THE IMPACT OF ADMISSION AND TRANSFER POLICIES ON LONG TERM CARE CLIENTS AND THEIR FAMILIES

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by

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Abstract

There are approximately 1000 publicly funded nursing home beds in St. John's, and admission to all of them is administered through a Single Entry System, which maintains a waitlist and prioritizes admissions based on greatest need. Approximately one third of admissions to nursing homes in St. John's come from acute care, with the remaining two thirds coming from the community and Personal Care Homes. This study focuses on the one third coming from acute care. Over the past years, various policies and procedures have been put in place to facilitate timely and equitable movement of individuals into and around the nursing home system, particularly from acute care. These policies are the First Available Bed Policy, the Internal Transfer Policy, and the Transition Unit Policy.

Each of these policies stood on their own merit at the time they were enacted. However, there has not been a previous review of how these policies function in concert, and what impacts (positive or negative) they are having on long term care clients and their families. This thesis provides a research-based critical analysis of these policies from an individual and systems perspective.

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Introduction

Background/Context & Rationale

There are approximately 1000 publicly funded long term care (also called nursing home) beds in St. John's. These beds are spread out across seven sites within the city limits – The Hoyles/Escasoni Complex, The Salvation Army Glenbrook Lodge, St. Patrick's Mercy Home, The Agnes Pratt Home, Saint Luke's Homes, Masonic Park Nursing Home, along with 30 government-funded beds at Chancellor Park, a 180-bed, private, for-profit nursing home. The population is approximately 70% female and approximately 75% of long term care clients have Alzheimer's disease or some type of dementia.

Originally, the nursing homes maintained their own individual waitlists. If a client wanted to access St. Patrick's Mercy Home for example, he or she would contact that home, the social worker would do a home visit to complete an application, and that person would be added to the St. Patrick's waitlist. Operationally, each nursing home was very independent, having little or no contact with each other except for occasions when a resident moved between sites.

In September 1996, Provincial Health Minister Lloyd Matthews announced the creation of the St. John's Nursing Home Board, to consolidate administrative structures of the six nursing homes in St. John's (http://www.releases.gov.nl.ca/releases/1996/health/0924n02.htm). Chancellor Park was not included in this regionalization because it is a private, for-profit

home. With this regionalization came the creation of the Single Entry Waitlist System for the publicly funded nursing homes in St. John's. Each home gave up its private waitlist and paid a fee to Health and Community Services to administer a master waitlist for all sites. The task of completing nursing home applications and assessments became the responsibility of community-based assessors – nurses and social workers who visited applicants in their homes, completed the necessary paper work, then submitted it to the Placement Coordinators who facilitated the Single Entry System at Placement Services to be reviewed and added to the waitlist in the appropriate care category. Applicants were, and still are, classified according to four levels of care, with each successive level providing more assistance with personal care, or what the system calls Activities of Daily Living (ADLs). According to the Policy and Procedure Manual of the Continuing Care Program, the Department of Health and Community Services defines the four levels of care as per Appendix A.

The move to a Single Entry system resulted in people being offered beds in nursing homes that were not their first choice, and subsequently, a number of applicants began declining nursing home beds. Those who declined chose to wait where they were until their home of choice had a bed to offer. Depending on where they were (in hospital, at home, or in a Personal Care Home), or the source of referral, this denial of the first bed offered became problematic from a systems perspective. For those living at home, a refusal meant that the family's informal support system would continue to meet the applicant's needs as well as

possible; for those residing in acute care or a Personal Care Home (a privately owned and operated home with anywhere from ten (10) to one hundred (100) beds offering care to clients requiring level 1 or level 2 care), a refusal meant a "blocked bed" while the applicant waited in a less than ideal environment for a bed in his or her home of choice to become available.

Acute care responded to the issue of blocked beds, or beds used inappropriately, in the late 1990s by creating two Transition Units (Appendix B) in the city that would facilitate movement from hospital into a holding area while a person awaited the home of his or her choice. One 15-bed unit was opened in the Escasoni building of the Hoyles/Escasoni Complex and another 15-bed unit was opened at the Leonard A. Miller Centre. Acute care clients who were medically discharged (no longer requiring acute care services) no longer had the choice to remain in hospital until a nursing home bed of choice became available.

By early 2001, another bottleneck was identified – created by those who were in transition beds waiting for a bed in the home of their choice. A similar bottleneck was created by those on the internal transfer list who rarely made it to their home of choice because subsequent nursing home vacancies were being filled by applicants from acute care and transition to keep 'the system' moving; and from the community; clients on the transfer list were not seen as a priority because they already were being cared for within a long term care facility.

In order to facilitate movement of the internal transfer list and help offset some of the frustration of clients forced into a first available bed against their

wishes, an Internal Transfer (IT) Policy (Appendix C) was created by the St. John's Nursing Home Board in November 2001. This policy stated that nursing home admissions would be filled first by applicants on the internal transfer list, with the resulting vacancies being filled by applicants from other referral sources, namely acute care, transition, the community, and personal care homes.

In order to facilitate movement from acute care and the transition beds, the First Available Bed (FAB) Policy (2002) (Appendix D) stated that a medically discharged client must move into the first available, appropriate bed on one of the city's transition units. Any potential bed blocking in transition was addressed by the introduction of the FAB Policy. This meant clients could not wait in transition for a bed in their home of choice to open up as they previously had been able to do; now, clients had to take the first available, appropriate bed in a nursing home and go on an internal transfer list (internal to the St. John's Nursing Home Board, comprised of the six publicly funded nursing homes named above) for the home of his or her choice.

"Appropriate bed" refers to a bed that matches the client's assessed care needs in terms of gender, care level, and cognitive status. For instance, a person determined to require level 3 care would not be referred to a level 2 bed. From a client perspective, the creation of the transition units caused mixed reactions: Some clients and families were pleased with being able to get out of acute care and wait somewhere else for long term care; others expressed anger, frustration and confusion. Some of this second group of clients and their families

expressed displeasure with having to leave hospital when a bed in their home of choice was not available. Some clients and family members perceived the system as shuffling them or their relative around unnecessarily if they had to move to a nursing home that was not on the person's list of preferences. Some individuals held the perception that the larger system (acute care and long term care) should work together to keep people 'where they were' until they got 'where they wanted to be.' Social workers in acute care and transition reported that clients and families sometimes were confused by the concept of transition beds, assuming that once admitted to a bed other than an acute bed, they were in long term care. In fact, the transition beds were, and continue to be for those not yet moved to a long term care bed, operated under the auspices of acute care. This means clients in transition are medically discharged from hospital and have been required to pay the medically discharged rate of approximately $30 per day to stay there. Officially, these clients do not enter the long term care system until they are moved from transition into a first available nursing home bed.

Since the inception of these policies, many clients have taken exception to having to move out of acute care into transition, and then into another first available bed before getting to his or her home of choice. Equally, family members of these clients have spoken out against their relatives having to make multiple moves to get where they ultimately want to be. Social workers in long term care have heard from many clients and families who reported high levels of stress and dissatisfaction with having to make multiple moves, sometimes within

a few weeks. One particular point of concern was the multiple, rapid movement of individuals who were physically, but in particular, cognitively compromised. It has been noted that multiple moves can have detrimental effects on elderly people, particularly individuals experiencing some form of dementia or cognitive decline (Sherman, 2006).

Another criticism resulting from the combination of the FAB and IT policies was from waitlist clients and their families who wanted to access a particular nursing home but could not do so in an immediate or timely way because of how the system now was structured. The internal transfer list grew as an increasing number of people awaited admission to the more popular homes in the city. Subsequently, those in the community waiting for a bed in one of these homes knew they had a better chance of getting where they wanted to go by taking a less desirable bed, going on the internal transfer list, and subjecting themselves or their relative to unwanted (and in their opinion unnecessary) moves.

Applicants on the waitlist who lived in the community, along with their caregivers, began to see some futility in making the informal family support system work while waiting for their home of choice. There was little incentive to keep things working at home when most nursing homes could not be accessed directly from the community with any acceptable degree of timeliness. People learned that before they could access a particular home, people on the transfer list for that home would be given access first, and that this transfer list continued

to grow as other people were admitted to nursing homes that were not their first choice.

Following a government announcement in 2004 (http://www.releases.gov.nl.ca/releases/2004/health/0910n02.htm), the former St. John's Nursing Home Board was dissolved early in 2005, and Long Term Care St. John's became part of Eastern Health (one of the province's Regional Integrated Health Authorities). The vision of Eastern Health is "Healthy People, Healthy Communities" and its six core values are collaboration, confidentiality, excellence, growth, integrity, and respect (http://www.easternhealth.ca/AboutEH.aspx?d=1&id=49&p=73). Eastern Health also utilizes the four major principles of health care ethics (autonomy, beneficence, non-maleficence, and justice) in the development of all policies and procedures.

Since regionalization of health services there has been a growing attitude that the time is right to look closely at the movement of clients between sectors of the health care system – namely acute care and long term care. There is an increasing awareness among service recipients and providers that the system needs to change the way it moves people into and around long term care. It is acknowledged by policy makers in acute and long term care that the Transition Units introduced in 1999, the Internal Transfer Policy of 2001, and the First Available Bed Policy of 2002 worked well, individually, to meet their set outcomes. In early 2007, however, two questions became the impetus for

change in how these policies are applied: How do these policies work together? Is there a need for a transition service given that occupancy on these units has dropped in some cases to 60 and 70%?

In April 2007, the Manager of Placement Services (who is also the principal investigator of this study) was tasked with composing a document that outlined some initial action toward the dissolution of transition services at Escasoni and the L. A. Miller Centre (Appendix E). The action plan outlines how the number of moves between acute care and home of choice may be reduced and how access to all nursing homes may be made more equitable.

To date, there has been no structured analysis of the policies that govern admissions and transfers in long term care and there has been no formal structure provided to people (recipients or providers) to make observations, give suggestions, or ask questions from their unique experiences of long term care. This study provides such an opportunity in that it solicits and synthesizes stakeholders' input for a comparative analysis of the six months preceding and following the proposed procedural changes that came into effect in May 2007, toward the formulation of recommendations that potentially will inform and influence program and policy makers within Long Term Care, St. John's.

Literature Review

A review of relevant literature reveals a substantial amount of information regarding all of the key junctures in the chronology of older people's placement into long term care. These key junctures include perception of oneself in the

aging process, resistance to the idea of leaving home and entering an institution, acute care admission, factors that precipitate functional decline in acute care and subsequent need for nursing home placement, the impact of the transitions on older people and their families, how physical and cognitive deficits come into play, and facility staff's role in facilitating successful transitions.

Two major topics of discussion in the studies dealing with the movement of older people into and about long term care systems are the concepts of Functional Decline and Relocation Stress Syndrome (RSS) (Brooks, 1989; Covinsky, et al., 2003). Mecocci, et al. (2005) state, "It has been shown that during hospitalization elderly subjects have a high risk of adverse events – defined as an unintended injury caused by medical management that resulted in prolongation of hospitalization or disability at discharge – which can cause an irreversible decline in functional status" (p. 263). This concept is discussed in more detail below.

Brugler et al. (1993) note that Relocation Stress Syndrome (RSS) is defined as "a state in which an individual experiences physiological disturbances and/or psychological disturbances as a result of a transfer from one environment to another" (p. 45). While there is debate about the validity, causes, and severity of RSS (Grant, et al., 1992; Castle, 2001), researchers tend to agree on some fundamental issues: Moving from one location to another has an impact on individuals, particularly those who are physically and/or cognitively compromised; the move also has an impact on the individual's family (Jackson, et al., 2000;

Castle, 2001; Paul, 2004); and individuals involved in the move (including family) require information and support in order to facilitate a successful transition (Pino, et al., 1978; Holen, 2006; Heliker & Scholler-Jaquish, 2006). Based on the work of Mallick & Whipple (2000), Melrose (2004) notes that, "dependency, confusion, anxiety, depression and withdrawal are the five defining characteristics of relocation stress syndrome" (p. 15). This concept also is discussed in further detail below.

The issue of relocation of elderly people and its impact on health and functional status has been of interest to researchers for many decades. Keville (1993) outlines the first such study conducted by Aldrich and Mendkoff in 1963, who concluded: "the death rate within one year of transfer to be thirty-two percent, with a substantial percentage of deaths occurring in the first three months after transfer" (Keville, 1993, p. 422). Their particular sample group was 233 residents.

Others have duplicated this study through the years with varying results, and some researchers completely disagreed with these initial findings. However, studies that deny the reality and minimize the impact of relocation-related stress come under some criticism: "Contradictory studies that have not found an increased mortality risk for transferred patients often have methodological problems. Some of the methodological concerns include small sample sizes, inadequate statistical power and a lack of control groups" (http://www.bcpolitics.ca/left_relocation.htm, 2005, p. 2). Castle (2001) also notes

that studies looking at the impact of relocating older people have failed to provide consistent results: "Despite [a] relatively large body of results, few commonalities are evident. Post relocation mortality rates, for example, vary from 0 percent (Nirenberg 1983) to 43 percent (Bourestom and Tars 1974)" (p. 296). Lee, et al. (2002) remark that, "little effort has been made systematically to review and synthesize the body of knowledge relating to older people's experiences with placements. This has led to lack of concerted effort in the development of strategies to help elders adjust to such placement with dignity and success" (p. 19). Thomasma, et al. (1990) state, "Despite the research indicating that institutionalization and relocation have adverse effects on the elderly [sic], other studies that focused on health of older people did not document deleterious effects of relocation. Major methodological shortcomings were cited as reasons for the discrepancy in the findings: most of the studies were small scale, populations were not comparable, selection of subjects was not random, and longitudinal design was lacking" (p. 18).

"I Want to Stay Home" – Meanings of Place & Movement

There are numerous references in the literature to the difficulty people face when considering long term care placement for oneself or a relative, as well as references to the resistance people have to making this decision (Schneider & Bibhuti, 1998; Buckwalter, et al.,1998; Rossen & Knafl, 2003).

One of the difficulties people face is the fact they do not want to leave home. Having to leave home, enter an institution, and get help from others,

signifies a loss of control and independence, and a loss of a way of life that might have been stable for decades. Schneider & Bibhuti (1998) state, "If anything epitomizes the independence of a person, a house is probably the clearest example. Owning and living in one's home means being in as near complete control of one's life as possible" (p. 103). Oswald & Rowles (2006) reemphasize the point stating, "A basic underlying motivation of most elders is to avoid moving to an institution" (p. 16). For any of us, where we are means much more than simply a space we occupy. Our homes can come to mean a great deal to us throughout our life times. 'Home' can signify who we are, and what we have accomplished. Heliker & Scholler-Jaquish (2006) cite Hammer (1999) who describes home as "lived space that has significance and meaning for an individual...a space where one can be oneself most truly" (p. 37).

As time progresses, and individuals age, some come to a realization that they cannot go it alone like they used to. "It is widely accepted that older adults want to stay in their own homes for as long as possible. Difficulty arises when there is disagreement about what possible means" (Green Mintz, 2005, p. 38). An exploration of what is possible can take individuals down the road of home care, relying on family and friends to supplement their failing abilities to meet their own needs, and often ends in a concession that something has to change. Slowly reaching this conclusion has the potential to make a person more amenable to his/her changing reality, or at least afford a person a perceived sense of control of what is happening. Hsueh-Fen (2004) cites McAuley, et al.,

(1999, 1997), and Travis, (1997) , saying that "for most individuals, relocation to a nursing facility is not by personal choice and the final choice of destination is often driven by factors that have little to do with the older adults' personal control over the decision" (p. 12).

> Independent living, either alone or with a spouse, is the preference of the majority of older adults. This desire, called by some 'aging in place,' means that most older people want to stay in familiar surroundings, regardless of the condition of their housing unit, the nature of the neighbourhood, or their own changing personal needs. (Himes & Fang, 2007, pp. 295 – 296).

Ideally, the movement of an individual from his/her home to an institution should be done slowly with as much anticipation, self-realization, and support as possible (Schneider & Bibhuti, 1998). However, reality frequently differs from the ideal. More often than not, admission to a long term care facility occurs rapidly and unexpectedly, often the result of an acute episode that results in acute care admission. Hsueh-Fen, et al. (2004) describe nursing home placement as "just one part of a cascade of stressful events (e.g., illness, hospitalization, relocation to institutional care), which tend to occur during a very short period of time" (p. 12). Smith adds, "In most resident moves, the transfers take place very quickly, sometimes with less than 24 hours notice. This makes the whole situation overwhelming, not only for the residents, but also for family members, significant others and staff" (p. 10).

So what is the impact of this sudden, radical change? Mitchell (2005) posits that, "the lived experience of leaving a familiar situation was found to be aloneness amid uncertainty, initial isolation with emerging interpersonal

encounters, restricted freedom and anger accompanying loss of independence" (p. 3). While there can be commonalities in the response, individual differences cannot be ignored. Each individual's experience will be slightly different from another's. Rossen & Knafl (2003) point out that "transitions are complex person-environment interactions embedded in the context and the situation that consist of both the disruption of the individual's life and the person's responses to this disruption (p. 21). Green Mintz (2005) offers what to an outsider might seem like a simplistic example, but one that undoubtedly had a very significant impact on the woman involved: "The agency paid a moving company to bring only what would fit in her new room. She never stopped grieving the loss of her books, which had been her best friends" (p. 39).

Prior to admission to long term care, many individuals face an acute episode that results in a hospital admission. This is often the gateway to nursing home admission, and presents its own challenges, which are discussed in the next section.

Risks of Functional Decline

Once some people are settled or are in a routine in an acute care setting, there can be resistance to the idea of moving elsewhere until he or she feels ready or better. In the report *Innovations in Best Practice Models of Continuing Care for Seniors* (1999), the then Minister of Public Works and Government Services Canada notes that, "clients often have a very different perception of 'entitlement' versus 'need' which makes reductions in hours or program services

that much harder to implement" (p. 22). In other words, many people who are medically discharged and advised that they will have to leave the hospital do not agree with that decision, and see that they have a right to stay until they perceive the time is right.

In fact, some older people and their family members perceive this discontinuation of service as a form of ageism, in which they presume the medical staff would rather focus its services on younger people, or people supposedly who will improve as a result of treatment. Is there some validity to this perception? Smith (2004) cites Andre & Velasquez (1990) in discussing the term "age-based health care rationing" which suggests that younger patients benefit when money is health care money is rationed on the basis of age (p. 6). Be it ageism or legitimate exhaustion of acute care resources, many people are reluctant to leave the hospital before they believe they are ready.

There are numerous references in the literature to the risks inherent in unnecessarily extending hospital stays, with some studies saying that any acute care admission can have a significant impact on an older person (Inouye, et al., 1993). The impact can be experienced differently depending on each person's level of physical and cognitive functioning, but researchers maintain that functional decline is a real phenomenon with negative outcomes (Inouye, et al., 1993; Creditor, 1993; Covinsky, et al., 2003; Cochran, 2005; Wu, et al., 2006; Pullman, et al., 2006).

> For older patients, the hospital can be a hostile environment. Raised beds make getting up and laying down difficult and risky. Cold, shiny floors look

> wet and make getting out of bed uncomfortable and frightening. Cluttered hallway corridors discourage independent ambulation and contribute to the risk of falling. Sterile-appearing walls and corridors fail to provide the orienting clues that permit independent way-finding. These factors may foster functional dependence, accelerate functional decline, and induce delirium. (Palmer, 1995, pp. 121 – 122)

> Functional decline can occur in a matter of days… a common result of the older adult's … normal aging changes, combined with bed rest or immobility, result in irreversible physiologic changes, poor outcomes at discharge, and for many, placement in a nursing home. (Graf, 2006, p. 58)

Some studies have shown this decline can happen at a rate as high as 5% per day (Williams, 2007). Some maintain that functional decline can begin within 48 hours of admission (Cornette, et al., 2005). Others have shown that extended stays in acute care can result in what some refer to as the four geriatric syndromes: pressure sores, fecal incontinence, urinary incontinence, and falls (Mecocci, et al., 2005).

From a systems perspective, allowing medically discharged patients to stay in acute care as long as they wish presents both ethical and legal challenges.

> Discussion of risk is not limited to self-harm, physical harm to others, or damage to property, but might also include consideration of the stress and burden placed on the health and community service system through inappropriate utilization of services. These situations are ethically problematic for several reasons: it often offers an unreal or false hope to the client, it is often not the appropriate setting to meet the long term needs of the client which then results in poor utilization of resources and can lead to a worsening of the client's underlying conditions or co-morbidities, it can cause delays or deny the service and programs to individuals who would benefit from them. (Singleton, 2007, p. 6)

Others raise a similar point, but from a cost perspective:

> Acute hospital services constitute the costliest segment of health care budgets, and any initiative aimed at efficient use of limited health care resources will have to pay close attention to inappropriate utilization of hospital beds by older patients, particularly through the unnecessary delays in hospital discharge after resolution of the acute clinical problems. (Chin, et al., 2001, p. 593)

Relocation Stress Syndrome

The literature offers copious examples, opinions, and discussion from multiple decades on what is most commonly referred to as Relocation Stress Syndrome (RSS) (Schneider & Bibhuti, 1998; Capzuti, et al., 2006; Bonardi, et al., 1989; Mallick & Whipple, 2000; Jackson, et al., 2000; Castle, 2001; Paul, 2004; Lee, et al., 2002; Pino, et al., 1978; Melrose, 2004; Grant, et al., 1992; Dupuis, 2007; Walker, et al., 2007; Cohen, 1996; Amenta, et al., 1984; Hirsh, 1983). Other terms for this condition include multi-move syndrome, or multi-transfer trauma. Capzuti, et al. (2006) say, "Relocation has been described as a process with 3 distinct stages: an anticipatory (pre-transfer) stage, an effect (relocation and adjustment in the immediate post-transfer) stage, and a settling-in (decline and plateau of stress reaction) stage" (p. 491).

As one study states,

> Statistics show that as many as 65 percent of elderly nursing home patients in the U.S. die within two months after being indiscriminately moved to a new nursing home. The cause of death is rooted in the trauma they feel at the loss of their old home - however bad - and the inability of the staff in the new home - however good - to help them adjust. (Judge, 1977, p. 21)

Another study says,

> The North American Nursing Diagnosis Association (1992) adopted the term 'Relocation Stress Syndrome' to define the condition resulting from

> moving into a new environment. Relocation Stress Syndrome is characterized by anxiety, confusion, and depression, as well as physical problems, such as respiratory, gastrointestinal, and antimicrobial-resident infections, and coronary heart disease. (Iwasiw, et al., 2003, p. 46).

Other definitions provide additional descriptors:

> Symptoms of RSS are the same in all age groups. They can include exhaustion, sleep disturbance, anxiety, financial strain, grief and loss, depression, and disorientation. In older people, these symptoms can quickly become exacerbated by dementia, mild cognitive impairment, poor physical health, frailty, lack of support system, and sensory impairment. (Green Mintz, 2005, p. 38)

Spader (2005) offers that RSS is "the result of the physiologic and psychosocial disturbances that happen when elders are suddenly uprooted from routines and familiar surroundings" (p. 2). Hsueh-Fen, et al. (2004) explain that characteristics of RSS include, "anxiety, depression, apprehension, loneliness, and increased confusion, sad affect, withdrawal, physiological consequences (e.g., sleep disturbances, weight loss, gastrointestinal disturbances)" (p. 12).

Consideration for Individuals Living with Cognitive Impairment

Much of the literature that looks at aging, transitions, and adjustment is directed toward, or from the perspective of older people and/or their families. For older people living with cognitive impairment (e.g.: Alzheimer's disease, or another form of dementia) and their families, coping with change can be an even more stressful event.

> For the frail elderly [sic] with complex care needs, as well as those with Alzheimer's disease, experiencing an unwanted, misunderstood and involuntary relocation as a bed becomes available, is equivalent to a traumatic event. Increased depression, disorientation, passive behaviour, and serious illness may occur. The loss of familiar surroundings and being assailed by unfamiliar sights, sounds, smells and even textures, explains

> why some residents with AD [Alzheimer's disease] may never become oriented to their new surroundings. For residents suffering Alzheimer's disease, and with any remaining awareness, this sense of constant change or loss is troubling and confusing. (Smith, 2004, p. 8)

Friedman et al. (1995) say, "It has been theorized that individuals with less cognitive control, for example, residents with dementia, would be subject to more stress following relocation" (p. 1241). Lander, et al. (1997) concur: "Dementing illnesses from degenerative brain changes decrease an elder's ability to adapt to environmental changes" (p. 36).

The Challenge of Multiple Moves

As noted above, involving older people and their family/caregivers in decisions and preparations for moves has the potential to contribute greatly to a successful transition for all concerned. This fact emphasises one of the challenges and drawbacks of moving older people multiple times within a short period of time: It takes time to get to know people and to nurture a care relationship. Older people want to be part of that relationship. The reality, however, is that the person on the receiving end of the transfer is minimally involved.

Some authors emphasize the importance of ensuring the person with dementia is

> Involved in the process and that they understand and consent to the decision as fully as possible; assur[ing] relatives and friends of the importance of their continued involvement in the resident's life; begin[ning] the process of 'getting to know the person' by finding out as much as possible from carers, relatives, friends, other services and the resident themselves; do[ing] as much as possible to ease the transition for the resident by bringing along familiar objects and involving familiar people;

> respond[ing] to the emotional needs of the relatives, for example, feelings of loss or guilt; recogniz[ing] that a resident with dementia will take extra time to get to know their new environment. (Cantley & Wilson, 2002, p. 28)

Oswald & Rowles (2006) pose a reality that differs from the ideal: "Often there is limited personal involvement in the decision making process. Consequently, relocation into institutions has been viewed primarily from a loss perspective, emphasizing the risks and consequences of stress and trauma" (p. 16).

The presence of dementia adds a layer of challenge when it comes to knowing the older person, but the benefits are undeniable:

> A greater emphasis is needed to 'know' the person with dementia - especially those with advanced dementia. However, 'knowing' the person requires vigilance on part of the family and professional caregivers alike. It necessitates looking beyond the losses of memory, function, and cognition and focusing on the unique spirit contained within...Not only will the person's primary, inner, and social needs be satisfied but also dignity and respect can be maintained until the very end. (Dougherty, et al., 2007, p. 13)

Duffy (1999, cited in Brody, 2006): talks of the rich, idiosyncratic character that lurks just beneath the surface and commends therapists to be curious about it, and to do what they can to forge strong therapeutic relationships" (p. 100).

Some suggest that,

> For older adults with cognitive impairments, the relocation process may become entangled in faulty memory, reasoning, and judgement skills. Way finding in a new environment, developing new social relationships, and feeling safe in a new setting will present significant care planning challenges for staff who work with these residents. (Hsueh-Fen, et al., 2004, pp. 13 - 14)

Lander, et al. (1997) state, "Since the ability to adapt to changes involves an understanding of the situation and the development of coping strategies, an elderly person with a cognitive, mood, or psychotic disorder may be more vulnerable to deleterious effects of relocation" (p. 35).

Recommendations for Further Study

A number of studies suggest ideas for ensuring the successful transition of older people into and about the long term care system, and point out where further study and consideration are needed (Buhr, et al., 2006; Sager, et al., 1996; Reinardy, 1995). One study notes that

> Little effort has been made systematically to review and synthesize the body of knowledge relating to older people's experiences with placements. This has led to lack of concerted effort in the development of strategies to help elders adjust to such placement with dignity and success. (Lee, et al., 2002, p. 19)

Despite this, several studies emphasize the importance of the healthcare team getting to know the person who is moving into their care. Multiple moves within a short period of time deprive caregivers and care receivers of this opportunity. Another study points out that

> Establishing trust and a safe feeling for new residents cannot be understated. We are asking someone who may have moved unwillingly to trust a set of strangers to help them shower, give them their pills, handle their finances, take away their laundry. It is normal for a newcomer to have some trepidation, so staff need not get offended if help is refused or questioned initially. (Green Mintz, 2005, p. 39).

So why would the team not make every effort to get to know those entrusted to their care? Kennedy Holzapfel, et al. (1992) state that, "Advancing age is not a

barrier to the individual's willingness and capacity to learn and adapt, to enjoy and participate" (p. 194).

One consistent theme that runs through the literature recommendations is the importance of involving and supporting older people and their families through transitions (Kaplan & Cabral, 1981; Brugler, et al., 1993). Odell (2000, cited in Paul, 2004) suggests that "focusing on information giving, as part of an agreed transfer process, supported by written information that the patient and relatives can refer to, may help reduce transfer anxiety" (p. 398). Even the earliest study surmised that the impact of transfer could be minimized through the intervention of healthcare staff:

> Aldrich and Mendkoff concluded [in 1963] that relocation in and of itself can have social and psychological effects that result in increased mortality. [They] recommended that case work or psychiatric help be provided whenever transfer of elderly patients becomes necessary, and stressed that efforts to facilitate adaptation to new surroundings are especially crucial in the first three months after transfer. (Keville, 1993, p. 423)

Healthcare professionals play a key role in facilitating transitions for clients between services. This responsibility cannot be taken lightly. Rossen & Knafl (2003) posit: "Health care professionals who work with [older people] in a variety of health care settings must not only assess for risk factors of partial or minimal integration but also develop, implement, and evaluate effective interventions to promote and sustain healthy responses to late-life relocation transition" (p. 33).

Some authors suggest that that this therapeutic relationship building can and should start in the acute care setting: Palmer, et al. (1994) state, "One

emerging approach to the prevention of functional decline is the development of acute care geriatric units that create innovative environments of care and include interdisciplinary assessment and management of acutely ill patients" (p. 545). Sager, et al. (1996) look at a structured program for planned discharges: "Hospital Admission Risk Profile (HARP) can be used to identify patients who might benefit from comprehensive discharge planning, specialized geriatric care, and experimental interventions designed to prevent/reduce the development of disability in hospitalized older populations" (p. 251). One study reiterates the importance of a comprehensive assessment in hospital in order to help avoid functional decline:

> Quality improvement programs should implement performance measures to evaluate patients' functional trajectories during hospital stays. They should use these data to drive interventions during hospitalization, design discharge planning programs that consider such changes, and promote the individuals' return to independent functioning. (Wakefield & Holman, 2007, p. 174)

Despite these recommendations, not a lot of emphasis has been placed on the assessment and planned discharge areas. Coleman & Fox (2004) note that, "the amount of effort expended in admitting a patient is often far greater than that expended in discharging a patient, when in fact the two should be comparable" (p. 34). They go on to explain that things as simple as a patient transfer checklist can be helpful in facilitating smoother transitions by ensuring that healthcare providers cover the necessary information with patients and families. Another study offers a similar observation:

> Despite its importance, [discharge planning] has been a neglected aspect of patient care. Recently, however, some institutions have designed models for interdisciplinary discharge planning that identify high-risk patients, evaluate and optimize their functional status, develop a comprehensive plan that is reassessed throughout hospitalization, and ensure continuity of care during the transition from hospital to home. (Palmer, 1995, p.126)

Studies on this matter are limited to specific transfer events, with limited, convenience samples, over a short period of time. Brown, et al. (2002, cited in Oswald & Rowles, 2006) note: "most studies do not have the resources to follow relocation trajectories as they evolve longitudinally over many years and in parallel with the process of aging and an individual's passage through multiple residential transitions" (p. 31). While there are data to support the existence of functional decline and RSS within the acute and long term care sectors of Eastern Health, a longitudinal study of these 'relocation trajectories' may reveal trends and patterns that would be potentially useful in program and policy development. For instance, Palmer (1995) states that, "Patients not terminally ill should not be discharged from the hospital if they have evidence of clinical instability on the day of planned discharge...Elderly patients sent home in an unstable condition are twice as likely to die within 30 days than those whose condition is stable" (p. 126). Yet, long term care does admit people who care team members describe as very medically unstable. A longitudinal study may offer some helpful data in terms of the ongoing effects of the relocation process. Further to this, Inouye, et al. (1993) outline a Geriatric Care Program where

individuals' needs are assessed throughout the acute care stay, and discharge plans are coordinated by an interdisciplinary team.

McVey (1989) notes that the mere presence of an interdisciplinary team may not be sufficient to avoid functional decline in acute care, but that "geriatric units or consultation teams may have to offer direct preventive or restorative services in addition to advice if improvements are to be made" (p. 79). Dickinson (1996) emphasizes the point that, "an absence of pre-relocation preparation programs is generally associated with negative effects" (p. 99). This is by no means a new concept: Pino, et al. (1978) found in their study that "the preparation program had an effect and this was reflected in lower mortality rates" (p. 170). Kaplan & Cabral (1981) add, "The use of relocation counselling has proven an effective tool to alleviate much of the trauma associated with moving. It would, therefore, be important to offer this service particularly to those elderly persons who are considered in the high risk category" (p. 328). This has implications for workloads and responsibilities of social workers in the acute and long term care sectors. For instance, the work and support needed from social work upon admission to long term care cannot be limited to the day of admission, or end once the vacancy is filled. Jackson, et al. (2000) posit that "reducing [the] negative outcomes [of relocation-related stress] can not only lead to enormous cost savings but, more importantly, to improved quality of life for patients and to realization of the overall goal of 'aging in place-once placed'" (p. 8).

On the receiving end, where people leave acute care and enter long term care, more work is needed on the effectiveness of current admission policies and procedures. Given the fact that many people entering long term care are doing so against their wishes, or do not fully appreciate the experience due to some cognitive impairment, are individuals and their families being informed, oriented, and supported in the most helpful manner? Given that the majority (approximately 80%) of individuals coming into long term care have Alzheimer's disease, or some other form of dementia, what are professional caregivers doing to support and educate families, get to know the person moving into the facility, and help alleviate the often overwhelming guilt and confusion experienced by families? Smith (2004) states it simply: "Methods for reducing relocation stress for residents include education, transition teams, re-examining admission and discharge policies" (p. 9). Brooks (1989) says, "Information dissemination to everyone involved in the move is of utmost importance and is often overlooked during the rush of a relocation. Information of interest to residents includes: When is the move to take place, and what can be expected from the new environment?" (p. 46).

In one particular study, the authors discuss what they call 'good admission practices:'

> Ensure that the person with dementia is involved in the process and that they understand and consent to the decision as fully as possible; assure relatives and friends of the importance of their continued involvement in the resident's life; being the process of 'getting to know the person' by finding out as much as possible from carers, relatives, friends, other services and the resident themselves; do as much as possible to ease the

> transition for the resident by bringing along familiar objects and involving familiar people; respond to the emotional needs of the relatives, for example, feelings of loss or guilt; recognize that a resident with dementia will take extra time to get to know their new environment. (Cantley & Wilson, 2002, p. 28)

As noted above, many caregivers in facilities maintain that the extra time required to know the person is not there due to heavy workloads and an ever-increasing complexity of care needs. However, this reality does not diminish the need individuals and their families have to be supported and included throughout the transition process, nor does it negate the positive effect this knowing can have on the care relationship between individuals, families, and staff. Heliker & Scholler-Jaquish (2006) posit that, "understanding the experiences and expectations of residents during the actual transitioning process will lay the foundation for program strategies that focus on consumer-directed care" (p. 34). This is an interdisciplinary responsibility, but the majority of work in this area rests with the social workers in long term care because these individuals are the point of initial contact between the long term care system, and those preparing for admission and their families.

In addition to the work that must be done by professional staff to help facilitate successful transitions, the environment itself plays a crucial, parallel role.

> Due to the large numbers of nursing home residents with physical, cognitive, and emotional disabilities, attempts to improve quality of life must focus necessarily on the environment. Environmental manipulations that focus on optimizing interactions are one such example of attempts to improve quality of life. One manifestation of this shifting model of care is

> the impetus to train the nursing staff in behavioural interventions, with emphasis on communication skills. (Burgio, et al., 2000, p. 238)

This training places demands on the time of already busy staff, and on the resources of what is often seen as an under-resourced healthcare system. However, evidence exists that such interaction and support from staff helps reduce anxiety of individuals and their families, and helps foster and maintain more positive working relationships between residents, families, and staff.

Given that the majority of people accessing long term care have some degree of cognitive impairment, every effort should be made to minimize change and environmental stress. While it is acknowledged that acute care is not an appropriate place to await what one perceives as the ideal long term care bed, subjecting individuals with dementia to multiple, rapid changes in environment can have detrimental effects. Cohen & Weisman (1992) observe, "Because people with dementia are quite limited in the amount of new information that they can incorporate, relocation from setting to setting can be confusing and should be limited when possible" (p. 38). Another study offers that

> A sense of security or safety is essential. The symptoms of Alzheimer's disease make the patients' world frighteningly unpredictable. A stable, predictable, calm, and nonthreatening environment can relieve the insecurities that memory loss and perceptual impairments create, enabling the patient to make full use of the abilities that she has retained. (Turnbull & Turnbull, 1998, p. 260)

This fact further emphasizes the need to reduce the number of transfers experienced by older people moving into the long term care system.

For staff in long term care, today's admission might be the fifteenth one this month, thus making things rather routine. However, for the older person and his or her family, this is the first admission they are experiencing, and the onus is on the healthcare team to facilitate as supportive a transition as possible. This requires time, patience, a genuine curiosity to know the client and family, and a willingness to let people share their story, despite any physical or cognitive deficits.

It is evident from the literature that multiple moves can be traumatic, and that age and poor cognition are positively related to this trauma. It is equally evident that unnecessarily extending a person's hospital stay can have a negative affect on his/her physical and cognitive function; again, age and cognition factor quite highly in this functional decline. What is not clearly evident is how health care provider systems can balance these factors for their clients, particularly for those clients moving from the acute care to the long term care sector. The 'how' is the challenge faced by providers and must be based on evidence. Finding this balance is one of the key challenges facing Eastern Health. The question of how has been the impetus for this study.

Purpose of the Study

This study examines the functioning of the First Available Bed (FAB) Policy and the Internal Transfer (IT) Policy with regard to system efficiency in relation to meeting the long term care needs of clients and their families.

From a systems perspective there is a requirement to provide care and services to clients. This implies responding to clients' needs as they present on a daily basis, having a bed available when the client needs a bed. The system has an obligation to operate in the most effective and efficient way as it functions as a need-meeting service for clients. Clinical efficiency means ensuring that people move through the system to the most appropriate place to meet their needs, based on client assessment and the purpose of particular programs and services. It means not leaving people in inappropriate beds, services, or programs while waiting for a bed in another part of the system to open up. The literature indicates that there potentially are detrimental effects on clients when they are left in inappropriate beds while awaiting transfer (Graf, 2006). This frequently presents a challenge for the system as demands for its services outweigh its resources.

From a client perspective, there is a need for safety, emotional well-being, maintenance of autonomy, and the ability to function at one's greatest potential given physical and cognitive status; and an expectation that these needs will be met through the provision of long term care. The system has an obligation to respond, an obligation to ensure the individual receives the appropriate service in the appropriate place and in the appropriate amount of time from the appropriate people. Many clients do not know or care about the larger system's mandate to balance its obligations with individual need, just that they, as individuals, have come in need of help. Understandably when people are in acute need or crisis,

they are not interested in hearing about shortages of staff or the person waiting in the hallway for their bed because somebody deemed that person to have a greater need.

Client need is the chief concern, although perspectives on how or whether needs are met vary. The system may consider a client's need met if he or she is moved from an inappropriate bed in acute care to an appropriate bed in long term care or transition based on assessed need. The client experiencing the move may consider his or her needs unmet because he or she feels unheard by an impersonal system that appears to move people where it wants, when it wants. For the client, it can come down to the difference of being provided *a* bed versus *the* bed he or she wants. How can the optimal balance between system efficiency and client need-meeting be reached? In a resource-limited system the 'good of many' frequently overrides the 'good of one.' The hospital system may recognize that moving a particular client will cause much stress and upset for that client and his or her family, but is forced to proceed with the move given the demand for the finite number of beds in the acute care system. One challenge the system faces is finding the balance point between individual need-meeting and its obligation and responsibility to provide for everyone in need.

This study addresses the following questions:

1. What is the nature, positive and negative, of the impact of the First Available Bed Policy and the Internal Transfer Policy on need-meeting of long term care clients and their families from the perspective of the clients and their families?

2. What is the nature, positive and negative, of the impact of the First Available Bed Policy and the Internal Transfer Policy on need-meeting of long term care

clients and their families from the perspective of the long term care system (as represented by the COO, Director, Nursing Home Administrators, and Nursing Home Social Workers)?

3. How can the system function optimally to meet the needs of individuals requiring long term care; that is, what changes could be made to policies, procedures, or programs in order to facilitate the most positive experience of the move between acute care and long term care, within the context of Eastern Health's philosophy of person-centred care (www.easternhealth.ca)?

Design & Methodology

Data were solicited from residents, family members, front line staff and managers of Eastern Health toward identifying elements of the FAB and IT Policies that are working well from a systems and a client perspective, what is not working so well, and what could be done differently. From the findings, recommendations are made for the consideration of program and policy planners of Long Term Care, St. John's. Practical alternatives to current policy and practice are identified, as well as proposed ways to evaluate the changes currently proposed.

The study is designed as an inquiry using questionnaires, interviews, and focus groups to gather both quantitative and qualitative data from long term care service recipients and providers (that is, residents, family members, front line staff and managers of Eastern Health) toward identifying elements of the FAB and IT Policies that are working well from a systems and a client perspective, what is not working so well, and what could be done differently. Quantitative data indicates bed utilization and turnover from a systems perspective in an effort to quantify demands on the system.

There were two sample groups of clients in the study. Sample Group A were those who were admitted to long term care from acute care from January 2007 to April 2007 (four months preceding the proposed changes) ; and Sample Group B were those admitted from May 2007 to August 2007 (four months following the policy changes. As Group B is the population to date for the post-policy change group, it was decided that a similar time frame of four months would be appropriate for determining the size of the Group A sample.

Family members of clients who were not capable of participating for physical or cognitive reasons completed the surveys on the resident's behalf. Additionally, a focus group was held with nursing home social workers; and interviews were conducted with nursing home administrators. The actual admissions for January 2007 to April 2007 (Group A) and May 2007 to August 2007 (Group B) were 207 and 168 respectively, for a total of 375. Once the criterion was applied that an individual would have to have been admitted from acute care to long term care, the actual sample sizes for Groups A and B were 98 and 83 respectively. Of these groups, only one resident from each was cognitively well, and therefore received a questionnaire directly.

A questionnaire (Appendix F) was designed to gather data about long term care clients' perceptions of how the system has met their needs and about wait times and movement of clients through the system. This questionnaire was circulated to cognitively well residents, or family of cognitively impaired, who have been admitted to their home of choice after having moved from acute care,

to transition, and then to First Available Bed during the months of January 2007 to April 2007. Other quantitative data was collected from monthly reports of Long Term Care St. John's on numbers of admissions and new applications obtained from Placement Services (the department which is responsible for the Single Entry System discussed above), along with bed utilization statistics obtained from the Office of Clinical Efficiency within acute care.

A similar questionnaire (Appendix G) was designed to gather similar data from cognitively well clients who were admitted during the months of May 2007 to August 2007 from acute care directly to FAB. It is acknowledged that not all people designated as cognitively well nursing home residents are able to read, and therefore the letter that accompanied the questionnaire invited residents to discuss and complete it with family members if they chose to do so.

Questionnaires also were designed for residents' next-of-kin, or substitute decision maker (SDM) of residents identified as cognitively impaired; one for residents admitted from January to April and one for residents admitted from May to August (Appendices H and I). In cases where a substitute decision maker was not identified in advance by the client, the long term care sector was asked to identify the substitute decision maker by the application of Section 10 of the Advance Health Care Directives Act (http://www.hoa.gov.nl.ca/hoa/statutes/a04-1.htm). This is routinely done on admission to long term care for clients who are cognitively impaired. While this does preclude some family members, the assumption of the Advance Health Care legislation is that the SDM speaks for

the cognitively impaired resident. The Social Worker in each nursing home provided the Principal Investigator with this contact information. The rationale for exclusion of cognitively impaired residents from the questionnaire portion of the data collection is the fact that many of these residents are not oriented to person, time, or place, and therefore may have had difficulty in identifying where they are, where they transferred from, or how long they had spent in any one place through the admission and transfer processes. Reminder letters and follow up surveys were forwarded to the group again one month after initial mail out to encourage increased participation. To provide additional assurances of anonymity, the surveys were sent to the School of Social Work

Qualitative data were collected through questions (Appendices J and K) that sought clients' and substitute decision makers' perceptions of the system and the experience moving through it from the point of initial entry into the system, that being acute care, to their admission or the admission of their relative to their home of choice. Interviews were available to residents and substitute decision makers from both sample groups, that is, those admitted during the four months prior to the May 2007 decision and those admitted in the four months since, if they preferred to speak in detail. They understood that an interview meant that their identity could not be anonymous as it was through use of the questionnaire. The cover letter that explained the study (Appendix L for cognitively well residents and Appendix M for residents' substitute decision makers) accompanied the questionnaires, inviting them to complete the

questionnaire, and additionally, to participate in an individual interview. No respondents chose the interview option. If any had chosen this option, written consent would have been obtained before proceeding with the interview (Appendix N). Interviews would have been conducted by nursing home social workers.

The Principal Investigator facilitated a focus group with long term care social workers to provide data from their perspective (Appendix O). It was acknowledged by him at the beginning of the focus group session, that anonymity would be impossible to maintain. This was addressed with a request that participants respect one another's views and that matters discussed in the focus group not be discussed outside the group. Interviews also were conducted by the Principal Investigator with nursing home administrators, the Director of Clinical Efficiency with acute care, and the Director of Pastoral Care and Ethics with Eastern Health (Appendix P) in order to obtain a management viewpoint. These people were identified by the Principal Investigator as having vested interest in, as well as some degree of control over, the admission and transfer procedures of long term care. An informal, email invitation was sent to these individuals, explaining the study.

Implementation of the study commenced once ethical approval was granted by the Interdisciplinary Committee on Ethics in Human Research (ICEHR) at Memorial University. The ICEHR application is attached as Appendix Q.

Survey Findings

The sample size for groups A and B was smaller than anticipated. At least two factors contributed to this fact. The actual number of admissions from acute care was lower than anticipated, and the overall number of admissions for group B was lower than normal due to the temporary closure of some long term care beds as a result of summer staffing challenges. Despite these factors, the responses were varied, and provide some insight into people's experiences with these policies.

All data were gathered, entered, and analyzed to provide a comparison of system efficacy and client satisfaction from the pre-change and post-change periods. These data will serve as a basis from which to recommend and inform policy directions about system functions.

Quantitative and qualitative data were collected. The quantitative data came from questionnaires and include satisfaction levels and experiential characteristics in relation to a number of factors including wait times, and number of moves. These data were analyzed using SPSS to determine similarities and differences between the groups on key issues. Qualitative data also were collected from interviews, and from a focus group with nursing home social workers with Long Term Care, St. John's. Analysis of the data revealed recurrent themes and concepts, which are discussed in detail below.

Findings from Group A Questionnaires

Twenty people responded from Group A for response rate of 20.4%. Satisfaction was scored out of 5, with 5 being completely satisfied. The mean responses were compared. For those individuals who were well informed by hospital staff of the FAB policy, they scored their satisfaction with wait time for the first available bed at 2.50, wait time for their home of choice (HOC) at 2.80, the number of moves they had tc go through before reaching their home of choice at 2.63, and the quality of communication at 3.30. For those who were told about the FAB policy but felt they did not receive adequate information, the scores for wait time for first available bed and home of choice are slightly higher, at 3.25 and 3.57 respectively. The satisfaction score for number of moves before reaching home of choice did not change (2.63), and interestingly, the satisfaction score with communication increased slightly to 3.86 out of 5.

Most noteworthy in these data are the satisfaction scores of people who said they were never informed of the FAB policy. The score for satisfaction with wait time for first available bed – 4.50; for wait time for home of choice – 4.00; for number of moves before reaching home of choice – 4.00; and for satisfaction with communication – 4.00. This anomaly is discussed in the Analysis/Applications section below. The following table (Table A) summarizes the results:

Table A

FAB Policy	Satisfaction with wait time for FAB	Satisfaction with wait time for HOC	Satisfaction with number of moves before reaching HOC	Satisfaction with communication
Those who felt well informed of policy	2.50	2.80	2.63	3.30
Those who thought they were told but did not receive much information	3.25	3.57	2.63	3.86
Those who thought they were never told of the policy	4.50	4.00	4.00	4.00

From the qualitative data in Group A, several individual and systems-related themes emerge. On an individual level, respondents reported being pleasantly surprised with the quality of care their loved one received in the first available bed, despite it not being in their home of choice. A number of people noted that they experienced confusion about how the transfer process was supposed to work once their relative was admitted to the first available bed. Others expressed confusion and disappointment with the hospital staff for discharging their parent too early – before the family thought the discharge should have happened.

From a systems perspective, the majority of respondents expressed the desire to have more long term care beds in the system to address wait times, and the need to discontinue the second forced move precipitated by the application of the FAB policy for clients in Transition beds (prior to May 2007). Two other themes emerged. People expressed desire for more choice instead of being streamed into the long term care system through one nursing home, which receives all the new admissions while beds at other sites are filled by people on the Transfer List. Some people also expressed a need to have patient advocates – individuals who would help them and their relative navigate what many people describe as a confusing system.

Findings from Group B Questionnaires

Nineteen individuals responded from Group B for a response rate of 22.9%. The scores from this group are inversely related to the scores from Group A. Table B below provides a summary. In this group, those who felt well informed about the FAB policy reported a satisfaction with their wait times for FAB and HOC at 4.18 out of 5 and 3.43 out of 5 respectively. They rated their satisfaction with the number of moves required to access their home of choice at 3.71, and their satisfaction with communication around the process at 4.00. The scores dip slightly for those who reported being told about the FAB policy, but not given much information: For satisfaction with wait times for FAB and HOC, this group averaged 2.57 and 1.50 respectively. In terms of satisfaction with the number of moves experienced before accessing the home of choice, the average

score was 2.33. Finally, the average score for satisfaction regarding communication of the policy was 1.83. No one in this group reported that they were never informed of the FAB policy.

Table B

FAB Policy	Satisfaction with wait time for FAB	Satisfaction with wait time for HOC	Satisfaction with number of moves before reaching HOC	Satisfaction with communication
Those who felt well informed of policy	4.18	3.43	3.71	4.00
Those who thought they were told but did not receive much information	2.57	1.50	2.33	1.83
Those who thought they were never told of the policy	0.00	0.00	0.00	0.00

Qualitative data from respondents in Group B revealed a number of themes that were similar to those of Group A, along with some unique ideas. As with Group A, most respondents whose relative was admitted to a first available bed versus a bed in their home of choice, expressed satisfaction with the care they received. Again, there was some degree of confusion surrounding policies and procedures, and an expressed need for written material that is clear, concise, and relays a consistent message. Some respondents in this group (as

with Group A) indicated they were disappointed and confused when acute care presented the idea of discharging their relative.

In terms of the long term care sector, some people indicated a need to have additional beds. More specifically, some respondents pointed to the current arrangement between Eastern Health and Chancellor Park, noting that government should be increasing public/private partnerships in order to allow access to sites that are newer and more aesthetically pleasing, with fewer residents per room than some of the current public buildings provide.

Three themes were unique to this group. Firstly, a number of respondents indicated they thought moves were too rushed, even if that move resulted in their relative getting a bed in their home of choice. One person in particular noted that such transfers should take days, not hours, explaining that the family had to make decisions about home of choice in a very short period of time. Secondly, some people commented on their perception of the "lack of consideration for individuality" when it came to moving older people into first available beds. For these people, 'the system' seemed more interested in vacating hospital beds than in ensuring an appropriate match for their relative on the receiving end in the nursing home.

The third theme unique to this second group of respondents was that of anger. One individual stated, "The elderly [sic] are neglected, avoided, and abused in this process." This person goes on to talk about the lack of choice in

the system, along with larger systemic issues like staffing ratios and the physical make up of some of the older facilities in the city.

Findings from Nursing Home Social Work Focus Group

Social workers representing the nursing homes in St. John's had an opportunity to share their insights and experiences of the first available bed policy. From their perspective, the FAB policy results in people moving too quickly through the system – from acute care to long term care. There was agreement that the current system does not consider the human side of the placement process; rather, it tends to be driven by the need for beds in acute care. This group noted that the rapid turnover is also taking its toll on staff who are not afforded the time to forge meaningful relationships with residents and families before they transfer elsewhere. The rhetorical question was posed: If assessment is supposed to take time, where is the time?

The observation also was offered that long term care is under resourced to be adequately able to provide what this group described as the "crucial support piece." The group acknowledged a sense of frustration given that, from their perspective, the Internal Transfer Policy combined with the FAB policy only further accelerates the process. As one participant offered, "People move into a first available bed without adequate support, and then move on before they've had time to adjust."

The feedback on the May 2007 decision to change the Transition service elicited positive input from this group based on comments they received from

residents and family. It was noted that feedback from residents and families is generally positive given that one less move is a good thing, and being able to have choice once the first available bed is reached is an improvement. In addition, this group commented that wait times for people getting to their home of choice seems to have increased since people in Transition beds can wait for preferred home to have a vacancy. There was some discussion on whether or not this is a bad thing. As noted above, having more time for staff to nurture the therapeutic relationship with residents and families is viewed as positive from an adjustment perspective. In addition to having more time to build relationships, this group of social workers speculated that some type of more thorough support, preparation, and bridging from acute care to long term care would be helpful in terms of resident and family adjustment.

Finally, the group emphasized the need for more timely and thorough evaluation of policies. Several participants offered that social workers in long term care had been asking for a review of the FAB and IT policies since their inception. They also, unanimously, stressed the fact that now that Transition clients can wait for their home of choice, all nursing homes should go back to rotating sources of referral for admissions (as outlined in the Action Plan).

Findings from Interviews with Eastern Health Staff

All interview comments revolved around six key points, which are discussed here:

Perception of Control

The individuals interviewed commented that people's satisfaction with long term care placement and the processes around it are largely related to the degree of control these individuals perceive they have over this process, and the degree to which they perceive their engagement in the process. The greater the sense of involvement and control, the greater an individual's acceptance and adjustment for changing circumstances.

Communication

There was consensus amongst interviewees that an earlier connection with clients and their families about the realities of long term care would do a great deal to help facilitate smoother transitions from acute care to long term care. A link was made between the quality of information and how it is communicated, and individuals' perception of control over what is happening to them, in that having more information afforded people the opportunity to make more informed decisions and be a more active part of the process.

Importance of Acknowledging Feelings

It was readily acknowledged by each interview participant that admission to long term care is an emotionally charged experience for the person being admitted, along with his or her family. Interviewees observed that the emotionality of the transition to long term care is only magnified by the fact that the first available bed is most often in the nursing home in the city that is the least

sought after and this creates another layer of challenge in terms of individuals' attempts and ability to cope with the changes that are happening.

Role of the Health Care System to Make Decisions

One respondent said, "At some point, everyone's best intentions have to give way to reality" (personal communication, November 13, 2007). He added that Eastern Health and its employees live the policies of FAB and IT, along with countless others, on a daily basis. This means that the system makes decisions about resource utilization, transfer, and admissions based on a myriad of variables that often change on an hourly basis. Amidst this complex of factors, practitioners are tasked with keeping the system moving.

Another interview participant summarized it this way: "Ultimately, we cannot give everyone the health services they expect or need in the manner they request them. The provider must make decisions weighing the best interests of the individual in relationship to other individuals seeking similar services and in relationship with the service resources which are available".

Significance of the Transition Period

The impact of the actual act of transition on clients and families was acknowledged and explored by each respondent. As noted above, the emotional response of the service recipients was recognized by all interviewees. In addition, the importance of staff's role at this crucial stage was discussed. One person proffered that the transition time is "make or break time" for the three-way relationship between clients, families, and staff. This individual added that at

this critical juncture, the process needs to slow down so everyone involved has time to absorb the significance of what is happening, and the impact it is having.

The Need for Post-Acute Programming

Several respondents talked about the need for Eastern Health to fill the gap that often results in moving people quickly from acute care to long term care without what many recipients of this move would call adequate preparation. A number of interviewees said that if communication and education could happen before people actually leave acute care, this may serve to alleviate some of the dissatisfaction and uncertainty being reported on a regular basis. One person observed that any such offering by acute care would require the "infrastructure and political will" to make it happen.

Analysis/Applications

Resident/family data, and health care provider data (pre and post procedural changes of May 2007) are discussed in this section. This information showed a strong cross section of opinions and demonstrated some clear directions for recommendations as well as some questions which remain unanswered.

Group A

It is interesting to note from these data that the less information people reported having, the more satisfaction they reported with wait times, number of moves, and communication. Two facts may explain this incongruity. Firstly, the more detail people had about how the FAB policy would impact them and their

relative, the more anticipation of problems might have been coupled with people's resistance to leave the acute care setting, whereas those who reported having received little or no information did not have a frame of reference with which to anticipate what was happening and why. This might have been a case of 'ignorance is bliss.' If a person is not clear on the 'what' and 'why,' it is harder to be critical of policies and processes. Secondly, the actual number of people who reported never having been told about the FAB policy was 10% of the total (N=2). With a smaller sample, fewer high scores were required to result in a high average.

From a systems perspective, it is affirming to see a level of satisfaction being expressed with the care received in the FAB home while individuals are waiting for a bed in their home of choice. This speaks to the similarities in the quality of care provided in the public long term care system. Given that all nursing homes under Long Term Care, St. John's are staffed using the same formula to determine ratios and skill mix, the main differences between the nursing homes come down to physical layout (including residents per room and aesthetics), religious affiliation, and proximity to family and friends for visiting.

The fact that some respondents in this group identified the need to eliminate a step from the process (the application of the FAB policy for clients in Transition Beds) confirms the fact that Long Term Care, St. John's made a move in the right direction when this step was removed from the process in May 2007.

The comments made about the need for more concise and available information, along with patient advocates supports the idea that further public education is required in order to ensure clients and their families have consistent information, in an easy to understand format, in a timely manner. This need is further supported by the comments of individuals who thought their relative was discharged from hospital too soon. More information about the discharge process, functional decline, and care in appropriate settings might have alleviated some of this disappointment and frustration.

Group B

A similar line of reasoning is applicable to the results from Group B, but in the inverse. The most well informed people in this sample also are the most satisfied. The fact that everyone in this group reported having received information about the FAB policy is indicative of the work that has recently been carried out in acute care to educate staff, so they in turn can better educate patients and their families about policies that may affect their discharge and transfer status.

The satisfaction level of the wait time for home of choice is lower in Group B than in Group A. This is most likely due to the level of expectation created for people in Group B once they were informed they would be able to wait in their first available bed until a bed in their home of choice became available.

The comments from respondents in Group B help to further enforce the need for better information and education for clients and families throughout the

discharge, transfer, and admission phases. One individual described the current coordination of information as a "learn as you go" arrangement that leaves clients and their families scrambling for information and consistent messages.

There is an interesting reference in the Group B responses to the lack of individuality in the current FAB and Transfer policies. This speaks to the different approaches: Acute care sees its filling of vacancies as an interim arrangement undertaken to address the immediate needs of a transient population that will be moving elsewhere in a matter of days or weeks. Conversely, long term care scrutinizes vacancies and applicants more carefully because this sector maintains that its admissions are much longer term, and meant to provide newly admitted clients with some sense of comfort, safety, and home as they try to adapt to their new circumstance. The process in long term care then becomes much more deliberate from a room-mate matching perspective.

The anger expressed in some comments from this group is not representative of the group as a whole. In fact, these comments came from one respondent, but this sentiment is in line with findings in the literature, and not unexpected, and therefore cannot be ignored. The strong, negative response provided by this individual is evidence of the fact that each person's and family's experience of this process is unique, no matter what changes are made at the policy and procedure level.

Comparison of Comments from Groups A & B

The similarity in themes between these two sample groups supports the need for acute care and long term care to improve the way the system notifies and informs clients and their families about policies and procedures that have to do with discharge, admission, and transfer. The disparity in the comments, with some people from both sample groups being very pleased and very frustrated with processes and wait times, is explained by considering that each person speaks from his/her own unique experience and perception, and was not unexpected. The challenge remains, and the onus comes back on 'the system' of Eastern Health to consider these perspectives, and respond accordingly, realizing that policies and procedures will never address everyone's needs and expectations. The goal becomes balance in need-meeting between using system resources efficiently and addressing the expectations of the individual.

Nursing Home Social Workers' Focus Group

Three major themes emerged from this discussion: a general sense of frustration with the shortage of human resources and time necessary to meet the adjustment and support needs of newly admitted residents and their families; an empathetic view of residents', families', and staff's experience of multiple moves within a short period of time from the perspective of not being able to establish and nurture meaningful relationships that are viewed as necessary to successful adjustment and person-centred care; and, from a system point of view, a desire to educate and join with acute care with the objectives of fostering a better,

mutual understanding of both sectors of the healthcare system, and facilitating smoother transitions for individuals and their families by becoming part of the process at an earlier point.

A position paper published in 2002 by the Canadian Association of Social Workers (CASW) describes the ten main functions of social workers in long term care (www.casw-acts.ca/practises/longtermcare.htm): admission preparation, screening, assessment, counselling, practical assistance, identifying and arranging resources, internal and external advocacy, education, group work, and discharge planning. The reality for the social workers currently providing service for residents and families in Long Term Care, St. John's is that the facilitation of admissions consumes the majority of their time, while other critical areas of practice receive less attention. This fact is supported by the monthly workload measurement reports completed by these practitioners, and reviewed by the principal investigator, which show 85 to 90% of time being spent on admissions. The social worker's scope of practice in this setting ideally involves, "influencing the social determinants of health that are relevant to the resident by intervening with the resident, the family, other residents and staff within the facility, and also the broader community. Emphasis is on building on existing strengths, modifying risks and seeking solutions to issues that interfere with optimal quality of life" (www.casw-acts.ca/practises/longtermcare.htm).

The acknowledgement this group expressed for the difficulty that multiple moves cause for residents, families, and staff comes out of their experience of

working in the system with each of these groups. This empathy, coupled with the frustration of wanting to do more work in the transitioning process, manifested itself in very passionate and lively discussion in the focus group when we explored what the social workers would like to be doing with residents and families if they were resourced differently. Interestingly, the notion of the impact on staff came up repeatedly in this group's discussion, and reveals an important, and under-considered aspect of the negative impact multiple moves can have on staff as well as residents. This focus is logical, given that any relationship requires more than one party. The primary focus of this study has been on the impact of system policies on residents and families, not on staff. This may be an area for future study, as staff satisfaction is undoubtedly linked to staff performance, which manifests itself as direct care to residents in these facilities.

Besides the acceptance of the fact that multiple moves can have negative impacts on residents, families, and staff, this group also observed the negative effects that abrupt transitions can have on older individuals. The third major theme of this group's discussion revolved around the need for acute care clients and staff to have an earlier and a better understanding of the long term care sector. The long term care social workers suggested this could be accomplished by more accurate and consistent messaging about long term care, and an earlier preparation of clients and families to enter the long term care sector. This notion of 'earlier preparation' is congruent with feedback from clients and their families in terms of wanting more information and support, and is also in keeping with

evidence in the literature that supports the creation of geriatric assessment teams and units within the acute care sector.

Eastern Health Staff Interviews

Discussion with staff members of Eastern Health from acute and long term care revolved around the themes of communication, participation, and balance. These staff members acknowledged the need for more consistent communication that happens earlier in the process. This is reflective of what service recipients noted as a weakness of Eastern Health in terms of being informed and involved in processes that affect them. In addition to simple information sharing, data suggest that any communication that happens between acute care and long term care should explicitly deal with expectations that clients and their families have of the long term care system. This is supported by the social workers in long term care who observed that many complaints and issues revolve around unmet needs and expectations that individuals had before entering the long term care system. Given that no service will ever be able to meet everyone's expectations, discussion of the parameters of service would help set up a more realistic outlook for those about to enter long term care.

Linked directly to the concept of better communication is the need to have individuals involved in processes and decisions that affect them. Even if there are no perceived options, frank discussion about people's intentions and realities can involve them in the process to the point where they at least are involved in the less-than-ideal decision from the outset. The idea of the system "doing with"

the client as opposed to "doing to" most certainly can make people more amenable to whatever has to happen next.

Both the concept of communication and involvement are linked to the system's willingness and ability to do things differently. As noted above, any change in process inevitably requires the resources to make it happen. This unavoidably has implications for budget and program planners. For instance, the need for a more structured transition program has been identified by staff, service recipients, and the literature, but such a program will require deliberate planning, a belief in its potential, and the resources to move it from concept to reality.

One of the key themes from the interviewees' responses is that of balance. People will continue to put pressure on the system, to advocate for their individual needs, or the needs of a loved one, and the system will continue to make day-to-day and hour-to-hour decisions based on the good of many versus the good of one. The challenge lies in the "how" of the balance issue.

Dissemination of Findings

A report of this study including its findings and recommendations will be submitted to the Chief Operating Officer of Long Term Care and Community Living and Supportive Services. From there, it will be submitted to the Director of Long Term Care, St. John's, for discussion at the Long Term Care Liaison Committee. This committee, made up of representatives from acute care, mental health, long term care, and community health, debates and determines matters

of policy and procedure relevant within and across sectors and serves as the decision-making body for Long Term Care St. John's. However, because agreement and cooperation from the individual nursing homes will be essential to the success of any proposed changes in policy or procedure, any policy changes proposed by the Long Term Care Liaison Committee will be discussed at a meeting of Senior Leadership, comprised of the six site administrators, the Chief Operating Officer (COO) of Long Term Care and Community Living and Supportive Services and the Director of Long Term Care St. John's. The principal investigator, who serves as Manager of Placement Services, will be available to all these groups associated with Long Term Care for discussion, clarification, and decisions around 'next steps.'

Conclusions

Recommendations & Implications for Policy & Procedure

The study's findings suggest several recommendations to strengthen the system's ability to uphold the six core values and four ethical principles of Eastern Health and to be experienced as such by clients and their families. These recommendations focus on changes that could be sustained or made within the long term and acute care systems to maximize the positive aspects of the First Available Bed Policy and the Internal Transfer Policy on clients and their families.

Dr. Sherry Dupuis is the Director of Research of the Murray Alzheimer Research and Education Program at the University of Waterloo. In an undated

article entitled *Easing Transition in Long Term* Care (http://marep.uwaterloo.ca/PDF/OLTC-Easing%20Transitions-handout.pdf), she outlines ten principles that can be helpful when assisting residents and families to make the transition into long term care:

1. The fewer moves, the better
2. Prepare families and residents for the move
3. Be aware of the experience for family members and new residents
4. Help families feel more in control of the process
5. Ensure the actual move is as easy and welcoming as possible for family members and the resident
6. Get to know the new resident and family
7. Enhance communication between families and staff
8. Help family members and residents build their resource base
9. Strive for the highest quality of care
10. Maintain continuity in the resident's life

Based on these principles, other literature, and input from service users and providers, the following recommendations are offered that may be helpful in guiding discussion on policies for long term care:

1. Creation of assessment & slow rehabilitation units for elderly people situated in acute care and establish on-going evaluation processes for the program.

Studies show that when older people have the opportunity to slowly heal over time, they can often return to pre-morbid levels of functioning and independence. One of the points made by respondents in this particular study was that the move from acute care was made too quickly, often before the person or his or her family felt the time was right. The needs that older people have in acute care frequently go beyond their presenting diagnosis; they need time to heal, support, and the resources around them to truly explore available options and make the most informed decision as possible. This is accomplished

by increasing staff to client ratios, having access to consistent and timely assessments by psychogeriatrics, physiotherapy, occupational therapy, social work, and other disciplines. These professionals would be better able to assess a person's needs outside the pathology of acute care, and outside the urgency of an emergency department where patients are rapidly triaged and moved elsewhere. Upon implementation, the benefits, drawbacks, and cost-efficiencies of a more structured acute care unit, along with a more coordinated discharge assessment and plan, should be evaluated within Eastern Health.

Additionally, there are examples where a person has been admitted to long term care, slowly convalesced, and reached a point in their functional ability that they could return home. While cases like this are the minority, they do point out that the existence of a slow rehabilitation service could see some people avoid the admission into long term care completely.

2. Improve literature on the logistics of long term care admission and develop improved communications strategy.

Feedback from respondents to this study indicates that more written material on the logistics of long term care admission would have been helpful in making informed decisions and making adjustments to institutional living. In many instances, a nursing home social worker reports sharing verbally a particular piece of information with a new admission, only to have that resident and/or family later insist they never received that piece of information.

The Resident/Family Handbook would contain:

1. Admission checklist which would help ensure that accurate information is shared consistently, and that it can be referred to later as questions arise.
2. Frequently asked questions about things like finances and processes.
3. Site-specific information for the particular nursing home a person is entering or wishes to transfer to.

Included in this work should be a review of the way Eastern Health uses technology such as its own website, public service announcements, and information lines to provide multiple avenues of access to timely and critical information.

3. Conduct longitudinal study of relocation trajectories

A longitudinal study of what the literature calls 'relocation trajectories' may reveal trends and patterns that would be potentially useful in program and policy development. On a go forward basis, Eastern Health should consider the commissioning of a long term study, following a select group of residents and their families. This study would look at such factors as cognitive and physical decline, quality of the relationship between the resident, the family, and the staff, as well as overall satisfaction.

4. Review LTC admission policies & acute care discharge policies

Given that dramatic changes in policy and procedure take time, are there any interim changes that could be made in the information or practices of this critical cross-over point? A sample of a small but significant change occurred in May, 2007, when the individuals in the Transition beds at the Miller Centre and the Escasoni Building were given the option to place their names on the Internal Transfer list for their home of choice, instead of having to again take the first available bed as they wait for their home of choice. Based on feedback from questionnaire respondents, this sense of choice and control is positively related to people's level of satisfaction with the system.

Further to this change, again based on respondents and interviewees, all nursing homes under LTC St. John's should return to a rotating admission process. This would address the issue of people not having equal access to their home of choice due to the current preference that is given to Internal Transfer List clients.

5. Create and offer evidence-informed education/orientation sessions for acute and LTC staff

The literature suggests various approaches that older people, including those with cognitive deficits, would find helpful – communication, assessment, and engagement strategies that focus on client strengths. As previously noted, these interactions and interventions can be time and labour intensive. Therefore, a review of staffing levels in relation to national benchmarks is recommended.

The hiring of a clinical educator for LTC St. John's is recommended, as this person could coordinate ongoing education assessments and sessions for staff on relevant issues related to best practice. This person would be also able to gage the impact the movement of clients through the system is having on staff, and consider this when developing education tools. The introduction of patient advocates into the system also is recommended as these individuals would partner with individuals and their families and assist them navigate the system; get answers to their questions, and better understand their care options.

6. Conduct Post-admission and Post-residency satisfaction surveys

There is a clear need for additional study in this area to identify challenges and solutions associated with moving people with dementia into and around the long term care system. This will necessarily include the tracking of bed utilization, lengths of stay, and occupancy rates of all beds within the acute and long term care sectors of Eastern Health. It will also be helpful to hear from clients and clients' families at two key points in time: The first is approximately four weeks post-admission when the admitted individual and his or her family have had time to establish at least some preliminary routines and sense of place. The survey administered at this juncture will seek the resident's and/or family's input on the admission experience. Such a survey can be crafted to illicit specific thoughts about communication processes, logistics, sources of frustration and success. The second is approximately four to six months after an individual's death. The survey in this instance will be administered to the deceased

resident's family. The logic behind waiting for this period of time is two-fold: This period of time will hopefully give families the time they need to sort through the emotionally and logistically difficult time immediately following the death of a loved one; It will also allow some chronological and emotional space from the experience of long term care in order to facilitate more honest, retrospective insights about the resident's and family's experience in long term care. As with the first survey, this one can be crafted to get input on everything from site-specific services, to over-arching elements like communication processes, involvement in care planning, quality of assessments and interventions, etc.

Again, these recommendations are outlined for the consideration of policy makers within Eastern Health, Long Term Care St. John's. As the population of Newfoundland and Labrador continues to age, demands on health care resources will only rise. This will create an ever increasing demand to have a health care system that functions optimally in meeting the balance between the expectations of health care recipients and providers.

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Appendix A: Levels of Care

Level One

An individual:

- is independently mobile, with or without mechanical aids, inclusive of a wheelchair
- may need specialized aids for independently transferring
- may require limited assistance with bathing, dressing, and/or grooming
- may require reminder for routine toileting
- may require minimal assistance with toileting
- may need nutritional monitoring
- may have sensory deficit which interferes with activities of daily living and may or may not require minimal assistance
- may have full use of mental functions
- may have a sensory/perceptual deficit but with adaptation will have the ability to be responsive, understand simple instructions, and express needs
- may demonstrate mild difficulties in orientation to day, time and place
- may demonstrate mild difficulty with memory and recall
- may have inappropriate behaviour which does not interfere with other people
- may have medical problems that are stabilized and do not require daily professional supervision
- may require accompaniment for (doctors, dentists, specialists, etc.) visits
- may require therapies (e.g. oxygen concentrator, ventolin masks) or procedures (e.g. colostomies) and is able to independently complete care required

Level Two

An individual:

- may be independently mobile with or without mechanical aids, inclusive of a wheelchair
- may need specialized aids for one person assist for transferring
- may need a moderate amount of assistance with bathing, dressing, and grooming
- may require a reminder of and/or assistance with routine toileting to avoid frequent incontinence of bowel or bladder
- may need occasional fleet enema, as directed by a physician
- may require nutritional monitoring of and/or assistance with eating

- may have sensory deficit which interferes with activities of daily living and requires moderate assistance
- may have mental functioning with moderate cognitive impairment
- is responsive to verbal stimuli; may have some difficulty with simple instructions, numbers and time concepts
- may have sensory/perceptual deficit but even with adaptation needs assistance for understanding and expressing needs
- may tend to pace or wander in own environment, but is not at risk for elopement
- may demonstrate inappropriate behaviour which may interfere with others, which can be stabilized
- may require therapies (oxygen concentrator, ventolin masks) or procedures (e.g. colostomies). Requires assistance to compete task. May require assistance with set up and/or cleaning of equipment
- will require professional monitoring

Level Three

An individual:

- is dependent for transfer or mobility
- requires assistance to turn or move about in bed
- is dependent for assistance with dressing, washing, grooming and bathing
- has incontinence of bladder and/or bowel
- requires supervision and assistance with eating or requires feeding
- requires daily professional care
- may have sensory deficit which interferes with activities of daily living and requires ongoing assistance
- may have severe cognitive impairment
- may have a sensory/perceptual deficit and even with adaptation, needs ongoing assistance for understanding and expressing needs
- may present with management problems due to behaviour, e.g. wandering, aggressiveness, hostility
- may demonstrate varying degrees of difficulty with orientation to place or person
- has medical programs which require continuous supervision and may require frequent professional intervention

Level Four

An individual:

- may be technology dependent or need both a medical device to compensate for the loss of a vital body function and ongoing professional health care to maximize functioning or prevent further disability, e.g., tracheotomy, enteral feed, vascular access device, mechanical ventilation

Appendix B: Transition Unit Policy

Transition Beds Overview:

Transition beds are designed as a temporary accommodation for Health Care Corporation of St. John's clients who are medically discharged and waitlisted for permanent long term care placement through the regional single entry system.

The transition beds are located at the health Care Corporation of St. John's (Dr. L. A. Miller Centre) and the St. John's Nursing Home Board (e.g., Hoyles/Escasoni).

Access to the transition beds is coordinated through Placement Services at Health and Community Services – St. John's Region.

While clients are occupying a transition bed they will be charged the medical discharge accommodation rate in accordance with the Department of Health and Community Services guidelines. Clients will maintain the medical discharge status while occupying a transition bed and will be considered in the category of "hospital source" for the purposes of filling a permanent bed.

Clients occupying a transition bed will be discharged to a home of choice in the long term care sector within or outside the St. John's Region or be moved to the first available bed to match level and care category if placement in a home of choice is not available within three (3) months of the medical discharge date.

If the client has not moved to home of choice within three (3) months of medical discharge date, then the anticipated time to placement will be reviewed by the Placement Coordinator at Health and Community Services and the Coordinator of the Transition Program at the applicable site.

- If the anticipated time to placement is less than two (2) weeks, then an extension may be granted for continued stay in the transition bed.

- If the anticipated time to placement is greater than two (2) weeks, then the client will be required to accept the first available bed with the long term care sector to match – gender, level, and care category, and be prioritized in the internal transfer grouping for placement

Eligibility:

Clients accessing a transition bed shall meet the following eligibility criteria. The client shall:

- have a medical condition which is stable
- be medically discharged and awaiting permanent placement;

- be panelled and approved through the Assessment and Placement Committee;
- understand the nature of the transition bed service or have a substitute decision maker who has this understanding

Placement Process:

A Placement Coordinator shall coordinate access to all transition beds within the Health Care Corporation of St. John's and the St. John's Nursing Home Board.

The Placement Coordinator shall accept notification from the Patient Care Coordinator at the Health Care Corporation of St. John's that a client has been medically discharged and shall ensure the necessary documentation (i.e., needs assessment, medical assessment, chest x-ray, financial assessment, and medical discharge waiver if applicable) is received from the unit social worker for panelling and approval at the Assessment and Placement Committee.

The Placement Coordinator shall accept verbal notification from the Coordinator of Transition Beds at the Health Care Corporation of St. John's and/or the St. John's Nursing Home Board that a vacancy exists in a transition bed and obtain information regarding any special consideration in filling the vacancy.

The Placement Coordinator shall review the medically discharged list to determine the client with the most outstanding medical discharge date, which is a match for the gender, level, and care category. The assessments, communication updates and panelling summary shall be forwarded to the Coordinator of transition beds.

The Placement Coordinator shall respond to transition bed vacancy notification within a 24 hour period or in the case of a weekend, no later than the end of the next working day.

Admission:

The Transition Unit shall accommodate medically discharged clients from the acute care sector. These individuals have identified a specific nursing home, however, a vacancy is not immediately available at the facility of choice. The Transition Unit will act as a temporary residence until a bed of choice becomes available or the client is required to move to the first available bed to match level and care category (3 months post medical discharge date).

1. Once a vacancy occurs, the Placement Coordinator at Health and Community Services, St. John's Region will forward the assessment of the next suitable candidate. This will be based on gender and medical discharge date. Other contributing factors may include need for special equipment or behavioural issues.

2. The Coordinator of the Transition Program will review the assessment and ensure information is accurate, that necessary equipment/supplies are available and that service can be provided within resources available.

3. The client/substitute decision maker will be offered a tour of the unit, as well as receive reinforcement of the philosophy of the unit as transition. The terms of temporary placement will be reviewed.

4. Admission may occur on any day of the week including weekends if necessary.

Appendix C: Internal Transfer Policy

Preamble:

Residents of long-term care facilities shall maintain the right to request a transfer to a facility of their choice. A facility may also initiate a transfer request based on the inability to provide appropriate care. Transfers within an individual nursing home shall continue to be managed within that home and transfers between nursing homes shall be managed within the St. John's Nursing Home Board.

Procedure:

Requests shall be forwarded to the Clinical Practice Leader for Social work and information shared with the clinical Social Work team through monthly meetings. A wait list is maintained by the Clinical Practice Leader for Social Work and residents/families shall be notified of the waitlist procedure. Individual homes will reserve the right to accept/reject requests for transfer based on shared information and appropriateness of available vacancy related to care requested.

The Clinical Practice Leader receives daily admission/vacancy information from the nursing home Social Workers and will discuss appropriateness of current vacancy for requested transfers.

The Social Worker shall maintain contact with the residents regarding their pending transfer and update residents/families regarding their status on the waitlist. If residents decide to cancel their transfer request, the Social Worker shall notify the Clinical Practice Leader for Social Work.

Once the transfer request has been identified:

The Social Worker in the referring facility will:

- Coordinate completion of the transfer request form or stamp the "paneling summary" for continuing transfer and obtains signature of client/family members;
- Forward the completed form to the Clinical Practice Leader for Social Work (fax – 726-0274);
- Present information at the monthly Social Work team meeting.
- Advise the resident/family of acceptance on the transfer list.

- Maintain ongoing contact with the client/family after wait listing regarding the pending transfer and keeps resident/family updated regarding status on the waitlist; and,
- Update transfer request.

The Clinical Practice Leader for Social Work will:

- Present the transfer request to the Social Work Clinical Team;
- Waitlist the resident if approved for transfer; and,
- Ensure that the Social Worker of the facility of choice receives a copy of the transfer request.

When a vacancy occurs, the Clinical Practice Leader for Social work and the Social Worker in the home of choice will discuss transfer requests (if any) and will:

- Forward the transfer form to the facility.

The Social Worker in the home of choice will notify the Social Worker in the referring nursing home of the current vacancy and will:

- Review transfer request to screen for suitability of resident;
- If referred resident is screened in, the Social Worker will contact the referring Social Worker for additional information if necessary;
- Confirm approval by requesting an updated Continuing Care Adult Long Term Care Assessment;
- Initiate admissions process upon receipt of the Continuing Care Adult Long Term Care Assessment and approval of the resident by contacting the resident/family and referring home.

The Social Worker in the referring facilities will:

- Coordinate completion of discipline specific assessments and/or summaries and the transfer of resident's chart and medications to the receiving facility; and,
- Forward a vacancy notification form to Placement Services, Health and Community Services, St. John's Region.

Upon notification by a resident/family member of the decision to cancel the transfer request:

- The Social Worker in the referring facility will notify the Clinical Practice Leader for Social Work.
- The Clinical Practice Leader for Social work will remove the name from the waitlist.

RESIDENT TRANSFER REQUEST

Resident Name: _____ Gender: M ___ F ___

Date of Birth: _____

Contact Person: _____ Telephone: _____

Transfer Requested by: Resident ___ Family ___ Facility ___

Name and Relationship: _____ Other: _____

Transfer From:

_____

Facility Requested:

_____

Care Requirements: Level I __ Level II __ Level III __ Level IV __
CW __ CI __ PCU __ ADU __ DDU __

Reason for Transfer:

_____

_____

_____

_____

SPECIFY DEGREE/TYPE OF ASSISTANCE/SUPERVISION REQUIRED

Physical ADL	IND	MIN	MOD	MAX	DEP	Comments
Dressing/Personal Care						
Tub ___ Shower ___ Sponge ___						
Toileting __ Incontinent ___ Bowel ___ Bladder ___						

Physical ADL	IND	MIN	MOD	MAX	DEP	Comments
Ambulation						
Transfer/Turns						
Coping Ability:						
Mental Status: Orientation: Person, Time place Retention and receipt of information Short/long-term memory Judgment/Decision Making	MSA Score _____/10					

Sleep Pattern:

Psychosocial Information:

Other Comments:

Approved by: _____ Date: _____
Signature and Title

Date Reviewed: _____ Date Revised: _____

Appendix D: First Available Bed Policy

Policy:

Inpatients who are ready for discharge but who can no longer be cared for in their pre-hospital living environment will be designated as alternate level of care (ALC) awaiting "Transfer to Long Term Care". This designation is based on an interdisciplinary assessment in collaboration with the patient and family. These patients must request placement in a personal care home or nursing home by applying to the Placement Services Program through the appropriate regional single entry system for Health and Community Services. The following will apply:

- Care will continue as needed for the patient, and adjusted as necessary to meet care needs.

- Patients of the Health Care Corporation awaiting long-term care may be transferred to a transition bed. These transition beds provide a temporary care environment for patients awaiting level 3 and 4 care in a nursing home.

- Patients and families will be required to accept the first available bed in a long-term care facility that meets the assessed care needs. This applies to patients in an acute care or transition bed.

- Once designated as Transfer to Long Term Care, patients will be required to pay for each day of hospital stay as per the Provincial Government guideline.

Procedure:

The Physician will:

- Write the order to discharge the patient from acute care and change the patient's status to Transfer to Long Term Care. Once this designation is written, it will not change unless that patient's status changes and he/she is discharged home.
- Complete the medical portion of the application to Long Term Care form within five working days

The Social Worker will:

- Explain the transfer to the patient and family as outlined in the "Guidelines for Patients and Families Regarding Transfer to Long Term Care/Personal Care Home" *(Appendix A).* The social worker will ask the patient/family to sign the guidelines document to indicate their understanding of the transfer process.

- Inform the patient/family that billing will occur once the order is written. If necessary a financial assessment and waiver is completed and is retroactive to the date the Transfer to Long Term Care order is written.

- Notify Financial Services of the patient's Transfer to Long Term Care status.
- Coordinate the completion of the application for long term care placement within five working days. The social worker will enter the date the application was forwarded to the appropriate Placement Services Program in the appropriate section of the Enter/Edit Administrative Data Screen.

- Upon notification from the Placement Services Coordinator of the first available bed, meet with the patient/family to inform them of the availability of a bed in a home that meets the patient's needs.

The Patient Care Coordinator will:

- Enter the Alternative Level of Care Status as "Transfer to Long Term Care" in the Enter/Edit Administrative Data Screen.

- Make the necessary arrangements to transfer the patient.

Notify the Site Admission/Discharge Facilitator or Division Manager of any problems related to the transfer.

Appendix E: Action Plan for the Discontinuation of Transition Services at Escasoni and the L.A. Miller Centre

Action Plan for the Discontinuation of Transition Services at Escasoni and L. A. Miller Centre

Prepared by: Henry Kielley, Manager, Placement Services

Preamble

Within Eastern Health there are three major policies that facilitate the movement of clients into and around the long term care system: First Available Bed (FAB), Transition, and Internal Transfer Policies. These policies often result in multiple moves for residents in a short period of time before they get to their home of choice.

In consultation with all care sectors of Eastern Health (acute care, long term care, and community) and to strengthen our focus on resident-centred care it is most timely to discontinue transition services at Escasoni and the L. A. Miller Centre. Furthermore, there are data to support that thirty beds are not required given the decreasing occupancy rate of both units.

This paper will outline a two-phased approach to discontinuing this service. Firstly, to discontinue transition services at two sites and creating a FAB service at one site; secondly, to reinstate a rotation for admissions to all sites. This is a change from the current practice of filling vacancies primarily from the internal transfer list. This approach will help facilitate more equitable access to long term care, and maintain the system's ability to respond to emergency situations as they arise in acute care and the community.

Phase I – Conversion of 'Transition Unit' clients to 'First Available Bed' clients

1. The clients currently occupying the transition beds at Escasoni and L. A. Miller Centre are notified, in writing that their status has been changed and they are now permanent residents of long term care, occupying a First Available Bed. As permanent residents of long term care, these clients now have access to the transfer list.

2. The resident occupies the First Available Bed until they transfer to their home of choice.

3. Hoyles/Escasoni Complex changes their fifteen (15) bed transition service to FAB service on one unit. The L. A. Miller Centre discontinues its transition service. Ten of the current fifteen beds at L. A. Miller move to Hoyles/Escasoni to create a 25-bed FAB service. (Operationally, this arrangement only impacts the Hoyles/Escasoni Complex – no other site is affected).

4. The Leonard A. Miller Center (LAMC), in collaboration with acute care, community and LTC, will determine a new service delivery for the vacant beds.

Phase II – All Sites Rotate Admissions

1. The discontinuation of Transition services means the number of referral sources for long term care beds is reduced from six to five. These five are: acute care, community, Personal Care Homes, transfer list, and out-of-region (It was agreed that further discussion will be required to more clearly define "out-of-region").

2. There is a need to equitably respond to the needs in acute and community and to facilitate timely transfers to home of choice. Therefore all sites will go back to rotating admission referral sources with one change: Every second admission will be from the internal transfer list. For example, the next eight vacancies at St. Patrick's Mercy Home would be filled by the following rotation: acute care, transfer list, community, transfer list, Personal Care Home, transfer list, out-of-region, transfer list.

3. Throughout the rotation, allowance will be made so that the process can be interrupted by an emergency admission or the admission of a Cottage or Villa tenant, or retired clergy in consultation with Placement Services.

Evaluation

The Manager of Placement Services will monitor daily vacancies (including occupancy, type of vacancy, date vacant, date filled and referral source) at all sites and admission referral statistics on a monthly basis. The statistics will include length of stay for new admissions and transfers.

The change in service will also be a standing item for the Long Term Care Liaison Committee with a formal evaluation at six (6) and twelve (12) months.

Conclusion

These changes will result in a more resident-centred system in long term care and provide an opportunity to develop a comprehensive and responsive First Available Bed service. Furthermore, they will help facilitate more equitable access to long term care, and maintain the system's ability to respond to emergency situations as they arise in acute care and the community. Cooperation and consultation from all sectors (community, long term care, acute

care) and all sites, as well as careful monitoring by the Manager of Placement Services will be required to ensure a more resident-centred approach.

Appendix F: Questionnaire for Cognitively Well Residents – Sample Group A

Please check the response that best captures your experience.

1. What was your understanding of the First Available Bed (FAB) Policy and the Internal Transfer (IT) Policy before receiving this letter and questionnaire today?

( ) I was well informed of this policy by hospital staff
( ) I was told about the policy but not given much information
( ) I have never been told about this policy

Comments:

_____
_____
_____
_____

2. How long were you 'medically discharged' in hospital before you moved to another bed?

( ) less than 1 month
( ) 2-4 months
( ) 5-7 months
( ) 8-12 months
( ) more than 12 months
( ) I don't know

Comments:

_____
_____
_____
_____

3. When you moved from hospital, where did you go?

( ) Transition bed
( ) First available nursing home bed
( ) Nursing home bed in the home of your choice

Comments:

_____
_____
_____
_____

4. If you moved into a Transition bed, what was your understanding of this service?

( ) I understood I could move from transition to the home of my choice
( ) I understood I would have to move into another first available bed from transition
( ) The transition service was not explained to me
( ) Not applicable

Comments:

_____
_____
_____
_____

5. Once you moved into a First Available Bed (either from hospital or transition) did you place your name on the transfer list to the home of your choice?

( ) Yes
( ) No

6. How would you describe your level of understanding of the transfer list?

( ) This service was well explained by my social worker
( ) I heard about the list, but I still am not sure what it is

Comments:

_____
_____
_____
_____

7. Which statement reflects your experience with the transfer list?

( ) I waited on the transfer list until I moved into my home of choice
( ) I decided not to put my name on the transfer list once I went into the FAB
( ) I took my name off the transfer list because the wait was too long
( ) I took my name off the transfer list because I was content with where I was
( ) Other: Please explain

_____
_____
_____
_____

8. Once you moved into a First Available Bed (either from hospital or transition) how long did it take you to get to the home of your choice?

( ) less than 1 month
( ) 2-4 months
( ) 5-7 months
( ) 8-12 months
( ) more than 12 months
Comments:

_____
_____
_____
_____

9. To which nursing home were you first admitted (after transition)?

( ) The Agnes Pratt Home
( ) The Hoyles/Escasoni Complex
( ) Masonic Park Nursing Home
( ) Salvation Army Glenbrook Lodge
( ) Saint Luke's Homes
( ) St. Patrick's Mercy Home

Comments:

_____
_____
_____
_____

10. Which nursing home was your first choice?

( ) The Agnes Pratt Home
( ) The Hoyles/Escasoni Complex
( ) Masonic Park Nursing Home
( ) Salvation Army Glenbrook Lodge
( ) Saint Luke's Homes
( ) St. Patrick's Mercy Home

Comments:

_____
_____
_____
_____

11. What are your thoughts on how the system might have met your needs better or how it could be improved?

_____

_____

_____

_____

12. How would you rate your overall satisfaction with the admission and transfer process in long term care based on the following factors (1 is poor, 5 is very good)? *Please circle one.*

Wait time for first available bed	1	2	3	4	5
Wait time for bed of choice	1	2	3	4	5
Number of moves before reaching bed of choice	1	2	3	4	5
Communication about the process	1	2	3	4	5

Thank you for your participation. It is very much appreciated.

Appendix G: Questionnaire for Cognitively Well Residents – Sample Group B

Please check the response that best captures your experience.

1. What was your understanding of the First Available Bed (FAB) Policy and the Internal Transfer (IT) Policy before receiving this letter and questionnaire today?

( ) I was well informed of this policy by hospital staff
( ) I was told about the policy but not given much information
( ) I have never been told about this policy

Comments:

_____
_____
_____
_____

2. How long were you 'medically discharged' in hospital before you moved to another bed?

( ) less than 1 month
( ) 2-4 months
( ) 5-7 months
( ) 8-12 months
( ) more than 12 months
( ) I don't know

Comments:

_____
_____
_____
_____

3. When you moved from hospital, where did you go?

( ) First available nursing home bed in a home that was not my first choice
( ) Nursing home bed in the home of my choice

Comments:

_____
_____
_____
_____

4. If you moved into a first available nursing home bed that was not in your home of choice, did you place your name on the transfer list?

( ) Yes
( ) No
( ) Not applicable

5. How would you describe your level of understanding of the transfer list?

( ) This service was well explained by my social worker
( ) I heard about the list, but I still am not sure what it is

Comments:

_____
_____
_____
_____

6. Which statement reflects your experience with the transfer list?

( ) I waited on the transfer list until I moved into my home of choice
( ) I decided not to put my name on the transfer list once I went into the FAB
( ) I took my name off the transfer list because the wait was too long
( ) I took my name off the transfer list because I was content with where I was
( ) Other: Please explain

_____
_____
_____
_____

7. Once you moved into a First Available Bed how long did it take you to get to the home of your choice?

( ) I moved to my home of choice from acute care
( ) less than 1 month
( ) 2-4 months
( ) 5-7 months
( ) I am still waiting to get to my home of choice

Comments:

_____
_____
_____
_____

8. To which nursing home were you first admitted (after your stay in hospital)?

( ) The Agnes Pratt Home
( ) The Hoyles/Escasoni Complex
( ) Masonic Park Nursing Home
( ) Salvation Army Glenbrook Lodge
( ) Saint Luke's Homes
( ) St. Patrick's Mercy Home

Comments:

_____
_____
_____
_____

9. Which nursing home was your first choice?

( ) The Agnes Pratt Home
( ) The Hoyles/Escasoni Complex
( ) Masonic Park Nursing Home
( ) Salvation Army Glenbrook Lodge
( ) Saint Luke's Homes
( ) St. Patrick's Mercy Home

Comments:

_____
_____
_____
_____

10. What are your thoughts on how the system might have met your needs better or how it could be improved?

_____
_____
_____
_____

11. How would you rate your overall satisfaction with the admission and transfer process in long term care based on the following factors (1 is poor, 5 is very good)? *Please circle one.*

Wait time for first available bed 1 2 3 4 5

Wait time for bed of choice	1	2	3	4	5
Number of moves before reaching bed of choice	1	2	3	4	5
Communication about the process	1	2	3	4	5

Thank you for your participation. It is very much appreciated.

Appendix H: Questionnaire for the Substitute Decision Maker of Cognitively Impaired Residents Sample Group A

Please check the response that best captures the experience of you and your relative.

1. What was your understanding of the First Available Bed (FAB) Policy and the Internal Transfer (IT) Policy before receiving this letter and questionnaire today?

( ) I was well informed of this policy by hospital staff
( ) I was told about the policy but not given much information
( ) I have never been told about this policy

Comments:

_____
_____
_____
_____

2. How long was your relative 'medically discharged' in hospital before he or she was moved to another bed?

( ) less than 1 month
( ) 2-4 months
( ) 5-7 months
( ) 8-12 months
( ) more than 12 months
( ) I don't know

Comments:

_____
_____
_____
_____

3. When your relative moved from hospital, where did he or she go?

( ) Transition bed
( ) First available nursing home bed
( ) Nursing home bed in the home of your choice

Comments:

_____
_____
_____
_____

4. If your relative moved into a Transition bed, what was your understanding of this service?

( ) I understood I could move from transition to the home of my choice
( ) I understood I would have to move into another first available bed from transition
( ) The transition service was not explained to me
( ) Not applicable

Comments:

_____
_____
_____
_____

5. Once your relative moved into a First Available Bed (either from hospital or transition) did you place their name on the transfer list for the home of their choice?

( ) Yes
( ) No

6. How would you describe your level of understanding of the transfer list?

( ) This service was well explained by my social worker
( ) I heard about the list, but I still am not sure what it is

Comments:

_____
_____
_____
_____

7. Which statement reflects your experience with the transfer list?

( ) My relative waited on the transfer list until he or she moved into the home of choice
( ) I decided not to put my relative's name on the transfer list once he/she went into the First Available Bed
( ) I took my relative's name off the transfer list because the wait was too long
( ) I took my relative's name off the transfer list because I was content with where he/she was

8. Once your relative moved into a FAB (either from hospital or transition) how long did it take him or her to get to the home of choice?

( ) less than 1 month
( ) 2-4 months
( ) 5-7 months
( ) 8-12 months
( ) more than 12 months

Comments:

_____
_____
_____
_____

9. To which nursing home was your relative first admitted (after transition)?

( ) The Agnes Pratt Home
( ) The Hoyles/Escasoni Complex
( ) Masonic Park Nursing Home
( ) Salvation Army Glenbrook Lodge
( ) Saint Luke's Homes
( ) St. Patrick's Mercy Home

Comments:

_____
_____
_____
_____

10. Which nursing home was your first choice for your relative?

( ) The Agnes Pratt Home
( ) The Hoyles/Escasoni Complex
( ) Masonic Park Nursing Home
( ) Salvation Army Glenbrook Lodge
( ) Saint Luke's Homes
( ) St. Patrick's Mercy Home

Comments:

_____
_____
_____
_____

11. What are your thoughts on how the system might have met your needs better or how it could be improved?

_____
_____
_____
_____

12. How would you rate your overall satisfaction with the admission and transfer process in long term care based on the following factors (1 is poor, 5 is very good)? *Please circle one.*

Wait time for first available bed	1	2	3	4	5
Wait time for bed of choice	1	2	3	4	5
Number of moves before reaching bed of choice	1	2	3	4	5
Communication about the process	1	2	3	4	5

Thank you for your participation. It is very much appreciated.

Appendix I: Questionnaire for the Substitute Decision Maker of Cognitively Impaired Residents Sample Group B

Please check the response that best captures your experience.

1. What was your understanding of the First Available Bed (FAB) Policy and the Internal Transfer (IT) Policy before receiving this letter and questionnaire today?

( ) I was well informed of this policy by hospital staff
( ) I was told about the policy but not given much information
( ) I have never been told about this policy

Comments:

_____
_____
_____
_____

2. How long was your relatively 'medically discharged' in hospital before he or she moved to another bed?

( ) less than 1 month
( ) 2-4 months
( ) 5-7 months
( ) 8-12 months
( ) more than 12 months
( ) I don't know

Comments:

_____
_____
_____
_____

3. When your relative moved from hospital, where did he or she go?

( ) First available nursing home bed in a home that was not my first choice
( ) Nursing home bed in the home of my choice

Comments:

_____
_____
_____
_____

4. If your relative moved into a first available nursing home bed that was not in your home of choice, did you place their name on the transfer list?

( ) Yes
( ) No
( ) Not applicable

5. How would you describe your level of understanding of the transfer list?

( ) This service was well explained by my social worker
( ) I heard about the list, but I still am not sure what it is

Comments:

_____
_____
_____
_____

6. Which statement reflects your experience with the transfer list?

( ) My relative waited on the transfer list until he or she moved into the home of choice
( ) I decided not to put my relative's name on the transfer list once he/she went into the First Available Bed
( ) I took my relative's name off the transfer list because the wait was too long
( ) I took my relative's name off the transfer list because I was content with where he/she was

_____
_____
_____
_____

7. Once your relative moved into a First Available Bed how long did it take them to get to their home of choice?

( ) My relative moved to their home of choice from acute care
( ) less than 1 month
( ) 2-4 months
( ) 5-7 months
( ) My relative is still waiting to get to their home of choice

Comments:

_____
_____

8. To which nursing home was your relative first admitted (after their stay in hospital)?

( ) The Agnes Pratt Home
( ) The Hoyles/Escasoni Complex
( ) Masonic Park Nursing Home
( ) Salvation Army Glenbrook Lodge
( ) Saint Luke's Homes
( ) St. Patrick's Mercy Home

Comments:

9. Which nursing home was your first choice?

( ) The Agnes Pratt Home
( ) The Hoyles/Escasoni Complex
( ) Masonic Park Nursing Home
( ) Salvation Army Glenbrook Lodge
( ) Saint Luke's Homes
( ) St. Patrick's Mercy Home

Comments:

10. What are your thoughts on how the system might have met your needs better or how it could be improved?

11. How would you rate your overall satisfaction with the admission and transfer process in long term care based on the following factors (1 is poor, 5 is very good)? *Please circle one.*

Wait time for first available bed	1	2	3	4	5
Wait time for bed of choice	1	2	3	4	5
Number of moves before reaching bed of choice	1	2	3	4	5
Communication about the process	1	2	3	4	5

Thank you for your participation. It is very much appreciated.

Appendix J: Interview Questions - Sample Group A or their Substitute Decision Makers

1. How long were you/your relative medically discharged before moving out of hospital?

2. Where did you/your relative go from the hospital?

3. What was it like for you/your relative to wait in hospital for a nursing home bed? Do you think it is the most appropriate place to wait for a nursing home bed?

4. How did you learn about the First Available Bed policy? How has this policy impacted you/your relative?

5. How did you decide which nursing home was right for you/your relative? What factors were important in making this decision?

6. How many moves have taken place to get you/your relative to the current placement?

7. What impact has these moves had and you/your relative?

8. Did you remove your/your relative's name from the transfer list? How was this decision reached?

9. What has the communication been like during this process? Have you/your relative been kept 'in the loop' on what is happening next, when it is happening and why?

10. Acute care has to have beds available to respond to emergencies. How could long term care get people to their home of choice without having to make multiple moves?

11. Transition services are being discontinued at Escasoni and the Miller Centre. This means people will be able to wait in the First Available Bed until they get to their home of choice. What do you think of this change?

Appendix K: Interview Questions - Sample Group B or their Substitute Decision Makers

1. How long were you/your relative medically discharged before moving out of hospital?

2. Where did you/your relative go from the hospital?

3. What was like for you/your relative to wait in hospital for a nursing home bed? Do you think it is the most appropriate place to wait for a nursing home bed?

4. How did you learn about the First Available Bed policy? How has this policy impacted you/your relative?

5. How did you decide which nursing home was right for you/your relative? What factors were important in making this decision?

6. How many moves have taken place to get you/your relative to the current placement?

7. What impact has these moves had and you/your relative?

8. Did you remove your/your relative's name from the transfer list? How was this decision reached?

9. What has the communication been like during this process? Have you/your relative been kept 'in the loop' on what is happening next, when it is happening and why?

10. Acute care has to have beds available to respond to emergencies. How could long term care get people to their home of choice without having to make multiple moves?

11. Prior to June 1, 2007, there was a Transition service at Escasoni and the Miller Centre. This meant people who went there from hospital had to take another First Available Bed before moving to the home of their choice. What do you think of this change?

Appendix L: Letter to Potential Participants - Resident

<DATE>

<NAME>
<ADDRESS>

Dear <NAME>

My name is Henry Kielley. I am a Masters student in the School of Social Work at Memorial University and I currently am conducting some research on the First Available Bed Policy and the Internal Transfer Policy, and their effects on residents of long term care and their families. You should also know that I am currently the Manager of Placement Services, which oversees administration of these policies. Please note that this study is being conducted for my program at university, and is not being conducted in relation to my job with Placement Services. Completion of this questionnaire can have no effect on current or future medical or long term care services for you or your family.

You may recall that before you reached the nursing home you currently are in, you had to make more than one move – perhaps you moved into a transition unit from hospital, and from there to another bed to await the home of your choice. These moves happened as a result of the First Available Bed policy that says a person cannot wait in a hospital bed or a transition bed for a vacancy in the nursing home of his or her choice. Now that you have reached this point in your journey through the long term care system, I am interested in your thoughts about your experiences.

It is my intention that the information collected will be presented in a report to policy and decision makers within Long Term Care, St. John's, to help in the development of policies and programs that focus on people's needs and minimize the effects of moving through 'the system.' Please be assured that the information you provide is anonymous and that the confidentiality of that information will be protected. No one will know what you say on the questionnaire, or even when you completed one.

The proposal for this research has been approved by the Interdisciplinary Committee on Ethics in Human Research at Memorial University. If you have ethical concerns about the research (such as the way you have been treated or your rights as a participant), you may contact the Chairperson of the ICEHR at icehr@mun.ca or by telephone at 737-8368. If you have questions or comments about this study, you may contact me by email at kielley@gmail.com or by telephone at 570-2719.

I invite you to participate in this study. If you are willing, please complete the enclosed questionnaire and return it in the self-addressed, stamped envelope

provided. No one will know who you are or what you have answered on the questionnaire. Your name is not requested. Answer only the questions you feel comfortable answering. If you do not answer all the questions, feel free to return the questionnaire anyway. If, in addition to the questionnaire, you would like to share some thoughts in an individual interview, please contact your social worker for details. Those who choose to take part in an interview will remain anonymous as well. Only your social worker will know who you are, and your name will not be associated with the answers you provide. The summary of the responses will be sent to me without any identifying information. Again, please note that although I work with Placement Services, this study is being conducted for my program at university. Completion of this questionnaire can have no effect on current or future medical or long term care services for you or your family.

Sincerely,

_____

Henry Kielley, BSW, RSW
Principal Investigator

Appendix M: Letter to Potential Participants - Substitute Decision Maker

<DATE>

<NAME>
<ADDRESS>

Dear <NAME>

My name is Henry Kielley. I am a Masters student in the School of Social Work at Memorial University and I am currently conducting some research on the First Available Bed Policy and the Internal Transfer Policy, and their effects on residents of long term care and their families. You should also know that I am currently the Manager of Placement Services, which oversees administration of these policies. Please note that this study is being conducted for my program at university, and is not being conducted in relation to my job with Placement Services. Completion of this questionnaire can have no effect on current or future medical or long term care services for you or your family.

You may recall that before your relative reached the present nursing home he/she had to make more than one move – perhaps into a transition unit from hospital, and from there to another bed to await the home of choice. These moves happened as a result of the First Available Bed policy that says a person cannot wait in a hospital bed or a transition bed for a vacancy in the nursing home of his or her choice. Now that your relative has reached this point in his/her journey through the long term care system, I am interested in your thoughts about what the experience was like for your relative and your family.

It is my intention that the information collected will be presented in a report to policy and decision makers within Long Term Care, St. John's, to help in the development of policies and programs that focus on people's needs and minimize the effects of moving through 'the system.' Please be assured that the information you provide is anonymous and that the confidentiality of that information will be protected.

The proposal for this research has been approved by the Interdisciplinary Committee on Ethics in Human Research at Memorial University. If you have ethical concerns about the research (such as the way you have been treated or your rights as a participant), you may contact the Chairperson of the ICEHR at icehr@mun.ca or by telephone at 737-8368. If you have questions or comments about this study, you may contact me by email at kielley@gmail.com or by telephone at 570-2719.

I invite you to participate in this study. If you are willing, please complete the enclosed questionnaire and return it in the self-addressed, stamped envelope provided. No one will know who you are or what you have answered on the questionnaire. Your name is not requested. Answer only the questions you feel comfortable answering. If you do not answer all the questions, feel free to return the questionnaire anyway. If, in addition to the questionnaire, you would like to share some thoughts in an individual interview, please contact your social worker for details. Those who choose to take part in an interview will remain anonymous as well. Only your social worker will know who you are, and your name will not be associated with the answers you provide. The summary of the responses will be sent to me without any identifying information. Again, please note that although I work with Placement Services, this study is being conducted for my program at university. Completion of this questionnaire can have no effect on current or future medical or long term care services for you or your family.

Sincerely,

_____

Henry Kielley, BSW, RSW
Principal Investigator

Appendix N: Consent Form for Participation in an Individual Interview

I, _____, agree to participate in the research study conducted by Henry Kielley, Memorial University MSW student, looking at the effects of admission and transfer policies on Long Term Care clients, and their families as approved by the Interdisciplinary Committee on Research Involving Humans, Memorial University.

I understand that every effort will be taken to protect my privacy and my right to confidentiality.

I understand that this interview may be audio taped with my permission and that all tapes will be erased once the research study is complete.

I understand that I have the right to withdraw from the research at any time and that I can choose not to answer any question(s) of my choice. If I do withdraw, I have a right to have my partial interview either included or excluded from the research.

I understand that there will be no personal repercussions, and the care provided to me/my relative at the nursing home will not be affected should I choose to withdraw from the research at any point in time. I also understand that if I/my relative currently is on the transfer list for another nursing home, that my decision to participate or withdraw will have no effect on my/my relative's position on that transfer list.

I understand that I am agreeing to an interview that will last approximately twenty (20) minutes during which I will be asked questions about my experiences with the First Available Bed and Transfer Policies.

I understand that I have the right to discuss any concerns or questions I may have about the research with Henry Kielley, the principal investigator. I understand he can be contacted by email at kielley@gmail.com or by phone at 570-2719.

I understand that the proposal for this research has been approved by the Interdisciplinary Committee on Ethics in Human Research (ICEHR) at Memorial University.

I understand that if I have ethical concerns about the research (such as the way I have been treated or my rights as a participant), I may contact the Chairperson of the ICEHR at icehr@mun.ca or by telephone at 737-8368.

I hereby consent to participate in this study. By signing below, I acknowledge that I have been informed and understand my rights as a volunteer participant.

Please circle one: **I agree** or **I do not agree** to have my interview audio taped.

_____ _____

Participant Interviewer

_____

Date

Appendix O: Questions for Focus Group with Long Term Care Social Workers

1. What has been your experience of the First Available Bed (FAB) policy?

2. What part, if any, has the current internal transfer policy played in people's experience of the FAB policy?

3. What are your thoughts on the proposed Action Plan that was circulated in April 2007?

4. Are you noticing any difference in terms of adjustment in those residents admitted before and after May 2007?

5. What are you hearing from residents and family members about the practice of admissions and transfers within long term care?

6. Given that acute care cannot change its FAB policy, how can the long term care (LTC) sector handle admissions and transfers in the most equitable way? Is there anything long term care needs to do differently to reduce the impact of multiple moves on clients and families?

7. What additional thoughts would you add?

Appendix P: Interview Questions - Eastern Health Staff

1. What has been your experience of the First Available Bed (FAB) policy?

2. What part, if any, has the current internal transfer policy played in people's experience of the FAB policy?

3. What are your thoughts on the proposed Action Plan that was circulated in April 2007?

4. What are you hearing from residents and family members about the practice of admissions and transfers within long term care?

5. Given that acute care cannot change its FAB policy, how can the long term care (LTC) sector handle admissions and transfers in the most equitable way? Is there anything long term care needs to do differently to reduce the impact of multiple moves on clients and families?

6. What additional thoughts would you share?

Appendix Q: ICEHR Approval and Application

Memorial
University of Newfoundland

June 11, 2007

Office of Research
ICEHR No. 2006/07-128-SW
Mr. Henry Kielley
School of Social Work
Memorial University of Newfoundland

Dear Mr. Kielley:

Thank you for your submission to the Interdisciplinary Committee on Ethics in Human Research (ICEHR) entitled *"The impact of admission & transfer policies on long term care clients and their families"*. The ICEHR is appreciative of the efforts of researchers in attending to ethics in research.

Overall, the Committee feels that this is a thorough and solid proposal on a very important research topic. The Committee suggests the following points which you might want to consider:

1. It would be useful to clarify whether interview subjects would include health care clients/family members or only include health care professionals. Nor is much information provided on how interview subjects would be recruited.

2. The proposal should acknowledge that it is difficult, if not impossible, to guarantee anonymity in the focus-group setting.

3. The interviewers/facilitators should be specified.

4. It might be useful to anticipate that, given the age of some of the clients/participants, there may be concerns about literacy, even if a person meets the test of competence

5. In Appendix K – you should probably declare explicitly, in the first paragraph, that you are the Manager of Placement Services rather than in passing in the last paragraph.

Subject to the changes noted above and in accordance with Tri-Council Policy Statement (TCPS), the project has been granted full approval for one year from the date of this letter.

If you intend to make changes during the course of the project which may give rise to ethical concerns, please forward a description of these changes to ICEHR for consideration.

If you have any questions concerning this review, you may contact the ICEHR Co-ordinator, Mrs. Eleanor Butler at ebutler@mun.ca. We wish you success with your research.

The TCPS requires that you submit an annual status report to ICEHR on your project, should the research carry on beyond June 2008. Also, to comply with the TCPS, please notify ICEHR when research on this project concludes.

Yours sincerely,

L. F. Felt, Ph.D.
Chair, Interdisciplinary Committee on
Ethics in Human Research

LF/bl
cc. Supervisor – Dr. Nancy Sullivan, School of Social Work

St. John's, NL, Canada A1C 5S7 • Tel.: (709) 737-8251 • Fax (709) 737-4612 • http://www.mun.ca/research

Research Proposal to the Interdisciplinary Committee on Ethics in Human Research (ICEHR)

The Impact of Admission & Transfer Policies on Long Term Care Clients and Their Families

Prepared by Henry Kielley, MUN # 9210105
School of Social Work
Memorial University of Newfoundland

Summary of the Research

Scope and Objectives

This study will examine the role of the Transition Units (Appendix B) functioning of the Internal Transfer (IT) Policy (Appendix C) and the First Available Bed (FAB) Policy (Appendix D) with regard to system efficiency in relation to meeting the long term care needs of clients and their families.

From a systems perspective there is a requirement to provide care and services to clients. This implies responding to clients' needs as they present on a daily basis, having a bed available when the client needs a bed. The system has an obligation to operate in the most effective and efficient way as it functions as a need-meeting service for clients. Clinical efficiency means ensuring that people move through the system to the most appropriate place to meet their needs, based on client assessment and the purpose of particular programs and services. It means not leaving people in inappropriate beds, services, or programs while waiting for a bed in another part of the system to open up. The literature indicates that there potentially are detrimental effects on clients when they are left in inappropriate beds while awaiting transfer (Graf, 2006). This frequently presents a challenge for the system as demands for its services outweigh its resources.

From a client perspective, there is a need for safety, emotional well-being, maintenance of autonomy, and the ability to function at one's greatest potential given physical and cognitive status; and an expectation that these needs will be met through the provision of long term care. The system has an obligation to respond, an obligation to ensure the individual receives the appropriate service in the appropriate place and in the appropriate amount of time from the appropriate people. Many clients do not know or care about the larger system's mandate to balance its obligations with individual need, just that they, as individuals, have come in need of help. Understandably when people are in acute need or crisis, they are not interested in hearing about shortages of staff or the person waiting in the hallway for their bed because somebody deemed that one to have a greater need.

Client need is the chief concern, although perspectives on how or whether needs are met vary. The system may consider a client's need met if he or she is moved from an inappropriate bed in acute care to an appropriate bed in long term care or transition based on assessed need. The client experiencing the move may consider his or her needs unmet because he or she feels unheard by an impersonal system that appears to move people where it wants, when it wants.

For the client, it can come down to the difference of being provided *a* bed versus *the* bed he or she wants. How can the optimal balance between system efficiency and client need-meeting be reached? In a resource-limited system the 'good of many' frequently overrides the 'good of one.' The hospital system may recognize that moving a particular client will cause much stress and upset for that client and his or her family, but is forced to proceed with the move given the demand for the finite number of beds in the acute care system. One challenge the system faces is finding the balance point between individual need-meeting and its obligation and responsibility to provide for everyone in need.

This study will attempt to identify elements of the FAB and IT Policies that are working well from a systems and a client perspective, what is not working so well, and what could be done differently. A comparative analysis of system efficiency and client satisfaction will be completed using data collected from two sample groups - one each from before and after the proposed system changes in May 2007 outlined in Appendix E. The first sample group will be made up of individuals who were admitted to long term care from acute care via transition and a first available bed for the four months prior to May 2007 and the second will be made up of individuals who were admitted to long term care from acute care via a first available bed for the four months following the May 2007 decision to discontinue transition services. From the findings, it is expected that recommendations may be made to program and policy planners of Long Term Care, St. John's. Practical alternatives to current policy and practice will be identified, as well as proposed ways to evaluate the changes currently proposed.

Scholarly Significance

Long Term Care, St. John's strives to deliver its services in the most person-centered way possible while responding to urgent needs for placement as identified in community and acute care settings. The FAB Policy plays a central role in determining how service users move into and about the system of long term care, yet no analysis of the effectiveness of this policy has been conducted since its inception in 2002.

This study has scholarly significance given that little research has been conducted locally within long term care from a Social Work and systems perspective. As health providers struggle to move from medical to more social models of care, looking at service delivery through the lenses of person-centred care, social justice, equality, and the Social Work Code of Ethics has potential scholarly significance. The profession of Social Work will find its practitioners more involved in this field given current and projected demographics and this profession has a broad, whole-person perspective that can help shape person-centered systems.

Potential Social Relevance/Practical Importance

The population of this province continues to age and one of the results is increased strain on our acute and long term care systems. The challenge facing each of the province's Regional Integrated Health Authorities (including Eastern Health) is to provide quality care that is ethically and fiscally responsible. This sometimes creates dilemmas where service recipients perceive shortfalls in a system that is not able to meet their identified needs.

This study will look at the system through the lenses of person-centred care and social justice and posit potential ways to achieve a greater balance between system efficiency and client satisfaction. From the findings, it is expected that recommendations may be made to program and policy planners of Long Term Care, St. John's. Practical alternatives to current policy and practice will be identified, as well as proposed ways to evaluate these alternatives if implemented.

Research Questions/Expected Outcomes

This study is designed to address the following questions:

1. What is the nature, positive and negative, of the impact of the First Available Bed Policy and the Internal Transfer Policy on need-meeting of long term care clients and their families from the perspective of the clients and their families?

2. What is the nature, positive and negative, of the impact of the First Available Bed Policy and the Internal Transfer Policy on need-meeting of long term care clients and their families from the perspective of the long term care system (as represented by the COO, Director, Nursing Home Administrators, and Nursing Home Social Workers)?

3. How can the system function optimally to meet the needs of individuals requiring long term care; that is, what changes could be made to policies, procedures, or programs in order to facilitate the most positive experience of the move between acute care and long term care, within the context of Eastern Health's philosophy of person-centred care (www.easternhealth.ca)?

Theoretical Approach/Conceptual Framework

This study will look at current policies and practices of Long Term Care admissions and transfers through the lenses of person-centred care and equality, as well as from an ecological and anti-oppressive perspective (Payne, 1997). The vision of Eastern Health is "Healthy People, Healthy Communities" and its six core values are collaboration, confidentiality, excellence, growth, integrity,

and respect (http://www.easternhealth.ca/AboutEH.aspx?d=1&id=49&p=73). Eastern Health also utilizes the four major principles of health care ethics (autonomy, beneficence, non-maleficence, and justice) in the development of all policies and procedures.

These principles will be considered as this study looks at how Long Term Care, St. John's practises a model of care delivery that promotes clients' rights and autonomy and whether proposed changes to current practice (Appendix E) helps Eastern Health to better uphold its vision and values. The literature has referred to such practices as a "culture shift" as institutions try to move from traditional, medical models to more social models of care.

Research Methods

The study is designed as an inquiry using questionnaires, interviews, and focus groups to gather both quantitative and qualitative data from long term care service recipients and providers. Data will be sought on their perceptions of how the long term care placement system currently is meeting individuals' needs while maximizing the ability to respond to needs of other individuals waiting to access this system on a daily basis, and what may be done differently. Quantitative data will indicate bed utilization and turnover from a systems perspective in an effort to quantify demands on the system.

The sample groups for this study will be clients who were admitted to long term care from acute care from January 2007 to April 2007 (four months preceding the proposed changes, called Sample Group A) and from May 2007 to August 2007 (four months following the proposed changes, called Sample Group B); family members of clients who are not capable of participating for physical or cognitive reasons; nursing home social workers; and nursing home administrators. The average monthly admissions to long term care in St. John's are fifty-five (55), giving a total possible sample size over the eight months of 440 people representing client views and ten nursing home social workers and six nursing home administrators.

A questionnaire (Appendix F) has been designed to gather data about long term care clients' perceptions of how the system has met their needs and about wait times and movement of clients through the system. This questionnaire will be circulated to cognitively well residents who have been admitted to their home of choice after having moved from acute care, to transition, and then to First Available Bed during the months of January 2007 to April 2007. Other quantitative data will be collected from monthly reports on admissions and new applications obtained from Placement Services (the department which is responsible for the Single Entry System discussed above), along with bed utilization statistics obtained from the Office of Clinical Efficiency within acute

care. A similar questionnaire (Appendix G) has been designed to gather similar data from cognitively well clients who are admitted during the months of May 2007 to August 2007 from acute care directly to FAB.

Questionnaires also have been designed for residents' next-of-kin, or substitute decision maker (SDM) of residents identified as cognitively impaired; one for residents admitted from January to April and one for residents admitted from May to August (Appendices H and I). In cases where a substitute decision maker has not been identified in advance by the client, the long term care sector will be asked to identify the substitute decision maker by the application of Section 10 of the Advance Health Care Directives Act (http://www.hoa.gov.nl.ca/hoa/statutes/a04-1.htm). This is routinely done on admission to long term care for clients who are cognitively impaired. While this does preclude some family members, the assumption of the Advance Health Care legislation is that the SDM speaks for the cognitively impaired resident. The Social Worker in each nursing home will be asked to distribute the questionnaire so the principal investigator does not have to be provided with this contact information. The rationale for exclusion of cognitively impaired residents from the questionnaire portion of the data collection is the fact that many of these residents are not oriented to person, time, or place, and therefore may have difficulty in identifying where they are, where they transferred from, or how long they have spent in any one place through the admission and transfer processes.

Qualitative data also will be generated by interview questions (Appendices J and K) that will seek clients' and substitute decision makers' perceptions of the system and the experience moving through it from the point of initial entry into the system, that being acute care, to their admission or the admission of their relative to their home of choice. Interviews will be conducted with residents and substitute decision makers from both sample groups, that is, those admitted during the four months prior to the May 2007 decision and those admitted in the four months since. The cover letter that explains the study (Appendix L for cognitively well residents and Appendix M for residents' substitute decision makers) will accompany the questionnaires, inviting them to complete the questionnaire, and additionally, to participate in an individual interview. Written consent will be obtained before proceeding with the interview (Appendix N). Interviews will be conducted by nursing home social workers. Depending on the number of interviews requested, nursing home social workers will complete interviews with residents and/or family members from their specific site. This may have to be revisited if the number of interviews requires that they be more equally divided among the ten social workers in long term care.

The principal investigator will facilitate a focus group with long term care social workers to provide data from their perspective (Appendix O). It is acknowledged that it will be impossible to maintain anonymity in the focus group. This will be

acknowledged by the principal investigator at the beginning of the focus group session, with a request that participants respect one another's views and that matters discussed in the focus group are not discussed outside the group. Interviews also will be conducted by the principal investigator with nursing home administrators, the Director of Clinical Efficiency with acute care, and the Director of Pastoral Care and Ethics with Eastern Health (Appendix P) in order to obtain a management viewpoint. These people have been identified by the principal investigator as having vested interest in, as well as some degree of control over, the admission and transfer procedures of long term care. A written invitation will be extended to these individuals.

Statement of Ethical Issues

Scholarly Review

The proposal and this ethics application for the study have been reviewed by the principal investigator's Thesis Supervisor and other colleagues in the formulation of the study questions.

Harms and Benefits

Admission to institutional living is an event filled with emotional responses, some of which are negative. The emotions surrounding this transition often are exacerbated by perceived inefficiency or unjust practices within 'the system.' Discussion of admission to long term care has the potential to elicit a negative, emotional response from participants, particularly in cases where the move into institutional care was perceived as unfair or unnecessary. Participants will be told in advance that they are free to terminate their participation at any point in the process.

Another potential harm is the fear perceived by some residents and their relatives in long term care that "complaining" or "speaking against the establishment" will somehow come back negatively on the resident. The perception and experience of some residents of long term care and their families have been that staff treats residents differently or less well if they are perceived as "troublesome" or "outspoken." This issue raises two responsibilities for the principal investigator – to ensure participants that participating in this study will have no impact on any aspect of their care, and also to ensure that should any encounters uncover these sentiments, they referred (with the participant's permission) to the appropriate staff person or manager for follow up. To ensure these responsibilities are met, the cover letter that accompanies the questionnaire and the consent form that accompanies the individual interview will explain emphatically that the information collected from both procedures will be anonymous, and coded in a way that ensures anonymity. Participants will be

informed of the interviewer's duty to report in cases where there is actual or suspected harm to an individual. This limitation will be explained prior to the participant's involvement in focus groups or individual interviews.

A potential benefit for participants of this study is the satisfaction derived from 'having your say' and contributing to the future policy direction of a particular service or organization. It will be emphasized to participants that participation in this study does not mean that programs or policies will be changed to reflect necessarily their particular ideas or suggestions. As with the potential harms, it will be emphasized that participation in the study will not have any impact on the person's experience in the nursing home or on the transfer list awaiting a move to the home of his or her choice. In other words, participation in the study will not stand you in good stead for a quicker transfer. The process of transfer will be reiterated and the integrity of this process will be ensured by the principal investigator who is also the coordinator for the institutional transfer list. This dual role may be perceived as a conflict of interest, so the principal investigator will not facilitate individual interviews or client or staff focus groups to help safeguard the integrity of the system, the integrity of the research process, and the ability of participants to give free and informed consent.

Free and Informed Consent

All participants in this study will provide free and informed consent with the knowledge that their information will remain anonymous and that withdrawal from the process at any point is a right and will not be viewed negatively and will not have any negative ramifications for the participant in the long term care system.

These facts will be outlined clearly in the cover letter that accompanies the questionnaire and the consent form that precedes every individual interview. According to the Policy on Ethics of Research Involving Human Participants, "free and informed consent must be voluntarily given, without manipulation, undue influence or coercion" (http://www.mun.ca/research/researchers/human_subjects2.php#9). This is another reason for excluding the principal researcher from direct contact with residents or substitute decision makers given that his participation may be overtly or covertly perceived by some participants as pressure to participate and "say the right thing."

Competence

Approximately 80% of the people living in institutional long term care in St. John's have some degree of cognitive impairment with most cases being manifested as Alzheimer's Disease or some other form of dementia. During the application process to long term care, people are assessed for orientation to person, place,

and time. People are categorized as competent if they are found to be oriented to these three realms. Residents of nursing homes who are deemed as "competent" based on the application assessment will be invited to participate in this study. It is acknowledged, however, that not all people designated as cognitively well nursing home residents will be able to read, and therefore the letter that accompanies the questionnaire will invite residents to discuss and complete it with other family members if they choose to do so.

Under the guiding ethical principle of *Respect for Justice and Inclusiveness*, Memorial University's Policy on Ethics of Research Involving Human Participants says that researchers have the obligation and responsibility "neither to neglect nor discriminate against individuals and groups who may benefit from advances in research" (http://www.mun.ca/research/researchers/human_subjects1.php). Given the population served by Long Term Care, St. John's, the perspectives of residents with cognitive impairments and their families must be included. In cases where a resident's next-of-kin is contacted about having an interview, the option will be provided to have their relative sit in on and participate in the discussion, despite any cognitive deficits.

Parental or Third Party Consent

Only non-identifying, demographic, and admission transfer data will be collected on residents in institutional settings. Residents of nursing homes who are deemed "incompetent" based on the application assessment referenced above will not be contacted directly about this study. In these cases, the residents designated next-of-kin or substitute decision maker will be invited to participate. Each nursing home has a formal, legal process for identifying a substitute decision maker for residents who are deemed incompetent.

Age of Consent

No one in this study will be below the age of consent.

Free Consent

It will be made clear to potential participants that their participation in the study will not have any positive or negative impact on the person's experience in the nursing home or on the transfer list awaiting a move to the home of their choice. Questionnaires will be sent to all people newly admitted or transferred, or their substitute decision maker (as identified by nursing homes' social workers) for the period of December 2006 up to and including November 2007. The returning of the questionnaire will demonstrate consent. The option to participate in an interview will be presented in the letter introducing the questionnaire.

Classroom Administration of Questionnaires

Classroom administration of questionnaires is a non-applicable issue in this study.

Informed Consent

The purpose of this study will be communicated in writing to potential participants by means of a letter (Appendices I and J) and communicated verbally to all face-to-face participants.

Deception

No form of deception will be used in this study.

Documentation of Informed Consent & Process of Obtaining Consent

Participants who return a completed questionnaire will demonstrate their consent through its completion and return. Participants who will engage in an individual interview will have signed a consent form (Appendix M). Participants who engage in focus groups will demonstrate their consent by attending the session.

Outcome of the Consent Process: Proof of the Participant's Free and Informed Consent

This is discussed in the previous section.

Statements of Information/Consent Forms

Please see Appendix M. This form will contain the text, "The proposal for this research has been approved by the Interdisciplinary Committee on Ethics in Human Research at Memorial University. If you have ethical concerns about the research (such as the way you have been treated or your rights as a participant), you may contact the Chairperson of the ICEHR at icehr@mun.ca or by telephone at 737-8368"
(http://www.mun.ca/research/researchers/guidelines_committee.php#statement).

Consent for Various Aspects of the Study

Informed consent will be collected from all participants using the methods discussed. Participants will understand that they may refuse to engage in any part of the interview, that their decision to withdraw from part of the process will have no negative consequences, and that should they choose to withdraw, any portion of their input can be incorporated into the study's findings with their

permission. This will be explicitly explained prior to the interview's commencement.

Consent Versus Release

Participants will be required to provide consent. Participants will not be required to sign or provide any type of legal release to participate in this study.

Privacy and Confidentiality

Privacy and confidentiality will be ensured through anonymity of participants. This will be accomplished through anonymous questionnaires, focus group summaries that do not name any of the participants or at which institution they work, as well as individual interviews that exclude any identifying information. Only the interviewer will have access to identifying information about interview participants and this information will not be shared with the principal investigator. Instead, taped interviews will not contain the participant's name and notes from interviews that are not recorded will not include any identifying information. Participants will be advised that all data will be kept in a locked filing cabinet in the principal researcher's home office until all reports on findings and scholarly articles have been completed, at which time they will be destroyed.

Limits to Confidentiality

Limits to confidentiality will be explained to participants who engage in individual interviews. There may be instances when confidentiality cannot be protected. Such instances may include (but not be limited to) a report of abuse, a threat to harm oneself or another person, or any other such event as outlined in Section 3 of the Tri-Council Policy Statement (TCPS) guidelines describing "compelling and specifically identified public interests" (http://pre.ethics.gc.ca/english/policystatement/section3.cfm).

It will be acknowledged in the focus-group setting that anonymity is impossible to maintain. Participants will be asked to respect others' opinions and to not discuss the contents of the focus group discussion outside the meeting.

Barriers to Anonymity

One potential barrier to anonymity will be the familiarity of social workers with people who choose to complete an individual interview. The social worker will take time at the beginning of each interview to inform the participant that he or she should feel free to speak openly given that no identifying information from the interview will be shared with the principal investigator.

Conflict of Interest

A potential conflict of interest is the fact that the principal investigator is also the Manager of Placement Services, which is the section of Long Term Care St. John's responsible for the screening and admission of people into nursing homes. The Manager of Placement Services also coordinates the transfer list and is the person whom nursing home social workers contact when they have a vacancy to find out who is next to be referred to that vacancy. Participants may perceive this dual role as too entwined to engage in and facilitate objective discussion on this subject.

In order to address this potential conflict of interest, the principal investigator will not have contact with participants who engage in individual interviews. The interviewers will explain clearly to participants that this study is being conducted to determine the impact of policies on service recipients and that any future discussion on policy direction would do well to be informed by people who use the service.

The principal investigator has no reason to believe that any member of the ICEHR is ineligible to review this application.

Inclusiveness

The only criteria for participation in this study are residency in a nursing home in St. John's or a relationship of substitute decision maker to a resident of a nursing home in St. John's. No individuals will be excluded from this study if they meet one of these criteria.

Aboriginal Peoples

Current admission data indicate that fewer than five (5) residents in long term care are Aboriginal. If a person who is Aboriginal falls into the study sample, the principal investigator will connect with the resident or his or her representative to respect the culture, traditions and knowledge of the Aboriginal group and to examine how the questionnaire and/or interview may be presented or modified to address the needs and concerns of the person as per Section 6 of the TCPS guidelines (http://pre.ethics.gc.ca/english/policystatement/section6.cfm).

Participant Observation

This study will not include participant observation.

Related Documents

Please see the attached appendices.