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Department of Educational Studies  
(Adult Education)  
The University of British Columbia  
Vancouver, Canada

Date Oct 5/95
ABSTRACT

Statistics reveal that only a small percentage of the older population is likely to experience mental incapacity due to illness, disease or accident. Yet, older adults greatly fear such circumstance and the repercussions that may follow — namely a lack of control over decisions about their person and their affairs.

Preplanning for possible incapacity or future need of assistance can relieve such fears and will enhance independence and autonomy should an individual experience temporary, gradual or permanent loss of ability to manage her affairs. Preplanning involves choosing a person or persons to represent one's values and wishes if assistance is needed. Types of assistance may include making decisions about health care treatment, paying bills or signing consent for entering (or leaving) a facility.

Interest in preplanning is growing. This thesis highlights some of the factors influencing this interest. Among them is the implementation and imminent proclamation of British Columbia’s new adult guardianship legislation, specifically the Representation Agreement Act which provides for a comprehensive preplanning tool.

This qualitative study explored older adults’ perceptions of and experiences with preplanning. Individual and group semi-structured interviews were conducted with 12 adults over the age of 65. Although participants comprised a small and non-representative group, their perspectives provided insight into the meaning of preplanning to some older adults and pointed to opportunities for informational and educational initiatives on the topic.
Participants’ experiences indicated that formal and legal procedures to document one’s choices are the final step in preplanning efforts. Yet existing education and information focus exclusively on this aspect of preplanning. Research results identified numerous other, and more important, issues that require attention.

One of the necessary elements for successful preplanning is the existence of trusting, personal relationships. Those who lack such relationships are extremely vulnerable to public guardianship, that is, to becoming a ‘file’ or a ‘case’ among many others in the system. Lack of access to natural sources of support such as a spouse, children or friends, means there is no one to represent the person and her wishes if assistance is needed. The challenge is to connect isolated older adults with individuals and groups in the community and thereby facilitate opportunities for them to develop personal relationships.

This study concludes with the proposal that educational initiatives must include a community development component if preplanning is to be accessible to all older adults. Particular attention is given to the role of community associations, especially those led by older adults, in implementing this approach. Specific recommendations highlight the value of peer counsellors in supporting individual preplanning efforts. Recommendations also call for the need to expand the places and times where education on preplanning occurs including where people seek health services, when people make arrangements for their will or burial/cremation and when people are engaged in retirement planning.
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For Madge Elizabeth (Price) Taylor
CHAPTER I
INTRODUCTION

Many seniors are more afraid of dependency than of death. The thought of dependency conjures up images of being powerless, of becoming a burden on others and of being kept alive by artificial means. Yet some will prepare meticulously for disposal of their property and of their body after death but may hesitate to plan for the weeks, months or even years prior to death. (National Advisory Council on Aging [NACA], 1991, p. 1)

The above comments are excerpted from The National Advisory Council on Aging newsletter, and were written by the guest editor, herself a senior. In her article, she encourages other seniors to preplan as a way to stay in control of their own lives, “to the very end.” The message of the newsletter is that preplanning is a right as well as a responsibility. Suggestions on how to prepare range from evaluating the availability of social support to finding out about provincial laws related to power of attorney and guardianship.

Because aging brings an increasing likelihood of disability and loss of capacities, maintaining independence and autonomy are relevant issues for older adults in particular and society in general. Decisions regarding personal, financial and health matters are made daily as well as during crisis situations. A problem may surface when an adult is no longer able to make these decisions independently and someone else has to assist her or make the decisions for her. When there is no one to do this, or the authority of the person helping is challenged, the public guardianship system takes over. The older adult who is no longer capable then loses control over the choice of who will help her and has

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1 Because English has no third person singular pronoun to refer to individuals of both sexes, this thesis uses ‘she’ and ‘her’ to refer to both.
no voice in the decision-making process. Instead, decisions are made according to others’ perceptions of her ‘best interests,’ not necessarily what she would want. How can older adults prevent this? How can older adults ensure someone they know and trust is responsible for making these decisions and that their wishes will guide how decisions are made?

While incapability may affect anyone at any time, the risk of incapacity due to disease and disability increases with age. Ageism in society also makes older adults vulnerable to loss of decision-making power. All too often, older adults are labelled incapable simply because of their age.

Preplanning is promoted as a tool older adults can use to ensure that control is not compromised or lost, even temporarily, due to incapability. If an adult becomes unable to express her wishes or to make decisions independently, she can enable others to decide or act for her, according to her wishes and values, by preplanning for possible future need of assistance.

Not only is preplanning a way to ensure self-determination in the future but it may also enhance quality of life in the present. Thinking about, discussing with others and implementing plans for one’s future is to be vitally involved in life and living. These activities not only enhance an individual’s sense of purpose, autonomy and dignity, they also benefit her relationships with others who support and value her. For some, preplanning will involve creating these supportive relationships. This requires social as well as personal action.
Preplanning is a social issue. An adult must have the resources to preplan — to arrange for assistance with decision-making if needed. This will involve access to education and information about preplanning, money for legal documentation and a person or persons who can be trusted to speak for her. Being able to preplan with confidence that wishes will be honoured requires that institutions and systems (banks, hospitals, social services, etc.) acknowledge and uphold the principle of self-determination.

Formal future planning mechanisms such as enduring power of attorney and living wills currently provide British Columbians with legal and quasi-legal ways to specify a person or actions to guide decision-making if a person becomes incapable. However, there is no available data concerning who is using the current tools, what triggers their use or how effective they are. In fact there is a lack of research and data about how older adults view or do preplanning of either a formal or informal nature.

Although there is virtually no information about older adults’ experiences with preplanning, most education and information on this topic are directed toward the older population to encourage their use of these formal instruments. The approach of these activities assumes that older adults will use formal preplanning documents if they know how to fill them in or where to get help with completing them. Most programs are initiated by financial institutions, health care facilities, legal professionals and government ministries and are delivered from the perspective of these systems. The need of the system to avoid liability is the driving force behind these programs rather then the need of older adults to be self-determining. The scant research that is available suggests
this approach has limited effect in increasing the use of formal preplanning vehicles among older adults.

As the quote on page one suggests, independence and autonomy are highly prized by older adults, yet actions that seek to maintain these may be infrequently used. Preplanning for possible future need of assistance is proposed as a way of maintaining autonomy and control in the future and perhaps even of enhancing quality of life in the present. But is this the perception or experience of older adults? Understanding the meaning of preplanning to them is necessary prior to developing relevant education or information about it.

With little or no information in this topic area, a qualitative, exploratory study of the phenomenon was in order. Such a study can help identify some of the important issues and questions that may warrant pursuit by other researchers.

The findings of this study will be of interest to older adults and those closest to them (family, friends), seniors’ organizations, community associations, service agencies, businesses and professions that offer services to the older population (particularly in the fields of health, law, retirement planning, adult education), government programs and services directed at older adults and researchers.

Purposes

The purposes of this study were to explore older adults’ experiences with and perceptions of planning for a time when they are no longer able to express their wishes or make decisions independently and to use this information as the basis for developing educational and informational initiatives and policy in this area.
Significance of the Study

This study is significant and timely for a number of reasons. For one, an increasingly greater proportion of the province’s population is older (Gutman, Gee, Bojanowski & Motte, 1995). The increase in the population age 65 and over in British Columbia is substantially greater than for Canada as a whole. Older adults are living longer. The oldest of the older population, those aged 80 and over, are also aging. As will be shown in the next chapter, it is the very old, many of them women, who are most vulnerable to a diagnosis of incapability and likely to require decision-making assistance.

Trends that encourage the use of formal preplanning mechanisms — consumer demand for self-determination, third party concerns of liability, concerns about abuse and rationalization of health care costs — are discussed in more detail later. Technological advances also highlight this issue. People can live longer with the means of artificial support and this creates dilemmas and debates about quality of life versus prolongation of life, about honouring self-determination versus protection from abuse.

This study is also particularly valuable and timely due to the current efforts of the community and government to encourage preplanning as an alternative to public guardianship. Background on these activities is provided in the next chapter and explains how this study offers citizens an opportunity to be part of an organized effort to influence major social policy reform from the perspective of ‘users.’
CHAPTER II
BACKGROUND AND CONTEXT

Clarification of Terms

Choosing a suitable term or definition for the population of this study was problematic. Some adults call themselves ‘seniors’ or ‘senior citizens;’ others firmly reject these terms. Part of the problem is in the definition of ‘senior’ or ‘older adult.’ Mandatory retirement practices and some government benefit programs use age 65 as their criteria, at least in part, for marking a change in social status and implying a transition from middle age to old age. However, many adults age 65 or over do not consider themselves old. Other adults may refer to different criteria, such as becoming a grandparent, to identify a new social role.

The researcher sought a term to use in this paper that did not ‘label’ the research population. Wherever possible, the terms ‘participants’ and ‘individuals’ were used. In certain cases it was necessary to use ‘older adult’ or ‘senior.’ However, the researcher recognizes that these are not neutral words.

Because this study was concerned with the perceptions of the participants, during the research process the researcher took her cues from them. The researcher issued the invitation to participate to ‘older adults’ without defining the term according to specific age or social role criteria. Generally, participants in the study referred to themselves and their peers as seniors.

Although the research topic is preplanning for possible future need of assistance, sometimes only the word preplanning will be used. This is simply for the purposes of
This study focuses on preplanning only in the event of someone being
labelled or at risk of being labelled incapable; it does not deal with preplanning for other
situations such as retirement.

Throughout this paper, reference is made to the terms ‘support’ and ‘assistance.’

With respect to those engaged in preplanning, these terms are best defined by the
individual who employs them. The reader should understand these terms to include a
wide range of activities from the practical — fixing a leaky tap; to the emotional —
giving encouragement, love, comfort; to the physical — feeding and bathing; to the
intellectual or decision-making — consent for treatment, where to live; to the social —
conversation and companionship.

Support and assistance provided by those with whom the individual has a personal
relationship places these activities within the social realm. Kahn (cited in Rosenthal,
1987) defines social support as “interpersonal transactions that include one or more of the
following: the expression of positive affect of one person towards another; the affirmation
or endorsement of another person’s behaviours, perceptions, or expressed views; the
giving of symbolic or material aid to another” (p. 313).

Another term used in this thesis, particularly in later chapters, is the community.
It is employed here to refer to what John McKnight calls “the space in which citizens
associate in their own individual and collective interests” (Cayley, 1994, p. 3). He
differentiates between community and other social structures such as corporations,
universities and government service systems. In another description, McKnight (1987)
provides examples:
[community is] the social place used by family, friends, neighbours, neighbourhood associations, clubs, civic groups, local enterprises, churches, ethnic associations, temples, local unions, local government and local media...this social environment is also described as the informal sector, the unmanaged environments, and the associational sector. (p. 56)

**Autonomy and Need of Assistance**

The terms, 'independence' and 'autonomy,' are often used interchangeably. However, it is important to distinguish between them (Wigdor & Plouffe, 1992).

Independence may be described as the ability to rely on oneself in carrying out life's activities. Autonomy refers to the capacity to make free and authentic choices about one's life. Authentic choices are those that maintain the person's identity, values and dignity.

This differentiation shows that even if a person's activities are restricted and she has to rely on others, autonomy can still be maintained. The person can make free choices concerning her restricted lifestyle and thereby preserve her identity and values.

Some gerontologists believe that for older adults, the real issue is mental competency or decision-making capacity, not autonomy. Mental competence involves both cognitive and functional aspects (Checkland & Silberfeld, 1993). Loss of competence threatens autonomy and independence.

If a person is no longer competent to make or to act on her own decisions, someone else will have to speak for and make decisions about that person. This may seriously undermine the person's autonomy.

Loss of or reduction in decision-making capability can occur due to mental illness, degenerative disease, stroke, head injury or other conditions leading to cognitive
impairment. Decreased decision-making capability can be temporary or permanent. It is usually not an ‘all or nothing’ state. For example, someone can have capacity in one area such as managing daily medications, but need assistance in another area such as giving consent for surgery. In other cases, capability can diminish gradually, over time, as a person’s condition worsens.

There is no definitive test of mental competence or decision-making capability (Checkland & Silberfeld, 1993). It usually becomes an issue when a third party such as a bank manager, health care professional or social worker becomes involved with the individual.

Decision-making capability is really a matter of having access to social resources. If a person has the assistance of others to help her function safely and autonomously, there will likely be no need for a declaration of incapability and therefore no threat to autonomy. As those in the community disability movement suggest, “incompetence, incapability and incapacity are a measure of society’s inability to support an individual, rather than an individual’s limitations” (Etmanski, 1992, p. 2). For this reason, the researcher prefers to refer to an individual’s need of assistance rather than her incapability.

Factors of Aging Related to Need of Assistance

While adults of any age can suffer loss of capability through illness, disease or accident, as a group, older adults may be vulnerable to loss of capacity due to the particular conditions or circumstances of aging. It must be noted that linking need for assistance and aging in this sense is not to suggest that old age is always or inevitably a
state of dependence, decline and incompetence. The approach of this study recognizes the capability and wisdom of older adults. The researcher believes that it is older adults’ perspectives and experiences on preparing for their futures that must form the basis for developing educational and informational initiatives and policy on preplanning.

Following is a brief overview of some mental health and related problems that may affect the older population and may impact on their need of assistance. Given the sources of this information however, capability is determined largely by assessments of decision-making and intellectual abilities rather than actual need of assistance.

The incidence of mental illness is no greater among older adults than among other age groups (Wigdor & Plouffe, 1991). The prevalence of mental disorders generally decreases after age 45 except for organic causes of brain disorder such as dementia (D’Arcy, 1987).

Of persons 65 years and over, about 5% suffer from dementia but of those over 80 years the incidence increases to 25-30% (NACA, 1993). Dementia greatly affects intellectual ability. Alzheimer’s disease is the most common and well-known form of dementia.

Medication can affect cognitive function. More senior women use mood-altering drugs such as minor tranquilizers and sedatives for mental health symptoms, than any other group in Canada (Perodeau, 1991). Many elderly, especially those in facilities, are subjected to excessive or inappropriate use of medication (NACA, 1992). In fact, “illnesses associated with adverse drug reactions account for a significant number of hospital admissions of seniors each year” (Bergob, 1994). Improper use of and
combination of prescription and non-prescription medications by the adult or the
caregiver, lack of personal support and inadequate monitoring by professionals of
potential conflicts from multiple-drug use are among the reasons medications can pose
problems for some older adults.

Depression also affects intellectual function and is more common among older seniors. Approximately 13% of seniors over 85 years living in the community have some degree of depression compared to 30-40% of seniors living in institutions (NACA, 1992). Much of the depression in the elderly is brought on by life circumstances such as the death of a spouse, serious illness or moving into a long-term care facility. Depression under these circumstances is usually a temporary condition but in the elderly it often goes undiagnosed or misdiagnosed and may result in the person being labelled as incompetent (Fales, MacKeracher & Vigoda, 1981).

Physical health is closely related to mental health (Wigdor & Plouffe, 1991). One in three of those 65 and older questioned by the Independence and Aging Survey (Health and Welfare Canada, 1993) reported at least one limitation to their physical activities and the number of limitations increases as one ages. For some, adjustment to these losses may result in depression and grief reaction both of which may interfere temporarily with decision-making ability (NACA, 1992).

Stroke is predominantly a disease of those over 65 years. Death from stroke has declined in recent years but the disease is still an important cause of hospitalization. In many cases, survival is accompanied by depression and a long period of difficult rehabilitation (MacKenzie, 1987). In fact, more older adults are and will be living longer
with chronic physical and deteriorating disabilities than in the past (Simmons-Tropea & Osborn, 1987).

It seems that one of the realities of aging is a decrease in physical abilities and decline in physical health. While physical disability does not mean a decrease in mental or decision-making ability, many physical symptoms that occur with common and treatable conditions are similar to those present with organic brain disorders. Such symptoms are more likely to lead to a diagnosis of mental dysfunction if the adult is perceived as being ‘old’ (Fales, MacKeracher & Vigoda, 1981). If the adult is perceived as young the physical symptoms are more likely treated as acute and physiologically based.

Although the above discussion suggests that older adults risk being judged incapable, it is primarily those 80 years and older and those in institutions who are the most vulnerable to loss of decision-making capacity. And, because the life expectancy of women exceeds that of men (Simmons-Tropea & Osborn, 1987), more women are at risk. Those most vulnerable to loss of decision-making capacity are also often those with limited social resources. Elderly unattached women are among the poorest in Canada and their personal and social relationships are likely few in number and variety or non-existent. Those in institutions are often elderly women who have health problems and no informal supports.

Preplanning for possible future need of assistance offers older adults an opportunity to maintain control in the face of this decline and to put into place now,
assistance for the future. The next section provides background on one of the major social policy responses to this issue — formal preplanning instruments and procedures.

**Formal Preplanning Tools**

In Canada, legislation governing preplanning for possible incapability is a provincial matter. Each province has different means to address these issues. There are two types of preplanning tools: instruction directives and proxy directives. Both are called advance directives because they are made in advance, when an individual is considered capable, to take effect if she needs assistance (and hopefully before being labelled incapable).

Instruction directives designate specific decisions a competent individual wants made if she becomes incompetent (Meslin & Sutherland, 1993). Living wills and advance health care directives are examples of this type.

Proxy directives designate someone else (a proxy) to make decisions if necessary, on one’s behalf. The proxy is usually someone who knows the individual well and who the individual can trust to make decisions that respect her autonomy. Examples include enduring power of attorney and health care proxies.

Advance directives deal with various aspects of an individual’s life or areas of decision-making. Living wills and health care directives cover health care decisions such as artificial life support or resuscitation. Enduring power of attorney covers only financial and legal decisions such as depositing and withdrawing money from the bank. Ulysses agreements are used by people diagnosed with a mental illness to outline their wishes for intervention and choices for treatment and care. Currently, preplanning
options in most provinces are limited and fragmented and this is one reason guardianship reform is taking place in most jurisdictions of Canada (Gordon & Verdun-Jones, 1992).

In British Columbia, living wills, health care directives and Ulysses agreements are used but do not have legal status. Health care institutions and physicians may honour them but there is no law requiring them to do so. Enduring power of attorney has legal status but is limited to financial and legal matters. New legislation was passed in July 1993 to introduce a new instrument called a representation agreement. This proxy directive will cover all areas of decision-making: personal, health, financial and legal.

The purpose of formal preplanning tools is to maintain and ensure respect for an individual’s autonomy in the event she needs assistance. These processes give legal recognition and authority to the individual’s wishes and her chosen proxy.

The following section reviews evidence for older adults’ interest in preplanning and some of the factors influencing that interest, particularly those related to formal procedures. Some evidence is offered regarding the actual use of formal preplanning tools and the effect of educational and informational initiatives to increase their use.

Interest in Preplanning Among Older Adults

Survey and anecdotal evidence suggests that older adults are interested in preplanning. For example, an informal unpublished survey of 150 seniors found that 72% have thought about what they would do if they could no longer care or make decisions for themselves (NACA, 1991). Of those, 40% have considered moving into an old age home. This is a form of preplanning, although it does not involve completing a formal preplanning document.
A survey of 108 providers of legal services in British Columbia (Thornton & MacDougall, 1990) reported that guardianship and preplanning issues are among the types of services elderly clients need and bring to the various agencies. Interest groups such as the Alzheimer’s Society and the Family Caregivers Association, strongly support the availability and use of formal preplanning mechanisms. A four year community-led law reform process included input from older adults and seniors groups and resulted in stronger, more comprehensive legislation on preplanning mechanisms being passed by the British Columbia government.

The above examples provide some evidence of older adults taking initiative around preplanning issues. However, there is little to indicate what is influencing their interest in preplanning and whether or not their experiences with preplanning are meeting their needs.

Factors Influencing the Interest in Preplanning

Traditionally, people relied on family members to help them make decisions or to make decisions for them when necessary. In fact, within families, decision-making was often accepted and practiced as an inter-dependent process. However, changes in family and other social structures and values have influenced the types of solutions used to address the problem and have been factors in promoting the development and use of formal preplanning tools.

For older couples, spouses are most often the primary support although this favours older men more than older women (Rosenthal, 1987). For women, especially
those 50 years and older, widowhood is an expectable life event (Matthews, 1987). Many older women will live out their lives as single people.

The globalization of the economy, changing work structures and disappearing resources are requiring workers to be more mobile. Often traditional sources of support, the family, live too far apart to assist one another. Women, the main caregivers, are entering the paid workforce in increasing numbers by choice and economic need. They may be unavailable to provide support to aging relatives due to lack of proximity, time or energy (Rosenthal, 1987).

Society’s increasing reliance on formal paid services and ‘experts’ has also alienated family members, friends and others in the community from voluntarily assisting one another. According to McKnight (1987), “as institutions gain power, the care of community is replaced by the service of systems” (p. 57).

The unavailability or alienation of the traditional or ‘natural’ sources of assistance necessitates that preplanning draws on other sources of support. However, while the common law tradition recognizes next-of-kin as having an inherent right to make decisions for a relative, support systems made up of friends, neighbours, non-profit organizations, advocates, and others do not have the same status in helping an individual. Formal preplanning mechanisms can be a means to give legal authority to non-family relationships.

At the same time, though, formal mechanisms themselves cannot create these relationships. Yet some older people may not have the resources, awareness or opportunity to develop them on their own. Life circumstances can mean that the older
adult finds herself in a situation that she did not expect, with no family nearby. Women whose career was looking after their husbands and children and the extended family may not have had the experience, the need or the time to establish personal relationships outside the home. She may require help or encouragement to build connections with individuals and groups in the community.

A major force leading the preplanning movement is consumer demand for self-determination. The perspective reflected in traditional public guardianship and legal forms of private guardianship is a paternalistic one that is characterized as ‘doing for’ vulnerable adults and ‘acting in their best interests.’ This means that interests other than those of individual autonomy can be used to justify a decision made on the individual’s behalf. In many cases, the interests of the system and service providers have taken precedence. Today, the public is more aware and demanding of their right to information and control over decisions affecting their lives.

In British Columbia, new legislation to reform public guardianship and promote alternatives to guardianship (such as preplanning mechanisms) was initiated by citizens and voluntary associations. These individuals and groups, including older adults, created new laws and a vision for a new system that is based on a self-determination and an interdependent decision-making model. This community-led law reform initiative is referred to by the B.C. Attorney General, as the most important package of social policy legislation in recent years (C. Gabelmann, at a community event to introduce the new legislation, June 17, 1993). The new legislation replaces the best interests principle with that of self-determination and the notion of ‘doing for’ with the notion of ‘doing with’.
The proposed new formal preplanning mechanism (to replace and expand enduring power of attorney and living wills) is called a representation agreement. It will give legal authority and recognition to an individual’s private wishes and personal trusting relationships.

The individual and groups in the community who led the law know that the opportunities presented by the new legislation will not be accessible to those who do not have anyone to be a representative. Therefore they have made it their mission to encourage the development and nurturing of personal relationships for people who are isolated or marginalized so they may have someone in their lives (other than those who are paid) to represent them if needed. The community’s vision and activities related to alternatives to guardianship continue to influence the implementation of the new laws and reform of the current system. This study has direct application to this endeavour.

Other forces influencing promotion of formalized preplanning to the older population include: third party fears of liability; concerns of abuse; and the rationalizing of health care costs.

Family, friends, neighbours and others with whom an individual has a personal relationship usually provide the most effective and least intrusive forms of assistance and support to an individual. However when a third party (financial institution, health care or social service agency, legal professional, etc.) becomes involved, there is pressure to provide evidence that this support is formally and legally sanctioned. This pressure results from the fears of third parties about their liability. They fear reprisal if they act on the instruction of someone other than the individual, even when the individual appears in
need of assistance (personal communication K. Cunningham of Royal Trust & H. McLellan of the Canadian Bar Association, at Representation Agreement Task Group Meeting, November 1993). Whether or not this fear would be upheld by the court is difficult to tell, but the fear is strongly promoted through the ranks so that third parties are reluctant to go against the policy. Insistence upon documented proof of someone's authority to assist another with decision-making has created a need for formal preplanning tools with legal status.

Concerns about abuse of vulnerable adults, including older adults, is also a factor in the promotion of formal preplanning procedures by government and professionals (Meslin & Sutherland, 1993). The public's growing awareness of and fear of abuse puts pressure on the government to respond. However, once again, issues of liability means the response focuses on the informal sources of support having to prove they are acting on the bidding of the individual. Legal documents such as the formal preplanning mechanisms give proof of this authority and allow for legal interventions in the case of abuse (McKenzie, 1992).

Some suggest that the promotion of formal preplanning is a way to generate health care cost savings (Meslin & Sutherland, 1993). Tools such as living wills are often interpreted and promoted as a way to express wishes regarding non-treatment. Non-treatment would reduce costs of the health care system. When these instruments are promoted by the health care or other government-funded system, this creates a conflict of interest and may jeopardize individual self-determination.
The interest in and demand for preplanning, particularly legally-sanctioned procedures, comes from both ‘users’ and the formal service system. The following provides some background on the actual use of formal mechanisms by older adults.

Use of Formal Preplanning Tools by Older Adults

Unfortunately, data on the actual use of formal preplanning instruments are scarce, or non-existent, particularly in Canada. This is partly due to the fact that living wills are not supported by legislation in Canada and are promoted through informal channels. The enduring power of attorney, though legal, does not have to be registered or drawn up by a legal professional so it is difficult if not impossible to determine how many have been completed or implemented.

The reader should regard any research findings reported in this area with caution. There are very few studies available and these focus only on very traditional forms of preplanning that have been developed largely by legal and professional interests.

Information on the use of formal preplanning tools by British Columbians comes from a recent study (Spencer, 1995) which found that about 13% of 200 seniors surveyed had designated an enduring power of attorney. The results showed that more men than women had used this financial preplanning instrument and that use was related to advancing age and socioeconomic status. The older the person and the higher the financial status, the more likely such a document is completed.

Research in the United States looks only at preplanning tools for health care. By the end of 1992, 50 states had living wills statutes. A review of studies conducted on the use of living wills found that only a minority of people fill them out (High & Turner,
Usage rates ranged from 4% to 20%. The review also concluded that the rates of use among elderly persons is no higher than for the population in general. Yet these same studies report that the majority of respondents express positive attitudes toward such preplanning vehicles.

There is an apparent discrepancy between the number of older adults interested in and supportive of legislation concerning preplanning tools versus the number who actually use them. This led some researchers to explore the effectiveness of educational interventions to increase use of available preplanning options.

**Educational Interventions to Increase the Use of Formal Preplanning Tools**

Education and information about preplanning has focused on increasing the use of formal and legal mechanisms. Little data are available and most come from the United States.

The United States Patient Self-Determination Act, a federal law, took effect in December, 1991, and makes educational interventions a legal requirement of health care services in order to promote the use of preplanning mechanisms (Lynn & Teno, 1993). The Act authorizes the health care system to educate and inform the public but does not provide guidelines on how this is to be done. Unfortunately there are no data as yet to determine the impact of this specific legislation. However, some researchers express concern that making the health care system responsible for education may compromise patient self-determination (Sabatino, 1993).

British Columbia has a wide variety of public legal information and education resources on preplanning alternatives, many are targeted specifically to older adults and
many are free. These resources are produced by non-profit, for-profit and government institutions. As well, most lawyers and notaries provide information and counselling on preplanning alternatives to clients who ask about them. Unlike the United States, B.C. has no legislation requiring that the public be informed or educated about preplanning tools.

No research has been conducted in B.C. to determine the effectiveness of interventions provided by public legal education initiatives or legal professionals. Nor is there any information on how many people in the province are aware of these resources. The interventions themselves focus on the legal requirements for preparing a preplanning document. They are generally more concerned with describing and explaining preplanning from the systems' (financial, health care and legal systems) viewpoints than the perspective of the individual who wants to make plans because of a particular life circumstance.

Some U.S. research, unrelated to the Patient Self-Determination Act, suggests that educational interventions may be minimally effective in increasing the use of formal preplanning mechanisms. At least three studies (cited in Lynn & Teno, 1993) have attempted to enhance the use of legalized living wills through education. One study of outpatients, with a control group, found an intervention using an educational booklet and physician-initiated discussion, resulted in only eight of 52 patients preparing a living will. Another randomized controlled trial of an educational intervention in a geriatric setting found that 85 percent of patients did not complete a living will. However, a study conducted in a home care setting reported that 48 of the 74 homebound patients who were
counselled implemented a living will. The results of these studies are inconclusive as the
detail provided is insufficient to allow comparison of the different interventions or
settings. As well, the studies were undertaken on the assumption that living wills were
perceived as effective and useful to the participants.

In a larger and more comprehensive study, High (1993) tested various educational
interventions with participants from a variety of settings. He also sought to discover the
reasons older adults (65 years and older) offered for completing or not completing
preplanning tools for health care. The study reported on 293 participants from three
different sources: seniors housing units; a volunteer pool at the University of Kentucky
Center on Aging; and the University geriatric outpatient clinic. The control group
received no intervention; the remaining participants were distributed among six different
intervention strategies. The interventions were characterized as minimum, moderate and
maximum. Each level of intervention received a different type of educational material.
Three of the six groups received educational materials only, the other three groups
received educational materials plus an invitation to attend a meeting. At the meeting, a
lawyer and notary public were available for free advice and assistance on completing
formal preplanning tools, as requested by the participants. Comparison of the six
intervention and control groups found that only the moderate materials with meeting
intervention produced a statistically significant increase in use, from 25% to 50% for
mechanisms that give instructions for decision-making (instruction directives) and from
14% to 30% that appoint a person to make decisions (proxy directives).
The reasons given by participants for completing the instruction directives included (in order of frequency): not wanting to burden their family; not wanting to be kept on artificial life support; and not wanting to suffer. The reasons for completing a proxy directive included: needing someone to make decisions when they become incapable; it was the smart thing to do; and wanting to make sure things were taken care of. The most frequently designated proxy was an adult child (or children) followed by a spouse.

The reasons offered for not completing either type of directive were: meant to but haven’t; and others will take care of it if the time comes. It’s interesting to note that these reasons came from the youngest respondents who were in good health and living with their spouse. High (1993) speculates that participants defer action because their present perceived states of affairs do not imminently require preplanning directives and there is considerable confidence that they can rely on others, especially family members.

High concludes that an educational intervention can significantly increase knowledge of and familiarity with advance directives but not necessarily their actual use. However, the interventions in this study and others share the same approach to education as the interventions currently promoted to older adults in British Columbia. The needs are defined by the system not by the consumer, the older adult. The system assumes that older adults do not use preplanning directives because they lack the knowledge of how to make them. This assumption is proving to be true for only a few older adults. In fact, it may be that the system is the problem: “the needs of committees, agencies and
administration have taken priority over the needs of old people. In this way the supposed solutions have become part of the problem” (Marshall, 1987, p. 27).

It seems that little is known about what factors influence the use of preplanning options by older adults. The limited empirical data from United States sources described above do not necessarily hold true for older adults in Canada. The approach to health services in each country is fundamentally different and this may influence the use of formal preplanning tools by older adults. As well, most educational interventions originate from the needs of the system and are designed and delivered by those within the system. This may not serve the rights or the needs of older adults, especially if they are in some way dependent on that system. Of particular significance is the fact that all interventions on preplanning for possible future need of assistance focus only on formal and legal tools.

As suggested by the B.C. community-led law reform project and the proposed new legislation, formal preplanning tools alone may be insufficient for many preplanning efforts. It will also be important to facilitate opportunities for those who are isolated and marginalized to develop personal relationships with other citizens in the community. This will require a different emphasis on education and information related to preplanning for possible future need of assistance.

This thesis proposes that the perspective of older adults in the community is necessary for determining the focus and content of such education and its delivery. As Dorothy Marshall (1987), a 75 year old community activist and author, says:
...new insight could help us to understand how to bear and share with others the loss of old friends and the making of new ones, how to prepare ourselves and our families and friends for the inevitable death...we, the old ones, with all our experience and knowledge must be prime movers in this (p. 99).

Thornton (1986) states that life-span education “must help individuals and groups of individuals to become self-constructing architects of their own futures” (p. 85). If preplanning offers such means, that is to enable older adults to be and stay in control of their lives, then their participation in educational efforts is necessary. But, “it is not enough simply to democratize access to existing information...[but to also consider]...what knowledge is produced, by whom, for whose interests and toward what ends” (Park, 1993, p. 40). This philosophy provides the context for the proposed study.

**Context for and Applications of the Research Study**

Education and social policy related to preplanning described in this thesis contrasts two approaches. The dominant one sees that the needs of the system are met. This may be described as a ‘top down’ approach. In adult education terms this is characterized as education from above (Jarvis, 1985). In the top down model, education is functional to the social system and the individual is shaped through education to fit into the dominant order in society.

The other approach, and the one proposed by this study, grows out of the experiences of individuals and community groups with law reform. It wants to meet the needs of the ‘users’; it starts from the bottom, with the experiences of those who are vulnerable to guardianship. This approach is most closely associated with ‘radical adult education’ philosophy espoused by Freire and others. This approach says that people have the capacity to transform their social situation. A research method that corresponds
to this philosophy will allow this study to challenge and potentially transform the existing knowledge base (and practice?) on preplanning for possible future need of assistance.

For example, in order for the new guardianship package to be a significant reform of social policy legislation, as the B.C. Attorney General hopes, the implementation of the new laws and the policies and structures that will support them must represent a shift away from the top down approach. Otherwise, the power remains with the system, not the citizens they are meant to serve. Given that the legislative package is concerned with honouring and promoting self-determination (Ministry of Attorney General, 1993) the traditional top down approach would be a contradiction of and failure to achieve reform. The crucial question is: Whose knowledge will drive this implementation process?

According to this thesis, it is the experiences of those who are affected by the system and policy who must create the new order; in particular they must determine the process, content and delivery of education and the development of policies related to preplanning for possible future need of assistance that are directed at them.

The impetus for this study arises out of the researcher’s activities as volunteer chair of the Community Coalition for the Implementation of Adult Guardianship Legislation Representation Agreement Task Group and as Director of Publications at People’s Law School. This study has application for both endeavours.

The Coalition is community-based and is made up of individuals and groups that have re-organized, following the law reform process, to create and promote alternatives to formal and public guardianship. Part of the Coalition’s efforts is also to ensure a ‘consumer-driven process’ for the implementation of the new legislation, particularly the
comprehensive preplanning tool called representation agreements. Through the Coalition, older adults have identified themselves as important users of representation agreements. Other constituencies include people with disabilities and people with chronic or terminal illness.

The Coalition's Representation Agreement Task Group (RATG) conducted workshops with individuals in the target groups to discuss policy and community development issues related to making preplanning accessible to those who want to do it. Some of the information gathered at the workshops came from older adults and provided background to this study.

The People's Law School operates in a different structure from the Coalition. It has recently emphasized its' role and mandate as a deliverer of public legal education from a community-based (versus systems-based) perspective. However, operationalizing this concept in a centralized, government funded, hierarchically structured non-profit organization is a challenge. A recent evaluation of the People's Law School publication program recommended working more closely with those in various communities (for example, persons with AIDS, the poor, seniors, new immigrants, women, etc.) in developing and producing titles. However, individuals and groups within these communities are expressing reluctance with being advisors or consultants to projects or ventures where their experiences become someone else's knowledge and power. They want, at least, to be partners. The results of this study may provide a model for developing legal educational/informational initiatives and policy from the bottom up in a top down structure.
CHAPTER III

METHODOLOGY

Choosing a Methodology

In choosing a methodology, the researcher considered the purposes and context of the study. For example, the focus of this study was on the 'insiders' view — how older adults, themselves, understand, experience and view preplanning.

Since the area of exploration in this study deals with issues related to autonomy and self-determination in decision-making, the researcher wanted to ensure participants had some direct say in the process and outcomes of the study not only through the information they provided, but also in how that information was interpreted and reported. Croft and Beresford (1990) refer to this as democratizing the standard practice of the researcher exercising unilateral control over the research process. They suggest that giving more control to participants is especially relevant for research in the social service sector. For other researchers, adopting a more democratic approach to research with older adults is an ethical issue and may no longer be avoidable due to criticisms expressed by older adults themselves (Burnside, 1988).

According to these researchers, the research design must allow participants power and influence over how the information/data they provide are analyzed and used. This is done by providing opportunities in the research process for participants to confirm or deny the researcher's interpretation of the participants' information. Also important is to make sure the reported results and recommendations are presented in a format that is accessible to participants and the public to use for their own purposes.
Choice of methodology is also influenced by the 'state of the research' on the topic. The background section of this paper revealed the lack of data on this issue, especially from an 'insiders' view. Much more needs to be understood in a general way about the concept of preplanning and its meaning to older adults in order to design more specific and large-scale investigations.

The context within which the study takes place is another factor influencing research design. This study took place during a period when social movements were influencing the reform of adult guardianship laws and practices throughout Canada and the Western world. The Community Coalition is a provincial initiative for social reform on behalf of those vulnerable to guardianship and is guided by principles that have shaped the milieu in which this study occurred. These principles advocate a consumer-driven process, respect for individual autonomy, the development of policies and procedures from the ground up, doing 'with' instead of doing 'for' and ensuring all products and processes are accessible.

Given the above discussion, the methodology chosen for this study had to be one that valued the experiences and expertise of participants, provided opportunities for participants to become 'colleagues in... [the] research' (Burnside, 1988, p. 205), addressed the exploratory nature of this study, and developed interpretation and analysis of information from the bottom up. Qualitative research as a philosophy and a methodology offered a framework within which these goals could be achieved. The study also drew on strategies used in participatory research as it is described and practiced in the field of adult education.
A qualitative approach is equated with exploratory and discovery research and the term is typically applied as the 'catch-all' for alternatives to traditional experimental or correlational research (McMillan & Schumacher, 1989). This research method and philosophy is concerned with understanding social phenomenon from the participant's reality or perspective. The researcher becomes part of and interacts with the phenomenon being studied. Qualitative researchers use an emergent design whereby they begin with a tentative plan regarding who to talk to and some questions to explore but subsequent activities and strategies emerge during the study and are shaped by information gleaned from previous activities. Because the qualitative approach allows for multiple constructions of reality, subjectivity is a strength and is taken into account in the analysis and interpretation of data.

Qualitative research methodology recognizes the influence of social context on people's actions. By concentrating on the social context, the researcher develops context-bound generalizations. While generalizations are limited to the specific and unique context, the understandings gained in the study of that context may be extended to other contexts.

Ethnography is synonymous with qualitative research. Some also use the term to refer to a type of data collection strategy. Ethnography is interactive research requiring the researcher to spend time in the field to observe, interview and record processes. “An ethnographer seeks to understand people’s constructions — their thoughts and meanings, feelings, beliefs and actions as they occur in their natural context” (McMillan &
Schumacher, 1989, p. 387). The researcher’s involvement in the Community Coalition and the People’s Law School provided her with considerable ‘field’ experience.

The philosophy and approach of ‘participatory research as practiced in adult education’, also informed the design. As an alternative to traditional research, this model of participatory research falls within the qualitative paradigm. The advent of participatory research in adult education is relatively recent and was the result of two forces. One force was a reaction against traditional research methodologies and a search for alternative approaches that made sense in the ‘real world’. Professional researchers working in developing countries became dissatisfied with the quantitative, positivist approach — that is, with applying the methods of natural science to understanding and controlling human behaviour (Hall, 1975). These researchers believed that social systems had to change in order to achieve social justice and equality for all people.

The other force that promoted participatory research came from the successes of oppressed people in Africa, Latin America and other third world nations in creating change for their own benefit. The term participatory research was first used in the early 1970s in a community research project in Tanzania (Hall, 1981). Since then, participatory research continues to be refined by researchers/practitioners in developed and developing nations. The participatory research project of the International Council for Adult Education was located in Toronto in 1977 and became the North American node of an international participatory research network (Hall, 1993).

Participatory research operates on the belief that knowledge is power and that the knowledge gained through research should empower the participants — people in the
community — not the researcher, the research institution or other interests. Participatory researchers believe that for people in the community to gain this power they must be deliberately and actively involved in the research. This is the essence of participatory research. Participatory research puts ownership and control of the entire research process (the generation of knowledge, its interpretation and its utilization) in the hands of the people (Tandon, 1981).

Another key feature of participatory research is the linking of research and the knowledge it generates to social action and social change. Social action is one of the goals of participatory research. Participatory research also stresses collaborative processes: critical and collective analysis leading to collective action.

Aspects of the Community Coalition work on representation agreements, of which this study is an extension, is rooted in a participatory research philosophy and approach. Due to limited time and university requirements, this particular study did not undertake participatory research as practiced in adult education. However, out of respect for the origin and context of this study and to enable the findings to lead to meaningful action, this research design incorporated an essential element of participatory research by involving participants at key points in the research process. As much as possible, the researcher wanted participants to feel the knowledge generated in this study belonged to them and that the research process was a joint learning venture.

The term 'participant' rather than 'subject,' 'informant' or 'respondent' was used in this study because it recognizes the active and interactive role of those recruited. Participant is also a term from everyday usage and is familiar to the general public.
Likewise, the word ‘information’ was preferred to the term ‘data’ as it better reflects popular and plain language usage and captures the emphasis in qualitative/ethnographic research on words and description rather than numbers and statistics.

Research Questions

Consistent with the chosen methodology, research questions were expected to emerge and be clarified through the conversations with participants about their experiences. However, the researcher’s immersion in the work of the Community Coalition over a nine month period and a review of the literature suggested some specific areas for initial exploration. These included: what does preplanning for possible future need of assistance mean to these participants; do these older adults plan for possible future need of assistance and, if they do, how do they go about it; do they know about and use formal preplanning tools; do they plan for all areas of decision-making (financial, health, personal, legal); do they plan for maintaining personal and social relationships; what triggers them to preplan; where do they get information and resources about preplanning; what helps with preplanning or makes it difficult; what things have they learned and wish they had information or education about.

The above research questions deal with content, but process was also part of the context. Questions that may be answered by the methodology included: what are these older adults’ preferences for discussing this issue with others — do they prefer to discuss it with other older adults or not; do they learn from one another and does this change their view; what areas of discussion are easier or more difficult.
In its design, the current study followed guidelines for conducting ethnographic interviews (as a strategy for collecting information from participants) and referred to some of the procedures of qualitative inductive analysis (as a strategy for analyzing the information). Semi-structured individual and group interviews were the primary information-gathering tool. The research plan was set out in five stages or phases: 1) planning and preparing for the interviews; 2) gathering the information; 3) organizing the information; 4) analyzing the information; and 5) reporting and presenting the information. Discussion on the strategies and tasks associated with each of these stages follows.

Planning and Preparing for the Interviews

Following acceptance of the research proposal by members of the thesis committee, an application was made to the UBC ethics review committee. The proposal was approved by the ethics committee as submitted. Then began the task of preparing for the interviews. This involved recruiting participants, making logistical arrangements and preparing the interview format. Each of these activities are discussed under separate headings.

Recruiting Participants

The researcher used a specific type of purposeful sampling to recruit participants for this study. Purposeful sampling is employed in qualitative research where the purpose of the research is to gain insights and a deeper understanding about an issue rather than to generalize the findings. In this type of sampling, the researcher seeks "information-rich key informants, groups, places or events to study" (McMillan &
Network sampling is a specific form of purposeful sampling. It is also called snowball sampling. The researcher and participants use their networks to recruit and suggest others who fit the participant profile/criteria of the study.

Because the current study was concerned with exploring in depth the experiences and perceptions of older adults with respect to preplanning for possible future need of assistance, the researcher concentrated on recruiting those who were interested in the topic and were willing to talk about it. This is what makes the participants 'information-rich key informants.'

This study did not attempt to recruit a representative sample of older adults from any particular community. For example, this study did not target older adults who are from cultural minority or First Nations communities, who have disabilities or who live in facilities. Therefore it was anticipated that the majority of participants would be white, Canadian or European born, middle class, less than 75 years of age, high school educated or more, healthy and mobile. These characteristics do describe the participants for the most part except that some were older than 75 years and some had problems with health and mobility. A profile of participants is given in the following chapter which reports the interview results.

Because those invited to take part in this study had an interest in preplanning, the researcher expected that they had undertaken some specific preplanning activities. All participants were aware of the issues and had engaged in preplanning to varying degrees. Again, this is discussed in more detail in the next chapter.
As mentioned earlier, the participants defined themselves as ‘older’ adults. The researcher did not impose any specific criteria. However, if asked, the researcher was willing to engage the potential participant in discussion about the various criteria (age, social role, functional ability) that are often used to define older adult or senior and the participant’s perception and preference. The choice remained with the individual participant. One potential participant who declined to take part in the study gave her reasons as “I’m too busy and I don’t think I fit what you are looking for — older adults.” The individual’s name was suggested by another participant (also her neighbour). The researcher discussed the meaning of the term with the potential participant; her view was that this term and the term senior referred to someone older than herself (although she did not give her age).

The researcher began recruitment by asking older adults (those who had publicly identified themselves as seniors or older), who were members of the Coalition or who had attended the RATG forums, if they wanted to participate. They were then invited to suggest others who the researcher could contact. The researcher attempted to recruit a maximum of 15 or a minimum of 12 participants for the first stage of interviews.

The researcher recruited five participants through her relationships with members of the Community Coalition, two others from her connections with individuals through People’s Law School activities, two more were referred by a former UBC student and friend and three individuals were referred by one recruited participant. This made a total of 12 participants. Four potential participants declined due to time constraints; one of the four also said she did not fit the criteria (as discussed in a previous paragraph).
The researcher planned to recruit a minimum of five participants for interviews during the other research stages (organizing the information, analyzing the information and reporting the information). These five participants (a minimum number) could be individuals from the first interview/discussion session or recruited as needed. It did not prove necessary to recruit additional participants.

The researcher contacted some potential participants in person. These potential participants were given a letter introducing the researcher (see Appendix A), a description of the research (see Appendix B) and a consent form (see Appendix C) to take home. The researcher then followed up by phone to answer questions and ascertain their interest in participating.

Those individuals referred by others were contacted initially by the person who suggested their names were then contacted by the researcher by telephone. The researcher believed it was appropriate to make initial contact in person (as described in the previous paragraph) or by telephone because she was either contacting someone she knew from a workshop or a meeting or she was following up on a specific referral. Sending a letter as initial contact in these situations may have been perceived as formal and impersonal. The telephone contact following referral was a courtesy and was only to establish willingness on the part of the individual to receive the introduction letter, the description of the research and the consent form. A week after mailing the information, the researcher followed up with a second telephone call to confirm the individual’s interest in being involved in the study.
Although the researcher recruited individuals she knew personally, she stressed that they were not obligated to take part and there would be no ramifications if they refused. The networks of the Community Coalition and the People’s Law School are wide-spread and fluid enough that if the researcher was perceived to be pressuring people to become involved, she would risk not only jeopardizing this study but also her credibility in the community and at the workplace.

Each person who participated signed a consent form. Before the consent was signed, the researcher explained the purposes of the research, how they were connected to the work of the Coalition and The People’s Law School, how confidentiality would be protected and the research plan.

When participants agreed to participate they were asked if they wanted to take part in an individual interview or in a small group discussion (with a minimum of five and a maximum of eight participants per group). Offering an option to participants was an attempt to address issues of accessibility, availability and individual preference. The choice of individual interview or group discussion was also thought to provide information about how participants preferred to discuss the topic.

Most participants did not have a preference for either the individual or group format, however, many opted for the individual interview because of busy schedules. Because the researcher wanted to have at least one group interview experience in the initial stage of the study, she specifically asked four participants who lived in close proximity to one another or who knew each other if they were willing to attend a group
interview. All indicated they would enjoy it and one of the participants offered his home as the location.

**Logistical Arrangements for the Interviews**

The interviews took place at locations and times convenient to the participants. The researcher stated that she had access to a meeting room in a downtown location or was able to meet in the participant’s home. Through her contacts, the researcher expected to be able to arrange free meeting space with local non-profit organizations if it was needed.

Interviews were conducted with participants during December 1994 and January and February, 1995. All interviews, except one, took place in participants’ homes (in one case, home was a room in a private care facility). The other interview was conducted after a meeting at a non-profit organization. Participants were very generous with their time and expertise. Interviews ranged from one hour to two hours. Most participants also made it a social occasion by serving refreshments. Many of them set aside time for an informal visit following the interview. They all invited the researcher to make contact if more information was needed and they expressed interest in hearing the results.

In ethnographic interviewing, audio tape recording of interviews is invaluable for obtaining verbatim accounts of the conversations. For the current study, participants were asked to give their permission for audio taping the interview/discussion. Each participant agreed and assisted in making sure the microphone was set up in a good location. There were no mishaps with the audio-taping. The researcher advises taking an extension cord and batteries as back-up to the interviews.
The researcher tried to schedule the interviews with a few days between each one so she could review her notes and the transcripts from the previous session(s) and make changes for the next one. This was not always possible; some interviews took place on consecutive days.

**Preparing the Format of the Interviews**

In ethnographic interviews, questions are framed in an open-ended format to avoid yes/no or short phrase responses. The interviews/discussions conducted in this study concentrated on information about participants’ experiences, values and knowledge. Demographic information was not formally solicited but gathered incidentally during the discussion.

The researcher drew on information gathered through discussions and questions from the community workshops conducted by the RATG when making up the interview guide (see Appendix D) for this study. She also sought assistance from the thesis committee with developing suitable open-ended questions.

As is typical of qualitative interviews, the interviews and discussions with participants adopted a conversational tone and were conducted in an semi-structured format. The conversations were guided by the prepared list of general questions and probes as outlined in the interview guide. The researcher determined the sequence and modified the language during the interview according to the situation and the interest and knowledge of the participant. The format was flexible to allow the researcher to follow up on hunches and new ideas that developed during the session.
The individual interviews or the small group discussion included conversation about the research process. This ensured participants were informed about upcoming activities and opportunities for input. They could then decide on their involvement in the next stage(s).

Gathering the Information

In some respects, information is generated by participants during all stages of the research. Even initial contact during recruitment provides information. The particular stage discussed here, however, generated the bulk of the information reported in the results, analysis and recommendations.

This stage began with the researcher conducting the first scheduled individual interview. The session started with a brief introduction that covered the following: the purposes of the study; how the study links to community action and practice (the Community Coalition and The People's Law School); issues related to confidentiality and the format of and time frame for the interview/discussion. Special attention was given to obtaining permission to audio tape the conversation. The participant was told that a volunteer may assist in transcription of the tapes but that confidentiality was protected and only first names (or a pseudonym if preferred) should be used during the interview. Participants were not concerned about using their own name. In some cases when talking about other people and specific cases, they instructed the researcher to turn off the tape. The researcher did so and also refrained from taking any notes during these times.
Although audio taping was critical for capturing participants’ comments verbatim, the researcher took some notes to capture nonverbal communication or points to follow up on. The researcher let participants know that she would take notes during the conversation.

In the case of the small group discussion, the researcher also briefly outlined the ‘rules for discussion,’ for example: all comments are respected (no put downs); everyone has an opportunity to participate (share the spotlight); one person speaks at a time. As it happened, one participant in the group interview actively assisted in facilitating the discussion by drawing out those not heard from and by censoring himself when he had already made a number of contributions to the discussion.

Focus group interviews are a variation on the ethnographic interview. Participants meet together in a small group to focus on and discuss a particular issue. They may or may not know each other. Focus groups create a social environment whereby group members may be stimulated by others’ opinions, ideas and experiences. The information gained in this form of interview can be rich and diverse and more efficiently obtained than by conducting numerous individual interviews. The interchange among participants provides information as valuable as the content of the discussion. This proved true in the current study and is reported in the following chapter called Results.

The researcher began both the individual and the group interviews with prepared, open-ended questions. The researcher facilitated the conversation and took notes. In the interview, the researcher’s role was to facilitate the discussion. It was important to create a safe, open, respectful, affirming climate where participants’ experiences were valued
and accepted. In ethnography, establishing rapport is a critical first step prior to asking prepared questions.

The researcher as facilitator was both directive and non-directive during the interviews, depending on the situation. A directive approach was sometimes necessary at the beginning to give focus to the conversation and to help the participant become comfortable with the format and with the researcher. The researcher also had to take a more directive approach in order to keep the conversation focused on preplanning for possible assistance because participants often wanted to discuss, in detail, their plans for after death (for example, their will, organ donation, burial arrangements). The researcher tried to always be aware of her power in her relationship to the participants. Even a facilitative role is an influential one.

Before the allotted time was up, (for individual interviews this was at 15 minutes left, for the group discussion at 20 minutes left) the researcher summarized the conversation and the key points that were raised. She asked the participant if this summary was accurate and if there were any additions or corrections. She also reviewed the next steps in the research process and invited the participant to indicate if her interest in future involvement including a group session to affirm the results. The researcher also asked for names of potential participants she could contact. All participants were eager to be informed of the results.

Immediately following the interview (the same day if possible) the researcher reviewed her notes and reflected on the format of the interview and the information gathered. She noted questions and ideas to explore in future interviews. Ethnographers
prescribe the content of this step as "self-reflections on ...[the interviewer's] role and rapport, interviewee's reactions, additional information and extensions of the interview" (McMillan & Schumacher, 1989, p. 411). One or two days following the interview/discussion, the researcher sent a written thank you note to the participant and referred to opportunities for future involvement (as volunteered by the participant at the interview).

The researcher prepared for the next scheduled interview/discussion by making any necessary revisions or adjustments. Most of the changes were made to the introduction and explanation portion of the interview schedule. Reflection on the format of the first interview led the researcher to be more specific about the focus of the discussion and to give examples of what was meant by preplanning for possible future need of assistance. The researcher's introduction became clearer with each subsequent interview, based on the responses of previous interviewees. This saved having to re-orient participants during the interview.

Some topics were added to the interview guide as information was generated. They included: Who do you think should do preplanning? Is it for everyone? How do we encourage others to do it? Do you have experiences of helping someone else plan or of being part of their plan? For example, did you provide assistance to someone else because they could not manage to do something? What kind of assistance did you give?

Organizing the Information

Organizing the information was seen as the first step in the analysis of the information. In ethnography, data analysis is an inductive process whereby "patterns,
themes and categories of analysis emerge from the data" (McMillan & Schumacher, 1989, p. 415).

All interviews were transcribed. A friend of the researcher assisted with typing transcripts of some of the audio tapes. The tapes and transcripts used participants first names. Only the researcher had specific identifying information about the participants. Issues of confidentiality were discussed with the volunteer. The volunteer was a fellow student in the UBC joint adult education/counselling psychology masters program. The volunteer did not transcribe the interviews of anyone known to her.

Prior to spending considerable time and effort on in-depth analysis, the researcher wanted to first apply a basic and rough organization to the information and then to share this 'whole picture' with participants and get their input on what seems important, what looks out of place and so on. It was anticipated that specific details on organizing the information and how to discuss it with participants would emerge as the researcher interacted with the topic and the participants.

It was apparent, even in setting up the initial interviews, that the research plan would have to be revised regarding the number of times participants would meet to verify the information. Everyone had extremely busy schedules and setting up group interviews was going to be difficult. Also, everyone indicated an interest. Getting 12 people together, even in two groups, would require significant time to coordinate. As well, the researcher would have considerable more information to transcribe, prioritize, organize and analyze.
It was also clear that without a direct action component to this study, participants did not feel the same sense of ownership and commitment that members of the RATG did toward their research project. As well, the organizing of information is tedious work and does not challenge the imagination or interest of participants. The researcher, on advice from her thesis committee, revised the research plan to provide an opportunity for a second interview with participants only after the information was organized and analyzed and before recommendations and this report were finalized.

The first step in the preliminary analysis of the information was to ensure all information generated was coded and could be referred back to the context and individual source. The researcher made extra copies of the transcripts and using a ‘cut and paste method,’ grouped and organized participants’ comments by similarity. Participants’ words or phrases were kept intact to support the groupings. The researcher organized comments under various headings. Many of the headings used came from the interview questions, such as what preplanning have you undertaken, what triggers people to do preplanning, how did you learn about preplanning. Some themes also emerged from the comments themselves and reflect the participants’ own perspectives on the topic. For example comments about how and who an individual chooses to assist with decision-making emerged as an important factor to consider when making preplanning arrangements.

The researcher suspended analysis of the information and concentrated on organizing and presenting the participants’ view. The Results Chapter which follows quotes extensively from participants’ own words to support the organization imposed by
the researcher. That chapter was reviewed by thesis committee members for format and clarity prior to analysis of the information.

Analyzing the Information

The period of review and reflection during the analysis stage took considerable time. The original and entire transcripts were re-read and portions of some of the audiotapes were reviewed. The information was sorted and re-sorted as the researcher looked for patterns and themes. Notes were kept on potential themes that emerged from comparing similarities and differences. Titles were given to the themes or categories. As well, during the organizing and analyzing of the information, the researcher critically examined her role and influence to ensure the information from participants was treated in a respectful and non-judgemental way.

The analysis chapter focused on the implications of the interview results for educational and informational initiatives. The chapter was presented to thesis committee members for discussion and guidance. The researcher then worked on the final chapter which includes specific recommendations. Many of these were implicit in the analysis chapter and now had to be made explicit.

Following completion of the final draft, the researcher contacted participants by letter (see Appendix E) to invite them to a group interview to discuss the research results and recommendations. A brief summary of the results (see Appendix F) was sent with the letter. The researcher followed up a week later with a phone call. All but one participant was interested in getting together.
A meeting was scheduled in Burnaby on a Friday afternoon at the home of a participant. The researcher mailed out a confirmation letter with a map. She also provided transportation for one participant and supplied refreshments for the meeting. Six participants attended. One participant cancelled two days prior to the meeting, another was expected but did not show up at the meeting. Three other participants had earlier declined due to family matters which prevented them from attending but all said they were interested if another meeting was scheduled. As it turned out these three all live in Surrey and the researcher hopes to arrange a get-together for them following completion of this report.

At the group discussion, the researcher referred to the summary of the results which were mailed to participants and asked for their comments. One participant indicated during the follow-up telephone call that she was interested to hear from others about their ideas concerning preplanning for financial matters. She was given opportunity to question other participants about this. The researcher asked for clarification and input on some specific areas including: What kind of assistance do you anticipate someone (spouse, child, other) would provide if needed? What would you specify in your preplanning for living arrangements, for example would you want to choose the facility if you could no longer live independently? What words would describe that assistance and the person or people providing it (to get at the concepts of ‘personal network’ and ‘support’)? What aspects of the research results and process will be useful to you or would be useful if presented in another format? New information gathered from this discussion is noted in the Analysis Chapter.
Reporting and Presenting the Information

The researcher asked participants at the group follow-up meeting for suggestions regarding the format of the report and its contents. They did not offer any ideas for producing 'user-friendly' materials for themselves or others to use. The did express their hope that the results will be used to educate all adults about preplanning.

Participants at the meeting also indicated that they wanted a copy of the finished thesis. The researcher will produce cerlox bound copies of the final report for interested participants. All participants will be sent a final note of thanks, a copy of the Acknowledgements page and a small token of appreciation.

As previously highlighted, the philosophy embedded in this study and its origin in the community makes it important that the findings be linked to practice and action in the community. The researcher will ensure that the results are available in a format that can be incorporated into the action of the Coalition and the practice of the People’s Law School publication program. Some of this has already happened (see the footnote reference on page 81).

The recommendations in Chapter VI describe some of the ways the researcher (as an employee with the People’s Law School and as a volunteer with the Community Coalition) plans to disseminate the findings of this study. Participants who expressed interest in educating others about this topic will be invited to take part, as opportunities to use the information from this study arise.
CHAPTER IV
RESULTS

The researcher conducted eight individual interviews and one group interview. The results discussed in this chapter are based on the initial interviews with study participants. Group interviews create a social environment due to the interaction of participants with one another. This has the potential to produce different results from those generated by individual interviews and deserves separate comment.

The Group Interview

The four participants in the initial group interview were recruited through the social and personal relationships of one of the participants. Although some participants did not know one another or the researcher, there was no hesitation to speak about the topic with one another or to use personal stories and examples during the discussion.

The researcher used the same interview guide with the group that she used in the individual interviews. There was considerable interaction among group members and the conversation was less directed by the researcher. For example, at various times, individuals in the group took on the interviewer role and asked other participants what they had done, and how they had done it. Or participants counselled each other on the best way to do something or what factors they should consider. Group members also affirmed and supported one another as they shared sometimes painful stories. There was also lots of laughter and camaraderie.

The group interview yielded less in-depth information about the specific choices and perspective of the individuals in the group, however, it did demonstrate that
individuals are willing to discuss this topic with others, including peers who are strangers, and that they found the experience of sharing ideas and opinions with one another helpful and informative. For example, participants made comments such as “I'm learning things” (J, p.12) and “what do you feel, P, what's the best way to handle it?” (I, p.13) and “I never thought of that, thanks” (J, p.9).

Profile of Participants

The researcher did not attempt to elicit specific demographic information from participants. However, through the interviews, information on some aspects of family, health, housing, economic status and social activities emerged. A brief sketch of the participants follows.

Twice as many women (eight) as men (four) took part in the study. The participants included one married couple. Of the remaining participants, five were married, one was divorced and four were widowed. All participants had children. Almost half of participants had four or more children. Two participants had only one child each.

Of the three quarters of participants who mentioned their age to the researcher, all were 70 years of age or older. Two participants were in their 80’s and one was over 90 years of age.

Only one quarter of the participants made reference to their health status. One participant suffers from severe arthritis (a condition of long standing) and osteoporosis which limited mobility, another participant had developed adult onset diabetes four years
previously and a third participant had a heart problem that recently required hospitalization.

All participants lived in the Lower Mainland. Five participants lived in Burnaby, four lived in Surrey and three lived in Vancouver. Of those living in Vancouver, one lived in the Kerrisdale area, another lived near the Shaughnessy area and one in the West End. All but one participant had been a homeowner. At the time of this study, eight participants lived in single family dwellings, one in a townhouse, two in an apartment and one in a private care home. The individual in the private care home had a private room and could come and go as he chose, although meals were served communally. All other single participants lived alone.

Two participants, both women, had never been employed in the paid workforce. All other participants were retired from the paid workforce. Four participants had been employed at universities; two participants previously worked in private industry, another two had worked for medical offices, one participant worked as a regional manager with government, and one participant was a member of the Protestant clergy.

All participants reported being involved in social activities in their community and many also described caregiving responsibilities and involvement as volunteers. Two participants were full-time caregivers of their spouses, and one participant was a full-time caregiver of her granddaughter when her daughter, a stewardess, was working. Another participant provided assistance to a parent, including visiting once a week and running errands or doing repairs as needed.
Over half the participants volunteered in their communities. Two participants were senior citizen counsellors, appointed by the Ministry of Social Services to provide information and referral to other seniors. Another participant was active as a counsellor in a peer counselling program. Four participants belonged to and provided leadership in well established seniors’ organizations. Still another participant described her volunteer work at an extended care facility and at a care facility for people with Alzheimer’s. Another participant had volunteered with a Meals on Wheels program (delivering meals to house bound seniors) but had to give it up due to health problems.

Preplanning Activities Undertaken by Participants

The interviews revealed that all participants had thought about a time when they might need assistance with decision-making and with managing their personal care/living arrangements, health care or financial affairs. Most had also taken specific action in some or all of these areas. This section presents participants’ responses to queries about the preplanning activities they considered important and in which they were engaged.

The researcher reminds the reader that this study did not attempt to select a representative sample of older adults in B.C. or even the Lower Mainland. This group was much less diverse than either of these populations. As the participants themselves acknowledged, they enjoyed a relatively privileged circumstance compared to some other older adults. They were educated, in fairly good health, most were financially secure and they were socially active. They all described the existence of trusting and caring relationships in their lives.
Preplanning for Personal Care/Living Arrangements

Under the heading of personal care/living arrangements, moving closer to family was the preplanning activity reported most frequently. One third of participants had moved to be closer to their children, and the majority had moved to B.C. from another province. Most moved shortly after retirement and on their own initiative; one participant moved following a change in health status and at the urging of family members.

For those who moved to be closer to family, all now live in the same city as one or more of their family members. One participant described moving closer to family as “step one” (V, p.1) in preplanning for the possibility of needing assistance.

The two-thirds of participants who did not report that they moved to be closer to family, all had family members living nearby (in the Lower Mainland) and all acknowledged that family was an important source of assistance. Many participants spoke of assistance as a reciprocal process. They provided financial or practical help to their children now and anticipated that someday they might need and will receive assistance from their children.

Living within walking distance of stores, services and public transportation and choosing housing to suit physical abilities (for example, moving from a detached house to a townhouse or a apartment, to a facility with nursing care, etc. as needed) were other activities some participants put forward under planning for personal care and living arrangements (J, L, C). They also acknowledged, however, that older adults on modest or low incomes are unlikely to be able to exercise these options.
As one participant related, “as I become more disabled, I could function here with some help for awhile but where is there for me to go?...I don’t want to go into subsidized housing...there is nothing...being built for anybody...in the market that is affordable rent; that I could afford” (L, p.12). Her preplanning activities included taking part in local government initiatives to create affordable housing options for older adults.

None of the participants suggested living with family members as part of their preplanning for personal care/living arrangements. This position was contrary to the reported willingness and expectation of some family members to provide this assistance if needed, and contrary to the fact that some participants had provided housing and assistance to their own parents in the past. As one participant said “while [my daughter] wants me to live with her...that is not what I want” (C, p.1). She indicated that if she needed assistance with personal care she would prefer an intermediate care home “where you have autonomy within your own little room and your own furniture” (C, p.2). Another participant said she would hire a homemaker or other services if she needed assistance with daily living (J).

**Preplanning for Health Care**

Overall, the most thoroughly discussed preplanning activities concerned instructions for end-of-life health care. None of the participants wanted heroic measures. Over three quarters of participants had taken some steps to formalize their wishes in this area. Participants chose to express their wishes for end-of-life care in a variety of ways. One participant reported making a living will using the form put out by the Jack Bell Foundation (M). Another participant incorporated health care decision-making into an
enduring power of attorney document (E). Other participants said they and their spouse had informally agreed to assume authority of health care decisions for one another if it became necessary (I, N). Another participant had composed the first draft of what she called a message to her children but had not yet shared it with them (V). Some participants discussed specific wishes with their family doctor and or their children and requested support for their wishes (C, K, A, L). In some cases, participants also instructed their doctor to record the wishes in their medical file (L, K). As one participant said "it might be [needed at] a time when...[the doctor] is away" (K, p.3).

Some participants expressed concerns about the drawbacks of living wills and similar types of directives, for example their lack of legal status and their inability to respond to changing contexts. These worries made them hesitant about the usefulness of this tool. As they stated:

I have reservations about a living will...for one thing it doesn’t carry any legal weight...If I were to sign a living will and say be in an accident,...and I say I don’t want resuscitation...and they took that as my wishes, and I didn’t really mean that. (K, p.3)

I wouldn’t want [to be kept alive] if I had no quality of life...Yet if you wrote this down,...maybe you’d say I wish I hadn’t written this down. I suppose that’s why you have to trust somebody to do it for you. (V, p.4)

One participant’s solution to these problems was to draft an enduring power of attorney that granted power for all decision-making, including health care decisions, to his spouse. He acknowledged that this was really beyond the legal authority of a power of attorney but was still worth doing.

If it was a case of pulling the plug, whether that would stand up is quite a different matter and we [my spouse and I] talked about that but realized there is nothing much we can do about that at this stage anyway, but we went as far as we could under the existing provisions. (E, p.2)
The participants who discussed their wishes with their doctor said they expected that the doctor would make these decisions in consultation with the family. As one participant expressed it,

_The doctor can assess medically my position, if he says to the children your mother is not going to ever be able to function intelligently again and she's on a respirator, I know my children would say, then take her off the respirator._ (C, p.7)

This conjecture suggests that determining quality of life ultimately rests with the doctor. If the doctor says there is no quality of life, the family will affirm the parent's wishes regarding treatment.

However, the following comments by other participants suggest that determining quality of life may not be simple or straightforward and is more likely based on individual values and beliefs rather than on a medical assessment. Here are the thoughts of two participants:

_Everybody has to decide. What is the point when you don't want to live?...My point is if I cannot communicate, if I can no longer read, if I can't use my hands, if I can't listen to music, I think I'm ready to go, I don't want treatment. As long as there's somebody I care [about] and who'll come and talk to me and spend some time with me, I think I still want to stay around._ (R, p.6)

_I think your values change...I think quality of life can change...I suppose that's the quality of life, if you close all your doors and have no more to open that's when it's over...Who knows? When you do sit around and reflect, maybe you do have a quality?_ (V, p.3)

Individual participants had definite ideas about activities people could take part in to support preplanning for health care. Specifically mentioned were: looking after your health through diet and exercise (V); finding a doctor who will make house calls (L); changing your doctor if your current one doesn’t support your wishes (L, K) and
choosing a doctor who is in a practice with other doctors so you have continuity of
service if your own doctor is unavailable (L).

Preplanning for Financial Affairs

Questions about preplanning for assistance with financial matters found one third
of participants had made an enduring power of attorney. They all appointed only one
person as ‘attorney’. One participant named a spouse, the others named a son or
daughter. All said they initiated the making of the enduring power of attorney themselves
and went to a lawyer or notary public to have it drawn up.

Of the participants who had not made an enduring power of attorney, half
indicated that they planned to do so. The reasons they gave for not having the
arrangements in place were that they were having difficulty deciding who to appoint as
‘attorney’ or that they were unsure of the procedure for executing them.

The other half of participants who had done no formal planning in this area said
they expected their spouse or children to manage their financial affairs if necessary.

While they trusted these informal arrangements, they were unsure how, without legal
authority, the spouse or children could intervene to provide assistance. Nor had they
spoken to their family members about these matters. As one participant stated: “I
presume they [the two children named as co-executors in my will] would look after my
[financial] affairs, too. Maybe I’m presuming too much?” (V, p.8).

Individual participants gave examples from their experience of ways to support
preplanning arrangements for finances such as making sure both spouses share in all
financial decisions and maintaining an inventory of all financial property. One
participant explained how he learned from the situation of his friend's parents — when the husband died, the wife didn't even know what bank their money was in. And so, as the participant emphasized "that's why I make her [my wife] look after all the finances" (I, p.4). Another participant said this situation happened to her when her husband died, and her children helped her (J).

Other participants reported how they kept a detailed and up-to-date record of all financial matters (insurance policies, RRSP's, investments etc.) so someone could easily take over if necessary (C, E, M). They also stated that they had done this for many years.

Planning for After Death

Although the interviews and discussions focused on preplanning for the possibility of needing assistance while still alive, all participants also referred to their arrangements and wishes at death and following. All had made a will and many described their specific wishes regarding organ donation, burial or cremation, a funeral or memorial service. These arrangements for after death were articulated with a firmness and clarity that was not always apparent in the discussion of preplanning arrangements made prior to death, especially those for end-of-life care. When asked why this might be, one participant suggested that leaving something in a will and prepaying funeral expenses is a reflection on "our social role and how we're remembered" (V, p.11). She further hypothesized that these are important values to many older people and therefore they may pay more attention to these matters than to arranging for possible assistance while still alive.
Participants' Experiences with Preplanning

This next section elaborates on the experiences of participants as they attempted to put their plans into place. The experiences highlighted here include: deciding who to choose to provide assistance if needed; approaching doctors and family members for endorsement of specific wishes; and consulting with legal professionals about documenting their choices.

All participants acknowledged that doing effective preplanning requires having someone available and willing to carry out their instructions or to act for them. Of the seven participants with a spouse, four identified their spouse as their immediate choice for assisting them if needed. Of the remaining three, two participants were providing this kind of assistance to their spouse now and therefore did not expect their spouse to be able to assist them in the future.

Participants who were single or who did not choose a spouse to help them, indicated they would turn to their children for assistance. However, two participants expressed some reluctance for or concern with this arrangement. One participant, a caregiver, stated that “there’s no way that [my spouse] could look after me...[I’ll] have to be dragging in the family” (P, p.4). The other participant worried about the vested interest of family members and searched for a way to provide some checks and balances. As she said during the interview “it was very helpful talking to you because I remembered about the trust company and maybe with two family members [I can make a power of attorney]” (R, p.8).
Most participants chose only one person to assist them. Those with more than one child described the criteria they used when choosing one child over another to assist with decision-making. One participant suggested that "[one child might be], more capable and more trustworthy" (A, p. 8). Other participants explained:

*I chose the son whom I’m not actually closest to but...I think that he would be less likely to be emotionally affected and try to soften the terms of what I want...and also I am quite sure he will live in the one place forever so he will be available.* (M, p. 1)

*I’m closest to my daughter...she would be the one that manages my affairs and she’s a woman, so she would know my needs a little bit better than my son. And I probably could discuss health care problems with her more easily.* (C, p. 3)

Informing others of their plans and wishes was a step in preplanning taken by nearly all participants. Some participants spoke to their doctor and/or family members and some participants consulted with legal professionals. The purpose of these discussions was to ensure their wishes were communicated to the other parties rather than to elicit advice on who to appoint or what to include in their preplanning arrangements.

The participants who spoke to their doctors about end-of-life care said they trusted their doctor to act on their wishes. Only one participant said the issue was raised by the doctor. In all other instances, the topic was introduced by the participant. The participant whose doctor initiated the discussion found it a very sensible approach (A). Among the other participants, a caregiver said she wished her doctor had raised the issue as it affected both herself and her spouse. She reported feeling much better when she brought it up for discussion with her doctor (K).
When approaching family members, many participants related how they were sensitive to the viewpoint and reaction of their family members. Comments from these two participants provide examples of such consideration:

*Two of the family don’t live here...and rather than sending [my message about end-of-life wishes] in the mail I’m waiting until they come [home], because I feel the shock element when you’re not home...they’d think, oh gosh what’s going on.* (V, p.1)

*She [my daughter] doesn’t like to talk about it but...I’m able to face my own mortality. But she’s not able to...think of the day when I will not be there...But in...the back of her mind she’s logging all this stuff anyway.* (C, p.3)

For most participants, discussions with a spouse did not require the same kind of careful approach as was sometimes required with children. However, one participant reported, sadly, that her spouse avoided any discussion of these matters. “*My husband just didn’t want to talk about it...any time I have mentioned what I would like to happen to me he says ‘let’s not talk about it’...so I make sure my daughter knows*” (K, p.4).

In some situations participants described taking into account or being influenced by the wishes and concerns of family members. For example, a participant related his experience shortly after being diagnosed with diabetes and becoming adjusted to the medication.

*Well my resistance was low so I gave in [to my daughters wanting me to move out from Quebec]. I rather in some ways regretted it yet I realize now that it was very beneficial to my health and then the climate here was very agreeable...and [my daughter] is close if I need her.* (A, p.2)

Those participants who consulted, or said they would consult, a lawyer or notary public did so because they were concerned that their wishes were properly documented and therefore more likely to have the intended effect. Participants were very specific
about their legal needs. For example, one participant reported, “I went to the lawyer and told him what I wanted” (E, p.3). Another participant knew she wanted certain information in the document “I particularly wanted the power of attorney with the enduring clause...[and]...the land title act...So knowing that I wanted these two things...I used the services of a notary public...I didn’t want any repercussions because it wasn’t done properly” (K, p.1-2). Still another participant knew that the signature of a lawyer or notary public accompanying her documented wishes may convey a higher standard of capacity and so she would “go to a lawyer so there would be no dispute among the children whether mom was in her right mind...[and]...what mother wanted” (C, p.9).

**Triggering Events for Preplanning**

Participants were asked what triggered or motivated them or others they knew to engage in preplanning. Some participants described how life events and perceptions of risk made the issue more relevant to them: “I just thought, well, I’m getting older and anything could happen. I’ve had a few accidents, a car ran into me once...so that’s what made me think.” (J, p.11) and “I come from a family where my mother lived to be 96 and the last 10 years of her life she had some kind of dementia...So I’m in a risk group...” (V, p.1) and “What triggered it was the fact that we were going climbing at the age of 70” (E, p.4).

Others replied that the trigger was connected to a decline in physical ability or health status — one’s own or that of someone close to them. As one participant portrayed it,
If you're in fine health you're not worried about that sort of stuff... You don’t think, what if I ran out in the road and had an accident... It’s not until you get into sort of failing health... you say to yourself, I’ve got to do something about this. (C, p.8)

One participant described how the change in her own health status led her to make plans: “maybe it was when they first discovered this heart failure... it was something that I have been meaning to do for a long time and finally I did” (M, p.2). In other instances it was the experience of someone close to them that prompted participants to take action; “primarily it was because of my husband’s condition. I could see that his mental capacity was deteriorating and it sort of gave me a push” (K, p.3). Another participant shared this sentiment:

I just got thinking about... all the horror stories I heard about and I have encountered during my work. Quite frankly, it happened to some friends of mine, I have seen them deteriorate and not be able to remember things and not coping well with their finances and I thought well this could happen to me anytime so I better do something about it. (L, p.2)

The Value of Preplanning

All participants said preplanning was important and they offered explanations for why they and others should do it. Their reasons for supporting preplanning rested on the notion of responsibility — for self and to others. Many talked about being responsible for oneself: “[you’ve] got to look after yourself these days. Even if you go into hospital, if you don't keep track of what... they are doing and your medications or whatever, you can really get into a mess” (L, p.3); “I’m the one that’s responsible for keeping me here... I can’t turn to a husband... I’m me looking after me” (C, p.12); and “I think people who are single are maybe more likely to be concerned about this than people who have a
mate... When you live by yourself, you live your own life, you are more likely to want to set things down” (M, p.2).

Mentioned with equal passion and commitment was the responsibility that participants felt toward others, especially family members. When asked why they support preplanning some participants replied: “I don’t want to be a burden on [my children]” (C, p.1); “because it makes it easier for my daughter who would have to deal with things... I think it is a duty to my daughter to do this” (K, p.1,6); “because your family is usually in a sandwich situation... they have older people... and they have younger people, and if you have problems with both ends... it's a difficult situation... It isn’t fair for middle agers... I think older people have a responsibility” (V, p.2); “I am the strong one of the family and [my spouse] depends on me to make the decision... I really worry if I go first what is going to happen to him” (L, p.2); and “I’ve had experience with illness, old people and dying... so I’m cautious to have these things settled beforehand... the consequences [to those left behind] of not doing it are very serious” (A, p.1,7).

For one participant, arranging for the possibility of needing assistance in the future was being true to her values as well as a source of pride and relief. As she said, “I am a very organized person and I wanted to have it all organized... To leave... a mess would be detrimental to my pride... When I help people... I always say, you will feel so much better when this is sorted out” (K, p.1,6,7).
Preplanning as a Process

The interviews revealed possible stages or a series of decision points in the preplanning exercise. One participant suggested that preplanning is a process, such that "gradually you prepare yourself...It's a gradual process, just like aging" (C, p.2).

The first stage of preplanning was learning about and becoming aware of preplanning tools or of the need for preplanning. When asked how they learned about preplanning and its tools, participants could not pinpoint a specific event. As one of them said "I pretty well knew there was a power of attorney" (J, p.11). All participants agreed, however, that they did not learn about them from a lawyer or notary public, even if they had consulted one of these parties when making their will.

Much of the learning about preplanning seemed to be incidental, through work-related activities or through other people's experiences. Sometimes the initial information was reinforced by subsequent information/education opportunities or personal experiences. One participant thought she first learned about living wills from a CBC radio program many years ago. Then years later, while at a health fair, organized by seniors' groups, she listened to a resource person from the Public Trustee's office tell about various preplanning options. When putting together her own plans this year, the participant was able to call on information from these two events (even though they occurred years apart and the second event took place three or four years prior to taking action) (M).

The reflections of another participant documents a similar process and demonstrates a transition from the awareness stage to a more active stage:
I was aware this vehicle was available, but we were a lot younger then and there is...a feeling of optimism and belief in your own invulnerability...which gradually dissipates as you get older and your attitude is changing...Although we had considered the premature death of one or other of us, we had not really taken full cognizance of total disability...Which is strange when I had been dealing with people who had catastrophic accidents and...with people who were involved with the Public Trustee’s office...That was all there in the background but it still had not become personal...I think it must be exposure to someone or to something which bring you face to face. (E, p.2)

Thus the second stage seemed to be marked by an event or incident which led participants to ‘think’ about preplanning in a personal way — a way that involved them. These events were usually related to perceptions of health and physical ability as discussed earlier under ‘Triggering Events for Preplanning.’ Once they were personally affected, some participants moved quickly to action. Others spent more time thinking through their plans including who to choose to assist them and what specific directions to give. At the time of this study, some participants were still in the thinking stage and had not taken action. The stumbling block was more often deciding who to choose rather than articulating specific wishes.

The next stage or action step involved formalizing one’s thoughts or plans. There were three ways participants did this: 1) telling someone (a spouse, children, doctor) their wishes and asking the person to carry out their wishes if a need arises; 2) writing specific wishes down and giving them to someone; and 3) executing a legal document. A few participants did two or more of these things for some or all decision-making areas.

The stage of formalizing or ‘publicizing’ plans may not be a final one. Participants noted that circumstances and people change. As one participant, a caregiver, cautioned “they may be quite willing if you ask them today but as time goes on, they have
got to get on with their own lives” (K, p.8). Therefore, plans may need to be reviewed and adjusted.

Key Elements to Consider When Preplanning

The interviews highlighted some of the elements that participants considered crucial for effective preplanning. These were identified as: trusting in those you expect or designate to assist you; communicating your wishes with your potential decision-makers; accepting it may not be possible for those providing assistance to honour your wishes in all circumstances; and making your arrangements when you are healthy.

The issue of trust was mentioned by every participant and was viewed as the foundation of preplanning for any area of life. They said: “[you have to have] faith in your family that they will do the right thing” (J, p. 22); “[My daughter] knows what I want...I trust her” (A, p.3-4); and “trust is the main issue, finding somebody that will not add to the trauma by betrayal of trust [is the key]” (R, p.8).

Some saw a close link between trusting someone and knowing someone over a period of time. One participant described how trust and length of the relationship are integral to relying on someone to know and to carry out your wishes. For example, he chose his wife over anyone else because “it is all based on trust of course. It is all based on having lived together for nearly 50 years, it is all based on that and on an intimate knowledge of the other person...I think it would have been much more difficult if we would have had to divide this up with children” (E., p.4). Another participant agreed that “you should choose people whom you’ve know for some time, not a new acquaintance” (A, p.7).
Trust may also be important where the person giving assistance is not family and perhaps not even a close friend. One participant told of her experience:

*I know she admired me because I was a very straightforward, honest, decent person...I wasn’t a friend of long-standing...I was just somebody...[that] made it my business to go and visit her in hospital and she sort of unloaded on me...So she actually trusted me; and I don’t know whether she would have asked somebody else?...She didn’t want her family to know about some things in her life.* (K, p.12)

Another key element raised by participants was the importance of communicating with the people who may assist you. As one participant discovered “*things I thought [my children] knew I found they didn’t know...I think you have to write some things down*” (V, p.2) and another participant questioned “*How many people really know their parents and how many parents know their children?*” (R, p.11). Along with communicating your wishes to those you want to assist you is the need to make sure the person is willing and able. As one participant reminded “*you have to have their consent*” (A, p.7).

Some participants related the difficulties they had experienced in trying to honour someone’s wishes when faced with realities that made this difficult. According to one participant “*it’s difficult dealing with old people because they want to, of course, retain their power and so forth and yet they’re not able to do it...It takes patience*” (A, p.7).

This was echoed by another participant who said,

*What we find with people who are very old and who have decided [to live at risk], sometimes they get to be very selfish...They expect their neighbours to do everything for them. They’re proud of living at risk. I can think of one particular one and she drives everybody crazy because she’s always wanting things...They help her down the stairs, see she doesn’t starve, and people get tired of that.* (V, p.9)

Another participant described a situation where his wife’s mother came to live with them:
We had her for twenty years in our basement and finally put her in a care home. I said...either you've got to go in or your daughter's got to go in because she is worn out...And she [my mother-in-law] put a heavy on me...[she said] "you told me ...I'll have a place for life and now you're backing out on your agreement." And that was hard to swallow. (I, p.7)

There was also an example of a successful arrangement:

My mother...[will] be 95 in a couple of weeks and she's determined to stay at home. I said maybe you'd like to go into a lodge...She worked herself out of the chair and said 'I'm not going anywhere.' And I thought fine...I really expect I'm going to go down one time and find her on the floor and that's the end of it. But that's the way she wants it...[So,] there's my one sister and...she has power of attorney and she looks after banking and that sort of thing. There's four of us living here and so I go every Saturday, my sister goes every Monday...another brother...goes Thursday and gets the groceries, I have a brother who goes Friday and he does bits and pieces. I think she's quite fortunate and I think she knows it too. (I, p. 1,2)

Finally, all participants encouraged people to make these arrangements when they are well. One participant, a caregiver, expressed regret at not being able to do better by his spouse's financial affairs:

The biggest mistake I made was in not insisting [my spouse] give power of attorney two, three, five years ago when she could legally [sign it]...It certainly would have helped because I'd have fixed up bank accounts so I could get money when I need it and get money invested where it should be, instead of sitting in an ordinary savings account. (P, p.13)

Reasons Some People Don't Preplan

Asked whether preplanning is for everyone, all participants acknowledged that it was a good idea but that it was unlikely everyone would do it. The most common reason they offered for why people avoid preplanning was the fear of facing one's mortality. As some participants stated, "we would all do it, but we're human and we don't want to face our own mortality" (C, p.9) and "a lot of people are afraid to look at their
mortality...I’ve got lots of time yet” (L, p.10) and “[people don’t preplan] because they think it will bring death closer” (A, p.4).

Participants cited cohort differences as another reason that people don’t preplan. They suggested that the current generation may be more reluctant than future generations to engage in formal preplanning.

The older age group, the people who are 70 now, are a lot different than people who were 70 ten years ago. They come from a different background, the women in particular...they had different life experiences...but we’re changing, the people who are coming into their 70’s and 60’s now, often they’re a lot more worldly and they understand these things. (V, p.11)

I think it would be a lot easier as time goes on, because the very elderly people now are the generation that really didn’t know too much about this thing, didn’t go out in the workforce. But now we are dealing with the up and coming elderly...they are much more aware of these things...they can talk to a lawyer, they can write a cheque and everything. (K, p.6)

Some participants believe personality or individual values may also be a reason why some people do not and may never do preplanning. They pointed out that “you are what you’ve been through life” (V, p.9) and “if someone has been organized all their life they would organize [this]...[but]...some people are of a dependent nature” (C, p.10,12) and “you’ll always get people who don’t want to talk about it or just actually are careless...They are always going to do it tomorrow but they don’t” (K, p.6).

One participant hypothesized that religious belief may play a role. She wondered if some older people think “I’m going to be looked after because I was okay in my life...and people will do the right thing for me” (V, p.12). They may see no need or even see a contradiction in making specific arrangements for the future.
As previously discussed, participants suggested that people have to experience the need for preplanning in a personal way before they will do it. Related to this is the gap between younger and older people in terms of their life experiences and expectations. As one participant put forward: “when they’re in their 20’s they deny the fact that they’re going to be killed in a car accident when they’re 35, and rightly, they shouldn’t even think about it” (V, p.12).

Not having anyone immediately available to assist you or to stand in for you if you can’t manage is a significant barrier to preplanning and may be a reason many people do not do it. Yet it may be more important for these people to express their wishes. As mentioned by some participants, single people may feel more of a need to spell out their wishes and identify someone to assist them if needed because there is no mate who could naturally assume this role (M, C). Individuals without natural sources of support may need to rely on ‘the kindness of strangers’ to assist them. This may not be an unrealistic expectation as witnessed by the fact that nearly half of participants had assisted more than one person with financial, health and or personal matters where no family members or friends were available or were trusted by the person. As one participant described it “it is one human being, being compassionate to another” (K, p.12).

How to Educate Others About Preplanning and How to Assist Them With Preplanning

Because many participants were also leaders of and advocates for older adults in the community, the researcher asked their thoughts on how to educate their peers about preplanning and how best to assist those who want to make specific plans for the possibility of needing assistance in the future.
Among the suggestions on education was this comment from a participant: “We learn from others’ experiences...you like to talk to someone that’s been down the road” (I, p.15-16). This point was demonstrated during the group interview when one participant recounted the experience she and her mother had with setting up and using an enduring power of attorney (N) and another participant in the group responded with the comment “I didn’t know that either, I’m learning things” (J, p.12).

A participant and also a peer counsellor referred to the type of knowledge her peers need and want. She said “most people need in depth [information] to point out the problems because there are lots of pitfalls, also lots of different possibilities” (R, p.1), she later referred to this as “honest education” (R, p.6). This call for a balanced approach is reflected in the comment from another participant who said that she “had never heard of anyone...[giving] the negative side of living wills” (V, p.3).

One participant who often speaks at seniors centres about preplanning issues stressed the need to give older adults practical information such as “not [to] leave it too late...[and what is] the best thing to do for a safeguard” (K, p.15). Also important is how information and education is presented. Her recommendation was that it be presented in simple language because “people of my generation...are intimidated by...anything that...has a legal connotation” (K, p.10). She also maintained that “you [have to] explain things over and over again, it takes a long time for...people to understand” (K, p.10).

In terms of who can best present the information, she proposed that “it goes over even better if a layman does it...[who has] training and knowledge...rather than a
lawyer” (K, p. 15). Her belief was that this may influence peoples’ confidence in and understanding of the information, for as she related: “I talk in an informal way...I am one of them, I’m an older person too...I have no axe to grind” (K, p. 15).

In terms of the context for education on preplanning for older adults, some participants suggested that it should be part of retirement education (M, V, K). Another idea is to “teach volunteers in the community to do [education] and not just the seniors classes, but...the people with AIDS group, or the Parkinson’s group, or people with cancer group...I think that all these people need to be taught how to help people do this” (K, p.15).

Many participants also had experience helping other older adults with issues affecting their lives. They spoke about the importance of listening, providing support and building trust because, as one participant reported, when someone asks you for help “you don’t get a quarter of the story to start with...they are putting out a feeler to see how you are going to respond...and do you care enough that I can trust you and tell” (L, p.12). Another participant described how “some people will spend the first three quarters of an hour crying” (K, p.13). Her approach to helping was to “sit down with someone and help them with their thoughts” (K, p.13).

Summary of Results

The following is a summary of the interview results beginning with a description of the participants. Participants in this study were all socially active and well connected to resources in their communities. Most were financially secure and in good physical
health. They all had a network of friends and family and most were able to imagine turning to them for assistance if needed.

Seventy-five percent of participants undertook specific actions related to preplanning for end-of-life health care compared to one third each for personal care/living arrangements and financial matters. Only one third of participants had made plans in two or more areas.

Just over one third of participants used formal preplanning tools. One participant made a living will to document health care wishes, three participants used an enduring power of attorney to cover financial matters and one participant adapted an enduring power of attorney to cover all areas of decision-making.

While participants gave more attention to preplanning for end-of-life health care than other areas, some also found it very difficult to define quality of life and therefore difficult to commit to a set of instructions such as a living will espouses. Rather, participants identified the importance of having a person who can exercise some judgement. For some participants, the doctor was the person to whom they entrusted this responsibility; for others it was a spouse or child.

Participants generally placed more emphasis on identifying a person who would honour and carry out their wishes rather than on articulating specific instructions. Choosing who to ask for assistance if needed was generally made easier if there was a spouse available. In situations where there was more than one child to choose from, the child chosen was believed to be better able to ensure the parent’s wishes would be honoured. Most participants preferred to name only one person to assist them although
for one participant, naming three parties was viewed as added protection from possible financial abuse.

Discussions with doctors about end-of-life care appeared straightforward and positive although they usually had to be initiated by the participant (the patient). Consultation with legal professionals was also straightforward, probably due to the fact that participants knew what they wanted. Discussions with family members sometimes required more tact and in some instances, participants tailored their message to the person.

Participants reported that a real or anticipated decline in physical ability or health status was the most common trigger for preplanning. This included the potential risk of injury or of inheriting a debilitating disease. Watching someone close to them experience a decline in ability to manage caused some participants to anticipate their own possible decline.

Participants perceived preplanning as an opportunity to maintain control of their affairs and to relieve family members of potential problems. They wanted family members to have the authority and direction they might need to provide assistance. However, not all participants had implemented their plans and some had undertaken preplanning in only one area of their lives. While they thought it was important, for some it was still just a good thought.

Stages in a preplanning process emerged from participants’ descriptions of how they learned about and came to act on preplanning. Many participants said they were aware of preplanning tools long before they thought of using them. An event or an
experience that happened to them or to someone close to them brought the need for preplanning to the forefront and led to action. Many participants referred to the preplanning process as a very 'human' process, fraught with procrastination and denial. This is articulated in the following comment made by a participant:

*With the typical lethargy of the average individual you grow aware of the need for it and sort of think, yes, I've got to do it. And then ultimately something else happens and you think I've got to do it now, and that's really how it happens.* (E, p.2)

Participants proposed some critical elements people should consider when doing their preplanning. The following points constituted their advice: choose someone you trust to assist you; it may be better to choose someone who has known you over a long period of time; let the person know you want them to take responsibility for assisting you or taking over your affairs if needed and give them any instructions; instructions may be particularly important where the person is not a spouse; be realistic in your expectations as circumstances may change and it may not be possible for the person to carry out all your wishes; and it is important to put plans in place while you are well and you are able to communicate your choices.

While participants agreed it would be desirable for everyone to engage in preplanning, they also accepted that this was unlikely. Fear or denial of death, cohort differences, personality traits and values, differences in social role between generations and lack of personal support were all discussed as reasons people avoid or dismiss preplanning activities. Some participants had countered the lack of personal support by assisting someone who had no family or friends available or who the person trusted to assist them with personal, health or financial matters.
According to some participants, educating older adults about preplanning requires training and supporting other older adults to do it. Individuals can better identify with and learn from someone who has similar experiences. They will also feel more confident with someone who has no vested interest in the subject or its presentation. Plain language and repetition are also important qualities of an informational/educational initiative. Participants also suggested that education should link up with seniors’ activities such as general retirement programs or support groups for caregivers or people with a specific illness.

Participants who help their peers with personal, health and financial issues affecting their current situation or as part of planning for the future reported that listening and supporting the person are critical factors in gaining the individual’s trust so you can help them. It takes time and patience to help someone figure out what they want to do and as for educating older adults about preplanning, their peers may be the best guide.
CHAPTER V

ANALYSIS

The most striking feature of the participants’ experiences with preplanning, as the results portrayed, was the lack of encouragement and guidance available. As such, the experience may best be described as heading off on a journey without a roadmap and no one around to give directions. Although others were also making or had made the same journey, generally those experiences were inaccessible to anyone else. Thus, each person had to create his or her own map, en route. This approach required considerable individual effort and resources.

Yet, despite these demands, the participants were strong advocates for preplanning. They saw it as part of a larger effort that encompasses pre-arranging the disposal of their body and estate after death. The participants perceived preplanning as enabling self-reliance, a quality practiced and much prized by them. As well, they had a clear sense of the roles of family and certain professionals in their preplanning activities.

This chapter offers an analysis of the results (reported in the previous chapter) of semi-structured individual and group interviews with 12 participants (all self-described seniors) about their experiences with and perceptions of preplanning for possible future need of assistance. The analysis also incorporates specific points that were emphasized or raised in the follow-up meeting held with six participants to verify and elaborate on the results. The brief summary of results mailed to participants prior to this meeting was discussed and affirmed.
Although the results of this study cannot be generalized to the older population, or any portion of it, they do provide a glimpse into preplanning from the perspective of some older adults. The information gathered from the participants can form the basis of further research and offer direction for developing educational and informational initiatives and policy on preplanning for older adults. As well, the findings have informed the ongoing work of the Community Coalition.  

Qualitative research recognizes the subjectivity of the researcher. This study was developed out of a particular context. The researcher brings her experience as chair of the RATG and director of publications at the People’s Law School to this project. In these positions the researcher has been involved in various facets of the topic under study. Through the RATG, she has been part of a concerted effort to ensure that the people most vulnerable to public guardianship have a voice at the policy-making table as new legislation is put in place. The RATG has also undertaken the community development work that will ensure the opportunities of the new legislation can be realized by those who most need it — the frail and isolated. These efforts have demanded strategic lobbying and negotiation with government as well as grass roots community organizing.

2 Beginning in fall 1993, the RATG began discussing representation agreement with people who are most likely to be affected by public guardianship. The information gathered was categorized, analyzed and distributed in a report: Designing Representation Agreements from the Ground Up. The report highlighted concerns to be addressed in the implementation (i.e. the policy-making process) of the Representation Agreement Act. A sub-committee of the Task Group studied the legislative issues raised by the community and recommended solutions. These are reported in the Task Group’s Report on the Legislative, Regulatory and Policy Issues (June, 1995). This report was distributed to community members and those in government who are involved in the implementation of the legislation. Due to the researcher’s involvement and the ground-up process employed by the Task Group, the issues raised by the experiences and perceptions of participants in this study have been incorporated in the policy report. Their sentiments reinforce those expressed in the Task Group’s report whose “recommendations aim to ensure that representation agreements can be used by everybody” (p. 4). For more information, contact: Community Coalition for the Implementation of Guardianship Legislation at: #800 - 1281 W. Georgia St., Vancouver, B.C. V6E 2Y2; telephone: 604-685-3425, facsimile: 604-685-7611.
In these processes, older adults have provided leadership and initiative in their communities and on behalf of all seniors in B.C. Their work informs the ideas and direction that emerges from the current study; and vice versa. References to Coalition activities are mentioned in this and the next chapter.

Likewise, the People’s Law School publications program, which produced a series of fact sheets for older adults on various preplanning options, has also developed analysis and action based on the subject of this research. Discussions with older adults during the development and distribution of the fact sheets has reinforced the need for different educational initiatives and distribution strategies. The researcher brings these realizations to the analysis phase in an effort to add deeper understanding to the patterns and themes uncovered in the interviews.

The following pages describe the individual effort of preplanning as experienced by the participants. Also discussed are some implications for others who want to engage in preplanning.

**Preplanning as an Individual Effort**

Most of the participants first learned about preplanning options incidentally — through experiences on the job, by being at the ‘right place at the right time’ (for example, catching a radio program and stopping at a booth at an information fair) or while assisting others. When it came to making their own plans, some wanted more specific information. It was not readily available, however, and most had to rely on their own ideas and past experiences. That many of the participants wanted education and information on the topic was evident from questions put to the researcher during the
interviews. Even those who made specific plans wanted to verify their approach or evaluate other options. They asked the researcher what she knew and had learned from others and where they could find out more.

The participants’ experiences suggest that those who engage in preplanning need to be highly motivated, tenacious and skilled at problem solving. The unfortunate irony is that many people are motivated to engage in preplanning only when they experience a deterioration or a crisis in their health. It is in these very situations that they are most likely to need to preplan but are least likely to possess or be able to marshal sufficient resources (physical, emotional, social, intellectual) alone to undertake it.

From whom or where may help be expected to come? From those closest to the individual? From professionals they encounter? From the community at large? According to the research results, both professionals and family members adopted a passive role with respect to preplanning. That is, they did not openly discourage or dismiss it but neither did they volunteer information or invite discussion. The onus for initiating, investigating and implementing preplanning activities rested almost exclusively with the participants themselves. Lawyers, notaries public and doctors missed or avoided opportunities to initiate conversations with their clients/patients about this topic. Many participants also noted that family members had to be approached ‘carefully’ and this participants usually did only after researching the options and making their choices.

The larger community and society in general appeared to be equally silent on the topic of preplanning. The participants found little or no organized help with or validation
of preplanning efforts. Only one participant was able to point to a specific community-
based source of information when making her own plans. She contacted the Jack Bell 
Foundation for a copy of the living will form they distribute. One other participant, a 
Ministry of Social Services senior citizen counsellor, described her involvement in 
educating and supporting older adults in the community to deal with these issues. 
However, none of the participants in the study referred to seniors counsellors as a source 
of their own knowledge.

Despite the uphill battle to find information and the lack of encouragement and 
guidance from family, professionals and community-based agencies, many of the study 
participants undertook some form of preplanning. It is important to note, however, that 
most of these participants were without major health problems and were financially 
secure. All of the participants were socially active and had a spouse and/or children. In 
addition, many were also advocates for and leaders of other seniors. Most of these 
participants, therefore, had considerable personal and social resources, skills and access 
to knowledge that made them aware of preplanning and enabled them to engage in it.

The implications of the participants’ experiences are: first, that older adults are 
very interested in preplanning. The second implication is that many older adults, 
especially those who have limited skills, experiences and resources, will find preplanning 
difficult or impossible to carry out unless they have additional help including education 
and information, emotional support and community advocacy.

The experiences highlight the opportunities for educational and informational 
initiatives on preplanning, the main focus of this study. While the results do not discount
the presence of existing educational and informational initiatives on the subject, they do suggest that older adults have difficulty accessing them.

The research findings offer ideas for improving access to or for developing new educational and informational initiatives. The rest of this chapter spells out these suggestions under headings related to the context, the target audience, the content and presentation strategies of educational and informational initiatives. The next chapter will focus on specific recommendations for action.

First, however, it is necessary to clarify the meaning of a term used in this and the following chapters. ‘Representative’ will be used to refer to the person or persons an individual chooses to make decisions for her or to manage her affairs if needed. This term is appropriate for a number of reasons. It connotes a role as the agent or ‘stand in’ for the individual. The term also reflects the principles and intention of preplanning which is to maintain the identity and autonomy of the individual by having someone to represent her values and wishes. As well, in the new guardianship legislation, the person named in a representation agreement is referred to as a representative.

The Context for Educational and Informational Initiatives on Preplanning

The participants’ experiences and perceptions provide valuable insights into the context for presenting educational and informational initiatives on preplanning. As the participants reported, they first became aware of preplanning from situations that did not directly relate to their own needs. However, they pointed to specific contexts where the topic became relevant to their experiences and needs and moved them to take personal action. Examples of these specific contexts are discussed here.
The context in which people will most likely become aware of preplanning issues is where their health is negatively affected. This could be as a result of a stroke, illness or disease, fracture, worsening of an existing condition, or other health related problem. A deterioration in health or physical abilities was perceived by those interviewed as a reminder that, while they may recover from an acute episode, they were at the end (as opposed to the beginning or middle) of their life and it was time to ‘be sensible’ and prepare for possible need of assistance and the surety of death.

Although these same participants strongly emphasized that individuals should initiate preplanning while healthy, they also readily admitted that most people will take action only when they perceive that their health is somehow jeopardized. Their perceptions suggest that if education and information on preplanning is readily available when and where people seek health services and treatment, it may find people who are more ‘ready’ to hear the message. Initiatives could target both formal and alternate health services and programs directed at older adults that are of a preventative, supportive or maintenance, palliative and rehabilitative nature.

Related to health care and treatment issues is the caregiving context. Caregivers act as decision-makers and advocates for their loved ones. Participants who were caregivers remarked in the interviews that it is often in this role that one becomes acutely aware of the need for formalized preplanning. Caregivers have a dual interest in preplanning. They want the wishes and values of their loved one to be respected; they are also concerned about their own possible future need of assistance and ensuring their own choices will be honoured.
Another context for introducing education and information on preplanning is when people are thinking about and making arrangements for disposal of their estate and their body. The interviews revealed that the participants perceived preplanning as part of a bigger package possibly titled ‘putting your affairs in order’. From the participants’ point of view, the topic of preplanning included both arrangements for post-death (making a will, deciding about organ donation and spelling out burial or cremation wishes) and preplanning for a time, when still alive, that they may need assistance. These perceptions indicate that education and information on ‘pre-death’ preplanning may best be introduced to people when they are considering any of these other issues. Many participants also remarked that preplanning should be part of all pre-retirement seminars.

Including preplanning on a larger agenda that focuses on taking control of one’s own affairs and one’s future, will likely appeal to individuals who, like those in the study, value self-reliance. As well, it may enhance the credibility of preplanning activities and generate broader understanding and interest among professionals and the general public.

At the same time, it will be important to recognize that incorporating preplanning in this larger context may not be immediately or widely accepted. It requires a change in attitude. Society places a high value and priority on activities such as writing a will and arranging burial or cremation. These activities are considered desirable and routine. As some participants remarked, there is a sense of duty attached to these matters and an expectation that a responsible individual who cares about her family will make sure they are attended to. However, there is no such public endorsement or expectation regarding preplanning for matters that may arise prior to death, as participants’ experiences concur.
Those interviewed acknowledged that they had their will and funeral arrangements in place long before they thought about or acted on arrangements for possible future need of assistance with personal, financial or health care matters while still alive.

The Audience for Educational and Informational Initiatives on Preplanning

Preplanning is an exercise in maintaining autonomy. It is therefore essential that the subject of preplanning, the individual, is in control — it is the individual's wishes and choices that are important. In the framework of this study, older adults are the primary audience for educational and informational initiatives on preplanning. With sufficient knowledge and resources they can put in place arrangements that will reflect their needs and wishes.

Although participants advocated for initiatives to target older adults in general, as they reflected on their own experiences and those of others they knew, it was evident to them that initiatives must particularly reach out to those who are vulnerable to dependence on formal systems and public guardianship. These will be people who have a terminal or chronic illness, a disability and/or no personal support. It is for the individual whose independence is threatened that the need for preplanning is most acute.

Preplanning offers an alternative to system-based externally-defined solutions.

The participants' experiences point to directing educational and informational initiatives to other audiences as well. This will create greater public awareness of preplanning and generate more resources for assisting individual efforts. First and foremost among this broader audience are those an individual would choose to turn to for
assistance. This may be family members, friends or others with whom she has a personal relationship.

As highlighted by many of the participants in this study, discussions with family members was one aspect of preplanning they thought important, but also found difficult. Education and information that is targetted specifically to those who are a source of assistance and that address their concerns may assist with such discussions.

The larger community is also a critical audience for education and information. The interview results showed participants looked to associations and agencies in their community for information and support. Seniors’ organizations and other community groups that address the needs and interests of older adults, particularly those that support independent living, can play an important role in providing leadership and support for preplanning to their members and to older adults in the community. Examples of such associations include the Alzheimer’s Society, Seniors Resources and Research Society, churches, the Royal Canadian Legion, the Old Age Pensioner’s Association and others. These organizations first need to understand preplanning from the perspective of older adults so they can be an effective resource to others in the community.

The interview results pointed out the private sector and formal service systems as potential audiences for educational and informational initiatives. This would include professionals, particularly those in the legal and health care fields. Those in the social work and mental health fields should also be included.

Participants also identified audiences in the service sector. Staff and management in other formal systems that provide services to older adults, such as the Ministry of
Social Services and Office of the Public Trustee, need education and information on preplanning. Staff and management of public institutions such as extended care hospitals and health care facilities and of private institutions such as banks and private care homes could be included as well. In terms of the current situation in British Columbia, participants, who were also members of the Community Coalition, argued that the education of politicians and senior bureaucrats may be advantageous in the hope that they will ensure that the policies developed and the resources allocated for the new guardianship laws will make preplanning truly accessible to older adults.

The Content of Educational and Informational Initiatives on Preplanning

The participants’ experiences and perceptions highlight content areas to be addressed by educational and informational initiatives. Specific topics will largely depend on the context within which they are discussed and the audience to whom they are directed. For example, if an individual is in the midst of a health crisis, the immediate focus of education and information will be related to health care matters. If the context is a pre-retirement seminar, the content will provide an overview of the elements of preplanning. If information is directed to representatives, the content will emphasize their role and responsibilities. The content areas that characterize the preplanning process as identified in the findings are outlined below. First on the agenda is to attract the interest and attention of older adults for preplanning.
Recognition of Potential Need — Making Preplanning Relevant

The research results clearly indicated that participants engaged in preplanning only when they were able to identify with the issues. Essential to the preplanning exercise, therefore, is that older adults recognize the potential need for preplanning.

The participants in the study who did engage in preplanning all had personal experiences as a caregiver, an advocate, a family member or a friend of someone who needed assistance. This implies that education and information on preplanning should focus on the potential consequences of 'real life' situations that are relevant to seniors' concerns and experiences. One example comes from a Kamloops senior, a board member of the Seniors Resources and Research Society, who when educating others about preplanning issues, begins his sessions with 'what if...' scenarios. He uses the real life (anonymous) situations of older adults in the community to facilitate discussions and motivate others to think about their own need for possible future assistance. The response has been very positive and he has supported many individuals to formalize their plans (B. Anhorn, personal communication, May 9, 1995).

Also pertinent to the discussion of how to make preplanning relevant and meaningful to older adults, are the findings that some participants perceived preplanning as a way to express their self-reliance. For them, preplanning provided a method whereby, if they needed assistance in the future, they could accept responsibility for decisions and ease the burden on their family. They did this by specifying their wishes and by authorizing someone to make decisions or take action. Fear of being a burden was of great concern to all participants. It follows from these experiences that education and
information which focuses on how preplanning values and enables self-reliance may encourage individuals to engage in preplanning.

It was not clear from the results, however, whether all the participants shared this perception of preplanning. Those individuals who did not make specific arrangements may in fact perceive that preplanning compromises self-reliance, takes away independence and burdens the family. This perception will prevent people from participating in preplanning. The comments of study participants who were also caregivers offer a response to these concerns. According to their experiences, the consequences of not planning were that the caregivers found themselves more burdened — first by not having the public or legal authority to take action and second by not knowing specific wishes. Thus, the family or others close to the individual do not feel burdened by having to provide assistance or help with decision-making, rather, the burden comes from having to do these things without being sanctioned.

Preplanning is a tool for facilitating that sanction. When an individual designates a representative she is also making public her choice. This endorsement enables representatives to act with authority. They do not have the burden of wondering if they have the right to provide assistance nor are they burdened with justifying and explaining their role to others, particularly by those employed in the formal system. Some participants interviewed also anticipated that formalizing and legalizing their preplanning may give added status to the representative’s actions.

Not only may preplanning make it easier for caregivers to act with authority, it may also allow them to preserve the identity and autonomy of their loved one.
Caregivers spoke passionately about standing up for the values and wishes of their loved one, even in situations where their own values were different.

Other content areas for informational/educational initiatives include the basic components of preplanning, namely, specifying the areas where assistance might be needed and any wishes associated with them, choosing representatives and formalizing arrangements. Related to these components and the preplanning process are additional topics that deal with communication between the individual and her representative, the nature of their relationship, the role of individuals and groups with whom the individual has personal and social relationships and resources available to assist individuals with preplanning.

Articulating Wishes for Specific Kinds of Assistance

The participants interviewed found that specifying areas for assistance and articulating particular wishes were for the most part, simple and straightforward. It is necessary to point out that the researcher introduced the categories of financial, health care and personal care in the discussion of what kinds of assistance participants might specify. This was in part to gather information pertaining to the use of formal/legal preplanning tools. However, using to these categories has the potential of falling into the trap of framing participants' responses according to a system-based perspective — the very approach this research wanted to avoid.

By listening ‘between the categories,’ it was possible to discern the most critical features regarding the kind of assistance participants want and that they perceive as necessary for a quality of life. In short, they want to be and to remain connected to others
and to the social world. For them it is important to be in a relationship that values them and their abilities and that recognizes them as an individual rather than as a patient to be cured, treated or palliated or as a customer to be served or as a dependent parent to be cared for like a child. This is not to say that they do not want services and external help but want to ensure that they (or their representative) can make choices about them according to their values and the quality it gives to their lives.

The specific areas of assistance introduced by the researcher in the interviews are outlined next. They warrant mention as a reflection of participants’ values and wishes and as potential topics to address in educational and informational initiatives.

Content issues for financial matters. Under preplanning for financial matters it was evident that while all participants were aware of the enduring power of attorney document, only some fully understood its purpose and application. Because financial matters are the one area for which a legal preplanning mechanism currently exists, some participants felt concerned that people understand its legal implications. The existence of a legal mechanism may limit the power of informal arrangements between individuals and those closest to them.³

³ A current illustration of this comes from people’s experiences with the new B.C. Freedom of Information and Privacy Legislation. Parents of adults with a mental handicap are reporting to the Community Coalition that, since proclamation of the new FIP legislation, they find it more difficult to obtain information about their child from public institutions. Where previously staff would informally share information with parents who were providing decision-making assistance to their children, new policies, developed in response to concerns about privacy and consent requirements, now deny them access to this information unless they have legal guardianship. Many parents see this as a backward step because under the current law, legal guardianship is a court process that effectively takes away an individual’s citizenship rights. Spouses and children of individuals suffering from dementia are likely to have similar difficulties.

This is an example where interpretation of legislation leads to policies that disenfranchise the natural supports — assistance of family, friends — that exist and become a barrier to honouring self-determination and keeping people safe.
Preplanning for financial matters also raised concerns of potential abuse. Some participants expressed concern that a power of attorney is effective as soon as it is signed regardless of whether assistance is immediately required. They told of provisions they had made to deal with this situation including telling their representative under what circumstances the document is to become effective and/or leaving the document with a legal professional with instructions on when to release it.

Some participants’ comments emphasized that education and information on this topic (preplanning for financial matters) needs to stress the importance of trust when choosing someone to assist with or to make financial decisions. Perhaps of equal concern, a point raised by the caregivers who were interviewed, is how to protect that representative from suspicions of abuse by professionals and others outside the personal support network.

Content issues for health care decisions. Under the health care area, participants were primarily concerned about end-of-life care and treatment issues. They highlighted the importance of discussing these issues with doctors and with those closest to them. Many of the participants designated the final authority for end-of-life care or treatment decisions to their doctor but with the expectation that the doctor would consult with their spouse or children.

The results were not clear as to whether participants chose to give their doctor this power because they perceived the decision to be primarily a medical one or because they were concerned about family overriding their wishes. Whichever the reason, these results suggest that educational and informational initiatives on this aspect of preplanning will
urge people to find out about and discuss the specific policies and practices followed by their doctor and health facilities with regard to these issues. Other information also raises the possibility that patients and their physicians may have different perceptions of the physician’s role.

For example, a recent study (Pulling plug, 1995) indicates that health care professionals likely make decisions about end-of-life care and treatment according to their own values and beliefs, not the patient’s. In another event, the British Columbia Medical Association and the Ministry of Health recently encouraged doctors to distribute ‘Do Not Resuscitate’ consent forms to their patients (Wigod, 1995). The Charter of Rights and the influence of recent privacy legislation means physicians and institutions are becoming increasingly concerned about their liability. They are becoming more reluctant and, with the proposed new Health Care (Consent) and Facility (Admission) Act in B.C., unable to act without the consent of the patient, either directly, via some form of preplanning, or through a substitute decision-maker. The new Act lists who will have authority to be a substitute decision-maker starting with a spouse, adult children and so on. These factors and the participants’ own stories indicate that discussions with those likely to be a decision-maker about preplanning issues affecting end-of-life care and treatment will become increasingly important and necessary.

Some participants approached preplanning for end-of-life care and treatment issues from the perspective of quality of life. They saw these issues as an individual and subjective determination that could not find answers in the medical model. Instead, they implied that these matters must be addressed from a holistic perspective, one that
considers the whole person—their relationships, interests, values, beliefs—not just physical or mental capacity. This may involve getting input from a variety of disciplines and experiences such as offered by hospice and palliative care practitioners, religious and spiritual leaders, and members of organizations and self-help groups that support people with disabilities and degenerative illnesses.

The recent Senate Committee hearings and report on assisted suicide and euthanasia (Of Life and Death, 1995) demonstrate the need for ongoing public discussion of these issues. They also highlight the complexity of the topic. The responses of those interviewed for this study revealed some fear and frustration as participants attempted to understand and articulate their choices for end-of-life care. They expressed their own desire for more education and information on these matters in order to make informed choices. As this study indicates, end-of-life care and treatment is one of the chief concerns of older adults (including those who are healthy) who want to pre-plan.

**Content issues for personal care/living arrangement decisions.** The responses to interview questions about preplanning for personal care and living arrangements intimated that living/housing arrangements dictate most of one’s choices for personal care matters. For example, living in one’s own home and near convenient and inexpensive transportation enables access to shopping and to a variety of community amenities and activities. In this environment, individuals have considerable opportunity to exercise personal choice. However, while living in a care facility offers convenient access to medical services as well as meals and some forms of entertainment, it also means limited opportunity for expressions of individual preferences. According to participants’
experiences and perceptions, living/housing arrangements are a major determinant of one's lifestyle, including one's opportunities for social interaction.

Living arrangements was the one area of preplanning for which participants' responses did not vary. All were adamant that they did not want to live with their children and that they envisioned living in a facility as a last resort. This, however, was the extent of their specificity with respect to wishes or plans for housing or living arrangements if they could no longer manage on their own. Some participants made brief reference to the fact that if an individual is financially independent, she will have more options because the only real choices are found in the private housing market.

This topic was one of the areas explored in the follow-up meeting held with participants to review the results. Their comments at that meeting clarified their stated position that they did not want to live with children. What they meant was that they did not assume nor did they want others to assume that they would 'automatically' move in with a child if they needed assistance. If, however, they were asked by a child and the living accommodations allowed them privacy and autonomy (as they defined these at that time), they would likely accept the offer. They felt strongly that the success of such an arrangement depended on discussing both expectations of the parent and limitations of the child regarding the provision of assistance. It was also noted that it would be important to have an arrangement that allows for flexibility and doesn't have too many 'ground rules.'

As well, participants indicated that they were aware of various housing options, although they spoke disparagingly about most examples. They also suggested that there
are a lack of options. For example, there are fewer extended care facilities than intermediate care facilities. They offered that the most practical situation was one where all levels of care were offered within the same facility. Another comment was that people should be 'matched' to facilities. They noted that people become very isolated in a facility where others do not share similar interests or abilities. This was exactly the sentiment expressed by the study participant who lives in a private care facility.

Again, finances were seen as a key to having access to housing options. For example, if an individual is poor, space is available through subsidized housing programs. If someone is well off, there are a variety of private facilities to meet demand. For those in the middle income bracket (which would be the case for at least half of the participants, and a majority of the general population), the options may be more limited due to long waiting lists. A suggestion from participants was that the government provide a tax break to families who provide care and assistance to a parent who lives with them.

The most favoured living arrangement/housing option was the one described earlier in the Results Chapter where family members each took a turn (one day of the week) visiting and assisting their 95 year old mother who lives in her three-storey home. Everyone marvelled at this example but also agreed that this option was unlikely to exist for many. It is rare for more than one child to live in the same locale as a parent. Also, participants weren't sure if individuals other than family could be mobilized for such an arrangement.  

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4 In fact, there are examples where individuals and organizations have facilitated the creation and mobilization of personal support around individuals who have few or no personal relationships. One
One participant at the follow-up meeting proposed that the issue of preplanning for living/housing arrangements may be a phenomenon to which Canadian society is still adjusting. It was noted that people are living much longer than ever before and may therefore desire a variety of housing and living arrangements as they age. As well, many of the current elderly immigrated to Canada as young adults and therefore did not have the experience of responding to aging parents requiring assistance. Although there seems to be an expectation among many that parents will live with their children, this may not be based on any tradition or common experience. Participants also noted that recent immigration policies, which emphasized family re-unification, have resulted in a number of older adults immigrating to Canada. Participants saw that these individuals are often very isolated even within their families.

Education and information on housing/living arrangements will need to cover not only existing options but also assist individuals who share common interests and vision to develop new alternatives. During the initial interview, participants appeared to have little to say about this aspect of preplanning. Of course this could be due to the researcher's failure to ask the right questions. It does, however highlight the value of checking back with participants to verify the results. It would seem that this topic still needs further exploration and clarification.

example is Project Friendship in Prince George which grew out of a community-based association's attempt to respond to the downsizing of provincial institutions that had been 'home' to adults labelled 'mentally handicapped' (Cayley, 1994). The goal was to connect these adults, who were leaving the institutions for group homes or their own apartments, to individuals and activities in the community. The program was very successful and continues to operate today. Planned Lifetime Advocacy Network and the Greater Vancouver Citizen Advocacy Network are other examples of organizations whose purpose is to facilitate the connecting of people with disabilities with individuals and activities in the community so they may have the opportunity for developing personal and supportive relationships. Friends for Life Society and programs through AIDS Vancouver provide similar opportunities for people with a terminal illness.
Identifying and Choosing Representatives and Related Issues

The foundation of any preplanning effort is the availability of someone or more than one person to be a representative. Choosing a representative is one of the most important content areas to be addressed by educational and informational initiatives.

While this study did not attempt to describe the structure and content of participants' personal and social relationships, their comments may shed some light on these matters. This discussion is not an attempt to offer a recipe for identifying or choosing a representative but rather to illuminate the study participants' view of potential sources of support and some of the factors they considered.

A spouse is the first and immediate source of assistance and would be given complete authority and discretion over managing the individual's affairs. If a spouse is not available (due to death, separation/divorce or because of her own need of assistance) then the individual looks to a child. Although participants usually chose one child as a representative — that is, to have formal/legal authority — they also indicated that if there were other children in the family, these children would provide assistance as well, to the parent and to the representative. Participants explained that the interactions among family members would continue to exist as always. Some naturally do more than others; some hover and others are more aloof. These differences were not a concern; participants accepted them as a fact.

The participants' reasons for choosing one child over another were varied. Some mentioned emotional closeness, others referred to shared values; others noted particular skills and for others, geographical proximity was a factor. Their reasons were
expressions of their individuality and of their relationships with their family members. Although some participants agreed that their friends knew them better than their children, they still turned to their children for any formal representation. However, their relationships with friends remained an important source of social interaction and non-formal assistance, such as advice, emotional support and practical help.

Although participants did not always choose a representative based on geographical proximity, some of their other choices suggest that it is an important factor in preplanning. For example, many participants when asked about preplanning for living arrangements replied that they had moved to be closer to family. Some described it as the first step in preplanning. Living near to someone offers more opportunities to develop and nurture the relationship. Proximity to family and other sources of support offers an interesting area to pursue in future research.

Participants also observed that in some situations the existence of family or friends does not necessarily mean an individual has support. Nor is the quality of assistance able to be measured by the number of personal relationships one individual has. In their opinion, the personal relationship had to involve the dimension of trust. This is discussed in more detail shortly. Other elements of personal relationships (including family) that participants' responses suggest may influence the assistance sought or given include the length of time people have known one another and whether they have common experiences or shared interests.

But what about those who do not even have personal relationships? As previously noted, the participants in this study were very active in community associations and in
this capacity became involved with older adults who had few if any personal relationships. It was obvious from participants' own experiences assisting those who had no family or friends, that deliberate effort and commitment was required if these individuals were to have access to preplanning. Otherwise they were extremely vulnerable to losing their independence and autonomy. Educational and informational initiatives on this aspect of preplanning will want to include a component that facilitates opportunities for these individuals to develop personal relationships.

The interviews elaborated on a number of issues pertaining to the establishment and maintenance of personal relationships. These include the nature of the relationship between the individual and her representative, communication between them and the specific role and responsibilities of the representative.

Trust and caring were the basis of the participants' relationships with those closest to them — spouse and children. The participants' responses suggest that the decision to undertake preplanning, particularly to formalize plans, was related to the interdependent nature of the relationship between the individual and her chosen representative. Those who had no difficulty or hesitation in choosing a spouse or child to represent them described a relationship of great trust and mutual support. This underlines the importance of the relationship, over and above specific tasks or instructions.

It is appropriate to point out here that participants who recounted examples of assisting people who were not family or friends, did not describe their efforts as altruistic. Neither did they present the individual as 'a problem' nor did they boast about the good job they did. Rather, they described the relationship: "I wasn't a friend of long-
standing...[but] she actually trusted me” (K) and “he came across as an angry person but what he really wanted was someone to weed his strawberry patch. He couldn’t do it. So I did it. He was surprised and we got along good after that” (V). These and other participants do reach out to people they do not know. This is not because they are ‘do-gooders’ or ‘needy’ but because in assisting others they are relating to them as an individual. And, in these relationships, abilities and capacities are recognized and valued. This form of affirmation and reciprocity cannot be bought.

Communication between the individual and her representative was seen as crucial to preplanning. As pointed out in the results, children do not necessarily know their parent’s wishes or values. Some participants expressed reluctance, however, to have discussions with those closest to them because of possible negative reactions.

While much of the negativity (usually expressed as avoidance of the topic) toward preplanning may be due to the pain of imagining the death of a loved one, it may also result from confusion about and unfamiliarity with the concept of preplanning. In the case of ‘adult children,’ they may feel that there is no need to have a discussion because they assume their role is to ‘take care of and do for’ their parent, when the parent can no longer manage independently. They interpret their role to be that of a protector of someone who is dependent — in the sense of a parent for minor children. Some refer to this as ‘role reversal’ (Stevens-Long & Commons, 1992).

Clearly this perception was at odds with the study participants’ view of the relationship and their commitment to self-determination. However, this perception was,
until recently, reinforced by legislation, policies and practices associated with meeting the needs of vulnerable adults.

As mentioned earlier in this paper, recent social and legal reforms in approaches to adult guardianship (including preplanning tools) are based on the principle of self-determination. These reforms challenge the traditional notions of doing ‘for’ people in their best interest and for their protection. The study participants resoundly rejected these traditional attitudes and practices; they were most eager to express their own choices, and expected them to be acted on, despite risks. For them, autonomy outweighed protection. Therefore to address these findings, educational and informational initiatives that focus on communication between individuals and their representatives, need to make visible the social context and values underlying preplanning. Above, all, participants believed that representatives are entrusted to respect the individual’s autonomy and not take over and impose their own wishes.

According to the interviews, another issue that the individual and her representative will want to discuss deals with possible limitations that representatives may face when carrying out specific wishes. Circumstances will change and responsibilities that representatives previously agreed to uphold may no longer be practical or reasonable to carry out.

Support for representatives is a topic area identified by caregivers. As they pointed out, making decisions for someone else is a heavy responsibility especially if there is only one representative. Representatives may need information in order to make
these decisions as well as an opportunity to share information and learn from others who have experienced similar situations.

**Formalizing Agreements**

How to formalize preplanning arrangements did not emerge as a major topic of concern to the study participants. They all knew the legal status of their arrangements and some deliberately chose to formalize and ‘legalize’ their plans. Formalizing agreements refers to documenting the choice of representative and specific wishes. Only enduring power of attorney has legal status but living wills, advance directives and similar agreements are often written with the help of a legal or health care professional.

Seeking professional assistance was the last step in the preplanning process. The participants’ experiences suggest that those who do want to formalize their plans will need easy access to legal professionals or others who can provide technical assistance with formalizing preplanning arrangements. According to those interviewed, they will also want any advice and the executed document to be in language they can understand. This is in part so they can discuss it with their representatives and other parties.

**Resources for Preplanning**

Based on the participants’ examples, the list of resources for preplanning would be a short one. As previously suggested, resources to assist with preplanning do exist but appeared to be difficult for those interviewed to access or perhaps were not available when they went looking for them. Examples of some current resources include the People’s Law School’s free fact sheets on power of attorney and living wills and the free law classes on these same topics offered to the public throughout the province. The Legal
Services Society publishes a free booklet called *When I'm '64* which includes information on enduring power of attorney. Already mentioned is the sample living will form distributed by the Jack Bell Foundation. Self-Counsel Press sells reasonably priced books and forms for enduring power of attorney and living wills. All of these publications are popular and much requested, however, there is no information on or process for determining their effectiveness.

Another resource and a recent one is the Community Coalition. The Coalition, formed to provide an organized voice for those most affected by the implementation of the new guardianship legislation, has been a catalyst for the involvement of older adults in preplanning issues. Through research and community development work, the Coalition has reached out to individual older adults and seniors’ organizations never before involved in preplanning issues. This has been accomplished by encouraging and supporting older adults to assume leadership in educating other older adults in their communities about preplanning. Many communities in B.C. are developing resource groups made up of individuals who can help one another with preplanning.

While the participants interviewed described a role for professionals and the community as resources for older adults who want to preplan, actual examples from their own efforts were very limited. Therefore, some of the points that follow focus more on ‘what could have been’ than on actual experience.

According to participants, professionals, particularly those in the legal and health care fields, have a role as sources of information and technical assistance. Specifically, professionals and service providers can introduce the concept of preplanning, outline
various options and refer the individual to sources of community help. For example, legal professionals could have discussions about preplanning with clients when clients seek advice about making a will, or setting up joint ownership of property. Physicians could talk about it during regular visits with patients who have chronic or terminal illnesses and with their caregivers. Other professionals and service providers that older adults encounter for health related services and financial and estate planning can also be instrumental in creating awareness of preplanning.

Those interviewed did not perceive their family, friends or professionals as ‘experts’ or the primary resource on preplanning. Rather they sought (but did not find) an independent, non-judgemental source of information and advice. They envisioned getting help from an individual or agency based in the community which had no conflict or self-interest in an individual’s preplanning activities. This individual or agency could be available as a resource for information/education and for emotional and social support. This suggests that there is a large void for community associations and agencies to fill in promoting existing programs or developing new initiatives to support the preplanning efforts of older adults.

The results also revealed that existing sources of support such as Ministry of Social Services senior citizen counsellors and seniors peer counsellors may be under-utilized. Seniors counsellors provide unique assistance to other older adults. As peers, they can draw on their experiences as well as any special training. They are also in a position to establish the trust that may be necessary for discussing personal choices and
for enabling individuals who are isolated to make links with citizens and voluntary associations in the community.

Participants' complaints about not finding information or constantly being referred elsewhere, speak to the need for community associations, seniors counsellors, professionals and service providers to know about and communicate with one another. However, this would be for the purpose of meeting the need of the individual, not that of the agency or of coordination.

New resources or approaches may be necessary to address participants’ greatest concern — how to make preplanning accessible to older adults who are isolated and frail. Their analysis was that the current situation of relying on the individual to initiate preplanning is not viable for many and they suggested the need for new approaches. As suggested above, individuals are more likely to trust a peer or someone who has no perceived conflict of interest. For this reason, local, community-based associations and agencies are naturally suited to facilitate the connection of isolated, frail older adults to other citizens in the community who share their interests. This provides opportunity for the development of personal relationships.

Fundamentals of Education and Information on Preplanning

The interviews identified some strategies that might be considered fundamental to any educational initiatives on preplanning. First and foremost, education and information on preplanning will start with the experiences and perceptions of older adults. Starting from this perspective makes preplanning relevant and accessible to older adults; it is also consistent with the philosophy and intent of preplanning.
Similar to starting with individuals’ experiences is sharing stories. One of the most effective educational strategies identified by those interviewed and affirmed by the group interview session was learning from others’ experiences. This approach ensures a relevant context for the topic, it inspires confidence ‘if he can do it, maybe I can too;’ it focuses on practical information and it enhances personal relationships as people reach out to one another in empathy and to problem-solve.

Preplanning is an expression of an individual’s most personal and private wishes for a time when she cannot speak for herself. Individuals therefore want assurance that they are making the best choices. They seek a critical or evaluative approach to the topic. One participant characterized this as ‘honest’ education. Older adults who engage in preplanning need and want education and information that provides a full and complete picture of all the options and consequences — both the negative and the positive aspects. As some participants said, it means facing the ‘hard questions’ such as: Who can you trust? and What happens if the person you choose doesn’t or can’t carry out your wishes when the time comes?

Finally, participants’ experiences portrayed preplanning as a thoughtful and deliberate process as opposed to an impulsive one. Therefore, the most effective educational and informational initiatives will be those that are flexible and allow older adults to pursue questions and concerns at their own pace and in their own style with no pre-determined steps they must follow. Initiatives will be responsive to a variety of needs that may change over time.
The following chapter offers some general conclusions and makes specific recommendations that are consequent to the analysis of the results.
CHAPTER VI
SUMMARY, RECOMMENDATIONS AND CONCLUSION

Summary

"Many seniors are more afraid of dependency than death...yet [they] may hesitate to plan for...[the time]...prior to death" (NACA, 1991, p.1). This statement (abbreviated here) introduced this research report and set the stage for exploring the perspective of older adults on the issue of preplanning.

Twelve adults, over the age of 65, participated in semi-structured individual or group interviews. Six participants also met for a follow-up meeting, prior to the conclusion of the study, to validate the results.

The research results cannot and should not be used to make definitive statements regarding the experiences and perceptions of any seniors who did not participate in the study. As with any qualitative research, however, the information gathered is rich in possibilities and potential, offering avenues to explore and ideas to test in practice and in future research.

As mentioned in the background chapter of this thesis, current education on preplanning is based on the assumption that individuals only need to know the legal requirements and procedures for documenting/formalizing their plans. The results of this research, however, made clear that there are many other things to consider and they are more important and complex than filling out a form.

The major conclusions from this research is presented below. For a summary of the interview results, see page 75.
The findings of this study affirm and elaborate on the premise posed in the statement opening this chapter. The older adults who took part in this study do fear the possibility of losing their independence and being a burden on their families. However, they saw great value in preplanning and many of them undertook it despite a lack of external guidance and encouragement. The findings also allude to a number of factors that may cause some to hesitate to preplan.

Factors identified by this study that make preplanning possible and accessible to older adults are:

- recognition of the potential need for and value of preplanning;
- the existence of personal relationships based on trust;
- the receptivity of spouse, family, friends and other trusted persons to discuss specific wishes and limitations and to take on the task of representing the individual’s values and wishes;
- the willingness of third parties and professionals to recognize an individual’s representative and to act on the individual’s instructions;
- knowing about and having access to options for formalizing and legalizing plans; and
- the availability of community-based sources of information, advice and support.

Educational initiatives on preplanning must address these issues. Other considerations for educational initiatives are the context in which preplanning takes place and the format in which they are presented. Some examples are presented in the following list.

- The format must be interactive and should include ‘peers talking to peers.’
- Health-related concerns and situations (involving acute, preventative, rehabilitative or palliative care and treatment) offer an entree for raising the issue.
- Self-determination and self-reliance must be the central message in the promotion of and presentations on preplanning.
- The necessity of individual and community efforts in establishing and maintaining personal relationships must be emphasized.
The elements related to context and format are further explained below.

Participants’ responses clearly affirmed that individuals can benefit from assistance with thinking about, discussing and formalizing preplanning arrangements. Some individuals will need more help than others. This study demonstrated that although many participants were able to undertake preplanning without much outside help, they were eager for education and information. They wanted to explore and discuss others’ perspectives and experiences — especially those of other older adults — and they wanted to share their own expertise. In fact, the topic of preplanning served as an entree for engaging in a dialogue about some of life’s most profound moral/ethical issues and dilemmas. These individuals welcomed such opportunities to clarify and resolve their thoughts and wishes.

Although the study indicated that it is when an individual perceives a threat to her independence, usually as the result of deterioration in physical abilities or health, that she is most likely to recognize the relevance of and need for preplanning (and will most benefit from educational and informational initiatives), efforts must still be made to encourage older adults to engage in preplanning prior to this circumstance. A crisis may motivate someone to action, but it may not be conducive to the information-gathering, reflection and discussion that are necessary to uphold the intent of preplanning and to honour her values.

The appeal of preplanning is that it offers individuals an opportunity to express their personal preferences for possible future need of assistance. In this way, preplanning facilitates independence and honours self-determination — values of extreme importance
to study participants. This message must be at the core of educational and informational initiatives and policies on preplanning and may be helpful in facilitating preplanning among those who do not yet ‘feel the need.’

Personal, trusting relationships are the foundation of preplanning. If an individual has a spouse, who will be able to provide assistance if the need arises, preplanning is usually simple and informal. Increased effort and formality becomes necessary when the individual turns to children, other relatives, friends or neighbours. However, the greatest challenge noted by participants is faced by those who have few or no personal relationships. Many of these individuals tend to be frail and potentially vulnerable to becoming dependent on formal (and often costly) services and the public guardianship system. These individuals will require assistance with developing and maintaining personal relationships. Meeting this need must involve community action as well as individual effort.

In brief, this research calls for education and information on preplanning in formats that older adults can easily access, identify with and act on. Education and information have to be relevant and address a variety of circumstances and situations. Wherever possible, emphasis should be placed on developing expertise among older adults themselves to encourage peer support with preplanning. Efforts must be made to make preplanning accessible to those who need it most — individuals with limited social resources including few or no sources of personal or informal support.

The crucial factors identified by this research and summarized above point to the need for a particular approach to education. As concluded by one U.S. researcher (High,
1993) who studied the effect of educational initiatives to increase the use of advance health directives (reported in detail on pages 23 and 24), education increases awareness but not necessarily the use of preplanning tools. Although there is no evidence, in agreement or to the contrary, from B.C. sources, the experiences of participants in this study suggest that traditional approaches to informational/educational initiatives did not influence their decision or ability to engage in preplanning. However, the results of this research and the work of the RATG, provide a more complete picture of what is necessary to make preplanning accessible to older adults.

Educational initiatives must be guided by the principle of self-determination. Such an approach is most similar to a ‘bottom up’ process or what is sometimes called ‘radical adult education.’ This philosophy of education recognizes and affirms the capacities of individuals to create and re-create their reality — their community. In this context, the design and delivery of education/information on preplanning for older adults is led by the perspective of older adults.

This form of education also recognizes the importance of individuals working with one another to create change and to influence their social environment. Collective action will be necessary to make preplanning possible for the most vulnerable and isolated. But such action requires a two-pronged effort. On one hand, opportunities must be created for individuals who are isolated and marginalized to connect with others in the community who share their interests. On the other hand, it is also necessary to ensure

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5 This is not meant to suggest that individuals or groups can intrude or insist that another individual get involved in activities or make friends. Any efforts to link citizens with the community must operate from the principle of self-determination. The emphasis here is on creating and promoting opportunities, not expectations.
that communities are ‘hospitable’ places (Cayley, 1994) and ready to welcome citizen involvement. In both cases, this means starting with people who are interested and willing to participate. It also means letting people connect as individuals — not as defined by external systems (for example, as service provider or as receiver of services).

The goal of connecting isolated and marginalized individuals to the community is based on the assumption that these individuals have something to contribute (Kretzmann and McKnight, 1993). This contrasts with the assumption and mandate of the formal service system that sees these individuals as having a need or problem to be fixed. To be successful, efforts to connect and re-connect individuals to community must originate from citizens and community groups that derive no self-serving benefit from such relationships, other than building stronger and healthier communities.\(^6\)

This is the framework within which the recommendations are proposed. Although this model looks to the informal sector for initiative and leadership, the formal sector can facilitate and encourage these activities.

**Recommendations**

There is no attempt to respond to every issue raised by this study. The following recommendations focus on three main strategies: 1) developing expertise about preplanning among older adults in the community who can provide assistance and support to other seniors; 2) distributing information about preplanning to create

\(^6\) It is important to recognize that some community-based associations provide both advocacy and services. This is a potential conflict in the model proposed here. For example: in the process of developing an organized voice for people whose personal lives are affected by the implementation of the adult guardianship legislation, staff and boards of some organizations involved in the Community Coalition are being challenged by their memberships about the competing interests of their mandate.
awareness of preplanning among older adults and their family and friends and 3) developing and strengthening community-based supports to facilitate and enable individual efforts with preplanning and community action that will make preplanning accessible to those who lack personal relationships.

The recommendations are directed at specific organizations or types of organizations, including those with which the researcher is involved as already described in this report. Listing recommendations by organization makes it easier for readers to locate their specific interests, however, this also means that when taken as a whole some recommendations may seem repetitive. Recommendations are numbered consecutively.

It is understood that all organizations and institutions should include strategies to evaluate and monitor the effectiveness of their initiatives and make changes where indicated. This recommendation is not repeated below.

Where a recommendation says ‘involve older adults’ this does not mean consult with or include one representative. It means that the perspective of older adults must predominate. This does not necessarily require a majority in numbers but it does mean giving their viewpoint a veto. Also, the expression ‘link with’ is often mentioned. This means to establish an ongoing relationship with at least one individual within the organization at either the staff or board level.

Recommendations for the People’s Law School

The People’s Law School is a non-profit society that produces public legal education/information materials and events. The findings of the study call for such an organization to develop and present information/education on preplanning issues from the
perspective of older adults by involving older adults and by linking with community associations. It is therefore recommended that the People's Law School:

1. evaluate the effectiveness of its current series of publications on preplanning which target older adults, their family and friends. Explore how the information was used. Did it help readers to make a decision and/or take action, why or why not, what other information did they find helpful or need, etc.

2. make it a priority to involve older adults (individuals, from seniors' organizations and from community-based associations such as the Alzheimer's Society, the Parkinson's Association, the B.C. Caregiver's Association) and their perspectives in determining the content and presentation of information and education on preplanning.

3. explore the possibility of involving residents of a care facility in the development of information/education on preplanning from their perspective.

4. direct education on preplanning to older adults who are the natural leaders, advocates, counsellors and sources of information in their communities.

5. target free law classes and publications on preplanning issues to older adults in general, their family members, seniors citizen/peer counsellors and the general public.

6. work with the Community Coalition and RATG to develop a list of local, community-based sources of information and support for individuals who want to preplan. Contact seniors' organizations, community-based associations and seniors counselling programs about being listed and for assistance with distribution. Ensure this list of local resources is available to speakers at free law class presentations and is reproduced in any publications.

7. include mention of preplanning in classes and publications related to wills and estates, organ donation, retirement planning, tax or financial planning, funeral planning and property ownership.

8. develop a class or series of classes under the heading "Putting Your Affairs in Order" and include education on preplanning issues as well as on writing a will, making arrangements for burial or cremation and instructions for organ donation.

9. distribute information and promote classes and publications to various government, private and community services/programs that serve older adults. In particular, target preventative, supportive or maintenance, palliative and rehabilitative health services.
Recommendations for Senior Citizen/Peer Counselling Programs

The Ministry of Social Services Senior Citizen Counsellor Program is a network of older adults throughout the province, with a full-time paid Coordinator in Victoria. The older adults are chosen by the Ministry and volunteer their time (expenses are paid) to assist other seniors with their problems, particularly with issues related to government benefits. Study participants who were counsellors in this program indicated that they were a resource for much more than these matters. They described assisting people to find a physician, to arrange for home support, to do their income tax and much more. They believed that older adults came to them for help for a number of reasons: 1) they were peers; 2) they did not punch a clock and so could spend time; 3) they would not benefit financially from the contact and 4) they were accessible — they lived and were involved in the community. They also noted that some people just need a little bit of help to get started; others need a lot of support to gain the confidence to reach out to others.

Senior peer counselling programs may be community-based initiatives or sponsored by a government agency such as the Vancouver Health Department. Like senior citizen counsellors, peer counsellors are well suited to approach preplanning with older adults, especially those who are most isolated and vulnerable. It is therefore recommended that the Ministry of Social Services Senior Citizen Counsellor Program and seniors peer counselling programs:

10. include assisting older adults with preplanning as part of their mandates and services to seniors in the community.

11. incorporate preplanning issues in the training program for senior counsellors and involve older adults in the design and presentation of the program.
12. promote senior citizen/peer counsellors as a resource on the topic of preplanning through health related services and programs; for example: extended care facilities, public and community health programs, palliative care programs.

13. encourage senior citizen/peer counsellors to become aware of and known to local groups and any initiatives related to preplanning in their communities as well as linking with the Community Coalition and the RATG.

14. when recruiting senior citizen/peer counsellors, choose those who are well connected to the community and have ability and skill in ‘matchmaking’ the abilities and interests of isolated individuals to activities in the community.

Recommendations for Seniors/Community Associations

Community associations, particularly those led by seniors, have an important role in making preplanning accessible to older adults. They can be a valuable resource to individuals and groups by promoting preplanning, facilitating and enabling individuals to become connected to the community and thus to have opportunities to develop personal relationships, providing support to representatives and potential representatives and lobbying for legislation and policies to support informal assistance and remove barriers to self-determination and self-reliance. Community groups must also demonstrate and celebrate the expertise of older adults by encouraging and nurturing the leadership of older adults themselves — after all, preplanning is about self-determination.

One of the strengths of the Community Coalition and the RATG has been the diversity of perspectives expressed by the individuals and groups which belong. Yet the

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As of September 1995, the Community Coalition lists among its members, provincial organizations — including the Council of Senior Citizens Organizations, B.C. Association for Community Living, the Alzheimer Society, B.C. Coalition of People with Disabilities and the West Coast Mental Health Network — local groups — including the Network of Burnaby Seniors, Family Link, the Victoria Association for Consumer Empowerment, Self-Advocates on the Move and the Kamloops Seniors Liaison Council — and hundreds of individuals — including seniors, self-advocates, consumers of mental health services, caregivers, family members.
different viewpoints have come together under a single vision. Reflecting on the results of this study and the achievements of the RATG, leads the researcher to conclude that there is much that older adults and seniors groups can learn from the experiences of those in the disability movement. Community groups can benefit from building alliances and combining efforts and resources to achieve shared goals.

It is therefore recommended that seniors organizations, such as Seniors Resources and Research Society, Council of Senior Citizen Organizations, Old Age Pensioner’s Associations and other community-based associations which focus on issues that affect some older adults, such as the Alzheimer’s Society, Parkinson’s Association, BC Caregiver’s Association:

15. educate staff, board and membership about preplanning.

16. include members and older adults in the design and presentation of information and education on preplanning.

17. initiate educational programs for older adults. Give particular attention to older single women, individuals in facilities and caregivers.

18. provide organizing help, space and facilitation, if needed, for informal group discussions with older adults and their family members about preplanning. Some potential topics identified by this research include: choices for end-of-life care and treatment; defining quality of life; housing options and living arrangements. Encourage participants to take ownership of the program including suggesting other topics, inviting speakers, researching information on questions and concerns raised and reporting back, developing action plans to respond to common issues.

19. focus efforts on assisting individuals (including those who live in facilities) who want to preplan but who have no close personal relationships; that is, help them to make connections with individuals and activities in the community who share their interests.

20. educate citizens and groups in the community about preplanning and about ways that they can create a ‘hospitable’ and inclusive community that welcomes those who are currently isolated or marginalized. Consult some examples where
this has been done, for example Project Friendship in Prince George and Powell River.

21. form or assist in the formation of a diverse community resource group to help individuals with preplanning.

22. link with other agencies and efforts in the community including seniors citizen/peer counselling programs, groups that support people with disabilities, groups that support people with terminal illness, to share information and resources and to identify areas for research and action on preplanning issues.

23. provide support (information, education, advice, practical assistance, emotional support, networking, advocacy, etc.) for representatives.

Recommendations for the Community Coalition

The activities of the Community Coalition were referred to frequently throughout this thesis, suffice to say here that the following are specific recommendations related to furthering its mission to create and promote community-based alternatives to public guardianship. The Community Coalition should:

24. promote and advocate for the community voice in the implementation (policy-making process) of new guardianship legislation to ensure representation agreements will be accessible to older adults and honours the principles of self-determination and self-reliance.

25. work with existing community contacts and members of the Coalition’s advocacy network to facilitate and support the development of resource groups in their community to assist individuals with preplanning, especially those who have no one to be a representative.

26. nurture and build on consumer-led initiatives undertaken during implementation of the new guardianship legislation. These include the development of a GuideBook on Representation Agreements initiated by the Network of Burnaby Seniors; community workshops for seniors designed and led by seniors and education of senior peer counsellors.

27. consider incorporating as a non-profit society with a mandate to be a resource on preplanning for individuals and communities and to advocate for the creation and promotion of community-based alternatives to public guardianship.
28. work with the Office of the Public Trustee to develop criteria for the mandated evaluation of the new guardianship laws.

Recommendations for Professional Societies and Service Systems

The following recommendations are directed at professional societies and service systems. Professionals and service providers can be resource to provide introductory information and technical assistance on preplanning. However, in order to fulfill these roles, they need education about preplanning from the perspective of older adults. In particular they must be sensitized to the values underlying preplanning and their role in the preplanning process.

Professionals and service providers are often the first to come in contact with an individual who is isolated and frail (usually contact is precipitated by a health crisis). Their ultimate goal in helping an individual in this situation must be to facilitate connecting the individual to the community. The formal system can provide services and products. It is in the informal sector, however, that individuals will find opportunities for authentic relationships which in turn offer personal assistance, affirmation and caring.

It is therefore recommended that professional organizations (particularly from the fields of health, law and finances) and the service systems:

29. educate management and members/employees about preplanning issues from the perspective of older adults.

30. make it a priority to involve older adults in the development and presentation of information and education on preplanning to members/employees.

31. educate members/employees about local, community-based sources of information and help available for older adults who want to engage in preplanning.
32. encourage members/employees to introduce the topic of preplanning to clients/patients and to refer clients/patients to community-based sources of assistance.

33. assist (without co-opting or taking over) community initiatives to promote preplanning and to educate and support individuals. Offer financial and practical support (for example, photocopying and distribution of materials). Share expertise (knowledge of systems, computer skills). [The RATG is a model of how this can work successfully.]

Recommendations for Government

Although adult guardianship legislation falls under provincial jurisdiction, the federal government administers programs in some of the specific areas that affect preplanning such as health care and housing. Recommendations are limited to general ones that attempt to increase the awareness and use of preplanning and are directed to both levels of government. Obviously the government of British Columbia is responsible for the implementation of its new adult guardianship legislation. This process is described under the next heading. Specific recommendations for the provincial and federal governments are to:

34. encourage and fund local and community-based efforts on preplanning such as: developing promotional, informational and educational initiatives, reaching out to vulnerable and isolated individuals, establishing and supporting volunteer-driven resource groups and providing support to representatives.

35. include information on preplanning (including local resources) with government benefit cheques. For example: Canada Pension, Old Age Security, SAFER. Also consider including information in mailings from the Ministry of Health. For example: organ donation card.
Proposals for Achieving Accessibility for Everyone: The Experience of Guardianship Implementation

Action on some or all of the above-mentioned recommendations will make preplanning more accessible to older adults, especially to those who are similar in background and situation to study participants. The hope is that increased efforts will be made to reach older adults who are most vulnerable and isolated. However, the goal of making preplanning accessible to everyone is beyond the scope of this thesis and the specific recommendations. Such a vision will require significant social change.

As frequently stated, the findings of this study endorse preplanning as an important tool for adults in maintaining their independence and expressing their choices. The results also indicate that accessibility and viability of preplanning depends on the support of family, friends, citizens and voluntary groups in the community. In its roles as law/policy-maker, collector/distributor of public funds and service provider, the government has considerable power to enhance or restrict the accessibility of preplanning. The experiences of the Community Coalition and the RATG are illustrative here.

First, some background. The reform of B.C. adult guardianship legislation originated with individuals in the community, specifically parents of adult children labelled mentally handicapped. The group that formed around this initiative was all-inclusive. Professional groups (for example, the Registered Nurses Association and the

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8 The researcher’s involvement in the Community Coalition and the RATG affords her an insider’s view of the implementation process. The information reported here describes the general sequence of events which are supported and detailed in minutes of meetings with government, briefing documents and correspondence between the Coalition and government.
B.C. Hospital Association), service providers, advocates and consumers\(^9\) were all involved. During the drafting of the legislation (which entailed a formal partnership with government) and after it was passed in the legislature, consumers expressed a number of disappointments with the new laws. The disappointments largely concerned the legislation’s emphasis on programs and procedures that professionals and service providers should develop and its lack of emphasis on “the informal, citizen based, peer and family centred supports which are the hallmark of consumer movements for independent living” (Community Coalition, 1995, p. 2). Analysis of the experience of reforming and drafting the new laws, made it clear that, during the implementation period, consumers needed to have the same opportunities for an organized voice that providers and administrators had through their respective organizations and ministries. The Community Coalition formed to be that organized voice.

During the first year of implementation, government (specifically the bureaucracy), professional groups and service providers spent considerable resources questioning and challenging the rights of consumers to: a) be at the table, as an organized voice, and b) to receive government funding to promote community-based alternatives to public guardianship. The Community Coalition and RATG were required to define and re-define the community and consumers. In order to articulate the perspective of consumers and to address the deficits in the legislation, it became critical for the

\(^9\) The Community Coalition and RATG use a number of terms, including ‘consumer’ and ‘individuals who are vulnerable to public guardianship,’ to describe the unique perspective of those whose lives are personally affected by the legislation. While the legislation is for all citizens of B.C., the Coalition and RATG have organized the voice of citizens who are most immediately affected and who have a personal interest. This reflects both adult education principles and common sense which sees participation based on the interest and need of the individual/group. Older adults have identified themselves as a major ‘users’/consumers of this new legislation.
Coalition to differentiate between the interests of government, professionals and services providers and the interests of the community.

As suggested earlier in this thesis, government, service providers and professional groups have an interest in preplanning where it allows them to avoid liability. However, these groups may also find themselves in conflict with the principles of preplanning where it threatens current policies and practice based on the system’s judgement of ‘best interests.’ Through preplanning, citizens may reject services and choose to live at risk; they may also hold third parties more accountable for their actions or non-action. The community’s (consumers, their families and friends) interests in preplanning are to enhance self-determination and promote personal, informal supports.

From the perspective of this thesis the question is: which interest will view the isolated, vulnerable adult as a capable individual with the right to choose? (This is sometimes referred to as seeing the glass half full as opposed to half empty.) Which group is likely to put resources into creating opportunities (imperfect, messy or risky though they may be) to enable this individual to exercise her autonomy through assisted decision-making?

During implementation of the new laws, the Community Coalition challenged the traditional structure and process of working with government. It rejected consultation (which typically says ‘thank you for your input, we’ll make the final decisions’) and representation (where a senior from the government instituted Seniors Advisory Council is portrayed as representing all seniors in B.C.).
The Coalition proposed a consumer-led process for implementation. Like the philosophy guiding this research, it said implementation should be led by the experiences of those personally affected. The Coalition maintained that only by listening to the experiences of those who are most vulnerable will government know how to write the policies to make the legislation work for them. Considerable tension resulted from this approach because it was new, because it put power in the hands of the least powerful and because it valued the process not just tangible products and outcomes.

The Coalition’s vision of reform calls for government to channel resources out of the formal guardianship system and invest them in community-based alternatives. This vision is based on the experiences of individuals and families who have been personally affected by public guardianship. In recent decades, they have seen public resources and attention concentrated on building formal service systems in response to the need of assistance. But these systems have not generally led to an improved quality of life or increased independence for those being ‘cared for.’ Dissatisfaction with the human service system has led consumers, their families and policy-makers to search for alternatives. Attention has turned to the informal sector, the community. But it is naive to imagine that the community has the necessary resources to fill the gap or to develop new responses. In many cases, the growth of formal systems has been at the expense of the community. Informal sources of assistance have been ignored, devalued and in some cases destroyed. Deliberate effort must be made to value and support the

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10 An example of this is seen in the de-institutionalization of adults labelled mentally handicapped. When they returned to the community as middle-aged and older adults, many found themselves alone except for the individuals who were paid to be in their life (financial aid worker, social worker, home support worker, etc.). Family members were unavailable because of geographic or emotional distance
strengthening and re-building of the community. These lessons may be useful for understanding the issues and consequences of institutionalization and older adults. With little emphasis on creating and supporting community-based alternatives, older adults who need assistance may have few options. More on this issue, as it emerged from the study, is discussed in the next section.

**Further Research**

This study explored the topic of preplanning in general. During the course of the research some issues emerged which demand specific attention. More study needs to be given to clarifying the types of assistance people need and want from the informal sector versus the formal sector. Much may also be learned from detailing the experiences of older adults’ who provide assistance to others (often to people who have no family or close friends).

Future research also needs to target other populations. Considerable information exists detailing the features of older adults’ personal relationships. Examination of these results may identify at-risk populations (that is, older adults who have no personal relationships). This research may also provide insights relevant to the design of informational or educational initiatives on preplanning. For example, the type of assistance that one anticipates may depend on the nature of the relationship or geographical proximity.

usually as a result of policies related to institutionalization. Friends made while living in the institution were also inaccessible due to distance, lack of information on their whereabouts or lack of resources to maintain contact. De-institutionalization as a government initiative did not include policies to facilitate the creation or strengthening of personal support networks for people who returned to community. It was up to the community to take the initiative to respond (see footnote 4 on pages 99 and 100).
The results of the current study suggest that children have different perceptions of
preplanning than their parents. Information about this view will be useful for designing
educational initiatives for either or both groups. The older population itself is not
homogenous. The participants in this study had economic and social resources that
afforded them considerable choice and privilege. Future research on preplanning needs to
focus on older adults who come from different situations. It is important to explore this
issue with older adults from other cultural and ethnic backgrounds (non-European), with
those who live on fixed incomes, with those who live in care facilities, or with those who
have no family.

A similar approach as the one used in this study is suggested for research on the
above-mentioned topics and groups. The lack of existing information and the difficulties
in accessing some of the populations favour a qualitative methodology.

British Columbia's new *Representation Agreement Act* requires that
representation agreements be registered. This data base will offer opportunity for
quantitative research on the use of legal preplanning tools in this province. It may be
possible to report on: how many agreements exist (this can probably be listed by age);
who individuals consulted for assistance (a legal professional or a trained community
advocate); the number of representatives an individual tends to name; whether
representatives live in geographic proximity to the individual who made the agreement.
Research based on the data base (which has to comply with B.C.'s privacy legislation)
will only offer very limited information and allow for very broad generalizations about
people who make agreements. It will not identify the barriers that people encounter when
completing agreements or that prevent people from making agreements. This research focus will have to be incorporated in the evaluation that is required by the guardianship legislation. The criteria for this evaluation are still to be determined.

A specific and important issue identified by this study which needs immediate attention is that of housing options for older adults. Little is known about this issue from the perspective of preplanning. Current educational endeavours on preplanning simply mirror the areas encompassed by existing preplanning tools. Because these tools deal only with financial/legal matters, end-of-life health care or treatment or issues specific to psychiatric illnesses, there is little awareness of or information on preplanning for where one wants to live and with whom. As the participants in this study reported, housing/living arrangements was one of the first areas they identified under preplanning—choosing (in some cases moving) to live close to family. Follow-up discussion with participants identified this area as one of the critical determinants of other opportunities for choice including the opportunity to develop personal relationships.

Housing and living arrangements are an important issue for all ages. As the ‘baby-boomer’ generation ages, their numbers alone will necessitate the development of alternatives and options for living arrangements. Many older adults find that current options do not meet their needs or wishes or they are not affordable.

Research and action in this area are much needed. To be effective, the evaluation of existing options and the exploration of alternatives must be based on the experiences, interests and capacities of older adults. Unfortunately, those with the greatest knowledge of current structures and the most interest in changing them also have the least power and
resources. Care facility residents will require considerable support to take part in such efforts, especially if they take place outside the facility. On the other hand, organizing for change within the facility is likely an impossible task. Qualitative and participatory research which includes older adults (care facility residents and non-residents), their families and friends and which is linked to action offers an approach for defining the problems and for creating viable solutions.

**Conclusion**

This study revealed numerous opportunities for educational/informational initiatives on preplanning. Educational initiatives which take a ‘bottom up’ approach and which focus on community development can make it possible for all citizens, even the most vulnerable and isolated, to have the pre-requisite for preplanning — that is, a trusted personal relationship. However, this goal will not be achieved overnight and it will face many challenges.

The Representation Agreement Task Group and the Community Coalition have found that encouragement and validation are an important part of the support they give people who undertake preplanning, particularly in the initial stages. McKnight (1987) points out that, as individuals, families and community we have given over more and more of our capacities, our knowledge and our power to outside ‘experts.’ We have fooled ourselves into thinking that we can create systems that care, and have ignored and de-valued the natural and affirming assistance of families (a familiar sentiment expressed by mothers who stay home to raise children) and the community. Something is out of balance.
However, the development of community-based responses which seek to counter the imbalance come with a couple of cautions or conditions. First, service systems cannot continue to receive the same amount of resources or a larger share. Resources are needed to develop and strengthen community-based alternatives. "You cannot have both strong communities and strong bureaucracies or systems. You cannot have strong social service systems without communities getting weaker and weaker. The weaker the community, the weaker the ability of people, the weaker the willingness of people" (Etmanski, 1994).

The other concern is that as the community uses its' strengths and capacities to solve problems and to create alternatives, the movers and shakers within systems will see the community work as 'new territory to conquer.' McKnight worries that, "[community efforts] will become quantified, systematized, administered...to finally colonize more of the everyday life of community folks" (Cayley, 1994, p. 26).

Family, friends, neighbours, citizens and voluntary-based associations can meet needs in ways that formal systems cannot. Assistance from these sources is characterized by responses that are individualized, less intrusive, flexible and creative. As McKnight (1987) contends, the strength of relationships among families and among citizens are that they incorporate both fallabilities and capacities and value each person’s unique gifts.

This may be particularly important to older adults because they are often seen solely as recipients of services and government pension benefits (Kretzmann & McKnight, 1993). In fact, more frequently they are portrayed as consumers of the future generation’s pension funds. Some participants in this study expressed concern about the
ageism that they have experienced and which separates older adults from the rest of society. Kretzmann and McKnight (1993) suggest “communities need to rediscover seniors as assets, as possessing a wide range of skills, talents and resources” (p. 52).

Preplanning may be a catalyst for helping communities to recognize and realize the contributions of older adults. Preplanning demands that older adults be seen as self-determining. This leads to interactions which focus on the individual and her personal values and wishes. This process affirms the strengths and accepts the weaknesses of both parties. Preplanning is ultimately, an experience in community.

This thesis concludes with a message from the participants in this study. At the follow-up meeting they re-emphasized their belief that everyone, including young people, should preplan. One reason for this view is that ‘anything can happen.’ It was revealing to the researcher that in the six month period between the initial interviews and the follow-up interview, at least four participants had experienced some significant changes in their lives. The wife of one participant had died, another participant developed serious health problems that severely curtailed her activities, another participant (whose husband suffered from Parkinson’s for 16 years and lived at home) had to admit her spouse to hospital where he is awaiting placement in a care facility and one other participant has found her already limited mobility even more restricted. Although it was outside the parameters of this research, it would have been valuable to explore with these participants if they had different perceptions of or new experiences with preplanning as a result of the changes.
Participants were eager to encourage preplanning among younger people for another reason. They perceived preplanning as a lifelong process. They saw that it was influenced by choices made at earlier stages of life. They believed strongly that looking after one's health and one's relationships when young are preparation for a better quality of life in the future.
REFERENCES


Community Coalition for the Implementation of Adult Guardianship Legislation. (1995, July). Summary of the regulatory and policy issues that are essential to the promotion of alternatives to public guardianship. Brief presented at meeting with the Implementation Director of the Office of the Public Trustee, Vancouver, B.C.


Dear

My name is Joanne Taylor. I am currently working toward a Master of Arts degree in Adult Education at the University of British Columbia. For my thesis, I am interviewing older adults who have an interest in preplanning for possible incapacity. I hope that the information I gather will produce recommendations for the development of educational and informational activities on this topic.

I am writing to ask if you are willing to participate in my research study. I am interested in learning about your experiences with and perspectives on preplanning. You do not have to have made any plans, I am interested in your thoughts about the issue.

A detailed description of the study and a consent form are attached to this letter. If you are willing to participate, please sign the consent form and return it to me. You will keep the other copy of this information for your own records. Please read this letter and the description before signing the consent form.

All information from the interviews/discussions that take place during this study will be confidential. I will take notes during the interview/discussion and will also use a tape recorder. Only first names or pseudonyms will be used during the interview or discussion. I may enlist the assistance of two volunteers in the typing up of the recorded conversations. These volunteers will not have access to any identifying information about you. The tapes will be erased after the transcripts have been typed.

All transcripts and notes will be number coded and no real names or identifying information will be used in the report of the study. However, you may indicate on the consent form if you are willing to have your name listed under acknowledgments in the final report.

November 23, 1994
November 23, 1994

DESCRIPTION OF RESEARCH PROJECT

The title of this study is “Older Adults’ Experiences With and Perceptions of Preplanning for Possible Incapacity: Implications for Educational and Informational Interventions and Policy”

The researcher is Joanne Taylor, a master of arts graduate student in Adult Education at the University of British Columbia. Her supervisor is Dr. Tom Sork of the Adult Education Research Centre, UBC.

This research project involves interviewing seniors about their experiences and perspectives on preplanning for possible incapacity. The project takes place from December, 1994 to February 1995.

Participating in this study involves discussing your thoughts and experiences in one of two ways:

1. in an individual interview with the researcher that will take no more than two hours,

   OR

2. in a small group discussion led by the researcher (with up to five other participants). The group discussion will take no more than three and a half hours including breaks.

You will choose the format you prefer.

This study includes four phases in which participants can be involved. You may choose to take part in only one phase, some, or all phases. If you take part in more than one phase you may choose to take part in an individual interview one time and a discussion group another time.
CONSENT FORM

Title of study: Older Adults' Experiences With and Perceptions of Preplanning for Possible Incapacity: Implications for Educational and Informational Interventions and Policy

Researcher: Joanne Taylor, Master of Arts graduate student in Adult Education 596-3395

Supervisor: Dr. Tom Sork, Faculty Advisor, Adult Education Research Centre, 822-5702.

This consent form includes the cover letter and description of the research project, attached. Keep one copy for your records, return signed copy to the researcher.

I ______________________ agree to participate in this research project and I agree with the statements listed below. I indicate my agreement by signing on page two.

I have read the attached cover letter and description of the research project that outlines the purpose, procedures and the time involved in this research project.

I understand that, depending on the level of involvement I choose and the format, I am asked to give a minimum of two hours of my time to this project. If I choose to be involved in all phases of the project I am asked to volunteer from two to three and a half hours per month over 3 or less months.

I understand that my identity will be kept confidential as outlined in the cover letter.

I understand that I may refuse to answer any of the questions during the interview or discussion.

Consent Form
Page 1 of 2
I may withdraw from the study at any time. If I withdraw, there will be no penalty and I may request that my comments not be included in the study.

I have received a copy of this consent form and the cover letter and description for my own records.

☐ Please check this box if you are willing to have your name listed in the acknowledgments of the published report.

Signature: ________________________

Date: ________________________

If you are physically unable to sign, please have someone sign below, at your direction.

Name of participating adult (print): ________________________

I am signing at the direction of the adult named above:

Signed: ________________________

Relationship to participant: ________________________

Date: ________________________
Appendix D

INDIVIDUAL INTERVIEW OR SMALL GROUP DISCUSSION GUIDE

Note: some participants may have already engaged in preplanning, others may only be thinking about it, so the questions are worded to address past or (future tense).
⇒ = probes for elaborating on a particular area of questioning

What does preplanning for possible future need of assistance mean to you?
⇒ what is your interest in this issue?
⇒ what kinds of activities does it involve?
⇒ why do you think people do preplanning?
⇒ who do you think should be involved? - family? doctor? only the adult?
⇒ do you think preplanning is important? what makes it important?
⇒ who do you think should do preplanning? everyone?

What are your experiences with preplanning for possible incapacity?
⇒ what preplanning activities have you undertaken?
⇒ how did (will) you go about it - tell me the steps
⇒ what kinds of matters did (do) you specifically want to address in preplanning?
⇒ did (will) you put it in writing - did (will) you use prepared documents [living will, power of attorney...] or make up your own?
⇒ what were (are) some of the difficulties you found (anticipate) with your preplanning?
⇒ how did (do you anticipate) other people react? - your spouse, children, professionals
⇒ and how did you (do you think you will) feel about this, what did (will) you do?
⇒ where are your preplanning activities now? - complete? not started yet?
⇒ how do you feel about it at this stage? - relieved? worried? why?

What triggered you to think about this issue?
⇒ what things “push you” toward preplanning? who? what?
⇒ what things discourage you from preplanning or make you reluctant to do it? who? what?
⇒ was there a specific incident that happened? or someone else’s experiences?
⇒ what did (do) you want to accomplish through preplanning?
⇒ how important to you was (is) it to preplan?
Where did you learn about or get information on preplanning?

⇒ what information did (do) you want to know?
⇒ where did (will) you go for information/education about preplanning?
⇒ who did (will) you talk to? from whom did (do) you expect help?
⇒ what was helpful, what was not helpful? (what do you anticipate will be helpful and not helpful?)
⇒ what about this experience was encouraging, what was frustrating? (what do you anticipate will be easy, or more difficult?)
⇒ when did (will) you seek out information? - early on, after problems?
⇒ what were the steps for getting information? (what do you anticipate are the steps you will take to get information?)

Given the stage you are at now with preplanning ....

⇒ what will you do next?
⇒ what things would you do differently?
⇒ if someone else was in your situation, what would you advise them?

Are there other comments you want to make about this issue?
July 6, 1995

Dear:

It has been a number of months since I last communicated with you. Perhaps you thought I finished my thesis without you?? No, I'm still plodding away. In any case, I need to bring you up-to-date.

I transcribed all the interviews, organized the comments and wrote them up as a chapter of my thesis called “Results.” A brief summary of the results is enclosed. I recently finished another chapter called “Analysis” which is my interpretation of the results.

This is the part where I can use your assistance. I would like to set up a meeting of those who are interested to discuss the findings and analysis of the information gathered through the interviews. At the meeting I would present an overview of the analysis and get your input. It is like a safety check on my work — you will verify that I am on track and fill in any blanks or gaps.

However, I'd like to stress that this is purely voluntary on your part. I know the timing may not be the best as many people are on vacation or have visitors at this time of year.

I propose that the session would take a minimum of two hours (and I'll arrange refreshments). I think you would enjoy meeting the other participants. We will have to negotiate a convenient time and location to meet as a group.

I will contact you by phone to see if you are interested and available to meet. Thank you for your consideration of this request and for the assistance you have already provided. I have learned a lot and I know others will benefit from your expertise and experiences.

As you know, the purpose of my thesis is to make recommendations for the type of information and education seniors need about preplanning for possible future need of assistance. Because we are in the midst of implementing new legislation in British Columbia on this topic, your ideas will have very important and practical influence.

Regards,

Joanne Taylor
Appendix F

Dear study participants:

Here is a brief summary of the results of interviews with 12 seniors in the Lower Mainland about preplanning for possible future need of assistance. The following is a compilation of comments and are therefore generalizations rather than the opinions of any one individual.

You saw preplanning as a valuable and important exercise in ensuring your choices will be honoured if you need assistance and in relieving the burden on family members.

You tended to be more concerned about preplanning for end-of-life care and treatment (living will issues) than about preplanning for financial matters or personal care/living arrangements.

You placed more emphasis on identifying a person who would honour and carry out your wishes rather than on outlining specific instructions. Choosing this person was generally made easier if a spouse was available.

You generally preferred to name only one person to provide assistance if needed, rather than two or three people.

You found consultations with professionals such as a doctor, lawyer or notary public were usually straightforward and took place after you decided what their role should be. For example, telling a doctor your wishes for end-of-life treatments or asking the lawyer/notary to put your plans into a "legal" format.

You found discussions with family members sometimes required tact and in some cases you tailored the message to the individual.

You noted that the most common trigger for undertaking any preplanning measures was a real or anticipated decline in physical ability or health status. This included the potential risk of injury or of inheriting a debilitating disease. You also said that watching someone close to you experience a decline in ability to manage led you to anticipate your own possible need of future assistance.

July 1995
Your experiences suggest stages in a preplanning process. You became aware of preplanning tools (such as enduring power of attorney or living wills) long before you thought of using them personally. When something happened to you or someone close to you, the topic became more relevant and often lead to personal action. Thus you described a preplanning process as one that happens over time. Rather than being preoccupied with these issues, you take a practical and realistic approach to them & get on with it!

You identified some critical elements that you think people should consider when doing their preplanning. You advice was to:

• choose someone you trust to assist you
• if possible, choose someone who has known you over a long period of time
• let the person know you want them to take responsibility for assisting you or taking over your affairs if you cannot manage on your own
• give the person instructions about any specific wishes, this may be particularly important where the person is not your spouse
• be realistic in your expectations of the person you choose to help you as circumstances may change and it may not be possible for the person to carry out all your wishes
• put plans in place while you are well and able to communicate your choices

You suggested that educating seniors about preplanning is best accomplished by training and supporting other seniors to do it. Seniors can better identify with and learn from another senior — from someone who has similar experiences. They will also feel more confident of someone who has no vested interest in the subject or its presentation.

You also said that education should link up with other activities such as retirement planning programs, when doing a will or at support groups for caregivers or for individuals with a specific illness.

You indicated that the most important factors in helping someone with these matters is to be a good listener and to be non-judgemental. It takes time and patience for individuals to figure out what they want to do about their personal affairs.

July 1995