the consumers I observed: Donna, Jenny, Jim, and Rose. I use the same pseudonyms in quotations from log notes and interviews.

In this study, I particularly wanted to understand the needs of consumers, how these needs were met in the home, and how this social model of support was perceived by both family and formal (paid) caregivers. When I analyzed the data, three major categories emerged concerning the living experiences of people with a dual disability which I named: (a) death by reduction, (b) living by supported empowerment, and (c) barriers to supported empowerment.

First, *death by reduction* reflects a social process of marginalization inherent in life-changing events after the onset of dementia. These events present new needs for the person with a dual disability evident in three life domains: ability, home, and community. Second, support people facilitate a social process of *living by supported empowerment* in response to the new needs. This second social process, which will be discussed in the next chapter, counters the first by creating conditions that sustain ability, home, and community. Third, the social process of living by supported empowerment is constrained by weaknesses in service provision. *Barriers to supported empowerment* interfere with the empowerment of consumers in this study and risk the remarginalization of these individuals. I will now discuss the three categories, beginning in this chapter with death by reduction.

Death by Reduction

After the onset of dementia, all family caregivers, direct-care staff, and administrators (collectively referred to as *stakeholders*) described traumatic changes in

health, living conditions, and community participation that impeded the consumers' ability to continuing living full lives. Profound losses in mental and physical functioning led to progressive decline in skills and in ability to care for oneself, problem solve, and stay safe. Declining abilities required changing the living environment. As a consequence of changes in the living environment, the quality of community life declined and health progressively deteriorated, resulting in death.

An administrator described the declining effects of dementia as "*death by a thousand reductions*." I, therefore, adapted this phrase to name the social process of marginalization that reflects losses after the onset of dementia. Table 3 illustrates the themes found in the major category of death by reduction that leads to disempowerment.

Table 3

Major Category: Death by Reduction

Loss of ability	Loss of home	Loss of community
Mental decline	Supported independent living	Diminished participation in community activities
- Seizures	Family home	Shrinking social networks
- Fear	Group home	
- Confusion	Nursing home	
- Forgetting		
- Fluctuating moods		
Physical decline		
Dying and death		

Disempowerment falls into three themes: (a) loss of ability, (b) loss of home, and (c) loss of community.

The themes and sub-themes indicate that physical and mental decline come from the disease itself, while loss of home and community are compounded by the actions of interactions with them. For instance, how the immediate community and society at large respond to the changing needs of people with a dual disability marginalizes them by displacement from their homes and exclusion from community activities. Although dementia is a terminal disease, the stakeholders said that death can be hastened by healthcare providers' actions that isolate the individual from community. I will now elaborate on each of the thematic findings, beginning with the first main theme, Loss of Ability.

Loss of Ability

Prior to the onset of dementia, all stakeholders said that the consumers in this study needed minimal support to live full lives in the community. According to them, consumers "were able every day to get up and go to work or to a leisure program" and perform many of daily-living activities independently, such as handling money, taking buses, shopping, setting the table, bed-making, personal hygiene, and house cleaning. Two worked daily at a segregated sheltered workshop, one attended a segregated day program, and one spent her daytime in family activities.

In addition, the individuals enjoyed an array of group activities of their choice: volunteering, adult learning, watching movies, art classes, church, Christmas holidays with family and friends, and singing; as well as leisure activities: going to dances, swimming, bowling, ball games, hockey games, art and crafts, theatre, and eating out.

These activities had been rich with social connections and had created many special friendships with peers, friends of family, and support people.

The first postdementia reduction that marginalized the consumers was, according to stakeholders, declining ability to think and do for oneself. Decline in these abilities, being sudden, sporadic and insidious, made a clear medical diagnosis of dementia problematic. Stakeholders said that, while dementia was not confirmed by a medical diagnosis, they were left to “assume it is the Alzheimer’s” until consistent, long-term evidence of deterioration, backed by a medical opinion, confirmed the condition.

Nevertheless, all stakeholders reported that they noticed certain signs as consumers progressed through dementia. Early on, they lost ability in nonroutine activities, such as learning and retaining new information. As well, stakeholders said that signs of dementia differed among individuals, and the level of ability varied according to the stage of the disease. Individuals were able to maintain some independence in the first stage; then gradually became totally dependent on caregivers in the third and final stage. Irrespective of differing experiences of dementia, all stakeholders confirmed that the disease inevitably results in significant mental and physical decline, followed by death.

Mental Decline

Stakeholders mentioned various signs of dementia-caused mental decline, such as seizures, fear, confusion, forgetting, and fluctuating moods. They explained how each of these conditions impacted the consumers’ daily life and the people in their living environment.

Seizures. Seizures were an early sign of dementia. Rose’s family caregiver described them:

FC1: ... after we made the arrangement to go to [name of home] she had the first seizure she had ever had in her life. ... Something that never, ever happened before; that I think might have been the catalyst that everything went downhill.”

Seizures persisted throughout the progression of Donna’s dementia, varying in type and duration but seeming to escalate as the disease advanced. As I arrived at the home one morning, I noticed from the hallway that Donna, in the middle stage of dementia, was not looking her usual self:

FN: Donna is sitting up in her bed. Her bedroom door is open, and the light is on. Staff member says she is sleeping and often sleeps sitting up ... I notice that Donna’s left hand is jerking up. Staff member says that this is one of her pre-seizure activities.

A short while later the seizure became complicated by a fall. This field note depicts how the seizure impacted Donna, triggered an urgent response from staff, and affected Donna’s housemate Jim:

FN: At 8:00 a.m. Donna comes out of her room and is walking through the living room. Suddenly we hear a thump. Two staff members run to her in the living room. Donna is sitting on the floor, looking disturbed and confused. Her left side is still jerking. Staff member explains to me that it is common for people with dementia to lose their balance and fall. ... The two staff members decide that they will lift Donna from the floor using a mechanical lift.

Jim comes in the living room. He is dressed ready to go out. He seems really worried about Donna. He seems to want to assist with the lift. A staff member asks him to step aside. He sits down on the sofa and watches what is happening.

Staff gradually lift Donna off the floor and position her in her wheelchair. Donna is calm and responding to staff, who is talking to her, telling her what she is doing and asking if she is okay. Donna looks disturbed and is very quiet through the whole action. A staff member asks her again if she is okay. She replies in a crying voice, “Yes!” She is still having the jerks. Staff states it is unusual for Donna to be so quiet when being moved into a wheelchair. Usually, she will argue and resist intensely about going into the wheelchair. ... A staff member wonders if Donna herself realizes that she is not safe and needs the wheelchair.

At 8:15 a.m. Donna is still jerking in the wheelchair. A staff member sits in front of her and feeds her the meds with some pudding. She continues to talk to Donna, asking her if she wants some pudding. Donna says, "Yes." A staff member feeds her a can of supplement drink. Donna seems thirsty, and she readily takes her drink through a straw. A staff member says to Donna, "How was that? Was that okay?" She says, "Yeah."

At 8:20 a.m. Donna asks to go to the bathroom. One staff tries to wheel her but finds that the wheelchair is stiff and doesn't move smoothly. She says to the other staff that they can assist her to walk to the bathroom. They undo the wheelchair belt. Donna gets up saying, "Eh, all done!" The staff member assists her as she walks to the bathroom.

For the rest of the morning, staff supported Donna with her routines (shower, breakfast, and snacks) and continually monitored her. Minor, intermittent jerks in her left hand and face lasted for an hour. Periodically, staff checked in with her, asked if she was okay, and waited until she responded positively, "Yeah. Better!" They noted her confusion and the moods that accompanied the jerking, moods ranging from weepy to smiling. They engaged her with her favourite activities: singing, clapping, and listening to the radio. Donna gradually settled back into her normal self as the day wore on.

Fear. Fear took various forms, as direct-care staff explained: fear of the dark, fear of the seasons, fear of the temperature, and fear of water. One direct-care staff said, "... the individuals we have now and the individuals who have passed away, everyone has developed their fear of water. As soon as the water touches them ... it's an instant fear." Fear of water meant "gasping for air ... when showering" or no longer being able to enjoy water activities, such as swimming and going to the beach.

I often observed fear of the dark. One evening, Donna seemed happy and excited as she lounged in the living room with her housemates, watching a TV program on popular songs. As night drew close, a housemate walked over and closed the shutters on the living room windows. Another housemate protested but the one who closed the

shutters kept them closed. At this point, I saw Donna's mood change, from happiness to distress:

FN: Donna walks towards me, looking like she is about to start crying. She yells, "It's happening again!" It seems like she is afraid of the dark. A staff member puts all the lights on and, just then, the music on the TV starts up. I take Donna by her hands and start dancing to the music. Gradually she begins to relax and starts to dance to the music. She continues dancing by herself to the end of the song. When the song ends, she does not seem to be comfortable to stay in the living room. She decides to go into her bedroom.

Although Donna seemed to seek comfort in her bedroom, her family caregiver described how, for almost a year and a half, Donna had been afraid of her bedroom: "She used to love her room, and then she went through a time where she was afraid of her room. She wouldn't go into her bedroom, and she wouldn't sleep." Hence, fear affected Donna's sleep and also stopped her from participating in activities beyond the home. A direct-care staff said, "She is afraid to go out. She used to go to the mall and walk around. Now she doesn't even want to go out of the house, go in the van."

Confusion. Confusion was another common sign mentioned by stakeholders. An administrator said, "They might be cooking with vinegar or putting stuff in the closet that should go in the fridge." Confusion also entailed mistaking one thing for another or losing track of one's place in time. The person "didn't know where she was" and had no sense of time, wondering, "Is it day? Is it night?" Confusion translated into daily disruptions in sleeping patterns and mealtimes.

Jim, in the middle stage of dementia and with a hearing impairment, continued to go to his community activity program whenever he desired. The employment duties and routines in this place were familiar to him, as he had gone there almost every day for the past several years. However, one day when I observed him at work, Jim was confused.

He had arrived at work at 10:00 a.m. At 10:40 a.m., instead of working at his desk, he sat in the kitchen:

FN: Staff sees Jim is in the kitchen eating his Pizza Pops. She says to him, “You’re eating your lunch already? It’s not time!” She turns to me and asks if I saw him heat his lunch up. I say, “No.” She feels the Pizza and it is cold. She asks Jim if he wants to heat it up. He seems to motion, “It’s mine.” She asks if he wants to put it away for lunch, signing to him, “Later.” Jim signs back, “Yes, later.”

Jim’s confusion about times and activities meant that he could no longer participate in scheduled employment activities as he used to. As well, he needed additional supervision and support from staff at his workplace to attend the program.

Forgetting. All the stakeholders identified another sign of dementia, memory loss, which significantly affected individuals’ physical functioning. A direct-care staff explained the challenge for a person with dementia who forgets how to walk:

DCS1: She knew she wanted to stand up. She kept trying to stand up. She would yell at you to help her stand up. And then she would get scared halfway through and sit back down, and push herself to the back of the chair. So she spent the day in the wheelchair, and she felt upset about it. And I felt awful, because I knew she was walking yesterday, and I knew she was walking earlier this morning. But for some reason she couldn’t get up. She was forgetting how to walk.

Donna’s family caregiver described the impact of Donna no longer recognizing loved ones:

FC2: Now it’s dramatically different. [Before the onset of dementia,] you’d come to the door, and she’d run to the door and greet you, hug [you], and [be] very open and affectionate. Where now, there are times when she won’t necessarily know who I am.

However, all stakeholders said that general memory decline seemed to be interspersed with sudden, impromptu moments of clarity. In these moments, the person with dementia appears to “understand what is going on. They know who you are, and they are happy, laughing and talking about things that happened.” However, “the next

second, they want to know who the hell you are and what you are doing there.” In general, trauma caused by accumulating mental deficits as the individual progresses through dementia led to another significant sign, fluctuating moods.

Fluctuating moods. As the consumers’ mental health declined further, stakeholders witnessed fluctuating, unpredictable mood swings, sometimes accompanied by aggressive behaviour: “People can become aggressive, yell and scream,” and become “somewhat moody ... with sudden bursts of crying, anger, and happiness.”

Mood changes not only impacted caregivers but also peers living in the home. On one occasion, a staff member documented Jim’s concern: “Jim appeared very concerned when peer began acting out. Jim comforted staff. Staff reassured him that it would be fine.” As well, a direct-care staff explained the struggle for peers who see the impact of dementia on their housemate or are at the receiving end of aggressive moods:

DCS3: It’s a struggle for these guys, too, living in the home. Some of them can grow very fond of each other ... and for them to see their roommate not being able to go on an outing with them, or ‘Why is so and so yelling at me?’ And then not getting it that the Alzheimer’s is setting in and, ‘She’s not meaning to yell at you, because she doesn’t know who you are.’

Invariably, mood swings appeared to communicate that something was wrong. On some occasions, the consumers were able to clearly articulate their reason for crying, as I observed: “Shortly after eating, Donna began crying and pointing to the picture of [name] by the front door.” In this situation, it was obvious that Donna was expressing grief for a dear friend and housemate with dementia who had passed on.

In other cases, the consumer was able to seek help for her distress. A family caregiver said that, when Jim was living independently in an apartment, he began to seek help for not feeling well. As a result, he sometimes called for an ambulance:

FC4: ... the landlord would call me and say, 'We think he is okay.' Because, when the ambulance came, his face would light up. He got the attention he was looking for. They would take him to the hospital and check him out, and then send him home. ... That's how he was able to get the attention he was looking for.

There was no apparent reason for Jim's call for help, but it is likely that he was experiencing the first stage of dementia, feeling anxious or just lonely. His mood change when the ambulance arrived seems to indicate that he felt relief.

However, many a time the consumer was unable to articulate what was wrong and unable to seek help. A direct-care staff said, "This one lady came up to me, and was crying. And I said, 'What's wrong?' And she said, 'I don't know what's wrong with me.'" As well, Jenny's family caregiver explained the challenge of understanding her moods:

FC3: She's a person who fluctuates in her happiness. She has very low days and very upbeat days. Nobody can tell why or what [the reason is]. I can't help anyone, more than say she may have a pain or a headache. But she doesn't tell you, or couldn't tell you, so you are constantly guessing.

Therefore, when the person could not articulate the reason for her mood change, it was left to the caregivers to figure out what triggered the resulting behaviour. A direct-care staff explained that aggression communicated distress: "They show us [distress] by becoming physically aggressive; because some of these people are not aggressive people."

It was evident, then, that whether consumers could communicate or not, their mood changes indicated the onset of dementia and the progression of the disease. Mood changes, together with other signs of mental decline discussed above, were accompanied by physical decline, adding another layer of loss.

Physical Decline

As a consequence of mental decline, loss was evident in many physical abilities, severely affecting ability to function. For example, a direct-care staff described how memory loss erased previously mastered skills:

DCS3: ... forgetting to put a shirt on before they come out or forgetting how to hold the spoon. ... Not being able to feed themselves, not being able to shower themselves ... wetting themselves, forgetting to go to the washroom.

As well, stakeholders said that functional decline varied among individuals and was evident in declining verbal communication, (“She makes sounds”), writing skills (“... where it becomes a scribble ... where you could spell a full name before”), activities of daily living (“She needs help with everything ... she is in a diaper ... not being able to eat [so] puree their foods, and then eventually liquids”), and mobility (“She can’t walk. ... She needs a wheelchair”). As people progressed to the final stage of the disease, profound deterioration in physical, as well as mental, health was evident. At this point, impending death became the primary concern of caregivers.

Dying and Death

Profound losses in mental and physical functioning terminated in loss of life. Some people with dementia went downhill rapidly, “from almost independent functioning to death within 1 to 2 years,” as reported by an administrator. Others seemed to experience bursts of intense decline, interspersed with well periods, before they reached the final stage of dementia and then died. Consequently, the rate of decline and timing of death varied, but stakeholders said that death was inevitable.

This prognosis was frustrating, emotionally draining, frightening, and confusing for all who were impacted by it. A direct-care staff expressed the grief and shock of sudden death:

DCS3: All of a sudden they are sick, and there is nothing you can do for them. ... That's very frustrating ... I had to deal with one [death] not too long ago. It will be a year soon. And we took her to the hospital, thinking she was sick, and she didn't come home that same day. And it was like [long pause]. It was just a whole other experience that you have to deal with.

Another direct-care staff told me how fear of impending death accompanied grief each time someone was taken to the hospital: "We also know ... [when] the ambulance is picking someone up, that there are four other people here [in the home] that are just as scared as we are. [And] as the other person [going to the hospital] is."

For peers in the home, administrators and direct-care staff said that the process of dying and death was "confusing" and a "struggle," as they lost their friends. This was evident in their individual expressions of grief: "Some cry, and some act out in different ways. They do things they do when they are upset; that behaviour that we know that they do."

Grief was not only felt at the time of death but also watching a person with dementia decline. Donna's family caregiver explained how grief consumed her daily as she witnessed the changes in her loved one:

FC2: I can be very emotional about it. There was an Alzheimer's Walk in the park, and when I saw it I almost started to cry. It's the loss of her. I'm getting emotional! Even though she is still with us, it's not the same Donna. I wasn't seeing her on a weekly basis, but I would talk to her on the phone. And now there is nothing. It's really sad. It's the loss of somebody that I love.

Indeed, stakeholders experienced grief and fear due to dying and death throughout the duration of dementia. Grief impacted the consumers, their housemates, the staff, and informal caregivers. They all grieved while watching the individual with dementia decline, grieved the loss of the person they knew, and then grieved when the loved one left the world.

All stakeholders said that “needs change drastically,” as the person progresses through the disease, which finally ends in death. A major concern for them was adjusting the living environment to cope with the demands of dementia. When resources to make the necessary adjustments were unavailable, consumers experienced the next major loss evident in the theme, Loss of Home.

Loss of Home

As the new and complex needs of dementia began to surface among the consumers I observed, it became apparent that their physical living space had to be adjusted. As well, resources were required to meet the new needs of the person with dementia. For most of their adult lives, consumers had lived in their own apartments with low levels of support, at home with their families, or in group homes. I will now discuss the challenges that prevented them from aging in place.

Supported Independent Living

Supported independent living (called in the literature *supported housing*) enables consumers to live on their own in the community with minimal support. An administrator described how people living independently get lost in the community after the onset of dementia:

A2: ... people that live quite independently now. And they forget how to get to the bank. Or they get off the bus and forget how to get home or forget which bus to take. They could be, [in] a worse-case scenario, wandering aimlessly around without anyone knowing they are gone if they live without a lot of staff support.

Likewise, administrators said that Jim had “had the ability to live on his own with limited supervision.” He lived in an apartment by himself for almost 8 years before he moved to the home to receive a higher level of support. Jim had begun experiencing confusion and memory loss, resulting in safety concerns.

Although Jim would perhaps have preferred to stay in his apartment with additional staff support, the Ministry of Community and Social Services only funded a few hours of staff support each day for independent living. When Jim's needs escalated, no additional funds were available for extra staffing hours in the supported housing program. An administrator said, "There has been no funding, and, because it's two ministries, it is tricky to get funding coming from both." Therefore, once Jim's needs exceeded the capacity of the supported independent living model, he had to move to a group home, where government funding for several individuals could be combined to provide a higher level of support and supervision.

It is evident, therefore, that the agency's decision for Jim to move to a group home was triggered by concerns for his safety and the lack of resources to adequately support him in his apartment. At the same time, this was supported by his family caregiver, who trusted the agency to act in Jim's best interests: "... And they've always got my blessings, because they have always been good to him and to the family." The trusting relationship had been built over the long-term and, in a sense, the agency had become an extension of the family. An administrator explained the depth of this relationship and the commitment that the agency staff felt for the people they supported:

A1: ... these guys have been supported by us for many years, some of them as long as we've been in operation. Some of these guys moved in or were supported in some manner through employment or something way back to when they were young. And [so] we really didn't feel like throwing in the towel and saying, 'Well, you're starting to show signs of dementia so it's time for a long-term care facility.' We thought if this was our family, we would do everything in our power to keep them at home as long as we could.

Keeping Jim at home meant supporting him in his apartment if possible, and if not, moving him to an agency group home. Jim's family caregiver concurred that the best

option for Jim was to move to an agency-run residence, because Jim had built a long-term relationship with it, and the agency could sustain his social, leisure, and vocational links in the community.

Family Home

Another residential choice for people with a dual disability is to stay with their families. The stakeholders in this study were not aware of many such people who lived with their families. In their estimation, most adults with an intellectual disability were living in the community with individualized supports from agency providers. However, Rose, one of the four consumers I observed, had moved to the home from her family home.

The option of staying in the family home after the onset of dementia was restricted by strict eligibility guidelines for government funded services provided through Community Care Access Centres. When consumers in the first stage of dementia were reasonably mobile and independent, they required some support to access leisure and recreation activities, as explained by an administrator: “CCAC access would be helpful if someone came to the home and took ‘John’ swimming, or for a walk, or to a concert.” However, the administrator elaborated that eligibility for any government funded respite or in-home service was very restricted:

A3: ... [In providing] respite for the families, CCAC really has to relax their rules around that and make that service available for families. At the moment they are saying, if you are living at home with a person who has Down Syndrome and early stages [of dementia] – say they have lost their independence and they are at home all day long so they need respite care – unless they haven’t reached a point where they can’t brush their teeth and their caregiver can’t do it for them, they are not eligible.

People with a dual disability who were able to access funding to hire a worker to come to their home found consistent service helpful: A direct-care staff reported that “the service

did help a lot ... and it was the same person that came all the time, so the person with Alzheimer's got to feel comfortable."

Administrators and family caregivers said that, if consumers chose to stay in their family home, they would have only limited access to government funding for in-home support or to hire additional help. The limited resources available in the first stage of dementia were insufficient in the mid to late stages of dementia. For instance, a direct-care staff said that difficulties for the parents of one individual arose when their son "mixed up day and night, so one of them needed to stay awake with him all night while the other one slept." As the parents were aging, they were "having a hard time coping" with the additional support at night time.

Therefore, in the absence of independent funding, the person with a dual disability living in the family home depended solely on family caregivers. The ability of family caregivers to provide 24-hour support depended on their own income, health, and stamina, as government funded resources were insufficient to meet the range of their loved one's needs. Even when the families could purchase the support required, care within the family home was challenging. Rose, who had personally funded support for her complex needs, faced difficulties at the onset of dementia: with the accessibility of her family home, hiring and scheduling support workers, and maintaining the level of support she wanted. Her family caregiver explained the difficulties if Rose had remained in the family home:

FC1: We'd have to buy a house and hire staff ... but it's hard to staff and have them dedicated 7 days a week ... too many people in and out of the house [and] you got to have people you can trust. ... I would have ended up still being there as much as everywhere else, making sure that this was right and that was right.

In Rose's case, it is evident that organizing support at home required substantial resources, planning, and continuous monitoring to ensure that the support received was accountable, efficient, and appropriate. Stakeholders in this study concurred that consistent, trusted, reliable formal caregivers are needed. In addition, the living environment must be dementia friendly; it must compensate for impaired memory, learning, reasoning, hearing, sight, and mobility. Further, as the level of government funding for dementia-related needs is barely adequate, even in the first stage of dementia, people with a dual disability who live with their families must face the decision to relocate. One such possibility is a group home for people with intellectual disabilities.

Group Homes

Two out of the four consumers in this study had lived in group homes prior to dementia, sometimes two or three over the past several years. Administrators in this study said that several people they serve live in group homes and are aging. The agency's group homes house up to six people. Depending on their needs (e.g., being medically fragile, nonambulatory, prone to behavioural challenges, hearing impaired), the agency offers a variety of housing, with support ranging from 1- to 24-hour support. These homes focus on assisting people with skill development for adapting, living, and participating in the community.

According to the stakeholders in this study, group homes were viable for people with a dual disability when the environment and staffing hours could accommodate their needs. The stakeholders said that out of three possible living environments (supported independent living, family home, and group home), the group home was the most resourced environment for a person with a dual disability to age in place. This was evident in a few cases, where agency staff continued to support an individual with

dementia in her group home: "... we have one individual that we were talking about moving [from her group home] ... and they [management] decided against moving her, because she is getting the same level of care at her current residence." Therefore, as long as adequate resources were available, people with a dual disability had the option of continuing to stay in their group homes.

Although this was an option for some people with a dual disability, the challenge remained when the capacity of the home could no longer meet the demands of dementia as stated by an administrator: "... in the latter part of her life ... she required a lot of support and probably should have been in a long-term care facility." Increased demands of dementia also impacted other residents in the home. A direct-care staff mentioned that a resident was "not comfortable living there anymore ... because she is not understanding the dementia." She elaborated that, "the resident doesn't understand the yelling and screaming; she thinks it is directed at her and it is not. So she becomes very upset and can be aggressive." Plus, an administrator reported that other residents are impacted by a change in their living environment:

A3: In other words, she [person with dementia] was using up a lot of staff time, and we kind of turned their house into a hospital [instead of a home] for the other people that were living there.

Thus, when consumers could no longer live in a group home due to lack of resources and negative impact on housemates, the only option was to move to a nursing home.

Nursing Homes

The nursing home is a model of support specifically designed to meet long-term care needs of all aging people with complex needs. The model is well enough resourced that people with a dual disability can choose to spend their final years there. The stakeholders in this study said that consumers' basic physical and medical needs could be

met in nursing homes. However, they identified several weaknesses in the nursing home model that had made it inappropriate for these individuals.

Rose's family caregiver said that long wait times limit access to nursing homes. Worried about her own health and aging, she waited for a year to seek a placement for Rose. Even though the caregiver's first choice was the home specializing in dementia support, lack of space in this home and the thought of Rose going to the bottom of a nursing home waiting list if she did not accept the first bed offered, forced the caregiver to make a decision:

FC1: We were on a list ... and nothing happened for about a year. ... All of a sudden [her name on the nursing-home waiting list] came up. And I said, 'What happens if I don't take this bed [in the nursing home]?' She said, 'You'll get put back on the bottom of the list.' ... and I said, 'Well then, I'm going to take it,' because [name of agency] didn't have anything to offer.

Weaknesses in the nursing home model, according to all the stakeholders interviewed, appear to impoverish quality of life for people with a dual disability. For example, administrators and direct-care staff said that lack of stimulation and loss of connections after moving to a nursing home led to deterioration in quality of life.

A2: She didn't make any connections with anybody else that lived there, and she wasn't encouraged to. If she didn't have family or staff dropping in to visit her from [name of agency], then I don't think she ever would have gone outside.

In addition, stakeholders were concerned about the appropriateness of placing people with a dual disability in nursing homes, "because they are young, and most people in nursing homes are old." They felt that the consumers, like others in the mainstream, would not want to live in a nursing home while they were still aware and alert. As an administrator put it,

A1: I think long-term care certainly fulfills a need. ... I've seen absolutely exceptional supports provided in long-term care. Long-term care, though, is a medical community, [with] a medical focus. It's like you or I going to hospital. Do we want to live there when we are still aware and alert? I don't think so. We may have to stay there for a period of time, but I don't think it's what any of us want to live like.

However, early placement of people with a dual disability in a nursing home due to lack of resources in the preferred living environment accelerated deterioration in the quality of life. The high patient-to-staff ratio in nursing homes, resulting in reduced time to accommodate individual needs, wants, and choices, compounded the lack of stimulation and loss of connections.

High patient-to-staff ratios in nursing homes were a major concern to all the stakeholders. Rose's family caregiver said, "My daughter works in a nursing home. She looks after 12 people on her shift. ... They don't have time." As well, when Rose lived in the nursing home, her family caregiver worried about Rose being "stressed out," due to lack of attention with "1.5 hours of nursing care a day." This lack of attention brought unwanted attention from other residents, because "some of the older people [on the ward] thought Rose was their baby, that had come back to live with them. And they wouldn't leave her alone."

A direct-care staff said that a low number of staff in Rose's nursing home meant that no one had time to "sit with her, massage her hands, put nail polish on her, or do the little things that would mean a lot to her, because they were so busy." In fact, Rose "was just left. She didn't participate, she was nonverbal." Rose depended on her family caregiver to take her out for the day. Her family caregiver felt obliged "to get [Rose] involved with the nurses, introduce them to her, try to get her to use a few words," as she worried that Rose might become "hard to manage."

All family caregivers and direct-care staff worried that, due to high patient-to-staff ratios, there was a strong possibility that consumers' dignity would be compromised, "because ... somebody might be left in a bed maybe not covered up ... or in a bathtub being exposed to other people." As well, all stakeholders concurred that nursing homes were clinical settings, where the tendency toward impersonal care and rigid routines objectified people: "... they are treated as a thing – mealtime at a set time, bath and showers at a set time. They put you through this routine ... because they have to."

Routines may be attempts to get individuals to conform to a set practice.

However, for Rose, this strategy led to errors in meeting individual needs, as was apparent when she tried to settle into her new routines at the nursing home. As stipulated in that particular nursing home, bedtime was 8:00 p.m. Rose's family caregiver said that the staff members were puzzled when she was up at midnight and undressing. Her family caregiver solved the puzzle by interpreting Rose's behaviour-communication:

FC1: 'Number one, you [staff] are putting her to bed too early.' ... The staff put her to bed at 8:00 at night and, by the time they did bed checks at midnight, Rose had had enough sleep. What she was doing was getting her up, [and] she wants her clothes. She refuses to put pyjamas – she wants to be up and out. The girls [staff] looked at me and said, 'yeah, because that's what she wants – she points to the cupboard where her clothes are!'

On the family caregiver's suggestion, Rose was allowed to "walk around with the night nurse doing meds and checks" until 11:00 p.m. After this change in her bedtime, she was able to sleep through the night. Hence, it is apparent that nursing-home staff needed the support of the family caregiver to interpret Rose's communication, understand her needs, and modify the routine to accommodate them.

Rose's experience in the nursing home speaks to the importance of knowledge about habits, likes, and preferences of the person with a dual disability. Prior to dementia,

consumers had been supported by staff trained in developmental services, which adopt a person-centered philosophy of support. Administrators and direct-care staff felt that, although nursing home's medical expertise was excellent, nursing-home staff could not understand the needs of people with an intellectual disability; they did not match the individualized support offered in developmental services. Overall, all the stakeholders felt that nursing homes were an "option of last resort" for people with a dual disability.

Indeed, for consumers, impoverished lives leading to death were the expected outcomes of dementia. Therefore, having the best possible living environment was of primary concern to stakeholders. When consumers had to stay in living environments that were under-resourced or were forced to relocate to unfamiliar living environments not of their choice, stakeholders found that they became more vulnerable to distress and isolation. Isolation was compounded by the loss of community, other reduction identified by stakeholders and the theme I will address next.

Loss of Community

Stakeholders emphasized that moving out of familiar living environments distanced consumers from their friends, family, support workers, and community spaces. Isolation increased as they lost opportunities to participate in former leisure and vocational activities, due to lack of resources to accommodate their needs with progressing dementia.

Diminished Participation in Community Activities

Participation in community was very important to consumers in this study. For many, community comprised segregated and integrated work and leisure experiences where they had made friends. Donna's family caregiver said that, while she lived in an agency-run home, she had been to segregated day programs for people with an

intellectual disability where she enjoyed crafts, singing songs, dancing, and other activities. She volunteered with cleaning up, making tea, meal preparation, and grocery shopping. As well, she went on “cruises, trips to Disneyworld, to concerts, to Toronto on the train,” and so on. Donna could do “anything that she wanted to do.” Being a “very friendly and outgoing” person who “always knew her own mind,” Donna had made many friends, some of whom she had known for over 20 years. She loved socializing with her friends at parties and dances. However, after the onset of dementia, it had been challenging to “expand Donna’s horizons outside of the building,” according to her family caregiver,

FC2: ... because now she is afraid to go out. She used to go to the mall and walk around, now she doesn’t even want to go out of the house to go in the van. So we have to coerce her gently into getting into the van and going for a ride. And then, when she goes for a ride, she’s fine. She enjoys it, but she doesn’t want to do it at first.

Likewise, Rose, who lived at home with her family, enjoyed social events in the community. Her family caregiver took her regularly to leisure activities at a seniors centre, as well as to musicals, on bus trips, on a boat, to dining at elegant restaurants, to Canada’s Wonderland, the Santa Claus Parade, and so on. Growing up in her parents’ home, Rose preferred to stay at home, rather than go to segregated day programs for people with disabilities. She helped out at home and enjoyed family rituals, as recalled by her family caregiver,

FC1: She was smart enough that, at their house, this is the way it used to be. We have stainless-steel cutlery for breakfast and lunch. For supper we had silverware, silver came out of the china cabinet. She used to set the table, and her father used to like to have breakfast with her – Daddy and Rose. ... At supper, when they had the silver and the candles and everything got done this way, it was just Rose and Daddy. When her father became ill, she helped to look after Daddy. She used to put on his socks in the morning and things like that.

However, the community life of Donna and Rose changed after the onset of dementia. Rose fell and “that did her in, it really did,” said her family caregiver. A direct-care staff said that, when Donna first moved into the home, “she had five full days of activity outside of the location, and that continued until the point where she just didn’t want to go, was not enjoying her times there.” Donna was unable to verbally express why she did not want to go to her community program. Her family caregiver assumed that she did not want to go, because she could no longer cope with social spaces: “crowds are an issue for her, and any change, like change in staff [or] strangers in the room, she doesn’t react well.”

An administrator offered another reason for reduced community participation: participation in mainstream programs (such as those for seniors and people with Alzheimer’s) depended on the “availability of enriched staffing support” to accommodate people with a dual disability. Enriched staffing entailed the additional hours, staff trained to work with people with dementia, and staff who could blend dementia support with developmental-service support. Enriched support was not available, however. Lack of enriched support was evident in Jenny’s situation. According to her family caregiver, Jenny, who used to go to a program five days a week, “became more of a burden to people in her [segregated] day program.” With about 30 people, it was difficult to support Jenny, who “had to change clothes several times a day.” Therefore, after the onset of dementia, Jenny’s time at her day program was cut to two days a week.

The findings of this study suggest that, for a variety of reasons, people with a dual disability reduce the time they spend in integrated or segregated activities in the

community. As they become housebound, they lose the opportunity to maintain social connections or make new ones. This shrinks their social network.

Shrinking Social Networks

Stakeholders observed considerable shrinkage of consumers' social networks, as they no longer visited the community spaces they had prior to dementia and as social contact with significant others declined in the last stage of dementia. Most of the stakeholders concurred that shrinkage of social networks could be attributed to decline in mental function. For instance, when a consumer with dementia could no longer recognize his family and friends, "even when we take him [to see] friends he used to have a lot of fun with, he doesn't know who they are."

As going out and socializing became stressful, friends and family reduced or withdrew their contact as well. They could not even visit their loved ones in the home, because it caused either one distress. Donna's family caregiver related how, after Donna became housebound; her world shrank, as friends could no longer come to visit:

FC2: There were people that came in for her birthday party last year. There had to be at least two or three other clients that came in from other group homes for her birthday. And this year there was nobody, [except] there was me. ... Her world is a lot smaller.

Summary of the Social Process of Marginalization

My findings in the themes of loss of ability, loss of home, and loss of community reveal gradual but profound reductions in quality of life for people with a dual disability – in health, function, living conditions, and social engagement – that lead to death. This process describes the first major categorical finding in this study, death by reduction.

In the thematic finding, loss of ability, stakeholders said that the medical diagnosis of dementia in people with an intellectual disability was problematic. Whether or not a diagnosis of dementia was confirmed, stakeholders reported that consumers had

severely declined mentally and physically. After the onset of dementia, they were prone to seizures, fear, confusion, memory loss, fluctuating moods, deterioration in communication, inability to perform daily-living activities, and loss of mobility.

Together with severe physical and mental decline, stakeholders in the study focused on the process of dying and death. Consumers and their peers living in the home felt fear and grief. In addition, their formal and informal caregivers profoundly grieved the loss of loved ones. Essentially, stakeholders said that the needs that arise in dementia are unpredictable and profound, causing emotional distress at several levels for people with a dual disability and their caregivers.

In the thematic finding, loss of home, stakeholders identified the three living environments of people with intellectual disabilities prior to dementia: supported independent living, family home, and group home. For people who were in supported independent living environments, few resources to age in place were available. The fixed funding tied to independent living programs could not be increased to meet additional needs. As these individuals were already funded by the Ministry of Community and Social Services, they could not access additional funding from the Ministry of Health and Long-Term Care. As a result, they had no option but to shift to group living, where greater flexibility to design supports was possible through combined funding.

For those living with family, minimal government funding was available to supplement community support in the first stage of dementia. It was expected that these individuals would purchase additional resources and that family caregivers would help with day-to-day living. Even when this was possible, organizing support at home was

challenging. It was evident that consumers in the second and third stages of dementia were unable to stay in their family homes without major circles of support.

Living in a group home was only possible if it could adequately meet the needs of individuals with dementia without affecting housemates. Aging in place in a group home succeeded as long as peers' needs were also met. However, as in the family home and supported independent living options, when needs became more complex with progressing dementia (i.e., health complications, safety in the home and community, night support, mobility, etc.) and resources were insufficient to support the person in the group home, they had to move to a nursing home.

Some stakeholders mentioned that basic physical and medical needs of people with a dual disability would be met in nursing homes. However, they identified several weaknesses in this option that jeopardized individuals' well-being. Stakeholders said that the nursing home environment was impersonal, devoid of "love, attention, [and] compassion." Other factors diminished quality of life for people with a dual disability: placement in middle age when the person is still aware and alert, high patient-to-staff ratios, non-expertise to support people with intellectual disabilities, lack of individualized support and social stimulation, and disconnection from significant caregivers.

In the thematic finding, loss of community, stakeholders said that, as a result of cognitive decline, consumers began to opt out of social activities they had enjoyed prior to dementia. They felt that, when consumers were unable to participate in a community event as they used to, this was a sign of disinterest or changing preference. This changing preference was attributed to the person not being comfortable in public, unfamiliar

spaces. Stakeholders perceived dementia as the cause of diminished participation in both segregated and integrated community activities.

Although the preferences of consumers did likely change with dementia, stakeholders also stated that consumers became distressed in community programs when their participation was not accommodated with additional staff trained in dementia and intellectual disability support. The absence of enriched supports to meet the changing needs of consumers led them to distance themselves from community.

Distancing from community led to shrinkage in social networks for consumers, which in turn intensified in the last stage of dementia when they could no longer recognize significant others. Stakeholders said that social contact with family and friends was reduced to minimize distress among both consumers and their significant others. When consumers became housebound, their social circles shrank even further, as others were no longer able to visit them.

The marginalization of consumers after the onset of dementia is evident in the findings of this study. Nevertheless, my findings also reveal a parallel process, the social process of empowerment that mitigates the reductions with dementia. In the next chapter, I discuss this process and the second major category identified in this study; living by supported empowerment.

CHAPTER FIVE

Findings: The Social Process of Empowerment

An empowering process to counter losses experienced in ability, home environment, and community participation was evident in the findings of this study. Administrators and direct-care staff identified a philosophy of person-centered support that facilitated the empowering process. Person-centeredness meant addressing the needs, goals, and aspirations of individuals with a dual disability in support practice. This philosophy placed the person at the center of planning. It meant determining services, supports, and their respective costs, in a manner tailored to the consumer's needs.

Living by Supported Empowerment

Three emerging themes were generated from the categorical finding of living by supported empowerment: (a) maintaining selfhood, (b) freedom of choice, and (c) self in community. Table 4 illustrates the thematic findings inherent in each of the categories that influence this social process. In the following discussion, I indicate how support workers actively facilitated empowerment when they operationalized the person-centered philosophy of support in day-to-day living. Their support focused, to a great degree, on combating dementia-related reductions in quality of life and on "celebrating life today." Their actions, and the actions of people in consumers' support circles, are captured in the three main categories and their respective themes. Some themes contain divergent perspectives found in the data collected from stakeholders and observations. These perspectives demonstrate the weaknesses in facilitating empowering conditions for consumers. I begin with the first theme, Maintaining Selfhood.

Table 4***Major Category: Living by Supported Empowerment***

Maintaining selfhood	Freedom of choice	Self in community
Maintaining health	Choice of dementia-friendly home	Self in outer community
- Flexible team of health support	- Divergent perspectives on choice of home	- Nurturing social liaisons
- Divergent perspectives on maintaining health	Moving with choice	- Participation in community programs
Opportunity for decision making	Consistent support	- Divergent perspectives on community activities
Exercising self-agency	- Divergent perspectives on consistent support	- Participation in planned activities
Sustaining autonomy	Person-centered support	- Participation in spontaneous activities
- Divergent perspectives on sustaining autonomy	Elevated empathy	Self in inner community
		- Participation in home activities
		- Participation in leisure
		- Socializing with peers
		- Nurturing relations with staff
		- Building mutual aid
		- Divergent perspectives on including family

Maintaining Selfhood

All stakeholders concurred that each person with a dual disability wanted to be respected, cared for, loved, and kept secure to the end of their life as a unique individual.

Their uniqueness lay in their personal history, relationships with others, strength of character, likes, mannerisms, assertiveness, emotional responses, needs, and strengths.

The challenge for others when relating to a person with a dual disability was the confusion caused by dementia. A family caregiver felt that she was “losing the person,” as her loved one changed to the point where others no longer recognized her. However, on a day-to-day basis, my observations noted how consumers related to others, sometimes in familiar ways and sometimes not, but relating nevertheless. Whether it was with verbal, nonverbal, or behavioural communication, they interacted, made decisions, and acted on their thoughts in the moment, indicating that their self was still present.

In order to sustain interaction with the environment and those in it, stakeholders in this study said that consumers needed support to maintain good health. When stakeholders spoke about “health” they referred to the physical and emotional health of the individual. Maintaining Health, then, was the first theme important to retain competency to apply the self.

Maintaining Health

Stakeholders said that remaining competent becomes a challenge for people with dementia as their health deteriorates. In addition to mental decline, they are vulnerable to physical health complications (such as seizures, pneumonia, chronic chest infections, kidney and heart malfunctions, and digestive failure). An administrator explained how people with a dual disability experienced deterioration in health without a sign: “We have had people with pneumonia, where the only sign they showed was their appetite was reduced. They had no fever, they had no coughing; they had nothing.”

Hence, direct-care staff and administrators said they had to be vigilant about the physical health of the consumer:

A1: So I think that's one thing the staff member has learned is you really have to involve the medical community whenever there is a doubt as to somebody's health, because otherwise you can end up with a very serious situation on your hands.

In the home I studied, staff took note of overt and covert signs of medical concerns and sought help from medical professionals as necessary. For instance, when Jim complained of pain in his knee, he was taken to his doctor, who ordered X-rays and prescribed a pain medication. As well, staff carefully documented and monitored any change in those who were unable to articulate health concerns. A log excerpt follows:

LN: Rose slept for the majority of the morning. She did not eat much of her lunch. Mini-seizure believed to be witnessed at around noon. She let out a yell, her hands flailed in front of her face and then a blank look for less than a minute. Rose responded to staff by looking up when her name was called.

Stakeholders also elaborated on the attention paid to the emotional health of individuals. For instance, the staff made every effort to enable the individuals to stay at home as long as possible according to an administrator: "Staff members are very comfortable with the person dying in the home and they support people as long as they can in that house." A direct-care staff added that staff members are like family members who tend to the comforts of the individual. She said,

DCS3: We're just making sure they are comfortable. I think in this house we can do a lot for that person. They are getting treatment as if their mother or father would give them and being in the hospital they might not get that kind of treatment. If we are just making sure they are comfortable, I think we can do wonders.

A focus on the emotional needs of the individual was noted by a family caregiver who mentioned how staff got "this little lady [in the end stage of dementia] up and moved her around and took her there and took her here ... she stayed right with it. Their care

was great.” Even when hospitalization was necessary, the staff maintained their physical and emotional support for the individual in hospital according to a direct-care staff:

DCS3: ... they will be on IV because at that point they won't be able to eat anymore and that's beyond our care if they reach that point. It is usually the hospital where they tend to be, but we still tend to support [at the hospital] and care for them there doing daily things ... we will continue to feed ... help the nurse to change the individual, roll them from side to side so they don't get bedsores ... and sometimes it's just to be there to support them.

Particularly important for the emotional health of consumers was grief support; death of peers was a struggle for consumers who “keep losing their friends.” An administrator said that the “biggest struggle” in the home was the number of deaths in a short period of time: “I think we had five people die in the first three years of opening which we were not at all prepared for.” According to a direct-care staff emotional health during time of loss was supported by inclusive grief counselling sessions: “The people who live there participate in the staff [counselling] sessions. ... They know that we are all in it together, so we don't exclude them in any way.” An administrator identified other measures used to provide grief support:

A2: Talking as a group ... getting pictures of the person who has died and putting together a collage. Other people might write poetry and share it with the group and be involved in planning the funerals ... be involved in the funeral and the visitation ... It's very much communication and openness and willingness to talk and ... be together at that time.

Stakeholders said that the support for physical and emotional health of individuals in the home was responsive. Administrators and direct-care staff said that staff members were trained in health interventions, such as first aid, CPR, administering medications, tube feeding, and palliative care. They reported that whenever individuals were “acting a little bit weird” or not being their usual selves, looked listless and lethargic, or

complained of pain, staff sought immediate assistance from their family physicians, specialists when recommended, and the paramedic emergency response system.

Family caregivers concurred that medical problems were looked after with the same diligence as all other support needs. Rose's family caregiver, who had worked in nursing homes, commented on how health concerns, such as infections, were contained in the home, efficiently and safely:

FC1: ... she had the runs. And I said, 'Thank you' [to the staff, because] it took a month [to recover]. And I was still going there all the time and no one else got it. None of the rest of us got sick, and I did tell them [staff] it was wonderful.

Further, this caregiver said that the attention given by staff to an individual in palliative stage even prolonged life: "They did things that wouldn't have happened in a nursing home. In fact, this person might have died much sooner." Stakeholders stated that the success of health interventions for consumers at the various stages of dementia required specialized training for staff and in-home health interventions. As well, a flexible team was required to provide the health support.

Flexible team of health support. Administrators and direct-care staff stated that staff in the home teamed up with mainstream medical professionals (family physician, emergency/hospital staff, and specialists) in the community. They named one aging specialist in the city who had seen people with an intellectual disability in his practice and who monitored them for dementia. In addition, each consumer's health team included a medical decision-maker, who staff and medical professionals consulted in all matters requiring medical intervention.

According to direct-care staff and administrators, such a team approach was necessary to effectively respond to the health needs of consumers. They elaborated that

medical professionals could not always detect health issues without input from staff, and staff did not have medical training to confirm health issues. A direct-care staff explained that “fabulous” health professionals relied on staff instincts to determine appropriate medical responses:

DCS3: ... because we know their background ... [and] their medical information ... we are their words. We tell [doctors], ‘This is what is going on.’ And the doctor will say, ‘How do you know that?’ And we just know it. Like you would know your child ... you know, with these guys, something is not right.

Furthermore, administrators and direct-care staff mentioned that health professionals had been flexible with their support when consumers were unable to go to their medical appointments or were in palliative stage. An analysis of data from interviews, observations, and log notes indicated that; doctors, nurses, counsellors, lab technicians, foot-care nurses, hygienists, dentists, and ultrasound technicians had been willing to make house calls.

All stakeholders agreed that vigilant healthcare was of primary importance for people with a dual disability. In particular, stakeholders were concerned about maintaining the physical and emotional health of consumers. However, some family caregivers and direct-care staff differed with the way health was maintained in the home; the next theme in the findings.

Divergent perspectives on maintaining health. Divergent perspectives arose around personal support, use of therapeutic interventions, and medical training in the home. Jenny’s family caregiver mentioned her conflict with the staff on how foot-care was provided in the home:

FC2: ... nobody would cut her toenails. I said [to agency staff], “You wouldn’t let an animal walk like that!” They said, “Well, we have someone come in every two months to look after her feet.” I said, “Well,

that's far too long. If my nails grow fast I may have to have them cut every week!"

A regular regimen of foot-care was offered to all consumers in the home according to an administrator. From her perspective, the issue was communication rather than the support. Administrators said that they welcomed feedback from family caregivers and were quick to resolve any grievances. However, family caregivers felt unable to complain: "You can't stir it up; make too much noise. You [would] get people on the wrong side. It should be up to organizations to do it right."

Successful resolution of different views on support was not evident in Rose's situation. Rose's family caregiver, who had a background in nursing, felt that Rose's mobility was prematurely lost in the absence of therapeutic regimens in the home to keep up this function. She felt that Rose had lost her mobility because she was not encouraged to walk: "My training is, if you don't use it, you lose it. She is losing it [mobility] because they [staff] don't do things like that."

On the other hand, direct-care staff and administrators said that mobility of consumers should be accommodated with consideration to their safety as well as according to their level of functioning. For them, an appropriate practice was to support the individual with an assistive device (e.g., a wheelchair) when mobility is lost; any therapeutic regimen to encourage mobility would not be implemented unless stipulated by the individual's health professional.

Rose's family caregiver linked loss of mobility to lack of knowledge regarding healthcare practice. Also, lack of medical training led to unnecessary use of medical services, according to Jenny's family caregiver. Health professionals called to the home had echoed the same sentiment; a direct-care staff said: "There have been times when the

ambulance has come and they [medical staff] think we are nuts and don't understand why we are sending this individual to the hospital." She added that health concerns were often based on staff instinct rather than overt signs of health deterioration. Another direct-care staff said, "we are not trained enough medically for the house." She was referring to medical conditions coexisting with dementia and bereavement.

Apart from divergent perspectives on maintaining health stakeholders portrayed a responsive, flexible system of health management to mitigate problems that arise from dementia comorbidities. Failing to do so would have limited the capacity of consumers to influence the quality of their lives through day-to-day decisions. The next thematic finding highlights this capacity, possible with good health.

Opportunity for Decision-making

Competency to make decisions was evident in the field notes when consumers were given the opportunity to make decisions about day-to-day living. In so doing, their autonomy was sustained. For example, staff often asked consumers if they wanted a snack or meal at regular intervals during the day. The two quotes below show how staff prompted Donna to decide when to eat her meal. Donna made a different choice each time.

FN: Donna is sitting in the office where I am setting up my computer. The staff member comes in the office and asks Donna if she wants supper. She says, 'Yes.' Donna goes into the kitchen. The staff member says to me that they offer supper to Donna anytime between 4:30 p.m. and 5:30 p.m. She usually decides to eat earlier. Also, she can decide to not eat at that time and eat later whenever she is hungry.

LN: Donna woke up shortly after 16:45h. Went to the washroom and didn't want to eat supper. Reapproached several times and Donna declined ... spent most of her time in her room. She did have a snack and a drink.

Apart from deciding when to eat, individuals also decided what to eat, as I observed: “Staff is trying to find out what Jim would like to eat today. She signs, ‘Chinese Rice?’ Jim gets excited and nods his head smiling.” Similarly, I observed individuals deciding what to wear, which bathroom to use, when to go to bed, and what to do with their time. A direct-care staff confirmed these opportunities to decide:

DCS3: So, if they want to be up all night, they can have that choice, and they can roam around. And, if they want to come and have juice, they can. And, if they want to watch TV, that’s their choice.

Even when a consumer’s decision was not easy to decipher, the individual was always supported to clarify and implement it. To clarify a decision, the support person patiently walked through it with the consumer, listened proactively, and interpreted multiple communication cues to understand the decision. For example, one evening when I was observing in the home Jenny was standing in her bedroom. The staff wondered whether she wanted to go to bed earlier than usual. The following field note explains how staff probing elicited Jenny’s decision:

FN: Jenny goes in her bedroom, and staff member follows to see what she wants to do. When staff comes back in the living room, she tells me that Jenny stood in her room. When staff asked her if she wanted to go to bed, she said ‘Nein.’ Then staff asked her if she wanted to go to the living room. She said, ‘Nein.’ Then staff asked her if she needed a hug. She said, ‘Ha!’ Staff gave her a hug, and Jenny crawled into bed. Staff said Jenny had decided to go to bed early today.

In this example, the staff member offered Jenny three options after she was unable to communicate what she wanted to do. Through a process of elimination, the staff member was able to decipher her decision to go to bed early and, further that, before she did, she wanted a hug. Jenny then implemented her decision. Hence, decision-making encompassed several areas of day-to-day life, acknowledging that a person with a dual disability is able to exercise self-agency.

Exercising Self-Agency

Exercising self-agency was another theme required to maintain selfhood. I often observed a consumer autonomously declaring a self-made decision. This was particularly evident in decisions about going out. A direct-care staff said, "... if people don't want to go to their day program for a day or a week or a month, it doesn't matter. They can hang out at home."

Jim exercised self-agency to stay at home rather than go to a vocational program each morning. If he wanted to go, he got dressed; if he did not, he left on his pyjamas. Jim, who usually left home at 8:00 a.m., could also decide to leave at a different time, as a direct-care staff said: "If, at 8:00 a.m. in the morning, he decides he doesn't want to go but, at 9:00 a.m. in the morning, he decides he wants to go, we put him in the van and we take him." It was evident that Jim exercised self-agency and, moreover, was allowed to. Being allowed to do so, sustained his autonomy.

Sustaining Autonomy

The following example demonstrates how sustaining autonomy, another significant theme in maintaining selfhood, facilitated multiple elements of empowerment in Jim's life. During participant observation, Jim frequently decided autonomously to go out. One afternoon, he decided to go shopping to purchase some paper. The staff member drove him to a department store and supported him in making purchasing decisions:

FN: Jim picks one pack of paper and gives to staff. The staff member puts it in the cart and asks him if he needs more. He nods, 'Yes' and picks up another pack. The staff member asks, 'Is that it?' He says, 'Yes. Then he signs that he needs some pens. We go to the pens and pencil aisle. The staff member shows a couple of packs of different pens. Jim picks one and puts it in the cart. Then staff asks him if he would like to buy some chocolate. Jim says, 'Yes.' We go to the chocolate counter. The staff member tells me that Jim has soft chocolate, as he has difficulty chewing. The staff member shows him a couple of examples of chocolate. Jim is not

sure. We show him another two on the shelf, and he picks one. Then he changes his mind and picks another one on the shelf. The staff member holds out the one he picked as well as the one he chose before. He chooses the [first] one he picked again. He puts it in the cart. ... Jim wants to pay for his purchases at the cashier. The staff member gives him \$20 to complete his purchase with the cashier. He follows her guide and puts the items on the counter, pays the cashier, takes the change, takes his bag of purchases, and wheels the shopping cart to the van.

In this example, it is evident that Jim made the decision to go shopping, was given support and transportation to implement this decision, decided on his purchases, used his skills to pay, and wheeled the purchases to the van. Because he maximized his potential to make decisions and act on them during every interaction in the shopping expedition, it is apparent that Jim had the competency to achieve a desired outcome with appropriate support. Jim showed his competency when the staff member gave him the power to implement his decisions.

Divergent perspectives on sustaining autonomy. Divergent perspectives on sustaining autonomy of consumers arose in my observations in the home. An important role of the staff was to ensure that the consumer was safe – safe from harm to self, harm from others, and harm directed at others. Ensuring the individual’s physical safety was of primary concern to family caregivers. Jim’s family caregiver described the safety issues that arose due to his decline in mental function associated with dementia:

FC4: He wouldn’t let the counsellor go into the fridge and food was starting to spoil ... he’d have papers piled up all over the place and he had baseboard heating so we started seeing some risky things ...

Along with risks to safety in the home, people with dementia are at risk in the community; direct-care staff and administrators in the study expressed concern about a person’s safety if they tried to “wander off” into the community.

However, the practice of implementing a safety measure was sometimes in conflict with the expressed desire of the individual. In such a situation, the issue of sustaining autonomy versus the professional's duty to care interfered with empowering practice. In the following case example of Donna, I provide citations of observed practice where duty to care takes precedence. Three examples in Donna's support are interpreted to demonstrate how duty to care can lie on a continuum of least-to-most oppressive practice, if left unchallenged.

Case example of Donna. In Donna's case, the duty to provide for good health was actualized by the creative use of historical knowledge about her food preferences. The first field observation showed this knowledge being combined with coaxing Donna to eat her meals, as her weight loss was posing a serious threat to her health:

FN: Staff says that all foods for Donna are "macaroni." So whatever food the staff member prepares for her, they call it "macaroni." This is a way to encourage her to eat her supper. Also, the staff member says that a while ago it was "Timbits." So the staff made food of a consistency that could be rolled up in small "Timbit" balls and Donna happily ate it thinking she was eating Timbits.

At the outset of this situation it appeared that the staff not only supported Donna's health by ensuring proper nutrition was taken but did so in a way that Donna perceived a personal choice in what she wanted to eat. Having been given the opportunity to eat what she desired encouraged her, in turn, to eat and moreover enjoy her meal.

However, did Donna truly exercise her choice or was she coerced into eating under false pretences? It is possible to argue that she was at risk of coercion due to her dementia-induced vulnerability and the power differentials in the support relationship. Hence, in this observation, deciphering whether Donna was making a choice of her own

volition or resigning to the staff was unclear. What was clear is that she did not seem to be distressed by the way her meals were presented to her.

In a second example, during field observation Donna tried to leave the house. The duty to provide for her safety if she succeeded in leaving the house unescorted raised a dilemma for the staff. The dilemma was which level of restraint to apply when ensuring that Donna did not leave the house:

FN: Donna comes out of her bedroom, goes to the kitchen, opens the patio door, and looks out. She sees the staff sitting on the patio. She comes back inside, walks to the door to the garage, opens it, and goes into the garage. A staff member who is in the office adjacent to the garage hears the garage door open. She goes to the garage and is persuading Donna to come back inside the house. Donna is fiercely resisting, pulling away from the staff. Staff calls out to second staff to assist and they hold Donna by each arm and escort her into the house.

The staff on duty said that trying to leave the house was a “new behaviour” for Donna and they had to act a little forcibly to keep her safe. When Donna was firmly held on both sides by the staff she succumbed to their pressure to come back in the house.

Over the next few weeks, during observation, Donna tried several times to leave the house from the garage door. The staff continued to escort her back, while talking to her and suggesting that they could go out later. A particular strategy they used was to leave the doors in the garage shut and the lights out. This seemed to prevent Donna from leaving the house through the garage, as she was afraid of the dark. During field observation, Donna was seen to open the door to the garage and stand in the doorway, afraid to venture farther. For the moment, this less restrictive intervention seemed to deter Donna from leaving the house, keeping her from venturing out alone into the community, and thereby keeping her safe.

While it was necessary to keep her safe, Donna remained resistant. Where in the first example there was some ambiguity about whether a preferred choice was facilitated, in this example it is clear that it was not. Donna still wanted to go out; the response she got from the staff was not satisfactory to her. She asserted her dissatisfaction by persisting for several weeks in trying to go out. However, each time she appeared to cave in to the restraint that was exercised over her by staff.

The third example shows how the duty to care led to an ethical dilemma over Donna's individual right to choose when she was at explicit risk of harm. Staff said Donna could experience threats to personal health if proper hygiene was not maintained, minor injuries from falls or cuts were ignored, or skin breakdown and infections were not treated in a timely fashion. It was particularly difficult to implement routine nail care with Donna given her intense resistance to having her toenails cut. She went through a period where her choice was respected: she did not have her toenails cut. However, this resulted in Donna having an infection from a broken nail.

Following this incident, a decision was made to regularly bring in a foot-care nurse to perform the procedure. In a field observation, I saw the intense trauma experienced by Donna and everyone present when the foot-care nurse arrived to cut Donna's toenails:

FN: The foot-care nurse arrives. Jenny is standing by her in the kitchen watching her set up. ... Donna shouts, "Go back!" Jenny is seated on a chair in the kitchen. She is ready to soak her feet in the water. Donna walks in the kitchen. Staff says, "Come and sit here." She says, "No!" and runs into the bathroom. She yells from the door, "Get out! I want to go outside! I don't like her!" Donna continues to hide in the bathroom.

Jenny sits quietly smiling while the nurse cuts her toenails, checks her skin, creams her feet, and puts on her socks and shoes. Donna has come in the kitchen. She picks up a towel. The nurse asks her if she wants to cut her nails. "No way!" says Donna and whips the towel at her ...

[After much cajoling, offering food, distracting with music, and so on, Donna continues to resist.] A staff member takes Donna in the bathroom. The nurse is planning to sneak in. The staff member decides to hold Donna down to cut her toenails. Donna is screaming loudly. Five minutes later Donna comes out yelling and crying. Her right toe is bleeding. She hits and screams as staff and nurse try to put a Band Aid on her toe. A staff member is holding her arms as she tries to struggle out and hit the other two staff. She is very, very upset.

Donna tried every level of aggression she could muster to avoid the toenail-cutting procedure. At the same time staff members were just as determined to complete the procedure, bearing in mind the harm that would come to Donna from an infection. After a hug, a rub on her back, and a snack, Donna was able to calm down and relax with her favourite bagpipe music; but her obvious fear of having her toenails cut was traumatizing to see. The intense trauma exhibited by Donna and felt by others watching could classify this event as overtly oppressive.

The examples in Donna's life are a clear indication of the tension between sustaining her autonomy and addressing the risks to her health and safety. Another element important to sustain the autonomy of a person with a dual disability is freedom of choice. Without choice, decision-making is restricted and the possibility of asserting autonomy is thwarted. Therefore, it is important to recognize opportunities for choice, when in some measure a person asserts a preferred choice and, further, when this choice is actualized. I observed all three in the home.

Freedom of Choice

As the consumers advanced through dementia, significant changes occurred in their living environment and daily-living activities. Therefore, administrators and direct-care staff paid much attention to the issue of choice. They saw it as a way for consumers

to retain control in the face of change: when considering new living environments, in transition to them, and in tailoring support for daily needs.

Choice of a Dementia-friendly Home

If aging in place was not possible, the home in this study was preferred by all stakeholders for its living-space design, small size, 24-hour support, and low patient-to-staff ratio (5:2 during morning and dinner peak times and 5:1 at night), allowing individualized support. Administrators said that additional staff members were scheduled if someone had to be transported to appointments or programs.

In addition, stakeholders said that the homey living environment in a residential neighbourhood was desirable. I observed that the home was a comfortable space specifically designed for people with dementia – one that was accessible, relatively safe, inviting, and calming, as well as intimate. Administrators and direct-care staff said that, in this home, they could create a “much more personal” environment, “tailored to the people that live there.”

Because the building was small, I observed that staff were always visible or could be heard from common spaces or consumers’ bedrooms. The ability of staff to cater to individual needs and consumers’ freedom of movement within the home usually maintained a low-stress ambience. Furthermore, the level of staffing and support meant that “no-one had actually been placed in a nursing home” according to an administrator. Out of the people that had died since the home was built, some died in the home and others after a short hospital stay as evident in this quote:

A1: But it has never progressed where they had to go from hospital to somewhere else besides [the home]. ... We have had others go in who have died in hospital. ... But the intent is to always take them back home to [the home] once they receive treatment, [just] like you or I do.

Indeed, some family caregivers expected their loved ones to stay permanently in this home: “I’ve never entertained the thought that she would have to go somewhere else. I see her being at [name of home] forever.”

Divergent perspectives on choice of home. All stakeholders stated that the preferred option for the consumer was to age in place: “Every individual would live on their own with their own support worker. They would all live in their own apartment or their own house.” In contrast, one administrator proposed a continuum of care offering three levels of support:

A3: ... we call it a comprehensive model of support services for people with dementia and dual disabilities. ... Seventy percent of people would require what we are calling enriched homecare or day away programs; these people would continue to live with their families or in a regular community residence ... [and] get some additional home support if they could no longer attend a day program that is geared for people with dementia. ... The remaining thirty percent would require extended residential support, similar to what we have [in the home]. We also continue to believe that ... there will be some people that need to go into long-term care [but in a] unit with enriched staffing support.

In as much as this administrator affirmed that the preference of consumers was to receive enriched supports in their community residence, he acknowledged the reality that the level of resource in community-care may not be sufficient to adequately support consumers to the end of life. Therefore, he proposed three levels of support and the inclusion of people with a dual disability in enriched mainstream long-term care services to avoid “a very traumatic experience” for consumers.

Stakeholders mentioned the risk of trauma when moving consumers from their homes. Family caregivers said that they were “very happy and satisfied” with the supports in the home specializing in dementia support, which were provided with “utmost care ... second to none.” Nevertheless, direct-care staff and administrators were cautious

to make certain that moving to the home studied was the choice of consumers. The next theme, “Moving with Choice,” identifies a process of listening to consumers’ verbal or nonverbal communication of their choice to move and, then, to continue living as they did in their previous homes.

Moving with Choice

In order to ensure freedom of choice in where to live and a stress-free transition, administrators and direct-care staff identified several strategies that staff employed before the move, on moving day, and during settlement into the home. An administrator said, “We meet regularly with families, at least once a year [or] more often, two or three times a year and it [moving] is something we talk about.” This administrator said that planning ahead depended on the length of time an individual was connected with the agency and whether the person was at risk of dementia due to Down Syndrome. In Jim’s case, a move to the home had been discussed with him and his family “five or six years prior” and when it did occur it “was really a standard of excellence” according to an administrator:

A4: [Jim] lived in a normal house in a neighbourhood with three other roommates. He was involved in the cooking, cleaning, and his own laundry. He came from a place where he had minimal supports ... for him it could have been a real difficult transition because he hadn’t lived with many roommates; he was always somebody that was really private and liked his own space. When he did move in [to the home] he set up his own room and recognized that as his private space.

Moves were planned according to individual needs but with common criteria in mind. With the goal of getting to know each other, consumers met with the staff of the home before they moved in. Consumers also had the opportunity to visit the home with their caregivers. According to a direct-care staff, visits began with “an hour to socialize” and built up “to come for dinner ... overnight visits.” In this way, consumers were able to

experience the home's environment and become familiar with future housemates. During these pre-move visits, staff observed each consumer's comfort level and gauged their assent to a move. A direct-care staff said that they invited the consumer to live in the home by simply asking, "Would you like to move here?" The individuals consented verbally or nonverbally on several visits to the home and moving in when they liked it.

Once the consumer's decision to move into the home had been ascertained, staff began planning by gathering information about the person's characteristics, service history, social networks, strengths, values, preferences, lifestyle, support needs, and so on. Information sources included documents and informants in each consumer's support circle: the consumer, family, friends, medical advisers, direct-care staff and manager of their previous home, and a person-centered planner from the agency.

The same process was used to offer choice to individuals in designing their bedrooms. A direct-care staff reported that staff helped individuals paint their rooms whatever color they chose and hang pictures of familiar people before they moved in. Consumers were encouraged to bring their furniture and belongings as stated by an administrator:

A2: They move with their own stuff. If they have a bedroom suite, for instance, at home, they move that with them. That's the biggest thing. The one person that moved is so proud of bringing people in and showing that, 'This is my room. Look, that's my bed, my dresser. That's my couch.'

When the individuals were satisfied with their bedrooms and appeared to be comfortable in their home, a date for them to move in was set. Again, the move was planned according to the individual's choices. Some consumers preferred a gradual transition, others a quick move according to a direct-care staff: "It is extremely individualized,

based on what the person is showing or telling us and what the family is showing and telling us.”

When the consumers moved in, staff they had already come to know, members of their support circle, and people they met on tours of the home were present to ensure a smooth transition. All consumers had experienced a smooth transition according to this administrator: “I can’t think of anybody that has had a difficult transition to [name of place].” The staff ensured that former caregivers came with the consumers and stayed for a while to help them and their housemates become familiar with their needs.

In the days after the consumers moved in, they had the opportunity to make choices about daily-living activities, such as bath times, food, and personal support. Ritual visits to places in the community were maintained. A direct-care staff said that it was imperative to ensure that each consumer felt supported to actualize the choices made during planning, not pressured “to conform to our schedule [in the home] but us conforming to theirs.” Consumers could choose to maintain ritual contacts with significant others in the community. For example, when Jim first came to live at the home, he continued to go to his favourite restaurant on Saturdays with his former support worker, now a friend.

In this manner, staff at different agency locations not only shared information on consumers’ preferences but also overlapped their duties so that these preferences were actualized as mentioned by a direct-care staff: “The staff knows that they can call the other house staff anytime if they need a hand, if they are confused, or if they don’t know what to do about something.” As well, previous communication and information-sharing

among members of the consumer's support circle continued, ensuring that historical information on individual's preferences was incorporated in support at the home.

A smooth transition to the new environment described above by administrators and direct-care staff was facilitated by ascertaining the consumers' choices. After the initial settlement period, and once the consumers were calm, comfortable, and had the support they needed, the staff began to develop and implement ongoing support. Stakeholders identified two significant criteria in providing ongoing support that was "comfortable" for the consumer: (i) consistent support and (ii) person-centered support.

Consistent Support

Stakeholders emphasized that consistent support is particularly important for people with a dual disability, who are at risk of intense distress and deterioration when exposed to change. Distress and deterioration in health impeded their ability to exercise choice. Direct-care staff said that information was rigorously collected when transitioning to the home to build consistent support in keeping with consumer choice. A direct-care staff said, "Things have to go in routine and be done the same way." Not being consistent would "totally screw up their day ... it does not just wreck the hour, it totally turns them confused for the whole day." Jenny's family caregiver concurred; Jenny experienced less confusion when her support was "the same, seven days a week."

As well, consistency in support approaches was the aim of administrators in this study who discussed strategic measures in the hiring and training of staff. Hiring practices sought consistency in educational qualifications, requiring a minimum of a Developmental Services Diploma or an equivalent undergraduate degree. Potential new staff's prior experience and knowledge of supporting people with dementia, willingness

to learn, and aptitude to support an aging population through retirement and end-of-life were also taken into account.

The administrators also emphasized hands-on learning about dementia, bereavement, and supporting people with a dual disability. Hands-on learning was provided by full-time staff, two of whom “had been with the agency for 20 years,” and by on-call supervisors and emergency staff to support new staff during a crisis. One direct-care staff member spoke about the guidance she received during her first experience of an end-of-life procedure:

DCS3: I had been to the hospital ... when they are going to take them off the respirator and you say your goodbyes ... everything was new; I didn't know what to do. So I called the [emergency staff who] walks you through it and you do it.

In addition, direct-care staff said that training was enhanced with information from workshops on dementia support usually attended by full-time staff and transferred to part-time staff. Thus, administrators confirmed that full-time staff members were the team leaders and gatekeepers of the support practices ensuring that new staff members were “coached and melded” into practicing dual disability support implemented in the home. Coaching and melding continued with ongoing dialogue at monthly or bimonthly meetings and written up in individualized plans according to direct-care staff.

Divergent perspectives on consistent support. As direct-care staff and administrators explained their efforts to provide consistent support in the home and to maintain choice, divergent perspectives among staff yielded inconsistent support. Divergent perspectives materialized depending on who was the caregiver, how they communicated with each other, and what views they had about support. For instance, inconsistencies in support occurred when staff had short-term exposure to the consumer,

had gaps in information about the consumer, and varied in their approaches when supporting the consumer.

Short-term exposure to the consumer occurred as a result of staffing practices in the home and affected the comfort in the relationship. Direct-care staff reported that the consumer's comfort experience with newer and part-time staff differed from that with full-time staff. A direct-care staff described how length of time in the support relationship affected the comfort of the consumer:

DCS1: I have been working here for four months and the one lady doesn't know me and she won't know me. She calls me by another name. I watch her with people who have known her for 10 years ... she knows their name; she is comfortable with them; she remembers them.

As well, although administrators talked about low turnover of staff in the home suggesting extended exposure of staff to consumers, Jenny's family caregiver stated that shift changes generated a high turnover of staff: "They [staff] don't live in the house; they work for a number of hours so there is a great turnover." Staff shifts in the home ranged from full-time weekdays to part-time or "just at weekends." According to Jenny's family caregiver, shift changes impeded the potential to cement consistent relationships and provide consistent comfort to consumers.

Short-term exposure to the consumer also affected the level of caregiver's knowledge about the person's needs. Although administrators stated that full-time staff mentored new staff on the team and oriented them to the needs of the consumers, family caregivers witnessed inconsistencies that led to a breakdown in support when new staff acted upon incomplete information. In Jenny's case, her family caregiver took it upon herself to orient new staff by "repeating things" hoping that "eventually it will get through:"

FC3: Every time I meet new staff I go back to zero and tell them everything I can tell them to help her which I always thought they would do internally, but it doesn't always work. ... For instance, in the wintertime, I never let her go out without her hat, because cold air can trigger a bad headache ... but then new staff comes in and I bring her home and she doesn't have a hat on.

Consistent support depended on efficient transfer of information about the needs of consumers. Gaps in information exchange in the home led to another breakdown in support as evident in this field note:

FN: 9:30 am. The day staff member is in the office while the night staff member ending her shift is getting Jim and another resident ready to go to their programs in the community. Jim is upset as his peer got into the front seat of the van. He has stormed back in the house and into his room. The two staff members discuss the incident. They decide to try and resolve the issue with Jim, and encourage him to go to work. The night staff member goes to Jim's room and speaks to him. She comes out of his room and leaves without him.

10:00 am. The day staff member comes out of the office. She says to me that Jim has gone to work. A bit later she mentions to me that Jim had a tiff with a housemate who had taken the front seat in the van. Then she opens the door to Jim's room and finds him to be in there. She says, "No, it seems like Jim decided to not go to work."

Lack of communication between the staff about what was resolved with Jim led to confusion about whether he was at home.

A more serious breakdown in support was reported by another staff during observation. She recalled an incident where a resident had tripped and broken her toenail. After a call to emergency, the staff member on duty was advised to put a dressing on the toe. Two weeks later when the same staff came back on duty she enquired about the injury. When she unwrapped the original dressing she found that the toenail had become infected. Follow-up support had not been given by subsequent staff as they were apparently not aware of the injury.

Some inconsistencies in practice were not due to communication gaps or length of relationship with the consumer, but rather concerned with staff views on how to provide support. A direct-care staff, stressing the need for consistency, explained the “struggles” with staff when a practice was changed between shifts:

DCS4 ... for example, if we are using a commode chair to sit people in [for showering] ... for safety for themselves and for staff, then that person is safe and comfortable and they are used to that. But [another] staff comes in and says, “It is easier for me to just put them in the shower and stand them up and get them out.”

When staff disagreed with a support practice they modified it during their shift changing the support experience for the consumer.

Similarly, personal support was delivered variously as evident in field observations and noted by family caregivers. As needed, staff provided the support to keep the person and their environment clean and comfortable, although some staff displayed more and some less vigilance in dealing with cleanliness for example, when wiping the consumer’s runny nose when she had a cold, or helping the consumer avoid food spills, not eat food spilled on the table, or wipe her face after eating. On the other hand, incidents of soiled faces, clothing, and furniture after meals and due to incontinence, were also evident during field observations, albeit less frequently. Staff approaches were not consistent when it came to personal support.

It is evident that several areas of challenge impeded the ability of caregivers to maintain consistent support. Nonetheless, all stakeholders emphasized the need for consistency to ensure that consumers’ choices were implemented; moreover, that they did not decline further and lose their capacity to exercise freedom of choice. Equally emphasized by administrators and direct-care staff was person-centered support, the next sub-theme in Freedom of Choice.

Person-Centered Support

Direct-care staff and administrators said that person-centered support tailors “your supports to meet the needs of the individual and you change the supports as the needs change.” It was developed from historical knowledge about the values and preferences of the consumer as described by an administrator:

A4: ...When they [staff] work with people they remember how they would like to be treated and what was interesting them. For example, somebody who really liked Elvis, even though they weren't able to verbally or physically or through gestures tell you that or show you that, they [the staff] would be playing Elvis music in the background.

During transition to the home, the consumer's voice was strategically solicited at meetings with the individual, caregivers, and family members. Documents about the individual (such as individual service plans) also contained the consumer's voice, which was heard at person-centered planning meetings where all significant relationships in the person's life were represented. Person-centred plans produced in this way were regularly clarified and modified at meetings with the consumer and caregivers.

Even when the consumer participated less in planning meetings, she had every opportunity to be included, as Donna's family caregiver described:

FC2: At the last meeting we had, she still participated in it. I don't think she said anything, but she was still asked and consulted about what's working for her and what's not working for her. ... We didn't sit at the table, [as] she was falling asleep in the lounge chair. So we moved out with her; so we had the meeting with her there.

Hence, staff used historical knowledge of the consumers' values, preferences, needs, dreams, and life goals to establish how each day of their lives could be celebrated.

Historical knowledge was particularly important when the consumers could no longer communicate their choices. As a direct-care staff explained,

DCS3: You try to keep their life, even though they are changing and their life is changing and their needs are changing. You just try to keep the same that they have had it the past 40 years. And because it has been their choice up to now and now it is kind of out of their hands. ... we can support that and say, this is something they might not like and this activity would be something they would like to do.

Another direct-care staff mentioned that the choice of a consumer, who was in the final stage of dementia and had historically liked bright rooms, would be supported by keeping the blinds open during the day: “Now she has slowed down, we respect the fact that she likes bright rooms.” Another direct-care staff related how an individual’s historical choice about the furniture arrangement in her bedroom was critical to her sleeping at night:

DCS4: In [name’s] room, her bed has always been against the wall, in the corner below the window. But because it was easier and convenient for staff to go around the individual while changing this individual or making the bed, they moved the bed in the middle of the room and did not put the bed back where it belonged. Well, that’s where the person has always liked it. She didn’t like her bed in the middle of the room ... They [staff] went through a few nights of where she wasn’t sleeping well, because things weren’t the same and they weren’t comfortable. As soon as the bed was moved back, she was back to herself.

Historical knowledge, then, was critical to providing person-centered support, particularly when the person was unable to communicate preferences.

In addition, historical knowledge was useful in developing individualized Life Plans. Life Plans captured the consumer’s ideal quality of life and set out specific goals, with timelines, to achieve it. All staff consulted consumers’ Life Plans, and managers regularly evaluated them. In this manner, any barriers to meeting Life Plan goals were identified, addressed, and resources assigned to remove the barriers. Life Plans were modified as needs changed and as new information about consumers’ preferences became

available. Hence, staff's use of Life Plans to drive person-centered support facilitated consumers' choices in the present and future.

The reason for applying historical knowledge in person-centered plans was to honour the preferences of consumers. An outcome of this practice was cumulative knowledge: historical knowledge combined with experiential knowledge gained in supporting the consumer. As staff applied historical and cumulative knowledge in person-centered support, they built greater empathy (or as I have called it, *elevated empathy*) for the person with a dual disability. Elevated empathy is a deepened form of ordinary empathy that is cultivated over time in an intimate caregiving dyad. This empathy enabled the staff to anticipate and/or understand suffering from a major cause (such as an illness) or a seemingly minor irritant (such as tight clothing). Elevated empathy also facilitated choice for consumers, particularly in the final stage of dementia.

Elevated Empathy

At the end stage of dementia the loss of linguistic, physical, and cognitive functioning meant that a person with a dual disability was unable to communicate, except perhaps through a characteristic sound or movement. At this point, elevated empathy, developed out of knowledge accumulated over time in a support relationship, provided a tool to facilitate choice. In their support role, staff had the potential to become "extremely aware of the needs of the people with dementia" in order to "think for them [and] to make them comfortable." According to a family caregiver, staff must be able to "put [themselves] in their body and say, 'Would I like that?'"

In their efforts to listen, staff became keenly attuned to consumers' spoken and unspoken wishes, increasing their ability to meet those needs. During field observation,

elevated empathy was evident when a staff member supported Rose to be comfortable in her wheelchair:

FN: Rose is sitting in her wheelchair in the living room. She starts to arch her back and stroke her arm. Staff sitting next to her responds immediately to her sudden change in composure. The staff member is looking intently at Rose's face trying to understand her motions. ... The staff member says, "Are you cold?" and begins to feel her arms. The staff member tells Rose, "No, you are warm." Staff checks Rose over and notices that her footrest needs adjusting. She adjusts the strap that supports the back of Rose's feet. Rose appears settled.

This example indicates the challenge of understanding a consumer's individual preference in the absence of clear verbal communication. A casual observer would not have known what was triggering Rose to arch her back and stroke her arm, and if the staff member had not known Rose as intimately as she did, she might have dismissed Rose's movement as insignificant.

In this case, the staff knew that Rose was trying to communicate that something was bothering her. At first she interpreted Rose's movement as having to do with her comfort with room temperature; Rose had often done this in the past. When she had ruled out the possibility of Rose's feeling cold, increasing her empathy she was able to pinpoint what could be causing Rose's discomfort – and found it was the footrest.

Rose appeared settled and relaxed again, seeming to indicate that she was satisfied with the outcome of what she had initiated in that moment. She alerted her support staff, she was listened to, an action was taken, and she was satisfied with the outcome. At all times during this interaction, Rose was in control of initiating and giving responses.

The findings of this study demonstrate that consumers were empowered when they maintained selfhood and had freedom of choice; the study's findings also highlight

how the self is empowered in community. The self is modeled in the interactions and felt experiences with others in the environment. The consumers in this study played several roles prior to dementia (e.g., student, volunteer, friend, and employee) allowing the adapted self to expand in assimilating skills for social life in community. The community inside the home extended to the community outside the home, creating further opportunities to expand choice and maintain selfhood. These opportunities are discussed in the next theme, *Self in Community*.

Self in Community

For this study, “community” included the external environment to which the person with a dual disability belonged as a citizen and the internal environment where the person physically lived. These outer and inner environments were crucial for affirming the self when accessing personal support, resources, leisure opportunities, activation, and sustenance from loving human connections. The experience of self-in-community, whether inner or outer, was vital in creating a meaningful life of belonging for the consumers in a place where they could be fully engaged and empowered to live a full life.

Self in Outer Community

Supporting people with a dual disability to be in the environment outside their home meant staff needed to facilitate their engaging with social liaisons, performing leisure- and work-related tasks, and participating in community activities. Maximizing people’s social interaction in community meant that staff also needed to facilitate planned and spontaneous activities individualized to the person’s preferences. Maintaining such activities enabled the person to continue to experience an integrated social life after the onset of dementia.

Nurturing social liaisons. To support an integrated social life in community, the first step was to cement relationships by nurturing social liaisons, as deepened relationships were seen as critical to reduce isolation, increase the social network, and involve informal supports. Stakeholders reported that consumers had family support and had developed friendships with peers, close family friends, and staff who supported them in the community. Findings demonstrate that due to the impact of dementia, these individuals' social worlds shrank as they became more and more restricted in their movement and ability to communicate and connect with significant others. Maintaining social links with family, friends, and peers through such strategic means as physical or telephone contact was evident in the data.

The staff member was cognizant of the significance of this issue. An administrator highlighted the importance of nurturing family contact thus: “[the] quality of life [for people with a dual disability] was making sure families are not only able to come [to the home] but also welcomed and encouraged.” Encouraging significant people to maintain contact was particularly important when the effects of dementia made it challenging to make sense of relationships. A direct-care staff explained that in spite of this challenge significant people were encouraged to visit:

DCS2: I have heard from a couple of people, “No, I don’t want to visit because she doesn’t know who I am and it is hard on me.” [But] we try to encourage people to visit, even if it is for a half an hour or an hour.

Accordingly, documented and observation data evidenced many occasions when consumers socialized with their family and friends. They went on day trips, weekend trips, and sometimes trips of several days’ time. The length of visits ranged from a few hours to overnight stays and from a couple of times to several times a month, depending on the individual’s health. For example, Rose’s family caregiver took her out “twice a

week to different places.” This caregiver continued to take Rose to her home for visits even though it was a challenge to manoeuvre her wheelchair into the home:

FC1: As soon as the weather gets warmer I will have her home. The only catch is now that she doesn't walk. I will have to get somebody I know to help ... [to lift] Rose and her wheelchair up the steps [here] and then we are stuck in the house. If we want to go out I have to call my friends [to help with lifting the wheelchair].

It is evident that despite the lack of mobility Rose was able, with the assistance of staff members and family friends who organized accessible transportation to the home and entry into it, to continue with home visits.

Family visits were significantly important to consumers; all sources of data in this study concurred with the importance of maintaining these social connections. In some instances contact with family was initiated by the consumer. This was supported in a way that was satisfactory for the individual. For example, an individual who missed her deceased mother was taken to “the cemetery to see her mom and dad.” Jenny’s mom regularly took her for home visits “at least two, three times a month, and once over for a weekend.” Between these regular visits, Jenny sometimes expressed a need to connect with her mom. Her self-expressed desire and subsequent connection with family was supported as evident in her documented log:

LN: Jenny was quite agitated and restless today. She spent most of the day wandering and pacing around the house. The staff member was having lunch. Jenny put down a picture of her mother directly in front of staff. She looked quite pensive. Jenny indicated “Yes” when asked if she wanted to see her mother. Jenny’s mother was called. Jenny brightened upon hearing her mother’s voice [on the telephone]. Jenny’s mother arrived shortly and brought two T-shirts from Las Vegas. Jenny was so happy. Jenny was ecstatic to leave with her mother [for a visit home].

Apart from having visits with significant liaisons, connecting with others by telephone was frequently encouraged. Jim often connected with his special friend by

telephone even though he was nonverbal and hearing-impaired, as was seen in this field observation:

FN: Staff and I are chatting in the living room. Jim walks in and stands near staff. He is appearing to mimic what the staff member is doing. Staff laughs and talks to him in sign language. Suddenly Jim picks up the phone and starts forming repetitive motions of words with his mouth. He appears to be “talking” earnestly to someone on the phone. The staff member explains to me that Jim likes to call [name of worker] at the house where he used to live. They are now friends and he calls her often.

Even though Jim did not actually dial a number and there was no person speaking at the other end of the telephone, the idea of phoning his friend was real for him. In his own unique way he had implemented his decision to connect with a significant person and convey his thoughts of the moment.

Jim did not seek the support of the staff to actually make this call, as others could only communicate with him face-to-face, using sign language. However, what staff did support was a method of promoting social contact accommodating his unique needs. A practice that focused on Jim’s self and not his disability emphasized connecting him to people. Whenever Jim desired to connect with his significant liaison, he could do so freely and without inhibition, using the house telephone. In his mind he had talked to his friend and his demeanour was content afterwards.

Connecting Jim to people in the community that he had already built social bonds with was a way of continuing human links in his life, human links that demonstrated love and caring. Furthermore, it was a way to motivate him to engage with life and, more importantly, to encourage others to engage with him when he was relating differently due to the onset of dementia. In this way, staff facilitated participation, interaction, and relating with others, keeping alive the opportunity to employ the growth of self of the consumer who was at risk of being “lost” in the dementia experience.

Participation in community programs. A second aspect of enabling the self in community was to continue with work- and leisure-related activities established before the onset of dementia. For consumers in this study, such activities comprised integrated experiences in mainstream spaces and segregated experiences in agency programs. Activities at familiar places were sustained for as long as possible, taking into account the individual's desires. Activities at community venues were seen necessary by stakeholders as they gave consumers opportunities to contribute their gifts and sustain their worth.

Two of the four consumers went regularly to structured day programs, where staff attempted to accommodate their changing needs. These day programs were segregated places of leisure, recreation, and work operated by the agency. For example, Jim had worked for several years in a vocational program "where they did silk screening and making canvas bags ... packaging products, shrink wrapping, stacking skids."

Jim participated in this daily work program except on days when he preferred to stay at home. In this way he maintained connections with coworkers, friends, and staff he had been with over the years. While previously he was a paid employee at this work program, he was now continuing on a volunteer basis. The following field observation describes Jim's participation and human interactions during an hour of cooking at work one morning:

FN: Time 10.20 am – 11.20 am. Jim picks up his lunch bag and grocery bag and takes them to his desk. He walks back quickly to the kitchen counter where staff members are laying out the groceries on the counter. He seems keen to take part. Jim takes his cap off and signs to his coworkers to do the same as he walks to his desk to put his cap away. He walks back to the kitchen. A staff member brings out the hairnets. A few other coworkers are putting their latex gloves on. Jim asks staff to put a hairnet on his head. She supports him to put his hairnet on. He walks over to the office and signs to a staff that he has his hairnet on.

A person who sells books walks into the office. Jim stands around, curious to see what he has brought. The person is demonstrating his products to the staff. Jim shakes his hand and gives him a pat on the back as they wish each other goodbye. Jim comes out of the office and speaks to a staff. She seems to say that she doesn't understand. He goes back in the office to show the staff the children's storybooks that the salesperson has brought.

Jim walks back to the kitchen with the staff. He picks up a latex glove and puts it on. He gets another and asks the staff to help him put it on. She does. There are seven coworkers seated at small tables involved in cutting, peeling, and grating vegetables. Jim asks if there is rice. A staff member says, "No rice." Jim looks at a table to see what his coworkers are doing. He comes back to the counter and asks to help. Staff asks him to wait till they wash the mushrooms and then he can cut them. He watches the staff wash the mushrooms.

Another person arrives at the office with a box of goods. Jim sees her come in and follows her quickly. He seems to be calling her attention and wanting to say, "Hello!" He pats her on the back and shakes her hand. He stands watching while she and a staff talk about the goods. Jim sees the person to the door as she is leaving. She gives him a bag of apples to carry into the kitchen.

A staff member asks Jim if he wants to sit at the table where his coworkers are chopping mushrooms. He says, "No." He sees another staff come in and follows her around. She asks him if he wants to help with the mushrooms. He shakes his head and points at the apples. A staff member shows him a soup can. He nods, "Yes." She gives him a can opener and Jim tries to open the can. He tries one and finds it difficult. Staff comments to me that Jim is gradually losing this skill. He used to open cans all the time. She gives him another opener and shows him how to use it. With constant reminders on how to turn the knob he succeeds in opening the soup can. He continues in this manner to open the remaining cans. He is excited each time he has completed opening a can.

Jim then pours the hash browns in the bowl, followed by sour cream. A staff member empties the soup cans he has opened and Jim throws the empty cans away. He stays by the counter helping and watching the staff, preferring to do this rather than sit at the table with his coworkers. Jim watches the staff chop the meat. His coworkers at the tables have finished their tasks. Gradually, one by one they leave the kitchen. Jim continues to work with the staff – opening jars, pouring, mixing, cleaning, etc. He seems to be content helping out in the kitchen.

This example illustrates the myriad of social connections that Jim made in an hour. He was able to do so because he was at a social location that was familiar to him,

where he had a built relationship with people, and where other people came into his view. The individuals there communicated, accommodated, and supported him in the tasks which he desired to perform. It was evident that staff included Jim in their interactions, was flexible to accommodate his choice in what he wanted to do, and created opportunities for him to participate in the activities of the vocational program.

In addition to participating in the activities planned at the segregated vocational program, the staff also facilitated Jim in volunteering in an organization adjacent to this program. In the mornings while at work, Jim walked to an integrated workplace to assist with bagging foods for delivery to seniors living in the community:

FN: A person bags the meals as ordered. Jim stands at a table as the person hands him a paper bag containing the meal order. He smooths the crease on the top of the bag and staples it. Then he puts the bag on a side table. Two people arrive with their boxes to collect the meal orders. Jim helps to stack the stapled bags in their boxes.

Hence, in a given day of participation in the community, Jim was able to contribute his skills in several ways while socializing with old friends and making new ones in his places of work.

While Jim's day consisted of going to work, Jenny preferred leisure and recreation activities which she participated in when she visited her segregated day centre twice a week. The centre was geared to run activities indoors and take small groups of people to integrated outdoor activities or to places in the community (e.g., shopping malls or parks). Staff encouraged outings in the community and Jenny liked to go on any trip that involved walking. While every effort was made to facilitate her preferences, during one field observation Jenny had to miss the community trip as it was expected to end later than her transport home from the day centre.

Nevertheless, the following field observation describes Jenny's activities and interactions at the day centre when she was not confined to her home and was able to participate in the external community:

FN: 9:30 am – 10:00 am. Jenny walks down the hallway. She stands at the reception area and watches people arriving through the sliding doors. A staff member walks by and says, "Hi" to Jenny. Jenny responds, "Ha!" She walks up and down the hallway checking into every room – the TV room, the multipurpose room, the creative arts room, the woodworking room, etc. She checks out her housemate from home who also attends this day centre and who is arranging the chairs in the multipurpose room for a music session. She comes out to the reception area and sits down on a bench.

The pet lady comes into the reception area with her dog. She sits next to Jenny and asks, "Do you want to hold Derby [the dog]?" Jenny replies, "Ha." She holds on to the reins of the dog lying at her feet. ... Jenny visits quietly with the dog and his owner for a while. Then she sees everyone settling in the music room and decides to go in. Soon after she comes back to the reception area and makes a line on a writing pad with a pen. She then goes to the office and stands with the staff.

12:55 pm – 1:30 pm. Jenny is standing at the reception where the staff members are planning the afternoon. She goes in the arts room and looks around. She comes back to the reception area and finds the garbage can. She throws in a tissue. She goes out the sliding doors at the front. The staff member calls her in. She asks Jenny if she wants to go out for a walk. Jenny says, "Ha." The staff member suggests that they go in the backyard. We walk out to the backyard and sit on a park bench in the sun. Jenny looks happy and content. She seems to like the outdoors.

The staff member has to go inside. She says to Jenny that she can sit outside if she likes. Jenny says, "Ha" but gets up and follows the staff inside. On the way they meet another person coming to sit outside. The staff member suggests to Jenny that she sit outside with her. Jenny says, "Nein" and goes in with the staff. She walks around for a bit and follows the staff to the multipurpose room where they are lowering a person on a floor mat with a hoist. Jenny watches for a while and has another walk in the hallway. She then comes back in the multipurpose room and sits down.

Someone is sitting next to her and her housemate is sitting opposite. The radio is on and the room is softly lit. The lady on the mat is resting. It seems that this is quiet time. Jenny seems to look less cheerful than when she was outside. But she is calm and stays seated here till 1:30 pm. She

then starts to walk the hallway, perhaps anticipating that it will soon be time to go home.

Jim's and Jenny's field observations indicate the contrast of activity and level of support that is required by people with a dual disability. While Jim could use sign language with others, Jenny's communication was apparent more in her actions. Even though she responded verbally with two words, it was her subsequent action that indicated what she really wanted to do. As well, what is apparent with both Jim and Jenny is that they frequently walked around when in their community programs seeking human interaction, observing what was going on, and deciding if they wanted to participate.

Divergent perspectives on community activities. An administrator said that the agency advocated for "supported inclusion" to enable consumers to fully participate in community programs. However, the data evidenced a divergent practice between the philosophical stance of inclusion and segregated participation in agency-run day programs. It seemed that this practice was carried over from previous experiences in community. Direct-care staff said that Jim, Jenny, and Donna had attended segregated programs prior to dementia. Staff, when applying the criteria of consistent and person-centered approaches, took consumer lifestyles into account and facilitated participation at these programs if the consumers desired to do so. Donna's fears of getting in the van had prevented her from going out according to direct-care staff. It was observed that Jim and Jenny continued with planned outings to their segregated day programs.

Community participation was a significant theme in this study. A direct-care staff worried that lack of resources at consumers' day programs might mean that "they don't go anymore" and they would not be able to "find a different spot [in the community]."

Lack of preparation in the community to include people with a dual disability in mainstream community programs has been identified by stakeholders in this study.

Administrators reported that additional resources and enriched supports are required to facilitate inclusion. Direct-care staff said that consumers stopped going when it was no longer comfortable.

When resources were available, the data showed that integrated participation in community was supported as stated by an administrator:

A1: ... Some days, the guy living there is still really active, so he has certain community events he attends weekly so you have to make sure you have staff there to take him and make sure he gets to it.

As well, a direct-care staff mentioned how change occurred when staff and person-centered planners pushed for resources as in the case of an individual who wanted a one-on-one holiday:

DCS2: One-on-one holidays with an individual were never heard of, thought of, five years ago. Where this person's dream was, 'I don't want to go with anyone else,' and we were able to do it; so that's a huge success. ... Management [had] to because the person-centered planner pushed for this too; and then it's a change when things start to shift ...

Similarly, I observed that participation of consumers in integrated activities depended on resources and opportunities in community. Jim attended both segregated and integrated vocational programs. I also met Jenny at her segregated leisure program, and due to transportation challenges, she did not participate in integrated leisure activities that were planned on that day. Field notes illustrate that Jim and Jenny appeared to find benefit when participating in their community activities. In the next two themes of participation in planned and spontaneous activities, the findings indicate that consumers had greater exposure to textured lives in integrated spaces in community.

Participation in planned activities. To further nurture social connections and attendance at places of work and leisure, consumers were supported to participate in the community through planned activities such as holidays and short trips. Rose was described as nonverbal and unable to walk; she required total support. She spent most of her day in the home seated in her wheelchair or in bed. However, she was supported to enrich her life within the community, as documented in a log about her trip to the fair:

LN: Rose had a fabulous time at the fair. She spent 4 to 4.5 hours there and was very alert and aware of her environment. [She] loved the comings and goings of people, the noise, and the food. Ate lots of junk food and loved every minute of it. Went to the casino and vocalized with much delight. Was assisted pulling the handle down on the slot machine. Laughed most of the time ...

Rose also liked to go to the seniors' center, where she had made many friends over the years. Evident in this field observation, at one such trip with her family caregiver, it seemed that Rose connected with the place, people, and music:

FN: Rose seems quite bright-eyed and wide awake. She doesn't look as tired and sleepy as she does some days. Rose watches a group of about 50 seniors line dance in the gym hall. She listens to the music. Sometimes she is up looking around. Other times she is bent over but mostly awake.

Several times during the morning old friends come and say "Hello" to her. They call her by name and wait for a response. Sometimes Rose looks at them intently and sometimes she makes a grunting sound. It seems as though she recognizes a face or a voice and looks up ...

Rose's friend caregiver leaves to dance for a while and Rose watches. A couple of times the caregiver stands Rose up from her wheelchair and holds her in an embrace; they dance together ...

Rose's experience at the Seniors' Center demonstrates that, even when a person has progressed to the later stages of dementia, there is much benefit to social activity and engagement outside the home. Rose seemed to enjoy the social stimulation on the outing, valued being among friends, and felt nurtured by loving human contact. The benefit of

the social activity was evident in how she stayed awake for the whole event, seemed alert to everything that was going on around her, and responded to familiar faces that came over to greet her.

In all instances of community activity discussed thus far, stakeholders mentioned a level of commitment was required by staff and caregivers to facilitate participation. Commitment was required to provide the resource and include the person in the environment. Donna's family caregiver said that the commitment to participate in community activities was what demonstrated the quality of life for her; a commitment that was honoured even in the face of adverse reaction:

FC2: She swore and cursed at the staff the whole day and kept up the staff at night. But the ability of the staff to go ahead and do that [take her out] because they knew that she liked the theatre ... [is what] I would gauge quality of life on.

Participation in spontaneous activities. Observations in the home indicated that as consumers progressed through dementia, their ability to engage with planned activities became more and more unpredictable, but their ability to engage spontaneously with others in the external community could be captured in the moment. Staff facilitated spontaneous activity according to the consumer's expressed interest, and documented consumers' visits to numerous venues in the community on an ad hoc basis, including a senior's centre, church, theatre, sports arena, recreation centre, park, tourist attraction, restaurant, shopping mall, or event.

During the study consumers were seen to request (and were supported) to participate in a spontaneous activity. Donna, who was usually hesitant to leave the house, expressed a desire to go out for an ice cream and to visit a friend. Jim, who went to his vocational program almost every morning, frequently initiated trips into the community

upon return from work. His usual request was for his special hamburger meal and a trip to the store to purchase a newspaper. As documented in his daily log, one such trip was then spontaneously expanded into an outing of leisure that incorporated several points of contact for stimulation and pleasure:

LN: Jim went to restaurant for hamburger and onion rings. Ate in restaurant. Went to gas station for gas and a car wash. Arrived at [name of chain] for paper and a pop. Drove for a small ice cream. Went to [name of place] for a walk in the park and stopped to look at the swans before heading back home.

Jim and Donna were able to make requests for an outing, engage fully with the activity desired, and had the support of staff to make it happen. However, as other people progressed through dementia, they were less able to initiate or communicate such requests. In the belief that all people could enjoy leisure and fun, opportunities for historically preferred activities (such as swimming, walking, visiting friends, going to concerts and musicals, driving to places of interest, eating out, and shopping) were offered, irrespective of knowing how the activity would be experienced. A direct-care staff stated:

DCS4: We have a woman who can go to the theatre. [We] went to see [name of musical] [and she had] a great time the whole two hours. Took her to another one, she didn't give a care, slept through the whole thing.

Whether the person enjoyed an activity or not was gauged by the individual's verbal response or nonverbal reaction at the time: "smiling and looked happy; had a great time, lots of laughs; slept through; refused..." and the activity was accomplished or terminated according to the person's demeanour. In this manner, the staff continued to offer opportunities for socialization, work, and leisure outside the home to sustain links with the external community.

When individuals reached the stage where participation in circles outside the home became severely restricted due to ill health, discomfort with crowds, confusion with unfamiliar environments, and fear of leaving home, they would become more confined to the home environment. Anticipating this change, especially as the person advanced to the later stages of the disease, practices of empowering the self focused on the inner community within the home.

Self in Inner Community

Sustaining an inner community environment in which consumers could experience a sense of self became a focus as they withdrew from community outside the home. The data evidenced several opportunities for genuine social relationships and active engagement within the home. Consumers continued to live a retired lifestyle performing their roles in a family of peers.

Active engagement in the home was inserted in an unstructured and individualized fashion according to the context of the moment. Administrators and direct-care staff said that this approach (as opposed to activation by structured programming) simulated the living of retired people in their natural settings. As they were in the external community, opportunities for interaction with the environment and socializing with others in the home were facilitated through work and play. The self in the inner community was nurtured through participating in home and leisure activities, socializing with peers, developing caring social liaisons with support staff, and building mutual aid.

Participation in home activities. Consumers were supported in their daily-living activities via a person-centered philosophy. Direct-care staff said they sought to support activation in a non-coerced way that would respect the person's desire and comfort.

Further, family caregivers in the study viewed activation in the home as a way of helping their loved ones “stay healthier.”

During field observations, consumers were seen assisting with cooking, cleaning, and doing laundry, house chores, paperwork, and self-care on an ad hoc and unstructured basis. That is, they were encouraged into activation when they showed an inclination to do so. A direct-care staff said, “When people initiate things [we] go ahead and help them with that initiation. All of a sudden they remember to wash dishes or they remember, ‘Oh! I used to wipe the table.’”

Thus, supporting the ability of the consumer did not mean telling them to do a chore but rather “feeding” into a memory which “may only last two seconds or five minutes or ... half an hour.” Staff “fed” into a memory by bringing in view a sign, such as “opening the dishwasher so they know where the dishes go because they are walking towards the dishwasher.” Direct-care staff said that this type of support was facilitative and impromptu, as opposed to directive and structured (which could be confusing for an individual with dementia).

Impromptu support was facilitated for Jim who was fairly independent and often indicated a strong preference for meals other than what had been prepared from the menu. During field observation he was seen requesting that staff prepare rice for his supper. This particular staff, knowing Jim’s aptitude for cooking, engaged him to prepare his own supper of rice and ketchup:

FN: Staff says, “Jim and I will prepare the meal together.” Jim fills a pan with water and gives it to staff. The staff member puts it on the stove. Jim points to the pantry. He walks over, opens the pantry, and shows the box of Minute Rice to staff. He takes it out and gives it to staff. Then he opens another door to the pantry and takes out a bottle of ketchup. Staff signs to him that there is an open one in the fridge. Jim puts the bottle of ketchup

back in the pantry. He comes over to the kitchen counter where staff is setting a measuring jug. The staff member shows Jim how much rice to pour in the jug. He pours the rice in the jug with the help of staff. He checks the jug and suggests they need to pour some more rice. Staff signs, "Go ahead." Jim pours a little more rice in the measuring jug.

This example shows how spontaneous and individualized participation in preparing a meal was facilitated in a moment when he desired to do so. In that moment, Jim occupied the role of cook – a role that he was familiar with from his work at the day program.

Similarly, Jenny was often seen in her role as homemaker – organizing, cleaning, and folding the laundry. Donna was the entertainer, rallying everyone to clap and dance to music, while Rose encouraged her peers to show care and gentleness toward fragile people. In addition, all the individuals continued with their role in self-care as much as possible. Staff calibrated their support according to what the individual was able to accomplish in each interaction, remembering that change in ability was sporadic.

This kind of sporadic change in ability was observed with Jim. After he cooked his meal with the staff, he sat down to eat, but seemed unsure about how to eat with his spoon. Staff assisted Jim to take a spoonful of rice, which was sufficient support to prompt his memory about eating:

FN: Jim appears to be confused about how to eat the rice with a spoon. The staff member holds Jim's hand and helps Jim to fill up his spoon with rice. She asks him to try it. He does and signs to the staff that it tastes good. Staff signs to him to eat it all. He starts to feed himself until he has finished his meal.

Consumers showed different levels of ability depending on how the effects of dementia were presenting in a given moment. It was evident that the consumers oscillated between clear and not-so-clear moments that were recognized by the staff. As well, support in each moment was adjusted to the change. In this fashion, every interaction in

daily living was maximized to encourage them to participate according to their preference and ability.

Participation in leisure. Another way that consumers participated in the inner community was through leisure interests. Supporting leisure interests was a way of creating opportunities for fun and socialization in a comfortable environment. A comforting environment needed to anticipate and respond on an ongoing basis to the wishes of the consumers as stated by a direct-care staff: “Sometimes people don’t prefer a big crowded area, they prefer more of a quieter tone,” or “they prefer not to do much at night, they would rather stay home and relax and watch TV or a movie.” During field observation, there were many occasions when consumers enjoyed quiet periods of leisure and rest in the living room:

FN: Jenny is sitting quietly in the living room next to Donna who is watching TV. Housemate is sitting on another sofa with legs stretched out on her rocking chair and playing cards. Donna is periodically dozing in between looking at the TV screen where soaps are playing. She sings or hums briefly as a song comes on. It looks like an ordinary afternoon in the home.

In the midst of ordinary life, leisure activities in the home were spontaneously inserted according to the interests that the individuals enjoyed. For example, the staff members were aware that Donna liked musicals and had assisted her to acquire a collection of her favourite CDs and movies. Often, this collection was used to entertain Donna and keep her in a happy frame of mind. The following field observation describes Donna’s demeanour when staff decided to put on a favourite movie that never failed to excite and entertain her each time it was played:

FN: Donna is finishing breakfast in the kitchen. Staff comments that Donna likes music and likes to dance in the morning at breakfast time. ... The staff member goes in the living room and puts on a movie. She says to Donna that her movie is on. Donna goes in the living room. As soon as the

movie starts, she walks back to the kitchen excited, a big smile on her face, looking happy. She says, "Look! What's this?" pointing at the TV in the living room. Then she exclaims, still smiling, "Not again!"

She goes in the living room and sits down on the sofa where she usually sits. She seems settled there for a long time, watching the movie, periodically calling out to the staff in the kitchen, and singing the songs. ... [When her song starts] she claps to the music and starts to sing. She gets up, waves her hands, smiling and dancing, stepping side to side. She sings the words of the song loudly raising her hands above her head. She sings louder as the music crescendos and ends when the song ends. ... A while later another song starts up on the TV. Donna shouts out, "Here it goes again!" She starts to clap and the staff member joins in.

Donna's enjoyment with her favourite movie was an impromptu leisure activity that was facilitated many times during field observation.

Other examples of impromptu leisure seen in the home involved going for short walks in the neighbourhood, watching TV, listening to CDs, listening to the radio, singing, dancing, watching movies, looking at magazines, cutting paper, playing cards, celebrating birthdays, having a manicure, and sitting out on the patio. The following field observation, for example, describes how consumers enjoyed leisure time on the patio, taking in the good weather, listening to the staff conversations, and hanging out with each other:

FN: Donna seems to be enjoying the day on the patio. Jenny is sitting drinking her juice. ... Donna sits down with a glass of juice [saying], "I got it!" Donna takes a sip of her drink and says, "Good drink!" She talks to Jenny about her trip on a boat that she is planning with staff. Every now and again she looks around and comments, "Nice house! Nice flowers! Good juice!" Jenny just sits quietly periodically glancing at Donna and smiling.

Conversations among the peers sitting on the patio demonstrate that they liked to socialize with each other. Participating in many moments of pleasure and joy individually or as an intimate group led to many more opportunities for building relationships while socializing with peers.

Socializing with peers. Opportunities for socializing with each other abounded through enjoying leisure time and working together as a small group of peers in the home they all lived in. These forms of socializing helped consumers to settle in with each other as a family, so that they did not become isolated in their bedrooms. Especially in the living room, I observed the consumers spending time relaxing in their favourite chair, watching television, busy with some activity, or just sitting with their housemates. While certain areas (e.g., bedrooms and bathrooms) were respected as private spaces, staff encouraged people to gather in the common areas – living room, kitchen, and patio.

Even when individuals were reluctant to venture into the common spaces, the staff used strategies to encourage them to interact with peers. When Jim first came to live at the home, he stayed in his bedroom with his door shut. Staff adopted the strategy of encouraging Jim to keep his door open. Gradually, after he opened his door, Jim began to venture out of his room to talk to his peers for short periods of time. In this way, he began to feel comfortable socializing with his housemates.

Jim's comfort in socializing with his housemates was evident in field observation.

Several times he came out into the common area and instigated playful interactions:

FN: Jim comes out of his room. He is making playful and friendly gestures to Jenny and Donna sitting in the living room. He goes up to another housemate who has just come home. He strokes, hugs, kisses, and play-fights with her on the sofa. Then they chase each other into the kitchen. They are laughing and appearing to be having a lot of fun.

Tender and caring exchanges of friendship were often noted during field observation – acts of smiling, stroking, hugging, kissing, rubbing someone's head, laughing, joking, sitting outside with peers, relaxing in living room with peers, and chatting with each other. Sometimes peers verbalized their affection for each other: "I kissed her. ... She is

my friend,” and giving compliments: “She is a cute girl,” and “That’s a good girl, keep it up!”

By having interactions with each other, encouraged and facilitated in their experience of daily living, the consumers were seen to relate to each other as friends. They formed a cohesive family of individuals who demonstrated care, support, friendship, interaction, and play. An important factor in creating an environment where consumers were able to occupy social roles and feel satisfied with their social relationships, productivity, and leisure, was the quality of their relationship with the staff.

Nurturing relations with staff. Stakeholders in this study said that qualities of “caring,” “compassion,” and “loving” were very important when supporting people with a dual disability. One caring practice, according to an administrator, was a support worker’s staying by the bedside of a person who was sick or dying: “I don’t know how many times I have read reports of staff sitting there all night holding someone’s hand,” and “being there for the person till the end.” Such practices were taken as indicators of success in the home; they showed that staff genuinely cared about and extended themselves in concern for the person with a dual disability.

As well, another administrator added that in the physically and emotionally challenging environment of dementia support, staff were committed to support even when the person did not have much time left to live:

A2: The one lady we supported ... her doctor had said that she didn’t think she would make it to Christmas. So the staff came to me [administrator] and said, “Is it okay if we celebrate Christmas early?” I said, “Of course it is, let’s do it.” So we had Christmas and she was involved and still hung in there. There was a part-time staff who worked on Christmas Day and she planned that she would take everyone to her house for a while ... and she [the person dying] still went. The lady died on Boxing Day night.

In this example the emotional stress of supporting a person who was dying was overridden by a commitment to facilitate one more experience of celebration. Such a level of commitment was driven by compassion and the ability of the staff to empathize.

A caring practice with a high level of commitment to support the individual as desired was evident to Donna's family caregiver. She highlighted how staff members were able to balance Donna's needs and deflect negative behaviours:

FC2: ... balancing [the support] with the times when she is not a very happy person. Verbally she is swearing at people and cursing; she has never done that before. So she is not always a very nice person now but they [staff] have done a good job of deflecting that anger to where it needs to go.

Additionally, family caregivers and direct-care staff said that negative interactions in the support relationship must be overlooked, to maintain the respect, dignity, and positive view of the person with a dual disability. Family caregivers claimed that, "They [staff] treat him with the utmost respect and dignity" and "[are] very respectful of her as a person and what she needs." Respect was evident in how staff modeled their practice as mentioned by a direct-care staff:

DCS4: Before I enter the house I knock on the door. I wait, I open the door and say, "Hi, hello! I am here!" I do it because it is not my home; I don't live there. I wouldn't walk into somebody's home ...

As well, respect and a positive view of the consumer were evident in the affect of the staff. Family caregivers noticed staff members who had a "good personality;" their affection was evident in their demeanour and discourse with consumers. Donna's family caregiver said: "They [staff] love what they do and I think that comes through in the feeling that they love the clients." Jenny's family caregiver echoed the same sentiments; even though Jenny "doesn't usually express anything" she responded to the love she felt from a staff:

FC3: When I bring her back on the Sunday night, often there is a man working. ... Oh! She loves him and he loves her. It's all very innocent but he makes a fuss over her and she likes that.

Jenny was not able to verbalize the affection she felt from the staff but it was clear to her family caregiver that Jenny had felt the affection and had engaged her in the social interaction.

Stakeholders said that having genuine affection and demonstrating it in the support relationship was imperative to nurture the self of the person with a dual disability. A direct-care staff concurred; if anyone came to work with people with a dual disability as a paid job, she said: "then you are in the wrong field." She added that one does this job because "you love these guys" and "you do so much for them and you are so personal with them that you become attached to them."

The display of affection and consequent activation of the experiential self were evident during field observation of staff and consumers mirroring their affection for each other with physical expression and verbal accolades: "Donna is happy, blowing kisses to staff feeding Rose. She says she likes [name of staff]." This verbal and nonverbal complimenting and cheering of each other generated an affirming environment.

Staff enhanced the affirming environment by using empowering discourse that bolstered the positive morale of the consumer. Such discourse, evident in field notes, included statements such as: "Thank you everybody for being so patient; thank you for doing a good job, thanks for the hug – I feel so loved, I feel so special." As staff used empowering discourse they playfully inserted "encouragers" into their interactions such as: "Nice to see you so happy and smiling – wonderful! Hi lovely! You look beautiful!" This enabled the person to feel successful in the interaction of the moment as noted in this field observation:

FN: Staff is supporting Jenny to fold the laundry. She asks Jenny, “Did you fold the laundry again?” Jenny says, “Ha!” The staff member gives Jenny a hug and compliments her for helping out.

Likewise, it was evident that the consumers sought the encouragement of staff to continue with an activity, as was observed in this interaction:

FN: Staff walks into the kitchen where Jim is having his supper at the table. She calls out to Jim, “Is it good?” Jim nods, “Yes.” He calls over to staff at the sink. He holds up his can of pop and staff animates with her hands saying, “Cheers! Bravo!” Jim chuckles and drinks his pop.

In giving and seeking encouragement, yet another function of empowering discourse materialized – that of stimulating a reflective assessment of the outcome of the interaction. For instance, when using empowering discourse, I observed that staff sought feedback from the individual: “Is it yummy? Is it okay? Good job [name]! Do you need help?” In a respectful way the staff asked permission of the individual and received a response: “Is it okay?” “No?” “Well then, do you want to do it yourself?” In such exchanges the staff used empowering discourse to elicit responses on how to do things with a person without assuming to make and implement even minute decisions.

My observations in the home demonstrated that empowering discourses enhanced the well-being of the consumers, by acknowledging their worth and self-efficacy in the interaction. Reinforcing a respectful approach, it kept the strengths and positive attributes of the person at the forefront. Modeled in a caring practice built on compassion, commitment, and genuine affection for the individual, empowering discourse raised the consumers’ morale and motivated them to respond. In turn, the consumers modeled the empowering language, engaged with activity, sought encouragement from the staff, and provided feedback on the support they had received. A reciprocal relationship formed in nurturing relations with staff created opportunity for mutual aid to flourish in the home.

Building mutual aid. Family caregivers' presence in the home generated more nurturing relationships, fostering an empowering condition of mutual aid as they, their loved ones, staff, and peers merged their roles in the support environment. Family caregivers were included seamlessly, as explained by this administrator: "We've had families that more or less moved in [the home], not really but it felt like [it] at times." Family was welcomed to be with their loved ones as often as they desired. Rose's family caregiver said, "They have made me feel at home. I can go there anytime I want and do whatever I want." A direct-care staff elaborated that including family caregivers was what consumers "would want so we need to respect that." Family members were encouraged to stay and care for their loved one:

DCS3: When an individual was really sick the parents had a couch in the room and they slept on the couch and stayed with him ... rotated shifts ... and that was fine with us. That's what they needed to do and he [person with a dual disability] needed it too.

As family caregivers became part of the support circle in the home, staff took it upon themselves to extend their support to them. Staff perceived this as a need, to ensure that "the family is okay – not that it is our responsibility but it is something you take on because they are important to that person [consumer] and that person would not want to see them sad." Staff became attentive to the emotional welfare of the family member, to help them stay strong and optimistic during critical hours of need, as mentioned by Donna's family caregiver:

FC2: ... the (staff) has never said it to me but the seizures [for Donna] could be more frequent and this [death] could be tomorrow, this could be a year, 10 years. But they [staff] are concerned about me ... I talk to them.

Care and concern extended to the family caregiver was, according to an administrator, "one of the most comforting things to families and to the people [who live in the home]."

In the act of extending support to the family caregiver a mutual aid system of caregivers handling the impact of losses from dementia was forged. Donna's family caregiver stated, "... it's great, sort of like we're all in it together, like a partnership, a team approach – so much so now that she needs more care." Administrators observed "a great deal of love, affection, concern and contentment on the part of the families," and staff were described as "wonderfully giving ... [they] watch people die before their eyes, grieve that, and then move on to the next person." It was evident that staff and family caregivers used their team to support each other during times of grief as mentioned by Donna's family caregiver: "She [staff] lost her dad a couple of years ago and I lost my dad ... we talked a lot about that."

A similar kind of support was extended by management to staff and peers in the home. An administrator said that offering support was particularly important when someone died:

A1: When it comes to notifying family that their loved one has passed away – to expect that of your staff member is not fair. We as management need to be on site, comforting staff, dealing with the coroner, dealing with the police, supporting the other people that live in the house and showing them that we are there for them.

The circle of mutual aid in the home, then, was expanded to include a team of family caregivers, staff, and management.

At the same time, strong bonds between the consumers in the home were evident. An administrator said that one housemate who had lived in this home since it had opened had become a "house mother. ... She takes people under her wing and helps them feel loved and comfortable in their house." In the same manner as for the staff and family caregivers, special bonds among the peers carried through to supporting each other in

difficult times. For example, Rose's family caregiver described the mutual aid extended by a peer during a long episode of sickness:

FC1: When Rose was sick for that month [name of housemate] actually sat in [Rose's bedroom] with a deck of cards and stroked her hair. ... And another resident who was having problems herself talked to Rose and said, "Come on, open your eyes," and tried to feed her.

As peers got involved in the act of caring, the support team expanded even further and included them in a mutual system of support.

Divergent perspectives on including family. The findings indicated that family caregivers were integral to the circle of support around the consumers. However, the data pointed to divergent perspectives between staff and family caregivers when providing dementia support. When knowledge about dementia support varied between these groups, tension arose in deciding whose knowledge to privilege.

A direct-care staff said that family caregivers, untrained in dementia support, persisted with feeding a loved one in the end stages of dementia:

DCS2: They had to learn about that from the doctor. He said, "You are killing your son because it is going into his lungs. When he is coughing, he is telling you he has had enough."

She continued to raise the concern with the family caregiver sensitively: "So supporting them [family caregiver] to remember what the doctor said ... and they would stop feeding him."

This tension between formal and informal caregivers was compounded when staff felt that they were displaced by the family caregiver. A direct-care staff explained: "It is a hard transition ... as staff you kept thinking, 'that's my job ... and I need to do this because I am here for that reason.'" Another direct-care staff said that sometimes it was easier for staff to give in to family caregivers:

DCS4: When parents are there whatever they say that's what you do ... Example, [name] is cold so mom gets a sweater and puts it on, when you know she can't stand it, but mom's the boss. You do as parents say."

Family involvement was "sometimes challenging" according to an administrator.

Reaching consensus, especially when safety of either the consumer or the staff was compromised was necessary as evident in this quote:

A4: There have been times with other families [when] we have had to say we can't be responsible for your behaviour; this is what we expect, this is what we will provide. If you want to do something different, you can do that when the person is visiting you at your home. We have had family members sign off on legal documents saying we are not going to be responsible should something happen.

In the absence of consensus between family caregivers and direct-care staff consumers were left to experience inconsistent support increasing their distress. Distress is disempowering for people with a dual disability. The divergent perspectives discussed in this chapter identify themes that result in the disempowerment of consumers.

Collectively, these themes address the third major category highlighted in this study: barriers to supported empowerment.

Barriers to Supported Empowerment

The findings of this study demonstrate that disempowerment resulting from a marginalizing social process of death by reduction can be countered with several empowering elements in a parallel social process facilitated with a person-centered philosophy of support. However, the findings also demonstrate barriers in the parallel social process that hamper autonomy, decision-making, self-efficacy, choice, participation, and mutual aid.

Barriers to supported empowerment fall into two categories: (1) practice deficits as evidenced through the themes of (a) lack of healthcare knowledge, (b) lack of enriched

supports, (c) inconsistent support, (d) balancing risk to safety, (e) caregiver disagreements, and (f) segregation; and (2) resource deficits as evidenced through the themes of (a) staffing shortages and (b) funding shortages. Table 5 illustrates the thematic findings in the category of barriers to supported empowerment.

Table 5

Major Category: Barriers to Supported Empowerment

Practice deficits	Resource deficits
Lack of healthcare knowledge	Staff shortages
Lack of enriched supports	Funding shortages
Inconsistent support	
Balancing risk to safety	
Caregiver disagreements	
Segregation	

Practice Deficits

Practice deficits are portrayed in divergent perspectives within interview and observation data. These perspectives emerge in the themes of maintaining health, sustaining autonomy, choice of home, consistent support, community activities, and building mutual aid by including family caregivers. Only an interpretive summary of these barriers to supported empowerment is provided here as they have already been demonstrated under their respective themes.

Lack of Healthcare Knowledge

Divergent perspectives highlighted the barriers to maintaining health of consumers. Some direct-care staff and family caregivers identified that the level of

medical training among staff fell short of understanding how to address comorbidities associated with dementia and bereavement. Deficit in healthcare knowledge led to poor quality of personal support and unnecessary use of medical services according to a family caregiver. Although, administrators welcomed feedback from family caregivers, family caregivers said that they felt disempowered to complain. Also, one family caregiver advocated for in-home therapeutic interventions to prevent loss of function, and direct-care staff and administrators supported the use of medical services integrated in the mainstream.

Lack of Enriched Supports

To adequately meet the needs of consumers in all stages of dementia, an administrator proposed three levels of support in a continuum of care. He stated that enriched supports to include consumers in community-care and long-term care services were needed where the majority would continue living at home and an estimated 30 percent would require supported (like the home studied) or nursing home living. However, majority stakeholders concurred that consumers would not only prefer to live independently in the community with adequate supports, but also to age in place.

Inconsistent Support

The quality of the living environment was another source of distress to the consumers. Stakeholders stated that inconsistencies in support resulted in consumers experiencing loss of control increasing their risk to mental deterioration. Inconsistencies occurred as a result of differential information upon which caregivers (family and staff – whether they were new, part-time, or full-time) operated. Differential information materialized from short-term exposures in supporting the consumer, communication lapses at shift changeovers, and varied understanding of dementia and personal support

among caregivers. Short-term exposure to the needs of the individual affected the comfort and quality of the support.

Balancing Risk to Safety

In particular, perspectives on whether a practice was harmful or not to the consumer led to actions on the part of staff. Consumers were disempowered when staff tried to balance risk to safety with the individual's right to self-determination. The case example of Donna indicated that duty to care took precedence for staff. For example, a different practice for Donna, such as supporting her to go out when she wanted to do so, could have resulted in more choice and a less intrusive intervention. However, professional responsibility to "keep her safe from wandering" stifled her ability to sustain her autonomy.

Caregiver Disagreements

Facilitating the choice of the individual became more tenuous when family caregivers and staff disagreed about a practice. In the absence of compromise, administrators and direct-care staff stuck to their positions protected by waivers against any harm subjected to consumers. Family caregivers retained the option to pursue inappropriate practices when consumers were in their care and in their home environments. Once again, consumers were disempowered to assert their autonomy.

Segregation

Finally, the findings illustrated a divergence from adherence to supported inclusion when consumers continued to participate in segregated day programs. Jim and Jenny continued to participate in segregated day programs; options continued from their historical liaisons with the agency. Although administrators and direct-care staff supported integrated activities they said that consumers were "traumatized" by

environments that did not offer individualized support. They cited lack of resources and enriched supports in community services as barriers. These barriers were confirmed in converging perspectives of stakeholders, discussed next.

Resource Deficits

All stakeholders agreed that a significant factor in ensuring individualized support is the availability of resources. Resource shortages were experienced when supporting individual needs and maintaining the home. Stakeholders stipulated that sufficient staffing and funding is necessary to ensure consistent, adequate, and empowering support to consumers.

Staffing Shortages

Direct-care staff and administrators said that their “biggest fear” was being unable to provide the quality of support required for the personal and emotional well-being of consumers. A direct-care staff said it was a challenge to provide adequate support with skeleton staff: “If I am staffed on my own between now and 3:00, and if an individual all of a sudden said, ‘Look I want to go shopping’ – that’s the barrier, because I can’t leave two or three more people behind.” Jenny’s family caregiver also mentioned that lack of staff was a restriction on her going out: “if there is one staff for four people, they can’t leave three people in the house alone and take her for a walk.”

In particular, the administrators and direct-care staff were very concerned that the existing level of staffing would not be adequate if more people moved into the third stage of dementia. It was already evident, according to a direct-care staff, that when an individual was hospitalized, staff shortages in the home resulted in deficient support: “The hospital does not happen all the time but when it does happen you struggle trying to

find staff for the house [and] for the hospital ... [if] we are short-staffed at the house ... somebody loses out there.”

Clearly, lack of staffing in the home restricted the opportunity for consumers to engage in activities outside the home. As well, staff shortages jeopardized their quality of life when staffing capacity was inadequate to meet their support needs. Another resource issue that diminished the quality of living for consumers was the shortage of funding required not only for more staff but also to maintain the facility.

Funding Shortages

Maintenance of the home environment was recognized as very important in ensuring adequate living conditions for consumers, but all stakeholders declared that maintenance of the home and equipment was a low priority, due to lack of funding. During observation it was evident that delays were experienced when equipment broke down (e.g., lifts, agency van). Two staff held the following conversation during field observation when the bathroom lift had not been repaired:

FN: Staff are discussing Donna’s morning ... Morning staff says that the lift in the bathroom is broken so she gave Donna a shower. She found it somewhat challenging to shower Donna on her own but she felt it was necessary to do so as Donna’s bathing protocol stipulates bathing must be done in the morning. She says that she was relieved when Donna was calm in the shower and did not scream as she usually does at bath time.

Donna always used the bathtub with a lift for her morning bath. As she had a fear of water, the staff felt that they could keep her safer and have better control of the situation if she became agitated, if she was in the bathtub. As well, it was necessary to keep to her routine of a morning bath in order to deter a state of confusion later in the day.

A dilemma in completing the usual bath routine for Donna arose: the bath lift was broken. Complicating matters, during Donna’s bath time only one staff was on duty. This

staff member was caught in a conflict – between waiting for the second staff to arrive so they could shower Donna together later and managing the shower on her own at the routine time. She chose the latter, feeling responsible to not create confusion for Donna even though she had some trepidation in showering Donna alone.

Funding was also required to ensure the safety of the built space. A family caregiver said that changing floor surfaces in the home posed a risk for falls when “she will lift her leg and try to climb over it.” A similar challenge was also noted during field observation: “Donna seems to be having difficulty stepping over the tiled floor onto the carpet.” Donna’s hesitation to step over was indicative of changes in depth perception, a condition that arises in dementia. Negotiating uneven floors that create differences in depth perception puts people with dementia at greater risk of falls and injuries. Family caregivers and direct-care staff had raised this concern with management, but they were told that there was no funding to renovate the flooring in the home.

Stakeholders said that shortage of resources can hamper the quality of life of people with a dual disability. Such resources also need to be flexible so that individualized needs can be met. All stakeholders concurred that additional resource was required when the needs of a person with dementia were escalating (e.g., staying awake during the night) or needing accommodation of a personal goal (e.g., going on a one-on-one holiday with a worker of her choice). They emphasized the need for adequate resource so that consumers could have choice, dignity, and safety at all stages of dementia.

Summary of the Social Process of Empowerment

The social process of empowerment was captured by the findings in the second major category in this study, living by supported empowerment, consisting themes of

maintaining selfhood, freedom of choice, and self in community. In the thematic finding, **Maintaining Selfhood**, a sub-theme of maintaining health was emphasized to mitigate dementia comorbidities that put consumers at risk of rapid deterioration. In the home, physical, as well as emotional, health concerns were managed by staff trained in basic health management, who teamed with the community health system. The flexible delivery of community health services according to the comfort of the consumers facilitated seamless healthcare. Good health motivated the consumers to interact with their environment and was critical to maintaining selfhood. The self was maintained when consumers participated in decision-making, exercised self-agency, and asserted their autonomy.

In the theme, **Freedom of Choice**, the first sub-theme identified was an alternative choice of living. While all stakeholders advocated that consumers age in place, the next best option, according to stakeholders, was the home specializing in dementia support. The findings highlighted processes whereby consumers were given the freedom to choose the move to this home. They were consulted about their wishes to relocate to the home and their assent was garnered through verbal and nonverbal communication. Spending time in the home, getting to know the staff, and building a relationship with those living in the home were some of the ways used to facilitate informed consent from consumers.

Once a successful transition was accomplished individual choice was facilitated with person-centered approaches and consistent practice for dementia support. Partnering with significant caregivers and past workers staff ensured that the environment and support could be personalized, helping to facilitate a stress-free settlement. Consumers were free to choose to live each day as they preferred. Their choices were

sealed in a Life Plan, and the individualized goals and method of implementation documented in the plan were regularly reviewed. Staff members were informed by historical and cumulative knowledge to implement person-centered support, activating the voice and wishes of the individual. For those in the advanced stages of dementia elevated empathy, built in the relationship between the consumers and their support staff, was used as a tool to continue facilitating choice.

The third theme, *Self in Community*, emphasized maintaining lively, meaningful connections and participation in a community; particularly relevant as a consequence of dementia is to fragment one's identity in how one relates to others and how others relate in return. For the consumers, belonging flowed between and within the outer and inner community spaces, providing opportunities for them to work, play, and socialize together, so that they felt a part of the community – a community that provided sustenance for a life of productivity, pleasure, and caring human connections.

In the outer community some consumers participated in segregated vocational and leisure programs. Field observations showed that both Jim and Jenny enjoyed being in these social spaces, used them as opportunities to connect and engage socially with others, and valued their participation in short bursts or long spells of work-related or leisure activity. As well, all consumers experienced integrated life when participating in work and leisure activities in mainstream spaces. These activities, planned or spontaneous, activated them, giving them purpose, a sense of competency, and the satisfaction of being part of social life.

In the inner community stakeholders said that the home fostered an intimate community in the small, homey, and welcoming environment. In supportive relationships

consumers participated in work and leisure-related activities and modeled acts of caring, affection, and social interaction. All stakeholders mentioned that the staff's qualities of compassion, commitment, and affection ensured the respect, dignity, privacy, and comfort that consumers needed. Key indicators that consumers were receiving a caring practice, these qualities enabled the staff to elicit a level of participation from consumers.

Staff extended their compassion in the support relationship, simulating family-type interactions of genuine care. Compassion enabled the support staff to be empathetic about the losses experienced by the consumer and forgiving of challenging moments in the support relationship. Forgiveness was possible because of genuine affection for the consumer. In turn, affection – because one loved the consumers, loved supporting them, or had become attached to them through the course of a working relationship – was a criterion that facilitated empowering discourse in the home. The use of verbal and nonverbal communication to demonstrate affection for the consumer highlighted the importance of using empowering language to raise self-esteem by feeling loved, valued, and successful in interactions.

Empowering discourse was seen to raise the morale of the consumer. Further, consumer morale was sustained by including significant family connections in the home. As an enlarged team of consumers, friends, family, and service providers they collectively immersed themselves in the dementia experience. Strong bonds were evident in a supportive network, helping to ease the grief of witnessing the profound effects of dementia. Furthermore, the network became a source of mutual aid to all who were affiliated with the home.

The findings in the social process of empowerment also identified barriers to supported empowerment. This third major category in the study indicated that empowering support was weakened by barriers identified in divergent and convergent perspectives in the data. Divergent perspectives mentioned in the study identified deficits in practice that challenged the support of health in the home, the ability of caregivers to maintain consistent practice, the lack of an option to age in place, the ability of the community to provide enriched supports (with staff experienced in intellectual disability and dementia support), the commitment of service providers to provide opportunities for integrated activities in community, the involvement of family caregivers in deciding the support of consumers, and the ability of staff to implement the choice of consumers who are deemed to be at risk.

Convergent perspectives in the findings identified deficits in resource which restricted participation in activities outside the home and jeopardized the quality of support staff members were able to give. Additional staffing and funding was required to meet goals set and spontaneously requested by consumers in the study, and for new needs as people progressed through dementia. Further funding was also required to maintain the home, its equipment and facilities so that daily support was not interrupted and consumers were safe from falls and injuries.

CHAPTER SIX

Discussion

Analysis of the data gathered in this study yielded a significant theme: marginalization of people with a dual disability. In addition, the data identified a major theme of empowerment within the practice of supporting people with a dual disability who sustain their desired quality of life. This pattern of empowerment led me to reflect on empowerment theory and how the findings of this study fit within it. In this chapter, I summarize the findings, give an overview of the principles of empowerment, and relate the contributions of this study to empowerment theory.

Summary of the Findings

The aim of this dissertation was to facilitate a subjective understanding of the needs of people with a dual disability living in a home specializing in dementia support. I wanted to understand what adjustments were made to support their needs and what service barriers and successes were experienced. The needs of consumers and service approaches to meet these needs were found in two social processes; marginalization and supported empowerment.

The Social Process of Marginalization

The social process of marginalization results from the onset of dementia and reflects profoundly debilitating changes in physical and mental ability. Stakeholders said that all individuals with a dual disability endure a “horrible, horrible disease” ultimately ending in death. Several new needs become apparent; needs for dementia-capable housing; financial assistance; ensuring safety; medical services and treatment (i.e., physicians, specialists, hospital, and emergency services); health technologies (i.e., foot-care, physiotherapy, and laboratory services); personal support; respite for caregivers;

accessible transportation; homemaking; nutritional services; dementia education for caregivers; intellectual disability education for health practitioners; social engagement; enriched integrated day programs; individualized support for activities of daily living, work, leisure, and recreation in the home and in the community; palliative care; emotional counselling; and support for grief from death and dying.

The consumers' experience of dementia was similar to that of seniors in the mainstream; cognitive and physical decline resulting in loss of memory, communication, social, occupational, adaptive, and mobility skills (Haxby, 1989; Lott & Head, 2001; Schapiro, 1988). As well, stakeholders confirmed that rates of decline and consequent level of need varied among individuals. However, a specific challenge for the consumers was getting an early diagnosis of dementia. This finding is confirmed in the literature where Schapiro, Haxby, and Grady (1992) found neuropathologic changes in brain scans of older adults with Down Syndrome but few were diagnosed with dementia. They found that caregiver reports and clinical exams were insensitive to the early signs of dementia.

Stakeholders concurred that a successful diagnosis and management of dementia is based on information gathered from caregivers. Studies indicate the benefit of using multiple sources of information such as family and professional caregivers, non-family members who see the individual in a variety of settings, physicians, language and emotional function measurements, family and personal history, and cultural background (Aylward, Burt, Thorpe, Lai, & Dalton, 1997; Burt et al., 1998; Manji, 2002).

The absence of a diagnosis creates several resource barriers for people with a dual disability exposing them to rapid deterioration. An early diagnosis of dementia may help to improve quality of life and well-being of these individuals who can begin planning for

new needs. Their caregivers can support them to maximize autonomy, stay safe (e.g., from accidents in the community), get treatments that slow down the progression of the disease, and benefit from efficient treatment of comorbidities with dementia (Cooper, 2002; Nygaard & Ruths, 2003; Relkin, 2000). Studies show that an early diagnosis can also increase access to needed education, mutual aid, resources and services for dementia, improve coping skills to live with the disease, and delay moving from home or being admitted to institutions (Cooper, 2002; DeKosky, 2003; Keady, Gilliard, Evers, & Milton, 1999; Relkin, 2000).

For the consumers in this study, living at home was restricted due to lack of resources. All stakeholders said that government funding for homecare was barely adequate to support people even in the early stage of dementia. Therefore, only those with private resources or caregiver support could live at home. While there is limited research on caregivers of people with a dual disability, the physical and emotional cost of supporting people with dementia is well documented. For example, in a survey conducted by the Caregivers Association of Ontario, 96% of family caregivers said that caring for loved ones was a “labour of love.” At the same time, they described this care as “frustrating” (90%), “draining” (87%), and “painful” (87%) (MOHLTC, 1999). In addition, caregivers said that they spent on average 69 to 100 hours a week caring for their loved ones, and 80% had made financial sacrifices to do so (MOHLTC, 1999).

Lack of resource for support threatened the safety of consumers living in supported independent living and group homes according to the findings of this study. These individuals required more staff support to manage disorientation and health complications with dementia. Even so, the decision to stay in a group home depended on

the home's accessibility, availability of staff to provide dementia support, and how changes in the physical and mental function of the person impacted other residents when relating to the living space and to others.

When unable to stay in independent, family or group home stakeholders said that a nursing home was the only option. However, they emphasized that premature placement in a nursing home diminished the life of the person with a dual disability. In Rose's case, her family caregiver saw that she had to not only supplement support at the nursing home but also actively interpret Rose's needs and ensure that staff met these. Overall, stakeholders felt that moving to an environment that was bigger, isolated from community and void of stimulation, significant connections, and personal advocates was detrimental to the welfare of people with a dual disability.

As dementia advanced, opportunities for community participation were lost even further with memory loss and changing preferences. Insufficient resources and inability of the community to tailor social participation to the changing needs of consumers led these individuals to distance themselves from community. Gradually, the individuals were excluded from community and their social connections shrank. When they no longer had meaningful relationships to enjoy they became apathetic: "She's not excited about anything anymore. ... She's lost whatever it is that makes you want to keep going." Losses in ability, home, and community ended in loss of life itself.

The Social Process of Supported Empowerment

In contrast to losses in the social process of marginalization, the social process of supported empowerment identified successes. Successes, from the perspectives of stakeholders, countered the losses experienced by the onset of dementia. Stakeholders said that while it was not possible to reverse physical and mental decline due to dementia,

it was possible to sustain health and quality of life by creating an empowering living environment.

Living environment. The living environment for the consumers in this study was the home in which they lived and the community outside the home. All the stakeholders in this study concurred that, ideally, people with a dual disability would live in their own home in the community, have choice about where to live, and likely choose familiar environments around people they knew. However, the stakeholders said that lack of resources and enriched supports stifled this option for people with a dual disability.

When independent living or aging in place was not possible, stakeholders advocated living in the home specializing in dementia support: “I don’t know if there is a better place than this [home] unless you are home with your family.” Specifically, they felt that the home studied was better than a nursing home, especially for people not in the advanced stages of dementia and not requiring extensive medical intervention. This alternative provided adequate support in a barrier-free, group home in a community environment. With its small size, staff members were able to tend one-on-one to individual needs.

However, group homes can be viewed as substitute institutions in the community. Pedlar et al. (1999) state that group homes are similar to larger institutions, in that they are fixed programs to be accessed by a specific population, people with disabilities. In that sense, people are grouped together with limited access to the larger community. Their participation in community life is segregated within leisure and vocational programs only for similar peers. Further, their dependency on paternalistic service

systems gives their support workers control to design and influence their daily living (Pedlar et al., 1999).

The agency involved in this study offered residential and segregated programs for vocation and recreation. However, they built a home specializing in dementia support to promote an integrated community living experience for its members; members who would normally end up in nursing homes. As an administrator articulated, “If we had not had that home [specializing in dementia support], a significant number of people would have gone into a nursing home much earlier and died there and not had any community involvement.” A few support workers seeing the onset of dementia in people they supported were the stimulus for the creation of this unique model of support for people in their agency. The administrators engaged in extensive research, collegial dialogue, and external consultations with organizations involved in the support of persons with dementia to pilot a home that kept current social and community linkages intact for the consumers in the study.

Administrators and direct-care staff were sensitive to the trauma experienced by people with a dual disability when changing their living environments. They created a model that provided flexible support for the changing needs of consumers. They expanded the circle of support with professional and family caregivers. Their practice incorporated a philosophy of retirement living honouring the self of the person with dementia, by maintaining health and autonomy, giving freedom of choice, and facilitating collective engagement.

Maintaining health and autonomy. Researchers agree that personal autonomy is a major element determining quality of life (Romney et al., 1994). A critical factor in

sustaining the autonomy of people with a dual disability is maintaining their health.

Doyal and Gough (as cited in Barnes, 1997), state that health and autonomy are the two most basic human needs. Autonomy is the ability to make informed choices about one's life; how such choices are realized depends in part on psychological health. Whilst absence of psychological capacity may deem a person incapable of exercising autonomy and thus 'handicapped,' people can be helped to maintain their capacity (Barnes, 1997).

Maintenance of health, along with empowerment, ensures individuals' ability to retain control over their day-to-day living. All the stakeholders stated that health complications for people with a dual disability are such that, if unattended, they can compromise autonomy and engagement with community. Accordingly, health strategies in the home included staff training in implementing treatments (e.g., medications and infection control), vigilant observation of changes in individuals, and efficient use of community medical resources. There were also built-in procedures to support staff with emergencies, end-of-life decisions, and bereavement.

Primarily, the findings indicated that as long as there were adequate medical resources in the community that could move with the individual (from community to hospital or home), the consumers maintained health. Nonetheless, ambivalence about the health support in the home was apparent in the divergent views of stakeholders. These views questioned the therapeutic content of in-home interventions (e.g., for mobility) and knowledge about health complications with dementia and bereavement.

Divergent views on the delivery of health support seemed to be tied to the model of living – social versus medical. Stakeholders agreed that in the support of people with a dual disability, medical and social practices were equally important. However, the

manner in which these were incorporated in a living environment offered a different experience for the individual. In the social model, which simulates life in one's own home, access to therapeutic or medical interventions from medical systems in the community seems to fit. In this model the person with a dual disability is exposed to the same level of risk as anyone else who is accessing those services. The risk is dependent upon the quality of community healthcare that is accessible to the individual.

In the medical model, such as practiced in nursing homes, therapeutic regimens are incorporated in a treatment program and carried out in the home. The level of risk for deterioration in mobility may be decreased in the medical model. However, the risk for deterioration in this model may be increased by lack of resources, such as low staffing ratios; or a low priority may be attributed to rehabilitative interventions for mobility in people who are not likely to regain their mobility as a consequence of dementia.

Ultimately, whether a best medical practice is available in-house via a medical model or in the community via a social model, it remains the prerogative of the individual with a dual disability to determine if the practice is desired or comfortable. In the case of people with a dual disability, if preference is difficult to decipher, their choice can still be accessed in ways that have been identified in this study (e.g., verbal and nonverbal communication). When the individuals are unable to articulate the reason for their distress, and when no access to in-house medical opinion is available, it may be necessary for staff to mobilize community health services even as a cautionary practice.

When the consumers in this study were physically and emotionally healthy, they sustained their autonomy to make decisions. Contrary to the idea that the dementia renders individuals dependent and docile, the findings indicated that when empowered to

do so, the consumers retained competence. They retained their competence when their self was maintained in a therapeutic environment. The therapeutic environment supported their emotional and psychological well-being as they were valued as individuals who occupied roles, experienced affection and caring social connections and were supported in grief and distress by a system of mutual aid. Their actions and interactions were affirmed when staff gave power to them.

Stevenson (1989) states that exercising “power over” the person creates felt experiences that are depriving and demoralizing, impoverishing that person’s self. But exercising “power to” that person creates felt experiences that are empowering and self-fulfilling, resulting in higher self-esteem for the person. When Jim’s support person gave power to him to make decisions on his shopping trip, she indicated that he had the “potential to take action to achieve certain ends, that is, enact transformative power” (Dominelli, 2002, p. 17). Transformative power enables individuals to act freely, participate in decisions, take responsibility, and access resources to achieve certain ends (Salzer, 1997).

In giving Jim power, staff enacted essential components of empowerment: self-efficacy to articulate choice, assertiveness to make decisions, and mastery to make purchases and payments. He was competent to complete his tasks (Bolton & Brooking, 1998; Kieffer, 1984; Weaver, 1982; Zimmerman & Rappaport, 1988), think critically when making his choices (Guitierrez, 1990; Lee, 2001; Moreau, 1990), and use shopping skills (Andrus & Ruhlin, 1998; Beaulaurier & Taylor, 1999; Cox, 1991; Zimmerman, 1995). Transformative power sustained Jim’s personal autonomy when he had the

freedom to make choices about his purchases and received the support and resources to implement his choice.

Freedom of choice. Choice for Jim was valid when it was made within uncoerced relationships. Strategies to facilitate freedom of choice were a particularly significant finding as the consumers lived in a system of care; a group home managed by an agency of programs funded by the government. Systems tend to fall into mechanical operations; people have rigid responsibilities about which procedure should be performed, when, and how. Rigid bedtime practices were evident when Rose went to live in a nursing home. Rigid practices of this nature take away choice and control from the individual and impede the opportunity to affect a different practice based on new information.

Stakeholders in this study said that staff in the home offered choice proactively; they believed that the comfort and morale of individuals was maintained when they had choices in where they lived and the way they were supported: “They have a lot of choice; a lot of support in their life; family involvement as they wish.” Direct-care staff said that the retirement model of living essentially offered choice “to keep on living their life the way they wanted to live their life.” Another direct-care staff member explained how the philosophy of support enabled choice:

DCS2: Now it is whatever the person wants, if they choose not to go to work then they don't have to go to work. If they choose that they would rather spend time in their room for 24 hours that's up to them. ... If they want to go on a helicopter ride, they go on a helicopter ride.

Opportunities for choice where consumers asserted a preferred choice and, further, where this choice was actualized were apparent in the findings. Choices were evident in planning a move and in the transition process of moving. Consumers expressed preferred choices at all stages of the disease, even when they had lost the function of

language as we understand it. Support people who were intimately knowledgeable about the person and/or their communication styles were able to decipher choices expressed through verbal and nonverbal communication.

Direct-care staff and administrators said that they facilitated choice by understanding the consumer's *historical self*. By reflecting on the historical self, comprised of identities, cultural contexts, value systems, life paths, dreams, and preferences, staff came to understand the whole person and how consumers would like to live life. Without historical knowledge, direct-care staff felt that moments of variability and moments of clarity would not be fully capitalized; indeed, they could distress the person with dementia "because, if there is ever a time they remember...there could be a wave of sadness of 'Where am I?' and 'What happened to me?'" Therefore, knowledge of the historical self was used to validate the individual's living experience.

The use of historical knowledge to highlight the self is an antioppression practice that balances power relations as individual autonomy is elevated. Practice that promotes individual autonomy privileges the voices and experiences of those with whom we work (Dominelli, 2002). Staff used historical information to facilitate the principle of self-determination as prior preferences of consumers were actualized. It seemed to be an empowering tool for giving control to the individual over support planning, and decisions about day-to-day and future living.

Jacques (1997) cautions that in the context of dementia, practice based on prior preferences of an individual can only be a form of implied or pseudo-autonomy. At best, one is left 'guessing' what the individual may like or that the individual is meaning what is being verbalized. When unable to decipher current choice, decision-making by staff

can range from paternalistic practice to subjective interpretations of the wants of care receivers (Jacques, 1997).

For example, which soup an individual is offered at a mealtime may be based on a decision that staff impose. On the other hand, staff may take into account prior preferences of individuals and what their relatives or advocates believe is the likely preference. Staff members could also base their decision on behavioural consent when an individual eats the soup or passive acceptance when the individual allows to be fed the soup. Finally, when the individual verbalizes satisfaction with the experience of a mealtime it could be said that the choice of soup on the menu was validated or the individual may respond “Yes” or “No” to choices offered confirming preference (Jacques, 1997).

Irrespective of the challenges with deciphering individual choice, stakeholders in this study believed that knowledge that was defined by the person with a dual disability and highlighted the historical self, acclaimed the distinct individuality and voice of that person. When dementia progressed such that communicating personal choice was difficult, it became especially important to know the selves of persons. Historical information helped direct person-centered support in a way that freedom of choice was respected, individual choice honoured, and autonomy asserted.

If the match between support of the historical self and the current self was accurate, the consumers appeared calm and comfortable, did not resist the choice, or communicated their satisfaction with it. Satisfactory support confirmed experiential knowledge that had been gained in the dialogic relationship between consumer and support person, “each learning from the other and each teaching the other” (Mullaly,

1997, p. 180). As well, knowledge of how the current self responded to choices resulted in greater empathy, enhancing staff's ability to honour individual choice.

Furthermore, staff cemented choices in a contract or a personalized Life Plan. An accurate Life Plan depended on input from significant liaisons critical to understanding the historical self of a person and a person-first viewpoint. Resources were planned to implement individual goals. When staff advocated for the implementation of individual goals in the Life Plan they stimulated change as administrators understood "the mechanisms that result in people being denied access to resources, and thus feeling powerless" and responding by providing "the means by which individuals can regain control of their lives" (Dalrymple & Burke, 1995, p. 18).

The findings indicate that staff made strategic efforts to implement the choice of the consumers. However, there were events when individual choice was not honoured. Of particular note was Donna's case when risk to health and safety competed with her right to self-determination. The staff did not seem to tap into why she wanted to go out and what she might have done had she been supported to do so. Rather, her behaviour was seen as the "wandering" associated with the progress of dementia – something to be deterred to preserve her safety.

Again, with regards to her foot-care, we may question why Donna's intense fight against what she possibly perceived as an oppressive practice was derailed by a duty to care. It was assumed that due to her dementia Donna was unable to make a sound decision about her hygiene care; that she would not understand the risk of infection and the safety concerns this would present. Further, it was assumed that even if she did understand the risks she would make a different choice because she was scared of the

procedure. Therefore, her support people assumed that they had to make this decision for her and implement the procedure; thus, endorsing a paternalistic practice (Jacques, 1997).

It was evident that Donna became more vulnerable to system needs that emphasize duty to care, unable to exert her autonomy. We have to question the position of elitist thought when professional responsibility to system needs dictates power over the person with a dual disability. An elitist view of a person's ability and needs might result in responsible practice taking over as opposed to supporting what fits the person. This aspect of care for vulnerable people makes it incumbent upon service providers to operate a reflective practice that curtails elitist thought. Especially in the absence of overt resistance, professionals should not mistake "a lack of protest for informed consent, habitual behaviour for active choice, and resignation to one's lot for contentment with that lot" (Shevin & Klein, 1984, p. 160).

Reflecting on the traumatic event experienced by Donna, I noticed that her desperate screaming affected the housemates, the staff, and me variously. The way we responded depended on our social location and self-awareness. Some of us were able to stay in the situation while others opted to move away. One staff said that she felt more traumatized than Donna and another said that she had been worried about injuring Donna when she was holding her down. Remembering my position as the researcher I felt a huge amount of pressure to stay at a distance and watch, ignoring my urgent feeling to intervene and alert the staff of the trauma I was observing. I too stayed in the experience, hoping that the professionals would use the benefit of their expertise to support Donna through this traumatic experience. After all, their expertise must include, I thought, knowledge of best practice for Donna.

It appears that individual beliefs, values, attitudes, and roles dictated the response of those present at Donna's traumatic event. It is, therefore, incumbent upon all professionals to self-reflect and become aware of how they can reproduce prejudicial, stereotypical, or discriminatory behaviours. Essentially, when system and professional needs conflict with individual needs, external oppressive forces layer on top of marginalization experienced from dementia. Such oppressive forces lead to lower quality of life and disempowerment.

Indeed, the reflections of Donna's professionals evidenced their mindfulness about conflicting system, professional, and individual needs. They engaged sensitively in reflecting on the oppressive nature of the practice of cutting her toenails as soon as the procedure was completed. They reflected on whether it was necessary to "take over" and how this compromised Donna's individual rights. They discussed whether they should respect her refusal of nail care. At the same time they showed just as much concern to resolve the issue of safety, discussing Donna's safety in general, the safety of the staff involved when Donna was intensely resistant, and liability issues if staff (as opposed to the nurse) performed the procedure.

In this vein, they explored current options used to reduce the distress expressed by people with dementia, such as the use of sedatives. They thought of less oppressive options, such as training Donna's favourite staff to cut her toenails. This incident evoked much thought in the practice of foot-care for Donna; it was also apparent that further discussion and involvement of the full-time staff and management was required to reach an appropriate, nonoppressive resolution.

The case study of Donna highlights that less intrusive interventions are formed in a reflective practice that privileges individual choice. A reflection by support people, together with the individual, other observers and professionals in the environment, and informants in the community, is required to determine if a practice is empowering or oppressive. An accurate reflection is best done in collective engagement of a community of members concerned about the welfare of the person with a dual disability.

Collective engagement. Living for the consumers in the study was most empowering when integrated in a collective of community members who were able to meet their instrumental, psychological, emotional, and social needs. For them, community included inside and outside spaces where they had opportunity to participate and contribute their gifts. The home was first, a physical space that was created by the agency, and second, a social space to foster the inside community. The self of the consumer stayed in high esteem as staff gave power to the consumer to engage with work-related activities, leisure, and socialization with peers in the home. The home community expanded when family members spent time with their loved ones and bonded with the staff. Family caregivers felt comfortable as part of a circle of support, negotiating compromises when differences in approaches occurred.

The findings in this study also identified non-negotiable conflict between service providers and family caregivers when deciding the support practice for the consumer. Just as professionals may engage in paternalistic practice, parental influence in the life decisions of people with disabilities can have negative impact. In a study conducted by Hendey and Pascall (1998), many respondents were quoted as saying that “the parental care situation extended parental control over their lives, keeping them as children despite

their years” (p. 423). Parental overprotection is often cited as “a hindrance to social experiences” (Baker & Donnelly, 2001, p. 74) and restricts the choice of people with a dual disability to make independent choice about their living experience.

Generally speaking, family caregivers and service providers in this study attempted to merge their views to support consumers’ choice. Family caregivers felt included in decision-making as confirmed by Jim’s family caregiver: “... They would ask me and advise me with what they were doing.” Mutual support between staff and family caregivers was expanded by support from agency administrators. In turn, the mutual support modeled in the home was mirrored between the consumers as they bonded with each other as a family of friends.

The bonds built in the inner community extended to the outer community. Community outside the home comprised of visits to family, friends, and places of interest. The agency’s person-centered philosophy advocating individualized support dictated the outcome for consumers in the study who gave their lead as to where and how they wanted to participate. Consumers participated in integrated community activities that they had historically enjoyed or were currently requesting depending on availability of resources. As well, they participated in segregated activities in day programs that were a part of their connections with the agency prior to the onset of dementia.

As individual preferences changed, the staff facilitated new social connections. The staff creatively supported the individuals to keep familiar roles as long as possible, to integrate these roles into community life, and adapt them to new abilities post dementia (Kitwood, 1997; Stevenson, 1989). Jenny was supported to go to the theatre when her family caregiver suggested an outing:

I said to one of the ladies [staff], ‘What if I get you a ticket to a performance? Would you take her?’ And she was happy to take her. But halfway through, they had to leave, as Jenny wasn’t interested enough.

Based on Jenny’s reaction to the performance, her family caregiver deduced that Jenny preferred walking outdoors as she liked to be busy and moving. Another way to view Jenny’s participation at her outing is to say that she went and stayed for half of the performance. She stayed while she enjoyed the entertainment and when it was no longer enjoyable, chose to leave. This accommodation of her need for a social outing in the community was just what she required to enjoy the performance.

On a case by case basis, administrators and direct-care staff continued to promote the ultimate aim of the consumers; to be included in community spaces. For example, when Jim went to a sheltered workshop for people with intellectual disabilities, it was recognized that he was involved in a segregated group program. When he walked next door to volunteer at a non-profit organization, he was supported to transfer his skills in an integrated community program. When he ate out at a restaurant or shopped in a department store, he was included in the community.

Although incidences of inclusive community outings were evident in the study, stakeholders said that funding and resource shortages stopped the inclusion of consumers in community spaces and programs. Administrators and direct-care staff spoke of “supported inclusion” necessary to enable the person with an intellectual disability, and who now had dementia, to belong in community. Supported inclusion was necessary to create opportunities, provide appropriate resources, and enhance supports to include people with a dual disability in integrated community spaces.

The findings of this study indicated resource and other barriers to empowerment. A reflection on these barriers and the many opportunities found in the social process of

supported empowerment assisted me in generating a model of living for people with a dual disability. Later in this chapter, under “Contributions of this Study to Empowerment Theory,” I outline this model based on the principles of empowerment explained next.

Principles of Empowerment

These principles’ roots are in the critical social science paradigm, which postulates that power differentials, class, and societal oppression prevent individuals from actualizing their goals (Payne, 2005). The goal of empowerment is social justice, achieved when greater personal security, as well as political and social equality, is evident. It follows that in order to achieve social justice, individuals must challenge oppression. This they do when they assert their needs by participating in decision-making and planning (Payne, 2005).

Inclusive decision-making gives “people a greater say in how services for themselves and their family are organized” and connects them with others to organize services befitting their needs (Payne, 2005, p. 302). Challenging oppression, asserting individual needs, and organizing services to fit personal goals increases the individuals’ capacity to control their life direction. Through this process, individuals develop confidence and greater self-esteem; they can be assertive, set goals, and acquire knowledge and skills (Dalrymple & Burke, 1995; Payne, 2005).

Empowerment, rather than being a concrete construct, then, is a process whereby “small steps toward wider goals” increase individual capacity to overcome social barriers to self-fulfillment (Rees as cited in Payne, 2005, p. 303). These steps help change conditions that oppress individuals and groups in society; they build a better world (Neuman & Kreuger, 2003).

Mullaly (1997) and Payne (2005) postulate that empowerment occurs at three levels: *the micro level or intrapersonal domain, the mezzo level or interpersonal and community domains, and the macro level or societal domain*. All three levels share common practice principles: (a) individuals have an emic understanding and knowledge about their condition or experience; (b) they have skills and the right to be heard, to control their own lives, to choose to participate or not, to define their issues and take action; and (c) individual problems always reflect issues of oppression, policy, economy and power, as well as personal inadequacies (Mullender & Ward as cited in Payne, 2005).

Another important principle of empowerment is that it takes on different forms for different people. Foster-Fishman et al. (1998) state that pluralistic personal histories and social opportunities, merged with different demographic and cultural characteristics (race, gender, ethnicity, class, and social backgrounds), will lead individuals to desire different forms of empowerment. Romney et al., (1994) add that although greater life satisfaction and emotional well-being is related to increased personal growth, self-efficacy, and self-esteem the level of satisfaction depends on individual expectations. Therefore, people with different expectations in similar situations will experience a different level of quality of life. When groups of people act together to create a collective narrative that sustains their personal story (Rappaport, 1995), the process of empowerment is powerful. By the same token, a “one size fits all” approach that ignores individual, cultural, and demographic differences is inconsistent with empowerment (Boehm & Staples, 2002, p. 457).

Ultimately, a dynamic, empowering practice facilitates rather than leads the process of challenging oppression. It incorporates elements such as raising awareness,

eliminating stereotyping, activating resources, building capacity and mutual support, facilitating community integration, freedom of choice and autonomy, and expanding opportunities for people to generate positive change (Frankel, Speechley, & Wade, 1996; Lord & Hutchinson, 1993; Nelson et al., 2001b; Perkins & Zimmerman, 1995). When such elements are offered to people with a dual disability, they mobilize a process of empowerment. Such a process was evident in the findings of this study. I will now discuss the contributions of this study to empowerment theory.

Contributions of this Study to Empowerment Theory

All stakeholders in this study identified dementia as a significantly disempowering agent in the lives of people with an intellectual disability. Despite this, my analysis of the data yielded evidence that people with a dual disability can become empowered provided that they are shielded from external conditions that restrict empowerment. As such, the contributions of this study to empowerment theory are fivefold.

First, I identify the theory of supported empowerment generated in this study. Second, I highlight the need to understand the social construction of dual disability and how it links with practices that can empower or disempower. Third, we can listen to people with a dual disability to understand their perspective on dementia and practice approaches. Fourth, I propose a *social model of supported empowerment* based on elements of empowerment found in the experiences of consumers in this study. Fifth, I illustrate how this model is translated into empowering practice.

Theory of Supported Empowerment

A significant contribution of this study is a theory of supported empowerment that identifies four major differences when compared to the components of empowerment

theory discussed in this paper. The first difference is concerned with the stages of personal empowerment (Keiffer, 1984). Keiffer suggests that an individual is thrust into the first or entry stage of empowerment by provocation; a life-changing event that renders the person powerless motivates him or her to engage with the process. In supported empowerment it is the supporting actor who refuses to accept the situation of powerlessness and *pulls* the individual into the process. In other words, it is the actor who engages the individual with the social world to create a change.

Secondly, there is no fixed end point to the four-stage development according to supported empowerment theory; staying empowered is a constant and lifelong struggle. Once the individual has entered the process of empowerment, personal development continues with the advancement, incorporation, and commitment stages. However, activity in the second stage of advancement is intensified where the person is mentored, supported in peer groups, and made aware of social and political relations. Movement in the third and fourth stages, where individuals become more politicized and apply their new competencies, is limited.

A third significant difference in the theory of supported empowerment is the emphasis on the interconnectedness of the personal, community, and societal domains. Empowerment theorists tends to speak of these domains as separate entities but this study shows that personal empowerment occurs in the social context of the dyad (individual and supporter), group in the home, and community outside the home. That is, the intrapersonal, interpersonal, and community domains are interdependent.

Finally, the study identifies a number of elements that are not found in the literature of empowerment theory and have the potential to be empowering. Elements,

such as person-centered, maximizing autonomy, integrated activity, textured involvement, and family need to be tested further to clarify the meaning of empowerment.

Social Construction of Dual Disability

An important factor in empowerment theory is how a social condition is constructed. Dual disability is constructed from social and medical models of disability and dementia. The social model of disability deciphers external social factors that disable people with disability (Crow, 1996). These factors restrict the capabilities and opportunities of individuals through prejudice, discrimination, inaccessible environments, and inadequate support. Deciphering these factors enables one to confront barriers constructed and attain civil rights. The social model of disability shifts the focus from impairment, which is perceived as medical dysfunction requiring treatment or cure, to social, environmental, and attitudinal barriers (Crow, 1996). In this sense, disability does not end at a cure or continue because there is no cure. Rather, expression of the full ability and citizenship of a person determine the social, environmental, and attitudinal forces in society.

As for dementia, it is evident that this condition is primarily viewed as a mental impairment, according to the biomedical model of disability. Dementia is simply the presence of disease that impairs the health of the individual. The body and mind are seen as discrete entities, each with distinct bodies of knowledge, methods of diagnosis and treatments. Neuman (2003) states that the medical model privileges objective and quantifiable information that can be observed in the physical body or the rational cognitions of the mind. In a positivist stance, the medical model views dementia as a natural process of aging. Inevitable physical and mental decline in an age-related disorder

can be responded to with standardized interventions of rehabilitation and adaptation (Aronson, 1999).

Medical discourses on dementia that inform models of treatment are evident in the views of society. An administrator said that his exposure to dementia “would be exposure in the ‘normal’ population – so people that were [in their] 70s, 80s, 90s.” Likewise, the responses of stakeholders in this study indicated that the medical discourse of dementia was adopted for people with an intellectual disability. When I asked what they understood by the term *dementia*, the majority said that it was “an older person’s disease” and something that seniors, such as their grandparents, had endured. In describing the condition, stakeholders used the words “aging,” “senility,” “asylums,” and “old folks.” Some stated that the word “Alzheimer’s” had replaced the word “dementia” and that it is a “genetic disease.”

Stakeholders perceived memory loss and regression in ability as the main symptoms of dementia. They said that people with dementia become “forgetful,” “lose their mind,” and are “unable to think as clearly as they used to.” One administrator said, “Dementia ... is seeing people who presented lots of skills, lots of abilities, and starting to see those skills and abilities decline.” Other stakeholders said that the process of decline was “like going back to a child-like state” and ending up “in a vegetable state” like “those poor people [who] end up in a nursing home.”

The views of the stakeholders in this study suggest that public perception of dementia is skewed toward a medicalized understanding. It is, therefore, assumed that treatment modalities in medicine will adequately manage the health of individuals with dementia. However, this assumption focuses on the body and stigmatizes the individual.

For instance, focusing on age, disability, and dementia facilitates the division of society into aged and nonaged, sick and able-bodied. From these divisions, we proceed to determine how the needs of these groups can be managed. The needs of someone who has dementia are delegated to the health system that caters to the needs of the sick and aged. This action privileges the expertise of medicine with its specific interpretation of fact and meaning (Bern-Klug, Gessert, & Forbes, 2001). People with dementia become passive recipients of the benevolent care of practitioners who perform procedures to alleviate disease.

Critical theorists challenge the biomedical model response to aging arguing that dependency is socially constructed to privilege medicalization (Estes, Biggs, & Phillipson, 2003). Intense focus on medical interpretations of dementia ignores the social, economic, and political relations inherent in aging (Estes et al., 2003). The biomedical model does not show how political economy impacts the discourse on managed care according to Aronson (1999). The author elaborates that a discourse of market principles is prevalent in the policies and practices of political, health, and social welfare agencies conducted in the context of bureaucratic procedures and competition for scarce resources. Managed people become subject to manufactured definitions of need, by professionals using standardized tools to determine eligibility for services and costs to support their needs. In this way, the biomedical model's devaluation of people couples with presumption of disentanglement due to age, frailty, and cost to society (Aronson, 1999).

Disentanglement exposes a cycle of oppression in which lack of resources limit opportunity to compete for them, perpetuating the powerlessness of subordinated groups. Jenny, for instance, was unable to compete for resources that could extend her time in

community activity. As a member of a subordinate group of people with a dual disability, she is submerged into another subordinate group of people with an intellectual disability, and juxtaposed with a dominant group of people; seniors aging with dementia. Dominant groups accumulate political, social, and economical power to take resources away from subordinate groups (Mullaly, 2002). Programs and services are tailored to the needs of the dominant group; enriched supports to meet unique needs of people with a dual disability are not configured in services. In this way, programs set limits excluding people from subordinate groups; limits are justified by attributing negative images such as difficult behaviours of people with a dual disability. Members of the subordinate groups internalize these negative images and learn to accept oppression as ‘their problem’ (Mullaly, 2002).

It is their problem because they do not measure up to the dominant group’s ideal, based on certain physical, psychological, and sociological characteristics. It is their problem because their social construction is deficit based: measuring what you are because of what you are not (Mullaly, 2002). Negative images divide people into *them* and *us*, creating, negotiating, recreating, and renegotiating the identities of *others* (Dominelli, 2002). When we define Jenny as a person with dementia, she is separated from those who do not have dementia. In addition, she is ‘othered’ as a woman of low income, aging with an intellectual disability, and a terminal illness.

Neuman (2003) argues that, in reality, dementia is only one of many components that make up a whole person. Layered on the construct of dementia are material conditions, cultural contexts of personal lives, and historical experiences that impact human behaviour, social relations, and socially created meanings (Neuman, 2003). Even

dementia can be broadly defined as an interaction of absence of disease, ability to cope with everyday activities, and capacity to satisfy personal needs (Marshall & Altpeter, 2005). This broader perspective directs equal attention to eradicating disease, maintaining daily living capacity, and individual aspirations. Looking at dementia in this way transcends the body, empowering and valuing the person in her full range of capacity as a sentient being (Minkler, 1996).

In broadening the construct of dementia, Crow (1996) cautions that even if all the disabling barriers in society were dismantled, impaired bodies (whether in pain, fatigue, mental turbulence, or chronic illness) would still remain. When we are silenced about our personal impairments, our self-expression is constrained and the experience of impaired bodies is minimized. This “subjective experience of our bodies is also an integral part of our everyday reality” relevant to the social reconstruction of disability to effectively build an abling environment (Crow, 1996, p. 59).

The stakeholders in this study were conscious of building an abling environment for people with a dual disability. When they came into contact with a medical discourse on impairment within dementia that differed from the social discourse on ability within intellectual disability, they tried to integrate the two discourses. Administrators and direct-care staff made a concerted effort to preserve the person: “People [in the agency] don’t look at them [consumers] as though that’s the *group home with dementia*. ... [rather] It’s a *house for five people*; the five people there are awesome.” Even though the stakeholders offered a medical understanding of dementia that debilitated people with a dual disability, they felt that these individuals “were not dis-abled” by dementia but, in fact, had numerous strengths to thrive when supported to do so. Their dementia, then, was

just a part of understanding the person's abilities and tailoring individualized support so that they could live a full and integrated life in the community.

Hence, they continued within the existing community living philosophy: "to do everything in our power to keep people [with a dual disability] in their community for as long as we can" and "to help them realize their dreams." Although stakeholders understood dementia as a disease, they resisted the idea of medicalizing someone needing assistance with mobility and personal support which they saw as "not medical needs." Stakeholders asserted that people with a dual disability can continue to participate in all spheres of community life: employment, volunteering, learning, socializing, and recreation. With this approach, staff continued to put the person first while administrators developed a practice that included dementia training, health management, and a dementia-capable home.

The notion of *person first* is also evident in literature on dementia that highlights personhood. Kitwood (1997) states that personhood is both an ethical construct, where a person is treated as an individual in his or her own right, and a social-psychological construct, where personhood is "standing or status, bestowed on one individual by others" (Kitwood, 1997, p. 13). Both constructs have to operate to maintain personhood; this may require that others unite to ensure that those losing their mental powers are never excluded from their rightful place in society (Post, 1995).

Honouring individuals' personhood is linked with how their self is situated in society. Kitwood (1997) suggests that the social self consists of an "adapted self" and an "experiential self" that tell us how a person is unique (p. 15). The adapted self is socialized in given roles, and the experiential self arises "from being with others in

conditions of equality, mutual attention and mutual respect” (p. 15). These two selves develop independently throughout the life course and constitute personal growth.

The social construction of dual disability, then, merges the social and medical discourses into a model that promotes person-centered, individualized practice that validates adapted and experiential selves. The model does not negate the medical or social models but combines elements of the two to create a holistic approach to supporting people with a dual disability. What is empowering or disempowering to the person with a dual disability can be gauged by examining practice in this model. A practice that honours an individual’s personhood is based on a thorough understanding of their physiological and social histories. Then we can predict, holistically, the physiological outcomes of dementia and how to create social environments that include and support people with a dual disability. We can dismantle attitudinal barriers built on misconceptions about the abilities of people with a dual disability and deal with practices that impoverish their daily lives. What is required to inform the social construction of dual disability and good practice is the perspective of people who live with this condition.

Listening to People with a Dual Disability

The perspectives of family caregivers, direct-care staff, administrators, and my own interpretations of what I observed informed this study. I felt a tension when analyzing the data to decipher what is and is not empowering for people with a dual disability. This tension arose from an internal debate on whether what looks empowering to me feels empowering to the individuals, and whether what key informants say is empowering *is* the case. Therefore, only by listening to people with a dual disability could I eliminate this tension. Their perspectives could clarify how service providers weight the social and medical models in facilitating empowering living conditions.

Further, it is difficult to define what is or is not empowering, because the empowerment process is a subjective experience. The quality and quantity of positive change can be experienced and assessed differently by different people. Therefore, while I offer a tentative understanding of the social construction of dual disability, I cannot decipher what is empowering or not without the voices and perspectives of people with a dual disability. To do this, I had to understand their unique modes of communication.

The voices of people with a dual disability in this study were not accessed through interviews as administrators suggested that they would not be able to communicate in that medium. However, my analysis of the participant-observation data showed that people with a dual disability each had their own modes of communicating, with each other and people around them. Moreover, they used their voices in speech, nonspeech sounds, and actions to gain personal control over their living environment.

Family caregivers and direct-care staff were able to interpret their desires and needs from their unique verbal and nonverbal language. During participant observation I observed incidences when consumers were satisfied with the interpretation of and response to their communication. The direct-care staff interpreted consumers' communication by translating historical, cumulative, collaborative, and behavioural expressions. The consumers conveyed agreement or disagreement not necessarily with speech. The knowledge gathered in each interaction informed staff members' individualized understanding of how the person felt in the moment, their daily living needs, preferences, and aspirations.

The unique communication of people with dementia has been noted in other studies. Communication modes unique to individuals developed historical knowledge

about them: verbal speech, nonspeech (e.g. “un-huhs”), and nonverbal body contact (Parker, 2003). In other words, communication is both cognitive and interactive. For people with dementia, difficulties in expression and comprehension are often overlaid with personal, professional, and social assumptions about communication (Parker, 2003). Therefore, to talk with, listen to, and understand people with dementia, we must adjust our expectations about communication.

Kitwood (1990a) suggests adjusting the pace of communication when listening to people with dementia:

We need to slow down our thought processes, to become inwardly quiet, and to have a kind of poetic awareness; that is, to look for the significance of metaphor and allusion rather than pursuing meaning with a kind of relentless tunnel vision. (p. 51)

Other researchers (Adams & Bartlett, 2003; Goldsmith, 1997; Parker, 2003) discuss different ways in which we can hear and interpret the voices of people with dementia through art, music, drama, photographs, magazine pictures, personal objects (such as ornaments, photographs, pictures, and furniture), painting, role play, and poetic imagination. Further, people with dementia respond to nonverbal communication through touch (such as massage, hugs, kisses, stroking, and holding hands), eye contact, tone of voice, and body posture.

Successful communication with people with dementia can be affected by several factors: the reason for meeting, the place and the context, other people in the environment, and how the meeting takes place (Goldsmith, 1997). On the last point, factors include the lighting and colors of a room, the level of noise or sounds, time spent with the person, the listener’s sensitivity to nonverbal cues, understanding of the meaning of null responses, relationship with the individual, as well as, empathy, genuineness, and

warmth conveyed toward the person (Adams & Bartlett, 2003; Goldsmith, 1997; Parker, 2003).

Thus, people with dementia can express themselves depending on the environment, the people, and individuals' communication modes in their surroundings. Their views can be elicited using multiple modes of verbal and nonverbal communication, within their individual context and without making them feel put on the spot (Parker, 2003). We can listen to their views in interviews or group meetings, during conversation, while in other activities (e.g., taking a walk), by observing their behaviour, and by talking to others with similar experiences (Adams & Bartlett, 2003; Parker, 2003).

As I have outlined, people with a dual disability have unique modes of communication. To bring the voices of these individuals to a research study, a process to document, relate, and interpret the unique communication modes of each person with a dual disability is required. Such a process needs to be incorporated into the research design, before eliciting the experience of people living with a dual disability.

Despite the limitation of my study to gauge what is and is not empowering to the individual with a dual disability, with the findings I am able to propose a social model of supported empowerment. This model is based on elements of empowerment theory that I observed in the home specializing in dementia support. The components of this model include elements of empowerment embedded in processes that exist in social environments. Further, particular practice strategies collectively qualify the conditions of living for people with a dual disability. These strategies avert the tendency to further oppress and impair the person. The next section outlines the model, followed by the elements and strategies of empowering practice.

Social Model of Supported Empowerment

Figure 2 illustrates the components of the social model of supported empowerment. It begins with a person-centered approach focusing on the person at the center rather than the disability. The individual, viewed as “Person First,” is surrounded by three interconnecting communities that influence each other: the “Micro Community” in the home, the “Mezzo Community” outside the home, and the “Macro Community” or society in which the individual resides.

The individual being the focal point, the square around the individual depicts the built physical space or building in which he or she lives. In a social model of supported empowerment, the individual chooses his or her home be it an apartment, a family home, an accessible home, or a shared residence. As well, the person chooses the resident community or neighborhood; urban, rural, or hometown location. In this micro community the focus is on the quality of life and day-to-day support required by the individual.

The mezzo community that encircles the home is a substantial resource for meeting the individual’s social, psychological, and physical needs. It is easily accessible to the individual and provides a myriad of opportunities in mainstream spaces to experience textured life. The empowering processes in this community promote the inclusion of people with a dual disability as equal citizens in all aspects of community life.

Both the micro and mezzo communities are influenced by the larger society; the macro community. Processes in this community monitor and adjust perceptions, attitudes, norms, and practices to ensure individual rights are realized. They sanction the legal, social, and health systems that impact the individual and determine the nature and means

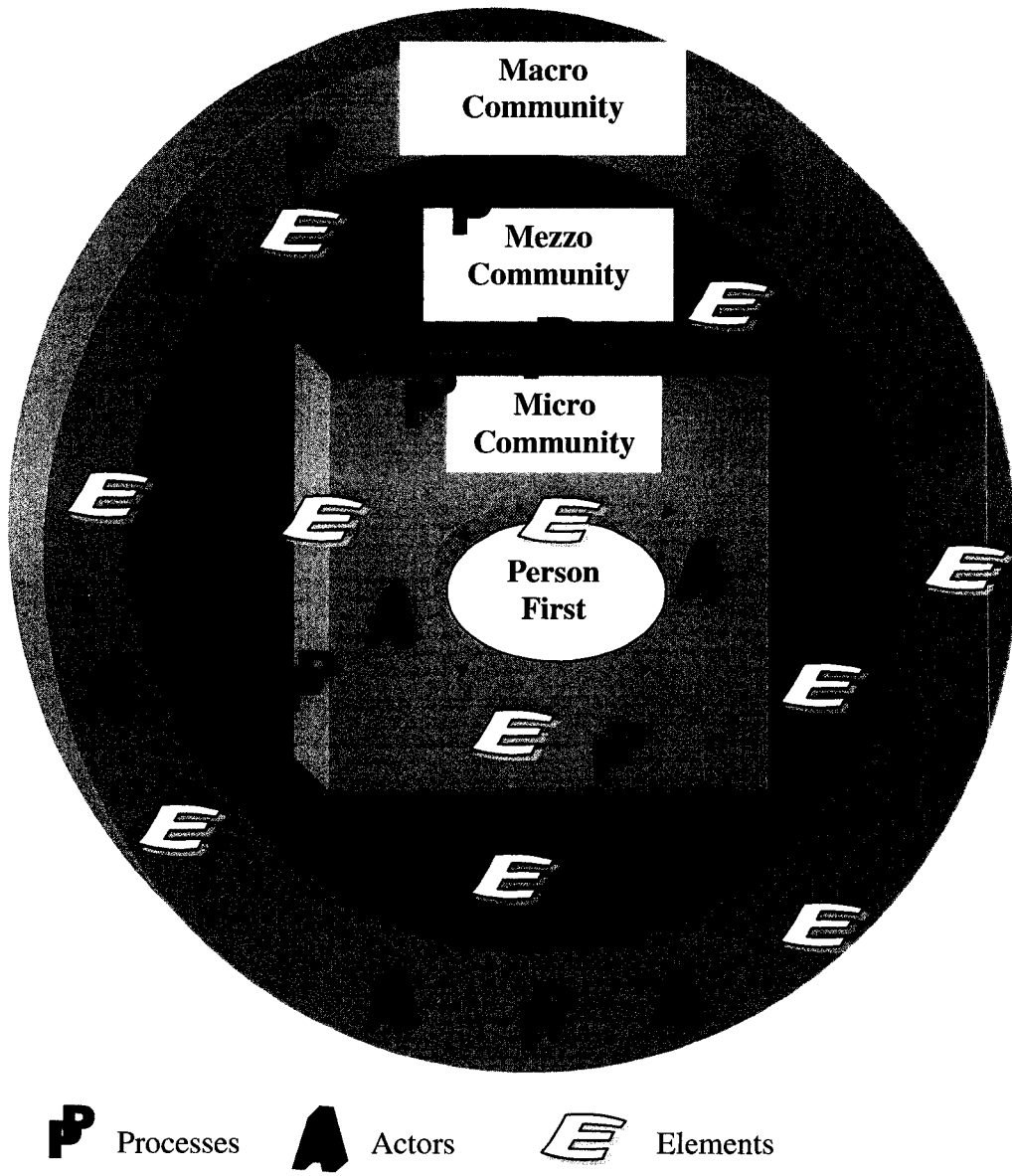


Figure 2. Social model of supported empowerment.

of investment to adequately address citizen needs. Social justice issues in the micro and mezzo communities are addressed in the macro community by directing how policy, funding, and services are implemented. In each of these interconnected communities are empowering processes (e.g., person-centered support, direct funding) which are championed by actors (e.g., support workers, policymakers). Table 6 indicates the actors and empowering processes that operate in each community.

Table 6
Actors and Processes in Communities

Actors	Empowering processes
Micro (in the home)	
Advocates; caregivers; family; friends;	Advocacy
peers; volunteers; students; support	Informed choice
workers; health technicians; healthcare	Socialization
professionals.	Decision-making
	Maintaining health
	Building mutual aid
	Sustaining autonomy
	Reflection on practice
	Exercising self-agency
	Person-centered support
	Generating elevated empathy
	Participation in activities of choice
	Nurturing in social and staff liaisons
Mezzo (outside the home)	
Advocates; advocacy organizations (e.g.,	Textured living
People First); caregivers; family; friends;	Accessible living
peers; volunteers; students; community	Flexible healthcare
citizens; support workers; healthcare	Moving with choice

Table 6 (continued)***Actors and Processes in Communities***

Actors	Empowering processes
providers; service providers (i.e., community, developmental, dementia).	Individual support planning Social inclusion in community Connecting with support circles Enriched individualized support Accessible services (e.g., health, transportation) Training for dementia and developmental support
Macro (society of residence)	
Advocates; advocacy organizations (e.g., People First); educators; policymakers; government ministry officials.	Research Community inclusion Public education Dual disability training Individualized funding Curriculum development Planning of diverse living options Future planning of changing needs Seamless health and social systems Retirement and end-of-life planning Developing support plans and teams

All three communities work in synergy to facilitate processes in the social environment that are founded on the principles of empowerment. The processes stimulate elements (see Figure 3) that transcend through all community levels, bolster the actors therein, and infiltrate the life of the person at the center.

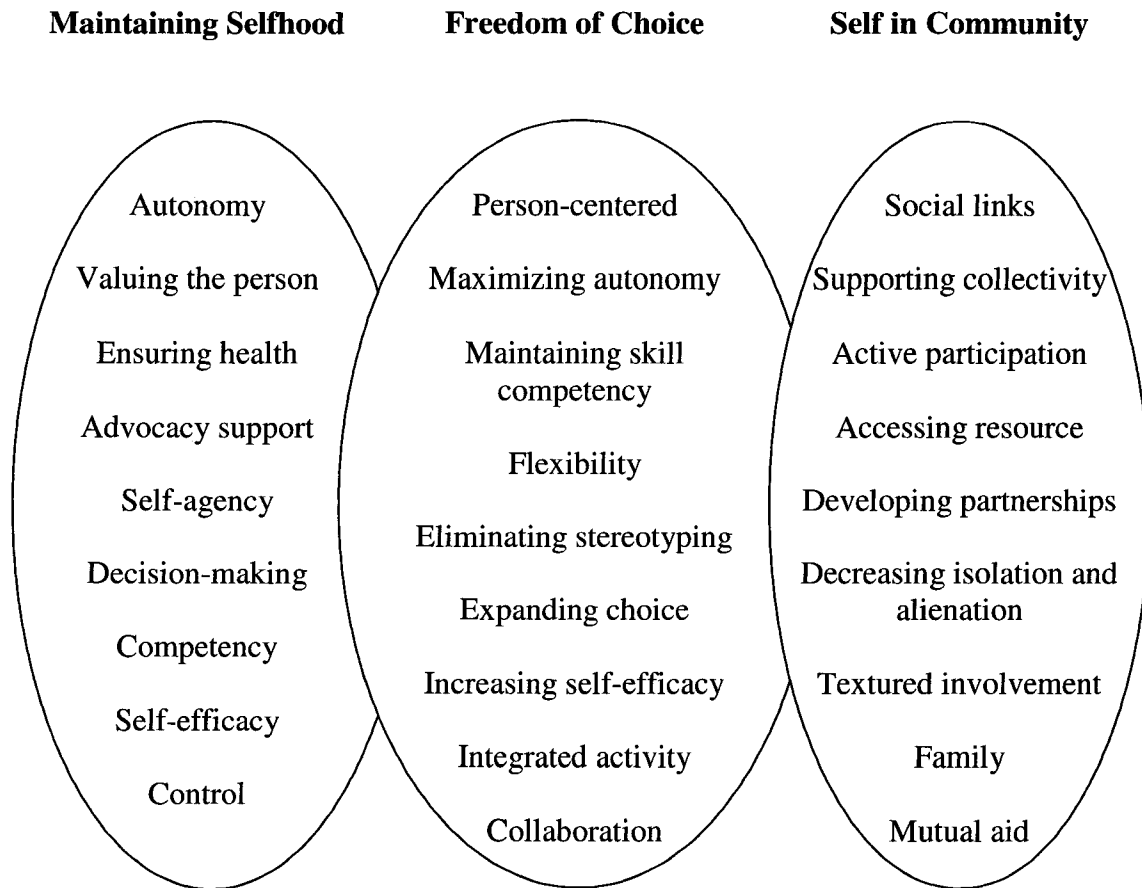


Figure 3. Elements of empowerment found in the social process of supported empowerment for people with a dual disability.

Elements of Empowerment. The empowerment of a person with a dual disability is linked to the elements reflected in the principles of empowerment outlined in this chapter and found in the general literature on empowerment (see Frankel et al., 1996; Lord & Hutchinson, 1993; Nelson et al., 2001b; Neuman, 2003; Perkins & Zimmerman,

1995). Figure 3 illustrates that these elements of empowerment were elicited from each of the thematic findings in the social process of living by supported empowerment. Further, person-centered, maximizing autonomy, integrated activity, textured involvement, and family were additional elements found in the data and specific to the consumers in this study. The findings of this study demonstrate that the presence of elements of empowerment in support practice maintain selfhood, give freedom of choice, and sustain the self in community.

Maintaining selfhood is conscious action on the part of service providers to facilitate the self-agency and competency of the individual. Keeping autonomy at the forefront of practice, despite the profound losses associated with dementia, support people recognize that the self remains intact until death and that the person, if supported, can make choice.

Freedom of choice is required to reinforce selfhood and is facilitated through multiple means of information gathering, and by capturing spontaneous and planned opportunities to exercise choice. Several situations where individuals were encouraged to participate in decision-making about moving to new homes, day-to-day living, and planning were evident in the home. Choice enables the individuals to have control and determine how to spend each day of their life. The principle of freedom of choice gives them the right to decide for themselves how, where, and with whom they wish to spend their time (Romney et al., 1994).

Self in community is the third theme. Support people nurture social participation and collectivity in both micro and mezzo communities to offset the loss of opportunity to sustain the self. Community participation is not in the form of segregated services, but

integrated in mainstream spaces to create textured lives. It enables consumers to access leisure, recreation, and resources to build mutual aid. As well, loving human connections enhance activation, self-image, and motivation in work and leisure activities. Having maintained and reinforced selfhood, social engagement and increased chances to participate in community sustain the selfhood of people with a dual disability.

Translating the Model into Practice

While many of the elements in Figure 3 may be present in social theory and policy documents within human services, a critical contribution of this study is to show how they are translated into micro-practice. The model illustrated in Figure 4, shows how support people facilitate empowerment in practice by using a philosophy of person-

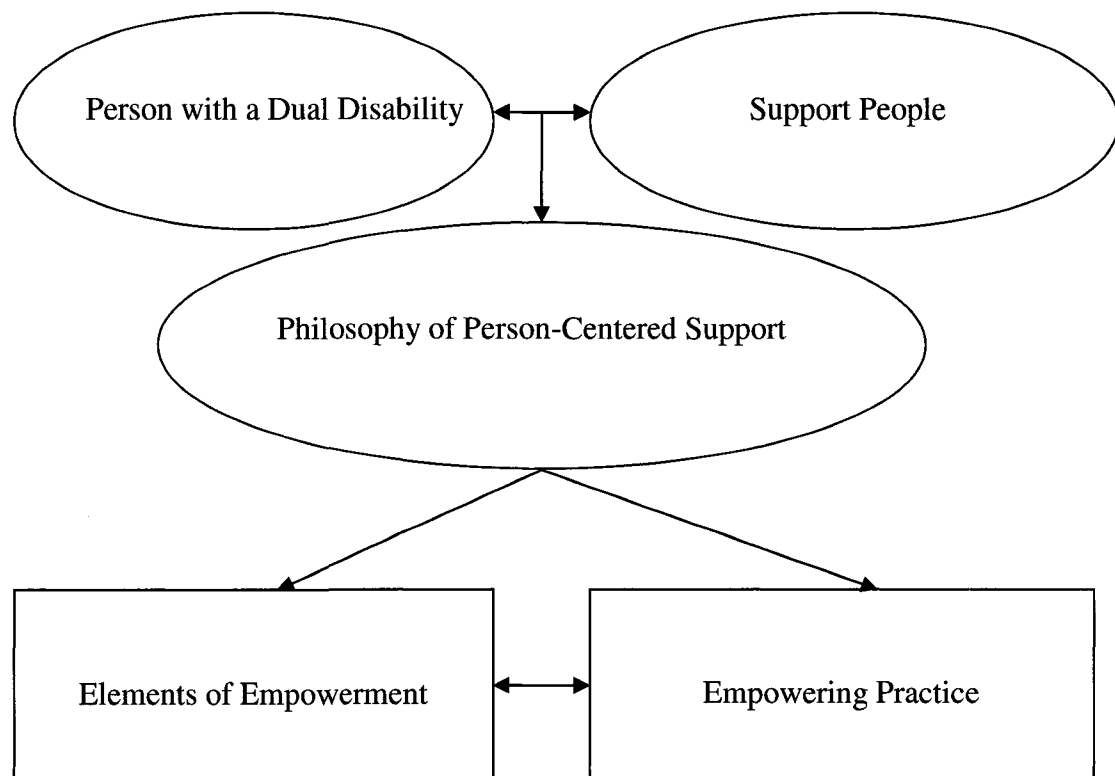


Figure 4. Facilitating supported empowerment in micro-practice.

centered support. The term *support*, in the literature on Independent Living, means people with disabilities receiving individualized support from support workers with

whom they have an equitable relationship, workers who follow their direction and facilitate the type of support they want (Nelson, Lord, & Ochocka, 2001a). In this fashion, the individual is supported to determine their own goals and meet these goals.

Hence, as illustrated, people with a dual disability are empowered when all factors (support people, person-centered philosophy, elements of empowerment, and empowering practice) are in place. People who are empowered act on their environment in relationship with people who promote their process of empowerment. Worthy of note, are barriers to supported empowerment identified in this study; highlighting the need to reflect on this process.

It is evident that elements and practice are interlinked in the social process of empowerment. A unique contribution of this study is the identification of specific strategies that are implemented by the support people noted in Figure 4. These strategies, which I will elaborate next, are tied to the empowering processes in the micro, mezzo, and macro communities and indicate that empowering elements are present in practice.

Empowering practice strategies. Practice strategies that contain elements of empowerment provide initial indicators of the level of empowerment in the model of support. Each supportive practice requires a thoughtful understanding of which elements of empowerment it evokes, as well as, their validity and priority in fuelling the process of empowerment. For example, the person-centered element drives individualized service, through which the person with a dual disability can exercise self-direction, autonomy, and choice in activities leading to participation in community spaces, social connections, and mutual aid. As such, the person-centered element is valid, as it evokes several other elements of empowerment.

Similarly, the empowerment element of control may be embedded in routines that reduce confusion for the individual. However, on closer examination, such a practice may privilege system needs over individual, may threaten to take away choice and control from the individual, and be less empowering. For instance, Donna's routine was to bathe every morning using the mechanical lift for safety. When the lift broke, Donna agreed to take a shower instead and felt less distress than when having a bath, according to the staff on duty. This example demonstrates a danger in routines that become mechanical. Only reflective, evolving practice will eliminate stereotyping and enable the individual to maintain autonomy. Therefore, reflective, collaborative, and integrative feedback among support people is required to determine the validity of control within routines.

Together with validity, it is also important to consider the priority of an element. A critical element of priority identified in this study was accessing resources. Lack of resources strongly impacted people with a dual disability when they could no longer live in environments of their choice. The agency built its home specializing in dementia support to fill a wide gap in resources. However, administrators and direct-care staff were concerned that the quality of support in the home dipped when staffing was transferred with an individual to the hospital.

Janicki et al. (2000) have identified the "tipping effect" where care demands for one or several persons with dementia in a home shift such that staff members are no longer able to maintain the level of support, thus, predicating a move. Likewise, the administrators in this study were cognizant of the fact that the current level of resource was insufficient to support multiple individuals in the late stage of dementia. An

administrator did not rule out the possibility that at some point it may become necessary for a consumer to be placed in a nursing home.

The findings of this study also identified a lack of resources to adapt community spaces for people with a dual disability. In Jenny's case, her participation in day programs was cut to two days a week due to lack of resources to meet her new needs. While the time she lost in day programs could be replaced by other activities that enhanced community integration (e.g., going for walks with a friend), to Jenny it seemed that activities to which she had access prior to dementia were withdrawn. In addition, she could only go for walks if staff members were available or volunteers were familiar with her communication methods.

One could say that Jenny's loss of opportunity to participate in segregated day programs creates opportunity for more enriching activities. Perhaps her time in these programs could be replaced with integrated activities in the community. Perhaps she could recruit members in her circle of support to go on walks with her. Ultimately, it would be empowering for Jenny to have a choice between day programs, other familiar places where she has established social links, and new opportunities. Recognizing that Jenny may not have been exposed to integrated community activities that may be more enriching than segregated day programs, empowerment gives her the right to choose what she finds comfortable.

Hence, it is evident that the accessing-resources element is crucial for empowerment. In order to expand choices in home and community, people with a dual disability need to be able to access resources. This brings me to another critical element of empowerment for people with a dual disability, personal advocacy.

Personal advocacy is a priority in meritocracies where individuals inevitably compete for resources or risk losing out. In this study, the element of advocacy was harnessed by support people who focused on the daily, and even moment-to-moment, life of the person. These support people activated the outcomes desired by people with a dual disability. The findings identify many examples of activation that enable people with a dual disability to experience control, choice, and flexibility.

Upon thoughtful consideration of the validity and priority of an element for people with a dual disability, support people implement practice strategies that empower these individuals. These strategies, albeit not all inclusive, are outlined in Table 7 and are implemented in three domains: intrapersonal (micro level), community (mezzo level), and societal (macro level).

Intrapersonal domain. This domain comprises an advocate or advocacy group, personalized support plans, informed choice, multiple opportunities for reflection, consistency in support and caregivers, and a balance of health and safety with choice (see example of Donna in chapter 4). Advocates (such as family caregivers, support people, friends, and community members) who bring skills, resources, and connections relevant to the needs of the individual facilitate their daily living and aspirations. Advocates seek the perspectives of the individual (and not use their own) to support preferences of the individual. For instance, the findings indicate that divergent perspectives of family caregivers and staff on how support is implemented disempower the consumer. Advocates understand the scope of the person's abilities and desires before and after dementia. They are able to engage significant others in the person's circle of support.

Table 7
Practice Strategies that Facilitate Empowerment

Domain	Empowering practice
Intrapersonal	<p>A personal advocate or advocacy body established</p> <p>Inclusion in all planning and decision-making processes enforced</p> <p>A personalized support plan developed, implemented, and evaluated</p> <p>Historical and cumulative knowledge gathered</p> <p>Informed choice and assent received at goal implementation</p> <p>Multiple informal and formal points for reflection of practice present</p> <p>Consistent, compassionate, long-term caregivers involved</p> <p>Efficient health management</p> <p>A protocol on balancing risk versus self-determination determined</p>
Community	<p>Caregivers trained in dementia and related support</p> <p>Flexible access to health and social services</p> <p>Individualized homecare available</p> <p>Connections to family, friends, and peers maintained</p> <p>Participation in planned, spontaneous, and textured activities of choice</p> <p>Integrated activities of work and leisure with diverse populations</p> <p>Enriched supports for inclusion in community activities</p> <p>Leisure and work-related activities evident</p> <p>Positive social interactions nurtured in the home</p> <p>Mutual aid with peers and between support circle members developed</p>

Table 7 (continued)***Practice Strategies that Facilitate Empowerment***

Domain	Empowering Practice
Societal	<p>Adequate resources available for individualized funding</p> <p>Funding used flexibly per individual choice</p> <p>Enriched supports resourced</p> <p>Choice of a variety of structured and textured activities</p> <p>Strategies for public awareness of dual disability issues developed</p> <p>Integration of intellectual and dual disability knowledge in curriculum</p> <p>Training needs of support persons developed and funded</p> <p>Strategies for research and evaluation of dual disability services</p> <p>Multiple living options available post dementia</p> <p>Policies & strategies for transitions developed</p> <p>Partnering between government ministries (e.g., health, social, housing)</p> <p>Planning for future living initiated before onset of dementia</p>

The circle of support has an informal, not a professional, affiliation with the person with a dual disability. Even if involvement with the individual has been or is still within a professional capacity, members of the circle collaborate with full commitment to the individual. They are the experts and decision-makers at the circle's center. The success of the collaboration is measured by satisfaction of the individuals in achieving their goals, set according to personal aspirations, choice, and comfort.

Personal support plans, using a person-centered approach, facilitate the measurement of success. Personal plans are updated by the circle of support with input from the individual with a dual disability, key informants, knowledge of the individual's historical preferences, and other accumulated knowledge in practice. These plans contain goals based on self-made choices about how to spend each day, including the quality and type of community integration and social participation.

Ensuring informed choice when developing support-plan goals is essential. It is also important to get verbal assent when implementing goals. In order to make informed choices, the person with a dual disability needs comprehensible information offered in flexible ways. For example, when individuals choose a new home, staff should offer visits and trial stays, opportunities to build relationships with new staff, and quality time with new peers. When individuals decide to move, their communication (e.g., about comfort level, stress level) should be gauged to confirm the choice.

When personal-support plans are implemented with informed choice, it is important to create multiple opportunities for reflection on the social location and role of personal advocates and caregivers. As well, in reflection, support people must evaluate their assumptions about the abilities of people with a dual disability, adherence to personal plans, and the satisfaction of the individual with their quality of living. Support people can reflect on these issues formally and informally through consultation at shift changeovers, meetings of the circle of support, discussions with previous and current caregivers, and by checking with the person with a dual disability.

An important empowering practice is the engagement of consistent and long-term caregivers selected by the individual and who can provide continuity and accurate

reflection. Consistency is enhanced by the efficient transfer of knowledge about individuals within the circle of support and between formal and informal caregivers. For instance, procedures for orienting new staff to ensure consistency can be built into the implementation plan. Further, practice can be improved by frequently evaluating the outcome of personal support plans in a forum that seeks multiperspective feedback.

Reflective practice based on multiperspective feedback is critical when staff try to balance self-determined choices with health and safety. Staff members need to pay attention to ensure individuals' optimal physical and mental health so that they can exercise autonomy and choice. As well, timely interventions can prevent rapid deterioration in health, which can lead to a restricted life of suffering.

Ultimately, staff need to reflect on each practice event and modify their practices as individuals' health and needs change. Modifications take into consideration each person's previous choices, as evidenced in their life history, life plans, health management directives, current preferences, and consensus with the circle of support. Empowering practices allow the person to take risks where informed choices have been made. It is critical to not oppress just for the sake of duty to provide care.

Community domain. The administrators in this study spoke about the need for the community to be enriched so that people with a dual disability can be included in social spaces. As members of micro and mezzo communities, people with a dual disability should be included in all planning and decision-making that affects their living conditions: styles of living, where they live, who their advocates are, their activities, the way they are supported, and so on. Further, supports and services should be flexible, accessible, and responsive to dementia. For instance, all staff and informal caregivers are

trained in dementia and related healthcare. Healthcare is available in the home, the community, and at medical institutions.

In addition, it is important that people with a dual disability are connected to family, friends, and peers inside and outside the home. To sustain social connections and engagement support people should facilitate planned and spontaneous opportunities to visit with loved ones, play, volunteer, and go on outings. These chosen activities can be with one other or with groups, with known people such as caregivers or peers, or with strangers. As well, support people should provide opportunities to participate in activities that promote a textured life in the community where nonsegregated and pluralistic expressions of life are modeled. Participation in integrated forms of life will expand the individuals' knowledge on possible community experiences and create opportunity for enhancing the quality of their social life.

The quality of social engagement is measured by the participation of the person with a dual disability, irrespective of how the participation is similar or different to what they expected. For instance, an individual may engage with people or an activity for a few minutes or longer at a social event. The individual may choose to go for a drive and engage with visual images that kindle memories of past social engagement or imagined engagement. Therefore, the meaning of engaging with community is broad and varies between individuals with a dual disability.

When health complications restrict movement outside the home, more investment is needed in nurturing social liaisons with family, support people, and peers at home. Such a nurturing environment promotes mutual aid between peers and the circle of

support. This mutual aid can ameliorate trauma experienced from loss and death of loved ones.

Societal domain. People with a dual disability must have access to individualized funding to adequately implement their personal plans. Further, resources (e.g., housing, staffing, transportation, accommodation in community activities) must be flexible to fulfill requests for integrated activity in the community, as well as to meet daily needs that change with dementia. Without individualized resources, universal practice for people with a dual disability leans toward the impersonal, fostering oppression and restriction of individual choice. Adequate resources include, of course, the investment of time and expertise to develop them. Measures, such as, system partnering (e.g., ministries), public education, training, research, and evaluation assist with the development and disbursement of appropriate resources.

One empowering societal response is offering choices of where to live. In the latter stages of dementia, when social life is spent at home than outside, the living environment dictates quality of life. For choice to exist, there has to be options, and residential options must be adapted for dementia, with built-in supports for daily living and community participation.

Also important is involvement of people with an intellectual disability in planning their futures. This must include discussion about age-related conditions such as dementia, so that informed choices can be mobilized prior to its onset. People may indicate their preference to age in place or move to specialized settings. They may stipulate preferences for living spaces (e.g., own room, furniture, decor, etc.) or dementia-friendly environments (i.e., barrier-free, calming, safe, etc.) that can accommodate their desired

quality of life. Planning must include transitions, end-of-life decisions, medical interventions, and retirement lifestyles.

Summary

In this chapter I have summarized the findings of this study and proposed a social model of supported empowerment. Application of this model must take into account the perspectives of people with a dual disability and their unique understanding of the social construction of this condition. According to the themes grounded in the data, empowerment is apparent when support people abide by a person-centered philosophy to deliver a practice infused with elements of empowerment. Such practices that I have identified in the intrapersonal, community, and societal domains comprise a template for empowerment in the living experiences of people with a dual disability. Empowerment is enhanced when elements evoked by practice are valid and of priority to the individual. Further, the level of empowerment is increased when empowering processes are championed in interconnected spheres of the micro, mezzo, and macro communities to maintain individual selfhood, provide freedom of choice, and integrate the self in community.

CHAPTER SEVEN

Conclusions and Implications

After the onset of dementia, inability to stay in their current homes creates severe crises for nearly all Ontarians with a dual disability. Their only choice appears to be a nursing home, as is the case for mainstream seniors with dementia who can no longer be supported at home. Stakeholders in this study emphasized that nursing homes were not their preferred choice as health systems have not been efficient for people with a dual disability. They stated that the diagnosis of dementia is problematic in people with an intellectual disability and medical practitioners need the assistance of caregivers to make a diagnosis and implement a treatment plan. Skill deficits among healthcare staff, lack of individual attention, and mismatch between procedures and individuals' needs were cited as factors that impoverish the quality of life in nursing home medical models of support. Moreover, the stakeholders emphasized that the medical model of support is not appropriate for people with a dual disability, who have an earlier onset of dementia than the general population and can potentially enjoy several more years of community living.

Some stakeholders in this study indicated that a nursing home is a viable living option for people in the advanced stages of dementia, because “the care in a nursing home would not be much different ... as she would be changed, fed ... [and] the level of care medically would be higher, [as] they have nurses on staff.” The preferred choice of all stakeholders, however, was that people with a dual disability would live in their own homes with adequate support. In the absence of this choice, the consumers in this study had a second, which the agency had created, a home specializing in dementia support.

This study's findings confirmed that, despite the debilitating consequences of progressive dementia, consumers in the home aspired, and were able, to enjoy

participation in activities of work, and leisure, and in relationships. Plus, their competency in a range of daily living activities was evident, indicating that, when supported to do so, people with dual disabilities retain control over their lives as they age.

I observed that consumers were supported within a person-centered philosophy that facilitated staff advocacy for resources to meet individuals' goals. Among other things, they addressed physiological and systemic barriers by creating a personal-and-family-oriented living arrangement, seamless access to healthcare, and built-in mutual aid for dealing with grief from dying and death. Further, staff actualized many consumers' aspirations for community participation, maximizing opportunities for textured lives with family and friends.

A critical factor in the social model I observed in operation was the supportive relationships between consumers and their direct-care staff. It was within these relationships that supporting staff gained collaborative knowledge, which enabled them to advocate from the perspective of the consumer. When I say "supporting," I am already implying a power differential, where the person who supports may hold more power. In this sense, the social model may become expert driven when system and professional needs take precedence over those of the people they support.

Primarily, what was evident was the conscious effort the support staff in the home made to avoid any power differential by putting the consumers in charge. They thus exercise their autonomy by declaring what they want. Their wishes are cemented in a formal contract with the agency, which lends its weight to ensure that individuals' goals are implemented. In this way, the concept of *power to* is embedded in the philosophy of support and translated into collaborative practice. A significant opportunity arises for the person with a dual disability in a collaborative relationship: to model the self.

The self comprises the experiential self and the adapted self. The experiential self is formed through “inner discourse” of feeling and emotion that reflects the person’s environment (Hobson, 1985). Love, friendship, spiritual commitment, and healing mediums (e.g., counselling, therapy) facilitate healthy development of the experiential self (Hobson, 1985). The consumers in this study lived in an environment in which affection, friendship, and healing were nurtured to offset the trauma within dementia.

In addition, the adapted self was maintained by supporting old and new roles of consumers, such as employee, volunteer, caregiver, homemaker, entertainer, and friend. These roles were based on historical and cumulative knowledge of individuals’ interests and preferences. Even when some roles were relinquished as people progressed through dementia, supporting staff continued to honour their desire to participate in and contribute to community.

In other words, whether support staff knew or not how individuals would experience activity outside the home, they offered them the opportunity and left it to them to indicate (verbally or nonverbally) whether they wanted to participate. Staff continued to offer these opportunities until it was obvious that the individuals’ preferences had changed (they strongly resisted the activity) or that the activity would jeopardize the person’s health: “Now she is sick ... it is more tiring for her.” When ill health restricted participation in the outer community, support staff focused more on enriching the quality of life within the home, especially social relationships. They continued to give opportunities to model the self in the home.

From the viewpoint of social constructionist theory, in dementia the self remains intact despite the loss of cognitive and motor functions (Sabat & Harre, 1992). Nor does the progress of dementia threaten the loss of self. Rather, a person with dementia

experiences loss of autonomy and personhood as a consequence of the relational behaviour of significant others (Sabat & Harre, 1992). For example, within an institution, the adapted self of a person with a dual disability can be either resident or inmate in custody. The role depends on the environment and its amenability to support existing roles or create opportunity for new ones (Sabat & Harre, 1992).

This study demonstrates that when support staff members give opportunities to model the self in a collaborative relationship, people with a dual disability sustain their sense of self. The self, formed of their external power and personal history, transforms into self-power when they declare their needs and actualize their aspirations. Butler (1997) states that self-power can be evoked within relationships to engage self-agency and generate change:

Subjection [to power] is paradoxical. To be dominated by a power external to oneself is a familiar and agonizing form power takes. To find, however, that what 'one' is, one's very formation as a subject, is in some sense dependent upon that very power is quite another. ... power is not simply what we oppose but also, in a strong sense, what we depend on for our existence and what we harbour and preserve in the beings that we are (Butler, 1997, pp. 1-2).

[But then] ... a significant and potentially enabling reversal occurs when power shifts from its status as a condition of agency to the subject's 'own' agency constituting an appearance of power in which the subject appears as the condition of its 'own' power (p. 12).

The consumers in this study exercised their own power by making decisions in their day-to-day life. As well, within a collaborative relationship, support staff refined their knowledge about the needs and aspirations of the consumer. Knowledge gained in the collaborative relationship was valuable to match practice to the needs of individuals, as well as to advocate for resources. Such knowledge propelled the supporting staff to advocate within the agency and the outer community for a home specializing in dementia

support. In this manner, advocacy rooted in knowledge gained in a collaborative relationship between supporters and the people they supported transformed a disempowering social structure; the goal of empowerment (Neuman, 2003).

In the process of empowerment, attitudes, thoughts, and beliefs need to be changed at the micro (individual) level in order to change views at the mezzo (community) and macro (societal) levels. Change at all levels is required to ensure effective and lasting change. To ensure empowerment at community and societal levels, formal/informal caregivers, peers (such as, People First), and community-level advocates need to take the collective narratives of individuals with a dual disability to policymakers. In so doing, they can mobilize social justice by obtaining appropriate services for people with a dual disability (Dominelli, 2002). It is evident in the findings of this study that this process succeeded in the construction of the home about nine years ago.

However, since then, the home has housed only a dozen or so people and, according to agency administrators, it has not been replicated anywhere else in Ontario. As a result, the option of living in a dementia-capable home has been limited to the very few Ontarians who happen to live in its city or were already clients of the agency that built the home. For the majority of Ontarians with a dual disability, nursing homes are the only option. Lack of resources to age in place, to create alternative living options, as well as restrictive living conditions in nursing homes all raise policy issues for these individuals. I will discuss these issues next and offer seven recommendations for the development of policy to address the needs of people with a dual disability.

Policy Implications

A goal of this study was to identify ways policymakers can better respond to the changing needs of people with a dual disability. The findings of this study point to

several priorities necessary to address in policy: housing, participation in both textured and programmed community activities, increased capacity to integrate people with a dual disability in community, respite for caregivers, portable medical services, individualized support, flexible funding, and collaboration between government ministries to fund social and medical services.

Policy planning for dual disability is necessary as many people with an intellectual disability are aging and are at risk of dementia. In 2001, there were approximately 55,000 Canadians 45 years and over living with an intellectual disability (not including those living in institutions, the territories, and reserves) (NACA, 2004). As well, a survey of 57 developmental service agencies in Ontario showed that these agencies supported 3,357 individuals with intellectual disabilities in 2005. Another 521 adults were waiting to move from institutions to the community (OPADD, 2005). Of all the adults living in agency-run homes, 49% were over 40 and 24% over 50 (OPADD, 2005). These statistics, while not inclusive of all people over 40 and with an intellectual disability, (e.g., those living independently or with family) demonstrate that there is a need to plan for living environments for people with a dual disability.

The findings of this study suggest that people with a dual disability are displaced from their homes that cannot meet their needs. Moreover, they are restricted in choices about where to live. The Ontario government policy of limiting services in one sector (such as homecare) in comparison to another (such as nursing homes) restricts choice and creates substantial hardship for individuals. If adequate funding and support were available in a system of homecare, it is likely that people with a dual disability would choose this option over nursing homes.

Presently, the Ontario government is poised to modify long-term care services to accommodate people with a dual disability. Irrespective of whether the stakeholders in this study feel that nursing homes are appropriate or not for people with a dual disability, the medical model of care seems to be the only option available. The medical model is supported by the Ministry of Health and Long-Term care that funds dementia-related needs in Ontario. It appears that the social agenda of this Ministry is to normalize healthcare for all seniors with dementia in their program of long-term care.

Normalization favoured the integration of people with an intellectual disability, who were deinstitutionalized in the 1970s and 80s, into community living. Similarly, the Ministry, following the normalization principle, favours the integration of people with a dual disability with seniors with dementia in mainstream services.

Herr and Weber (1999), among others, argue that normalization, rather than “demanding that the wider society unconditionally accept and integrate its members who are different in any respect, requires the [marginalized] individual to adapt to the norms of society” (p. 227). In the current climate, societal norms dictate that the needs of aging, medically fragile people be met in institutional settings operating within a medical model. Aging people with dual disabilities are expected to adapt to this norm.

However, the findings in this study indicate that as policy initiatives plan for the redistribution of resources to meet the needs of an aging population, people with a dual disability experience unequal distribution of benefits, preventing them from living out their years in the community (especially unfair, since they die earlier from dementia than the general population). They are thus ‘exploited’ to live an impoverished quality of life whether they age in place or in a nursing home. Young (1990) states that “the injustices of exploitation cannot be eliminated by redistribution of goods for, as long as

institutionalized practices and structural relations remain unaltered, the process of transfer will re-create an unequal distribution of benefits” (p. 53).

Current policy measures appear to re-create institutionalized practices for people with a dual disability in a system of custodial care that focuses on surveillance, remediation, rehabilitation, and monitoring. Viewed as an “at-risk” population to be managed, the focus is on the efficiency of the system, rather than the needs of individuals. Based on market principles, the system perceives the person with a dual disability as “... a person who embodies an economic cost that must be factored into society-wide economic policy decisions” (Bickenbach, 1993, p. 13). When people with a dual disability are perceived as economic costs, the programs that serve them are cut as budgets are outpaced by needs. It was evident in the findings that lack of resources and enriched staffing resulted in limiting the time consumers spent in textured community activities and excluded them from integrated community programs.

Such is the outcome when the affairs of people with a dual disability are managed as a business, when the rhetoric of equal rights is reduced to claiming rights to dollars and services within a competitive market. Herr and Weber (1999) state that business and clinical goals sometimes conflict with the human services perspective, as advocates of the latter seek to build an environment that capitalizes on people’s strengths and minimizes the impact of their weaknesses. This poses a challenge to policymakers, who tend to seek universal rather than particularistic solutions.

In social services, the push for universality intensifies the need to rationalize action taken. Turner (1995) states that “rationalization involves the increasing importance of systems of individual discipline and regulation by bureaucratic agencies related to the nation state” (p. 35). The state gains credibility when advisors provide a logical response

to a medical problem, evoking public support for its management of a tragic situation; people with dementia are victims or sufferers, whose caregivers endure this personal tragedy (Crow, 1996; Oliver, 1986). Hence, a paternalistic notion of impairment leads advisors to diagnose and then prescribe a cure. This dominant perspective becomes embedded in our perception of the term *impairment* and internalized by *others* who experience it.

To prevent exclusion and oppression, policymakers must become aware that knowledge and practice are synchronous and that, in the process of defining concepts, “we variably construct social problems, social actors and social solutions” (Chambon, 1999, p. 57). For example, if we focus on *impairment*, we perceive a social problem of disease or mental dysfunction to be treated by health practitioners with a solution being confinement in custodial care. If we shift the focus to *retirement*, we perceive a social problem of active living to be addressed by multi-disciplinary teams (e.g. housing, employment, and recreation planners) with solutions being adapted housing and redefined ways of working, leisure, and social participation.

Thus, a critical understanding of the abilities of people with a dual disability is necessary to identify, and change, oppressive practices that marginalize them. The findings of this study provide insights for policy to enable these individuals to age in the place of choice, prevent them from moving prematurely to a nursing home, limit the traumatic impact of transitions to unfamiliar environments, and maintain a participatory life in community. These insights are derived from the qualitative experiences of a very small unit of four consumers in this study, limiting my ability to generalize the findings to all people with a dual disability.

While it is not possible to formulate policy based on a small sample, policymakers can draw on information highlighted in this research. The strength of the findings in this study lies in the depth of information gained to understand the meaning of the experience of living with a dual disability. Rich qualitative descriptions of consumers' lives in the home and in the community provide a visual of what this experience looks like. Plus, the trustworthiness of the findings is strengthened by triangulating the data with 12 stakeholder perspectives, my observations, and documentation reviews. I, therefore, put forth seven considerations for policy development based on insights generated in the findings of this study.

First, a policy consideration is the expansion of homecare services to people with a dual disability in their own or family homes. Current homecare services include respite for caregivers, and limited hours of personal and nursing support. To sustain active living with dementia, urgently needed services include extended hours of personal and homemaking support, support to participate in programmed and textured activities in the outer community, nursing support to implement medical protocols, home visits by health professionals as required, and modification of living environments to make them dementia-capable. These measures require funds to purchase the level of service required according to individualized needs and to make structural changes in the home. As well, all support people (e.g., family, volunteers, and professional staff) must be adequately trained in approaches used for people with intellectual disabilities and those with dementia. The findings of this study postulate that policymakers consider a structured, long-term, home support program where services equal to institutional care can be brought to the residence of the person with a dual disability.

It appears that people with a dual disability benefit from living in familiar surroundings and maintaining community ties and connections with significant others, especially after the onset of dementia. The stakeholders in this study indicated that, if people with a dual disability could not continue living in their own or family homes, the home specializing in dementia support was the next best option. Nursing homes are only considered by service providers when dementia has progressed to the terminal stage, and the individual's medical needs can no longer be met in the home. Many middle-aged adults with intellectual disabilities have settled into group homes with a person-centered approach. For these individuals, aging in place means increasing the capacity of their homes when they have dementia. Therefore, a second policy consideration is that adequate funding across a range of living environments that have the potential to extend community, rather than large institutions, is made available. An administrator in this study proposed that 70% of people with a dual disability could continue aging in place and only 30% may require moving into a specialized model or nursing home. In this regard, policy can consider expanding options for people with a dual disability to live in dementia-capable living environments that simulate a home, such as the one in this study.

Further, the findings of this study reveal the weaknesses in each of the living options currently available to people with a dual disability. Evident are limitations in services for personal support, community engagement, and medical care when someone lives in their own apartment or family home. Nursing homes, which provide 24-hour personal and medical support, lack opportunities to live a textured life in the community and provide inconsistent support, due to the small number of staff. In addition, nursing-home staff are not trained to understand the communication modes and needs of people with a dual disability. Group home living is restricted by the lack of funding to maintain

the facility and sustain an adequate level of service. Confusion about which ministry is responsible for funding which needs when someone has both an intellectual disability and dementia creates barriers for accessing already restricted community-care services.

Such socially constructed oppressive factors *disable* people, restricting their capabilities and opportunities through prejudice, discrimination, inaccessible environments, and inadequate support (Crow, 1996). Social theorists point to injustices that flow from the nonrecognition of disability that make people with a dual disability ineligible for resources to fill basic material, financial, and social needs (Abberley, 1993). For example, when a medical diagnosis of dementia is absent for individuals with an intellectual disability they do not qualify for homecare. Furthermore, it is only when their ability to self-care is severely impacted by dementia and their family caregivers are unable to assist, that they can access government funded services in their home.

Therefore, a third consideration for policymakers is to examine how health, social, and community services are integrated to deliver seamless supports. It is likely that the restructuring of health services into the Local Health Integration Networks will make service provision more proficient. A critical factor for people with a dual disability is that their social and community participation supports are packaged with their health supports. Because dementia is a progressive, lifelong condition, it is important to provide seamless support to the end-of-life, both when people live in their residence of choice and when they transition to a new home. Seamless services are accessible to the individuals irrespective of where they live – in their own apartment, in their family home, in a group home, or a nursing home.

Seamless services are facilitated when funding is responsive, flexible, and portable. Direct funding, given directly to the individual, increases portability and

flexibility to manoeuvre transitions, service providers, and living environments.

Flexibility to change service packages is very important for people with dementia, as their physical and mental health are variable. Direct funding facilitates person-centered planning (Tindale et al., 2000) and evokes the elements of autonomy and self-agency; when individuals are able to choose from an array of services, they are more likely to be satisfied with the support they receive. When elements of empowerment are in place, empowering living conditions can grow. Such conditions are present when people perceive that they are able to affect their environment (Rosenfield & Neese-Todd, 1993). As such, a fourth consideration for policymakers is to ensure that people with a dual disability receive direct funding for individualized support.

Direct funding is efficiently used when individualized support is cemented in a support plan based on “dreams, strengths, personal goals, and directions of the person” (Lord & Hutchinson, 2007, p. 147). Access to individualized life planning is an important feature of supported empowerment, as it places the individual at the centre of all planning and implementation processes, giving the individual control over the use of resources. Meeting their goals, in turn, helps individuals to increase their independence and control over their own lives, take risks, make mistakes, and dream rather than focus on limitations (Nelson et al., 2001b). A fifth consideration for policy, therefore, is to take into account resources required to support the planning processes of developing an individualized life plan.

A sixth consideration for policy development is that individualized plans are independent of system and service mandates. If planning for an individual is tied to a service-delivery agency, for example, it is likely that it will be constrained by system goals and capacities. The literature offers mechanisms for facilitating individualized

plans that are controlled by the individual and increase choice to create innovative services. For instance, microboards (see Lord & Hutchinson, 2003), circles of support (see Mary, 1998), and wraparound teams of formal and informal support people (see Brown, 2000) are chosen by the individual to assist with the planning and implementation of personal goals. These people may be known to the individual or recently introduced to them.

A strong team includes individuals with a dual disability; individuals that they select who are intimately knowledgeable about their needs (i.e., peers, friends, family caregivers, community members, professionals); others who are well versed in their historical life experiences, preferences, and future aspirations; and advocates who have a broad understanding of community and government resources for disability, health, and aging. The level and type of support required, the community resources available (e.g., family, friends, volunteers, housing, community programs, medical services), and the level of government funding required to augment community and personal resources to implement the individualized plan can be determined with the team.

The role of the team is not just to determine current and potential future needs for one-time resources, but to give ongoing support to implementation of the plan and repackaging the supports according to changing needs over the individual's lifetime. In other words, part of individualized planning is establishing a lifelong support team. The team members can remain the same, or change depending on the needs of the individual and availability of team members. Ongoing support can take the form of regular consultation and problem solving about the plan's implementation, identification of emerging needs, assessing the cost and benefits of transitions, annual funding applications, advocacy for needed resources, and facilitating community engagement.

A critical aspect of support teams is the possibility of innovation in service delivery. The findings of this study indicate that, as people with an intellectual disability progress through the stages of dementia, their opportunities for social engagement diminish as community can no longer include them and significant others can no longer relate to them. If teams connect on a regional or national level, there is potential to consolidate substantial knowledge about the needs of people with a dual disability and the community's capacity to fill them. Cross-regional and national dialogue can generate new ways for restructuring services such that they include people with a dual disability in community.

Hence, the seventh consideration for policy is how to prioritize the funding of strategies that will prevent isolation and segregation of people with a dual disability from community participation. Considerable expertise and resources are required to include people with a dual disability in community, such as, education of the community, accessible environments, transportation, trained staff, modification of community programs, and opportunities for individually planned leisure and recreational activities. Enriched support for people with a dual disability is necessary to achieve the goal of "supported inclusion" in community.

The seven policy considerations made in this section will uncover oppressive expert-driven practices, confront barriers, and promote alternative thinking. The stakeholders in this study concurred with recent studies showing that people with dementia want flexible, responsive services that respect their individuality and better their quality of life (Banks & Roberts, 2001; Pickard, Shaw, & Glendenning, 2000; Riorden & Bennett, 1998; Zarit, Gaugler, & Jarrott, 1999). Plus, the template of practice strategies presented in chapter 6 offers a framework for building an empowering social model of

support. Policymakers can move toward giving people with dual disabilities control, flexibility, and choice; critical elements when matching their diverse abilities, strengths, and goals with appropriate community services. Additionally, effective policy responses to the needs of people with a dual disability require further research.

Recommendations for Further Research

The literature on dementia identifies several gaps in research to inform service plans for those who have a dual disability. More studies are required to understand the needs (some of which were identified in this study) of people with an intellectual disability who have dementia. Research could explore barriers to service, factors precipitating transition from one model of support (e.g., independent living) to another (e.g., nursing home), the suitability of existing supports, and the needs of caregivers, be it support workers, family, or support circle members. Caregiver research must consider factors such as grief from death and dying, the predominance of female family caregivers, their resources to support, and their aging at the same time as their loved ones age.

Research is also required to understand the impact of the physical design of living spaces on individuals. A case study of two different models of support (e.g., barrier-free housing versus nursing home) could illuminate factors that are conducive or adverse to good quality of life. A cost-effectiveness analysis comparing the social model of support with the medical model may influence policy on living options for people with a dual disability.

In addition, the findings in this study indicate that there are significant barriers for people with a dual disability to participate in integrated community programs after the onset of dementia. The findings also demonstrate that consumers participated in

spontaneous and planned activities in the community. McConkey, Sowney, Milligan, and Barr (2004) concur that, regardless of where they live, textured and integrative community lifestyles that include visiting local shops, going to church, outings, and being with people outside their homes are very important to people with an intellectual disability. Research on the type and quality of programs that support inclusive community participation of older adults with intellectual disabilities (including those with dementia) in employment, retirement, and recreation is needed (Salvatori, Tremblay, Sandys, & Marcacio, 1998).

Further, as the mental and physical health, and support practices of caregivers, ultimately impact on people with a dual disability it is vital that this be carefully considered in the design and implementation of interventions. We need a new approach to service provision that allows people with a dual disability to interpret their own experiences of impairment; their feelings and concerns; and the positive, neutral, or negative meanings of their personal histories. This study identified a concept of elevated empathy that enabled supporting staff to implement the choices of consumers in advanced stages of dementia. More research with people with a dual disability is required to verify how their daily living choices can be actualized and which elements of empowerment they prioritize in their support interventions.

A particularly significant limitation of research to date is that dual disability is socially constructed without the unique perspectives of those living with this condition. When planning my study I found that empirical literature explaining the condition was laden with biomedical knowledge. At the outset of the study, I decided to fill the gap by looking at social versus medical factors of disablement for people with a dual disability. However, when I was immersed in the daily lives of these individuals, I recognized the

futility of living with a debilitating disease that ended in sudden death. I struggled with constructing a model of empowerment that ignored the medical or physiological factors of disablement. In fact, it became apparent to me that ignoring them in an understanding of the dual disability experience would generate practices that limited individuals' opportunity to lead enriched lives.

My struggle leads me to assert that, in order to speak accurately about dual disability, we need to develop a discourse on the dementia experience from the perspective of people with a dual disability. Given what they face, researchers should endeavour to generate results as accurately as possible, understanding the construct of dementia from the perspective of people who live it, particularly, as this powerful construct is legitimized by a family physician's or psychiatrist's diagnosis. Social and behavioural scientists in the mid-20th century have used role theory to explain the social consequences of illness (Parsons, 1951). They have considered the behaviour of people with mental illness to be socially deviant, as it violates social or group rules. Later in the century, symbolic interactionists explored the concept of deviance within labelling theory (Lemert, 1967), explaining that groups undergo a social process in which those in authority label them. These labels impact the people labelled as well as those around them.

This labelling continues. For instance, people in the early stages of dementia report embarrassment and shame on being labelled (McGown, 1993). Labelling devalues and stigmatizes the person with dementia, whose social-norm-challenging behaviour is viewed as problematic (Dingwall, 2001). As I found in this study, the stakeholders had heard descriptions of people with dementia as senile, old, mentally incapacitated, and chronically sick. People with a dual disability may or may not concur with the

conceptualizations of dementia favoured by doctors or social and behavioural scientists. Indeed, it is their conceptualization of dementia that is missing in research.

The search for the distinct perspective of people with a dual disability has thus far met with some challenges as researchers have used the same research criteria when studying people with dementia in the general population and people with a dual disability. Research on dementia among the general population has been dominated by the biomedical paradigm. Funders of biomedical research have favoured traditional research methods based on clinical assessments, memory tests, brain imaging through X-rays, biopsies, and autopsies after death (Bond & Corner, 2001).

As well, people with dementia have been excluded from research, based on an assumption that their contributions are subject to judgment and error. Ethics committees have questioned the ability of a person with dementia to autonomously give informed consent. Researchers argue that the symptoms of dementia (e.g., memory loss, difficulties in communication and comprehension) can impact on the person's decision-making ability, although they may have "intermittent competency" during fluctuations in cognitive ability (Marson, Schmitt, Ingram, & Harrell, 1994, p. 9). In trying to reduce error, researchers over the past two decades have primarily sought the perceptions of people with dementia through the Other rather than the Self point of view.

Examining the complex social phenomena of a dual disability through a single, often medical, lens raises fundamental issues: who sets the research agenda, decides which research questions to ask, and what outcomes to seek? Wilson (2001) states that "whatever the research paradigm, a full conceptual framework must acknowledge the political stances implied by values, assumptions, implicit motivations, hidden biases and areas of silence" (p. 473). Good researchers must look for alternative ways to include

people with all ranges of abilities in research. Otherwise, input to research findings will remain limited to the few who can contribute within the framework of current methodologies. Continuing in this direction will lead us to yet another disabling situation, one where the actualization of civil rights and equality is compromised because only the voices of the elite few have been heard, at the expense of the majority (Crow, 1996).

New approaches to dementia research acknowledge that just as there is multiplicity in the construct of dual disability, there is multiplicity in the social life of the person who has it (Woods, 2001). Lyman (1998) states, “A phenomenological perspective requires that our understanding of dementing illness be empirically grounded in the lived experience of those who have the condition” (p. 49). To garner this experience, I propose four considerations for researchers which I will now outline.

First, researchers have to convince themselves that people with a dual disability can participate in dialogue, make valid judgments, and make decisions about their care (Nolan, Ryan, Enderby, & Reid, 2002). As noted by Wilkinson (2002),

... we can move on from early and essential work focusing on evaluation and using proxy voices, to other ways of exploring and challenging, at a deeper and wider level, the attitudes and processes which can reduce stigma and bring people with dementia more inclusively into society. (p. 20)

Indeed, the consumers in this study did make decisions about their support. More research is required to develop our understanding of how people with a dual disability communicate, some modes of which I observed in this study. In turn, strengthening *our* communication skills to be able to hear the perspective of people with a dual disability is essential to constructing their social experience. To not do so will result in fragmented services (Briggs & Aksham, 1998; Pickard, 1999; Zarit et al., 1999).

Second, when conducting research with people with a dual disability, researchers need to consider the appropriateness of the research paradigm they propose to use. While no single research paradigm is superior, each has important consequences for how an inquiry will be conducted, how the findings will be interpreted, and what will be seen as deserving attention. Thus, multiple research methods are needed to understand the complex lives of people with a dual disability using hermeneutic, multimedia, empowering methods that allow them to tell their stories in their own voices and by their own means of communication. Such methods encourage the silenced to speak, allow the researcher to sensitively explore what lies behind nonverbal communication modes (e.g., shrugs, smiles, and scowls), and to probe inconsistencies heard, seen and felt. Participants and researchers come to a common understanding of what they are creating through interactive dialogue and then commit to change through the process of reality construction.

Third, Woods (1999) cautions that research centering on the person in care is only an individualistic reflection; it does not take into account the “interdependencies and reciprocities” within relationships. Acknowledging the relational aspects of people with dementia, Kahana and Young (1990) state that research should move beyond “unidirectional and asymmetrical models of care” towards researching the “triad” (i.e., person with a dual disability, caregiver, and professional network). Research would then include the dynamic relational experiences of the individuals with a dual disability, as they are impacted by caregivers’ roles, new dyadic relationships, and the wider family and formal-care systems.

Fourth, Post (2001) suggests that we should consider “quality of lives” to capture how personhood is created (or diminished) in social relationships. For example, some

researchers have identified alternate ways to measure the quality of life experienced by people with dementia, such as self-esteem, feeling of belonging, positive affect, sense of accomplishment, aesthetic sensitivity, feeling lovable/likeable (Brod et al., 1999); personal worth, social confidence, hope (Kitwood & Bredin, 1992); meaningful use of time, stimulation/aesthetic quality, and quality of relationships with family and friends (Lawton, 1997). Other alternative ways to measure quality of life address negative emotions: anxiety, fear, lack of confidence and control, feeling devalued and unloved (Gwyther, 1997). Thus, researchers can use more inclusive research designs that affirm the Self of a person with a dual disability reflected in interdependent and reciprocal relationships.

Summary

The purpose of this dissertation was to understand the experiences of people living with both an intellectual disability and dementia. The findings indicate that experiences of dementia among people with intellectual disabilities are similar to those in the general population. However, their dementia occurs earlier in life and, according to the stakeholders in this study, its progression to death is faster. The findings also indicate that the challenges of making a clinical diagnosis of dementia, accessing additional resources for dementia support, and gaps in community capacity to support and include people with a dual disability results in marginalization of these individuals. People with a dual disability are not only marginalized by social factors; combined with the profoundly debilitating effects of dementia their quality of life is significantly impoverished to the point of death.

Thus, a critical question arises: with the onset of dementia, how will the medical, emotional, and behavioural needs of individuals, who progress into complex care, be

managed? The projected increase in dementia within the general population has attracted dollars to aggressive research for a cure, and in the interim, for researching ways to slow down and/or manage the disease. In addition, the Ontario government has expanded long-term care and restructured primary healthcare by decentralizing it at the regional level to provide seamless service to its citizens. While restructuring age-related services to meet the projected increase in dementia may yield some opportunities for additional support, restructuring alone will not ensure personal choice and civic engagement for people with a dual disability. Focusing only on health will drive policymakers to look at the presence or absence of dementia and legitimize the medical model, at the expense of models that focus on community integration, despite the latter's demonstrated success.

If we view dementia as an age-related terminal disease, we can surmise that multiple losses will perpetuate the loss of control over daily-living decisions; apathy will set in and the individual will decline social and community participation. We will view these changes as a natural progression of dementia; the person disengaging with the environment and self to prepare for death. As a consequence of dementia, the individual will become totally dependent on others who will effect decisions in their best interest. To this end, it is inevitable that the individual will become powerless because of aging and dementia.

Powerlessness of people with a dual disability occurs not only because of dementia's profoundly debilitating effects, but more so, because of the conditions in the living environment. For instance, when speaking about the conditions in nursing homes an administrator said that people with a dual disability "would not have the same zest for life, [and] a lot of people [would] go downhill a lot faster, because it's a little more depressing setting." Stakeholders said that due to the size of the institution, "simple little

things [like] listening to people, knowing people well, respecting them ... always giving people dignity” would remain a challenge. Similarly, the findings of this study indicated disempowering conditions in the home studied resulting from resource shortages, inconsistent practices, and oppressive caregiver interventions. These disempowering conditions dismantled freedom of choice, devalued the individuals’ autonomy, and excluded them from community.

As seen in this study, all support people have the “capacity...to produce intended, foreseen and unforeseen effects on others” (Cornell Empowerment Group, 1989, p. 2). These types of oppression are difficult to identify, as they are often not blatantly discriminatory but subtly maintain the status quo (Mullaly, 2002). As a consequence, it is important that support people replace their self-assurance that they are doing good and know what’s best with humility, proactive listening, and then with reflection of the person’s interests (Melton, 1987).

Consumers’ interests were actively sought by staff and administrators in this study. Adopting a social perspective on disability, they believed that dementia was a condition that could be managed, that the self of individuals was still intact, and their personhood could be actualized in the modeling of their experiential and adapted selves. Therefore, when supported to do so, the consumers thrived with work, leisure, and social opportunities. Furthermore, they exercised their autonomy to choose the desired quality of life.

Stakeholders aspired for the consumers to be empowered as persons, human beings, and citizens, living among their peers in community. The consumers enjoyed their days in a stress-free environment, with freedom to do whatever they wanted. In this

retirement style of living, staff honed in on quality of life issues and expanded the self-worth and self-efficacy of consumers. One direct-care staff member explained,

DCS4: There are successes everyday. ... Successes can be they have made it through the whole day, and they have had a great day – they didn't have seizures. Yesterday they couldn't feed themselves, today they can. ... Little, simple things we take for granted everyday. Are they up and walking around today? Yeah? That's a success for today or for the hour or whatever. ... Is it success they went on a holiday somewhere? Sure it is! Or it is still a success that they went, even if it wasn't a great trip. Whatever they have had [in] that cognitive moment and they have enjoyed [even] for 5 minutes [is success].

What was important was that consumers were living their best and participating in the community to the extent that they could. Staff put concerted effort into ensuring that people led lives that they themselves designed and that their desires for nurturing human relationships, integrated within a community living experience, were met. Failing to make these efforts, according to an administrator, would mean that the individuals were in “just another place where people are parked.”

Contrary to being “parked,” the findings of this study demonstrate that the consumers were empowered in an innovative social model of living; a model that enabled them to continue living meaningful lives, within a community of people – a community where their desires for participation were encouraged, their personal aspirations were achieved, and where engagement with others was nurtured. Using the findings, I generated a social model of supported empowerment in which people with a dual disability increase their capacity to control their life direction. Additionally, the insights gained in this study assist policymakers, researchers, and community advocates to stimulate an intentional process of empowerment; one in which people with a dual disability can sustain their ability, self, and community while living in a place of choice and aging with comfort and dignity.

Appendices

Appendix A: Institutions, Community Service, and Independent Living Models

Models:	Institutional Model-->	Traditional Community--> Service Model	IL Model of Programs
Decision Maker:	Medical Practitioners	Service Professional Providers	Consumers
Role of Participants:	Patient/Sick Role	Recipient/Client Role	Consumer/Decision Maker
Nature of Problems:	Sickness of Individual (Pathology)	Lack of Specialized Care in the Community	Dependency on Professionals etc. Physical, Social and Economic Barriers Lack of Effective Supports
Policy Principles:	Medicalization, Categorization, and Functional Limits	Professional Services Segregated Services One Service for Everyone	Consumer Control/ Self Direction Choices/Options Flexibility/Freedom
Program Realities:	Institutional Focused Service/ Failure Based	Often: Lack of Access, Availability, and Affordability Complex and Fragmented Limited Eligibility Lack of Responsiveness, Rigid, Limited, Little Variation, Cost Focused	More Responsive Services and Environment Stress Risk Taking, IL Skills, Peer Support, Self-help Advocacy and Removal of Barriers
Social Relations:	Categorization Separation Isolation Dependency Stigma	Categorization Separation Isolation Dependency Stigma	Normalization, Independent Living and Quality of Life (Social Involvement and Relations)

(Note: This schema incorporates some of the concepts of the comparisons of rehabilitation and IL paradigms initially outlined by DeJong, Gerben, (1981). *Environmental Accessibility and Independent Outcomes*. East Lansing, Michigan: University Centre for International Rehabilitation.)

Source: Dunn, P. A. (1999). *The development of government independent living policies and programs for Canadians with disabilities* (p. 234). Waterloo, ON: Faculty of Social Work, Wilfrid Laurier University.

Appendix B: Approval from Ethics Review Board

Wilfrid Laurier
University



Founded 1911

Thursday, February 03, 2005

Shehenaz Manji
Faculty of Social Work
Wilfrid Laurier University

Dear Shehenaz Manji:

Re: Your Research Proposal Entitled, "Living with dementia and an intellectual disability: The case of a specialist home in the community"

The Research Ethics Board of Wilfrid Laurier University has reviewed the above proposal and determined that the proposal is ethically sound.

If the research plan and methods should change in a way that may bring into question the project's adherence to acceptable ethical norms, please submit a "Request for Approval of Changes to a Previously Approved Project Form" as soon as possible and before the changes are put into place.

According to the Tri-Council Policy Statement, you must complete the "Sample Annual Progress Report on Human Research Projects" annually and upon completion of your project.

If any participants in your research project have a negative experience (either physical, psychological or emotional) you are required to submit an "Adverse Events Form" to the Research Office within 24 hours of the event.

All forms, policies and procedures are available on the Research Office website at http://www.wlu.ca/page.php?grp_id=157&s_id=97.

All the best for the successful completion of your project.

Yours sincerely,

A handwritten signature in black ink that reads "Bill Marr".

Bill Marr, PhD
Chair, University Research Ethics Board

Cc: P. Dunn

Faculty of Graduate Studies and Research
Wilfrid Laurier University, Waterloo, Ontario, Canada N2L 3C5 (519) 884-1970 Fax: (519) 884-1020

Appendix C: Guidelines for Inclusive Research with Persons with Dementia and an Intellectual Disability

The following considerations, generated from my own experience of working with people with intellectual disabilities and dementia and the experiences of researchers who have included people with dementia in research, will be used to guide the issue of informed consent, the design of research methods and the concept of validity in the above study.

Informed Consent

- Be flexible about the method of consent e.g. incorporate advance directives in the consent 'process' rather than viewing them as an 'event' (Sachs, 1994).
- Take into account the sensory and physical impairments and attitudes to signing forms. Visually explain the tools using examples, video recordings of what an interview looks like, transcripts stored in an archive, publications, etc. (Hubbard, Downs, & Tester, 2002).
- Show experientially what it is like to be physically and emotionally involved in the research process (e.g. by participating in a screening or consent feasibility interview). These feasibility interviews may show that some participants can only give verbal consent (Corner, 1999).
- Adapt the communication to a compatible medium (e.g. verbal, non-verbal, behavioural) by which both the participant and researcher can communicate effectively. This may mean that the researcher has to get an "interpreter" (e.g. a caregiver who has learned from the participant how to effectively interpret his/her communication), or use props, photos, etc., or spend time with the participant prior to the commencement of the research in order to build a relationship and learn their mode of communication (Booth & Booth, 1996; Dewing, 2002).
- Re-negotiate the consent at each research activity (Dewing, 2002). Clarke and Keady (2002) affirm that "Process consent is one of continual renegotiations and is particularly appropriate in social research where there is reflexivity between data to be collected and data already collected, and where participants may wish to place limits on the information that is available as research data" (pp. 38-39).
- Continuously assess if the participant wishes to be involved in the research and be vigilant whether or not they are distressed. The researcher must be more vigilant about whether or not participants with dementia are willingly participating, if they are misinterpreting the role of the researcher and if they need to opt out of research (Hubbard et al., 2002).
- At each meeting or activity the participants can choose to participate or not (Dewing, 2002). For example, they might communicate by their behaviour that they want to leave the room, or by their spoken words that they do not feel well, etc. The person with dementia, like any other research participant, is acting on their feelings and visual processing of the environment. This is a decision they are making based on

information and cues received in the situation. This decision is valid and comes from their 'self' in that moment.

- If they choose not to participate they could be offered the option to negotiate how and when they would like to participate in that particular activity. This method serves two aims: (1) a consent is validated in the here and now for a particular task, and (2) the participant's own medium of communication is used to interpret the consent (Dewing, 2002).
- Use these multiple consents, targeting specific time-limited research tasks as a collective that make up an informed consent for the study.

Research Methods

- Do not assume that people with dementia will not want to participate in research. Assume that it is their right to be asked. They may welcome the opportunity to discuss their experiences.
- Pay attention to the balance of control exercised by relatives, caregivers and supporters. These individuals may control their dependant's entry into the study and place their own meaning upon the value of the research process. However, the support of these individuals is crucial to build rapport, to ask the right questions and to conduct the research. The perspective of the caregiver is a valuable source of information (Clarke & Keady, 2002).
- Foster an empathetic relationship with the participant. This can only be achieved if the researcher appreciates the holistic self, including the past, present and future experiences with the world of living. This involves, for example, understanding the person's likes and dislikes, their social circle and how they communicate their agreement to participate in day-to-day activities (Dewing, 2002). This puts the emphasis on nurturing personhood and encourages the researcher to be with the person rather than research on or research for the person with dementia.
- Ensure that the participant has ownership of the process and product (Cotrell & Schulz, 1993). Use a collaborative approach where researcher and participant set the agenda, this being reinforced again before commencing every research interaction.
- Elevate their position to partner in research rather than passive participation by which the relationship of researcher and partner is not detached but that of mutual learning and exchange (Clarke & Keady, 2002; Hudson & Nurius, 1994).
- Have a preliminary planning phase that could also act as a practice and screening interview (Corner, 1999). The researcher can explore with the participant if they would like to have a supporter/interpreter to partner with during research activities. The participant could share how he/she could participate in relation to their cognitive and physical ability, the ways that the power differential could be minimized, and so on (e.g. if the participant would like to undertake interviews jointly with the supporter or individually) (Clarke & Keady, 2002).

- Explore the concepts to be researched in the study with the participants and their supporters. Some studies that have included people with dementia have suggested that researchers consider alternative views of socially constructed concepts (e.g. memory failure can be viewed as absent-mindedness, daydreaming, etc) (Froggatt, 1988).
- At the conclusion of the preliminary phase, the persons with dementia and/or their supporters could individually recommend if the research as designed is ethically sound and worth undertaking. At the same time they could signal their intention to participate in the study (Corner, 1999).
- Be open to diverse approaches to include people with dementia. Having a flexible approach means for example, being able to perform a 1-hour interview over 1-10 sessions of small chunks of time, having small sample sizes, letting the participant set the timing of the interview and giving him/her control over the research process (Clarke & Keady, 2002; Cotrell & Schulz, 1993).
- Be perceptive of the styles of communication of the participants. For example, Booth and Booth (1996) describe four styles found in people with intellectual disabilities which are transferable to research with people with dementia: (1) inarticulate language due to skills, low self-esteem, social isolation and anxiety; (2) question format eliciting limited responses; (3) absence of abstract visualization and frame of reference to generalize from experience; (4) life stories not bound by time or sequence. Adapt by using direct questions, gather concrete information, pay particular attention to non-verbal communication (e.g. by observation, videoing), verify time sequences and frequencies from other sources of information such as documented history, family, etc (Booth & Booth, 1996).
- Perform an environmental scan before commencing a research interaction or meeting (Dewing, 2002). For example, the researcher can check if the participant has had an irregular experience that day (e.g. withdrawal, restlessness, routine change, etc.) and vet the conditions of the interaction room that it is conducive to the comfort of the participant (e.g. not having things that can over-stimulate, such as, lighting, noise; has cues that provide a positive experience, e.g. refreshments, people and objects that provide comfort and ease (e.g. textured materials, personal objects, caregiver).
- Create a welcoming and friendly environment (Cotrell & Schulz, 1993). Use familiar territory to avoid tiredness and anxiety, for example, meet the participant in their own home, invite a few persons with dementia to a 'research club' where they meet once a week to take part in research activities (e.g. a one-to-one coffee chat about their experience of a topic (interview); a group chat (focus group); a videoing exercise during the week; storytelling of their lives; etc). Hence, the data for a particular research task (e.g. face-to-face interview) is collected in a manner and timeframe that is comfortable, and salient to the participant's regular means of interaction and social exchange.
- Ensure that each interaction and the whole study provide direct benefits to the participant (Berghmans & Ter Meulen, 1995). At the end of each research interaction, explore with the participants how they found the experience.

- Allow extra time to debrief and bring appropriate closure to each visit. Pace the research interaction with breaks and refreshment and show genuine interest in the life of the individual by continuing to visit after the end of the interaction to bring closure to the session (Clarke & Keady, 2002).
- Appropriately support emotional reactions during the research interaction. Set up a strong multidisciplinary team or identify a person (e.g. physician) that the participants can trust and rely on if they experience challenges in the planning, implementation and post-implementation stages of the study (Robinson, 2002).
- Ensure that the participants are included in reviewing the findings and are informed of the reports, their dissemination and any impact of the study (Robinson, 2002).

Validity of Data

- Identify valid measures used for baseline competency assessments of persons with dementia (Bartlett & Martin, 2002). For example, the Mini Mental State Examination (MMSE) administered by their physicians and the Behavioural Assessment Scale of Later Life (BASOLL) completed by relatives and caregivers (Brooker, Sturmey, Gatherer, & Summerbell, 1993).
- Document the participant's verbal and non-verbal communication during research activities, the meaning processed at the time and the understanding reached about the person's desire for future participation in that particular research task. This catalogue will assist the researcher to build skills needed to accurately interpret the participant communication.
- Assess the stability of the perceptions and accuracy of information by extending the time spent with the individual (e.g. repeated interviewing) (Knox, Mok, & Parmenter, 2000).
- Verify the data with other informant sources. Triangulate information from analyses of case records, interviews with health professionals, family members, caregivers, and participant observation.
- Distinguish between data that is consented to and pertinent to the study and data that is disclosed when the participant has moved into the private domain during a research interaction (Clarke & Keady, 2002). This in effect means that the researcher must distinguish in the reflexivity of the participant the data that must be disallowed (Clarke & Keady, 2002; Knox et al., 2000; Raudonis, 1992).
- Rigorously test and report dementia-friendly methods to be used or adapted in further research (Dewing, 2002).

Appendix D: Consent Form for Participant

LIVING WITH DEMENTIA AND AN INTELLECTUAL DISABILITY: THE CASE OF A SPECIALIST HOME IN THE COMMUNITY

Principal Investigator: Shehenaz Manji

You are invited to participate in a research study being conducted by Shehenaz Manji, a doctoral student in the Faculty of Social Work at Wilfrid Laurier University. The purpose of this study is to understand how persons with a dual disability of an intellectual disability and dementia experience living in a specialist model of care in the community.

You, as one of sixteen participants in this study, will be taking part in an individual interview which will take about 1 – 2 hours of your time. The areas of discussion in this interview may focus on the profile of persons with intellectual disabilities, their social connections, your understanding of the word 'dementia', practice changes with the onset of dementia, the moving and transition experiences of persons with dual disabilities, the specialist home as a care model, optional models of care for persons with dual disabilities and the dreams and needs of this population. The interview will be audiotaped. **All information you share with the researcher will be kept confidential.** Only the researcher will have access to these tapes which will be transcribed by the researcher or a transcriber. **The transcriber will keep all information confidential.** The transcripts will not contain any identifying information such as your name, agency names or references, the name of the person you care for, and so on. The researcher will send you a copy of the transcribed notes for any clarification or modification of the answers. These notes will be sent to you according to your preference (mail, email, hand delivery) as agreed at the end of the interview. The tapes and transcripts will be stored in a locked cabinet in the principal researcher's office. **Your identity will be kept anonymous.** At the end of the study, the tapes will be erased and the transcripts, without any identifying information attached, will be used for analysis.

Transcribed passages from this study will be shared with the researcher's dissertation committee comprising of Dr Peter Dunn, Associate Professor, Faculty of Social Work, Wilfrid Laurier University; Dr Juanne Nancarrow Clarke, Professor, Department of Sociology and Anthropology, Wilfrid Laurier University; Dr Anne Westhues, Professor, Faculty of Social Work, Wilfrid Laurier University; and Dr Heather Wilkinson, Senior Research Fellow, Centre for Research on Families and Relationships, The University of Edinburgh. A summation of the findings will be incorporated in the dissertation thesis; used for conference presentations; and possibly in future publication.

Participating agencies, family members, consumers of developmental and long-term care services and organizations involved with aging and intellectual disability issues may also receive a copy of the findings if requested. The researcher may want to quote some of the information you share, in the research reports and publications, to better describe your perspectives of the experience of persons with dual disabilities in a specialist model of care. This will be done in a manner that you, the person(s) with a dual disability you have spoken about or the agency you work for cannot be identified. If a passage includes such information, then it will be sent to you for your permission and/or modification.

There is no use of deception in this study. Sometimes talking about your experiences and the challenges of persons you care for can be an emotional experience. The researcher will make every effort to help you feel comfortable during the interview and you will be free to interrupt the interview, take a break, or end the interview at anytime. If you decide to end the interview before all the information is collected, the information you have shared with us can still be used with your permission, or the tape can be given back to you or destroyed.

If you experience any adverse effects as a result of participating in this study or if you have any questions about the study itself, you can call the researcher, Shehenaz Manji, (905) 290 9288, email sheenamanji@rogers.com, or the supervising professor, Dr Peter Dunn, (519) 884-0710 Ext. 2473, email pdunn@wlu.ca. For your information, this research study has been reviewed and approved by the University Research Ethics Board, Wilfrid Laurier University. If you feel your rights as a participant in research have been violated during the course of this project, you may contact the Chair of this Ethics Board, Dr Bill Marr, (519) 884-0710 Ext. 2468.

Your participation in this study is completely voluntary. You can choose not to participate, withdraw from participation at any time during the interview process, and not answer any questions. In all cases, there will be no repercussions for your decision.

I have read and understood the information given to me. I have received a copy of this form. I agree to participate in an interview that will be audiotaped.

Participant's
name _____ Signature _____ Date _____

Investigator's
name _____ Signature _____ Date _____

Do you wish to have a copy of the findings of this study? (Tick One) Yes _____ No _____

If 'Yes', please provide your mailing address:

Appendix E: Consent Form by Proxy

LIVING WITH DEMENTIA AND AN INTELLECTUAL DISABILITY: THE CASE OF A SPECIALIST HOME IN THE COMMUNITY

Principal Investigator: Shehenaz Manji

_____ [name of participant], a resident at _____
_____ [name & address of
specialist home], is invited to participate in a research study being conducted by Shehenaz Manji, a doctoral student in the Faculty of Social Work at Wilfrid Laurier University. The purpose of this study is to understand how persons with a dual disability of an intellectual disability and dementia experience living in a specialist model of care in the community. Your consent is being sought for the participation of the above-mentioned resident to participate in this study.

The resident will be one of sixteen participants in this study including other residents in the specialist home, their family or friend, their direct care staff, members of management in the agency, and peers with intellectual disabilities living in the community. These individuals will be participating in an interview process to discuss their experiences and perspectives of living in a specialist home.

As the resident mentioned above is unable to participate in an interview format of data gathering, the researcher requests your consent to undertake short-term unstructured observation of the resident's life in the specialist home and in the community. Each observation period will range from 1 – 8 hours in length depending on the comfort level of the resident, the accommodations possible by the staff and management of the residential site and discrete events to be observed. The research visits will occur once or twice weekly and will be varied to include the different aspects of the resident's home and community life. It is anticipated that observation will be completed within six months from commencement and total to approximately 150 – 300 hours of time in the resident's environment. A 'Participant Observation Guide' (Appendix G) is attached to this consent form describing the role of the researcher, the type and process of observation and the methods (i.e. field notes, photography, videoing, art therapy) that may be employed.

In addition, the researcher requests your consent to review the resident's records kept in the facility and agency. These records may include intake information, historical information gathered, medical charts, daily logs, case conference meeting notes, person-centered plans, and other documentation identifying the experience of the resident living with dementia in a community setting.

All information shared with the researcher will be kept confidential. Only the researcher will have access to this information which will be analyzed by removing any identifying information such as the resident's name, agency names or references, the name of persons involved in his/her care, and so on. The field notes, data material and borrowed documents will be stored in a locked cabinet in the principal researcher's office. The resident's identity will be kept anonymous. At the

end of the study, you will be invited to a seminar to discuss the findings of the study and be able to give your input in the interpretations of the researcher.

Data gathered from the observations and review of documents will be shared with the researcher's dissertation committee comprising of Dr Peter Dunn, Associate Professor, Faculty of Social Work, Wilfrid Laurier University; Dr Juanne Nancarrow Clarke, Professor, Department of Sociology and Anthropology, Wilfrid Laurier University; Dr Anne Westhues, Professor, Faculty of Social Work, Wilfrid Laurier University; and Dr Heather Wilkinson, Senior Research Fellow, Centre for Research on Families and Relationships, The University of Edinburgh. A summation of the findings will be incorporated in the dissertation thesis; used for conference presentations; and possibly in future publication. Participating agencies, family members, consumers of developmental and long-term care services and organizations involved with aging and intellectual disability issues may also receive a copy of the findings if requested. The researcher may want to quote some of the information in the resident's documents, in the research reports and publications, to better describe the experience of persons with dual disabilities in a specialist model of care. This will be done in a manner that the resident, the agency/staff that supports him/her or other named persons involved in their lives are not identified. If a text includes such information, then it will be sent to you for your permission and/or modification.

There is no use of deception in this study. Sometimes the entry of a 'stranger' in the resident's environment can be a disturbing experience for persons with dementia. The researcher will make every effort to help the resident feel comfortable during the observation periods by maintaining his/her routines and respecting his/her privacy as guided by the direct care staff. If the researcher perceives that her presence or interaction with the resident is interfering with his/her well-being, the researcher will withdraw from the environment and verify her perception with the direct care staff on duty. If the direct care staff perceives the same, the researcher will withdraw from the research interaction and modify future interactions based on staff feedback. If necessary, the data gathering can be ended before all the information is collected. The information collected can still be used with your permission, or field notes/data given back to you, or destroyed. In all cases, there will be no repercussions to the resident for withdrawing from the study.

If the resident experiences any adverse effects as a result of participating in this study or if you have any questions about the study itself, you can call the researcher, Shehenaz Manji, (905) 290 9288, email sheenamanji@rogers.com, or the supervising professor, Dr Peter Dunn, (519) 884-0710 Ext. 2473, email pdunn@wlu.ca. For your information, this research study has been reviewed and approved by the University Research Ethics Board, Wilfrid Laurier University. If you feel the rights of the resident as a participant in research have been violated during the course of this project, you may contact the Chair of this Ethics Board, Dr Bill Marr, (519) 884-0710 Ext. 2468.

I have read and understood the information given to me. I have received a copy of this form and attachment. I give consent to the researcher, Shehenaz Manji, to review the documentary records and observe _____ [name of participant] for the purpose of this study.

Proxy's name _____ Signature _____ Date _____

Investigator's name _____ Signature _____ Date _____

Do you wish to have a copy of the findings of this study? (Tick One) Yes _____ No _____

If 'Yes', please provide your mailing address:

Participant's name _____ Signature _____ Date _____

Investigator's name _____ Signature _____ Date _____

Do you wish to have a copy of the findings of this study? (Tick One) Yes _____ No _____

If 'Yes', please provide your mailing address:

Appendix F: Protocol for Addressing Sensitive Information

During the course of data collection, the researcher may observe or receive information that implicates harm to vulnerable populations participating in this study, i.e. the consumers with a dual disability residing in the specialist home and peers with an intellectual disability residing within accommodations at Community Living London (CLL).

In the event that such information should come to the attention of the researcher by way of disclosure from participants in the study and/or during the participant observation periods, the researcher will seek clarification with single or multiple internal and/or external representatives of vulnerable participants residing within CLL accommodations. These representatives will hear and respond to the information presented by the researcher and implement a resolution that maintains the safety of vulnerable participants in the study. To achieve an appropriate resolution, the researcher will consult with the following chain of command at Community Living London:

1. The Residential Supervisor of the home where the person resides.
2. The Managers of Person-Centred Planning and Accommodations Programs.
3. The Executive Director of Community Living London.
4. The Residential Rights Committee at Community Living London.
5. The Ontario Ministry of Community and Social Services.

Signed: _____ Date _____
Executive Director, CLL, Mr Murray Hamilton

Signed: _____ Date _____
Principal Investigator, Shehenaz Manji

Appendix G: Rationale and Objectives of the Study

This study is directed at understanding the lives and experiences of persons with a dual disability of an intellectual disability and dementia living in a specialist model of care in the community. This knowledge will address the gaps in research and education about this relatively new phenomenon in our society. As the population of older individuals with intellectual disabilities continues to rise, a new set of needs has stemmed from age-associated diseases. This has brought about increased pressures on families, community organizations and agencies who are confronted with different needs of their care receivers dealing with changing sensory levels, the onset of dementia, and general decline in both cognitive and physical abilities. Family members, significant others (e.g. friends, guardians, etc.), and frontline service providers in the developmental sector are often directly responsible for the health and welfare of adults with intellectual disabilities. They have a personal understanding of the transitory period of the deterioration of the quality of life of the person due to the onset of dementia.

It is assumed that changes due to the onset of dementia must impact on the physical and psychosocial health of persons with intellectual disabilities, present issues around their physical living environments, the role of their caregivers, the effectiveness and appropriateness of care, resource allocation, and access to services. In Ontario, policymakers have begun planning for the demand in dementia care projected to rise in the aging population. Dementia care strategies have focused on research for a cure for dementia, finding effective medical interventions, testing and monitoring by the individual's physician and providing in-home support through the Community Care Access Centres. When needs increase beyond the resources of the community, the option of moving to a 24-hour medical care facility (or nursing home) is offered. This long term institutional care setting is usually the only option available to seniors with complex needs in the mainstream including aging persons with intellectual disabilities.

While the intent of the Ontario government is to integrate services for persons with dual disabilities with aging persons with dementia in the mainstream, some studies indicate that this population has unique needs requiring the maintenance of familiar routines and continued involvement of their caregivers in the community. In addition, practical barriers to accessing health services identified in the literature continue to persist in Ontario making the transition to medical-focused nursing homes particularly challenging. The fact that people with intellectual disabilities experience the onset of dementia much earlier than seniors in the mainstream has led their service providers to question the appropriateness of placement in nursing homes with persons who are 30 – 40 years their senior.

To respond to these pressures, agencies supporting persons with intellectual disabilities have developed specialist models of care within their community living programs. However, it is unknown how persons with dual disabilities are experiencing living in these facilities and how such specialist models of care are responding to their complex needs. Hence, this project may highlight the successes and barriers of living in a specialist home, the additional support that persons with dual disabilities require because

of the onset of dementia, the practice wisdom gained in terms of support strategies and techniques that are effective for maintaining a good quality of life in the community, and so on. The intent of the researcher is to gather this information not just from the perspective of 'others' but also from the perspective of the persons with intellectual disabilities themselves. The broader intent of this study is to highlight potential options for good practice models that fit the unique needs of persons with dual disabilities.

The present study has the following objectives:

- to generate rich and descriptive data for a doctoral dissertation aimed at identifying ways families, agencies, and policymakers can better respond to the changing needs of people with dual disabilities.
- to understand how the onset of dementia in a person with an intellectual disability changes their needs, what adjustments have to be made in the community support and care practices and what service barriers and successes are experienced.
- to understand how persons with dual disabilities experience living in a specialist home in the community and how significant other individuals involved in their lives perceive this model of care.
- to identify quality of life indicators that are important to realize in the living conditions of persons with dual disabilities.
- to identify inclusive methods of research that can safely and effectively engage persons with intellectual disabilities and dementia in articulating their needs and preferences.

Appendix H: Participant Observation Guide

The following are suggested guidelines for the short-term observation of persons with dual disabilities participating in the above study. Observations will be focused on providing a view of the **experience of persons with dual disabilities** living in a specialist home in the community.

Please note that the guidelines will be modified and finalized with input from significant others involved in the preliminary planning phase of the study.

Access

Access to the specialist home for observation of residents **including a review of their records** will involve negotiations with the executive director, management staff and direct care staff of the agency/specialist home, as well as, family and/or guardians of the persons with dual disabilities. The site under consideration for this study (i.e. barrier-free home at Community Living London, London, Ontario) is familiar to the researcher who was employed in this agency from 1997 to 2001. The researcher has a built relationship with the staff and some of the service users of this agency.

At a preliminary meeting on September 22, 2004 with the Executive Director, the Accommodations Program Manager and the Residential Manager, the researcher was given informal consent to access the agency and the barrier-free home for this research study. Subsequent to receiving Research Ethics Approval and before commencing observation studies in the specialist home, the researcher will meet with key informants in the agency to identify specific protocols of access.

Type of Observation

The researcher has no specific predetermined factors or behaviours identified for observation. The researcher will use unstructured observation when in the field of the persons with dual disabilities in their natural environment. In trying to understand the life experience of persons with dual disabilities, the researcher will focus on discrete observations about the social setting including daily routines, behaviours and interactions that occur in that setting. Ideas of what to observe may change over time as the researcher is gathering data and participating in the environment.

Boundaries of Observation

There may be some instances (e.g. bathing, dressing, etc.) where the presence of the researcher may be an intrusion into the privacy of the participants or where the researcher cannot be included. These boundaries will be discussed with significant others and proxies during the planning phase of the study. As well, the exclusion or inclusion of the researcher in each observation period will be discussed and verified with the direct care staff during the data gathering phase.

Place of Observation

Observations will be recorded in the participant's natural environment where the researcher has been given access. In order to get a holistic understanding of the participant's life, observations will occur both within the home setting and at distinct places outside the home setting e.g. places visited in the community, medical appointments, etc.

Role of Researcher

The role of the researcher will be as a participant observer. The researcher is aware that persons with dementia may experience negative effects from changes in routine. As such, the researcher will involve herself in the environment in a manner that creates the least change for the participants. The type and level of this involvement will be thoroughly explored in the planning phase with stakeholders who have an intimate understanding of the participants' needs. The researcher will be overt about her role to the participants and significant others involved in their environment. The researcher will bring minimum disruption in the environment by immersing in the home culture with routine activities (i.e. meal preparation, eating together, watching television, etc.) and being part of the interactions that the participants initiate with her.

Informed Consent

It is possible that the persons with dual disabilities will not have the capacity to give informed consent to participate in the study. Although the researcher will employ an overt role in the research environment, it is probable that the persons with dual disabilities may not be able to distinguish the role of the researcher from that of a staff or a visitor to the home. The capacity of the participants to understand information will be verified with themselves and their key informants during the planning stage. Where necessary, consent will be requested from proxies and monitored continually during the data gathering phase. Continual monitoring of consent will be through the use of verbal assent by the participant, interpretation of non-verbal behaviour by caregivers most familiar with their communication and the documentation of an audit trail of the consent process.

Length and Time of Observation

Each observation period will range from 1 – 8 hours in length depending on the comfort levels of the participants, the accommodations possible by the staff and management of the residential site and discrete events to be observed. The research visits will occur once or twice weekly and will be varied to include the different aspects of the participants' home and community life. It is anticipated that data gathering from observation will be completed within six months and total to approximately 150 – 300 hours of observation time.

Recording

The observations will be recorded by the use of field notes keeping a detailed account of events in each observation period. To strengthen the validity and reliability of the field notes, the researcher will keep an audit trail of what is happening in the observation field, reflections on why the researcher deems it significant, her experience of being in the situation, personal life experiences that might be influencing her interpretation of the situation and her decisions and actions during the research observation.

The researcher will record observations as closely as possible to the time of the events observed. As well, she will reflect and journal broad patterns at the end of the observation period.

To further support the findings, the researcher may use other technologies such as videoing, photography and art therapy to supplement the field notes. The use of these technologies will depend on consent from proxies/participants and perceived benefit to the participants. For example, it may be perceived that the participants connect with positive affect with an album of photographs that depicts a day in their lives in their natural environment.

Disengaging

During the process of data gathering as a participant observer with the persons with dual disabilities, the researcher may experience difficulties to disengage from some care situations to write up field notes in which case stretches of data may have to be committed to memory to write up later. As well, some participants may become emotionally dependent on the researcher making her final withdrawal from the research setting a challenge. The researcher will endeavour to adopt strategies to minimize these challenges by withdrawing gradually, engaging in ritualistic practices of parting (e.g. farewell social, gifts, etc.) and continuing some contact where necessary.

Appendix I: Interview Guide for Family Caregivers

The following is a suggested semistructured interview schedule for **family members or friends of persons with dual disabilities** living in the specialist home. These participants will provide their view of the experience of persons with dual disabilities living in a specialist home in the community.

Please note that this schedule will be modified and finalized with input from significant others involved in the preliminary planning phase of the study and will be flexibly used depending on what the participants wish to share.

Relationship to Persons with a Dual Disability

1. What is your relationship to [name]?
2. How long have you known [name]?

Profile and Background of Person with a Dual Disability

3. Tell me what you know about [name].
 - a. Family, friends, support circle.
 - b. History: living, health.
 - c. Personality, likes, dislikes.

Living and Service Provision

4. How long has [name] lived in this home?
5. Tell me, in your opinion, what is it like for [name] to live here?
 - a. Do you think [name] is happy or unhappy?
 - b. Why?
 - c. What is the quality of care [name] gets here?
 - d. Needs met; services received; safety and security; physical comfort; enjoyment; meaningful activities; relationships; functional competence; dignity and privacy; choice and individuality; spiritual well-being
 - e. What is your view of the care being provided to [name] in this home?
6. What other places has s/he lived before coming here?
 - a. Describe the places.
 - b. How long did s/he live there?
 - c. What was it like for him/her to live there?
 - d. How did s/he spend his/her daily time?
 - e. Who provided the care/support?
 - f. How was the care in these places?

Moving and Transition

7. Why did s/he move to this home?
 - a. Reasons for transition.
 - b. Other options explored.
 - c. Persons involved in transition planning.
 - d. Was s/he involved in this process?
 - e. If so, how? If not, why not?
 - f. Describe the process of transition planning.
 - g. Describe the process of moving.

Defining Dementia

8. Have you heard the word “dementia”?
 - a. What does it mean to you?
 - b. In what context did you first hear it?
 - c. Do you know if [name] has dementia?
 - d. If yes, how do you know this?
 - e. How long has s/he had this condition?
 - f. Has it made any change in her/him as a person? How?
 - g. Has it made any change in her/his life? How?

9. In your opinion, what quality of life indicators are important to achieve for persons with an intellectual disability and dementia?

Dreams and Needs

10. Do you think this is the best place for [name] to be living in?
 - a. If yes, explain why?
 - b. If no, explain why? What would a ‘better’ place be?
 - c. Looking back how has his/her life changed as a result of the care s/he has received in this home?

11. Do you have any concerns or fears for [name]?
 - a. Immediate concerns?
 - b. In the future?

12. Do you have any hopes or special wishes for [name]?
 - a. In the immediate future?
 - b. In the distant future?

13. Looking ahead what do you think his/her life will be like over the next year or so?
 - a. Living circumstances.
 - b. Friendships.
 - c. Family relations.
 - d. Activities/recreation.
 - e. Health/ability.

14. Is there anything else you would like to tell me regarding [name] that we haven't already covered?

Experience with Research Interview

15. What was this process of taking part in this research interview like for you?
- a. Convenience.
 - b. Difficult or easy to manage?
 - c. Any thoughts on how we can make this interview better for participants?
 - d. Any questions we did not ask and should have asked?
 - e. Any questions we should delete?

Appendix J: Interview Guide for Direct-Care Staff

The following is a suggested semistructured interview schedule for the **direct-care staff supporting persons with dual disabilities** living in the specialist home. These participants will provide their view of the experience of persons with dual disabilities living in a specialist home in the community.

Please note that this schedule will be modified and finalized with input from significant others involved in the preliminary planning phase of the study and will be flexibly used depending on what the participants wish to share.

Relationship to Resident

1. How long have you been involved with the specialist home?
2. What has been the nature of your involvement?

Profile of Persons with Intellectual Disabilities

3. Without using names, can you describe the persons who live in the specialist home?
4. Without using names, can you describe the persons who live in your other accommodation settings?

Defining Dementia

5. Have you heard the word 'dementia'?
 - a. In what context did you first hear it (in general, then with disability)?
 - b. What does it mean to you?

Specialist Home As a Care Model

6. What has been your experience of this home as a care model for persons with an intellectual disability and dementia?
 - a. Needs met
 - b. Services provided
 - c. Quality of life
 - d. Struggles
 - e. Successes
 - f. Current issues
 - g. Barriers to care or operations

Moving and Transition

7. Where did the persons living in the specialist home move from?
 - a. Describe the places.
 - b. How long did they live there?
 - c. What was it like for them to live there?
 - d. How did they spend their daily time?
 - e. Who provided the care/support?
 - f. How was the care in these places?

8. Why did they move to their current home?
 - a. Reasons for transition.
 - b. Other options explored.
 - c. Persons involved in transition planning.
 - d. Were the residents involved in this process?
 - e. If so, how? If not, why not?
 - f. Describe the process of transition planning.
 - g. Describe the process of moving.

Optional Models of Care

9. Are you aware of any other models of care for persons with an intellectual disability and dementia apart from this type of specialist home model in the community?
 - a. If yes, what are they? What is your opinion of the appropriateness and effectiveness of these models for this population?
 - b. If a person with an intellectual disability and dementia is looking for supports today, what are his/her options?

10. Do you think this is the best (or a good) place for persons with dual disabilities to be living in?
 - a. If yes, explain why?
 - b. If no, explain why? What would a 'better' place be?
 - c. How is this home different from the other community living settings in your agency?

11. Looking back how has the residents' lives changed as a result of the care they have received in this home?

Practice Changes with Dementia

12. Were you supporting these individuals before they started showing signs of dementia?
 - a. If yes, what changes did you see in these persons?
 - b. What impact did this have on you/the agency?
 - c. What impact do you think this has had on the individuals you support?

13. As a result of these changes, what adjustments, if any, did you have to make in the way you cared for/supported these persons?
 - a. What practical and/or emotional challenges do you experience in providing the level of care you feel is needed for these individuals?
 - b. Is there a diversity of cultures or cultural perspectives to support?
 - c. Is there any family involvement?
 - d. If yes, how are they involved?
 - e. How does this impact on the staff?

14. If I was to make a list of 'good practice' recommendations, what in your opinion, contributes to 'good practice' when providing services to or working with persons with an intellectual disability and dementia?

15. In your opinion, what quality of life indicators are important to achieve for persons with an intellectual disability and dementia?

Dreams and Needs

16. Do you have any concerns or fears for the residents of the specialist home?
 - a. Immediate concerns?
 - b. In the future?
 - c. Policy concerns?

17. Do you have any hopes or special wishes for the residents of the specialist home?
 - a. In the immediate future?
 - b. In the distant future?

18. Looking ahead what do you think their lives will be like over the next year or so?
 - a. Living circumstances.
 - b. Friendships.
 - c. Family relations.
 - d. Activities/recreation.

19. Is there anything else you would like to tell me regarding services or the needs, successes and hopes of persons with dual disabilities that we haven't already covered?

Experience with Research Interview

20. What was this process of taking part in this research interview like for you?
 - a. Convenience.
 - b. Difficult or easy to manage?
 - c. Any thoughts on how we can make this interview better for participants?
 - d. Any questions we did not ask and should have asked?
 - e. Any questions we should delete?

Appendix K: Interview Guide for Administrators

The following is a suggested semi-structured interview schedule for the **management staff** involved in the administration of the specialist home. These participants will provide their view of the experience of persons with dual disabilities living in a specialist home in the community.

Please note that this schedule will be modified and finalized with input from significant others involved in the preliminary planning phase of the study and will be flexibly used depending on what the participants wish to share.

Relationship to Resident

1. What has been the nature of your involvement with the specialist home?
2. How long have you been involved?

Defining Dementia

3. Have you heard the word 'dementia' or Alzheimer's?
 - a. In what context did you first hear it?
 - b. What does it mean to you?

Profile of Persons with Intellectual Disabilities

4. Without using names, can you describe the persons who live in the specialist home?
5. Without using names, can you describe the persons who live in your other accommodation settings?

Specialist Home As a Care Model

6. Why was it decided to build a specialist home?
 - a. What were the events/factors that led up to this decision?
 - b. Who/what was involved in the decision-making?
 - c. What actions were required to open this home?
 - d. What policy, funding, staffing considerations were required?
 - e. What support was provided (e.g. government, families) to open this home?
 - f. What support is being provided to operate this home?

7. What has been your experience of this home as a care model for persons with an intellectual disability and dementia?
 - a. Needs met
 - b. Services provided
 - c. Quality of life
 - d. Struggles
 - e. Successes
 - f. Current issues
 - g. Barriers to care or operations

Moving and Transition

8. Where did the persons living in the specialist home move from?
 - a. Describe the places.
 - b. How long did they live there?
 - c. What was it like for them to live there?
 - d. How did they spend their daily time?
 - e. Who provided the care/support?
 - f. How was the care in these places?
9. Why did they move to their current home?
 - a. Reasons for transition.
 - b. Other options explored.
 - c. Persons involved in transition planning.
 - d. Were the residents involved in this process?
 - e. If so, how? If not, why not?
 - f. Describe the process of transition planning.
 - g. Describe the process of moving.

Optional Models of Care

10. Are you aware of any other models of care for persons with an intellectual disability and dementia apart from this type of specialist home model in the community?
 - a. If yes, what are they? What is your opinion of the appropriateness and effectiveness of these models for this population?
 - b. If a person with an intellectual disability and dementia is looking for supports today, what are his/her options?
11. Do you think this is the best place for persons with dual disabilities to be living in?
 - a. If yes, explain why?
 - b. If no, explain why? What would a 'better' place be?
 - c. How is this home different from the other community living settings in your agency?

12. Looking back how has the residents' lives changed as a result of the care they have received in this home?
13. If I was to make a list of 'good practice' recommendations, what in your opinion, contributes to 'good practice' when providing services to or working with persons with an intellectual disability and dementia?
14. In your opinion, what quality of life indicators are important to achieve for persons with an intellectual disability and dementia?

Dreams and Needs

15. Do you have any concerns or fears for the residents of the specialist home?
 - a. Immediate concerns?
 - b. In the future?
 - c. Policy concerns?
16. Do you have any hopes or special wishes for the residents of the specialist home?
 - a. In the immediate future?
 - b. In the distant future?
17. Is there anything else you would like to tell me regarding services or the needs, successes and hopes of persons with dual disabilities that we haven't already covered?

Experience with Research Interview

18. What was this process of taking part in this research interview like for you?
 - a. Convenience.
 - b. Difficult or easy to manage?
 - c. Any thoughts on how we can make this interview better for participants?
 - d. Any questions we did not ask and should have asked?
 - e. Any questions we should delete?

Appendix L: Participant Feedback on the Findings of the Study

Shehenaz Manji
10-2417 Old Carriage Road
Mississauga, ON
L5C 1Y6

January 16, 2008

Name of Family Caregiver
London, ON

Dear [Name of Family Caregiver]:

Re: Participant Feedback

I hope you are keeping well. It has been a long time since we last connected to chat about Rose's life experiences and her move to Dissing after the onset of dementia. Due to family losses I took a year off from my doctoral study. Since March of 2007, I have been analyzing the information that I had collected and writing the first draft of my thesis. I am now at the point where I would like your feedback on the material before it is presented to my Dissertation Committee.

I have enclosed four sets of documents for your perusal: 1) a copy of the transcript of the interview that we did together; 2) a one-page profile of Rose which will be included in the thesis; 3) a draft copy of the findings and discussion chapters of the thesis; and 4) two copies of Rose's photographs taken during her observation in the home.

As well, I have included a **Participant Feedback Form** which gives you instructions on each of the enclosures stated above and what feedback is required. Please complete this form as relevant, sign and date it, and return it to me in the prepaid envelope provided to reach me by February 15th, 2008.

Please note that all the participants in the study, that is family caregivers, management and direct care staff, will receive the draft copy of the findings and discussion to make their comments. However, as the person closest to Rose, I will let you look over the documents first before I send them to management and staff.

Therefore, I will mail the documents to the management and staff on Monday, January 28th, 2008, so that they receive them approximately a week after you have received them. I suggest that you look over the draft copy as soon as you receive it and let me know immediately if you have any concerns or wish to make any significant changes to the document before it is circulated to the rest of the participants in the agency. You can provide this feedback to me by email at sheenamanji@rogers.com or by telephone at 905 290 9288 after 8.30 pm weekdays and anytime on weekends. If I do not **hear from you by January 28th, 2008**, I will assume that you have no concerns and I will proceed with circulating the document to the management and staff.

When you read the draft document, please bear in mind that the discussion is an interpretation of many common themes that were evident in the data collected from interviews, observations and documents. As an academic effort, it is necessary to analyze a theme in-depth using all possible contrasting arguments. These arguments are my own interpretations of given situations and are not intended to be an evaluation of the agency, the home or the staff in the home.

Just as a caution, due to the sensitive nature of some of the situations described in this document, you may become emotional or upset when reading some of the content. I suggest that you find a quiet time and place to do your reading. It may be helpful to plan some supports around you – a family, friend or colleague to call, to be with and to debrief your thoughts.

As well, please note that, as for all your participation in the research study, this process of participant feedback is entirely voluntary. You do not have to read the material and provide any feedback if you do not wish to. This is just an opportunity for you to let me know if you are not comfortable with any of your quotes that I have used in the paper. As well, it is an invitation to comment on my interpretation of the collective feedback on the lives of the persons with a dual disability who participated in this study.

If you have any questions about this process, do not hesitate to contact me. If I am not by the phone do leave me a message on my voicemail indicating the best time to call you back. Thank you so much for your participation and support in this study.

Yours sincerely

Shehenaz Manji, M.S.W., R.S.W.
Principal Investigator

Encls.

**AGING WITH DEMENTIA AND AN INTELLECTUAL DISABILITY
A CASE STUDY OF A DEMENTIA HOME IN COMMUNITY LIVING**

PARTICIPANT FEEDBACK FORM

Please review the four sets of documents listed below and provide feedback as noted. Please use additional sheets if needed to write your feedback or add any personal comments on the findings of the study.

1. Transcript of the Interview

Your transcript contains verbatim the interview that we completed at the start of the above study. It is likely that some quotes that have not been used so far will be included in the concluding chapter of the thesis. Therefore, please read over your transcript and tick one of the following:

- I have read my transcript and have no modifications to make.
- Please modify the following: (e.g. Page 2; para 3; line 2: to state:)

2. Participant Profile

The participant profile will be included in the chapter on methodology to give the reader some understanding of the abilities of the person with a dual disability. Fictitious names have been used in the study to protect the identity of the individual. Please review the Profile and let me know:

- a) If you are okay with the fictitious name or if you would prefer that I use a different name.

b) If there are any inaccuracies in the description and/or if there is any further information that should be added to describe the individual. State N/A if no change required.

3. Draft Chapters on Findings and Discussion

The draft chapters contain many quotes some of which may be from your transcript. Please review your statements quoted in these chapters and let me know if you want anything omitted or changed. Tick the box and complete as applicable.

I have read the draft chapters and have no modifications to make.

Please modify the following: (e.g. Page 2; para 3; line 2: to state:)

Please delete the following: (e.g. Page 2; para 3; line 2, 3, etc.)

4. Participant Photographs

I have enclosed two sets of participant photographs which were taken during my observation in the home. One set is for you/the participant to keep. The second set which is numbered is to be returned with this Form.

Your consent is required should the Committee Members and I decide to insert some of these photographs in the thesis for publication. I may also choose to display them at oral presentations, such as, at the Defence, Conferences and Workshops. Therefore, please indicate your preference for the following by ticking the box and/or completing as applicable:

I do not consent for the photographs to be used in the thesis publication.

I consent for the following photographs to be used in the thesis publication. Give numbers of the photographs (e.g. 1, 2, 6, etc. or All) below **and** initial the photographs you are consenting on the set you are returning:

I do not consent for the photographs to be used in oral presentations.

I consent for the following photographs to be used in oral presentations. Give numbers of the photographs (e.g. 1, 2, 6, etc. or All) below **and** initial the photographs you are consenting on the set you are returning:

Your Name (print): _____

Signed: _____ Date: _____

Please sign and return this feedback form together with the numbered and initialed set of photographs in the prepaid envelope provided.

THANK YOU FOR TAKING THE TIME TO PROVIDE YOUR FEEDBACK!

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