

The influence of a low-income and linguistic minority context on post-stroke participation

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Table of Contents

List of Tables.....	v
List of Figures	vi
Legend.....	vii
Abstract	viii
Acknowledgements	ix
1. Introduction	1
2. Literature Review	7
2.1 The ICF Framework and Participation.....	7
2.2 Measuring Post-Stroke Participation.....	9
2.3 Low-Income and Health.....	10
2.4 Literature Review: Low Income and Post-stroke Participation	12
2.5 Linguistic Minorities: Health and Challenges for Franco-Ontarians	24
2.6 Life Course.....	27
2.7 Initial Conceptual Framework.....	29
3. Methodology and Method	32
3.1 Methodology and Study Design.....	32
3.2 Cases: Recruitment and Selection	34
3.3 Data Collection.....	37
3.4 Data Analysis	43
3.5 Trustworthiness of the Results	47
4. Data Analysis and Research Findings.....	50
4.1 Participant Characteristics.....	50
4.2 Intra-case Analysis: Low Income and Participation	56
4.2.1 Charlotte	57
4.2.2 Paul.....	74
4.2.3 Jackie.....	84
4.2.4 Laurent	99
4.2.5 Aimée	109
4.2.6 Josée	118

4.2.7 Sylvain.....	132
4.3.8 Daniel	147
4.3 Intra-case Analysis: Linguistic Minority Context and Post-stroke Participation.....	159
4.3.1 Charlotte	160
4.3.2 Paul.....	162
4.3.3 Jackie.....	164
4.3.4 Laurent	166
4.3.5 Aimée	168
4.3.6 Josée	171
4.3.7 Sylvain.....	173
4.3.8 Daniel	176
4.4 Cross-case Analysis.....	177
4.5 Synthesis of the Findings	183
5. Discussion	186
5.1 Summary of Findings and Associated Literature.....	186
5.2 Meso and Macro Environments	200
5.3 Language, Bilingualism, and Health Literacy.....	205
5.4 Life Course.....	210
5.5 Changing the Conceptual Framework.....	211
5.7 Recommendations	213
5.8 Limitations	214
6. Conclusion.....	216
Contribution to Rehabilitation.....	217
Future Research.....	217
Appendix A	219
Appendix B	224
Appendix C	226
Appendix D	228
Appendix E.....	229
Appendix F	230

Appendix G	233
Appendix H	236
Appendix I	239
Appendix J	241
Appendix K	243
Appendix L	246
Appendix M	248
Appendix N	250
Appendix O	252
Appendix P	254
Appendix Q	255
Appendix R	257
Appendix S	259
Appendix T	261
Appendix U	263
Appendix V	265
References	267

List of Tables

Table		Page
1.	Breakdown of data collection sessions with stroke survivors	42
2.	Characteristics of stroke survivor participants	52
3.	Stroke survivor cultural identification and language characteristics	54
4.	Stroke survivor participant income sources, monthly income, and monthly rent	56

List of Figures

Figure		Page
1.	Conceptual Framework: interrelationship between the stroke survivor, the context, and the experience of return to post-stroke participation.	31
2.	Example of a personal project and the events and categories that influenced the experience of return to a personal project (social outings).	45
3.	Example of a pattern (social system functioning) affecting the experience of return to participation in personal projects.	45
4.	Example of a simplified table of evidence for the pattern Social System Functioning, related to income replacement.	46
5.	Healthcare system trajectories for the eight participating stroke survivors.	51
6.	Depiction of the relative influence of the micro, meso and macro environments on return to participation for the low-income francophone minority stroke survivors.	212

Legend

CCAC	Community Care Access Centre (homecare)
CPP	Canadian Pension Plan
EI	Employment Insurance
ICF	International Classification of Functioning, Health, and Disability
LTD	Long Term Disability Insurance Benefits
OAS	Old Age Security
ODSP	Ontario Disability Support Program
OW	Ontario Works
POA	Power of Attorney
RH	Retirement Home
SES	Socioeconomic Status
STD	Short Term Disability Insurance Benefits

Abstract

Following a stroke, the majority of survivors experience challenges returning to participation, also known as “involvement in life situations” in the *International Classification of Functioning, Health, and Disability*. Contextual factors, such as low income and linguistic minority status, have been shown to have an impact on participation post stroke; however, the process by which this occurs is poorly understood. The aim of this research was to increase our understanding of how low income and official minority language status influence the experience of return to participation following a stroke.

A qualitative multiple case study approach was used with eight francophone stroke survivors living in a low-income situation in eastern Ontario (Canada). Data was collected from several sources: semi-structured interviews with the stroke survivors and with their care partners, participant observations, four measures, and chart reviews. Data was categorised, and patterns that furthered understanding of the experience of return to participation were identified during intra and cross-case analyses.

The stroke survivors were all able to access healthcare and social services in both official languages, and the findings suggest that official language minority status had limited influence on the experience of return to participation. Low income, however, influenced precursors to participation by limiting the stroke survivors’ ability to afford housing, goods (e.g., medication, equipment), and services (e.g., transportation, private therapy).

Certain personal and environmental factors modulated the experience of return to participation – specifically, age, knowledge of the healthcare and social service systems, support of family and friends, the built environment, and health literacy. The healthcare and social policies of the macro environment, which regulates the healthcare and social services, had a critical influence on the experience of return to participation for these stroke survivors, irrespective of their individual situations, unless wealth or financial support was available.

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1. Introduction

Stroke is among the major contributors of disability in the adult population (Adamson, Beswick, & Ebrahim, 2004), and in Canada alone, over 315,000 individuals are living with the effects of stroke (Heart and Stroke Foundation, 2014). The majority of stroke survivors experience some form of impairment stemming from this health event (Public Health Agency of Canada, 2011a), which often results in difficulties with participation in valued daily activities (e.g., housekeeping, leisure) (Mayo, Wood-Dauphinee, Côté, Durcan, & Carlton, 2002).

The International Classification of Functioning, Health and Disability (ICF) defines *Participation* as “involvement in life situations” (World Health Organization, 2013, p. 5). *Participation* relates to a person’s lived experience (AIHW, 2003) and reflects the daily activities and social roles a stroke survivor is actually taking part in, both at home and in the community (Piškur et al., 2014). According to the ICF, participation is linked to health conditions, impairments to body structures and functions, and limitations to basic activities, and it is inseparable from environmental and personal contextual factors (Gladman, 2008; World Health Organization, 2013).

Researchers have argued that an individual’s perceived ability to participate in self-identified meaningful activities and social roles is a fundamental aspect of successful rehabilitation (Whiteneck, 1994). Some researchers assert that participation is the most important outcome or goal of rehabilitation (Cott, Wiles, & Devitt, 2007). Among people who have experienced stroke, participation in activities that are personally valued is an important contributor to life satisfaction (Hartman-Maeir, Soroker, Ring, Avni, & Katz, 2007), quality of life (Mayo et al., 2002), and health related quality of life (Fróes, Valdés, Lopes, & Da Silva, 2011).

Following a stroke, a large proportion of restriction to participation is explained by impairment to body structures and functions (D'Alisa, Baudo, Mauro, & Miscio, 2005; Desrosiers et al., 2006). Contextual factors can also play a critical role in facilitating or impeding resumption of meaningful activities (Robison et al., 2009). The ICF defines contextual factors as both personal factors and environmental factors. These factors include socioeconomic and minority language status.

Socioeconomic status (or position), which is measured using social and economic factors such as income, can have a substantial impact on many aspects of health (Braveman, Egerter, & Williams, 2011; Galobardes, Shaw, Lawlor, Lynch, & Davey Smith, 2006a). It has long been recognized that health follows a socioeconomic gradient with those in the lower socioeconomic positions experiencing more health difficulties than those in higher positions (Braveman et al., 2011; Marmot, 2006). These differences can be related to income, which is a modifiable factor. This situation therefore represents a health inequity, as it is an avoidable inequality in health status or outcomes between groups of people, that results from the unequal distribution of resources (Marmot, 2007).

Income is a social determinant of health that affects health over the course of the entire life span (Galobardes et al., 2006a). Low income predisposes individuals to experience deprivation, which in turn affects their ability to purchase basic health needs (e.g., food, clothing, medication) and affects their ability to participate socially (e.g., educational, cultural, political and recreational activities) (Mikkonen & Raphael, 2010). This may lead to social exclusion, in that people become unable to participate in valued activities (Mikkonen & Raphael, 2010) and also have fewer choices regarding the life they would choose to live (Marmot, 2006).

Position on the socioeconomic gradient affects stroke health as well. For example, low

socioeconomic status (SES) is associated with a higher number of stroke risk factors (Aslanyan, Weir, Lees, Reid, & McInnes, 2003), higher stroke incidence (Addo et al., 2012), increased stroke mortality (Kapral et al., 2012), poorer functional outcomes (Dhamoon et al., 2009; Jakovljevic et al., 2001), and lower quality of life (Choi-Kwon, Choi, Kwon, Kang, & Kim, Jong, 2006; Dhamoon et al., 2010).

Health inequities also exist for post-stroke participation. Even when stroke survivors have received recommended care and the severity of their stroke has been taken into account, those people from very low-income neighbourhoods showed poorer participation at one year post stroke, and a tendency for participation to decline over time, compared to those living in more affluent neighbourhoods (Egan et al., 2015).

Effects of low income on participation may be compounded by additional personal factors, such as belonging to a linguistic minority group. Being limited in the ability to speak the dominant language in which services are provided reduces access to stroke rehabilitation (Mold, Wolfe, & McKevitt, 2006) and influences rehabilitation outcomes (Taylor & Jones, 2014). Further, stroke survivors in lower SES groups who also face language or cultural barriers are at higher risk of experiencing functional impairments (Haan & Weldon, 1996) and unmet needs in several domains including social participation (McKevitt et al., 2011).

In Canada, linguistic minority groups, such as francophone groups living outside of Quebec, could potentially experience greater challenges following stroke. This official language minority group tends to be older, to have lower education levels, and to have fewer social supports (Bouchard, Gilbert, Landry, & Deveau, 2006). Further, Francophones in Ontario tend to have a lower family income and a poorer self-perception of their health (Picard & Allaire, 2005). Although Francophones have a stroke incidence that is similar to the general Ontario population,

reports have indicated that they have to surmount linguistic barriers, such as lack of French speaking staff and services, when engaging with healthcare providers (Picard & Allaire, 2005). This disadvantage can affect rehabilitation (Picard & Allaire, 2005) and could impact longer-term participation levels.

An association between low income and poorer participation following stroke has been demonstrated, and several possible factors have been proposed to explain this link. However, the majority of the studies demonstrating an association between low income and factors linked to participation have drawn their conclusions based on stratification of data from larger stroke survivor population samples.

To date, studies investigating post-stroke participation at the level of the individual, specifically, the experience of returning to participation from the perspective of the low-income stroke survivor within his or her personal context are lacking. There is also a dearth of studies exploring the relationship between factors identified in the literature as leading to poor post-stroke participation, within the low-income context. Further, being a member of a minority group (ethnic or linguistic) is associated with poorer participation after a stroke, however, to date, the experience of stroke survivors living in a low-income situation coupled with a minority linguistic situation has not been explored.

We therefore did not have a clear understanding of how the context of living in a low-income situation in conjunction with being a member of a minority linguistic group influences resumption of participation in meaningful activities and social roles for stroke survivors. The present study targeted this knowledge gap.

The purpose of this research project was to understand how living in a low-income situation, while also belonging to a linguistic minority group, influences a stroke survivor's

attempt at returning to participation in meaningful activities. This project aimed to answer the following research question:

How do francophone stroke survivors living in a low-income and linguistic minority situation experience attempting to return to participation?

Research sub-questions were:

- *How does low income influence the experience of return to participation for stroke survivors living in a linguistic minority situation?*
- *How do francophone minority stroke survivors experience their attempt to return to participation?*

Based on the literature review, the initial study proposition was that: Low-income minority francophone stroke survivors' attempts to return to participation in previously valued activities are influenced by contextual factors. Specifically, these factors of the microenvironment are: social supports (personal and professional), financial resources leading to acquisition of goods and services (e.g., equipment, home assistance, community programs), and community or neighbourhood characteristics. While these contextual factors may have influenced participation prior to the stroke, their influence on participation after a stroke was assumed to be even greater in the face of stroke-related disabilities and stroke-related health costs.

A qualitative multiple case study research method, informed by Robert Stake's (2006) approach, was used to address the research question. Case studies research phenomenon within the real-life context (Baxter & Jack, 2008), in particular in those situations where the cases being examined are difficult to extricate from the context (Stake, 2006). The cases in this study were

eight low-income francophone stroke survivors living in Eastern Ontario, and the phenomenon, or issue under investigation, was return to participation following a stroke.

This study used multiple data sources in order to gather various perspectives (Baxter & Jack, 2008) and to develop a more holistic understanding of the cases' experiences (Crowe et al., 2011). Data was collected using semi-structured interviews with the stroke survivors, and care partners, as well as using participant observations, chart reviews, and four assessment tools:

- the Stroke Impact Scale-16 (Duncan, Lai, Bode, Perera, & DeRosa, 2003) ;
- the ICF Checklist (version 2.1a) Participation subsection (WHO, 2003);
- the Hospital Anxiety and Depression Scale (Zigmond & Snaith, 1983);
- the Assessment of Bilingualism (Vallerand, 1989; Vallerand & Halliwell, 1983).

Data was analysed, and assertions were developed from both the individual and multiple cases.

The ensuing document presents this research. It follows the process of discovery, from naiveté to new understanding, starting with the literature review, including the initial foreshadowed issues (also known as the theoretical proposition) and conceptual framework, followed by a detailed description of the methods and methodology, the research findings, the discussion, including the revised conceptual framework, and the conclusion.

2. Literature Review

A stroke, or a cerebral vascular accident is caused when the flow of blood to an area of the brain is stopped, whether as a result of a clot or a haemorrhage (Heart and Stroke Foundation, 2014). The majority of stroke survivors will experience some type of impairment related to this health event (Public Health Agency of Canada, 2011), and although impairments of physical, cognitive, and emotional functioning explain a large proportion of restrictions to post-stroke participation, contextual factors also play an important role (Robison et al., 2009). Living in a low-income situation is one such contextual factor that has been shown to have an influence on post-stroke participation. However, we do not yet understand how it influences participation following a stroke, particularly for minority linguistic groups.

This chapter will define the concept of participation within the ICF framework, provide a rationale for focusing on participation, address measures of participation, and discuss personal projects as a method to describe the experience of return to participation. The concepts of income, and SES within the context of health will be defined. This will be followed by a more in depth narrative review of the literature on the impact of low income on post-stroke participation.

This chapter will also review issues related to the health of linguistic minorities, in particular that of French-speaking Canadians living in English-majority regions of Canada, and review the life course perspective as it applies to stroke, low income, and participation. This chapter will end with the initial conceptual framework and the study proposition on which this research was based.

2.1 The ICF Framework and Participation

The International Classification of Functioning, Health and Disability (ICF), was developed by the World Health Organization (WHO) in 2001, and serves as a framework to

organize, classify, assess, and describe an individual or specific group's experience of functioning and disability (Gladman, 2008; WHO, 2013). The ICF explains functioning and disability in relationship to *Health Conditions*, *Body Function and Structures* (physiological and anatomical aspects of the body), *Activities* and *Participation*. Functioning is a concept that refers to *Body Functions and Structures*, *Activities* and *Participation*; disability refers to impairments, limitations or restrictions to any of these same domains (Schneidert, Hurst, Miller, & Ustün, 2003).

In contrast to *Activities*, which is defined as the “execution of a task or action” in a standardized or testing environment, *Participation* is defined as “involvement in life situations” (WHO, 2013, p. 5), or what is actually accomplished in the context of real life (Piškur et al., 2014; WHO, 2013). *Participation* encompasses an individual's meaningful activities and social roles, either at home or in their community, reflects the lived experience, and is influenced by the model's elements of functioning, in addition to *Environmental factors* and *Personal factors* (Australian Institute of Health and Welfare, 2003).

Environmental factors are those physical, social, and attitudinal features that affect functioning in the places where people live (Schneidert et al., 2003; WHO, 2013). *Personal factors* include characteristics such as gender, race, nationality, profession, lifestyle habits, and education (WHO, 2013). The ICF *Personal factors* have not yet been classified or finalized as a result of ongoing work by WHO committees to better define their scope while dealing with societal and cultural variances (WHO, 2013).

Critics have taken issue with the ICF. They highlight difficulties with its operationalization (Häggström & Lund, 2008; Heinemann et al., 2013), lack of clarity within its conceptual underpinnings, as well as the fact that time is not included as an influential factor

(Hemmingsson, & Jonsson, 2005). Further, the ICF does not account for risks and exposures over the lifespan (Cott et al., 2007). Specifically regarding *Participation*, critics have argued that the ICF does not account sufficiently for subjective dimensions such as meaning, satisfaction (Heinemann et al., 2010), choice (Cott et al., 2007), or autonomy (Cardol, Jong, & Ward, 2002).

Despite such shortcomings, the ICF model is widely accepted, and is used in many countries, in various settings (Bruyère, Van Looy, & Peterson, 2005), including stroke research and rehabilitation (Tempest & McIntyre, 2006). The taxonomy of the ICF was adopted for use in this work because of its widespread use across rehabilitation research audiences.

2.2 Measuring Post-Stroke Participation

Following a stroke, it is estimated that more than 85% of stroke survivors will experience participation restrictions in one or more valued activities (Eriksson et al., 2012). Studies have shown that returning to self-identified meaningful activities is often more important to stroke survivors than general functional return (McKevitt, Redfern, Mold, & Wolfe, 2004). Furthermore, patients measure their own recovery based on meaningful participation rather than discreet functions (Burton, 2000). In addition to being related to post-stroke life satisfaction (Hartman-Maeir et al., 2007) and quality of life (Mayo et al., 2002), participation is related to important concepts of self-identity (Fallahpour, Jonsson, Joghataei, Nasrabadi, & Tham, 2013), social identity, and social position (Anderson & Whitfield, 2013). It can be argued that measuring participation gives us a fuller picture of life following stroke (Gadidi, Katz-Leurer, Carmeli, & Bornstein, 2011) than do measures of activity limitations or function alone (Skolarus, Burke, Brown, & Freedman, 2014).

Addressing post-stroke participation is clearly an important goal; however, measuring or describing post-stroke participation in research presents several challenges. For example,

participation is a very complex concept with multiple definitions that can be assessed using several different tools. Additionally, studies have determined that participation is highly subjective (Burton, 2000; Fallahpour et al., 2013; Häggström & Lund, 2008), and that self-perceived participation restrictions are not the same as outsider observed restrictions. Differences between reported and observed participation are explained by the individual's context, values, expectations, and culture, all of which influence the experience of participation (Cardol, Jong, & Ward, 2002; Fallahpour, Tham, Joghataei, & Jonsson, 2011). This subjectivity makes it challenging to measure participation (Heinemann et al., 2010).

Participation is often measured using standardized tools with pre-established lists of possible meaningful activities for stroke survivors to grade. Interestingly, there is little consensus about which existing stroke participation assessment tools should be used with the ICF framework (other than the ICF's own *Participation* assessment) (Salter et al., 2005).

An alternative way of addressing participation is by focusing on personal projects. Drawing from the Personal Projects of Little (1983), personal projects can be used as the unit of analysis for "participation". Personal projects are meaningful goals, actions, or activities identified by the individual, which extend in time and have a beginning and an end (initiation and termination) (Little, 1983). Advantages to using this unit of analysis include that personal projects are generated and defined by the individual and do not come from a pre-set list, as well, they are embedded in the individual's life and therefore help us understand the context of this individual's everyday life (Little & Travis, 2007).

2.3 Low Income and Health

Health follows a social gradient; there is growing evidence that SES influences not only general health, but also stroke outcomes, including disability (Weir, Gunkel, McDowall, &

Dennis, 2005) and participation. SES describes the relative position that an individual holds within the social structure. It is measured using social, and economic indicators such as education, income, occupation, and housing (Galobardes et al., 2006a), and this status can change over time depending on life course and life situations (Galobardes et al., 2006a).

Income is a measure of access to material resources and services, and is based on earnings, as opposed to wealth, which considers all assets, possessions, and bank account savings (Braveman et al., 2011; Galobardes et al., 2006a). Income can be related to health through direct paths, such as the ability to afford material resources (e.g., nutritious food, medication, and housing), or the ability to purchase services that can improve health (e.g., therapies, education, leisure). Further, income can be indirectly related to health and wellbeing through increased control over life circumstances or empowerment (Marmot, 2006).

Poverty is generally understood as a state of income below a set level, and it can be measured in different ways. Poverty can be defined in relation to an absolute value (less than the minimum income needed to pay for basic needs), a relative value (less than an average standard income), or a subjective value (less than the individuals' perception of an income sufficient to meet their needs) (Raphael, 2004). Statistics Canada sets a relative poverty measure called the Low-Income Cut-Off (LICO). The LICO is an estimate of the income threshold at which families would likely spend 20% more of their income than the average family on food, shelter, and clothing (Statistics Canada, 2013a). The goal of setting a cut-off threshold is to facilitate statistical descriptions of the population (Statistics Canada, 2013a) and to determine eligibility for governmental income support programs.

Although wealth may be a more representative measure of socioeconomic position for health research, income is frequently used as it is easier to measure, and is a good predictor of

health (Braveman et al., 2011).

2.4 Narrative Literature Review: Low Income and Post-Stroke Participation.

The aim of the narrative literature review was to explore in more depth the published research that combined the concepts of low income and post-stroke participation. The review focused on the influence of income on participation following a stroke in developed countries. The review process is described in Appendix A.

Research has demonstrated that factors of socioeconomic position can influence stroke outcomes such as mortality and disability. Few studies have looked specifically at the influence of low income on post-stroke participation. Two studies were identified during the narrative literature review that explored these concepts.

- A cohort study conducted in Hong Kong, China, demonstrated that participation following stroke, measured using the London Handicap Scale, was negatively influenced by several factors including receipt of financial assistance (Lo et al., 2008).
- A Canadian prospective cohort study demonstrated that even when taking into account stroke severity, stroke survivors from very low-income neighbourhoods demonstrated lower levels of participation at one year post-event, compared to their more affluent counterparts (Egan et al., 2015). Participation was measured using the Return to Normal Living Index.

The narrative literature review revealed that several important studies had been completed on themes that were related to participation following stroke, and included themes of socioeconomic status (e.g., income or relative income, education, neighbourhood deprivation). Findings from these studies increase our understanding of the issue, and provide information on which to build the conceptual framework of this research. Findings from these studies have been categorized using the ICF framework and taxonomy, and using “stroke” as the common *Health*

Condition. The findings are organized under the following headings: *Body Functions and Structures and Activities, Personal factors,* and *Environmental factors.* Findings from studies involving people who have experienced stroke (not low income specific), and participation were included to provide a background on which to compare and better understand participation and low income.

Body function and structures, and activities. Following a stroke, severity of functional impairments or activity limitations has been shown to have an important direct impact on restrictions in participation (Chau, Thompson, Twinn, Chang, & Woo, 2009). However, stroke severity is not necessarily linked to a stroke survivor's perception of successful participation (Eriksson, Baum, Wolf, & Connor, 2013), which means, individuals with mild or moderate strokes can both report participation restrictions.

Physical impairments, such as difficulties with upper and lower limb use, are directly linked to participation restrictions following stroke (Desrosiers et al., 2006). Cognitive and perceptual impairments, including language and communication impairments, have also been shown to substantially affect post-stroke participation, particularly in leisure, household management (Spitzer, Tse, Baum, & Carey, 2011), and social activities (Dalemans, de Witte, Wade, & van den Heuvel, 2010; Hilari, 2011). Further, impaired affect and depressive symptoms are associated with decreased participation in meaningful activities and in social roles following a stroke (Cardol et al., 2002; D'Alisa et al., 2005).

When comparing low-income and higher-income stroke survivors, researchers have identified differences in terms of impairments and activity limitation (also known as function), as well as differences in mental health, which can lead to restrictions in participation.

First, having a low income or receiving financial or social assistance is a predictor for poorer functional independence following a stroke (Ostwald, Swank, & Khan, 2008), is associated with increased need for assistance in daily activities (Cloutier-Fisher, 2005; Jakovljevic et al., 2001), and results in a higher likelihood of institutionalization as a result of these impairments (Jakovljevic et al., 2001). Stroke survivors receiving Medicaid insurance or without a health insurance plan in the United States (an indicator of low income status) were found to have a steeper functional decline post stroke than those with health insurance (Dhamoon et al., 2009; Dhamoon, Moon, Myunghee, Sacco, Elkind, 2012). Stroke survivors residing in a deprived or low-income neighbourhood were more likely to have worse short and long-term functional outcomes than those from more affluent neighbourhoods (Chen et al., 2015; Weir et al., 2005). Stroke survivors who perceived their income to be inadequate and who were jobless at the time of the stroke (retired, homemaker, disabled, unemployed) were shown to have worse functional outcomes and to be more disabled than those who reported adequate income and were employed at the time of their stroke (Bettger et al., 2014).

Second, following a stroke, decline in mental health and emotional wellbeing is associated with low income and low socioeconomic status for stroke survivors. Living in a low-income situation is a risk factor for post-stroke depression (Jiang, Lin, & Li, 2014). In addition, living in a low-income neighbourhood has been shown to have an important impact on emotional wellbeing and participation restriction for stroke survivors (Egan, Davis, Dubouloz, Kessler, & Kubina, 2014).

Lower-income stroke survivors are more likely to experience more severe functional impairments, both physically and emotionally, and to require increased assistance with their activities. Even though limitations in *Activities* are associated with restrictions in *Participation*,

limitations do not independently explain or predict restrictions because participation is influenced by contextual factors (Bouffoulx, Arnould, & Thonnard, 2011; Gadidi et al., 2011).

Personal factors. *Personal factors* include age, gender, coping styles, education, culture, ethnicity, and language (World Health Organization, 2002).

Age and gender are two un-modifiable personal factors that can influence post-stroke participation. Statistics of stroke incidence show that the majority of strokes occur in older adults, although approximately one third of strokes occur in individuals under 65 years of age (PHAC, 2010). Having a stroke increases the odds of losing independence and experiencing a decline in participation levels greater than would occur in normal ageing (Desrosiers et al., 2005; Martel, Bélanger, & Berthelot, 2002; McKenna, Liddle, Brown, Lee, & Gustafsson, 2009). Advanced age is also related to poorer functional outcomes post stroke (Chau et al., 2009) and has been identified as a predictor for longer-term post-stroke participation difficulties (Andrenelli et al., 2015; de Graaf et al., 2017; Mutai, Furukawa, Araki, Misawa, & Hanihara, 2013). However, age as a predictor of participation is contested. In some instances, age has little impact on participation, specifically community participation (Jalayondeja et al., 2011), and in other situations, younger stroke survivors have shown to have more unmet needs in terms of participation. For example, in Australia, younger stroke survivors reported more unmet needs than older stroke survivors in several areas, for example leisure and return to work (Andrew et al., 2014). As well, a decline in social and leisure activities is more frequent with younger stroke survivors, in particular, women (Bhogal, Teasell, Foley, & Speechley, 2003).

Post-stroke experiences tend to differ between women and men. Specifically, (a) women tend to have a greater number of comorbidities at the time of stroke, (b) they tend to experience strokes later in life, (c) they have higher rates of institutionalization, (d) they tend to have poorer

functional outcomes, (e) they tend to have poorer SES with decreased social supports (e.g., being widowed or single at the time of the stroke) (Haast, Gustafson, & Kiliaan, 2012; Petrea et al., 2009), and (f) they are more likely to experience substantial post-stroke handicaps if they are dependent on welfare payments (Lo et al., 2008).

Many other personal factors have been identified as negatively influencing post-stroke participation, including poor self-esteem (Chau et al., 2009), low confidence (Horne, Lincoln, Preston, & Logan, 2014), and poor self-efficacy (Brock et al., 2009). Positive outlook and motivation (Le Dorze, Salois-Bellerose, Alepins, Croteau, & Hallé, 2014) and a higher perception of control has also been linked with increased post-stroke participation (Hammel, Jones, Gossett, & Morgan, 2006).

No studies were found that examined the association between personal characteristics, such as beliefs or thought patterns, and post-stroke participation, while also taking into consideration low income. However, the results of more general studies of individuals living with disabilities and chronic illnesses may also apply to stroke survivors. In their study of people living with disabilities, Yeung and Towers identified that an association existed between participation restrictions and low levels of self-efficacy, and that individuals with a low SES were more likely to have lower levels of self-efficacy (Yeung & Towers, 2014). Perceived sense of control also differs according to income levels, with low-income individuals feeling less control than those in higher income levels (Lachman & Weaver, 1998).

A number of studies addressing stroke outcomes among racial and ethnic minorities in the United States have found disparities in terms of functional outcomes compared with the dominant group (Ellis et al., 2015; Stansbury, Jia, Williams, Vogel, & Duncan, 2005). In their 2003 study, Horner and colleagues identified that stroke survivors in ethnic or racial minority

groups who were also living in low-income situations had worse functional recovery compared to more affluent ethnic or racial minorities (Horner, Swanson, Bosworth, & Matchar, 2003).

Other research has identified that language barriers can affect health outcomes. For example, language barriers can influence access to healthcare and social services (Bowen, 2001) or cause adverse effects because of difficulties understanding instructions for medication (Wilson, Chen, Grumbach, Wang, & Fernandez, 2005).

Specifically regarding stroke and language, a systematic review found that language and culture did not appear to have an impact on functional scores (admission versus discharge from hospital), discharge location, and length of stay while in hospital after stroke (Davies, Dodd, & Hill, 2016). A Canadian study found that stroke inpatients who did not have French or English as language of preference had reduced mortality in the first month and first year post stroke. They were more also likely to be discharged with ongoing neurological deficits, to have longer lengths of stay, and to have more encounters with allied health professionals during hospitalization (Shah, Khan, O'Donnell, & Kapral, 2015). Therapists in the United Kingdom providing post-stroke rehabilitation identified that difficulties with subtle communication, as is the case when the patient does not speak the same language as the therapist, affected therapists' ability to assess, identify rehabilitation goals, and provide emotional support during therapy sessions (Taylor & Jones, 2014). As well, stroke survivors in the lower SES groups who also experienced language or cultural barriers are at highest risk of functional impairments (Haan & Weldon, 1996) and unmet needs (McKevitt et al., 2011). Language barriers (English as a second language), in addition to communication problems, were also noted as barriers to accessing community services (e.g., challenges organizing services, filling in benefits forms) following stroke (Mold et al., 2006). Importantly, health literacy may also be playing a role in negative

health outcomes post stroke. Health literacy is defined as a combination of SES, culture, and language factors that may influence one's ability to understand or act on instructions of medical or therapeutic nature (Shaw, Huebner, Armin, Orzech, & Vivian, 2009).

Low-income individuals are less likely to have completed higher education (Statistics Canada, 2014). This is relevant because lower education, inadequate financial resources, and unemployment are associated with increased disability at three months post stroke (Bettger et al., 2014). Higher education has also been associated with better health and social system knowledge, which leads to better abilities to navigate within the system (Sumathipala, Radcliffe, Sadler, Wolfe, & McKevitt, 2012).

Knowledge about health and the healthcare and social service systems can be a personal factor, or an environmental factor if it is knowledge coming from family, friends or professionals. McKevitt et al. (2011) demonstrated that stroke survivors from lower-income neighbourhoods had limited stroke and healthcare system knowledge. Poor knowledge of the healthcare system and poor understanding of stroke (e.g., types of stroke and implications) were commonly reported by stroke survivors in low-income areas in the United States as well (Danzl et al., 2013).

In summary, *Personal factors* can influence post-stroke participation. Studies have shown that being from a low-income, linguistic minority, and ethnic or racial minority group, or having lower educational attainment or a lack of knowledge and information regarding stroke and the healthcare system, is linked to disadvantages in participation. Low-income stroke survivors' participation may also be affected by a higher likelihood of having decreased self-efficacy or decreased perception of control. In addition, stroke outcomes differ for women and men, with women more likely being in a lower SES group, with poorer social supports.

Environment factors. The environment in which people live can create barriers or can facilitate participation following a stroke (Hammel et al., 2006; Rochette, Desrosiers, & Noreau, 2001). The *Environmental factors* of the ICF are categorized under the following headings: *Products and technology*, *Natural environment and human made changes to the environment*, *Support and relationships*, *Attitudes*, as well as *Services, systems and policies* (Schneidert et al., 2003).

First, the *Products and technology* category includes products for consumption, equipment for daily living, mobility and communication, as well as the built environment (Schneidert et al., 2003; WHO, 2003). To compensate for impairments and support participation in meaningful activities, many stroke survivors will require equipment, adaptive aids, or home modifications (Hammel et al., 2006; Sumathipala et al., 2012). It has been estimated that at three months post stroke, 50% of stroke survivors require a technical aid (Bouffioulx et al., 2011).

Being financially disadvantaged decreases one's ability to afford such equipment and to make home accessibility modifications to support participation (Sumathipala et al., 2012). Low-income older American adults living in the community, in particular those with the highest needs (including stroke survivors) are less likely to have adaptive aids and equipment, or to live in modified or adapted houses (Tabbarah, Silverstein, & Seeman, 2000). In Canada, governmental programs are available to subsidize equipment and housing modifications for low-income individuals with disabilities at the municipal, provincial, and federal levels. Access to this funding is, however, complex, difficult to obtain, and dependent on the region in which one lives (Athanasopoulos et al., 2013).

Second, the *Natural and human made changes to the environment* category includes neighbourhoods (WHO, 2013). Neighbourhoods can affect general health and participation in

meaningful activities through their physical features, services, and social characteristics (Braveman et al., 2011). Specifically for older adults with chronic diseases including stroke, participation is enhanced when neighbourhoods have the following characteristics: a higher economic status, local resources and services, good social cohesion, a sense of safety, fewer mobility barriers, better mobility resources, and fewer physical issues (e.g., noise, poorer air quality) (Hand, Law, Hanna, Elliott, & McColl, 2012).

Low-income people tend to find themselves in poorer or more deprived neighbourhoods where residence is linked to poorer general health (Bernard et al., 2007). Low-income neighbourhoods are more likely to create participation barriers because of poor accessibility, of issues with traffic and road safety, and of lack of access to services and neighbourhood social supports (Stafford, 2003).

The third category, *Support and relationships*, includes those friends, families, peers, and healthcare professionals who can provide opportunities and support for participation. Social support and the social environment are important factors in enabling post-stroke participation (Barclay-Goddard, Ripat, & Mayo, 2012; Fallahpour et al., 2011; Robison et al., 2009; Sumathipala et al., 2012), both in the short and long term (Brunborg & Ytrehus, 2014). Availability of social support is also an important discharge destination criteria following a stroke (Bélanger, Bolduc, & Noël, 1988; Hinojosa, Rittman, Hinojosa, & Rodriguez, 2009; Meijer et al., 2004; Muro, de Pedro-Cuesta, Almazan, & Holmqvist, 2000).

Importantly, the majority of post-stroke support is provided by families (Perry & Middleton, 2011). Research has shown that social supports can have a positive or negative influence on participation; the quality of social supports is important in terms of its impact (Hammel et al., 2006; Sumathipala et al., 2012). Social support, in particular positive emotional or affective

support, is related to better overall functional outcomes, increased satisfaction with use of time during the day post stroke (Doble, Shearer, Lall-Phillips, & Jones, 2009; Hoyle, Gustafsson, Meredith, & Ownsworth, 2012), and increased overall general satisfaction with participation (Bouffoulx et al., 2011). Positive social support can create opportunities for participation by encouraging stroke survivors to re-engage in previous meaningful activities and social roles, and to try new activities when others are no longer possible (Anderson & Whitfield, 2011, 2013).

Low-income individuals with disabilities are more likely to have inadequate social supports (Yeung & Towers, 2014). Poorer social support is associated with decreased emotional wellbeing, which, in turn, influences participation (Jiang, Lin, & Li, 2014; Taylor-Piliae et al., 2013). Specifically for stroke survivors, those from deprived neighbourhoods have been found to have more unmet emotional support needs (McKevitt et al., 2011). In addition, caregivers of stroke survivors in lower-socioeconomic positions are more at risk of depression and other psychological morbidities (Bhugal et al., 2003). This could create participation challenges for the stroke survivor under their care.

With regards to professional support, lack of information or knowledge was a common issue for stroke survivors in several countries including Canada (Vincent et al., 2007) and Ireland (Walsh, Galvin, Loughnane, Macey, & Horgan, 2015). Insufficient knowledge and information about their health condition affected wellbeing of community dwelling stroke survivors (Baumann, Le Bihan, Chau, & Chau, 2014), caused challenges accessing community supports and services (Sadler, Daniel, Wolfe, & McKevitt, 2014), and influenced participation for younger stroke survivors (Hammel et al., 2006). Stroke survivors who felt they had made a good recovery reported that acquiring knowledge about their condition had helped them regain a sense of control, which lead to re-engagement in meaningful activities (Kessler, Dubouloz,

Urbanowski, & Egan, 2009).

Canadian caregivers also reported receiving insufficient information, and when they did receive information, timing was considered poor and this affected their ability to provide support (Ghazzawi, Kuziemy, & O'Sullivan, 2016). Increased knowledge and training (provided by healthcare professionals) has been recommended for caregivers of stroke survivors as a method to avoid burnout (Perry & Middleton, 2011).

Certain groups are more likely to experience unmet needs related to stroke information. These include stroke survivors from deprived neighbourhoods (McKevitt et al., 2011) and from ethnic minority groups (McKevitt et al., 2011; Yeung et al., 2015).

With regards to professional services, insufficient rehabilitation services in the community, including a lack of vocational support (Sadler et al., 2014), uncoordinated support services, and insufficient help (Baumann, Le Bihan, Chau, & Chau, 2014) were also reported by stroke survivors. Lower-income stroke survivors in Australia reported difficulties accessing private allied health services in the community to address their ongoing functional needs (Andrew et al., 2014). Resuming outpatient therapies following a stroke was associated with socioeconomic status, insurance coverage, and minority status in the United States (Ostwald, Godwin, Cheong, & Cron, 2009).

Attitudes is the fourth category of *Environmental factors*. These are influenced by the values, beliefs, and cultures in an individual's immediate surroundings, as well as in the community and larger society (Schneidert et al., 2003). The social environment's attitudinal barriers, including stigma, have been found to be linked to decreased community participation for stroke survivors (Anderson & Whitfield, 2013; Dowswell et al., 2000; Hammel et al., 2006; Le Dorze et al., 2014; Sumathipala et al., 2012), and increased social isolation (Hammel et al.,

2006). Literature was not found that specifically highlighted any differences between the experiences of lower or higher income stroke survivors for this factor.

Fifth, the municipal, provincial, and federal *Services, systems and policies* may influence participation. Examples include those policies related to health or disability support services and programs, transportation, and income supplements.

Participation in, for example, day programs and stroke clubs was found to be supportive for longer-term social participation among stroke survivors (Sumathipala et al., 2012). However, studies have identified a lack of access to low-cost or free social activities, programs, and services for lower income stroke survivors (Hammel et al., 2006; Rimmer, Wang, Smith, & Rimmer, 2008). Poor access to transportation has frequently been identified in research as having a direct negative impact on community participation for stroke survivors (Angeleri, Angeleri, Foschi, Giaquinto, & Nolfi, 1993; Keysor, Jette, Coster, Bettger, & Haley, 2006; Logan, Dyas, & Gladman, 2004; Sumathipala et al., 2012; Woodman, Riazi, Pereira, & Jones, 2014), in particular for those living in low-income situations (Hammel et al., 2006; Marzolini et al., 2016; Rimmer et al., 2008).

Hammel et al. (2006) demonstrated that stroke survivors' participation was affected by new financial challenges. Specifically, they found that income support programs provided insufficient assistance to stroke survivors and their families who experienced new financial difficulties (Hammel et al., 2006). A study conducted in Australia found that following a stroke, 61% of the participants faced economic household hardship regardless of their pre-stroke income status (Essue et al., 2012). Similarly, in an Irish study, 60% of stroke survivors stated their finances were affected following the stroke, either by an increase in expenses or a decrease in income, or by both an increase in expenses and a decrease in income (Walsh et al., 2015).

Financial hardship often resulted from caregivers' inability to work outside the home because of caregiving duties (Oliva-Moreno, Aranda-Reneo, Vilaplana-Prieto, González-Domínguez, & Hidalgo-Vega, 2013) or a stroke survivor's inability to return to pre-stroke employment because of impairments (Jerome et al., 2009). A British study found that many more stroke survivors from deprived areas suffered loss of income compared to stroke survivors from more affluent areas (McKevitt et al., 2011).

Financial hardship can have far reaching ramifications. Campbell and colleagues (2014, 2017) demonstrated that individuals with chronic cardiovascular disease and who perceived financial barriers affecting their ability to pay for necessities such as medication or healthy food had a higher likelihood of disease related visits to hospitals or emergency rooms, and higher mortality rates (Campbell et al., 2014; Campbell et al., 2017).

In summary, literature has demonstrated that *Environment factors* may play a role in negatively influencing post-stroke participation for low-income individuals by creating difficulties acquiring equipment and technologies and challenges funding modifications to their environment. Moreover, they are more likely to live in low-income neighbourhoods, which are associated with challenges to social supports and safe community mobility. Further, low-income individuals are more likely to have poor social supports and caregivers experiencing high stress. In addition, supports, programs, and services for low-income stroke survivors are lacking, and income loss may be greater following a stroke.

2.5 Linguistic Minorities: Health and Challenges for Franco-Ontarians

French and English are both official languages in Canada; however, both language groups are not distributed equally across the country. While French is the majority language in the province of Québec, it is a minority language in all other provinces and territories. In

Ontario, approximately 5% of the population identifies as Francophone. In Ottawa, nearly 18% of the population identifies as Francophone (Office of Francophone Affairs and Statistics Canada, 2011). In Ontario, laws guarantee an individual's right to receive provincial government services in French in designated areas, which include Ottawa (Office of Francophone Affairs and Statistics Canada, 2011). In designated areas, the law does not require healthcare and social service organizations, such as hospitals, to provide services in French unless these agencies have been designated by the government (Government of Ontario, 2016).

Bowen's systematic review of the literature highlighted evidence that language barriers can affect the safety of patients, and decrease their satisfaction vis-à-vis services received (Bowen, 2001; Bowen, 2015). Language barriers can limit access to healthcare services and participation in health promotion and prevention activities, as well as increase the risk of medication errors, and reduced compliance with treatment recommendations (Bowen, 2001; Bowen, 2015). An argument has been made that poor proficiency in English is linked to poverty, and as such, should be considered a social determinant of health (Bouchard et al., 2013).

Francophones in Ontario have a particular demographic profile. They are generally older, have lower education levels, and a higher proportion of them are in the lowest income quintiles compared to Anglophones (Bouchard, Batal, Imbeault, Gagnon-Arpin, & Makandi, 2012), particularly those over the age of 65, and living in rural areas (Bouchard et al., 2013). Francophones in Ontario have a poorer perception of their health, compared to the Anglophone population (Bouchard et al., 2013), and they have fewer social supports (Bouchard et al., 2006).

In Canada, approximately half of Francophones in minority communities reported that they never, or almost never, had access to services in French for healthcare at the various service levels (e.g. hospital, community services) (Consultative Committee for French-Speaking

Minority Communities, 2007). Access to services in French has been reported to be difficult for certain areas of Ontario including Northern, Eastern and Southern Ontario, and even in Ottawa, a city considered bilingual (Drolet et al., 2014). Even when services are available in French in a region, several issues can occur. For example, issues frequently arise with the availability of French language services across the continuum of care, and with lack of Francophone assessment tools, and educational materials for the professionals offering services to the minority Francophones (Savard et al., 2013).

Also, when French resources are available, Francophones living in minority situations experience particular barriers accessing healthcare and social services in French, including a perception that French services do not exist (Société santé en français, 2007), or that they will suffer a delay if they request services delivered in French (Drolet et al., 2014). Additionally, it has been demonstrated that Francophone minorities often feel insecure in their ability to adequately express themselves in French with a professional (Landry, Allard, & Deveau, 2008), which can lead to fewer individuals requesting services in French (Boudreau & Dubois, 2008).

Francophone minorities in Ontario have a similar prevalence of stroke compared to the provincial population (Bouchard et al., 2012); however, they have unique challenges linked to access to healthcare services, as well as community social services and programs, in their language.

Importantly, Francophones living in Ontario are a very culturally diverse group. Fourteen percent of the francophone population of Eastern Ontario identify as visible minorities (Government of Ontario, 2012). Although more highly educated, Francophone visible minorities experience higher rates of unemployment. This rate is higher than both other Ontarians and other Franco-Ontarians, with one out of every four living in poverty (Government of Ontario, 2012).

In Canada, being a member of a visible minority is considered a social determinant of health because, irrespective of language, visible minorities are more likely to be un- or under-employed, to experience housing or food insecurity, or to live in a low-income situation (Mikkonen & Raphael, 2010). Francophone minorities who are also visible minorities, living in a low-income situation and experiencing a disability stemming from a stroke event are thus in a particularly vulnerable situation.

2.6 Life Course

Several research groups, including the World Health Organization (WHO)'s Commission on Social Determinants of Health (CSDH), are studying health, and health outcomes using life course perspectives. This means investigating the complex impact or exposure of social, psychosocial or eco-social influences on health over the course of development (Ben-shlomo & Kuh, 2002; WHO, 2010). The CSDH has developed a conceptual framework that depicts the links between a larger socio-political environment, the social determinants of health (e.g., income, education), and resulting health inequities (WHO, 2010).

Within the life course perspective, socioeconomic circumstances are not simply environmental or personal factors; they serve as the backdrop to life as an exposure that influences health from birth until death (Galobardes, Shaw, Lawlor, Lynch, & Davey Smith, 2006b). Based on the life course perspective, low income is a life circumstance that affects health and participation even before a stroke occurs.

Looking at the risk factors, life course epidemiologists have shown that there is an association between low socioeconomic position, the timing of this exposure, and an increased risk of developing chronic diseases later in life (Lynch & Smith, 2005). For example, during infancy and childhood, socioeconomic position is a life course risk factor for developing type II

diabetes and chronic heart disease later in life (Lynch & Smith, 2005). As well, childhood exposure to deprivation is associated with the risk of stroke later in life (compared to adulthood exposures and life style factors) (Metcalf et al., 2005).

Functional independence, and by extension participation, can also be affected by one's socioeconomic position. For example, economically disadvantaged individuals are, over the course of life, more likely to become disabled or to develop a non-communicable disease (Jenkins & Rigg, 2004; Marmot, 2006). Canadian statistics have demonstrated that low income is associated with a steeper loss of independence in activities of daily living for older adults, compared to those older adults with higher incomes (Martel et al., 2002).

There are different models used to study life course in the context of health. One such model is the pathway model which examines how certain life experiences and trajectories, for example opportunities for education, employment stability, and relationships (e.g., marriage), could influence health, wellbeing (Heikkinen, 2011; Hertzman, 2000), and participation. For example, individuals coming from the low-income population group are more likely to live in poor neighbourhoods (Stafford, 2003), to have mobility issues (Guralnik et al., 1993), to experience social isolation (Nicholson, 2009), to suffer from depression (Patten & Juby, 2008), all of which can influence participation. A study also showed that those experiencing sustained economic hardship are more likely to have difficulties with instrumental and basic activities of daily living, as well as clinical depression, compared with subjects without economic hardship (Lynch, Kaplan, & Shema, 1997). Further, a study completed with Americans with chronic disease, specifically arthritis, demonstrated that perceived inadequacy of socioeconomic status was associated with poorer participation, even after adjusting for health and disability factors (Theis, Murphy, Hootman, & Wilkie, 2013).

Specifically related to strokes, prospective studies have found that individuals who suffered a stroke were more likely to have been experiencing a decline in independence in activities of daily living and in instrumental activities of daily living prior to the stroke event, compared to those who remained stroke-free (Capistrant, Mejia, Liu, Wang, & Glymour, 2014; Capistrant, Wang, Liu, & Glymour, 2013). This pre-stroke loss of function in instrumental activities of daily living was more important for ethnic minorities (Capistrant et al., 2014). In their prospective study, Dhamoon and colleagues (2012) also found evidence of greater pre-stroke functional decline among people receiving Medicaid in the United States or without insurance health coverage (both indicators of low income) (Dhamoon et al., 2012).

A life course perspective allows us to view the impact of disadvantages on participation and stroke over an extended period of time. Using this perspective, we can appreciate how many of the *Environmental* and *Personal factors* that negatively affect post-stroke participation may already have been present or even problematic prior to the stroke. Specifically, literature tells us that even before a stroke has occurred, an individual coming from the low-income population group is more likely to live in a poor neighbourhood, to be socially isolated, and to be experiencing decreased function, and possibly decreased participation.

2.7 Initial Conceptual Framework

Low-income stroke survivors from the minority Francophone community are predisposed to three disadvantages: low income, disability, and language barriers. They are therefore more likely to experience challenges with post-stroke participation. Clearly, not one single factor, but rather the amalgamation of several interrelated factors and disadvantages, as well as temporality (life course), may explain a link between post-stroke participation and low income.

Consistent with a multiple case study method drawing from Stake (2006)'s approach, a

theoretical proposal based on foreshadowed issues, as well as a conceptual framework, were formulated (Figure 1). Based on the literature review, the foreshadowed issues were: Low-income minority Francophone stroke survivors' return to participation in previously valued activities is influenced by (micro) contextual factors, specifically, (a) social supports (personal and professional); (b) financial resources leading to acquisition of goods and services (e.g., equipment, home assistance, community programs); and (c) community and neighbourhood (e.g., neighbourhood characteristics, services such as transportation). Although the identified contextual factors were present prior to the stroke, they now have a stronger influence on participation because of the addition of post-stroke disabilities and new stroke-related expenses.

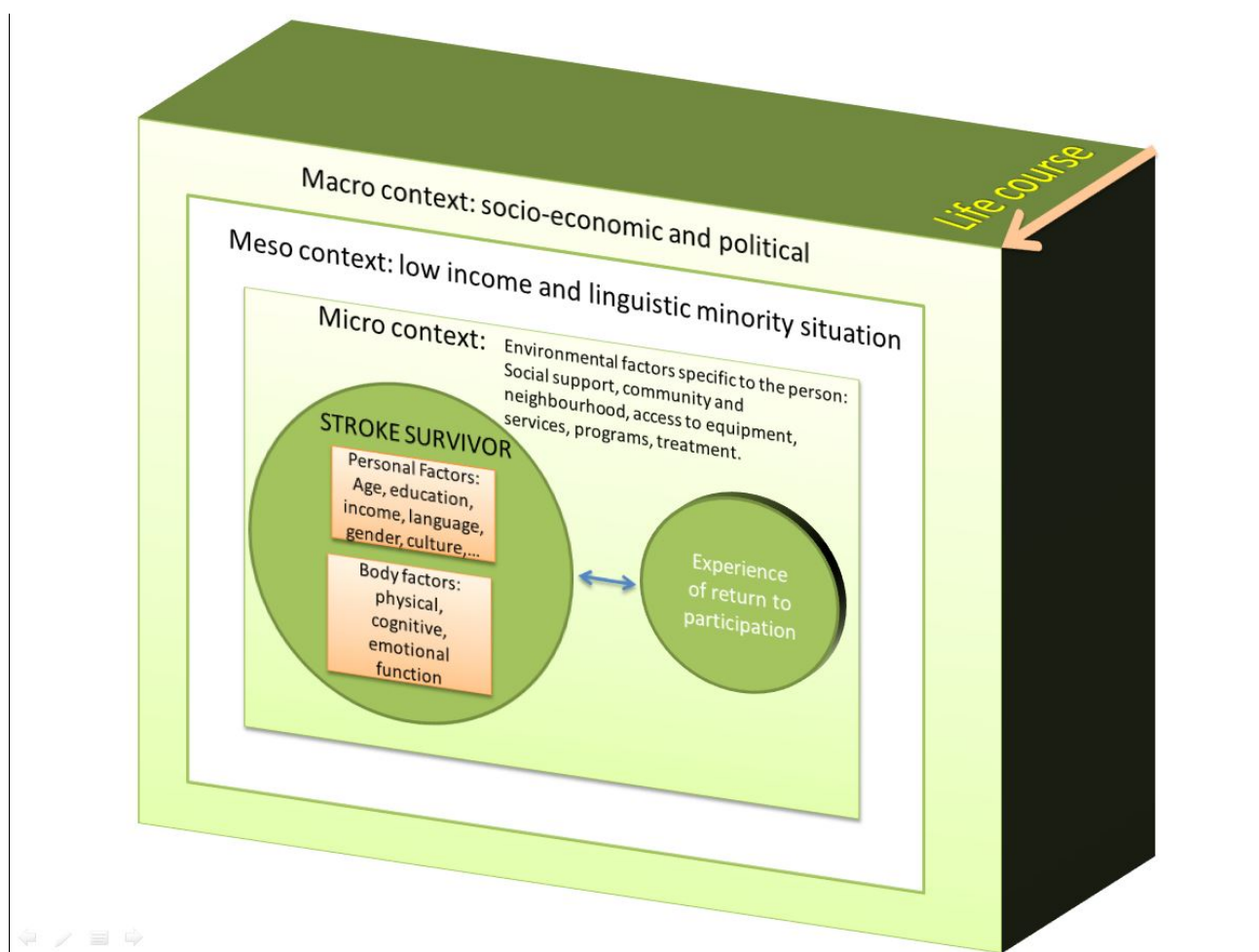
This initial framework draws from the ICF (WHO, 2013) as well as from the Commission on Social Determinants of Health's conceptual framework (WHO, 2010), and from the foreshadowed issues derived from the literature review. The conceptual framework depicts an initial understanding of how low-income minority Francophone stroke survivors (with unique personal factors and body functions and structures) experience return to participation.

In this conceptual framework, the stroke survivor (with personal factors) sits within, and is in interactions with, the micro, meso, and macro contexts, which are different levels of the environment that influence the stroke survivor, as well as the experience of participation (e.g., the environment allows for certain personal projects and not others).

The stroke survivor has certain characteristics or personal factors including age, body factors, income, gender, and language. The micro-context is comprised of factors that are immediately within the environment of the stroke survivor, for example social support, access to materials, equipment, services, programs and treatment, and features of the community and neighbourhood. The larger meso-context encompasses the low-income and linguistic minority

situation; this level is associated with these two concepts as social determinants of health linked to the social position of the individual. The macro-context is the larger socioeconomic and political context. It includes social and cultural values, policies, and governance. The stroke survivor, the macro, meso and micro contexts are nested components, and are in interaction with each other.

Figure 1. Conceptual Framework: interrelationship between the stroke survivor, the context, and the experience of return to post-stroke participation.



3. Methodology and Method

In the first section of this chapter, the methodology, including the philosophical underpinnings of this research, a reflexivity statement, and the study approach, are presented. This is followed by a description of participant selection, data collection methods, and data analysis strategies. The chapter finishes with a discussion of research trustworthiness.

3.1 Methodology and Study Design

This study aimed to improve understanding of a complex human experience within a natural setting (Andrade, 2009), therefore a post-positivist qualitative research perspective, informed and oriented by interpretivist philosophical assumptions, was adopted. Ontologically, in this paradigm, researchers accept that there is not one single answer or view, but rather, that multiple realities likely exist (Stake, 1995), and that the research process increases understanding of these realities rather than finding one “truth” (Lincoln & Guba, 1985). Further, researchers adhere to the belief that human experience is very complex and rooted within a context from which it cannot be isolated (Schram, 2003). From an interpretivist perspective, researchers focus on interpreting meaning from the collected data (Bakker, 2010). Epistemologically, the interaction between the participants and researchers is important as they both make interpretations, which lead to new knowledge and to better understanding (Stake, 1995). As well, within the interpretivist perspective, it is accepted that the researcher’s personal values and experiences shape and influence the research findings (Creswell, 2007).

A qualitative case study design was chosen to answer the study question. Qualitative case studies generally aim to provide a deep understanding of a complex social phenomenon, examined within a real-life context (Merriam, 1998). This design fits well with the study question, as the aim was to understand the complex experience of return to participation for

stroke survivors living in a linguistic minority and low-income context. Of the many possible case study approaches, this study is based on the work of Robert Stake. Stake follows an interpretivist-constructivist approach (Harrison, Birks, Franklin, & Mills, 2017). He defines the case as the base unit of analysis that will reveal something about the issue being studied. He specifies that the case must be an object doing an action or activity. For example, a case can be a family, an organization, or an individual, but not a process. Cases must be “bounded”, meaning that limits are set around the case for the research, and cases must be studied holistically within their complex contexts (Stake, 2006). The present study is a multiple instrumental case study, where the phenomenon or the issue of return to participation is investigated through several cases (Stake, 1995).

3.1.1 Reflexivity Statement. Reflexivity is the act of self-questioning, self-analysis, and introspection that serves to better understand and acknowledge the impact of one’s biases and beliefs on the research. “Reflexivity reminds the qualitative inquirer to be attentive to and conscious of the cultural, political, social, linguistic, and economic origins of one’s own perspective and voice as well as the perspective and voices of those one interviews and those to whom one reports.” (Patton, 2015, p. 70).

As the main researcher for this study, I find it important to declare that I am a Franco-Ontarian. I grew up in northern Ontario, and am fully bilingual in both official languages of Canada. I have worked as an occupational therapist in the public, and private healthcare spheres, and in hospitals, in rehabilitation centers, and in the community. This, in addition to other opportunities to work and volunteer with people who can be considered more vulnerable, for example Aboriginal peoples from Australia or Inuit people in northern Canada, have influenced my perspective of the research, as well as my interpretations and the patterns I have recognized

in the data. Further, I am an educated white woman, and this, in addition to my language, culture, and approach likely influenced my interactions with the participants during fieldwork (and vice-versa).

3.2 Cases: Recruitment and Selection

The cases in this research are stroke survivors. To increase our understanding of the cases, data was collected from the stroke survivors and also from other sources including the stroke survivors' care partners. The following section outlines the prospective participant inclusion criteria and discusses the number of cases included in the study. This is followed by a brief description of the recruitment procedure and case selection, and ethical considerations.

3.2.1 Inclusion criteria and number of participants. Inclusion criteria were identified to ensure that the prospective participants could provide a personal account of their experience of return to participation relating to their first stroke. All prospective participants had to meet the following inclusion criteria:

- Stroke survivor who experienced a first stroke no less than 6 months prior;
- 18 years old or older and capable of making own decision to participate in the research project;
- Living in a low-income situation determined by enrolment in the Ontario Disability Support Program or Ontario Works, or eligibility for either program as determined by a social worker, or referral to social work for assistance with applications for municipal or provincial income support programs, or having a family income less than \$25,000.
- Living in Ontario;
- French speaking and be considered Francophone, based on mother tongue or first official language spoken as defined by Statistics Canada (Statistics Canada, 2010);

- Living in the community (not in a long-term care facility).

Deliberate choices were made in terms of other inclusion characteristics for the cases. First, the age range of potential stroke survivor participants was kept wide so as not to limit the study to the experiences of younger or older adults. Although two thirds of strokes occur to people over the age of 65 years of age (Public Health Agency of Canada, 2010), and increased age appears to be associated with increased participation restrictions post stroke (Desrosiers et al., 2006), research has demonstrated that younger people also experience challenges related to return to participation after a stroke (Mold et al., 2006). Second, there are noted gender differences in terms of stroke and post-stroke experiences. Therefore, both men and women were included in the study. Third, people experiencing aphasia were not excluded from the study, unless they were experiencing severe receptive aphasia that prevented them from providing their own consent. In Ontario, approximately 35% of stroke survivors experience some form of aphasia (Dickey et al., 2010) and aphasia is known to present unique challenges for participation after stroke (Le Dorze et al., 2014). Fourth, the study aimed to obtain multiple perspectives, including those of care partners. Presence of a care partner was, however, not an inclusion criterion. Fifth, the choice of recruitment sites was purposefully limited to the geographical area of Eastern Ontario. This region was chosen because of ease of access to Francophone stroke survivors living in a minority situation (Francophones make up 18% of the population of the region), and because of the number of health institutions accessible through the research team's networks. As well, study feasibility was improved, and travel costs lower because of the geographical proximity of the recruitment sites to the research team's university.

Stake (2006) suggests selecting four to ten cases for a multiple case study. This case study initially aimed to have four to six cases, with the possibility of adding cases until

information redundancy became apparent. As subsequent cases were accepted from the recruitment sites, these cases were analyzed and the results were used to verify that information redundancy was being reached – cases were added until the further addition of cases was no longer providing significantly new information to the study (Aaltio & Heilmann, 2010; Fletcher & Plakoyiannaki, 2010), specifically no new patterns were emerging from the collected data. The final number of cases was eight.

3.2.2 Recruitment process and case selection. Stake (1995, 2006) specifies that cases should be selected for their ability to provide information and to increase understanding about the phenomenon of interest. Stroke survivors were recruited from two locations: from the roster of stroke patients who had previously received treatment from a regional interprofessional university clinic (*Clinique interprofessionnelle*), and from the active roster of patients who had a stroke and were being followed in the regional stroke outpatient clinic.

Potential participants were identified by occupational therapists in both organizations. Recruiting therapists targeted Francophone stroke survivors meeting the eligibility criteria; however, income did not need to be confirmed. The therapists approached Francophone stroke survivors who were potentially living in a low-income situation (e.g., the occupational therapist had knowledge that the patient was receiving or applying for income support, or from reports from other therapists that difficulties with funding equipment, services or transportation existed). The therapists forwarded the names of potentially eligible people interested in the study to the research team. Eligibility was then confirmed, and formal consent obtained. At this point, each stroke survivor identified a care partner. The care partner could be a family member, friend, or anyone that they felt could provide information and an opinion about their experience of return to participation in a low-income and Francophone linguistic minority situation. Care partners

provided their own consent.

All of the potential participants who were identified by the recruiting therapists, agreed to participate, and met the inclusion criteria were included in the study.

3.2.2 Ethical considerations. Ethical approval was received from the research ethics boards (REB) of Bruyère Continuing Care (Bruyère REB Protocol #M16-15-048) and of the University of Ottawa (#H01-16-09). Further submissions were made to these and other organizations to allow review of medical records; the Bruyère Continuing Care and University of Ottawa REB approved this modification in April 2016. Application to the REBs of the Montfort Hospital and The Ottawa Hospital were submitted for chart reviews for participants. These applications were accepted, Protocol #ME-06-02-17 and # 20170185-01H respectively. The Queensway Carleton Hospital accepted certificates from the aforementioned institutions and allowed a chart review with the patient's signed consent.

3.3 Data Collection

Qualitative case studies allow for the use of multiple data sources to help understand the issue under study (Baxter & Jack, 2008) and to provide a more holistic view of the experience being investigated (Patton, 2015). The following section describes the study's data collection strategies, the data collection process, and modifications that took place as the study progressed.

3.3.1 Data collection strategies. Several data collection strategies were used in this multiple case study. These included semi-structured interviews with the stroke survivors and with their care partners, chart reviews, participant observations, and four measures. The following section describes these data collection strategies.

Semi-structured interviews with participants: An interview guide (see Appendix B) was developed based on the theoretical proposition, and using the concept of personal projects,

drawing from Little (1983) and Little and Travis (2007)'s Personal Projects, as a way to address "return to participation" with the stroke survivors. During the interviews, the concept of personal projects was introduced to the stroke survivor, and was used to help them elicit a list of pre and post-stroke personal projects and to describe them. Experience of return to participation in these projects following stroke was explored. This included discussing obstacles, challenges, and facilitators, and the process they went through or events that took place in their attempts to return to participation in these projects. Information was also collected about the stroke event, affected pre and post-stroke body functions and structures, activity limitations, personal factors, and environmental factors (micro, meso, macro) that the participants identified as relevant to their experience. Interview questions also addressed perceptions about the impact of low income and of Francophone linguistic minority status on return to participation.

Semi- structured interviews with care partners: In order to obtain a more complete picture, and a different perspective of the issue of return to participation, the stroke survivors chose a care partner, for example a member of their family, a caregiver or a friend, who was involved in assisting or accompanying them in their everyday activities or providing them with support. During the interview with care partners, data was collected about their perception of how the stroke survivor experienced attempting to return to post-stroke personal projects. Questions focused on facilitators, obstacles, and challenges, and on the process of return to participation. Perceptions about the impact of low income and linguistic minority situations on return to participation were also collected, as well as information about pre-stroke personal projects, and any pre-existing issues or contextual factors that might have contributed to the current experience of participation. See Appendix C for the care partner interview guide.

Chart reviews: The medical records of the institutions where the stroke survivors received services were reviewed. Specifically, the records of the *Clinique interprofessionnelle*, which included documentation from inpatient and outpatient rehabilitation services, and the records of the acute care hospitals were reviewed. The review of medical records from the three acute care hospitals was added several months into the study when it came to light that decisions or actions that took place while the stroke survivor was in acute care might have had an influence on later participation. For example, decisions about where the stroke survivor would be discharged could affect later participation. Data extracted included past medical history, stroke outcomes, and potential issues identified by the health team regarding income, and the environment. See Appendix D for the chart review guide.

Participant observations: Data collection using observations of the participant in their own environments, for example, observing the stroke survivors in their homes, or in the community, as they participated in a meaningful activity of their choice, was planned. The observations were to be used to provide further insight into how the stroke survivor managed with participation in their physical and social environment. The participant observation guide was based on Merriam's (1998) suggestion of collecting observational data for case studies: describing the environment, the participant, interactions (social or environmental), and the activity taking place (Kawulich, 2005; Merriam, 1998). See Appendix E for the participant observation guide

Measures: In order to provide a fuller description of the cases in terms of stroke impact, mood, participation, and language abilities, data was collected using quantitative measures. Stake's case study approach does not include the use of quantitative data; therefore Merriam's 1998 case study approach's was borrowed so that collection and use of this information could be

used for descriptive purposes. Data was collected using the Stroke Impact Scale (SIS-16), the Hospital Anxiety and Depression Scale (HADS), the ICF Checklist (Version 2.0) Participation subsection, and the Assessment of Level of Bilingualism. This information was collected at the end of the second interview session so as not to influence the participants' perceptions or opinions during the first interview by possibly leading them to respond to interview questions largely in terms of these constructs.

The SIS-16 is a self-report assessment tool that measures physical function following stroke (Duncan et al., 2003). The participants rate their abilities in 16 functional physical tasks using a scale from 5 to 1 (no difficulties to impossible). It is a shortened version of the Stroke Impact Scale (SIS) version 3.0 (52 items), and has been shown to have good concurrent validity (Duncan et al., 2003). A score of 75/100 has been considered “good” recovery (Shobha, Sylaja, Kapral, Fang, & Hill, 2010). The SIS-16 translation for French Canada was used, although this translated version has not yet been validated. Concepts measured in the SIS-16 have a good fit with the ICF framework (Moriello et al., 2008).

The HADS is a self-assessment scale used to screen for anxiety and depression in outpatient clinical settings (Zigmond & Snaith, 1983). It is comprised of 14 questions, and the participant chooses a response that most matches how he has been feeling in the past week. The cut-off score is of 8/21 for anxiety, and 8/21 for depression questions (Zigmond & Snaith, 1983). The tool has been translated into Canadian French, and the translated version has excellent correspondence to the English version (Savard, Laberge, Gauthier, Ivers, & Bergeron, 1998), good reliability (internal consistency), and discriminant validity (Roberge et al., 2013) when administered to adults who have not experienced stroke. The English scale was validated and determined to be good for use as a screening tool for post-stroke depression and anxiety (Aben,

Verhey, Lousberg, Lodder, & Honig, 2002; Burton & Tyson, 2014) and is recommended by the Canadian Best Practice Recommendations for Stroke Care for this use (Eskes, 2013).

The ICF Checklist (Version 2.1a) is a shortened edition of the full ICF assessment; it gives an overview of all the categories of the classification. In the Participation subsection, respondents rate their performance in real-life situations for a list of participation domains using qualifiers (World Health Organization, 2013). The Checklist includes the opportunity for participants to add any missing and meaningful participation domains to this list (e.g., an unspecified hobby). In this research, this tool was used to elicit new or missing information on participation that might not have been brought up during the interviews and to obtain further details and an overall idea of participation challenges for the stroke survivor.

The Assessment of Level of Bilingualism (Vallerand, 1989; Vallerand & Halliwell, 1983) is a self-assessment tool that was used to determine the participant's perceived level of bilingualism for French and English. Using a scale from 1 to 4 (very little to perfectly), the participant rates their ability to understand and express themselves verbally, to understand written communication, and to write in English and in French. Each language sub-section is rated on a total of 16 points, and the authors suggest that a total score of 12/16 in both sub-sections demonstrates bilingualism (Vallerand, 1989; Vallerand & Halliwell, 1983). The assessment is standardized but is not norm-referenced.

3.3.2 Data collection procedure. The following is a description of the data collection procedure, including the breakdown of data collection sessions.

All sessions were conducted with the participants and care partners in their home environments and were digitally recorded. Interviewees had the option of being interviewed in French, English, or both. Participants with severe expressive aphasia were interviewed using

supported communication techniques, and, in these situations, the care partners were consulted to corroborate certain details and events.

Data collection with stroke survivors took place over three sessions, each lasting between 0.5 – 3 hours. Data collection with the care partner took place over one visit lasting between 1 and 2.5 hours. Importantly, the first two sessions with the stroke survivors and the interview with care partners were completed and analysed before the third session took place. Table 1 presents the breakdown of data collection sessions with the stroke survivors. See Appendix F for a table presenting all of the data sources by case.

Table 1: Breakdown of data collection sessions with stroke survivors

Session	Research activities
1	<ul style="list-style-type: none"> • Semi-structured interview, part 1. • Participant observations (modified)
2	<ul style="list-style-type: none"> • Semi-structured interview, part 2. • Measures: SIS, HADs, ICF Checklist (Participation subsection), and assessment of bilingualism. • Participant observations (modified)
3	<ul style="list-style-type: none"> • Initial findings for member checking. • Consent forms signed for review of medical records from acute care hospitals and inpatient rehabilitation units

3.3.3 Methodological modifications. There were two major changes to the method as it was originally designed. These related to changes to one data collection strategy (participant observations) and to the number of data collection sessions. Observations of participants taking part in valued activities were originally planned during one of the four data collection sessions; however, all the participants declined to be observed outside of the other data collection sessions. Participants asked to have observational data collected based on the visits only (for example, mobility in the home environment), with the exception of one participant who wanted observations from the consent visit to be used as well. As a result of this change, only three data collection sessions were needed instead of the four sessions originally planned.

3. 4 Data Analysis

As suggested by Stake (2006)'s approach to collective case studies, two levels of analysis were completed: intra-case analysis, followed by cross-case analysis. Nvivo 10 software was used to organize data and codes, and to keep track of the analysis of results.

All the data collected (interview data, observations, chart reviews, document review, measures) was initially integrated and interpreted for each case. The chronology of data (pre and post-stroke data) was taken into consideration. The result is a description of the various experiences of return to participation and the influences of the contexts. Importantly, data interpretation and analysis was carried out after each interview, so that subsequent interviews could delve deeper into the participants' experience of returning to participation (e.g., focusing on certain details, adding a question for clarification) during the next session with the case (Aaltio & Heilmann, 2010; Baxter & Jack, 2008; Merriam, 1998; Stake, 2006).

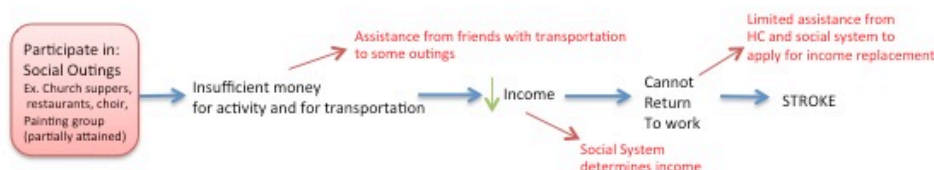
Following intra-case analysis, cross-case analysis was carried out. Commonalities across cases, and differences between and linkages across the cases were examined (e.g., experience of the issue, contexts, and identified patterns). Final findings were compiled and assertions made based on both the individual case and the cross-case analyses. The next section describes the intra- and cross-case analysis strategies in detail.

3.4.1 Analysis strategies. As a straightforward analysis process for this specific research context did not exist, intra-case and cross-case analysis strategies were created; these strategies were highly influenced by the work of Stake (1994, 1995, 2006), Miles, Huberman and Saldana (2014), and Patton (2015). The following section describes the analysis strategy that was used for intra-case analysis, followed by a description of the cross-case analysis process. Unless otherwise specified, analysis was carried out by KSS.

1. The interview recordings of the two interviews with the stroke survivor and one interview with the care partner were transcribed verbatim. The transcripts were read and re-read.
2. Units were identified – these were paragraphs or sentences in the transcripts that revealed information relevant to the case’s context and the issue being studied (Merriam, 1998). Units were assigned a provisional code using larger category themes (e.g., a larger category theme would be “transportation” rather than “public bus”) (Miles, Huberman, & Saldaña, 2014; Stake, 1995, 2006). Units were identified in the transcripts by applying two methods. First, a deductive coding strategy was used; here, units were identified based on issues that were noted during the literature review of the research proposal phase as *foreshadowed issues* (etic issues) (Stake, 1994). Second, an inductive coding strategy was used; here units were identified based on emerging issues or concerns (emic issues) as these were recognized (Stake, 1995, 2006).
3. Transcripts were re-read several times to further refine the codes, that is, to better match units with codes by re-sorting and re-naming the provisional codes. The codes were aggregated and categorised (“categorical aggregation”) (Stake, 1995). Each category was composed of codes that were similar amongst themselves, but without overlap with codes in other categories (Patton, 2015). Categories were reviewed and these were reworked until the best categories were found to fit the data. Earlier versions of the categories and the reasons for changes were documented in the research journal and in memos (Miles et al., 2014).
4. Each of the stroke survivor participants’ identified personal projects was used as a starting point for the next steps of analysis. A diagram was constructed depicting the stroke survivors’ and care partners’ experience of the events and factors influencing return to participation in each personal project and whether or not the attempt was successful. The

events and code categories involved in the reported experience were then examined. One illustration of the use of this strategy appears in Figure 2, in which issues related to return to regular participation in social outings, such as weekly church suppers, was considered.

Figure 2. Example of a personal project and the events and categories that influenced the experience of return to a personal project (social outings)



5. These personal project diagrams were then examined for larger patterns, as suggested by Miles et al. (2014) and Stake (1995). Here, these diagrams were examined for relationships or interactions between the different events and categories. These were called “patterns” if they reappeared several times and if they helped in understanding the participant’s experience. See Figure 3 for an example of a pattern based on social system functioning.

Figure 3. Example of a pattern (social system functioning) affecting the experience of return to participation in personal projects.



6. Data collected from the medical records and participant observations was then directly interpreted. This additional data was analysed together with the information gathered during the interviews and was examined for its fit with the already identified personal project diagrams and patterns. For example, did it corroborate or support the information gathered during the interviews? What new understandings did it bring?

7. Results of the SIS, HADS, ICF Checklist Participation subsection, and Self-Assessment of Bilingualism were used in case descriptions, and to further understand the personal projects identified. For example, a stroke survivor's rating of his ability to participate in housekeeping tasks on the SIS and ICF Checklist gave supplemental details about this person's housekeeping assistance needs to attain the project of living independently.
8. A table was constructed for each identified pattern, which included supporting evidence from all the relevant categories in the form of units from the various sources of data (e.g., interviews, medical records, observations, measures). Figure 4 depicts a simplified example of a table of evidence.

Figure 4. Example of a simplified table of evidence for the pattern Social System Functioning.

Case	Social System Function: income replacement, housing, medication, therapy Data taken from nodes: social system actions, post-funding, system, post-housing
001	<p><i>Data from interview with participant</i></p> <ul style="list-style-type: none"> • « J'ai appelé, pis appelé, pis appelé, pis...y disait tout le temps « ben tu fais trop d'argent ». Ben oui...ben voyons...j'ai 600 t'sais là? Je l'ai pas encore le ODSP. » <p><i>Data from interview with care partner</i></p> <ul style="list-style-type: none"> • « Fait que là, y'ont jamais regarder pour financial aid! Fait qu'à resté là, fait qu'à sort de d'là, a vit sur son chèque de CPP, \$646 par mois. » <p><i>Data from medical chart (recruitment site)</i></p> <ul style="list-style-type: none"> • Sept 19: Patient talked about income issues and related stress.

These tables helped with reviewing the data and assigning categories, as well as verifying whether or not the data fit within proposed patterns. If the units of data did not fit, alternative explanations were considered. Data and patterns were also reviewed with the thesis advisory committee during the various steps of analysis, and alternative explanations were discussed.

9. During the third session with each participant, elements of their micro context, personal factors, and the list of personal projects were reviewed with them. The diagrams depicting the stroke survivor's personal projects and the categories and events involved in the

experience of attempting to return to participation were reviewed and patterns verified. If the participant did not agree with information and interpretations, this was discussed and changes were made. During this interview, if new supporting information for the personal projects or patterns was provided, it was added to the case data.

10. Assertions were made based on the identified patterns. These assertions, as well as patterns and rival patterns were discussed with the thesis advisory committee.

This analysis strategy was repeated for each case. If during the process of coding data from one case, new or alternative codes and categories were required to better fit the data, all previously analyzed cases were reviewed and changes were made where necessary.

For the cross case analysis, the patterns and assertions from each case were compared (Stake, 1995). The following process was used:

1. The uniqueness and commonalities of each case were noted, as well as how this influenced understanding of the experience of return to participation (Stake, 2006).
2. The importance of each pattern for each case was noted. For some cases, a certain category or pattern may not have been important to the experience of return to participation. The patterns that retained importance across cases (Stake, 2006), as well as how each of these shared patterns were expressed for each case, was documented.
3. Existing intra-case assertions and patterns were reviewed and reworked based on the new understanding brought on by the cross case analysis where necessary.
4. Cross-case assertions were written.

3.5 Trustworthiness of the Results

The worth or rigor of qualitative research can be illustrated by describing the trustworthiness of the research results using parameters such as credibility, dependability, and

confirmability (Given & Saumure, 2008). The following describes these three parameters as they relate to this research.

Credibility of research results is enhanced by the steps taken to ensure that data is accurately represented (Given & Saumure, 2008). Here, as suggested by Lincoln & Guba (1985), strategies used to improve credibility of research results included: prolonged engagement with the participants, triangulation, and feedback from the stroke survivor participants (also known as member checking).

First, for each case, several hours were spent interviewing both the stroke survivors, and the care partners. In total, between 1.75 hours and 5.5 hours of interviews were carried out with stroke survivor participants over three sessions, and between 1 and 2.5 hour interviews with the care partners over one session. The first two stroke survivor sessions and the care partner interviews took place over the course of approximately one to three months for each case. The third session with stroke survivors took place approximately six to eight months following the first interview. See Appendix F for interview lengths and the period of involvement.

Second, the process of triangulation was applied by using different data sources, methods, and investigators. For corroboration of the information, two different perspectives were used, that of the stroke survivor and of a care partner. Different methods were used to collect data: interviews, chart reviews, and participant observations. Data and findings were discussed with the advisory team.

Third, member checking took place during the third session with the stroke survivors. Their feedback was sought about the identified personal projects and the interpretation of events and reasons behind their experience of attainment or non-attainment. Participants also provided feedback regarding the patterns. As well, the working analyses were presented to the advisory

team at different points in time to discuss patterns, and to look at the possibilities of alternative or rival explanations.

Confirmability looks at what was done to ensure that the interpretations match the data collected (Given & Saumure, 2008). Confirmability was addressed by providing a clear description of the method used during data collection and analysis, and by keeping a research journal documenting challenges and issues encountered during these two analysis phases of the research. Further, a detailed description of each case was provided and the stated interpretations were supported by quotes from the interview transcripts.

Dependability means that other researchers could, using similar data in similar conditions, come to the same explanations about the phenomenon being studied (Given & Saumure, 2008). To improve dependability, a detailed description of the analysis method was provided. As well, an audit trail was kept. Through a research journal and memos, the audit trail tracked the analysis process and its evolution (Miles et al., 2014; Stake, 2006; Yin, 2003, 2009). In the research journal, alterations, including the rationale for any changes, decisions and procedures during the research process, as well as personal reflections, concerns about data, leads for following interviews, and clarifications of events during data collection, were documented. Issues with codes or nodes and categories as well as any changes that took place with the research process were also noted. Memos were also used to document coding changes. A separate spreadsheet was kept to track each case and the use of the codes or nodes (for example, if a case had no information coded into a node) as well as the addition of new codes over time.

4. Data Analysis and Research Findings

The first section of the chapter presents the general characteristics of the eight stroke survivor participants in the study. This is followed by eight intra-case analyses focusing on the first research sub-question, eight intra-case analyses focusing on the second research sub-question, the cross-case analysis, and a synthesis of the main findings.

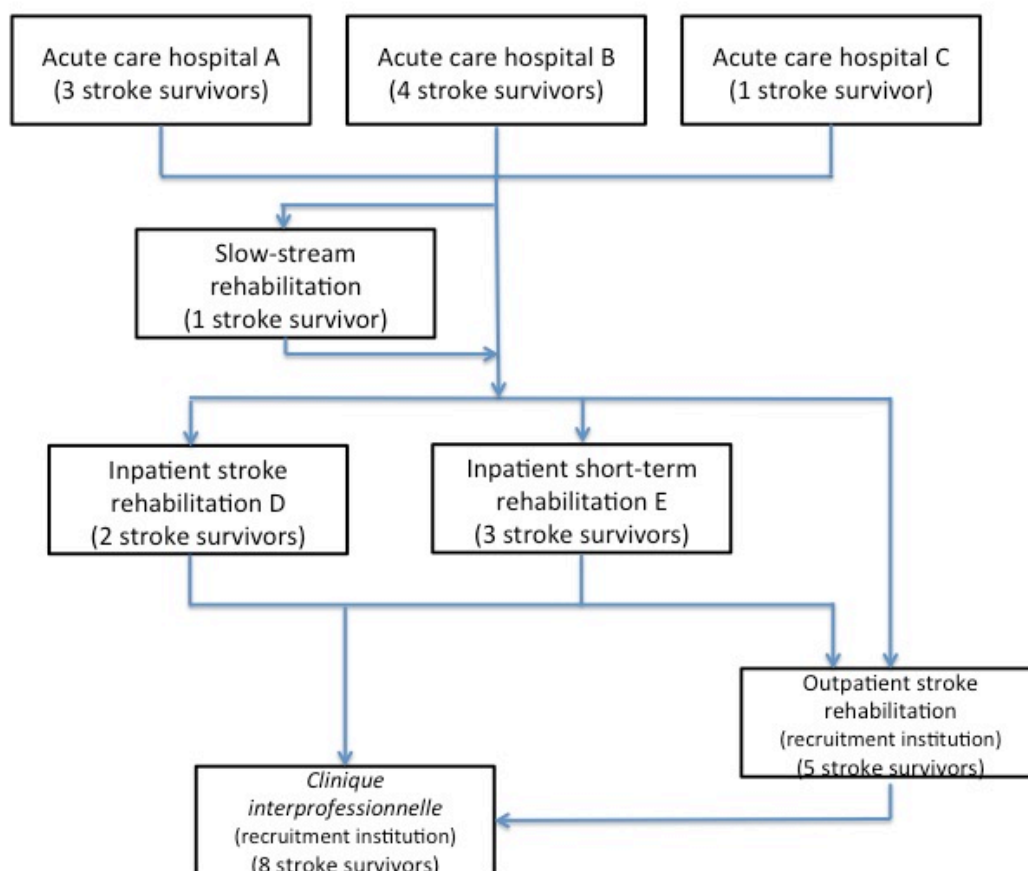
4.1 Participant Characteristics

During recruitment for stroke survivor participants, eleven names were forwarded to the researcher, ten from the *Clinique interprofessionnelle* and one from the outpatient stroke rehabilitation program. Two potential participants were not eligible for the study because they did not meet the low-income criteria. One potential participant met the inclusion criteria but declined to participate. Eight participants were included in the study, all but one of whom was recruited from the *Clinique interprofessionnelle*. Eight care partners were also interviewed. All participants completed the three interviews except for Paul, who could not be located for the third interview.

The eight stroke survivors were recruited from two institutions, but their trajectories through the healthcare system varied. They were admitted to three different acute care hospitals in the region at the time of their stroke, and five stroke survivors took part in one of three different inpatient rehabilitation programs. Five participated in the outpatient stroke rehabilitation program. All eventually accessed services from the *Clinique interprofessionnelle*. The *Clinique interprofessionnelle* is a private clinic, which was put in place by a local university in order to increase student opportunities for interprofessional clinical training and also to provide services to the region's Francophone community living in a linguistic minority situation. These services were provided free of charge through grants provided by the federal and

provincial governments. Figure 5 depicts these different trajectories through the healthcare system.

Figure 5. Healthcare system trajectories for the eight participating stroke survivors



Characteristics of the stroke survivor participants are provided in Table 2. Ages and time since stroke are provided in broad ranges to help maintain anonymity. At the time of data collection, the participants were between their early thirties and late seventies. Half were women. The approximate time elapsed between the time of stroke and the first interview for the research ranged between 7 months and 5 years.

Table 2. Characteristics of stroke survivor participants

Case number	Stroke survivor pseudonym	Gender	Age at time of stroke (yrs.)	Time since stroke at first interview	Education	Care Partner relationship to stroke survivor and pseudonym	Lives where and with whom
001	Charlotte	F	Early 60s	1 year	High school	Friend, Natalie	Alone, social housing apartment
002	Paul	M	Early 50s	5 years	College	Son, Simon	Rotation with various family members in their homes/ apartments
003	Jackie	F	Early 50s	1 year	High school	Brother and sister-in-law, Luc and Marilyn	Private retirement home
004	Laurent	M	Early 70s	Less than 1 year	Primary School – limited reading/ writing	Brother, Armand	Alone, granny suite on nephew's property
005	Aimée	F	Late 70s	3 years	High School	Daughter, Marie	Apartment with husband
006	Josée	F	Late 20s	2 years	University	Mother, Denise	Alone in condominium purchased by parents
007	Sylvain	M	Late 40s	Less than 1 year	College	Sister, Angèle	Apartment with roommate
008	Daniel	M	Early 50s	1 year	College, university courses	House-keeper/ landlady, Solange	Boarding house with landlady and other tenants

All participants were Canadian citizens or permanent residents. Culturally, three of the participants identified as Haitian; the other five participants did not specify a culture other than Canadian or French Canadian. All participants indicated that their mother tongue or their first spoken Canadian official language was French. Seven of the eight participants self-identified as being bilingual in both official languages (French and English), and on the self-evaluation of level of bilingualism (Vallerand, 1989; Vallerand & Halliwell, 1983), five participants met the criteria for French and English bilingualism.

Two stroke survivors, Jackie and Josée, were experiencing severe expressive aphasia and their interviews were conducted using supported communication techniques. Assistance from family was used to corroborate information from the interviews related to events and dates for these two participants. One participant, Daniel, had mild communication difficulties as well; supported communication strategies were used only for some sections of his interviews. Quotes used in this report are taken from these participants' interview transcripts and are but small portions of the conversations that took place. Not evident in the quotes are the strategies used to clarify and confirm the participants' messages, such as the use of multiple verification questions, written material, pictures, and body language. See Table 3 for details of culture, language and need for supported communication.

At enrolment, all stroke survivor participants met the criteria of income less than \$25,000 per year, and were receiving some form of government income support. Details of income, source of income, and rent can be found in Table 4.

Two of the participants asked to have family present during some of the interviews: Josée requested that her mother be present for the first and third sessions, and Aimée wanted her daughter present for the first and third sessions as well.

Table 3. Stroke survivor cultural identification, language characteristics, and need for supported communication

Pseudonym	Cultural background	Languages	Bilingualism self-assessment scores		Supported communication
Charlotte	Canadian	Bilingual (French and English), French mother tongue	French 14/16	Understanding 4/4 Expression 4/4 Writing 3/4 Reading 3/4	No
			English 12/16	Understanding 3/4 Expression 3/4 Writing 3/4 Reading 3/4	
Paul	Haitian	Bilingual (French and English), Creole mother tongue, French first official language	French 15.5/16	Understanding 3.5/4 Expression 4/4 Writing 4/4 Reading 4/4	No
			English 12/16	Understanding 3/4 Expression 3/4 Writing 3/4 Reading 3/4	
Jackie	Canadian	Bilingual (French and English), French mother tongue	French 12/16	Understanding 3/4 Expression 3/4 Writing 3/4 Reading 3/4	Yes
			English 16/16	Understanding 4/4 Expression 4/4 Writing 4/4 Reading 4/4	
Laurent	Canadian	Bilingual (French and English), French mother tongue	French 7/16	Understanding 1/4 Expression 4/4 Writing 1/4 Reading 1/4	No
			English 8/16	Understanding 3/4 Expression 4/4 Writing 1/4 Reading 0/4	

Aimée	Haitian	French, Creole mother tongue	French 16/16	Understanding 4/4 Expression 4/4 Writing 4/4 Reading 4/4	No
			English 0/16	Understanding 0/4 Expression 0/4 Writing 0/4 Reading 0/4	
Josée	Canadian	Bilingual (French and English), French mother tongue	French 15/16	Understanding 4/4 Expression 4/4 Writing 3/4 Reading 4/4	Yes
			English 16/16	Understanding 4/4 Expression 4/4 Writing 4/4 Reading 4/4	
Sylvain	Canadian	Bilingual (French and English), French mother tongue	French 11/16	Understanding 3/4 Expression 3/4 Writing 2/4 Reading 3/4	No
			English 16/16	Understanding 4/4 Expression 4/4 Writing 4/4 Reading 4/4	
Daniel	Haitian	Bilingual (French and English), Creole mother tongue, French first official language	French 16/16	Understanding 4/4 Expression 4/4 Writing 4/4 Reading 4/4	Partial
			English 16/16	Understanding 4/4 Expression 4/4 Writing 4/4 Reading 4/4	

Table 4. Stroke survivor participant income sources, monthly income, and monthly rent

Pseudonym	Source of income at time of interviews*	Approximate monthly income	Monthly rent
Charlotte	CPP	\$600/month	\$180/month (geared-to-income)
Paul	ODSP and CPP	\$1100/month	\$0 – no fixed address
Jackie	LTD	\$1680/month	\$1550/month
Laurent	OAS, CPP, retirement fund	\$1400/month	\$740/month
Aimée	ODSP	\$1495/month (for the couple)	\$1000/month (for the couple)
Josée	ODSP and CPP	\$1200/month	\$0 - Paid for by parents
Sylvain	OW, approved for ODSP during second interview	\$695/month on OW, estimated \$1200/month on ODSP	\$600/month
Daniel	ODSP	\$1175/month	\$450/month

*Terms
 CPP: Canada Pension Plan
 LTD: Long Term Disability Insurance Benefits
 OAS: Old Age Security
 ODSP: Ontario Disability Support Program
 OW: Ontario Works

4.2 Intra-case Analysis: Low Income and Participation

Each intra-case analysis begins with a case story that is structured on the events leading up to and following the stroke. Each case story addresses elements of the study's conceptual framework: the micro-context, the stroke survivor's personal factors, including body functions and structures, and related activity limitations, as well as pre and post-stroke personal projects. This is followed by an analysis focused on the first research sub-questions: *How does low income influence the experience of return to participation for low-income Francophone stroke survivors living in a linguistic minority situation?* This research sub-question is addressed through a description of the stroke survivor's personal projects, and the influence of low income on the experience of attempting to attain them. Quotes are chosen from the interviews with the stroke survivors and care partners, and in several instances, sections of the conversation between the interviewer and interviewee are used to support the analysis.

4.2.1 Charlotte

4.2.1.1 Case story. Charlotte is a woman in her early 60s born in a rural Francophone community, and she considers herself bilingual. She has worked and lived in Ottawa for most of her adult life. She has three adult children, and although she reported being relatively close with them, Charlotte stated that she has never turned to them for emotional support. She has always kept her children largely unaware of her private matters, such as relationships or health concerns.

Prior to her stroke, Charlotte was living in a rented house. She was working full-time in a contract position and experiencing a high level of stress in her work environment. She was looking forward to retirement. Charlotte had opted to start receiving her Canada Pension Plan (CPP) at the age of 60 years old to help supplement her income. Over the years just prior to her stroke, she had been through two emotionally difficult relationships that caused substantial financial losses. She was in a financially precarious position because she had no savings, and owed the bank money. Medically, Charlotte had diabetes and hypertension – she reported that both were difficult to manage because of her limited understanding of the diseases.

Approximately one year prior to the research interview, Charlotte had a stroke. She was admitted to an acute care hospital for a few weeks. There, she took part in some therapies and started to learn to manage her diabetes. During hospitalization, her children were given Power of Attorney for financial management.

Charlotte was unable to return to work following her stroke, and without an income, she was not able to afford to return to her rental home. Charlotte's two eldest children planned her discharge location without her input. Charlotte was discharged to her son's place for one month and then moved to her daughter's home. Both children lived in isolated rural areas.

Charlotte does not recall receiving any assistance or guidance from health care professionals regarding applications to income support programs, specifically to Ontario Works (OW) or to the Ontario Disability Support Program (ODSP), two programs for which she was eligible, or assistance and guidance with accessing funding for medication or other health services. The acute care records did not show evidence that this information or guidance was provided to her.

Charlotte was admitted to inpatient short-term rehabilitation and referred to two outpatient programs following her discharge from the acute care hospital. She participated in speech therapy, physiotherapy, and occupational therapy and received an audiology assessment.

While Charlotte was living with her daughter, their relationship was becoming increasingly tense. Charlotte's daughter asked her to move out and called the police because she thought her mother's difficulty communicating reflected mental instability. Charlotte went to live with friends for the next several weeks. These friends provided her with assistance to navigate the social system and apply for financial support. She was eventually able to secure municipal funding assistance for her medication, glasses, and dental repairs.

Charlotte could not afford an apartment, and her friends could not continue to house her. It is unclear at which point Charlotte's name was added to the municipal registry for social housing, but it seems, according to medical records, that this was done while Charlotte was in outpatient services. Approximately eight months post stroke, Charlotte became homeless while on the waitlist. She lived in a shelter for one month. During this time her situation was considered more urgent by municipal housing services and she was moved up the waitlist and assigned an apartment with geared-to-income rent.

At the time of the interviews, Charlotte was still settling into her apartment. Although she had given away a lot of her possessions, she was still having difficulty finding room for her things in her small apartment.

4.2.1.1.1 Charlotte's post-stroke body functions and structures, and activity. The medical records, participant observations, and interviews highlighted the following impairments to body functions and structures, and activity limitations: decreased verbal expression, reading and writing, organizing and planning, attention and concentration, and short-term memory. She was also experiencing difficulties managing frustration, as well as poor activity tolerance, decreased strength, and decreased walking endurance and balance.

At the time of the interviews, Charlotte scored 61/100 on the SIS-16. Standing without losing balance, walking up a staircase, and walking the distance of one block were scored as being mildly difficult. She identified heavy housekeeping, carrying heavy objects with her affected arm, shopping and walking quickly while retaining her balance as being very or moderately problematic. On the ICF Participation Checklist, she reported severe difficulties with doing complex calculations, and moderate difficulties with reading, speaking, lifting and carrying, moving around, and shopping. She did not drive because her driver's license was suspended following the stroke. Mental health was measured using the HADS. She scored within normal limits for anxiety and depression.

4.2.1.1.2 Charlotte's personal projects: pre and post stroke. Pre stroke, Charlotte reported that she organized karaoke events, both in and out of her home, and played music in a group that performed in nursing homes. She sang in a choir, did woodworking, participated in outdoors sports (rollerblading, hiking, walking), camped and fished. She owned a car and drove everywhere. She attended social events every Friday (church suppers and dances). She enjoyed

the company of many friends, several of whom she had met years earlier at a Francophone support group for divorced or separated individuals. She spent time with family as well.

Several post-stroke personal projects were identified during the interviews: secure income support, live independently (e.g., obtain housing, move in), find financial support for health needs (e.g., medication), participate in outdoor activities, get back into leisure, be independent with transportation, participate in social outings, prepare enjoyed foods, improve mobility and communication abilities, and better understand her health.

4.2.1.2 Influence of low income on return to participation

4.2.1.2.1 Personal projects. Charlotte identified many different personal projects. Each project is described focusing on the key elements of the consequence of low income. Diagrams in Appendix G depict the events and categories that influenced the experience of return to the personal projects.

Secure income support: As a result of her stroke, Charlotte was unable to return to gainful employment and needed to secure income support. She did not have access to disability benefits through her work (e.g., LTD). On discharge from the hospital, she was receiving Employment Insurance (EI) but had not received support to apply for longer-term governmental income support, for example ODSP. Securing income support became a personal project in itself.

Charlotte explained that, because of her new cognitive and communication impairments, she needed the assistance of her friends to help her find income support programs, to speak with workers in the system, and to help her go through the complex application process. “J’avais besoin de quelqu’un de de ...qui viendrait avec moi pour être capable certain que j’en que j’entends bien, pis que j’suis capable de remplir les formes.”

At the time of the research, Charlotte's only income was CPP (approximately \$600/month), and she had been denied ODSP multiple times because ODSP personnel felt that her income was too high. "J'ai appelé, pis appelé, pis appelé, pis...y disait tout le temps 'ben tu fais trop d'argent'. Ben oui...ben voyons...j'ai 600 t'sais là? Je l'ai pas encore le ODSP."

Live independently: Post stroke, Charlotte's personal project was to return to living on her own. However, Natalie, a good friend, explained that without income support, Charlotte could not afford the rent of her pre-stroke home. "Ben euh...Sa place...fallait qu'a déménage parce que là a l'avait pu l'argent là." When her daughter asked her to move out, Charlotte moved in with friends, and eventually Natalie invited her to stay with her and offered to assist with finding an apartment.

Charlotte's friends began helping her with her project of independent living by handling calls and interactions with social housing services. Natalie stated that they learned that the wait-time for a geared-to-income apartment was of approximately seven years for people such as Charlotte who were not considered priority clients.

Eventually, Charlotte could no longer continue living with friends, and the only option she received from municipal housing services was to go to a shelter. Following one month in a women's shelter, the municipal housing support services were able to provide her with an apartment in a building in the downtown area. Rent was set at 30% of her income. Her friend Natalie pays her internet, television and telephone bills because Charlotte still does not have sufficient left over funds at the end of the month to pay for these services.

Find financial support for medication, dental repairs, and new glasses: Once discharged from the hospital, Charlotte could not afford her medication (about \$500/month), and she had not received guidance and direction regarding funding assistance for health needs.

“...fait que, j’y dit ‘Ben j’ai pas d’argent à payer mes médicaments’ fait que j’y dit ‘C’est ben simple, j’vas juste arrêter des prendre. Si j’pas capable des payer, m’a m’a arrêter.’”

With friends’ assistance, she located, connected with, and applied to a municipal health funding support program, and after paying an approximately \$2000 deductible, the program has been paying her medications. They also agreed to pay for one pair of glasses, and repair of one problematic tooth. However, she lost her tooth before funding approval came through.

Participate in sports, camping, fishing: Charlotte expressed that pre-stroke outdoor activities were very important to her. “Ben j’aimais aller à la pêche, j’aimais pfft le camping, j’aimais... tout ça là, t’sais?” After the stroke, however, she had to get rid of her outdoor and sporting equipment because of the small size of her new apartment. “Mais, j’ai j’ai pu j’ai pu d’ligne à pêche, j’ai pu...j’avais un un p’tit, un canoë que tu soufflais? Fait que j’ai pu rien, j’ai pu rien de t’ça là t’sais?” She has been unable to purchase replacement equipment.

Get back to photography, karaoke, massage, woodworking: In her previous home, Charlotte used to set-up a photo studio for portraits, a bench for small woodworking projects, and a massage table for services to friends. She explained that she also enjoyed organizing weekly karaoke parties in her home. “Karaoké, oui. Je le faisais chez nous. T’sais? Alors euh... Toutes toutes les mercredis soir, les gens y euh venaient chanter avec...chez nous...J’aimais ça.”

Lack of physical space has been a limiting factor for these personal projects. The photography equipment is in Charlotte’ apartment but Natalie explains the impossibility of setting up the photo studio in the small space. “...le monde allait chez eux, pis avait pris une pièce, pis bon...Ben là dans son appartement, y’est grand comme ma yeule là. Fait qu’ça veut dire qu’a pourrait pas l’faire [la photographie] chez eux...” Woodworking is not possible in her small space either, but Natalie has been inviting Charlotte to use her garage, and providing

transportation. Also, some of the equipment is being temporarily stored at her daughter's home. "Vois tu j'donnais des massages aussi là...j'ai pus ...ma table à massage, ma fille a l'a, t'sais? C'est des choses que j'aimais, mais là...j'ai pas d'place t'sais? Fait que alors je suis limitée à cause de la place."

Return to driving and be independent with community mobility: Following her stroke, Charlotte's driving license was suspended for six months. Now eligible to undergo testing, she is unable to pay for the driving exam. Even if she did get her license, she reported that she would be unable to afford gasoline and insurance. "J'peux pus conduire, j'peux pus euh...mettre du...j'pourrais même pas mettre de gaz dans l'auto euh...t'sais?...Les assurances? Fait que... C'est un gros gros gros changement dans ma vie ça, t'sais, d'être indépendant."

As far as alternative transportation options, Charlotte is unable to afford taxis. She is able to take public buses, but she is limited in the frequency of trips because of the ticket cost. As well, when newly arrived in her apartment, Charlotte only had a cell phone. She reported that booking a trip with the disability transportation service (Paratranspo) was too costly in terms of minutes on her phone because of being on hold for long periods of time. She now has a landline, which makes this type of call more affordable.

Charlotte : Qu'est-ce qui est difficile c'est de de ..de les appeler [Paratranspo]. T'sais là? T'attends pis t'attends pis t'attends pis...j'viens juste d'avoir mon téléphone là OK? Avant j'avais juste mon cellulaire, pis mon cellulaire, j'ai 200 minutes mais que j'appelle ou que je reçoive, je paye. T'sais? Alors...j'devais payer \$25, pis un mois ç'a couté \$88. Fait que j'ai dit j'peux pas là, t'sais là?

Charlotte has been relying on friends to drive her to certain activities (e.g., choir practice). Furthermore, without a car, Natalie explained that Charlotte has been unable to transport heavier equipment, such as her karaoke machine and photography lights, if she were to set it up in another location. “T’sais, pis a pas d’auto. Fait que ça...t’sais, tu peux pas charrier ça là [l’équipement].”

Charlotte stated that with more money, she would buy a car and hire a driver to improve her ability to get places on her own. “...j’vas acheter une auto pis engager un chauffeur. Fait que là, ‘Tiens! Viens-t ‘en. On s’en va là, on s’en va là, on s’en va là’.”

Participate in social outings: Charlotte was involved in many social outings prior to the stroke and enjoyed outings to restaurants. She also went weekly to church suppers and dances with friends. Since her stroke, Charlotte has been unable to afford restaurant meals or event tickets. As she explains it, the money for a ticket to a church supper is needed for groceries.

Interviewer : Vos sorties du vendredi pour les bines...est-ce que vous avez été capable de reprendre ça?

Charlotte : Euh...non, parce que j’ai pas l’argent. C’est 8 dollars. Fait que à 8 dollars, quand je r’garde les les les flyers, ben, peut-être que j’capable d’avoir euh 2 piasses sur...pour avoir ça. Fait que j’ai pas été capable.

Interviewer: Pis c’est pus une priorité pour vous...

Charlotte: Ben j’aimerais ça! Mais...j’peux pus.

Charlotte has returned to her choir and painting group where she meets up with friends – these outings are low cost or free (community programs), and friends provide transportation. She has also been doing more low cost social activities such as knitting with a lady in the building, as well as volunteering, and playing darts with her apartment building’s social club.

Prepare foods she enjoys: Pre stroke, Charlotte enjoyed cooking and making large pots of soup. Her post stroke limited monthly income has made it difficult for her to obtain groceries and to cook foods she used to enjoy. She has been getting much of her food at the Dollarstore, and at the local Food Bank. Charlotte has been able to get more foods from the grocery store by way of an informal trading system - she helps out a disabled friend in her building by getting her groceries, and in return, this friend gives Charlotte food items. As Natalie explains : “ ...a va dire à [Charlotte], quand qu'[Charlotte] va pour ses commissions ‘T’as tu besoin d’quoi?’. Fait qu'[Charlotte] a dit ‘P’t’ête ben une pinte de lait.’ ‘Bon ben amène toi z’en du lait là.’”

Improve mobility and communication abilities: Post stroke, Charlotte had goals of improving her general mobility and her communication abilities. She was able to make gains and attain many of her mobility and communication goals while taking part in publicly funded therapies in a short-term rehabilitation program and two outpatient clinics. Medical records indicate that at times she had difficulty getting transportation to the clinic for appointments, and stress related to income and housing affected her ability to follow-through on home exercises. Family and friends provided transportation to majority of appointments, and one of the outpatient clinics also conducted some of their sessions wherever Charlotte was living.

Understand health: Charlotte reported that she was working on better understanding her health and how to prevent another stroke. While this post-stroke personal project was not related directly to income, it did have financial implications, as she was unable to consistently purchase healthy foods and, at one point, to pay for medication.

4.2.1.2.2 Patterns of influence on experience of return to personal projects. Six patterns of factors influencing Charlotte’s experience of attempting to return to personal projects in the context of low income were identified, and are depicted in Appendix H. These are: healthcare

system, family, friends, social service system, knowledge about the healthcare and social service system and understanding of health, and the physical environment.

Healthcare system: Healthcare services had an indirect impact on Charlotte's attainment of personal projects in the context of low income. The inpatient healthcare team provided discharge-planning services without fully considering Charlotte's preferences. Neither the inpatient or outpatient professionals provided actual guidance with regards to obtaining adequate housing, income support, medication, and dental care. Lack of public coverage for driving licence examinations following stroke limited her ability to return to driving.

The healthcare team and Charlotte's family planned discharge from hospital – they decided that she would relocate to her son and daughter's homes. Charlotte said that she was not involved in any discharge discussions and decisions. “Y’a personne qui m’a dit ‘Bon voici, aimerais-tu mieux faire ça ou faire ça...ou?’ t’sais là? ...Jamais jamais, depuis [mon stroke], tout le monde, prends ma vie en main.” She suspected that she was not involved in decisions because of her aphasia and the team's perception that she could not understand. Medical records indicate that even in the acute phase, she was reliable in yes/no expression and had insight. Medical records do not clearly document how decisions for discharge were made.

When asked if she would have chosen to relocate to her daughter's home if she had had adequate funds, Charlotte expressed that she would have preferred not to live with family. Her friend Natalie believed that sending Charlotte to live with her family, because she didn't have sufficient funds to pay her own rent and had limited income support, was a considerable life-changing event that affected reengagement in personal projects.

Natalie : ...j'trouve que l'hôpital devrait pas envoyer quelqu'un chez eux sans aviser...les personnes...t'sais comme si [Charlotte] était r'tournée chez

eux, dans sa maison, comme tu dis, qu'aurait des fonds, ...ç'aurait pas changé grand-chose. Mais là là, ça changeait toute sa vie là.

Further, as far as Charlotte remembers, on discharge from hospital, the healthcare team knew she would very likely not return to her work but she left the hospital without knowing how to apply for social housing, medication funding, or income support programs. Natalie spoke about this lack of guidance from the healthcare team regarding income support programs when return to work was known to be problematic. “Mais quand qu'est à l'hôpital là, le service social y va? Pour savoir c'est quoi ses besoins là? Bon ben drette là là, c'est comme bon. A peux-tu retourner travailler ou si a peux pas retourner?” Although the team documented that they were unsure if Charlotte would be able to return to work, there was no evidence in the acute care or inpatient short-term rehabilitation medical records that they had provided her with information or guidance on how to apply to social programs.

Outpatient services also provided limited assistance and follow-up in this area. The medical records indicate that Charlotte had started the paperwork for ODSP, but there is no indication that team members asked whether she was currently having any income-related difficulties, such as problems paying for medication. When Charlotte's daughter asked her to move out, the staff of the outpatient program assisted by delivering some therapy sessions at friends' homes to limit travel costs, and linked her with a municipal crisis line and budgeting assistance services.

In Ontario, stroke is a medical condition that must be reported to the Ministry of Transportation and results in automatic driving suspension. To resume driving, people must complete a driving assessment. Although the Ministry of Transportation regulates resumption of driving, exams are completed in private assessment centres, and there is no public funding to

cover the costs of these driving examinations. Post stroke, Charlotte expressed that the cost of this driving examination, \$700, was far too high for her to consider, as were the other costs associated with driving (e.g., insurance, gas).

Family: On discharge, Charlotte went to live with her children, even though prior to the stroke there were long-standing relationship issues. Once in her daughter's home, issues related to financial concerns, isolation, and stroke-related impairments created a high level of stress for Charlotte and her daughter. Charlotte's daughter had difficulty providing assistance with her mother's projects such as finding income or funding for medication. Natalie reported on how Charlotte's daughter seemed overwhelmed with the assistance she needed to provide her mother.

Natalie: Fait que là [sa fille] fallait qu'a travaille, pis là ben [Charlotte] a y disait 'T'sais, tu pourrais tu faire ce téléphone là?' Fait que là [sa fille] ça l'a frustrait. 'T'es icitte à journée longue pis tu veux t'en aller en appartement tout seule pis tu veux être indépendante, pis t'es même pas capable de faire des téléphones!'

Charlotte explained that high stress and misunderstandings eventually led to her daughter asking her to move out and to the subsequent housing crisis. "Fait que là, c'est ça. Elle m'a mis dehors. Fait que là... j'avais pus de place." The relationship between Charlotte and her family remained strained and unsupportive even while she was in the homeless shelter. Natalie explains that she informed family that Charlotte was in the shelter, but that no family visited.

Natalie : Mais à un moment donné, t'sais, je je je j'en ai parlé à sa sœur, pis ses enfants pis j'ai dit 'Est là [au shelter]'. Y'en a pas un qui l'a appelé. Y'en a pas un qui est allé la chercher tout le temps qu'a été là. Moi j'allais deux

fois, trois fois par semaine. Juste la sortir pour la soirée, euh aller l'amener, j'l'amenais souper au restaurant, ...

Family members seemed unable to understand that Charlotte was able to make decisions about housing but needed help communicating with authorities. It appeared that the combination of not understanding her impairments and strengths, and having little knowledge of the complex process of applying for income support, simply overwhelmed the family.

Friends: Charlotte's friends provided critical assistance that helped her attain many parts of her personal projects, such as independent living, securing income support, social outings, preparing foods, and independence with transportation. Specifically, they provided emotional support, transportation, help connecting with and communicating with authorities, help organizing paperwork while Charlotte was applying to social services (income support and housing), temporary housing when she left her daughter's home, financial assistance with paying utility bills, direct assistance with communication (e.g., making phone calls for her), support with specific leisure activities (e.g., casting on for knitting projects, physical space to do some woodworking), advocacy for social services, and mediation with family. One of the friends, Natalie, was a consistent support. She describes the assistance she provided with organizing Charlotte's paperwork when they were working on applications for financial support programs.

Natalie : Moi j'ai tout' pris, toutes ses papiers avec les numéros téléphones, pis j'ai fais une... So là je lui ai tout' faite une feuille Excel, que moi j'ai gardée, que j'y ai donnée, pis j'ai dit 'On va tout' déchirer tes 'tits papiers' parce qu'était tout mêlée.

Social service system: Municipal and provincial governments are responsible for social services such as income support programs, medication benefit programs, financial assistance

programs for health-related items (e.g., medication, dental care), and social housing. Unclear and complex application processes, rules and regulations that appeared contradictory regarding eligibility, expensive deductibles, lengthy waitlists, depersonalized application and appeal processes, lack of communication between social services, and absence of follow-up mechanisms influenced Charlotte's experience of participation in several personal projects. The municipal government is also responsible for regular and disability transportation services, and the functioning and cost of these influenced Charlotte's projects as well.

Regarding ODSP, the application process was complicated, and the wait times for decisions were lengthy. "C'est là qu't'as besoin [de ODSP]. Pas dans 6 mois. T'sais? Tu fais application, pis là faut qu't'attendes six mois. Ben ça pas d'allure, t'sais?" Charlotte was denied ODSP several times and there were no other income support programs that she could apply to until she turned 65 years old and would be eligible for the federal Old Age Security.

Her project of finding financial support for medication, glasses, and dental repairs was also influenced by the social systems rules and regulations. Even though she eventually successfully secured funding assistance through a municipal program, Charlotte explains that she had to pay a substantial deductible before receiving funding.

Charlotte : ...la ville m'ont donné...le...comment on appelle ça?.....le déductible.

Parce que ...parce que moi j'avais travaillé une partie de l'année, fait que, fallait que j'paye \$2,064 avant que mes médicaments soient gratuits...

Waitlists also affected access to geared-to-income housing (rent of no more than 30% of income). At the time of her application, the waitlist was of seven years. Charlotte only became a priority on the listing when she was living in the shelter. Natalie questioned how homelessness was the way to becoming a priority and how the hospital was unable to help with this "T'sais..."

aller l'amener dans un shelter pour être capable d'avoir un appartement? Pour la mettre sur la liste top-priority? Comment s'est fait qu'a pas été mis top-priority drette à l'hôpital?"

Charlotte and Natalie were informed that shelter staff would assist Charlotte for income support but this did not occur. This lack of follow through by shelter staff left Charlotte dependent on her friends for help to attain this personal project.

Natalie : Fait que là, a me dit 'On [shelter] va t'aider, on va t'avoir un appartement, on va t'avoir financial aid, on va t'avoir euh...toutes...' Fait que là, y'ont jamais regardé pour financial aid! Fait qu'a resté là, fait qu'a sort de d'là, a vit sur son chèque de CPP...

Difficult access to public disability transport also limited Charlotte's ability to get around town as often as wanted because of the complex process to set-up rides and the cost of tickets.

Knowledge about the healthcare and social service systems, and understanding of health: Charlotte and her care partners had limited knowledge about the healthcare and social service systems, and they had limited understanding of the impact of stroke impairments. Charlotte also had poor understanding of how to manage her own health conditions.

Prior to the stroke, Charlotte and her family and friends had little knowledge about the healthcare and social service systems. Specifically, they did not know what services were available, who to ask for help, and the process to access services such as social housing, income support, as well as medication and health funds. Charlotte and her friends learned about the system along the way, with limited assistance from those within the system. Natalie was surprised by assumptions made regarding her knowledge of the system and questioned why, having never used the system before, she should know anything about it. "Comme si on est s'posé savoir. Du monde qui ont jamais faite partie du système ..." Natalie gave an example of

the challenges of trying to access the system via telephone: after almost one hour and 20 minutes on the phone and being transferred seven times, Pierre, the operator, tells Natalie that it is her fault that she does not have the right questions for him to answer.

Natalie : J'ai dit 'Pierre, transfère-moi pus. Ça fait la septième fois que je suis transférée, ya... je j'veux pus j'veux pus transférer...j'veux juste avoir quelqu'un qui va aider.' Il dit 'Écoute madame.' Il dit 'Si vous posez pas les bonnes questions aux bonnes personnes là, c'est toujours ben pas de ma faute.' J'ai fait 'Ah-ff'.

As well, prior to the stroke, Charlotte had limited understanding of how to manage her diabetes and her high blood pressure. "J'savais pas quoi faire pour le baisser...T'sais, t'as arrêté de fumer c'est correct, mais tu peux pas arrêter de manger." Although preventing a further stroke is an important project, she also still does not understand what happened during the stroke and how to prevent another one.

Further, Charlotte felt that she had not received sufficient and timely information about her stroke that was adapted to her communication abilities. She explained how she would have liked straightforward and understandable information.

Charlotte: J'pense que c'est important que le patient soit plus expliqué et encore exactement qu'est-ce qui s'est passé euh...Vois –tu, les médecins ont dit que ça faisait plus que de 6 mois que je faisais des strokes...t'sais là? Mais moi j'm'en suis pas aperçu, mais, t'sais là? C'est pour ça que j'oubliais des choses...! J'aurais aimé mieux, ... pis quand qu'ils me disent 'Ben regarde, tu vois là? Garde. C'est ça là, pis ça fait là, pis ça ça ça pis...ça donne ça'.

Family and friends also had very limited understanding of the potential impact of the stroke. Natalie noted her limited knowledge and understanding of strokes and recounted how she was confused when she first saw Charlotte at the hospital:

Natalie: Non, pis qu'essé qui était surprenant, si tu l'a regardais, moi ... j'connais pas ça un AVC là, moi j'pensais que j'aurais arrivé à l'hôpital pis qu'a aurait eu des tubes partout pis tout' ça là! Mais était assis dans le lit, comme j'ai l'habitude de voir [Charlotte], a rit, a regarde tout le monde, tout' ça, fait que tu dis 'Ben coudons, a l'a tu eu quêcke chose? Ou si a pas eu rien?'

Family and friends had difficulty understanding Charlotte's stroke related limitations and assistance needs. Specifically, Natalie felt that Charlotte's daughter did not understand her mother's stroke related impairments and their impact on her ability to do everyday things. This limited understanding appears to have caused relationship strains and led to Charlotte's daughter asking her to move out.

Physical Environment: Within the context of low income, Charlotte's participation in personal projects was influenced by the neighbourhood, as well as by the housing characteristics of the places where she lived.

After the stroke Charlotte went to live with her son, and then with her daughter, who both lived in rural areas. These neighbourhoods limited participation in many personal projects such as social outings and getting around on her own. Charlotte reported feeling very isolated "Fait que ça...j'pouvais pas aller nulle part. C'était vraiment...j'me sentais vraiment pognée...j't'après mourir là." The apartment she eventually moved into was located in the downtown area. This improved her ability to get out on her own and to participate in other personal projects.

Housing characteristics influenced participation as well. In the homeless shelter, she was unable to participate in several personal projects due to lack of space, privacy and access to her personal belongings. In her social housing apartment, the small size limited the personal projects she could continue, because of lack of storage space and lack of space to set-up equipment for her hobbies and sports.

4.2.2 Paul

4.2.2.1. Case story. Paul is a man in his late 50s who emigrated from Haiti approximately 30 years ago. His first language was Creole, second was French, then English. Paul had a college education, and at the time of the stroke, he was working full time as a bus driver and lived alone in an apartment. His income was enough to ‘make ends meet.’ He was divorced, and his five adult children and other family members mostly lived out of the province.

Paul had his stroke approximately five years ago and was admitted to an acute care hospital for several weeks. He was then transferred to slow-stream rehabilitation for two months, then to an inpatient rehabilitation program, and then to outpatient rehabilitation services.

As is standard following a stroke, Paul’s driver’s license was suspended. Paul was not able to work, and without an income, he could not continue paying for his apartment. At the time of discharge from inpatient services, the rehabilitation team stated that it was unsafe for Paul to live alone because of his impairments and assistance needs. Paul and Simon, his son and care partner, understood that it was the team’s strong recommendation that he relocate with family. Paul did not want to leave Ottawa; however, the majority of his family lived in Montreal. As no family member could house him for extended periods of time, Paul lived with various family members (children, cousins, friends) between Ottawa and Montreal, changing homes every few

weeks. Family provided assistance with mobility, personal care, transportation, and housekeeping.

Paul and his family reported that on discharge, they had only received paperwork for application to CPP from the healthcare team in rehabilitation. After discharge, Paul filled in this paperwork with family and he began receiving this income approximately 12 months post stroke. Paul's CPP only partially covered his living costs. Family paid for his medication, basic living expenses, and several months of private physiotherapy services. Paul's son reported that this was a financial strain for the family as they were living in lower income situations themselves.

Four years after his stroke Paul discussed this financial strain with his family doctor and was referred to a social worker at the outpatient stroke rehabilitation program where he had previously been an inpatient. The social worker there provided him with information on ODSP, and geared-to-income Aquafit programs for stroke survivors. She also directed him to the *Clinique interprofessionnelle* where he attended further outpatient therapy.

At the time of data collection, Paul had only recently been accepted by ODSP, and he was still moving from one family member's home to the next between Ottawa and Montreal.

4.2.2.1.1 Paul's post stroke body functions and structures, and activity. The medical records, participant observations, and interviews highlighted the following impairments to body functions and structures, and activity limitations: limited left upper and lower extremity function, decreased walking and general mobility (e.g., stairs), poor activity tolerance, and pain. Changes to cognitive function were not noted by the participant or family but were noted by health care professionals. Professionals were also concerned about depression.

At the time of the interviews, Paul scored 52.5/100 on the SIS-16. He identified that dressing himself, housekeeping tasks, and going up stairs was moderately difficult. Shopping, quick

walking, walking one block and carrying heavy objects with his affect hand was very difficult. Getting in and out of a car was rated as mildly difficult. On the ICF Participation Checklist, he reported severe restrictions with employment and financial autonomy, as well as with walking and using transportation. A complete participation restriction was reported for driving. On the HADS, Paul scored within normal limits for anxiety and depression.

4.2.2.1.2 Paul's personal projects: pre and post stroke. Pre stroke, Paul was employed as a bus driver and was working on establishing an import-export business. He enjoyed visiting family and friends. He otherwise had few hobbies or leisure activities. Driving was very important to him, as well as the ability to go where he wanted, when he wanted.

Several post-stroke personal projects were identified: secure income support and funding assistance for medications, improve mobility, return to work, resume driving and be independent with transportation, and live independently (find accessible and geared-to-income housing).

4.2.1.2 Influence of low income on return to participation

4.2.1.2.1 Personal projects. Paul identified six personal projects; each is described focusing on the key elements of the consequence of low income. Diagrams in Appendix I depict the events and categories that influenced the experience of return to the personal projects.

Secure income support and financial support for medication: Paul could not return to work following his stroke because of his impairments, which prompted a need to secure income support. This personal project was not influenced by low income, but rather stemmed from being in a low-income situation following his stroke.

Paul initially received EI, but his previous workplace did not provide long- or short-term disability insurance. He indicated that on discharge, he was advised that his only income support option was CPP. He received approximately \$500 per month on CPP, from which he needed to

pay for his medications, which cost roughly \$300 per month. He was not aware that a provincial income support program existed (ODSP) until approximately four years post stroke. Paul explained his income situation on discharge from the hospital:

Paul: Avant de quitter l'hôpital, j'ai été conseillé que...la seule ressource financière au quelle j'avais droit c'était CPP, qui est le Canadian Pension Plan...et puis donc j'ai eu droit à 500 et quelques malheureux dollars par mois, pendant des années. Où j'ai là dedans, il fallait ... sortir l'argent...mes médicaments. Ce que je n'savais pas que j'pourrais ... avoir mieux avec ODSP. Je n'savais pas, je l'ai su....tout récemment.

At the time of the interview, Paul had applied for ODSP with the assistance of his family, and was recently accepted. ODSP also provided a drug card that covers the majority of prescriptions.

Improve mobility: Paul and his son expressed that improving mobility through rehabilitation is linked to other projects such as driving and employment. Paul's son Simon indicated that rehabilitation is a priority project: "Si faut qu'on parle en nombre de priorités, ...Si on va dire que le but c'est de ...redevenir autonome, retourner au travail, atteindre ses buts, la première chose à faire c'est se réhabiliter."

Following discharge from the rehabilitation program, Paul's children paid for private rehabilitation services because they were unable to find sufficient publicly funded services in Ottawa or Montreal. After two years, the family was unable to afford further rehabilitation.

At the time of the research, Paul was still looking for publicly funded or subsidized therapy options to improve his mobility. Simon explained that his dad, even with ODSP, is still

unable to afford such services on his own. "...si faudrait que mon père paye sa réhabilitation tout seul, il pourra pas."

Return to work: Paul was very clear about his personal project of returning to work. He was not ready for retirement: "Moi je ne vise pas la retraite tout de suite, je veux travailler." Paul felt that he would be unable to return to his previous line of work because of his physical limitations and lack of a driver's license. Paul considered self-employment to be his only option: "Tout sera difficile, de me trouver un emploi. Donc, je vise une carrière, un travail à mon compte, à mon propre compte." He was hoping to open a small business, and he identified several challenges including: a driver's licence, a place to set-up his business, and equipment, all things that require money. With an insufficient income to support return to work, Paul indicated that he is considering returning to Haiti where labour is cheaper. He stated that he could get the assistance to run a small business, irrespective of his activity limitations: "Si j'ai un commerce là-bas, j'pourrais avoir deux, trois personnes avec moi, moi j'suis là juste pour contrôler. J'ai un, deux, trois, vendeurs, et un p'tit pour balayer pis faire tout ce dont j'ai besoin."

Return to driving and be independent with community mobility: Paul expressed that owning a car and driving was very meaningful to him. "...j'ai toujours eu une voiture. Toujours." Post stroke, his driver's licence was suspended. He only recently found out that he needed to pass an exam before being allowed to drive and that he may need vehicle adaptations. Paul stated that return to driving was a priority for him because it would open up possibilities for many projects including return to work: "...tout commence avec un permis valide."

At the time of the interview, Paul indicated that he was vaguely aware of the potential cost of the exam and adaptations "Mais mon permis de conduire jusqu'à date je ne sais pas combien ça va me couter pour l'avoir, et il faut que je l'aie." When told the approximate cost, he

indicated that since he has been receiving income support from ODSP, he might be able to save up enough money to afford it, plus insurance, gasoline, and adaptations. This would, however, affect his ability to attain other projects such as paying for private therapy or living on his own.

His inability to drive has created general transportation challenges. He stated that the cost of taxis and buses is too high, and he therefore frequently relies on family to drive him.

Live independently: Prior to his stroke, Paul lived in his own apartment. Following the stroke, Paul recalls being informed by the rehabilitation team that he should live with family, as it was unsafe for him to live alone. “...une semaine avant le congé, il a [le médecin] réuni ma famille pour leur faire savoir que c’était pas prudent que je retourne à la maison tout seul. Qu’il fallait que j’aie vivre avec la famille.” He has been moving from home to home of different family members every few weeks since the stroke. This arrangement is rent-free.

For the first four years post stroke, Paul said he could not afford rent, but since receiving ODSP, he has begun the personal project of finding an apartment to live in on his own. Simon reported that he believes his father will not be able to afford an apartment even on ODSP.

Paul and Simon came to the recent understanding that an application to social housing in Ottawa had to be made. Paul believed the process would be relatively easy. “Dans ma situation, j’imagine qu’on va qu’on va me répondre favorablement, assez rapidement.” But Simon believed that there might also be the challenge of a long waitlist. “L’appart ... est difficile. C’est juste ça l’affaire. Quelle est la liste d’attente pour les gens qui sont sur ODSP pour un appartement subventionné? Elle est longue! Ça, je le sais! Elle est longue!”

At the time of the interviews, Paul and his family still had no plans in terms of housing. Paul’s son was working on finding stable work in Ottawa and helping his dad find his own place to live. Simon understood that Paul would need help with housekeeping, but believed that

between himself and his wife, they could avoid having to pay for private housekeeping. Paul stated that he realized costs might be an issue and stated that he was considering relocating to Haiti where home assistance and accessible housing were cheaper. “La meilleure façon de... reprendre ma vie? Ah mais, c’est de quitter le Canada.”

4.2.2.2.2 Patterns of influence on experience of return to personal projects. This section will present four patterns of factors and describe how they influenced Paul’s experience of attempting to return to personal projects in the context of low income; these are depicted in Appendix J. These are: healthcare system, social service system, family, and knowledge about the “System” and understanding of health.

Healthcare system: Paul’s experience of returning to participation was influenced by inpatient discharge planning services, the healthcare system’s availability of publicly funded outpatient services, and what portion of costs is covered by the healthcare system for resuming driving after a stroke.

During discharge planning from the inpatient rehabilitation program, Paul and Simon stated that they were presented with unclear and insufficient information about their options in terms of discharge locations. The medical records showed that the team was aware of the discharge challenges: “Patient has no POA assigned, no income at this time. No home at this time in Ottawa.” “If patient to live with his sister or his son, he could likely go to Montreal.” The medical chart also indicated that they recommended relocation to a long-term care facility and that family declined this option. Paul did not want to relocate out of town with family, but Simon stated that the healthcare team offered only two options: long-term care placement or to Montreal with family.

Simon : Ils lui ont juste dit que il ne peut pas habiter tout seul ...en tout cas...

Si il n'a pas de famille ou y'a personne qui peut s'occuper de lui, 'we strongly suggest you place him in a home' ... On savait pas quoi faire! Parce que idéalement, si on avait plus d'options, mon père n'aurait jamais été à Montréal. Parce que ce n'est pas sa volonté personnelle. Il déteste Montréal...

Paul also felt that they were not informed clearly about all possible discharge options, for example, convalescence care in Ottawa, which he would have preferred. "...on m'avait pas pas pas, pas aussi informé que j'aurais droit à un centre de...convalescence..."

On discharge from inpatient services, Paul and Simon received information regarding applying to CPP but neither recalls receiving any information about ODSP or income support programs in Quebec. Further, they were given information about the Ontario Trillium program for assistance with medication funding, however, the team recommended that Paul relocate to Quebec. It took Paul a second time through the healthcare system, about four years post stroke, through outpatient services, to receive guidance about ODSP. "Lorsqu'elle [la travailleuse sociale] a su que j'avais, que je recevais seulement CPP, elle m'a dit 'Mon Dieu..., ce n'est pas suffisant ça. Ça va pas vous aider.' Et elle m'a suggéré ODSP."

Further, the healthcare system offers very few publicly funded outpatient therapy programs. Even though he is now receiving ODSP, Paul does not have sufficient funds to afford private therapy.

Paul and his family also spoke of lack of information regarding the driving licence suspension and the procedure for resuming driving. As well, the costs of the driving assessment and vehicle adaptations for physical disabilities are not covered by the healthcare system and are unaffordable for Paul.

Social service system: The social service system is responsible for income support programs, social housing, and public disability transportation options. The system's services and policies influenced Paul's participation in several personal projects.

In terms of income support programs, Paul was accepted by ODSP, which covers medication. The amount of income received has however been insufficient to cover all of the costs related to his personal projects.

In terms of housing, Paul continues to live with family because he is unable to afford an apartment in Ottawa. Although he is on a waitlist for social housing, it may take several years before he is offered a place to live, and he will then still need to pay for housekeeping services.

As well, the lack of access to public disability transport, because of costs, has limited Paul's ability to participate in many personal projects by limiting his ability to get around on his own.

Family: Paul's family have provided assistance that has supported his attempts to return to participation since his stroke. For example, they have collectively provided rent-free housing for the last five years, assistance with personal care and housekeeping, transportation, financial support for therapy and health items, and opportunities for social outings. Despite a limited understanding of health and knowledge of the healthcare and social service systems, the family has had some success in providing advocacy, and assistance with managing applications for various services. Often with inadequate resources, family tried to provide housing and care. For example, Paul was discharged from hospital to live with a cousin in a small inaccessible apartment in Montreal with no elevator.

Paul : ...un bloc appartement normal où je dois, je devais vivre, où il fallait monter toutes les marches. Et puis l'appartement se trouve à être un petit peu plus coincé,

...plus petit qu'ici... Très tassé. Donc il n'y avait pas de place pour une chaise roulante là dedans.

Similarly, Simon indicated that the family, particularly him, one brother, and one cousin, have been experiencing hardship because they have been providing the majority of financial assistance without adequate resources to do so. Simon stated that even in difficult financial times, he felt he needed to help his dad. "...des fois il vient, pis j'suis pauvre. T'sais! C'est comme! J'suis pauvre, je suis vraiment pauvre. J'lui dis 'Ben OK, viens t'en!'. Puis, j'm'arrange, j'm'organise..."

Knowledge of the “System” and understanding health: Paul and his family's limited knowledge of the healthcare and social service systems and understanding of stroke-related health influenced several personal projects.

Paul and his family did not have pre-existing knowledge of how the healthcare and social service systems function. They did not know what they could request, what social programs and resources were available and how to access these. They also did not know the procedures and rules for driving assessments. Further more, as Simon describes it, the healthcare team may have explained many things, but he and his father did not understand. No one took the time to make sure they understood “Y'a plein de détails que j'peux dire que ...qui nous a été échappé. I won't say that they didn't care, I am just gonna say that they were eager to let us go.” Simon felt that the discharge meeting was too short and he summarized the meeting content as:

“Blablablablabla, Good Luck Mr. [Paul].”

As well, Paul and his family had limited understanding of health, particularly of stroke and stroke prevention, of the impact of stroke on function and expectations for future recovery. For example, regarding the “cause” of the stroke, Simon expressed that it was never clear to him

why his father had a stroke. "...est-ce que j'ai une raison directe de dire qu'est-ce qui a causé l'ACV? Non. Médicalement, on me l'a jamais donnée. On ne l'a jamais donnée à mon père."

As for stroke prevention, even five years post stroke, the medical records of the *Cinique interprofessionnelle* indicated that Paul had a limited understanding of how to manage his hypertension through diet, and his diabetes through insulin and glucose testing.

In terms of the impact of the stroke, during the interviews, Paul expressed several times his limited understanding of, for example, the medical cause behind the driver's license suspension "...je ne voyais pas comment on aurait pu m'enlever mon permis pour des raisons médicales parce que je ne suis pas malade. J'ai aucun problèmes cognitifs." Paul and Simon also appeared to have limited understanding of the likely course of stroke recovery and the impact of rehabilitation. For example, Simon stated that his father had not yet recovered to expected levels according to the doctor and to Internet sources.

Simon: ...mon père a eu son AVC, à maintenant, il est supposé d'être au moins à 80% de ses capacités. Le médecin lui a dit, l'internet le dit...tu sais c'est comme...mais mon père en ce moment, y'est à peine à 50% de ses capacités.

Simon expressed how he felt that lack of knowledge about the healthcare and social service system and understanding of health may have delayed his father's attainment of all of his personal projects "Le fait qu'on était vraiment mal informé a pesé pour beaucoup, parce que si on était mieux informé, ç'aurait pas, ç'aurait jamais duré tout ce temps là."

4.2.3 Jackie

4.2.3.1 Case Story. Jackie is a woman in her early 50s who was working fulltime at a call centre and was leasing a room in a friend's home prior to her stroke. She has one adult child, but has been estranged from him for several years. Her only other relative is her brother Luc. She

and Luc grew up in separate foster homes and only truly met as adolescents. Luc indicated that they did not regularly keep in touch, and prior to the stroke had only seen each other a few times over the course of their lives.

Jackie's stroke occurred approximately one year prior to the study. Her housemate called an ambulance, and Jackie was admitted to hospital. Luc was contacted, and he spent several weeks visiting her in hospital. Jackie was experiencing severe stroke-related communication difficulties, and Luc was appointed Substitute Decision Maker.

After a few months in hospital, Jackie was transferred to an inpatient rehabilitation program for seven weeks. She continued to be very limited in her ability to communicate and, with the help of the rehabilitation team, Luc and his wife Marilyn started the process of becoming her power of attorney (POA) for financial decisions. As Jackie's return to the community was being planned, her housemate indicated she was not willing to take her back home. The rehabilitation team suggested that Jackie move in with Luc and his wife, however, they declined. The team and the family were unable to make a final decision on where Jackie would go on discharge because of the lack of information on her financial status. Jackie was therefore moved to convalescence care at a retirement home (RH) for 90 days until more information was available and a plan could be made.

Soon after Jackie arrived in convalescence care, she began outpatient rehabilitation. Luc and Marilyn received POA designation, and they became aware that Jackie had no savings and some debts. After 90 days in convalescence, the family, as POA, became responsible for finding Jackie a new place. Luc and Marilyn applied for subsidized retirement homes; however, they were declined because Jackie was making approximately \$4-5/month over the eligibility criteria on Long-Term Disability insurance benefits (LTD). After visiting several retirement homes that

were unsuitable or unobtainable (e.g., poor accessibility or too expensive), they were offered a discounted rate at one RH. Here, Jackie spends all but \$130 of her monthly income on her room and board and, with the remaining money, she pays for all her personal items, transportation, and leisure.

At the time of the research project, Jackie was receiving LTD benefits. She was finishing up physiotherapy sessions in outpatient rehabilitation. She had received outpatient speech therapy, and had declined further sessions even if she still had severe expressive aphasia. Luc and Marilyn were still very involved with responsibilities related to income and housing.

4.2.3.1.1 Jackie's post-stroke body functions and structures, and activity. Several impairments to body structures and function, and activity limitations were identified using data from the medical records, interviews, participant observations, and measures. These included: decreased vision in the right eye, right side hemiplegia (decreased upper and lower extremity function), decreased hearing, changes to thinking and memory, pain, decreased endurance, expressive aphasia, and limited ability to write and read.

On the SIS-16, Jackie scored 45/100. She identified that standing without losing her balance, walking, and getting in and out of a vehicle were moderately difficult, that housekeeping, quick walking, stair climbing, walking a distance of one block were very difficult, and that lifting heavy objects with her affected hand was impossible. On the ICF Participation Checklist, she rated herself as having light performance difficulties with the majority of self-care tasks and leisure. She indicated moderate restrictions with listening, writing, undertaking a simple task, receiving spoken messages, lifting objects, fine motor tasks, walking, and taking care of her health. Jackie rated herself as having severe restrictions with vision, reading, doing calculations, problem solving, and taking care of others. She reported complete participation restrictions with

employment and economic self-sufficiency, intimate relationships, speaking, driving, and undertaking multiple tasks at once. On the HADS, she scored within normal range for anxiety and depression. Medical records indicate that she was being treated for depression prior to and after the stroke.

4.2.3.1.2 Jackie's personal projects: pre and post stroke. Prior to the stroke, Jackie owned a dog and loved to walk him, she enjoyed watching movies, going out with her friends, shopping, getting her hair and nails done, and getting tattoos. She enjoyed taking trips to the Caribbean. She drove a car, worked full-time, and rented a room in a multi-level house.

Post stroke, Jackie expressed that she did not want to live in her current retirement home and wanted to go on more outings. She wanted the opportunity to get her nails and hair done more often and to shower more frequently than twice a week as is provided by community health services. Jackie identified return to driving and independence with community mobility as a personal project. She also wanted to be able to improve her mobility (walking), and to go travelling again. Importantly, Jackie's brother and sister-in-law, as POA, had been working on personal projects on her behalf as well – finding housing and securing income support.

4.2.3.2 Influence of low income on return to participation

4.2.3.2.1 Jackie's personal projects. Jackie's eight personal projects are described with a focus on the key element of the consequences of low income. Diagrams in Appendix K show the events and categories that influenced the experience of return to the personal projects

Secure income support: Luc and Marilyn were appointed POA for financial decisions, and as Jackie could not return to her previous employment because of her stroke-related impairments, they took charge of applying for income support on her behalf. Initially they applied for EI, then STD, and LTD benefits through the insurance company with Jackie's

employer. Marilyn reported spending much time working through the different complex application processes “They constantly need re-assessments, that you are still ... ‘Send us your updated medical, we, we need the doctor to fill in A through G...’”

At the time of the research interviews, Jackie was receiving approximately \$1600 per month and only had a few more months before this income source ended. Luc and Marilyn were aware that they would need to apply to provincial income support programs. Marilyn explained her understanding of the process “And ODSP doesn’t kick in until you have nothing. I think. Ontario Works will come in between...” When asked how much income Jackie would be receiving with ODSP, they stated that they didn’t know, but that it would likely be less.

Marilyn: She will not make more than she’s making now on Long Term...she potentially, I suppose, could make less.

Luc: Ya, there’s more likelihood of her making less than more, that’s for sure.

Find housing: While Jackie spent over three months in convalescence care, Marilyn and Luc worked on finding her a place to live that would meet her accessibility and assistance needs. Income being limited, they applied for a subsidized retirement home (domiciliary hostel), but as Luc stated, Jackie did not meet the income cut-off “...she makes \$4 too much to receive ...And we...And at first the woman said ‘No that’s...I am sure they will see past that...’ And it was like ‘No, she doesn’t qualify.’ 4 bucks. ...Ya...it’s silly.”

Luc and Marilyn visited several private retirement homes. Marilyn reported that income was an important barrier “She couldn’t, she couldn’t afford any of them. To be honest with you...” After discussing the income issue with a director of care in a retirement home, they finally came to an agreement on a price that Jackie could afford “...and she [the director of care]

said ‘Well, for a semi it’s \$2195.’ And I said ‘OK. Perhaps I’m out of my league then...because we make \$5 too much for the subsidy.’ And she said ‘Well, I can do \$1550.’”

Jackie has temporarily attained this personal project with the assistance of her POA. Her LTD benefits will however soon end, and while on OW and ODSP, she will be unable to afford her current retirement home, and new housing options will need to be explored.

Live somewhere else: Jackie expressed that she did not want to live in the retirement home she was in, and this was corroborated by the family. Jackie expressed that she would prefer to live with others closer to her age group or live on her own.

Interviewer: ...where would you rather be?

Jackie: Hmmm...

Interviewer: Out there? You are pointing out there...

Jackie: Yes, ya.

Interviewer: In your own place?

Jackie: Yes.

Jackie indicated that the location of the retirement home was problematic. Living in an area where she would have easier access to activities and friends was preferable. She felt that the facility where she received convalescence care was geographically better because it was closer to friends, but she was aware that she could not afford the retirement home in the same neighbourhood. Jackie was also generally aware that she was in this particular retirement home because she could afford it.

Luc and Marilyn were conscious that Jackie was unhappy in the current retirement home, however, Jackie’s income was either too high for subsidized housing, or too low to be able to

choose a retirement home with, for example, an optimal location, or to live on her own with appropriate levels of care services.

Go on more outings: Prior to the stroke, Jackie stated that she enjoyed going to the movies and shopping. Her brother commented on Jackie's pre-stroke activities: "I think she misses too, you know, going to a bar with her...going dancing with her friends, and...and...and, you know, going shopping. 'Cause that's what she did."

Since her stroke, Jackie has been limited in the number of outings she can take part in because she cannot go out on her own. She requires assistance because of her physical impairments and her limited communication abilities. Friends and family are only occasionally able to take her out; Jackie would have to hire an attendant to go out more frequently. Jackie was aware that this lack of assistance was the biggest limitation for her to attain this personal project.

Luc also stated that the cost of transportation limits the number of outings Jackie can afford. As well, the family stated that the retirement home where she lives does not offer a transportation service to community locations as other more expensive homes often do.

Income has also limited Jackie's ability to afford the outing itself, for example, movie tickets. Jackie agreed that more money would lead to more outings for her.

Participate in more self-care activities: Prior to the stroke, Jackie enjoyed getting her hair and nails done, and showered daily. Post stroke, she expressed to her POA that she would like to continue having her hair done regularly. Luc explained that although this was possible while in convalescence, now, with only \$130 per month, it was not financially conceivable.

Luc: ...she likes to get her hair done once a month. I told her 'You can't really...' It was OK when she was [in convalescence] and she was on OHIP's dime, and her cheques they were coming in, there was a little extra money right? So, it's like,

that's not a problem. But...here, 'Now you're covering the whole cost on your own. You can't. You can't!'

Jackie has been receiving publicly funded homecare services via the Community Care Access Centre (CCAC) for daily assistance with grooming and dressing, and two showers per week. Jackie expressed that she would like to have more showers, however, this type of assistance would be an unaffordable extra cost.

Be independent with community mobility: Prior to her stroke, Jackie drove. Her brother indicated that the stroke was a big change from previous independent lifestyle "She is so used to coming and going..." Post stroke, Jackie expressed that she would like to be independent getting places in the community. Luc explained that one limitation is that Jackie requires their assistance to organize and book outings because she is unable to call the disability bus service on her own. This type of assistance with calling is not included at the retirement home where Jackie is living and would come at an extra cost. Jackie's independence with going out is also limited because of the cost of transportation and of a private attendant to go on outings with her.

Jackie also reported that her wheelchair was a limiting factor in her ability to get places on her own. She often needs someone to push her outdoors. Jackie has brought up to her family that she would like to have a power chair. Although they feel there may be a safety risk involved (for example, how would she manage a breakdown), they acknowledge that it would make her more independent to go out on her own than propelling her manual wheelchair.

The medical records indicated that Jackie was not eligible at that time of the interviews for funding for a new wheelchair with the provincial government subsidy program – the reason for this ineligibility was not given. Luc reported that Jackie would require financial help to pay

for a power chair, even a second-hand power chair. “Not at some of the costs I’ve seen. \$13,000, \$14,000 for a chair. People are selling them on Kijii...”

Improve mobility (walking): Following her stroke, Jackie identified mobility, specifically improving function in her left leg for walking, as an important personal project.

Interviewer: ...what are you trying to work on?

Jackie: Euh... Yes.

Interviewer: Your leg?

Jackie: Yes.

Interviewer: Getting your leg moving?

Jackie: Yes.

Jackie linked this project of improving her mobility with attainment of other personal projects including being independent with community mobility or living elsewhere (alone).

Jackie received physiotherapy treatment from two outpatient services in the community and had begun walking with a cane with some physical assistance. However, treatment sessions were limited, and no further publicly funded community physiotherapy services were available. Jackie felt that she had not finished improving her leg mobility and that she would benefit from more treatment, but she expressed that she did not have the funds.

Travel: Jackie and her family reported that she was an avid traveller, in particular to the Caribbean. Jackie informed Luc and Marilyn that she would like to return to travelling however, Marilyn informed Jackie that her income was too low to be able to return to this project.

Marilyn: I tell [Jackie] ‘You know, this is how much money you have now, you’ve had your fun, you’ve had your cruises, your trips to Cuba, you’ve done all this stuff.’ I said ‘This is where you are now so... You gotta get used to it.’

The cost of travelling, in addition to equipment and attendant services that would be needed, would be too high for Jackie to afford at this time.

4.2.3.2.2 Patterns of influence on Jackie’s experience of return to personal projects. The following section presents five patterns of factors influencing Jackie’s experience of attempting to participate in personal projects in the context of low income. These are: healthcare system, social services system, family and friends, knowledge of the “System” and understanding of health, as well as the physical and social environment. Diagrams in Appendix L show the patterns that influenced the experience of return to participation in the personal projects.

Healthcare system: Jackie’s experience of participation in personal projects was influenced by inpatient and outpatient services, including the timeliness of the POA application, and the limited discharge planning assistance from convalescence care to the community. Jackie’s experience was also influenced by the lack of available public outpatient therapy programs, as well as by the rules of the provincial government for equipment subsidy programs, and by the limits of personal support services through homecare.

While in acute care for nearly three months, the process of assigning POA for financial decisions had not begun. Issues with bill payments were indicated in the medical records in acute care: “Patient’s brother asked to see Social Worker re: finances. Brother indicated that patient does not have a POA for finances and that she has bills to pay and he is not able to do this on her behalf.” Luc confirmed that the process of assigning POA was not started in acute care.

Luc: There...there was a little bit of an attempt in [acute care] near the end to try and get her to euh...huh...what is it...oh no...and to have her, to have the doctors deem that she was incapable of dealing with...? And there was one doctor that was kind of teetering on it and didn't really want to do it...so it never happened.

Delaying the application process for POA had an impact on timeliness of applications to income support programs, and complicated discharge planning from rehabilitation. Marilyn outlines that while Jackie was in inpatient rehabilitation, still without a POA, they were given two discharge choices. "Discharge planning options: to their own home with CCAC homecare, or to your home. Those are your choices." Marilyn further clarified that subsidized homes were not initially offered to them as these options hinged on financial status, which was still unknown. "Nothing subsidized. Everything is on what you have, what you can afford and...we still don't have a power of attorney right?"

Once in convalescence, Luc and Marilyn expressed that there was a lack of communication, as well as some confusion about who was supposed to help them find a new home for Jackie. Marilyn stated that she was initially unaware that Jackie had a social worker appointed to help her. "And then you say... 'Does she have a social worker?' But I didn't know that whole outpatient time she had a social worker." Marilyn then explained that there was confusion as to who was in charge "...the discharge planning is part of CCAC. But then CCAC, apparently put it back on the other one [outpatient social worker]." Lack of guidance about how to find housing for Jackie also delayed the process. Marilyn stated that convalescence care staff was calling her, and she expressed her frustration "You want to help me? Get the person who is supposed to help me. And don't tell me that you need the funding for the bed. Right? 'Cause I need assistance with placing her where she actually belongs."

In terms of the healthcare system, there are few publicly funded outpatient therapy programs. Jackie did not have sufficient funds to pay for private physiotherapy. This influenced her ability to attain her personal project of improving mobility and walking.

With regards to equipment, the medical records indicated that professionals believed Jackie would not qualify for funding assistance from the provincial government program for wheelchair modifications or a power chair, which means she would need to pay out of pocket. The healthcare professionals, gatekeepers to the program, however never clarified for what reasons Jackie would not be eligible for the funding assistance. This, in addition to the program's rules influenced Jackie's community mobility because she was unable to afford any equipment modifications.

Further, the public homecare service has rules and regulations that state that Jackie can only have two showers per week. As she is unable to pay for the extra showers, her project of participating in more self-care is limited to what they provide.

Social services system: Jackie and her POA had to engage with both private and public entities for income support programs, and housing options. The complex process of applying for income support and navigating between the different programs, as well as the policies of housing and limited housing options influenced Jackie's participation in several personal projects.

Jackie's income support was managed initially by the provincial EI program, and then privately with insurance companies (short and long term disability benefit programs). Navigating between the programs was a complex process with wait times between application and acceptance, and a lack of communication between organizations. Luc and Marilyn explained some of these challenges they experienced when transferring Jackie between programs.

Marilyn: And Short Term is a different company than Long Term, and they cannot share that information.

Luc: They cannot share that information. So it's like starting all over again.

Marilyn: Her files are closed.

Interviewer: So then you stop receiving money...

Marilyn: She stopped ya...

At the time of the interviews, Jackie's POA were in the process of starting applications for government based income support programs (CPP, OW and ODSP).

Finding housing was a challenge because of the limited choices of affordable options with sufficient self-care assistance. Choices were limited to either privately owned and operated retirement homes or privately owned domiciliary hostels that were subsidized by the municipality. Jackie's income was too low to afford a retirement home and too high for the subsidized domiciliary hostels. A private RH director offered Marilyn a better price, but Jackie's shared room and cares use up approximately 90% of her monthly income, which leaves very little for other expenses including toiletries, incontinence briefs, wheelchair repairs, or outings.

The limited housing options continue to be a problem because Jackie's income will decrease as she transitions to OW and then to ODSP. Further, even if she meets the income threshold for domiciliary hostels in the future, the family is unsure if Jackie's care needs might be too high and if the hostels will be sufficiently accessible and safe for her.

Family and friends: Jackie's brother and sister-in-law have provided assistance to support her with her attempts at returning to participation in personal projects even though their relationship was limited prior to the stroke. Luc expressed how he became involved with Jackie after her stroke, and how Jackie's friends gradually stopped visiting.

Luc: She's alone right? And I...she doesn't know what's going on and...I wanted to make sure that there was somebody there cause...It's amazing how friendships dilute when issues like this happen right? There is not a soul around. Her roommate and her her friends, you know, ...the one friend stuck around for a couple weeks and then that was it, haven't heard from them again.

Since the stroke, Luc and Marilyn became POA and have provided advocacy, financial management assistance, and assistance with securing housing. Luc spoke of the quantity of time Marilyn has invested in administrative work to manage Jackie's particular needs "...Like she's got books! And she's got notes...like the amount of time she spends on the phone trying to do all this stuff right? And it's...I can't...Who...if there, if it wasn't for us, God only knows what would have happened to [Jackie]." They also do Jackie's shopping for personal products and support her with some outings. Luc and Marilyn also provide assistance with communication (for example, arranging transportation, attending appointments with her).

Social isolation was identified as an issue by the therapists in the community outpatient rehabilitation program. Jackie also stated that she felt limited in terms of social support (friends), mostly because of geography, but that increased social support would help her with outings.

Knowledge of the "System" and understanding of health: Jackie and her family had limited knowledge about healthcare and social service systems – specifically how to find retirement homes, how to get medical equipment, and what free therapies are available in the community. They also had a limited understanding of the impact of Jackie's impairments, of how to communicate effectively with her to support participation, and of her care needs.

Luc and Marilyn felt they had little guidance about the process of finding a retirement home for Jackie and about options. Luc and Marilyn were eventually able to figure out the rules and processes of the system and to find housing for Jackie. It is their understanding that once Jackie is on ODSP, they will go through the process of finding housing once again.

Luc and Marilyn also had limited knowledge and understanding about the process of choosing and obtaining a power chair to support her project of independence with getting around in the community. Luc reported on his confusion with the process: “I don’t know anything about [how to get a power chair]!”

Jackie’s project of improving her mobility and walking also required additional therapy in the community. At the time of the interview, Luc and Marilyn were still in the process of finding what types of free services might be available to Jackie, if any.

Further, Luc and Marilyn appeared to have a limited grasp of Jackie’s impairments and their impact on her daily life. For example, they did not know if Jackie would be able to drive a power chair, if more physiotherapy could be beneficial to her, or what type of self-care services she needed. As well, their understanding of aphasia and how to effectively communicate with Jackie appeared to be limited. Luc and Marilyn reported that they had not received any assistance from the healthcare system, at any point, to learn how to communicate effectively with Jackie.

Physical and social environment: Jackie’s physical and social environment, specifically her neighbourhood and the retirement home services, influenced her participation in personal projects.

The retirement home that Jackie has been able to afford is in a neighbourhood that she would not have chosen because it is far from any friends who might come and visit or take her out. While in convalescence care, at least one friend visited and took her to bingo games.

The retirement home's neighbourhood presented with accessibility issues when using a manual wheelchair. Luc indicated that even though there is a plaza near the retirement home, Jackie is not able to get there on her own because of the uneven sidewalks and road.

Luc: I have a hard time getting that chair on the sidewalk with some of the ruts, you know.... It's difficult with someone helping. I can imagine on her own, it's frustrating?

As well, they types of services provided at the retirement home influenced Jackie's participation in her project of going on more outings. For example, her retirement home does not offer help with organizing transport or outings in the community as part of their services.

4.2.4 Laurent

4.2.4.1 Case Story. Laurent, a retired man in his early 70s, was living in his brother Armand's home for approximately one year prior to the stroke. He was in the process of moving into a granny-suite at his nephew's home in the same rural community. Laurent had recently lost substantial amounts of money following the fall-out of a relationship, and he lived with family as he felt unable to afford an apartment on his fixed pension. He was receiving the governmental old age pension (Old Age Security or OAS), CPP, and a small amount from a previous employer, for a total of approximately \$17,000/year.

Just over one year ago at the time of the interviews, Laurent had a stroke during the night. Armand found him the next morning and called the ambulance. Laurent spent one month in the acute care hospital and inpatient short-term rehabilitation program. While he was in hospital, Laurent's family moved his belongings to his nephew's granny suite, and he moved-in on discharge. Although stroke-related changes to his physical function were minimal, Laurent was experiencing changes to his cognitive function. He was assessed at an outpatient geriatric clinic

and was told that he needed to undergo formal testing before being able to return to driving. He also participated in outpatient physiotherapy and occupational therapy, and he was followed by a nutritionist at the *Clinique interprofessionnelle*. Following these therapies, Laurent completed the return to driving examination and passed.

4.2.4.1.1 Laurent's post-stroke body functions and structures, and activity. The medical records, participant observations, measures, and interviews indicated that Laurent had mild impairments to body function and structures, and mild activity limitations. Laurent experienced changes to balance and lower extremity strength, as well as fatigue, which largely resolved according to outpatient rehabilitation records. Cognitively, he was assessed several times in hospital, and in an outpatient geriatric clinic. Issues with short-term memory, problem solving, insight, and visual perception were identified. He was re-assessed at the *Clinique interprofessionnelle* and again at a private clinic prior to the driving exam, and cognitive function was no longer problematic.

Laurent scored himself 100/100 on the SIS-16, and he reported no participation restrictions on the ICF Participation Checklist. The HADS revealed possible anxiety.

4.2.4.1.2 Laurent's personal projects: pre and post stroke. After retirement, Laurent enjoyed doing small renovation and repair contracts, spending time with friends and family, helping family members in need, going to church, and travelling.

Following his stroke, he identified the following personal projects: resume driving and be independent with community mobility, participate in social outings with friends and family, return to travelling. He also wanted to improve his ability to manage his diabetes and improve his understanding of his post-stroke health, participate in renovations projects, and address his housing situation.

4.2.4.2 Influence of low income on return to participation

4.2.4.2.1 Laurent's personal projects. Laurent's six identified personal projects are described through a lens of the consequence of low income and stroke. Of these six personal projects, the impact of the stroke, low income, and a combination of the two factors varied, as is described below. Diagrams in Appendix M show the events and categories that influenced the experience of return to his personal projects.

Resume driving and be independent with community mobility: Prior to his stroke, Laurent enjoyed driving. “Ah oui j’ai conduit des camions pour ma vie...euh...pis j’aime beaucoup à chauffer...” Following his stroke, Laurent stated that he was surprised to have his driver’s licence suspended and he was determined to get it back.

Laurent: Fait que [la gériatre] m’a dit ‘... J’va me sentir mieux si vous y allez sur la route, faire un test sur la route.’ Là a l’a été dans son bureau pis est r’venue pis a m’a donné une un morceau de papier pis a dit ‘C’est... les places’ où j’peux aller. A dit ‘C’est d’valeur’, a dit ‘ça coûte cher.’ C’était \$700. Et puis euh...j’ai dit ‘Pourquoi faudrait j’fasse ça? J’ai pas...vous m’avez dit... ‘ Euh... Fait qu’a dit ‘C’est la seule manière. Vous voulez avoir vos permis’ a dit ‘Faut vous aillez là.’ Fait que j’ai attendu un ‘tit peu, j’avais comme la tête dure. J’ai attendu un ‘tit peu. Finalement j’ai dit ‘Ben, si faut que j’paye 700, m’a l’payer, j’veux ravoir mes permis.’

Laurent felt the cost of the driving evaluation was very high, and equated it to a month of rent. “Ben j’voulais pas l’dépenser, t’sais? Pour moé je regardais pis j’disais, c’t’un mois d’loyer là t’sais?” His brother Armand found it somewhat objectionable that his brother needed to pay a private company for the driving evaluation and also felt that the cost was very high. “Alors là,

qu'est qu'y'ont dit qui est, qui est un p'tit peu choquant, c'est qu'y'ont dit, 'Ben là faut qu'tu ailles voir une compagnie qu'est...', ça d'l'air que c'est une compagnie privée là...Euh, ça ça lui a coûté 700 dollars.' An extra cost was also associated with the \$40 eye examination required to qualify to take the driving exam.

Laurent was living without a driver's license in a rural area that did not have public transportation options, and he was limited in his ability to afford taxis or senior driving services. Laurent stated that he was never restricted because family assisted with all community mobility. "N'importe quoi j'ai voulu faire! Euh...j'dis à mon beau frère 'Ouais, j'veux aller m'faire couper les ch'veux' 'OK! Quelle heure tu veux? M'a t'ramassé!' "

Laurent felt that outpatient occupational therapy services helped him to understand the process of resuming driving and to prepare for the assessment. Following his therapy sessions, he went to the driving evaluation with his brother Armand. He paid the evaluation fee with money from his savings, and he has been back to driving.

Participate in social outings with friends and family: Prior to the stroke, Laurent enjoyed socializing with his friends and his siblings, and regularly visited his children. His participation in these social outings hinged on his ability to return to driving and on his independence with community mobility.

In addition to helping with transportation, Laurent's siblings also encouraged his social participation by introducing him to different affordable community social activities.

Laurent: Y font ça dans cave d'église là,...eh! Pis c'est tout' du monde de campagne là, fait qu'là y font des maudits bons soupers! ...Et puis euh...après ça, après souper là, y jouse au bingo. Et jouse des parties

d'bingo. Ça t'coûte 5 piasses pour jouer au bingo là t'sais? Ça passe la soirée, t'sais? Fait que...Eh! Du fun à mort! J'aime ça! J'aime ça!

Once back to driving, Laurent reported that he was able to achieve his personal project of participating in social outings in and out of town "...pis l'autre jour, j'ai parti, pis on a monté, pis on été jusqu'à Petawawa. ...Y'avait un show..." Armand corroborated that Laurent was now back to previous levels of socializing.

Get back to travelling: Prior to the stroke, Laurent enjoyed being able to decide on a whim to travel. "...nous autres on partait pis on s'en allait à Terre Neuve là. Moé j'ai vu nous autres là, assis, ...après souper, dire 'Eh, on vas-tu à Terre Neuve? ...paquette, on s'en va!' Paqueté, pis on partait!"

After the stroke, Laurent was limited in his ability to travel because his driver's licence was suspended. However, once he completed the driving examination, he returned to travelling "...j'ai un frère à Kingston, j'y ai été là...deux semaines passées!". He has many future travelling plans as well. "Ça m'tente de r'tourner à Terre Neuve là c't'été..."

Improve diabetes management and improve understanding of the impact of stroke: Laurent stated that following the stroke, improving his ability to manage his diabetes and better understanding the impact of his stroke was a personal project. He indicated that his ability to manage his diabetes had been influenced by income in that the Ontario Drug Benefit program did not cover his insulin needles, which were needed since the stroke. He also noted that nutritious food was expensive. Neither project was otherwise influenced by income, but rather, understanding health was a larger pattern having an impact on participation in the context of low income and was influenced by language. These issues are described in the following sections.

Participate in renovation projects: Prior to the stroke, Laurent enjoyed doing small renovation projects and grounds keeping for family and for a few private clients. “J’y allais à toutes les semaines, couper l’gazon, faisais tout’ qu’est-ce que...peinturer la galerie, j’ai tout’ faite l’ouvrage.” Following the stroke, Laurent felt physically limited and stopped all participation in renovations projects. A few months post stroke, his family began offering him small jobs. Laurent stated that he was proud to be able to do a stippling job on his nephew’s ceiling. “...j’l’ai faite pis aille, c’est...Aille j’tais fière de moi-même là après là, t’sais?” Laurent’s experience of returning to renovation projects was influenced by his family giving him opportunities to test out his abilities and to work his way back to full physical participation.

Address housing: Just prior to his stroke, Laurent was working on moving to his nephew’s home because there was more space, and he would have his own kitchen. He moved in on discharge from hospital. At the time of the interviews, Laurent mentioned that his nephew was renovating his home, downsizing, and moving out. He needed to find a new home. With limited income, he indicated that he was hopeful another family member would take him in.

This personal project existed prior to, and was not affected by the stroke. Low income has restricted Laurent’s housing options, and the cost of his current place limits his available cash for other expenses as he is paying over 50% of his income on rent.

4.2.4.2.2 Patterns of influence on Laurent’s experience of return to personal projects.

The five patterns of factors influencing Laurent’s experience of attempting to participate in personal projects in the context of low income are described in this next section, and depicted in Appendix N. These are family, physical environment, social services system, healthcare system, knowledge about the “System” and understanding of health.

Family: Laurent's family (siblings, nephews and nieces, children) was present and supportive even before the stroke. They socialized together and helped each other out during difficult times. For example, Armand explained that while Laurent lived with him, he had not charged him rent so that he could accumulate some savings "...pendant qu'y'était ici, j'y chargeais pas aucun loyer..."

Following the stroke, Laurent expressed that his family continued to be very supportive and that it would have been very challenging without their assistance. He indicated that family attended the vast majority of his appointments in hospital. They assisted with organising and provided transportation to community appointments, shopping, and social outings. They also gave him opportunities to return to renovation projects. Laurent stated that his sister or niece regularly assisted him with reading and understanding paperwork given to him by various specialists or government agencies (for example Ministry of Transportation). Following his stroke, family helped with the move to his nephew's where he pays less rent than he would elsewhere: \$740/month with all utilities, including television. Armand reported that family also provided emotional support to Laurent, especially when his driver's license was suspended and when he was preparing for the driving examination.

Physical Environment: Laurent lived with family in a rural area prior to the stroke because he was unable to afford rent closer to city services. The physical environment, in terms of the neighbourhood where he was living, influenced his ability to be independent with community mobility and social outings because of the lack of services such as public buses. However, close proximity of family was advantageous in that he continued to participate in these projects with their assistance.

Social services system: Laurent's experience of return to participation was influenced by income support programs for seniors and public transportation options. Participation was indirectly influenced by social housing programs.

At the time of the stroke, Laurent was receiving government income support from two programs in addition to his retirement plan from a previous employer. While living on this income, Laurent reported that he had to be mindful of his spending, and after the stroke, he had new expenses that were now difficult to cover. Support from these income programs did not, however, preclude him from having savings, which was helpful because he used his savings to pay for the driving exam.

With regards to transportation, Laurent lived in a rural area on the outskirts of Ottawa prior to his stroke, with no public transportation services and only fee-for-service volunteer drivers. This did not cause any difficulties until after his stroke when he could not drive, and he could not afford transportation services.

Further, Laurent was already living in a low-income situation prior to his stroke and living in unaffordable housing. Having a high rent made it challenging for him to afford the additional costs of his post-stroke personal projects while on his limited monthly budget.

Healthcare system: Laurent's experience of return to participation in personal projects was influenced by the healthcare system's availability of outpatient services, the coverage provided by his drug plan, as well as what portion of certain health services, of equipment, and of the return to driving process are covered by the healthcare system.

Once discharged from the hospital, Laurent was able to participate in publicly funded community therapy services, which he states helped him return to participation in several of his personal projects, such as resuming driving and improving his diabetes management. "Y m'ont

aidé pas yaink avec mon stroke, y m'ont aidé...je suis diabétique, ils m'ont aidé avec ma diabète, y m'ont aidé avec beaucoup d'affaires.”

The Ontario Drug Benefit Program, regulated by the healthcare system, covers the majority of Laurent's prescriptions because he is over 64 years of age. Certain items are not covered, such as his insulin needles, which were prescribed after the stroke. Laurent says he has been reusing his needles several times in order to save money. As well, a portion of his upcoming cataract surgery will not be covered nor his audiologist-prescribed hearing aids and batteries. These extra costs incurred have limited Laurent's available funds for other projects.

Further, the Ontario Health Insurance Plan does not cover the cost of the professional services required to re-instate a driver's license. Laurent explained that he disagreed with having to pay to be able to get his driver's licence back because of a medical condition. “En premier, j'ai dit 'Je l'paye pas'. Pourquoi j'devrais payer...j'ai pas perdu mes licences là parce que...j'tais saoul ou quechose!” Further, he disagreed with the high cost and the fact that the process was mandatory. “Fait que, finalement, y m'ont dit, 'L'argent c'est la seule manière. C'est la seule manière. Vous avez pas vos permis si vous l'faites pas.' Ben. OK. J'vas l'dépenser l'700 piasses, qu'est-ce tu veux qu'j'te dise?”

Knowledge about the “System” and understanding of health: Laurent's knowledge about how to resume driving was limited, as was his understanding of the impact of his stroke on everyday activities and his general understanding of his health (managing diabetes, prevention of a further stroke).

Laurent had limited knowledge about the process of resuming driving. The medical records from the geriatric outpatient clinic and from the *Clinique interprofessionnelle*

corroborated this. *Clinique* records indicated that he benefited from education and support to set up the driving evaluation. This assistance eventually led to his return to driving.

Laurent also had difficulties understanding the sequela of his stroke, in particular the cognitive changes. He explained that the association between cognitive testing and driving was not understandable to him and caused much frustration. Family attending appointments at the outpatient geriatric clinic with Laurent stated that they didn't understand either.

Armand: Y ont donné des tests, que j'va être franc avec vous autres, que moé j'trouve pas mal niaiseux. J'étais pas avec lui, mais ma sœur était avec lui. Et puis euh, elle, elle-même, ma sœur s't'un ancienne institutrice là, t'sais? A l'a enseigné à l'école, pis euh, elle, a dit, euh, 'J'peux presque t'garantir qu'avoir faite ces tests-là, y m'enlèveraient mes licences à moé-ci'

Laurent explained that the therapists at the *Clinique* were able to help him understand the link between his cognitive abilities and return to driving well enough.

Also related to understanding his post-stroke health, Laurent reported long-standing issues with managing his diabetes, which he had for over 30 years. "T'sais, y'avait pas personne qui m'avait euh...faire...er'garder qu'est-ce mon sang était...mon sucre était à toutes les jours, t'sais?" After the stroke, he felt it was important for him to learn to manage it, in particular because post stroke he was now taking insulin. Laurent explained how the dietician at the *Clinique interprofessionnelle* taught him to control his blood glucose. "A m'a aidé elle!...Depuis la journée qu'a m'a er'gardé, mon sucre a toujours été improuvé depuis c'temps -là."

Laurent felt that, in general, he had difficulty understanding the medical professionals he encountered following the stroke, because they often used complex words. "Le docteur y use des

noms des fois des grands noms...qu'on comprend pas à rien.” He indicated that he hesitated to ask the doctors to use words and a language he could understand (as in, slang). “Arriver pis dire à un docteur ‘Es-tu capable d’me l’expliquer dans notre langage à nous autres?’” This generally resulted in difficulties understanding how his stroke happened, the treatments that were being recommended, and how he could prevent a subsequent stroke. Specifically pertaining to stroke prevention, Laurent stated that he did not know how to prevent a future stroke other than taking his prescribed medication. He specified that he would not know because the doctors are the ones who are intelligent “...moi je l’sais pas, eux autres sont...c’est eux autres qui sont smart.”

Armand also reported that when he attended hospital appointments with Laurent, he was unable to understand health information or instructions, and therefore could not help either.

Armand: J’sais que moé...les instructions qu’y’ont données quand qu’y’a sorti de l’hôpital, de faire ci, de faire ça, euh quand y devrait faire quoi, euh, t’sais, j’m’avais assis avec lui, pis y’en a là-dedans moi j’ai dit ‘Va falloir que tu demandes ça à [notre soeur l’institutrice d’école], j’ai aucune idée c’est quoi que ça veut dire ça’.

4.2.5 Aimée

4.2.5.1 Case Story. Aimée is a woman over the age of 75, who arrived in Canada from Haiti eight years ago with her husband. They were placed on ODSP on arrival, and have, uncharacteristically for their ages, continued to be supported by ODSP rather than being transferred to OAS without CPP, likely because they immigrated after retirement. They live in an apartment in a high-rise building. One daughter lives in the same neighbourhood and provides a lot of support, another son lives relatively nearby.

Aimée arrived from Haiti with health concerns – most of which resolved over the next few years, except for an issue with low blood pressure that causes her to fall. Following a fall about one year prior to the stroke, she was hospitalized on a geriatric rehabilitation unit where she received some counselling to address emotional wellbeing, and where they recommended she participate in a francophone day program.

Aimée had a stroke approximately three years prior to her participation in the study. She was admitted to the local bilingual hospital and inpatient short-term program where she spent a total of two months before going home and participating in outpatient treatment services. Aimée's daughter Marie stated that following her stroke, Aimée initially made gains – she was walking, and going on outings with family, but during recent months, participation has been decreasing.

At the time of the first and second interviews, Aimée was no longer participating in any outpatient rehabilitation services, but continued to work towards personal projects with the support of family. By the third research interview session, Aimée had moved in with Marie and her family as her husband was in hospital and, because, since the stroke, she could not be left alone. Aimée was given a second floor bedroom, and could not, on her own, descend the stairs or walk with her walker in the very small home. Marie reported that Aimée experienced further decline in function over the last five months since her mom moved in with her.

4.2.5.1.1 Aimée's post-stroke body functions and structures, and activity. After her stroke, Aimée was experiencing the following impairments to body function and structures, and activity limitations: decreased balance, decreased strength and endurance, decreased hand function, limited walking endurance, fatigue, mild changes to cognitive function and to communication. Marie reported that her mother's mobility had been gradually declining prior to

the stroke, but that the stroke created more important losses in terms of mobility, such as having increased difficulties going up or down stairs or being limited in her walking distance. By the third interview session, Marie reported a further decline in her mother's general mobility.

Aimée scored 57.5/100 on the SIS-16. On the ICF Participation Checklist, she reported the following light participation restrictions: vision in daily activities, hearing, writing, problem solving, and lifting objects. Moderate restrictions were reported for fine motor tasks, walking with her walker, using transportation, washing, and getting herself dressed. Aimée reported complete participation restriction for meal preparation, shopping, and housekeeping.

The HADS indicated that Aimée may be experiencing both anxiety and depression. Marie stated that Aimée had a history of untreated low mood and anxiety. Marie also believed that since the stroke, her mother had given up and lost interest in doing many previously enjoyed hobbies, and that low mood appeared to have been a barrier to return to participation.

4.2.5.1.2 Aimée's personal projects: pre and post stroke. Prior to the stroke, Aimée was independent with self-care, and some meal preparation. She enjoyed outings, particularly shopping trips with her daughter, sewing, and embroidery projects, traveling in and out of country to visit family, and taking walks. She recently started attending a geriatric day program.

Aimée identified two personal projects: participate in more cooking activities, and attend the day program three days per week instead of two. Marie identified other personal projects for Aimée: improve mobility, go on more outings, participate in sewing activities, have daily assistance with shower, and find affordable and accessible housing.

4.2.5.2 Influence of low income on return to participation

4.2.5.2.1 Aimée's personal projects. Aimée's personal projects are described by focusing on the consequences of low income on her experience of attempting to return to participation in

personal projects. Diagrams in Appendix O show the events and categories that influenced the experience of return to her personal projects.

Do more cooking: Prior to the stroke, Marie stated that Aimée enjoyed participating in light cooking tasks. “Elle aidait, ...par exemple elle pouvait faire ses œufs...” She was limited in the amount of time she could spend in the small warm kitchen as this reportedly brought on dizzy spells, therefore she did many cooking tasks sitting in the dining room.

Since the stroke, Aimée has not returned to any cooking tasks. She explained that she felt the kitchen was too small for her walker and that the heat created by cooking could bring on a fall. “...la cuisine est petite, le foyer est tout près comme ça donc...on dirait que la chaleur me ... je me sens trop chaud et puis je je saute tout de suite pour là, ou bien je tombe là dans la cuisine...”. She stated that if instead of a galley kitchen in a rented apartment she had a larger home with windows and air circulating, she could participate in more cooking tasks. Marie’s home and kitchen were not larger and were not accessible for a walker, so her mother has been unable to participate in cooking tasks in her home as well.

Going three days per week to a day program: Aimée began attending a francophone senior’s day program following a fall that had her hospitalized prior to the stroke. Her children were paying for the program because Aimée and her husband could not afford it on their fixed income. Following the stroke, Aimée continued to attend the day program, and in an effort to further improve her mobility, the family paid for three days per week. The family has not been able to continue to afford attendance for this extra day every week, even though Aimée would like to. “Parce que avant elle allait trois fois par semaine, donc on a du couper, parce que c’est quand même...[15\$ par jour].” The day program costs \$15 per day, plus an extra fee for special event outings, in addition to transportation there and back.

Twice per week, Aimée went by disability bus service to the day program. She was able to get herself independently to the apartment building front door for pick-up. At the program, she enjoyed socializing and exercising. Marie explained the benefits of the program for her mother:

Marie: [Au centre] elle voit du monde, elle aime ça. Donc une belle robe, et puis elle dit ‘Ah!’ tout, elle doit raconter tout ce qui c’est passé, donc elle aime ça socialiser. Je peux pas dire c’est quelqu’un qui n’aime pas socialiser. Elle aime ça. Mais...et elle n’a pas la possibilité de le faire tous les jours ou bien...vous voyez?

Since Aimée has moved in temporarily with her daughter, sustaining participation twice per week has been difficult. She needs extra assistance getting down the stairs inside the home and down the steps outside to meet the disability bus service. Marie has not been able to afford the cost of hiring an attendant to help her with this. For the last five months, Marie’s son has been able to organize his schedule in the morning to help Aimée to get to the front door for bus pick-up. In the evening, Marie takes care of picking Aimée up.

Improve walking and mobility: Since the stroke, Aimée’s mobility has declined. She uses the walker at all times, and she has increased anxiety related to falling. One of her goals in outpatient community rehabilitation was to return to walking without the walker. This goal was not attained – the *Clinique interprofessionnelle* chart indicated that there was a lack of “resources” and that is why she was discharged prior to making serious gains on her goals.

Marie reported that her mother would benefit from doing more exercise, however, she stated that Aimée does not initiate exercising (e.g., walking in the halls of the building). Marie said they had exhausted all publicly funded therapy options. “Un endroit pour faire la thérapie? Parce qu’elle a, elle a cessé avec la thérapie après [la *Clinique*], c’est fini la thérapie.”

During the third interview session, Marie stated that she requested a homecare physiotherapy assessment for Aimée. This therapist referred Aimée to a three month, two day per week, outpatient program to improve ambulation and strength. At the time of the interview, the family had not yet figured out how they were going to get Aimée to the front door for pick up with the disability bus service for those two extra days. The estimated cost of an attendant for this was \$50/day. As well, once therapy sessions were finished, Marie believed that maintaining gains would be difficult without a private attendant to assist Aimée at home.

Participate in sewing: Aimée was a seamstress in Haïti and, once in Canada, continued to enjoy sewing and embroidery. Since the stroke, she has not done any sewing and reported this was because of decreased hand function “Mais quand je...fais de la couture..., ça me fatigue, je ne sens plus mes doigts donc, c’est comme une faiblesse comme ça.” Marie indicated that addressing hand function with more physical therapy may be beneficial, but was not affordable.

Marie felt that in addition to the physical limitations, Aimée had given up on sewing because she had lost interest or abandoned the hobby. “Des fois je me demande si c’est pas quelqu’un qui a baissé le bras aussi.” Marie believed that more support at home, for example, a personal support worker, might increase Aimée’s participation in sewing, and other personal projects, but would come at an unaffordable cost.

Go on more outings: Prior to the stroke, Aimée enjoyed going on outings, in particular shopping. She most often went with her daughter and liked trying on clothes and jewellery. Since the stroke, Marie explained that her mother is more fatigued and more limited in her ability to walk up and down aisles in stores. Marie also stated that her mother seems to have lost interest in shopping. “C’est pourquoi, elle a perdu même ce goût-là, même d’aller faire du magasinage...”. Marie also stated that, because she works full time, she does not have much time to bring her

mother on such outings. Her father is unable to drive her mother to the stores. Marie stated that having someone take Aimée out would be the best solution “Quelqu’un qui l’accompagnerait...tu vois? Quand nous nous n’pouvons pas...” She specified that her mother would need a francophone assistant to translate when shopping “...c’est rare qu’on arrive à Winners et puis que l’employé parle français. C’est souvent anglais. Je dois dire ‘Ah, elle dit ceci, elle dit ça.’ Tu vois?”

Marie stated that in Haiti, such assistance would be easy to obtain. A live-in attendant, available all day, would be \$100 US dollars per month. Marie has investigated the cost of such a service here and they are unable to afford the service at \$25 per hour.

Have daily assistance with showers: Prior to the stroke, Aimée’s usual routine was to take daily showers. Since the stroke, Aimée has been receiving shower assistance once per week from a personal support worker from homecare services. Marie said that her mother would like to have someone come daily to supervise her during shower time and to assist her only as needed so that she could regain or maintain her function and independence “Oui, tous les jours, mais quelqu’un qui la surveillerait.” Marie was aware that it was possible to hire weekly shower assistance but the cost was too high for them to afford.

Find accessible and affordable housing: Aimée and her husband live in a rented apartment that costs approximately \$1000 per month. At the time of the interviews, Aimée reported that the owners were going to increase the rent, and Marie indicated that her parents would no longer be able to afford their apartment.

If she could, Marie said she would have her parents move in with her permanently, however, she lives in a multilevel cooperative house with her husband and kids, and since her mother’s stroke, stairs are no longer possible without assistance.

Marie: C'est pour ça qu'on essaie de trouver ... un logement... subventionné?
 Mais, qui serait quand même là encore proche. Parce qu'on peut pas prendre n'importe... Ils peuvent pas venir à la maison aussi parce que moi j'ai des escaliers, je n'ai pas de chambre au premier. So, so c'est vraiment compliqué. On est en en stade de chercher un logement pour eux, mais...qui serait sur un seul plancher.

Marie has been helping her parents look for subsidized housing in the same neighbourhood. She indicated that she had just recently put her parents' name on the social housing registry, and she was hoping it would take no more than one year to get an apartment. Marie stated that with the extra money they would save, her mother could have, for example, a third day at the day program. "Donc ils pourraient, par exemple, toujours commencer encore aller...maintenant payer la physio, aller au centre..."

4.2.5.2.2 Patterns of influence on Aimée's experience of return to personal projects. Four patterns of factors influencing Aimée's experience of attempting to return to participation in personal projects in the context of low income are described in this next section and are depicted in diagrams in Appendix P. These are: healthcare system, social services system, family, and physical environment.

Healthcare system: The availability of outpatient community therapy services, the cost of the day program, and rules of community homecare services influenced Aimée's experience of return to participation.

Aimée and her family would like her to participate in more physiotherapy, however, Aimée has already accessed all publicly funded services, and private services are unaffordable.

Aimée attends a day program that is jointly run and organized by the rehabilitation centre she attended and by homecare. The cost is fixed at \$15/day plus transportation, and Aimée and her family cannot afford more than two days per week of attendance at the program.

As per the rules for home services, homecare provides Aimée with one shower per week. Aimée and her family are unable to afford more days per week of shower assistance. Further, they are unable to afford more personal support services to accompany Aimée to the store or to help her get ready and down the stairs for the disability bus when she goes to the day program.

Social services system: Aimée's experience of return to participation in personal projects has been influenced by social services, in particular the ODSP income support program, and the social housing program.

Aimée and her husband were placed on ODSP on their arrival in Canada. Together, they receive approximately \$1495 per month. After paying for rent, they are unable to cover all of their regular living expenses. They are also unable to pay for extra expenses stemming from the stroke (e.g., private physiotherapy or a private attendant).

Aimée and her husband spend approximately 70% of their income on housing. At the time of the interviews, Aimée and her husband were on the social housing waitlist.

Family: Aimée lives with her husband who is several years her senior. Her daughter Marie lives in the same neighbourhood, and she has a son who lives in town as well. Family was very involved with Aimée and her husband before the stroke – providing financial assistance with expenses such as food, cable and television, and telephone, as well as support with housekeeping, grocery shopping, transportation, translation services, advocacy, and assistance with understanding health. Since the stroke, they have provided additional support in terms of paying for the day program, assisting with finding housing, and looking for additional services.

Further, at the time of the third interview session, Aimée had been living with Marie for roughly five months because her husband was in hospital, and she could not stay home alone.

Physical Environment: Aimée's neighbourhood and the housing characteristics have played a role in return to participation. Being in her current neighbourhood has been beneficial because Aimée is near her daughter's home and this facilitates receiving assistance from family.

In terms of housing characteristics, the current apartment has a cramped galley kitchen, which has made it difficult for Aimée to participate in her return to cooking. The apartment is otherwise accessible. Since living with Marie, the home's two-storey layout has limited Aimée's participation in daily activities and in her personal projects of mobility, cooking, and outings.

4.2.6 Josée

4.2.6.1 Case Story. Josée is a woman in her early thirties. At the time of her stroke, she worked full time as a bilingual administrator in a small business, and was living with her fiancé. Her mother tongue is French, and she completed university studies in both official languages.

Her stroke occurred approximately two years before the research interviews. Josée spent her first days post stroke in the intensive care unit in an acute care hospital, and had to undergo a craniotomy. She was then transferred to an inpatient rehabilitation program. The stroke had caused severe difficulties with communication, general mobility, thinking and memory. When the healthcare team identified that she had also lost vision in one eye during the stroke, inpatient rehabilitation was extended a number of weeks.

Josée was eventually discharged back to her multi-storey home. On discharge, she used a wheelchair, and she required a high level of assistance with transfers and with all self-care activities. Her family purchased a stair-glide so that she could get to her bedroom in the basement. The other equipment was partially paid for by her fiancé's work insurance. She herself

had no insurance. Josée's mother took time off from work, without pay, to assist with her daughter's personal care.

Josée and her fiancé eventually felt unable to continue the relationship, and Josée needed to find a new place to live. This was challenging because Josée had minimal income from CPP, and she was not on the waitlist for social housing. Her parents purchased her a condo.

From the time she left inpatient rehabilitation, Josée has been participating in outpatient rehabilitation programs. Initially, she was receiving services from the *Clinique interprofessionnelle* and from outpatient speech therapy at a local hospital. Her extended family have been paying for additional weekly private physiotherapy sessions for the last two years.

Josée was not living in a low-income situation prior to her stroke; this occurred as a result of being unable to return to work after her stroke. At the time of the research interview, she was receiving CPP and ODSP. She had only started receiving ODPS approximately two years following her stroke when her father was searching the Internet for additional income support programs for Josée. The family state that they had not received any information or assistance from any of the health professionals they encountered regarding possible income sources. Josée's mother Denise stated that the financial support that she and her ex-husband have been providing has been a great burden. As a result, she has needed to postpone her retirement by several years.

4.2.6.1.1 Josée's post-stroke body functions and structures, and activity. Josée was experiencing the following impairments to body function and structures, and activity limitations: decreased strength on the right side, no functional use of the right upper extremity, decreased dynamic standing balance, loss of vision in the right eye, decreased walking speed and endurance, moderate expressive aphasia, and mild receptive aphasia.

Josée scored 71.3/100 on the SIS-16. She rated herself as having some difficulty with shopping, walking quickly, and walking a distance of approximately one block. She indicated that she was unable to carry heavy objects with her affected hand. On the ICF Participation Checklist, she reported the following light participation restrictions: multitasking, understanding people speaking, participating in conversations, walking, getting in/out of a car, shopping, making meals, and using the telephone. Moderate difficulties were reported for meeting new people. She reported severe participation restrictions for reading, writing, calculating and problem solving, lifting objects, doing dishes, and working in paid employment. With regards to mental health, Josée scored within normal ranges for anxiety and depression on the HADS.

4.2.6.1.2 Josée's personal projects: pre and post stroke. Prior to her stroke, Josée enjoyed watching baseball games, having “girls’ nights” and socializing with friends, driving her car, taking care of her dog, going to the gym several times per week, and travelling. She worked full time, and owned a house with her fiancé.

Post stroke, Josée’s personal projects are to live independently, improve mobility, improve her communication, return to work, continue to socialize with friends, be independent with community mobility, participate in leisure activities, travel, and secure income support.

4.2.6.2 Influence of low income on return to participation

4.2.6.2.1 Josée's personal projects. Josée identified ten personal projects, which are described with a focus on the influence of low income. Diagrams in Appendix Q show the events and categories that influenced the experience of return to her personal projects.

Secure income support: Josée did not have disability insurance through her employer. Early on after the stroke, her fiancé was POA and organized for her to receive CPP. Her father and mother became POA after the end of Josée’s relationship. Josée started receiving income

support from ODSP approximately two years following her stroke after her father found out about the program online.

Denise: Puis là, à ce moment-là, [le père de Josée] y trouve, y dit ‘On en train de s’saigner tout’l’monde’ fait qu’y dit ‘Faut que j’trouve quêcke chose.’ Pis y’a fouillé, y’a fouillé, finalement, y’a trouvé qu’y’avait un programme au niveau d’la province. Personne nous a jamais parlé de ça là. C’est quoi? ...ODSP.

Denise reported that applying for ODSP was a complex process in itself, but that staying on ODSP has been a very frustrating process as well. Since Josée works a few hours per week, the wages must be declared to ODSP. Filling in this paperwork has been a monthly challenge and has frequently resulted in withheld income cheques, and in Josée’s parents needing to go in person to the ODSP office to rectify problems.

Live independently: Prior to her stroke, Josée lived in a home she had purchased with her fiancé. Following the stroke and the end of the relationship, Josée needed a new home. At that time, with only CPP income, Josée could not afford to rent an apartment, in particular an accessible apartment in the neighbourhood where her mother and friends lived and that would allow her dog. Having her name on the social housing registry would not have met her housing needs in a useful amount of time therefore her parents purchased an accessible condo for her.

Friends and family have been providing Josée with housekeeping assistance because she cannot afford private services. Since moving in to the condo, her parents and friends have progressively needed to give her less and less support because she has been able to do more for herself. Josée currently only receives help with washing dishes, a few heavy housekeeping tasks, as well as transportation for errands and shopping. Denise stated that having Josée live alone was

a very important personal project. She felt that having Josée move in with her would not have been as beneficial to Josée's ability to attain this project because Josée would not have needed to do things such as housekeeping on her own.

Denise: Fait que là on sait que, a l'a son indépendance parce que c'est pas...on savait que pour elle, être indépendante c'était très important. Pis aussi, que si elle était venue vivre chez moi, ben t'sais c'est facile 'Ah Mom, amène-moi ci, amène moi ça.' Tandis que là, a l'est toute seule, a s'lève et a l'fait.

Now receiving ODSP in addition to CPP, Josée has been paying her parents some utility fees, the condo fees, and taxes. Denise stated that, on ODSP, if Josée had to pay actual rent in addition to utilities, condo fees, and groceries, she would not have any money left over for other expenses including outings.

Improve mobility (walk without an ankle brace and independently walk the dog):

Prior to her stroke, Josée enjoyed taking long walks with her dog and went to the gym to work out two or three times per week. Following her stroke, when she was discharged home from rehabilitation, Josée was using a wheelchair, and required assistance with all her transfers. At that time, her extended family started paying for weekly private physiotherapy at \$120 per session. Denise reported that improvements have been slow but steady over the last two years. Josée progressed from a wheelchair to a cane and from a full ankle brace to a partial one. She is now able to walk without any aids for short distances in her home.

Denise: Pis là tranquillement pas vite, a l'a commencé à la faire marcher avec euh une canne, puis,...là, au début a l'avait une brace complètement rigide, puis là après ça a l'a eu une brace que c'était le le talon il plie. Puis là a l'a

encore cette brace là, mais là y ont coupé le bout des orteils pour que les orteils aillent de la sensation.

Josée: Oh ya, ...so....

Denise: C'est ça. Pis là a l'a des exercices à faire nu pieds dans la maison. Comme a peut marcher nu pieds dans la maison.

Josée: Ouais. Slowly. Ouais.

At no point in her recovery was Josée able to pay for these private physiotherapy sessions. Denise expressed that family will continue paying for physiotherapy treatment until Josée can walk without a brace. “Mais, tant qu'a marchera pas normalement, on n'arrêtera pas.” Denise stated that at one point, the family was paying for two treatment sessions per week, and they were seeing clear results, however, this was not financially sustainable.

Denise: Parce qu'à un moment donné a en faisait, on, on a payé pour qu'a n'en fasse deux fois par semaine. Pis on voyait encore plus de résultats. Mais j'ai...Deux fois par semaine ça...c'était euh...On n'a faite pour un 'tit bout là mais... C'était trop. On pouvait pas euh...Mais si a l'avait plus d'argent, a pourrait faire plus de physio!

Josée: Oh my god, everyday! Hahaha!

The private physiotherapist recommended that Josée have services from a personal trainer once per week as well to accelerate results. However, Denise did not think that they could afford this service at an extra \$60-70 per week.

Josée has set specific benchmark projects with her mobility – to walk without a brace and to be sufficiently stable in her outdoor ambulation to be able to walk her dog on a leash safely.

Josée has yet to attain these smaller projects but continues to attend weekly physiotherapy and she feels she is getting closer to meeting her goals.

Return to work: Prior to the stroke, Josée was working full time in a small company. She had a very good relationship with her boss and his family. Following her stroke, Josée was unable to return to work because of her physical and communication impairments.

Approximately two years post stroke, her boss, wanting to support her recovery, started giving her small tasks that were remunerated, such as writing letters or filling in forms on the computer. Josée reported that she is slow at using the computer but that she has been able to complete these tasks.

Josée has had no formal support for return to work. When asked if anyone spoke of or addressed eventual return to work, her mother responded that it was never discussed and that goals were more short term in nature. “Y’a jamais personne qui nous a parlé de ce qui se passerait après qu’on serait sorti de là.”

Josée’s boss has provided assistance by grading the difficulty of activities and providing Josée with feedback. At the time of the interviews, Josée had progressed to working three to five hours per week and felt very well supported by her work environment.

Interviewer: ...Est-ce que c’est difficile faire ton travail?

Josée: Non, parce que...like my boss, so good. Oh my god, oui. So like he like slowly, pis ouais, so...ouais ouais ouais.

Interviewer: Est-ce que tu fais...Tu fais combien d’heures pas semaine tout de suite?
How many hours?

Josée: Maybe like euh...like là?

Interviewer: Three hours?

Josée: Pis one, two, so like là, là...So...like 1,2,3,4,5...

Interviewer: Five hours?

Josée: Ouais so...

Interviewer: So three to five hours a week?

Josée: Ouais.

Josée's experience of pursuing this personal project is not directly influenced by current income, however, it is influenced by her mother's ability to provide transportation, and by her previous work and her relationship with her boss who is committed to her rehabilitation.

Improve communication: Josée has been working on communication goals since the stroke; specifically she has been trying to improve reading and expressing herself verbally. Josée has participated in several outpatient therapies with various public services. Her parents have been very involved as well. In addition to providing all transportation to the therapy sessions, Denise reported that she does near daily homework with Josée to help her along with reading and verbal communication.

On discharge from the *Clinique interprofessionnelle*, Josée was accepted for speech therapy at a local hospital outpatient communication clinic. Josée expressed that it was good that these treatment sessions were publicly funded by the healthcare system. During the third interview session, Josée and Denise reported that this hospital outpatient communication clinic had recently decided to continue providing Josée with treatment until no progress was made – she had so far attended over one year of therapy. Denise expects that this service will eventually come to an end; at that point, they will pay for private services. “Pis là, à [la clinique ambulatoire de l'hôpital], t'as de l'orthophonie mais, quand t'en auras pu, on veut engager quelqu'un privé parce qu'on veut pas arrêter.”

Participate in social outings and leisure activities: Josée was very active socially and in her leisure activities prior to the stroke. Following her stroke, she has been able to get back to social outings and leisure activities, and her pre-stroke social circle has remained largely the same. Her friends have made efforts to facilitate participation in group activities. For example, Josée enjoyed baseball prior to the stroke, and her friends helped her participate in the game by teaching her how to be point keeper at local games. Denise also reported that over the last year, Josée's mobility has improved, and she is now able to walk on the grass at the baseball field.

Josée stated that there are some outings where she cannot go on her own, notably hockey and baseball stadiums, as well as some restaurants, because of the physical accessibility issues (e.g., stairs without railings, bathrooms in basements). Her family and friends help her out physically in these situations.

Denise clarified that Josée has been able to afford to pay for outings to restaurants or sporting events mainly because her rent is very low and this allows her to have extra money. Friends and family have also helped by providing transportation at no cost.

Travel: Josée enjoyed travelling prior to the stroke. Since her stroke, she has been hoping to get back to travelling. Initially, her needs for assistance were too high (e.g., she needed help with basic self care). At the time of the interviews, Denise was planning and paying for a trip out east with her daughter. Improved mobility has made it possible for Josée to start travelling, but she still requires some assistance. She requires help, for example, with carrying luggage, managing stairs in inaccessible locations, and managing complex communication situations. She is otherwise independent. Denise and Josée also have a goal of going on a cruise once Josée is able to walk without the ankle orthotic.

Josée: And like euh, like a goal... Like euh...no...like euh...stroke...hmmm...a shoes? Pis like, mais là, so oui.

Denise: C'est ça. Le but, le incentive qu'a l'a, c'est que le jour où a l'aura pu de brace, pis qu'a va pouvoir marcher normalement, on s'en va en croisière toutes les deux.

Josée: Ouais. C'est a goal.

Further, Josée may be going to Florida with her boss's family in the near future. They have an accessible condo, and they will be paying for her trip.

Be independent with community mobility: Josée drove a car prior to the stroke. Since the stroke, Josée's driver's licence has been suspended, and she has been relying on friends and family for transportation. She would like to return to driving so that she can be less dependent on her friends.

Interviewer: Est-ce que t'as des goals par rapport à ton cercle social?

Josée: Car.

Interviewer: A car? Ça ça aiderait avec sortir...?

Josée: Ouais, ya, ya. Like a ride, t'sais? I'm sorry, t'sais?

Interviewer: Tu aimerais mieux être capable de dire : ride, do you want a ride?

Josée: Ouais, ouais, ouais. Exactly. Ya. Ouais. Ouais.

Josée is aware that her physical limitations may make it difficult for her to resume driving. She feels that functional improvements may help her with this project, which is likely related to her family's ability to continue paying for private therapy. This project also hinges on her ability to pay for the driver's examination and possibly vehicle adaptations.

4.2.6.2.2 Patterns of influence on Josée's experience of return to personal projects. Five patterns of factors influencing Josée's experience of attempting to return to participation in personal projects in the context of low income were identified and are depicted in Appendix R. These were: healthcare system, social services system, family and friends, physical environment, and knowledge about healthcare and the social services systems.

Healthcare system: Josée's attempts at returning to participation have been influenced by the lack of information and guidance received during discharge planning from inpatient rehabilitation, as well as by the availability of publicly funded community therapy services.

On discharge from the inpatient rehabilitation program, Denise stated that the family were advised that Josée was eligible for CPP, for which they applied.

Denise: [La travailleuse sociale] lui a donné [au fiancé] les renseignements euh, où, où appliquer pour euh avoir le [CPP] disability là, pis tout ça. Pis là, ben à ce moment-là, y'a, y'a rempli les papiers pis là les médecins, pis ç'a pris un certain temps-là, mais là à ce moment-là, on était seulement au courant que y'avait des, des, un programme fédéral.

They were unaware that Josée was eligible for other income support programs and had to find this information on their own. Denise stated that there was a lack of information and guidance regarding income support from the healthcare professionals.

During those two years before starting to receive ODSP, Josée was not limited in her personal projects because her parents were paying for all of her expenses in order to make sure she did not go without.

Denise: Euh, ben l'impact pour [Josée] comme j'l'ai dit est minime parce que l'impact a été sur nous autres, parce qu'on a payé. C'est, c'est, c'est ça la

situation parce qu'on veut pas qu'[Josée] manque de rien, s'fait que la m..., le moindre moment où on voit que son compte de banque descend, on lui donne d'l'argent, c'fait que.

Once Josée completed all the available publicly funded physiotherapy in the community, she was able to continue with her project of improving mobility because of the financial support from her family. Josée has been able to access publicly funded speech therapy for over two years of services in the community. When she is discharged from this program, Josée will likely have the opportunity to continue with therapies because her parents will find the necessary funds.

“Fait que j’espère que on va pouvoir le faire, juste nous autres même, mais sinon, ben on trouvera un orthophoniste pis on payera encore, parce qu’on peut pas la laisser tomber, t’sais?”

Social services system: Josée’s experience of return to participation was influenced by the social services system, which is responsible for income support programs and public transportation services.

Josée receives income support from CPP and ODSP. The income received would be insufficient, according to Denise and Josée, if Josée had to cover her rent and all other living expenses related to her personal projects.

Interviewer: C’est...euh...assez pour qu’est-ce que tu as besoin?

Denise: Ça serait pas assez si t’avais un appartement à payer.

Josée: Ouais, ouais.

Denise: C’est assez pour tout le reste.

Josée: Ouais.

Denise: Mais a pourrait pas avoir un appartement avec l’argent qu’a reçoit.

Josée: Non, non, non, non.

Public transportation services are also a social service. Josée has not used public disability transportation because of the complexity of organizing rides by telephone, and the challenges with waiting for the service to arrive.

Family and friends: Josée's immediate family, extended family, and friends have provided substantial support towards Josée's return to participation.

Since the stroke, Josée's mother and father have been very involved with her recovery and the pursuit of her personal projects. Denise and her ex-husband have provided financial assistance – they purchased the condo in which Josée lives, purchased equipment such as the stair glide that she used on discharge from inpatient rehabilitation; they also paid participation fees in different services (e.g., post-stroke municipal swimming program) and are ready to pay for private speech therapy services when the public services come to an end. Since she lives on her own, they have also provided her with direct assistance with housekeeping tasks, meal preparation, transportation, assistance with communication and therapy homework, travelling, as well as assistance with financial management as POA and assistance with organizing rehabilitation. At least one of Josée's parents provides support nearly everyday of the week.

Denise: C'est parce qu'a l'a d'la, a l'a d'la physio le mardi pis a l'a d'l'orthophonie le jeudi, fait que, son père ces deux journées-là. Moi j't'avec elle la fin de semaine, euh...souvent le mercredi on est ensemble parce qu'on avait une émission de télé qu'on regardait ensemble, fait que...ce soir-là on fait un bon repas, pis souvent ben on en fait plus comme ça qu'a peut juste le réchauffer le lendemain.

Denise also indicated that she and Josée's father continue to provide advocacy for Josée. Despite a still imperfect understanding of Josée's needs and of the healthcare and social system, they have not stopped asking questions and pushing for services for their daughter.

In addition to these contributions, Josée's extended family, that is her grandmother and aunt, have been financing all of her private physiotherapy sessions since discharge from inpatient rehabilitation, and have provided financial support towards several other therapy expenses.

Josée's friends provide much support as well – they organized a fundraiser in the first months following the stroke to help pay Josée and her fiancé's bills. In the months since the stroke, they have provided transportation to outings, as well as communication assistance and physical assistance during social and leisure outings. Her boss and his family are also providing support towards Josée's return to work and travelling projects.

When asked what she thinks would have been different if Josée didn't have the same level of support from her family and friends, Denise reported that Josée would not have an apartment, or rehabilitation, and would likely have needed to be institutionalized on discharge from the rehabilitation unit.

Physical Environment: The neighbourhood and housing characteristics and the accessibility of event sites in town have influenced Josée's participation in personal projects.

The neighbourhood where Josée lives was chosen specifically to be close to both her mother and her friends' homes, so as to facilitate transportation and outings. She is also relatively close to her previous workplace.

In terms of housing characteristics, Josée initially had difficulties managing the stairs to get out of her condominium – there are several steps to the front door and the builder had not installed the railings, and the inside stair lift was problematic. Josée's father pushed hard with the

builder and the railings and ramp were finally being built at the time of the third interview. The apartment itself is spacious and the bathroom accommodates all of her adaptive equipment. Her space does not limit her participation in any projects.

The physical environment in the community has limited Josée in some projects. Josée mentioned that accessibility has been problematic at sporting events and some restaurants.

Knowledge about the healthcare and social services system: At the time of Josée's stroke, her parents had limited knowledge about the healthcare and social services systems: they were unaware of income support programs, and did not know what opportunities for additional rehabilitation were available to Josée.

In terms of income support, it took them two years to find out about ODSP and to apply for it. They have since learned more about how ODSP works and are able to advocate for Josée when, for example, cheques are being withheld.

Denise and her ex-husband were unfamiliar with rehabilitation. They attended all of Josée's appointments and learned how to help with exercises and with communication homework. Denise explained that Josée's dad was a good advocate – reading a lot about Josée's condition and asking for extra services rather than waiting for these to be offered.

4.2.7 Sylvain

4.2.7.1 Case Story. Sylvain is a bilingual man in his late 40s. At the time of the stroke, Sylvain was living in an apartment. His housemate had just recently moved out, and he was looking to find a replacement. He had a large circle of friends and two older sisters living in the rural area near town. He was working part-time and was transitioning to a full-time position in a few weeks. Sylvain was at work when a co-worker identified that he was having a stroke and

called the ambulance. He was seen in emergency and discharged. The hospital called back the next morning and admitted him.

Sylvain remained in the acute care hospital for roughly one week, and he was told about his discharge and was discharged home on the same day. He called his sisters for help because he was unable to walk without a walker and had difficulty using one arm; he was unsure how to manage his return home. One sister brought him home, picked up his prescriptions, and helped with food. His other sister Angèle, who was working in a long-term care facility, brought equipment that her employer lent her. Angèle set up the equipment and taught him how to use it. When she realized that Sylvain could not manage to get dressed with one arm or get in and out of bed, she provided the education. In the following days, his sisters assisted with groceries, re-organized his home environment to support his mobility needs, and got him to the Ontario Works office to apply for emergency funding to cover his rent. When Sylvain was accepted to outpatient rehab, his sisters guided him to get the assistance of the social worker to apply for ODSP.

At the time of the first interview, Sylvain was living on Ontario Works and still waiting to hear if he had been accepted to ODSP. He was trying to understand if he was eligible for further therapies. By the third interview session, Sylvain was receiving ODSP, and had completed outpatient therapies at the *Clinique interprofessionnelle*.

4.2.7.1.1 Sylvain's post-stroke body functions and structures, and activity. Following the stroke, Sylvain had right-sided weakness in the upper and lower extremities, and difficulties walking. He used a 4-wheeled walker and an ankle-foot orthotic. He had limited general right hand use and difficulties writing. In the weeks post stroke, he experienced expressive aphasia, but later regained his ability to communicate with minimal word finding difficulties. His energy and concentration levels continued to be decreased.

Sylvain scored 50/100 on the SIS-16. He scored himself as being unable to walk quickly. He indicated having severe difficulties with shopping, housekeeping, and walking one block. Moderate difficulties were reported for dressing, washing, and stair climbing. Light difficulties were reported for getting to the bathroom on time, standing without losing balance, walking without losing balance, getting in and out of a car, and carrying heavy objects with his affected hand. On the ICF Participation Checklist, he reported the following light participation restrictions: human rights (in this situation, he alluded to some difficulties with public transport staff and his disability), community living, watching, completing simple tasks, receiving spoken messages, receiving non-verbal messages, participating in conversations, and drinking. He stated having moderate restrictions with multitasking, producing non-verbal messages, lifting and carrying objects, fine motor control, walking with and without the walker, taking care of his health, preparing meals, completing self-care activities (e.g., washing, dressing), interacting with others, intimate relationships, and participating in further education. He rated himself as having severe restrictions with taking part in leisure activities, housekeeping, caring for others, using transportation, and shopping. Sylvain stated that he was experiencing a complete restriction participating in driving, and economic self-sufficiency. With regards to mental health, the HADS indicated that Sylvain might be experiencing anxiety.

4.2.7.1.2 Sylvain's personal projects: pre and post stroke. Prior to his stroke, Sylvain was working towards full-time employment. He drove his housemate's vehicle, enjoyed being free to travel around the city and out of town. Sylvain enjoyed organizing and attending medieval festivals, as well as selling trinkets at a vending stand at these events. He enjoyed camping, organizing brunch parties at his apartment, and going out for coffee with friends. He dreamed of opening an eco-retreat.

Since the stroke, Sylvain's personal projects were: to secure income, to continue living independently in his apartment, to obtain all recommended medical equipment, to improve his mobility and function, to improve his general health, to resume driving, and to return to work. As well, he wanted to increase participation in social activities and in his festivals.

4.2.7.2 Influence of low income on return to participation

4.2.7.2.1 Sylvain's personal projects. Sylvain's nine personal projects are described with a focus on the consequences of low income, and are depicted in Appendix S.

Secure income support: Prior to the stroke, Sylvain worked part-time. Following the stroke, his impairments prevented him from being able return to his former job; he needed a source of income. This personal project of securing income support stemmed from the loss of employment following the stroke, rather than being influenced by his low-income situation.

On discharge from acute care, Sylvain's sisters helped him apply to EI and helped him negotiate at the offices of OW for financial assistance with his rent. Angèle explained that OW agreed to pay for one month of rent. "...mais l bien-être social y'ont aidé, y'ont déboursé mille dollars parce que là, y'avait pas payé sa partie pis la partie d'l'autre était pas payé à cause de tout' ça qu'est arrivé là." Sylvain then found a roommate, and OW agreed to provide income support until EI started (approximately six weeks post stroke).

When he started participating in an outpatient rehabilitation program, Sylvain explained that his sisters encouraged him to see the social worker to ask for assistance applying for ODSP. Angèle coached him with specific questions. "Actually, my sister asked that a lot. She said 'Ask. These are questions to ask.' So they made me a list of questions and stuff like that." Sylvain stated that the social worker was a great resource and helped him fill in the forms.

EI provided Sylvain with approximately \$1200 per month. “Well, quand j’étais sur EI, j’faisais 600 piasses chaque deux semaines.” This lasted approximately 18 weeks, and then, because he was unable to return to work, EI cut him off income support, and he was back on OW. “Astheure chu back sur Welfare, j’fais 700 piasses...par mois.” About nine months post stroke, Sylvain’s ODSP application was accepted. He reported feeling great relief.

Sylvain: Cause of the stroke and stuff. I want drama free. And going to the [rental] office and saying “I know I’m in arrears.” I, now, I can say “I am in arrears but I’ve got accepted by ODSP, so everything’s good, can be caught up as soon as ODSP starts coming in.” So I’m able...I think it’s gonna get better that way.

Sylvain stated that governmental income support is insufficient to meet all of his expenses. He has been illegally selling cigarettes in order to make ends meet.

Live independently: Days before being admitted to the hospital for his stroke, Sylvain lost his roommate. Following the stroke, without income from work or a roommate, Sylvain was at risk of losing his apartment. He was unable to afford the \$1100 per month rent on his own. His sisters assisted him with requesting rent assistance from Ontario Works, which he received.

Angèle believed that Sylvain’s apartment, although it was accessible, was too expensive for his income. Even with a roommate, his monthly rent was around \$600. She knew that the wait time for social housing in her rural area was over five years. “La liste d’attente, la liste d’attente pour le prix modique est de cinq ans. Cinq ans et plus, pis j’pense que c’est plus que ça à Ottawa.” She stated that, in the event that he lost his apartment, she would have taken him in, however, she lived on a farm in a very inaccessible home. Sylvain knew about Ottawa Housing

and the waitlist, but reported that having grown up in social housing, he was not willing to consider living in the “projects”.

To support his independence, Sylvain’s sisters helped him organize his apartment and the provided several meals. Sylvain has not been able to afford private housekeeping services, and stated that friends have been helping him.

Sylvain: Like doing dishes, you know. I get tired. I get tired doing dishes. I...[my friend’s] pretty good about it. I do most of the plates and bowls, and [he] will do the cups and utensils, because those are things that are harder for me to... Euh...I have some neighbours who came down to help me clean.

Sylvain also pays friends a small stipend to pick up groceries for him when they are out doing their own. He would have difficulty shopping for groceries even if there was a store closer by, and grocery delivery services are too costly.

Sylvain stated that housing has caused him much stress, for example, his landlord recently brought him to court because he was in arrears. To help with budgeting, ODSP now provides a direct deposit service to his landlord. Even so, with limited income, Sylvain continues to be at risk of losing his apartment.

Get equipment: On discharge from the hospital, Sylvain was given a list of recommended adaptive equipment. He did not have sufficient time or funds to organize and rent equipment prior to leaving the hospital. His sister Angèle borrowed equipment from her workplace (a 4-wheeled walker and a cane) and got quotes for the other equipment (bathroom grab bars, bath chair) through a vendor. She then brought her brother to OW to organize reimbursements. Angèle clarified that Sylvain did not have enough money to rent or purchase equipment himself. “Pour payer, parce que y’avait pas les fonds là [Sylvain]. Y’a avait pas les

fonds. Fait que la le bien-être social y'a aidé à payer une partie." OW did not approve the purchase of a walker at that time and, ten months post stroke, Angèle indicated that Sylvain still did not have his own walker "Pis encore aujourd'hui y'a pas la marchette." He was still using the one that her work lent to him. Sylvain explained the problem was caused by his flip-flop between OW ("Welfare") and EI support in the first months following his stroke.

Sylvain: Well that that got all mixed up, euh, originally, it was approved by Welfare, and before I get a chance to grab it, it got switched immediately to EI. And which, when euh, Ontario Medical Supplies tried to euh charge euh Welfare, they said "No, he's not one of our customers anymore." So that left me stuck with the old walker and not the new one.

In addition to this equipment, Sylvain's sister and mother purchased other equipment that he could not afford: a 4-wheel cart to help with his laundry and a long handle reacher.

Resume driving and be independent with community mobility: Sylvain drove his previous roommate's car and following his stroke, his driver's license was suspended. Sylvain stated that being independent with community mobility was an important personal project because he felt limited in his ability to carry on with several activities such as socializing. "Faut que j'planifie tellement en avant. Juste pour aller voir quelqu'un."

Sylvain has been taking the public disability bus service, taxis, as well as the regular bus. Angèle stated that paying for transportation has been a challenge, especially when he was on OW and attending outpatient rehabilitation four days per week. "Encore là, y faut qui paye pour Paratransport. Ses fonds sont minimes, fait que fallait quand même qui paye pour Paratransport."

In addition to the cost, Sylvain explained that disability transportation takes a lot of organizing and the rides are not guaranteed. "It's a pain in the ass. 'Cause you gotta call the day

before, before 9 o'clock if you even hope to get a ride the next day." He stated that using if for daily needs has been complicated "Like if I want a ride to grocery store right now. That's not here. I can't rely on ParaTranspo. I don't know if I'm gonna get a ride from them." He has needed to rely on friends, or pay for taxis, which has limited his participation in outings. "Oh ya, I do a lot less things that that I did before. And now I gotta rely of friends for rides and stuff."

Sylvain understood that to drive again he would need to do an examination and likely need an adapted vehicle. Angèle doubted that, with all of his other living expenses, he could afford the examination or the car upkeep and modifications. "Y'a son loyer, son manger, j'pense même pas qu'y s'rait capable d'avoir un véhicule pour l'assurance pis tout'. Pis le gaz, pis... réparations pis tout' ça. Pis si y'est obligé d'avoir un véhicule adapté." Sylvain participated in therapy at the *Clinique interprofessionnelle* – this helped him understand his physical limitations related to driving and to understand the process of resuming driving. Sylvain indicated that it will take time, but he is determined to save his money for the driving exam, the adaptations, the vehicle, and other associated costs, such as gas and insurance.

Improve mobility: Sylvain identified that improving his physical function was an important personal project which he felt was also related to other projects, such as resuming driving, returning to work, and camping. He had received information from the Stroke Survivors' Association while in hospital. He felt that the programs were for seniors and was not sure if they were free. Further, he was interested in one-on-one therapy rather than for example, an Aquafit class, as he felt he would make more gains.

Sylvain did have the opportunity to participate in two outpatient programs. He felt these were very helpful but too short in duration. On discharge, he had not yet attained his mobility

goals and felt he needed more long-term follow-up. Sylvain had not investigated the cost of private physiotherapy yet.

Sylvain: I need, I need more therapy. I do. Like I need to keep working on my leg.

Interviewer: Do you have any idea how much it costs per hour a private physio?

Sylvain: No, I've been afraid to go and check.

When informed of the approximate hourly rate for private therapies, Sylvain reported being unable to afford physiotherapy or an alternative such as a personal trainer.

Return to work: Prior to the stroke, Sylvain was working part-time in a physically intense job. He stated that return to this job is unlikely because of his impairments. “J’voulais, j’voulais retourner au travail que j’avais. Un peu impossible avec le drop-foot.”

Sylvain has an alternative self-employment plan that he has been working on for several years now. He would like to open an eco-retreat, and he believes that if his mobility improves and if he can do some educational retraining, he may be able to bring this plan further ahead. However, he does not have the funds to pay for more physiotherapy, or to take the college courses that he feels would help him. He was hoping that ODSP would cover the costs of further schooling. “If ODSP covers, I would like to take a green business course that I’ve had my eye on. Maybe take some other courses like accounting and stuff like that.”

Angèle is aware of Sylvain’s plan, but feels he still needs some further rehabilitation or the involvement of a vocational specialist before trying to get back to employment of any type. She was not aware if vocational rehabilitation services were available to Sylvain in the publicly funded system but stated that he would not be able to afford it if he needed to pay privately.

Participate in festivals: Sylvain has been organizing and participating in medieval festivals for several years. He usually camps at the event and sells trinkets there. Since the

stroke, his ability to participate at the festival has been limited because he has not been able to afford entry fees or to buy the trinkets that he sells to offset the entry fees.

Sylvain: Euh, y'a un autre festival à fin du mois, ...euh m'a manquer l'festival parce que j'ai pas d'cash pour vend' pour vendre, des affaires de même. Habituellement j'vends, j'vends des choses pour les festivals. Ça couvre le coût. Mais j'ai pas le, j'ai pas l'argent pour.

Further, Sylvain usually camps at the events. He has tried setting up his camping gear and sleeping outside at a summer festival. He reported that he needed a great deal of assistance from friends to set-up his heavy gear and that sleeping on the ground was very problematic for him.

Sylvain: I think, my ideal camping, my friend just put up his trailer for sale, so I just asked him 'How much?' because I might, once I have a car, I might have to have a trailer hitch for the trailer because it will be easier for me to camp in a trailer than try to get off the bed, euh, off the ground.

His plan to address the problematic situation, purchasing new gear, or a vehicle and trailer, is too costly at this time.

Participate in social events: Sylvain explained that prior to the stroke, he enjoyed social outings such as going for coffee and organizing brunches at his apartment. He reported needing to rely more on friends now, for example, asking his friends to assist him with cooking and with cleaning the apartment before an event because he cannot afford to pay for such a service. "Pis astheure, comme, j'appelle [mon ami] une fois d'temps en temps, surtout les journées avant le brunch 'Hey pour le brunch tu peux-tu rentrer deux heures d'avance pour m'aider à nettoyer un peu?'" He also needs to rely on friends for free transportation to go to coffee or to other outing. He is limited in what he can afford as an event as well.

Eat healthy foods: Sylvain’s medical team indicated to him that he needed to adopt a better lifestyle in order to prevent further strokes. Sylvain understood that he needed to stop smoking, and he needed to eat more healthy foods, in particular vegetables. He stated that good foods are expensive. He reported a link between his income, his rent, and what he could afford to eat while on OW. “...[je fais] 700, mon loyer icitte c’est 500...so après, tu calcules 100 piasses de manger peut-être pour le mois, pis ça m’donnait...very little euh to survive on...” He stated that even on ODSP, because of his limited income, he often eats foods that are cheaper even though it is not good for his health. “Comme Jamaican patties. C’est pas bon pour la santé...” “...une boîte de...Jamaican patties. C’est 10 piasses, ça va m’faire beaucoup de repas...”

4.2.7.2.2 Patterns of influence on Sylvain’s experience of return to personal projects. The following five patterns of factors were identified: healthcare system, family and friends, physical environment, social services system, and knowledge about the “System” and understanding health. The pattern diagrams are shown in Appendix T.

Healthcare system: Sylvain’s experience of returning to participation in personal projects was influenced by the lack of assistance he received during discharge planning from the hospital, the guidance he received from the rehabilitation program for application to ODSP, the availability of public therapy services in the community, and by what portion of the return to driving process the system covers.

In the context of low income, discharge planning from acute care hospital was an important factor affecting Sylvain’s personal projects of living independently, getting equipment, and securing income support. Angèle indicated that her other sister tried to delay discharge because Sylvain lived alone and did not have the funds to purchase assistance or the

recommended equipment to support his safety, or to pay for his medications because he didn't have insurance.

Angèle: [Ma soeur] a l'essayé d'leur dire, 'Ben donne-nous au moins la chance de trouver de l'aide ou trouver une marchette, d'l'équipement propice pour la situation à mon frère'.

Interviewer: Pis y vous ont pas, est-que y, so y'avaient pas un papier qui disait son nom d'sur voici l'équipement qu'vous avez besoin?

Angèle: Y'ont donné d'l'information.

Interviewer: ...ou c'était juste tiens, vas-y, take care of it?

Angèle: Y'ont donné d'l'information, y'ont donné une prescription, mais y'ont pas donné de médicaments pour 24 heures. Là y'était avec la haute pression, y'était avec le cholestérol, y'était euh, y'avait des médicaments d'autres médicaments à prendre, puis, comme si y'aurait été à maison, qui s'qu'y'aurait été cherché ses médicaments? C'était le soir.

The medical records show evidence that Sylvain had informed acute care staff that finances were going to be a problem for apartment rent, equipment, and medication. Records show that he was provided with information about EI, but very little else.

While participating in the inpatient rehabilitation program, Angèle indicated that she and her sister had to guide Sylvain to initiate conversations about income support programs with the rehabilitation team. She felt that if they had not, Sylvain's project of securing income support would have been delayed because he required physical assistance with filling in forms, and neither he nor his sisters had the knowledge needed to complete the forms.

Interviewer: C'est pas [la travailleuse sociale] qu'y'a commencé ODSP pour disability?

Angèle: Non, c'est moi qu'y'a dit, pour le disability, j'ai dit 'Là quand tu vas aller à Bruyère, va voir, ça c'est l'enveloppe', parce que l'assurance, non, bien-être social nous ont donné un enveloppe pour le ODSP.

Interviewer: Uh huh. Est-ce que tu penses que ça l'a aidé qui l'a rempli à l'hôpital, pis pas comme à maison lui-même pis là y serait rentré?

Angèle: Y pouvait pas, y pouvait pas lui-même. Y peux pas écrire de sa main droite, y'est droitier. Pis y'avait, j'ai dit, j'ai dit 'Ça c'est un formulaire que moi j'connais pas', j'ai dit 'J'veux pas m'embarquer dans quêcke chose qui si y'est pas bien rempli, ça va, on va s'lancer la balle parce que qu'est pas bien rempli.'

Sylvain and Angèle felt that the team would not have offered assistance and guidance with the application to ODSP without their prompt, but they were, in the end, satisfied with the assistance they received. Sylvain's ODSP application was accepted nine months post stroke.

In terms of availability of publicly funded therapies, Sylvain had participated in all available therapies in the community by the third interview for the research project, but he had not yet attained his project of improved mobility, and he could not afford private services.

The *Clinique interprofessionnelle* medical records indicated that Sylvain was ready to attempt the return to driving examination, however, he was unable to cover the cost of the examination fee or of the needed vehicle adaptations.

Family and friends: Support provided by family and friends helped Sylvain in returning to several personal projects. His sisters provided assistance with getting equipment, obtaining income support, advocacy, organizing his home after the stroke, emotional support, understanding health and navigating the system. His mother also provided a long-handle reacher

and bus tickets. Sylvain stated that his sisters' approach, "being vocal", helped him navigate the system more efficiently— he specified that instead of waiting for instructions and information, his sisters actively sought the information and requested assistance.

With regards to his friends, Angèle stated that Sylvain had a great supportive circle of friends who helped him in many personal projects including returning to participation in festivals. "T'sais, euh, y'est allé à un festival que je sache cet été, même avec le stroke, pis le monde y'aidait, euh à marcher, parce que des fois c'est d'l'herbe. Fait que la marchette, ça marche pas tout l'temps bien dans l'herbe." Further, his friends have provided assistance with housekeeping, grocery shopping, transportation, and emotional support.

Physical environment: Sylvain's neighbourhood and the housing characteristics had an influence on participation.

Sylvain's apartment is accessible with his walker. He is able to get in and out of the building without difficulty, and to get around the main areas of his apartment. He is unable to use the walker in the bathroom, and his bathroom is too small for the over-toilet commode that was recommended.

Sylvain feels that his neighbourhood and his apartment set-up have been a facilitator for his all around ability to live independently. While there is a grocery store and a coffee shop in Sylvain's neighbourhood, his walking endurance is limited, and he needs assistance to get there. However, because of proximity to the shops, it is easier for friends in the building to walk over and help him obtain what he needs.

Social services system: Sylvain's experience of returning to participating was influenced by the rules and regulations of the different income support programs, and by the public transportation services.

Sylvain explained that the application process for the various income support programs was complex and that without assistance from his sisters in the early days following his stroke, he would not have been able to meet his basic needs or keep his apartment. Sylvain reported that even when he was accepted to the programs, difficulties continued because OW provided insufficient income to support basic needs (e.g., rent, food, and transportation to rehabilitation). Further, EI only provided support for 18 weeks before referring him back to OW. Sylvain stated that the transition from program to program (OW to EI and back to OW) created issues with continuity of services, in particular for equipment such as the walker. Sylvain also stated that in terms of his project of improving his health, some medical equipment was not covered by any of the programs (e.g., his doctor recommended blood pressure monitor).

Sylvain also stated that using the public transportation service has been challenging, particularly organizing rides and paying for the service.

Knowledge about the “System” and understanding health: Angèle explained that Sylvain’s understanding of his stroke and impairments and his knowledge of the system was very limited. She explained that her experience working in long-term care with stroke survivors was an advantage for her brother. For example, she was able to provide him with a lot of the teaching he required on discharge from hospital when she realized he did not know how to go about completing self-care activities in his home environment.

Angèle: ...je l’sais que y’avait d’besoin de plus de, de d’aide pour apprendre à quoi faire, quand l’faire, comment l’faire, embarquer dans l’lit, embarquer dans l’bain, comment se glisser sur l’siège de bain, comment se t’nir dans l’bain pour pas tomber, mettre des euh des strips antidérapantes dans l’bain, parce que si y’a l’pied trempe, y peut glisser dans l’bain, s’casser

quêcke chose, qu''était pas adéquate, qu'y'était pas une option pour lui comme c'est là, y'en avait assez. Mais toutes ces choses-là, c'est moi qu'y'a faite ça.

Angèle and her sister also had existing knowledge about the social service system, having both had personal experience navigating within it. Angèle stated that she also received further information from several friends. One friend worked at ODSP, and she cautioned Angèle about timelines and the possible challenges of being accepted to ODSP.

Angèle: Là j'ai une de, mes amie a m'a dit, 'Sois toi pas surpris', elle a travaille dans ça, a dit 'Soit pas surprise qui soit refusé le premier coup.' J'ai dit 'Tu dis ça pour?' Parce qu'y dit, 'Des fois sont refusés du premier coup pis faut qui rempli d'autres papiers qui manquent, pis de d'là, y, ça peut retarder que quand qui va tomber sur disability.'

Sylvain stated that his personal knowledge of the healthcare and social service system was very limited and that, on his own, he would not have been able to manage. He spoke of feeling overwhelmed with all of the information he received at different points of care and stated that he couldn't understand what was, at the time, relevant to him or not. He stated that it was beneficial for him to have sisters who knew how to sift through information, could help him understand his condition, and knew what services to request and when.

4.3.8 Daniel

4.3.8.1 Case Story. Daniel is a gentleman in his early 50s. At the time of his stroke, he was renting a room in a house and worked as a janitor for a school in a full time contract position. Although he has three children from past relationships, he is not close to his family, with the exception of his mother who lives out of the country. He has few friends.

Daniel had his stroke during the night, approximately one year ago at the time of the interviews. His landlady found him collapsed in the bathroom and called the ambulance. Daniel was admitted to an acute care hospital for about one month. His landlady Solange took charge of his situation, because no family or friends stepped in to do so. She became the contact person and POA while he needed help making financial decisions. She expressed that she felt that it was her religious duty and mission to help Daniel. Importantly, Solange, also from Haiti, speaks Creole and French but not English.

Daniel spent one month in inpatient rehabilitation and on discharge from this institution, he returned to his rented room with equipment rented from a second hand medical shop and a subsidized emergency call button. Solange cooked his meals, got his prescriptions, helped with housekeeping and self-cares (e.g., supervising showers, emptying his bedside urinal). At the time of the interviews, approximately one year after his stroke, Daniel was receiving income support from ODSP and was still depending on Solange for assistance with housekeeping and transportation, as well as for support with community events such as attending church.

4.2.8.1.1 Daniel's post-stroke body functions and structures, activity. Following his stroke, Daniel's impairments to body function and structures, and activity limitations included weakness of the right lower limb affecting balance and walking, right hand weakness, difficulties with writing, and mild difficulties with verbal expression. Daniel used a walker for outdoor ambulation, and expressed that his thinking and memory were not as good as prior to the stroke.

Daniel scored 57.5/100 on the SIS-16. He indicated that he was unable to do heavy housekeeping. He stated that dressing, walking without losing his balance, walking quickly, walking one block, and getting in and out of a vehicle were moderately difficult. He reported that washing himself, standing without losing his balance, going up one flight of stairs, and carrying

heavy objects with his affected hand were mildly difficult. On the ICF Participation Checklist, he reported light participation restrictions with watching, problem solving, and speaking. Moderate participation restrictions were reported for multitasking, participating in conversations, lifting and carrying objects, fine motor tasks, walking, using transportation, cutting foods, caring for others, economic self-sufficiency, and participating in leisure. Severe restrictions were reported for writing. Complete participation restrictions were reported for driving and working in paid employment. With regards to mental health, he scored within normal ranges on the HADS.

4.2.8.1.2 Daniel's personal projects: pre and post stroke. At the time of his stroke, Daniel was working full time. He was hoping to eventually open a restaurant. He enjoyed attending church, helping out in the community, as well as photography and house painting.

Following his stroke, his personal projects included securing income support, returning to some form of work, participating in ongoing education, attending social outings, resuming driving or being independent with community mobility, better understanding his health, and improving his general mobility and writing.

4.2.8.2 Influence of low income on return to participation

4.2.8.2.1 Daniel's personal projects. Daniel's eight personal projects are described through a lens of the influence of low income on his experience of attempting to return to participation. Diagrams in Appendix U show the events and categories that influenced the experience of return to his personal projects.

Secure income support: Daniel was employed full time as a janitor at the time of the stroke. Following the stroke, he was not physically able to do his previous job, and he needed to find a source of income support. Daniel was aware of the EI application process, and with the assistance of Solange, was able to organize this while in hospital. Daniel stated that while on EI,

he received approximately \$880 every month. “Euh...chômage ça me donnait...aux environs 400, 400 aux environs 440, aux environs ça, 440. Chaque deux semaines.” He received EI for four months, which did not cover medications. The social worker in acute care hospital assisted Solange to fill in paperwork for the Trillium program to cover medications while receiving EI.

Daniel, with the assistance of Solange, applied for OW. He already understood the system. “Euh...dès que tu, dès que tu ne travailles pas, dès que tu ne travailles pas, tu tu dois aller à Ontario Works.” Once EI was finished, having already applied to OW, he began receiving income support, which was \$625 per month. While on OW, he reported that finances were very tight because, in addition to rent and general living expenses, he needed to pay for a portion of his medications, and rental of bathroom equipment (bath chair at \$10/month).

Acquaintances had offered Daniel advice about ODSP and encouraged him to have the rehabilitation team assist with filling in the paperwork while he was still an inpatient. Daniel initiated the application to the ODSP and stated that the rehabilitation team helped him complete the forms. He was accepted to the ODSP months later. He was receiving approximately \$1150 per month at the time of the interviews.

Live independently: Prior to the stroke, Daniel was renting a room in a boarding house. He was responsible for his personal housekeeping and meal preparation. Following the stroke, he returned to his room where rent was \$450 per month. Daniel stated that his rent took up a large portion of his monthly income, which he felt was problematic, but he believed that he was unable to do anything about it. “Oui c’est c’est un problème pour moi, c’est un problème pour les autres. Je peux voir, je peux rien faire.” When asked if he knew about social housing programs, he responded that he did not. By the third interview session, Daniel stated he had spoken to friends, and he was planning on adding his name to the housing registry,

Daniel was able to manage in his room in the boarding home because of the assistance with housekeeping, personal care, and transportation provided without cost by his landlady Solange. He would be unable otherwise to afford such services.

Daniel also explained that, on his current income, he has not been able to pay for all his basic expenses and has been unable to maintain a cell phone. "...ils m'ont pas donné assez ça, assez d'argent pour survivre." "J'avais un téléphone cellulaire avant. Je l'ai pas encore, je l'ai pas encore renouvelé." He has been using Solange's landline as his own.

Resume driving and be independent with community mobility: Prior to the stroke, Daniel took the city bus and drove a car. Following the stroke, his driver's licence was suspended. "J'avais une voiture. J'ai encore une voiture qui est garée là. Mais euh...après mon ACV, j'ai, j'ai conduit plus parce qu'ils ont retiré la licence."

Daniel was aware that he needed to go through an examination process prior to resuming driving. He thought the cost was, at most, \$145 and that he could regain his licence in a regular driver's examination. When told that the average price for the return to driving examination, Daniel felt that it was too expensive for him to cover. "700? Je veux pas l'faire. Haha! ...700? Qui va payer pour?" He stated that paying for the driving examination would make him unable to pay his rent as well. "Non! Je j'aurais j'aurais pas, j'aurais pas payé mon loyer!... Je peux pas payer ma chambre."

Daniel had been taking the public disability bus service (Paratranspo) to get to therapies and to medical appointment. He reported that scheduling trips was challenging. "...parfois, vous avez pris le...vous avez, vous avez appelé Paratranspo, il peut te déposer, il peut pas retourner te prendre." "...c'est bizarre, mais c'est la réalité. Parfois, parfois ils peuvent me déposer au docteur et ils peuvent pas venir me prendre." The medical chart also indicated further challenges,

for example, an altercation between Daniel and a Paratranspo driver that needed the intervention of clinic staff – clinic staff helped Daniel make a formal complaint against the driver.

Daniel was of the opinion that the price of the subsidized pass was acceptable compared to the regular \$100 fee for a bus pass “41 dollars, c’est pas mal.” But he was not able to afford the pass every month, and he found taxis to be too expensive. Further, he has not been able to organize and pay for all transportation. Solange has been driving him to church and to community activities. She also picks up his prescriptions and groceries.

Solange: ...c’est comme, quand je vais à l’église si il avait besoin de le médicament, je vais à la pharmacie...

Interviewer: ...les épicerie pis les choses comme ça?

Solange: Non, c’était moi, c’est moi.

Improve health: Daniel stated that he had hypertension and diabetes for many years. He stated that he does not yet understand how to manage these chronic conditions, in particular diabetes. “Parce que je je je sais jusqu’à maintenant c’est une maladie que j’essaie de comprendre.” Since the stroke, he has been trying to improve his health, mostly by eating more vegetables. He stated that good foods are more expensive and difficult to afford.

With regards to medications, Solange indicated that while in hospital, she applied to the Trillium program so that he would have assistance with paying his medication while on EI and until he received ODSP. Now on ODSP with a drug card, Daniel stated that not all of his prescriptions are covered. He indicated that his family doctor prescribed aspirin and calcium, which are not covered by ODSP and neither are his insulin needles. “Et quand tu prends l’insuline, l’insuline est couverte, mais l’insuline est venue avec des aiguilles, les aiguilles ne

sont pas couvertes.” Insulin is new for Daniel since the stroke. Daniel stated that depending on the month, he could be charged more than \$40 for these items, which is difficult to budget.

The medical records indicated that Daniel was having difficulty paying for his medication even before the stroke because of inadequate medication insurance coverage while employed.

Return to work: Daniel worked full-time as a janitor, a physically demanding job. After his stroke, he has been unable to return to this employment. “Travailler? Je ne peux pas travailler maintenant.” Daniel had a plan to open a restaurant prior to the stroke, and he hoped to continue with this project with a friend to help him. “Parce que la cuisine c’est pas, c’est pas moi seulement qui va l’faire. J’ai quelqu’un d’autre.” The plan is to open the restaurant in a few years, however his low-income situation is delaying the process. Daniel stated that if he had more money, it would simplify the process “Si j’ai l’argent, j’fais, j’aurais mon restaurant.”

Participate in ongoing education: Daniel was planning, even before the stroke, to take a community program from the city to learn the basics of how to use a computer. He had already purchased a computer and felt that knowing how to use it might be a useful skill. “Je veux, je voulais avoir l’ordi c’est parce que euh...je si je connais un ordinateur, y’a beaucoup de choses que je peux faire.” The program with the city is free, and Solange has already offered to drive him to the classes. At the time of the interviews, Daniel had not yet started the course.

Daniel did not specify what further courses he would like to complete following the computer course, but he was clear in stating that he was planning to continue to participate in learning activities for the rest of his life and felt that income might influence his ability to participate in ongoing education in the future.

Improve mobility and hand function: Daniel indicated that he was still aiming to improve his general post-stroke mobility and hand function. At the time of the interviews, he was

participating in publicly funded outpatient therapy services, but these were coming to an end.

During the third interview session, Daniel stated that he had been discharged from the outpatient program but felt that he would benefit from, but could not afford, ongoing physical therapy services or a physical trainer. He stated that was searching for free gym memberships instead.

Solange did not know if further publicly funded therapy sessions would be available to Daniel. "... il en a un nombre de temps, ça veut dire, c'est comme si que, si si on va lui donner cinq semaines, alors c'est une session, alors ce que quand c'est fini, c'est fini." She believed that Daniel could not continue to participate in or request further therapy sessions once he was discharged from the *Clinique*. When informed that further treatment existed but would have a cost associated, Solange indicated that he would not be able to afford private sessions.

Solange: Donc euh, si si par exemple il a le moyen il voulait avoir plus peut-être il pourrait chercher trouver quelqu'un privé. Vous voyez?

Interviewer: Est-ce qu'il pourrait se l'payer ça?

Solange: Non! Hahaha!

Participate in leisure activities: Prior to the stroke, Daniel enjoyed many leisure activities such as photography and dancing. Since the stroke, he has been doing photography, walking to church in nice weather or to visit friends in the neighbourhood. He occasionally has gone for coffee. He stated that he has needed to limit all of his outings with a cost, and limit his spending on any leisure items he might be interested in. "...je peux plus sortir et trouver des affaires que je voulais acheter, mais je peux pas." "J'ai tout diminué, j'ai pas le choix." Solange also stated that Daniel was no longer able to go as often to the restaurant. "...ça veut dire que si par exemple un jour tu décides d'aller dans un restaurant, non tu peux pas y aller."

4.2.8.2.2 Patterns of influence on Daniel's experience of return to personal projects. Five patterns of influence were identified: healthcare system, social services system, friends and family, physical environment, and knowledge of the "System" and understanding of health. These are depicted in Appendix V.

Healthcare system: Daniel's experience of return to participation in his personal projects was influenced by discharge planning services, as well as the availability of publicly funded outpatient therapies, the coverage of the drug plan, and the cost of the driving evaluation.

Daniel's project of living independently was influenced by discharge planning decisions. Daniel stated that he did not participate in any discussions regarding discharge options. Solange stated she did have some conversations with the team, but she understood that the only option was for Daniel to return to his room in her house on discharge from inpatient rehabilitation. "Ça ça veut dire que c'est là qu'il habitait. Alors, si ...il était là donc, qu'est-ce que je peux faire? Rien. C'est là son appartement, ses affaires, ses..." She stated that no other options were discussed, such as long-term care, convalescence, or retirement homes.

It would appear that the inpatient rehabilitation team did not facilitate communication between Daniel and Solange regarding discharge planning, and some difficulties regarding assistance surfaced. Specifically, Solange wanted assistance from homecare, but Daniel declined. This resulted in Solange being responsible for activities such as shower supervision, personal laundry, and emptying Daniel's urinal, in addition to all housekeeping.

With regards to discussions about income replacement programs, acute care medical records documented that Daniel informed the team of financial concerns and that he was provided with information about EI. In rehabilitation, Daniel stated that he went to see the team to initiate conversations about income support programs prior to discharge. He felt that, had he

not initiated asking them for assistance with the ODSP application, this help would not have been offered.

Daniel: Dès que j'ai dit ODSP, c'est eux qui ont m'aider avec.

Interviewer: OK OK. Puis si vous aviez pas dit 'ODSP', est-ce que vous pensez que ça serait...?

Daniel: Non.

Interviewer: Vous pensez pas que ça serait faite?

Daniel: Non.

Once Daniel asked for assistance, he reported that the inpatient rehabilitation team was very helpful with filling in the forms and this resulted in timely acceptance by ODSP.

Daniel was able to participate in outpatient rehabilitation in two institutions, however, not all goals were fully attained by the end of these services, and he was unable to afford any private services.

Further, the healthcare system, through the drug plan with ODSP chooses what prescriptions are covered and which are not. In Daniel's case, he has several medication expenses every month, specifically his aspirin and calcium prescriptions, and his insulin needles.

Further, Daniel's ability to participate in his personal project of resuming driving was influenced by the fact that no portion of the driving examination or adaptations is covered by the healthcare system. Daniel stated that return to driving is unaffordable for him.

Social services system: Daniel's experience of returning to participation in several personal projects was influenced by the rules and regulations of the different income support programs he accessed, the waitlist for social housing, and the public transportation services.

Daniel had knowledge about existing income support programs and how to access them. He was able to request assistance from Solange for the applications to EI and OW, and from the rehabilitation team for ODSP. He stated that income variations from one program to another were challenging (from EI to OW, and then to ODSP). In particular while receiving support from OW, he had great difficulty meeting his basic needs. Although he has been receiving more income from ODSP, in his own words, he reported that the amount was still not enough to “survive” on.

Daniel informed himself about the social housing program in the city, and he is planning to put his name on the waitlist. The long waitlist means he will need to continue to live in his current place, likely for several more years.

The disability transportation services have been difficult to use and costly, therefore Daniel has been relying on Solange for transportation assistance.

Family and friends: Daniel had some family in the area - an ex-wife and some children. However, his relationships with them were not close, and they did not offer to care for him post stroke. The only person who offered to assist was the landlady/housekeeper where he was renting a room. Solange assisted Daniel while he was in hospital by bringing clothes and needed items back and forth and helping deliver forms for EI and OW. For a period of time, Solange was also his POA for financial decisions.

When Daniel was discharged from inpatient rehabilitation, Solange provided free assistance with self-care activities (supervising showers, doing laundry, changing bed sheets, emptying his urinal in the morning), preparing meals, and assisting with medication management. She also she did all housekeeping. At the time of the interviews, Daniel had

progressed to being independent with his self-cares, however, Solange continued to provide assistance with all housekeeping, transportation, groceries, and medication pick-up.

Physical environment: Daniel's physical environment, specifically the house and neighbourhood where he lives influenced his participation in several personal projects.

The characteristics of the home where Daniel lives have been a bit problematic in that there are several steps to get in and out of the home. According to the medical records, Daniel has fallen on the stairs. As well, initially when he got home, the narrow hallways and rooms made it impossible to use his walker inside. He has since progressed in his mobility and is able to manage without the walker inside the home.

Daniel feels that he lives in a friendly neighbourhood. He is within walking distance to the church and the coffee shop. He also knows the public bus routes in his neighbourhood, which has been helpful in terms of community mobility.

Knowledge of the "System" and understanding health: Daniel's personal projects of living independently, securing income support, and improving health were influenced by knowledge of the "System" and understanding of health. Daniel had limited knowledge of the income support programs and no experience with social housing or discharge options from the hospital. He also had limited understanding of his post-stroke health.

Daniel had some pre-existing knowledge about income support programs (OW and EI), but benefited from the knowledge of friends. They informed him about the ODSP application process, and this eventually helped him access ODSP in a timely manner.

Daniel however had limited knowledge about other social service programs such as social housing. He felt that housing was expensive for him; however, he was initially unaware of the

existence of social housing programs and of how they worked. He was able to obtain information from friends, but he was poorly informed about the waitlist length and the priorities.

As well, Daniel stated that at the time of discharge from inpatient rehabilitation, he did not meet with the team or with Solange to discuss discharge options. He specified that he did not know that other options might have been available or how to access them, such as convalescence, because, as he clarified, it was his first time in hospital.

Interviewer: ...est-ce que vous auriez voulu quelque chose de différent [comme lieu de congé]?

Daniel: ...je j'ai pas, c'est la première fois que je suis à l'hôpital.

Interviewer: Right OK. Alors pour vous, vous aviez pas...

Daniel: Non.

Interviewer: ...vous saviez pas qu'est-ce qui était possible.

Daniel: Je...pas non.

With regards to understanding his health, Daniel reported that since the stroke, doctors have sent him to a clinic to help him manage his high blood pressure through nutrition, however he felt that the information he was provided was of little use. He indicated that he wanted more help with understanding and managing his diabetes and more information on how to prevent another stroke. He stated that he has so far not received any of this education, and he specified that education would need to be personalized to his needs for him to better understand.

4.3 Intra-case Analysis: Linguistic Minority Context and Post-stroke Participation

This section aims to answer the second research sub-question: *How do francophone minority stroke survivors experience their attempt to return to participation?* This question is addressed by describing how the cases self-identified in terms of official language groups, their

perceived language abilities, and the language of services received in the health care system following the stroke. Communication challenges, opportunities received for francophone community services, and the perceived impact of language on participation in personal projects is also described.

4. 3.1 Charlotte

Charlotte's mother tongue is French. She started learning English with her first job out of high school and continued working in English up until her stroke. Charlotte self-identifies as bilingual, and places value on this as a skill. "Ben moé j'aime ben dire bilingue parce que... c't'important pour tout le monde, moi je pense, d'être capable dans les deux langues là t'sais?"

On the self-assessment of abilities in both French and English, Charlotte met the French and English bilingualism criteria. During the interview she spoke about how French is often a more complicated language compared to English (e.g., sentence structure). She also expressed how she feels she has a limited vocabulary in French because of her education level and of her years of working in English. "...j'ai pas le vocabulaire que la langue français a besoin..."

In terms of healthcare and social services following the stroke, Charlotte requested services in both English and French, rather than in only one language.

During the acute care period, the medical records indicate that Charlotte was experiencing aphasia and that she had requested Speech Language Pathology testing in both official languages. Charlotte stated that French was not necessarily easier for her. "...drette après mon AVC, c'est que j'travaillais en anglais, alors, l'anglais ...c'tait plus facile que le le français." She also indicated that she experienced aphasia in both languages, and that both languages were mixed up for her.

Charlotte: ...dans ma tête, ça faisait pus de sens, anglais, français, y'avait pus euh...Faullait que je con...concentre beaucoup pour dire 'OK, ça ça veut dire, c'est ça là', t'sais?

In the first outpatient therapy program that Charlotte attended, services were provided in English, and she expressed that language didn't affect her rehabilitation services because she understood staff. Services were provided in French in her second outpatient program. Charlotte also indicated that the social services she received were in French, specifically services from Ottawa Housing. Her family doctor is francophone as well.

When asked if she thought there might be an advantage or disadvantage to being francophone, Natalie stated that she felt that there was no difference because of bilingualism: "J'pense pas qu'y'aille de, j'pense pas. Mais moé, j'ai pas vu de différences...[...] ...Pas pour le langage toujours, mais t'sais...on est bilingue fait que...on saute de l'anglais au français."

In terms of return to participation in personal projects, Charlotte's projects of improving mobility and communication and understanding health seem to have been influenced by linguistic minority status.

First, with the project of improving her mobility and communication skills following her stroke, Charlotte, as a francophone, was eligible to participate in further outpatient treatment at the *Clinique interprofessionnelle* designed to reach minority Francophones in the region. In addition to providing therapy services, the *Clinique* also gave her some information when she was having difficulties with her daughter (e.g., phone number for crisis line). Had she been unilingual Anglophone, she would not have been eligible for these *Clinique* services.

Second, when trying to attain her project of understanding her health. Charlotte spoke of the difficulties she experienced understanding professionals using "big words" in French or

English. She often felt that the French vocabulary that professionals used was not the French that she could understand. It was too complex or jargon-filled. Aphasia may also have affected Charlotte's ability to understand health information, for example, she could not initially read the stroke documentation provided to her in rehabilitation.

Although French was her mother tongue, Charlotte preferred flexibility between English and French in particular because of her aphasia. Level of language (e.g., vocabulary) was also often problematic for her understanding. As a French speaker, she had access to the *Clinique interprofessionnelle*, which positively influenced participation.

4. 3.2 Paul

Paul's first language is Creole, and he learned French and English in Haiti. He went to college in Canada, both in English and in French. He self-identified as bilingual in both official languages; his son agreed that his father was bilingual "Mon père est... bilingue." On the self-assessment of level of bilingualism, Paul met the French and English bilingualism criteria.

In terms of healthcare, Paul indicated that he received services in English in acute care, but that this worked out for him. "Dans mon cas à moi, ça fonctionnait quand même. Étant donné je suis assez fonctionnel en anglais. Ça bien été."

Paul reported that he was offered, and he chose, services in French in the slow-stream and regular rehabilitation programs he attended before being discharged. "Si on me donne le choix, je vais sauter sur le français!" There were a few professionals who could not speak French, but Paul felt that this was not a problem because of his level of bilingualism "Parce que je suis bilingue. Assez bilingue, Dieu merci, je n'ai pas de problèmes avec ça." Services were also provided in French at the *Clinique interprofessionnelle* and in English when he returned to outpatient stroke rehabilitation. In terms of social services, workers with the ODSF provided

French services. However, some social service correspondence was sent in English, which he would have preferred in French: “Comme la lettre que je viens de recevoir [du Ministère des transports], j’aurais préféré qu’on me l’envoie en français.”

When discussing language and vocabulary, Paul felt he had no difficulties in French but preferred that the speaker not use jargon when speaking in English or when conveying an important message “Jargon en anglais, on met ça de côté. Message important... je ne veux pas de raccourcis. Faut dire tout, avec les mots de vocabulaire que je connais.” There are several entries in the various medical records that show that some attempts were made to explain different aspects of health and the system, in French and English, however, much appears to have been misunderstood. For example, the dietician at the *Clinique interprofessionnelle* reported that on discharge from her services, Paul still had difficulty managing his insulin and glucose tests at correct times.

As a Francophone in Ottawa, Paul was eligible to take part in the rehabilitation services offered in French at the *Clinique interprofessionnelle*. Language may have therefore indirectly influenced the personal projects of improving mobility and return to driving. First, by participating in the clinic therapies, Paul had the opportunity to participate in additional free therapies, which may have supported his efforts to attain improved mobility. Second, the clinic provided Paul with important information regarding the examination process for resuming driving, information that he had not obtained or understood beforehand.

Paul’s mother tongue was Creole, and although he would have preferred services in French, receiving services in English was reportedly not an issue. Level of language (e.g., vocabulary, jargon) was however problematic, and professionals often did not adapt their

language to meet Paul's needs. Language positively influenced return to participation in that Paul had access to the regional *Clinique interprofessionnelle*.

4. 3.3 Jackie

Jackie identified herself as bilingual. Her brother clarified that Jackie grew up in the province of Quebec with a French family and was able to communicate in both official languages. As far as he knew, prior to the stroke, Jackie spoke French and English at work and with friends. When asked which she preferred, Jackie indicated that there was no difference. In terms of her self-perceived language abilities, Jackie met the bilingualism criteria.

Following her stroke, medical records indicate that Jackie was experiencing severe expressive and mild-moderate receptive aphasia. Jackie received services in English in acute care and initially in rehabilitation as well, until staff became aware that she was bilingual. At that point it appears that bilingual services were offered. Speech therapy treatment was however carried out in English. She received services in French in convalescence care, and bilingual services at the *Clinique interprofessionnelle*. Jackie expressed that she was thinking in both languages at once.

Interviewer: OK. Was it easier or more difficult, after the stroke...

Jackie: Oh ya...

Interviewer: ...because you are bilingue?

Jackie: Oui, oui.

Interviewer: OK. Why was it harder...

Jackie: Because hmmm.....I ...

Interviewer: Was it mixing up?

Jackie: Ya.

Interviewer: Français, English, Français, English...

Jackie: Oui. Yes.

Luc and Marilyn indicated that Jackie had been using French and English interchangeably, and this, in combination with the aphasia, may have caused miscommunications. Marilyn gives the example of a recent assessment with homecare (CCAC) where Jackie was answering English questions in French, with little reliability.

Marilyn: I just sat with CCAC last week? And...it was the first time I had ever seen her...She is usually like 90% on her yes, no, and it was...everything was off. Every single question. And she says, CCAC care coordinator says to her “Do you have any pain?” and she says... “Là, là, là,...” “Do you speak French?” “Non.”

Luc and Marilyn reported that speaking in both languages has been problematic for them as well in terms of understanding Jackie and supporting her communication.

Marilyn: ...she speaks as much English as French right now, which is limiting...

Luc: But she'd do that right? Because...she'd speak to you in English but when she got mad at ya, or pissed off, she'd start going in on ya in French.
Right? Like she's always used both languages interchangeably I guess.

With regards to the influence of language on the experience of return to participation in personal projects, Jackie's care partners perceived that being Francophone in Ottawa was an advantage as it allowed Jackie access to services that she would otherwise not have been eligible for. Jackie had the opportunity to take part in the rehabilitation services offered in French at the *Clinique interprofessionnelle*. Luc explained this advantage in terms of therapy sessions “I would say it has helped her, because those 20 extra weeks of physio through the university...,

she wouldn't have gotten that if she wasn't a francophone. And OT. And Speech.” Jackie's project of improving mobility may therefore have been indirectly influenced by language.

French was Jackie's mother tongue, but she required services in both French and English to meet her needs as a bilingual person with aphasia. Language influenced return to participation because Jackie had access to the regional *Clinique interprofessionnelle* services.

4. 3.4 Laurent

Laurent grew up in a bilingual neighbourhood in Ottawa. His first language was French, and he attended primary school in French. Laurent describes his French as slang. “Moé, parce moé j'parle un français slang qu'y'appellent. Slang French là t'sais? Nous autres d'où c'qu'on été élevé là...t'sais?”

Laurent stated that he had great difficulties in school with reading and writing. He did not go beyond grade 7-8. As a young adult, he tried again to learn to read and write without success. As he understood it from the specialists he consulted, he had a learning disability that affected his literacy skills “Pis après ça lui m'a dit que j'tais v'nu au monde avec quechose en haut là, dans ma tête, ma brain. Ma brain là? Mais j'connais pas ça moi là...Qu'y'avait quechose, là là qui m'empêchait de faire ça.” He stated that he learned English as a child playing with the Anglophone kids in the neighbourhood, but really became comfortable with the English language after he married an Anglophone and spoke English at home, even with the kids, and worked in English as well.

Laurent : Ma femme était anglaise. Fait qu'mes enfants y'ont été élevés ben en anglais. Y parlaient pas français à maison. Ça fait que...Pis là ben...c'est pareil comme moi, aussitôt que...quand j'ai été travailler pour les

compagnies d'gaz, c'tait tout' en anglais. J'vivais dans l'anglais à journée longue pis, l'soir à maison, n'importe quoi...

With support from his wife, he was able to eventually learn to read a few words in English but continued to have difficulty reading formal English, for example medical letters.

Laurent: Euh...le seul temps que j'ai vraiment des problèmes avec l'anglais, que c'est pas vraiment un problème, c'est si y'a des mots... comme j'dis, j'vas, j'vas r'garder une lettre de docteur, m'a lire pis y'a y'a des mots que j'sais pas, même pas qu'est-ce ça veut dire.

Laurent self-identifies as French and English bilingual. "Moi je suis bilingue. J'parle les deux langues." On the assessment of self-perceived language abilities, he did not meet the criteria of bilingualism – he scored himself 7/16 in the French language and 8/16 in English.

Laurent stated that often he didn't understand the words or terms used by medical professionals. "Fait que...les mots qu'y usent là t'sais? Euh...Le docteur m'a donné euh...je l'ai ici...le rapport quand j'ai eu le stroke. Devrais voir les mots là d'dans!" Armand reported that Laurent has relied on family to read written documents to him, as well as relied on his family to explain different complex verbal messages from medical professional to him. "...là j'disais 'OK, ça ça veux dire ça ', pis là j'le traduisais moi en anglais, j'disais ça ça veux dire ça en anglais." His brother Armand stated that at times choice of language would not have improved Laurent's understanding.

Armand: OK, si y'avait un terme qui comprenait pas. Euh, à d'autres tantôts, euh, y'a peut-être des certains médecins qu'y'auraient peut-être dit c'est quoi en anglais, pour voir si y'l'comprenait en l'anglais ou si c'était un terme médicaux que anglais, français là, c'est c'est c'était tout' du chinois.

Medical records also show evidence that Laurent did not always understand information given to him : “Questionnons sa compréhension des instructions et conversations médicales (i.e. du médecin concernant conduite, inquiétudes/recommandations [ergothérapie et physiothérapie]).”

While in acute care, Laurent requested his services in French and cognitive testing in English. He received outpatient treatments in both languages, as he requested.

Laurent and Armand felt that being bilingual was an advantage because it did not exclude Laurent from any services, and in particular, being Francophone gave him access to the Francophone outpatient *Clinique interprofessionnelle*. According to Laurent, services at the *Clinique* were beneficial in helping him attain his personal projects of resuming driving, in helping him understand his stroke, and in supporting his attainment of his project of managing diabetes. Laurent indicated that his diabetes had been uncontrolled for many years and that he was now independent to manage it as a result of the services he received.

Laurent’s mother tongue was French, but he did not want all his services in French. He preferred flexibility between the two languages, and, depending on the activity, often felt more comfortable in English. Level of language (e.g., vocabulary, jargon) was also often problematic, and professionals did not adapt their language to meet Laurent’s needs. Language influenced return to participation in that he had access to the regional *Clinique interprofessionnelle*.

4. 3.5 Aimée

Aimée grew up in Haïti and Creole was her first language. She learned French as a second language. Aimée identifies as a Francophone. On her self-assessment of French and English abilities, she did not meet the bilingual criteria for French and English, as she reported

having no English language skills. Aimée's husband does not speak any English either, and speaks minimal French. Their children provide translation services as needed.

At the time of the stroke, Aimée was admitted to a bilingual hospital and received all of her services in French, she also received French services with every subsequent service, including homecare in the community. Aimée specified that all healthcare professionals she has encountered have been French speaking, with the exception of her Anglophone family doctor when she initially arrived in Canada. She has, this year, been able to transfer to a French-speaking family doctor.

Even when receiving services in French, Aimée's daughter accompanies her mother to all appointments. Marie stated that she senses that her mother does not comprehend all the medical terms and concepts and is unsure whether this is a question of education or language (French versus Créole).

Marie: Oui, mais les termes...ils n'auraient pas pu comprendre les termes médicaux, parce que c'est pas des gens vraiment ...scolarisés.

Interviewer: Même si c'était en français?

Marie: Oui, en français. Parce qu'il y a certains termes, ou bien qui, probablement qu'y comprenaient pas, parce que en Haïti, ils allaient chez leur médecin, seuls. Donc ils prenaient la voiture, ou bien un taxi, ils allaient chez le médecin donc, ils parlaient, donc le médecin parlait créole...

Interviewer: ...il pouvait expliquer les choses?

Marie: ...il pouvait expliquer les choses donc maintenant, ici, non. Donc c'est sûr qu'on qu'on on s'attend pas que les médecins parlent créole, mais...au moins que quelqu'un ait un médecin francophone.

Aimée specified that French is her second language and, she confirmed that at times, she does not understand words in French. She would prefer to have services in Creole if these were available.

Interviewer: Est-ce que ça serait plus facile si le médecin parlait créole?

Aimée: Ah oui! Haha! Bien sûr.

Interviewer: Alors ça fait quand même une différence parce que le français, c'est pas votre langue maternelle.

Aimée: Oui.

Interviewer: OK. Alors ça serait encore plus facile si tout le monde parlait le créole avec vous.

Aimée: Oui...Ah oui.

Marie felt that being French speaking may have given her mother extra opportunities that influenced personal projects, for example, taking part in therapies at the *Clinique interprofessionnelle* and in the Francophone day program. Marie pointed out that her mother's inability to speak English has meant that she and other family members have needed to support her for participation in community outings. For example, Aimée needs to be accompanied when shopping because cashiers at stores in the region are generally only English speaking. As well, any assistance that comes in the home to help her mother must be Francophone, which might limit choices but has not been an issue so far.

Aimée's mother tongue is Creole and she spoke French. Aimée would have preferred services in her mother tongue, but she was able to communicate in French with professionals. However, she required support from her daughter to better understand. Access to services from

the *Clinique interprofessionnelle* was noted to be a benefit to her experience of return to participation.

4.3.6 Josée

Josée identified as bilingual. She was raised in French and went to Francophone primary and high schools. She completed her university studies both in French and English. Her fiancé was unilingual Anglophone. Most of her friends are also Anglophone. Her mother, Denise, stated that Josée was fluent in both official languages. “C’était vraiment juste la façon...elle était tellement bilingue, parce que les jeunes d’aujourd’hui y vont...y changent de langue en plein milieu d’la phrase, pis personne fait d’cas right? Moi aussi!” On the language ability self-assessment, Josée met the criteria for French and English bilingualism.

While in acute care, Josée’s parents could understand both languages therefore services were given in English to accommodate Josée’s Anglophone fiancé at the time. Inpatient rehabilitation and outpatient rehabilitation were given in both English and French. Denise stated that in the weeks following her stroke, Josée expressed herself in English and French as if it was one language. She could not tell which one she was speaking. “Au début, pour elle, c’était une langue.” Josée specified that she has had no difficulties understanding either French or English.

Interviewer: ...est-ce que tu comprends toujours ce que les anglophones te disent?

Josée: Yes.

Interviewer: Pis les francophones aussi?

Josée: Ouais.

When asked which language she would prefer to receive health services in, she responded English because it was easier to speak and is the language that her friends speak. Her mother

further added that it is the language of the majority, and speaking English can be seen as an advantage in everyday life.

Interviewer: Toi, si tu avais le choix. Tu veux que quelqu'un te parle en français ou en anglais à l'hôpital?

Josée: Like là...

Interviewer: OK, pourquoi?

Josée: Parce easy like, around, like always friends. T'sais? Maybe là mais all like...

Denise: Ouais, ta famille est francophone, mais tout' le reste du monde est anglophone.

Josée: Exactly.

Interviewer: OK. Pis pour toi c'est plus facile?

Josée: Ouais. Oui. Oh my god oui.

Denise: Pis c'est plus pratique. Juste parce que t'as plus de chance de rencontrer quelqu'un qui parle en anglais que rencontrer quelqu'un qui parle en français.

Denise stated that she believed that the language of services was not as important as the listener being able to understand both French and English during treatment because Josée was unable to speak only one language at a time.

Denise: Parce que a l'était tellement bilingue que a sait même pas dans quelle langue tu lui parles.

Interviewer: Oui, oui, alors c'est important que l'intervenant puisse parler les deux.

Denise: C'est, c'est, c'est important que quand t'as, a s'met à parler en français, que l'autre comprenne de quoi tu parles, t'sais?

Denise felt that being a bilingual person with aphasia likely made it more difficult to regain language. However, she believed that bilingualism was an advantage in terms of aphasia because she may be able to figure things out, language wise, with both language groups.

Denise: ... a sait pas dans quelle langue qu'a parle, mais d'un autre côté, qu'a rencontre un anglophone, ou un francophone, ça fait pas aucune différence. C'fait que a peut retirer des deux langues. T'sais? So, a l'a plus de monde à qui a peut parler, a peut s'débrouiller plus facilement, a... Fait que j'pense en quelque part, a l'a plus, justement parce qu'a l'est bilingue.

In terms of language specific opportunities, Denise felt that being Francophone was an advantage for Josée because she was able to participate in treatment in health services specifically for Francophones. "...j'pense que ça l'a aider, parce que y'a des services pour les francophones qui sont pas disponibles pour les anglophones." Denise also specified that as far as she knew, low-income Anglophones did not have similar opportunities. Denise also highlighted the fact that it is the *Clinique interprofessionnelle* that referred Josée to the hospital outpatient communication clinic and that, had she not had the specific opportunity to received treatment with the *Clinique*, this ongoing therapy would not have been possible.

French is Josée's mother tongue, however, as a bilingual individual, she preferred receiving both French and English services, in particular because of the aphasia she was experiencing. Language positively influenced return to participation for Josée because she had access to the regional *Clinique interprofessionnelle*.

4. 3.7 Sylvain

Sylvain considers himself bilingual. He grew up in a French household, attended primary school in French and college in English. He was in an Anglophone military unit and has mostly Anglophone friends. In terms of his self-perceived language abilities, Sylvain did not meet the assessment criteria for French and English bilingualism; he scored his English skills as better than his French language abilities. He explained that although he understands French “beaucoup”, he felt his vocabulary in French was limited, in particular for conversations using medical terms. “...blood pressure en français j’sais pas c’est quoi.” Because of this, in hospital, he requested English documentation and forms because he felt that French wording was particularly difficult to understand in written material provided by the hospital.

His sister Angèle agreed that Sylvain could understand both French and English equally but stressed that Sylvain understood basic everyday language and that the French language of the “educated” would not be understood “Parce que le gros français, éduqué, éduqué, c’est pas lui.” She further clarified that if someone were trying to explain a health concept to Sylvain, language choice (English versus French) would make little difference on his ability to understand. “... ça aurait pas passé mieux ni l’un ni l’autre.” She stated that in such situations, he needs someone to explain it to him in a very simple way “Y faut, y faut trouver du monde qui sont capables de leur parler terre à terre...”

With regards to the language of services, he received services in English in acute care. He explained that he did not need services in French and did not request it. He felt he understood both languages equally well. “Euh, pis j’avais j’avais pas vraiment de need que l’monde me parle en français. J’comprends l’anglais aussi ben que l’français.” In outpatient rehabilitation, he also stated that he had no preference for English or French services.

Following the stroke, he experienced speech difficulties. Sylvain indicated he was slurring only in English, and not when speaking French. Word finding was equally difficult in both languages. In outpatient rehabilitation, his speech therapy was in English. He initiated his own exercises in French himself in the evening.

Interviewer: [L'orthophoniste] a faisait ta thérapie en anglais?

Sylvain: Ouais.

Interviewer: Pis toi tu la faisais un peu en français toi-même?

Sylvain: Ouais, des des personnel choses, euh j'faisais en français. Comme a-o-i-o-u.

Angèle stated that Sylvain was really comfortable with both English and French and agreed that the language of services was not an issue. She felt that being bilingual was useful when he could not find a word in one language. As a Francophone, Sylvain felt that language had not influenced his general experience following his stroke.

Interviewer: Alors pour toi, c'est vraiment toute la même chose, la question de ...la langue pis tout' ça, ça rentre pas dans dans ton expérience vraiment là.

Sylvain: Non, non. Pas vraiment.

Sylvain however understood that he was eligible to participate in therapy at the *Clinique interprofessionnelle* because he was Francophone, and felt that this extra therapy was an advantage in that it helped move him forward in his personal projects of improving mobility, living independently, and returning to driving.

As a French and English bilingual individual, Sylvain preferred receiving services in both official languages however, he felt that the level of language, particularly in French, was often

too elevated. This reduced his ability to understand the professionals or written materials.

Speaking French was an advantage for return to participation because of access to the *Clinique*.

4. 3.8 Daniel

Daniel's mother tongue is Creole. He completed his schooling in Haiti in both French and English. He attended university and college in English in the United States, and worked in English both there and when he immigrated to Canada. His current friends and church community are Francophone. Daniel identified as bilingual, and met the language assessment criteria for French and English bilingualism.

Following his stroke, the *Clinique* records indicated that he had mild issues with receptive comprehension for complex messages, and difficulties with language in terms of being understood. Daniel specified that when he did express himself, he did not mix both languages "...Ah si, en anglais c'est en anglais, quand c'est en français, c'était français."

He stated that while in hospital and in rehabilitation, he received services in English and in French, and that for him, there was no difference. He stated that if a clear choice between services in either language had been offered, he would have chosen French. He further specified that receiving services in Créole would have been even better as it is his mother tongue.

Interviewer: Puis le Créole, ça serait encore plus confortable? Ça serait encore mieux?

Daniel: Oui. Parce que il y a, le créole c'est ce que ta mère te parle.

Importantly, his care partner Solange spoke only French and Creole. She indicated that her English was extremely limited. At the acute care hospital, she said French services were difficult to obtain, but she received them. She stated that services in French were easier to obtain in the inpatient rehabilitation centre.

Neither Solange nor Daniel was able to identify advantages or disadvantages of being Francophone with regards to his experience of returning to personal projects. However Daniel acknowledged that he did have access to the *Clinique interprofessionnelle*, which offered him therapy for mobility and for hand function, advanced him in his attainment of the related personal project.

Daniel would have preferred services in Creole, his mother tongue, or French. However, he felt comfortable receiving services in either official language. Speaking French gave him access to services with the *Clinique*, which influenced return to participation.

4.4 Cross-case Analysis

The following section is an analysis of the eight cases together, as a whole, looking at the similarities and the differences in terms of cases but also patterns of influence. This inter-case analysis is organized according to the conceptual framework and addresses the main research question: *How does low income influence the experience of return to participation for Francophone stroke survivors living in a linguistic minority situation?* Only those factors related to the situation of low income and language, and that could be compared and contrasted between cases are addressed.

4.4.1 Stroke survivor personal factors:

Age: Laurent and Aimée were already receiving government pensions and medication funding at the time of the stroke because they were over 65 years old. Age was a facilitator as the other participants had to apply for income support and medication coverage post stroke.

Language: In general, having French as a first official language was an advantage for all participants in that they were able to access additional community therapy services, which supported all of them towards attainment of many of their personal projects. None identified

issues with the language of services provided to them from within the healthcare system, although two of the bilingual survivors would have preferred services in French or Créole. Several felt that being bilingual gave them access to both French and English services and resources compared to those who only speak French. Not speaking English can be a challenge for participation when it involves interacting with the general public, for example in a store, as has been the case for Aimée since living in Ottawa where English is the majority language.

Level of language, for example use of jargon and standard vocabulary, was also stated as a factor affecting the stroke survivors' understanding of the professionals and written materials within the healthcare and social service system.

The experience of aphasia following the stroke also presented a particular challenge in terms of language of services for Charlotte, Jackie, Josée, and Sylvain. They considered themselves bilingual, and felt they required speech therapy for their aphasia treatment in both French and English rather than in just one or the other language.

Knowledge and understanding of own health and “system”: All the stroke survivors had limited knowledge of the healthcare and social services systems prior to the stroke. Difficulty developing this understanding after the stroke was a barrier to return to participation. They needed to depend on the resources in their environment to get the information they needed and not all care partners had this knowledge.

4.4.2 Stroke survivor micro-environment:

Family and friends: Although the type and level of assistance provided was different, every stroke survivor depended on either a family member or friend who facilitated return to participation. For Charlotte, family was a barrier to return to participation, whereas friends became the facilitators.

Community and neighbourhood: Charlotte, Paul, Jackie, and Josée did not return to their pre-stroke homes, and were limited in their housing options because of income. Charlotte lived in two neighbourhoods that were barriers to her participation, and then lived in a homeless shelter before being able to relocate to a neighbourhood downtown that facilitated participation. Paul continues to have no fixed address in either Ottawa or Montreal. Jackie lives in a retirement home far from social supports and inaccessible to the shops – her neighbourhood has been a barrier. Josée relocated to a condominium purchased by family, in the same neighbourhood as her family and friends who support her participation. Sylvain, Daniel and Aimée returned to their previous neighbourhoods, which were generally facilitators of participation because of proximity to areas they visited and to social supports.

Physical characteristics of the home environment: Charlotte's current home is physically very small and has been a barrier to participation. Paul has lived in many different homes and apartments; the majority were not a good match to his abilities, therefore were also a barrier to participation. Josée, Sylvain and Daniel's home environments may have posed some issues initially following the stroke, but at the time of the interviews, their homes were no longer a barrier to participation. Jackie's physical environment has been a facilitator of participation in terms of physical accessibility, however, extra services at the retirement home, which are too costly, would further facilitate participation. Aimée's apartment posed some issues in terms of the kitchen size but was otherwise not a barrier to participation. She is experiencing many more barriers since temporarily living at her daughter's home.

Access to housing: For all the stroke survivors, cost of housing (rent) was a direct or indirect influence affecting participation in projects. For Charlotte, housing was initially a barrier, but was later a facilitator of participation when she moved in to social housing; here she

pays less for housing, leaving more resources to spend on her personal project. For the others, housing is a substantial monthly expense that limits availability of money for personal projects.

4.4.3 Stroke survivor meso-environment:

Healthcare services and healthcare system: Discharge planning services provided by the healthcare teams, in the context of low income, influenced the experience of return to participation, specifically as they related to the stroke survivors' need to relocate and to those who needed to access income support.

For those who needed to relocate, Charlotte, Paul and Jackie, the first option suggested by the healthcare teams was to move in with family, this was done with, it appears, little consideration of the long-term implications. Relocation with family did not work for Charlotte or for Paul; their families did not have the resources to help them in the long term, and the teams did not provide assistance with alternate planning (e.g., help with applications to social housing for the future). When Jackie's family made it clear to the team that she could not live with them, they received little assistance with finding housing. Laurent, Aimée, Josée, Sylvain, and Daniel were not involved in any real discussions about discharge or housing options.

Timely access to income support was linked to the level of assistance provided by the healthcare teams with the application process. All those eligible to apply to EI did so all with assistance from family and friends. Charlotte, Paul, and Josée left inpatient care, and outpatient services, without information about, or assistance to apply to ODSP. Those who received formal assistance, Sylvain and Daniel, had informal supports that had informed them of the need to initiate the process while still actively receiving services from the healthcare system. Jackie's family had a different process to go through which first involved insurance benefits. Laurent and

Aimée were already retired at the time of the stroke, and were not eligible to apply to any other income support programs.

In the context of low income, what was covered by the healthcare system, specifically outpatient community therapies, prescription medications, equipment, and driving examinations and vehicle adaptations, influenced the experience of return to participation.

For the majority of cases, with the exception of Charlotte and Laurent, the stroke survivors felt they needed more rehabilitation than what was funded publicly by the healthcare system. Availability of treatment services was a barrier to return to participation. Only Josée was able to continue with community therapies because she had the financial assistance from family.

Being able to afford medication was noted as a barrier for Charlotte and Paul immediately after the stroke. Charlotte was eventually able to obtain funding assistance – although the application process was a barrier. Paul paid for his medications for several years, until accepted by ODSP. The limited coverage of the drug program, which resulted in frequent out of pocket expenses, was highlighted as a barrier for Paul, Laurent, Sylvain, and Daniel.

Sylvain and Jackie identified access to equipment as a barrier to return to participation. The other stroke survivors were able to access equipment with the financial assistance of family members (Josée), had no unaddressed equipment needs (Charlotte, Daniel, Aimée), or stated needing equipment but felt that not having it did not impact participation (Paul).

The cost of the driving assessment and of vehicle modifications was a barrier for Charlotte, Paul, Laurent, Josée, Sylvain and Daniel. Because family provided Laurent with rent-free housing for several months prior to the stroke, he was able to save money and afford the examination (savings or wealth is not an eligibility factor to receive income support from OAS).

Healthcare services were available in French in the majority of institutions, even though they were not necessarily offered or requested. Bilingual services were also available – which was perceived as a facilitator.

Social services system: For all stroke survivors, whether income support was received from EI, LTD, ODSP, CPP, OAS, OW or any other combinations, income was a barrier to the attainment of personal projects, in that the stroke survivors did not have sufficient funding to afford all aspects of their return to participation in their personal projects. Timely access to income support programs was a barrier for many, as were the complex application forms, waitlists, and unclear eligibility criteria. Especially difficult were transitions between support programs, for example, from EI to OW.

With the exception of Charlotte who became homeless and was subsequently prioritized on the social housing waitlist and received geared-to-income housing, the other stroke survivors are all living in unaffordable housing (according to the CMHS rule of spending no more than 30% of income on housing) (Canada Mortgage and Housing Corporation, 2009). Paul, who continues to move from one family member to another, and Aimée, are currently on the social housing waitlist. The others have chosen to continue with their current housing arrangements: Laurent is renting from family, Sylvain remains in his apartment with a roommate, Daniel continues to rent his room but plans to add his name to the social housing waitlist. Jackie is in a private retirement home because of her assistance needs – she spends the largest percentage of her income on housing (which includes food and some physical assistance).

With regards to public transportation services, all stroke survivors considered public transportation and private transportation services too costly and thus a barrier to participation, except for Josée who did not take public transportation because she had family and friends.

In terms of language, social services were available in French if requested, in this region.

4.4.4 Macro environment:

The stroke survivors reported challenges that were linked to the macro environment, for example, the amount of income from income support programs, the coverage of the provincial drug program, the availability of community rehabilitation services, the accessibility of public and disability transportation services, and the availability of social housing.

4.5 Synthesis of the Findings

The aim of this study was to answer the research question *How do Francophone stroke survivors living in a low-income and linguistic minority situation experience attempting to return to participation?* A multiple case study approach was used with eight low-income Francophone stroke survivors from Canada's national capital region.

The eight stroke survivors were of various ages and backgrounds. Time since the stroke varied from less than a year to several years. Although these stroke survivors were pursuing many different personal projects, there were similarities in the types of projects, for example projects related to income, housing, transportation, community mobility, and ongoing recovery.

The stroke survivors identified that living in a low-income situation negatively influenced their experience of attempting to return to participation, and all expressed that the amount of money they were receiving from income support programs was a barrier. Income limited their ability to purchase goods and services. It influenced housing situations and the related personal project of living independently - this was a common challenge for all the stroke survivors.

Even in similar situations of low income, every stroke survivor had a unique experience of attempting to return to participation. Patterns of factors were identified that mediated these experiences for each case. Many of these patterns were noted to be similar among the eight

cases. These were stroke survivor personal factors, as well as factors within their micro, meso, and macro environments.

Personal factors, specifically age, language, and knowledge of the system and understanding of health were found to play a role in these stroke survivors' experience of return to participation.

Age influenced access to social services for the stroke survivors in this study, in that being below the threshold of 65 years of age meant that the stroke survivors were employed at the time of their stroke, were not eligible for OAS and the seniors' provincial drug plan, and needed to go through the complex application process to secure income support and access the drug plan following their stroke. Those over the age of 65 were already receiving income support, and the stroke did not influence their income sources or amounts.

In terms of official languages, all but one of the stroke survivors considered themselves bilingual. One participant spoke French but no English. Three identified Creole as their mother tongue. All of the participants in this study had access to extra community therapies in a regional French language clinic – which helped many of the stroke survivors move forward in their pursuit of their personal projects. In this region, the participants did not report any difficulties with access to services in their preferred official language, but those whose mother tongue was Creole would have preferred services in that language had it been available. Notably, even if the services were offered in the preferred language, a common comment from the participants was that they had difficulty understanding concepts, instructions, and explanations from the professionals, pointing to a possible issue with health literacy.

Another personal factor influencing participation was knowledge of the healthcare and social services systems, and understanding of health, which was generally limited for the

majority of the stroke participants. For example, they were not aware of what services they needed, or existed, and how to access them once they became aware. Lack of information and guidance was a common complaint from the stroke survivors.

Importantly, each stroke survivors' micro-environment appeared to play a more substantial role in supporting participation than did the personal factors because the microenvironment could facilitate or create barriers to participation that could not necessarily be overcome by the personal factors. For example, family and friends could compensate for a stroke survivor's limited knowledge of the system if they had this knowledge and were effective advocates. In addition to family and friends, housing, and the physical environment were also elements of the microenvironment that influenced participation.

The micro-environment exists within a meso-environment that is composed of larger structures, such as the healthcare and social service systems. Gatekeepers are workers within the system who mediate access to these services within this larger structure. Once access is granted, the processes continue to be complicated, waitlists may exist, and there are unclear or hidden rules and regulations in many instances. Knowledge about the inner workings of the system facilitates access to certain services, but is not a guarantee. This level of the environment manages access to services such as income support programs, affordable housing, public transportation services, drug benefit programs, equipment funding programs, driving examinations, as well as access to services in either official language. This level of the environment thus had a substantial influence on the experience of return to participation for the stroke survivors in this study. Importantly, it is the larger macro environment, which determines the availability and regulations of these needed healthcare and social services that ultimately influenced the experience of return to participation for the stroke survivors in this study.

5. Discussion

The aim of this study was to increase our understanding of the influence of living in a low-income and linguistic minority situation on post-stroke participation. In the following chapter the main study findings will be reviewed and examined in relation to the existing literature. The influence of the meso and macro contexts, language, bilingualism, and health literacy will also be discussed. The revised conceptual framework will be reviewed, as well as recommendations stemming from the study, and study limitations.

5.1 Summary of Findings and Associated Literature

5.1.1 Participant characteristics and personal projects. The stroke survivors who participated in this research varied in terms of age, gender, education, culture, their relationships with the care partners, and time post stroke. French was the mother tongue for five of the stroke survivors; three identified Creole as their first language. All stroke survivors identified as English and French bilingual except for Aimée.

While the survivors' personal projects varied, there were many similarities. For example, securing income after stroke was a project for the six stroke survivors under the age of 65. Other common projects included taking part in ongoing rehabilitation, returning to living on their own as they had before the stroke, maintaining or improving their health, and getting around in the community – either by resuming driving or finding alternative affordable transportation.

Income was a barrier to participation for all cases examined in this study, regardless of income before the stroke. Income influenced precursors to participation, such as the ability to afford housing, goods (e.g., sporting equipment, healthy food), and services (e.g., physiotherapy, housekeeping assistance, transportation).

5.1.2 Patterns of influence. In this context of low income, each stroke survivor had a unique experience but, these unique experiences were affected by similar patterns of influence, which can be classified as personal, micro, meso, and macro-environmental factors.

5.1.2.1 Personal Factors. Personal factors identified in this study were age, language, and knowledge and understanding of health and of the healthcare and social services systems. These factors appeared to influence access to services rather than directly influencing participation in personal projects.

Age: This study demonstrated that older age could confer certain advantages in access to services that support return to participation. Those stroke survivors over the age of 65 were already receiving income support at the time of their stroke. Even though they considered this income to be insufficient to meet their needs, their income was not altered by the stroke. As well, eligibility for OAS does not require exhausting personal savings, as does ODSP, which is usually the income support program for those under 65. This was beneficial for Laurent who was able to pay for his driving examination with personal savings. Further, the older stroke survivors were already covered by the provincial drug program, which offers universal coverage for residents 65 and over. This finding was similar to that of researchers from the United Kingdom who found that younger stroke survivors had a disadvantage because they could not access many social and health services because they were under the age of 65 (Mold et al., 2006).

Importantly, age also influenced the types of personal projects the stroke survivors were pursuing, specifically, the project of return to work. The majority of the stroke survivors under 65 wanted to return to some kind of employment but were not provided with any assistance or referred to related services. This lack of community services and of professional assistance for

return to work was previously reported as a disadvantage for younger stroke survivors in the United Kingdom, regardless of income (Mold et al., 2006; Sadler et al., 2014).

Language: Language is a personal factor that did not appear to be a disadvantage to the experience of return to participation for the stroke survivors. In the urban region where this study took place, the stroke survivors were able to access services, from acute care to community rehabilitation in the official language they preferred or in the language they felt they understood or mastered sufficiently. Importantly, those stroke survivors who identified as French and English bilingual received services in institutions where, for the most part, they were able to change the language of services according to their perceived need – for example, choosing to complete a cognitive assessment in French or English. Being able to alternate between French and English was noted to be important for the bilingual stroke survivors who had difficulty consistently using one language during therapy, in particular for Josée and Jackie who were experiencing severe expressive aphasia and used both languages together.

The stroke survivors in this study felt that being bilingual was important, and was an advantage as it allowed them to benefit from membership in both language groups. The one stroke survivor who did not speak English reported issues with participation only when it involved interacting with the public, for example, cashiers in stores. This challenge existed prior to the stroke as well.

The stroke survivors were admitted to three different acute care hospitals, and participated in various inpatient and outpatient rehabilitation services, but were all eventually admitted to the *Clinique interprofessionnelle*, which supported them in moving forward in pursuit of their personal projects. It should be noted that this clinic is a unique regional

advantage, and since early 2017, this French language clinic has become a fee-for-service facility, and would not be affordable for those who participated in this study.

Notably, language should be considered not only on the personal level but also on the meso and macro environmental levels, as access to healthcare and social services in French or English is legislated provincially and federally. Also, language is a personal factor that interacts with characteristics of the environment – making it an indicator of social position (Johansson & Śliwa, 2014). For example, speaking French in the French majority province of Québec, may position one more favourably than would speaking French in an English majority region.

Knowledge and understanding of health and of the healthcare and social service systems: The stroke survivors in this study had limited knowledge and understanding of stroke-related health issues and of the healthcare and social services systems. This created barriers to return to participation.

Lack of information regarding stroke-related health issues (e.g., cause of stroke, secondary prevention, lifestyle) has previously been noted as a challenge for stroke survivors living in low income situations (Danzl et al., 2013; McKeivitt et al., 2011), as well as for stroke survivors more generally (Walsh et al., 2015). Lack of information about social resources has also been reported following stroke in Canada and abroad (Ganesh, King-Shier, Manns, Hill, & Campbell, 2017; Sadler, Daniel, Wolfe, & McKeivitt, 2014b; Yeung et al., 2015). In this context of low income, the consequences of not knowing about social resources had foreseeable health implications. Foreseeable consequences included onerous housing costs and a precarious housing situation, or an inability to afford prescribed medication, which is associated with a higher risk of disease-related hospitalizations (Campbell et al., 2017).

Sumathipala et al. (2012) found that stroke survivors who were members of the healthcare or social service group (e.g., worked in the system prior to the stroke), and had a high level of education or higher SES, had an advantage. They possessed cultural capital which made it easier for them to negotiate within the systems to obtain needed information and to access health services (Sumathipala et al., 2012). Likewise, this type of cultural capital also shaped the stroke survivors' expectations in terms of information they felt they should receive, and this improved their ability to ask for and receive it (Sadler et al., 2014).

Cultural capital, according to Pierre Bourdieu, is one of three types of capital, along with social and economic capital. All are linked to social position or social class. Cultural capital is acquired through socialization and education (Bourdieu, 1986). It helps someone "fit in" with the social group with which they are interacting. Relating to health, cultural capital can also include health values, behavioural norms, and health knowledge (Abel, 2008). In practical terms, a person with cultural capital in healthcare may not necessarily have the knowledge or understanding they need for their particular situation, but they would, for example, know how to ask a social worker for information, understand health jargon, know who to call for income support, or understand how to obtain health equipment. Cultural capital has been linked to inequalities in health as it is an advantage that is unequally distributed across social groups (Abel, 2008). The second type of capital, social capital, encompasses an individual's potential resources and the benefits that can be mobilized from within the social network (Bourdieu, 1986); this form of capital is also unequally distributed among people (Lin, 2000). In this study, the social capital included family, neighbours, bosses, friends, and friends of friends. Third, economic capital is, according to Bourdieu (1986), all that can be immediately and directly

converted into money, as opposed to social and cultural capital, which can impact economic capital but not be readily converted.

In this study, none of the stroke survivors personally had a notable cultural capital advantage that would aid them in terms of navigating the healthcare and social service systems on their own. All of them needed to rely on resources from the micro or the meso environments. For example, Sylvain and Daniel were able to benefit from the cultural capital of people in their social network whose members were able to provide them with instructions regarding accessing income support programs. Josée and her network, on the other hand, even with the highest education level and SES, did not have the needed cultural capital, as no one had previous related experience or knowledge with the healthcare and social service systems.

5.1.2.2 Micro-environment. While personal factors had an influence on post-stroke participation, factors from the micro-environment appeared to have a greater influence. These factors included family and friends, the physical characteristics of the home environment, the community and neighbourhood, and housing.

Family and friends: The stroke survivors' family and friends, or social capital, were seen as facilitators of returning to participation in the context of low income. This finding that family and friends were important for return to participation following a stroke was consistent with the literature regardless of income group (Fallahpour et al., 2011; Robison et al., 2009; Sumathipala et al., 2012). The results of the present research demonstrated, however, that family and friends were particularly important in the context of low income as they mediated the effects of income by helping to “fill in the gaps” when income was a barrier. For example, they provided free transportation, did housekeeping for free, or paid the Internet and telephone bills so the stroke survivor could continue to live on their own. For Josée, her larger social network even

provided assistance with return to work. The type of support provided by the care partners and the larger social network varied greatly from one case to the other, and enabled return to participation to different degrees. Friends and family could even negatively affect participation, as was the case for Charlotte and her daughter.

For all the stroke survivors, family and friends also provided support as system navigators, regardless of whether or not they had the skills or knowledge to do so. This has been found to be true for stroke survivor caregivers even in situations where income was not an issue (Ghazzawi et al., 2016; Lutz, Ellen Young, Cox, Martz, & Rae Creasy, 2011). This type of assistance appeared to be more critical for the low-income stroke survivors as their survival depended on it, because it was linked to their ability to pay for medication, food, and housing. The cultural capital and advocacy skills of family members and friends were important too. The influence of the care partners' advocacy skills has been noted to be a facilitator in other circumstances as well, for example when negotiating hospital discharge plans (Allen, Griffiths, & Lyne, 2004), or pushing for services such as referrals to stroke rehabilitation (Lynch, Luker, Cadilhac, & Hillier, 2015).

The family and friends' economical capital could also facilitate participation for the stroke survivor – did they own a car, could they pay for rehabilitation services, or purchase an accessible condominium? Related to this was the family and friends' personal situation, such as their availability (e.g., were they employed and did they have employment that allowed them flexibility to leave work to provide assistance to the stroke survivor).

There appeared to be an underlying assumption by those in the system that families and friends were able and willing to support the stroke survivor by providing assistance such as housekeeping, transportation, system navigation services, or help with finding housing. Home

with family was often the first proposed option at discharge, even when the strength of a relationship was tenuous (e.g., Charlotte and her daughter, or Jackie and her brother) or when the physical environment was not accessible (e.g., Paul's family living in an inaccessible apartment). Further, the costs and the financial burden of providing this support to the stroke survivors were largely unrecognized by the healthcare team during discharge planning. For example, according to the medical records, the discharge plan for Josée included assistance from her mother for personal care, which was only possible if her mother took a three month unpaid leave. As well, Paul's discharge plan to family in Montreal was only possible because the family paid for his living expenses. Even though personal and caregiver financial cost is often mentioned as a challenge for the stroke survivor and their care partners following stroke (Heart and Stroke Foundation, 2017; Mittmann et al., 2012), this actual financial burden of stroke remains largely unknown and, in this study, was not discussed with family and friends before they took on the care of the stroke survivor.

Characteristics of the home, community and neighbourhood: The community and neighbourhood, and the physical characteristics of the home environment where the stroke survivor lived could be either a barrier or a facilitator to participation; this finding concurred with the literature (Jellema et al., 2016). More important, however, was that the low-income stroke survivors in this study had limited decision-making power regarding where they could live. Their income also limited their ability to remediate any environmental or accessibility issues if it was needed.

Housing: All eight stroke survivors lived, at some point following their stroke, in a housing situation that was considered unaffordable according to the indicators set by the Canadian Mortgage and Housing Corporation, meaning that rent was more than 30% of pre-tax

income (Canada Mortgage and Housing Corporation, 2009). This finding that stroke survivors exceeded the housing affordability threshold was not surprising since it is known that disabled Canadians are more likely than non-disabled people to live in unaffordable housing (Rea, Yuen, Engeland, & Figueroa, 2008).

Stroke survivors living in low income and unaffordable housing situations are at high risk of homelessness. This became a reality for Charlotte who moved to a homeless shelter before affordable housing became available to her. As well, Paul has been living in a hidden homeless situation for the last five years, as he has no fixed address. Hidden homelessness is a situation that is also more common for Canadians with disabilities (Rodrigue, 2016).

Unaffordable housing has previously been recognized as a barrier among people with disabilities (Hammel et al., 2015). Housing as an issue following stroke has been identified in the literature, but often, the focus has been on the physical characteristics of housing (Sumathipala et al., 2012), with some studies highlighting issues with stroke survivors' ability to afford modifications to their environment and adaptive equipment (Reid, 2004; Tabbarah et al., 2000), or reporting simply on the lack of information regarding rehousing post-stroke (Sadler et al., 2014) rather than affordability.

Rent was an important monthly expense for the stroke survivors that competed with other personal project expenses. In clinical practice, failure to inquire about or to acknowledge housing affordability following a stroke could have important implications. Challenges affording rent can signal issues with affording other expenses post stroke, such as medication or transportation, and a need for information and assistance accessing income support programs.

5.1.2.3 Meso environment. The meso-environment includes the healthcare and the social service systems, including their policies. This level of the environment exerted a stronger

influence on the experience of participation for the stroke survivors in this study than did the micro-environment and personal factors. Discharge planning, availability of community therapies, public transportation, the process of resuming driving, drug plan coverage and equipment funding programs, social housing, and income programs were noted as challenges.

Discharge Planning: The influence of plans made during discharge had far reaching effects on participation for the low-income stroke survivors in this study. The two main challenges were the lack of discussion regarding all care and relocation choices, as well as issues with provision of information about healthcare and social service resources.

The majority of the stroke survivors did not return to their previous homes following the stroke, and they encountered challenges related to the professionals' expectations about the role of family and friends. The discharge plans for these individuals rested on the assumption of adequate informal supports. Professionals assumed that family and friends wanted to, and were able to take on the responsibility of caring for the stroke survivor, such assumptions appear to be common, and lead to problems such as caregiver burnout, safety issues, familial financial burdens (Lutz et al., 2011; Young, Lutz, Creasy, Cox, & Martz, 2014).

Families and friends in this study felt that the only option at discharge was to take the stroke survivors home with them, even if they did not have the resources to do so. Information about other possible options was not provided. Homelessness was not the only adverse outcome. Most families faced substantial financial burdens providing needed care.

Further, during discharge planning, the healthcare professionals either provided too little or no information tailored to the stroke survivor's needs, and timing of information provision often led to challenges with access to necessary services. This challenge with information and timing of information is well reported in the literature in particular as it relates to the needs of

stroke survivor caregivers (Cameron, Naglie, Silver, & Gignac, 2013; Ghazzawi et al., 2016). Importantly, the healthcare professionals had the needed information; however, if stroke survivors did not request it, it was not offered. In some instances, medical records showed evidence that even when a stroke survivor made a request, only partial information was provided. For example, while in acute care, Sylvain reported to the team that income was going to be a major problem on discharge, but the team only gave him information on EI, not ODSP.

Again, those stroke survivors whose social network included people with relevant cultural capital were better able to manage discharge planning and to accommodate for any missing information. This was an underappreciated advantage for those stroke survivors

Publicly funded therapies: Limited availability of publicly funded therapies was also a challenge influencing participation. Although two stroke survivors felt they had reached their maximum recovery, the other six felt they would benefit from more therapy, however it was not affordable. In the region of this study, publicly funded therapies are not available in the later period of recovery. Affordability of private therapy has also been identified as an issue for stroke survivors in other regions of Canada (Ganesh et al., 2017), as well as for a large portion of stroke survivors in Ireland (Walsh et al., 2015), and in Australia (Sadler et al., 2014).

In three cases, the stroke survivors' families were able to make substantial sacrifices to fund continued rehabilitation. Only Josée's family was able to afford longer-term therapy as a result of their economic capital; the other two families were not able to continue paying for treatment up to the stroke survivors' or their expectations.

Furthermore, publicly funded vocational rehabilitation was not provided to those who wanted to return to work. Although the evidence supporting vocational rehabilitation for return

to work is mixed (Wei, Liu, & Fong, 2016), such a service may offer stroke survivors the opportunity to participate in return to work personal projects.

Resuming driving: The ability to resume driving was viewed as an important facilitator to return to participation, and the literature shows evidence that stroke survivors who return to driving have higher levels of social participation (Norlander et al., 2016) and are more likely to return to work (Doucet, Muller, Verdun-Esquer, Debelleix, & Brochard, 2012). The process of resuming driving was a particular challenge for several of the stroke survivors in this study; the costs of the examination and vehicle adaptations were reported to be unaffordable for the majority, and they felt they received too little information from healthcare professionals regarding the process to regain their driver's licence.

The process of regaining a driver's license is not publicly funded. Resuming driving requires a substantial cash outlay from the stroke survivor (over \$700). Many of the stroke survivors felt they could, over time, possibly save up for the driving examination, but believed that their income would not cover the other costs involved with driving, such as insurance, gas, or adaptations. Similarly, acquired brain injury survivors in Australia felt ill informed about the return to driving process (Liddle, Hayes, Gustafsson, & Fleming, 2014), and the cost of driving assessments also deterred some Australian stroke survivors from resuming driving (Chua, McCluskey, & Smead, 2012).

The stroke survivors indicated that they had received insufficient information regarding resuming driving while they were inpatients. The *Clinique interprofessionnelle* did provide the stroke survivors in this study who were interested in resuming driving with the information they had not received from other services and also provided driving-related therapy. However, the *Clinique* did not provide the examination and vehicle adaptations.

Transportation: In this study, the stroke survivors reported that the cost of bus tickets and of other means of transportation such as taxis or volunteer senior drivers were generally unaffordable for them. Although the cost of bus tickets is relatively low, these were not affordable within their monthly budgets. There were additional costs related to the disability bus service, such as the cost of cell phone minutes while waiting on the line to book a trip. Particularly challenging was the cost of rides to and from outpatient rehabilitation clinics early on in recovery when stroke survivors were only receiving income support from OW or when income support was not yet being received. Unsurprisingly, the cost of transportation as a barrier to participation following a stroke has frequently been stated in the literature (Logan et al., 2004; Marzolini et al., 2016; Rimmer et al., 2008).

Moreover, the stroke survivors reported that organizing rides with the disability bus service was difficult, in large part because of the rules and regulations around what can be booked, how, and when. This was a particular issue for those with communication problems (aphasia), or no telephones. Complaints about waiting times, flexibility, and geographical coverage of the service were also voiced.

In a low-income situation, community mobility was facilitated by friends and family. Characteristics of the friends and family who could offer the most flexible assistance with transportation included retired or unemployed people with time during the day, those with flexible work schedules, who were geographically close, or had a car.

Drug plan coverage and equipment funding programs: There were many additional health-related costs that were not fully covered by the healthcare or social systems. These were difficult for the stroke survivors to afford within their monthly budgets.

The cost of prescription drugs was problematic for several of the stroke survivors. Either they were paying out-of-pocket for some time because they left hospital without information or assistance with applying to financial assistance programs for medication, or if already accepted for funding assistance for medication, the drug plans did not cover all prescriptions. Similar issues were noted regarding access to medical equipment – items were either partially covered, not covered, or the stroke survivor was not eligible for financial assistance.

Out-of-pocket costs of medication has been highlighted as an issue for low-income Canadians with cardiovascular disease including stroke (Campbell et al., 2014), as have been issues with paying for equipment following a stroke (Ganesh et al., 2017).

Social housing: The municipal government's social service system is responsible for social housing programs in this region, along with the assistance of community organizations. The program aims to provide housing that is geared to income. Wait times are upwards of 5 years in this region, and priority guidelines are unclear. Housing was the biggest monthly expense for the stroke survivors in this study, and while waitlisted for social housing, they were at an ongoing high risk of homelessness.

It should be mentioned that, in the region of this study, the municipal government also manages the domiciliary hostels (that is, subsidized retirement homes) where Jackie was hoping to relocate. Jackie experienced a particular problem with housing because her income level was slightly over the limit (over by about \$5/month) to be eligible for a domiciliary hostel, but was too low to afford the regular prices for a retirement home. The social services system did not recognize her situation and housing needs, and there was very little assistance offered to Jackie and her POA by the healthcare and social service professionals to find post discharge housing.

Income support programs: Gatekeepers to the social services system managed access to income support programs, and this access was complicated by a lack of information regarding the programs, complex application procedures, and long wait times. Those working within the system appeared to assume that the stroke survivors and their care partners would be aware of the various programs and would be able to complete the applications without assistance. Only two stroke survivors, Sylvain and Daniel, had the social and cultural capital needed to access these programs in a timely manner. This need for assistance with applying to income support programs was not unique to the stroke survivors of this study. It has been noted as an issue for other Canadian, British, and Australian stroke survivors as well (Ganesh et al., 2017; Kersten, Low, Ashburn, George, & McLellan, 2002; Sadler et al., 2014).

While waiting for acceptance to income support programs, additional challenges presented themselves. For example, the required waiting periods between income support programs were difficult to manage; these no income periods were particularly difficult to manage when initial benefits were very low (OW was substantially lower than EI or ODSP). Ability to pay for rent, food, medication, and transportation, was particularly challenging during these no income transition periods. Even after the stroke survivors were accepted to ODSP or to another long-term income support program, they remained in a low income situation and lived under the Low Income Cut-Off (LICO) (Statistics Canada, 2013b). The stroke survivors felt their income did not meet their needs. Canadian researchers and disability advocacy groups have highlighted this issue as well: “The evidence shows that these programs generally fail to come close to meeting the basic needs of those on social assistance.” (Bryant, 2010, p. 256).

5.2 Meso and Macro Environments

A striking finding of this research is the overwhelming influence of the meso and macro environments on the experience of return to participation for the stroke survivors in the study. This was unanticipated because much of the literature on return to participation post stroke focuses on the role of the individual and his or her ability to return to participation (e.g., therapy interventions, functional recovery, self-efficacy, motivation), and on elements of the individual's micro-environment (e.g., social supports, the built environment). As well, the majority of the measures of participation used in rehabilitation and disability research have a limited focus on the impact of the environment on participation (Magasi et al., 2015), which may bias how researchers and clinicians consider participation. To date, minimal focus has been placed on the impact of the meso and macro environments on participation following stroke.

The meso environment, as described earlier, encompasses structures such as the healthcare and social services systems. This level manages services such as income support programs, housing programs, employment insurance, and homecare services. The meso environment also operationalizes provincial and federal language laws – ensuring that official language minority groups have access to government services in either English or French.

Cultural capital (a personal or micro environment factor) was shown to be a facilitator to accessing such needed services in the meso level more quickly, in particular income support programs. The findings of this research however, highlight that timely access to many needed services could be hindered because it was dependent on gatekeepers within the system and involved complex application processes.

The findings also pointed to challenges beyond this issue of timely access to individual services. One such challenge was lack of intersectorality or a tendency for healthcare and social services to operate in silos rather than collaboratively. This is a problem that has previously been

reported for stroke survivors who move between health services (Meyer et al., 2012). In the present study, intersectorality was a problem between healthcare and social services. For example, ODSP and the healthcare system do not interact directly. Rather, the stroke survivor is responsible for gathering and submitting paper-based medical assessments and applications. Similarly, short-term disability benefit programs do not communicate with long-term disability programs, and applications to government income support programs are separate and unrelated (EI to OW to ODSP). Silos within healthcare interdisciplinary teams were also observed: finances appeared to be under the jurisdiction of the social workers, with other professionals deferring to social workers for all financial concerns and failing to consider financial issues in their own work (such as, providing lists of recommended equipment to people who had no ability to purchase it). As well, continuity of care when moving from one healthcare service to another was similarly problematic. For example, if a financial resource problem was highlighted as early as during the acute care admission, the professionals down the line in outpatient services did not necessarily provide the stroke survivor with follow up on this financial issue.

Issues with lack of continuity between healthcare providers and healthcare services with regards to French language services were not apparent for these stroke survivors. A good example of this was that language was identified as being important in the assessments of several professionals within the interdisciplinary teams of acute care and rehabilitation services. Further, while participants were initially admitted to one of three different acute care hospitals, following their strokes, all were eventually referred to the *Clinique interprofessionnelle*, an important healthcare resource for Francophone stroke survivors.

Another general meso-environment issue was the lack of, or only superficial consideration of the stroke survivors' context, in particular financial constraints and the

implication of this context on return to participation. The healthcare professionals often appeared to work under the assumption that the stroke survivors would not experience problems following discharge if the discharge location seemed to fit their physical needs or if there was another person in the environment. Whether the stroke survivor had the financial resources to carry out plans recommended by the team, for example, to pay for the rental of the recommended raised toilet seat or for the prescribed insulin needles, rarely entered into the teams' recommendations. It is not clear why this happened. It is possible that the healthcare professionals believed that they could not make any changes to the patients' financial context, so it was pointless to note these issues, or perhaps they simply believed that it was not their responsibility to ensure that recommendations could be carried out.

This meso-environment operates under the influence of the macro environment which includes the policies, regulations, and laws that are shaped by the values, ideologies, culture, and politics of society (Graham, Swift, & Delaney, 2012). In practical terms, the macro environment influences, for example, the level of income from disability support programs, the quantity and characteristics of social housing, and the availability of post discharge publicly funded services. The macro environment also influences, for example, the policies for deinstitutionalization and family-centered frameworks - the impact of which can be seen in the downloading of caregiving responsibilities from the government to families and friends (Hankivsky, 2004).

The macro environment was the most influential factor in the experience of return to participation for the stroke survivors in this study. The macro environment placed the stroke survivors on the same level, because, regardless of other personal or micro-environmental advantages (e.g., cultural capital), the stroke survivors could not bypass the system at this level unless they had wealth or access to outside financial resources.

Even if a stroke survivor managed to access the needed social and healthcare services in a timely manner because of cultural or social capital advantages, the income support was still too low to support post-stroke participation needs, the housing registry waitlist still existed because there was insufficient affordable housing for all those in need, and extra publicly funded rehabilitation services in the community were just not available.

The only way to bypass certain aspects of the influence of this environmental level on return to participation was with wealth or through the financial support from the social network. This was the situation for Laurent and Josée – both could be considered as having had the most positive experience of return to participation. In both cases, financial assistance with housing was key: Laurent had been able to accumulate some personal savings while living rent-free with his brother, which he was then able to use to pursue his project of resuming driving. Josée's social network had the financial resources to purchase a condominium so that she could live independently and have the funds to attain several other projects on her limited income. In Josée's situation, direct financial contributions from family towards private physiotherapy treatment were also important for personal project attainment. Although the family members and friends of the other stroke survivors made financial contributions, the overall impact on participation was limited because it was insufficient to make substantial gains in the pursuit of their project. For example, Sylvain's mother purchasing bus tickets, or Natalie paying Charlotte's Internet bill.

The importance of the influence of the macro environment is not a new concept and has previously been highlighted in the general health literature (Bryant, 2010; Pearce & Smith, 2003) as creating inequities, and has been found to be an important environmental domain affecting participation more generally for people with disabilities (Heinemann et al., 2015). This study

adds to this by showing that even in a universal healthcare system, and modern welfare state (Bryant, 2010), the macro environment can be considered the strongest influence on return to participation following a stroke.

5.3 Language, Bilingualism, and Health Literacy

In the contextual framework developed during the design of this research, language was a personal factor that had been anticipated to play a substantial role in the experience of return to participation for the Francophone stroke survivors, both as a personal and as a meso environmental factor. Language did have an impact, however, the impact was not as important as anticipated. In addition to possibly being attributed to the unique features of the study participants (majority of them were French and English bilingual, and three had Creole as their mother tongue) and of the region (availability of services in French), this unanticipated result may also be attributable to other factors. These include overestimating how well the findings from other language and health research could be applied to this research, failing to anticipate that participants might identify as “bilingual”, not accounting for health literacy, and not positioning language as an intersectional factor along with ethnicity and culture.

The literature review on which the conceptual framework is based, considered the impact of language barriers on health from a global perspective. This possibly resulted in an overestimation of the applicability of the results of these studies, majority of which were conducted with other language groups or countries, to the stroke survivor group’s experience. For example, the healthcare experiences of Spanish speaking individuals in the United States might not be applicable to the French speakers in English-majority Ontario. This is unsurprising, as the impact of the language barriers on health and social outcomes will strongly depend on the language and its social status within the micro, meso, and macro environments where the

individual lives. For example, Chinese-Canadians, Creole speakers in Canada, and members of an official language minority in Canada cannot expect to experience the same types of language or communication barriers while receiving healthcare and social services. French in Canada has a much higher status than other non-English languages and is protected by legislation. The Canadian Charter of Rights and Freedoms has given French and English equal status, rights, and privileges. It also exerts considerable influence on the situation of official languages. Availability and access to French language services in the healthcare and social service systems depend on number of French speakers in an area or community (Forgues & Landry, 2014), and is regulated by provincial or territorial legislation. Further, there have been recent federal investments to support official language minority communities in the area of health (Health Canada, n.d.). Even though there is still much work to be done to rectify a historical lack of services, this demonstrates a commitment to the official linguistic minorities. Other minority language groups do not have this type of legislative or political lever.

Another issue with language in the conceptual framework was the underlying assumption that Francophones in Ontario would want to have French services; this assumption did not account for the experience of bilingual stroke survivors. Seven out of the eight stroke survivors participating in the study identified as being French and English bilingual. All of the stroke survivors in the study stated that they had received services in their preferred official language, or in an official language they felt comfortable communicating in throughout their care. They had felt no disadvantage or discrimination.

The stroke survivors who identified as bilingual accepted or requested both French and English services. These individuals used both languages when receiving healthcare. They expressed wanting to have flexible access to language services (e.g., being interviewed by

therapists in French, but completing cognitive testing in English). Flexibility of use of the two languages was most important for the two individuals with severe expressive aphasia who had difficulties expressing themselves in only one of the two languages at one time. They appreciated working with professionals who were bilingual.

Interestingly, the healthcare service literature is limited in terms of the needs of bilingual Canadians. In fact, the experiences of these individuals are often not communicated or even included in such research. For example, several studies on the health of minority French speaking groups use an algorithm to define the linguistic identify of their participants and classify all participants into only two groups: French or English, even if individuals identify having both languages as their mother tongue. In some studies, these individuals are taken out completely – such was the case in a large Statistics Canada study on basic literacy, where those identifying themselves as having French and English as their mother tongue were excluded from the study analyses altogether (Statistique Canada, 2013).

Even though the bilingual participants in this study expressed that they were proud of their status as bilingual and placed high value on belonging to the two language groups, such identification is not always positively viewed by language researchers. Some hold that Francophones who identify as bilingual are a threat to linguistic vitality and will assimilate (Landry, Deveau, & Allard, 2006). Others, though, appreciate the advantages of membership in both the minority and the majority language groups (Pilote, Magnan, & Vieux-Fort, 2010).

Bilingualism can have disadvantages in a health care context. Bowen (2015) cautions that when providing services to patients who identify as being bilingual, healthcare professionals have a tendency to overestimate language ability in the patient's second language, for example, overestimating a Francophone's abilities in English. This would mean that five stroke survivors

were at risk of experiencing language barriers because their English language abilities were overestimated. However, in the current study, the stroke survivors with French as a mother tongue expressed that they felt the healthcare professionals overestimated their *French* language skills. The majority expressed that they had difficulties using and understanding formal or standard French, as well as difficulties with jargon and health specific vocabulary (vocabulary that they only knew in English, for example the term “stroke”). Rather than overestimating their English abilities, it appeared that health care providers were overestimating the bilingual stroke survivor’s ability to speak standard French, and stroke survivors indicated that accommodations were not made in the majority of organizations where they received French services to ensure they understood. There are indications that the stroke survivors did not always let the professionals know when they could not understand, but the reasons why they did not ask for further clarifications are unknown.

By the same token, three of the stroke survivors ran the risk of having professionals over estimate their French language abilities because Creole was their maternal language. These three stroke survivors from Haiti had unique needs – although able to understand one or both official languages, it remained that they may have been more comfortable communicating in Creole.

The “quality” of spoken French has also been reported as a challenge for Francophone professionals working with Francophone minorities in healthcare and social services, however in the opposite sense. In a study exploring the challenges faced by bilingual healthcare and social service professionals in Eastern Ontario, the professionals identified that clients from low income environments spoke a French that was far different from their spoken standard French. Although they felt that they did their best to accommodate the clients’ needs, they believed it was a problematic situation “...the [healthcare professionals] also described a feeling of being

pulled in an opposite direction, reluctant as they were to contribute to the weakening of the French language.” (Drolet et al., 2014, p. 299).

For bilingual clients, even though not always practical or possible, the healthcare and social service professionals should be striving to communicate with their clients by adapting their language level to the client’s abilities and needs along the continuum of language between French and English. By not providing clients with the language support or accommodations they need (for political or other reasons), healthcare and social service professionals can perpetuate the same problems they were trying to avoid – miscommunications because of a “language barrier”.

The original conceptual model for the current study considered that language could be an element of vulnerability in health care because language barriers can place a person at increased risk of adverse effects (Hurst, 2008). Health literacy, which is based on a combination of socioeconomic status, culture, and language factors (Shaw et al., 2009), can lead to challenges with obtaining and understanding health information, and ultimately to making appropriate health related decisions (Magasi, Durkin, Wolf, & Deutsch, 2009). Health literacy is an important personal factor that was not included in the original conceptual model. All but one of the stroke survivors demonstrated evidence of difficulties with health literacy or challenges understanding health information delivered during verbal interactions or in printed format. This was noted to occur not only when services were received in French, but also when services were received in English. Health literacy appeared to influence many aspects of the stroke survivors’ experience following stroke, including the return to participation and pursuit of personal projects, and would have been valuable to explore.

Furthermore, although language is frequently studied as if it had a unique impact on outcomes, it is better understood as an indicator of social position and of power in interaction along with culture and ethnicity (Johansson & Śliwa, 2014; Ng, Pottie, & Denise, 2011). These were not explicitly explored in this study, and should be examined within the larger concept of health literacy and over the life course.

5.4 Life Course

A pathway model life course approach focuses on the life trajectories of individuals and on how these influence health and wellbeing over time (Heikkinen, 2011; Hertzman, 2000); life trajectories are composed of events such as opportunities for education, employment stability, and relationships. In the initial contextual framework developed during the design of this research, the low-income stroke survivors' life trajectories were anticipated to play an important role in the experience of return to participation. Specifically, it was anticipated that the life trajectories would lead to various personal or micro-environmental factors that would be present before the stroke and would influence post-stroke participation; however, these trajectories proved to be much less important to return to participation for these participants.

The eight stroke survivors had very unique life trajectories, and these life trajectories lead them to be in unique circumstances and to having particular personal factors or micro-environments at the time of, and following, their stroke. Based on the findings of this study, in a context of low income, personal factors and the micro-environment played a role as facilitators or barriers to participation in personal projects. However, these were not as influential as elements of the meso and macro environment.

The one factor that seemed to significantly facilitate participation post stroke for the low-income stroke survivors was access to economical capital in the form of “unaccounted for”

financial resources or donations from the social network. Rent-free housing from family led to Laurent's ability to save money for his projects, and these savings did not need to be declared for his continued eligibility to OAS. For Josée, rent-free housing and additional family donations, all of which did not need to be declared to ODSP as they were not considered to be extra income, facilitated her return to participation. Importantly, there does not appear to have been a specific life trajectory or series of life events that lead to circumstances where such financial resources were available. For example, Laurent and Josée were the stroke survivors with the lowest and the highest education levels, and they were the two who fared the best in terms of pursuing their personal projects after the stroke. Laurent and Josée ended up having similar financial advantages for their return to participation, and this, regardless of their life trajectories.

Life trajectories are essentially personal factors in interaction with the micro-environment, and the findings of this study showed that post-stroke participation in the context of low income was more dependent on the influence of the macro environment. The life course perspective, which was initially presented in the conceptual framework as an underpinning concept, was therefore removed from the revised framework as it did not add to our understanding of the experience of return to participation for the stroke survivors in this study.

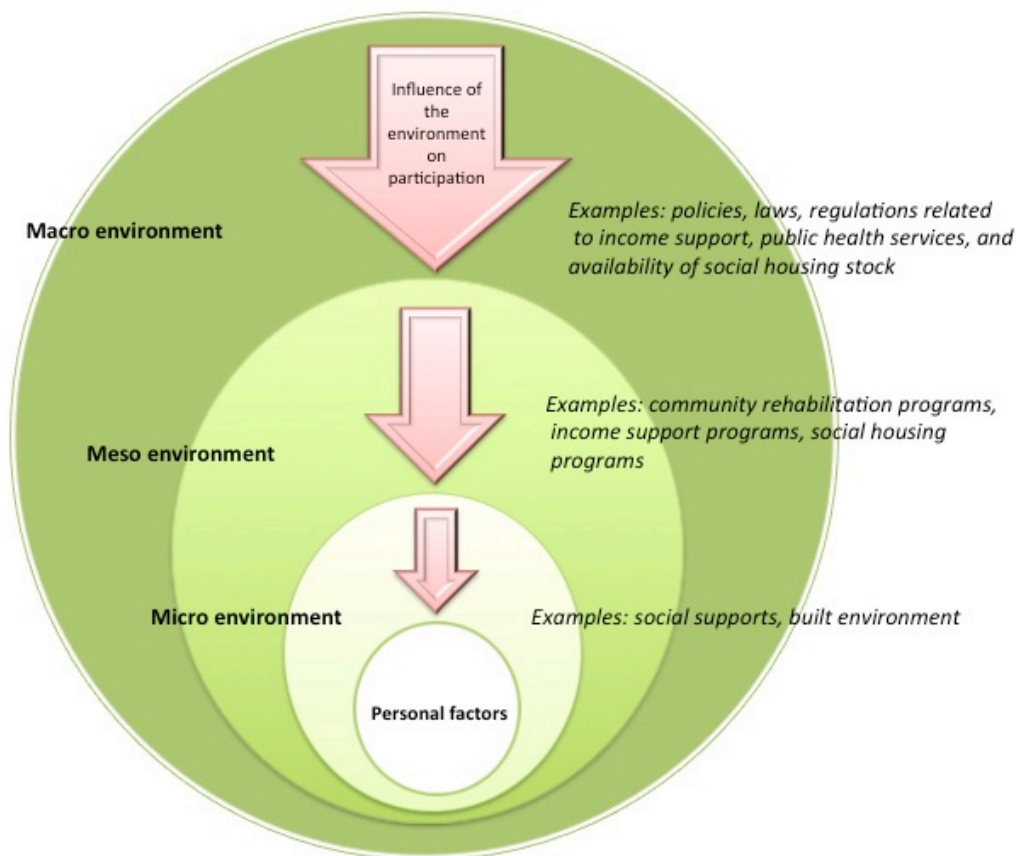
5.5 Changing the Conceptual Framework

The original conceptual framework and foreshadowed issues presented in Chapter 2 captured several aspects of the experience of return to participation among stroke survivors in this study. The visual representation of the original conceptual framework however placed too much emphasis on the stroke survivor (personal factors) and the micro-environment in the experience of return to participation. Therefore the model was revised with respect to the relative importance or influence of each aspect of the framework on the experience of return to

participation. The framework now shows personal factors as being relatively less influential than the other levels of the environments on the experience of return to participation (Figure 6).

Further, the life course perspective, present in the original framework, was removed as it no longer added to our understanding of the experience of return to participation for the stroke survivors in this study.

Figure 6. Depiction of the relative influence of the micro, meso and macro environments on return to participation for low-income francophone minority stroke survivors.



5.7 Recommendations

The findings of this research point to several areas of the macro and meso environments that could be improved to facilitate return to participation for low-income stroke survivors.

On the macro level, based on the findings, certain actions should be prioritized. Macro level policy changes are generally complex long-term actions as they rely on governance and political discourse. First, social housing policies for people with disabilities need to be addressed. Specifically, social housing stock must be increased so as to reduce waitlists, which would be related to a decreased risk of homelessness (and associated health issues) downstream. Improved access to social housing would also increase the portion of income that the stroke survivors would be able to use for other needs. Second, the level of income provided by support programs could also be increased. Current income support programs place people with disabilities under the LICO, creating health and participation issues. Similarly, drug plans, which are difficult to access or non-comprehensive (in terms of medication, equipment, or services needed to support the effective use of the medications), exacerbate health problems and should be addressed. Issues with public transportation costs, including the hidden costs, should also be tackled to improve participation.

Meso environment solutions can usually be implemented in the shorter term, and should target healthcare and social service professionals. First, stroke care services need to formally account for factors such as income, housing, and ability to afford medication so that the whole team can address these issues while the stroke survivor is still in hospital. Specifically, this means having standard initial assessments that contain questions about income, housing and medication, addressing the resource information needs of the stroke survivors, and supporting or assisting with applications to related programs before discharge, for example to income support, subsidized housing, and equipment subsidies. Follow up on these issues should happen along the

continuum of care from one service to another. For example, after a transition to another service, teams should follow up on whether applications were completed in the previous service and if all resource questions were answered. This responsibility needs to be shared within teams (e.g., nursing staff, social work, occupational therapy), and across services (e.g., acute care, inpatient rehabilitation, outpatient rehabilitation or homecare).

As well, the healthcare professions should be encouraged to shift their focus away from personal and micro-environment factors as the main barriers or facilitators to participation for low income stroke survivors, and move towards a larger appreciation of the impact of the meso and macro environments. In practice, this means having a greater awareness of the real impact of living in a low-income situation and its implications on participation and of how income may influence discharge planning (e.g., location or social supports), and treatment recommendations (e.g., ability to afford equipment or assistance). As well, it would be important to support healthcare and social service professionals to become more cognisant of the importance of their role as gatekeepers to the system, of the limits of the system, and of the need for them to actively support and advocate for stroke survivors to access needed services.

With regards to official linguistic minority stroke survivors, healthcare and social service professionals should be supported to provide their bilingual clients with services in the official language of their choice, or both, and to provide services in a level of language adapted to the person's needs along the entire continuum of care. Such "person-centred language use" should be encouraged.

5.8 Limitations

There were three main limitations in this study. First, the study participants were stroke survivors who were all recruited from two outpatient rehabilitation units in the region. It would

have been interesting to also capture the experiences of those who did not take part in outpatient therapies, including the *Clinique interprofessionnelle*, and were discharged following acute care or inpatient rehabilitation services.

Second, the ability to understand what part French linguistic minority status played, compared to low income, on post-stroke participation might have been facilitated by having mostly French, rather than bilingual stroke survivors, and having English participants as well. As well, the particular region where the study took place is a designated region with a high Francophone density within the English majority, and may not have been the best to highlight the possible challenges faced by official language minority groups. Adding stroke survivors from another region may have increased our understanding of the possible impact of region on return to participation. Also related to language, bilingualism was seen as an important factor however, level of bilingualism was defined by each stroke survivor and measured using a self-assessment.

Third, medical records are valuable tools to track events and decisions made during admissions to hospitals and rehabilitation centres. As a data source, a big limitation was that they do not include all the information that would have been important to understand particular situations. Interviews with healthcare professionals might have provided certain missing important details.

6. Conclusion

The experience of return to participation for the low-income stroke survivors living in an official language linguistic minority situation was influenced by income, but also by personal and environmental factors that were barriers or facilitators to participation.

Having a low income limited the stroke survivors' ability to afford housing, goods, and services, which were precursors to participation in personal projects. For many, securing income became a personal project in itself.

In this context of low income, personal factors such as age, language, and knowledge and understanding of health and of the healthcare and social service system played a role as facilitators or barriers to participation. However, these were not as influential as elements of the stroke survivors' micro-environment. Family and friends, and the larger social network, including their capital (social, cultural, economical) had a stronger influence on return to participation, either by their direct actions (e.g., providing transportation to outings), or indirect actions (e.g., sharing knowledge and advocating for access to services).

The meso and macro environments had the greatest impact on the stroke survivors return to participation as these environments determined access, availability, and the parameters, rules and regulations of the healthcare and social services that the stroke survivors required. This study also provided some evidence that a health inequity exists based on income - the stroke survivors in the study who had economical capital in the form of savings or had additional financial supports outside of the formal system were able to return to participation in more personal projects than the others.

Official language minority language status had an impact on participation however, was less influential than initially anticipated. This was likely do to the characteristics of the services

that could be accessed in the region of the study, and to the participants who, in majority, identified as English and French bilingual. Issues with health literacy also appeared to be a challenge within the group.

This research not only demonstrated how return to participation for these stroke survivors was influenced by income and official minority language status, but importantly how the macro system was the most influential barrier to return to participation.

Contribution to Rehabilitation

Participation is a concept that is central to rehabilitation (Hemmingsson, Jonsson, 2005) and can be considered to be the ultimate desired outcome of rehabilitation (Cott et al., 2007). Health professionals have the responsibility to address health disparities resulting from existing inequities (Allen, Allen, Hogarth, & Marmot, 2013) in particular as they lead to or create challenges to participation in everyday life (Braveman et al., 2013).

A health inequity had been demonstrated for low-income stroke survivors, in that they experienced more participation restrictions than more affluent survivors (Egan et al., 2015). Through the use of a multiple case study approach, this study has contributed to the understanding of the mechanisms behind this inequity from the perspective of the stroke survivors. This study points to actions at the meso and macro levels that may help to address this inequity.

Future Research

Based on the findings of this study, further research is needed to better understand the transitions from inpatient and outpatient healthcare services back to the community, particularly in terms of health professional perceived roles and responsibilities regarding discharge planning and income. From this, interventions could be designed, implemented, and outcomes verified.

Further, it would also be valuable to explore housing policies and post-stroke disability, and to investigate ways to include the concept of housing affordability as an important factor affecting post-stroke participation into research, and in the clinical setting during discharge planning. Similarly, it would be valuable to explore the personal financial impact of return to participation for both the stroke survivor and the care partners, so as to have a clearer understanding of the costs associated with post-stroke participation.

With regards to official linguistic minority stroke survivors, no studies could be found that focused on the influence of the two official languages of communication on post-stroke participation in the Canadian context. Therefore, the experiences of French and English bilingual individuals should be further explored, in particular the health and social service needs of this group, as well as their language and health literacy requirements. Similarly, the particular situation and needs of those who have French as their first official language and not mother tongue should be investigated. The study findings also demonstrated that the bilingual stroke survivors with aphasia had complex unique needs that need to be better understood.

Appendix A

Search strategies for narrative literature reviews

A first narrative literature search was completed in 2015. This review identified research that combined the three concepts of participation, stroke, and low income (in developed countries) (see Table 1), was written in French or English, was published between 1990 and February 2015, and was accessible via Pubmed, CINHALL, and Embase through the University of Ottawa library or inter-university library loan system.

Table 1. Literature review #1: Search strategy used with PubMed, CINHALL, and EMBASE databases.

	Concept 1	Concept 2	Concept 3
	Stroke	Participation	Low income
OR	Cardio Vascular Accident	Daily activities	Poverty
OR		Everyday activities	Socio-economic
OR		Meaningful activities	Neighbourhood
OR		Everyday life	Economic
OR		Engaging	Social Class
OR		Occupations	Deprivation
OR		Purposeful activities	Social capital

A second narrative literature review was done to update and expand on the previous search. The databases CINHALL, Medline (Ovid), and PsychInfo (Ovid) were searched, using the following strategy to combine the three concepts of participation, low income (in developed countries) and stroke: (ParticipationMeSH OR ParticipationTextWord) AND (IncomeMeSH OR IncomeTextWord) AND (StrokeMeSH OR StrokeTextWord). See Table 2 for search strategy details. Only articles in English, or French, published over a 10-year period between January 1, 2006 and May 9, 2017, and accessible online through the University of Ottawa library or inter-university library loan system, were reviewed. A review of references was also completed.

Table 2. Literature review #2: Search strategy used with OVID-Medline, PsychINFO, CINAHL

OVID-Medline database
Concept Participation
MeSH terms: community participation/ or patient participation/ exp human activities/ or exp "activities of daily living"/ or exp independent living/ or exp social participation/ or leisure activities/ Social Marginalization/ Health Services for Persons with Disabilities/ "activities of

daily living"/ or occupational therapy/ or rehabilitation, vocational/ *Self Care/ Occupations/ exp sports/ or return to sport/ or travel/ or work/ education/ or schools/ or *teaching/

Text words:

((meaningful or valu\$ or significant or everyday or purposeful) adj1 (activit\$ or leisure\$ or work or occupation\$)).tw

(social participation or community participation or activit\$ of daily li\$ or social role\$).tw

((restric\$ or limit\$ or reduc\$ or diminish\$ or decreas\$ or modif\$ or resum\$ or return to) adj5 (participat\$)).tw

(everyday li\$ or return to normal or daily li\$).tw

Concept Income

MeSH terms:

*Poverty/ social problems/ or social welfare/ or *community integration/ exp socioeconomic factors/ or poverty areas/ or *social class/ *Social Conditions/ Income/ *social capital/ *housing/ or *housing for the elderly/ or *public housing/ Economics/ Residence Characteristics/ Financing, Personal/ Economics, Medical/ Socioeconomic Factors/ Healthcare Disparities/

Text words:

(low\$ or lesser or high\$ or family or household or poor or neighbourhood) adj3 (income).tw

(Medicaid or poverty or disadvantage\$ or vulnerab\$ or inequality or unequal).tw

Concept Stroke

MeSH terms:

basal ganglia hemorrhage/ or brain ischemia/ or exp intracranial arterial diseases/ or "intracranial embolism and thrombosis"/ or intracranial embolism/ or intracranial thrombosis/ or intracranial hemorrhages/ or cerebral hemorrhage/ or intracranial hemorrhage, hypertensive/ or pituitary apoplexy/ or subarachnoid hemorrhage/ or stroke/ or brain infarction/ or stroke, lacunar/ Stroke Rehabilitation/

Text words:

(brain or subarachnoid) adj2 (hemorrhage\$ or ischemia or stroke or infarction or vascular accident).tw

(intracranial) adj2 (embol\$ or thrombos\$ or hemorrhag\$).tw

(cerebral) adj2 (infarct\$ or vascular accident or vascular apoplexia or stroke).tw

CINHAL database

Concept Participation

MeSH Terms:

(MH "Social Participation") OR

(MH "Leisure Activities") OR (MH "Human Activities+") OR (MH "Activities of Daily Living") OR (MH "Exercise") OR (MH "Home Maintenance") OR (MH "Holidays") OR (MH "Recreation") OR (MH "Mass Gathering") OR (MH "Physical Activity") OR (MH "Vacations") OR (MH "Work") OR (MH "Vehicle Operation") OR (MH "Rehabilitation+") OR (MH "Occupation (Human)") OR (MH "Sports+") OR (MH "Schools+")

Text words:

TX ((meaningful or valu* or significant or everyday or purposeful) n1 (activit* or leisure* or work or occupation*)) or (social participation or community participation or activit* of daily li* or social role*) or ((restric* or limit* or reduc* or diminish* or decreas* or modif* or resum* or return to) n5 (participat*)) or (everyday li* or return to normal or daily li*)

Concept Income

MeSH terms:

(MH "Healthcare Disparities") OR (MH "United States Centers for Medicare and Medicaid Services") OR (MH "Medicaid") OR (MH "Medicare") OR (MH "Financing, Government+") OR (MH "Insurance") OR (MH "Insurance, Health, Reimbursement") OR (MH "Reimbursement Mechanisms") OR (MH "Single-Payer System") OR (MH "Housing+") OR (MH "Homelessness") OR (MH "Residence Characteristics+") OR (MH "Social Capital") OR (MH "Social Welfare") OR (MH "Income") OR (MH "Poverty") OR (MH "Socioeconomic Factors") OR (MH "Social Class") OR (MH "Poverty Areas")

Text words:

TX (low* or lesser or high* or family or household or poor or neighbourhood) n3 (income)
TX (Medicaid or poverty or disadvantage* or vulnerab* or inequality or unequal)

Concept Stroke

MeSH Terms:

MH "Intracranial Hemorrhage") OR (MH "Cerebral Hemorrhage") OR (MH "Subarachnoid Hemorrhage") OR (MH "Cerebral Ischemia") OR (MH "Intracranial Embolism and Thrombosis") OR (MH "Carotid Artery Thrombosis") OR (MH "Intracranial Embolism") OR (MH "Intracranial Thrombosis") OR (MH "Intracranial Hemorrhage") OR (MH "Stroke") OR (MH "Stroke, Lacunar") OR (MH "Basal Ganglia Hemorrhage") OR (MH "Cerebral Aneurysm")

Text words:

TX (brain or subarachnoid) n2 (hemorrhage* or ischemia or stroke or infarction or vascular accident)
TX (intracranial) n2 (embol* or thrombos* or hemorrhage*)
TX (cerebral) n2 (infarct* or vascular accident or vascular apoplexia or stroke)

TX (brain or subarachnoid) n2 (hemorrhage* or ischemia or stroke or infarction or vascular accident) or (intracranial) n2 (embol* or thrombos* or hemorrhage*) or (cerebral) n2 (infarct* or vascular accident or vascular apoplexia or stroke)

PsychINFO database

Concept Participation

MeSH Terms:

athletic participation/ or participation/ or recreation/ or *social interaction/ or community involvement/ or involvement/ or volunteers/ or *marginalization/ or leisure time/ or daily activities/ or hobbies/ or holidays/ or recreation/ or relaxation/ or exp "activities of daily living"/ or exp occupations/ or exp daily activities/ or exp extracurricular activities/

Text words:

((meaningful or valu\$ or significant or everyday or purposeful) adj1 (activit\$ or leisure\$ or work or occupation\$)).tw
 (social participation or community participation or activit\$ of daily li\$ or social role\$).tw
 ((restric\$ or limit\$ or reduc\$ or diminish\$ or decreas\$ or modif\$ or resum\$ or return to) adj5 (participat\$)).tw
 (everyday li\$ or return to normal or daily li\$).tw

Concept Income

MeSH Terms:

social programs/ or housing/ OR
 socioeconomic status/ or family socioeconomic level/ or income level/ or lower class/ or social class/ or disadvantaged/ or economic security/ or "income (economic)"/ or poverty/
 Neighborhoods/
 Poverty/ or Lower Income Level/
 Poverty Areas/
 Health Disparities/
 economics/ or money/ or resource allocation/
 Financial Strain/
 Social Capital/
 income level/ or socioeconomic status/ or lower income level/ or middle income level/ or upper income level/ or financial strain/ or "income (economic)"/ or salaries/ or social class/
 MEDICAID/

Text words:

(low\$ or lesser or high\$ or family or household or poor or neighbourhoood) adj3 (income).tw
 (Medicaid or poverty or disadvantage\$ or vulnerab\$ or inequality or unequal).tw

Concept Stroke

MeSH terms:

cerebrovascular accidents/ or cerebral hemorrhage/ or subarachnoid hemorrhage/ or cerebral ischemia/

Text words:

(brain or subarachnoid) adj2 (hemorrhage\$ or ischemia or stroke or infarction or vascular accident).tw

(intracranial) adj2 (embol\$ or thrombos\$ or hemorrhag\$).tw

(cerebral) adj2 (infarct\$ or vascular accident or vascular apoplexia or stroke).tw

Appendix B

Interview Guide for the Participant

Introduction to the study:

We are hoping to better understand your experience of having a stroke and of trying to get back to those everyday activities that are meaningful to you. As previously discussed, this first interview should last no more than 3 hours and will be digitally recorded. Please feel free to stop me at any time if you have questions or concerns, or if you would like to stop the interview.

First interview session		
Question	Probes/Guidance	Information to obtain
Tell me about your stroke.	When did it happen? Where did you go, what programs did you attend?	Stroke details Timeline of events Treatment and Services
People have all kinds of activities or concerns that are important to them at different times in their lives. These can be called “projects”, and they are the goals, concerns, things that we are planning, thinking about, working on or working towards. They can be related to any part of your life (insert examples). Tell me what about your projects prior to your stroke.	What activities or projects were meaningful to you before your stroke? Think of different aspects of your life: work, school, community, social outings, family life,...	Pre-stroke meaningful projects/ activities/tasks/ occupations (everyday life).
What types of projects are you thinking about/working on now? What about 3-4 months ago?	What are you working towards or doing that is meaningful to you? How are these projects different compared to prior to the stroke and over the last 3-4 months?	Current and recent meaningful projects/ activities/ tasks/ occupations since stroke (everyday life). Differences between pre and post stroke projects.
4. Tell me about your experience of trying to return to participation or of trying to get back to these projects since the stroke?	What tasks/activities/roles or projects where you able to get back to and why? What tasks/activities/roles or projects have you not been able to get back to and why? What do you think helped/didn't help you and why? Social support, assistance Transportation Services, programs Neighbourhood/ community access Equipment ... Can you explain how you went	Self-reported participation restrictions Obstacles/facilitators (e.g. environmental factors, personal factors) Process of return to participation

	about trying to get back to the task/activity/role or projects?	
5. You mentioned factors X as being helpful/unhelpful when trying to get back to projects/ activities after the stroke. Were these factors present/absent before the stroke as well?	How was your social support, transportation, neighbourhood, etc. before the stroke?	Self-reported pre-stroke situation
6. This research is looking at income and the impact it might have on participation after a stroke. Do you think that living in a low-income situation has affected your ability to participate before the stroke? And since the stroke? If yes, how? If no, how has it not affected?	Did your reduced income limit you from doing or acquiring something? Did your reduced income help you obtain or have access to something?	Perception of impact of income on participation
Has being a francophone minority affected your participation in projects/ tasks/ activities before the stroke? And since the stroke? If yes, how? If no, how has it not affected?	Was there a language barrier to, for example, access services or other opportunities? Did being a francophone help you or not help you in any way?	Perception of impact of linguistic minority situation on participation
How do you perceive yourself and your situation compared to your community/linguistic social group?	Do you feel you or your situation is similar or different than others (low income, francophone)? Do you think that others in your situation would be experiencing the same thing?	Self-perception of 'fit' within social group.
9. Discuss next session: participant –observation and timeline (dependent on chosen activity/ task/ occupation to be observed).		
Second interview session		
(Ask remaining questions from first interview session)		
Complete Participant Observation		
Third interview session		
1. REVIEW INTERPRETATIONS		
2. Can you tell me how many years of school you were able to complete?		Education
3. What is your mother tongue/first language?		Language/ culture
4. Are you receiving government supports?	Can you give me an idea about your income and sources of income? Where you receiving this same support before the stroke?	Income and governmental supports/ supplements
5. Do you own your own home or are you renting?		Housing and wealth
6. COMPLETE ASSESSMENTS: SIS, HADS, ICF Checklist (Participation), Evaluation of bilingualism		
Fourth Interview Session		
Complete any remaining questions or assessments.		

Appendix C

Interview Questions for the Care Partner

Introduction to the study:

We are hoping to better understand (insert participant's name)'s experience of trying to get back to those everyday activities that are meaningful to him/her since the stroke. As previously discussed, the interview should last no more than 2 hours and will be audio recorded. Please feel free to stop me at any time if you have questions or concerns, or if you would like to stop the interview.

Questions	Probes/guidance	Information to obtain
1. What is your relationship to the participant?		Type of support/ relationship
2. If not living with the participant, how often do you see/visit the participant?		Type of support/ relationship
3. What can you tell me about the participant's stroke?	When did it happen? Where did she/he go afterwards? What programs or treatment did they receive?	Stroke details Timeline of events Treatment and Services
People have all kinds of activities or concerns that are important to them at different times in their lives. These can be called "projects", and they are the goals, concerns, things that we are planning, thinking about, working on or working towards. They can be related to any part of life (insert examples). Can you tell me about (insert participant name)'s projects prior to the stroke? What were they involved with or working towards?	What activities or projects were meaningful to them before the stroke? Think of different aspects of life: work, school, community, social outings, family life,...	Pre-stroke meaningful activities/tasks/ occupations (everyday life).
What types of projects are they thinking about/working on now? What about 3-4 months ago?	What are they working towards or doing that is meaningful to them? How are these projects different compared to prior to the stroke and over the last 3-4 months?	Current and recent meaningful activities/ tasks/ occupations since stroke (everyday life). Differences between pre and post stroke projects.
5. Can you tell me about (insert participant name)'s experience of attempting to return to participation or of trying to get back to his/her everyday activities or projects after the stroke?	What activities/tasks/roles or projects has the participant been able to get back to and what activities/tasks/roles have they not been able to get back to? What do you think helped or did not help him/her get back to these activities or projects?	Proxy reported participation restrictions Obstacles/facilitators (e.g. environmental factors, personal factors) Process of return to participation

	<p>Social support, assistance Transportation Services, programs Neighbourhood/ community access Equipment ... Can you explain how they went about trying to get back to the task/activity/role?</p>	
<p>6. You mentioned factors X as being helpful/unhelpful to (participant's name) when trying to get back to activities/ projects after the stroke. Where these same factors present/absent before the stroke as well?</p>	<p>How was their social support, transportation, neighbourhood, etc. before the stroke?</p>	<p>Proxy reported pre-stroke situation</p>
<p>7. This research is looking at income and the impact it might have on participation after a stroke. Do you think that living in a low-income situation has affected (insert participant name)'s ability to participate since the stroke? If yes, how? If no, how has it not affected?</p>	<p>Did their reduced income limit them from doing or acquiring something? Did their reduced income help them obtain or have access to something?</p>	<p>Perception of impact of income on participation</p>
<p>8. Has being a francophone minority affected (participant's name) ability to participate before the stroke? And since the stroke? If yes, how? If no, how has it not affected?</p>	<p>Was language a barrier to, for example, services, opportunities? Did being a francophone help them in any way?</p>	<p>Perception of impact of linguistic minority situation on participation</p>
<p>9. How do you perceive (participant's name) and (his/her) situation compared to your community/linguistic social group?</p>	<p>Do you feel that they and their situation are similar or different than others (low income, francophone)? Do you think that others in this situation would be experiencing the same thing?</p>	<p>Proxy perception of 'fit' within social group.</p>

Appendix D

Chart Review Guide

Age

Diagnosis

Medications

Comorbidities and past medical history

Affected body structures or body functions (ex. balance issues, high tone, cognitive impairments, depression)

Initial and discharge functional status (ex. FIM scores) and participation status

References to environmental factors or personal factors impacting function and/or participation

References to needs (i.e., equipment, support), including referral to social work services

References to income

Appendix E

Participant observation form

Date: _____

Location: _____

Activity/task being observed:

Context:

Description of the environment:

Description of the participant in interaction with the environment (i.e., social, physical, linguistic):

Description of the participant participating in the activity.

Appendix F

Table of the research data sources by case

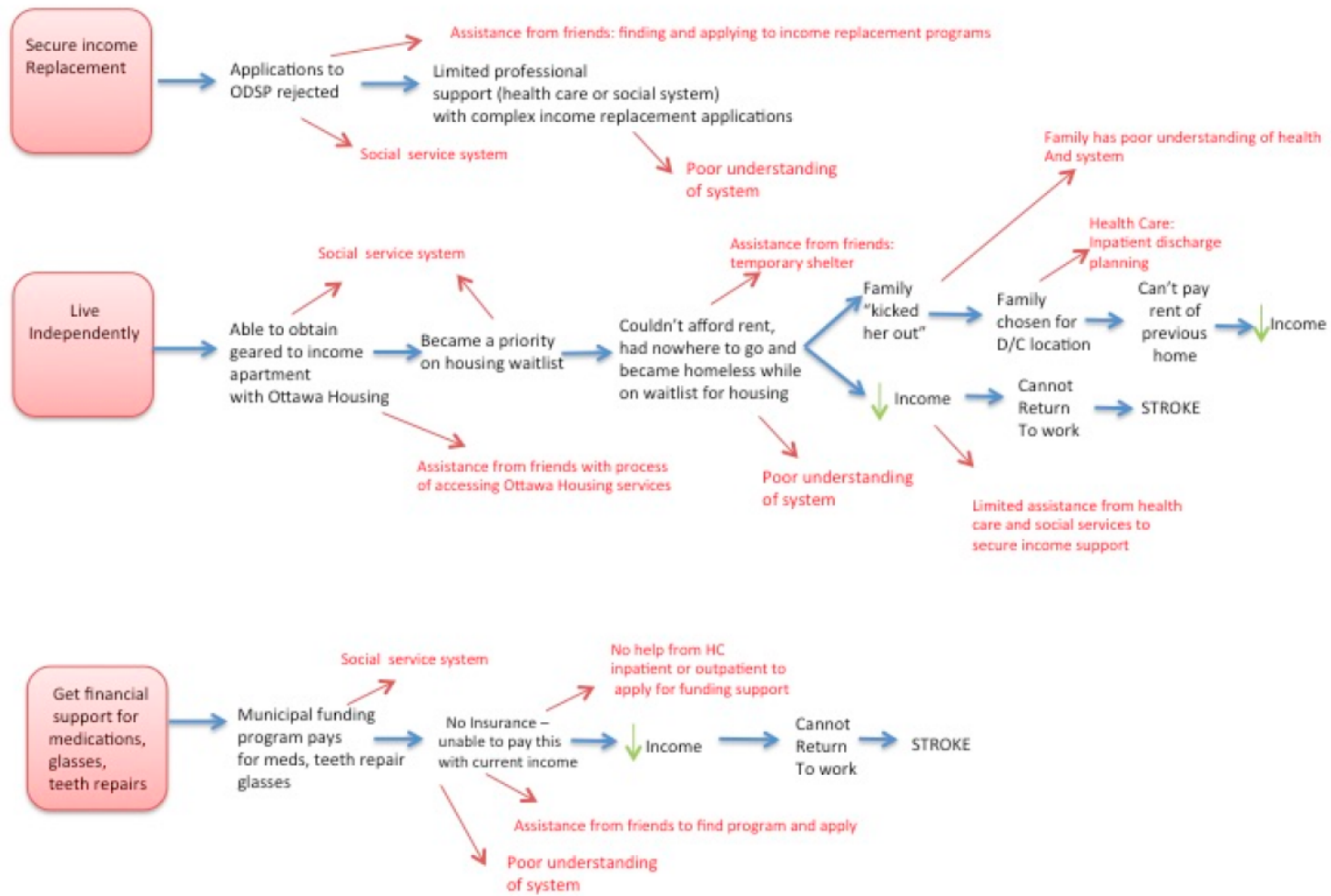
Case	Data source		
Case 001	Interviews with Charlotte	Approximate interview time: Interview 1: 1 hour 55minutes Interview 2: 2 hours 30 minutes Interview 3 (member check): 1 hour 5 minutes	Period of involvement: Interview 1: April 2016 Interview 2: April 2016 Interview 3: January 2017
	Interview with care partner Natalie	Interview: 2 hours 30 minutes	Interview: April 2016
	Measures	HADS, SIS-16, ICF Checklist (Version 2.1a) Participation subsection, Assessment of bilingualism	
	Review of records	<i>Clinique interprofessionnelle</i> , acute care hospital, inpatient short-term rehabilitation program	
	Participant observations	Observation guide filled in for sessions 1 and 2	
Case 002	Interviews with Paul	Approximate interview time: Interview 1: 1 hour 55 minutes Interview 2: 1 hour 30 minutes Interview 3 (member check): loss to follow up	Period of involvement: Interview 1: March 2016 Interview 2: April 2016 Interview 3: loss to follow up
	Interview with care partner Simon	Interview: 1 hour 20 minutes	Interview: April 2016
	Measures	HADS, SIS-16, ICF Checklist (Version 2.1a) Participation subsection, Assessment of bilingualism	
	Review of records	<i>Clinique interprofessionnelle</i>	
	Participant observations	Observation guide filled in for sessions 1 and 2, plus for consent session	
Case 003	Interviews with Jackie	Approximate interview time: Interview 1: 45 minutes Interview 2: 30 minutes Interview 3 (member check): 30 minutes	Period of involvement: Interview 1: June 2016 Interview 2: July 2016 Interview 3: March 2017
	Interview with care partners Luc and	Interview: 2 hours 10 minutes	Interview: May 2106

	Marilyn		
	Measures	HADS, SIS-16, ICF Checklist (Version 2.1a) Participation subsection, Assessment of bilingualism	
	Review of records	<i>Clinique interprofessionnelle</i> , acute care hospital	
	Participant observations	Observation guide filled in for sessions 1 and 2	
Case 004	Interviews with Laurent	Approximate interview time: Interview 1: 1 hour 55 minutes Interview 2: 2 hours Interview 3 (member check): 1 hour	Period of involvement: Interview 1: May 2016 Interview 2: May 2016 Interview 3: January 2017
	Interview with Armand	Interview: 1 hour 55 minutes	Interview: June 2016
	Measures	HADS, SIS-16, ICF Checklist (Version 2.1a) Participation subsection, Assessment of bilingualism	
	Review of records	<i>Clinique interprofessionnelle</i> , acute care hospital, inpatient short-term rehabilitation program	
	Participant observations	Observation guide filled in for sessions 1 and 2	
Case 005	Interviews with Aimée	Approximate interview time: Interview 1: 1 hour (with daughter) Interview 2: 55 minutes Interview 3 (member check): 30 minutes (with daughter)	Period of involvement: Interview 1: May 2016 Interview 2: May 2016 Interview 3: January 2016
	Interview with care partner Marie	Interview: 1 hour 15 minutes	Interview: May 2016
	Measures	HADS, SIS-16, ICF Checklist (Version 2.1a) Participation subsection, Assessment of bilingualism	
	Review of records	<i>Clinique interprofessionnelle</i> , acute care hospital, inpatient short-term rehabilitation program	
	Participant observations	Observation guide filled in for sessions 1 and 2	
Case 006	Interviews with Josée	Approximate interview time: Interview 1: 1 hour 15 minutes (with mother) Interview 2: 45 minutes Interview 3 (member check): 40 minutes (with	Period of involvement: Interview 1: May 2016 Interview 2: June 2016 Interview 3: April 2017

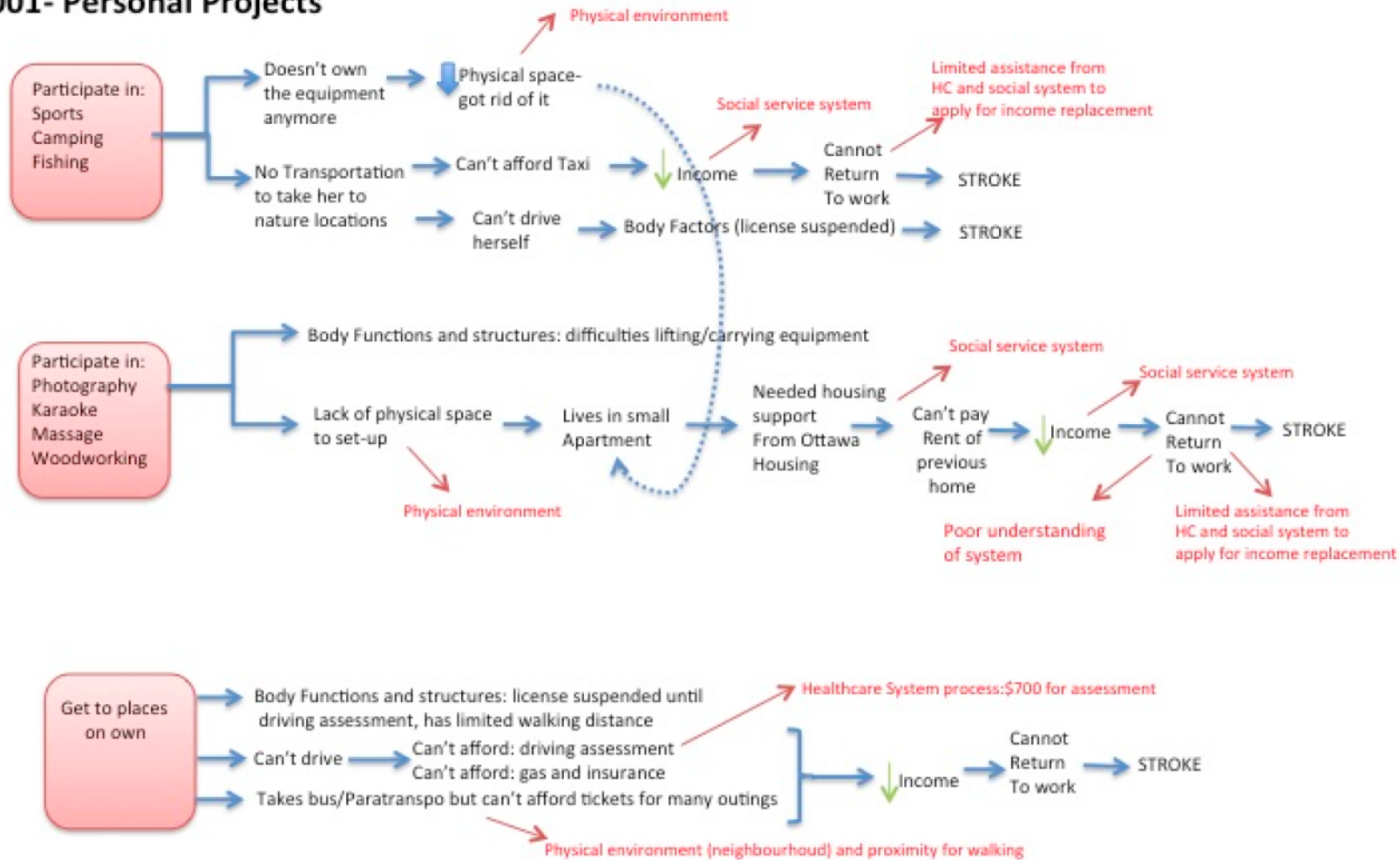
		mother)	
	Interview with care partner Denise	Interview: 1 hour 25 minutes	Interview: June 2016
	Measures	HADS, SIS-16, ICF Checklist (Version 2.1a) Participation subsection, Assessment of bilingualism	
	Review of records	<i>Clinique interprofessionnelle</i> , acute care hospital	
	Participant observations	Observation guide filled in for sessions 1 and 2	
Case 007	Interviews with Sylvain	Approximate interview time: Interview 1: 1 hour 30 minutes Interview 2: 1 hour 50 minutes Interview 3 (member check): 1 hour 40 minutes	Period of involvement: Interview 1: July 2016 Interview 2: August 2016 Interview 3: April 2017
	Interview with care partner Angèle	Interview: 1 hour 30 minutes	Interview: October 2016
	Measures	HADS, SIS-16, ICF Checklist (Version 2.1a) Participation subsection, Assessment of bilingualism	
	Review of records	<i>Clinique interprofessionnelle</i> , acute care hospital	
	Participant observations	Observation guide filled in for sessions 1 and 2	
Case 008	Interviews with Daniel	Approximate interview time: Interview 1: 1 hour 20 minutes Interview 2: 1 hour 15 minutes Interview 3 (member check): 45 minutes	Period of involvement: Interview 1: September 2016 Interview 2: November 2016 Interview 3: April 2017
	Interview with care partner Solange	Interview: 1 hour 5 minutes	Interview: September 2016
	Measures	HADS, SIS-16, ICF Checklist (Version 2.1a) Participation subsection, Assessment of bilingualism	
	Review of records	<i>Clinique interprofessionnelle</i> , acute care hospital	
	Participant observations	Observation guide filled in for sessions 1 and 2	

Appendix G

001- Personal Projects



001- Personal Projects

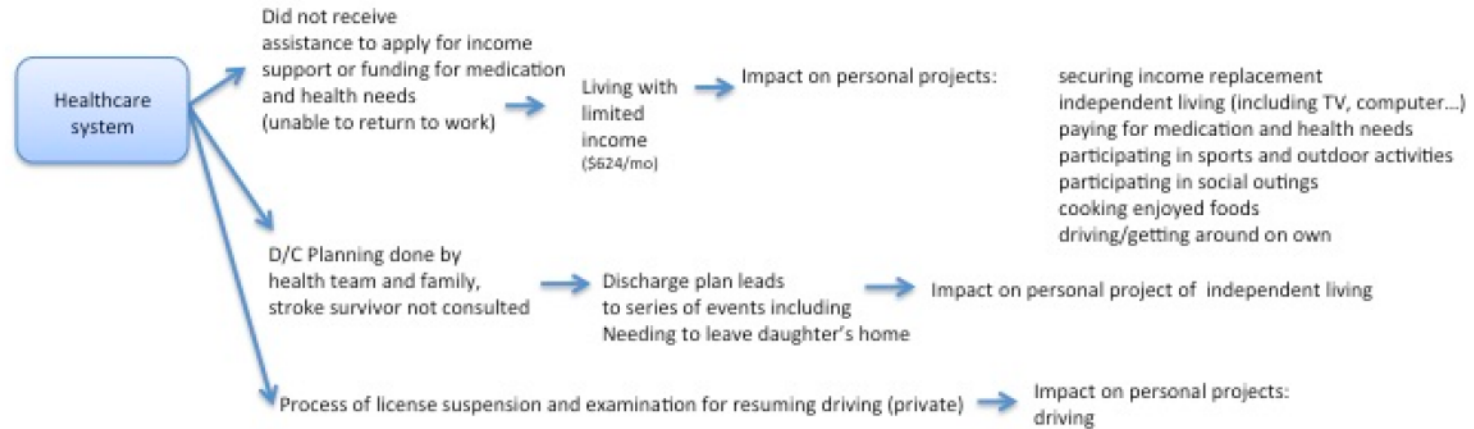


001- Personal Projects

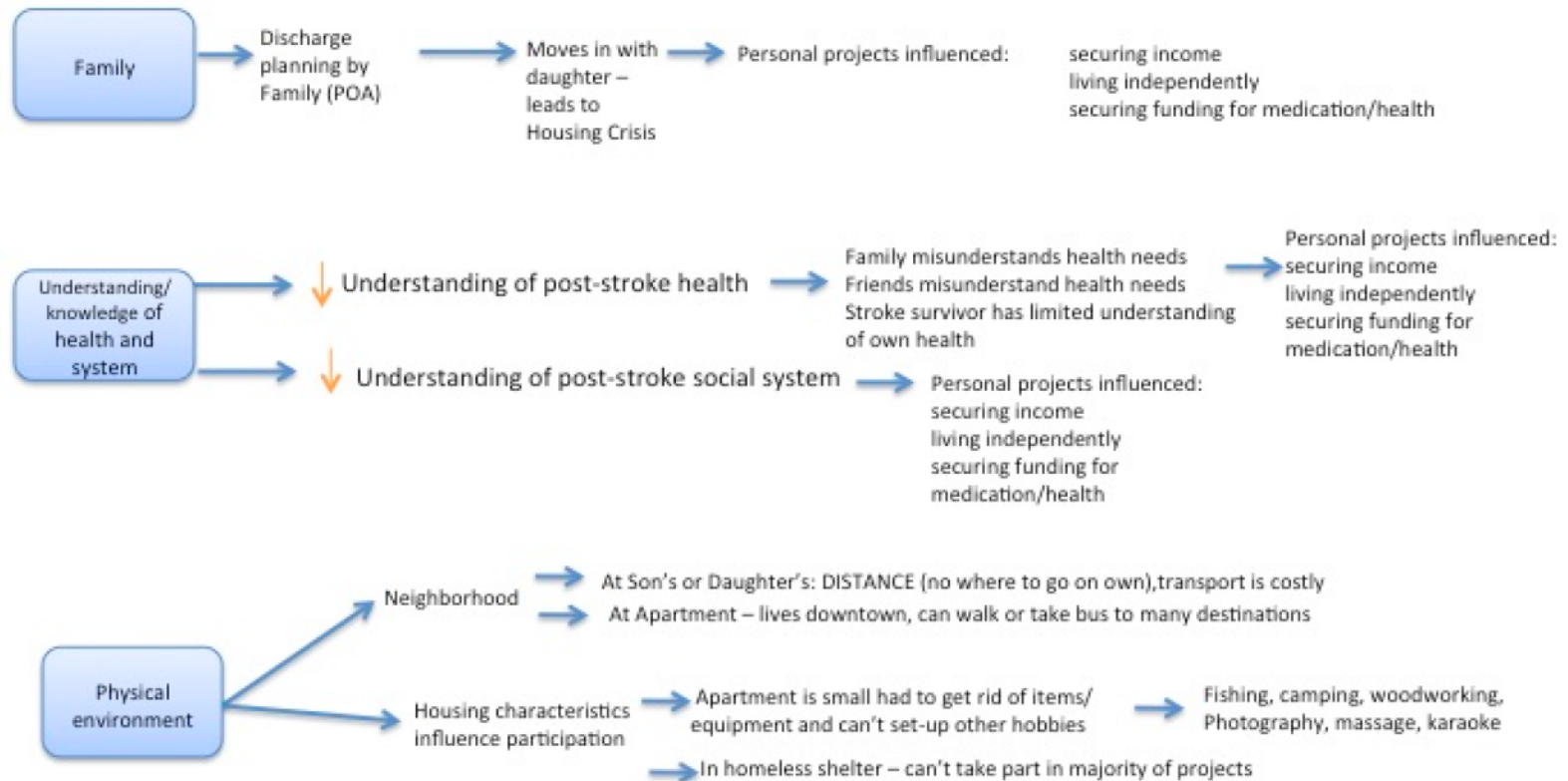


Appendix H

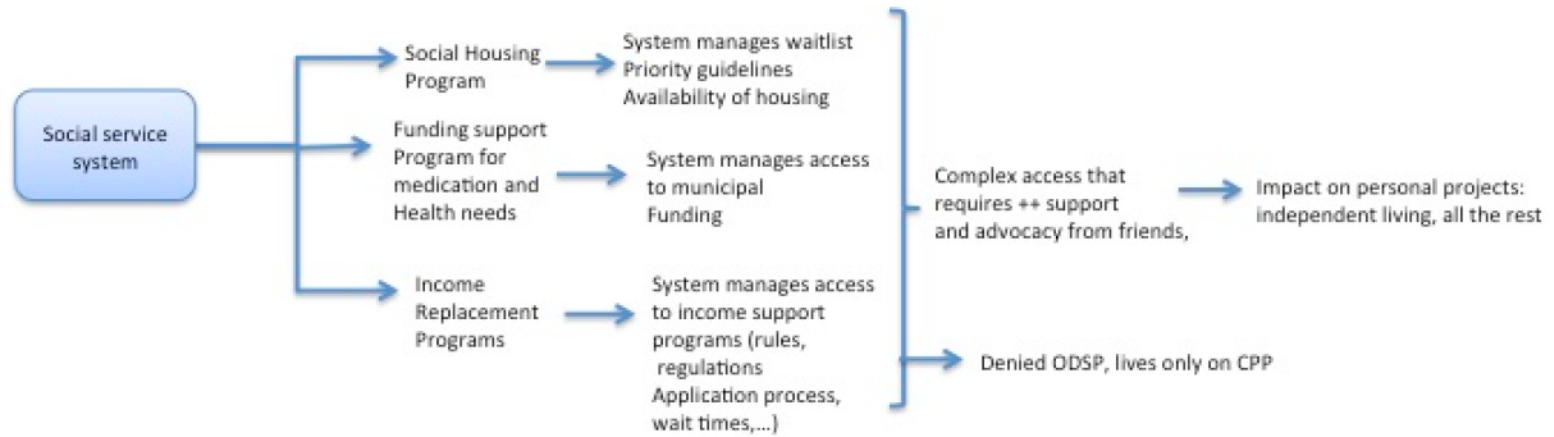
001- Patterns



001- Patterns

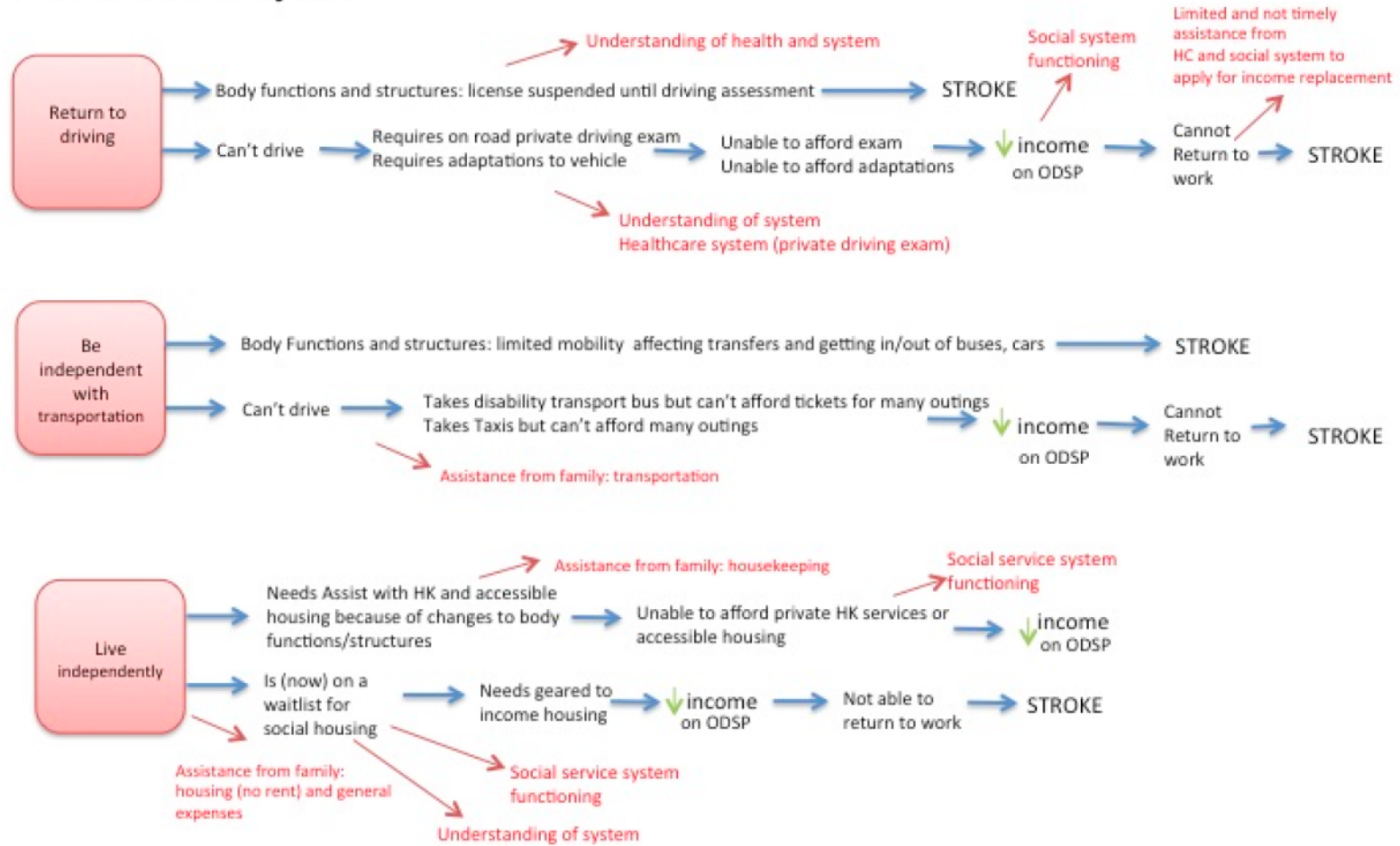


001- Patterns

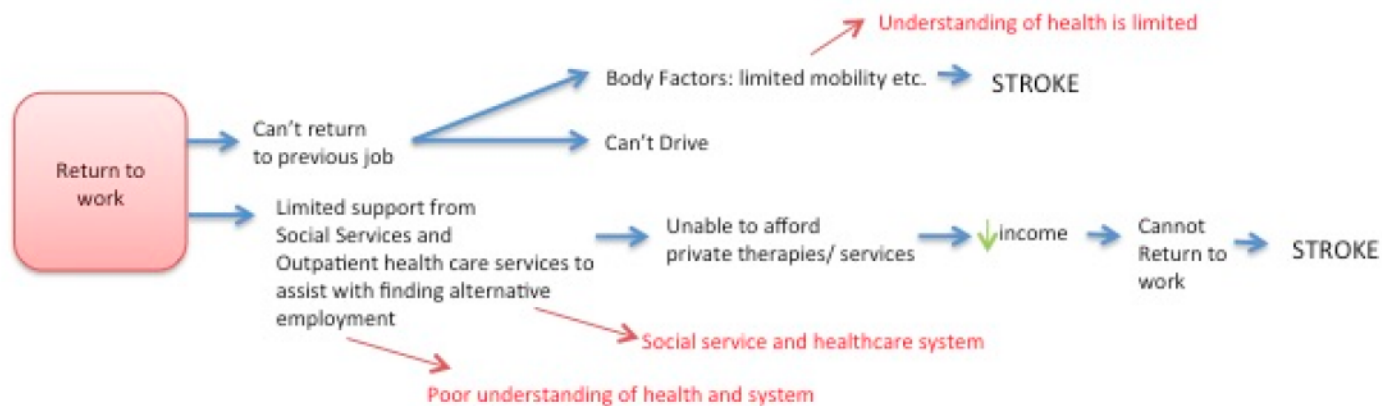
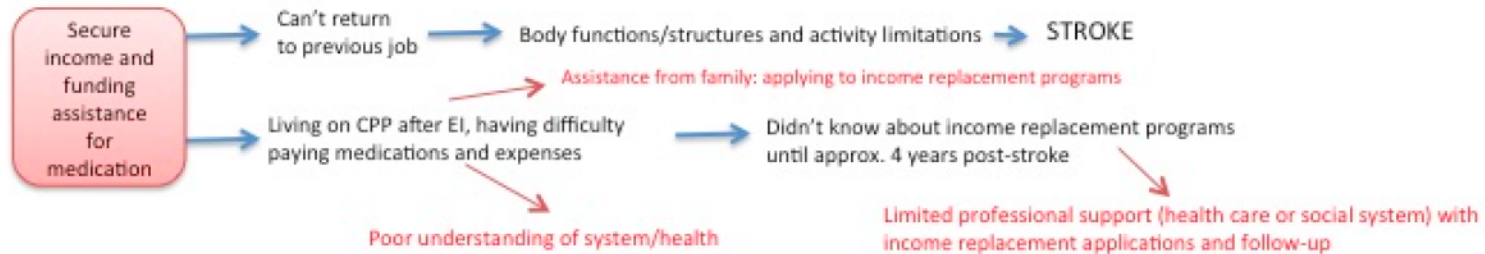


Appendix I

002 – Personal Projects

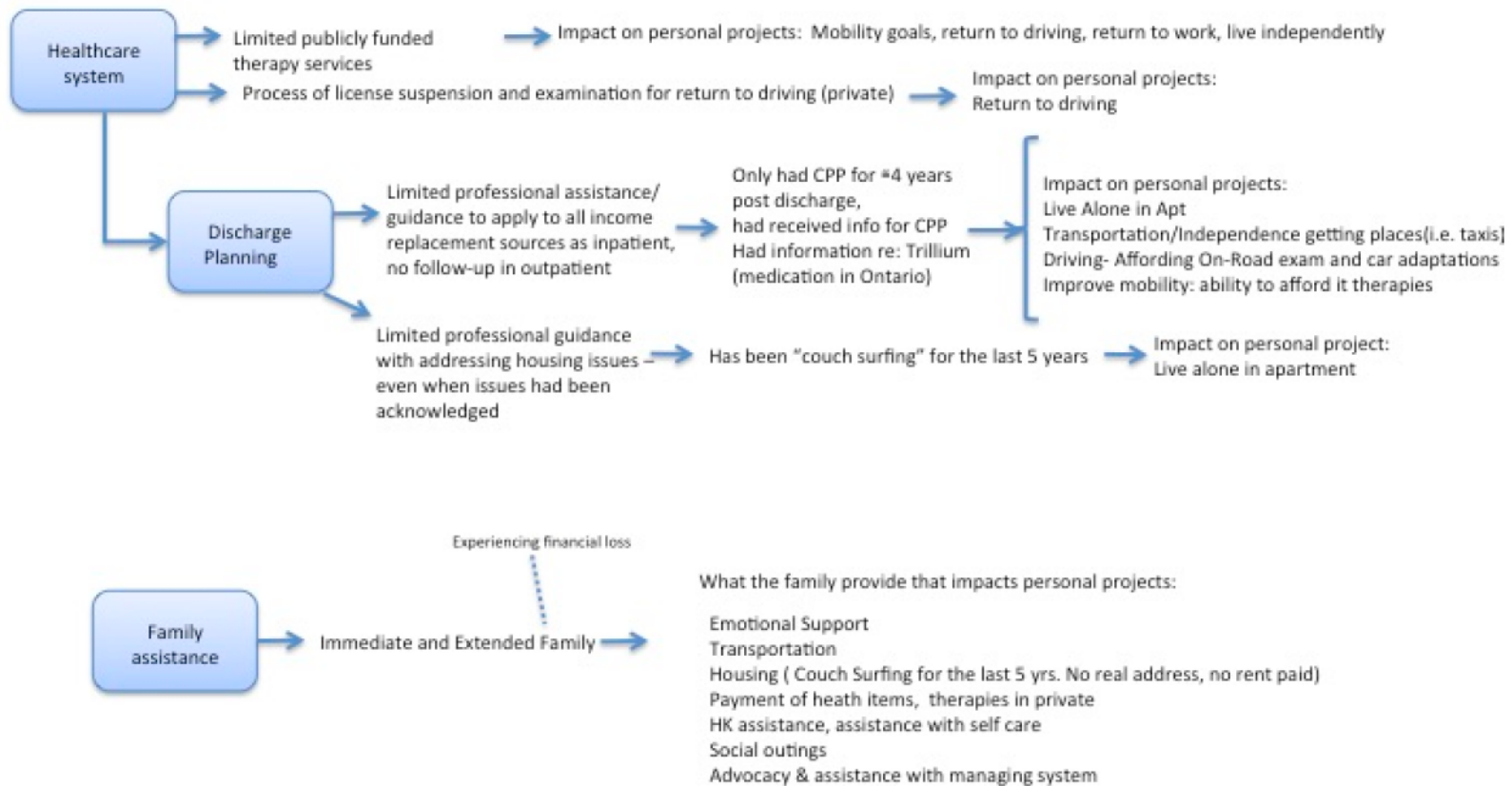


002 – Personal Projects

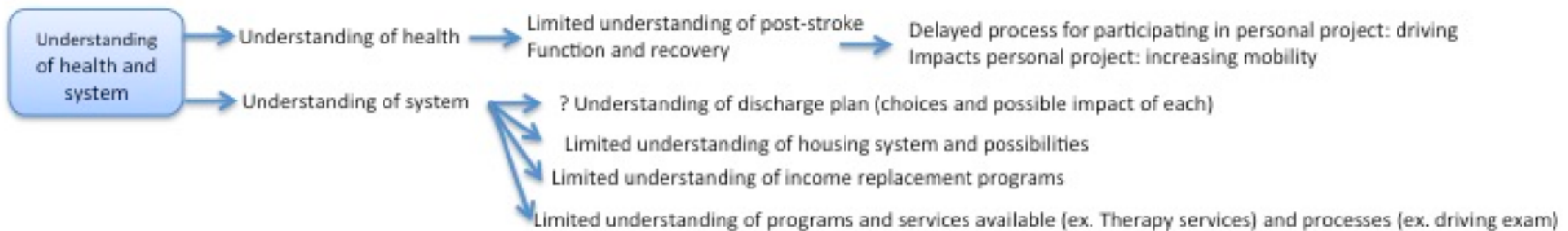
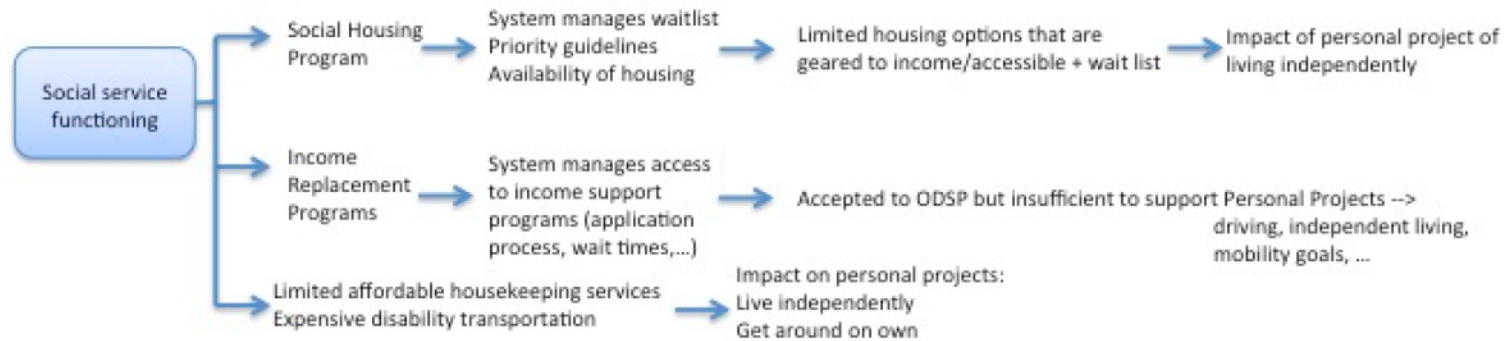


Appendix J

002 – Patterns

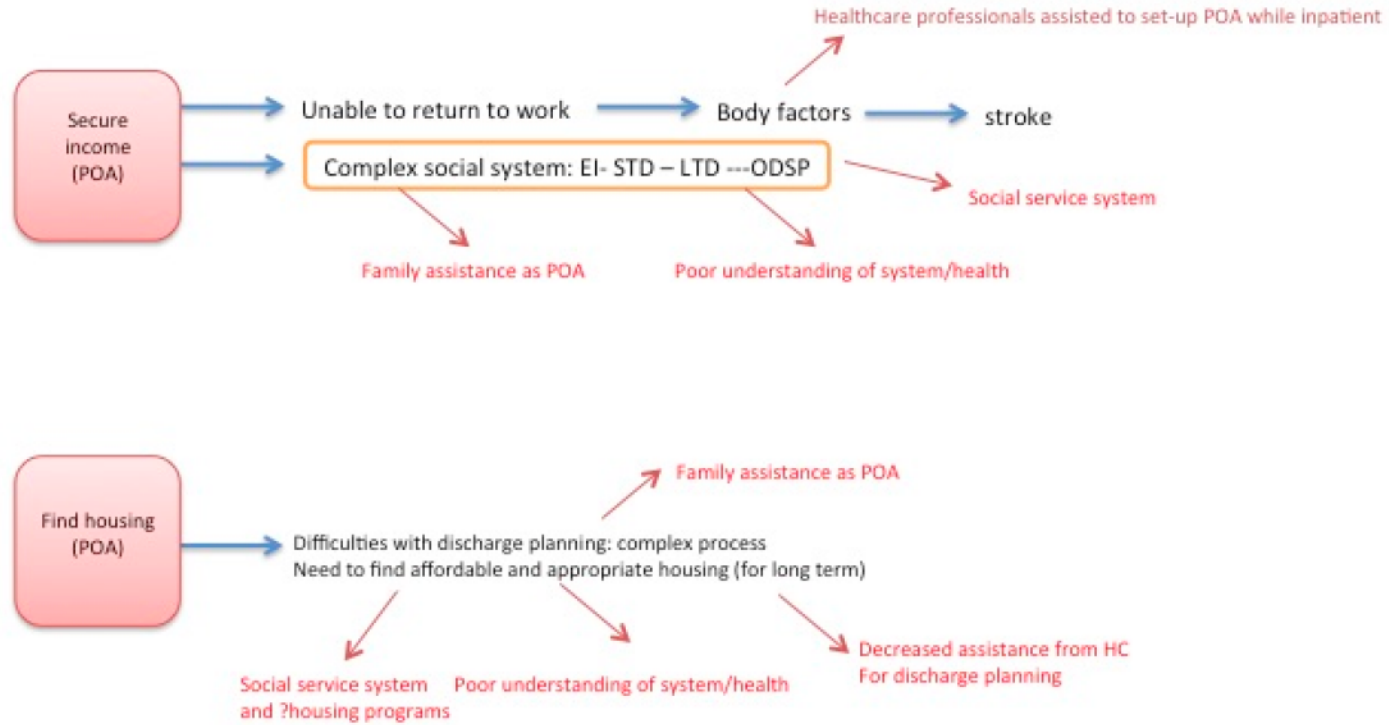


002 – Patterns

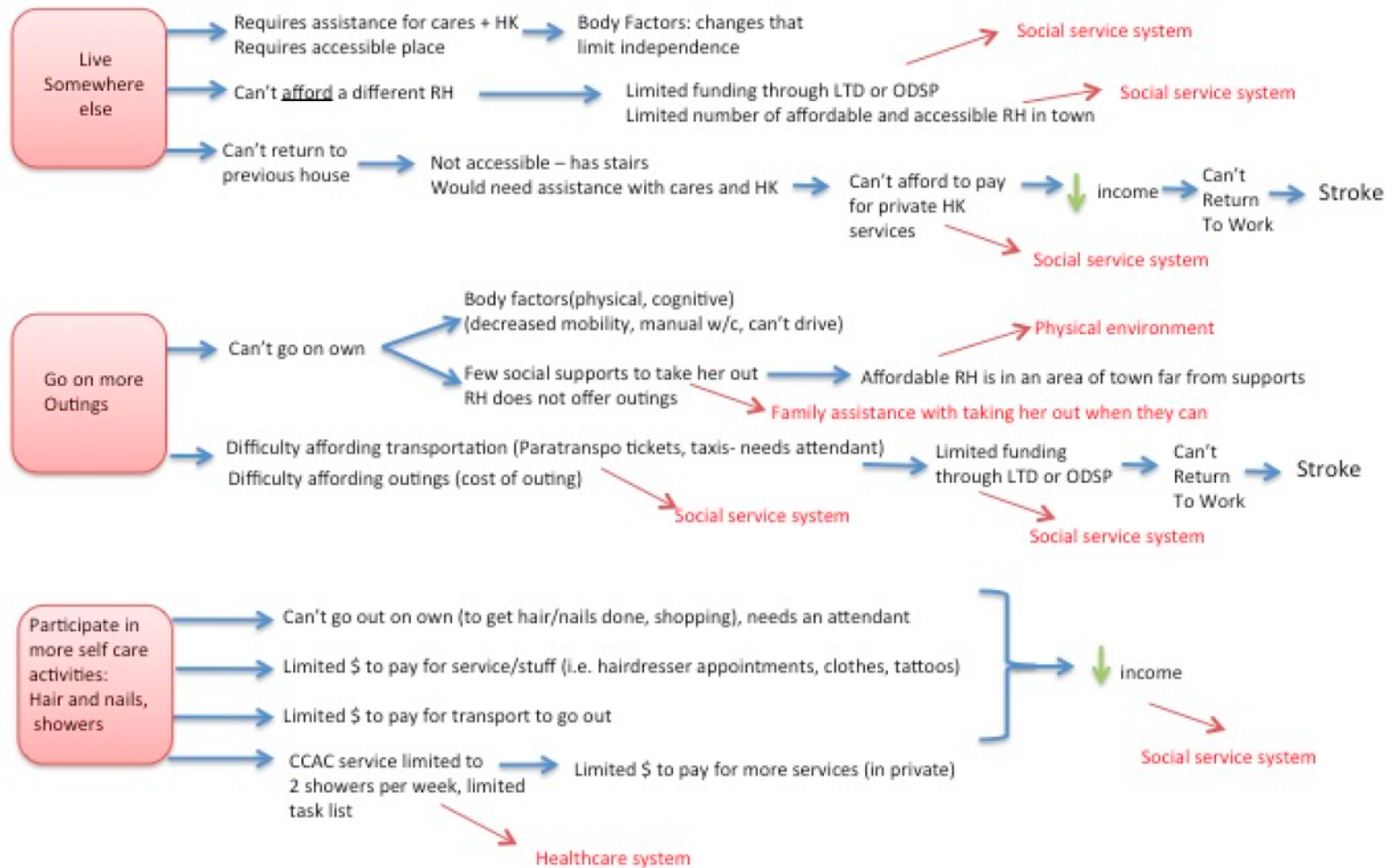


Appendix K

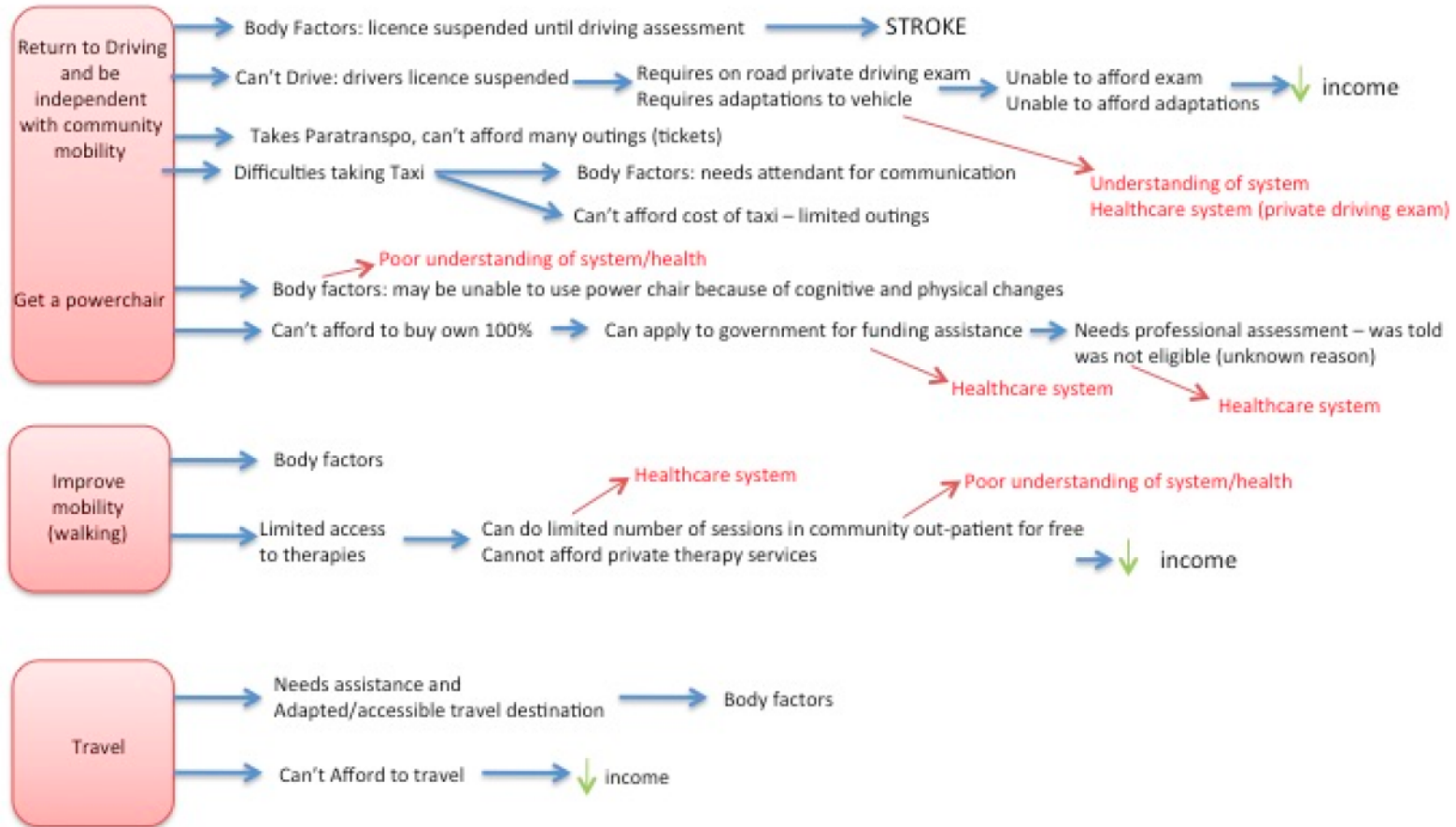
003 – Personal Projects



003 – Personal Projects

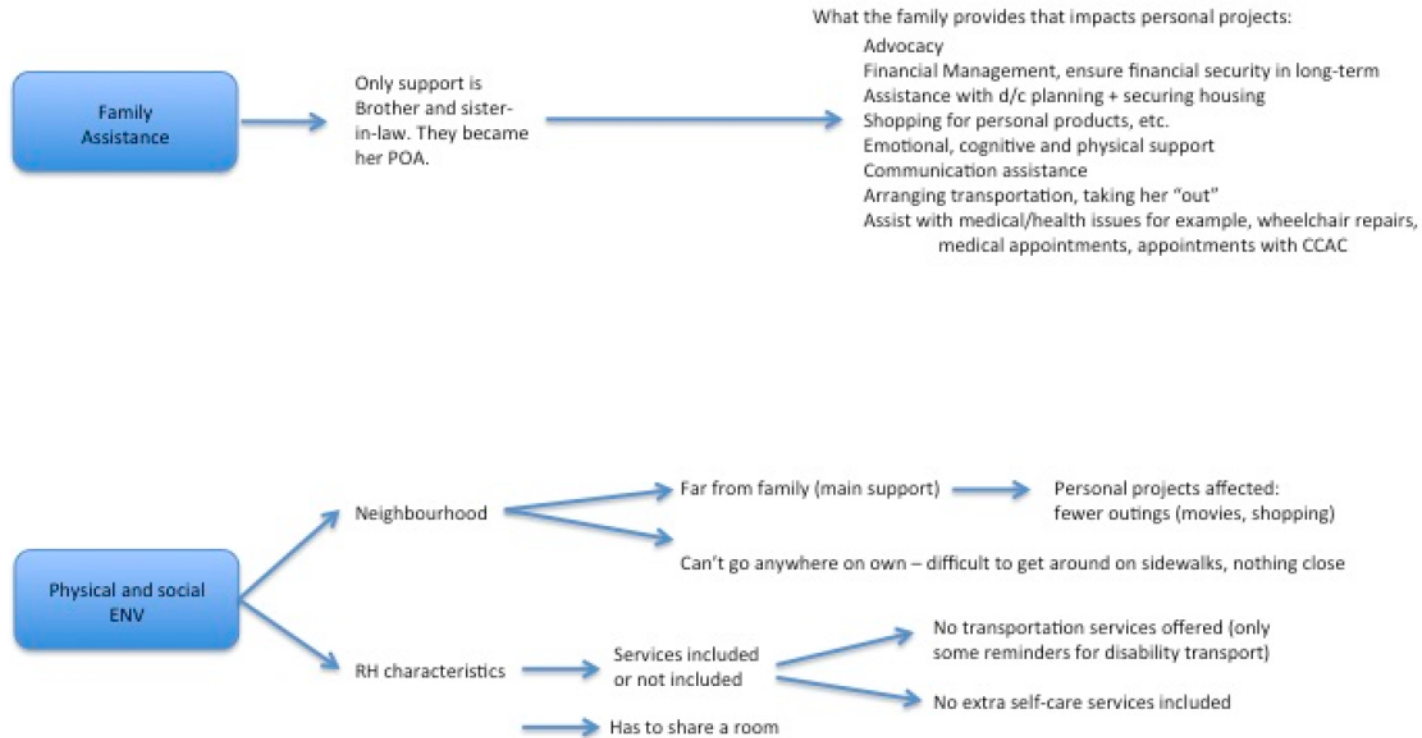


003 – Personal Projects

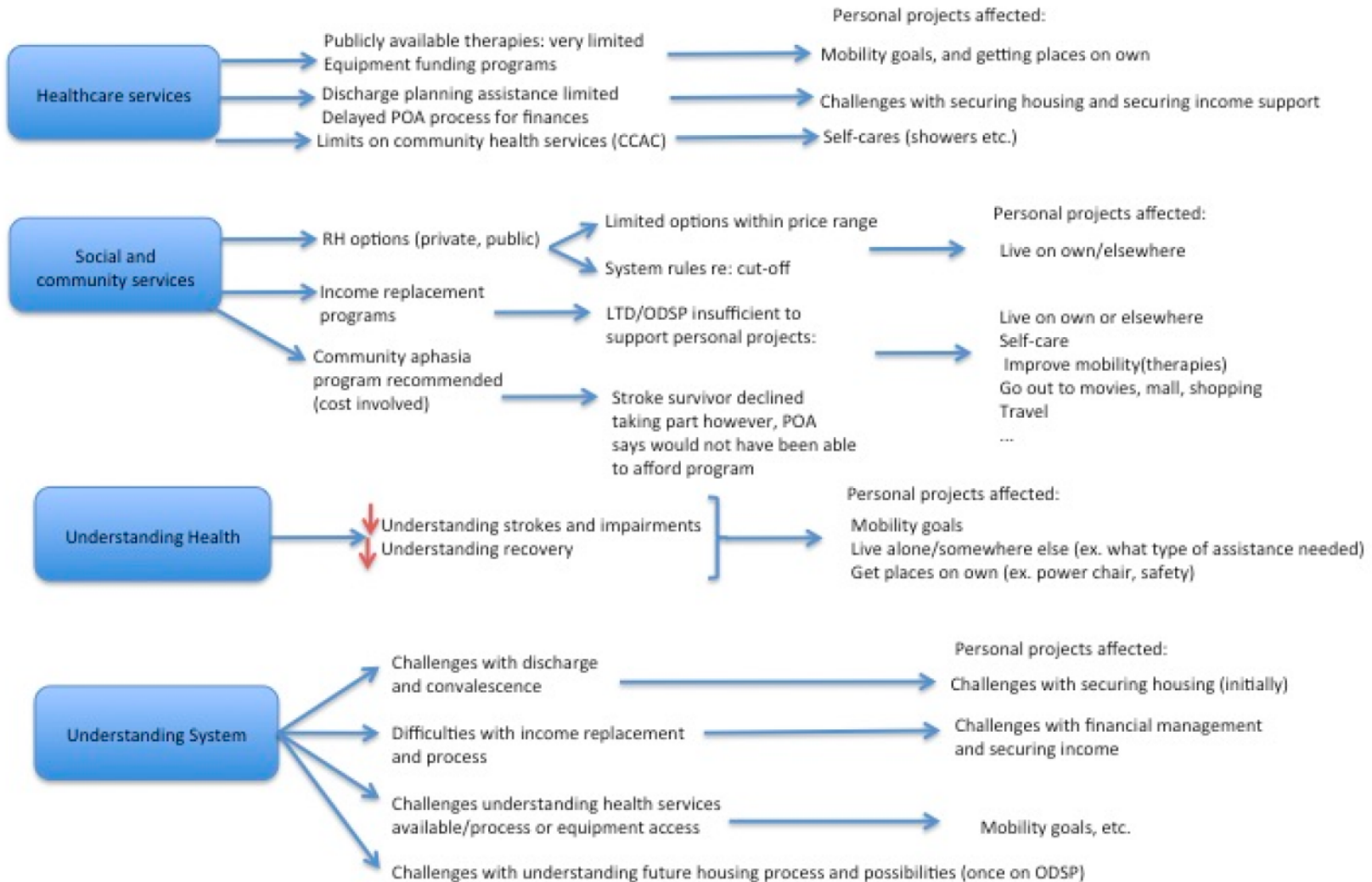


Appendix L

003 – Patterns

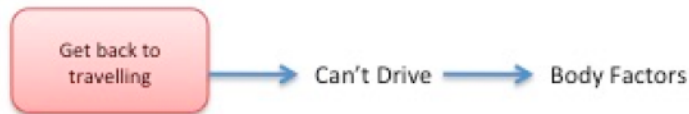


003 – Patterns

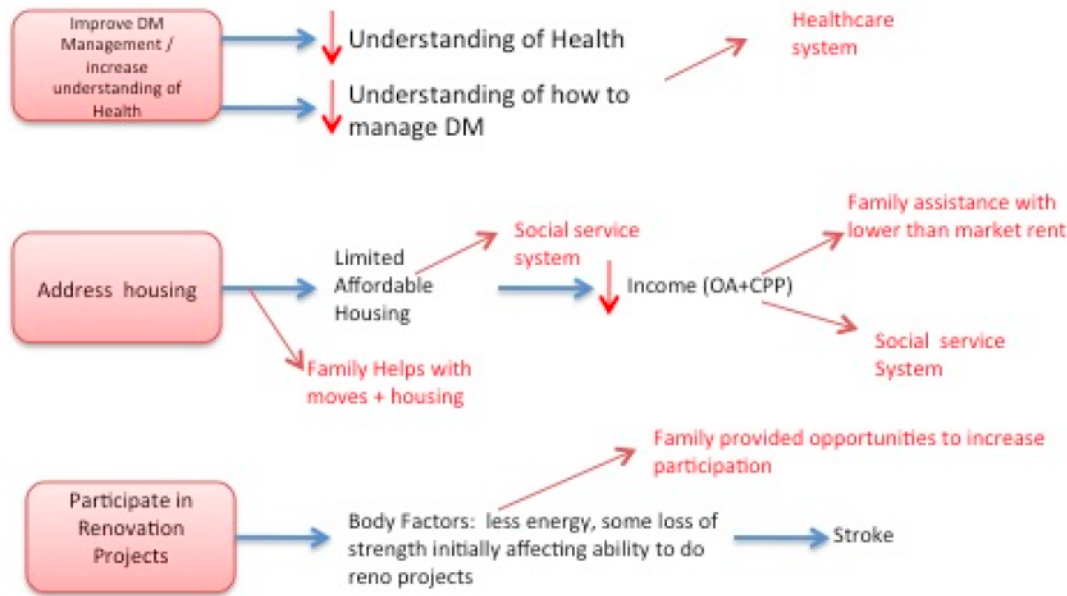


Appendix M

004 – Personal Projects

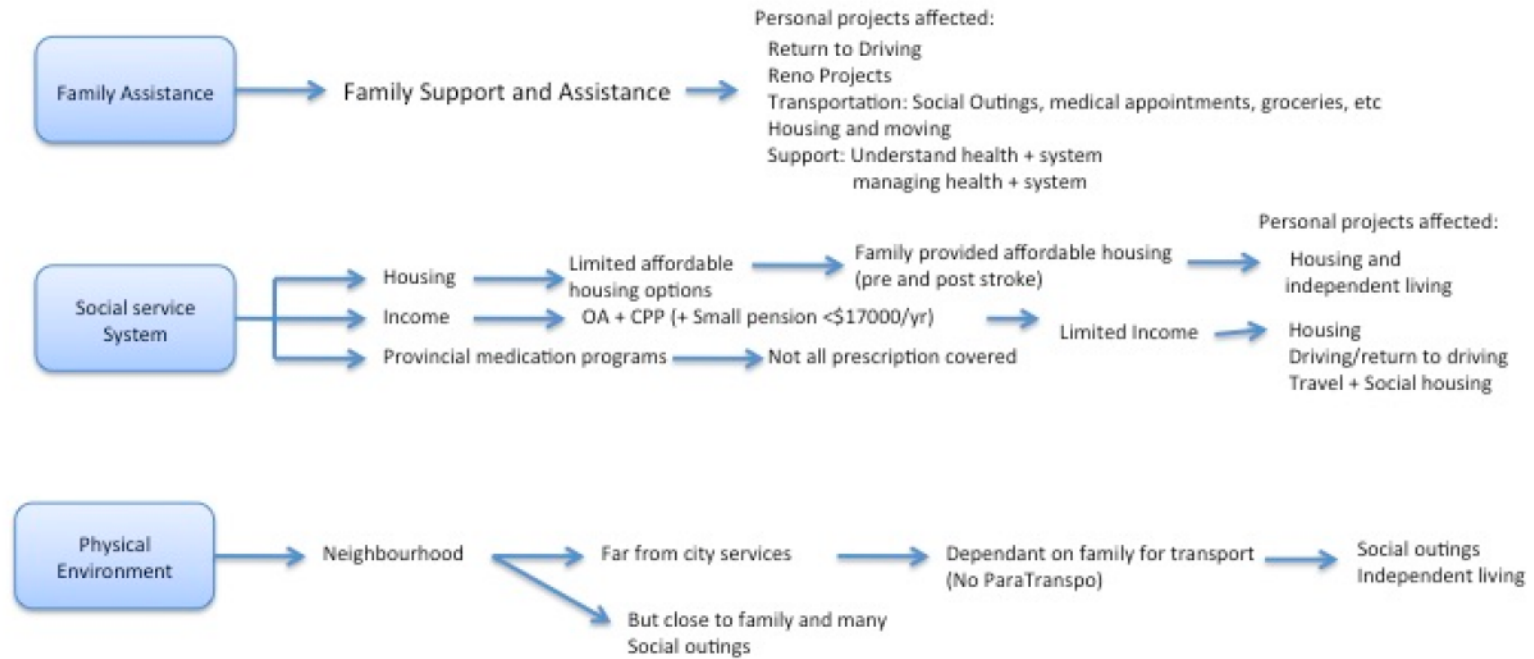


004 – Personal Projects

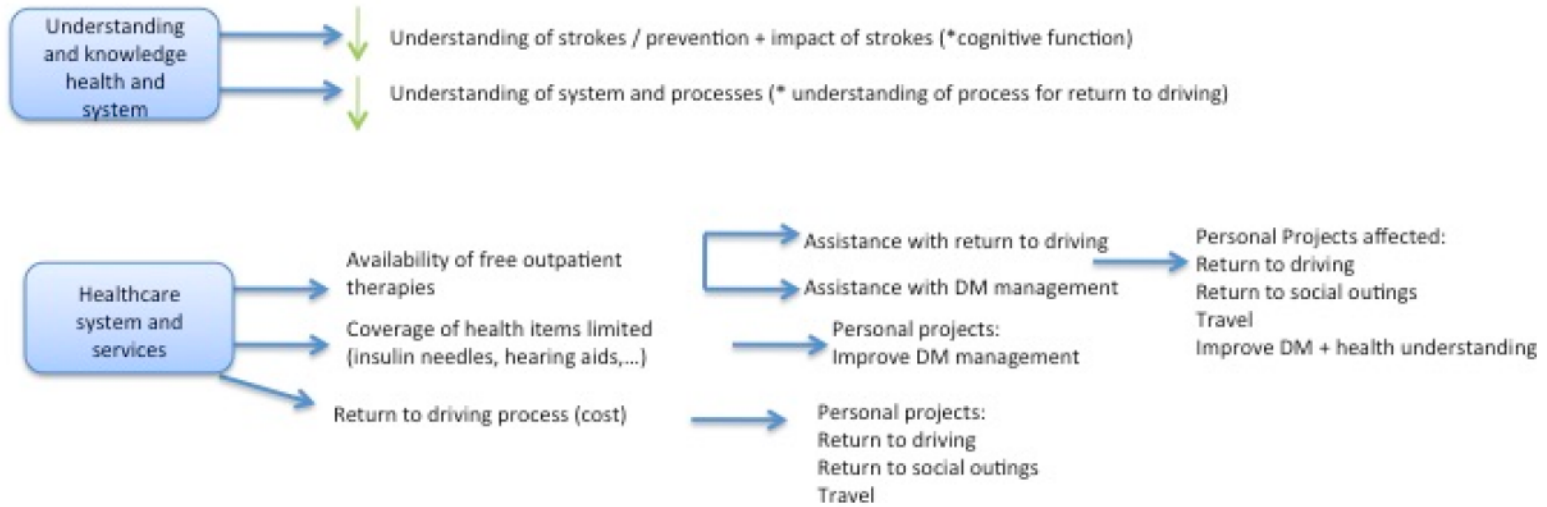


Appendix N

004 – Patterns

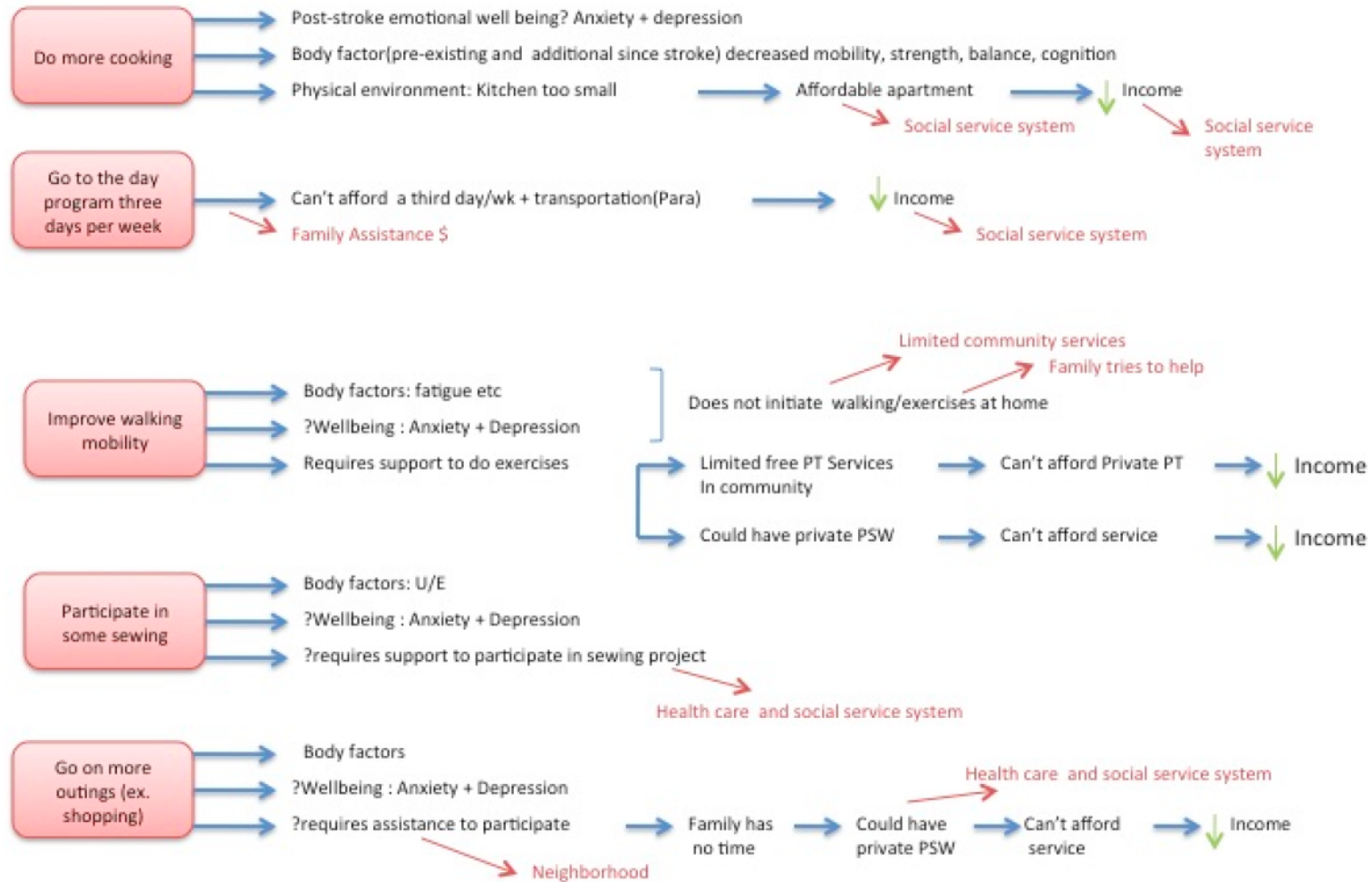


004 – Patterns

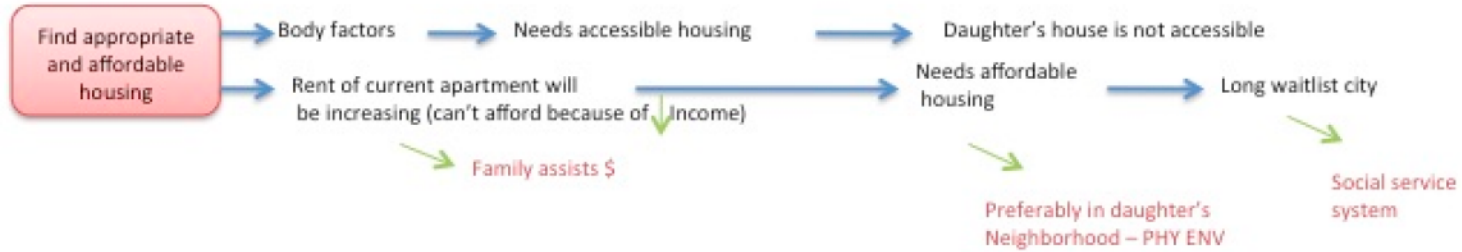
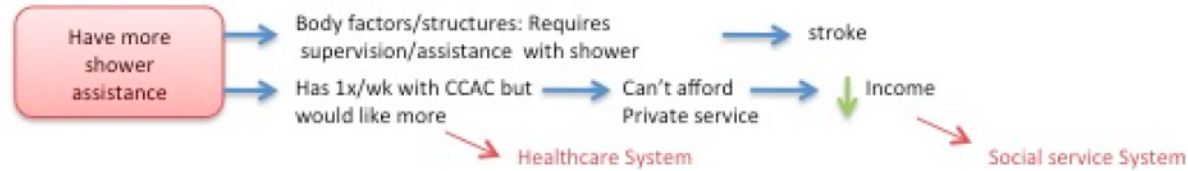


Appendix O

005 : Personal Projects

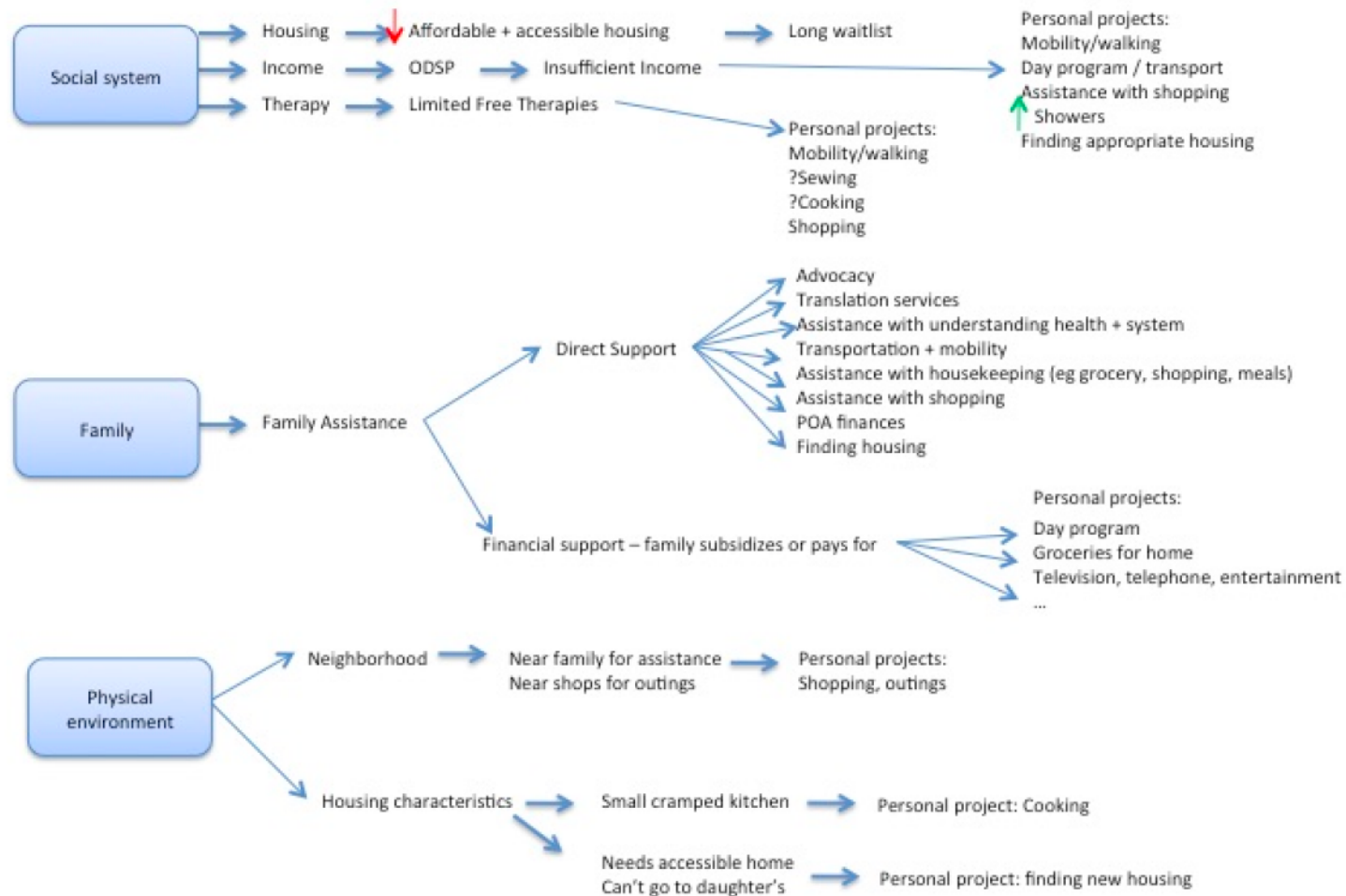


005 : Personal Projects



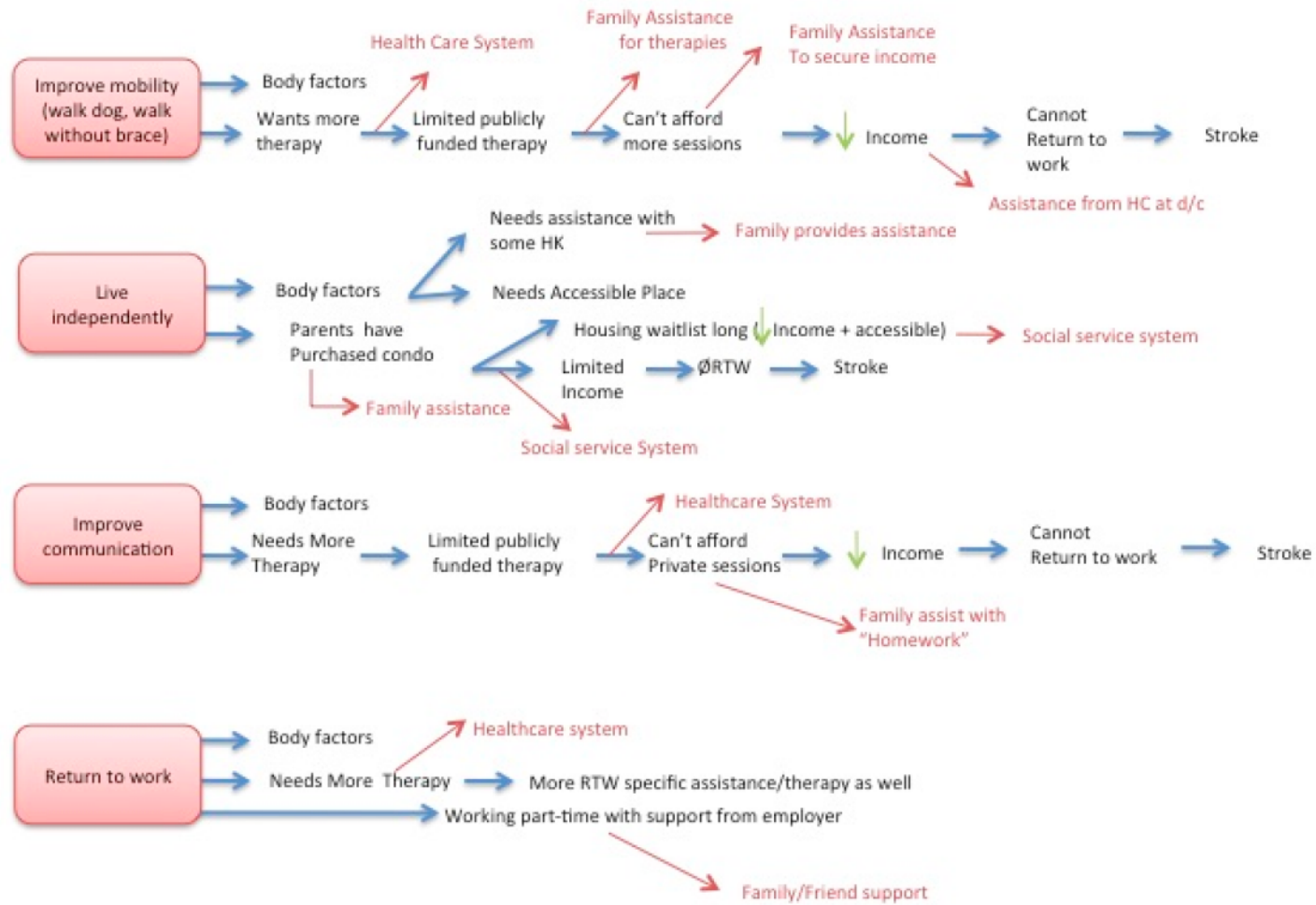
Appendix P

005 : Patterns

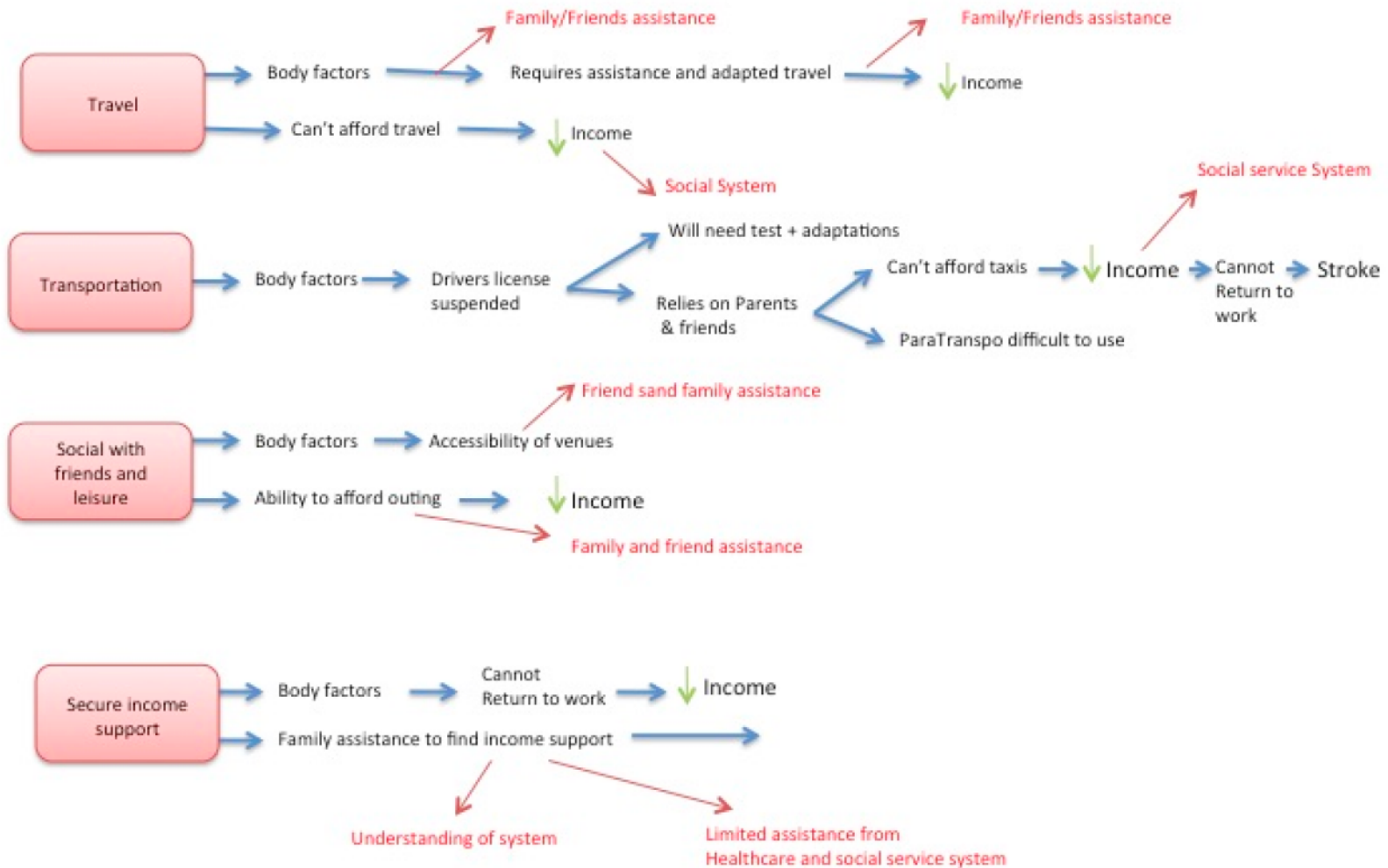


Appendix Q

006- Personal Projects

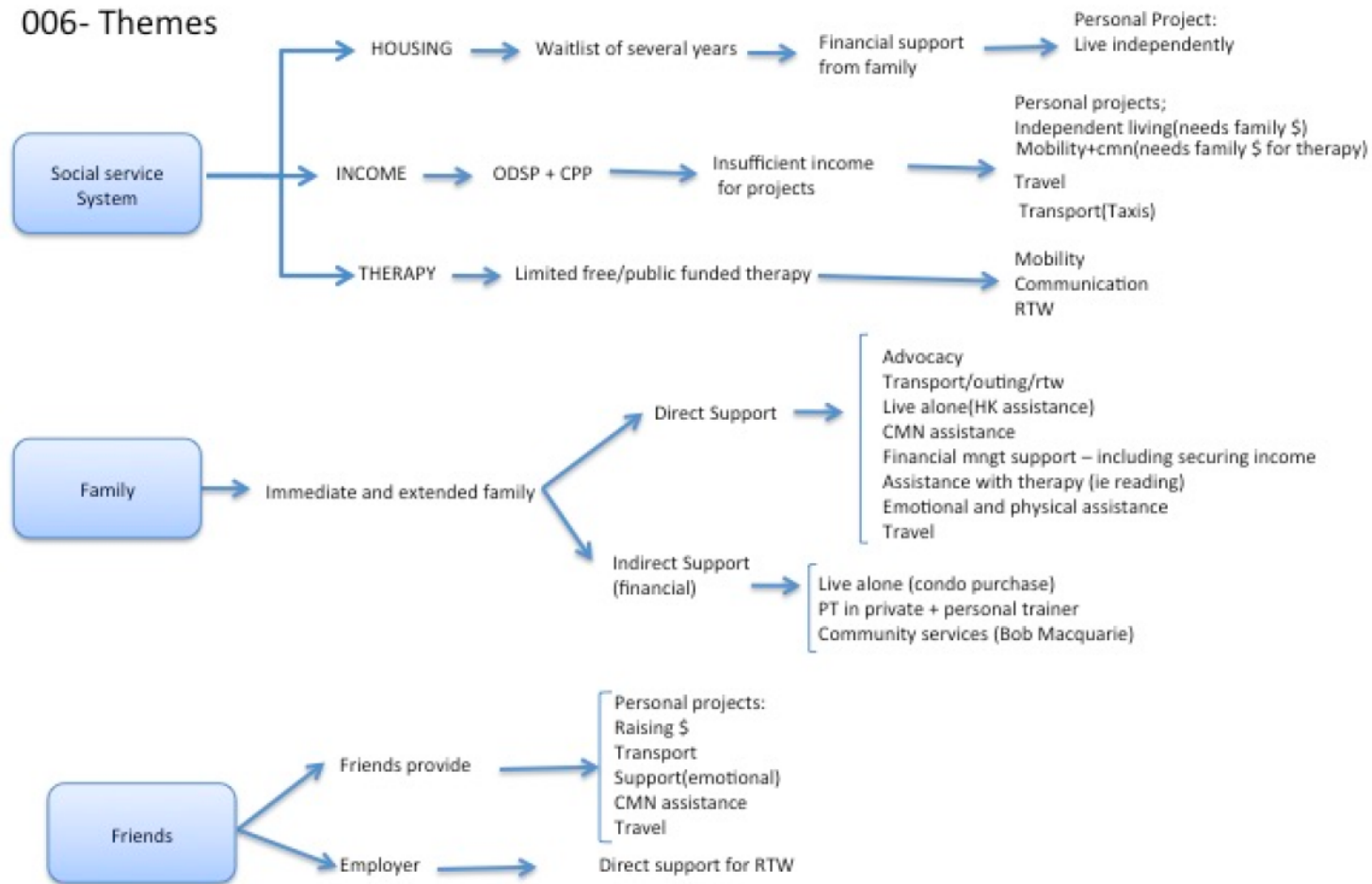


006- Personal Projects

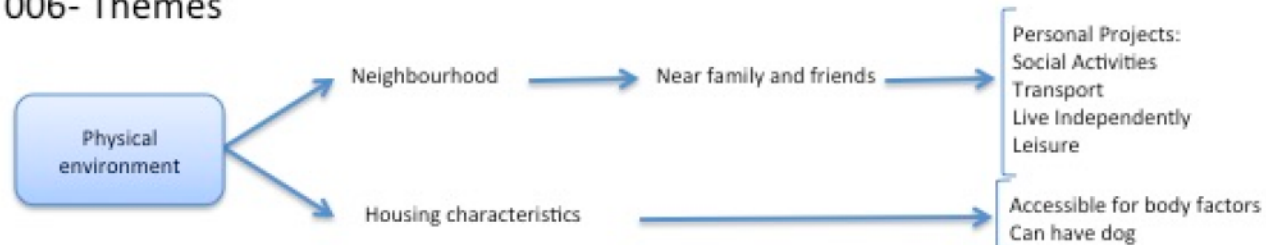


Appendix R

006- Themes



006- Themes

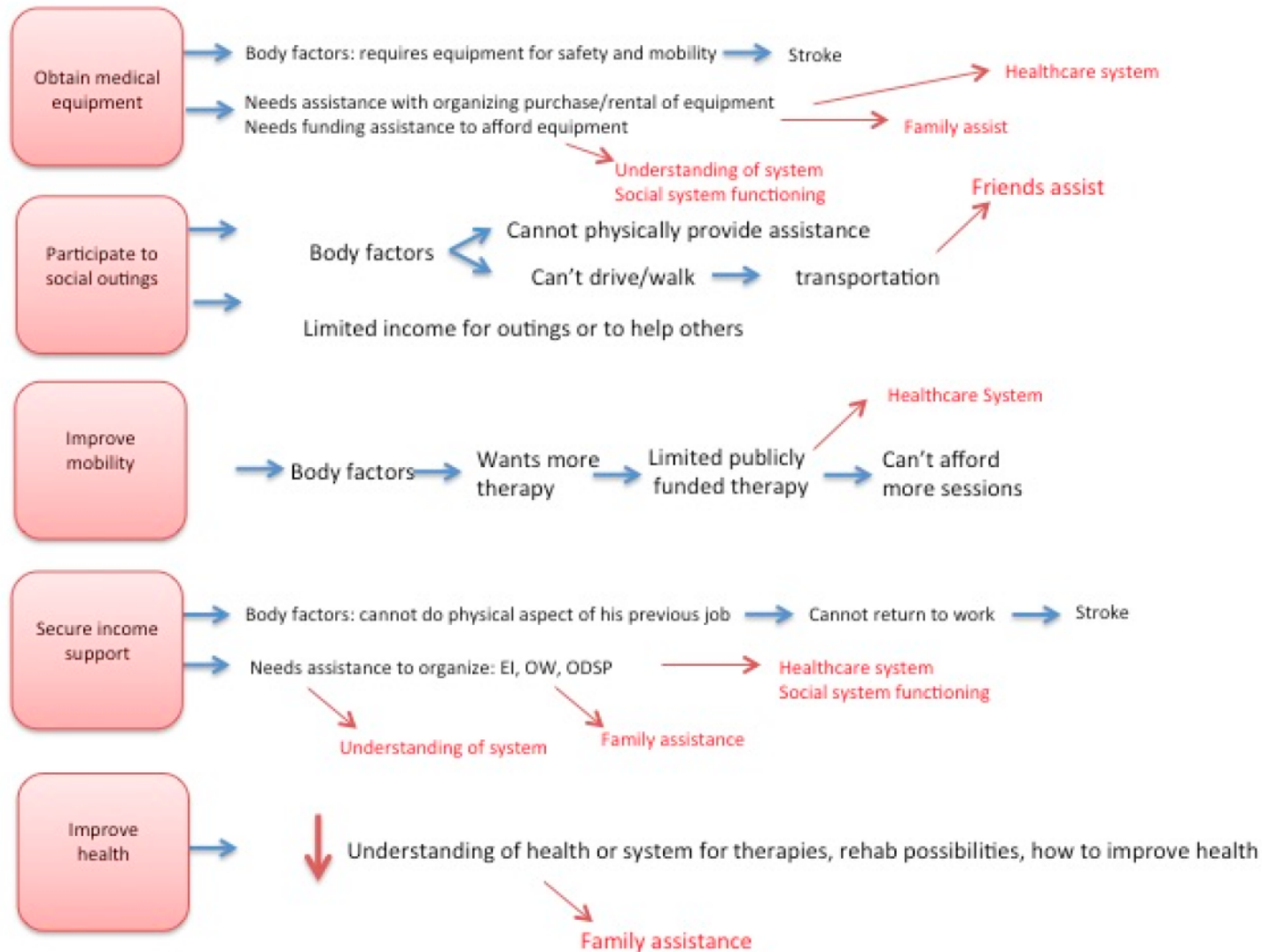


Appendix S

007- Personal Projects

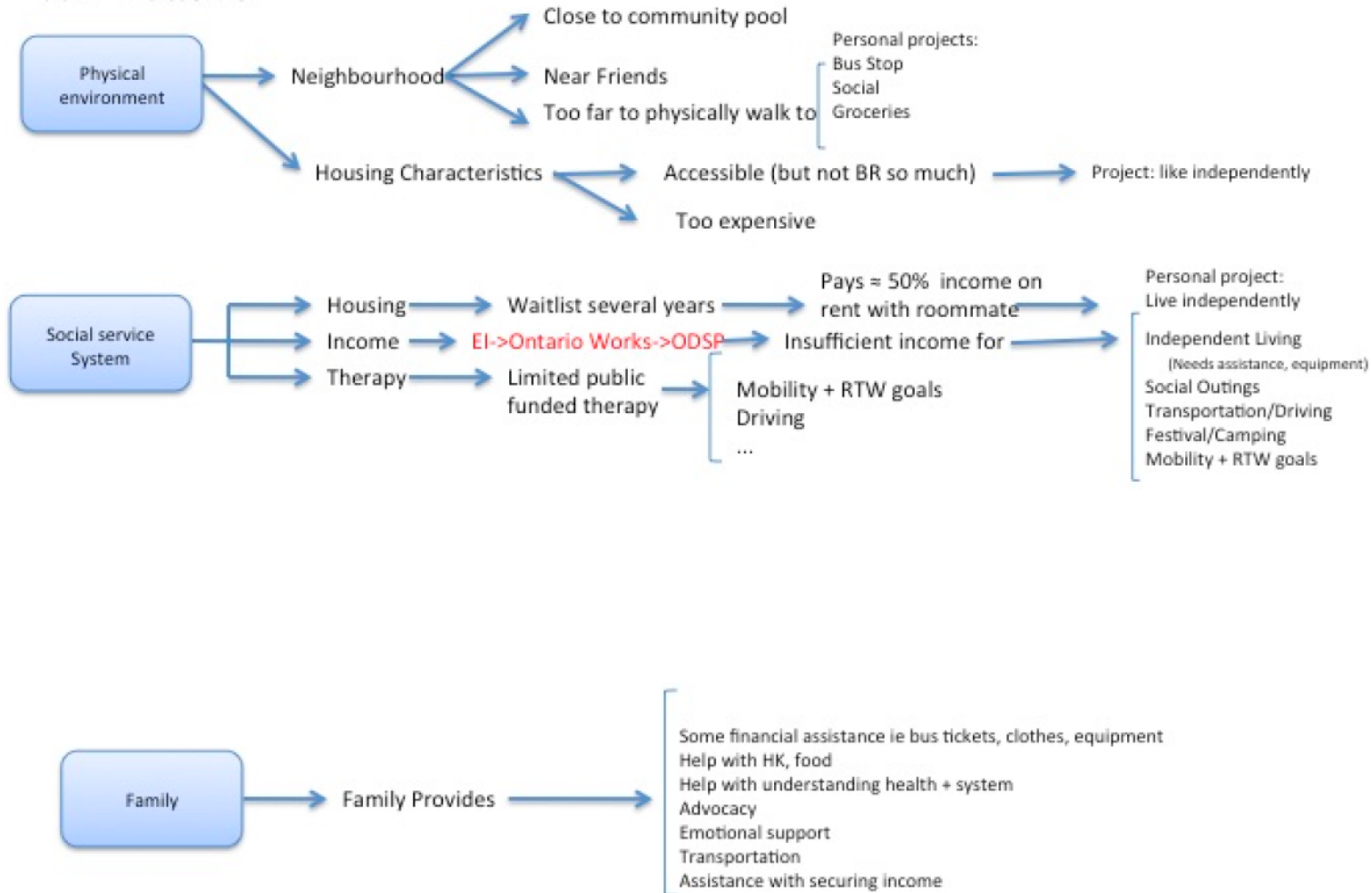


007- Personal Projects

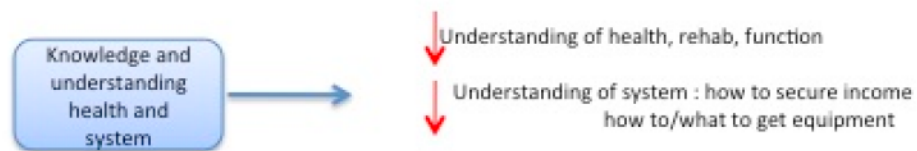


Appendix T

007 – Patterns

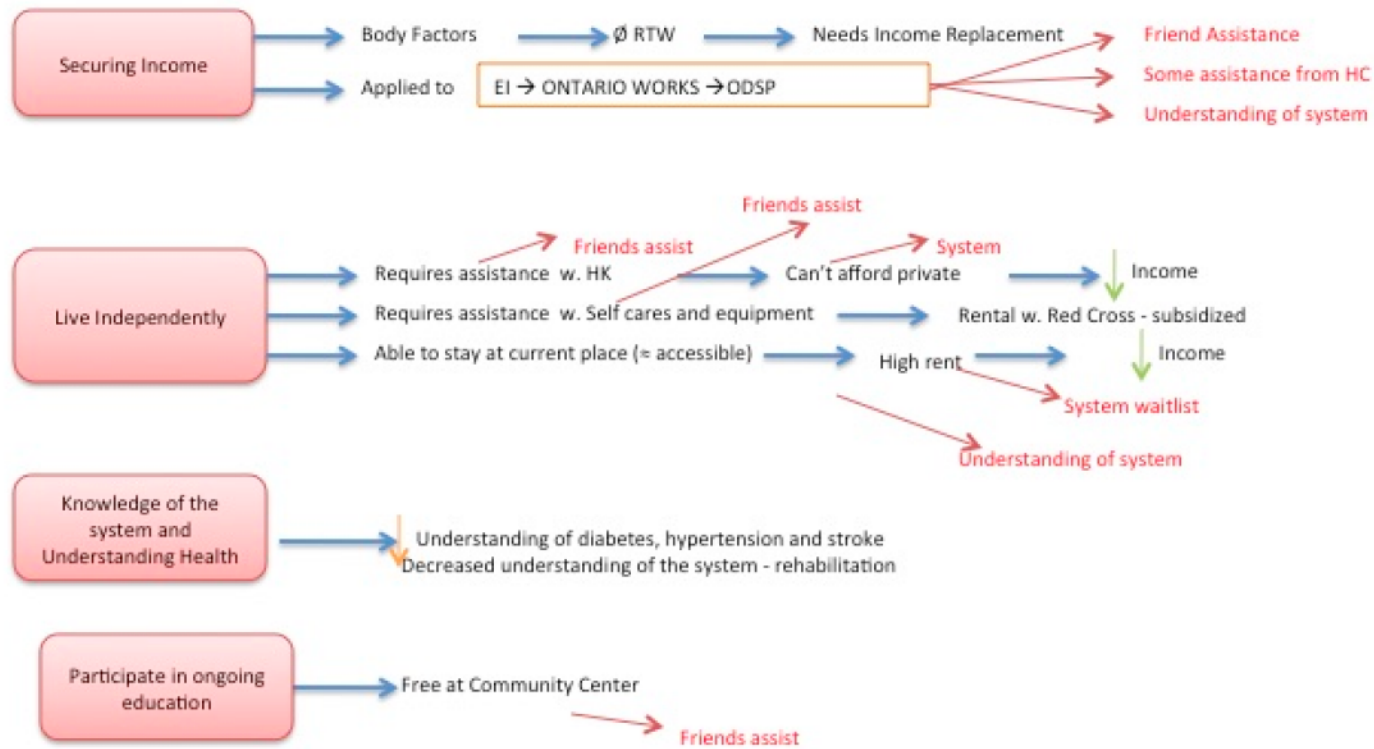


007 – Patterns

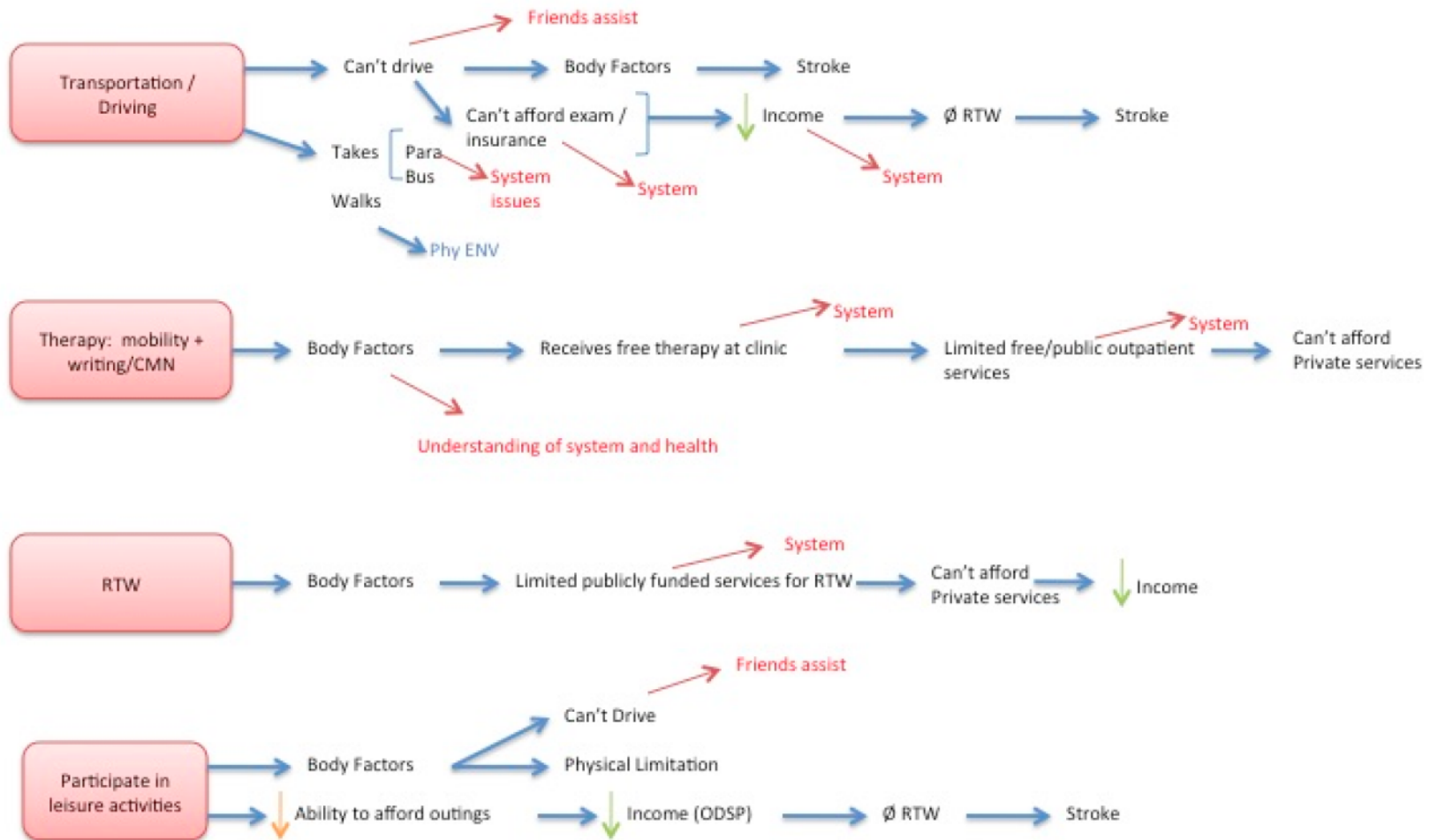


Appendix U

008 – Personal Projects

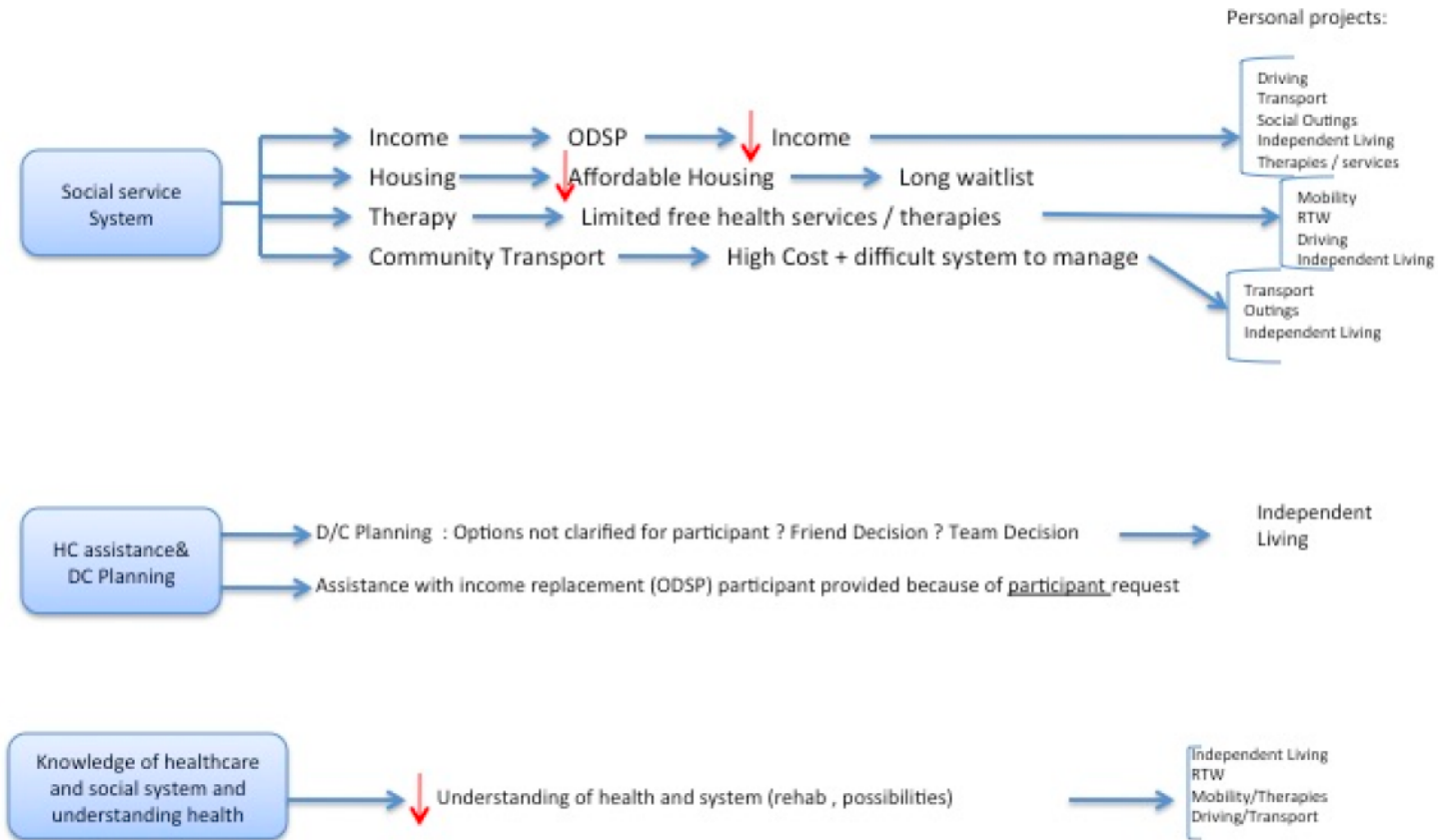


008 – Personal Projects

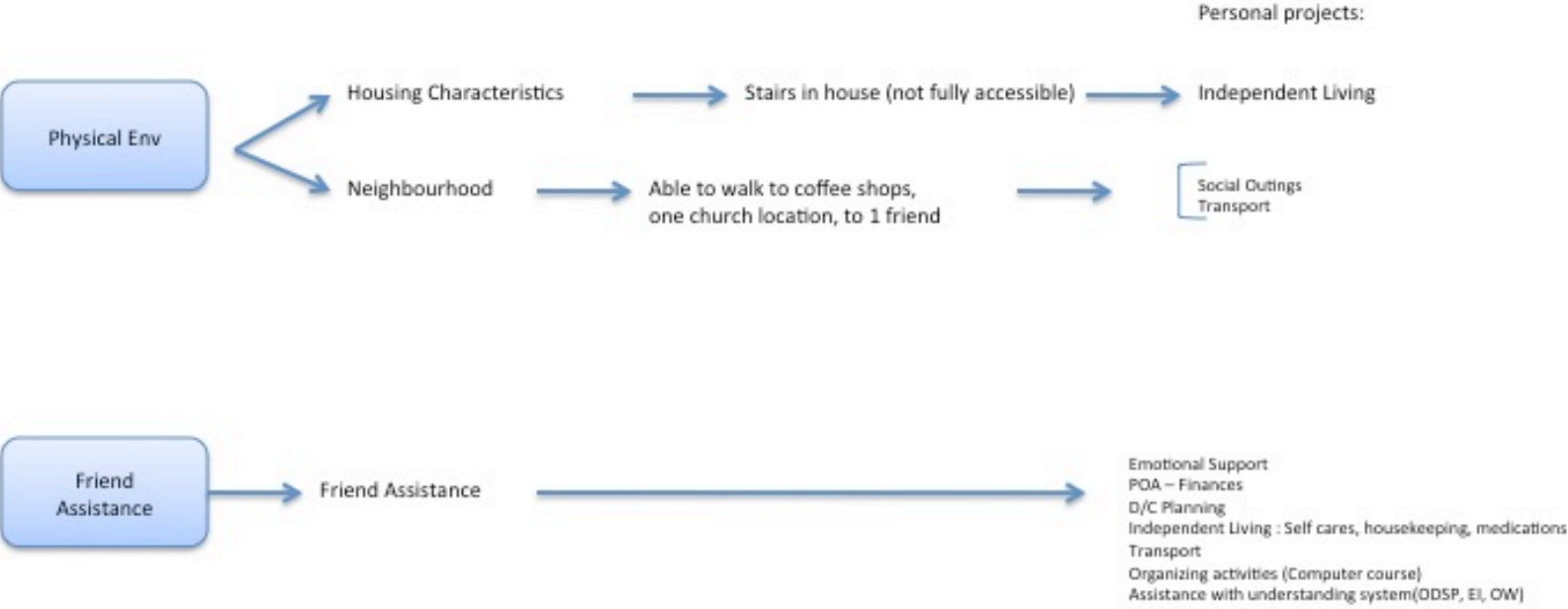


Appendix V

008 – Patterns



008 – Patterns



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