'What is going to happen to me now?' Systemic uncertainty and complexity between hospital and home for older people, people with disability, carers and service providers

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ABSTRACT

The focus of this thesis is on the impact that a hospital admission can have on the continuing ability of Home and Community Care\(^1\) (HACC) clients (older people and people with disability) to remain living in their home. Of concern to HACC service providers were their clients’ readmissions to hospital and/or unnecessary institutionalisation after hospitalisation. Both events were considered poor outcomes by HACC service providers. The desire to improve these poor outcomes and to alleviate discontinuous care led the HACC program to fund a project in Adelaide, which I undertook as action research.

In this thesis I investigated how poor outcomes could be avoided and continuity of care improved in the South Australian hospital and HACC systems. A literature review revealed that population ageing, the demand and resource pressures on acute hospitals and community services and the paucity of discharge planning were factors leading to discontinuity of care of older people and people with disability, as well as impacting on their carers. Theoretical perspectives first look at the divisions between the biomedical and social models of health, as well as the critiques of medical care and the role of bureaucracy put forward by iatrogenesis and medicalisation. Next, the theoretical lens turns to the lives of people, where the centrality of ‘care’ and interdependence are considered, along with the need to improve our understanding of the nature of vulnerability and the importance of resilience to moving beyond the dominant ‘problem-based’ discourse of ageing and disability.

Processes in the action research included two cyclical phases of making plans, embarking on actions and observing the results of the actions. Methods for collecting data included surveys (n=16 older patients and 10 carers), an evaluation (n=28), face-to-face interviews (n=52), one focus group (n=8), three Reference Groups (n=46), a workshop (n=14) and a nominal group (n=14). The interviews and surveys provided the opportunity to analyse the admission, hospitalisation and discharge issues for HACC clients and their carers from the perspectives of hospital nurses (n=19) and 33 community care providers. The latter participants were clinicians and case managers from domiciliary care\(^2\) (n=23) and community nurses\(^3\) (n=10). These interviews were analysed thematically.

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1 The HACC program, funded jointly by the Australian, State and Territory governments, targets community-dwelling frail aged people, people with disability, and their carers, who in the absence of basic maintenance and support services are at risk of premature or inappropriate long-term residential care.

2 Domiciliary care services are provided to older people (aged 65 years and over) and younger people with disability whose ability to care for themselves is reduced. Domiciliary care assists them to stay living in their own homes, by providing physical assistance, rehabilitation and personal care, as well as respite and support for carers. By promoting independence and improving quality of life for clients, domiciliary care services aim to prevent unnecessary admission into hospital or residential care.

3 Community nursing services provide community based health and care services, including rehabilitation, therapy and nursing care.
Results from the action research project yielded valuable research insights and successful actions which were reflexively planned, implemented and evaluated. The actions increased local linkages between the hospital and community service providers, collaboration, communication and access to information about the HACC program. Despite this, the action research project appeared to have little or no direct effect on avoiding poor outcomes or improving discontinuity of care. Such effects were more complex and beyond the scope of a project of this size. Achieving the necessary systems and structural changes to address these problems would have required more time, resources, capacity and leadership to be committed by government departments and the agencies.

The descriptive statistics of surveys with patients and carers and the key issues identified by the Reference Group supported triangulation of the interviews with domiciliary, community nursing and hospital participants. Findings from the interviews with domiciliary, community nursing and hospital participants point to uncertainty and complexity before, during and after hospitalisation of older people, people with disability, their carer/family, and also for service providers. Before admission to hospital there are four ‘dimensions of uncertainty’, and during hospitalisation, there were four categories which contributed to ‘complexity in discharge planning’. When leaving hospital, ‘adjustment and adaptation’ highlights individual patients’ and carer/families’ adjustments. In addition, it points to the need/potential for service adaptation to support people’s ability to return home. Putting these dimensions together, the main themes to emerge in this context are ‘systemic uncertainty and complexity’. In building upon these themes, I have developed a model of systemic uncertainty and complexity before, during and after hospital. Given this new knowledge about the context of uncertainty and complexity on the one hand, and adjustment and adaptation on the other, I conclude by considering the implications of these understandings for theory, policy and practice.
DECLARATION

This work contains no material which has been accepted for the award of any other degree or diploma in any university or other tertiary institution to Rosie King and, to the best of my knowledge and belief, contains no material previously published or written by another person, except where due reference has been made in the text.

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Rosie King
September 2009
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I have experienced many inspiring, humbling and transforming moments on the long and winding road of this thesis. These moments have reminded me of one of the ideas I discuss at a conceptual level in this thesis, and have been reminded about experientially many times since I began. I refer to our interdependence on others for all kinds of physical, emotional and intellectual nurture. I think about my thesis and interdependence with others as the village that helped raise this thesis, the many fellow travellers who have walked along beside me and helped me to cross the rocky and unpredictable terrain towards completion. This is my expression of gratitude to you.

I dedicate this thesis to my father and mother. Dad, without knowing you always managed to ‘keep it real’ and in the last months of your life when I had only just began this project, your experiences galvanised me into believing that this real-world topic was important enough to stick it out. Mum, for being ‘the carer’ that I know you are and for looking after dad in his time of greatest need. This is for you both, Billy and Val.

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ABBREVIATIONS

ABS: Australian Bureau of Statistics

ACAT(s): Aged Care Assessment Team(s)

ACCT: Australian Coordinated Care Trials

AIHW: Australian Institute of Health and Welfare

ADL: activities of daily living

ACC: Ageing and Community Care

ATSI: Aboriginal and Torres Strait Islander

CASA: Carers’ Association of South Australia

CALD: culturally and linguistically diverse

CCC: Commonwealth Carelink Centres

CEO: Chief Executive Officer

CIK: Carers’ Info Kit

CNM: Clinical Nurse Manager
<table>
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<th>Acronym</th>
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<tr>
<td>CSP(s)</td>
<td>Community Service Provider(s)</td>
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<tr>
<td>CSTDA</td>
<td>Commonwealth State Disability Agreement</td>
</tr>
<tr>
<td>DHS</td>
<td>Department of Human Services</td>
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<tr>
<td>DoHA</td>
<td>Department of Health and Ageing</td>
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<td>GP(s)</td>
<td>General Practitioner(s)</td>
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<td>HACC</td>
<td>Home and Community Care Program</td>
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<td>HOP</td>
<td>Hospital Home Pathways</td>
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<td>HREOC</td>
<td>Human Rights and Equal Opportunities Commission</td>
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<tr>
<td>IADL</td>
<td>instrumental activities of daily living</td>
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<tr>
<td>ICF</td>
<td>International Classification of Functioning, Disability and Health</td>
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<tr>
<td>LGA</td>
<td>Local Government Areas</td>
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<tr>
<td>LGCSAA</td>
<td>Local Government Community Services Association of Australia</td>
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<tr>
<td>LOS</td>
<td>length of stay</td>
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<tr>
<td>MDS</td>
<td>Minimum Data Set</td>
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<tr>
<td>Abbreviation</td>
<td>Full Form</td>
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<tr>
<td>NESB</td>
<td>non-English speaking background</td>
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<td>NGO(s)</td>
<td>non-government organisation</td>
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<td>NOA</td>
<td>Notification of Admission</td>
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<tr>
<td>OECD</td>
<td>Organisation for Economic Co-operation and Development</td>
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<tr>
<td>RAC</td>
<td>Residential Aged Care</td>
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<tr>
<td>RCT</td>
<td>randomised control trial</td>
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<tr>
<td>RMO(s)</td>
<td>Resident Medical Officer(s)</td>
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<td>RN</td>
<td>Registered Nurse</td>
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<td>RW</td>
<td>Recommendations Workshop</td>
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<td>SA</td>
<td>South Australia</td>
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<tr>
<td>SCRGSP</td>
<td>Steering Committee for the Report on Government Services</td>
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<tr>
<td>UK</td>
<td>United Kingdom</td>
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<tr>
<td>UN</td>
<td>United Nations</td>
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<td>USA</td>
<td>United States of America</td>
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UNESCAP: United Nations Economic and Social Commission for Asia and the Pacific

YHR: Your Health Record

WHO: World Health Organisation
PART ONE: OVERVIEW
CHAPTER 1: OVERVIEW OF DISCONTINUITY OF HEALTH AND COMMUNITY CARE FOR OLDER PEOPLE, PEOPLE WITH DISABILITY AND THEIR CARERS

"Then into the New Wing! We'll see Dr. Spreckles, who does the Three F's – Footsies, Fungus, and Freckles. Nextly, we'll drop in on young Dr. Ginns, our A & S Man who does Antrums and Shins, and of course, he'll refer us to Drs. McGrew, McGuire, and McPherson & Blinn & Ballew & Timpkins & Tempkins & Diller & Drew, Fitzsimmons, Fitzgerald, and Fitzpatrick, too, all of whom will prescribe a prescription for you." Dr. Seuss, You’re Only Old Once: A Book for Obsolete Children (1986) Random House Children’s Books

1.1 BACKGROUND
Providing adequate and timely health and community care services to people in need of assistance has been for many years fraught with problems. Hospital and community care systems have come under pressure from population ageing, which is the demographic change that has arisen from reduced birth rates coupled with increased life expectancy. In many developed countries, these changes have led to an increase in the number and percentage of older people (United Nations Economic and Social Commission for Asia and the Pacific [UNESCAP], 2006). People with disability are also living longer and their needs add to the level of demand for hospital and community care. Moreover, as they leave a hospital and return to the community, older people and people with disability need their care to be continued over time and place.

Continuity of care between the hospital and community care sectors is crucial in avoiding poor outcomes for older people and people with disability. Yet supporting continuity of care across the health and community care sectors has become a challenging task because of the complexity of clients’ needs, the lack of services and the ways in which Australia’s federal system fragments service structures and processes. Furthermore, Australia’s economic resilience has not been matched by providing adequate community care programs or services that have kept pace with the actual numbers of older people and people with disability in the population. A confluence of political influences, demographic shifts and technological developments form the background to these current problems in the health and community care sectors. This thesis explores the issues facing older people and people with disability and their carers from hospital and community service providers’ perspectives, as well as the policy implications for providing continuity of care between the hospital and the community.
First introduced by the Australian (Labor) Government as a cooperative social policy initiative in aged care, the Home and Community Care Act 1985, enacted through the Home and Community Care (HACC) program, was intended, where possible, to enable older people to remain living in their communities until the end of their life (Jamrozik, 2005). Emerging as part of an aged care system, HACC is now the main vehicle delivering ‘community care’ services in the form of maintenance and support targeted at older people and people with disability, as well as their carers. Through delivering its community care services, the HACC program aims to help older people and people with disability to live independently in the community and avoid premature or inappropriate long term residential care. It is funded jointly by the Australian Government, States and Territories.

The need to improve pre-hospital admission and discharge planning processes for HACC clients was identified as a priority by a HACC funded regional collaboration at a planning workshop held in the specified region of Adelaide. HACC regional collaborations were established to facilitate networking, information sharing, identification and response to regional need (HACC Regional Collaboration, 2000). This workshop was attended by one hundred representatives from fifty separate organisations in the specified region. A collaboration was formed by fifteen of the agencies attending, including a public hospital, a division of General Practice, domiciliary care and a community nursing service. The value of the project was also recognised through other local community consultations (Carers' Association of South Australia [CASA], 2000; Alfonsi 2000) and was consistent with the State Government of South Australia’s strategic directions (1999 – 2000), which proposed the development of improved service coordination and linkages (Department of Human Services [DHS], 1999).

Forum participants were concerned about the dearth of post-discharge programs available to their HACC clients, as the funding of two successful transition care programs had not continued and no replacement programs were forthcoming. According to the original funding submission, the aim of the study was to enhance pre-admission and discharge planning events and improve transitions between community and acute care for HACC clients who lived in a specified region of Adelaide. Carers (informal and unpaid) of the target group were also included in the study. The collaboration recognised that although the hospital had traditionally taken responsibility for discharge planning, discontinuity of care was a major problem and an exploration of options was needed. Ideally discharge would not be a separate event from admission but part of a seamless process with more involvement of HACC clients, their carers and the community care sector to improve continuity of

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4 In Australia, the term ‘community care’ (or domiciliary care) is used to cover the range of Government-funded and community-based services which provide personal care; health and allied health care, housing maintenance, modification (minor) and assistance. In the United Kingdom (UK) community care is generally referred to as ‘social care’ and as ‘home health care’ or ‘community-based care’ in the United States of America (USA).

5 More detailed information about the HACC program is provided in Chapter 2.
care. The collaboration hoped this study would therefore have direct outcomes for improving the continuity of care of the HACC client population by producing changes to the systems and processes between the hospital, General Practitioners (GPs) and community service providers (CSPs). The funding of this study is an example ‘from the coalface’ of the way in which there has more recently emerged a focus on finding ways to improve the continuity of hospital and community care for older people and people with disability.

A workgroup of twenty-three service providers was established to develop a proposal for HACC funding to focus on exploring improvements to pre-admission and discharge planning for HACC clients in the specified region of Adelaide. Importantly, the largest acute care provider in the region, the hospital, was also represented in the workgroup. The hospital’s involvement was essential and would prove a unique feature of the study. Professorial approval was given for the project to take place in two hospital wards. The project was successful in obtaining fixed-term funding for 2 years from HACC through the Department of Human Services (Ageing and Community Care [ACC], Incorporating Office For The Aged [OFTA]). This collaborative effort among HACC service providers and the hospital led to a submission being funded by the HACC program to conduct the study to be described in this thesis.

1.2 WHY IS CONTINUITY OF CARE IMPORTANT TO THE AGED AND PEOPLE WITH DISABILITY AND THEIR CARERS?

Most people understand that their health care needs do not simply start when they enter hospital or visit a GP, nor end when they leave. As our health needs are known to exist in a continuum over time and place, continuity of care is generally understood as being an important goal. Consequently, more importance is being placed on care continuing between one health service provider and another (Barnett, 1986; Hudock et al., 1997; Wiles, 1997; Castro et al., 1998; Clare & Hofmeyer, 1998; Cummings, 1999; Bower, 1999; Bull et al, 2000; Stuart, 2003; No author, 2002; Hautala-Jylha et al., 2005). It is claimed that patients in particular would be better off with continuity of care, but there are also numerous benefits for carers, health and community care practitioners and organisations involved in the delivery of services.

Because of their particular needs, there are risks to continuity of care that concern older people, people with disability and their carers when they move from hospital to home. When discontinuity of care occurs, it can trigger a chain of stressful events that may culminate in readmission to hospital or losing their home. As the impact of discontinuity of care is under-recognised and under-reported (for example, it is not reported as an adverse event) knowledge of its occurrence is mainly anecdotal. Explanations may point to the stresses and strains on the hospital system and the need for more
(government) funds, and/or individuals working in ‘the other’ sector (hospital or community) are targeted as people look for someone or something to blame. The fact that community care services are also under-resourced and overstretched is seldom discussed. Until they are readmitted with ‘dysopia’⁶, hospital staff know little about what happens when an older person or person with disability is discharged home and has trouble coping⁷.

In the range of professional and emotional responses to discontinuity of care, health care professionals may also feel inadequate, unsupported and undermined by their organisation. Indeed, from the outside they can be misrepresented as being careless or judged as being negligent. Such criticisms of people often elicit defensive reactions from them. The responses to this problem have a tendency to personalise it, politicise it, or professionalise it, as a ‘blame-game’ unfolds between the health and community care sectors. This type of reaction is counterproductive to the development of any solutions to change or improve the situation. Furthermore, specific instances are seldom studied on a case-by-case basis. Aside from the obvious humanitarian concerns, boundary issues and blaming, there is little clarity about the actual problem. Who does it chiefly concern? Which people are more or less vulnerable (to discontinuity of care) and why? Would better identification of those at risk (of discontinuity of care) help? Does anyone know whether more money would be effective? Who is responsible for providing continuity of care and when are they responsible? What are the implications for community care policy? Are all HACC clients vulnerable? How much did the hospital sector understand and know about the community care sector and vice versa?

When I commenced this study, I was both concerned about, and interested in, the type of tensions and debates outlined above. I was also aware of the level of concern and dissonance expressed by service providers in the hospital and community care sectors about an aged person or person with disability being discharged from hospital to the community, and the potential for difficulties to arise. As Freshwater (2005) explains:

“Dissonance is not comfortable, but often comes before action, and can be the motivating force to encourage the practitioner to move beyond routinized and habitualized practices to a more conscious reflexive occupation of their position”. (Freshwater, 2005, p.213)

⁶ A term used to describe someone who cannot cope or look after themselves.
⁷ Refer to Appendix 1 for a typical situation described by community service providers. This scenario was based upon research (a Reference Group consultation) with community service providers which identified the key issues faced by older people or people with disability following discharge from hospital. It was used as a ‘visualisation’ at the beginning of the Nominal Group.
However, not all workers were dissonant. Some appeared detached, possibly finding it “preferable to remain anaesthetized to conflict”, (Freshwater, 2005. p.213) as this meant they were likely to have more energy available to get on with their work.

I was also interested in the growing literature on implications for service provision to an ageing population. In general conversation, however, hospital workers can be heard to refer to the frail aged as ‘bed blockers’, a derogatory and mechanistic term which contravenes the patient’s rights to care and denies his/her status as a human being. These attitudes made me feel curious about the difference between the culture of a group (in this case, nurses) or an organisation and individual attitudes. Had nurses been “Socialised into a culture of uncritical acceptance or received wisdom…” of or about attitudes they should show towards the frail aged in front of their colleagues? (Freshwater, 2005. p.213) What were their attitudes to people with disability? What were the constraints that shaped hospital nurses care of aged patients or patients with disability, especially during the discharge process? Why did nurses use and the hospital allow the (unchallenged) use of the term ‘bed blockers’? What was the attitude of community care workers to older people and people with disability? Regardless of age, frailty or disability, most people value their autonomy. What were people’s expectations of continuity of care?

Drawing on my own hospital experience as a Registered Nurse (RN) and in my more recent role as a Social Worker in the primary care sector, I became increasingly suspicious of the dominant discourse of blame and mistrust that prevailed across both sectors. In an optimistic ‘change agent’ frame-of-mind, I was interested in using action research as a method that would facilitate changes at the local level, while enabling more to be understood about attitudes and the concerns from all sides. My hope was that by shedding light on these issues, the study had the potential to generate awareness, which might then lead to activity and change. Action research has been accepted widely and used in the nursing field as a method to bring about change (Cowley & Billings 1999; Hart & Bond 1995; Robinson & Miller 1996; Coghlan & Casey 2001). Although there has been an emerging literature on action research methodology (Webb 1989; Lilford & Braunholtz 2003) and on using action research in the health and social care fields to bring about change (Hart & Bond 1995; Morton-Cooper, 1999; Winter & Munn-Giddings, 2001), there are few examples which explore the use of action research as a method to improve continuity of care collaboratively in the hospital and community care systems. Research in this area is complex and is carried out by members of many professions and disciplines, including health care (nursing, gerontology and allied health professionals), health economics, demography, sociology, politics and health care.
Problem Statement
The focus of this thesis is on the impact that an episode of hospital admission can have on the continuing ability of HACC clients (older people and people with disability) to remain living in their own home. Next to their carers and/or families, the sectors most often at the forefront of providing care to older people and people with disability are the health and the community care sectors. The susceptibility of older people and people with disability to discontinuous care and poor outcomes following a hospital admission is recognised by both hospital and community care service providers. The desire both to reduce poor outcomes (in particular readmission to hospital and premature or inappropriate institutionalisation) and to alleviate discontinuous care, led the HACC program to fund a project located in a specified region of Adelaide.

1.3 AIM AND OBJECTIVES
This action research study explores the boundary between the health sector (in particular, hospitals) and the community care sector (which includes primary health care providers, such as GPs and CSPs) when people aged 65 years and over, and people with disability, aged 18 years and over, required hospitalisation. The participants in this action research were HACC eligible patients of the hospital and their carers, and the hospital medical, nursing and allied health staff, GPs and HACC service providers.

Research Aim
The aim of this research is:
To identify the nature of the changes needed in the South Australian hospital and HACC systems to reduce poor outcomes and improve the continuity of care of older people and people with disability, as well as their carers.

Objectives
In order to address this research aim the following objectives were proposed:

1. To analyse the factors in the literature that lead to discontinuity of care of older people and people with disability and their carers in transition between the hospital and community care systems in the specified region of Adelaide.
2. To plan and implement actions to improve the continuity of care for older people and people with disability, and their carers, living in the specified region of Adelaide.
3. To observe the effect of the actions taken to improve the continuity of care for older people and people with disability, and their carers, living in the specified region of Adelaide.
4. To analyse the results and reflect on their wider implications for theory, practice, policy and future research on the continuity of care for older people and people with disability and their carers.
5. To reflect on the utility of action research as a means to analyse and improve the discontinuity of care for older people and people with disability and their carers in transition across the acute and community care interface.

The first, second and third objectives flowed directly from the aim of this research. The fourth and fifth objectives set out the manner in which I reflected upon my fieldwork in the second action research cycle.

1.4 RATIONALE

Acute Illness can lead to a temporary or progressive loss of one’s ability to manage the regular activities of daily life, such as personal hygiene, dressing, mobility and food preparation. The extent to which one can perform these ‘activities of daily living’ (ADL), or access enough care to assist with ADL, can affect whether or not a person is able to remain living in their home after a hospital episode. Because of their particular needs (health, functional and social care) and circumstances, older people and people with disability are more likely to need continuity of care after an episode in hospital. Continuity of care and of carers (formal and informal) plays a crucial role in the lives of older people and people with disability.

Many professionals working in hospital and community care refer to continuity of care when discussing the importance of improving the quality of health service delivery systems: also included for improvement are issues about reducing the fragmentation of services and creating seamless transitions for people when they move from one sector or service provider to another. In this case, the collaborators recognised that multiple discontinuities existed between the ‘interface’ of hospital and community care. By virtue of their functional or disability status, such discontinuities make it more likely that older people and people with disability, more than any other group, are at risk of being on the receiving end of discontinuous and/or inadequate care. According to Clarfield, Bergman and Kane (2001), there are multiple reasons for discontinuous care:

“The community/hospital split, the social medical dichotomy, the acute/continuous care divide and multiple overlapping entitlements existing within various governmental and quasigovernmental jurisdictions all interfere with the efficient, humane and even logical care of patients.” (Clarfield et al., 2001 p. 1714)

Furthermore, the regional collaborators were aware of instances of poor outcomes where discontinuity of care had led to emergency readmission to hospital or premature institutionalisation of older people and people with disability. Avoidance or alleviation of this type of poor outcome was their main

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8 The term interface is frequently used by health and community care service providers to describe the physical boundary or gap between the sectors. The policy ramifications of this term are explored in Chapter 2.
motivation for seeking funding for this study. They viewed this study as an opportunity to be innovative and develop targeted measures to improve the continuity of care for HACC clients, recognising that they are relatively disadvantaged and insecure compared with the rest of the population.

1.5 THESIS OVERVIEW

In Chapter 2, I outline the aims, targeting and funding of community care services for older people, people with disability, their carers and family. Approaches to defining the notions of independence, disability and frailty are discussed. Future predictions about population ageing and disability in Australia, and the role played by informal carers, all point to the need to provide adequate health services, appropriate housing and stable community living and care arrangements for older people, people with disability and their carers. As it is the main community service program in Australia servicing the community care needs of older people and people with disability and their carers, the policy and effectiveness of the HACC program is discussed.

Chapter 3 begins with an overview of the impact of an ageing population and chronic illness on public hospitals and a review of the literature in relation to hospital discharge. The interface between hospitals and residential aged care (RAC) is covered, when older people and people with disability are discharged from hospital to RAC. Next is a review of continuity of care. These are the concepts underlying and the main practices employed to facilitate discharge of patients from hospital to the community. Finally, I provide a summary of this chapter which, in drawing together the key arguments and research in the literature, contextualises the problem of this thesis.

Chapter 4 considers theory and the way in which people’s experiences of ageing, disability, illness and care reflect the social values and organisation of society. The biomedical approach and the social model of health are understood to contribute to the divisions between the acute (or hospital) sector and the community care sector. A pathogenic or problem-focused perspective dominates the biomedical approach to ageing and disability. Following this, I discuss iatrogenesis, aspects of Care Theory, vulnerability and Resilience Theory. This review raises complex questions about the limitation of applying any single theory and the extent to which one can apply concepts from several theoretical approaches to the one study. However, my analysis is mainly drawn from the broad framework of social, economic and health problem areas to describe the intersection of vulnerability, resilience and health and community care transitions of people with disability, older people, and their carers.

In Chapter 5, I discuss how my methods and professional background have influenced my philosophical orientation towards advocacy, participation and social constructivism. During the action
research study I was reflexive, which meant that as the researcher I examined myself to make explicit my place in the research. Critical reflection took place after the action research project had finished, when I looked back on what I did, identified the study’s strengths and limitations and suggested ways to improve the process.

Chapter 6 presents the research methods and design used in this thesis. It provides the history, rationale strengths and limitations of using action research as the method to conduct this research. An overview of the data collection methods and thematic analysis is provided. In this thesis, the action research study facilitated a more detailed qualitative analysis of continuity of care between hospital and home for HACC clients, as well as the impact of these transitions on their carers.

The processes involved in the two iterative cycles of action research undertaken in this study are described in Chapter 7. How the cycles were planned, the actions taken to improve the situation and the observations made are presented. My critical reflections on the process, and strengths and limitations of the outcomes are provided in this chapter.

Chapter 8 presents the findings from the interviews with domiciliary and community nursing practitioners, the Reference Group and the surveys with patients and carers. Multiple perspectives contributed to the findings in this chapter. Highlighted is the importance of understanding the diverse circumstances of older people and people with disability and their carers. It is also necessary to identify the opportunities for interventions to improve continuity of care by the hospital and community services before, during and after hospitalisation.

In Chapter 9, I present the implications of the findings for practice, policy and theory, and outline the strengths and limitations of the action research method in this study. Finally, I discuss the implications for future research and provide the conclusions of this thesis.

1.6 FINDING A GOOD FIT THEORY FOR THIS THESIS: JEANS AND JIG-SAWS
In doing this research, I found it necessary to embark on a long and winding process to unearth a theory that sat comfortably with my findings. This took time and I was only able to link the ideas during the final stages of writing my conclusions. However, I had an ongoing internal dialogue that compared aspects of my findings with anything and everything that I read. I was constantly asking myself questions such as: does this (concept, theory or notion) fit with this or that finding? Where does this (concept theory or notion) fit within the whole of the thesis? When I thought I had found ‘it’ (the theory), I felt a sense of satisfaction for a little while. But then niggles of discomfort would begin to
surface and I would start to see that there was a mis-fit with some aspect of the findings. I would have to figure out how I could include one idea with other ideas - or abandon some ideas altogether.

Part of the problem in finding a good fit theory was that it needed to capture aspects of the individual, the organisation and the system levels of analysis. It could not be too esoteric or abstracted from findings that concerned ideals (such as continuity of care), services and behaviours (caring practices, for example). Finally, the theory needed to embody a critical perspective to help answer my research question. Considering all these caveats, I concluded that one theory would not suffice.

It was like trying to find a perfectly fitting pair of jeans off the rack. One must endure and spend time looking and trying them on. You cannot give up because you know that there is likely to be a pair ‘out-there’ that will fit. There may be personal ethical considerations involved in your decision, such as preferring those that are made with organic cotton over those that are ‘fair trade’ jeans. You know it is likely that you will have to do a few nips and tucks here and there, but the effort will be worthwhile. You may even be able to fulfil your ethical constraints in the same pair of jeans, but the question remains, - do they fit? Because at the end of the day (or week or year), you will need to feel comfortable wearing them. You will need to look in the mirror at yourself in your pair of jeans, in full view of the costs, the effort, the adjusting, the luck and the success. Even though they may be made locally or a long way away, they are a part of your unique style now. They measure-up. The fit is good. Wearing them, you are comfortable with yourself.

Moving from jeans back to the fit of theory, it was perseverance that led to a series of ‘ah ha’ moments in finding good fit theories, and a bit of luck. In reflecting on the process I now see that there were four sequential steps which resulted in the final theoretical outcome presented in the discussion. First, was building up a theory repertoire to which to return later. In this phase it was important to keep looking at a range of theoretical ideas that seemed to have a hook into the findings. Second, conceptualising the findings into dimensions laid the foundation for building the model. Third, after steps one and two, I took my conceptual model back to the theory repertoire to select which theories fitted into the model. Finally, I asked the following question: did the model-theory make sense and strike a chord with reality? The important part was not to give-up, or to cast too narrow a net when looking. I needed to be like a detective on ‘the case’, seeking evidence to support the claims for its theoretical claims. I followed-up references that had interested me. In the end, I rested my case, relieved in the knowledge that a reasonable resolution had been found to what had started out as pile of jigsaw pieces. While it is not a perfect fit, all of the parts of the puzzle are now in place. We can read the big picture well enough to conceptualise most of the details of the story.
CHAPTER SUMMARY
This chapter has described the background to my study, as it evolved from recognition of a problem among HACC and hospital service providers, and the development of my aim and objectives, using an action research design. The impact that an episode of hospital admission can have on the continuing ability of HACC clients to remain living in their home is an important area of research where greater understanding is needed. In addition, this study provided the opportunity to explore more broadly the adequacy of social policy for the care of older people, people with disability and their carers. A brief overview of this thesis is provided, as well as the process I went through in finding a good fit theory. In the following chapter, I describe community care in a context of population ageing and increasing disability.
PART TWO: APPRAISAL OF CURRENT POLICY, PRACTICE AND THEORY
"It is the success of medicine, not its failures, that has created the problem of sustaining and paying for decent health care for the elderly. It is the success of the campaign against ageism, increasing the expectations of everyone for a medically and socially transformed old age, that has added to that problem. If there is any blame to be apportioned it should be directed at our dreams, some of which have come true. It is just that we did not know what that would mean. Now we are finding out." (Callahan, 1994, p.398)

“It is widely acknowledged that a society which plans to grow old can afford to grow old...Disability and ageing are realities for our society, each unique but interwoven. Clear policies reflecting the realities of peoples' lives, rather than the categorisations of the health services, need to be developed.” (Councillor Eibhlin Byrne, Opening of the Seminar cited in Cox ed. 2006, p.6)

“Governments fund a wide range of care and support services. Many work well, but some require urgent attention in the form of funding, research and policy development. A priority must be to provide support services that allow people with disability and older people to participate as fully as possible in their communities.” (HREOC, 2007, p.7)

“…although public rhetoric acknowledges the need to help carers of the aged and people with a disability to balance their work and caring responsibilities, in reality tangible support is insufficient and ineffective. This is evident in relation to public policy (e.g. legislation, financial support and service provision)...” (TOCC 2007, p.4)

2.1 INTRODUCTION
Like two sides of the same coin, the four opening quotes of this chapter represent the interconnections between, on one side, the success of medicine in producing longevity and population ageing, and on the other side, the failure of social policy to provide adequate community care for older people and people with disability, their carers and family. The interlinking between the health and community care systems and supporting the care transitions of older people, people with disability and their carers, are central to the concerns of this thesis. Topics that are relevant to understanding the system and social policy include population ageing, the prevalence of disability and the impact of providing care on informal carers. With the central concern of this thesis in mind, the purpose of this chapter is to provide an entrance for the reader, beginning with pertinent definitions of independence, disability and frailty. I then move to the major categories used by allied health practitioners (such as physiotherapists) to determine a person’s independence, disability and frailty, being ‘activities of daily living’ and ‘instrumental activities of daily living’. To provide a sense of ‘the bigger picture’, these definitions and categories are followed by an overview of the trend of population ageing, the
prevalence of disability and the role of carers. This chapter finishes with the system of community care in Australia, by outlining the services for providing community care to older people, people with disability and their carers.

2.2 APPROACHES TO DEFINING INDEPENDENCE, DISABILITY AND FRAILTY

INDEPENDENCE

“Old people in this country have been influenced by the American ideal of independence and autonomy. The most important thing in the world is to be independent. So old people live alone, perhaps on the verge of starvation, in time without friends but we are independent … It is a poor ideal and pursuing it does a great deal of harm … We have reached the point where we think the only thing we can do for our children is to stay out of their hair … So in the end older people have to devote their energies to ‘not being a burden.’” (Mead, 1971 cited in Secker et al., 2003, p. 379)

According to the Oxford English Dictionary, when used as an adjective, ‘independent’ means:

“Not depending upon the authority of another, not in a position of subordination or subjection; not subject to external control or rule; self-governing, autonomous, free… Not depending on something else for its existence, validity, efficiency, operation, or some other attribute; not contingent on or conditioned by anything else…Not depending upon the existence or action of others, or of each other; existing, acting, conducted, or obtained in a way apart from and unaffected by others…” (Oxford English Dictionary, 2009).

When discussing independence, Leeson et al. (2003) noted that it:

“…is most often measured in terms of dependence, in terms of functional disability rather than ability, basing assessments on activities of daily living (ADL) and instrumental activities of daily living (IADL). In fact, IADLs like using the telephone, controlling medication and preparing meals, are more relevant to older people’s ability to remain in the community. Regardless of the indicators employed to measure (in)dependence, it is clear that threats to independence are much more complex.” (Leeson et al., 2003, p.35)

A similarly nuanced difference between formal measures of independence such as ADL and IADL and elderly people’s attitudes towards independence was noted by Russell (1999), who found the main reason for attachment to their homes was elderly people’s perception of home as being the most likely place to support their independence, autonomy and personal identity. For female respondents in particular, independence was seen as living in one’s home and dependence was seen as living in an institution. Indeed, being independent was more complex than being physically independent and the receipt of formal care services was irrelevant to this group of elderly people (Russell, 1999).

In the first population-based survey in Australia exploring older Australians’ fears for their future, Quine and Morrell (2006) found large proportions were concerned with losing their independence.
Similarly, in qualitative research conducted in Britain, the onset of old age was marked by inability to sustain independent living (Thane, 2005). The following statement encapsulates most men and women’s fears for their future:

“As the years go on, if there is one paramount overriding fear it is that of being unable to be in control of one’s life or one’s bodily functions, a fear of being an enormous and rather revolting burden on one’s children” (Thane, 2005, p.300)

In the findings of Quine and Morrell (2006), there was quantitative evidence to:

“…support policies and expansion of practices that enable older people to remain in the community for as long as possible, rather than enter institutional care prematurely…(and), while a large proportion of older people are concerned about losing their independence, only a small minority have specific concerns about nursing home admission.” (Quine & Morrell, 2006, p.1).

In a literature review concerning independent living in later life, Leeson et. al. (2003) found that a great deal of research had been done in the concepts related to independence and independent living were addressed, but that the concept of independence in later life was never explicitly defined. For example, they noted that the Australian Council on the Ageing had argued for separation of the concepts of independence and economic self-reliance, making the case for a broad definition of independence, which incorporated choice in life-style and the maximisation of opportunities for social and economic participation. Independence in older age would be most effectively achieved by sound economic, social and environmental conditions, including adequate and equitable income distribution through paid employment and social security provisions; well developed communities with high levels of accessibility and appropriate living situations; and a range of health and community service programmes that support healthy ageing (Australian Council on the Ageing, n.d. cited in Leeson et al., 2003). Leeson et al. concluded that:

“…independence is a complex and subjective concept, yet one which is generally regarded by both policy makers and many researchers as having a positive impact on the quality of life of older people.” (Leeson et al., 2003, p.21)

Indeed, they found differing interpretations of the concept of independent living in later life between researchers, older people, policy makers, practitioners, family members and local authorities. Although they identified a number of factors that clearly influenced the independence of the individual (these included control/empowerment, the person’s living arrangements/housing, his/her economic security, his/her social and familial networks, and his/her health and social care). Leeson et al. found the weighting of each of these factors in the collective assessment of independence varied from
person to person. If independence was threatened on one or more fronts, older people and their families developed compensatory strategies, which enabled overall independence. Since there was so much overlap between the factors that influenced and supported independence, a rigid definition of independence was not provided. Similarly, when they considered independence in comparison with dependence, they found characteristics of dependence were counteracted by interventions like home adaptations, targeted service provision and/or family care support. These types of interventions allowed individuals to maintain a large degree of independence in the setting he or she had chosen. It therefore seemed that promoting even modest degrees of independence was vitally important to the individual for maintaining his/her self-respect and dignity. In concluding the review, Leeson et al stated:

“It seems clear that user-centred services and a user-centred appraisal of needs, which includes the broader familial and social network of older people, would support older people’s perceptions and experiences of independence. Equally important is a norm shift among all players which would see services supporting independence rather than underlining dependence.” (Leeson et al., 2003, p.46)

Like Britain, the HACC program in Australia promotes independence and in Australia it is generally assumed that we know what independence means. But the reality is that the concept is rarely defined in social policy. In looking for an operational definition, Secker et al. (2003) did a literature review on independence in old age and found it revealed extensive work on dependence and much less on independence. Despite a decision not to include dependence in their search terms, Secker et al. found that the predominant concern in the literature was for avoiding dependence, or for older people not having to rely on others to carry out everyday activities. However, there were two problems with this interpretation of independence. First, the perceptions of older people show that although they think of independence as not overly relying on others’ help with everyday activities, they also want to be able to exercise choice and have a meaningful social role and identity. Second, the emphasis on independence as avoidance of reliance on others is a cultural construction. This notion is based on the ideology of self-reliance which is predominant in Britain, the USA and Australia. It is unlikely to be as important in other cultures or to be viewed so negatively, as a sign of weakness, sickness or lack of character. Older Chinese people for example, do not value self-reliance and would be proud to be looked after by their children. Therefore, Secker et al. sought to conceptualise independence in a way which took account of older people’s perceptions and cultural variation in the value attached to self-reliance. They proposed a two dimensional model which reconceptualised independence as two intersecting dimensions representing levels of dependence and levels of independence. Thus, they explain:
“While dependence equates with reliance on others, independence can be seen as subjectively self-assessed lived experience. Thus it becomes possible to combine high levels of dependence with high levels of experienced or felt independence, a particularly pertinent combination for service providers.” (Secker et al., 2003, p.375)

Wray (2004) found measures of autonomy, independence and dependence in later life were uncritically understood and applied from a British/American standpoint. This application rendered culturally diverse interpretations and experiences invisible. Through examining accounts of older women from different ethnic backgrounds, Wray concluded that the meanings associated with independence, dependence, autonomy, agency and empowerment are contextually based.

As the discussion thus far indicates, definitions and measures of independence in the health and community care literatures tend to be unclear and/or attempt to define independence by a negative association with dependence. Older people’s perceptions of independence mirror these definitions and measures. Rather than describing the meaning of independence, they reveal negative perceptions about dependence as being a burden on others and/or society and no longer being able to live in their home.

**DISABILITY**

The International Classification of Functioning, Disability and Health (ICF) definition of disability includes the impairment of body structure and function, limitation of activity and restriction of participation in life areas. The ICF’s definition also recognises the role that physical, social and environmental factors play in disability (WHO 2001). In referring to people with disability, I adopt the meaning given in the Commonwealth State/Territory Disability Agreement 2002–07 (CSTDA):

“…‘people with disabilities’ means people with disabilities attributable to an intellectual, psychiatric, sensory, physical or neurological impairment or acquired brain injury (or some combination of these) which is likely to be permanent and results in substantially reduced capacity in at least one of self care/management; mobility and/or communication, requiring significant ongoing and/or long-term episodic support and which manifests itself before the age of 65.” (AG, 2002-07, p.9)

Biomedical model ideas of disability understand it as an individual problem, equated with physical, sensory and/or intellectual impairment and directly caused by disease, trauma or another health condition. Treatment is understood as medical care. In contrast with this approach the social model definition of disability distinguishes impairment - understood as a condition of the body - from disability, which are the circumstances of social exclusion caused by the organisation of society.
(WHO, 2002). This model of disability places the focus of change on social institutions and the environment, rather than on the individual. Further, it stresses the agency of people with disability in effecting change through empowerment, participation and leadership.

Amelioration of disability according to the social model demands a political response, since the problem is created by an unhelpful physical environment brought about by the attitudes of society or an inaccessible built environment. Neither model used on its own is adequate, however both are partially valid. The complex phenomenon of disability is always an interaction between the problem at the level of a person's body, as well as social phenomena such as the context in which the person lives. But some aspects of disability are almost entirely internal to the person, while other aspects are almost entirely external. In other words, since appropriate responses to the problems associated with disability include both medical and social responses; we cannot wholly reject either kind of intervention. Hence, the ‘biopsychosocial model’ advocated by the WHO, offers a fusion of the medical and social models (WHO, 2002).

**FRAILTY**

Frailty generally refers to:

“…a multidimensional syndrome of loss of reserves (energy, physical ability, cognition, health) that gives rise to vulnerability.” (Rockwood et al., 2005, p.489)

However, as the numbers of people considered frail (or ‘at-risk’) in the population increases, awareness grows of the need to define this condition more precisely and identify the range of factors which lead to frailty. As noted by Ahmed et al. (2007), the study of frailty:

“…may provide an explanation for the downward spiral of many elderly patients after an acute illness and hospitalization.” (Ahmed et al., 2007, p.748)

In the past, definitions of frailty primarily focused on the physical and physiological processes (Walston et al., 2006). The following definition from Fried et al. (2004) expanded upon the former more narrow aspects of frailty to include disability, dependency and the need for care:

“…a state of high vulnerability for adverse health outcomes, including disability, dependency, falls, need for long term care, and mortality.” (Fried et al., 2004, p.256)

After conducting a literature review which aimed to identify factors contributing to frailty, Levers et al. (2006) found seventeen different definitions of frailty. Among the definitions were factors of ageing
and disease, and strong agreement over the common clusters of cognitive/psychological, nutritional and social factors. They concluded that:

“Without a clear explanatory theory of the path from contributors to frailty to outcomes, research will continue to produce confusing results. A theoretical framework that includes bio–psycho–social–spiritual factors as contributors to frailty is recommended as the most useful framework for gerontological nursing.” (Levers et al., 2006, p.282)

At the time of writing this thesis, such a theoretical framework was not found in the literature. Community care would also benefit from a theoretical framework that included bio–psycho–social–spiritual factors as contributors to frailty.

### 2.3 ACTIVITIES OF DAILY LIVING (ADL) AND INSTRUMENTAL ADL (IADL)

Bearing the former definitions of independence, disability and frailty in mind, it is important to understand how they form the basis of the categories used by allied health practitioners in the community (and in hospitals) to determine a person’s ADL and IADL (see Table 1). In other words, these categories provide the basis for professional assessments (and decisions) to determine whether or not a person is able to maintain themselves and to live independently. Such assessments are fundamentally important to care transitions between a hospital and the community, as they are necessary to fulfil the legal requirements for the provision of aged and community care.

With regard to physical health, a person’s functionality is described in relation to three hierarchical categories: general physical health or the absence of disease; the ability to perform ADL; and the ability to perform IADL. A higher level of functioning distinguishes ADL or the more basic levels of activity, from the ability to perform the more complex IADL activities. Within the list of basic ADL are four core activities which are fundamental activities for self-maintenance. While ADL and IADL are considered essential for self maintenance and independent living, IADL are tasks which provide greater independence (Dunkle et al., 1994).

**Table 1. Basic ADL and Instrumental ADL**

<table>
<thead>
<tr>
<th>Basic ADL</th>
<th>Instrumental ADL</th>
</tr>
</thead>
<tbody>
<tr>
<td>Feeding one’s self</td>
<td>Meal preparation</td>
</tr>
<tr>
<td>Dressing and undressing</td>
<td>Using telephone</td>
</tr>
<tr>
<td>Toileting</td>
<td>Grooming</td>
</tr>
<tr>
<td>Transferring (moving from chair to bed or toilet and vice versa)</td>
<td>Laundry</td>
</tr>
<tr>
<td></td>
<td>Shopping</td>
</tr>
<tr>
<td></td>
<td>Housework</td>
</tr>
<tr>
<td></td>
<td>Taking medicine as directed</td>
</tr>
</tbody>
</table>

Source: Adapted from Crews (2005) and Wanless (2006)
2.4 POPULATION AGEING, DISABILITY AND CARERS

POPULATION AGEING

Population ageing is a long-term developmental challenge which needs to be mainstreamed into relevant policies (WHO, 2002; ESCAP, 2008). Along with many countries world-wide, Australia is experiencing population ageing (UN, 2005 cited in ABS, 2006). While the WHO (2002) favours active ageing, which is a rights-based approach to how individuals and populations age, in Australia the HACC program uses a needs-based approach. Chronic illnesses are the leading cause of morbidity, disability and mortality and are costly to individuals, families and governments in all regions of the world (WHO, 2002). Yet while old age and disability are not diseases, their increasing medicalisation raises a number of social, ethical, policy, economic and quality of life challenges to individuals, families and governments (Thane, 2005).

Ageing in Australia

The ageing of the population, resulting in an increase in chronic disease and frailty, is one of the major causes for the rise in health expenditures in Australia and contributes to the pressure on hospitals. While governments in developed countries are preoccupied with containing their health budgets, maintaining equitable access and ensuring the quality of health and community care services present an ongoing challenge.

According to the latest population projections from the Australian Bureau of Statistics (ABS), the already evident trend of the ageing of Australia's population will continue. Over the next decades government spending is projected to be significantly affected by population ageing in the areas of health, aged pensions and aged care. Sustained low levels of fertility combined with increased life expectancy at birth have resulted in population ageing. This will bring considerable change to the age composition of Australia's population (ABS, 2007). The change is most acutely seen by comparing the age and sex of the Australian population for 1987 and 2007 with that of 2004 to 2101. This represents the rapid population ageing that will continue in Australia over the next 50 years until the large ‘baby boom’ generation, which is those born from 1946 to 1965, pass out of the population pyramid (ABS, 2006; ABS, 2007)

People aged 65 years and over

ABS population projections conducted in 2006 found that among the main considerations for older people (people aged 65 years and over) were health and housing services, and that both the number of older people and their proportion of the total population will increase rapidly to the middle of this century (ABS, 2006). On the 30 June 2007, Australia had 2.75 million (or 13.3%) people aged 65 years and over out of a total population of just over 21 million (ABS, 2007). This age group will increase to between 4.5 million and 4.6 million in 2021, to between 7.0 million and 9.0 million in 2051.
and in 2101 is projected to reach between 6.9 million and 12.8 million. As a proportion of the population, this age group is projected to increase from 13% in 2004 to between 18% and 19% in 2021, to between 26% and 28% in 2051, and to between 27% and 31% in 2101 (ABS, 2006).

People aged 85 years and over

In June 2004 there were 295,600 people aged 85 years and over and this age group is projected to more than double within 20 years (to 608,800 people in 2021), to double again by 2034 (1.25 million), and to double once more by 2049 (2.5 million). By 2101 the number of people aged 85 years and over is projected to be 4.3 million. This group will have the highest growth rates of all age groups, reaching a peak in 2032 due to the large cohort born in 1947 (ABS, 2006). Therefore, the importance of the provision of health services and appropriate housing for this age group can only increase (ABS, 2006).

Australia’s experience of population ageing is an established trend that also helps explain the increase in the volume of care transitions for older people, and the likely impact this has on hospital and community care services. Further, adequate planning to meet the care transition needs of older people will be needed as the projections for population ageing will continue to intensify over the next 50 years.

DISABILITY AND CARERS

In 2003, one in five people in Australia had a reported disability and there were 2.6 million carers in Australia, with around 230,000 of these carers living in the state of SA (ABS, 2003). Among ATSI people, the prevalence rates of disability were at least twice as high when compared with non-indigenous Australians (Australian Institute of Health and Welfare [AIHW], 2007). SA had one of the highest disability rates in Australia (ABS, 2003). Many people with a disability have reported needing assistance to manage their health conditions or ADL, and those with more severe core activity limitation were less likely to have their need for assistance met (AIHW, 2008).

Most people with disability living in households and needing assistance received help from informal carers (relatives and friends, mainly partners, parents or children), while formal providers (home-care workers and voluntary workers) were used by about half of those with disability (ABS, 2003). Between 1998 and 2003 the number of people needing assistance with ADL increased. The most common areas where help was needed were mobility, housework, cognition or emotion, health care and transport (AIHW, 2008). Carers of people with a disability were more likely to be older and/or have a

9 This projection is from Series A, which used the assumption of high life expectancy at birth. Although the series of ABS populations projections vary, high growth in this age group is common, though considerably less for Series B and C from around 2030 onwards. For example, by 2051 the population is projected to be 1.6 million in Series B and C.
disability themselves (ABS, 2003). However, often their caring work came at a personal and financial cost that is largely unrecognised, as demonstrated in the following statement from the Human Rights and Equal Opportunities Commission (HREOC):

“Attitudes and behaviours towards caring, such as the perception that it is only women’s responsibility, are often the result of unquestioned gender assumptions that become entrenched at an early age and need to be actively challenged if they are not to form artificial barriers to balancing work and family life.” (HREOC, 2007, p.xiv)

Nearly a third of older people lived alone in private dwellings and, among people aged 85 years and over, this was their most common living arrangement (AIHW, 2007). The trends between 1998 and 2003 indicated a future higher demand for disability support services to be community-based rather than institutional, underlying the importance of establishing stable community living and care arrangements for clients and carers (AIHW, 2008).

THE SOUTH AUSTRALIAN CONTEXT
In 2006 the total population of South Australia (SA) was 1,514,336, with the majority of people (1,060,381) living in metropolitan Adelaide (ABS, 2006). Population ageing is projected to continue in SA, substantially changing the age structure by 2051 with greater proportions of older people and fewer younger people. By 2051, there will be between 472,000 and 563,200 people aged 65 years and over, who will account for one-third of SA’s population, compared to 15% in 2004. Furthermore, the number of people aged 85 years and over will also increase significantly, from 28,000 (or 2%) in June 2004 to between 116,200 and 188,200 in 2051, making up 7%–11% of the population (ABS 2006, p.66). On 30 June 2007, with 15.2% aged 65 years and over, SA had the second highest proportion of aged people (ABS, 2007). In 2003, there were an estimated 230,000 carers in SA (ABS, 2003) with around half (53%) of this group also in paid employment (ABS, 2003).

According to the 2006 Census of Population and Housing, 15.3% of people in SA aged 65 years and over lived in the Adelaide metropolitan area (ABS, 2006). In the same year, when considering only those people aged 75 years and over, there were 87,647 (or 8%) usually resident in Adelaide, an increase of 0.6% from 2001 (ABS, 2008).

This research was situated in a specified region of Adelaide, defined within particular Local Government Areas (LGA), which are referred to here as LGA A, LGA B and LGA C. Among the three LGA of metropolitan Adelaide, LGA A had the lowest total population (52,154) but with 19.4% had the highest proportion of aged persons (or 10,133) (ABS, 2006). Then followed LGA B with 19,056 (18.9%
of the council’s total population) and LGA C, with 17,038 (16.5% of the council’s total population) (ABS, 2006) and (ABS, 2006).

At the 2006 Census, comparisons across metropolitan Adelaide showed that several suburbs in the specified region of Adelaide had high proportions of people aged 75 years and over. This region had high proportions of people who lived alone and also had high proportions of people who needed assistance in one or more of the three core activities of self care, mobility and communication (ABS, 2008). According to the ABS Index of Relative Socio-economic Disadvantage (IRSD)\textsuperscript{10}, LGA B was ranked in the 2\textsuperscript{nd} decile, placing it towards the most disadvantaged end of the scale\textsuperscript{11}. This compared with LGA A (in the 5\textsuperscript{th} decile) and LGA C (in the 6\textsuperscript{th} decile) (ABS, 2006).

This study took place in one of the most disadvantaged regions of Adelaide, where nearly a fifth of the people were of an older age, with many of them who lived alone and needed assistance with ADL. Consequently, many were also likely to experience frequent care transitions or need assistance from community care services in order to remain living at home.

2.5 COMMUNITY CARE FOR OLDER PEOPLE, PEOPLE WITH DISABILITY AND CARERS IN AUSTRALIA

Over past decades, the needs of older people and people with disability have been reflected in the steadily increasing demand and funding assistance for community services (Department of Health and Ageing [DoHA], 2003). Because of the decline in functional ability brought about by the ageing process and the higher levels of disability and chronic illness prevalent in older people and people with disability, they are more likely to need support from community services. In this next section I focus on the role and performance of the community services sector in providing support to older people, people with disability and their carers. Particular attention is paid to the HACC program and disability services.

COMMUNITY SERVICES SECTOR

What are community services?

According to the ABS, families are the principal providers of care for children, older people and people with a disability (ABS, 2001). Community services aim to help families undertake or assist with these


\textsuperscript{11} In the IRSD, a score of 1 equals the most disadvantage and 10 equals the least disadvantage.
roles when families are not in a position to provide care. It is in circumstances of vulnerability and unmet need where community services are able to provide special interventions (Steering Committee for the Report on Government Services [SCRGSP], 2008). According to the Local Government Community Services Association of Australia (LGCSAA), community services are defined as:

“…a system for providing support to sustain and nurture the functioning of individuals, families and groups, to maximise their potential for development and to enhance community well being. Outcomes and processes in community services are directed by the principles of social justice… [Which embraces]:

Equity in the distribution of resources
Access to quality services
Participation in decision-making
Equality of opportunity." (LGCSAA, 2002)

The LGCSAA maintains that community services are often, but not always, directed toward target groups such as families, people with disability, aged people, people from non-English speaking backgrounds and ATSI people. However, according to the AIHW (2005), community services are provided to:

“…individuals and families of widely differing ages and in widely different social and economic circumstances. They protect and support vulnerable individuals and families at key stages of their lives. [They also] contribute to the development of community infrastructure and networks that in turn promote the social, emotional, physical, psychological and economic wellbeing of individuals and families.” (AIHW, 2005, p.11)

Service provision occurs across a range of areas, such as housing, public and community transport, health, education, community information, community safety, and counselling / emotional support (LGCSAA, 2002). Usually services are provided by government and the not-for-profit sector, but the for-profit sector also has an important role (for example, as owners of aged care facilities). They also contribute to the community’s service needs through infrastructure development (AIHW, 2003, cited in SCRGSP, 2008). Notably, community services exclude acute health care services, long term housing assistance and income support (such as pensions and allowances). Such broad understandings about the nature of community services mask their complexity (SCRGSP, 2008).

Funding

Some services are funded solely by the Australian Government, some are funded by State and Territory governments only and some are funded jointly. Residential aged care (RAC), accommodation support and other community services are primarily provided by non-government organisations, while disability services are funded by government and are partially delivered by government. Most of the recurrent funding for aged care services is provided by the Australian
Government, whereas State and Territory governments contribute most of the recurrent funding to
disability services (FaCSIA, cited in SCRGSP, 2008).

According to the most recent estimates of community services expenditure produced by the AIHW
(2007), in 2005-6 total government welfare expenditure was $90 billion, which comprises cash
payments and welfare or community services. Compared with the 1998-99 welfare expenditures, this
was an increase of $33 billion, or nearly a third (from $57 billion). This increase placed welfare
expenditure at a similar level to health expenditure (at $87 billion) in that year. In 2005-06 the figure
was $29 billion (or $1,404 per person), which represented 3.0% of GDP, spent by governments, non-
government organisations (NGOs) and individual households on providing services to assist members
of the community with special needs. This was 32% of total welfare expenditures, excluding welfare
payments and was limited to families and children, older people, people with disability and other
disadvantaged groups. While government provided 71% of the funding for welfare services in 2005-
06, with NGOs providing the remaining 29% of funding, NGOs provided most welfare services ($20
billion worth out of $29 billion). In 2005-06, welfare services for older people had the highest recurrent
funding from the Australian Government with 64%, while State and Territory governments expended
their highest amount, at 39%, on welfare services for people with disability. Over the period 1998-99
to 2005-06, the average growth in Australian Government funding of welfare services for older people
was 2.6% per year, while growth in welfare services for people with disability was 4.2% (AIHW, 2007).

As the proportion of older people in the Australian population doubles over the next forty years, the
proportion at traditional working age will correspondingly fall and economic growth per person is
projected to slow. These factors will result in the emergence of substantial fiscal pressures and likely
increases in government spending, particularly in the areas of health, age pensions and aged care. If
productivity, population and participation are the most important contributors to GDP, then it is argued
that GDP is a key factor in the ability of the economy to sustain provision of community services

An additional concern is the volume of care provided outside the home by informal carers. As they
struggle to balance their work and caring roles, the health and welfare status of informal carers raises
the question of the need to consider care as a community responsibility, as the HREOC report ‘It’s
About Time: Women, men, work and family Final Paper 2007’ contends:

“Demographic changes such as low birth rates mean that in future many more people will not
have family members living with them as they age. Providing support and care for people
outside of one’s home is likely to become a larger part of what we consider to be family and
carer responsibilities. This also raises the need to consider care as a community responsibility, rather than simply that of individual households. This is particularly important for elder care, as many frail older people are choosing — and are increasingly encouraged — to remain in their own homes as they age.” (HREOC, 2007, p.xiv)

As many of the pressures on men and women relate to the balance between work and family and to the provision of support in areas where community services could intervene if their capacity was assured, the HREOC report asserts that urgent attention is needed to fund, research and develop community services:

“Governments fund a wide range of care and support services. Many work well, but some require urgent attention in the form of funding, research and policy development. A priority must be to provide support services that allow people with disability and older people to participate as fully as possible in their communities.” (HREOC 2007, p.7)

The Home and Community Care Program

The HACC Program is a joint Australian Government, State and Territory initiative operating under the Home and Community Care Act 1985. HACC is the central element of the Federal Government’s ageing policy and is therefore the largest program providing formal aged care services to eligible people living at home. The HACC program aims to provide a comprehensive, coordinated and integrated range of basic maintenance and support services for frail aged people, people with a disability and their carers, as indicated in HACC Guidelines. This support is intended to enable the program’s clients to maximise their independence at home and in the community, and enhance their quality of life (DoHA, 2002). The program targets those people living in the community, who, in the absence of basic maintenance and support services are at risk of premature or inappropriate long-term RAC (DoHA, 2007).

The older population in Australia is traditionally defined as people aged 65 years or over, which is the entitlement age for males to receive the Age Pension. Notably, while there is reference to ‘older and frail persons’, HACC and aged care services are delivered on the basis of a person’s need for assistance due to frailty or functional disability rather than specific age criteria. Thus, although chronological age is an element of population-based planning, access to services is based on eligibility for approval as a care recipient. The principle of assessed need for aged care is described in the “Aged Care Act 1997” as:

“A person is eligible to be approved under this Part if the person is eligible to receive:
(a) residential care ...; or
(b) community care ...; or
(c) flexible care ...” (Aged Care Act, 1997, s.21-1, p.73)
People who are eligible for community care or HACC funded services include:

“(i) older and frail persons, with moderate, severe or profound disabilities;
(ii) younger persons with moderate, severe or profound disabilities; and
(iii) such other classes of persons as are agreed upon by the Commonwealth Minister and the State Minister; and
(b) the carers of persons specified in sub-clause (a).” (DoHA, 2002, p.5)

Therefore, the HACC program is not age specific and is available to people with profound, severe or moderate disability and their carers.

The cost of the HACC program is shared between the Australian, State and Territory Governments, with the Australian Government providing 60% of program funding and maintaining a broad strategic role, and the States and Territories providing 40% and the day to day administration. Bilateral agreements between the Australian Government, the States and Territories (the HACC Amending Agreements) are the formal basis through which the HACC program is arranged.

In 2008–2009, $1.788 billion will be provided nationally for the HACC Program. Compared to funding in 2007–2008, this was an increase of over 8%. Of these funds, the Australian Government will provide $1,090 billion and the remaining $698 million will be contributed by State and Territory governments (DoHA, 2008). In June 2006, there were approximately 3,400 active agencies registered on the HACC Minimum Data Set (MDS) Agency Register, including a wide range of NGOs (DoHA, 2007). People can access HACC services through contact with localised HACC assessment agencies (SCRGSP, 2008).

Established in 1984 by the Australian Government, the Aged Care Assessment Program (ACAP) provides access to specialist Aged Care Assessment Teams (ACATs), who determine (1) eligibility for admission into residential aged care (RAC) and (2) the level of care required (and the subsidy paid to such services). The core objective of the ACAP is to assess the needs of frail older people and recommend appropriate services. Assessment and recommendation by ACATs are mandatory for admission to RAC or receipt of community aged care12. People may also be referred by ACATs to the HACC program, although an ACAT referral is not mandatory for HACC services (SCRGSP, 2008).

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12 Community aged care can include a Community Aged Care Package, an Extended Aged Care at Home package, and the Extended Aged Care at Home Dementia package or the Transition Care Program. Community support services for people who need aged care are delivered under the auspices of a number of other government programs that cover both residential and community-based aged care services. These programs are administered by the DoHA. The Veterans’ Home Care and Veterans’ Home Nursing programs are administered by the Australian Government Department of Veterans’ Affairs. There are also various programs for people with dementia and their carers, the Day Therapy Centre Program, the Continence Aids Assistance Scheme, and flexible aged care services through Multipurpose Services and services under the National Aboriginal and Torres Strait Islander Aged Care Strategy (AIHW, 2005 cited in Hales et al. 2006). AIHW. (2005). "Australia’s welfare 2005." Retrieved 24.6.08, 2008, from
Residential aged care is administered by the Australian Government Department of Health and Ageing (DoHA) and comprises accommodation plus care services within the accommodation setting (for example, nursing care, personal care, meals and laundry). A RAC subsidy is provided for low and high level care in accredited aged care facilities. This includes permanent and respite residential services (Hales et al., 2006).

A range of HACC services are available to the aged and people with disability, including maintenance and long-term care. The basic community care tier for people requiring lower levels of support may include the following services, provided according to assessed need:

- domestic assistance, including cleaning, shopping, meal preparation
- home maintenance / modification
- social support
- nursing care, including home visits by a community nurse
- allied health care, including occupational therapy, physiotherapy, podiatry and speech therapy
- personal care, including assistance with hygiene and dressing
- delivery to the home of a daily midday hot meal on weekdays at a nominal charge
- respite for carers
- information and advocacy
- formal linen services
- goods and equipment
- transport, and
- counselling / support. (DoHA, 2003)

When someone is considered to have complex care needs or is at risk of admission to RAC, a more intense level of community services can be provided through a comprehensive assessment and package of community care that is case-managed (DoHA, 2003).

Respite care is designed to give carers a break from their caring duties. The respite can be: centre based day care, in home respite care (funded through any of the previous programs or by the National Respite for Carers Program) or in the form of residential respite care for the care recipient (DoHA, 2003).

According to the AIHW (2008), in 2005–06 there were an estimated 777,471 people, or 3.8% of the Australian population, who received assistance from the HACC program (AIHW, 2008). This was an

increase of 33,274 individual clients from 2004-05, or 3.7% of the Australian population in that year (DoHA, 2006). In 2005-06, 76% (or 588,731) of HACC clients were aged 65 years and over (DoHA, 2007). There were 188,740 clients aged under 65 years. Over 68% of HACC clients are aged 70 years or over. Nevertheless, with nearly 12% of program recipients under 50 years of age, it is an important source of community care for younger people with disability. Furthermore, in 2005-06, 9.2% of HACC clients nationally were in receipt of a Disability Support Pension. In the same year, 45.5% of HACC clients classified as care recipients reported that they were also receiving assistance from a relative or friend (DoHA, 2007 cited in SCRGSP, 2008).

There are many linkages between different community services, stimulating governments (and others) to begin to stress the need for integrated, client-centred community services. This issue was noted in the most recent Productivity Commission “Report on Government Services 2008”:

“Many community services are linked by the provision of these services to individuals at different stages of life. Although some community services only apply to people in specific age groups (for example, aged care services), other services are not as strictly age-specific (for example, disability services…). Some individuals may receive multiple services. Disability services may continue throughout an individual’s lifetime and overlap with provision of aged care services.” (Steering Committee for the Report on government Services [SCRGSP], 2008, p.18)

Although a succession of community service interventions has been referred to as ‘pathways’, to date there is limited information on the patterns of access by individuals to the range of community services, either concurrently or in succession, over a lifetime. The SCRGS report called for better understanding of the pathways, of the usage and links between various community services, the nature of these links, and whether interventions in one area of service provision result in reduced need for other services. It was noted that this information would enhance the effectiveness and efficiency of the sector overall (SCRGSP, 2008).

Furthermore, the report recognized the links between community services and other government services and the close relationship between community services and the health sector. It raised the importance of access to effective community services and their potential to influence outcomes for clients’ health (education, justice, housing etc). At the same time, access to health services may affect outcomes for clients with regard to community services. These issues pivot on the effective interaction between services in both sectors (SCRGSP, 2008).
During hospitalisation, people with disability, including those with psychiatric disorders or intellectual disability, may be approved for RAC when the person was assessed as either:

> “having a condition of frailty or disability requiring at least low level continuing personal care; and being incapable of living in the community without support; and meeting any other eligibility criteria for the level of care assessed for the person that are set out in the classification level applicable under the Classification Principles 1997; and for a person who is not an aged person—there are no other care facilities more appropriate to meet the person’s needs.” (Department of Health and Aged Care, 2006)

This involves the hospital sector calling for an assessment by the ACAT. Within hospitals little is known about community services and supports available for people with disability. Furthermore, once a person has passed the acute phase of their illness, most hospitals are keen to move the person out of a hospital bed and an ACAT assessment is the first step towards achieving this objective. However, there appear to be problems associated with the way in which the disability sector and the aged care sector act on one another, confounding an already fraught area of discharge planning:

> “Community aged care programs act on the disability sector by blocking access to community-based aged care specific services for CSTDA\(^{13}\) consumers in supported accommodation. Correspondingly, the disability sector acts on the aged care sector by steering disability services clients who are ageing and younger clients with complex needs that cannot be managed at home towards residential aged care.” (Hales et al., 2006, p.36)

Furthermore, the issue of ‘related’ or ‘cross-cutting’ services adds to the complexity and confusion in the hospital context and is a culmination of the considerable overlap between the type of basic living support delivered to people with disability and the types of assistance delivered to older people. People with disability who age prematurely and older people with disability usually experience an increase in support for personal assistance, domestic assistance and social support, especially following hospitalisation. Some other areas of assistance such as community access services for people with disability and allied health care, occupational therapy, physiotherapy and podiatry are provided by the HACC program to HACC eligible clients, but CSTDA clients cannot access these ‘unrelated services’ through the HACC program (Hales et al., 2006, p.36).

**Performance appraisal of the HACC Program**

Until very recently, information about the performance of the HACC program was unavailable. In its place, service providers, consumers of community services and their carers have voiced their concerns over the fact that the supply of HACC services has not kept pace with increasing demand, leading to the formation of a coalition of an advocacy group (the National Community Care Coalition).

\(^{13}\) CSTDA is the abbreviation for the Commonwealth/State Territory Disability Agreement
In the lead-up to the 2004 federal election, this group lobbied the government and opposition with the following message:

“Many older people and younger people with disabilities can’t access enough care services for them to stay at home. I ask you to urgently increase funding for well-coordinated community care services so people can be supported to live at home.” (Rimmer, 2004, p.16)

The shortage of supply of HACC services results in many older people remaining in hospital after the acute phase of their illness has passed due to delays in the delivery of HACC services (Wilson et al., 2003). After the completion of a reform process which resulted in the release of “The Way Forward: A New Strategy for Community Care” (DoHA, 2004) questions continued over the adequacy of funding for community care to those people who need it (Bruen, 2005; Sadler, 2006). The slow progress of reform, according to Aged and Community Care Services Australia (ACSA), has not led to any significant improvements for people receiving community care (ACSA, 2008).

A framework of performance indicators for government aged care services was developed by the SCRGSP (2008)\textsuperscript{14}. The framework provided information on equity, efficiency and effectiveness, while also distinguishing the outputs and outcomes of community services. The objectives for aged care services identified the accessibility of services, their appropriateness to the needs of older people and their carers, and the quality and efficiency of services that promote the wellbeing and independence of frail older people and their carers. There were no outcome indicators for aged care services available in this report. However, it is noted that the three outcome indicators identified for development and reporting in future reports include ‘social participation in the community’, ‘maintenance of individual functioning’ and ‘enabling people with care needs to live in the community’ (SCRGSP, 2008, pp. 28, 29 and 58).

The focus was people 70 years and over and ATSI people aged over 50 years. Among this age group, there were substantial differences in accessibility between all users and ATSI users across all areas. No data were available to measure waiting times for community care. Unmet need was calculated at over one third of people aged 70 years and over who self-identified and needed assistance with at least one ADL. In 2005-06, there were almost 20% of separations for patients who had a care type of ‘maintenance’ with a diagnosis (either principal or additional) of either ‘awaiting admission to residential aged care’ or ‘no-one to provide care at home’, and whose separation was 35 days or longer. This proportion varied across jurisdictions and only reflected a small proportion of all public hospital separations for patients of this age group. There were 85% of HACC agencies measured for

\textsuperscript{14} A summary of the framework of performance indicators for the HACC program is provided in Appendix 2A
quality and the average score nationally was 16 out of 20. Expenditure on HACC services per person varied across jurisdictions. Nationally, the total expenditure per HACC target population for 2005-06 was $777 and for 2006-07 was $823. Across the eight jurisdictions, there was an average increase of $48 (or 0.05%) between 2005-06 and 2006-07. (SCRGSP, 2008; DoHA [unpublished] cited in SCRGSP 2008, Attachment 13, Table 13A.52)\(^{15}\). In summary, the SCRGSP called for improvements through the continued expansion of reporting on the characteristics of community services and ongoing investigation of issues that cut across services (SCRGSP, 2008).

Performance reporting on community aged care services is an essential step towards understanding and evaluating the ‘who, what, where and how much’ of such government funded services. The development and inclusion of indicators such as social participation in the community, maintenance of individual functioning and enabling people with care needs to live in the community are urgently needed to understand the impact of the HACC program as well as the transition into RAC. Furthermore, it appears that there is still a long way to go before the reliability of the data is adequately established so it can be used to make direct inferences and predictions to better understand the impact and cost of the present, as well as enabling the intelligent planning for the future of community services for an ageing and disabled population (SCRGSP, 2008).

Pressure is mounting to expand the HACC target population to enable access to a greater number of people and carers (Howe, 2008). It is also important to understand the complexity and multi-faceted nature of vulnerability, which is not necessarily age-related (Marsh, 2007). Greater flexibility and streamlining or packaging of HACC services are needed, as are client-centred approaches to care provision (The Allen Consulting Group, 2007; ACSA, 2008).

**Disability support services**

In Australia, disability support services are shared between the Australian, State and Territory governments. A complex blend of disability-specific services and income support services, as well as mainstream services available to the community as a whole, for example various health programs, are provided at the local and federal levels. These factors make it difficult to achieve clarity across Australia with regard to disability support, the services and the amount of funding provided.

Most funded services for people with a disability are provided under the auspices of two programs, the CSTDA and the HACC Program. Briefly, the CSTIDA forms the basis for the delivery, funding and

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\(^{15}\) A summary of Australian, State and Territory government expenditure on HACC services per HACC target population is provided in Appendix 2B
development of specialist disability services, where the person’s disability manifests before 65 years of age and for which they require ongoing or long term episodic support. However, CSTDA places no age-based restrictions on access to services. The major objective of CSTDA services is to enhance the quality of life of people with disability by assisting them to live as valued and participating members of the community. People who receive CSTDA services live in a range of accommodation settings, including private homes and supported accommodation (SCRGS, 2008).

The HACC national guidelines state that the HACC program generally does not provide services to recipients of disability accommodation support services. Yet people with disability who are younger than 65 years of age may seek to access complementary combinations of support from the CSTDA and HACC programs (for example, respite services from CSTDA and home modification and allied health care from HACC). In practice, there are regional variations in HACC eligibility requirements and prioritising practices which most likely limit the extent to which younger people with disability can access both HACC and CSTDA services. Nonetheless, HACC clients aged less than 65 years, and particularly those aged less than 40 years, may apply for CSTDA services, and may indeed be accessing both CSTDA and HACC services (AIHW, 2007). As this thesis is focussed on the HACC Program, no further details of CSTDA are provided here.

With regard to HACC services for people with disability, in 2005-06 there were 188,740 people (or 24.3%) aged under 65 years (DoHA, 2007). This was a small increase from 23.2% aged under 65 years in 2002-03 (DoHA, 2003). However, for the same period, the average number of support hours for this age group declined from 64 hours per year in 2002-03, to 58 hours per year in 2005-06 (AIHW, 2007). Data analysis from the HACC Program in 2005-06 indicated that clients aged under 65 years were considerably over-represented in specific assistance types, including counselling support (33.3%), counselling for carers (34.0%), centre-based nursing care (38.3%), and respite care (60.8%) (SCRGS, 2008).

Government spending on disability support services during 2005–06 totalled $3.95 billion, with just under half used to fund accommodation support services (AIHW, 2007). On the whole, HACC services are delivered to eligible people living in private residences or in rental accommodation (SCRGS, 2008). Between 1981 and 2003, among those aged under 65 years with a severe or profound limitation, there was a steady increase in the number and rate of people living in households and a decline in the number and rate of people living in institutional settings. The trend is towards community-based care for people with a severe or profound disability, mostly due to new service users remaining in community-based living arrangements rather than changes in the current
population in institutional settings. If these trends continue, it would suggest that the future growth for
disability support services, in particular accommodation services, is unlikely to be met through the
expansion of institutions. Again, these trends also show the importance of providing programs to
support carers and to support and stabilise community living and caring arrangements (AIHW, 2007).

CHAPTER SUMMARY
In order to place the issues to do with care transitions in a community context, this chapter outlined
community care for older people, people with disability, their carers and family. I began by providing
several approaches to defining independence, disability and frailty. As a concept, the notion of
independence is unclear and is often defined by a negative association with dependence (Russell,
1999; Leeson et al., 2003). It is rarely defined in social policy. Older people’s perceptions of
independence are contextually based and mirror negative associations with dependence (Secker et
al., 2003). This begs the questions: What is independence? Can anyone be truly independent?
The ICF definition of disability includes the impairment of body structure and function, limitation of
activity and restriction of participation. This definition also recognises the role that physical, social and
environmental factors play in disability (WHO, 2001). Also discussed was the contrast between
biomedical idea’s of individual disability, and that of social models which demand a political response
(WHO, 2002).

With regard to frailty, as the number of people in the population considered frail increases, a more
precise approach to the identification of the features of frailty is needed. Past definitions of frailty have
focussed on physical and physiological processes (Walston et al., 2006). While a theoretical
framework which includes bio-psycho-social-spiritual factors has been recommended as having more
utility than former definitions, such a framework is not yet available (Levers et al., 2006). I described
how a person’s functionality is determined by their ability to perform ADL and IADL (Dunkle et al.,
1994; Crews, 2005; Wanless, 2006).

Like many countries, Australia is experiencing population ageing (UN, 2005 cited in ABS, 2006) and
this will continue until the middle of this century (ABS, 2006; ABS, 2007). This trend, coupled with the
impact of chronic illnesses, raises social, ethical, policy, economic and quality of life challenges
(Thane, 2005). Moreover, the importance of providing health services and appropriate housing for
older people and people with disability will increase over time (ABS, 2006). Nearly a third of older
people lived alone in private dwellings and among people aged 85 years and over, this was their most
common living arrangement (AIHW, 2007).
In 2003, disability was reported by one in five Australians (ABS, 2003). Many people with a disability have reported needing assistance to manage their health conditions or ADL, and those with more severe core activity limitation were less likely to have their needs met (AIHW, 2008). Among ATSI people, the prevalence rates of disability were at least twice as high compared with non-indigenous Australians (AIHW, 2007). SA had one of the highest disability rates in Australia (ABS, 2003). In the future, there is likely to be more demand for community-based support services for people with disability, rather than institutions. This highlights the importance of establishing stable community living and care arrangements for people with disability, their carers and family (AIHW, 2008).

The important role currently played by informal carers will only increase as the number of people needing assistance with ADL increases (ABS, 2003). Carers may be older and/or have a disability themselves (ABS, 2003) and often their caring work results in personal and financial costs that may not be taken into account. The volume of care provided outside the home by carers, who are struggling to balance their work and caring roles, raises the need to consider care as a community responsibility (HREOC, 2007).

All levels of government play a role in the provision of community services. The HACC program is the main provider of care services for older people, people with disability and their carers. Disability services are funded by government and are partially delivered by government. There are many linkages between the HACC program and other community services, resulting in a complex community service structure (AIHW, 2008; SCRGSP, 2008). Furthermore, information on the patterns of access by individuals to the range of community services is limited; timeliness of access to the HACC program is unknown (SCRGSP, 2008) and there is no nationally consistent reporting mechanism for HACC (AIHW, 2005). Access to community services can influence clients’ health outcomes and vice versa (SCRGSP, 2008). A major issue facing the HACC program is that the supply of services has not kept pace with increasing demand (Wilson et al., 2003). Consequently, as the following statement indicates, the adequacy of HACC services is an issue that will continue to gain attention:

“For many people in a whole variety of classes, in different places in Australia, with different needs, there were inadequate or even no services. And our concern is that the present disability system in Australia is fragmented, in some respects quite dysfunctional.” Media Release from The Honourable G. Humphries, Liberal Party Senator cited in Donald 2007.

Reported levels of unmet need for community services to people who need assistance, the lack of flexibility, reliable data, timeliness of access to services and a client-based approach to community

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care, all confirm the need for reform of the HACC program. Reform would be inadequate if it did not take up the challenge to commence planning for sustainable community services, which also take account of population ageing and the impact of chronic illness. Finally, in a study about how the health and community care systems are interlinked with the care transitions of older people, people with disability and their carers, this chapter has pointed to the range of problems which include the approaches to defining independence, disability and frailty, determinations of ADL and IADL, the impact of population ageing, the prevalence of disability and the role of carers. Importantly, in the overview of the HACC program, I conclude that this program needs to more effectively consider the impact of care transitions on their client-base and on their capacity to deliver timely and appropriate services, as current reports show there are inadequate responses to people’s needs.
CHAPTER 3: CONTINUITY OF CARE AND THE IMPACT OF HOSPITAL TRANSITIONS ON OLDER PEOPLE, PEOPLE WITH DISABILITY AND THEIR CARERS

“...I have become increasingly uncomfortable with the use of the word “system” in regard to the numerous ways different societies make health care available to their people. System may imply a carefully thought out plan, and appropriately coordinated sets of arrangements, whereby people get access to high-quality health care in an efficient and effective manner. This is universally not the reality when one examines health services throughout the world. If, however, one interprets system as a set of interdependent parts, regardless of how well they function, then it is appropriate to talk about a health system.” (Southby, 2008, p.266)

“Older people receive care services across acute, aged, primary and community care sectors. Wherever older people interact with these systems and associated interfaces there is a risk of harm to the older person, a risk of functional decline and altered quality of life. It is no longer possible to consider one sector without the impact of the other.” (Department of Human Services [DHS], 1999 cited in House of Representatives Standing Committee on Health and Ageing, 2005, p.116) (#1184)

3.1 INTRODUCTION
In Chapter 2, I drew attention to topics which are relevant to understanding the situation of care transitions and social policy for older people, people with disability and their carers. I pointed out a range of problems that affect care transitions, including the potential impact of transitions on HACC clients and on this program’s capacity to deliver timely and appropriate services. In this chapter, I consider the impacts of an ageing population and the incidence of chronic illness on hospitals with regard to discharge planning and providing continuity of care. I report on the results of a systematic literature review for which I used the search algorithm which is provided in Appendix 3A. I review the difficulties associated with the care transitions of older people and people with disability and their carers across the ‘interface’ from hospital to residential aged care. In the last section, I consider the goal of achieving continuity of care and briefly review health-care integration.

3.2 IMPACT OF AN AGEING POPULATION, CHRONIC ILLNESS AND INCREASING DEMAND ON PUBLIC HOSPITALS
Since the late 1980s hospitals have had difficulty in balancing predictions for hospital beds with pressures to reduce LOS, and with the changes in patient care that have come about because of the ageing of the population and the number of patients with chronic conditions who have unplanned readmissions. Future predictions for hospital beds may be problematic if they are based on forecasts which predict a continuing decline in ALOS in contrast to the level of care required during an admission (Howe, 2002).
In the late 1980s, the Australian Government made efforts to manage hospital demand by improving the efficiency of hospital services through the implementation of a casemix classification system. Casemix was intended to represent the relative resource use for inpatient services and provide financial incentives to reduce length of stay (LOS) (Piccone, 1998). By linking reimbursements to the average cost of an episode (or ‘case’) of illness, casemix-based funding aimed to allow service providers flexibility at the same time as ensuring incentives for achieving efficiency (Fine, 1998). However, perverse incentives associated with casemix-based funding were the premature discharge of some patients and the seeking of patients who were less costly to treat because they fell within a particular health category (Banks, 2008).

In 1994, an official inquiry identified reduced LOS and premature discharge as two of the three trends which were contributing to pressures on community care (Morris, 1994). Other researchers raised concerns about: the potential risks to quality of care posed by the discrepancy between medically required LOS and the expected LOS based on Diagnosis Related Groups (DRGs) (Mushlin et al., 1991; Rutledge & Osler 1998); the impact that DRGs and clinical pathways had on health services to provide care within the shortest possible time (Schaldach, 1997); under-estimations to actual LOS needed by patients with comorbidities (Munoz et al., 1988; Mushlin et al. 1991; Devo et al., 1992) and too little time spent in hospital that limited patients and their carers exposure to medical and nursing staff to ensure proper coordination and management of continuing care (Cummings, 1999).

Many elderly patients experienced functional decline during admission; yet when their treatment was complete, the increasing demand on hospitals meant there was no longer room for them (Nixon, 2003). It could be argued that an unintended consequence of the financial incentives to reduce LOS in casemix-based funding was that hospital efficiency was prioritised over flexibility, especially when older patients with comorbidities were prematurely discharged without post-hospital care or with care that was inappropriate to their needs. As premature discharge occurred within an interdependent health care system, it then impacted on the community care sector and RAC, as well as carers and family.

In parallel with the introduction of casemix-based funding, demand for hospital services has risen at around 4% per annum (Swerissen, 2002; AIHW 2008). Public hospitals have taken most admissions

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16 The third trend identified by Morris (1994) was the increasing incidence of day surgery.
17 Diagnosis Related Groups (DRGs) are the index underpinning Casemix and are meant to represent the relative resource use for inpatient services.
Between 1997-98 and 2006-07 patient separations from public hospitals increased by 23.9% and patient days increased by 10.2%. The proportion of same-day separations increased (46.3% in 1997-98 and 55.8% in 2006-07), and the average length of stay (ALOS) in hospitals decreased by 19.1% from 4.1 days in 1997-98 to 3.3 days in 2006-07. For patients staying at least one night in a public hospital, the ALOS was 6.2 days in 2006-07. International comparisons illustrate that in 2004-05 for overnight separations per 1,000 of population, Australia was in the middle of the range reported by other Organisation for Economic Co-operation and Development (OECD) countries (AIHW, 2008).

Furthermore, between 2002-03 and 2006-07, Australian public hospital separations of patients aged 75 years and over increased by 25% and by 25.3% for those aged 85 years and over. In 2006-07, people aged over 64 years had more separations per 1,000 of population than any other age. While LOS increased steadily with age, older patients were more likely to be discharged into RAC or to die in hospital (AIHW, 2008).

In sum, the major changes since casemix-based funding was introduced and between 1997-98 and 2006-07 have been: increased hospital demand (4% per annum); increased patient separations (by 23.9%); increased patient days (by 10.2%); decreased ALOS (4.1 days in 1997-98 down to 3.3 days in 2006-07); increased hospital separations of older people (75 years and over increased by 25% and 85 years and over by 25.3%); increased LOS with age and the greater likelihood that older patients will be discharged into RAC or die in hospital.

A study from the UK found that the steady increase in demand for hospital care was mainly due to older people's illnesses and their presentation at a hospital Emergency Department (ED) and/or their need for admission. Between 1990 and 2004, managing older patients' investigations took more ED time; patients aged 70 years and over were 5 times more likely to be admitted; and their average length of stay (ALOS) was 7 times longer. George et al. concluded that ED pressures associated with increasing numbers of elderly patients and the likelihood of investigations pointed to the central importance of population ageing in planning health services (George et al., 2006, p.379)

Cameron (2006) and Braitberg (2007) have argued that for Australia, although population ageing is important when considering hospital overcrowding, a range of other factors need to be taken into account. These include changes in the workforce; demand for access to aged care; fewer hospital beds; and increased funding and demand for new treatments and procedures. Cameron identified strategies to improve 'access block' (the lack of available beds within the hospital for ED patients),
which included reducing hospital demand and optimising hospital bed capacity (including better discharge and access to rehabilitation, RAC and community outreach). Better discharge included:

“Addressing physical, social and psychological issues through care coordination in the [ED] and after hospital discharge can also help reduce [LOS] and readmission.” (Cameron, 2006 p.204)

Braitberg claimed that the likely savings from reducing hospital demand were limited because of population ageing and older people’s need for increased community support. According to Braitberg access block was a blocked systems problem, where overall patient flow was restricted, and not just from the ED. Thus, the main problem was insufficient hospital beds to cope with the surges in the number of patients with high levels of acuity and who needed admission.

It has been suggested that almost 20% of older patients remain hospitalised inappropriately because of delays in discharge, diagnostic tests and medical and other specialised consultations; and a lack of post-acute services outside the hospital (Australian Government National Health and Hospitals Reform Commission, 2009). However, while some older people no longer need acute care and remain in hospital awaiting placement, the perception remains that much of the burden on hospitals is because of the disproportionate bed occupancy by older people and this is judged as an inappropriate use of acute hospital care. As counteractions mount to such narrow notions of older patients’ entitlements, the call has arisen to view them as equal members of the population with the same health care rights. Such policy improvements would be assisted by better data collection and analysis to assist with developing system-wide funding arrangements for post-acute care (Howe, 2002).

Others have argued that preventing hospital admissions with timely and adequate non-hospital health care must be considered, as managing all of the acute care needs of older people and of those with chronic disease in hospitals is unsustainable:

“The current situation of using hospitals to assess and manage almost all acute episodes of care for older people is unsustainable given [predictions of population ageing]…This requires a change of mindset to see the community as the natural setting for health care with the hospital as the expensive alternative if the illness is severe, requires surgery or high technology.” (John Ward cited in Australian Government National Health and Hospitals Reform Commission, 2009, p.102)

### 3.3 DISCHARGE FROM HOSPITAL TO HOME AND COMMUNITY SETTINGS

Discharge planning is the routine method used in hospitals for ensuring patients’ needs will be met after they leave the hospital. Yet discharge planning can be complicated and problematic for older
people, for people with disability and for family and carers. Numerous studies have demonstrated the low impact and effectiveness of discharge planning processes: where eligibility criteria for access to community supports and gaps in communication impeded execution of the discharge plan (Bull & Roberts, 2001); and where aspects of discharge planning were overlooked, neglected or uncoordinated because nurses lacked the time to collate accurate information and communicate effectively with others in the multidisciplinary team (Atwal, 2002; Watts & Gardner, 2005). The results of studies contradict one another, as one study demonstrated that the impact of discharge planning on readmission rates, LOS, health outcomes and cost was unclear (Shepperd et al., 2004), whereas another found discharge planning was more effective when the planning and support components were used in combination (Mistiaen et al., 2007).

Fine (1998) commented on the role of discharge planning as one attempt to link hospital and post-hospital extended care. Eight principles developed in 1994 by the Australian Council on the Ageing were presented. Fine stated that the effectiveness of discharge planning relied upon the cooperation of numerous service providers outside the hospital (Fine, 1998). Rosswurm and Lanham have argued that inadequate discharge assessment, including home assessment and referral to community services, should be understood as a compounding problem likely to increase the chance of institutionalisation for older patients if hospital staff considered the patient unable to manage safely at home (Rosswurm & Lanham, 1998). Communication problems which impact on discharge have also been found within the hospital, between patients, doctors, nurses and social workers (Bull & Kane 1996; Lundh, & Williams 1997; Huby et al., 2007).

Poor patient and carer experiences of discharge planning indicate a more comprehensive exploration is needed (Naylor et al., 1994). Carers and family need to be included in the discharge planning process (Franey, 1995). When older people’s physical, psychological, social and environmental issues were considered well ahead of discharge then some older people may be discharged earlier, with better health outcomes (Cunliffe et al., 2004).

Patient perceptions and experiences of discharge suggested a complex interplay of poor communication and lack of involvement with patients by hospital staff which needed to be more patient-centred, respectful of older patients’ adaptive coping strategies and to have involved them in the discharge planning team (Congdon, 1994). More effective communication between nurses and patients ensured that patients understood discharge plans (Reiley et al., 1996) and likewise, more effective communication between physicians and patients ensures patients understood their post discharge treatment (Calkins et al., 1997). Furthermore, the person with continuing care needs may
find that the provision of community services has been delayed or insufficient (Armitage & Kavanagh 1998). Rowe et al. found that the types of problems patients experienced were more related to hospital resources than community resources, which suggested the importance of examining hospital issues even when the services were going to be delivered in the community (Rowe et al., 2000). Grimmer et al. (2004) supported the argument that it was the complex interplay between numerous systems involved in hospital discharge planning which impacted on older people’s experience of discharge and lack of preparation for discharge (Grimmer et al., 2004).

Communication problems which impacted on discharge were found within the hospital, between patients, doctors, nurses and social workers (Bull & Kane 1996; Lundh, & Williams 1997; Huby et al., 2007). Moreover, effective communication and negotiation between all parties involved in the discharge planning process were reported by elderly, recently discharged patients as the hallmark in both satisfaction and continuity of care (Mistiaen et al., 1997; Clare & Hofmeyer, 1998; Williams et al., 2006).

A range of issues affecting patients included their physical and functional status (Franey, 1995; Grimmer et al., 2004); and their recovery from illness, coping strategies, and informal and formal support (Grimmer et al., 2004; McKeown, 2007; Swinkels & Mitchell, 2008).

Hospitals have a tendency not to involve or communicate with carers in discharge planning (Armitage et al., 1995), or alternatively to overestimate or implicitly depend upon, carers to support and manage older people or people with disability at home after discharge (Grimmer et al., 2000; Williams et al. 2006; O’Connor, 2007).

From the perspective of health services, the main discharge planning issues were: pressures to reduce LOS which resulted in elderly people being discharged when they were still in the very early phases of recovery from illness (Proctor et al., 1996; Mistiaen et al, 1997). Once discharged from hospital, little was known about how older people progressed (Waters et al., 2001; Mistiaen et al., 1997) and the person with continuing care needs found that the provision of community services was delayed or insufficient (Armitage & Kavanagh 1998). Delayed discharge of older people from hospital was another health service issue, and was found to originate from administrative/organisational issues and community service constraints. It is therefore a topic of significant policy relevance (Victor et al., 2000).
Information exchange and communication between hospital staff and the community care sector were among the major problems associated with discharge. These problems are well documented in the literature. Inadequate communication between hospital and community (Lurie et al., 1984; Armitage & Williams, 1990; McKenna et al., 2000) resulting in inadequate notice of discharge (Neill & Williams, 1992) when other primary health care providers are involved can cause interruptions to continuity of care (Kripalani et al., 2007). Transfer of information between the hospital and community sectors was crucial to patient wellbeing (Waters, 1987), as was interagency collaboration across the hospital and community care sectors during the discharge process (Rowe et al., 2000; Eija & Marja-Leena, 2005; Auslander et al., 2008).

It is claimed that discharge planning and the hospital-community interface improved when patients received timely and informative risk screening, referrals were made to community health service providers and efforts were made to improve communication processes between hospital staff and community health service providers (Bolch et al, 2005). Models of care that used a care facilitator and educated patients in self management provided better access to services and improved service coordination as well as reduced hospital demand (Bird et al., 2007).

The process, effectiveness and outcomes of hospital discharge are important issues, especially as the use of hospital services by older people and people with disability is predicted to increase over the next 50 years. Furthermore, the need to know more about all aspects of hospital discharge will only intensify as we learn more about the vulnerabilities of older people, people with disability and their carers when they cross the interface between hospital and community settings. The variety of findings in this review demonstrates the complexity of hospital discharge in the case of older people and people with disability, as well as their carers.

3.4 THE ‘INTERFACE’ AND DISCHARGE FROM HOSPITAL TO RESIDENTIAL AGED CARE

In this next section I explore the ‘interface’ and its influence on discharge from hospital to RAC of older people and people with disability. Important and complex questions arise for hospital staff while...
discharging aged people and people with disability: Are any community services available to meet this patient’s needs? If not, what will happen to this patient when she/he is discharged? If services are available, can they be delivered to the patient’s home to meet their needs and provide continuity of care?

When it follows directly from a hospital admission, entry to RAC can present significant personal, professional and ethical dilemmas for everyone involved (Clemens 1995; Grimmer 1997). The interface between hospitals and the disability and aged care sectors is difficult, and is characterised by sectoral exclusivity and narrowly constructed legislation (Hales et al., 2006). Commonwealth State/Territory Disability Agreement (CSTDA) consumers are normally excluded from HACC-funded services and people who receive a disability pension are not identifiable within the hospital sector. One example of the difficulties arising when the three factors of disability, aged care and hospitals interact is apparent when a younger-aged patient with disability is institutionalised in RAC following hospitalisation. This mainly occurs because the younger person may need high levels of personal care and low levels of nursing care, a combination which is generally not available in the community. In March 2008 there were 874 people aged less than 50 years living in permanent RAC facilities nationally (Young People in Nursing Homes National Alliance, 2008). Current methods used to identify the needs of people with disability after discharge are not usually based on the persons’ perceptions of their needs, pointing to a lack of responsiveness and accessibility over time in health and community services (Rotondi et al., 2007).

For an increasing number of older people the move from home-based living to RAC care occurs via an admission to hospital (Challiner et al., 2003; Richards & Coast, 2003). Collaboration between residential and community care providers on programs aimed at restoring the functional capacity of older people after discharge from hospital have been successful in avoiding inappropriate residential care (Kroemer et al., 2004). Multiple clinical measures as well as interdisciplinary collaboration are needed to effectively predict post-hospital outcomes for older people. Furthermore, a hospital admission followed by residential placement often involves conundrums and undesired outcomes, such as when the successful treatment of the older person’s illness is paradoxically accompanied by a decline in ADL, leading to an undesired discharge destination of residential placement or readmission to hospital. For older people, the risk of placement into residential care after hospital discharge is similar to that of mortality, readmission and ill health. Therefore, discharge from hospital to RAC is both a marker of perceived risk, while also being an intervention to reduce risk (Denson, 2006).

A few examples include cooperate, exchange information and collaborate. Such uses of the word are confusing and can be misleading.
The movement of people between hospital and RAC was recognised by the AIHW as an important issue for many years, but until recently the data were not linked to analyse and report on this issue. To explore the movement of people (aged 65 years and over) from acute hospital care to RAC; the impact of LOS before admission into RAC and the main factors that influence admission to RAC on discharge from hospital, the AIHW linked and analysed national hospital morbidity data and RAC data for 2001-02. During this period there were 30,400 new admissions to RAC for hospital separations lasting at least 1 night. There were 5% more admissions of people aged 65 years and over into RAC from hospital than from the community. The three most significant predictors of entry to RAC from hospital for older people were extended LOS in hospital, being diagnosed as ‘awaiting admission elsewhere’ and having dementia or dementia-related disorders. Admission from hospital to respite care was twice as likely to turn into permanent RAC, yet residential respite care was also used as transitional care by people leaving hospital, with over a half of people who moved from hospital to respite care returning to live in the community within 12 months (AIHW, 2008).

3.5 DESCRIBING CONTINUITY OF CARE

In this thesis, the word continuity refers to:

“...the smooth development and continuation of a system, way of life etc over a period of time...” (Sinclair et al., 1987, p. 306)

When linked with care, the phrase ‘continuity of care’ has been used across disciplinary and organisational boundaries in health care, including primary and community care, mental health, disease-specific and nursing care. Although the concept of continuity of care first emerged around the 1960s, and has since been used in policy documents and in general health care parlance worldwide, an agreed definition has proved elusive (Haggerty et al., 2003).

With reference to the dictionary definition of continuity (above), it would appear that a person’s health care would continue unimpeded by time or place within the system. Putting it simply, a person’s health needs do not stop when they leave their GP and go to the hospital, or move from one discipline to another, for instance, from the discipline of medicine to psychiatry or from physiotherapy to nursing. References abound stressing the importance and need for the health care of all people to be continuous between one health or community service provider and another.

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19 The AIHW report also reported on what happens to people after admission into RAC from hospital, but these findings will not be covered here.
During recovery from illness after discharge from hospital, older people and their carers have reported the problems caused by a discontinuity between health and community care services. Premature discharge or delayed discharge from hospital without proper arrangements for continuing care in the community can lead to readmission to hospital (Devenny, 2007). The boundary between hospital and community care together with arguments over eligibility criteria can lead to people not getting the continuity of care they need (Brown et al., 2003). Regardless of age, the majority of people would expect to need contact with their GP if they were admitted to hospital for a serious condition, such as a heart attack or a malignancy, or during a major life event, like a birth or death in the family. Most patients presumed this contact would be initiated by the GP. In contrast, patients’ expectations were lower for contact with their GP during hospitalisation for minor conditions, such as a minor foot operation (Schers et al., 2004). Furthermore, patient outcomes after discharge could be improved if they were visited first-up by the physicians who treated them in hospital rather than by other physicians. It has been reported that follow-up visits with a hospital physician, rather than another physician, could improve patient outcomes following discharge from hospital (van Walraven et al., 2004).

When people require continuing care from community services after discharge, their return home may be delayed or made unsafe because of the discharge process, coupled with inaccessible or unavailable community services. The importance of continuing care was highlighted in the following submission to Australian Government National Health and Hospitals Reform Commission:

“Timely return home after acute hospital stays must be supported by adequately resourced programs such as...rehabilitation, transition care, home delivered personal health care and access to in-home and residential respite, as well as access to permanent residential care...Community support must be an ever evolving program to ensure maintenance of autonomy, fostering independence and limiting dependency.” (National Aged Care Alliance cited in Australian Government National Health and Hospitals Reform Commission, 2009, p.106)

Discontinuity of care interferes with effective, appropriate and timely community and clinical care of people with disability and older people and when continuity of care fails, there may be adverse consequences for the person and an additional burden on carers. Multiple and complex interactions with patients and at all levels of an interconnected health-care system that are sustained over time contribute to continuity of care, which is assumed to be seamless and uninterrupted care (Sturmberg, 2003; Haggerty et al., 2003; Crilly, et al., 2006). Discontinuous care occurs when practitioners are snowed under by the churning workload of the system and unable to use the normal mechanisms to detect gaps in information or momentum or interruptions in the delivery of care (Cook et al., 2000).
Sustained continuity of care has been shown to improve the quality of care for patients with chronic conditions (Cabana & Jee, 2004; Preen et al., 2005; Wilson et al., 2003) and reduce the readmission rates of elderly patients (Townsend et al., 1988; Lim et al., 2003).

Changes to improve the system include: establishing an accepted definition of continuity of care for use across all health care settings (Crilly et al., 2006); the introduction of a case management model which can work across the interface (Hegney et al., 2003); effective communication between hospitals, GPs and community service providers and patients and carers (Massey-Westropp et al., 2005; Balaban et al., 2008); information exchange systems which include discharge summaries automatically created from medical records (van Walraven et al., 1999 cited in Coiera, 2006; Massey-Westropp et al., 2005; Balaban et al., 2008); quality discharge planning and involvement of patients and carers in the process (Preen et al., 2005; Massey-Westropp et al., 2005); and finally professional and patient education (Advocate Health Care, 1997; Harrison et al., 2002; Phillips et al., 2004).

Although we know that older people have frequent hospital transitions, more understanding is needed about providing transitional care to improve continuity of care of older people (Coleman, 2003; Boockvar, 2004; Sherman, 2006). A range of interventions and tools have been developed and tested to improve transitional care. The best outcomes have combined telephone contact; homecare coordination and service provision; and information transfer and education, particularly concerning medications and support from case managers, such as advanced practice nurses (APNs), chronic disease nurse consultants (CDNCs) or transition coaches, who are able to move between sites to visit patients and their carers (Advocate Health Care, 1997; Harrison et al., 2002; Phillips et al., 2004). (Advocate Health Care) The benefits of APNs, CDNCs or transition coaches are apparent in helping reduce hospital use and improving patient satisfaction and carer strain (Naylor et al., 2004; Coleman et al., 2004; Naylor, 2006).

Outreach from the hospital and in-reach from the community are both effective in reducing discontinuity. When discharge medication guidelines and reviews are included, transfer-related medication errors are less likely. The importance of providing comprehensive transitional care for outpatient support and home health follow-up has been demonstrated with a range of positive outcomes. These include reductions in health care costs, the length of time between readmission and use of the ED (Coleman et al., 2004; Naylor et al., 2004; Naylor, 2006). However, better methods are needed to identify patients in need of post-discharge referral and support (Coleman et al., 2004). Furthermore, researchers of transitional care need to be aware of the value of utilising mixed methods.
due to the complexity of the systems being analysed and the potential for patient and disease factors to confound and influence research outcomes (Brand et al., 2004).

Having significant literature in its own right, the subject of health-care integration concerns the efforts undertaken to better connect the health care system with other human service systems, while also aiming to improve clinical, patient/consumer and efficiency outcomes (Leutz, 1999). Thus, continuity of care is understood to fit within the broader context of health-care integration, which is directed toward large-scale system redesign (Fine, 1998).

The research in this thesis focuses on two aspects of the health and community care of older people, people with disability and their carers: continuity of care and poor outcomes. In Chapter 1, I explained why continuity of care is important to older people, people with disability, and their carers, as well as service providers. Therefore, as this research was not aimed at health-care integration, I have limited my review of this literature to a small selection of articles that provide relevant insights.

Drawing from lessons learned in the US and UK, Leutz (1999) proposed five laws for health-care integration. Essentially, these laws assert:

1. There are three levels of integration: linkage, coordination and full. Identifying which level of integration is being aiming for has implications for the target group and the types of operations used to implement the level of integration.
2. Integration will always cost more before savings are made.
3. As providers, managers and researchers drive integration, they also choose the operations used to affect it (e.g. documentation, consultation etc.). Such operations are often administratively demanding and time-consuming (on practitioners) and may lead to greater fragmentation.
4. “You can’t integrate a square peg in a round hole.” (Leutz, 1999, p.93). This law points to the differences in philosophy, financial scale and access between acute and long-term care.

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21 While I acknowledge Leutz’s (1999) insights and recommend reading the entire article, there is not the space here to cover it in more detail.
5. As integration has mostly been a provider-professional initiative, the power and choices about how and what was integrated is in the hands of providers and professionals, rather than the public.

The ACCT were a joint initiative of the Australian and state and territory governments and were aimed at health sector reform to improve the care and health outcomes of people with chronic and complex illnesses, as well as reducing costs. Two rounds of trials were conducted, the first was from 1997 to 1999 (CCT1); and the second from 2002 to 2005 (CCT2) (Australian Government Department of Health and Ageing, 2007).

South Australia hosted the largest of the nine trials in CCT1. Called ‘SA HealthPlus’, eight projects were located in four regions to implement a generic model of care which involved:

“...targeting ‘at risk’ people with assessment of medical, functional, social, and emotional needs; provision of optimal medical treatment, self care education, and integrated services; and monitoring of progress and early signs of problems.” (Battersby et al., 2005, p.662)

Battersby et al. (2005) reported on CCT1 and the changing attitudes of health professionals and consumers before commencement of SA HealthPlus, and twelve months after it had begun. A survey was used to determine pre and post beliefs and expectations of ten project groups. While numbers of pre and post completions were small (n=34), the study demonstrated Leutz’s third, fourth and fifth laws:

“...how initial enthusiasm gave way to appropriate anxiety as the complexities of creating a new system of care...became a reality.” (Battersby et al., 2001, p.172)

Similarly, from the Tasmanian CCT1 (called ‘Careworks’), a study reported on care coordinators’ relationships (GP and non-GP), during which personal and professional tensions between care coordinators and other health providers were identified. The main tensions arising from Careworks were a generalised sense of threat; profession-specific competition; communication difficulties and a clash of belief systems (Shannon, 2002).

The final report of the national evaluation of CCT2 (Australian Government Department of Health and Ageing, 2007) detailed the overall program objective, which was to:

“...provide additional benefits to clients and communities through coordination and integration of care and effective use of resources for identified populations.” (Australian Government Department of Health and Ageing, 2007, p.13)
CCT2 consisted of five trials, two mainstream and three Indigenous. Each trial was designed differently, making comparisons between them problematic. In regard to the overall CCT2 program objective, the evaluation found the effectiveness and efficiency of the three Indigenous trials compared with the two mainstream trials:

“...difficult to judge...” (Australian Government Department of Health and Ageing, 2007, p.32)

However, the key trends to emerge from the mainstream trials suggested that access to primary care services increased for the intervention group; the costs for the intervention group were higher than the control group (but were expected to fall had the trial run for a longer time - demonstrating Leutz’s second law); and hospitalisation of the intervention participants was lower relative to the control group (Australian Government Department of Health and Ageing, 2007).

Clearly, Leutz’s five laws developed from health-care integration experiences in the US and UK also apply to Australia, and serves to warn of the complexity and limitations of achieving health-care integration. This point is also reiterated below by Glendinning (1998):

“...it is simplistic to assume a straightforward, direct relationship between demographic pressures and changes in the funding, location, organisation and delivery of services. The formulation and implementation of policy is never so simple. Service responses to demographic trends...are also shaped by underlying global trends and ideologies...[and also] by histories, institutional and cultural traditions...[which] may, to a greater or lesser extent, place limits on the extent of any [international] convergence.” (Glendinning, 1998, p.1 and 2)

CHAPTER SUMMARY

In this chapter I have presented a review of the impact of an ageing population on hospitals; discharge of older people and people with disability from hospital to home and community settings and the interface between hospitals and RAC. In the last section of this chapter I review the literature on continuity of care.

In appraising the literature on community care (Chapter 2) and continuity of care and the impact of hospital transitions on older people, people with disability and their carers (Chapter 3), I found a number of issues which led to the development of my research question. My research aims to identify the nature of the changes needed in the SA hospital and HACC systems to reduce poor outcomes (readmission to hospital and premature or inappropriate institutionalisation) and improve the continuity of care of older people and people with disability, as well as their carers.
First, there are numerous studies from around the world which concern the increased demand for acute hospital services from ageing populations and people with disability and/or chronic disease that result in overcrowded and blocked hospital systems. Second, in Australia, casemix contributes to the problem by an over-emphasis on hospital efficiency - primarily through reducing LOS - which results in the premature discharge of older people and people with disability.

Third, the international literature points to the low impact and effectiveness of discharge planning for providing post-hospital care to older people, people with disability and their carers. Difficulties arise from the conflicting pressures on hospital services to fill demand, provide appropriate patient care and accommodate those awaiting RAC placement. Other issues relating to discharge planning include premature or delayed or unsafe discharge; the lack of community services; insufficient communication or information; inadequate linkage or notice of discharge, and a lack of interagency collaboration between the hospital and community care systems.

Fourth, the interface between hospitals and RAC was identified as being problematic for younger-aged patients with disability who need high levels of personal care and low levels of nursing care. This was due to the lack of responsiveness to and accessibility of the younger-aged person’s needs. For older people, there were 5% more admissions into RAC from hospital than from the community. These admissions were predicted by longer LOS in hospital, a diagnosis of awaiting admission elsewhere, dementia or older age.

Most appear to accept the idea of continuity of care as something to aspire to, especially as people’s health care becomes increasingly specialised and concerns mount about the fragmentation of services. Yet, continuity of care is an ideal that is simply unachievable in a highly fragmented, under-resourced and specialised health care system. While it is understood that multiple and complex interactions at all levels of an interconnected healthcare system contribute to continuity of care, gaps in care occur with inaccessible or unavailable community services. This leads to adverse consequences for older people and people with disability and places an additional burden on carers. Although more accurate measures are being sought to test the effectiveness of transitional care, some hope for improving the continuity of care of older people between hospital and home is found in the range of approaches used. The complexity of health-care integration is briefly explored as it relates to continuity of care.

Finally, Australia has a complex and fragmented community service structure that is difficult to navigate. This issue impacts on gaining timely access during transition from hospital to home when
such services are urgently needed by many older people and people with disability and their carers to maintain continuity of care. The HACC program also exhibits signs of being a blocked system as the supply of services has not kept pace with demand. Each of these aspects of the interdependent systems of hospital and community care are considered to contribute to the overall difficulties experienced by older people and people with disability and their carers as they transit between the sectors. Indeed, the problem studied by this research has no single cause and is understood to have multiple contributing factors, resulting in being hitherto largely unrecognised and under-researched.
CHAPTER 4: THEORETICAL PERSPECTIVES USED IN THIS THESIS

“As researchers, we have to devise for ourselves a research process that serves our purposes best, one that helps us more than any other to answer our research question. Having perused and mused over the opinions of this array of scholars and practitioners, we are in a much better position to do that. We engage in a running conversation with these thinkers. We knock our ideas against theirs. We glean from them an understanding of what is possible in research. We learn how to evaluate strengths and weaknesses in research. Importantly, we become better able to set forth the research process in ways that render it transparent and accountable. All this is educative, not prescriptive....Could we then be accused of doing what we agreed we should not do? Are we guilty of merely plucking a research approach off the shelf? No, we are not. Rather than selecting established paradigms to follow, we are using established paradigms to delineate and establish our own.” (Crotty, 2003, p. 216)

4.1 INTRODUCTION
In this chapter, I drew upon my professional experiences as a Registered Nurse and Social Worker and my interest in sociological theory. With this background acting as an influence in my approach to this study, I started my theoretical explorations with searches into the classic, post-modern and feminist sociological literatures to see if any would assist with explaining the care transitions between hospital and home for older people, people with disability and their carers. Several concepts in the sociological literature struck a chord with my experiences in the field. These were the different approaches to health and illness between the hospital sector and the community sector, the impact of iatrogenesis and the medicalisation of older people and people with disability. In my ‘jeans and jigsaws’ approach (explained in Chapter 1), I also investigated the social work literature. I observed that, in the field, practitioners understood people’s need for care and the impact of caring on carers. They tended towards overall descriptions of people as being frail (discussed in Chapter 2) and vulnerable. However, many of the people who were described as being vulnerable had lived long lives during which they had faced many obstacles and overcome them. If they were provided with sufficient support, perhaps they were vulnerable for a period, but had the capacity to recover. At a theoretical level, I trace these influences and observations which I considered were relevant and would lead to a deeper understanding of the health and community care transitions of people with disability, older people, and their carers.

In the final decades of the 19th century the medical profession rose to social dominance with the success of germ theory, new practices in surgical interventions and with the use of more reliable drugs (Berliner, 1984). By the 1950’s a more critical sociology of medicine developed when Talcott Parsons developed the notion of ‘the sick role’. This concept led to a more interdisciplinary approach
to the nature of illness by combining Freudian psychoanalysis with a sociological analysis of roles, as well as a comparative cultural understanding of the importance of values in structuring the character and distribution of illness in industrial societies (Turner, 1992; White, 2002).

Discontent with the medical profession along with changes in the structure of illness were significant for the sociology of health, illness and the body (Berliner, 1984). Sociological analysis began to recognise that people’s experience of illness and disease are both a reflection of social values and an outcome of the organisation of society (White, 2002).

More recently, social pressure to preserve and maintain one’s body has become understood as a personal moral responsibility, one of the aims of which is to avoid becoming dependent on others for care and/or being a burden on society. As a result, the aged and those with chronic conditions are encouraged to be active, fit and engage in preventative medical care, which, according to Turner (1992) has:

“...brought chronicity to the forefront of medical problems, giving a special urgency to personal fitness.” (Turner, 1992, p. 165).

Turner goes on to claim that nowadays, age is socially constructed as a status position. A fundamental change has occurred in the way in which the ageing body is represented, emphasising endless youth and activity achieved through a range of interventions, such as exercise, liposuction, face-lifts and so on. However, the emphasis and status of youth is problematic as it is achieved against ageing and has implications for personal identity, our status and place in society and the meaning we ascribe to ourselves. Furthermore, with the passage of time and the ageing process, our bodies become frail and more vulnerable to accident or illness, raising important political questions for the role of institutions in sensitivity to ageing (Turner, 1992) and social policy.

In this thesis I have chosen to focus on the theories which I consider are directly relevant to analysing the problem of providing continuity of care to the aged, people with disability and their carers (HACC clients) in transition from hospital to home. As indicated in Chapters 2 and 3, this subject area is multifactorial and points to the complex relationships between: ageing, frailty, disability and independence; the cared-for, their carers and the provision of care; vulnerability and resilience; and values, social policy and social structure. It provides an opportunity to review the relevance of some of the ideas of Ivan Illich about iatrogenesis and to integrate aspects of vulnerability, Care Theory and Resilience Theory into a systematic study of the care of older people and people with disability and their carers.
4.2 TWO PARADIGMS OF HEALTH: THE BIOMEDICAL MODEL AND THE SOCIAL MODEL

Two different interpretations of health which underpin the approach to health in the acute and the primary care sectors respectively can be understood to contribute to the divisions between them. In the acute sector the biomedical\(^{22}\) model is dominant, whereas in the primary care sector, which includes community care, a social model of health has somewhat greater influence. The biomedical model views health as the absence of illness or disease from the body, and is characterised by:

“1. the assumption that all disease is materially generated by specific etiological agents such as bacteria, viruses...genetic malformations, or internal chemical imbalances;
2. a passive patient role; and
3. the use of invasive manipulation to restore/maintain the human organism at a statically derived equilibrium point (health).” (Berliner, 1984, p. 30)

The biomedical interpretation of health assumes that, like disease, health is located within the body. Although health is created and recreated through objective events and in relationship with one’s external reality, at its most basic the biomedical model assumes that people experience their health subjectively, in isolation from social life and larger forces (Warren Salmon, 1984).

A realisation of the limitations of the biomedical model in providing equitable access to healthcare for the whole population was clarified in the 1960’s. According to Berliner (1984), a range of factors culminated in an incisive critique of the biomedical model. These factors included changes in the disease structure of modern societies\(^{23}\); in demographic patterns\(^{24}\) and in the patient-physician relationship.

The limitations of the hospital also became apparent, for when people enter hospital they are removed from much that is familiar to them, such as their social, familial, environmental, cultural, geographic and occupational surroundings. These factors are not recognised as they should be by the biomedical model for the role they play in the disease process. By not allowing for the social mediation of disease, hospitals are less effective than they potentially could be and the cost of medical care is


\(^{23}\) In the last 120 years disease structures have changed from the dominance of infectious diseases towards diseases affecting people at older ages along with a decline in death rates over the last 100 years (Berliner, 1984).

\(^{24}\) Changing demographic patterns resulting from the increase in ageing populations; their high demand and usage of medical and hospital services; the predominance of chronic conditions which cause disability among this age group, and the need for specialised supervision, support and rehabilitation over a long period of time, are discussed in Chapter 2.
higher. The invasiveness of medical procedures often results in the need for convalescence and recuperation and this is mostly provided in a context that is completely disconnected from the patient’s routines and support network (Berliner, 1984).

There were also problems associated with the technological and machine model orientations of scientific medicine. Costs of medical care were burgeoning and the focus on cure over prevention in medical research and practice were other areas of concern (Berliner, 1984). Medical research and practices treat the body as a cluster of independent, but functionally related systems. This makes it difficult to explain any relationship between mental states and physical functions. However, a person’s psychological state exerts an influence over the physical severity, and his/her propensity to acquire and ability to cope with an illness. Other influential factors, such as social, environmental, occupational and stress-related factors are still not given the consideration they deserve. Meanwhile, the heroic attitude of experimentation in the biomedical model, manifest in transplants, genetic engineering, drug therapy and the like, has raised many ethical questions and dilemmas, concerning quality of life and control over one’s life (Berliner, 1984).

Alternatively, primary health care approaches to health are underpinned by a social model of health. This model recognises that there is an intimate connection between one’s experience of health and one’s family, work, social, environmental and economic circumstances. In 1946, the World Health Organisation (WHO) provided the following definition of health:

“Health is a state of complete physical, mental and social well-being and not merely the absence of disease or infirmity.” (Official Records of the WHO, 1946, p.100)

Several decades later, at the first International Conference on Health Promotion in Ottawa, November 1986 a social model of health was adopted by the WHO in the “Ottawa Charter” (WHO, 1986). Discussions focused on the Declaration on Primary Health Care at Alma Ata, the WHO's Targets for ‘Health for All’ document and the debates at the World Health Assembly on intersectoral action for health. The Ottawa Charter asserted that health promotion incorporates five key action areas and three basic strategies: to enable, mediate, and advocate for health.

Proponents of this model understand that the existence, or lack of, social capital (that is, family, friends, neighbours and community networks), can impact upon health. A social model of health clearly broadens the concept of what and who constitutes the healthcare sector. Using this model, the primary health care sector is meant to embrace a wide range of organisations and groups, including
those concerned with promoting positive changes in the social, economic, cultural, environmental, and community factors that impact upon health.

4.3 THEORETICAL ANALYSIS
Ageing has traditionally been conceptualised in terms of the decline of physical and mental faculties. Some have argued that the origins of such associations may be related to a gradual devaluation of old age and to the medicalisation of life in general that began with the emergence of modernity in the late 1800’s (Kennedy, 1998). Observations from the field of practice have led me to understand that there are different philosophical approaches to health and illness between the hospital sector and community sector. These two interpretations are best articulated as the biomedical approach and the social model of health. In a study that was generated and collected and analysed data from both a hospital and several community care sites, it seemed logical to compare and contrast these ideas.

A number of critical sociological insights into health and ageing are found in the ‘iatrogenesis’ critique, which argues that medical treatment can cause illness; and the ‘medicalisation thesis’, in which people are encouraged to seek more and more medical treatments the effect of which undermines their autonomy.

Following consideration of these insights, I discuss aspects of Care Theory, vulnerability and Resilience Theory. Continuity of care, health-care and community care are central to the aim of this thesis, pointing to the importance of an analysis of care as a concept. We all need care to survive, but there are pivotal points in our lives when we are more or less vulnerable; or more or less resilient. In the context of ageing or of having disability and needing hospitalisation, I am interested in understanding more about vulnerability and resilience. Consequently, when I was searching for a ‘good fit theory for this thesis’ (refer to Chapter 1 for this discussion) these concepts and theories struck the strongest chord with the importance of the topic, the aim and objectives, the rationale and method. I assess the extent to which aspects of these approaches can be integrated to provide particular insights into analysing the care of older people and people with disability and their carers as they move between hospital and home.

4.3.1 Iatrogenesis and medicalisation: contextualising health, ageing and disability
In the 21st century more medical treatments are being found for chronic diseases and more areas of life are subject to the study and control of health professionals, including experiences hitherto understood as a normal part of the human condition, like ageing. Max Weber (1864 - 1920) is noted here for developing a broad critique of the ‘iron cage’ of modernity, in which the growth of scientific rationality, professional expertise and bureaucratic control over more areas of society was responsible.
for taking away ordinary people’s capacity to manage their own lives (Taylor, 1997). In 1975, Ivan Illich argued along broadly similar lines to Weber in relation to medical control when he presented the radical polemic that:

“The medical establishment has become a major threat to health.” (Illich, 1975, p. 11)

Our increasing dependence on the medical profession, pharmaceutical companies and medical equipment suppliers (Illich’s ‘medical establishment’) was progressively undermining our health through a process of iatrogenesis, which refers to illness caused by medical treatment. According to Illich, there were three levels of iatrogenesis: clinical, social and structural. Clinical iatrogenesis was injury done to patients by ineffective, noxious and/or unsafe treatments. Social iatrogenesis, or the ‘medicalisation’ of life, referred to the process by which the medical and preventative care industries are perceived to reinforce an excessive preoccupation with health making people dependent on their opinions and encouraging them to consume more and more medical treatments. This process allegedly undermines their individual capacities. Most serious was cultural iatrogenesis, which was where the medical institution, directly or indirectly, eroded traditional ways of dealing with sickness, pain and death. Cultural iatrogenesis undermined our social character and ability to deal with human weaknesses, vulnerabilities and uniqueness; and subsequently impacted on our independence, our social relations and our vitality (Illich, 1975). Illich encouraged people to resist medical dominance by taking more responsibility for their own health and health care (Taylor, 1997). Nevertheless, his approach to reducing our dependence on the professional management of pain, illness and death was a harsh one that advocated the refusal of medical treatment in preference for:

“…the healing power in sickness, patience in suffering and fortitude in the face of death” (Illich, 1975, p.92)

Furthermore, Illich argued that medicine was becoming increasingly separated from its traditional role of looking after the sick and was instead interfering and expanding its role in people’s everyday lives. By challenging the fundamental premise of medical ‘progress’, he argued that institutional medicine was more significantly iatrogenic than it was health-producing. Large numbers of patients experienced unnecessary harm at the hands of the medical establishment and, with the medicalisation of life, they risked losing control of their health to institutions. Accordingly, medicine was the cause of much ill-health, not only through direct interference with individuals’ autonomy25, but also because of the impact of its social organisation upon the total milieu (Illich, 1975).

25 When it is used to refer to an individual, autonomy is defined as: “the ability to make your own decisions about what to do rather than being influenced by someone else or being told what to do.” (Sinclair et al., 1987, p.85) Sinclair, J., Hanks,
Alternatively, a Marxist critique would analyse the causes of medicalisation to lie in the operation of capitalist industrial societies, in which pharmaceutical companies, medical equipment manufacturers and providers of private health care are organised for profit and therefore have a vested interest in promoting and selling health care products and treatments to any exploitable areas of life. The power of capitalism causes people to become alienated from their ‘natural’ creativity and people compensate for this loss by engaging in consumerism (Taylor, 1997).

However, as Taylor (1997) points out, there are obvious theoretical limitations with both the Illichian and Marxist analyses of medicalisation. The rates of medical cures for diseases once thought untreatable have markedly increased and the range of assistive equipment and technologies has, for many people, not only resulted in an extension to their life but also manifest improvements to their quality of life. Also, as Williams and Calnan (1996, cited in Taylor, 1997) argue, the extent of medicalisation has been exaggerated and people are more sceptical of modern medicine than once thought (Calnan & Williams, 1996, cited in Taylor, 1997). Through their capacity to make choices and decisions about their life, people are perhaps more self-governing and less alienated from their natural creativity than proposed by Illich or Marx. Furthermore, Illich’s medicalisation critique negates the fact that many individuals who are part of the medical establishment act responsibly and actively research ways to avoid or reduce iatrogenesis. This type of research is particularly notable and prolific in the literature in the areas of health promotion and prevention, of which two examples are provided here. Elkan et al. (2001) explored the effectiveness of home visits to older people in avoiding adverse events, such as death, admission to hospital and admission to institutional care, as well as changes to functional and health status. They found home visiting reduced mortality and admission to institutional care (Elkan et al., 2001). While Illich’s analysis of the medical establishment is too pessimistic, some aspects of his medicalisation critique have merit and continue to stimulate critical reflection in the literature and among health practitioners (Smith, 2002), which is an important aspect of self-evaluation and program/treatment appraisal.

Ward (2000) argues that ageism and ageist attitudes explain poor quality health and community care of older people, the lack of support for carers, the belief that the needs of older people are less important than those chronologically younger and the abuse of older people by both the general public and health and community care service providers. Ward’s analysis is typical of literature which, while being critical, is also a-theoretical. Because its central analytical tool relies on an attitude, which is ageism, Ward oversimplifies the situation and casts older people as victims, denying them any notion
of personal agency. Furthermore, it disaggregates ageism from culture and the politics and processes of society and government.

When sickness in old age is categorised as a ‘social’ (or inappropriate) problem, rather than a ‘medical’ (or appropriate) problem, older people can have useful hospital care denied them. An alignment between policy and professional agendas generally works to make it seem inappropriate to provide older people with access to specialist medical and nursing care, meaning that when an older person is admitted to hospital it is often seen as a failure of the health and community care system. This situation led Latimer (2000) to focus on how the tension between defining illness in old age as medical or social is played out in the management of hospital ED admissions. Discourse analysis was used to understand the process of diagnosing older patients as having either an appropriate or inappropriate reason for admission to hospital. Latimer found that gerontology physicians played a pivotal role by using their knowledge and status to influence and prevent the over-socialising of older people’s health troubles. By doing this, they legitimated older patient’s treatment on medical grounds. Latimer’s main concern was that the social and personal aspects of old age were being over-emphasised to legitimise the illness and suffering of older people into categorising their medical problems as social problems. This process had the effect of marginalising the place of disease in an ageing person’s life. The findings from this study were then used to point out the limitations of the sociological critique of biomedicine, in that medical categorising can sometimes be a process of social inclusion, instead of excluding the aged and other social groups of people whose diagnosis is not considered medical enough. Such inclusion in positive medical categories helped older people to access treatment, care, shelter and other resources as well as hindering the judgement that older people were ‘social problems’. In conclusion, Latimer suggested that the critique of the biomedical model may have underestimated how medical categorising, as a rite of passage to access important resources and life chances, can act as a process of social inclusion.

There are several limitations to Latimer’s study. First, the link between the critique of the biomedical model, its use of medical categorising and the larger structural processes that contribute to the exclusion of certain social groups are not adequately explored. Second, while from the outset Latimer criticises the hospital system and the labelling practices (social or medical, appropriate or inappropriate) of doctors and nurses who work in it for denying hospital treatment to older people, she then appears to contradict herself to argue in support of particular professionals (namely, gerontology physicians and ‘others’) and the processes of geriatric medicine (such as the ‘social round’ and geriatric assessment) to maintain the knowledge and practices of treating disease as separate from the social and personal aspects of people’s lives. There is a danger here in undermining or negating
the social and personal aspects of people's lives that determine their health outcomes on the basis of their age. Finally, although Latimer refers to a policy and professional alignment that makes it inappropriate for older people to get the medical and nursing care they need, the role of policy is absent in this study.

Two recent articles examined the discourse of welfare reform in the UK and its possible impact on the domiciliary care of vulnerable older people (Scourfield, 2006) and policy reforms that promote ‘rational responsible choices by service users and providers’ (Taylor-Gooby, 2008). Scourfield found the discourse of modernization effectively censored any proposal for expanding state-provided community (or social) care services because such ideas were considered ‘anti-modern’, backward-looking and out of touch with what the public wanted, which, according to politicians, was the choice that the quasi-market offered. Consequently, the expansion of social care in response to ageing populations, so as to provide fairer and more consistent domiciliary care services to vulnerable older people was unlikely as long as the anti-welfare politics of market-based, privatised models dominated. Similar findings on the implications of welfare reform towards a quasi-market approach and individualised incentive systems were made by Taylor-Gooby, who concluded that market norms differed from welfare norms. Applying market norms, like choice and individualisation, to social goals in the form of providing support for vulnerable groups, risked damaging the norms that sanctioned social support within the existing institutional framework.

4.3.2 ‘Care’ and the influence of Post-modernism and Feminist Theory

Background
Care and caring are central to a sociological analysis of health and community care of the aged, people with disability and their carers. Over the last 30 years academic research on informal care has come from two sources: first, those who recognised the role of care in the informal sector and how the provision of care impacted on welfare and social policy; and second, feminist writers who focused on the sexual division of labour between men and women, the exploitation of women’s labour in their role as carers and the ways in which these division were maintained by the state. A powerful critique of community care policies developed from such research, with central themes being the concept of care as oppressed labour as well as the demand for greater recognition and reward for carers (Williams, 2001).

The Emergence of ‘Care Theory’
With the publication of Carol Gilligan’s work, “In a Different Voice” (1982), a significant challenge was presented to accepted psychological opinion on the theory of boys and girls moral development. Prior
to Gilligan it was claimed that boys were morally superior to girls because they tended to score higher than girls did on issues of moral reasoning. However, Gilligan argued that rather than the superior-inferior judgement, boys and girls were more accurately described as having ‘different’ approaches to moral reasoning. This difference was found in how boys and girls made decisions. Boy’s (and men’s) reasoning process was underpinned by a notion of rights that were subject to public and rational assessment, or ‘what the rules allowed’; whereas girl’s (and women’s) reasoning process tended to concentrate on relations and responsibility, or ‘the caring thing to do’ (Gilligan, 1982). In this analysis, Gilligan had positioned a female ethic of care against a male ethic of justice, sparking a debate which continues today (Williams, 2001).

In summary, critiques of Gilligan’s thesis were based on her central focus on gender (and gender differences) and her reinforcement of traditional stereotypes of the ‘good woman’. Indeed, there were other important omissions in Gilligan’s analysis, such as sexuality, the role of power in care relations and how care is affected by different sites and contexts (Williams, 2001). Some care theorists and feminist researchers responded by analysing care and gender to show the ‘natural’ ability of the female to care resulted arising from the realities of domestic exploitation and how the caring role of women led to a denial of social rights. More recently, Williams (2007) has focused on the migration of women from developing countries to provide home-based care within western welfare states (Williams, 2007). Other opinions came from writers representing the disability movement and people with disability, where their accounts of the way in which the care provided to some people exposed people with disability to oppressive situations, indignity, dependency and denied their rights. People with disability asserted the practical reality and strategic centrality of independence as being a central concern in their struggle for equality, independent living and the ability to exercise choice and control over their lives (Williams, 2001). These critiques developed into a ‘paradigm of difference’ as a response from people who, as providers of informal or formal care, had found themselves marginalised in the policy context.

While there were limitations to Gilligan’s ideas, they are credited with forming the basis of the ‘ethic of care’, now also known as ‘care theory’ (Levy, 2006), which more recently has developed into several streams. Feminist theorists, Kittay (1999, 2002) and Fineman (2004), also critiqued interpretations of liberal political theory, which they argued played a central role in influencing the power disparities that often exist in relationships of care. In their view, personal autonomy and independence have been excessively valorised at the expense of the ‘universality and inevitability’ of human dependency. However, in this thesis I will focus on the ethic of care and the practices, processes and principles

**The ethic of care: relationships and care, practices and processes**

The analysis which informs the care ethicists’ ideas is based on the fundamental need for care, to give or to receive, which can vary at different points in one’s life:

“The simple fact that care is a fundamental aspect of human life has profound implications…Since people are sometimes autonomous, sometimes dependent, sometimes providing care for those who are dependent, humans are best described as interdependent. Thinking of people as interdependent allows us to understand both autonomous and involved elements of human life.” (Tronto, 1993, p.162)

Care is practiced in relationship with another person and our need for relationships with others affects our quality of life:

“The guiding thought of an ethic of care is that people need each other in order to lead a good life and that they can only exist as individuals through and via caring relationships with others. On a daily basis, everyone needs care and commitment in the course of their lives, though this may differ in nature and degree and be provided by different relevant others. And, just as important: everyone is in principle capable of giving care.” (Sevenhuijsen, 2003, p.183-4)

As social beings, care is one of the most basic features of our lives (Fine, 2007). Born dependent, we become interdependent over the span of our lives due to illness, disability, ageing and/or the need for human companionship. Care forms an integral part of the human condition during these times of need. When writing about interdependence and autonomy, Sevenhuijsen (2003) offered the following explanation:

“The most important point is that the ethic of care encapsulates a constructive critical perspective on the norm of independent citizenship. The notion of human nature embedded in the ethic of care diverges from the unilateral individualism which is central to many a moral theory and thus also to the normative assumptions of many policy theories. Relationality and interdependence are core concepts in the ethic of care.” (Sevenhuijsen, 2003, p.183)

Our need for care is beginning to enter public discourse at the state level, reflected in the report on women, men, work and family by the Australian Human Rights and Equal Opportunities Commission (HREOC) (2007):

“At some point in their lives all Australians will be receivers of care. The overwhelming majority will also be providers of care.” (HREOC, 2007, p. 7)
In the groundwork done by Tronto, care was understood as being an interpersonal human activity of and for the world. Accordingly, care is:

“…a species activity that includes everything that we do to maintain, continue and repair our ‘world’ so that we can live in it as well as possible. That world includes our bodies, our environments, all of which we seek to weave in a complex, life-sustaining web.” (Tronto, 1993, p.103)

Tronto and Fisher (1991) elaborated and extended Graham’s (1983) two distinctions of caring about and caring for another person (Graham, 1983). In 1993, Tronto developed the more complex process of an ethic of care, identifying four stages of care: attentiveness, responsibility, competence and responsiveness:

- Attentiveness involves caring about, or ‘becoming aware of and paying attention to the need for caring’ by attentive listening, observation, assessment and prioritising of needs. An attentive awareness of the self and of others ‘with as little distortion as possible’ (Tronto, 1993) in today’s society means that one must avoid attentiveness becoming overly intrusive or a form of surveillance or being negligent through a lack of awareness (Lloyd, 2004).
- Responsibility is taking care of someone, or when ‘someone assumes responsibility to meet a need’ by organising the necessary resources and people to respond to needs.
- Competence is ‘the actual material meeting of the caring need’ through care provision. This involves knowledge and skill in how to conduct the activity of caring.
- Responsiveness is when the care-for responds to the care-givers about whether or not their care needs were met successfully (Tronto, 1993). However, in considering responsiveness, Tronto (1998) notes its complexity:

“…because it shares the moral burden among the [cared-for to respond] but it also involves the moral attention of the ones who are doing the caring work and those who are responsible for care…the caring process in this way comes full circle, with responsiveness requiring more attentiveness.” (Tronto, 1998, p.15-17)

A fifth element, integrity, was added later. Integrity requires that the four former stages have been taken into account (Lloyd, 2004) Tronto’s later (1998) conceptualisation of care linked the two domains of care, namely the emotional aspect (or ‘mental disposition of concern’), with the physical work, which are:

“…the actual practices we engage in as a result of these concerns” (Tronto, 1998, p.16).
As a result, the ethic of care evolved into a normative\textsuperscript{26} ethical theory that emphasises the importance of relationships and care. This view contrasts with the ethic of justice\textsuperscript{27}, which focuses on doing the right thing even if it requires personal cost or sacrificing the interests of those to whom one is close (Botes, 2000). However, Williams (2001) notes that Tronto (1993) and Sevenhuijsen (1998, 2003) have worked to settle the tensions between the ethic of care and the ethic of justice by exploring how care ethics may operate as a moral and political concept to influence public democratic practices and enhance our understandings of citizenship (Williams, 2001). According to Tronto (1993), in the USA:

“Care…can serve as a political concept to prescribe an ideal for a more democratic, more pluralistic politics...in which power is more evenly distributed...[and] care can serve as a strategic concept to involve the relatively disenfranchised in the political world.” (Tronto, 1993, p.21)

To achieve the goal of the ethic of care, operating as a moral and political concept, Sevenhuijsen (2003) calls for the relocation of care and politics in the construction of new social policies, which:

“...need to be flexible and multi-locational and that they need to call on the moral competencies and caring capacities of citizens and the diversity of perspectives existing among them. With this, I argue for a ‘caring citizenship’, an ideal in which caring is part of collective agency in the public sphere.” (Sevenhuijsen, 2003, p. 193)

While Tronto’s formulation is appealing for bringing together the different meanings of care into a single constructive process, there are several problems. According to Fine (2007), it allows each phase or task in the ethic of care to be broken up and treated separately, bringing into question the relative value of each. Furthermore, Fine points to the ‘disposition’ and ‘activity’ aspects of the process which are acted on by the care-givers, implying that the cared-for is passive and inactive in the care relationship. Therefore, Fine claims that by positing a generalised set of tasks in an ethic of care, the important and diverse particularities of active engagement of each party in the processes and relationships of care are underplayed or lost altogether. When the values informed by ‘intimate life practices’ are writ large into feminist ethics, new dilemmas and exclusions arise:

“...[as] both respect for the complexity and ambiguity of practices of care - their dark and their light sides - and attentiveness to the constitutive function of their different contexts and purposes, as well as to the personal biographies of their participants, appear to pose fatal limitations and insoluble problems for the ‘ethic of care’. (Bowden, 1997 cited in Fine, 2007, p.37)

\textsuperscript{26} A normative ethical theory is a theory about what makes actions right or wrong.

Other writers, particularly those considering the ethic of care and disability, join Fine in criticising the way in which a number of feminist care ethicists imply that the relationship between the care-giver and the cared-for is conveyed as being passive and dependent (Watson et al., 2004), or submissive and unequal:

“Most feminist discussions of an ethics of care and its relationship to the practices and politics of caregiving are conducted from the perspective of the caregiver, most discuss caregiving as though the caregiver were not also in need of care, and most assume that the receivers of care are not equals with whom the nature of the care and the conditions of it being provided are negotiable.” (Wendell, 1996 cited in Clapton, 2008, p.578)

Vernon and Qureshi (2000) note that for people with disability, the main concern in relation to community care is the issue of independence. Indeed, in policy documents the use of the term independence, or not having to rely on others, has been confused with autonomy, or having the ability to live the kind of life one desires. The concerns shown by people with disability, however, are more about their need to maintain autonomy rather than a desire to reject assistance from others. To explain this Vernon and Qureshi refer to Barnes (1991):

“Independence does not refer to someone who can do everything themselves, a feat that no human being can achieve whether they have an impairment or not, but indicates someone who is able to take control of their own life and to choose how that life should be led. It is a thought process not contingent upon physical abilities.” (Barnes 1991,cited in Vernon & Qureshi, 2000, p.256)

Such limitations are contentious and point to the way in which care has been understood and practiced historically. Besides these differences, there are commonalities between the ethic of care and the analysis by disability activists as both share a general critique about the way in which care is organised and argue against any structures or processes that perpetuate inequality (Williams, 2001).

Importantly, however, in articulating the ethic of care, Tronto (1993) and Sevenhuijsen (1998) have developed the concept of interdependency so as to move away from the criticism that the ethic of care reinforces dependency relationships. Furthermore, they argue that because the ethic of care is a normative approach to care, it is possible to develop the kind of care that contributes to:

“...behaviours and choices which enhance people’s feelings of self-respect.” (Sevenhuijsen, 1998, p. 140)

Tronto and Sevenhuijsen have revealed care as an important social practice which should be considered in political deliberations about institutional responses to need. Their analysis of care has
elevated its role and value from intimate private practices into an analytical approach for examining care practices and social policy. While Tronto’s efforts are acknowledged for establishing a foundation for the debate about the ethic of care, she did not provide any direction in the form of case studies or approaches to analysing policy, or the way by which an ethic of care might actually transform social policy or institutions in liberal, democratic and pluralistic societies (Hankivsky, 2004).

In applying Tronto’s ethic of care, Parks (2003) pointed out the important difference between caring for, that is, attending to someone’s physical needs, and caring about, which is providing attentive care that is responsive to the needs of the cared-for, free from any distortion imposed by the care giver. In her critical analysis of the home care industry in the USA, Parks comments:

“...the value expressed by the home care industry is in caring for clients’ bodies and not caring about them in the moral sense Tronto has in mind. While caring for bodies certainly must be accomplished in the home care field, this is surely not all that is required for a rich philosophy of home care.” (Parks, 2003, p.39)

Furthermore, Parks looked at other analyses28 of the medical system and home care industry (in the USA) and claimed that neither scheme was able to care about patients because, workers in the system are not allowed enough time to care for anything but the ‘bare mechanics’ of their patients/clients. Further, the lack of time reduces the opportunity for caring about to occur, as ‘symmetrical reciprocity’29 and meaningful relationships are denied both cared-for and carers. This, she concluded, was morally wrong, unsustainable, and led to high rates of worker ‘burn-out’ in this industry (Parks, 2003). A shortcoming of Park’s analysis is that it only used the first two phases of Tronto’s formulation (caring about and caring for). Despite mounting a strong critique of the system and industry, Parks presents an incomplete and heuristic case which exaggerates her moral argument.

Sevenhuijsen and Švab (2003) developed the ethic of care from an idealistic polemic into a analytical tool to assist with transforming the policies of liberal, democratic and pluralistic societies. They called

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29 To explain the notion of symmetrical reciprocity Parks draws together Frank’s (1991) [see footnote 11] experience about the importance of reciprocity, or give-and-take, in caring for others, and Benhabib’s (1987) [see footnote 11] analytical distinction between the “generalised” other - being an abstracted or ideal-type of other; and the “concrete” other – which embraces an attentiveness to the particularities of individuals (Parks, 2003, p.40-1).
their method ‘Trace’\(^{30}\), and they use this method to carry out a process of ‘tracing, analysing, evaluating and renewing’ to reveal:

“…the normative assumptions and values underlying policy papers, and to evaluate them from the ethics of care perspective.” (Sevenhuijsen & Švab, 2003, p.8)

Several contributors used Trace to identify the assumptions and values underpinning a range of Slovenian social policies, which included topics of the family, nursing, housing, poverty and social exclusion. Overall, the evaluations revealed the gap between the purported directions claimed in the policy documents and the reality of changes on the ground (Sevenhuijsen & Švab, 2003). The main benefits of Trace are that it provides a straightforward method to analyse policy and it can be used creatively to stimulate change and debate in the field. These are important steps towards policy renewal, but the difficulty remains in moving analysis from the philosophical level, albeit a philosophy that leans towards dependency and vulnerability, into concrete policy change.

More recently, Lloyd reviewed policy and applied the ethic of care model to develop a better understanding of dependency and care in relation to the circumstances of death and dying in old age (2004), and of the insights which can be gained by using an ethic of care in the practice of social work with older people (2006). This model applied Tronto’s (1993, 1998) ethic of care concepts of attentiveness, responsibility, competence, responsiveness and integrity. In both articles, Lloyd concluded that the ethic of care was useful in providing greater insight into dependency and care as follows: in death and dying the ethic of care had the potential to generate new policy and practice approaches in health and community care (2004); and in social work practice with older people, it provided useful insights relevant to practice in the contemporary context (2006). In applying an ethic of care model approach to both situations, Lloyd achieved a similar outcome to the Trace method developed by Sevenhuijsen and Švab (2003). Again, even though the analysis and the debates raised are a significant beginning, it is unclear how concrete policy changes can proceed from this approach. Furthermore, regardless of which ethic of care method (Trace or model) is used, there is an over-reliance on detailing the signs of dependency and vulnerability to stimulate social policy debate and reform, to the exclusion of the need to also include signs of coping and of strengths.

Reconsidering the politics of an ethic of care

Notable for further developing an applied ethic of care are Williams (2000a; 2000b; 2001) and Hankivsky (2004), who propose a reconsideration of politics and values to fully extend an ethic of care into social policy. Hankivsky argues that we are vulnerable and dependent on others in private and in public. The ubiquity of human interdependence informs a moral landscape from which normative assumptions can be developed to prevent harm, suffering or hurt. An ethic of care should fully extend into social policy through the three guiding principles of:

- Contextual sensitivity, which is fundamentally important to the centrality of care in our lives;
- Responsiveness, where caring is met with a response to others’ needs and promotes the welfare of citizens by preventing harm, suffering and hurt; and
- Choice, which is a prime democratic principle and is important for making decisions about care.

A perspective of care through these guiding principles would enhance our understanding of human beings, and stimulate a shift in values and priorities to create a better balance between private and public responsibilities for care. Applying these principles would enhance both the ethical imperatives of service providers and decisions about policy formulation (Hankivsky (2004).

In reviewing the British political critique of the post-war welfare state, Williams (2000a; 2000b) provided a conceptual framework by means of seven ‘equal worth’ principles based upon the values of recognition and respect for a reordering of the social relations of welfare in the UK. Williams’ conceptual framework included:

- Interdependence: this principle engages the emotional, material and physical networks of unequal reciprocity, creating the basis for autonomy. It emphasises a reciprocal commitment to welfare and acknowledges that we are all necessarily dependent on others but, there is a need to challenge the institutions, structures and social relations which leave some groups needlessly dependent. This connects to the second principle, that of care.
- Care: requires recognition, but also negotiation about practice and of the different interests among the cared-for and carers involved. Care suggests duty, responsibility, power, control, oppression, obligation, conflict, love, altruism, solidarity and reciprocity. The ethic of care presumes mutually interdependent relationships and practices which involve particular values (developed by Tronto, 1993 and Sevenhuijsen, 1998 and discussed earlier). However, as cared-for and carers we need to take account of others’ needs and of diversity. This provides the basis for civic virtues of responsibility, tolerance and awareness of ‘otherness’, diversity and competing claims. In this regard, the values of care can inform concepts of citizenship.
Intimacy: asserts diversity and democratic relationships, as care relationships are often but not always intimate ones and intimate relationships are usually, but not always, relationships of care.

Bodily integrity: respect for the integrity of the body is essential to uphold the autonomy of the welfare citizen. Integrity is a prerequisite of any policy which encourages people to maintain their body’s health.

Identity: recognition of identity, as both a sense of self and a sense of belonging, is vital for understanding individual and collective struggles against disrespect.

Transnational welfare: questions nationality as a basis to rights.

Voice: asserts experiences of welfare users and their own definition of their needs are central to the organisation and delivery of welfare services. (Williams, 2000a; 2000b)

Later, Williams (2001) argued that a new political discourse is emerging in debates about the work/life balance. In recent years achieving a balance between the mix of careers and care responsibilities has become more challenging as people have less time and space to engage in work, care, self-care, personal relationships and other meaningful pursuits. We need to know more about care and the real-life vulnerabilities of people to enable a more coherent link with current concerns about the work/life balance. Williams has called for the adoption of a new political ethic of care, where there is:

- Connection between the issues of care and the real-life difficulties/vulnerabilities of people;
- More consideration about the economic viability of care; and
- Better understanding of care as a form of work that is structured by economic forces.

Acknowledging the disability critique, Williams asserts that a political ethic of care entails care being provided in ways to support the autonomy of those reliant on the support provided by others. This practical approach links care with principles of justice and citizenship, she argues.

The following examples demonstrate the types of issues that arise when there is no value-base or set of principles to guide social policy and the provision of care. Foster et al. (2006) found that despite the aspirations of social policy to provide greater choice through personalised care, it resulted in less choice for people with disability due to the constraints of the organisational and broader service environment. Haggstrom et al. (2007) detailed the situation of ongoing struggle for improved and just care by relatives of older people living in specialised housing who depended on others for care. Thus we should ask how, without a set of discrete operational principles, can social policy, aimed at providing a safety-net of care and support to older people and people with disability and their carers, operate to bridge the constraints of the organisational environment and reduce the social neglect and personal indignity of an ongoing struggle?
Towards a normative approach

With the development of Sevenhuijsen’s Trace, Lloyd’s model, Hankivsky’s principles and William’s conceptual framework and new political ethic of care, we observe the emergence of a more normative approach to care. In their deliberations on the ethic of care and social policy, these writers have led the way in the search for a less idealistic and more realistic method congruent with the intent of an ethic of care, but also one applicable to the vulnerabilities of people in the real world. Their approaches collectively stimulate a rethinking of social policy and its intersection with the family, work, education, health, housing and welfare. As the field of care becomes more complex, these are important directions for social policy and care in liberal democratic societies. Although the emergent normative approach does not (yet) fully answer Popper’s (1980) critique of essentialism, it does represent a move away from idealism towards realism, by providing detailed description and analysis of people’s circumstances and proposals to guide change and action in the real world.

4.3.3 Vulnerability

When someone or something is described as vulnerable, it refers to being:

“...able to be hurt or wounded...[or] unprotected, exposed to danger, temptation [etc].”
(Ludowyk & Moore, 1996, p.935)

From a social work perspective, people who belong to vulnerable groups are:

“...individuals who share common characteristics within a community or society...who are at greater risk of experiencing harmful social, environmental, health, economic, and political conditions than the population as a whole, and who, in general, have access to fewer resources for coping.” (Barker, 1995, p. 404).

A determination of vulnerability for any group should reflect the context of policies, programs, and services within a country and region (Davis, 2005). According to Schröder-Butterfill and Marianti (2006a; 2006b), understanding what constitutes vulnerability in old age is important because of the humanitarian concerns as well as the potential for certain threats to become compounded, thereby reducing a person’s to cope independently. Consequently, knowing more about the causes and consequences of vulnerability in old age has implications for the prevention of bad outcomes and for improving social policy (Schröder-Butterfill & Marianti, 2006b). Rather than identifying old age

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31 Karl Popper set the notion of methodological essentialism against methodological nominalism. Essentialism, he proposed, was the task of science in its effort to discover the true nature of things. The essence of a thing is captured by defining it, for example: What is care? What is frailty? What is disability? What is health? Nominalism describes how a thing behaves in various circumstances, and especially, whether there are regularities in its behaviour. Words are a way of describing and explaining things, not names of essences. For example: How does ageing / disability / frailty / vulnerability / dependence / independence effect health and independent living? Popper’s main point was to argue that in politics; the essentialist approach leads invariably to Utopianism and doctrinal conflict. More genuinely important questions concern: "What should we do in the circumstances? What are your proposals?"
vulnerability as belonging to a high risk group, such as older people living alone as identified by Kharicha et al. (2007), Schröder-Butterfill and Marianti (2006a) understand that vulnerability is a function of exposure to hazard or risk plus the ability to cope (Hossain, 2001).

To formulate vulnerability as an analytical concept, Schröder-Butterfill and Marianti (2006a) first studied the environmental sciences for the impact of natural disasters on people. From here, they took up the notions of hazard, or external threat, as well as that of a vulnerable population. However, since not every hazard results in disaster, it was important to understand both the hazard itself and the population group’s level of exposure to risk. In the social sciences, distribution (or level) of risk has been understood by some analysts as being socially constructed, as demonstrated in the following claim:

“[s]ocial processes generate unequal exposure to risk by making some people more prone to disaster than others, and these inequalities are largely a function of the power relations operative in every society”. (Hilhorst & Bankoff, 2004, p.2 cited in Schröder-Butterfill & Marianti, 2006a, p.10-11)

Schröder-Butterfill and Marianti found that the limitations in the ‘threat’ and ‘structural’ approaches were mainly due to a tendency to produce over-determined accounts of vulnerability which did not allow for human agency. In view of this, they turned to Chambers’ (1989) definition of vulnerability, which is:

“...the exposure to contingencies and stress, and difficulty coping with them...[Vulnerability] has...two sides: an external side of risk, shocks and stress to which an individual or household is subject; and an internal side which is defenclessness, meaning a lack of means to cope without damaging loss” (Chambers, 1989, p.1 cited in Schröder-Butterfill & Marianti, 2006a, p.11)

This account recognises that exposure to risk is unequal and people have different coping abilities. In summary, Schröder-Butterfill and Marianti state:

“A person’s risk...her vulnerability – is the incremental outcome of a set of distinct but related risks, namely: the risk of being exposed to a threat, the risk of a threat materialising, and the risk of lacking the defences to deal with a threat.” (Schröder-Butterfill & Marianti, 2006a, p.11)

Schröder-Butterfill and Marianti’s framework of vulnerability is reproduced in Figure 1 (below) with the domains of exposure, threats, coping capacities and outcomes. These domains can interact to reduce or intensify the outcome and characterise a person’s degree of vulnerability. Exposure includes marital status, socio-economic status, early-life factors which correlate with insecurity in old age (e.g. homelessness or poor socialisation), location disadvantaged and/or living under discrimination.
Threats can include natural and human-made hazards, shocks, crises, illness, bereavement, physical decline, disability, war, crime and economic crises. Coping capacities come under three broad groups: individual capacities, such as the ability to manage and transform initial assets into income, food or other basic necessities; social networks, such as family, friends, neighbours and community institutions; and formal social protection, like pensions, health and social services. In this framework there are also potential intervention points: before a threat occurs to reduce susceptibility, or afterwards, to build on defences and prevent a worse outcome.

**Figure 1 A framework for understanding vulnerability**

![NOTE:
This figure is included on page 89 of the print copy of the thesis held in the University of Adelaide Library.](image)

Source: Adapted from Schröder-Butterfill and Marianti, 2006a, p.12

Schröder-Butterfill and Marianti (2006a) provide two case studies of the creation and distribution of vulnerability across the lifecourse. The first focused on homelessness in Britain and the second on familial care provision in Indonesia. In Britain, they found responsibility for the welfare of older people was largely secured by the state. Some people fell outside welfare provisions and became homeless in old age because of personal disadvantages and the compartmental structure and inflexibility of services. By comparison, in Indonesia, support for needy older people is provided by the family and community, but the operation of this support is uneven. Here, demographic histories and socio-economic status were important aspects of people’s vulnerability. While these case studies were quite different, they showed that this framework was capable of producing comparative research in both developed and developing countries. Both studies underscored people’s sensitivity to crises and resilience as being influenced by events earlier in the lifecourse. Sudden events, like loss of a carer or illness, were also influential, but poor outcomes in response to these events were never inevitable, as the vulnerable person may mobilise resources to avoid a crisis or another person or institution may intervene. Schröder-Butterfill and Marianti conclude by commenting that the complexity and uncertainty of vulnerability make it difficult to study, but nevertheless an important field of study to pursue (Schröder-Butterfill & Marianti, 2006a).
In a mixed methods study examining vulnerability, ill-health and care support in urban areas of North Sulawesi (Indonesia), Van Eeuwijk (2006) summarised the pressures on older people within a ‘triangle of uncertainty’, which included social, economic and health dimensions in relation to the process of health transition. In approaching care, Van Eeuwijk has been influenced by Niehof’s ‘care arrangements’ (Niehof 2002 cited in Van Eeuwijk, 2006), Geest’s practices and phases of care (Geest 2002 cited in Van Eeuwijk, 2006), and Phillip’s view of care, which encompasses social care, housing, material welfare and religious wellbeing (Phillips 2000 cited in Van Eeuwijk, 2006). In addition, Van Eeuwijk includes insights from other researchers focused on care of the elderly and kinship systems in Southeast Asia, as well as the vulnerability and coping capacity described by Schröder-Butterfill and Marianti (2006). Older people and care support were analysed in accordance with socio-demographic characteristics, health profiles, care-giver arrangements, the types of support provided and care-giver burden. Van Eeuwijk found the vulnerability of older people was strongly related to the resources, capability and willingness of family and others (not family members), to act as carers for extended periods. Older people mainly relied on close family, who were mostly wives and/or daughters, to provide treatment, care and support. Support from carers tended to lessen as the severity and duration of illness increased and carers themselves were burdened by their role. Inadequate care was associated with marital status, gender (widows and unmarried women were most at risk), weak support networks, poverty and having carers who were themselves vulnerable (Van Eeuwijk, 2006).

In another study, Lloyd-Sherlock (2006) sought to assess the most comprehensive method between the standard ‘poverty line’ delimiter and the ‘asset vulnerability framework’ (developed by Moser, 1998 cited in Lloyd-Sherlock) to identify vulnerable older people in Thailand. The poverty line delimiter is widely applied in developing countries to measure income and basic needs. Moser’s asset vulnerability framework combines environmental exposure to risks (epidemiological and economic changes are included), and resilience, including their effects. The key analytical categories are: access to labour markets, human capital, including health, skills and education; productive assets, including land, housing and machinery; household relations, including income pooling and shared consumption, and social capital, including household and communal reciprocity based on social ties and resources.

According to Moser (1998 cited in Lloyd-Sherlock), economic vulnerability is:

32 Curiously, Van Eeuwijk refers to Niehof’s description of care as having four phases: caring about, taking care of, care-giving and care-receiving, and to Geest’s phases as ‘removing from awareness and intention to actual practice and response’ and care as a ‘process that sustains life’. While these ideas are almost identical to the earlier work of Joan Tronto (1993), no reference is made to Tronto or the ethic of care.

33 At the time of writing, I found the source documents for these articles were unavailable.
“insecurity and sensitivity in the wellbeing of individuals, households and communities in the face of a challenging environment, and implicit in this, their responsiveness and resilience to risks they face during such changes” (Moser 1998 p.3 cited in Lloyd-Sherlock 2006, p.85).

The findings showed that understanding the vulnerability of older people in Thailand was enhanced by using the asset vulnerability framework rather than the poverty line delimiter. However, Lloyd-Sherlock claimed that the missing link in Moser’s portfolio was older people’s social entitlements, which was their access to resources beyond their local kinship networks or community, such as state pensions. The advantage of including social entitlements in the portfolio was the exploration of the interaction between public policies, vulnerability and wellbeing. Overall, this study demonstrates the value of applying an expanded asset vulnerability framework to assess specific forms of risk rather than opting for using frameworks that have singular or limited dimensionality (Lloyd-Sherlock, 2006).

In considering the processes and circumstances that created vulnerability in older people in several European countries, Grundy (2006) developed a multifaceted and specific conceptualisation of vulnerability to poor quality of life or an untimely or degrading death. Grundy provides the following definition of vulnerable older people as those:

“...whose reserve capacity falls below the threshold needed to cope successfully with the challenges that they face.” (Grundy, 2006, p.107)

There are three main elements to Grundy’s analytical framework:

- **Reserve capacity** can be mediated by the diverse range of ageing experiences in the complex interplay between individual factors, environmental influences and other lifecourse factors. Reserves include structural and ‘actor’ dimensions of physical and mental health status, family relationships and social networks, personality and social skills, and coping strategies and wealth. Other material resources include legal or moral rights and forms of intergenerational or collective support. Although all of these factors are important, the effect of current circumstances needs to be included to understand the level of vulnerability. Current circumstances include the availability of health and welfare services, pension provisions, the physical environment which may facilitate or limit access, and the broader social environment.

- **Challenges** faced in later life vary from intense, such as bereavement or an accident, to more subtle challenges, such as declining health or social roles. Older people may not have as many resources or reserves as those younger than them, but the challenges they face may be greater, like being at higher risk of developing acute illness, or having to give up one’s home and move into an institution.
- **Compensatory supports** are interventions used to ameliorate the effect of a challenge and to restore reserve. Some examples include rehabilitation after acute illness and home modifications and equipment in the home to assist with ADL.

Complex interactions between the three domains mean that compensation, or the reverse, loss and decline, may occur. Grundy provides the following example:

> “...the effect of health-related limitations...[on] quality of life may be mitigated or compounded by their reserves of family support and social networks...Conversely, the consequences of physical mobility limitations may be very serious for someone with poor support networks...hamp[er]ing their...social ties, which further increases their risk of isolation.”

(Grundy, 2006, p.109-110)

Grundy discusses the ageing and vulnerability of older people in relation to income and material resources; family and social support, health, autonomy and self-actualisation. In summary, Grundy found intersecting sources of ageing and vulnerability in people who were very old, those on low incomes, or with poor social ties (current and in the past), and those with few opportunities or capacity to exercise autonomy. Policy approaches aimed at reducing vulnerability needed to focus on each part of the dynamic process that creates vulnerability, Grundy asserts. Building people’s reserves as they become older, reducing the challenges and providing adequate compensatory supports are steps along the way to reducing the vulnerability of older people. In particular, Grundy’s approach to analysing old-age vulnerability is congruent with, and provides a link with resilience, which is taken up in the final section of this chapter on theoretical approaches.

### 4.3.4 Resilience

As a quality, being resilient suggests that someone or something is able to bounce back or to recover from a hazard or stressor (Ludowyk & Moore, 1996). In the last two or three decades, Resilience Theory has grown into a broad field of study which focuses on the strengths that people and systems use to rise above adversity at an individual (over the lifespan), family, community, workplace and policy level (VanBreda, 2001). In relation to the theoretical aspects of this thesis I will focus on resilience at the individual, community and policy levels. I will also refer to the emerging research on resilience amongst people with disability and older people, as these studies support a paradigm shift away from the problem-focused and deficits-based perspectives of ageing and disability pervasive throughout the biomedical discourse, and from some approaches to the ethic of care.

**Individual resilience in people with disability and in older people**

As a concept, resilience has evolved into meaning much more than recovery. It is now understood as:
“...a dynamic process that influences the ability to deal with, survive, overcome, learn from, and recover from inevitable adverse experiences of life by incorporating traits such as hardiness, high self efficacy, and external factors, such as social support, that promote coping.” (Resnick, 2008, p.85)

In other words, at the individual level, resilience is the ability and degree to which an individual can fend off adversity or the negative consequences of experiences. Some people cope with adversity better than others, and some even appear to thrive and discover strengths that they did not know they had. In individuals, resilience consists of both internal traits and external factors. Patient’s adaptive responses to developing illness or disability, including the role of ‘healthy denial’; ‘hardiness’ and ‘ego-strength’ in maintaining resilience, were explored by Druss and Douglas (1988). They found that these patient’s positive outlook and beliefs towards a better outcome should be supported and not challenged by professionals involved in their care. Yet, as Smith and Zautra (2008) concluded from their study on vulnerability and resilience in women with arthritis, greater consideration to vulnerability and resilience is needed in theory, research and interventions.

As women with intellectual disability aged, Dew et al. (2006) found their resilience was manifest in their self-acceptance, family support and friendships, being part of a community and having adequate money to buy what they needed. These internal and external resilience traits enabled this group of women to age well with meaningful, productive and sustainable lives. Adversity in their lives was attributed to having an intellectual disability and to life circumstances. These findings have implications for policy, practice and further research.

Kendall and Terry (2008) looked at the composition of effective coping in people following traumatic brain injury. They found that when ‘problem-focused coping’, or attempts to actively manage situations were used by these patients, an association with emotional distress endured in the long-term. This led them to conclude that people’s coping in situations is complex. Therefore it is best to avoid making simplistic assumptions about coping strategies.

In conducting a review of the risk (or vulnerability) factors and protective (or resilience) factors of young people with high-incidence disability during their post-high school transitions, Murray (2003) produced a framework to explore the effect of individual, social and contextual experiences on long-term outcomes. Although the framework identified the risk and protective factors and the relationships between these indicators and the outcome status of young people with disability, Murray concluded that greater insight into their lives was needed to improve prevention and intervention efforts.
King et al. (2003) conducted a study on the components of resilience in people with chronic disability. The ‘turning points’ identified were emotional experiences and realisations gained via notions of belonging, doing and understanding themselves or the world, while the major protective factors were social support, spiritual beliefs and personal traits, such as perseverance and determination. New protective factors identified from this study were transcending loss with a gain, self-understanding and accommodating loss. Risk factors were not explored in this study. Overall, the researchers observed that while the turning points for people with disability were both normative and disability-related, they were also similar to the protective factors and processes discussed in the literature.

In a study by Jang et al. (2004), age differences (between people in their 60s, 80s and 100s) had an impact on subjective health, with those in advanced old age’s subjective rating of their health and depressive symptoms proving to be less affected by disability compared to the younger old, indicating that centenarians had higher levels of resilience than the younger-old. Furthermore, regardless of age, subjective health mediated the effects of disease and disability on depression. These findings led the researchers to conclude that while age differences had consequences for health problems, subjective perceptions also played an important mediating role between physical and mental health. Mehta et al. (2008) also found differences in depressive symptoms and associations with apathy, resilience and disability in the young-old (<80 years) and the old-old (>80 years). In the young-old, resilience, apathy and disability all had had similar contributions to depression scores, whereas in the old-old, depression was most highly correlated with apathy. Similarly, focusing on the self-rated successful ageing of community-dwelling older people, Montross et al. (2006) found that 92% rated themselves as ageing successfully. There was a significant correlation between subjective ratings of successful ageing and resilience, health-related quality of life, greater activity and having close friends. Despite having physical illnesses and disability, most of the older people in this study viewed themselves as ageing successfully.

Hardy et al. (2002; 2004) studied stressful life events (2002) and resilience (2004) among community-living older people. Among the wide range of stressful life events reported, four event types were outstanding. A minority (18%) considered physical illness as being the most stressful event, compared with 42% who perceived the death of a family member or friend, 23% the illness of a family member or friend, and 17% a non-medical event. However, the participants also reported that stressful events can have negative and positive consequences for their lives, a finding of variation indicative of different degrees of resilience among them. In 2004, Hardy et al. assessed the resilience of community-dwelling older people based on responses to a stressful life event and aimed to identify the demographic, clinical, functional, and psychosocial factors associated with high
resilience. They found a wide range of resilience among participants, with high resilience associated mainly with having few depressive symptoms, having good to excellent self-rated health, functional (independence in IADLs) and psychosocial factors (living with others).

In a qualitative study of resilience among older women, Kinsel (2005) found resilience across the lifespan was variously affected by individual, developmental, social-structural and historical influences. Several factors emerged as important for resilience. These were social connectedness, taking a direct approach to challenging situations, having a spiritual grounding, being curious, extending oneself to others and moving forward after adversity by taking an unconventional approach.

Windle et al. (2008) examined the concept of psychological resilience in old age to integrate it with a number of theoretical perspectives described in the literature. Survey data were used for a secondary analysis to test the hypothesis that resilience, as an overarching construct, accounts for the functioning of a number of psychological resources. A higher order model was developed which explained the relationship between the concept of psychological resilience and the sub-categories of self-esteem, personal competence and interpersonal control. Although the authors provided a baseline account of psychological resilience in old age, they also noted this study's limitations, namely its use of secondary data and the exclusion of spirituality, religion and self-acceptance as factors contributing to psychological resilience in old age.

Community resilience

Some of the stressors which individuals (and families) need to deal with come from the community, which is understood as the system that lies around or above the family and the individual. Examples of community stressors that can impact negatively on people include poverty, a lack of community resources and discrimination. Yet the community can also be a source of protective factors; of particular interest here is ‘social support’. Social support is thought to involve the caring exchange of information and has three parts: emotional, esteem and network support (Cobb, 1982 cited in VanBreda, 2001). Other types of support include:

- Instrumental support: which helps people towards better coping (includes counselling);
- Active support, a more total support which can lead to dependency; and
- Material support, which involves the provision of goods and services.

However, Cobb believed that social support was the most important form of support, which acts indirectly on health to:

According to Cobb, better adaptation to environmental stressors occurs when a person has esteem support and emotional support, as these supports allow a person to take control of and change the effect of the stressor.

In their review of the literature, McCubbin and McCubbin (1992 cited in VanBreda, 2001) found four main sources of social support, including neighbourhoods, family and kinship network, intergeneration supports and mutual self-help groups. While each of these sources has a range of characteristics, neighbourhoods and family/kinship are the ones most indicated as providing the kind of practical, informational, problem-solving, recuperation and validation needed in times of illness and recovery. Sources of support function as a buffer between the stressor and the stress. Generally speaking, support enables people living in community to recover faster than those who are unsupported in the community. Support is therefore understood as promoting resilience (McCubbin & McCubbin 1992 cited in VanBreda, 2001).

In the research literature there is agreement on the protection and benefits to health and wellbeing that social support provides for people living in community. Research on the value of social support to health and wellbeing includes: home-based management of people presenting for the first time with psychotic illness (Fitzgerald & Kulkarni, 1998); the effects of disablement and the onset and management of late-life depression (Prince et al., 1998); the relationship between health, social support and carers (Robinson & Steele, 1995); the integration of British health and social care services (Glendinning & Means, 2004); the nature of resilience in people with chronic disability (King et al., 2003); mediating the relationship between disability and depressive symptoms across time (Taylor & Lynch, 2004); the resilience of community-dwelling older people (Hardy et al., 2004); the benefit and burden of “ageing-in-place” in an aged care community (Horner & Boldy, 2008) ; predicting nursing home admission in care dependent older people (Thygesen et al., 2009) and families caring for a person with a disability (Edwards, 2009). There are also studies that include social isolation, as a lack of social contact or social support (Boland & Sims, 1996; Wellard & Street, 1999; Aronson, 2002; Stoltz et al., 2004; Rockwood et al., 2004; Kharicha et al., 2007), and as a contributing risk factor to the health and wellbeing of people. Yet social isolation is seldom identified as a risk to the resilience of people in the community.

Research on social support is sporadic and appears to be constrained by the discipline from which it emerges. For example, in sociology, social support is more likely to be linked to social capital,
whereas in the professional disciplines of social work and psychology, social support tends to be associated with resilience. Gray’s (2009) study is unique in this regard, as it addressed the gap between social support and social capital and links these concepts. Gray described social capital as:

“…an individual resource, which is partly developed by the individual’s own past and present activities, but is also contingent on the attitudes of others. People can choose with whom to associate – subject to the constraints of their health…their neighbourhood, family and social environment, and…class, ethnicity and gender – but they cannot choose how helpful their friends, neighbours and relatives are…or whether these people have the time, physical capacity and above all the inclination to talk, help and visit. Thus…[as] an individual resource, the support available for individuals depends partly on social capital as a collective resource…shaped by prevailing norms and values. This inter-dependence reveals the complementarity of Putnam’s\textsuperscript{34} concept of social capital as a public good…and Bourdieu’s\textsuperscript{35} …emphasis that social capital varies among individuals”. (Gray, 2009, p.7)

In the context of Gray’s (2009) research on older people and social capital, social support is understood as an outcome of social capital. Her paper analysed the British Household Panel Survey data. While it did not measure or refer to resilience, it examined the extent to which people felt they could count on social capital (or social support in the form of emotional and practical support) from a person’s social network (of friends and relatives). The poorest support was found among people who were childless or who had been continuously without a partner. Relatively rich support was experienced by those who had frequent contact with other people, including neighbours, and who regarded their neighbourhood as a positive social environment. Informal social contacts had more effect on social support than being active in organisations, although activity or engagement through religious organisations and sports clubs had a positive association with social support (Gray, 2009).

**Resilience-based policy**

Until the mid 1980s, many policies (particularly family policy in the USA) were based on a problem-centred approach:

“…policy formulation with its intense focus on problem definition and assessment has not been coupled with similar attention to assessment of the strengths of the people and environment that the policy targets.” (Chapin 1995 p.5 cited in in VanBreda, 2001).

Policies intentionally developed to promote resilience are based less on correcting deficits and more on creating a social environment conducive to individual, family and community well-being and functioning. Previous policy approaches judged individuals as being inherently deficient. According to


resilience-based policies, people are excluded from social processes because of demographic characteristics. This is why resilience-based policies focus on common human needs, as opposed to ‘deficient people’, assisting to identify individual and community resources for use in the creation of opportunities and alternatives to the traditional system (Chapin 1995 cited in VanBreda, 2001).

Figley and McCubbin (1983 cited in VanBreda, 2001) argued that policies were needed to establish the resources within communities that fostered ‘resistance’ to the negative consequences of adversity, whereas Weick and Saleeby (1995 cited in VanBreda, 2001) proposed the development of ‘enabling niches’, or environments in which people fitted, felt comfortable and were able to thrive. With a particular focus on families, and all families who ‘deserve support’, Ooms and Preister (1996 cited in VanBreda, 2001) developed five principles to evaluate the impact of policies on families: Support and Responsibilities; Membership and Stability; Involvement and Interdependence; Partnership and Empowerment; and Diversity and Vulnerability. In regard to Involvement and Interdependence, Ooms and Preister stated that policies needed to recognize the interdependence of relationships, the strength of ties and obligations and the resources of (family) members. The underlying value of Involvement and Interdependence was understood as:

“Solutions to individual problems shouldn’t harm other family members”. (Ooms and Preister 1996 cited in VanBreda, 2001, p.165)

Insofar as vulnerability was concerned, their underlying value was that:

“Policies should give special consideration to those with the greatest social and economic limitation and to those most likely to break down.” (Ooms and Preister 1996 cited in VanBreda, 2001, p.165)

In summary, while more work is needed to expand what is meant by resilience-based policies, the key elements appear to be policies that:

- Emphasise strengths over deficits;
- Create environments conducive to healthy resilient individuals, groups and families;
- Incorporate resilience research (which identifies protective community factors);
- Focus on all families and individuals, not just those considered vulnerable;
- Are flexible in catering for diversity and involve the participation of clients; and
- Aim to create experiences that promote resilience and reduce the creation of vulnerability (VanBreda, 2001).

The work-life interface represents another area of interest within the resilience-based policy literature, although it is noted here that none of this literature is specifically grounded in resilience. Two sets of
changes have led to theorising on this topic, these being changes in the workforce and changes in organisational processes. In this field, work-life conflicts have become apparent concerning expectations of the self, society and employers, the allocation of time and energy, and caring and household responsibilities. Role-overload is another topic, which may result in strain, recognition of an individual’s limited resources and the gendered nature of role overload (VanBreda, 2001).

CHAPTER SUMMARY
In the late 20th century, discontent with the medical profession and the rise of chronic illness were significant in the development of critical sociology. How people experience ageing, disability, illness and care are reflections of social values and the organisation of society. Indeed, age and functional ability are key variables in shaping the production and distribution of the community care of people with a disability and the aged.

The two interpretations of health, the biomedical approach and the social model of health, are understood to contribute to the divisions between the acute (or hospital) sector and the community care sector. A pathogenic or problem-focused perspective dominates the biomedical approach to ageing and disability. Illich’s notion of iatrogenesis has merit for continuing to stimulate debate, reflection and evaluation of the practice and outcomes of medical care. However, his invective has limitations, particularly in its austere condemnation of tangible medical achievements.

In identifying the ethic of care, Tronto (1993) turned our attention to the practices and processes of care and to the centrality of interdependence. As a normative ethical theory, care ethics are understood to have moral and political implications. Sevenhuijsen’s (2003) caring citizenship, Hankivsky’s (2004) moral landscape and William’s (2001) political ethic of care have each contributed to the ethic of care by evolving practical principles that can be used to guide social policy. However, apart from these writers the ethic of care overemphasises dependency and vulnerability and marginalises disability. This also leaves this approach lacking a conceptual basis for analysing the resilience of the cared-for and of carers.

With regard to Schröder-Butterfill and Marianti’s (2006) vulnerability framework, the complexity and indeterminate nature of vulnerability are exposed. It shows, at least, the points at which crises can be averted and that poor outcomes are not inevitable. Although the intention of this framework was to capture aspects of vulnerability most relevant to the study of ageing, it can equally apply to understanding the vulnerability of people with disability and be used in comparative (cross-cultural) analysis. However, while it provides for an analysis of exposure, threats and coping capacity, Schröder-Butterfill and Marianti’s framework subsumes the place of care under coping capacity and
the role of structural forces is spread across the framework, which, in my view, potentially weakens the power of the analysis. There are similarities between Moser’s framework (cited in Lloyd-Sherlock, 2006) and Schröder-Butterfill and Marianti’s, but Lloyd-Sherlock demonstrated the importance of including people’s social entitlements. Comprehensive in its analysis and impressive in its condensed simplicity, Van Eeuwijk’s (2006) ‘triangle of uncertainty’ is a broad framework of social, economic and health uncertainties used to analyse old age vulnerability, care and coping capacity in North Sulawesi. Van Eeuwijk and Grundy’s (2006) analytical frameworks are congruent with a resilience approach to analysis.

By giving preference to the strengths that people use to rise above adversity, Resilience Theory could almost be described as an antidote to the deficit or problem-based discourse of ageing and disability. However, in its recognition of adversity at the individual, community and policy levels, resilience also provides for the identification of risks, stressors and needs. At an individual level, this theory recognises that there are dimensions and levels of resilience. In a community context, resilience is understood in relation to identifying the stressors and the protective factors that act on communities. Resilience-based policy focuses on common human needs and is directed towards identifying individual and community resources that can be utilised in times of need to build upon the resilience of those with the greatest social and economic limitations. Across the spectrum of resilience at the individual, community and policy levels, interdependence, vulnerability and social support are each recognised for their effect on health and wellbeing.

This review, while providing an overview of theory-based directions for analysing the findings of this thesis, has also raised complex questions. These questions concern the limits of applying any single theory and the extent to which one can apply concepts from several theoretical approaches to the one study. However, as theories are explained and applied, it is important to acknowledge how they inform one another and that each contributes to ways in which the problem of this thesis can be analysed. In my description of the intersection of vulnerability, resilience and health and community care transitions of people with disability, older people, and their carers, my analysis is mainly drawn from the broad framework of social, economic and health uncertainties. Therefore, instead of presenting a limited theoretical focus, I have argued that the complexities and uncertainties of care transitions can only be adequately understood by canvassing a range of theories to aim for the best fit available between the reality and the theory. As a result, the range of theories presented is understood as being particularly relevant to understanding the care transitions of older people, people with disability and their carers.
PART THREE: METHODS AND RESEARCH DESIGN
CHAPTER 5: METHODS: MY APPROACH TO THIS STUDY

5.1 INTRODUCTION

In Chapter 4, I pointed out that people’s experience of ageing, disability, illness and care reflect social values and the organisation of society. Then I mentioned that my professional experiences and interest in critical sociology had influenced the theories that I use to analyse my data. This led me to using a ‘jeans and jig-saws’ approach, where concepts from a range of theories were selected in search of the best fit between reality and theory. The theories and concepts included: understanding the difference between the biomedical approach and the social model of health, iatrogenesis, the ethic of care, vulnerability and Resilience Theory. In this chapter, I review my approach to the conduct of the study, including my philosophical orientation, and the difference between applying reflexivity in action research and critical reflection afterwards.

As someone reading this thesis for the first time, I would want to know why, of all the possible ways to conduct research, this researcher chose this approach? Therefore, providing readers with this information is to assist with orientation and understanding of the method. My approach to this study evolved from my life experience and professional background. As a Registered Nurse I have a broad interest in health. More recently as a Social Worker, I am interested in policy, social change and community development. My values as a nurse are congruent with the health promotion framework presented in “The Ottawa Charter for Health Promotion” (WHO, 1986), which includes the objectives of enabling, mediating, strengthening community action, developing personal skills and moving into the future for health promotion. In addition, I agree with “The Cuenca Declaration” (PHA, 2005), which strives for a just and peaceful world, where everyone is respected and can claim their right to health, life, nature and diversity.

5.1.2 Philosophical orientation

"...no self is an island; each exists in a fabric of relations that is now more complex and mobile than ever before. Young or old, man or woman, rich or poor, a person is always located at ‘nodal points’ of specific communication circuits, however tiny these may be" 36 (Lyotard, 1984, p.15)

From a philosophical perspective, I lean primarily towards an advocacy/participatory approach and to a lesser extent, social constructivism. I believe that, as humans, we are not atomised independent

36 This quotation from the French post-modern philosopher and literary theorist, Jean-François Lyotard (1924 to 1998), has a familiar resonance with the following famous passage by the British poet, John Donne (1572 to 1631), who wrote “No man is an Iland, intire of it selfe; every man is a peece of the Continent, a part of the maine; if a Clod bee washed away by the Sea, Europe is the lesse, as well as if a Promontorie were, as well as if a Mannor of thy friends or of thine own were; any mans death diminishes me, because I am involved in Mankinde; And therefore never send to know for whom the bell tolls; It tolls for thee.” from “Meditation XVII” of Devotions Upon Emergent Occasions”.(Donne, circa 1600) Donne, J. (circa 1600). “Meditation XVII.” Retrieved 26.4.06, 2006, from http://www.brainyquote.com/quotes/authors/j/john_donne.html.
units operating autonomously in time and in social systems. This individualist conceptualisation has been championed in Western philosophy for the last 2,000 years through the work of Plato, Aristotle, Machiavelli and Locke – to name a few. Western notions of the individual self appear detached from their social background, as if the self is entirely independent of the society. These theories are distinct from non-Western cultures around the world, many of which conceptualise the inverse of the Western view, that is, that the social or the community lies ahead of notions of the individual. In Western thought, the theories of the individual self have acted as definitions which impact in a variety of ways at the social level and justify patterns in cultural life (Du Preez, 2004, p.146).

However, this concept of the individual self has been challenged by the post-modern perspective, which focuses on the processes and contexts in which people live (Freedman & Coombs, 1996). In contrast with Western individualist definitions, the post-modern notion of the self is characterised by movement, multiple selves and reflexivity, discerning that we are social beings and language beings, situated within a community, rooted in our culture and interpreting and negotiating multiple cultural meanings. As there is a close relationship between the stories we tell and hear and who we are, these stories form the cornerstone of our identities (Du Preez, 2004). Therefore, because we are social beings living with others in time and place, our stories are not and can never be wholly personal. It is the case that:

“...we perceive reality in terms of stories, and ultimately how we construct, interpret, digest and recount for others our own experiences bears a strong relationship to the story-lines that are already ‘out there.’” (Andrews et al., 2004, p.112)

The assumptions of the social constructionist’s belong to the post-modern grouping, but with unique characteristics. Social constructionists maintain that individuals seek understanding of the world in which they live and work and develop subjective meanings of their experiences (Cresswell, 2003). Further, they consider that our identity is socially constructed and constituted through narratives, which are organised and maintained through language (Freedman & Coombs, 1996). As much as possible, the social constructionists’ goal of research is to depend upon participants’ views of the situation being studied (Cresswell, 2003).

I also work and write with the paradigm of a Social Worker37. In this field, I have spent most of my professional life working with groups and individuals in situations where we attempted to address

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37 I abide by the Australian Association of Social Workers (AASW) values, which provide Social Workers with a set of ideals upon which to base their work. These values are defined in the AASW’s “Code of Ethics”, and include Human Dignity and Worth; Social Justice; Service To Humanity; Integrity, and Competence. (AASW, 1999) Australian Association of Social Workers (1999). AASW Code of Ethics. Canberra, Australian Association of Social Workers: 33.
issues of social justice. Ethical dilemmas, where one value comes into conflict with another value, are a regular feature of Social Work practice. Although professional development provides the opportunity to work through such dilemmas in the workplace, satisfactory resolution is not always possible. There is often a process of balancing the matter between personal and professional values and the complicated messiness of reality. In my early work as a counsellor living in Adelaide, I was drawn to the work of Michael White (1948-2008), with whom I undertook Narrative Therapy training. This led me to reject the pathogenic paradigm (or problem-focused perspective) in social work theory and to use the strengths and capacities perspective in my work. Furthermore, the nature of the work that I had done led me to the advocacy/participatory approach, in the form of action research, because social constructivism:

“...did not go far enough in advocating for an action agenda to help marginalised peoples...[Advocacy/participatory researchers] believe that inquiry needs to be intertwined with politics and a political agenda. Thus, the research should contain an action agenda for reform that may change the lives of the participants, the institutions in which individuals work or live, and the researcher’s life.” (Cresswell, 2003, p.9-10)

In addition, the advocacy/participatory approach needed to address important social issues of the day and proceed collaboratively, with the researcher and the participants to bring about reform and change. Thus, in order to conduct the research from within an advocacy/participatory approach, I chose the action research method, as it integrates with the theoretical perspectives I draw upon in my analysis, namely aspects of feminist theory (the ethic of care), disability inquiry, notions of vulnerability and Resilience Theory (Cresswell, 2003). Finally, I acknowledge that in my role as the author of this text that I cannot objectively describe the reality I present here. In this, I agree with Tierney (1994), who proposed that as researchers, another facet of our research capability:

“...must be to exhibit a sense of care and concern to understand the “other’s possibility”. I am suggesting that our research endeavours need to be reformulated so that they include a capacity for empathy.” (Tierney, 1994, p. 105)

5.1.3 Reflexivity and Action Research
In my capacity as a Social Worker, I am also interested in change and the potential to influence practice through intelligent enquiry. With this background, I was drawn to the potential of action

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39 Refer to Chapter 3 for the theoretical perspectives used in this thesis.
research to be practical and bring about real change in real situations. Prior to this thesis, I completed a range of projects that have all aimed at improving access to health and community services for various population groups, who, by virtue of a range of personal, psycho-social, economic or political circumstances, have been neglected or overlooked. After graduating as a Social Worker in 1997, the first research project I completed was located in the Hills Mallee Southern region of SA. This study assessed the quality, quantity and integration of services provided to adult survivors of childhood sexual abuse. I conducted qualitative interviews with ten women adult survivors of childhood sexual abuse and surveyed service providers (N=106) in the region. In its Terms of Reference and Recommendations, this study endorsed a health promotion approach (King, 1998). Likewise, the following year, I was involved in a WHO trial aimed at developing effective partnerships between the health sector and community groups and organisations (King, 1999). Both studies used mixed methods and were consistent with my broad interest in the health and Social Work paradigm. Yet while many qualitative texts encourage researchers to be reflexive or reflective (Holloway, 2005; Neuman, 2003; Creswell, 2003), because these former studies were located in the workplace they did not allow the time for, or anticipate a process of reflection. Hence, in choosing to use action research which is structured to include reflection as part of the cyclical process, undertaking the present study marked a point of departure from my previous work.

During the action research study I was reflexive, which meant that as the researcher I examined myself to make explicit my place in the research. Before I distinguish my reflexive method (described above), from that of being critically reflective (discussed in the next section), I will point out that reflexivity and reflection are often used interchangeably (Holloway, 2005). In addition, there are many definitions of reflexivity. However, I agree with Nightingale and Cromby’s (1999) who suggest that the position of reflexivity is concerned with the researcher examining themselves and making explicit their place in the research:

“Reflexivity requires an awareness of the researcher’s contribution to the construction of meanings throughout the research process, and an acknowledgment of the impossibility of remaining ‘outside of’ one’s subject matter while conducting research... (reflexivity urges us) to explore the ways in which a researcher’s involvement with a particular study influences, acts upon and informs such research.” (Nightingale and Cromby, 1999, p. 228)

In his theory on how professionals think in action, Schön (1983) discusses the ways in which two different professionals are reflective in response to a practice problem. After consideration of Schön’s work and other more recent commentators on the need for researchers to be reflexive or reflective, I
propose that Schön’s references to reflection are more accurately described by the current notion of reflexivity, or self-examination of the practitioner’s place in their work.

As a practitioner, I approached the practice problem (concerning the types of changes needed in the system to reduce poor outcomes and improve the continuity of care and of older people and people with disability and their carers) as a unique case. I had relevant prior experience and my own ways of seeing and doing things (biases, motivations and behaviours), but found I also had to discover and attend to the particularities of this problematic situation and to design interventions. The whole process was, as Schön described, one which was complex and uncertain and where the actual problem was not given. In fact, there was ‘a problem in finding the problem’ which created ‘the conditions for reflection-in-action’ and the need to reframe the problem.

Schön describes how progress on tackling the problem is made ‘through a web of moves’, where the practitioner discovers:

“...consequences, implications, appreciations, and further moves. Within the larger web, individual moves yield phenomena to be understood, problems to be solved, or opportunities to be exploited...These are local experiments nested within larger ones...but the practitioner’s moves also produce unintended changes which give the situations new meanings. The situation talks back, the practitioner listens, and he appreciates what he hears, he reframes the situation once again...In this reflective conversation, the practitioner’s efforts to solve the reframed problem yield new discoveries which call for new reflection-in-action. The process spirals through stages of appreciation, action, and reappraisal.” (Schön, 1983, p.131-132)

I was familiar with the reflection-in-action approach, as it is strikingly similar to notions of reflexivity and the Problem Solving Approach commonly used by Social Workers in counselling. Furthermore, Schön’s approach and description of reflection and the spiralling stages of appreciation, action and re-appreciation are similar to the action research cycles of plan, act, observe and reflect. As a reflexive practitioner, I gradually built my perception of the problem into an interpretive synthesis congruent with my epistemology (Schön, 1983).

In this thesis, I have had an opportunity to examine and reveal my place in the research process. In the practice and write-up of previous projects nothing more than a temporal narrative was needed. This approach tends to skim the surface of the story, like a pebble skipping over a body of water and getting to the other side, but never penetrating the surface. Much of interest stays hidden in the watery subtext or is excluded altogether, including such aspects as how decisions are made, one’s role as researcher and the dynamics between myself and the research participants (Holloway, 2005). In
addition, without this reflexivity, readers know little about the researcher’s approach to analysis and her or his involvement in the study. Not having this information diminishes other readers’ opportunity to connect with the study, through their own subjectivity, whether they are someone with general interest in the topic (like the numerous ‘baby boomers’ who ask me to fix this problem before they get old and frail) or as a service provider, an aged person, a person with disability or a carer.

This study was not attempting to be neutral or value free. Rather, I took seriously one of the purposes of action research - to stimulate intense self-reflection about one’s own practice and the practices of research participants. Indeed, the interpretations of the underlying meaning on the basis of the actions taken were relative to the situation. Although the actions have to be understood in relation to the original aim of this research, reflexivity has demanded that, in order for my interpretations to be theoretically generalised, they needed to be located in the wider social, political and ethical context (Freshwater, 2005).

While being reflexive enables a more complete picture of the study, it is important to maintain rigour, as, compared to more conventional quantitative research methods, action research has been criticised for its lack of scientific rigour. Freshwater (2005) argues that one criterion for judging the thoroughness of action research is its level of reflexivity in both describing and constituting a social setting and subjecting the research itself, as far as possible, to the kind of critical appraisal that tries to understand what effect the practitioner has on the research. The rigour of this research is best judged according to my interpretations drawn from the self-reflective spiral of observing and reflecting; and from the justifications of actions taken in the constructive phases of planning and action (Kemmis, 1993).

5.1.4 Critical Reflection

“Critical inquiry cannot be viewed as a discrete piece of action that achieves its objectives and comes to a close. Within every action taken, the context changes and we must critique our assumptions again. Viewed in this way, critical inquiry emerges as an ongoing project. It is a cyclical process (better seen perhaps, as a spiralling process for there is movement forward and upward) of reflection and action.” (Crotty, 2003, p.157)

Critical reflection is not only integral to qualitative research, but is also an essential part of the method of action research. Critical reflection took place after the action research project had finished, when I looked back on what I did through the lens of this thesis (Holloway, 2005). This is where this process differs from reflexivity, as the former occurs afterwards and the latter is contemporaneous. Critical reflection has meant:
“...taking a critical stance towards the research and suggesting ways to improve it or go beyond its limitations as well as thinking about future solutions to the problems encountered.”  
(Holloway, 2005 p. 278)

Therefore, critical reflection is an important part of the research process and is necessary for the integrity and legitimacy of the study. It also provides the opportunity to determine the strengths and weaknesses of a study.

5.1.5 Validity in Action Research
It has been noted in the literature that validity in action research is measured by:

“its process of validation, that is, the dialectical movements between practice, theory, research, and its examination of the tensions, contradictions and complexities of life.”  
(Waterman, 1998, p. 103)

While I accept that mirrored images of reality are not possible, to legitimate the findings in this study I have conceived validity from a variety of viewpoints, as the above quotation implies. I have maintained a questioning attitude to the findings and have sought opposing perspectives including: the range of theoretical approaches I have explored (discussed in Chapter 4), the methods of data collection (surveys, interviews, focus and nominal groups and consultations), the level and quality of participation and engagement with the research process and findings, evident in the number and range of participants. I have maintained a reflexive stance with regard to the ways in which I have influenced the study and I have critically reflected on the tensions and processes that occurred during the study. I have provided a full account of the course and outcomes of the action research and discussed the strengths and limitations of this study.

5.2 CHAPTER SUMMARY
In summary, my approach to this study has been influenced by my philosophical orientation, [involved] reflexivity at the time of the study and critical reflection afterwards. My professional influences come from nursing and social work, both of which have influenced my philosophical orientation towards advocacy, participation and social constructivism. During the action research study I was reflexive, which meant that as the researcher I examined myself to make explicit my place in the research. Critical reflection took place after the action research project had finished, when I looked back on what I did, identified the study's strengths and limitations and suggested ways to improve the process.
CHAPTER 6: RESEARCH DESIGN: AN ACTION RESEARCH APPROACH

6.1 INTRODUCTION: RESEARCH METHODS AND DESIGN
In Chapters 2 and 3 I presented the literature review in which it was demonstrated that discontinuity of care for older people and people with disability in transition between hospital and home is an area of concern to the people themselves, their carers and service providers in both sectors. From my survey of the relevant literature I have concluded that the multiple factors which contribute to discontinuity of care of older people and people with disability are poorly understood, as are the ways in which continuity could be enhanced. Furthermore, research in this area is compartmentalised within a particular sector or analytical framework. The literature typically focuses on: hospital processes (that is, inadequate or failed discharge planning and demand management strategies); on epidemiology (such as the nature of chronic illness and/or aging); on discussions about policy (the conflict of values between the medical model and primary health care and the fragmentation of primary care services); or on studies that point to the inadequacies of professional education. While there is an emerging literature on ‘the interface between the hospital and the community’, there is little research that conceptualises this problem as a boundary problem, or as a problem arising from the barriers between the sectors themselves. I required a research design where it was possible to conceptualise discontinuity of care of older people and people with disability as a boundary problem in need of exploration across the sectors, as well as facilitating exploration with all stakeholders to find out where and how changes were needed.

An action research method was chosen over other methods as it enabled the participatory study of a situation with a view to generating solutions to practical problems and implementing actions to bring about change. Action research has been widely used in health care research and is gaining increased attention in community and public health research. Numerous accounts (Robinson & Miller, 1996; Webb, 1989; Hart & Bond, 1995; Morton-Cooper, 1999; Cowley & Billings, 1999; Winter & Munn-Giddings, 2001) support this method of research into service systems improvements, education, change management and development in the field of health and community care. Negotiation and collaboration with key stakeholders constituted critical components (Wilson, 2000). The collaborative effort included extensive consultation to explore what the key issues were from patient, carer, hospital and community service provider perspectives, and the type of changes needed in the hospital and HACC systems. Actions were implemented to improve the continuity of care for older people, people with disability and their carers. The planning and direction of the research remained flexible and
continued to develop as the work progressed through the cycle of identifying problems, proposing action and evaluating change as a result of the action.

6.2 BACKGROUND OF ACTION RESEARCH

6.2.1 History

Kurt Lewin (1890–1947) is generally credited for first introducing the term ‘action research’ as a distinctive way of finding out about a social system while also attempting to change it (Elden, 1993). Although this section provides an overview of Lewin’s contribution to action research, several writers (Kemmis & McTaggart, 1992; Hart & Bond, 1995) provide accounts which attribute the earliest origins of this method to several earlier researchers, including:

- Buckingham (1926, cited in Hodgkinson, 1957) who described a similar method to action research in his text titled “Research for Teachers”;
- The educational philosopher, John Dewey (1929), who argued in favour of practice-based and scientifically-tested methods to change education practice, and
- John Collier (1945), who between 1935 to 1945, advocated participation by indigenous Americans themselves and action-orientated methods for addressing the social problems experienced by indigenous Americans.

However, as Lewin’s ideas appear to have had a continuing influence on this method, the contributions of Buckingham, Collier and Dewey will not be covered in any further detail here.

Kurt Lewin (1890 to 1947) first coined the term ‘action research’ around 1944. Following his interest in philosophy and psychology, in the 1930s Lewin delved deeper into his research of group dynamics, social processes and social change. He was involved in applied research initiatives, and was commissioned to conduct a number of significant studies into religious and racial prejudice, while also maintaining his social commitments (Smith, 2001; Greathouse, 1997).

In 1946 the term ‘action research’ appeared in his paper ‘Action Research and Minority Problems’, where he offered this early definition:

“The research needed for social practice can be characterised as research for social management or social engineering. It is a type of action research, a comparative research on the conditions and effects of various forms of social action, and research leading to action.” (Lewin, 1946)

Lewin was deeply interested in narrowing the gap between high level theory and applied problems in the social sciences. He claimed:
“...that there is nothing so practical as a good theory”. (Lewin, 1951)

Lewin’s ideas developed in reference to the social milieu and he emphasised the importance of participation of ‘the researched’ in the instigation of change (Lilford, 2003). An enquiry aimed at improvement or change in a real situation should be collectively (or collaboratively) conducted and be self reflective. Lewin described action research as proceeding in a spiral of steps which synthesized theory and practice through cycles of data collection, analysis, action and evaluation of the result of the action (Kemmis & McTaggart, 1992). Figure 2 represents the action research process:

Figure 2 The action research cycle adapted from Smith (2001).

Lewin described the first cycle:

“...to examine the idea carefully in the light of the means available. Frequently more fact-finding about the situation is required. If this first period of planning is successful, two items emerge: namely, “an overall plan” of how to reach the objective and secondly, a decision in regard to the first step of action. Usually this planning has also somewhat modified the original idea.” (Lewin, 1946, p.205)

The second cycle is:

“...composed of a circle of planning, executing, and reconnaissance or fact finding for the purpose of evaluating the results of the second step, and preparing the rational basis for
planning the third step, and for perhaps modifying again the overall plan.” (Lewin, 1946, p.206)

The approach is open to literal interpretation, is oriented to learning from experience and problem-solving in social and organisational settings and takes a sequential form (Smith, 2001).

It has been argued by Meyer (1993) that Lewin’s conception of action research ‘steps’ have formed the basis for more recent definitions of the action research cycle of planning, action, observing and reflecting. Figure 3 graphically represents this cycle as:

![Figure 3 The action research cycle of plan, act, observe and reflect](image)

Action research has been applied to a broad range of fields including organisational research, community development and nursing (Hart & Bond, 1995).

At this point it is important to clarify the difference between ‘participatory action research’ and action research. According to McTaggart (cited in Rice, 1999), participatory action research (PAR) has its origins in community development approaches in underdeveloped countries, where it aims to provide the impetus and actions for social change with disempowered, marginalised and oppressed groups of people (de Koning, 1996). In contrast, action research has been applied in education and management in developed countries like Australia, Britain and the USA (Hart & Bond, 1995; Kemmis & McTaggart, 1992).
6.2.2 Action Research: Definition or Typology?
Since Lewin defined action research, additional definitions have emerged and, to varying degrees, they capture the general characteristics of action research as it is applied to education, organisational research, community development and/or nursing. The definitions vary according to the historical context in which they were written and the purpose for which they were developed. Lewin’s definition highlights a form of ‘rational social management’ not compatible with community development pursuits. Other definitions, such as those of the ‘participatory action research’ stream, emphasise emancipation of oppressed groups and take a particular anti-positivist stance to social change, which may not fit as well with organisational research, for instance.

Numerous writers in the literature have reported on the characteristics or key themes of action research (Altrichter et al., 1991; Kemmis & McTaggart, 1992; Elden & Chisolm, 1993; Waterman et al., 2001; Winter & Munn-Giddings, 2001). In a review of action research literature, five key elements were identified: flexible planning, an iterative cycle, subjective meaning, simultaneous improvement and unique context (Lilford, 2003).

Waterman et al conducted an extensive review of action research used in healthcare settings in the UK and provide the following comprehensive definition:

“Action research is a period of inquiry that describes, interprets and explains social situations while executing a change intervention aimed at improvement and involvement. It is problem-focused, context specific and future-oriented...(It is) a group activity with an explicit critical value basis ...founded on a partnership between action researchers and participants, all of whom are involved in the change process. The participatory process is educative and empowering, involving a dynamic approach in which problem identification, planning action and evaluation are interlinked. Knowledge may be advanced through reflection and research, and qualitative and quantitative research methods may be employed to collect data. Different types of knowledge, including practical and prepositional, may be produced...Theory may be generated and refined, and its general application explored through the cycles of the action research process.” (Waterman et al., 2001, p.11)

In discussing the range and variety of action research, Winter and Munn-Giddings (2001) summarised the key themes as being concerned with power, collaboration, validity and reflection on personal experience. They suggest that through practicing this method the action researcher would construct their own definition of action research.

Hart and Bond (1995) developed a typology which represents the developmental shift in action research over time as it moved from a scientific approach to social change and towards a more
qualitative and social constructionist methodology. Within this framework, four ‘ideal types’ of action research were identified:

- Experimental
- Organisational
- Professionalising, and
- Empowering (Hart & Bond, 1995)

Under these four types of action research, Hart and Bond described how each approach is varied and adjusted to fit within the following seven criteria, which they claim distinguish action research from other methodologies:

“Action Research:
- is educative;
- deals with individuals as members of social groups;
- is problem-focused, context-specific and future-orientated;
- involves a change intervention;
- aims at improvement and involvement;
- involves a cyclic process in which research, action and evaluation are interlinked;
- is founded on a research relationship in which those involved are the participants in the change process.” (Hart & Bond, 1995, p.37-8)

This thesis is located within Hart and Bond’s typology, is consistent with the seven criteria listed above, and spans the organisational, professionalising and empowering types of action research. It involved educational activities with participants. Older people, people with disability and carers were involved as members of social groups as well as being HACC clientele. Problems were identified (poor outcomes and discontinuity of care) which occurred in specific contexts (between hospital and home). Change interventions that would lead to improving these problems in the future were sought. There were two cycles of research, namely actions and evaluations, during which the participants were involved as part of the change process.

Wilson (2000) described action research as both a method to bring about change and a research activity, where qualitative and/or quantitative data were collected and analysed. Wilson notes the importance of negotiation throughout the process. The ‘ideal-type’ of action research described here consists of eight cyclical components of: data collection, feedback, discussion, action plans, implementation and monitoring, evaluation, feedback and problem re-definition. The cycle began with data collection. Although qualitative methods are mostly used, quantitative methods may also be utilised. The next step is to feed back the data directly to those from whom the data were collected. This is an essential element in action research, which distinguishes it from most other research
methodologies. Feedback may be given by written report or by oral presentation at meetings. This is particularly important if management and other organisational members are to be persuaded of the need for action(s). Discussion follows the feedback phase and may include the initial generation of ideas for action(s). Ideas for action(s) may be modified through negotiation, and will finally be developed into detailed action plans with time-lines, responsibilities etc. After the action plans are finalised, they are implemented and then monitored, which provides the opportunity to collect a range of suitable (quantitative and qualitative) data to assist with the evaluation process. The evaluation process is used to determine the 'success', 'usefulness', or 'value' of the action(s) and will often involve making value judgments about the emphasis given to different kinds and sources of data. Feeding back the results of the monitoring process is the next step, to enable further decisions to be made about whether to continue or to change the innovation. Finally, any changes that result from the feedback need to be incorporated into a process where the problem is re-defined, a process which may lead to another round of data collection, action planning, etc. The withdrawal of the researcher may, or may not follow, depending on the context or organisation involved and on the availability of research funds.

6.2.3 Rationale, strengths and limitations of using action research

Rationale for using action research

Action research was chosen because this study has involved particular ‘action’ elements and ‘research’ elements. This method also enabled the issues of organisational change and research utilisation to be tackled directly.

The epistemological theory behind action research is known as ‘critical realism’, a theory which recognises that reality is complex and requires specific research capable of producing meaningful material that can be interpreted in ‘here and now’ situations. The process of action research is important and should be reflexive rather than objective, and collaborative and participatory rather than detached and external. Key stakeholders need to be involved as participants in the research, with dialogue and negotiation about areas of conflict being used to resolve the problems. As there is always the potential for transformation in any social activity, the purpose of research is to understand situations in such a way that will enable quality action within it, or change that is grounded in the real world circumstances of the particular situation (Winter & Munn-Giddings, 2001). In particular, action research was chosen for its suitability to identify the problems and help develop potential solutions to improve practice in health-related settings (Meyer, 2006).
Strengths of action research

Participation has been identified as one of the strengths of action research, as it promotes an understanding of the context of the study and allows for problem identification and actions by and with the participants. Through participation, the barriers to change are overcome as the change is owned by the participants and educational opportunities can arise through the sharing of experience, knowledge and ideas. This also results in generating interest in the project, assisting with the development of rapport and providing support, leading to more sustainable change (Waterman et al., 2001; Karim, 2001; Cunningham, 2008; Scott, 2009).

A further strength of action research is the role played by key people in the research, who may request the study, obtain permissions, authorise access to staff, link the study in with different meetings or agendas, champion activities for change, provide skills and resources, and help with sustaining the change (Waterman et al., 2001).

Other strengths concern the research relationship. If an action researcher was an ‘insider’, or someone who had a formal and usually paid position in the study setting, through their increased commitment they could assist with improving understanding of the issues and context, could build the credibility of the study with participants, and could challenge the barriers to change and help sustain change. From an ‘outsider’ view, being someone with no formal role in the setting other than as part of the project, fresh perspectives for the researcher were possible and other participants are more likely to be empowered by an outsider action researcher (Waterman et al., 2001; Karim, 2001).

Flexibility in research methods to use qualitative and quantitative procedures was also a strength, and could include rapid appraisal methods (such as local interviews, workshops or meetings) to provide direction and develop a plan of action or to demonstrate rigour by triangulating qualitative and quantitative data (Karim, 2001). As qualitative methods can perform dual functions of data collection and increase participation, in the process of problem identification participants’ motivation to act can also increase (Waterman et al., 2001).

Having a real-world focus, with the capacity to reflect real situations and clarify contexts and issues, is another strength of action research. This focus potentially increases the relevance of the research and can assist with reducing the theory-practice gap. A service-led approach is promoted by the real-world focus and this focus can help define the difference between operational and strategic issues. Finally, action researchers are exposed to the realities of practice by this method (Waterman et al., 2001; Karim, 2001).
Positive aspects of the *process and management of projects* include responsiveness, flexibility, feedback mechanisms and evaluation of action research. Producing *knowledge* and contributing to theory are strengths (Raymer, 2009), by identifying gaps in service delivery and by highlighting inappropriate policy. In addition, the events and outcomes of change are described, issues are clarified, appropriate innovations and practical knowledge are developed and inappropriate interventions are prevented.

**Limitations of action research**

Negative aspects of participation in action research can involve the shifting of existing boundaries of relationships and problems within decision-making. Maintaining participation requires time and energy and resistance to change may occur (Beukema & Valkenburg, 2007; Cunningham, 2008). There may be domination of the project by more powerful participants, or participants may react negatively if changes are not implemented (Waterman et al., 2001; Cunningham, 2008).

While key people can *make* an action research study, they can also *break* it by imposing the study on others or opposing it or dominating the study environment and manipulating the study findings and participants by introducing their own agendas (Beukema & Valkenburg, 2007). They may refuse to allow shifts in power or not participate with sharing information, not attend meetings or not engage with change initiatives, thus affecting their impact (Waterman et al., 2001; Karim, 2001).

The insider research relationship had a number of limitations. The insider may have other work commitments that conflict with their research role or their understanding could be obscured from being ‘too close’ to the problem or the participants, thereby challenging this form of inquiry by introducing potential bias (Waterman et al., 2001; Karim, 2001). Other participants may be less inclined to disclose information to an insider or feel vulnerable to the external approval of an insider researcher. An insider researcher may take ownership of the data or have limited access to sensitive or confidential information. They may experience threats from other alliances or be in a dependent relationship with the participants, and vice versa. While an outsider researcher has fewer limitations than an insider researcher, they may have difficulty understanding the context of the study and need to spend time establishing their knowledge-base and credibility. An outsider researcher may be less committed to achieving lasting change and may appear to be involved for their own personal gain (for example, getting a higher degree) (Waterman et al., 2001).

A negative aspect of the flexibility in action research as a method is that, in the rush to produce practical research findings, attention to the quality of the inquiry may be reduced (Karim, 2001). This
also points to the limitations that resources such as time, money, staff and material can impose, with time being the most critical (Waterman et al., 2001; Beukema & Valkenburg, 2007).

Limitations of the real-world focus of action research include the potential for conflict and tensions to arise as complex issues are addressed, the disruption to existing relationships, and the failure to meet expectations. Attention may be directed to issues that have a low priority, and, as the real-world focus of action research requires time for education, reflection and analysis, participants may be taken away from clinical practice. A final limitation is that practice development is prioritised over the type of knowledge that leads to theory development (Waterman et al., 2001).

6.3 ETHICS
It is necessary for researchers working with humans (and animals) to obtain ethical clearance. This research involving human participants complied with specific requirements to ensure that potential participants were able to provide informed consent and knew whom to contact if there were any grievances.

Four Ethics Committee applications were completed as the research was for a doctoral thesis and also involved participants from the hospital and community nursing and initially aimed to include Aboriginal people although this did not eventuate. Ethical clearance was sought from and provided by the Aboriginal Health Research Ethics Committee, the University of Adelaide Human Research Ethics Committee, the Queen Elizabeth Hospital Ethics Committee and the Royal District Nursing Service Ethics Committee.

6.4 OVERVIEW OF METHODS

6.4.1 Selection Criteria
The following selection criteria for participation in interviews applied to the HACC eligible patients and their carers:

- Male or female
- 65 years or over
- With or without a carer
- Living in the specified region of Adelaide
- Able to give informed consent in writing
- Discharged home, and
- Contactable by phone at home.

HACC eligible patients and their carers were excluded from the research if they:
• Were unable to give informed consent in writing
• Were considered too ill, as judged by the hospital staff
• Refused to participate
• Were confused
• Needed an interpreter and none was available
• Had a hearing impairment
• Did not have access to a home telephone
• Were receiving palliative care services, or
• Had a documented cognitive impairment or memory deficit.

The selection criteria for medical, nursing and allied health staff of the hospital, General Practitioners and HACC service providers included:

• Medical, nursing and allied health staff of the hospital who had an active interest or role in pre-admission and discharge planning
• General Practitioners who practiced within the specified region of Adelaide and had an active interest or role in pre-admission and discharge planning, and
• HACC service providers who provided services to clients within the specified region of Adelaide and had an active interest or role in the pre-admission and discharge planning of HACC eligible clients.

The exclusion criteria for medical, nursing and allied health staff of the hospital, General Practitioners and HACC service providers included:

• Any service provider who refused to participate
• Any service provider who only spoke a language for which interpreter services were not available.

6.4.2 Methods of data collection

Introduction

In this study I chose from both quantitative and qualitative methods (interviews, Focus Group, Nominal Group, surveys and minutes of meetings) because they were appropriate and useful to the “nuances of (this) particular area of study as well as the idiosyncrasies of the subjects involved” (Patton, 1994, p.297-9.). Congruent with Creswell’s (2003) criteria for choosing a research strategy, the qualitative and quantitative methods were implemented concurrently, equal priority was given to collecting qualitative and quantitative data, the data were integrated at interpretation and a theoretical perspective was made explicit. I anticipated that using mixed methods would extend my understanding of the problem (Ritchie & Lewis, 2003; Mason, 1995), and might provide an internal measure of the validity of the research process (Brewer & Hunter, 2006). Generating these different
types of data facilitated triangulation, the primary values of which were the checking and extension of
the inferences which could be drawn (Ritchie cited in Ritchie & Lewis, 2003). Furthermore, employing
multiple methods ensured that there were sufficient research options available, if, for example,
following the planning phase taking action became problematic (Liddell, 2002).

Sample
I used a purposefully selected sampling approach for this study. According to Creswell:

“…the idea behind qualitative research is to purposefully select participants or sites….that will
best help the researcher understand the problem…This does not…suggest random sampling
or selection of a large number of participants…as found in quantitative research.” (Creswell,
2003, p.185)

I aimed to investigate the problems in the system that led to discontinuity of care for HACC clients and
identify actions that could be implemented to improve continuity of care for the target group. At the
start I developed a range of questions for interviews with domiciliary, community nursing and hospital
personnel. I then asked the Steering Committee for feedback and incorporated their comments into
the interview questions.

I was aware that I needed to develop a level of trust and acceptance among domiciliary, community
nursing, hospital and other HACC service providers as, unless I was able to develop an in-depth
understanding of ‘the problem’, any changes I attempted to introduce were likely to be met with
resistance.

Given the circumstances of this study, larger samples and a more controlled environment were not
possible without changing the entire context in which the research was conducted. This approach
fitted with using action research, as I was aiming to achieve 'change' and 'understanding' with the very
people who were being affected by the changes that were being introduced.

Participants
The participants of the research came from three sources:
1. HACC eligible patients at the hospital and their carers, specifically from one medical and one
   surgical ward, who lived permanently in the designated region of Adelaide and of HACC services.
2. Medical, nursing and allied health staff of the hospital.
3. General Practitioners and HACC service providers who worked within the HACC metropolitan
   planning area or who had an active interest or role in pre-admission and discharge planning.
Recruitment

Recruitment involved finding patients in each of the pilot wards who conformed to the eligibility criteria, were HACC eligible, lived within the specified region of Adelaide and could provide informed consent. The recruitment phase commenced at the beginning of June 2003. There was a 4 week remission during July during which I took annual leave. Recruitment recommenced in August and continued until the end of December 2003. Thus recruitment occupied a total of six months.

Data collection

The following data were collected, grouped here by participant categories, not by collection order:

HACC eligible patients and their carers were surveyed, using a purpose-designed survey adapted from several validated instruments, including ‘PREPARED’ (Grimmer & Moss, 2001) ‘Assessment of Quality of Life’ (AQoL) (Hawthorne et al., 2000) and the ‘Caregiver Strain Index’ (CSI) (Robins, 1979). The surveys (Appendix 4A ‘Patient Questions’ and Appendix 4B ‘Carer Questions’) asked questions about:

- preparations for admission to hospital;
- information received in hospital to prepare for discharge;
- arrangements that were made prior to discharge;
- perceptions about managing at home and delays prior to discharge;
- functional ability, worries, timeliness, needs and contacts with community services after discharge;
- quality of life before and after discharge;
- caregiver strain and how prepared and supported the patient/carer felt to return home from hospital.

The survey instruments were endorsed and piloted through consultation with the Reference Group. The instruments were then piloted with a small group of patients and carers and amended as necessary.

The sample size was aimed at 93 patients and 38 carers to establish the baseline data. Krystyn Willson from the University of Adelaide Discipline of Public Health calculated the sample size. The method of calculation was the comparison of two independent proportions using the normal approximation to the arcsin transformation of the binomial distribution.
The importance of discontinuity of care to Aboriginal and Torres Strait Islander (ATSI) people aged 45 years and over resulted in their inclusion in the research. A sample size of 20 ATSI patients was determined with the help of Dick Leeson, a hospital statistician. This sample was based upon the number of ATSI patients admitted to the hospital. However, no ATSI patients were found to be eligible during the recruitment period.

Focus Group consultations and interviews were held with the following groups and individuals to determine the key factors that led to the problem and also to discuss and review ideas for techniques that could be implemented to improve pre-admission and discharge planning processes and outcomes. Groups and individuals interviewed included:

- The Reference Group, which reviewed the survey instrument, identified the key pre-admission and discharge issues for older people, people with disability and their carers. The Reference Group also reviewed the proposed discharge information pack for HACC eligible patients.
- Medical, nursing and allied health staff of the hospital
- A Focus Group was held at the domiciliary care service to review a Draft Referral Process. An evaluation of a data link between the domiciliary care service and the hospital was also undertaken.

A Nominal Group was held with a range of community service providers. This technique was chosen as it was recognised to be a useful way to organize a focused and productive meeting for problem-solving the contested issues. This method also balanced and increased participation and reduced the potential for errors in any decisions made by the group. The appeal of this consensus development method lay in its potential to produce a collection of views on the research problem, rather than discussion to produce an overall community view (Black, 2006, p.132). Two questions were asked of the participants: 1). What are the limitations to providing continuity of care for HACC eligible clients when they return home following acute care? 2). What opportunities are there for improving the transition of HACC eligible clients as they move between acute and primary care services?

The planning, design and implementation of actions was based on data analysis of interviews and consultations. Discussion and review of techniques that had demonstrated success elsewhere also occurred.

Face to face interviews were conducted with:

- Domiciliary clinicians and case managers,
- Community nurses and
- Hospital nurses.
The development of the questions asked of the participants during these interviews sprang from the aim of the research and drew upon key ideas pertaining to the topic identified during consultations with the Steering Committee, the Reference Group and the literature review. These included: the main issues facing the aged and people with disability and their carers before and after hospitalisation; what they knew and how they knew about the hospital admission and discharge processes; whether or not the worker was notified (including electronic notification and documentation) about a client’s hospital admission and discharge; what kind of admission/discharge information would be useful for the worker’s purposes; the process that was followed at the domiciliary care service and community nursing service following a client’s discharge from hospital; what they thought were the most important issues in relation to pre-admission and discharge planning; and their ideas for improvement and what changes they would like to see in the system. The same eighteen questions were asked of domiciliary and community nursing practitioners in face-to-face interviews (see Appendix 4C) and hospital nursing staff were also asked that same questions (see Appendix 4D).

Minutes were recorded systematically at every Steering Committee meeting throughout the course of the project.

6.4.3 Data Analysis

In Chapter 5 I gave an explanation of my methodological orientation as being most closely associated with, and interested in, social constructionism. Nevertheless, I also agree with Brannen who stated:

“…the practice of research is a messy untidy business which rarely conforms to the models set down in methodology…In practice, it is unusual, for example, for epistemology….to be the sole determinant of method….There is no necessary or one-to-one correspondence between epistemology and methods.” (Brannen cited in Pope & Mays, 2006, p.3)

I therefore believe there is value in studying a problem from different epistemological perspectives. As a practitioner, I have tried to be reflexive and engage with critical reflection in the process of this action research study.

Earlier, I explained that both quantitative and qualitative approaches were used to collect the data. It should now be understood that, although quantitative methods are generally regarded as coming from an objectivist epistemology, I agree with Crotty (2003) who claimed that neither social constructionism or objectivism are ‘watertight compartments’ (p.9). Indeed, as an emerging literature on using mixed methods testifies (Creswell, 2003; Neuman, 2003; Tashakkori & Teddie, 2003; Brewer & Hunter, 2006, O’Cathian & Thomas, 2006), quantitative and qualitative methods are now less likely to be
considered as mutually exclusive, and when employed conscientiously, can provide practical and analytical benefits (Moffatt et al., 2006).

Two examples of the practical and analytical benefits were:

1. The (qualitative) Nominal Group process provided the practical benefit of developing a consensus view among the participating stakeholders, who elsewhere generally competed with one-another, as well as collaboration among them for the ordering of key concerns.

2. The (quantitative) survey with HACC eligible patients and their carers was, on a practical level, considered much less invasive of their time and privacy than a qualitative method, but provided the analytical opportunity for a more ‘rounded and comprehensive picture’ to emerge from the data (Mason, 1995, p.105).

Therefore, using mixed methods in this research provided the opportunity to gain greater insight into the problem than would have been possible by using one method only (O’Cathian & Thomas, 2006). Importantly, using mixed methods allowed the continued representation and active participation of a range of key stakeholders with organisational and/or domestic time and resource constraints.

In this thesis, I have used an inductive approach which began with detailed observations of the world and moved towards more abstract generalizations and ideas. However, at the beginning of the action research project, the approach was deductive, as the aim and objectives of the original project had been set in advance to meet the requirements of the funding agency, the HACC program. Furthermore, mixed methods had been chosen, with the survey instrument (‘PREPARED’) (Grimmer & Moss, 2001)) and extensive consultation with key stakeholders had been expected. Nevertheless, on closer inspection I found that although I had a topic, the concepts concerning it were vague. As I progressed through the action research cycles of planning, acting and observing, I inductively refined the concepts, developed empirical generalisations and identified preliminary relationships. Neuman (2003) pointed out that many qualitative researchers primarily follow an inductive route, where they begin with empirical data, follow with abstract ideas, relate the ideas and the data, and end with a mixture of ideas and data. In contrast, at the outset of this project, there were deductive aspects to the conduct of the research, which began with abstract, logical relationships among concepts, and aimed to move towards concrete empirical evidence.

As the project and the thesis progressed, it became clear that a tension (or some would say, epistemological conflict) had developed in the research design. This tension was about whether the research would be more deductive and aim to test ideas against hard data; or:
"Was it more important to explore inductively, what changes were needed and which actions could be taken to improve the problem?" (Neuman, 2003, p.51)

Such tensions were more apparent when I was unable to recruit the sample sizes of patients and carers needed for analytical statistics on the survey instruments ‘PREPARED’ (Grimmer & Moss, 2001), ‘Assessment of Quality of Life’ (Hawthorne et al., 2000) and the ‘Caregiver Strain Index’ (Robins, 1979). As only descriptive statistics could be used, the quantitative testing of hypotheses against hard data was not possible. This tension was resolved by making a considered decision about the future direction of the study, specifically focusing on what realistically could be achieved in the time and with the resources available. The decision favoured induction, in which the theoretical aspects of the action research study were explored qualitatively, then discussed in relation to their contribution to theory and policy.

**Triangulation of the Data**

According to Brewer and Hunter (2006), triangulated measurement:

> “…tries to pinpoint the values of a phenomenon more accurately by sighting in on it from different methodological viewpoints.” (Brewer & Hunter, 2006, p.5)

Triangulation can mean combining several qualitative methods or combining qualitative and quantitative methods (Flick, 2006). In this study, the data from the interviews, Focus Group, Nominal Group and minutes of meetings and the surveys were presented as discrete findings in Chapter 7 and Chapter 8. In Chapter 8, the qualitative and quantitative results are linked using triangulation to show the broader aspects of the issues under study and to mutually validate the findings of both approaches (Flick, 2006). Descriptive statistical packages (Epi Data, Microsoft Access and Microsoft Excel) were used to process and analyse the data and enhance the validity of the survey findings. Analysis of the Assessment of Quality of Life (AQoL) used the raw data. The data were not transformed. The various methods played an equal role in the study and were conceived to complement each other and compensate for the weakness and/or blind spot in each single method (Flick, 2006).

In Chapter 8, I used ‘Thematic Analysis’ to analyse the qualitative data. This approach is described in more detail below.

**Thematic Analysis**

Thematic analysis refers to a generalised approach applied to qualitative data, in which ideas important to the description of a phenomenon are identified followed by the analysis (or interpretation)

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40 This problem is discussed in more detail in Chapter 9.
of various aspects of the research topic which are reported (Boyatzis, 1998; Braun & Clarke, 2006; Fereday & Muir-Cochrane, 2006)). As it is relatively theory-free and more exploratory than other qualitative procedures (such as grounded theory or phenomenology), thematic analysis is compatible with constructionist paradigms and is regarded as a flexible and useful research tool (Braun & Clarke, 2006; Schwandt, 2007). This method is credited with potentially providing a rich and detailed, yet complex, account of data. Braun and Clarke (2006) have identified six phases (see Figure 4).

**Figure 4: Braun and Clarke's (2006) six phases of thematic analysis**

<table>
<thead>
<tr>
<th>Phase</th>
<th>Process</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. Becoming familiar with the data</td>
<td>Data is transcribed (if necessary) and read over and over, while initial ideas are written down</td>
</tr>
<tr>
<td>2. Generating initial codes</td>
<td>Interesting features of the text are coded systematically across the entire data set. Data relevant to each code is collated.</td>
</tr>
<tr>
<td>3. Searching for themes</td>
<td>Codes are collated into potential themes; all data relevant to each potential theme is gathered.</td>
</tr>
<tr>
<td>4. Reviewing themes</td>
<td>Themes are checked in relation to the coded extracts (Level 1) and the entire data set (Level 2). A thematic ‘map’ of the data is generated.</td>
</tr>
<tr>
<td>5. Defining and naming themes</td>
<td>Analysis continues until the specifics of each theme are refined and the overall story of the analysis is told, producing clear definitions and names for each theme.</td>
</tr>
<tr>
<td>6. Producing the report</td>
<td>The analysis is finalised to include the selection of vivid, compelling extracts from the data and reference back to the research question and literature. A scholarly report of the analysis is produced.</td>
</tr>
</tbody>
</table>

Source: Adapted from Braun and Clarke (2006, p.87).

Boyatzis (1998) described thematic analysis as a form of pattern recognition within the data, where emerging themes become the categories for analysis. The method of analysis chosen for this study evolved reflexively from the deductive *a priori* codes in the original aim and objectives, into a more data-driven inductive approach. This approach complemented the action research methodology by following the iterative cycles of action research integral to the process of deductive thematic analysis, while at the same time allowing themes to directly emerge from the data using inductive coding. Boyatzis explained that the coding process involves recognizing (or ‘seeing’) the ‘codable moment’ and encoding it (seeing it as something) before the process of interpretation begins. A ‘good code’ is one that encapsulates the qualitative richness of the phenomenon. Encoding the information organizes the data to facilitate the identification of themes. A theme was defined as:
The process involved reading and re-reading the interview transcripts while a highlighter was used to manually identify the key themes or patterns of experience in the transcripts. Then, as patterns were recognised in the data, the theme was added into the particular narrative it represented (using Microsoft Word). Next, specific parts of the text were selected from the interviews for verbatim quotation to underscore the theme. Notes were taken during the interviews and all the interviews were audio-recorded, providing an accessible method for transcribing verbatim accounts from the audio-tapes in order to highlight and authenticate the themes through the voice of the participants. The audio-tapes were checked and the quotations carefully transcribed. The themes that emerged from the participants' stories were pieced together to form a comprehensive picture of their collective account (Aronson, 1994), the coherence of which relied on the rigour that I applied to fitting the ideas together in a meaningful way (Leininger, cited in Aronson, 1994).

Initially, I considered presenting the findings of this study as two inter-linked action research cycles. Having an overlying a simple structure was appealing and would correlate with the conduct of this study and with the literature of action research as a method. However, I decided against this approach as early attempts proved that it did little to ‘tell the story’ as a cogent narrative that unfolded with all the complexity and messiness of reality.

I then found an exemplar in Hart and Bond’s (1995) book, ‘Action Research for Health and Social Care: a guide to practice’, which provides researcher-practitioners with a guide to doing action research and closing the theory-practice gap. Hart and Bond present five case studies, covering large and small-scale projects in health and social care, in which they (and others) were directly involved as researchers and as change agents. Hart and Bond comment that the presentation of these studies provided the opportunity to reflect on their experience in each of the projects, as well as to re-emphasise the importance of paying attention to process and outcome in action research. Their insights struck a chord with my intentions in writing the findings of this thesis and so I proceeded with my reflexive presentation of the action research study.

This study was an empirical inquiry which used qualitative and quantitative methods to investigate a contemporary phenomenon - discontinuity of care of older people and people with disability and their carers - in the real-life context of an acute hospital and community care service providers in Adelaide. The boundaries between the phenomenon under investigation were not clearly evident (where did the discontinuity begin and end and who was responsible?); there were more variables than data points,
meaning there were multiple sources of evidence collected which, upon analysis, were amenable to triangulation. Data collection and analysis benefited from prior theorizing about ‘the problem’, during which I wrestled with the extent to which the problem was concerned either with: the hospital-community care system (systems, complexity and organisational theories); attitudes towards ageing and disability (sociological critiques of medicine and post-modern theory); professional ethics; or the demographic shift towards an ageing population (epidemiological and ethical concerns) and private and public (welfare and policy) dimensions of ‘care’ (Care Theory, vulnerability and Resilience Theory). As such, the findings presented in this study are consistent with an action research approach that is reflexive and pays attention to outcome as well as process.

6.5  CHAPTER SUMMARY
This chapter has described the history, rationale strengths and limitations of using action research as the method to conduct this research, and has described how the research was actually conducted. An overview of the data collection methods and thematic analysis has been provided. This thesis has facilitated a more detailed qualitative analysis from practitioner’s perspectives of continuity of care between hospital and home for HACC clients, and the impact these transitions in care has on their carers. An overview of this study’s research methodology is provided on the following page in Figure 5.
Figure 5: Overview of research methodology from an action research perspective

Identify the nature of the changes needed in the South Australian hospital and HACC systems to avoid poor outcomes and improve the continuity of care of older people and people with disability, as well as their carers.

1) Analyse the factors that lead to discontinuity of care of older people and people with disability and their carers in transition between the hospital and community care systems in the specified region of Adelaide.

2) Plan and implement actions to improve the continuity of care for older people and people with disability, and their carers, living in the specified region of Adelaide.

3) Observe the effect of the actions taken to improve the continuity of care for older people and people with disability, and their carers, living in the specified region of Adelaide.

4) Reflect upon the findings of this study and their wider implications for theory, practice, policy and future research on the continuity of care for older people and people with disability and their carers.

5) Reflect on the utility of action research as a means to analyse and improve the discontinuity of care for older people and people with disability and their carers in transition across the acute and primary care interface.

FIRST ACTION RESEARCH CYCLE

Mixed method approaches included:
- Face to face interviews with domiciliary and community nursing practitioners
- Focus group discussions
- Evaluation surveys

SECOND ACTION RESEARCH CYCLE

- Face To face interviews with hospital nurses
- Telephone surveys with hospital patients and carers
- Nominal Group consultation
- Reference Group consultation
- Recommendations Workshop
- Reflections on action research
PART FOUR: THE ACTION RESEARCH STUDY
CHAPTER 7  PROCESSES OF ACTION RESEARCH ACROSS THE
HOSPITAL/COMMUNITY CARE INTERFACE

7.1  CHAPTER INTRODUCTION
This chapter presents the processes and outcomes involved in the two cycles of the action research study. The background of the study and the participants are described. For each cycle, the plans, changes and observations are presented. Following this, I outline my reflexive engagement during the action research study and provide my critical reflections on the processes and outcomes.

7.2  ORIGINAL AIM OF THE PROJECT
The original aim of the project from the funding submission was:

“To develop, pilot and evaluate collaborative system/s for enhancing existing services around pre-admission and post discharge events...piloted by five key agencies...among the hospital, GPs and CSPs, with a focus upon improving client transition between community and acute care and access to services.” (HACC Regional Collaboration, 2000, p.3)

The main objectives included:

- Establishing ongoing consultation with a Reference Group and consumers throughout the project
- Identifying and evaluating existing pre-admission and discharge planning systems and processes from the perspectives of clients, carers, GPs and CSPs;
- Developing tools to assist GPS, CSPS and the acute sector with communication and work together more effectively, as well as the development of tools to assist clients’ access to services; and
- Evaluating the impact of tools (HACC Regional Collaboration, 2000).

The aim and objectives identified the boundaries of the project: including which agencies/organisations should be involved, the project’s focus and where the project should take place. The types of collaborative processes that should be used in order to achieve the project’s desired outcomes were also outlined in the brief (HACC Regional Collaboration, 2000).

The collaborative partners provided a vital support structure for the research. The major collaborative partners, outlined below, aimed to maximise participation as well as facilitate ownership from a diverse range of agencies and promote transparency and accountability. The research was overseen by the HACC collaboration’s Steering Committee which included representatives from each of the
participating agencies. The Steering Committee assisted by providing a forum to discuss the broader policy and strategic directions emerging from the project.

The Steering Committee met as often as required initially and thereafter once a month for the duration of the project. During the first months of the project, the Steering Committee decided on a more culturally and organisationally inclusive approach to its membership. As a result a decision was made at a Steering Committee meeting to send out ‘Expression(s) of Interest’ for Steering Committee membership from the following agencies:

- Non-government organisations (NGOs)
- Culturally and Linguistically Diverse (CALD) service providers
- Aboriginal and Torres Strait Islander (ATSI) service providers
- Mental Health Services for Older People: Selected by an ‘Expression of Interest’ process by Steering Committee, and
- Options Coordination.

The Steering Committee then selected additional members from the ‘Expression(s) of Interest’ received. The Department of Ageing and Community Care (ACC) was also invited to provide a representative; however this member attended as an invited guest and did not have any voting rights. As the project progressed, the Steering Committee invited additional members as required. Nominations were received from the Steering Committee members for the position of Chair. This position was then reviewed every six months.

The role of the Steering Committee was to:

- Oversee and guide the administration and direction of the research and the work of the Project Officer
- Maximise service provider input and participation
- Ensure the research remained focused on and achieved the objectives of the project
- Receive and monitor monthly reports from the researcher
- Endorse reports
- Actively promote and facilitate communication and collaborative working relationships between the research and other interested agencies, and

41 Options Coordination was the main collaborative program operating in South Australia which provided support services to adults with disability. This program ceased operating in March 2006. It has been replaced by three agencies, which are Disability SA, which provides services and support to children and adults with intellectual disability; Disability SA-Highgate Park, for people with brain injury, physical and neurological injuries or disabilities; and Novita Children’s Services Inc., for children with disability.
- Review recommendations and discuss sustainability options.

A Reference Group was utilised to raise awareness about the research and provide a forum for ongoing consultation and participation of service providers, consumers, carers and other stakeholders. The role of the Reference Group was to maximise participation of community service providers in the specified region of Adelaide and provide a forum for ongoing consultation between consumers and other stakeholders. The Reference Group met as needed and provided ongoing support and expert guidance.

7.3 PARTICIPANTS

In the region under study, a culture of collaboration among Home and Community Care (HACC) service providers had been established for several years and served to capture their participation throughout the project. A range of HACC service providers were involved as Steering Committee, Reference and Nominal Group members; and domiciliary and community nursing practitioners.

Steering Committee members included key stakeholders with a special interest and/or role in pre-admission and discharge planning. The key stakeholders included the hospital, the division of General Practice, domiciliary and community nursing services. On average there were 6 Steering Committee members and occasional invited guests who met for a total of 21 times between June 2002 and September 2004. This average figure does not include my attendance as Project Officer at every meeting.

The Steering Committee was crucial to the action research design and the outcome of the study. However, apart from Steering Committee members who participated in the Recommendations Workshop, attendance at meetings has not been included in the table on the following page showing the ‘Number of Participants’. This decision was made to avoid duplication of Steering Committee members as participants in the total participants.

The Reference Group was formed out of the numerous service providers who were consulted during the development phase of the project, prior to the success of the funding submission. Any person could join, as long as they had an active interest in HACC clients and wanted to contribute to the development and improvement of links between home, hospital and community services. Membership of several consumers was actively sought and obtained. The Nominal Group was conducted as a once-off procedure during the study and included the same HACC service providers that had participated in the third Reference Group meeting held earlier. In addition, nurses from two wards of
the hospital participated, as well as other nursing, medical and allied health personnel from the hospital.

Consequently, within the total number of participants (see Table 2) there was overlap when the same people attended different groups, meetings and consultations. No overlap occurred among hospital patients and their carers or in the interviews with hospital nurses.

Table 2 Number of Participants

Domiciliary, Community Nursing, Hospital, HACC service providers & HACC eligible hospital patients & their carers

<table>
<thead>
<tr>
<th>Interviews</th>
<th>Number of Participants</th>
</tr>
</thead>
<tbody>
<tr>
<td>The domiciliary care service</td>
<td>23</td>
</tr>
<tr>
<td>Community nurses</td>
<td>10</td>
</tr>
<tr>
<td>Domiciliary care Evaluation of Notification of Admission</td>
<td>28</td>
</tr>
<tr>
<td>Focus Group at the domiciliary care service</td>
<td>8</td>
</tr>
<tr>
<td>Hospital Nurses</td>
<td>19</td>
</tr>
<tr>
<td>Patients</td>
<td>16</td>
</tr>
<tr>
<td>Carers</td>
<td>10</td>
</tr>
</tbody>
</table>

Reference Group Consultations (3 meetings)

| Key issues/review info pack                                              | 18                     |
| Pilot patient and carer survey                                           | 11                     |
| Finalise info packs*                                                     | 17                     |

Nominal Group Service Providers                                          14

Recommendations Workshop                                                  14

TOTAL PARTICIPANTS                                                         Total = 188

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42 HACC stands for the Home and Community Care program.
The third Reference Group meeting was held in the morning and had 14 service providers and 3 consumers to finalise the information packs. The same afternoon, after the 3 consumers had departed, the 14 service providers stayed for the Nominal Group meeting.

7.4 TWO INTERLINKED ACTION RESEARCH CYCLES
Figure 6 represents the overarching spiral process of this study, in which there were two action research cycles.

Figure 6: Illustration of the cyclical nature of a typical action research process

The model (see Figure 7) shows the two inter-linked action research cycles that formed the basis of this study. The first and second cycles overlapped and informed each other, as the planning for the second cycle had to start at the beginning of the study in July 2002. Each cycle is divided into quarters, representing the four processes of planning, acting, observing and reflecting. While the sequence of the cycles was more or less chronological, the planning for some actions had to take place well in advance of implementation. On several occasions, this meant that plans which were made in the first cycle did not become actions until the second cycle. For example, a desk mat was developed to provide quickly accessible information on community services for hospital nurses. The information that was put onto the desk mat was partly informed by the interviews with domiciliary and community nursing practitioners, but the desk mat itself also needed to be relevant to the nursing

staff. Consequently, implementing the desk mat had to wait until after the interviews with hospital nurses. This action is discussed in more detail later in this chapter.

**Figure 7:** Model of Two Inter-linked Action Research Cycles identifying the cyclical process of planning, acting, observing and reflecting in this study.
The following Figure 8 and Figure 9 outline the planning, acting and observing steps within the two cycles. My reflections are not outlined here as they are discussed in Chapter 9. Starting in June 2002 with the first cycle, the study continued into a second cycle which was completed in September 2004. The reader’s attention is drawn to the way in which the plans, actions and observations that are listed in each box are identified from one another. The plans, actions and observations fall within a sequence that, while it is linear to make it easier to read, represents the cyclical process of action research presented on the preceding page.

**Figure 8: FIRST CYCLE: Domiciliary and Community Nursing Services, June 2002 to December 2003**

### PLAN
1. Re-defined the problem.
2. Reviewed tools and processes being used elsewhere for similar purposes.
3. Developed interview questionnaire to use with HACC-eligible/hospital patients and carers.
4. Applied for and obtained ethical clearances.
5. Developed interview questions for domiciliary and community nursing practitioners.
6. Planned first Reference Group meeting.
7. Planned second Reference Group Meeting.

### ACT
1. Interviewed domiciliary and community nursing practitioners.
2. Adapted domiciliary/hospital data link.
3. Initiated Discharge Planning Network.
4. Ran a case-study competition.
5. Conducted domiciliary care Focus Group.
6. Conducted first Reference Group Meeting (October 2002). The first task concerned identifying the main issues for older people and people with disability before admission and after discharge from hospital. The second was reviewing a discharge information pack for patients.
7. Conducted second Reference Group Meeting (March 2003). The main task was to seek input into the patients and carers survey.

### OBSERVE
1. Trialled and evaluated domiciliary care/hospital notification system.
2. Observed hospital workshop on discharge planning with domiciliary care case-studies.
7.5 DETAILS OF ACTION RESEARCH PROCESSES IN THE FIRST CYCLE

7.5.1 Background of the project
The funding of this study by the HACC program recognised the concerns about continuity of care between the hospital and community care sectors for the aged and people with disability, as well as the impact such transitions had on their carers. Moreover, hospital admission often led to breaks in the ‘chain of care’, culminating in a revolving door of admission, discharge, followed by readmission. Breaks in care and readmissions jeopardised the possibility that the aged and people with disability could remain living at home. The worst possible outcome of a hospital admission was premature institutionalisation. This sequence of events is represented by Figure 10:
According to the developmental consultations with HACC service providers, a key factor in avoiding hospital readmission, and in some cases, premature institutionalisation, following discharge was the provision of adequate and timely support services from community services. HACC service providers claimed the avoiding premature institutionalisation would also avoid profound change in the life of the person concerned.

Setting the boundaries in a changed context

By the time I commenced the study (in 2002), eighteen months had passed between the development, funding and commencement of the project. Many changes had occurred during this time, including regional boundary changes\textsuperscript{44}, new initiatives\textsuperscript{45} and the amalgamation and re-structuring of the former domiciliary care services into one metropolitan service\textsuperscript{46}. In addition, many of the original service providers who had collaborated to develop the project were no longer involved.

\textsuperscript{44} The major regional boundary changes were a part of the South Australian Generational Health Review implementation and changed the configuration of what was previously the specified region for this study (GHR, 2003, p.60). GHR. (2003, April, 2003). “Better Choices Better Health: Final Report of the South Australian Generational Health Review.” Retrieved 31.1.07, 2006.

\textsuperscript{45} These included the development of hospital substitution and hospital avoidance programs aimed at providing safe alternatives to hospitalisation.

\textsuperscript{46} The new domiciliary care service was created in 2002 by amalgamation of four previously unincorporated units that included Western Domiciliary Care, Eastern Domiciliary Care, Northern Domiciliary Care and Southern Domiciliary Care.
Domiciliary services operate within the community providing support services to people with significantly reduced capacity to remain living in their homes and the community. The service provides access and referrals to other parts of the community and primary care health system, and specialised domiciliary services for clients including expertise in paramedical aid, Occupational Therapy, Physiotherapy, Social Work, Dietetics, Speech Pathology, Podiatry and Medical services. Domiciliary care services include:

- Health promotion/early intervention (including falls prevention)
- Information provision
- Equipment provision
- Home help
- Home modification
- Aged care assessment
- Personal care
- Rehabilitation (in home and centre based)
- Assistance for people with memory loss
- Services responsive to people from culturally and linguistically diverse backgrounds
- Specialist Aboriginal services, and
- Palliative care.

Between March and December 2003 there was an average of 150 hospital patients who were current domiciliary clients admitted per month.

The specified regional office of the domiciliary care service was the auspice of the project. While helpful in managing their large workload of clients, the re-structure of the larger organisation was causing an atmosphere of anxiety and confusion among clinicians and case managers. This was due to the sense of disregard and powerlessness that accompanied a management-controlled change of direction, as well as job insecurity and the possibility of being relocated to another region.

There were those in the organisation who were supportive of this study and others who were cynical and defensive about the potential for improvement. This raised a question about the operation of self-fulfilling prophecy as stated by Wilson (2000): would resistant individuals seek to undermine the research to justify their own negativity towards change? Because it was directed towards creating and implementing actions, it seemed clear that the project called for an action research approach. Nevertheless, in talking about the action research design with the key stakeholders, they mentioned their concerns that there might be ‘too much research and not enough action’.
In contrast with these tensions, there were also high expectations about what the project would deliver. The original submission, developed by the HACC regional collaboration (HACC Regional Collaboration, 2000), stated that the project would provide the following benefits to consumers of HACC services:

- Smoother transition between acute, general practitioner and community services
- Improved access to information about services available upon discharge to facilitate independent living
- A more coordinated and integrated approach to discharge planning
- Reduction in unnecessary hospital readmissions, and
- Reduction in premature institutionalisation.

The first three benefits (listed above) appeared within the reach and scope of the project. But the last two, namely reducing unnecessary hospital readmissions and reducing premature institutionalisation of HACC clients were much more complex tasks.

An initial evaluation of discharge planning and HACC eligible patients’ satisfaction with community services was needed to establish the base-line data of the project. This evaluation would be followed by the development and implementation of actions, as had been described in the original submission. These actions would be followed by measuring their impact on pre-admission and discharge planning outcomes for the HACC eligible patients, as well as the impact on the system. I was informed that no data existed on unnecessary hospital readmissions and premature institutionalisation of the aged and people with disability in the health and HACC systems. A gap had emerged between what was written on paper in the submission and the messiness of the reality.

Discussions about the impact on information sharing brought about by the implementation of the ‘Privacy Legislation’ 47 had just begun in the health and community care sectors. At the same time, there was excitement in some quarters about the potential of computer technology to provide the mechanism to share health information. However, no cross-sector data linkage existed. Having no solid data to measure the effectiveness of the project was a problem in itself, and not one which would be remedied by a small project such as this. Facing these problems and discussing them with the Steering Committee and others validated the rationale of re-defining the project and refining the aim to make it more achievable.

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47 The proper title of this act is the ‘Privacy Act 1988’.
Finding common ground and re-defining the problem

As the project’s boundaries began to shift, submerge, or disappear altogether, I became concerned about what could be retrieved from the original project and what could be achieved within the time allowed and resources provided. Furthermore, in early meetings, there were times when some collaborative partners’ involvement appeared more motivated by their organisations’ aspirations for the project rather than the existing project’s aims and objectives. This led me to detect instances of competing agendas among the collaborative partners.

Clarity was called for, not only in regard to the aim and objectives, but also because of the changed circumstances that now prevailed. Decisions were needed to define what type of project was needed: was it academic or evaluative or exploratory or implementation or action research?

During this early phase, I briefly considered designing the project as a randomised controlled trial (RCT). This idea was abandoned as it would too hard to organise and control with one researcher in a multi-sited context. Further, it would not have been supported by the project’s collaborative partners, who wanted practical outcomes, not hypothesis testing. Nevertheless, a research question was needed in order to design the method and this was explored and finalised in conjunction with the collaborative partners and my university supervisors (discussed below). After providing information to the collaborative partners, they discussed the alternatives and agreed that action research was the most appropriate approach. All were in favour of this approach and the project took another step forward.

During this planning and analysis phase, I found a lot of passion among service providers in the region about the importance of the issues, and some anecdotal stories and divided opinions about ‘who was to blame’ for the problem. However, there was minimal hard information on which to base a project plan. For example, there were service providers who could describe the effect of poor discharge planning on their clients and blamed hospital nursing staff, but were not able to state clearly what the actual problems were. As I approached the problem, I began to understand that it had multiple sources, within the organisations involved, in management and in the government departments that controlled them (Wilson, 2000). During this phase, I obtained access to the original consultation notes. This information helped establish a more explicit ‘problem’. I identified six problem areas, encompassing inadequate preparation and planning for admission and discharge, and a lack of information and boundary issues between the health and community care systems. However, the literature review showed that successful discharge planning was also dependent upon adequate functional assessment before discharge. Without changing the focus of the project, the aim needed to
be clarified and simplified. Inquiries were made and expert guidance was sought from the university, resulting in the finalisation of the aim, which then became:

To improve the continuity of care for HACC eligible clients in the specified region of Adelaide as they move between home, hospital and the community.

The aim led to the following research question:

What types of changes are needed in the hospital and HACC systems to improve the continuity of care for the aged and people with disability as well as their carers before admission and after hospitalisation?

Re-designing the research method
During this period of consideration of the research design and project method, it became clear that more in-depth information was needed. Adequate supervision for this type of research was not available in the field. Consultation had occurred with the Discipline of Public Health at the University of Adelaide during the development of the HACC funding application. When my research proposal was accepted by the University of Adelaide’s Discipline of Public Health the link between the project and the university was further enhanced.

Taking this approach to the project seemed opportune in bringing research to the field of practice and practice to academia. However, I underestimated the difficulty ahead in negotiating this research as an academic activity at a time when the key stakeholders were more concerned with survival and growth in their own organisations and when using action research was uncommon for writing a thesis in my university’s discipline. Was I more concerned to try to take control of a project that already began to feel unmanageable or was I genuinely recognising the need for change that had a solid foundation in ‘the facts’?

Four ethics committee applications then followed, which, on the one hand, had the benefit of developing a more thorough method and on the other hand, consumed time and project resources, a fact which was also discussed by the collaborative partners. Unaccustomed to university requirements, some of the collaborative partners were suspicious of my motives for doing the project as a higher degree and legitimately asked: who (you as the researcher) or what (the project) will benefit most by the project being used for a higher degree?

Applications were prepared and accepted by The University of Adelaide Human Research Ethics Committee, The Queen Elizabeth Hospital Ethics Committee, the Royal District Nursing Service Ethics Committee and the Aboriginal Health Research Ethics Committee. Details of these applications are discussed in Chapter 6.
7.5.2 First Cycle: Planning for action
Initially, I accessed resources and consulted with others in the field about the potential to adapt existing tools and processes developed elsewhere to local circumstances. A summary of this research was presented to the Steering Committee. Early identification and preparation of possible tools and processes was needed, as the opportunity to combine interviews and consultations with reviewing potential tools was a more efficient use of time and resources.

Before commencing data collection, agreement was needed from the Steering Committee about using ‘PREPARED’ (Grimmer & Moss, 2001). Grimmer and Moss devised the acronym PREPARED to refer to the most important elements in the phases of healthcare between hospital and community care. These are represented by the capitalised words, being:

“Prescriptions, Ready to re-enter community, Education, Placement, Assurance of safety, Realistic expectations, Empowerment, Directed to appropriate services.” (Grimmer & Moss, 2001, p.109)

Discussions were held with the Steering Committee on the pros and cons of using this instrument. In its favour, the survey was validated for a local Adelaide population of elderly patients recently discharged from hospital to assess the quality and outcome of discharge planning across the hospital and community care systems. However, its disadvantages were its length (eight pages) and the sample sizes needed to produce statistical significance. Patients were divided into two groups, the aged and people with disability. An essential measure would be the change in the proportion of pre and post measures with the patients (n=97) who were aged or had disability and their carers (n=93) being ‘prepared’ and ‘supported’ in relation to pre-admission and discharge planning. As carers needed to provide informed consent via contact with me, there were concerns about recruitment as there would be fewer contact opportunities with carers compared to patients. Thus, 368 patients needed to be surveyed before and after the implementation of tools to establish the significance of patients being ‘dissatisfied’ or ‘satisfied’. Another issue was the flexibility of data collection, for instance: ‘what were the pros and cons of using this instrument as a telephone interview, or face-to-face interview or as a postal survey?’ Finally, using the survey would be labour intensive and limit the potential of any other practical outcomes of the project. Most importantly, the surveys had to be appropriate to the aim and the research question.

It was originally intended that patients would be identified in hospital, then given the survey by the researcher to complete by themselves after discharge. The surveys would be sent back to the researcher by mail. When Grimmer and Moss (2001) piloted PREPARED, the participants (100
patients and 24 carers) were assisted by a researcher, who visited them in their homes. Once I became more aware of the potential frailty of HACC clients and the high levels of social disadvantage in the specified region of Adelaide, I was concerned that this approach would not yield an adequate response rate. In addition, even though carers were central to the HACC program and the discharge of patients, they had not been included for survey in the original submission.

Furthermore, PREPARED asked questions about preparations for admission to hospital and how prepared and supported the patient felt once s/he had returned home from hospital. It did not include any questions about any potential changes in the patient’s quality of life before admission to hospital and following discharge. Therefore, adaptations of PREPARED were made and are mainly described in Chapter 6. In addition, as I did not have the time or resources to visit patients and carers in their homes, the survey was adapted for use as a telephone interview. The adapted surveys (Appendix 4A ‘Patient Questions’ and Appendix 4B ‘Carer Questions’) were then piloted at the second Reference Group meeting (March 2003) with Reference Group members and a small group of patients and carers to ensure their appropriateness and clarity. They were then amended as recommended by participants.

With the exception of The Aboriginal Health Research Ethics Committee (AHREC) application, all the ethics committee applications had retained the sample sizes of 97 patients and 93 carers. However, the Steering Committee and I were concerned about the difficulty and impact that recruitment and interviews would have on the project as a whole. These concerns were discussed and agreement was reached concerning the difficulty with recruiting 170 patients, an average of three per day. The minimal sample size was decided upon, being 93 patients and 38 carers.

A misunderstanding about which ethics committees had approved and/or could approve the research had occurred when the consultations to develop the HACC funding submission took place. Time was needed to establish and resolve this issue. (For further details on ethics applications refer to Chapter 5: Research Design)

Development of the interview questions that domiciliary and community nursing practitioners were asked was done in consultation with senior personnel from both organisations, who were also members of the Steering Committee. The questions focused on eliciting individual’s perspectives on the key areas of interest of the study. Refer to Appendix 4C for the questions.
Prior to the first Reference Group meeting, the group’s ‘Terms of Reference’ (TOR) and membership were discussed in Steering Committee meetings. It was decided that membership would include the original group of approximately 30 service providers and anyone with an active interest in developing or improving the hospital/home/community linkages. Consequently, additional regional representatives were invited to join. The importance of consumer representation in the group and in the project was also discussed. The potential disparity between paid service providers and unpaid consumers was recognised, with both of these groups being asked to attend monthly meetings at which they were all expected to be equally active and engaged. On balance and considering the commitment, time and effort involved to achieve consumer representation, several people were invited to participate in the Reference Group in a voluntary capacity, with reimbursement of any transport and respite costs. The potential tokenism of only inviting one consumer representative was avoided by having active and participatory collaboration and consultation from several consumers. Furthermore, the Steering Committee decided that the Reference Group would also be needed for consultation and to provide comment about the future recommendations of the project. Once the membership of the Reference Group was established, the first meeting was planned. The aim of the first meeting was to consult members on the key pre-admission and discharge issues that concerned people with disability and older patients. Second, there was a review of the concept and the contents of an information pack designed for patients and carers.

7.5.3 First Cycle: Actions for change and observations
In this cycle, I interviewed domiciliary and community nursing practitioners conducted a focus group with domiciliary clinicians and case managers and consulted with the Reference Group (October 2002 and March 2003). The interviews, focus group and consultations involved both actions and processes. A brief explanation of the process is presented here and with a selection of the findings specific to the action research project.

The planning for and conduct of data linkage between the domiciliary care service and the hospital
A data-linkage system operated between the hospital and the domiciliary care service. From Monday to Friday data on all patients admitted to the hospital in the preceding 24 hours were electronically transferred to the domiciliary care service where the client’s name and date of birth were matched against this service’s existing client database. A list of domiciliary clients was produced and this information was transferred back to the hospital for use by hospital discharge planners.

An oversight in the flow of information between the administration and practitioners at the service, resulted in the list of clients not being circulated to the clinicians and case managers who looked after them. During interviews, domiciliary clinicians and case managers expressed the need to know when
their clients were admitted to and discharged from the hospital. After completion of the domiciliary care service interviews, I worked with the administrative personnel to adapt the current system to allow a print-out of domiciliary clients admitted to the hospital. This information could then be provided to the clinician or case manager concerned, and they would be notified by letter when the system became operational. With their participation, the system would be evaluated after one month of operation for a period of two months (11th April to 11th June inclusive), or until I had collected 100 evaluation forms. The purpose of the evaluation was to find out the importance of the ‘Notification of Admission’ (NOA) information and to understand the impact on clinician and case managers’ ability to provide continuity of care to their clients. The evaluation was voluntary and confidential. No client identifying information was required or revealed and it was a straightforward process to minimise the amount of time spent by clinicians and case managers.

The notification system was also used to let clinicians and case managers know about the numbers of domiciliary clients admitted to the hospital per month. It showed that between the 6th and 31st March 2003 seventy one domiciliary clients were admitted to the hospital.

Between June 4th to July 4th 2003 there were 203 NOA distributed. Responses to the evaluation were less than half (42%). A mismatch of client details on the NOA and the client’s details on the service’s database occurred in 10% of cases. A third of NOA was read and filed in client’s case notes and 13% led to the clinician or case manager telephoning the hospital, with most wanting to know the expected LOS, the reason for admission and the client’s diagnosis.

Following the evaluation, I initiated a meeting with a senior practitioner who told me that notification of every admission of a domiciliary client was not required, as many client admissions were already known to them. Most important was advance warning (48 hours or longer) of their most vulnerable clients’ discharge. The most vulnerable domiciliary clients were those who lived alone, did not have a carer, had difficulty with their ADL and had a disabling condition. This led to the idea of developing a streamlined ‘referral process’ in the form of a flow chart, to be positioned near the telephones on the wards for use by hospital staff. The community nursing service already had a similar referral process. A domiciliary care version would require support by the service’s clinicians and case-managers through consultation and would also need an education strategy with nursing staff prior to implementation.
The conduct of the Focus Group with domiciliary clinicians and case managers

There was consensus among domiciliary clinicians and case managers that the NOA assisted with providing continuity of care. They claimed that the basic information it provided, namely that a client had been admitted to the hospital, 'was better than nothing'.

A 'Discharge Summary' and 'Notification of Discharge' would be desirable and highly beneficial in providing continuity of care. However, concern about patient confidentiality was the biggest obstacle to getting a discharge summary from the hospital. Furthermore, clinicians and case managers were embarrassed when they did not know their client had died in hospital, so notification about a client’s death was needed. If provision of the discharge summary was dependent the existence of having a relationship with, and being known by hospital staff, then clinicians and case managers faced another barrier in that time would be needed to establish relationships. A hospital discharge program had assisted with improving links between the domiciliary care service and the hospital, but more work was needed in this area.

Although the information was scant, the majority (6) of domiciliary clinicians and case managers present rated the NOA as being useful for assisting with their preparations for a client's discharge from hospital. They were able to follow-up clients with a limited range of services. However, they were critical of the additional work that the NOA generated, due to having to spend more time following up clients. This was an issue as no additional resources were provided to assist. The participants acknowledged that the early identification provided by the NOA ‘may prevent a disaster later’.

The NOA benefited clients because their domiciliary clinician or case manager knew about their hospital admission. The majority of participants reported that the NOA provided a greater ‘feeling of confidence in the system’, as clients and carers knew their health care was being coordinated. When the NOA initiated a phone call to carers, they ‘felt reassured’.

The participants discussed what their requirements were when they knew a client had been admitted to hospital. The role and responsibilities of clinicians and case managers at the domiciliary care service varied depending on the client and the client’s diagnosis. Generally, they believed they needed: to be involved in the exchange of information between their service and the hospital about the client’s living situation before admission; to provide consultation and clinical appraisal of domiciliary clients based on their knowledge of the client and the information provided on the NOA; to liaise with the hospital about discharge and to advocate on behalf of their client. However, domiciliary
clinicians and case managers felt the primary responsibility for discharge planning was with the hospital.

The conduct of the Discharge Planning Network
The ‘Discharge Planning Network’ was initiated to bring together Project Officers, managers and others involved in any services or programs or research involved with pre-admission, discharge planning or post-acute care from the health and community care sectors. The Network’s general purpose was to collaborate, raise awareness, and discuss and share information of current work being undertaken in metropolitan Adelaide on pre-admission, discharge planning and post acute care issues. This included the development, implementation and evaluation of services, programs or research. The meetings fostered informal discussions where knowledge, information and approaches were shared through individual presentations and group discussion. Several meetings were held between November 2002 and December 2003. An article was published in the ‘Bulletin’ (May 2003), produced by Aged and Community Services, SA & NT. Although there was strong interest expressed in this network, participant numbers gradually diminished from around 10 to 4 in attendance. With the effort and resources involved in organising these meetings, such low numbers made continuing the Network unsustainable.

The conduct of the case-study competition
Without doubt, the amount of forward planning in preparation for discharging the aged and people with disability varied greatly according to the person’s circumstances. In order to demonstrate this, two case studies were developed to provide a picture of the types of situations that nurses and doctors faced while planning for the discharge of a typical HACC client. These scenarios (provided in the following pages) were developed as an activity with domiciliary clinicians and case managers, a local GP and hospital doctors. In addition, the development and presentation of the case studies encouraged greater engagement between the sectors.

The clinicians and case managers were given guidelines and asked to draw upon their experience to develop a scenario which described a HACC eligible patient who was about to be discharged from hospital. The situation could be simple or complex and the scenarios were judged on their brevity, suitability for use with the doctors, and capacity to encapsulate the situation of the person who did or did not need community support to remain living at home. They were also asked to create questions to stimulate doctors’ thinking in planning the persons discharge. A gift voucher for a book provided from the study’s resources was awarded to the two best entries. The entries were judged by the GP who participated in the problem-based learning exercise with hospital Resident Medical Officers (RMOs) and myself.
These scenarios were then used as a tool in a problem-based learning activity on discharge planning with hospital RMOs. A local GP experienced in running education sessions with the doctors about discharge planning was also involved. Hospital doctors needed more information about community services to assist them in thinking about the person’s return to the community. The case studies were used with RMOs. Domiciliary clinician/case manager(s) were also present to help solve the major issues presented by the scenario. About 15 minutes were put aside for each scenario. The characters and circumstances of Tatiana Gorbachev and Bernice Radcliff were loosely based on real people who were given fictional names. As well as attending to their medical needs, their discharge required liaising with community services and using common sense.
Case Study One

Tatiana Gorbachev is an 83 year old woman who lives at home with her eldest of two daughters, Alexandra. Her first language is Russian, although she speaks English well enough not to need an interpreter. Recently, Mrs Gorbachev was admitted to hospital after developing a chest infection, which her GP was concerned, might develop into pneumonia. She had moderate to severe dementia and a medical history of arteriosclerosis, which led to a heart attack 12 years ago, at which time she was hospitalised and had a heart valve replacement. Her vision was impaired because of cataracts in both eyes; she had non-insulin dependent diabetes; osteoarthritis, particularly in her hands, and a history of urinary tract infections which tended to make her more confused.

Before this hospital admission, Mrs Gorbachev was able to mobilize and bear her own weight. During this admission, she had become distressed when, after many attempts, the medical staff were unable to install an intravenous line. After this event, Mrs Gorbachev had stopped talking to the hospital staff, could not always reliably carry her own weight and required two people to assist with all her transfers. However, when she was discharged from hospital, she wanted to return to her home and to Alexandra, as she was the main person looking after her. Alexandra had Guardianship of her mother and had moved in with her mother eighteen months ago to care for her. Mrs Gorbachev’s youngest daughter, Anastasia, looks after her mother on Sunday and Thursday mornings to give respite to Alexandra. Both daughters were adamant that they wanted to continue to care for their mother at home. They had declined placing their mother into a Nursing Home permanently or for their own respite.

Mrs Gorbachev was a client of domiciliary care and had assistance with showering twice a week. She was on a waiting list for a third shower. A community nurse visited once a fortnight about her incontinence and to check on the development of a potential pressure area at the base of her spine. Her daughters had teamed up to provide comprehensive care for their mother and aimed to move her every 2 hours. Prior to hospitalization, Alexandra was ensuring her mother went for walk twice a day.

While planning for discharge, the doctors and nurses needed to ask the following types of questions: 1. What are the implications of this client’s deterioration in mobility on her daughter (carer)? 2. What support services may her daughter need to continue caring for her mother? 3. What training will her daughter and family require to care for their mother, once she returns home?
Case Study Two
Miss Bernice Radcliff was a 75 year old articulate and somewhat eccentric woman, whose first language was English. She was admitted to hospital after collapsing when her blood sugar levels had become too low (hypoglycaemia). Miss Radcliff was on insulin for her diabetes and had high blood pressure (hypertension). She was single and had never been married or had children. She strongly voiced her wishes to return to her own home as soon as possible, as she had always been independent and had not needed any help from anyone in the past.

On admission to hospital, Miss Radcliff was very unkempt, she had bad body odour and her clothing appeared worn. Her blood sugar levels were very low. It appeared that she wasn't managing her diabetes. She was unsure what tablets, if any at all, she had been taking before this admission. During her visit she spent most of her time in bed, and complained about feeling tired to the various therapist’s who came to see her to assess her functioning. Nursing staff had noted possible cognitive deficits, particularly in the early part of Miss Radcliff’s stay, but no formal test was undertaken because Miss Radcliff had refused to participate. As she came close to being discharged, Miss Radcliff seemed alert and superficially orientated, although at times she was still mildly confused.

While she was in hospital, Miss Radcliff was visited once by her neighbour and an old friend had called a number of times from Tasmania to check on her progress. The friend was planning a visit to Adelaide to be with Miss Radcliff. Both her neighbour and her friend had said that they were keen to support Miss Radcliff when she got out of hospital. Miss Radcliff’s neighbour reported that until she went into hospital, she had not been inside the house for some time, because of a strong odour coming from the house. Since then, the neighbour had obtained access to the house to find what she described as a ‘big mess’, which included animal faeces throughout the house, large piles of unwashed clothing and dishes, and out of date and decaying food in the fridge. Furthermore, there was no electricity. The neighbour added that this was a longstanding life-style choice of Miss Radcliff, but that she couldn’t remember her being without power previously and that the condition of the house was now worse than it had been in previous years.

While planning for discharge, the doctors and nurses needed to ask the following types of questions: 1. If agreeable, what agencies or programs would be able to assist Miss Radcliff to return home safely and prevent further hospitalizations for her medical management and review, medication monitoring and diabetes education, case management, ongoing assistance with cleaning, meals, and assistance with personal care and podiatry? 2. What would need to occur prior to Miss Radcliff being discharged from hospital? 3. If Miss Radcliff either did not want to return home, or the hospital deemed she was not able to return home, what services would need to be engaged and/or processes would need to occur?
When observing the workshop, I noted that the doctors actively engaged in the problem-solving exercise. They commented on learning the importance of thinking more broadly about the options available to patients and the need to expand their knowledge of community services. However, most of them were contracted to the hospital for relatively short periods, were overseas-trained and spoke English as a second language. Because of this, they felt at a constant disadvantage with regard to their local knowledge-base. Although the session was primarily aimed at educating and improving the skills of the doctors, the domiciliary clinician/case manager(s) who assisted gained insight into the constraints operating on the decision-making of doctors and in the hospital system. They understood the dilemmas and difficulties with re-orientating their ‘medical’ view towards an ‘independent-living/community’ perspective.

The conduct of the first Reference Group meeting (October 2002)
At the first Reference Group meeting, the main issues faced by older people and people with disability before admission to hospital and after discharge were identified. These issues were prioritised and strategies for addressing them were developed. A summary of the issues described by the eighteen participants is provided in the Chapter 8 “What is going to happen to me now?”: Thematic and Descriptive Analysis Before, During and After Hospitalisation.

Following this discussion, the participants were keen to move to a process that would lead to tangible outcomes with the potential to ameliorate the situation of their clients. They made a range of suggestions that they believed, would make a difference. These included early intervention, developing good communication skills and empathy, providing information to the key people involved, tackling the equipment issues, and the establishment of a low cost wellness planning agency dedicated to post acute care.

The second task of this meeting was to review an example of the ‘Going Home Pack’ developed and used by Noarlunga Community Hospital. At Noarlunga, the ‘Going Home Pack’ was primarily given to older patients to take home after discharge, allowing them easier access to their medical information and details about support services in the community. Reference Group members responded positively to the idea of developing a similar localised information pack for patients. They made a number of suggestions to improve the content and specificity of the packs. The development of an additional pack for carers was also supported. Importantly, members thought that the information in the packs should empower HACC clients by promoting choice and assisting them to remain home. Although the packs were convenient for service providers, this was not their primary purpose. The information
needed to be carefully targeted at the needs of HACC clients. Details of the suggestions made by Reference Group members are provided in Appendix 5C.

7.6 DETAILS OF ACTION RESEARCH PROCESSES DURING THE SECOND CYCLE

7.6.1 Second Cycle: Planning for action
The planning for the interviews with hospital nurses
Crucial input and support in planning the interviews with hospital nurses was given by a Steering Committee member, who held a senior nursing role at the hospital. This person helped me gain entry into the hospital by organising an office for my use introducing me to key personnel and assisting me in the development of questions for the nurses. We agreed on a list of questions (Appendix 4D) which covered aspects of discharge planning practices, issues, education and administration, knowledge of community services and suggestions for changing the system.

The planning for the Nominal Group with Community Service Providers (CSPs)
Conducting the Nominal Group needed careful planning, as the information and decisions that would result were important to the project as a whole. I needed to ensure that the right questions were asked of a range of CSPs. I also needed to step back from showing any influence over the outcomes, although I would be present during the group meeting and provide material assistance to the consultant. Approval was sought from and given by the Steering Committee to sub-contract the role of group facilitator to an experienced and independent consultant. The consultant suggested that a preparatory visualisation would help the participants to engage with the task more effectively. I provided the consultant with the list of pre-admission and discharge issues developed during the first Reference Group meeting. This document was used by the consultant to develop the visualization (Appendix 1), while I developed the overall questions.

The planning of the third Reference Group meeting
Plans for the third Reference Group meeting began early in October. The Steering Committee agreed that the aim of this meeting was to harness the participation of Reference Group members in the development and finalisation of the information pack for patients and carers to take home when they
left hospital. Prior to the meeting, consultations about the packs had also begun with Commonwealth Carelink Centre (CCC) and the Carers' Association, as both organisations were peak bodies for providing information and the Carers' Association also provided support services to carers. When it was found that none of the consumers involved in the Reference Group could attend the late October date, the meeting was cancelled and rescheduled for December 2003.

7.6.2 Second Cycle: Actions for change and observations
In this cycle, I interviewed hospital ward nurses and surveyed HACC eligible patients and their carers after discharge (from hospital). A third Reference Group meeting (December 2002) was held as well as the Nominal Group and the Recommendation Workshop. While the interviews, surveys, Nominal Group and Recommendation Workshop are actions and briefly presented here as part of the action research process, they also produced findings which are presented in Chapter 8.

The recruitment and conduct of the interviews with hospital nurses
As early as possible in the Second Cycle, I visited the two pilot wards in the hospital and introduced myself to the respective Clinical Nurse Managers (CNM). Although they both expressed support for the project and willingness to be interviewed themselves, I understood that one of the biggest hurdles I would face was successfully engaging the nurses in the project and recruiting them for interview. A plan to engage the nurses was made in consultation with the CNMs. The first step was my formal introduction by the CNM to the day and afternoon shifts of nurses during their in-service period, which was continuing professional education immediately following the handover from the morning to the afternoon shifts. I had made a one-page information flyer about the project, copies of which were circulated to the nurses present, while I gave them a brief talk about the project. The nurses were given the opportunity to ask questions about the interview and the project. They were told that the interviews would be conducted in a confidential manner and take place in a private office elsewhere in the hospital. Each CNM told the nurses that they would lead by being interviewed themselves. The CNM gave me the names of the nurses who were either permanent staff in the ward or had worked there for sufficient time to gain a working knowledge of the practices of the ward. Recruitment of ten nurses in each of the pilot wards was relatively straightforward after this preparatory work with the CNM. Nevertheless, throughout the interviews it was important and strategic that I remained flexible and accommodated the needs of both the nurses and of the wards.

Notes were taken during the interviews and all the interviews were audio-recorded, providing an accessible entrée into analysis and where desired, transcription of verbatim accounts from the audio-tapes to highlight and authenticate key issues in the voice of the nurses. When read in conjunction with the interviews conducted with domiciliary clinicians and case managers and community nurses,
the hospital nurses' narrative provided insight to the ‘other’ side of the community/hospital divide, and therefore a more complete picture of the hospital/community care transitions of the aged and people with disability emerged.

The recruitment of HACC eligible Patients and Carers from hospital
From having interviewed the nursing staff, I was already familiar to them. Their cooperation continued as they assisted me in identifying suitable patients and carers to approach for informed consent. The sampling frame of patients and carers (Figure 11) numerically summarises the sequence of steps that resulted in the final sample size. Recruiting patients commenced at the beginning of June 2003, with four weeks of remission during July, then continuing until the end of December 2003. Forty one recruitment attempts were made in the two pilot wards. On each of these occasions, the handover sheets used by the nursing staff in the two wards were collected. These sheets provided varying levels of detailed information about each patient. For example, in the surgical ward, the patient’s age was not given. I therefore had to get a separate print-out of the sheet which included ages from the ward clerk. Overall, the handover sheets proved invaluable as a starting point, saving the amount of time I needed to spend with the CNM or the most senior nurse on duty. I used these sheets as a preliminary assessment tool to establish which patients and carers (if known by nurses) might be eligible for the study.

Between June and December 2003, out of a total of 916 patients, there were 256 who initially appeared from the handover sheets to be considered HACC and study criteria eligible and 33 carers were identified. I approached the patients and carers and found that 225 patients were not eligible. Informed consent to ring the patient and carer seven days after discharge was provided by 31 patients and 12 carers. None refused at this point. However, at the time of phoning, 15 patients and 2 carers withdrew or were unwilling to proceed with the interview. The hospital did not collect data about people who received a Disability Pension, making ‘disability’ difficult to determine without being too intrusive. I was therefore only able to determine one patient with disability aged 18 years or over, who then did not consent to be interviewed.

The reductionism required in a sampling frame does not allow description of the recruitment process itself and the realities of doing research with the aged or patients with disability in a busy suburban hospital. The much lower numbers of patients and carers interviewed is a limitation of this study, and this and the other issues are discussed in more detail in Chapter 9.
Figure 11: Sampling Frame of Patients and Carers

Patients admitted to 2 wards (1 surgical and 1 medical):

915 patients aged ≥ 65 years, 1 patient known to have a disability ≥ 18 years

256 HACC eligible patients were identified as possible participants

33 Carers of HACC eligible patients were approached to participate*

31 patients gave informed consent
12 carers gave informed consent

All of these patients and carers received a phone call 7 days after discharge.

15 patients and 10 carers were able to do the survey at the time of the 1st phone call.
1 patient did the survey at the time of the 2nd phone call.

15 patients and 2 carers were unable to participate:
- Refused
- Re-admitted to hospital
- Not available
- No longer living at home
- Deceased

225 patients were found not eligible:
- Unable to give informed consent in writing
- Too ill
- Refused
- Cannot be contacted by phone at home
- Interpreter not available
- Hearing impaired
- In receipt of palliative care services
- Documented cognitive impairment or memory deficit
- Unable to give informed consent in writing
- Too ill

Total of 16 patients completed the survey (7 surgical and 9 medical)
Total of 10 carers completed the survey (7 carers of surgical patients and 3 carers of medical patients)

*The low numbers of carers who could be approached is partly due to the logistics of simultaneously working between two wards, coupled with their availability on the ward during the restricted visiting hours of the hospital between working part-time Monday to Friday. No carers were approached after 1630 as by then it was too late to go through the informed consent process with each individual.
The conduct of the third Reference Group meeting (December 2003)
This meeting was organised to achieve two tasks. The first was a consultation with the Reference Group, including carers and consumers, about finalising the content of hospital discharge information packages in readiness for piloting with hospital patients and carers in 2004. The second task was to conduct the Nominal Group.

The Carers' Association and CCC were involved in planning for and conducting the workshop. All the participants were reminded that the main purposes of the packs were to: a) provide a vehicle for the transfer of limited medical information between the hospital and community care sectors; b) identify current community services which supported the needs of the aged and people with disability. Participants knew to avoid providing excessive information, which could overwhelm and confuse recipients. Indeed, although all the service providers wanted their organisation's brochure represented in the pack, they knew this was not possible. Therefore, they needed to exercise discipline in their decisions about what to include and what to leave out of the packs.

Two forms of take home packs were agreed upon, one for patients and another for carers. Each of the fourteen people in attendance was asked to vote on what needed to be on the cover of the pack (which was an opaque PVC plastic sleeve printed with text) and the information cards and brochures which would form the contents of each pack. Everyone agreed, as they had at the first Reference Group meeting, to keep the packs simple, concise and community generated. The pack would have a list of useful contact numbers printed on the back, and contain:

- a modified discharge planning checklist for patients and carers (Grimmer, 2004)
- a list of outpatient appointments
- the National Relay Service49 brochure
- a modified Ethnic Link brochure, and
- the individual's emergency medical information.

The packs for carer’s could be much smaller and would include the CCC brochure and contact information for carer’s which would enable them to be sent a more comprehensive ‘Carer’s Kit’, if required.

The conduct of the Nominal Group
In my opening address to the participants I introduced the consultant and informed them about the process which would occur. I explained that the purpose of the nominal group was to cast a wider net

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49 The National Relay Service is a nation-wide telephone service for people who have are deaf or have a hearing or speech impediment. For more information on this service visit http://www.relayservice.com.au/
over the consultative process, by doing detailed consultations with a wider range of CSPs, other than the key stakeholders of the project (the hospital, the domiciliary care service, the community nursing service and the GPs). Participants were reminded that their involvement was voluntary and confidential. The first step was a ‘silent generation of ideas’, using the visualization (Appendix 1), after which each participant spent five minutes recording their responses to the following two questions:

1. What are the limitations in providing continuity of care for HACC eligible clients when they return home following acute care?
2. What opportunities are there for improving the transition of HACC eligible clients as they move between acute and primary care services?

Responses to the visualization were independently recorded on Post-It notes. Next, there was a ‘round robin recording of ideas’. Here, the Post-It ideas were shared with the other members of the group and developed into a list, which was then used to guide further discussion. After all the ideas listed on a whiteboard, a ‘serial discussion’ of each idea was held, the purpose of which was to clarify the meaning of each item. It was also an opportunity to express the logic behind each idea and its relative importance. Then followed a ‘preliminary independent vote’ by each group member as to the most important ideas on the list. Finally, a ‘listing and agreement on prioritised items’ was undertaken. By the end of the meeting, the participants had mapped the limitations on the provision of continuity of care for HACC eligible clients and opportunities to for its improvement. They had also reached agreement on the priority of each item.

In summary, the main limitations on providing continuity of care to HACC eligible clients when they returned home following hospital were understood as (a) information and the quality of information; and (b) knowledge. The main opportunities for improving the transition of HACC eligible clients as they moved between hospital and community care services were in the areas of developing better communication and data information systems between the hospital and community sectors. Overall, the major themes of the discussions concerned the need for service integration, the importance of developing more effective communication systems, the need to streamline existing community services to reduce the complexity and fragmentation of services and the need to focus on a prevention approach. A copy of the written themes from the Post-It notes and the prioritised votes is in (Appendix 5D).
The development and piloting of the Desk-Mat
The interviews with hospital nurses showed that they had very limited knowledge about the range of community services to which they could refer patients during discharge. Nor did they have any fast and accessible way of finding out which services catered to a particular patient's needs. With this in mind, a ‘desk-mat’ called ‘Hospital to Home Pathways’ was developed. Desk-mats were durable information sheets designed for the nurses’ station desk and for placing near the telephone. The aim of the desk-mats was to provide the nursing and medical staff with up-to-date and easily accessible information about discharging aged patients and patients with disability. More exploration of the idea was approved by the Steering Committee.

An elimination process, based on relevance and simplification of a complex community service system, was used to select the information and determine which services would be represented on the desk-mats. The final product needed to be attractive, clear, comprehensive and durable. A graphic designer was sub-contracted by the project to create the overall design. Originally, the information was conceived of as being presented on a laminated ‘mouse-mat’. However, this idea was abandoned when I found that a computer company had already been approved by the hospital to supply mouse-mats. At that point, the design of the mouse-mats had already been completed. Nevertheless, as there were no desk-mats, an opportunity opened when I conceived of keeping the intention of the action, but changing the delivery method by enlarging it into a desk-mat. Bigger in size, the desk-mat idea was an acceptable compromise and would be more noticeable.

Visits were made to several plastics manufacturing companies to view products and get production quotes. The final design was printed onto A-3 size paper sheets, which were backed by thin card of the same size. These were inserted into a plastic sleeve that had a clear front and an opaque back. The edges of the desk-mats were sealed. The cost per desk mat was $6.00. The Steering Committee approved the production and trial of twenty mats.

The desk-mats described the HACC program and identified HACC patients at risk of complex discharge. They linked potential patient ‘need’ with the name and contact details of the specific CSPs that provided the services. Nine areas of needs and services were displayed. These were:

- language assistance
- follow-up health care
- nursing care
- home care needs
- low-level needs
The desk-mats were placed close to every telephone in the nurses’ stations of the two pilot wards. There was insufficient ‘project’ time for a formal evaluation of the desk-mats. I therefore relied on observing where the mats had been deposited during my visits to the wards. This was inadequate, but I noticed that because they could not be fixed to the desks in the nurses’ station, some of the desk-mats ended up being regarded as unnecessary clutter and put away into cupboards. Once again, I was reminded that the nurses were fully occupied with providing the practicalities of patient-care and did not have time to read the information on the desk-mat. Or, perhaps, it was not part of nursing culture to sit or stand at the nurse’s station reading the desk-mat. It appeared that when the mats were out of sight, the information on them was ‘out of mind’.

An example of the desk-mat is provided on the following page.
NOTE:
This image is included on page 162 of the print copy of the thesis held in the University of Adelaide Library.
The piloting of ‘Your Health Record’ and ‘Carers Info Pack’ for distribution in the hospital
By February 2004, the patient’s pack was close to being finalised. Around this time, the name of these packs was changed from “Take Home Information Pack” to “Your Health Record” (YHR)\(^50\). The reason for the name change was that “Take Home Information Pack” implied they could only be taken home from hospital, rather than taken by their owner during their transitions across the health and community care sectors. This was one of the intentions of the packs. The Reference Group and the Steering Committee agreed to re-name the packs YHR.

Another initiative of the hospital committee representative on the Steering Committee was removing the hospital logo from the cover of YHR. The rationale was that this mobile client group were likely to use multiple services and the packs needed to look like a generic endorsement of hospital and community care services.

An alternative and more economical wallet design, called a ‘glove box wallet’, was chosen by the Steering Committee, as it allowed updating the outside cover without having to reprint the entire wallet. The Steering Committee endorsed the expenditure of project money for the production of 500 glove box wallets.

Similar health wallets were in use at the Lyell McEwin Hospital and the Noarlunga Community Hospital. Both had been evaluated and their continuation was supported from consumers’ perspectives. While the other health wallets had a similar purpose, YHR was unique for having developed original content in the form of ‘Your Health and Community Services Record’ and ‘Your Medicines Card’. Being concerned about project time and resources, the Steering Committee decided against an evaluation of YHR, as it would entail another ethics committee approval and this was viewed negatively. The Steering Committee was prepared to accept the evaluations of the other two hospitals and so pursuing consumers’ perspectives for YHR seemed like unnecessary replication to them. It was decided that this study’s evaluation of YHR would be best achieved through consultation with CSPs, GPs and hospital staff, to find out if they were using the packs and providing them to patients.

During the pilot at the hospital, I hoped to distribute 100 packs to HACC eligible patients and 100 to carers of HACC eligible patients. It soon became clear that I would need to rely on the ward’s nursing staff to distribute the packs, as it would be up to them to carry on giving the packs out after my contract with the study was over. I also needed to be sure that they were willing and able to distribute

\(^{50}\) Coincidentally, New South Wales Health had developed a similar record, called ‘My Health Record’. More information about it could be found by visiting their website: http://www.health.nsw.gov.au/qcp/mhr/.
them. Also, as the end of my contract approached rapidly, I was unable to spend more time at the hospital. Therefore, an alternative evaluation of the distribution of the packs by the nursing staff was needed. Furthermore, I would need to hold in-service meetings with the nurses from both wards to inform them about the packs and encourage them to distribute them to appropriate patients. This is discussed below.

The pilot of the 100 YHRs (for patients) and 100 Carers Info Kits (CIK) commenced in July 2004, after completion of an in-service induction with permanent nursing staff of the participating wards. The first photograph below shows YHR in the centre, surrounded by the custom-made brochures. The second photo shows all the brochures which were included inside YHR. All of the brochures were provided without charge by CCC, with the exception of the ‘Emergency Medical Information Book’ and hospital specific brochures. The CIK was a wallet sized information card and was an existing resource developed by the Carers Association of SA Inc, on how to get a free Carer Support Kit and the CCC brochure. One hundred CIK were provided by the Carers’ Association, at no cost. As it was not specifically developed for this project, no photographs of CIK appear.
The development of an information package about discharge planning for hospital nurses
In an education session with hospital nurses, information packages about discharge planning and guidelines for distribution of YHR and CIK were given. These sessions were held with permanent nursing staff in both wards once YHR and CIK were ready for distribution (June 2004). An information package was given to every nurse present. The contents of the package were developed in response to the interviews with nurses, which had indicated their knowledge limitations and their need to know more about how to achieve effective discharge planning with elderly and/or HACC patients at risk of complex discharge. A range of brochures went into the packages, as well as a summary of who could be offered (or the eligibility criteria for) YHR and CIK and instructions for distribution of the kits.

The nurses were told that patients at risk of complex discharge included: those of advanced age; people who lived alone and/or lacked support networks; people who seemed to lack confidence or were fearful of being discharged; those who had problems managing their personal-care (for example, washing, meal preparation, shopping); and/or people whose medical condition was disabling or was deteriorating. Criteria for undertaking discharge planning for elderly patients (Rosswurm, 1998) were provided to the nurses, as were performance indicators for effective discharge, which included: provision of timely and informative risk screening, commencement of the preparation of the discharge plan, timely notification to community care providers, provision of a timely and informative discharge summary, and follow-up of the discharge plan (HRRU, 2000).

With regard to piloting YHR and CIK in their ward, the nurses were told about the development of these initiatives and their purpose (discussed earlier). Patients receiving YHR would be advised to take the record with them whenever they visited their local GP, specialist, hospital or community service provider. YHR belonged to the patient, who would voluntarily choose to use it. If a patient decided against using YHR, their health care would continue as usual. With the patient's permission, health care providers could access information contained in YHR. Similarly, the purpose of CIK was to involve and inform carers of services available in the community.

The nurses were told who should be offered YHR, namely older people (65 years and over) and people with disability (18 years and over). YHR should be offered as early as possible before a patient's discharge home. Patients and carers who should not be offered YHR or CIK included any patient who was not being discharged home; any patient or carer who refused and any patient receiving palliative care services or the carer of someone receiving palliative care services. CIK could be offered to carers of older people and people with disability prior to discharge home. The nurses
were asked to approach the patient/carer with YHR and/or CIK with the following explanation, a sample of which follows:

“Hello (patient’s name). We have noticed that people with a number of health conditions benefit from using this special folder, called Your Health Record. It has been developed to keep all of your health information in one place. This should make it easier for you, your carer (if applicable) and your health care providers to manage your health care in the best possible way. We are trialling Your Health Record to see how people find it. If you would like to have this folder, it will belong to you. You may have your own copy at no cost (financial). Your health care providers cannot look at it without your permission. If you want, you can choose to keep certain information confidential, because you decide what details are included in Your Health Record. Using Your Health Record is also voluntary, so if you decide not to use it, your health care will continue as usual. If you decide to use Your Health Record, can you please take it with you every time you see your local doctor (GP), specialist, community service provider (for example, community nursing or domiciliary care) and if you need to return to hospital for admission, outpatient’s appointment or the Emergency Department.”

Similarly, when approaching carers, the nurses could say (sample):

“Hello. We have noticed that people who provide care and support (carers) to people with a number of health conditions are often not aware of services in the community that can help them. This kit can put you in touch with services in the community that could help you look after (patient’s name). If you would like a copy of this kit – it is given freely to you.”

If a carer was eligible and wanted CIK, all the nurses needed to do was give him or her a kit. If a patient wanted YHR, they needed to show the patient the brochure ‘While you are in hospital...plan for your return home’ and ask them to take the time to read it. Time permitting, the nurses were asked to start filling-in the ‘Emergency Medical Information Book’ and ‘Your Health and Community Services Record’ (Appendix 5A). Lastly, the nurses were asked to fill out a ‘Your Health Record Provider Feedback Form’ (Appendix 5E) or a ‘Carer’s Info Kit Provider Feedback Form’ (Appendix 5F) for every kit that was given out, to assist with the evaluation of the kits. Finally, I thanked the nurses for their time and attention.

Inside the boxes containing YHR and CIK, I had placed a ‘YHR and CIK Prompt Sheet’ (Appendix 5G) to remind nurses about eligibility criteria and what they needed to do once they had given out YHR or CIK. Evaluation sheets were placed in a sealed box. By regularly visiting both wards, I was able to keep track of the number of YHR and CIK that had been given out. One of the wards had the advantage of having a daily discharge planner, who took responsibility for distributing the kits to any

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51 The Emergency Medical Information Book was developed as a community service project through ambulance associations, the Rotary Club and the Lions Club. More information about the Emergency Medical Information Book can be found at http://www.emib.org.au/index.html
eligible patients and carers. The other ward had problems completing the discharge medication list and distribution of YHR had to be delayed until the problems were resolved, sometimes resulting in the patient not being given YHR at all. I had to negotiate with the hospital’s pharmacy personnel to resolve this problem. None of the packs were distributed on weekends as the link up with pharmacists for the discharge medication list was not available.

YHR and CIK were piloted for 6 weeks in the wards, finishing at the end of August 2004. Over both wards a total of 27 YHR and 7 CIK were given to consenting eligible patients and their carers. When I visited the wards, I had brief conversations with the CNMs and nurses to see how the distribution was progressing. These conversations and the evaluation sheets both confirmed that the problems encountered by the nursing staff in issuing YHR and CIK were mostly due to the patients not fitting the HACC or regional criteria, patients not being discharged home or being too confused to consent or too ill to want it. From the nurses’ perspectives, they became less inclined to participate in the pilot because of the amount of time it took to give out the packs and do the evaluation. They commented that the process: ‘took me away from patient care’. Clearly, targeting patients in hospital to give them YHR proved unsuccessful.

On reporting these findings back to the Steering Committee, we considered other possible points for the distribution of YHR and CIK. A group of alternative and potential key distributors from within the hospital, including medical and surgical nursing liaison, Social Work and Allied Health, and community providers met to discuss finding a more successful mechanism to continue and sustain YHR and CIK. A list of potential sites was developed. Other options were to offer YHR to healthy people already receiving community services before they become unwell and were admitted to hospital and/or to broaden the net of potential recipients to include people with disability and any older people with a chronic condition. Hospital participants at the meeting were keen to review YHR as a method as well as the documentation of the discharge medication profile. In response to this request, I adapted ‘Your Health and Community Services Record’ (Appendix 5A) and developed a generic medication record, called ‘Your Medicines Card’. (Appendix 5B).

The development of a proposal and negotiation of a site for Home and Community Services Hub in the hospital
During the months I spent at the hospital and as my knowledge of my research topic grew, I began to nurture an idea that would benefit hospital patients, visitors and staff, as well as CSPs. I observed the merchandise sold and customer volumes in three shops in the main entrance of the hospital. The smallest shop was run by a group of hospital volunteers. The other two shops belonged to the
hospital’s research foundation. The biggest hospital shop, located outside the main entrance, had a steady stream of customers purchasing the snack foods, stationary, flowers and other gift items.

The little hospital shop inside was seldom occupied and had vending machines for cold drinks and snacks, cards and hand-made teddy bears. From my perspective, this small shop was in an ideal location to hold a range of CSP information, as well as a ‘freecall’ telephone to CCC, who would be responsible for its maintenance. There was enough room for a computer (not networked into the hospital’s system) with the Community Information Strategies Australia Inc. (CISA) database. This facility could be run by a trained volunteer. If the hospital’s research foundation was concerned about losing the income generated from the vending machines, then the machines could remain in situ. The re-vamped shop could be run as a joint venture between hospital’s research foundation, the hospital and its volunteers and CCC. There was great potential to make this shop more CSP, patient and carer focused, while still raising money for research. It would also be a good public relations exercise, while providing a resource to nursing and medical staff. The central location would lend itself to a rotation of CSP specialists to visit and conduct interactive and personalised education with hospital staff and passers-by. The shop also afforded privacy, during the collection of information that one would prefer to do away from the view of others.

I canvassed the idea with several hospital staff members, including the Steering Committee, who all agreed that it was worth pursuing. A hospital research proposal application was submitted to the research foundation’s board. The aims were to:

“...increase access to information about community services and increase the usage of the CCC service by hospital patients, visitors, medical, nursing and allied health staff”

An urgent application was submitted to the research foundation, as there were only eight weeks remaining until the contract for the project finished in July 2004.

In mid-July the proposal was approved by the research foundation to establish the ‘Home and Community Services Hub’ in the shop. Very little time remained to prepare ‘The Hub’, as it came to be called, for opening. In fact, it took months for the in-kind assistance provided by hospital trades-people to paint the shop and make and install appropriate signage. CCC were then able to install the direct link ‘free call’ telephone for use by patients, visitors and hospital staff. They purchased and installed brochure racks and provided 100 each of a range of twenty-five brochures. The design for signs on the outside of The Hub from the official opening in June 2005 are provided below.

52 For more information about this database, visit the website at http://www.cisa.asn.au/cgi-bin/wf.pl
The Hub
For free information on Home and Community Care Services to assist you to stay at home

Freecall 1800 052 222
Located in the Foyer

‘Brought to you by your local Commonwealth Carelink Centre’

Welcome To The Community Information Hub

Proudly supported by Commonwealth Carelink
1800 052 222

This area has been developed to provide you with information about community services in your local area including:

- Accommodation
- Advocacy and Information Services
- Assessment Agencies
- Aboriginal and Multicultural Services
- Community Aged Care Packages
- Carer Support
- Continence Issues
- Council Services
- Dementia
- Disability
- Domiciliary and Nursing Care Equipment
- Home Support
- Mental Health
- Palliative Care
- Respite
- Support Services
- Therapy Services
- Transport
- And others!
The planning of the Recommendations Workshop (RW)
In previous work, I had observed others’ problems and had encountered problems myself with writing clear and achievable recommendations. Once a project is over, in many cases project officers leave and steering committees are disbanded. Others who may have had nothing to do with a project or know little about it are left to ‘do something’ with recommendations. In addition, recommendations may not be ‘owned’ because the personnel who remain to implement them were not involved in their development. Some recommendations are criticised because they are too simple and/or do not define who is responsible for their implementation. By reflecting on these previous experiences and in an effort to avoid similar scenarios with this project, I decided on a participatory approach (also consistent with action research) to involve the Steering Committee in knowing what the data (key findings) were saying and how recommendations could develop out of these findings. Furthermore, as collaboration across sectors had been a vital feature of this study, collaborating on the recommendations seemed the obvious approach to this final activity.

I presented this idea to the Steering Committee at the July 2004 meeting and they agreed on the collaborative workshop approach to review drafted recommendations, which I would prepare in advance of the meeting. We would also discuss the sustainability of the study’s actions at the workshop and invite additional service providers to attend the workshop. Those invited to the workshop needed to be at managerial level and have decision-making capacity for their agency. Advance preparation of invited RW participants was achieved by sending them the agenda and a document which tabled the key findings of the study one week before the workshop. The findings (summarised from the interviews and consultations at the domiciliary care service, the community nursing service, the hospital, the Nominal Group, the Focus Group and the three Reference Groups) detailed: the deficiencies in knowledge and information transfer; the failure to make contact and coordinate or communicate with other service providers (both CSPs unable to contact hospital staff and visa versa); the inflexibility of community service provision; the lack of effective discharge planning and safe, supported community resettlement, coupled with a lack of consultation with patients/clients and involvement of carers; insufficient community services and ensuring patient safety (including transport); the difficulties with accessing equipment when needed and ensuring its appropriate use and installation and an absence of post-acute restorative care available in the community.

I discussed having an independent facilitator for the RW, although at that point, the Steering Committee thought this unnecessary. I later expressed concerns about the ongoing political nature of the study and that this would intensify if I, being so close to the findings and project, facilitated the
RW. My rationale was that other participants may be less inclined to speak out when they disagreed with a recommendation being discussed. I was also concerned about the effect of my influential role as the researcher on the meeting. Listening to these concerns, the Steering Committee agreed to allow an independent facilitator to run the workshop. I was then involved with organising the workshop and pulling together the key findings to give the facilitator before the meeting. Below is an excerpt from the email invitation:

July 15, 2004: Email to Steering Committee members
“Thank you for your swift responses! Please mark out in your diary’s (sic) 11.00 to 2.00 on the 11th August for the Recommendations Workshop. My apologies to those that will not be able to make this time, but I had to put a priority on making sure that the key stakeholders and the funder (HACC) could come. For those fellow collaborators that can’t come, can you ask a proxy to attend on your behalf? I am happy to help brief proxies – if this helps…”

The recommendations developed at the workshop were based on the key findings of the study at that point in time. In order to simplify the key findings and their link with and review of the drafted recommendations, the independent facilitator suggested that we utilise a tool, which listed the ‘issue’ or key finding, who or what was ‘responsible’ and the ‘evidence/sustainability’ for the recommendation. I prepared this document for each of the participants to use while clarifying each key issue during the workshop.

Co-facilitation of the RW
There were fourteen participants in the RW. Engaging the independent facilitator allowed me to keep track of the time spent on each agenda item, observe the participants and engage with the clarification process for each finding. Successful completion of the clarification process for each recommendation was achieved in the time allowed for the workshop.

Drafting of the ‘Final Report’
After the RW, I had five weeks (mid-August to the end of September) remaining to write a draft of the final report, get feedback from the Steering Committee and organise printing. I completed drafting the report and produced a document (King, 2004) that was written for the key stakeholders and the final Steering Committee meeting, held on 8th September 2004. By the 16th September, amendments from Steering Committee members were included. On the 21st September, I emailed copies of the final report to the Steering Committee, in lieu of sending a hard copy when it was published. My contract as Project Officer finished at the end of September.
By April 2004, there were signs of difficulties with HACC program representatives being able to attend Steering Committee meetings. I was disappointed when this extended to the RW. Nevertheless, the project and my contract finished at the end of September. Publication of the report would occur while I temporarily back-filled for HACC regional collaboration\textsuperscript{53} in October.

Meanwhile, I had also commenced a new part-time position in another SA government department. I was unexpectedly called me into an impromptu meeting with a person responsible for administering the HACC program. There were concerns expressed about the implications and level of detail of the report’s recommendations. As a result of further discussions, I was verbally instructed to recall the final report document. In addition, I was asked to replace the existing Recommendations with a simpler set that were provided to me. Once the report was circulated and signed-off by a higher authority, it may or may not be published. This was a regretful situation, and as a conciliatory gesture approval was given for the remaining project funds to be used for printing additional YHR and for setting up The Hub. The former Steering Committee members were informed about these changes. This process did not occur as I expected it to and resulted in the withdrawal and censoring of the report.

7.7 REFLEXIVE ENGAGEMENT AND CRITICAL REFLECTIONS ON PROJECT PROCESSES AND OUTCOMES

7.7.1 Introduction
As explained in Chapter 5, I am using the term reflexivity in the same manner described by Nightingale and Cromby (1999) and Schön (1983) to discuss my self-examination and to make explicit my professional responses to the research at the time of this study. For the sake of creating a cogent narrative, a certain amount of reflexivity is integrated into the preceding sections of this chapter. As the project got underway time for reflexivity was limited by data collection combined with the pressing need for action. However, several examples of reflexivity are provided in the sub-section below ‘Reflexive engagement’.

A related but different activity, critical reflection plays a particular role in the cyclical conduct of action research. Critical reflection is when the researcher thinks back on the projects’ processes and

\textsuperscript{53} HACC funded collaborations operate in Adelaide. The role of the collaborations is to progress the goals and directions of the HACC program with a focus on improved service provision for older people, people with disability and their carers. This is achieved through working in collaboration with both HACC and non-HACC funded service providers to share knowledge and experience, and to reduce service duplication, identify service gaps and improve/reform current practices.
outcomes and explores the strengths and limitations of the study (Holloway, 2005). Under the subheadings ‘Reflections on process’ and ‘Reflections on outcomes’, I reflect critically on the strengths and limitations of the action research project. In Chapter 8, I critically reflect on the strengths and limitations of action research as a method of inquiry.

7.7.2 Reflexive engagement
A thick research context

Early during the first cycle, when the Steering Committee and I were re-setting the boundaries after the context had changed, I faced an internal crisis of confidence as I saw the growing complexity of the tasks ahead and realised that the whole effort could be de-railed because of stakeholders’ agendas. My concerns related to others’ expectations about what the study could achieve. I questioned whether I had the skills and knowledge to manage it successfully. It was around this time that I sought educational support from universities. My personal doubts had to remain concealed as I knew I needed to appear confident in dealing with the Steering Committee and Reference Group to negotiate the necessary changes (Wilson, 2001).

My investigations at the time of this study suggested there were two camps, the hospital sector and the community sector, engaged in a blame-game over common clients moving across the interface. How can two camps that operate so differently function as one system? From my experience as a hospital nurse and having worked as a social worker in community settings, I knew there must be at least two sides to this conflict. Furthermore, my concerns were with the unintended consequences of a fragmented system on HACC clients and their carers. Clearly, domiciliary and community nursing practitioners needed to know when their existing clients were admitted to and discharged from hospital. At the very least, they needed to know when discharge would occur for their most vulnerable clients, who were described as those who lived alone, did not have a carer, had difficulty with their ADL and had a disabling condition. When a HACC client was judged as having been prematurely institutionalised, HACC service providers blamed hospital staff. But what can one do with blame? Surely the way in which the system was designed had contributed to the situation? Yet these were not questions that I could ask as it would potentially alienate me from domiciliary and community nursing practitioners, with whom I needed to maintain open communication channels. I began to understand the contradictions in people’s practice, the politics and loyalties of the research context and the need to exercise diplomacy.

Both domiciliary and community nursing practitioners were unfamiliar with the hospital unless they had worked there in the past and were still known to hospital staff. However, they generally avoided going there. Hospital staff knew very little about CSPs, as CSPs had no presence at the hospital. What did
the hospital nurses think and know about the community sector? Would this conflict improve by the hospital and community sectors becoming more familiar with one-another through better communication channels? How could the project help them clear the air and find common ground? Conflict and blame were barriers to the exchange of information about clients/patients in transition between hospital and home. What kind of system had we created that unwittingly resulted in the premature institutionalisation and readmission of people? The system was fragmented and chaotic and difficult for everyone to negotiate, even those who knew it and worked in it. How could I best work for change and conduct research in the face of such conflict and resistance?

**Lack of data**

Accurate data was not available and most people who received services from the HACC program could not be tracked when they were admitted to hospital. There were many reasons for this, but the main ones given at the time were the incompatible and unlinked data systems, the lack of a common identifier between the hospitals and community care systems (making the trends of this group very difficult to ascertain) and the Privacy Legislation. As a researcher, this was both a barrier and an opportunity for the project. The barrier was establishing a solid factual basis which tracked HACC clients admitted to hospital and what happened to them when they were discharged. Yet if I attempted to establish these facts it would not be consistent with the aim and objectives of the project and would be rejected by the Steering Committee because of its quantitative research focus. The opportunity was to design the project to incorporate a change focus which included the quantitative surveys, as well as studying the system qualitatively through interviews and consultation.

**Ageing populations**

A noticeable change had occurred in the hospital patient population since I nursed in the 1970s. Apart from emergency admissions, younger patients were generally admitted into day-surgery, whereas older patients comprised the majority of overnight or longer-stay admissions. The phenomenon of ageing populations was reflected in the structure of the hospital patient population, although from my observations in many respects the hospital was unprepared and ill-equipped for this demographic change. Why were some patients referred to as ‘bed blockers’? Older people who lived alone and/or were socially isolated were of particular concern when they were hospitalised. I wondered how hospital nurses managed to provide them with adequate care in hospital and with a plan for when they returned to the community.
Who keeps the system going and why do they bother?
While trying to come to grips with this complex but significant problem and the systems that created it, I also realised that a system is nothing without the people in all their diversity who make it work. Apart from financial motivations, if the ‘clunky’ system was so fraught with problems, what motivated these people to go to work every day? Part of the answer is that people were motivated by their relationships with other people. Despite the system, people working in the community sector appeared to be more fulfilled and satisfied with their work than those working in the hospital sector and many among them were passionate about working with older people and people with disability. There was plenty of scope to make a difference at a personal, community and organisational levels and to policy and knowledge. But what changes would be possible in the hospital?

7.7.3 Reflections on process
Overall, this action research project had a range of successes within the cyclical process of planning, acting and observing change. As the researcher within a participatory framework, I have described and interpreted the focus of the study and executed a range of change interventions aimed at improving the problem areas. As much as possible I worked in partnership with the participants, many of whom were involved in one way or another in the change processes. Within the limits of the multi-sited study, aspects of the process were educative and empowering spanning a range of participants across the research setting. The process educated and empowered the following:

- Patients and carers, by developing and distributing Your Health Record (YHR) and the Carer’s Info Kit (CIK) and through providing the information in the Home and Community Care Info-Hub (The Hub);
- The domiciliary care service participants by facilitating access to information on their clients’ admission to hospital;
- Domiciliary, community nursing and other community service providers by giving voice to concerns about their clients in Reference Group and Nominal Group processes and by providing a site in the hospital, i.e. The Hub, to raise the profile of community services within the hospital;
- Commonwealth Carelink Centre (CCC) by facilitating the establishment of The Hub in the hospital, the first of its kind in Australia, based on collaborative-working principles;
- Domiciliary participants and hospital doctors through their engagement in an educative session on discharge planning;
- Hospital nurse participants by the conduct of an education session on complex discharge planning and the definitive community services available, as well as providing them with an information package,
- The research activity of the hospital; in providing additional relevant research, and
Other hospital and community services for which the main findings of this thesis may be generalised and resources seen to be helpful, if not applicable for reproduction to other contexts.

With their small beginnings grounded in research and participation, The Hub and YHR are noteworthy successes. Moreover, the sustained success of The Hub demonstrates the shared interest, responsibility and desire of service providers for change and service integration.

In critically reflecting on the limitations of the project, there were two interlinked issues. Having no final report and recommendations disseminated was linked to there being little evidence of the study’s achievements, as well as its lack of usefulness in guiding the future direction of the work. This act of censoring and withdrawal of the final report from publication and dissemination disempowered the participants and deprived others in the field of any reference or information about the project. It had a ripple effect on the project’s participants, with those closest to the centre of the project being most affected.

When control was asserted over the recommendations I was told they did this because the project had, in their view, gone beyond its original aims and objectives. Potential damage to senior people was controlled and to the department in advance of the report moving higher up the chain of command for signing. Alas, power over the project was achieved by disciplining its findings. It is also possible that a contributing factor in the censoring of the report was the momentum that the project had developed.

This intervention exposed the external nature of the complex and ambiguous relationship between the central and regional offices, and collaboration in projects, each component of which had aspired to meaningful change and development. The following warning of Hart and Bond applied in this situation:

“...action research which is initiated by senior people to promote change at grass roots level is fraught with potential difficulties...(which)...involves a clash of both values and of methodological approach, such that top-down goals and bottom-up initiatives come into conflict, despite what might appear as a convergence of interests around a particular problem...the structure and values of the organisation, the sponsors' value system, and the willingness of sponsors to approach the problem in a spirit of enquiry all influence the possibilities for action research as an appropriate and effective approach for change.” (Hart & Bond, 1995, p.8)

While efforts were made to salvage the situation, the report had already gone beyond anyone’s capacity in the region to control or influence it. The pity was that this study had led to a degree of trust, optimism and empowerment among service providers, who represented their organisations’
commitment of time, energy and resources to work on a shared and difficult problem. It was understandable for some of those involved to feel disenchanted and exasperated about the inputs and outcomes of collaborative efforts.

Under the circumstances, this outcome concerning the report was a professional and personal blow. In hindsight, I was perhaps naive not to have given greater consideration to the political implications of the recommendations, even though they were developed collaboratively. While it would have been difficult to accomplish, I should have insisted on a follow-up workshop attended by the all key stakeholders to review the recommendations and resolve any outstanding problems. At least then the report may have been published and disseminated, the conflict resolved transparently, damage controlled and I would not have been left with an over-riding sense of unfinished business in need of closure. Final celebrations marking the end of the study were also overshadowed by these events.

From my own experience as a reflexive practitioner, I have appreciated the legacy of reports during the developmental phase of project work in order to find out what others did, which approaches worked and which did not work. This is important information which forms part of the history and learning culture within an organisation.

Indeed, this process demonstrated the gulf between policy and practice. Collaboration was a practice value mandatory in funding applications and for practitioners in the field, but this value did not appear to extend to the central office itself. On the contrary, at any point the power and authority of the central office had primacy over collaboration. This carrot and stick approach to funding is of concern to those in the field that have no other choice but to comply with the conditions of the funding body. Furthermore, the central office disclaimed any responsibility for, or association with the project. Such techniques served short-term state-based interests at the cost of devaluing the community-level work (Milbourne, 2009). It is paradoxical that this final act by the central office undermined the foundation upon which the success of the study was laid, namely the commitment and collaboration of the participants in the field.

I found myself wondering why they did what they did. In trying to understand their motives and actions I understood that the recommendations crossed the boundaries of inter-departmental sectoral exclusivity. Such detailed recommendations were not the norm of projects this size and so they were surprised. It would be an inconvenience and potentially troublesome for the government departments to be held to recommendations that directed them to work together more effectively. Furthermore, I
came to understand that the central office, like any unit that operates within a larger bureaucracy, was also affected by the:

“…thick context of organizational possibilities, constraints and contingencies” (Strauss, 1985, p.266)

Public servants work to a range of unwritten rules or conventions, some of which involve protecting or shielding their CEOs and Minister from criticism that develop from inside their own department. Unless they have a strong and trusted relationship with the CEO and Minister, they tend more toward giving a ‘Yes Minister’ answer rather than ‘frank and fearless’ advice.

7.8.4 Reflections on outcomes

In this section I reflect on the actions implemented (or material outcomes) of the action research study. These included the desk mat, distribution of Your Health Record and the Carers’ Information Kit and the establishment of The Hub.

Desk mat
The desk mats had a very low impact as they were not fixed onto the nurses’ station. On numerous visits to the wards where they were implemented, I found the desk mats stowed away in cupboards where they did not provide ready access to referral information that the nurses needed. Once they were out of sight they were literally out of mind. However, there was interest demonstrated from other regions for access to the design template of the desk mats.

Distribution of Your Health Record (YHR) and Carer’s Info Kit (CIK)
Nurses found distributing YHR to patients and CIK to carers too time-consuming, taking them away from delivering patient care, which is their main priority. They reported that patients often refused the information as they were simply keen to get home; were often still unwell, weak and tired and did not have the capacity to take in anything new. Some were suspicious that they would be charged for the packs after they arrived home. Therefore, distribution via CSPs and GPs proved a better option.

In the Steering Committee, we had extensive discussions about how we could ensure the sustainability of YHR. Although the Steering Committee supported the development and piloting of YHR, they were concerned about its sustainability over time once all the project funds had been used. The first batch of five hundred wallets cost $1,420 and it was agreed by the Steering Committee that
they be paid for from the project’s budget. Each YHR cost around $4 if it included the ‘Emergency Medical Information Book’\textsuperscript{54}, or $2 each for 500 wallets without this book.

In the final days of my contract, I worked with the Project officer for the HACC regional collaboration and hospital personnel and other health and community agencies to show them YHR and discuss their capacity to distribute it. As the Carers’ Association was a viable alternative for the distribution of CIK, the HACC regional collaboration would put its efforts into YHR only. A range of possible distribution points for YHR were identified\textsuperscript{55}. Aside from distributing YHR, it was clear that procuring the funds to sustain YHR would continue to be a struggle for the HACC regional collaboration. After the remaining project funds had been used, the HACC regional collaboration secured sponsorship for the production costs of the plastic glove-wallet from ‘Vital Call’, a production and retail company for home alarm systems. Their sponsorship agreement was subject to a small product advertisement on the back of the wallet. Over time, changes to the content of the pack were made, such as the inclusion of a national medications card similar to the YHR purpose-designed ‘Your Medicines Card’, but supplied free of charge.

An evaluation of YHR was done by the HACC regional collaboration in December 2006. GPs who had distributed YHR were sent a brief survey to assess its distribution, how YHR was being used by patients and to gauge future demand. Of the thirty one questionnaires that were sent out, seventeen were returned, yielding a response rate of 54%. Nine were returned by GPs themselves and eight were returned by GP Practice Nurses (HACC Regional Collaboration, 2006).

Less than a third (29%) of patients brought their YHR back to appointments with their GP, while some patients took them when they travelled interstate and to appointments with other allied health services. Half (53%) of the respondents found YHR a useful tool to use with their patients, and just under half (47%) claimed that they would continue to use it. Orders for around five hundred YHR were placed by those respondents who indicated that they would continue to use YHR. The majority (88%) felt that the information was relevant and the average rating for ‘Your Health and Community Services Card’ and ‘Your Medicines Card’ was ‘useful’\textsuperscript{56}. The GPs and Practice Nurses rated Your Medicines Card as being slightly more useful than Your Health and Community Services Card (HACC Regional Collaboration, 2006).

\textsuperscript{54} For more information on the Emergency Medical Information Book visit http://www.emib.org.au/
\textsuperscript{55} Distribution options various units and departments within the hospital, hospital liaison practitioners and the local division of GPs, after surveying GPs to determine their interest. The domiciliary care service was approached, but no one was allocated to attend meetings.
\textsuperscript{56} This rating was calculated on a five point Likert Scale, where ‘1’ indicated ‘not useful’ and ‘5’ indicated ‘very useful’ (HACC Regional Collaboration, 2006).
Without any qualitative information to help interpret the moderate rating (as useful) of Your Health and Community Services Card and Your Medicines Card, I assume that GPs and GP Practice Nurses found the additional effort of filling-out the cards another demand on their time. Their efforts benefited their patients, but did little to fulfil their own professional information needs. In this respect, the ad hoc nature of the cards and lack of systemic approach most likely tempered their response about their overall usefulness.

Although accurate numbers were not available, approximately thre thousand YHR were handed out during from September 2004 to April 2007. These were mostly given out by GPs and the hospital transition care unit. CCC had sent a number of YHR to CSPs who had requested them. In April 2007 there were back-orders for two thousand YHR. The HACC Regional Collaboration was hoping to produce four thousand. However, the biggest problem was securing sponsorship from an appropriate business in the region. The domiciliary care service was not interested in funding YHR as they perceived it as a ‘health-driven’ initiative and not part of their core business. Efforts were being made to get sponsorship from hospital and regional health service authorities.

Sticking to its former view of YHR, the central office would not consider having any role in supporting it. Despite the fact that most YHR were distributed by GPs in the community, the central office still perceived it as a health initiative, rather than something that was specifically designed to benefit HACC clients in their transition between health and community services.

Comparing YHR with ‘My Health Record’ and the ‘Personal Health Record’, attention is drawn to two issues. First, the national and international need and value of hand-held health records (Baker et al., 1999), and second, the difference in resources and capacity between health departments and the community sector. Therefore, while the strength of YHR lies in the content, value and need which are generalisable beyond this project, its sustainability in this setting is understood to be a limitation of this project.

The New South Wales (NSW) Department of Health has committed $1M to reprint and distribute more records. In a telephone conversation (13.07.2009) with an employee engaged with My Health Record from NSW I was told that there had been 99% positive feedback from consumers on the content and there were approximately 60,000 records being distributed every 6 months. An independent evaluation would be available in October 2009.

The Hub

The Hub has survived to this day and continues to fulfil its intended role to raise the profile of community services in the hospital and provide access to information to practitioners, patients and visitors about community services. Between June 2005 and June 2009, the Hub has had over 25,700 brochures taken. CCC continues to play a central role in its success and maintenance, by making regular visits to fill the brochure racks. CCC was pleased with the operation of The Hub and reported that it had led to an increase in telephone calls from older people and people with disability wanting information and/or access to community services, more familiarity with CCC and other community-based services and with hospital staff. Another positive feature of The Hub was the cooperative relationship that grew between CCC, the hospital and the hospital’s research foundation. Furthermore, the development of The Hub was used as a vignette on ‘innovative work with information partners’ in ‘Centre Guidelines for Information Support Services and Carer Respite and Support Services’ (2007). While the location of The Hub is not identified, the vignette is used to suggest a quality approach to providing information on a national scale. (Department of Health and Ageing, 2006).

All of these initiatives demonstrate the importance of having enough time to develop and implement actions in projects of limited duration. No matter how useful actions are, there must be time properly develop, implement and evaluate them, as well as to consider solid mechanisms for sustainability. While The Hub is the most sustainable and successful outcome of the project, too much priority was placed on implementing actions speedily. In this respect, the lack of time and resources to establish sustainable outcomes was a limitation of this project.

7.8 CHAPTER SUMMARY

This chapter has described the iterative process of the two cycles of action research undertaken in this project. Results from the project yielded valuable research insights (presented in Chapter 8) and successful actions. A range of actions, some of which included piloting YHR with patients and facilitating the creation of The Hub in the hospital, was reflexively planned, implemented and evaluated. These actions increased local linkages between the hospital and community service providers, collaboration, communication and access to information about the HACC program.

Critical reflections on the process of the project demonstrated strengths of commitment and motivation for change through participation, the provision of educational opportunities and empowerment. Limitations of the process include the censoring and withdrawal of the final report and the collaboratively developed recommendations. This disempowered the participants and left them without any future directions for change. Reflecting on the YHR outcome, the strength of its value, need and generalisability are recognised. However, this outcome was limited because it could not be
sustained beyond the finite resources of the project. The Hub however, continues as the most sustainable and successful outcome of the project.

The strengths and limitations of YHR and The Hub point to the importance of timing and sustainability in this project. Despite this, the project appeared to have little or no direct effect on avoiding poor outcomes or improving discontinuity of care. Such effects were more complex, and achieving the necessary systems and structural changes to address these problems would have required more time, resources, capacity and leadership to be committed by government departments and their agencies.

In Chapter 8, I extend my analysis of the interviews with domiciliary and community nursing practitioners, hospital nurses, the Reference Group consultation and the surveys with hospital patients and carers. While these data were collected as part of the action research process, on further analysis, they provide a deeper understanding of the complexities and uncertainties of care transitions for older people, people with disability and their carers.
CHAPTER 8: “WHAT IS GOING TO HAPPEN TO ME NOW?” THEMATIC AND DESCRIPTIVE ANALYSIS BEFORE, DURING AND AFTER HOSPITALISATION

CHAPTER INTRODUCTION
This chapter focuses on a thematic analysis of the findings of the many people who so generously gave of their time to help me understand the phenomena I was observing. The analysis includes interviews with domiciliary clinicians and case managers (n=23), community nurses (n=10) and hospital nurses (n=19); the first Reference Group (n=18) meeting and the surveys with hospital patients (n=16) and carers (n=10). Taking place at the end of the second action research cycle, this analysis is conceived as an important addition to the theoretical dimensions of the action research study which could not be achieved during the research.

When reading this chapter, it is important to remember that the interviews with domiciliary, community nursing and hospital practitioners and the Reference Group were thematically analysed and are written as a narrative based on these particular practitioners’ knowledge and observations about the main concerns of older people, people with disability and their carers. Therefore, this narrative represents the service providers’ perspectives. In my view, this narrative is crucial and conveys unique perspectives - the voices from the system, of the system. These voices present another side of the story and are not to be confused with the perspectives of older people, people with disability and their carers.

As a matter of style, selected parts of quotations are used throughout this chapter to underline a particular theme. This means that other parts of the text that do not contribute substantively to this theme have been deliberately omitted and represented as three dots, shown as … Where text has been quoted from the middle of a sentence, no capitalisation is used.

Descriptive statistical analysis of the surveys with hospital patients and carers, presented after the interviews, was found to support the main themes identified in the interviews. This data did not provide the same level of analysis as was possible from the interviews. Furthermore, the questions asked in the interviews compared with those in the surveys were different both in content and in methodology, ruling out the possibility of making comparisons between the two.
8.1 INTERVIEWS WITH DOMICILIARY AND COMMUNITY NURSING PRACTITIONERS

8.1.1 Introduction
In their role as HACC service providers, domiciliary and community nursing practitioners were interviewed on their perceptions of the issues faced by their clients before admission and when leaving hospital. A broad range of practitioner’s quotations are represented in these findings. With the domiciliary practitioners, most of the discussion focused on older people and their carers, as three quarters (n=16) did not work with people with disability, or their work with them was minimal. This limited their capacity to respond to questions about people with disability and their carers. However, as 60% of community nurses worked with people with disability, the questions concerning this group were adequately covered. Using a thematic analysis, a detailed understanding of the issues emerges and provides an in-depth account of what the practitioners observed about the transitions between the hospital and their home of older people, people with disability, and their carers. These accounts yield detailed qualitative data, compared with the more descriptive data gained from the surveys with patients and carers.

8.1.2 Before admission to hospital: dimensions of uncertainty
According to domiciliary and community nursing practitioners, the way in which their clients (older people and people with disability) responded to a hospital admission varied due to the individual characteristics of the person concerned, as well as the circumstances in which they lived. How a HACC client responded:

“[It] depends on the circumstances of that particular person.” (Domiciliary Practitioner)

However, as this domiciliary practitioner pointed out, in an unplanned (or emergency) admission, there would be no time to think things through or to plan, as in an emergency older people:

“...don't have much choice...” (Domiciliary Practitioner)

Emergency admissions were an intense period of upheaval as well as emotional and physical stress for the older person:

“If it is an unplanned admission they can find themselves in a crisis situation...The stress on the older person...” (Domiciliary Practitioner)

However, while planned (or elective) admissions may be less intense and entailed a degree of choice compared to emergency admissions, the preparations can take significantly more time, organisation
and resources. Depending on the circumstances, such preparations may include some or all of the following interlinked aspects of their personal characteristics and health status, familial and social relations, home and community circumstances and service response.

**Individual circumstances and health status**

In the opinion of domiciliary and community nursing practitioners, before an older person was admitted to hospital, there was uncertainty about the impact on everyday activities (activities of daily living – ADL59):

“As you get older and frailer it is more difficult to do those everyday things you take for granted, whether…it’s getting in and out of bed or being able to do your shopping or…all those… [ADL] that you need to do…If they know that they are going into hospital [their concerns]…would be related to those everyday things [needed]…to live home independently. Paying bills… cleaning, cooking, laundry…[and depending on the reason for admission] the setup of the home [afterwards].” (Domiciliary Practitioner)

If older people’s circumstances showed they needed help with ADLs in order to stay living at home and/or had an impairment60, facing planned or unplanned admission to hospital was a particularly anxious time when their life, their health, their home and future became uncertain, or thrown into crisis:

“Afterwards, when they come home are they going to be better or more dependent?...Sometimes they don’t know what is available...In that sense ignorance is not bliss because the ignorance means that they are more concerned about how they are going to cope with everything.” (Domiciliary Practitioner)

“It is often a time of crisis...[this involves] huge anxiety about ‘what is going to happen to me now?’” (Domiciliary Practitioner)

Hospital admission posed three levels of risk for older people from the practitioners’ perspectives. First was not going back to their life at home as they knew it. Second, they worried about being admitted to residential aged care (RAC; nursing home), and the third risk was that the hospital admission threatened their mortality: Each level of risk was reflected in the following comments:

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59 Activities of daily living (ADLs), is a way to describe the functional status of a person. It is a tool useful for assessing, among others, the elderly, the mentally ill and those with chronic diseases. Typically, there are 11 categories of ADLs considered fundamental for self care. These are bathing/showering; bowel and bladder management; dressing; eating; feeding; functional mobility; personal device care, including items like hearing aids, glasses, prosthetics, adaptive equipment, etc; personal hygiene and grooming; sexual activity; sleep/rest and toilet hygiene (Covinsky et al., 2003). Covinsky, K. E., Palmer, R. M., Fortinsky, R. H., Counsell, S. R., Stewart, A. L., Kresevic, D., Burant, C. J. and Landefeld, C. S. (2003). “Loss of Independence in Activities of Daily Living in Older Adults Hospitalized with Medical Illnesses: Increased Vulnerability with Age.” Ibid. 51(4): 451-458.

60 Impairment can be psychological, physiological or anatomical.
“Another thing they think about is ‘I don’t want to leave my home and what if I never come back?’.” (Domiciliary Practitioner)

“They may be fearful that it is the beginning of the end in the manner of a nursing home, if they already had the prior concern that placement is imminent.” (Domiciliary Practitioner)

“Many people are reluctant to admit that they are ill…[and] that there may be something happening that will …put them in a nursing home. They’re very scared of changing the pattern of their life. People prefer to stay home and keep their head in the sand.” (Domiciliary Practitioner)

Concerns about ‘something happening’ during a hospital admission were close to their biggest fear, namely dying in hospital, in the estimation of practitioners:

“They’ve got the issue of mortality, they are going in and they’re not sure if they are going to be coming home again. That’s a big thing….” (Community Nurse)

“They are at a life-stage where many of them feel that they are existing on borrowed time.” (Domiciliary Practitioner)

It seemed to practitioners that older people were concerned or fearful about the effect of illness and hospitalisation on their quality of life and how they would manage afterwards with the physical, emotional and financial impacts. The people with disability were more anxious about the practicalities and assistance needed to arrange and maintain their younger stage of life, which included consent, accommodation, employment and finances:

“Who looks after their life while it is ‘on hold’ and issues around who can give consent and privacy during that cross-over period of childhood/adulthood” (RNDS)

It was thought that they would often put themselves last, and could experience intense feelings of losing their quality of life, which was intrinsically linked to being separated from a partner, carer(s) or family:

“It is almost bereavement being separated from their loved ones.” (Domiciliary Practitioner)

In order to cope, or perhaps as a lifelong habit, practitioners noted that some older people transferred (or repositioned) their concerns about themselves to second place. Their uppermost worries were about their partner or family, as several practitioners expressed:
“They worry about families; they tend to worry about everything but themselves.” (Community Nurse)

Carers and families
Practitioners observed that while there were those people who faced the uncertainties of a hospital admission alone and unsupported, others enlisted the help of carers, family or friends:

“A lot of clients wait until someone can go with them; they want a family member or a care worker to take them.” (Domiciliary Practitioner)

An older person who was also responsible for an aged and impaired partner was concerned about leaving this partner at home while he/she was in hospital. In this situation, practitioners found that many relied on advance preparation, which included placing the cared-for into respite in case the carer’s admission was extended or if they were unable to return home at all:

“In many cases they have responsibility to partners, sometimes those partners have impaired cognition or physical disabilities and this can be very very stressful for the older person entering hospital...they have to make all these decisions prior to accepting an admission...the scenario is multitudinous [including] fear for their loved one, if they don’t come through.” (Domiciliary Practitioner)

The stress of this situation brought into focus the uncertainties of their circumstances and the extent to which an older couple were dependent on one-another to maintain the ‘fine line’ of their life, as relayed in the following practitioner’s comment:

“Quite a lot of the older people...are very reluctant to go to hospital. Many of them are living in situations where they’re balanced, I think, on a very fine line. They may be caring for someone else or they may be in a fairly co-dependent relationship with someone else and many people put their health behind what they see as the ability to continue that relationship. So that’s probably the biggest issue is people who are reluctant to upset the apple cart,...possibly put the other person in the relationship into respite.”(Domiciliary Practitioner)

In a relationship where both people were elderly, the caring role usually alternated between them. Practitioners described how one person in the relationship being left alone at home could distress the partner to the extent of jeopardising a hospital admission for necessary treatment:

“Quite often the carers are elderly themselves...and there is a co-existence between the two [people]...I’ve had experience where one [of them] doesn’t want to go into hospital because of the other one being left alone.” (Domiciliary Practitioner)
Before admission of the (older) cared-for person, carers usually had their own anxieties and questions, which practitioners commented may be unanswered for some time to come:

“They worry about what could happen…[to the patient, who] might not come home, because they are frail and disabled or have dementia and really the situation is not holding up…they fear that the person they care for may end up in a worse state than before, over some problem that they can’t fix in the hospital…it really depends on the situation at home prior to admission.” (Domiciliary Practitioner)

It was reported that carers’ anxieties included the cared-for’s health and day-to-day treatment/management during admission, as well as disruption to their own routine from having to spend a lot of time at the hospital:

“They are wanting them to have the best possible care. Most of the families [I see] there has been a lot of family support… to maintain them at home, so that if they are giving up that caring role they’re often very worried if they are going to get appropriate care.” (Community Nurse)

Between visits to the hospital, practitioners knew that carers also had to find the time and energy to look after themselves and their households:

“At the same time, they are having to keep their own house going…getting their own food, paying bills, shopping (etc) and often spending a long time in at the hospital.” (Domiciliary Practitioner)

Some carers were so busy with the process of going between home and the hospital and trying to find out what support they might need when the person came home, that it appeared to practitioners they put their own stress ‘on hold’:

“There’s a whole emotional side of things that is put on the back-burner because they are busy with the process of getting in and out of the hospital…it certainly is an emotional stress for them.” (Domiciliary Practitioner)

When a person with dementia goes into hospital, practitioners reported that their carer was often involved in all aspects of the patient’s care. This was crucial, as carers needed to provide consent, and assisted with feeding, mobility, security and advocacy:

“[Patients with dementia] aren’t able to make decisions on their own behalf…[The carer is relied upon]…to make decisions and be there for them. They might not be able to eat…[The carer] goes into hospital…and helps [the patient]…eat because [he/she] refuses to open [his/her] mouth for anyone else…[this involves making] plans to have the money to get to the
hospital to feed [him/her], which is extra expenses and putting aside time and added stress… [as well as] the stresses associated with having to play a really strong advocacy role for that person.” (Domiciliary Practitioner)

In some cases, it was observed that there was initial relief about handing over the caring role, which provided an opportunity for respite especially where there were high demands:

“Sometimes it can… be a blessing as they hand over the care to someone else.” (Domiciliary Practitioner)

“They get to have a bit of a rest.” (Community Nurse)

Respite potentially provided an opportunity for carers to reappraise their situation. It was thought by practitioners that, as a result of this reappraisal, carers may come to doubt their ability to manage the care at home following discharge:

“How they are going to manage when and if the person they care for is able to come home? What help they can provide? What services are available to provide the right level of care that they would like to keep them at home?” (Domiciliary Practitioner)

“We…get phone calls from carers asking us what to do. You often find that the person with the health problem doesn’t know what to do, they don’t necessarily have a GP.” (Domiciliary Practitioner)

Reappraising their situation was confronting for carers in this situation, practitioners observed. It was understood as presenting a challenge to their identity, their interdependency with the cared-for and reliance on one another for different needs:

“Whether they are going to come home again and what they are going to do with all the time on their hands……Because their whole life is usually revolving around the person they are caring for and all of a sudden they are not there, they’re lost. It’s more of an emotional problem. A lot of them actually identify themselves as ‘the carer’ rather than being a person in their own right.” (Community Nurse)

“When a [carer’s] sole role is caring, they are at an absolute loss when that person goes into hospital, and that’s quite an emotional thing.” (Domiciliary Practitioner)

“Separation is the big thing…[the carer] may feel that they can’t cope by themselves.” (Domiciliary Practitioner)
According to practitioners, some carers resolved before admission that they could not continue with their caring role any more. So hospitalisation of the cared-for provided a window of opportunity to explore alternative arrangements:

“For the carer, total relief, because they were at their wits end and...they had initiated the admission to hospital [of] the disabled person so that they wouldn’t crack under the strain of the caring and just needed to have a break. So sometimes it needed to be a ‘unplanned admission’ and it is very heart wrenching and very distressing for the carers in that situation because they have to admit that they cannot cope anymore.” (Community Nurse)

However, this could be difficult especially if they had not yet disclosed their intentions to the cared-for, and the latter had expectations that the carer would continue with the care:

“Sometimes…the client might be going into hospital and probably not coping all that well at home but [the carer is] not saying that they are having issues or problems at home. So the client goes into hospital and that can actually be a good time to… discuss alternative care and [the carers] don’t want to say anything because the client themselves wants to go home again.” (Community Nurse)

Practitioners also commented that other carers feared that a decision to admit the cared-for to RAC would occur without the carer’s involvement:

“And there is always fear…they don’t want to be placed if the supports aren’t there at home. That goes both for the person themselves and carers. The majority of carers don’t want to see them placed.” (Domiciliary Practitioner)

Carers, who already showed signs of strain before the hospitalisation, were known to wonder how they would continue the care if and when the cared-for came home from hospital:

“Whether they are going to be able to come home or whether the carer is going to be able to manage them if in fact they do come home...they might be at the end of their limit in being able to manage them at home, so they’re at that point where they are wondering ‘what’s going to happen to them now?’ ” (Community Nurse)

With the many uncertainties surrounding the hospitalisation of older people already described, as well as the extra work involved for carers, it was understood by practitioners that hospital admission was an added burden:

“It is an added burden for those carers even though the person isn’t home and they aren’t caring for them.” (Domiciliary Practitioner)
Home environment and transport

Practitioners commented that leaving their home involved the older person having to prepare and secure their home:

“If they don’t have a carer there are often huge issues around securing the house [and] anxiety about leaving the house empty…” (Domiciliary Practitioner)

They may have one or several pets and pet care during the older person’s absence was another worry for many:

“If they are living on their own they could have pets and little things like that mean a lot to elderly people, [because] a whole lot of their life is based around their home and their pets.” (Community Nurse)

“They may be fearful if they have a dog or a cat that they are really concerned about that they have to leave behind and no-one’s looking after [the animal]” (Domiciliary Practitioner)

According to community nurses, being taken out of their home environment and the disruption to routine was a major concern for people with disability:

“The person with a disability is often better at home, because they are more comfortable, people know them, how they have their meals and stuff like that.” (Community Nurse)

It was understood that people with disability also worried about the additional demands their hospitalisation would have on their ageing parents:

“[They are] getting older and [so] are their parents…[who] spend a lot of time in the hospital” (Community Nurse)

When older people or their carers/partners did not have transport, getting to and from the hospital presented another difficulty. Practitioners noted the concerns about the costs of ambulances and taxis, whereas the high demand on the limited numbers of ‘disabled taxis’ made them less available and reliable:

“Even getting there is an issue. If you’ve got to get a disabled taxi…they are a whole other issue, [and] often they don’t come.” (Community Nurse)

Community nurses described the same transport problems were had by people with disability:
“It’s the apprehension of using the service because you have to have an ambulance or a disabled taxi just to go there.” (Community Nurse)

Similarly, carers needed transport to and from hospital. This issue was usually dealt with by family, community services, neighbours or others outside the hospital, as this domiciliary practitioner pointed out:

“…quite often… (carers) can’t get in to see the person that they are caring for…” (Domiciliary Practitioner)

**Service response**

According to practitioners, if older people knew about the kind of support they would get from community services, they wondered how to get help – particularly if there had been no prior involvement. For those who were already getting help from community services, cancelling the service worried them as they were unsure about whether or not they would get the services back again. When an older person had not used community services before, but knew they existed and could provide them with help, they were unsure about how to access them.

Older people found hospitals intimidating and alienating places, practitioners commented. Everyone was busy. As the hospital churns through each day, prospective patients were likely to wait for long periods before being given a direction or outcome. Noted by practitioners was the combined effect on older people and in people with disability of busyness, anticipation of treatment, the waiting and uncertainty leading to anxiety, which in turn made them fatigued:

“Whether they’ll actually be admitted or be sent home, the amount of waiting time before being seen.” (Domiciliary Practitioner)

“They get the letter saying that they are going in on a certain day...So they change their whole routine to go into hospital that day and a lot of them get a [cancellation] phone call the night before, even on the day so that is quite unsettling for them...very up in the air for people.” (Community Nurse)

“There’s a lot of anxiety about hospital...if something is wrong...before you are even seen...you know that you wait.” (Community Nurse)

Before a planned admission there were many appointments to attend, which involve trips to and from the hospital. Once there, the way in which people were processed was in accordance with hospital protocols, which contributed to the perception that the hospital system had difficulty accommodating or understanding the needs of older people. The culmination of all these factors disempowered older people, as described by this community nurse:
“The system sometimes isn’t user-friendly… the pre-admission things that elderly people have to go through…they have to go there for three or four hours…the hospitals forget…they make so many appointments for people… waiting a long time and then having to come back… It’s a real strain on elderly people…they won’t do everything in one hit, you have to keep going backwards and forwards from the hospital” (Community Nurse)

In this confusing and disempowering environment, older people were known to avoid asking questions about their medical care. Although they wanted to choose their own doctor, they were recognised as accepting that this was unlikely. A lack of information and/or knowledge gave rise to fear, apprehension and concern in anticipation of what might happen, especially if they faced major treatment:

“They often feel really worried about what is going to happen and have difficulty getting good information about what’s going on.” (Domiciliary Practitioner)

“If it is a major procedure, unbelievable stress.” (Domiciliary Practitioner)

Familiar observations from practitioners were the effects of language barriers and rigid procedures surrounding the return of forms. These were notorious for causing angst and difficulty for older people from culturally and linguistically diverse (CALD) backgrounds, and who spoke limited English, or those who had poor eyesight. This meant they often lacked understanding of what would happen to them and when it would happen:

“A lot of the paperwork is sent to people. [A client who]…speaks a little bit of English…[was] sent…about five pre-admission forms to fill in [and return]…He didn’t even know what they were, he couldn’t understand the dates [and] it had on there that you had to ring to confirm. If you don’t ring…they cancel your theatre…[Also] if they’ve got poor sight they can’t read these letters” (Community Nurse)

While they were ready to acknowledge the nurse’s role in providing hospital care, people with disability knew from their previous experience that their care required more time, knowledge and understanding than nurses could usually provide. Nurses were generally not equipped to look after the particular personal care needs of people with disability, such as specialised bed transfers and feeding techniques:

“The nurses and everything is really good in hospital, the worry is that there is not enough time…They just look at them – they don’t know how to move them…change them…feed them – so they often just leave them. It’s more the system than the actual individual people [in the system].” (Community Nurse)
Consequently, to facilitate proper care, people with disability needed their information and practical know-how transferred to the hospital. Practitioners commented:

“If the appropriate information about medications and so forth doesn’t go with them they don’t know and then a lot of the staff are then unaware of…their needs.” (Community Nurse)

Another concern understood by practitioners for people with disability and their carers/families was the potential of the patient developing a pressure-sore, which would then take a long time to heal:

“One of their biggest concerns is a lot of the times when they go into hospital they come home with pressure sores…I [saw] one guy…he had an operation and they kept him on his side so long that it turned into a pressure sore…[then] while they were trying to cure [that] one they created another one [on the opposite side].” (Community Nurse)

“Families’ concerns are things like pressure areas….which a lot of them come out with…The nursing staff aren’t going to be aware of the client’s normal routine, which these clients really need.” (Community Nurse)

Additional concerns mentioned by practitioners about older people before admission were about having to share a room with other patients. They were also concerned about whether or not they would be looked after properly, particularly if they had continence issues or specific dietary requirements, and if they would stay as long as they needed for proper recovery.

During hospitalisation, it was reported that older carers in particular were intimidated by the hospital and staff, as many were busy and unapproachable, or unavailable when needed. While older carers were unlikely to seek the information they needed, hospital staff had a tendency not to consult with carers about the knowledge they had:

“They don’t know the system …They feel that they aren’t given the information that they need to look after [the person], they don’t know who to go to.” (Domiciliary Practitioner)

“The system is just too overwhelming for people to deal with, so unless they have support networks that can help them, the carer and the client [patient] have very similar issues.” (Domiciliary Practitioner)

This led to practitioners being concerned about older people picking-up on and interpreting incomplete or misleading pieces of information:
Lots of people who haven't had much contact with the health system are not very confident about asking and don't know who to ask…Sometimes, things are misheard or they hear part of something [and] get the wrong idea." (Domiciliary Practitioner)

Summary: Before admission to hospital

Before admission to hospital domiciliary and community nursing practitioners revealed a pervading context of uncertainty about the circumstances of individual patients and their uncertain health status, the role of carers, in the home environment and access to transport and the responses from community services and the hospital system. This context of uncertainty and what the future held when an older person or someone with disability was admitted to hospital was most succinctly captured in the thematic observation: ‘It depends on the circumstances of that particular person’.

Uncertainty is:

“…a state of doubt about the future or about what is the right thing to do.” (Sinclair et al., 1987, p. 1582)

While the differences in relation to time, organisation and stress between an emergency and a planned admission of an older person or a person with disability were reported, both experiences raised questions about the outcome of hospitalisation. Uncertainties about the impact of hospitalisation on their level of dependency were commonly identified across both patient groups. Practitioners reported that older people had questions relating to their quality of life and their ability to cope or manage afterwards and people with disability tended to question the effect on their stage of life, their routines, need for familiar surroundings, and the impact on their elderly parents.

In the context of being a carer of an older person or someone with disability before hospitalisation, practitioners commented that the prospect of an admission raised a number of uncertainties which highlighted the complexity and difficulty of the caring role. Where possible, this role alternated between couples who were older. For others who identified themselves as ‘the carer’ because their role was longer term, the burden and strain before the patient’s admission to hospital was more evident. In this case, uncertainties proliferated about their ability to cope with the additional demand on them during the admission and afterwards. As carers were observed to cope with their anxieties over the patient’s health, the treatment and care in hospital resulted in them being seen to put their own feelings and life ‘on hold’. Furthermore, carers were known to be concerned about the disruption to established routines, the amount of time they needed to spend at the hospital and how they managed their household and self-care. Carers role was regarded as being crucial, particularly when
someone had dementia or brain injury. For some carers having time to themselves afforded them respite, but it also provided an opportunity to reappraise their situation and/or their identity. Hospitalisation was often a challenging period for carers, with implications of losing their identity with as carers. Practitioners reported that it also provided the opportunity to find additional support or look at alternatives, such as RAC and respite. Practitioners comments about the impact of hospitalisation on carers were encapsulated in the understanding that it:

“Brings up more issues than it solves.” (Domiciliary Practitioner)

Home was the focus of many people's lives, but this was particularly so for the shelter it provided older people and people with disability, who tended to invest more in the companionship of their pets, spend more time at home and felt secure in the familiarity of their routine and surroundings. Practitioners acknowledged that having to leave their home and pet(s) for hospital treatment threatened a core aspect of the lives of older people and people with disability. Although less emotive by nature, the issue of transport was understood in terms of its important practical value for getting someone to hospital who was likely to have fewer resources and choices than others in the community.

Another cluster of doubts about the future recognised by practitioners involved the kind of responses from community services and the hospital system to carers and the hospitalisation of an older person and a person with disability. Access to community services, the suspension and the resumption of these services was vital, but uncertain. Multiple trips would need to be made to the hospital for a planned admission, causing disruption to home-based routines. At the hospital there were lengthy periods of time spent waiting, causing anxiety and fatigue. Lastly, there was the uncertainty as to whether or not the admission would go ahead ('as planned') or be cancelled. The main focus of the period before admission to hospital was the hospital as a churning system, with its own processes and timetable, unaccommodating and disempowering to the diversity of cultures and needs in the population (people with disability, older people, carers, CALD people, people with visual impairment).

According to practitioners, the circumstances that created the state of uncertainty were multidimensional, inter-linked and subject to change. A small number of these aspects of uncertainty were within the person's control, but many are not. To varying degrees, uncertainty was dependent on chance and was subject to a range of unpredictable factors. These factors included individual circumstances and uncertain health status, the uncertainties of 'the caring role', an uncertain home environment and access to reliable transport, and the uncertain response from both community
services and the hospital system. Refer to Figure 12 on the following page for an illustration of the context of uncertainty that emerged from this part of the interviews with domiciliary and community nursing practitioners. In particular, note the multiple categories that fall within each dimension of individual circumstances and uncertain health status, uncertainties of ‘the caring role’, uncertain home environment and transport, and uncertain community services and hospital system responses.
Figure 12: Dimensions of Uncertainty: “It depends on the circumstances of that particular person”

- **Emergency (E):** No time to think/plan; crisis; stressful
- **Planned (P):** Takes time, organisation & resources; concerns about ADL, home set-up
- **E/P Questions:**
  - Better/more dependent
  - Older People: effect on quality of life; fears/anxiety - decline/RAC/mortality, dependency & ability to cope/manage; respite
  - People with disability: effect on stage of life & ageing parents; need routine/familiarity

- **Community Services:** Access, suspension, resumption
- **Hospital System:**
  - Churning of system & processing of patients = patients’ disempowered, no choice & lacking information
  - Disruption to routine: multiple trips
  - Nurses limited knowledge/time to care adequately, espec. people with disability (e.g. pressure sores)
  - P: Cancelation or admitted
  - Long waiting times: exacerbate anxiety & cause fatigue
  - Unaccommodating to CALD & visually impaired
  - Carers: lacking guidance

- **Burden & strain:** coping
  - Elderly partners: caring role alternates
  - Complex/dependent relationship
  - Anxious about patient's health, treatment & care
  - Disruption to routine-time at hospital, self-care
  - Reappraise identity: loss of caring role
  - Puts self 'on hold'
  - Opportunity to find alternatives-RAC, respite
  - Crucial role of carers: dementia, brain injury

- **Home & routine is the focus of life**
  - Security of empty house
  - Pets-cared for or not
  - Transport: 'even getting there is an issue'

- **Uncertainties of ‘the caring role’**
  - Individual Circumstances & Uncertain Health Status
  - Uncertain Community Services & Hospital System Responses
  - Uncertain Home Environment & Transport

Key: Indicates dimensions of uncertainty are inter-linked
Text-box contains codes for corresponding dimension
8.1.3 When leaving hospital: circumstantial adjustment and adaptation

Anticipation and preparation for leaving hospital and arriving home was the beginning of an adjustment and adaptation phase for older people and people with disability, and their carers, which also depended on their circumstances. Both adjustment and adaptation refer to changes. Adjustment refers to the changes people can make in their behaviour; whereas adaptation concerns the changing of ‘something’ to make it more suitable for a new situation or purpose (Sinclair et al., 1987). For example, the adaptation of houses or community services is done to make them more suitable to the changing needs of a person after hospitalisation. Depending on a person’s adjustment and the adaptation of houses and services, the intensity and experience of this phase varied considerably and included physical, emotional and practical adjustments. In the interviews with community nursing and domiciliary practitioners, the major theme to emerge was circumstantial adjustment and adaptation, with the dimensions of this phase being personal adjustment to changing health status, carer and family adjustment and service adaptation.

Personal adjustment to changing health status

Well-known to practitioners was the variation in the way in which older people adjusted to their changing health status when they left hospital. In part, their adjustment process was understood to depend on whether or not they lived alone or with a carer and/or had family to help them:

“It depends on whether they have partners or not...are alone and socially isolated.” (Community Nurse)

“(It) depends on what they are going home to - or where they are going.” (Domiciliary Practitioner)

In this context, domiciliary and community nursing practitioners commented that older people who lived alone had particularly pressing concerns where there were more ‘unknowns’ compared to the adjustment of those who had carers (including partners) and/or family who could assist them. According to this community nurse, the following questions were typical of those asked by an older person who lived alone before returning home from hospital:

“What am I returning to? What…maintenance has my house had while I’ve been away? Am I returning to cobwebs and mouldy food and a dead dog and a dead cat?...What sort of supports, either medical, nursing or others, are available to me if I am carrying an increased disability?” (Community Nurse)

Generally, older people’s adjustment was be understood to affected by, and depend on, a number of variables, such as their health and living status before admission, the effectiveness of treatment and
their physical response during admission, and their capacity to bounce-back (emotionally and physically) at discharge:

“Depending on how fit they are, some are fairly fit and healthy...[but many others] come home with...problems that they didn’t have when they went in.” (Community Nurse)

“It’s just how they are going to manage when they’re home. They’re often feeling weakness...They’re deconditioned...[and] feeling anxious about that...Often... they are in a lot more pain and it’s very difficult for them to...deal with [the pain].” (Domiciliary Practitioner)

“[Having] just survived at home when they were ‘well’...being sent home sometimes does pose a lot of physical and other challenges...that they may not cope with, which is quite distressing...and...puts them at very high risk of...[falls etc.]...Just not getting their act together and coping as well as what they maybe did prior to a hospital admission.” (Community Nurse)

When they left hospital, it was acknowledged that some older people were unprepared for the physical and emotional challenges ahead of them:

“What to expect, in terms of their function: ‘How soon they are able to resume certain activities?’ That’s particularly important for people who have had a hip replacement...a lot of people in hospital are very very emotional when they are discharged.” (Domiciliary Practitioner)

“[Some] think ‘Yes, I can [manage] at home’, but at home suddenly you have steps... it all doesn’t go as straightforward...they might actually need more care [at] home...[than] in the hospital environment, where everything is set up.” (Domiciliary Practitioner)

Not knowing what to expect when they got home and having to adjust while still recovering from the admission was thought to engulf them in emotions:

“They’re just glazed-over with all of this...it can just be overwhelming [for them].” (Community Nurse)

Conflicting emotions were noted, such as perhaps at first denying their need for assistance, then wanting to know who would look after them, then having to adjust to ‘strangers’ entering their home to provide care, and all the while, not wanting to be a burden or reliant on others for help:

“To maintain their independence and if they don’t have it and they have insight enough to realise [this], Then [they] have to acknowledge it and to ask for support and to accept it...This is an issue for that generation as they don’t want to feel to be a burden.” (Domiciliary Practitioner)
Practitioners recognised that others were so desperate to get home that they minimised the challenges and fabricated their ability to manage:

“Often, they desperately want to get home, but...there would be some angst about how they would cope, although some people will try and minimise the difficulties [to get home sooner]. On occasion...people will lie if they think it will get them out of hospital and home.” (Domiciliary Practitioner)

In comparison with older people, people with disability differed in their approach to adjustment, according to community nurses. While leaving hospital was strongly associated with regaining their independence, this was understood as the adjustment they needed to make to re-connect with their life before they went into hospital:

“Maintaining their independence; ‘Are they able to continue to do the things that they can do, or are they more disabled?’” (Community Nurse)

“Anxieties about reconnecting with whatever their pre-hospital life was, whether that was social circles, employment circles, schooling circles.” (Community Nurse)

However, being younger in age, people with disability generally seemed to be more adjustable after hospitalisation as they were already known to service providers, as observed by this domiciliary practitioner:

“[For people with disability] it’s not as stressful...as it’s almost a relief and their needs are more understood at home...so they settle in quite quickly...[and their] routine settles back into place...because they’re younger, even though they’re disabled, the effects of pain and weakness don’t seem to have such a de-conditioning effect on them So they don’t have to build-up...as slowly as older people [do].” (Domiciliary Practitioner)

From the emotional side, it was understood that some people with disability had ‘insight’ and were more accepting of their disability:

“It depends on the severity of their disability...some of them [have] some insight...” (Community Nurse)

Others had trouble accepting their situation, according to practitioners. This could impact on their attitude towards leaving hospital and receiving assistance for personal care:

“Their needs are very similar [to older people]...[but]...it’s often possibly harder for younger people, because...they feel that they shouldn’t be at that point, even if it can’t be helped. It must be frustrating to think ‘Why me?’...When you’re older, perhaps...you’d be a bit more
accepting of it…[They] feel funny about accepting help, especially in terms of personal care, because of [their] age…even if [they] needed it, but I imagine that would be a battle within yourself.” (Domiciliary Practitioner)

A part of the adjustment process for some people with disability was the expression of pent-up grief and anger, which practitioners found could be directed at carers once they had returned home to a ‘safe’ environment:

“[If] they’ve been placed into an environment that they didn’t like…there’s a lot of…grief and anger…towards the carer in particular, [as] everybody is trying to settle back into…their normal routines.” (Community Nurse)

Illness may have left an older person with having to adjust to temporary or permanent treatment intervention or disability, which required learning new skills. This was known to be hard for an older person undergoing stress, as was the loss of dignity and the threat of dependency:

“They can be feeling a whole myriad of emotions about having to accept care…dignity losses…how they’re going to cope independently and sometimes fear [like having to clean a tracheotomy themselves for the first time] because it’s not something they can come to terms with.” (Community Nurse)

Older people who had suffered a stroke had particular difficulty adjusting to their changed circumstances, their disability and to learning new skills. These changes presented a challenge to their confidence, communication and willingness to re-engage socially, as this domiciliary practitioner explained:

“There’s life has changed…They may have disabilities and find it difficult…with certain instructions…After…hospital their lives are just focused on the everyday things for survival…They don’t really have much recreation…They’re a lot more restricted…without a lot of real enjoyment. Sometime…they’ve lost confidence and they may not feel as comfortable going out…[Their]…life is really just involved in showering and breakfasting [etc]…[Some] are embarrassed…[about] swallowing problems. Perhaps they might take a very long time to eat because…they might choke and cough a lot and the same with their communication. They often lose confidence.” (Domiciliary Practitioner)

Financial losses and strain were frequently mentioned by community nursing and domiciliary practitioners as being another issue that affected older people when discharged:

61 A ‘stroke’ is a cerebrovascular accident. A stroke happens when the blood supply to the brain is disturbed in some way, starving the brain cells of oxygen. This causes some cells to die and leaves other cells damaged. Stroke can lead to a range of symptoms, including weakness down one side of the body and/or face, speech and swallowing difficulties, confusion (etc.) (McMurdo, 2008). McMurdo, M. (2008, 17.01.08). “Stroke (cerebrovascular accident).” Retrieved 29th August, 2009, from http://www.netdoctor.co.uk/diseases/facts/stroke.htm.
“It’s the financial side, if they’re getting all the equipment and [other expenses] it’s a huge stress…” (Community Nurse)

“Apart from the obvious issues, of getting their meals [etc]…. they need more resources, as they need more medication, more heating or cooling, [etc]…. “ (Domiciliary Practitioner)

Carer and family adjustment
Depending on the circumstances and health of the older person discharged from hospital, around the time of discharge carers were seen to begin to understand that their life was also about to change:

“There life isn’t really quite the same as it was before…(There is) huge change and needing to adapt.” (Domiciliary Practitioner)

It was observed that they began a process of adjustment by asking themselves the following types of questions:

“Is this going to be the same as what they were before they came in to hospital or is it going to be changed? Is this person going to be more dependent or not and how am I going to cope with that extra dependency?” (Domiciliary Practitioner)

“Will I get any help? Who do I contact if things go wrong? (and) Will it all fall back on me?” (Community Nurse)

“And, um, if it gets too much ‘Who can I contact - to scream help!’” (Domiciliary Practitioner)

After hospitalisation, changes in the older person directly affected carers and had implications for their ability to adjust. Adjustment was known to vary according to the age, health and ADL needs of the carer and cared-for, as well as their access to adequate and timely support:

“(HACC) clients are very elderly (and many are)… very very frail…so when a client who is very very frail and complex goes home to the carer, they might be a little bit better but they’re quite often not all that well and so the carers got to deal with that… it’s a whole new scenario, new medication, um, perhaps change in transferring, perhaps it’s a change in what’s needed in the home…” (Domiciliary Practitioner)

“Sometimes what they go in with, they come out in a slightly different way [e.g. changes in mobility from having had a stroke]…[These physical changes] take some adjustment from the carer’s point of view.” (Community Nurse)

“[Going home raises] really big issues for the carer…People go home and…can’t get in and out of bed, can’t get in and out of the chair, um, and has no wheel chair or no equipment to deal with that…so the carer has been besides themselves, not knowing what to do.” (Domiciliary Practitioner)
“Quite often they’re not [as mobile] and [carers] can do damage to their back or all sorts of things like that…especially if they come home…with incontinence. It’s quite a shock sometimes when all of a sudden, this person who’s been continent prior to going into hospital is wetting the bed…” (Community Nurse)

Community nursing and domiciliary practitioners agreed that carers were often left without any clear idea of changes to medications and directions for taking them:

“Medications is a big one…(often) people are confused about it, their medications have changed when they were in hospital, their old medications have been taken away.” (Domiciliary Practitioner)

Such changes were viewed as being emotionally distressing and led carers to question their ability to cope with this ‘whole new scenario’:

“They’re often a bit fearful, anxious I suppose about how…the person they are looking after has changed…which may make it more difficult for the carer to provide the care that is required.” (Domiciliary Practitioner)

“To see that person in that state or having deteriorated…it can be quite distressing…no matter how many support services you have.” (Community Nurse)

“Ah, that questioning of their ability to manage…Often that’s a big issue which is raised, um, yeah after the horse has already bolted, so to speak, when they’re already home!” (Domiciliary Practitioner)

In some situations, discharge from hospital may have been forced upon the carer either by the cared-for themselves, the hospital or by other family members. The strain on carers when caring for someone with dementia or a cognitive impairment after hospitalisation was acknowledged in the following comments made by domiciliary practitioners, which reflected how carers’ ability to cope can be compromised by the assumptions and expectations of significant others and by hospital demand:

“Often…the discharge…might have been a self-discharge [which was] already a compromise…[or] put on [by] the hospital…or through the family to get that person home…[Carers could be] feeling guilty to have to continue with ongoing care although they might not really cope that well but don’t want to speak up…Ongoing depression because certain things might not have been picked up and they see this ongoing mountain of work and commitment coming back…Caring is a long-term issue…for a family member with dementia. Yes, the caring part is very hard, it’s very hard.” (Domiciliary Practitioner)

“People with a cognitive impairment can be very difficult to manage behaviourally and carers can be loathe to openly identify their difficulties.” (Domiciliary Practitioner)
Carers may need to learn a number of new skills, such as changing dressings, managing transfers or toileting. This was known to challenge otherwise self-reliant carers who were aged and faced a stressful situation where they needed professional supervision and reassurance:

“Elderly people often have an elderly carer…it can often be a very very stressful time…(when, for example) the wife’s been shown how to do an enteral feed\(^\text{62}\) and it’s OK in that controlled condition where you’ve got a nurse down the corridor. But we’ve often been there (in the hospital) when they’ve set the pump up that night, because they are just so stressed about ‘I just want someone there when I do it this time’. Because even though they’ve got someone at the end of the phone it’s still different to having someone at the end of the corridor.” (Community Nurse)

“[When elderly carers have to learn new skills they] don’t always retain all the knowledge…They may be confused [or ill themselves and] wanting to minimise stress, not wanting to be a burden on anybody else….A lot of elderly people don’t want to seem reliant.” (Community Nurse)

According to domiciliary and community nursing practitioners, some carers managed by creating a hospital-like routine at home, as for example, when the cared-for had had a stroke and needed peg-feeding:

“Because hospital has this real routine, they feel as if they have to have a definite routine and the carers… [Everything] becomes a real routine.” (Domiciliary Practitioner)

Other carers were understood to manage by setting achievable goals for themselves:

“They have to make little goals themselves…Small things become quite an achievement.” (Domiciliary Practitioner)

It was well-known by practitioners that the initial period after discharge was generally the most physically and emotionally demanding period of dependency on carers:

“The person who’s come home…[is]…often still recuperating. It’s…more work, um, being vigilant, um, having to have more hands-on, maybe helping in and out of bed, maybe helping to the toilet, in and out of the chair, having to be there more because the client needs more input for a while until they sort of settle back into the level…that they were, or even improve. Some will improve too, but there’s a period where everyone is just a bit more, um, anxious and more stressed because they are having to put more work in and they’re already usually stressed as it is.”(Domiciliary Practitioner)

\(^{62}\) Enteral feeding, or tube feeding, is used for people who have a functioning gastrointestinal tract, but are unable to orally ingest adequate nutrients to meet their metabolic needs.
Assumptions were made about carers’ ability to cope when many felt their capacity was already stretched to the limit. Moreover, some older people needed an extended period of care, which in turn prolonged the burden on carers:

“[For carers who are elderly themselves] There’s the extra burden, of um, caring. ‘Cause most people having been discharged do convalesce for a significant period of time once they leave hospital and they may not ever return to their previous sort of abilities and stuff like that, depending on what they were admitted for, obviously.” (Community Nurse)

Questioning their ability to cope with the caring and with the new scenario, and possibly in need of respite (for themselves or for the cared-for), carers would ask community nurses if the patient returning home could instead be sent elsewhere to recover.

“A lot of people…ask me if they can be sent somewhere...[for respite]...because they don’t feel that they can cope at home...[They are] acknowledging that they perhaps need more services that aren’t there yet.” (Community Nurse)

However, it was understood that carers and families both questioned and assessed their ability to cope after discharge. Whether the caring was done by a partner or the family, it required a high level of commitment. For families, this meant balancing the care with their other responsibilities:

“Family support is very important and...families have got their own agendas, their own families, their own lives and to put in the time necessary to keep someone at home it’s a lot of commitment.” (Community Nurse)

Older carers needed support from elsewhere, such as community services, or because of the increased burden on them they may have had to face the tougher reality and their worst fear - of seeking institutionalised care:

“They suddenly have to look after them much more...There’s that increase in caring and support. They may not be able to, due to their own medical limitations or conditions or whatever...to care for them like they want to....So, um...sometimes...carers may have to face ‘Will they ever be able to cope looking after this person?’ ‘Is this the end now?’...They will have to accept a whole bunch of support services maybe, or they may have to face the reality of placing their partners into a nursing home or hostel or whatever.” (Community Nurse)

There were a number of similarities between carers of people with disability and of older people after discharge. These included the stress and strain of the added workload, not knowing the discharge date or if treatment would be comprehensive, and the additional expenses and the amount of time needed at the hospital. However, there were some identifiable differences vis-à-vis hospital admission
between carers of older people, many of whom were also ageing, and carers of people with disability. Having more knowledge, confidence and the ability to solve problems were identified by practitioners as key differences:

“Carers of...disabled people tend to have a bit more knowledge [than older people] and if they don’t have the knowledge then they tend to be able to problem solve...especially in speaking with the GP or other specialists involved, they seem to have a bit more confidence. Whereas...there is a bit more tentativeness from the older carer as far as liaising with doctors and asking for an answer which they can understand in everyday language.” (Domiciliary Practitioner)

Of the domiciliary practitioners who worked with people with disability (n=7), there was the perception that for carers discharge was less stressful than admission, as it allowed the carer and the person being cared for to re-establish their daily routine. Whereas community nurses commented that some carers adjusted well and had their needs as carers met, other carers, particularly those with their own health issues, had more difficulty. Carers needed to be physically and mentally healthy to cope with the extra burden of care put on them by hospitalisation. Carers and families needed support, time and effort to identify what they needed. It took around 2 weeks for carers to get over the hospitalisation of the cared-for and some felt disappointed by the lack of positive outcomes afterwards, while for others it was a repetitive cycle:

“Here we go again, how long will it last this time?” (Community Nurse)

For paid carers, some issues identified were ensuring they were instructed about any changes to medication and that the cared-for was sent home with the correct medication and with a repeat medication authority from the doctor. Paid carers cannot do everything and they also needed more support.

In reference to older people leaving hospital and the response of the health system, a domiciliary practitioner made the following observation:

“In general, I often feel we treat clients [as a] liability to society and at least to the health system and they’re not being seen as an asset.” (Domiciliary Practitioner)

Service adaptation
Hospital obstacles
The following example demonstrates a variation of the ‘liability’ attitude sometimes shown by hospital staff towards older people. On this occasion it is manifested as disregard for the safety of an older person who lived alone:

“Someone who came home very recently...had to stay in the Emergency Department for quite a long time [and]...lived alone [and was] sent home in a taxi...She had her arm in a sling and a damaged shoulder and couldn’t reach up and even open her door...There was nobody at the hospital who thought to ring and say ‘Can we have somebody at the other end to meet you or to help you when you get home?’...That is unfortunate because it’s not an isolated incident.” (Community Nurse)

Being sent home at an appropriate time of day was another safety concern expressed by community nurses:

“They don’t seem to have an appreciation that they will send people home at inappropriate times...I have known people who have come home in the middle of the night”. (Community Nurse)

With regard to their safety, it was reported that many older people left hospital without proper assessment of their ability to cope at home. In addition, they were not given information about community services that could assist them with the recovery process and were discharged too soon:

“How will they cope at home? Are they being sent home too early?” (Community Nurse)

Examples were given of people leaving hospital who were not given any explanation and information about their current state of health:

“[Some would] like to know what the current status is in regard to their health, because that hasn’t been explained to them.” (Domiciliary Practitioner)

Confusion and lack of understanding about new medications was reported by community nursing and domiciliary practitioners, with resulting in older people not knowing what their hospital medications were for and what to do with their old ones at home:

“Sometimes [they] aren’t given quite enough direction [about medications]...they will send them home with the limited [hospital] supply...[and] they don’t say to them ‘You need to go to your local doctor and continue with these tablets and get a further prescription… a lot of [them] say ‘Do you think I should stay with these?’ So once they are out of the hospital they think it reverts back to what they’ve had.” (Community Nurse)
Leaving the hospital with their discharge medications and all their personal belongings was described as the ‘mechanics of getting home’ by this domiciliary practitioner:

“All the mechanics of getting home, ‘Have they got their medication [etc]?’ Which sounds simple, but that often takes a very long time and often there are hiccups, like people come home without medication, or their glasses,[etc]…some things get lost in hospital.” (Domiciliary Practitioner)

Domiciliary and community nursing practitioners thought that some people with disability were also discharged prematurely, though the reasons were different than those for older people and pointed to the hospital staff’s inability to understand and/or manage the behaviour of people with disability:

“If they’ve been discharged too early is always an issue for them…there’s that perception that ‘they’re too difficult to look after’” (Community Nurse)

Several community nurses reported that being ‘too difficult’ particularly affected people with brain injury, who often had problems understanding why they were admitted and what had occurred. Further, explanation of discharge was often lacking because of the extra time and effort needed by the nursing and/or medical staff to assist them with understanding.

When older people left hospital, it could be like heading into the unknown as they were unaware of what the continuing role of the hospital would be:

“Follow-up, if there is going to be any ongoing contact with their specialist or a review at the hospital.” (Domiciliary Practitioner)

Furthermore, when they left hospital they had not been told how they would be supported and treated in the community:

“What sort of supports, either medical, nursing or others, are available to me if I am carrying an increased disability…? How will those people treat me, value me, respect me? [and] Who do I contact if something goes wrong?” (Community Nurse)

“If the services they need…have been arranged…there’s a multitude [of things they may need such as meals, shopping, assistance with mobility, bathing and toileting]...it can just be overwhelming [for them].” (Community Nurse)

Carers and the hospital
Practitioners claimed that during the hospital’s discharge planning process there were opportunities when carers could begin to make adjustments for the time when the cared-for left hospital. Even when
discharge was imminent, domiciliary and community nursing practitioners were concerned that the questions asked of carers during discharge planning did not help carers plan ahead for managing the patient at home:

“The questions that [carers] are asked before the discharge aren’t necessarily appropriate for the discharge, like ‘Who does the shopping and all the different things at home?’...[carers] don’t stop and think [if they can or can’t manage] and forget to broach that until they get home [and find] that they haven’t got the time to go out and do the shopping...the initial ‘going home’ is very overwhelming and daunting...some people have been re-admitted into hospital because the carers haven’t coped.” (Community Nurse)

From the perspective of domiciliary and community nursing practitioners, carers were generally disregarded and overlooked by the nursing and medical staff during discharge. Yet domiciliary and community nursing practitioners asserted that carers were crucial to the success and effectiveness of an older person’s discharge and they therefore should be consulted and briefed about looking after the cared-for:

“Often, um, carers will comment to me that they are just not able to catch the doctor. They don’t know, they’ve heard rumours about discharge planning but that’s not being directly communicated with them. So they feel this real lack of control over what’s happening and...why the plans are happening. Um...one instance...I can think of, a client of mine who has been in hospital many many many times and the carer is quite often disregarded. She’s seen as a bit of a trouble-maker and so then [is] overlooked...they’re not consulted or recognised.” (Domiciliary Practitioner)

“Quite often there is a lack of knowledge of what’s actually gone on while the persons been in hospital, um, lack of education around what might be needed for the future, which... is very closely linked with the discharge plan...Quite often, people are discharged from hospital in a hurry...so the carers haven’t had the time to actually understand what has been going on for the client and they’re discharged and the clients not really well, but they don’t know how to care for them...the person’s very weak...they just don’t understand...” (Domiciliary Practitioner)

Too much information given during discharge could have the unintended effect of confusing carers, who were trying to process the whole new scenario and were less able to absorb new information:

“When a person is discharged from hospital there can be a lot of input with carers about getting services in the home and for elderly people it can be very confusing, because we have multiple services and it’s not a priority for carers to remember the names of services, they’re just interested in what help comes in the door.” (Domiciliary Practitioner)
Carers could also be subjected to pressure from the hospital to take the patient home, regardless of their ability to manage, by playing upon their loyalty, as pointed out by the following practitioner’s description:

“There is often pressure on carers to take people home even though they are really struggling to manage. [There was] carer loyalty to the person they care for. So often they’ll cover up just how bad it is at home.” (Domiciliary Practitioner)

While the domiciliary and community nursing practitioners recognised that the busy pace of the hospital contributed to carers being overlooked or labelled (for example, as trouble-makers) they also observed firstly, that some hospital nurses and doctors attitudes were unhelpful; and secondly, that the hospital’s pace had unintended consequences of contributing to uninformed and ill-prepared carers.

Practitioners observed that when a carer thought that the older person they looked after was discharged prematurely, he/she was angry at the hospital staff because it put the carer’s ability to cope under more duress:

“[Carers] didn’t think that mum, dad, aunty, whoever was ready [for discharge and] they were discharged anyway and they can sometimes feel quite angry about it. If the carer’s living in the same residence, again (they question) whether they are going to be able to cope.” (Domiciliary Practitioner)

“They’re concerns are whether they can cope with them…particularly if they think they have come home a bit early and not coping.” (Community Nurse)

Community services

Undoubtedly, one question with major implications when older people and people with disability left hospital was: ‘Who’s going to be doing the care?’ Generally, they looked for the kind of assistance they needed to help them to ‘bounce-back’. When domiciliary and community nursing services played a part, the importance of the timely delivery of their services was emphasised:

“The other thing is making sure that services start again, straight away, if they have been having services or that extra services are put in [place]…[and] there can be a delay with that, so that’s always a problem…being concerned about getting back on track…they’re looking for input.” (Domiciliary Practitioner)
Better access to community services was likely for people with disability, as those who were known to service providers like community nursing (in particular) already had carers who understood them and were prepared for any change in their needs:

“[They] have already got carers…Their needs don’t really change and they have such a good support system…If they are in the loop [of community services]…because we all know that things might change depending on what they have done.” (Community Nurse)

Nevertheless, there were concerns about people with disability who did not already have access to community services and were therefore less prepared and had less support for the changes that a hospital admission might bring to their independence:

“But the ones that haven’t tapped into all those social supports yet, that’s a huge thing, because they have been quite independent and then, all of a sudden, with a hospital admission, things change so much…Often they are discharged before things can be commenced.” (Community Nurse)

Indeed, older people and their carers needed certainty that services would be immediately available to them, as this would also help them avoid an additional health or care-related crisis arising from not having their needs met during this recovery phase, not to mention the anxiety of a readmission to hospital. However, when services had not been organised for them, practitioners observed that many older people had trouble knowing where to find what they needed:

“Knowing what services to ring and what they can offer you and a prompt response is essential [for]…personal care, cleaning, equipment.” (Domiciliary Practitioner)

Older people’s needs raised the importance of communication and service coordination between the hospital and community services during the first 2 weeks after discharge, as articulated by the following domiciliary practitioners:

“Care coordination…it’s the most the most important thing. Those first two weeks when a person comes home from hospital is a really critical time…often the communication just falls down…having knowledge of what’s happening…often people aren’t as clear as they should be on ‘What are the plans when they go home?…What are the follow-up appointments?’ All those nitty-gritty things, the person really needs to be quite involved in that process and feel that they’ve got control over it.” (Domiciliary Practitioner)

“Confirming support services…Re-scheduling…The nightmare of chasing up support services and I use the word nightmare quite specifically…especially equipment.” (Domiciliary Practitioner)
While respite may not first appear to be an immediate issue following discharge, the levels of strain that many carers experienced could easily develop into a crisis. Knowing that the first 2 weeks were the most demanding on carers, domiciliary and community nursing practitioners conveyed the importance of preparing carers for respite in advance of a crisis:

“The carer also needs to be aware of things like respite if they’re not coping or if things crash or fall – you know, who do they go to for help? And often... it’s a crisis point. Sometimes you might get someone who’s reached crisis and they don’t know where to turn to and they want help and they want it now. That’s probably a big concern to them. They probably get frustrated too, getting the run-around a bit, not quite knowing where to turn to and who will help and who won’t.” (Domiciliary Practitioner)

Furthermore, carers generally preferred the type of respite provided in the home as it was less disruptive to the routine of the cared-for and provided the opportunity for the carer to have a proper break. However, this type of respite was very difficult to access:

“[Carers] all complain of ‘in-house’ or ‘in-home’ respite… It’s very very difficult [to access]…for example...[a person with disability]...ended up in a tertiary institution [because planned respite was unavailable]...for the young person...[it] was absolutely unacceptable...and they hated it, um, so there was a lot of tension prior to any type of respite between the carer and the young person, you know, their son or daughter…and thus we left it till the last minute until the carer couldn’t cope anymore...in the disability area,...‘in-home’ respite is basically not a reality. And the same goes for elderly...[Carers who] look after a demented partner ...are very hesitant of placing them into ‘a respite facility’, whilst they have a break...[because they will] visit them twice a day, which is just as tiring...in terms of their time and energies and stuff, so you might as well just keep them home. But they will be quite prepared to leave their home and [go for a holiday or interstate]...if we could guarantee that that person could be cared for at home and wasn’t taken out of their normal environment...it’s a very big issue for them.” (Community Nurse)

**Summary: When leaving hospital**

Domiciliary and community nursing practitioners reported that the lives of older people, people with disability and their carers’ changed after a hospital admission. There was potential for adjustment in people’s behaviour, carers included, adaptation of their houses and provision of community services when they left hospital. Such adjustments had varying effects on the intensity and experience of this phase.

It was found that an individual’s adjustment to their uncertain health status depended on the person’s living situation, namely whether or not they lived with anyone or alone and the set-up of his/her home. When individuals lived alone, there were more uncertainties, or ‘unknowns’ about what they would find when they arrived home from hospital, how they might manage on their own and who would be able to
help them. Older peoples’ adjustment depended on their health and living situation before admission and the effectiveness and their physical response to treatment. Capacity to ‘bounce back’ emotionally and physically after hospitalisation varied, as did their understanding of what to expect physically and emotionally during their recovery and their ability to learn new skills that would help them cope with impairment or maintenance of their condition.

Leaving hospital really appeared to be an emotional period for both older people and people with disability, during which they could feel a range of conflicting emotions, including fear, denial and a loss of confidence. Older people were more inclined to focus on the everyday things for survival, while feeling a loss of dignity and worrying about losing their independence. Losing independence was a conflicted concern associated with knowing that they needed help as well as not wanting to be a burden. People who had had a stroke often experienced communication difficulties when they went home and this problem could impact on their ability to reconnect socially with family and friends. People with disability wanted to reconnect with their life. For a range of reasons, leaving hospital could be less stressful for this group, as they tended not to get as deconditioned as people older than them, were understood at home, possibly already had services in place and were quicker to establish a routine. Their emotional response depended on where and how they were treated during hospitalisation, as going home could be a great relief or lead to a release of pent-up grief and anger. Acceptance of support services could represent ‘a battle within’ the person with disability, in which they asked ‘why me?’, a question related to the acceptance of their disability. Both older people and people with disability were reputed to experience financial losses and strain when they left hospital.

When they left hospital, changes in older persons or persons with disability had a direct impact on their carer and/or family, who in turn would need to make their own adjustments. Immediately after hospitalisation, carers and/or family generally found the volume of work became a ‘mountain of work’, which would need to be sustained for the length of the recovery period. Caring for someone at home always required a strong measure of commitment, and after hospitalisation it became ‘a whole new scenario’ which often involved new medications, skills and equipment, as well as new approaches to assisting with transfers, home modifications and mobility. Additional vigilance was needed, especially if the person had a stroke, dementia or cognitive impairment. Despite the mountain of additional work after hospitalisation, it was generally assumed that all carers would continue to cope even when they had been feeling strained or depressed before the admission of the cared-for. The extent to which carers and or family could adjust to this added workload was understood in terms of personal agency. Agency depended on their age, physical and mental health, their level of confidence with asking help-seeking types of questions to anyone able to assist them (such as from whom, where, what and when
would help come), their ability to assess their situation, problem-solve, create workable routines and set achievable goals for themselves. Practitioners reported that carers and family adjustment was affected by their access to professional advice and reassurance, skill development, timely and adequate support, respite and institutional care.

Service adaptations, or the services' ability to manage the changes that accompanied a person leaving hospital, were affected by a range of hospital-based obstacles, the involvement or exclusion of carers, and the certainty of community service provision. Hospital-based obstacles concerned the staff's attitudes to older people and people with disability, especially to people with brain injury who were considered 'too difficult' to look after. There were also obstacles to the assessment of people's ability to cope, the provision and explanation of information about patients, their discharge, when or where follow-up would occur and to the involvement of carers. The main obstacles to patient safety were with their medications, discharge time of day and whether or not the discharge was rushed or premature. Patients preferred to have all their personal belongings with them at discharge so they would not have to return to the hospital.

Rather than being disregarded, overlooked or having their loyalty to the patient exploited, carers were understood as being vital and needed to be included in discharge planning. Community services' ability to deliver certainty was affected by communication from the hospital and their capacity to deliver services in a timely fashion. The first two weeks after hospitalisation were recognised as a critical time for older people and people with disability, as well as for their carers, to get timely and coordinated community services and equipment to help them 'get back on track' and reinforce their sense of control. Being already 'in the loop' of services was an advantage to getting support. Early intervention in the first two weeks after discharge, for example, with 'in-home' respite, helped avoid a possible crisis if carers were unable to cope during this time.

Figure 13 presents an overview of practitioners' perspectives of the dimensions of adjustment and adaptation when older people, people with disability and their carers left hospital. The boxes differ in colour and represent the three dimensions of individual adjustment to changing health status, carer and family adjustment and service adaptation. Under each dimension are detailed the categories that pertain to that dimension. Further analysis of these findings is provided in Chapter 9.
Figure 13: Adjustment and adaptation: “Their life isn’t the same as it was before."

**Individual Adjustment to Changing Health Status**
- Living situation: with/without partner or family, isolated, home set-up
- More 'unknowns' for people living alone
- What to expect? physical & emotional preparation/challenges
- Conflicting emotions/needs: fear, denial, needing help vs not wanting to be a burden, loss of dignity/independence, confidence, communication difficulties (stroke), focused on everyday things for survival
- Financial losses/strain

**DEPENDS ON:**
- Health & living status before admission
- Treatment: effectiveness/physical response
- Capacity to 'bounce back' emotionally & physically
- Learns new skills-coping with impairment

**PEOPLE WITH DISABILITY:**
- Desire to reconnect with their life
- Less stressful/deconditioning, understood, have services, quicker to establish routine
- Acceptance of disability: 'why me?', need for care-'a battle within'
- Recovery depends on where/how treated-relief or emotional release-grief/anger

**Service Adaptation**
- **HOSPITAL OBSTACLES**
  - Attitudes: older people & disability
  - Follow-up information & explanation
  - Safety: medications; coping ability; time of day & rushed/premature discharge
  - Personal belongings

- **CARERS ARE CRITICAL**
  - But disregarded or overlooked in discharge planning & loyalty exploited

- **COMMUNITY SERVICES:**
  - Critical time-first 2 weeks post discharge: being 'in the loop'
  - Timely delivery to ‘get back on track’
  - Access: services, equipment, respite
  - Communication & coordination
  - Early intervention averts carer crisis

**Carer & Family Adjustment**
- **PRE-ADMISSION:** strain, depression
- **CHANGES DIRECTLY AFFECT CARERS:** assumption of coping
- **BURDEN OF CARE:** mountain of work/commitment/length of recovery/vigilance (stroke, dementia, cognitive impairment)
- **WHOLE NEW SCENARIO:** medications, transfers, skills, equipment, home modifications, mobility

**AGENCY DEPENDS ON:**
- Age, physical & mental health
- Confidence to ask help-seeking questions: who/where/what/when
- Able to problem-solve
- Self-assesses
- Creates workable routines
- Sets achievable goals

**ACCESS TO:**
- Professional advice & reassurance
- Skill development
- Timely & adequate support
- Respite
- Institutional care
8.2 FINDINGS FROM THE REFERENCE GROUP MEETING

This meeting was held in October 2002. The purpose of this meeting was to identify the key issues that older people and people with disability faced before hospital admission and after discharge. The issues for carers of older people and people with disability were not discussed by this group. There were eighteen participants, representing a range of HACC agencies throughout the specified region of Adelaide including Commonwealth Carelink, local government, HACC-funded non-government services, a rehabilitation hospital, several carers, as well as hospital personnel. In comparing the range of issues identified by this group of service providers and carers with the domiciliary and community nursing practitioners, many similarities were found regarding the uncertainties faced by older people and people with disability before admission to hospital and after their discharge.

The participants reported that in their experience, older people had numerous fears about a hospital admission, of having surgery or procedures undertaken, of complications occurring, of their survival and the problems and impact hospitalisation may have on their spouse or carers. Again, they did not want to be a burden to anyone but did want follow-up and support after discharge. People with dementia had comprehension problems when they were admitted to hospital and the language barriers of CALD clients were raised. The number of older people who could not access transport for admission, discharge and follow-up (estimated at 25%) was discussed, and the lack of preparation for elective compared to emergency surgery. Leaving their home and their pet(s) was another stress for older people before admission to hospital.

Before admission to hospital, people with disability were stressed and anxious about being separated from their carers and/or family. Hospital staff lacked understanding about disability in general and paraplegia, quadriplegia and brain injury in particular. Patients with mental health problems were 'not believed' by hospital staff. There were problems if the person with disability was significantly younger in age than other mainly older patients in the ward, for example someone in their 20s compared to others in their 70s and 80s. There were also problems with the process of unplanned admissions of patients with disability, in relation to communication, consent and ensuring they understood procedures.

After discharge from hospital, it was known that older people and people with disability had fears about their ability to cope and that the support they needed was lacking. Hospital nurses were criticised for not giving information about community services before discharge. The need for providing complete information, proper medications and the timely arrival of services to the home was highlighted. However, there were concerns about the number of community services that had waiting
lists and the impact this had on service delivery. Stress and anxiety were identified as being barriers to retaining information. Another problem was the discharge of patients with gross memory loss and/or dementia. From participants' perspectives, the inconsistent supply and additional expense of equipment, the lack of transport options from hospital to home and other financial concerns were the remaining problems found after discharge from hospital. Figure 14 summarise the key issues identified by the Reference Group. The problem areas identified by this group are discussed further in Chapter 9.
Figure 14: Key issues of the aged and people with disability before admission and after discharge as identified by the Reference Group

**Older people before admission**
- Fears: of admission, surgery, procedures, complications, survival, problems with spouse, impact on carers
- Not wanting to cause concern to anyone
- Follow-up & support after discharge
- Dementia clients not understanding
- Language barriers: emergency & during admission
- Transport: 25% can’t afford transport for follow-up
- Preparation: elective surgery compared to emergency
- Stress leaving home: concern for house & petcare

**People with disability before admission**
- Stress & anxiety: separation from carers &/or family
- Lack of understanding about disability: paraplegia, quadriplegia & brain injury
- Attitudes: mental health patients 'not believed'
- Younger people in wards with mainly older people
- Process of unplanned admissions: communication, consent & ensuring understanding of procedures

**Older people & disability after discharge**
- Fears: ability to cope & lack of support
- Hospital nurses: not giving information about services before discharge
- Service delivery on arrival home: timeliness, complete information & medications
- Community services: concerns about waiting lists
- Stress, anxiety & uncertainty: barriers to retaining information
- Problem: discharging patients with gross memory loss/dementia
- Equipment: inconsistency with supply
- Lack of transport options from hospital to home
- Financial concerns: equipment & services in the home
8.3 INTERVIEWS WITH HOSPITAL NURSES
There are always at least two sides to any story. The findings in this section represent the observations from hospital nurses about their experiences of discharge planning. The data from the nurses was crucial in developing an understanding of the complexity of discharging older people and people with disability from hospital to the community. Conducting the interviews gave nurses an opportunity to stop for a time and reflect on their practice. Being interviewed about discharge planning reminded the nurses of the range of factors which weigh upon them as well as their hopes to improve discharge planning. They wanted to ‘get it right’ more often, as the following comment made by a more senior, highly committed and very experienced nurse indicates:

“I’m glad that this issue is being addressed because discharge planning is the bane of our lives.” (Hospital Nurse)

8.3.1 The process of discharge planning during admission
Every patient embarked upon a particular process when they were admitted to a public hospital. In a planned (or elective) admission, the patient was referred by a GP to a consultant. The consultant arranged the admission and assessed the patient for theatre and pre-admission clinic. The patient was usually admitted on the day of surgery and was seen firstly by clerical staff and then assessed by nursing staff. A hospital doctor then reviewed the patient. If the patient was admitted by the Emergency Department (ED), he or she was admitted by reception staff and placed in a clinical team. The patient arrived in the designated ward, where he/she was assessed by nursing staff and reviewed by a hospital doctor.

Public hospitals are usually large institutions with assumed capacities in assessment or information gathering, diagnosis, analysis and treatment provision. Accurate and reliable information was needed in order to conduct any of these tasks. How much accurate and reliable information was provided by community service providers, including GPs, to the hospital? According to the nurse respondents, reliable and accurate information was patchy and getting it depended on where the person was before the hospital admission. If the person was an existing community nursing client and the admission was planned, fairly reliable information would be provided by the community nursing service. GPs often presented a brief letter of referral, and hostels and nursing homes were known to give limited information. If the person was a domiciliary care client, information would need to be sought from their domiciliary practitioner, who it seemed, was unlikely to be available and would therefore need to be conscientiously followed up, time permitting. It would be very unusual for patients admitted by ED to have any information about their medical history, medications and community supports with them. In this case, if the person was accompanied by carer and/or family, these people were sometimes
consulted. Most of the time, however, no information was provided to the hospital staff ahead of a patient’s admission. Nevertheless, it was recognised that if more information was needed, this could always be sought from the community nursing and/or domiciliary care service, or from the person’s GP.

Nursing staff or hospital social workers did not usually notify existing services of a patient’s admission. The exception was the community nursing service, who generally already knew about patients with elective admissions. It was reported by domiciliary practitioners that they only found out when they arrived at the client’s home to find they were not there. They would then need to investigate the whereabouts of the person. Sometimes the patient’s carer and/or family were asked or would notify them about any existing services, and at other times additional services would only be identified by chance on the day of discharge. At the time of this study, there was no existing hospital policy concerning notification of admission. Occasionally, domiciliary practitioners would ring the ward to find out the anticipated date of discharge.

Preparation for discharge
Ideally, planning for a patient’s discharge would commence within the first 24 hours of admission. A ‘nursing history’ would be compiled and this assisted in determining the expected length of the patient’s stay, foreseeing any problems, what supports were needed, and helped determine the most likely discharge location. An ongoing assessment of a patient’s needs would be done, which included home supports. The discharge plan would be reviewed periodically and communicated to everyone involved. The medical ward involved in the study held a weekly discharge planning meeting. If the person was medically unstable, then discharge planning started with their stabilisation. As far as nurses were concerned, a key aspect of discharge was patient safety.

A discharge summary prepared by doctors was faxed or posted to the patient’s GP. At the time of this study there was no electronic discharge summary available. Nurses were responsible for compiling a discharge notification that was provided to other hospitals or to nursing homes, but this was not generally available to community service providers like domiciliary care.

Simple and complex discharge plans
A simple discharge plan ensured medications arrived from the pharmacy before the patient left the hospital and any letters needed were written and ready to be taken by the patient. A complex discharge plan was inevitably a longer process, sometimes taking weeks to complete. The two case studies reported in this thesis (see Chapter 7) are examples of more complex situations. The doctors
would supervise the discharge plan and took responsibility for the medical and other aspects (for example, psychological assessment) and initiated involvement of the SA Guardianship Board, when needed. The nursing staff would seek allied health input (e.g. dietician, occupational therapist, social worker etc.), which would focus on the patient’s functional capacity, such as mobility and ability to perform ADL. Services would be arranged by social workers and referrals would be made for support from CSPs, such as community nursing. The patient and their family or carer would be involved and if necessary, family meetings would be held to clarify the discharge location. GPs rarely came into the hospital, but occasionally they would phone to check on a patient’s progress. When all the tasks of a complex discharge plan had been completed, the supports were in place and the person was ready to go home. They would then be discharged.

Approaches to discharge planning: individual versus standardised

For all the factors that could impact on a patient’s discharge, the nurses interviewed favoured an individualised approach to discharge planning, because it was flexible in relation to the patient’s circumstances which became known to them during the course of his/her admission. This was likely to increase its effectiveness. However, individualised discharge planning had to be initiated in the first 24 hours and often relied upon community-based services. A standardised discharge planning approach, which had been used in the past, was now unworkable for the majority of patients due to changes in the levels of acuity in the patient population, the older ages of patients and the likelihood of greater dependency:

“A few years ago everybody used to do their own discharges...[This worked because]...when I first started working here the patients were different [nurse’s emphasis], they were more independent, semi-independent. Whereas now they’re more dependent upon social services and all those kinds of things.” (Hospital Nurse)

However, there were several aspects of the current approach to discharge planning that hospital nurses felt were successful and wanted to maintain.

8.3.2 Nurses’ perspectives on discharging patients who were aged or had disability

According to the nurses, the main reasons for a ‘failed’ discharge plan, that is the non-arrival of community services, insufficient staff, the timing of discharge, unavailable domiciliary care or community nursing services because of waiting lists or no notification about a patient’s discharge, insufficient community services due to funding and/or a breakdown in communication. While all these

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63 The Guardianship Board may become involved when a person is unable to make certain important decisions for their self due to having a mental incapacity, such as dementia, intellectual disability, brain damage, mental illness, and coma. The Board can make Guardianship Orders, Administration Orders, and Orders giving consent to treatment.

64 As these comments refer specifically to the hospital, they have been included in Appendix 6.
factors are understood to contribute to failed discharge, they do not explain why discharge planning was so fraught with uncertainty and complexity.

Hospital nurses painted a complex picture as they spoke of the range of problems they encountered when attempting to discharge older patients or patients with disability. Apart from one junior nurse who had not yet discharged any patients, the types of problems that arose fell into four categories. These were:

1. Patient’s readiness and safety;
2. Dynamic triad relationship (between the patient, their carer/family and nurses);
3. Hospital-based obstacles to the patient’s discharge; and
4. Timely and coordinated access to community services; RAC and transport.

In the following pages I address each category in more detail.

Patient’s readiness and safety

Patient’s readiness and emotional adjustment

A patient’s readiness for discharge related to physical changes which could impact on their continuity of care in the community, such as getting to community nursing clinics rather than the community nurse coming to them. Among the nurses there were varying levels of concern about the readiness and safety implications of patients with mobility and balance problems when, for example, they needed to use the toilet in a bathroom without handrails already installed to support them. However, there was a tendency for some nurses to normalise the risks associated with discharging older patients:

“Usually it’s fairly easy things...you can just refer them to the GP...or get dom care [domiciliary care] or that sort of thing involved...sometimes it’s just about rails in bathrooms and that sort of thing...just concerns that they’re going to be independent still or be able to cope at home.” (Hospital Nurse)

Nurses reported that their discharge readiness could change due to a sudden deterioration in their condition, or other problems such as accidents or incidents that halted discharge and extended their stay in hospital:

“We’ve had some people fall over the morning they’re meant to be discharged, so we can’t send them home if they’ve fallen. So we start all over again.” (Hospital Nurse)
Among the most complex discharge decisions for nurses were those that involved patients who had pre-existing psychiatric disorders and who lacked insight into their needs, or those with drug and substance abuse issues and who were generally unwilling to accept referral to any services:

“Patients with…psychiatric and I guess personality disorders [pauses] who you can assess for as long as you want and try to put things in but ultimately those services all get refused [by the patient]. And I guess lack of insight into their actual physical and I guess psycho-social needs… When you know that they have a disability and can’t make their own decisions and are in a situation which is not safe for them at home so when you are looking at Guardianship to make decisions about their wellbeing.” (Hospital Nurse)

As this nurse indicated above, these situations raised ethical issues about nurses’ duty of care, as well as the need to assess the decision-making capacity of the patient, in which case the SA Guardianship Board would be called in to facilitate the process.

Some patients had unrealistic expectations about the potential of hospital treatment to make them better, despite their age or condition; others refused to engage with their recovery process or health care. As a nurse explained:

“Sometimes people expect to come to hospital and to ‘be fixed’…and they have a poor understanding that their disease process is ongoing and takes some commitment from themselves so that it’s reliant really on them being responsible, taking their medications, um, attending appointments out in the community. This [is] the minority group though. Most people are very good and they just want to do the right thing.” (Hospital Nurse)

Many nurses observed that, during discharge, patients underwent a process of emotional adjustment that helped them prepare to cope with leaving the hospital. Many older patients would maintain an appearance of coping during their admission, but the closer they came to leaving the hospital, the more likely it was that they would start to become fearful and anxious about managing at home. This could be manifested as their ability to manage:

“Most of the clients we get here are pretty stoic and any fears or anxieties that come up are usually said on the day before discharge or a couple of days before discharge, um, a lot of the clients…will say ‘Keep a stiff upper lip’ you know, ‘I’m brave I can handle it’ and then later they’ll say ‘What shall I do?’, ‘Do I need this?’ or ‘Where shall I go’ and then you realise that they need a bit more education here…They’ll say… ‘Who can help me with my gardening?’ or ‘Who’ll be taking me blood tests?’…they want someone to support them…” (Hospital Nurse)
Alternatively, they may signal their fears and anxieties by directly identifying what they know they cannot manage to do, and this could be misinterpreted by nurses as complaining:

“Um…generally we try to identify them as we go along but if they do right at the end it’s normally like ‘Oh, I actually can’t cook my meals at home’. They very rarely will say ‘Oh, I can’t do this can I have some help?’ They normally just complain about things they don’t like or that they think are wrong and it’s up to us to question them about that, to ascertain what’s actually going on.” (Hospital Nurse)

Older patients’ initial response to hospitalisation could be bravado which, as discharge grows closer, changes into fear of decline and their ability to manage and control their life during the recovery process:

“A lot of people come in…with bravado and they fear that we’re probably going to take them away from the home or we are going to interfere too much with them…They have fear about growing old, fear about losing independence.” (Hospital Nurse)

During this period of emotional adjustment patients needed reassurance about going home with someone organised by the hospital to check on them. The level of willingness and empathic response to accommodate patients’ fears varied among nurses, with some demonstrating greater insight and skill in their approach to working with older people’s needs:

“I think [fear of ageing and losing independence is] quite a significant psychological fact that’s blocking people being discharged and we have to break those barriers down, so they can understand that we are working with them not trying to take away all their dignity…” (Hospital Nurse)

Insightful and skilled nurses were more flexible in satisfying patient’s needs and fears, by offering reassurance, by finding information and organising services for the patient:

“If they say that they don’t feel comfortable going home or they’re a little bit worried ….a bit frightened…we’ll get [the hospital outreach service] to check on them for the next few days…Sometimes that’s the only time people will leave the hospital is if there’s someone to look at them the next day because they’re isolated and they’re lonely and you know they’re frail. But we can’t always provide that …” (Hospital Nurse)

However, the number of aged patients in hospital could also lead to compassion fatigue or distancing by some nurses, whereby a patient’s fear and anxiety was disregarded and actions not taken in the best interest of the patient:
“It’s just normal probably fears and anxieties just prior to discharge but along the way we certainly learn a lot.” (Hospital Nurse)

There were occasions when patients thought they were well enough to go home, even though nurses disagreed. Such patients were also likely to refuse support services. In this nurse’s view, their avoidance was related to their desire to remain independent:

“Usually they don’t [nurse’s emphasis] tell you. I think it’s the whole independence thing, they don’t want to think that they’re not independent anymore so they keep it to themselves.” (Hospital Nurse)

A patient may become depressed if they felt overwhelmed with fear and anxiety about their home circumstances and their ability to manage:

“Sometimes...um, they might talk about falling down all of a sudden. We had a patient yesterday...he told the nurse that he didn’t want to go back and live on his boat and that’s the only place he had to live and then the next day all of a sudden he’s suicidal, ‘cos he doesn’t want to go home”. (Hospital Nurse)

**Patient safety: ability to manage and home readiness**

Patient safety is a primary consideration of a nurse’s duty of care and is aimed at ensuring patients were ready and able to manage their recovery once they left the hospital. Quite often, patients revealed information about their circumstances to nurses late in the discharge process which, in the nurses’ view, impacted on the patient’s safety and ability to manage at home. A range of circumstances impacted on patient safety, such as the home-setup, the patient’s role and responsibility to others, the patient’s physical, medical and mental status and the availability of community services needed to assist them with his/her recovery. For example, nurses were concerned about a patient’s safety and their ability to manage if she/he lived in an upstairs apartment but was unable to climb the stairs because of functional decline; or when a patient reliant on food delivered by ‘Meals On Wheels’ (MOW) was discharged on the weekend when MOW did not operate; or if a patient was unable to dress him/herself but also had responsibility to look after an unwell, frail or impaired family member or partner. The circumstances that led to the patient’s admission could also affect both the patient’s response and the nurses’ assessment of his/her safety and ability to manage when discharged:

“So you’ve got people who are living alone who are on the floor for five hours before they were found.” (Hospital Nurse)
A major patient safety and management concern that nurses had about older patients was whether or not they understood how and when to take their medications:

“Sometimes it about their medication, how they’ll take it and whether they’ll remember to take it.” (Hospital Nurse)

Organising suitable services and appropriate accommodation for patients with disability was of particular concern to the nurses interviewed:

“And when there’s no services out in the community tailored to meet their needs and I would be thinking of the young person with a disability who also has…cerebral palsy and tracheostomy, and other needs. And I guess people with drug and substance abuse who are unwilling to accept referral too, so they go back to the same situation, they might be homeless.” (Hospital Nurse)

Patients with disability who lived alone were harder to accommodate with community services, a factor which in turn affected the nurses’ confidence in their safety and ability to manage.

If patients had not disclosed any concerns had about their home during the initial nursing assessment, the discharge process provided another opportunity to re-assess their circumstances and readiness of their home:

“Sometimes you get sneaky ones that won’t tell you anything at all and you sort of find out at the last minute that they need all this stuff and you get others who will tell you that they’re having problems getting to the bathroom or they’re having problems cooking.” (Hospital Nurse)

During discharge other problems could arise, ranging from having no food at home, to being unable to get inside:

“Having no food in when it’s Friday afternoon…maybe having lost their key or the ambulance having locked the door or didn’t lock the door when they left.” (Hospital Nurse)

Each of these issues would have to be dealt with separately by the nursing staff, and usually involved liaison and negotiation with a range of other people, including carers, family, neighbours, hospital allied health staff and/or community service personnel.
Dynamic triad relationship (between patient, carer/family and nurses)

While it was up to carers to make themselves known to nursing staff so that they could be consulted, involved and even relied upon for input into discharge, the nurses generally understood that carers and family knew much more about the patient than they themselves did:

“More often than not it’s actually the family members that tell us what the problems are. It’s not the patient themselves.” (Hospital Nurse)

If there were concerns, then family meetings could be arranged. When discharge was imminent, it would bring into focus the circumstances and relationships between patient, carer and/or family. In many situations, carers or families wanted to take home patients who would be difficult for them to look after, but they wanted to be given the chance. Some carers/families needed respite before taking the patient home. Other carers/families could not be contacted to inform them about the patient’s discharge. Carer and family responses could include similar emotional adjustment responses such as fear, anxiety, denial as had been shown by patients.

During discharge, nurses could find out about family dysfunction to a level that could potentially impact on patient safety, alternatively, the family might reverse their decision to take the patient home. The carer of the patient might be unwell or even admitted to hospital, delaying discharge of the patient:

“We’ve got patients down there who are in hospital and you know, their loved ones are in hospital because they’re their primary carers so that makes it difficult as well.” (Hospital Nurse)

Conflict could arise within a family over which member would care for the patient and/or to which location the patient would be discharged. The timing of discharge could also cause conflict or concern. The potential financial costs and losses (such as benefits and pensions) were another area of concern for families and carers.

During discharge, disagreement between nurses and carers and/or families could also arise because of the impact on the social or lifestyle activities of the patient’s carer/family. There could be conflict between the patient, who wants to go home, and their family, who is not confident about the patient’s ability to manage. In some situations, discharge was actually delayed or complicated by relatives who wanted services that were not considered necessary by the nurses, or carers/families who wanted services available prior to discharge and did not understand why this could not be arranged or how long it took to establish services.
The cultural values and practices of CALD people could differ from the mainstream society and might complicate discharge. For example, it was generally understood that Australians who had an Asian cultural background would not place their relatives in RAC, even if such placement was recommended.

Family size was another factor, as with large families discharge could be either easy or very hard, depending on the availability, willingness and relationship between the patient and his/her children. Discharge may be near and the patient's family may avoid the nursing staff altogether or refuse to cooperate with any decisions or arrangements, including RAC placement or assistance from community services or any other discharge options put to them to consider.

Some of the more complex discharges that nurses negotiated with carers ended successfully with the patient being discharged home. However, this outcome could conceal a difficult process where nurses endured lengthy and stressful negotiations, which could include conflict and be personally and professionally challenging:

“I know one particular instance where [the carer was] present with [the niece/nephew] who [the carer] had cared for 24 years who had a...intellectual [and] physical disability. [The niece/nephew needed] a tracheostomy...and [the carer] considered [him/herself as the parent], um, just the actual threatened violence and um, the staff being made to feel very uncomfortable caring for [the patient]. I guess that worked out in the end but it took a long process - months and months of continual negotiation, meetings, um, parameters put on what [the carer] could unload on the staff and [what couldn’t be unloaded]...eventually we did get [the patient] home but it was a very long process...it’s very draining for the staff to go through that.” (Hospital Nurse)

This intensive process was a long-term negotiation that involved the patient, the carer, the hospital and multiple community-based services aimed at discharging the patient home. While this objective was achieved, the process took its toll on everyone involved. It also exposed the types of ethical dilemmas that can arise in complex discharge planning, where there are conflicting objectives between succeeding with the discharge and maintaining duty of care:

“Not only us but getting every service in here to input and there were a lot of services involved in that case and all made very uncomfortable by [the carer’s] approach and all initially quite unwilling to take on the care again. Um, that’s a sad fact of life that happens more and more out in the community with dysfunctional families and violence and aggression.” (Hospital Nurse)
Difficulties arose when carers and/or families were confronted by their own mortality as they began to anticipate the potential grief and loss over the death or deterioration of a loved one. This raised other issues about not understanding the capacity of hospitals and of medicine to provide a cure:

“Expectations by the community, I guess that we can make people better no matter what their age, so if they’re 95 and deteriorating that they should remain in hospital rather than hospice.”

(Hospital Nurse)

Some carers/families expected that the hospital would keep the patient admitted until they were well enough to return home.

Figure 15 on the following page describes the dynamic triad of relationships between the patient and nurses; the nurses and the carer/family and the carer/family and the patient. Between patients and nurses there can be conflicting objectives over planning a successful discharge compared with ensuring duty of care. Between nurses and the carer/family, the patient’s carer/family needed to make themselves known to the nursing staff to enable the sharing of discharge information. But between the carer/family and nurses, there could also be refusal, denial and avoidance of the carer/family in response to the discharge efforts made by nurses, which could lead to conflict. Cultural backgrounds also impacted and the carer/family not understanding the limitations on the hospital and on medicine in treating and sustaining the admission of the patient. There were also other factors between the carer/family and the patient pointing to the quality and functionality of their relationship, in which dysfunction, conflict and cultural background each played a role in the discharge of the patient.
Hospital-based obstacles to the patient’s discharge

The nurses interviewed had no formal orientation about discharge planning approaches for the ward in which they worked. A ‘discharge planning orientation package’ had been developed several years before, but very few of the nurses knew anything about it. They tended to learn about discharge planning from their peers, by demonstration, or more gradually from experience. If discharge occurred on the weekend, then senior staff were involved. Staff shortages resulted in the need to bring agency nurses into the hospital on a regular basis, but they were not normally given a discharge planning role. Most nurses did not know when, or if, the process and documentation of discharge planning had been evaluated in their ward. Their general impression was that, via informal discussion, evaluation was continuous.

Patients were often of advanced age and the level of complexity involved in their health care both in the hospital and community sectors was increasing. Nurses were concerned that they only had time to focus on the acute care of patients, which resulted in little or no time to fully engage with discharge planning. They acknowledged that the hospital did not tend to work on an individual model of need, but instead had to work with groups of people’s needs:
“[The] hospital doesn’t work on one individual’s needs it works around a whole lot of needs and we’re not able to accommodate everyone when they think they should be [attended to or accommodated for].” (Hospital Nurse)

Despite everyone agreeing on its importance, proper discharge planning was a struggle under these circumstances. If the relevant information was not available, then the impact of its absence was felt at the time of discharge or afterwards, when the patient had already returned to the community. The most common obstacle to the timeliness of discharge was getting discharge medications delivered from the hospital pharmacy to the ward. Delay to discharge or rushed discharge was also caused by the timing of doctors’ rounds, or the arrival of individual doctors at the ward too late in the day to proceed with a patient’s discharge. Doctors’ workloads made it difficult for them to plan ahead and prepare information for patients and for nurses in time for discharge. This led to problems with prescribing discharge medications, writing discharge letters and summaries, completing external and internal referrals, educating patients and carers on discharge medications and the completion of tests in time. Occasionally, opinions differed between doctors and nurses concerning a patient’s readiness for discharge, and this could either delay or rush a discharge. Overall, the nurses felt that doctors needed to communicate more effectively with nurses, patients and their carer/families about their discharge.

Timely and coordinated access to community services, RAC and transport

Access to community services

The fourth category of problems was gaining timely and coordinated access to community services. A nurse commented:

“The big thing is that people want to live at home - they don’t want to go into placement, they want to be able to go back to their house or their home or whatever but the services just are not available for them.” (Hospital Nurse)

This comment reflected the general observation made by nurses that supply of community services could not meet demand as patients’ needs changed and/or increased after hospitalisation. Moreover, the lack of community services delayed discharge:

“These days because there’s a waiting list for GPs as well, they’re overwhelmed in the community.” (Hospital Nurse)

Some patients were unable to access community services because they did not fit the criteria specified or they lived outside the service’s catchment. In this situation the divide between the hospital and the community felt like ‘them and us’ for discharge nurses trying to access services for patients. If
a patient was being discharged after regular working hours or on the weekend, then coordinating community services would have to wait until the following morning or weekday. It was always harder to discharge patients on the weekend, as community services were closed. Organising the appropriate services and equipment for patients was time-consuming and became more of a challenge as patient’s needs became more complex.

When older patients and patients with disability were discharged, the interdependence of the hospital and community care systems was highlighted. Patients were being let down because hospital nurses and community service providers lacked the time and resources to provide consistent and continuous care.

As just under a quarter of the nurses interviewed knew of a least three agencies in the community that assisted the aged and people with disability to continue to live at home, more nurses needed to be given information about community services. However, most knew about community nursing and domiciliary care and these particular services were the ones most commonly used for referrals. They found out about community agencies through a combination of experience, common sense, and ‘detective work’, as well as from other patients who used community services or from those who had complex needs.

Nurses recognised that, as well as the hospital needing more resources, community services were also under-funded and this resulted in waiting lists for some services which often delayed discharge of patients who were aged or had disability and who did not have the ability to undertake illness prevention. As this nurse stated:

“It would be nice to see more funding out in the community so we actually can prevent hospital admissions and put services in place before the patient actually falls in a heap. So it all comes down to resources and I don’t think we can necessarily afford to take away from the hospital the way we are now but moving towards more of a ‘preventative society’ rather than a ‘treating the illnesses’ [society].” (Hospital Nurse)

The lack of respite services for carers in the community impacts on hospital admissions, where people who were being cared for were admitted to hospital with their carer as there was no other place for them to go:

“We’ve got a gentleman in at the moment and his wife was admitted because he was the main carer...Also another example...yesterday we had a patient down in emergency service and the husband knows he’s going in for surgery on his hips in two weeks and he’s a carer but no respite or anything had been organised [for the cared-for].” (Hospital Nurse)
Furthermore, changes in society mean that families are no longer relied upon to care for recovering older parents or relatives. Nevertheless, older patients still wanted to return home after hospitalisation, with support from community services provided as early as possible after discharge and targeted to their needs:

“I suppose the ageing population in the [the region] and the fact that the services are limited and there’s so many people that actually want to now stay at home. They’re reluctant to either to put themselves or their loved ones in nursing homes and there’s just not enough services for them. Um, patients are sicker I think these days than what they used to be and I’m only talking 3 or 4 years ago…and society in general plays a big part, especially if you’re relying on your family or whatever to look after you and people these days have all got jobs you know, busy jobs, busy lives, family, children of their own and to have to look after a loved one it’s quite detrimental to themselves and to their loved one or whatever.” (Hospital Nurse)

Such changes in the patient population and society have made discharge planning uncertain. Other problems were not being able to liaise with all the parties concerned so that discharge information, decisions and assessments could be made in an efficient manner. Examples include SA Guardianship Board hearings and ACAT assessments.

**Residential Aged Care**

When a patient had been admitted from home, but it was no longer adequate or appropriate as a discharge destination, alternatives of placement in a nursing home or a hostel needed to be found. Gaining access to a hostel, RAC facility and/or convalescent care was challenging, as most were full. Discharge would be delayed while the patient went onto a waiting list for an ACAT assessment, which took about 2 weeks. If approved, it could take up to 12 weeks to get a placement, during which time the person concerned continued to stay in hospital, albeit as an inappropriate admission. On some occasions, a RAC facility changed their decision about taking a patient or refused to accept the return of an existing resident:

“…a classic example…where a nursing home refused to take the patient over the weekend because they didn’t have staff on. Well, you know, sorry but…[weekends are difficult] especially if they are going back to a nursing home or a hostel or even if they are to go home with services.” (Hospital Nurse)

Finally, nurses described occasions where the RAC had given the patient’s position at the facility to another person, leaving the hospitalised patient with nowhere to go.
Transport

Access to transport for taking patients home from hospital was another problem during discharge. This problem was mentioned by many nurses, whether transport was by ambulance, family car, taxi or ‘Access Cab’\(^6\). Patients may not have enough money with them to pay for a taxi trip home and those who lived in the country were likely to have even more trouble getting transport home. The patient’s carer or family may not be able to transport the patient home, or discharge could be delayed while waiting for family members to finish work to provide transport. If an ambulance was used, it came late in the day as transporting patients home for the purpose of discharge was not a priority. On some occasions, nurses had driven patients home.

Summary: Dimensions of complexity in discharge planning: “…they want someone to support them…”

In the interviews, hospital nurses detailed the potential complexity of discharge planning with older people and people with disability and their carer/family. To draw up a discharge plan, accurate and reliable information was needed from GPs, community nursing, domiciliary care, hostels and RAC. Yet the information needed was mostly provided by the community nursing service only. Preparation for discharge, as it was described by hospital nurses, sounded systematic and achievable. While the process and preparations laid the groundwork of a discharge plan, every aspect of the plan could be changed according to the relative simplicity or complexity of the plan, and if it had been an individualised or standardised process. The nurses preferred an individualised approach because of its flexibility and effectiveness. However, this approach relied on it being initiated in the first 24 hours of admission and on the availability of community services.

Considering the perspectives of hospital nurses when discharging older people and people with disability, there were four main dimensions that constituted the complexity of discharging these patients. Although these dimensions are relatively hierarchical, they also affect one another and the whole process of the discharge. The first dimension, patient readiness and safety, describes a range of issues that directly impact on the patient and the discharge. In relation to patient readiness, discharge was directly affected if the patient had an accident, incident or their condition had deteriorated. Patients’ mental capacity, emotional adjustment and expectations each contributed to their readiness. Patient safety included patients’ ability to manage their circumstances, their physical, medical and mental status, other roles or responsibilities, the services needed and the readiness of their home.

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\(^6\)The SA Government subsidises a fleet of 70 wheel-chair accessible taxis designed specifically for use by people with disability.
A second dimension of complexity in discharge planning was the dimension of a dynamic triad of relationships, where in one corner were the patient and the nurses, in the second corner were the nurses and the carer/family and in the third corner were the carer/family and the patient. Between patients and nurses there can be conflicting objectives of planning a successful discharge in relation to ensuring duty of care. In the context of the relation between nurses and the carer/family, a patient’s carer/family need to make themselves known to the nursing staff to enable the sharing of discharge information to occur. There could also be refusal, denial and avoidance by the carer/family in response to the discharge efforts made by nurses, with resulting conflict between them. Cultural backgrounds also impacted on this corner of the discharge relationship, as well as a lack of understanding by the carer/family of the limitations facing the hospital and medicine in treating and sustaining the admission of older patients or patients with disability. As the links between the carer/family and the patient depended on the quality and functionality of their relationship, factors such as dysfunction, conflict and cultural background might also play a role in the discharge of the patient.

Hospital-based obstacles to patients’ discharge form the third dimension of complexity in discharge planning. Sub-categories here were insufficient time, training and information, and the systemic versus individual model of discharge planning. In the case of a delayed or rushed discharge, factors such as doctors’ communication and workload, delivery of medications, the writing of letters and summaries, making referrals and the completion of tests had an impact on patients' discharge.

The fourth dimension was community services, GPs, RAC and transport. Services’ availability and accessibility (including after hours services and respite), the timeliness of provision (including the delivery of equipment), the communication with and coordination of services, the eligibility criteria, the community resources available and the work/life balance were issues that impacted on this category. The four dimensions that make up complexity in discharge planning are represented in the figure following. The circle is divided into four coloured quadrants, representing as follows: patients' readiness and safety, unstable triad of relationships, hospital-based obstacles and community services, GPs, RAC and transport. Beside each dimension and linked to it in a text box are the detailed concepts that comprise that particular dimension. Figure 16 on the following page summarises the dimensions of complexity in discharge planning.
Figure 16: Dimensions of Complexity in discharge Planning: "...they want someone to support them..."

- **Patient readiness:**
  - Accident, incident or deterioration
  - Mental capacity
  - Emotional adjustment
  - Expectations

- **Patient safety:**
  - Ability to manage: circumstances
  - Physical, medical & mental status
  - Roles & responsibilities
  - Services needed
  - Home readiness

- **Patient & nurses: conflicting objectives**
  - Discharge & duty of care

- **Nurses & carer/family**
  - Make themselves known/share knowledge
  - Refusal/denial/avoidance/conflict
  - Cultural context
  - Capacity of hospital/medicine

- **Carer/family & patient:**
  - Quality/functionality
  - Dysfunction/conflict/cultural context

- **Patient readiness & safety**

- **Unstable triad relationships**

- **Community services, GPs, RAC & transport**

- **Hospital-based obstacles**

- **Services:**
  - Availability
  - Access & after hours
  - Timeliness
  - Coordination
  - Communication
  - Criterion
  - Equipment
  - Resources
  - Respite
  - Work/life balance

- **Insufficient:**
  - Time
  - Training
  - Information

- **Models of care:**
  - Systemic vs. individual

- **Delayed or rushed discharge**
  - Doctors: communication & workload
  - Medications, letters, summaries, referrals, tests
8.4 SURVEYS WITH HOSPITAL PATIENTS AND CARERS

The telephone surveys with patients (n=16) and carers (n=10) did not provide the volume of data needed for quantitative analysis. The low numbers of patients and carers who were surveyed was due to having calculated sample sizes that were unachievable given the multiple eligibility criteria, the circumstances of individual patients and the time and resources available for this phase of the study. This is discussed in more detail in Chapter 9. Nevertheless, these data did provide some useful insights into the pre-admission and post-discharge circumstances of the small sample of eligible patients and carers.

8.4.1 Demographics of Patients and Carers

In the sample of patients there were 25% more males recruited than females, and in the sample of carers there were 60% more females recruited than male carers. No younger patients with disability or carers of this group were surveyed and no interpreters were required for patients or carers. However, 25% of patients and 20% of carers were CALD. Although over one third (37.5%) of patients lived alone, all the patients surveyed had carers. Half of the carers were the wife or the husband of the care recipient. The majority of patients (87.5%) were emergency admissions. See Table 3: Demographics of Patients and Carers for further details.
<table>
<thead>
<tr>
<th>PATIENTS: Number= 16</th>
<th>CARERS: Number= 10</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Gender</strong></td>
<td><strong>Gender</strong></td>
</tr>
<tr>
<td>Males = 62.5% (10) Females = 37.5% (6)</td>
<td>Males = 20% (2) Females = 80% (8)</td>
</tr>
<tr>
<td><strong>HACC eligibility</strong></td>
<td><strong>HACC eligibility of cared-for</strong></td>
</tr>
<tr>
<td>Frail aged = 0</td>
<td>Frail aged = 0</td>
</tr>
<tr>
<td>Age ≥ 65 = 100% (16)</td>
<td>Age ≥ 65 = 100% (16)</td>
</tr>
<tr>
<td>Person with disability(s) = 0</td>
<td>Person with disability(s) = 0</td>
</tr>
<tr>
<td><strong>Main language spoken</strong></td>
<td><strong>Main language spoken</strong></td>
</tr>
<tr>
<td>English = 87.5% (14)</td>
<td>English = 80% (8)</td>
</tr>
<tr>
<td>Languages other than English = 25% (4) (Italian, Polish, Hebrew and French).</td>
<td>Languages other than English = 20% (2) (Italian and French)</td>
</tr>
<tr>
<td>Interpreters needed = 0</td>
<td>Interpreters needed = 0</td>
</tr>
<tr>
<td><strong>Living Arrangements</strong></td>
<td><strong>Living Arrangements</strong></td>
</tr>
<tr>
<td>Lived alone = 37.5% (6); Lived with partner = 43.8% (7); Lived with children = 6.3% (1); Lived with partner &amp; children = 12.5% (2) Had carer = 100%</td>
<td>Lived alone = 0; Lived with partner = 50% (5)</td>
</tr>
<tr>
<td>Lived with partner &amp; children = 10% (1)</td>
<td>Lived with parent(s) and sibling(s) = 20% (2)</td>
</tr>
<tr>
<td>Lived with other unrelated adults = 10% (1)</td>
<td>Lived with other unrelated adults = 10% (1)</td>
</tr>
<tr>
<td>Other = 10% (1)</td>
<td>Other = 10% (1)</td>
</tr>
<tr>
<td>Relationship to care recipient</td>
<td>Relationship to care recipient</td>
</tr>
<tr>
<td>Partner = 50% (5)</td>
<td>Partner = 50% (5)</td>
</tr>
<tr>
<td>Child = 30% (3)</td>
<td>Child = 30% (3)</td>
</tr>
<tr>
<td>Friend = 20% (2)</td>
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</tr>
<tr>
<td>Other relatives = 50% (5)</td>
<td>Other relatives = 50% (5)</td>
</tr>
<tr>
<td><strong>Reason for admission</strong></td>
<td><strong>Reason for cared-for’s admission</strong></td>
</tr>
<tr>
<td>Heart attack = 18.8% (3)</td>
<td>Falls = 30% (3); Heart attack = 30% (3)</td>
</tr>
<tr>
<td>Pneumonia = 12.5% (2)</td>
<td>Other medical/surgical reasons = 30% (3).</td>
</tr>
<tr>
<td>Other medical/surgical reasons (e.g. bowel obstruction, shingles, diabetic/medical stabilisation etc) = 69.3% (11)</td>
<td>Carer needed treatment (care recipient had dementia) = 10% (1)</td>
</tr>
</tbody>
</table>
8.4.2 Telephone surveys with patients

Entry to hospital

The majority (87.5%) of patients surveyed were admitted from the ED, with only two admissions planned in advance. None of the patients had attended a pre-admission clinic.

Both elective patients were given written information by staff in the Outpatients Department or by another health worker before their admission. One patient had had the information explained by the person who gave it to her/him and one was given information about community services. Both had as much information as they needed about equipment and felt very prepared for their admission to hospital.

Preparation for discharge

Over half (56%) of the patients were given instructions in hospital about their discharge medicines and a third were provided with an explanation about their discharge medicines. Just under a quarter of patients did not need instructions about discharge medicines, as they were taking the same medicines as before admission. Few patients (13%) were given information about the side effects of discharge medicines.

Just over half (56%) of patients were given information about help they may need to manage at home (for example, to do shopping, showering, bathing, dressing, toileting, feeding, mobility, transport etc). Over a third (38%) were given information on services available in the community that provide support (for example, domiciliary care, community nursing, meals-on-wheels etc) and over half (56%) were given information in hospital about equipment that could be used at home.

With regard to other aspects of discharge, just under half (44%) were discharged from hospital on a Friday between 7am and 6pm and a fifth (19%) were discharged on a Monday between 7 am and 6pm. None of this sample of patients reported being discharged during the evening or during the night. More patients were taken home from hospital by private car (56%) than by taxi (44%).

Support provided by community services after discharge

With regard to the arrangement of community services prior to discharge, under one fifth of patients (n=3) needed services arranged by hospital staff before they went home, 30% already had services in place and 30% did not need any help from community services. Of the three patients who had community services arranged from hospital, the service arrived the same day of discharge or the following day. However, for 13% of patients there was too long a wait for the arrival of community
services; 25% felt that community services had met their needs and 31% felt that services had not met their needs.

The hospital arranged equipment to be used at home for 38% of patients and this equipment had arrived, was being used and was meeting the needs of the majority of patients. No equipment was needed by a fifth of patients (19%); 13% already had adequate equipment and 30% did not need to use equipment.

Half of the patients reported that their carer had not been involved in their discharge; 38% of patients reported that their carer had been involved in their discharge and 13% did not know if their carer had been involved.

Discharge was not delayed for the majority of patients (63%). Of the third of patients (38%) who reported their discharge was delayed, the cause was waiting for medications (13%) or for other reasons (25%).

Although the majority (69%) of patients were not concerned about their ability to manage at home, a third (31%) were concerned. Many patients (69%) were very concerned about accident falls after discharge. Almost all patients (93%) were able to contact GPs and services in the community if needed. For the majority of patients (69%) no unexpected problems had arisen following discharge from hospital.

During the first week home after discharge, none of the patients interviewed had needed to return to the Emergency Department. They reported having help with home modifications (13%), shopping (13%), house cleaning (44%) and other (for example, gardening) activities (6%).

Patients’ levels of preparation for discharge and support from community services
The majority of patients (88%) felt very prepared for discharge; one could have been better prepared and one felt unprepared for discharge. Half of patients felt that they had enough support from community services; one felt there was not enough community support; 13% felt they could have been better supported, while 31% did not need support from community services.

Patients’ Assessment of Quality of Life (AQoL) before and after hospitalisation
Comparisons of patients’ AQoL before hospitalisation with their AQoL seven to ten days after discharge, revealed a sharp increase in their need for help with household tasks, a moderate increase
in reliance on medical aids and a slight increase in their need for help with personal care. There was a pronounced decline in patient’s mobility in the community during the week after discharge, although most could still manage mobility in their home.

Before hospitalisation, 19% could get around their home but could not get around the community and 12% could not get around their home or community. This compared with 50% who could not get around the community, but could get around the home with some difficulty and nearly a quarter (19%) who could not get around their home or the community after hospitalisation.

With regard to the patients’ need for help with personal care, before hospitalisation 63% needed no help, 13% needed occasional help, 13% needed help with the more difficult personal care tasks and 19% needed daily help. After hospitalisation, 56% needed no help with personal care, 13% needed occasional help, 13% needed help with the more difficult personal care tasks and almost 19% needed daily help with personal care.

As far as feeling anxious, worried or depressed before hospital were concerned, 63% did not feel anxious, worried or depressed; 25% were slightly anxious, worried or depressed; one was moderately anxious, worried or depressed and one felt extremely anxious, worried or depressed. After hospital, 38% did not feel anxious, worried or depressed; 38% of patients were slightly anxious, worried or depressed; 19% were moderately anxious worried or depressed; and one was extremely anxious, worried or depressed.

Among those patients needing help with household tasks before hospital, 38% needed no help; one needed occasional help; 38% needed help with more difficult household tasks and 19% needed daily help with doing household tasks. After hospital, one patient needed no help with doing household tasks; 13% needed occasional help; 56% needed help with the more difficult household tasks and 25% needed daily help with doing household tasks. These people reported having seen or visited the chemist more than any other community service, although visits to GPs were only slightly lower than chemists.

Following discharge from hospital, the majority (69%) of patients used five or more medicinal drugs regularly. Before hospital, 31% had to constantly use a medical aid (that is, a walking frame, wheelchair etc) compared with 38% having to constantly use a medical aid after discharge.
Furthermore, almost a quarter (19%) was reliant on regular medical treatment after discharge. The majority of patients had very close and warm personal relationships (74%), and a quarter felt that they sometimes had close and warm personal relationships. Almost 70% felt they had enough friends and were never lonely. For 56% of patients, their role in the family had been unaffected by their health. Half of them had normal vision; 80% had normal hearing and 80% had no trouble speaking or being understood. Although 38% slept without difficulty most of the time, the same numbers (38%) slept in short bursts only or were awake most of the night. Three quarters of patients had either no pain or moderate pain; 20% had severe pain; one person had unbearable pain.

In summary, since discharge the mean score of this sample’s quality of life was moderately good. This study found that where patients had a poorer quality of life after hospitalisation, this was mainly affected by illness and the inability to live independently. Poorer psychological wellbeing after hospitalisation affected quality of life. However, this purposefully selected sample did not represent people with complex care needs.

8.4.3 Telephone surveys with carers

Entry to hospital
Most carers (90%) surveyed reported that the cared-for had been admitted to hospital from the ED. Regarding the one elective admission, the carer had not been involved in pre-admission planning.

Preparation for discharge
Under half (40%) of carers were given instructions in hospital about the discharge medicines of the cared-for and a third of carers did not need instructions about discharge medicines, as the cared-for was taking the same medicines as before admission. None of the carers were given information about the side effects of discharge medicines and a third of carers were provided with an explanation of the discharge medicines.

A third of carers were given information in hospital about the type of help they might need with managing the cared-for at home. Four carers were given information on services available in the community that provided support and three were given information in hospital about the range of equipment that could be used at home.

According to carers, the day of discharge was more likely to be Monday (30%), Wednesday (30%) or Friday (20%), between the hours of 7am and 6pm on any of these days. None of the carers reported
an evening or night-time discharge. The majority (80%) of carers reported the care recipient coming home from hospital by private car.

With regard to the arrangement of community services prior to discharge, 40% of carers needed services arranged before discharge; 20% already had services in place and 20% did not need any help from community services. Services had arrived the following day for 30% of carers, one carer reported that services arrived 2 days after discharge; one had services arrive 4 days after discharge and another had not yet (7 to 10 days after discharge) had any services arrive. Two carers mentioned that it had taken too long for community services to arrive.

The hospital arranged equipment to be used by the cared-for for 50% of the carers, and the equipment had arrived and was being used. Such arrangements were not needed by two carers, as equipment was already in place. No equipment was needed by the cared-for according to two of the carers.

Four carers reported that the hospital had not involved them at all in planning for the cared-for’s discharge home. Among the six carers who had been involved by the hospital in discharge preparations, three thought they could have been more involved and three felt they had been very involved.

Half of the carers found discharge was on schedule and for the other half where discharge was delayed, the main cause was for reasons other than medications (30%). Waiting for transport (10%) was also cited by carers as causing delay to discharge, while 10% did not know the cause of the delay.

The majority (70%) of carers were not concerned about their ability to manage the cared-for at home, leaving almost a third (30%) who were concerned. Almost all (90%) of the carers were very concerned about the potential of the cared-for to fall after discharge from hospital. All the carers were able to contact GPs and services in the community as needed. The majority (80%) of the carers had not had any unexpected problems arise following discharge from hospital.

**Support provided by community services after discharge**

In the first week at home since discharge, one carer had help from services with shopping, one had help with house cleaning and two had help with gardening. Carers reported having seen or visited the
chemist more than any other community service, although visits to GPs were only slightly lower than chemists.

**Carers' levels of strain in looking after a recently discharged older person**

With regard to the levels of strain that carers were experiencing, 50% had a score of 7 or higher and had therefore experienced high levels of strain. Scores ranged between 0 and 13, where an individual score of 7 or higher indicated a high level of strain. Among this group of carers, the mean score of strain was 6. Overall, this sample was skewed towards high levels of strain. Ninety percent of carers were upset by how the cared-for had changed from him/her former self; most (80%) were physically strained and most had experienced changes to their personal plans (80%). Feeling confined and being forced to make family emotional adjustments affected over half (60%). Sleep disturbance and being upset by the behaviour of the care recipient was experienced by half of the carers and four of them felt completely overwhelmed by their caring role.

**Carers' level of preparations for discharge and support from community services following discharge**

The majority of carers (80%) felt very prepared for discharge; 10% could have been better prepared and 10% felt unprepared for discharge. Four carers felt that they had enough support from community services, while one felt there was not enough community support, one felt he/she could have been better supported while four did not need support from community services.

**8.5 A reflexive account of the interviews and surveys**

**8.5.1 Comparisons and contrasts between interviews and surveys**

Overall, using mixed methods of surveys with patients and carers and interviews with domiciliary and community nursing practitioners and hospital nurses generated more insights than would have otherwise been possible with either method alone. I adopted a ‘pragmatic’ approach of ‘if it works then do it’, as described by O’Cathain and Thomas (2006, p. 103). With regard to the surveys with patients and carers, I persisted with trying to recruit for as long as possible and made a pragmatic decision to stop, as there were obvious reasons which showed that this approach was not working (discussed in Chapter 9). In comparison, I had much more success conducting the interviews with domiciliary and community nursing practitioners and hospital nurses and this data generated more insights than would have been possible if a survey had been used.
The following table contrasts and compares the surveys with the patients and carers to the interviews with practitioners and nurses. The interviews with the practitioners and nurses are based on their perceptions of the main issues of patients and carers. In the section on contrasts, the main discrepancies between patients/carers and practitioners/nurses were the levels of patient preparations before admission, how prepared patients and carers were for discharge, how involved carers were in the discharge process, the comparison between few post-discharge problems experienced by patients compared with the perception of uncertainty, the numbers of readmission and the quality and extent of personal and social relationships that patients had with carers and families. There were similarities between the reported strain on carers, concerns about patients falling after hospital, delayed discharge, the emotional/psychological response of patients after hospital, the level of support needed and received from community services after hospital, delayed or inadequate community services after discharge, contacting GPs, the number of medications taken/day, what affected quality of life after discharge and carers needing services arranged before discharge occurred.

In sum, contrasting and comparing the surveys and interviews has revealed a number of contrasts and areas where there seemed to be agreement between the different data types. While it is problematic to draw any conclusions from this exercise, it demonstrates the variation between perceptions about service provision and about the differences between how patients and carers see themselves (as managing and resilient) and how practitioners and nurses perceive them (as vulnerable and unprepared). See Table 4 for a summary of this discussion.
Table 4: Contrast and comparisons between surveys and interviews

<table>
<thead>
<tr>
<th>Surveys with patients &amp; carers</th>
<th>Interviews: perceptions of practitioners &amp; nurses</th>
</tr>
</thead>
<tbody>
<tr>
<td>All patients were older and all had carers.</td>
<td>Information about older patients/clients and those who were younger with disability.</td>
</tr>
<tr>
<td>Patients felt prepared for admission.</td>
<td>Pre-admission uncertainty: ‘It depends on the circumstances of that particular person.’</td>
</tr>
<tr>
<td>Half had carers involved in discharge.</td>
<td>Carers excluded.</td>
</tr>
<tr>
<td>Most patients not concerned about ability to manage at home (more resilient).</td>
<td>Emphasis on patient safety and vulnerability.</td>
</tr>
<tr>
<td>Majority of patients and carers felt ‘very prepared’ for discharge.</td>
<td>Patients and carers are not prepared for discharge.</td>
</tr>
<tr>
<td>Patients AQoL showed sharp increase in needing help with household tasks, moderate increase in reliance on medical aids, less increase for help with personal care; pronounced decline in community mobility, most managed to get around their home.</td>
<td>No AQoL equivalent measure.</td>
</tr>
<tr>
<td>Knows how to contact community services.</td>
<td>Many do not know how to contact community services.</td>
</tr>
<tr>
<td>Few had unexpected problems after discharge.</td>
<td>Life is uncertain: ‘There life isn’t really quite the same as it was before’.</td>
</tr>
<tr>
<td>No readmissions.</td>
<td>High levels of readmissions</td>
</tr>
<tr>
<td>Most patients had close and warm personal relationships.</td>
<td>Concerns about the numbers of patients/clients who are socially isolated, in co-dependent relationships or dysfunctional families.</td>
</tr>
<tr>
<td>After discharge most carers not concerned about managing cared-for at home.</td>
<td>After discharge perception that most carers were concerned about managing cared-for at home.</td>
</tr>
</tbody>
</table>

Comparing the surveys with the interviews

<table>
<thead>
<tr>
<th>Surveys with patients &amp; carers</th>
<th>Interviews: perceptions of practitioners &amp; nurses</th>
</tr>
</thead>
<tbody>
<tr>
<td>High levels of carer strain.</td>
<td>Increased burden on carers.</td>
</tr>
<tr>
<td>Patients concerned about falling</td>
<td>Concerned about patients/clients falling.</td>
</tr>
<tr>
<td>Discharge gets delayed: reasons unknown.</td>
<td>Discharge gets delayed.</td>
</tr>
<tr>
<td>Increased anxiety, worry depression after hospital.</td>
<td>Patients/clients experienced fear, denial, loss of dignity and confidence.</td>
</tr>
<tr>
<td>60% had help already or did not need help.</td>
<td>Seemed most patients getting help or ‘stoical’.</td>
</tr>
<tr>
<td>Delayed or inadequate services for majority.</td>
<td>Delayed or inadequate services for majority.</td>
</tr>
<tr>
<td>Knows how to contact GP.</td>
<td>Knows how to contact GP.</td>
</tr>
<tr>
<td>Majority use 5 or more medications/day.</td>
<td>Most need 2 or more medications/day.</td>
</tr>
<tr>
<td>Poorer quality of life affected by illness and inability to live independently.</td>
<td>Poorer quality of life affected by illness and inability to live independently.</td>
</tr>
<tr>
<td>Carers need services arranged before discharge.</td>
<td>Carers need services arranged before discharge.</td>
</tr>
</tbody>
</table>
The cognitive dissonance of practitioners and nurses

In Chapter 5 (section 5.1.3) I demonstrated how reflexivity and critical reflection were part of my methods. I applied those methods to what I was hearing from the practitioners and nurses and felt I could not simply follow what they said at face value, but had to question why people who apparently had sound insight into the problems of care transitions were also telling me elsewhere in the interviews of their frustration and demoralisation. It was apparent that knowledge and empathy were insufficient for worthwhile system change for the patients/clients. Initially, I expected more empathy and less knowledge. But I was struck by how much knowledge practitioners and nurses had about the problem area, yet were still unable to make sufficient use of this. I wondered how they managed to cope with the internal conflict and still act as competent and committed professionals.

According to Aronson (1969), cognitive dissonance is a negative state of mind which occurs whenever a person has ideas, beliefs or opinions which are inconsistent. The practitioners and nurses seemed to be experiencing cognitive dissonance. Despite the clear insights into the problems associated with care transitions provided by domiciliary and community nursing practitioners, hospital nurses and other community service providers in the region, they were unable to achieve organisational change. It seemed there were a number of contributing factors that acted as barriers which helped explain this situation. First and foremost, they were practitioners and nurses engaged in providing patient/client care. Many just wanted to get on with their job. Bringing in change was not considered to be their role or responsibility. Unless they were delegated with a specific role to do so, practitioners and nurses were not mandated to act as change-agents. This was not the case for those at the managerial level, such as members of the Steering Committee, who were able to make decisions and were expected to assist with managing their organisations, including change-management processes. Even if practitioners and nurses were given some change-agent capacity, most were busy with their patient/client workload and did not have the time or motivation to engage in change.

Change is a complex and risky business, especially in the context of larger organisations like the hospital. Apart from the fact that many practitioners and nurses had change-fatigue from the regular rounds of restructuring over the years, being a change-agent was generally regarded as a specialised activity reserved for CEOs, managers, consultants or project officers. Still, those mandated to bring in change encountered resistance and sometimes it was not until one tried to bring about change that barriers to it emerged. If practitioners and nurses believed the organisation did not respect or value their ideas, they would be less inclined to attempt change, even if they knew it would benefit their clients/patients.
I have observed that when people’s morale is low, they tend toward stability and are less inclined to contemplate change. Change could be seen as another disruption to managing their workload. Moreover, there is instability in the nursing staff in hospitals evident in the number of agency nurses working to supply adequate staffing levels. This constant turnover of staff militated against change.

Finally, there were the diverse individual attitudes toward change that also need to be considered. Some people were cynical about change altogether, others embraced change and would be willing to act as champions, and others again feared the unknowns that change could bring. For many it was a case of ‘if it isn’t broke, don’t fix it’.

8.6 CHAPTER SUMMARY
In this chapter, I have presented the findings from the interviews with domiciliary and community nursing practitioners, the Reference Group, the hospital nurses and the surveys with patients and carers. The qualitative research contextualised the importance of continuity of care for HACC clients and for their carers, and the problems with provision of continuous care from service providers’ perspectives. Although the small sample sizes of patients and carers ruled out applying statistical measures of significance to the survey data, the descriptive statistics were found to support triangulation of the qualitative data. The Reference Group found many similarities to the uncertainties faced by older people and people with disability before admission to hospital and after their discharge, as well as gaining additional insights into people with mental health problems, paraplegia and quadriplegia, and the process of unplanned admissions of patients with disability.

Before admission to hospital domiciliary and community nursing practitioners located a fourfold context of uncertainty in the circumstances of individual patients and their uncertain health status, the uncertainties of ‘the caring role’, an uncertain home environment and access to reliable transport, and the uncertain response from both community services and the hospital system. The outcomes of an emergency or a planned admission were questionable. Uncertainty with regard to the impact of hospitalisation on older people was in relation to their ability to manage, their level of dependency and their quality of life. People with disability questioned the effect of a hospital admission on their stage of life, on familiarity with their surroundings and their routines, and on their elderly parents ability to manage the extra demands that hospitalisation made on them.

For carers, with the burden and strain arising from the complexity and difficulty of their caring role already apparent before admission, there was added uncertainty about their ability to cope with the additional demands of admission and afterwards. Carers were understood to play a crucial role, but
during admission they can be anxious and may need to put their own feelings, routines and life ‘on hold’, as well as managing the household and their self-care. Some carers were able to take respite during admission, or they may have reappraised their situation and/or their identity, and assessed alternatives. This could be a challenging period.

Home is the focus of people’s lives, and this was particularly so for older people and people with disability, who invested in the companionship of their pets, spent more time at home and felt secure in the familiarity of their routine and surroundings. Having to leave home for an admission threatened a fundamental pillar of security in their life.

Access to transport for a hospital admission had an important practical and financial value for someone with fewer resources and choices than others in the community. Gaining or maintaining access to community services was vital but also uncertain. Organising a planned admission caused disruption to home-based routines and involved many hours spent waiting, causing anxiety and fatigue. Uncertainty continued as to whether or not the planned admission would go ahead or be cancelled. Characterised as a churning system, the hospital has its own processes and timetable and was mostly unaccommodating and disempowering to the diverse cultures and needs in the population. These circumstances of uncertainty are multidimensional, inter-linked and subject to change or chance. Some aspects of uncertainty are controllable and predictable, but others are not.

When they leave hospital, the lives of older people, people with disability, as well as their carers, have changed. There is potential for adjustment in everyone’s behaviour, and adaptation of houses and in the provision of community services. Such changes can impact on the intensity and experience of this phase.

An individual’s adjustment to the uncertainty of his/her health status depended on the person’s health and living situation before admission, and the effectiveness and response to treatment. There was variation in the capacity to ‘bounce back’, to know what to expect and to learn new skills after hospitalisation. Living alone increased the potential for uncertainty. Leaving hospital was an emotional period for older people and people with disability, during which they feared losing their independence. Older people were more inclined to focus on the everyday things for survival, while people with disability wanted to reconnect with their life and tended to experience less stress than their older contemporaries. Both experienced financial losses and strain.
Changes in patients had a direct impact on their carers and/or family, who also had to adjust so as to cope with the ‘whole new scenario’ and the increased workload. Personal agency was involved in adjustment and assisted carers to assess, to problem-solve, to create workable routines and set achievable goals. Such adjustments were affected by access to professional advice and reassurance, skill development, timely and adequate support, respite and institutional care.

Service adaptations were affected by a range of hospital-based obstacles, the involvement or exclusion of carers, and the certainty of community service provision. The first two weeks after hospitalisation were recognised as a critical time for getting timely and coordinated community services and equipment to help ‘get back on track’ and reinforce their sense of control. Being already ‘in the loop’ of services was an advantage and facilitated early intervention to avoid a possible crisis if carers were unable to cope after discharge.

Hospital nurses detailed the potential complexity of discharge planning with older people and people with disability and their carer/family. While preparation for discharge sounded systematic and achievable, accurate and reliable information was needed from GPs, community nursing, domiciliary care, hostels and RAC. There were four dimensions that added to the complexity of discharging older people and people with disability. These were: (1) Patient readiness and safety, (2) The dynamic triad of relationships, (3) Hospital-based obstacles to the patient’s discharge, and (4) Community services, GPs, RAC and transport.

In this sample of older patients, the majority were admitted to hospital from the ED. Elective patients felt very prepared for their admission. Regarding discharge preparations, around half of patients were given instructions about their discharge medications and about home-help. Timely and adequate provision of community services to patients after discharge applied to 25% of patients. The arrangement of equipment was managed successfully by the hospital. Discharge was delayed in a third of cases. Apart from two patients who felt unprepared for discharge, all others felt very prepared. Despite this, a third of patients felt very concerned about their ability to manage at home and about falling. In their first week home, none of the patients were readmitted to hospital. Overall, quality of life since discharge was moderately good. The main reasons for poorer quality of life were illness, lack of independence and poor psychological wellbeing. However, none of the patients had complex care needs and all had carers, a third did not need community services and most had access to private transport.
A satisfactory level of involvement in discharge planning was reported by 30% of carers. Less than half were given information about medications and none were told about side-effects. A third was given information on community services and for those carers who needed support from community services after discharge, the services arrived the following day in 30% of cases. While the majority of carers were not concerned about their ability to manage at home and felt very prepared for discharge, half experienced high levels of strain as a result of the post-acute care they provided.

Multiple perspectives contributed to the findings in this chapter. Highlighted here is the importance of understanding the diverse circumstances of older people and people with disability and their carers, as well as identifying the opportunities for intervention to improve continuity of care by the hospital and community services before, during and after hospitalisation. According to the domiciliary and community nursing practitioners, before admission to hospital four dimensions of uncertainty, depending on individual circumstances, are operative. Hospital nurses reported that discharge planning was complicated by these four dimensions, and emphasised that older people and people with disability wanted assurance that someone would help look after them when they left hospital. Once they had returned home, domiciliary and community nursing practitioners pointed out the need for adjustment and adaptation as they were people whose ‘life isn’t really quite the same as it was before’. The next chapter will discuss the implications of these findings for practice, policy and theory.
PART FIVE: CONTRIBUTION TO NEW UNDERSTANDINGS
CHAPTER 9: DISCUSSION

“The situations of practice are not problems to be solved but problematic situations characterized by uncertainty, disorder and indeterminacy.” (Schön, 1983, p. 16)

9.1 CHAPTER INTRODUCTION
In the first section of this chapter a review of the main findings is presented. I then compare the differences between my results and those of similar studies in the literature. I consider the extent to which the key findings of this study are novel and are generalisable. I describe the implications of the findings for theory, policy and practice. In the next section I discuss the strengths and weaknesses of action research in relation to its application to care transition planning. Finally, I suggest areas for future research on this topic and present the conclusions to this thesis.

9.2 REVIEW OF THESIS
This thesis has applied action research to identify the nature of the changes needed in South Australian hospitals and HACC systems to reduce poor outcomes and improve the continuity of care of older people and people with disability, as well as their carers. In order to address this research aim the following objectives were proposed (see Chapter 1):

1. Analyse the factors in the literature that lead to discontinuity of care of older people and people with disability and their carers in transition between the hospital and community care systems.
2. Plan and implement actions to improve the continuity of care for older people and people with disability, and their carers, living in the specified region of Adelaide.
3. Observe the effect of the actions taken to improve the continuity of care for older people and people with disability, and their carers, living in the specified region of Adelaide.
4. Analyse the results and reflect on their wider implications for theory, practice, policy and future research on the continuity of care for older people and people with disability and their carers.
5. Reflect on the utility of action research as a means to analyse and improve the discontinuity of care for older people and people with disability and their carers in transition across the acute and community care interface.

9.3 THE MAIN FINDINGS
The main findings from the action research project and the thematic and descriptive analysis before, during and after hospitalisation are presented below.
The thematic analysis before, during and after hospitalisation has led to the development of a model of ‘Systemic Uncertainty and Complexity Before, During and After Hospital’. This model incorporates the key findings from the thematic analysis over time (before, during and after hospitalisation) and is a unique contribution to theory and practice as it incorporated vulnerability and resilience over time.

These findings are considered with respect to their differences with and similarities to the literature review in Chapter 2. Where a finding from this research was unanticipated in the original literature review, additional references were sought for their consistency or otherwise with the finding and added where applicable.

9.3.1 The action research project

Actions

A range of actions, which included piloting YHR with patients and facilitating the creation of The Hub in the hospital, were reflexively planned, implemented and evaluated. Educational opportunities were provided with reflexively planned sessions for hospital doctors and nurses. These actions increased local linkages between the hospital and community service providers, enhancing collaboration, communication and access to information about the HACC program. Importantly, The Hub continues as the most sustainable and successful outcome of the project. Your Health and Community Services Record, which was custom-designed for YHR, is still being distributed in the region. The main reasons for the success of these actions was: they were developed and maintained in collaboration, key people took responsibility for maintaining them once the study had finished, the costs and resources were shared across a number of agencies during the development phase, and the purpose of the action fitted with the goal of the organisation or agency that took ongoing responsibility.

Critical Reflections

Critical reflections on the process of the project demonstrated strengths of commitment and motivation for change through participation, the provision of educational opportunities and empowerment. Limitations of the process include the censoring and withdrawal of the final report and the collaboratively developed recommendations. This was disempowering to the participants and affected the momentum for change. As a result of reflecting on the YHR outcome, the strength of its value, need and generalisability are recognised.

Strengths and Limitations of Project

The strengths and limitations of YHR and The Hub point to the importance of timing and sustainability in this project. Despite this, the project appeared to have little or no direct effect on avoiding poor outcomes or improving discontinuity of care. Such effects were more complex, and achieving the
necessary systems and structural changes to address these problems would have required a commitment to greater time, resources, capacity and leadership by government departments and the agencies.

The action research project generated significant good will between the community and hospital sectors in the region and an ongoing commitment to work together to address common issues. As a process, excellent levels of participation were maintained. The study has led to cross-sector representation by the hospital in the HACC program in the region, which keeps community and hospital sector issues at the forefront of Steering Committee agendas. Information continues to circulate on cross sector issues. This ongoing link is essential to maintaining effective communication and information sharing.

9.3.2 Thematic and descriptive analysis before, during and after hospitalisation
The descriptive statistics of surveys with patients and carers and the key issues identified by the Reference Group supported triangulation of the interviews with domiciliary care, community nursing and hospital participants. From the Reference Group additional insights were gained into people with mental health problems, paraplegia and quadriplegia, and the process of unplanned admissions of patients with disability.

Context of uncertainty before admission to hospital
With regard to the key findings before admission to hospital, the domiciliary and community nursing practitioners conveyed a pervading context of uncertainty in the:

1. the circumstances of individual patients and their uncertain health status,
2. in ‘the caring role’,
3. in the home environment and access to transport, and
4. in the responses from community services and the hospital system.

This context of uncertainty about what the future held when an older person or someone with disability was admitted to hospital was most succinctly captured in the thematic observation: ‘It depends on the circumstances of that particular person’. Practitioners had doubts that older people and people with disability would be able to access services and they were concerned about the kind of response they would get from community and hospital services. Bringing together these four dimensions under the theme of uncertainty before admission to hospital is unique to this study and contributes a comprehensive understanding of the effect of hospitalisation on this group of people.
1. Circumstances of individual patients and their uncertain health status

<table>
<thead>
<tr>
<th>Key Findings</th>
<th>Similarity with literature</th>
<th>Novel findings</th>
</tr>
</thead>
<tbody>
<tr>
<td>Improving health-related quality of life (Brand et al., 2004; Harrison et al., 2002), transitional care (Advocate Health Care, 1997; Bixby et al., 2000; Coleman, 2003; Coleman et al., 2004; Boockvar, 2004; Phillips et al., 2004; Naylor, 2000; Sherman, 2006) and post-discharge outcomes (Almada &amp; Archer, 2009).</td>
<td>Differences in relation to time, organisation and stress between an emergency and a planned admission of an older person or a person with disability were found. Both experiences raised questions about the outcome of hospitalisation. Uncertainties about the impact on their dependency level were common among older people and people with disability. Older people questioned their quality of life and ability to cope or manage afterwards and people with disability tended to question the effect on their stage of life, their routines, need for familiar surroundings, and the impact on their elderly parents.</td>
<td></td>
</tr>
<tr>
<td>Key Findings</td>
<td>Similarity with literature</td>
<td>Novel findings</td>
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<tr>
<td>-----------------------------------------------------------------------------</td>
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</tr>
<tr>
<td>2. Uncertainty in ‘the caring role’</td>
<td>Complexities of caring role (HREOC, 2007; O’Connor, 2007; Carers Australia, 2008). Carers of people with disability and issues of identity; stress; crisis about the future or adaptation strategies of incorporating the caring role into their life; or personal anguish and unresolved issues (Chamberlayne &amp; King, 1997). Fears social isolation, maintain social and learning needs and desired respite (Stoltz et al., 2004). Health and financial strain, high stress levels and low sense of wellbeing among carers (Emanuel et al., 2000; Nepal et al., 2008). Behavioural changes in older person being cared-for predict carer distress (Venables et al., 2006). #1354}</td>
<td>Although the findings presented here concur with other research on the challenges, uncertainties and complexities of the caring role, the focus on the period before admission to hospital has extended what was already known in the literature.</td>
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<td>3. Uncertainty in the home environment and access to transport</td>
<td>Personal significance of home to older people or people in need of long-term care (Argus et al., 2005; Ryan et al., 2009). Perceptions of a good quality of life include access to local facilities and services, including transport (Zahava &amp; Bowling, 2004).</td>
<td>Older people’s concerns about leaving their home and pets for a hospital admission and problems accessing transport was a distinctive contribution to the literature.</td>
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<td>Key Findings</td>
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<td>4. Uncertain responses from community services and the hospital system</td>
<td>Dependency ratio national/international policy (ABS, 2006)</td>
<td>A unique finding here were older people’s and people with disability doubts about accessing services and their concerns about the kind of response they would get from community and hospital services before admission to hospital.</td>
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<td>Critiques of structural dependency (Kennedy &amp; Minkler 1998; Conroy et al., 2006).</td>
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<td>Regional level: high proportions of older people, people living alone and people needing ADL assistance contributed to socio-economic disadvantage, relatively higher burden of disease, and high levels of demand for hospital and community services (ABS, 2008; ABS, 2006).</td>
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<td>Older people found health professionals ageist (Minichiello, et al., 2000).</td>
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During hospital admission: four dimensions of complexity in discharge planning

During a hospital admission, hospital nurses painted a complex picture as they spoke of the range of problems they encountered when attempting to discharge older patients or patients with disability. The types of problems that arose fell into four categories. These were:

1. Patient’s readiness and safety,
2. Dynamic triad relationship,
3. Hospital-based obstacles to the patient’s discharge, and
4. Timely and coordinated access to community services; residential aged care (RAC) and transport.

In bringing together the four dimensions under the theme of complexity in discharge planning, I have gained a comprehensive understanding about the inter-relationship between the various people and sectors involved in this component of care transitions. In particular, by identifying the dynamic triad relationship is a unique addition and helps explain the underlying tensions and complexities that result in discharge planning being ‘the bane of our lives’, as a nurse remarked.
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<th>Key findings</th>
<th>Similarity with literature</th>
<th>Novel findings</th>
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<tr>
<td>1. Patient’s readiness and safety</td>
<td>Multiple aspects of patient’s readiness impact upon the complexity of discharge planning (Franey, 1995; Sager et al., 1996; Naylor et al., 2000; Covinsky et al., 2003; McKeown, 2007; Swinkels &amp; Mitchell, 2008; Wakefield &amp; Holman, 2007). During and after hospitalisation older people can become confused, fearful, anxious or depressed over their health status and circumstances: Reduced levels of wellbeing could be caused by insecurity and were not necessarily due to hospitalisation (Kvaal &amp; Laake, 2003); Older patients recovering from hip-fracture at risk of depression had less chance of recovering ADL and mobility than patients at no risk of depression (Shyu et al., 2008); When depression was diagnosed in older patients after discharge it was a major risk factor for reduced time of survival in the community (Wilson et al. 2007) and those with ADL limitation and depression were more likely to be readmitted than those only with ADL limitation (Mast et al., 2004).</td>
<td>This finding describes nurse's perspectives of the range of issues that directly impact on the patient and their discharge. Nurses mentioned patient’s readiness included their mental capacity, emotional adjustment and expectations and Nurses thought that patient’s safety included their perceived ability to manage their circumstances, their physical, medical and mental status, their additional roles and responsibilities, the services they needed and the readiness of their home.</td>
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<td>Key findings</td>
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<td>2. Dynamic triad of relationships</td>
<td>Complex interplay of poor communication and lack of involvement of patients by hospital staff (Congdon, 1994; Reiley et al., 1996; Calkins et al., 1997; Armitage &amp; Cavanagh, 1998; Rowe et al., 2000; Williams et al., 2006; Efraimsson et al., 2006a; Huby et al., 2007). Hospital's tendency not to involve or communicate with carers in discharge planning (Armitage et al., 1995; Williams et al., 2006; O'Connor, 2007; Carers Australia, 2008). Hospital’s overestimate the role of or implicitly depend upon carers to support and manage older people or people with disability at home after discharge (Grimmer et al., 2000; Procter et al., 2001; Williams et al. 2006; O'Connor, 2007; Carers Australia, 2008). When relatives of older patients were thought to obstruct discharge planning, their concerns were focused on the lack of community services. (Gallagher et al., 2008).</td>
<td>Conflicting objectives can operate between patients and nurses, (successful discharge planning versus ensuring duty of care). A patient's carer/family needed to be familiar to nursing staff, but there could also be refusal, denial and avoidance from the carer/family to nurses. Other issues were cultural, or included a lack of understanding by the carer/family of the limitations to hospital and medical treatment. The links between the carer/family and the patient depended on the quality and functionality of their relationship.</td>
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<td><strong>3. Hospital-based obstacles to the patient’s discharge</strong></td>
<td>Low impact and effectiveness of discharge planning processes (Mamon et al., 1992; Hedges et al., 1999; Atwal, 2002; Watts &amp; Gardner, 2005; Bull &amp; Roberts, 2001; Shepperd et al., 2004; Mistiaen et al., 2007). Early or delayed or unsafe discharge (Proctor et al., 1996; Mistiaen et al, 1997; Victor et al., 2000; Mountain &amp; Pighills, 2003; Nygard et al., 2004). Insufficient communication or information (Lurie et al., 1984; Armitage &amp; Williams, 1990; Smith, 1996; Bryan et al, 1997; Lundh &amp; Williams 1997; Marks et al., 1999; Luker et al., 2000; McKenna et al., 2000; Eija &amp; Marja-Leena, 2005; Satzinger et al., 2005). RNs inevitably experience complexities and contradictions in their work arising from the distinction between personal and organisational morale (Day et al., 2007).</td>
<td>Insufficient time, training and information, and the systemic versus individual model of discharge planning are hospital-based obstacle. Also, when discharge was delayed or rushed, the doctor’s roles and their communication, workloads, patient’s medications, letters, summaries, referrals and tests were contributed to hospital-based obstacles.</td>
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| **4. Community services, GPs, RAC and transport** | Significance of:  
- Accessibility and availability of community services (Armitage & Kavanagh 1998; Victor et al., 2000), GPs (Massey-Westropp et al., 2005; Balaban et al., 2008) and RAC (AIHW, 2008).  
- Communication with and coordination of community services (Lurie et al., 1984; Armitage & Williams, 1990; Smith, 1996; Bryan et al, 1997; Lundh & Williams 1997; Marks et al., 1999; Luker et al., 2000; McKenna et al., 2000; Eija & Marja-Leena, 2005; Satzinger et al., 2005).  
Work and life balance understood as affecting communication with carers (Armitage et al., 1995; Williams et al., 2006; O’Connor, 2007). | Role of transport in relation to discharge planning is underestimated. |
When leaving hospital: three dimensions of adjustment and adaptation

Anticipation and preparation for leaving hospital and arriving home was the beginning of an adjustment and adaptation phase for older people and people with disability, and their carers. Their adjustment also depended on their circumstances. Both adjustment and adaptation refer to changes. Adjustment refers to the changes people can make in their behaviour; whereas adaptation concerns the changing of ‘something’ to make it more suitable for a new situation or purpose, for example, the adaptation of houses or community services to make them more suitable to the changing needs of a person after hospitalisation. Depending on a person’s adjustment and the adaptation of houses and services, the intensity and experience of this phase varied considerably and included physical, emotional and practical adjustments. In the interviews with community nursing and domiciliary practitioners the major theme to emerge was circumstantial adjustment and adaptation, with the dimensions of:

1. Personal adjustment to changing health status;
2. Carer and family adjustment, and
3. Service adaptation.
### Key findings

| 1. Individual adjustment to changing health status | Aspects of resilience in older people and people with disability in numerous other studies (Druss & Douglas, 1988; Felten & Hall, 2001; Aronson, 2002; Hardy et al., 2002; King et al., 2003; Murray, 2003; Hardy et al., 2004; Jang et al., 2004; Kinsel, 2005; Dew et al., 2006; Montross et al., 2006; Kendall & Terry, 2008; Mehta et al., 2008; Smith & Zautra, 2008; Windle et al., 2008). Research on the emotional impact on older people leaving hospital is scarce and tends to medicalise the process by focussing on the incidence and persistence of depression (Koenig et al., 1992). Sexton (1996) identified four major themes which represented an older patient’s return home following discharge from hospital. Socio-economic status is recognised as a significant factor in the determination of health and wellbeing and in predicting post-discharge service use (ABS, 2008; ABS, 2006; Moore et al., 2007; Roe-Prior, 2007). |
| Similarity with literature | Novel findings | Individual adjustment depended on: living situation (alone/others) and home set-up. Those living alone had more uncertainties about going home, managing and getting help. Older peoples’ adjustment related to health and living situation, effectiveness/response to treatment. There was variation between older people and people with disability in capacity to ‘bounce back’, in understanding about what to expect, in ability to learn new skills and depth of emotional adjustment. |

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<td>2. Carer and family adjustment</td>
<td>Aspects of carer and family adjustment in the literature include the increased workload or burden on carers and family (Grimmer et al., 2000; Emanuel et al., 2000; Horner &amp; Boldy, 2008; Nepal et al., 2008; Ornstein et al., 2009). Moral obligation to provide care (Procter et al., 2001). Adjustment to the whole new scenario and need for skill development (Morrow-Howell &amp; Proctor, 1998; Pickard &amp; Glendinning, 2002; Stoltz, 2004; Hendrix &amp; Ray, 2006; Venables et al., 2006). Access to respite and institutional care (Dellegesa &amp; Nolan, 1997; Stoltz, 2004; Sundstrom &amp; Johansson, 2005). Inter-relationship between carers’ capacity to adjust and the types of supports to help them adjust (Ornstein et al., 2009).</td>
<td>Carer and family adjustment involved: ‘a whole new scenario’, sustaining additional workload during the recovery period, commitment, vigilance (esp. stroke, dementia or cognitive impairment), learning about new medications, skills, equipment and home modifications. Personal agency depended on: age, physical and mental health, confidence with asking questions, ability to assess their situation, problem-solve, create workable routines and set achievable goals. Carers and family adjustment was affected by: access to professional advice and reassurance, skill development, timely and adequate support, respite and institutional care.</td>
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<td>3. Service adaptation</td>
<td>Shortfalls in the supply of HACC services (Rimmer, 2004). Rationing of services in the home (Aronson, 2002). Delays in delivery of service result in many older people remaining in hospital after the completion of treatment (Wilson et al., 2003). Adequacy of funding for community care (Bruen, 2005; Sadler, 2006). Slowness of reform to community care (Aged and Community Services Australia, 2008). To assist with recovery: Importance of timely referral to district nursing services (Wilson et al., 2002); Other community services (Bolch et al, 2005); Being given adequate information in the community (Worth et al., 2000). Community care enabled older people with complex needs to remain at home (Ryan et al., 2009).</td>
<td>Affected by hospital-based obstacles: (attitudes, information and explanation, safety, personal belongings); critical role of carers and certainty of community service provision (first 2 weeks is critical time, timely delivery, access, communication, coordination and early intervention for carers)</td>
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9.4 MODEL OF SYSTEMIC UNCERTAINTY AND COMPLEXITY BEFORE, DURING AND AFTER HOSPITAL

Putting these dimensions together, the main themes to emerge in this context are ‘systemic uncertainty and complexity’. In building upon these themes, I have developed a model of systemic uncertainty and complexity before, during and after hospital. The model is presented on the following page.

Figure 17 illustrates that for older people, people with disability and their carers, uncertainty and complexity occurs over linear time and over care transitions between community and hospital care. This is demonstrated by the yellow arrow running from left to right across the bottom of the figure. Time is divided into three shaded blue spheres, which are before admission to hospital, during a hospital admission and after hospitalisation. Running parallel and in sequence with time are the transitory states of vulnerability and resilience, implying that older people, people with disability and their carers can bounce back from being vulnerable to becoming more resilient as time passes. However, their vulnerability and resilience is affected by the four dimensions of uncertainty, the four dimensions of complexity in discharge planning and the three dimensions of adjustment and adaptation. Thus, vulnerability and resilience are transitory and difficult to predict. For these reasons, it is important to recognise the orange flag containing two critical intervention times. These are: 1. the first 24 hours after discharge for people who are frail or have complex care needs, and 2. the first 14 days after discharge for older people, people with disability and their carers. There are three additional intervention opportunities, represented by the red dashed arrows leading downwards from the spheres and intersecting with the time line. These opportunities relate to preventing hospital admissions, reducing complexity in discharge planning, and supporting adjustment and adaptation. This practice-based model of systemic uncertainty and complexity has implications for theory, policy and practice.
Figure 17: MODEL: SYSTEMIC UNCERTAINTY AND COMPLEXITY BEFORE, DURING AND AFTER HOSPITAL
9.5 IMPLICATIONS OF UNCERTAINTY AND COMPLEXITY FOR THEORY, POLICY AND PRACTICE

“A man doesn't know what he knows until he knows what he doesn't know.” (Peter, unknown)

Introduction

According to the dictionary, uncertainty is a lack of assurance about an outcome. Complexity is:

“a state of having many different parts, which are connected or related to each other in a way that may be difficult to understand or to deal with.” (Sinclair et al., 1987, p.284)

Complexity describes the system from service providers’ perspectives. Systemic uncertainty and complexity involves the difficulties with understanding the system and the lack of assurance about the inter-connections between hospital and community care. Uncertainty and complexity in this context is not only difficult for carers, families and service providers, but can result in poor outcomes for older people and people with disability and for service usage.

In this study exploring continuity of care and poor outcomes between hospital and home for older people and people with disability, uncertainty and complexity is fundamental to the difficulties in understanding the system and the lack of assurance about the inter-connections between hospital and community care. The combination or uncertainty and complexity in this context are not only difficult for carers, families and service providers, but can result in poor outcomes for older people and people with disability and for service usage. Uncertainty and complexity applies to older people, people with disability, carers, families and service providers.

From community service provider’s perspective, uncertainty and complexity applies before hospital when:

- There are expectations of an improvement in health, to have a condition treated or to simply feel better,
- Their carer/family is able enough to reasonably assist with the admission process and anticipate coping with the additional burden of care afterwards,
- Their home environment is adequate to support them,
- Transport is available and reliable,
- They can rely on community services afterwards, and
- They can rely on the hospital to proceed with the admission and treat them in a reasonable and respectful manner.
During a hospital admission, nurses conveyed the lack of assurance of aspects of discharge planning for older people and people with disability as to whether:

- The patient would be well enough to go home safely,
- There would be no last minute changes or problems with the carer/family raised when the patient was ready to be discharged,
- The patient’s doctors would have completed all aspects of their role in discharging the patient (discharge summaries, medications, letters etc.) and these were ready for the patient to take with them,
- Referrals were made to community services and services would be delivered within 24 hours of the patient’s arrival home,
- GPs would be able to visit the patient at home or see the patient in their surgery to prescribe medications and continue treating the patient in the community,
- The patient was assessed as not being able to manage at home and needed admission to RAC, an ACAT assessment was completed and approved and a place was available for the patient, and
- The patient could be transported to their discharge destination.

From community service provider’s perspectives, as the patient left hospital uncertainty and complexity applied when:

- The patient returned home and adjusted to their changing health status,
- The patient’s carer/family adjusted sufficiently to provide most of the care, and
- Timely and adequate support was provided by community services during the critical recovery period.

Uncertainty and complexity pervades the system over the period before, during and after hospital. Thus, it is the system, not individuals, that is largely responsible for discontinuity and poor outcomes. The implications of these findings for theory, practice and policy are now discussed.

**Theory**

The contributions that I make to theory are in conceptualising a hybrid understanding of care transitions as involving systemic uncertainty and complexity, and temporal and transient vulnerability and resilience. I have developed these concepts into the practice-based model of systemic uncertainty and complexity. This model is informed by Schröder-Butterfill and Marianti’s framework of vulnerability (2006a; 2006b), Niehof’s (2008) understandings of resilience and William’s (2001) notion of the social practice of care. My findings also indicate that there are critical intervention times for practitioners as well as opportunities to support resilience within the context of vulnerability of older people, people with disability, and their carers. This is consistent with Niehof’s understanding of resilience. There are
two critical intervention times that provide a window of the opportunity to prevent poor outcomes. For people who are frail or have complex care needs, the first 24 hours after discharge from hospital is a critical intervention time. The first 14 days after discharge from hospital is a critical intervention time for older people, people with disability and their carers.

Iatrogenesis and medicalisation
We live in a medicalised society. The lives of older people are more intensely medicalised than people of other age groups because of their greater likelihood of having multiple chronic diseases, which increases their chance of hospital admission and readmission (Moore et al., 2007). The lives of people with disability are medicalised too, but in this study this factor appears to a lesser degree because of their age, ability to recover more rapidly, access to a carer or family and their mistrust in the hospital system.

Readmissions and prolonged hospitalisation of older patients and patients with disability are associated with illnesses caused by medical treatment, or clinical and cultural iatrogenesis (Illich, 1975). Clinical iatrogenesis occurs during the hospitalisation of older patients when they develop confusion and/or functionally decline; or have an adverse drug reaction, or if people with disability develop pressure sores. Cultural iatrogenesis was particularly analogous to the experiences of a proportion of older patients, especially people who may be living ‘on borrowed time’ (like ‘Tatiana Gorbachev’ or ‘Miss Bernice Radcliff’66). Medical treatments are enacted upon people without a clear understanding of the uncertainties of their circumstances and complexity of discharge planning, both of which contribute to cultural iatrogenesis.

Illich argued that when people surrendered themselves and their trust to the medical profession they also relinquished the resilience and resourcefulness which helped them cope with adversity. To a limited extent older people surrender their trust to the medical profession, internalising their fears and anxieties about resuming their life and role in their family. However, they are also capable of demonstrating stoicism and resilience in their recovery from illness, in an effort to hold onto their life, their autonomy and their home. In this study and in the literature people were more disempowered by the hospital environment than from surrendering their trust, as Illich claimed. Furthermore, Illich’s critique of the medical establishment did not assist with analysis of individual professionals, as none of the medical professionals I encountered during this study were profit-driven and heartless as characterised by Illich. On the contrary, most were committed and worked hard in a difficult system.

66 Although the names given here are fictitious the account of the circumstances were drawn from the real-life situations of domiciliary care clients. Refer to Chapter 6 for details.
In this study the main reasons for the occurrence of problems were organisational factors, such as time pressures and workload constraints. On the whole, this was because their work takes place in:

“…a thick context of organizational possibilities, constraints and contingencies” (Strauss, 1985, p.266)

By identifying the theme of systemic uncertainty and complexity, I have extended Strauss’s context of an organisation to the context of the system, which being comprised of multiple dimensions, is a thick context of uncertainty, complexity, adjustment and adaptation.

Not all institutionalisation is premature, but I argue that a proportion of that which occurs following hospitalisation could be avoided if people’s capacity to return home is better resourced by timely community services and if their carers/families are better supported during the first 24 hours after discharge. Here I am arguing that hospitalisation is potentially iatrogenic (cultural) for older people and people with disability and this ought to be reconsidered within a context of uncertainty and complexity. Without a doubt this reconsideration should occur not as a reason to curtail or deny treatment, but instead to identify needs holistically and find better ways to:

“…make sense of complexity and to reduce uncertainty to manageable risk.” (Schön, 1983, p.18).

In sum, Illich’s clinical and cultural iatrogenesis resonates as a critique of some aspects of treatment and care at the system-level, but not at the individual level of patient/client, carer/family or as professional. Medicalisation is wide-spread in our society and older people and people with disability are particularly prone to being over-medicalised. Producing contradictory outcomes, medicalisation of older people and people with disability contributes negatively to iatrogenesis, yet positively to treatments for health conditions and for improvement of quality of life. Thus, the medicalisation of older people and people with disability offers the uncertainty of functional decline during hospital treatment, or the potential of an adverse drug reaction, as well as the opportunity to lead a more comfortable, healthier and longer life.

**Ethics of care, vulnerability and resilience**

Even though the HACC program is premised on the social value of independence, this analysis of the needs of this group and their carers suggests that independence is a myth. Indeed, the social discourse of independence contributes to HACC clients’ and/or their carers' fear of losing their independence following hospitalisation. It also adds to the dissonance experienced by service providers through their blaming one-another for poor outcomes (the blame game) or by their
recognition that other service providers make their best effort to provide continuity of care, but they too are working under similar constraints. These constraints include knowing that the needs of the older people and people with disability are complex, that information flows and communication lines between the sectors are inadequate, that the systems of care are fragmented and that the resources are limited. Before admission, the uncertainties of older people and people with disability and their level of dependency on others after discharge have invoked the analysis of interdependence by care theorists like Sevenhuijsen (2003) and Hankivesky (2004). In theorising about care, the role of carers has been separated from those who are cared-for (Fine & Glendinning, 2005). Recognising people’s interdependence, autonomy and the role of carers has important implications for how we value care. A greater valuing of our need for care and reliance on others to provide it at certain points in our lives could lead to an enhanced social commitment to provide adequate care.

Vulnerability is associated with systemic and individual uncertainty and complexity. The framework proposed by Schröder-Butterfill and Marianti (2006a; 2006b) is a useful theoretical tool to assist our understanding of what might constitute the vulnerability of older people and people with disability to poor outcomes following discharge from hospital. Resilience is associated with adjustment and adaptation and while resilience in older people and people with disability is a nascent field, little is known about this group’s resilience and how they cope and thrive after hospitalisation. As both vulnerability and resilience have been identified as important overlapping themes in this study, I am arguing (in agreement with King, 2003; Murray, 2003; Tanner, 2007; Niehof, 2008), that frameworks or analytical approaches which include both concepts are preferred as being a closer representation of people’s real lives and are therefore of much greater theoretical and practical value.

Uncertainty and complexity
Analysis has helped take out the abstract problems of uncertainty and complexity from their respective ‘messes’. Ackoff (1979) described messes as:

“...the complex system of changing problems that interact with each other” (Ackoff, 1979, p.99).

Describing the practitioner’s relationship between theory and practice, Schön (1983) used a geographical metaphor which I adopt to describe the dilemma I faced when thinking about the theoretical implications of systemic uncertainty and complexity in practice:

“In the varied topography of professional practice, there is a high, hard ground, where practitioners can make effective use of research based theory and techniques, and there is a swampy lowland where the situations are confusing ‘messes’ incapable of technical solution. The difficulty is that the problems of the high ground...are often relatively unimportant to
 clients or the larger society, while in the swamp are the problems of greatest human concern. Shall the practitioner stay on the high hard ground where he can practice rigorously...but where he is constrained to deal with problems of relatively little social importance? Or shall he descend to the swamp where he can engage the most important and challenging problems if he is willing to forsake technical rigor?” (Schön, 1983, p.42.)

I am using the term ‘messy problems’ to describe uncertainty and complexity. While it appears that the situations of movement between hospital and home of older people and people with disability and their carers are messy problems that cannot be fixed by research based theory or by technical solutions, I argue that these problems are nevertheless important to understand for the sake of clients, the larger society, as well as for theory. With regard to Schön’s topography, these problems are like the plateau between the high, hard ground of theory and the swamp of human concerns.

Many commentators have described the health system in Australia and in other developed countries as complex and fragmented. The problems of uncertainty and complexity change and interact over time, as the four dimensions of uncertainty before admission, four dimensions of complexity during admission and three dimensions of adjustment and adaptation described in this study demonstrate. Uncertainty and complexity are embedded in the process of the movement between hospital and home for this group of people. As such, changes or adjustments inevitably occur over time.

Uncertainty is largely left out of theoretical discussion because it is difficult to use as a way of explaining the way things are. Furthermore, as Rifkin et al. (2007) explained, the case for certainty is far more appealing as we look to science and experts for concrete answers, particularly about our health. Uncertainty is left out of reporting about health risks and benefits partly because it leads to anxiety, and also because of the need by authorities to project power and control when protecting the public from exposure to risks. However, the public also want to know about health risks in absolute terms and rather than sounding ‘wishy-washy’ (or uncertain), it is easier for authorities to reduce the range of risks to concrete answers (or single-number goals), despite the fact that this is unrealistic.

The findings from this study on the continuing health and community care needs of older people and people with disability provides a comparative example of a situation where the goal of providing continuity of care in a fragmented and complex system is unrealistic. Similarly, when health authorities maintain continuity of care as a goal they are projecting power and control over uncertain and complex messy problems. However, I agree with Rifkin et al. when they claim there are good reasons for delving into the subject of uncertainty. Even though the context discussed by Rifkin et al. differs from the one presented here, I argue from a theoretical perspective that two (of their four) reasons can be applied here.
First, we need to understand uncertainty to find out what we know and what we don’t know. If it is found that the goal of providing continuity of care to this group of people in this system is unrealistic, then this provides us with the knowledge and rationale to conduct further research. Such research should be aimed at developing evidence-based outcomes for the reasonable, achievable and effective management of the health and community care of this population. Second, conveying the results of complexity and uncertainty to health and community care practitioners would facilitate a broader understanding of uncertainty as systemic, thus individuals are considered less culpable. This could have an effect on morale as people may be less inclined to blame themselves or others and provide the basis for identifying ways to manage uncertainty and reduce complexity. While it is not a panacea, understanding uncertainty is the plateau between messes and certainty.

By highlighting a problematic situation like the one studied here, Ackoff (1979) warned against treating problems independently from one another. A multi-disciplinary approach would assist with developing a broader understanding of systemic uncertainty that reflects the circumstances of people’s lives and of a range of workable interventions from service providers. The dominant discourse is ‘problem-focused’ in theory and in practice and this affects the capacity to change. Analysis of problems needs to move from problem-focused reactions and medicalised approaches to a multidisciplinary analysis. This approach would assist with understanding the multiple factors that contribute to uncertainty and complexity and identify the factors and opportunities that contribute to vulnerability and resilience.

Hospital and community service providers are burdened by failing to live up to their own norms (proper discharge planning; providing continuity of care; avoiding readmission; preventing premature institutionalisation) and by an incapacity to help society achieve its objectives and solve its problems. Practitioners experience dissonance and face an ongoing crisis of legitimacy (Schön, 1983). Under these circumstances, it will become increasingly important to develop knowledge about the phenomena of uncertainty and complexity before, during and after hospitalisation.

**Policy**

The problems of uncertainty and complexity have to be understood within the wider context of population ageing, disability and community service provision. Both the problems themselves and the wider context are unlikely to generate enough media or government ministers’ interest to make them reach the policy agenda and become a government priority. People have strong beliefs that often are not dislodged by research evidence. For example, at the beginning of this study, community service providers believed that older people were being prematurely institutionalised after hospitalisation to a greater extent than they appear to be from the data available at the time of writing. However, to
change policy it is necessary to do the primary research and this study has made a start toward that goal.

In reflecting on policy this study has limited its implications to aspects of discharge planning, continuity of care and community care.

**Discharge Planning**

Hospital policy on discharge planning needs to:

- Support an individualised and holistic model of discharge planning particularly if the patient is considered vulnerable or at risk of having a complex discharge or is socially isolated, as this would help patients to access appropriate services for their health and community care.

- Support patient safety to ensure the patient’s accommodation was appropriate and that discharge to the patient’s home did not occur unless nurses were sure the person would cope and had all the appropriate supports in place.

- Reflect the spectrum of discharge planning from simple to complex, and time spent and resources involved in discharge planning. Simple discharge planning is achievable. Complex discharge planning is less achievable due to organisational factors, the complexity of patients (population ageing, chronic disease and disability) and the lack of accessible community services. However, some patients with complex needs have prolonged hospital stays while intense and effective discharge planning negotiations involving the patient, their carer and family and numerous hospital and community practitioners work to provide appropriate services. If hospital policy provides the framework for identifying the range of discharge planning activities and reporting protocols, then comparisons are possible and wards that need a designated discharge planner would be better positioned to argue their case for having this resource.

- Support liaison with and consideration and involvement of the person’s carer/family (or next of kin) to facilitate a smoother transition home and ensure they understand and can manage the patient’s after-care at home. The patient’s carer/family needs to know when the patient is likely to be discharged, understand what has happened to the patient and what his/her needs are most likely to be after discharge from hospital. The carer/family’s skill development needs should be identified and their needs provided for by the most available and appropriate source in the hospital or in the community.

- Provide a follow-up phone call 24 hours after the patient’s discharge to ensure they are managing and have the services and equipment they need.
Support the involvement and ensure the timely resumption of community services and supports, including assistance with ADL, needs assessment and follow up care to ensure that wounds (etc) are properly taken care of.

Develop a range of transport modalities from hospital to home.

Ensure medication safety, supply and know that patients will manage their medications and can properly dispense them, especially if they live alone. Patients need to know that their supply of medicines is limited and that they need to attend their GP for continuing medication. A pharmacist designated to the ward should educate patients about their medications and identify any safety concerns he/she may have about the patient’s ability to manage his/her medications before they are discharged.

Ensure discharge notification to the patient’s GP and/or their local pharmacist, including the patient’s discharge medication list.

Ensure that staff’s continual learning needs are met and reporting processes are maintained.

**Continuity of care**
Using a qualitative methodology I have explored the process of continuity of care from practitioners’ perspectives. In particular, I have focussed on the key issues that act as barriers to continuity of care for older people, people with disability and their carers (HACC clients) before, during and after hospitalisation. The understanding of continuity of care that has developed through this study highlights uncertainties and complexities in the process before, during and after hospitalisation. As continuity of care appears more fragmented and disconnected than it is connected, it is understood to be an ideal that is increasingly difficult to achieve within the constraints of the hospital and community care sectors. Hospitalisation of the above group is potentially hazardous with the possibility of developing iatrogenic illness, and the contribution of uncertainty and complexity to their vulnerability and discontinuity are underestimated. A lack of time, resources, professional networks or contacts and/or clearly defined linkages between the sectors contributes to a false dichotomy and a barrier between them (a silo effect). This group of people are particularly dependent on receiving care, yet providing continuity across this interface is a challenge, full of uncertainty and is put at risk by the silo effect.

**Community care**
Current demand for HACC services outstrips their supply and there are unmet needs both within the program and beyond it. The findings in this thesis are congruent with supporting interdependence as a guiding principle for social policy. The notion of interdependence acknowledges that we are all necessarily dependent on others for care at different points in our lives and that this need is integral to our living as social beings. A critical analysis of the emphasis on independence in the HACC program is needed to rethink how interdependence and resilience can be incorporated for the benefit of clients.
and their carers, across the lifespan. This change would facilitate a re-evaluation of the role, value and distribution of care, and by implication, community care. If community care services were adequately funded it is likely that older people and people with disability could stay living at home for longer, they would be less likely to be readmitted to hospital and there would be fewer premature institutionalisations.

**Practice**

Data collection for this study was limited to the specified region of Adelaide, South Australia. This regional limitation makes generalising the findings to other areas problematic. Nevertheless, the care transitions between hospital and home of older people and people with disability, as well as the role of carers, are recognised nationally and internationally as key government issues. By virtue of the depth of the findings undertaken in this study, it is considered to contribute to the debate about the major aspects of this issue.

Furthermore, the findings extend a deeper understanding of the personal, carer/family, practitioner, organisational and inter-professional uncertainties and complexities of providing continuity of care to older people and people with disability and their carers when they move between hospital and home. Hospital and community care practitioners need to find ways to make sense of the complexity of patients/clients’ circumstances and reduce uncertainty to manageable risk or to manageable plans (Schön, 1983). After hospital, people with complex needs can return home if their care is well-supported with more funding for community care to increase capacity and eradicate waiting lists. In developing the implications of uncertainty and complexity for practice, I have further developed aspects of Ackoff’s maxims for the ‘treatment of messes’. In the context of this study, the following guidelines are suggested:

- In hospital and community care, people who make decisions need to learn and adapt more effectively than they do currently. There are under-rated and under-utilised opportunities for interventions to avoid hospitalisation, reduce uncertainty and support resilience. For example, hospital nurses could first ask: whether the hospital patient is likely to need a simple or a complex discharge plan. Rather than over-reliance or disregard of carers and family, as early as possible (and to avoid last minute surprises), carers and or family need to be involved in drafting the discharge plan. Doctors could review medical care to prevent iatrogenic illness. Likewise, community service providers could make a more determined effort to engage with hospital nurses about discharge planning activities when they know their client has been admitted to hospital. The more the service providers become known by hospital nurses, the more likely it is their clients will have better outcomes.
• When decisions are made about hospital and community care, more effective account should be taken of the values and preferences of older people and people with disability, and their carers. Clients’ and patient’s values and preferences are important to their emotional wellbeing and quality of life. Practice needs to change toward person-centred care, where people’s interdependence is understood and they are treated as whole entities.

• Uncertainty and complexity are abstracted from systems of problems, that have been described here as ‘messes’. I agree with Ackoff’s assertion that such messy problems require a holistic approach. The best possible outcomes will not be found as long as these problems are approached by detaching them analytically into separate problems from philosophically divided models (the biomedical model and the social model). Discharge planning and readmission and or premature institutionalisation need to be approached holistically as systems of problems that are inter-connected over time. The focus needs to be on designing a system inclusive of both models and the invention of ways to bring it about.

• Effective approaches to messy problems requires the creative and engaged interaction of a wide variety of disciplines to identify a range of opportunities for interventions before, during and after hospitalisation.

• Everyone affected by the outcome of decisions needs to be directly involved in making them. If their involvement is not possible, then their interests should be represented by advocates who are informed by research about the affects of decisions on those concerned.

9.6 SUMMARY OF IMPLICATIONS FOR CHANGE AND KNOWLEDGE TRANSFER

This section summarises the implications for change and knowledge transfer in relation to theory, policy and practice.

THEORY

I have developed a practice-based model of systemic uncertainty and complexity which indicates critical intervention times and opportunities to support resilience. This model could be used to educate and inform hospital staff and community care practitioners about the situation of systemic uncertainty and complexity and the two critical intervention times to prevent poor outcomes:

1. The first 24 hours after discharge from hospital for people who are frail or have complex care needs.

2. The first 14 days after hospital discharge for older people, people with disability and their carers.
In part, health care workers need to understand that older people surrender their trust to the various health professions, internalising their fears and anxieties about resuming their life and role in their family. However, they are also capable of demonstrating stoicism and resilience in their recovery from illness, in an effort to hold onto their life, their autonomy and their home. In this study people were more disempowered by the hospital environment than from surrendering their trust. In the hospital and community care system, most practitioners are committed and hard working under difficult circumstances. The main reasons that problems occur are due to organisational factors.

Hospital doctors and nurses need to understand that readmissions and prolonged hospitalisation are potentially iatrogenic for older people and people with disability. Examples of clinical iatrogenesis, or illnesses caused by medical treatment, are mental confusion, functional decline, adverse drug reactions and pressure sores. Cultural iatrogenesis occurs when medical treatments are enacted upon people without adequate information about the uncertainties of their circumstances. When information/understanding is lacking, discharge planning can become complicated and time consuming. This is no justification for curtailing or denying treatment, but instead to allow more time to understand the whole picture of a person’s life and identify their needs holistically to find better ways to reduce uncertainty and manage risk. Domiciliary care practitioners and community nurses have unique insights into the impact of clinical and cultural iatrogenesis and could participate in transferring their knowledge to hospital doctors and nurses through interactive workshops based around case scenarios drawn from their experiences with clients (removing identifying information).

Government policy-makers and peak bodies need to understand that independence is a myth and contributes to peoples’ fears about losing it and to the dissonance experienced by service providers (the blame game). Recognising people’s interdependence, autonomy and the role of carers has important implications for how we value care and these values should be reflected in social policy. A greater valuing of our need for care and reliance on others to provide it at certain points in our lives could lead to an enhanced social commitment (and adequately funded community care) to provide reasonable, achievable and effective care.

Vulnerability is associated with systemic and individual uncertainty and complexity. Resilience is associated with adjustment and adaptation. Frameworks and policies which include both concepts are preferred as being a closer representation of people’s real lives and are of greater theoretical and practical value to practitioners who use them and people whose transitional care is informed by such models.
Uncertainty and complexity are messy problems that are important to understand for clients, the larger society, as well as theory. Analysis of problems needs to move from problem-focused reactions and medicalised approaches to an intersectoral and multi-disciplinary approach to assist with developing a broader understanding of systemic uncertainty and to generate workable interventions.

POLICY

Discharge Planning
My study demonstrates that hospitals need to develop discharge planning policies and procedures that:

- Support an individualised and holistic model, particularly if the patient is considered vulnerable or at risk of having a complex discharge or is socially isolated.
- Support patient safety to ensure their accommodation is appropriate and that discharge home does not occur unless nurses are sure the person can cope and has all the appropriate supports in place.
- Reflect the spectrum of discharge planning from simple to complex, and time spent and resources involved in discharge planning. Simple discharge planning is generally achievable. Complex discharge planning is less so due to organisational factors, the complexity of patients and the lack of accessible community services. If hospital policy provides the framework for identifying the range of discharge planning activities and reporting protocols, then comparisons are possible and wards that need a designated discharge planner would be better positioned to argue for one.
- Support liaison with and consideration and involvement of the person’s carer/family (or next of kin) to ensure they understand what has happened to the patient and what his/her needs are most likely to be after discharge; and have the skills and can manage the patient’s after-care at home. They also need to know when discharge is likely. Their skill development needs should be identified and needs provided for by the hospital or in the community.
- Provide a follow-up phone call 24 hours after the patient’s discharge to ensure they are managing and have the services and equipment they need.
- Support the involvement and timely resumption of community services and supports, including assistance with ADL, needs assessment and follow up care (including wound care).
- Develop a range of transport modalities from hospital to home.
- Ensure medication safety, supply and management know-how of patients, especially if they live alone. Patients need to know that the supply of medications they are discharged with is limited and that they need to attend their GP to be able to continue with their medication.
designated pharmacist should educate patients about their medications and identify any safety concerns about the patient’s ability to manage medications.

- Ensure discharge notification to the patient’s GP and/or their local pharmacist, including the patient’s discharge medication list.
- Ensure that staff’s continual learning needs are met and reporting processes are maintained.
- Uses action research to evaluate and change the hospital’s discharge planning policy, as many of the points above will require a change in the way that hospitals understand their role. Furthermore, any changes to the hospital’s discharge planning policy need to be accompanied by a professional education program of hospital staff, as well as enhancing communication and linkage primarily with domiciliary care and community nursing services, and any other key CSPs.

**Continuity of care**
Continuity of care is an ideal that is fraught with uncertainties and complexities before, during and after hospitalisation. Achieving continuity of care is difficult within the constraints of the hospital and community care sectors, due to the lack of time, resources, professional networks and key contacts. Poor or non-existent linkage and/or coordination processes between the sectors is also a constraint which works against continuity of care. Any organisation that upholds continuity of care as a value needs to define what they mean, scope the range of services who could assist with achieving continuity of care and develop linkage and coordination procedures to assist practitioners to achieve continuity of care.

**Community care**
The Australian Government, states and territories need to engage in reforming the HACC program as current demand outstrips supply and there are unmet needs both within the program and beyond it. These findings are congruent with supporting interdependence as a guiding principle for social policy and the HACC program. A critical analysis of the emphasis on independence in the HACC program is needed to rethink how interdependence and resilience can be incorporated for the benefit of clients and their carers, across the lifespan. More funding is needed for community care to increase capacity, eradicate waiting lists and provide better support to carers. If community care services were adequately funded it is likely that older people and people with disability could stay living at home for longer, they would be less likely to be readmitted to hospital and there would be fewer premature institutionalisations.

**PRACTICE**
These findings extend a deeper understanding of the personal, carer/family, practitioner, organisational and inter-professional uncertainties and complexities of providing continuity of care to
older people and people with disability and their carers in transition between hospital and home. Hospital and community care practitioners need to find ways to make sense of the complexity of patients/clients’ circumstances and reduce uncertainty to manageable risk or to manageable plans. After hospital, people with complex needs can return home as long as their post-hospital care is ascertained.

In hospital and community care, people who make decisions need to learn and adapt more effectively than they do currently. There are under-rated and under-utilised opportunities for interventions to avoid hospitalisation, reduce uncertainty and support resilience. As early as possible, carers and or families need to be involved in assisting to draft the discharge plan. The multi-disciplinary hospital and community care team (which could include doctors, nurses, allied health personnel, GPs, CSPs and carers/families) could review medical care to prevent clinical and cultural iatrogenic illness. Likewise, GPs and CSPs could make a more determined effort to engage with hospital doctors/nurses about discharge planning activities when they know their patient/client has been admitted to hospital. The more the CSPs become known by hospital nurses, the more likely it is their clients will have better outcomes.

We need to understand that not all institutionalisation is premature, but some of that which occurs following hospitalisation could be avoided if people’s capacity to return home is better resourced by timely community services and by carers/families that are better educated and supported for the first 24 hours after discharge.

When decisions are made about hospital and community care, more effective account should be taken of the values and preferences of older people, people with disability and their carers. Ideally this should happen before someone is admitted to hospital. People themselves need to be encouraged and/or assisted to clarify and record or make known their values and preferences. This could also involve partners, carers, family, GPs, CSP and advocates. Clients’ and patient’s values and preferences are important to their emotional wellbeing and quality of life. Practice needs to change toward person-centred care, where people’s interdependence is understood and they are treated as whole entities.

The creative and engaged interaction of a wide variety of disciplines is needed to identify a range of opportunities for interventions before, during and after hospitalisation. As much as possible, everyone affected by the outcome of decisions needs to be directly involved in making them. If their involvement
is not possible, then their interests should be represented by advocates who are informed by research about the affects of decisions on those concerned.

9.7 STRENGTHS AND LIMITATIONS OF THIS STUDY

In Chapter 5, I referred to a number of themes in the literature for discussing the strengths and limitations of action research. In particular, those that apply to my thesis are:

- Participation and key people,
- The research relationship, and
- Flexibility in research methods and real world focus.

Participation and key people

The strengths of the participation of key people in this study were their willingness to put their own agendas and pre-conceptions aside, to enter into the spirit of enquiry and to become motivated towards a common change-agenda. Through the interest, attendance and contribution of the Steering Committee, Reference Group and Nominal Group, the participation of key people promoted understanding of the project, contributed to problem identification and the development and implementation of actions. Most of the changes and actions were implemented through the participation of key people obtaining permissions, authorising access to staff, linking the study with other meetings and agendas and championing activities.

There are numerous examples of the benefits of the participatory approach and the role played key people in this study. Their involvement provided invaluable input into the content of YHR and increased its utility. A less obvious example of the engagement of key people was the gesture of co-operation shown by the hospital’s Steering Committee member to remove the hospital logo from the cover of YHR to facilitate community and patient ownership. Research and action co-existed in service provider settings with the participants, rather than about the ‘subjects’. The participants became a part the team working towards a common goal and change. The Steering Committee and the Reference Group fulfilled their crucial role in supporting and guiding the direction of the study and provided a forum for ongoing consultation with CSPs, consumers and other stakeholders. The study remained focused and achieved its objectives within the scope of the resources available. Input and participation from CSPs was maximised through the collaborative process and developed effective working relationships between those already involved in the study and other interested parties. The decision to call Reference Group meetings on an ‘as needed’ basis was important in freeing up the amount of time and resources used in organising, running and reporting on such meetings. Running a Nominal Group was a useful approach to organise a focused and productive meeting for problem-solving about a contested issue. This method balanced and increased participation and reduced
errors in the group’s decisions. The Recommendations Workshop was important in reviewing the draft recommendations and linking each recommendation to the key findings. The workshop participants were then able to discuss how the recommendations could be supported and carried forward both within their organisation and as a part of an ongoing collaborative. Although the collaborative process was initially not an easy one, its participatory approach, together with the role of key people were strengths of the action research method and provided the opportunity to bring about real changes.

A limitation in the participation of key people was related to aspects of the collaborative process. Collaboration is promoted as key element of social policy frameworks, including the HACC program. However, it is not an easy process to implement and maintain and requires a determined effort to achieve results. In this study, there were underlying tensions between collaborative agencies that were also in competition with one another over tendering for government funding. Achieving an effective collaborative process was time consuming in terms of establishing goodwill and trust among the Steering Committee members, and in getting information understood for collaborative decision-making about the use of resources and the study’s directions. Furthermore, people work hard in the hospital and community care sectors, are stressed and have ‘change fatigue’. The participation of these key people in the collaborative process required them to do additional work and engage with the shifting of existing boundaries through the decision-making process. On the surface, change agents can encounter a negative culture and dismissive attitudes, challenging their perseverance and confidence. However, once the aim, methodology, relationships (managerial and intersectoral) and trust had been established, this study progressed and maintained the participation of key people.

The research relationship
Re-definition of the problem was not done collaboratively, as at that point in time it was not practical to call together all the agencies that had collaborated to get the project funded. The Steering Committee, most of whom were managers, expected that I would ‘just get on with it’. Adding to the Steering Committee’s concerns were doubts about my motives and the potential success of the project when I began discussion with the University of Adelaide about developing the project into a thesis. Various Steering Committee members questioned whether or not my personal motives and ambition would lead to the kind of practical outcomes they wanted the project to achieve. Another issue raised by the research relationship was that the problem of discontinuity of care of older people and people with disability was more complex than any of the organisations involved had previously recognised. At numerous Steering Committee meetings and at the Recommendations Workshop, I was aware of the challenges I faced while presenting the findings of the action research and negotiating the next action.
Action research was the optimum method for the study. On the one hand, however, in calling it ‘research’ my professional motives and knowledge were challenged by having to convince the Steering Committee (and others in the field) of the potential benefits, which were not entirely clear at that point in time. On the other hand, at the University of Adelaide there were time constraints and institutional obstacles in gaining ethics approval and acceptance of action research as a method to conduct research. For example, I was called in for an interview with the university ethics committee about my willingness to comply with protocols regarding research with humans; it felt like I had to convince my university’s discipline (of public health) about the value and validity of action research as a vehicle of closing the practice-research gap. While I was employed as the Project Officer doing the study, I had difficulty meeting my university obligations. Therefore, a limitation of the action research method is that the requirements of the workplace can be in conflict with those of the university if one undertakes action research for a thesis.

As a practitioner-researcher I engaged with these concerns. Convincing research-sceptics, who abound in a practice-focused field, was difficult. I tackled this problem by retracing the origins of the project and using education about action research to allay concerns. At some point, we moved on. Nevertheless, negotiations were difficult at every level and at every stage. I was regularly reminded that Steering Committee members, for example, did what they could but were ‘busy people’ concerned with their own workloads and the running of their organisation. In other words, the study was placing extra demands upon them that they had difficulty fulfilling. Eventually, a negotiated outcome was reached or approval of the innovations was gained, but there were times when it was prone to inter-personal and inter-sectoral power-games, that seemed removed from the aim of the study.

These challenges about negotiating the research relationship across conflicting objectives between conducting research, the University’s main objective, and changing practice, the workplace’s main objective, were tensions that were eventually reconciled. However, they remained throughout the duration of the study. In the process I had to maintain my belief in the benefits of change informed by ‘bottom-up’ research and to fulfil the University’s thesis requirements. The research relationship is both a limitation and strength of action research and this study, however, in the end, changes occurred in the workplace and the University’s requirements were fulfilled.

**Flexibility in research methods and real-world focus**

An example of the different demands of the university and the workplace was the university’s apparently higher regard for quantitative over qualitative research, which resulted in the development
of an unachievable sample-size of surveys with patients and carers. Adding to this were multiple eligibility criteria, which made recruiting HACC eligible patients and their carers an arduous and time consuming task. Pursuing eligible participants consumed more time and resources than anticipated. For example, it is common knowledge among hospital staff that many older people experience periods of mental confusion following admission to hospital. During the 7-month recruitment and data collection phase for the survey, the exclusion criteria prevented me from approaching anyone who had shown any signs of confusion following their admission to hospital, even if it was apparent to the nursing staff that the person was orientated and had regained mental coherence. This particular exclusion criterion substantially reduced the numbers of people I approached for informed consent on a daily basis and over time impacted on the numbers of interviews I completed with patients and with carers.

Indeed, these criteria effectively excluded the very people I most urgently needed to survey, being older people with complex care needs, those who were socially isolated or had hearing difficulties. There were 225 patients who were not eligible. I identified one younger patient with disability, as the hospital did not collect data about persons receiving the Disability Pension, making ‘disability’ hard to determine without being intrusive. Of the 31 patients who gave informed consent, almost half (15) were not available or withdrew when I called for the interview. A total of 12 carers gave informed consent and 2 withdrew. Consequently, from the original sample size of 93 patients and 38 carers, I surveyed 14% of patients and 38% of carers. The small sample sizes meant that the data could not be transformed and were limited to descriptive statistical analysis. The eligibility criteria together with the circumstances of the patients and their carers led to no surveys with anyone considered frail or vulnerable. These limited the numbers and skewed the data results, as the participants were at the healthier and less complex end of the scale of potential participants.

This draws attention to the impact that multiple and rigid eligibility criteria can have on recruitment of older patients and patients with disability in the critical and often difficult period of hospitalisation and recovery afterwards. Researchers need to be aware of the potential difficulties they may face doing research with older unwell hospitalized patients. The majority of public hospital patients are of advanced age, have complex, chronic, co-morbidities, may have dementia or become confused once admitted, and are too ill or frail to be appropriately engaged in anything that they find challenging to their capacity to think or take in new information. Furthermore, many older people are compliant with medical authority, are generous and will persevere, even while they feel unwell. From the researcher’s perspective, sensitivity and judgment is needed to work out if someone is being generous at his/her own expense, but is not really up to going through an informed consent process. Otherwise, the
process may be an imposition of the researcher’s power and authority over the patient. Other researchers have found similar limitations when attempting research with older people and advocate the importance of developing ways to include older people in research (Bugeja et al., 1997; Hancock et al, 2003; Chouliara et al., 2004; Dewar, 2005; Warburton, 2009) (Chouliara, Z., Kearney, N. et al. 2004; Warburton, J., Bartlett, H. et al. 2009)

Although these limitations are more about doing research with older hospitalised patients than about action research, they highlight the importance of spending time during the study design phase to carefully plan the research design around what is already known about the study’s target population and the context in which the study is taking place. Before the researcher enters the data collection phase, the implications of having multiple ethical and eligibility criteria should be explored to determine if the research is still feasible, practical and achievable in the time frame.

Strengths derived from the flexibility in research methods of action research allowed the collection of data as well as the increased participation and motivation for change. As Chapter 7 documents, the interviews with practitioners from the hospital and community care sectors and consultations with the Reference Group have led to an improved understanding of the processes, complexities and uncertainties during the movement of older people and people with disability and their carers between hospital and home. The different types of data generated from using mixed methods did not produce the concordant evidence sought. This reduced the certainty with which any inferences could be made about overall preparedness for discharge and provision of community services, patient quality of life following hospitalisation and levels of carer strain. However, triangulation of the data enhanced security of the findings. For example, there was strong congruence in the interviews with domiciliary and community nursing practitioners and hospital nurses about the experience of older people and people with disability and their carers before, during and after hospitalisation.

Limitations of the real world focus of this study were that it required more time for education, reflection and analysis by the participants, which would have taken them away from the workplace. In addition, the real world focus led to conflict and tensions when trying to address the recommendations, which was followed by the disruption of relationships in the region. Unfortunately these tensions overshadowed the successes of the study. There were also strengths to the real world focus of the study in its capacity to reflect the real situation of uncertainty and complexity before, during and after hospitalisation of older people and people with disability, as well as the uncertainty and complexity of carers and practitioners. This has increased the relevance of this research and contributed to reducing the theory-practice gap.
Although this study has made a start there is great scope for future research on this topic at factual, practice and policy levels. To affect policy, primary research needs to establish:

- The indicators of premature institutionalisation,
- The percentage of older people and people with disability who are a) readmitted to hospital; and b) prematurely institutionalised,
- How much (poor) discharge planning results in a) hospital readmission; and b) institutionalisation, and
- The key health and social determinants of a) hospital readmission; and b) institutionalisation.

Research across the health and social care sectors is needed to explore:

- The preparedness of informal carers to provide ongoing home-based care of older people and people with disability after discharge from hospital,
- The relationship between home-based and supported informal care to quality of life of older people and people with disability after discharge from hospital,
- The factors that support resilience in older people, people with disability and their carers after discharge from hospital, and
- In the context of interdependence and resilience: ways by which the HACC program might ensure adequate and timely community care services to older people and people with disability and their carers?

Knowing about the uncertainty and complexity of health and social care transitions of older people and people with disability, localised action research would be suitable for the planning, implementation, evaluation and reflections of discharge planning with the aim of producing a model of effective, evidence-based discharge planning. Studies with older people, people with disability and carers are needed about the key factors that contribute to uncertainty and their circumstances, health status, the caring role, the home environment, transport, community service responses and hospital system responses. After hospitalisation, studies with older people, people with disability and carers are needed on the key factors that affect individual adjustment, carer and family adjustment and service adaptation.
9.8 SUMMARY OF FINDINGS AGAINST OBJECTIVES

In this section I provide a brief summary of the findings as they relate to this study's objectives.

Objective 1: To analyse the factors in the literature that lead to discontinuity of care of older people and people with disability and their carers in transition between the hospital and community care systems in the specified region of Adelaide.

Findings: In the literature I found the main factors that led to discontinuity of care of older people and people with disability and their carers in transition between the hospital and community care systems were:

- The increased demand for acute hospital services from an ageing population and people with disability and chronic disease which resulted in overcrowding and a blocked hospital system.
- The tendency in casemix-based funding to over-emphasise hospital efficiency primarily through reducing LOS, which results in the premature discharge of older people and people with disability.
- The low impact and effectiveness of current approaches to discharge planning in relation to the post-hospital care needs of older people and people with disability and their carers. Other contributing issues which also impact on discharge planning include premature or delayed or unsafe discharge; the lack of community services; insufficient communication or information; inadequate linkage, notice of discharge and/or interagency collaboration between the hospitals and community care system.
- A complex community service structure that is difficult for anyone to navigate, which in turn, impacts upon access in a timely way when these services are needed. Community care is also a blocked system as the supply of services has not kept pace with demand.

Objective 2: To plan and implement actions to improve the continuity of care for older people and people with disability, and their carers, living in the specified region of Adelaide.

Findings: Actions which were planned and implemented to improve the continuity of care for older people and people with disability, and their carers, living in the specified region of Adelaide included piloting YHR with patients; facilitating the creation of The Hub in the hospital; providing educational opportunities for hospital doctors and nurses. These actions increased local linkages between the hospital and community service providers, enhancing collaboration, communication and access to information about the HACC program. The Hub continues as the most sustainable and successful outcome of the project.
Objective 3: To observe the effect of the actions taken to improve the continuity of care for older people and people with disability, and their carers, living in the specified region of Adelaide.

Findings: The effect of the successful actions was due to them being developed and maintained in collaboration; that key people took responsibility for maintaining them once the study had finished; that the costs and resources were shared across a number of agencies during the development phase, and that the purpose of the action fitted with the goal of the organisation or agency that took ongoing responsibility.

Objective 4: To analyse the results and reflect on their wider implications for theory, practice, policy and future research on the continuity of care for older people and people with disability and their carers.

Findings: Analysis of the results and reflections on their wider implications for the continuity of care for older people and people with disability and their carers indicates:

- For theory: the main themes to emerge from this research are ‘systemic uncertainty and complexity’. I have built upon these themes to develop a practice-based model of systemic uncertainty and complexity before, during and after hospital. The contributions that I make to theory are in conceptualising a hybrid understanding of care transitions as involving systemic uncertainty and complexity, and temporal and transient vulnerability and resilience.

- For practice: As data collection for this study took place in the specified region of Adelaide (SA), generalising the findings to other areas is problematic. All the same, the care transitions between hospital and home of older people and people with disability, as well as the role of carers, are recognised nationally and internationally as key government issues. The depth of the findings in this study is considered to contribute to the debate about the major aspects of this issue.

- For policy: The problems of uncertainty and complexity have to be understood within the wider context of population ageing, disability and community service provision. Any change to policy requires primary research and this study has made a start towards that goal. The policy implications of this study are limited to aspects of discharge planning, continuity of care and community care.

Objective 5: To reflect on the utility of Action Research as a means to analyse and improve the discontinuity of care for older people and people with disability and their carers in transition across the acute and community care interface.

Findings: When considering the utility of action research as a means to improve the discontinuity of care for older people and people with disability and their carers in transition across the acute and
community care interface I concluded that this method was the optimum one for this study. While there were a number of limitations (refer to the earlier section on strengths and limitations of this study) the main strengths were:

- The participation (through their interest, attendance and contribution) of key people in working towards a common change-agenda.
- The flexibility in research methods which allowed the collection of different types of data and their triangulation, as well as increased participation and motivation for change.
- The real world focus of the study, which reflects the actual situation of uncertainty and complexity before, during and after hospitalisation of older people, people with disability, as well as the uncertainty and complexity of carers and practitioners.
9.9 CONCLUSIONS

“The study you and I have made has not removed the mess. It has not even reduced it significantly. But it should help us to make our way through it. And that, we may feel, is reward enough.” (Crotty, 2003, p.216)

This thesis has been concerned with the impact that a hospital admission can have on the continuing ability of older people and people with disability (HACC clients) to remain living in their home. I aimed to identify the nature of the changes needed in the South Australian hospital and HACC systems to reduce poor outcomes and improve the continuity of care for older people and people with disability, as well as their carers. This study was undertaken as action research, providing qualitative and quantitative data for a thematic and descriptive analysis of the processes before, during and after hospitalisation of older people and people with disability.

Although the scope of the action research study was defined by the resources available, a range of actions were implemented. The value, need and generalisability of the YHR outcome and the success and sustainability of The Hub are recognised. The impact of these and other actions has led to:

- Increased participation and collaborative processes for the duration of the study;
- Educational opportunities and empowerment of the participants;
- Increased local linkages between hospital and community service providers;
- Increased communication between the sectors, and
- Improved access to information about the HACC program.

There were a number of strengths and limitations in the action research study and in the study as a whole and these are outlined in the discussion of this chapter.

The interviews point to systemic uncertainty and complexity in the process before, during and after hospitalisation of older people and people with disability. From practitioners’ perspectives, before admission to hospital there were four dimensions of uncertainty which arose from the circumstances of older people, people with disability and their carers. Bringing together the four dimensions before hospitalisation into the model is unique to this study and provides a comprehensive understanding from service providers’ perspectives of the effect of uncertainty about hospitalisation on older people, people with disability and their carers. From hospital nurses’ perspectives, during hospital admission, in relation to discharge planning there were four dimensions of complexity which could confound nurses’ activities aimed at ensuring patient safety and their carer/family involvement, as well as nurses’ ability to manage the range of hospital-based obstacles and achieve timely and coordinated access to community services. The linking of the dynamic triad of relationships with hospital-based
discharge obstacles and with community services, GPs, RAC and transport provides an innovative analysis of the complexity in discharge planning. From practitioners’ perspectives, after hospital there were three dimensions of adjustment and adaptation pertaining to older people, people with disability and their carers, since the patients’ lives were changed after admission. These dimensions highlighted the need for individual, carer and family adjustments and service adaptation to support HACC clients’ ability to return home. While aspects of functional decline and frailty are widely regarded as the main reasons for producing poor outcomes, this analysis emphasises the role of numerous other factors. The descriptive statistics of surveys with patients and carers and the Reference Group consultations supported triangulation of the interview data.

Uncertainty and complexity in this context are found in the systems of messy problems both before, during and after hospitalisation. These problems concern the timing of interventions, involve difficulties with being disempowered and not understanding the system, as well as the lack of assurance about the inter-connections between hospital and community care. This can lead to discontinuity of care and poor outcomes for older people, people with disability, and to difficulties for carers, families and practitioners. Organisational factors, time pressures and workload constraints are additional components of these problems. Aspects of these findings point to several theoretical approaches, including:

- Clinical and cultural iatrogenesis;
- Medicalisation of ageing and disability, which contributes negatively to iatrogenesis and positively to treatments that address health conditions and improve quality of life;
- The ethics of care as well as the burden of care and the place of interdependence;
- The multiple factors that constitute vulnerability, and
- The ways in which adjustment and adaptation are associated with resilience.

However, the theoretical implications of systemic uncertainty and complexity are akin to messy problems that interact with each other. Such messy problems are important to understand for clients, the larger society and for theory. They require multidisciplinary analysis of the factors that will assist in their understanding and present the opportunity for change or adjustment, managing uncertainty and reducing complexity.

In identifying the nature of the changes needed in the South Australian hospital and HACC systems to reduce poor outcomes and improve the continuity of care for older people and people with disability, as well as their carers, the policy perspectives of this thesis point to:
• Taking a holistic approach to discharge planning and poor outcomes as systems of problems that are inter-connected over time - a range of areas that would enhance hospital policy on discharge planning are suggested in the former discussion;

• An understanding of continuity of care which highlights the uncertainties and complexities before, during and after hospitalisation of older people and people with disability and their carers;

• The review of medical care by doctors to prevent iatrogenic illness;

• A new framework to guide the HACC program which focuses on supporting the interdependencies and resilience of clients and carers across the lifespan, and

• A ‘Memorandum of Understanding’ between the South Australian Department of Health and Department of Families and Communities to identify the ways in which older people and people with disability and their carers can be more effectively supported when moving between sectors.

From a practical point of view, the focus needs to be on designing a system inclusive of the biomedical and social models of health, then inventing ways to bring it about. Hospital and community care practitioners need to find ways to make sense of complexity and reduce uncertainty in their patient’s/client’s and their carers/families, to managing risk or managing plans. In so doing, they need to:

• Learn, adapt and engage with one another more effectively than they do;

• Take account of people’s values and preferences and appreciate the significance of home;

• Engage a wide range of disciplines to identify a range of opportunities for interventions before, during and after hospitalisation, and

• Involve the person or their informed advocate in any decisions that will have an affect upon them.

Provided that community care is timely and adequate, poor outcomes could be reduced and risks better managed. This requires more funding for community care to increase capacity and eliminate waiting lists for community services. Finally, this study contributes to and provides a deeper understanding of the personal, carer/family, practitioner, organisational and inter-professional uncertainties and complexities of the movement between hospital and home. This is a globally significant challenge and one that requires creative solutions, both at local and national levels.
APPENDIX 1

It’s five minutes to five on the Friday afternoon of a long weekend. You are at work, sitting at your desk looking over a client list trying to prioritise next week’s work when the phone rings.

You answer it. The call is about a client that you have not heard from for over four weeks, despite you twice phoning them without the phone being answered. The caller is clearly worried and tries to explain their concerns to you. They keep saying that they don’t want to bother you, but they really need some help from someone. They sound as if they are at the end of their tether.

You find out that the client has been in hospital. It appears that the hospital treatment was successful, but the client is confused about what to do now. Hospital discharge wasn’t smooth. They left earlier than they thought they would. There were transport complications, but they finally managed to get home. You hear the full story.

When they arrived home they didn’t feel that they had the required support. They describe what it’s like at home and how worried they feel about safety at home. You discover that the client is confused and worried about their medication. You hear the whole story about their medication and their fears.

They tried to get support at home and although people say they would like to help them, they have no real success in getting what they want. You hear the story of what they need and what they have done to try and get it. They ask you whom they should contact to get the support, because they need it straight away. Their usual support people are away for the weekend and at least the next week. They describe a problem that they are having with equipment. They don’t know what to do about it and they want you to help them sort it out. They tell you about money problems.

They want help immediately and ask you what they should do. You have now been on the phone for 40 minutes, you had planned to do some food shopping before you go home. You reassure the caller that you will do whatever you can and you hang up. What have you told them that you would do? You shut your eyes to think it over.
NOTE:
Appendices 2A and 2B are included in the print copy of the thesis held in the University of Adelaide Library.
APPENDIX 3

Search Strategy
Database searches were conducted through PubMed, CINAHL, MEDLINE, ScienceDirect, Blackwell-Synergy, Academic Search Premier Expanded Academic Index, Health Source Nursing, Meditext and the Conchrane Library for studies dated between 1990 and 2008 which used both qualitative and quantitative methodology.

The initial PubMed search conducted in May 2003 used the following algorithm:

This retrieved approx 550 references which were then reviewed in turn for their applicability in the literature review. The reference lists of those articles retrieved were also reviewed and relevant articles retrieved. A broad search strategy was repeated in November 2008, along with more specific searches of 'continuity of care' AND 'discharge planning' AND 'disability' AND 'institutional care' AND 'social care'. These search strategies were linked with electronic updates and alerts. Masters and PhD theses were retrieved from known authors. Conference abstracts were reviewed for the relevant conferences attended by the student to keep most up to date with the most current and often unpublished research.

Below shows the results from a literature review update in Blackwell-Synergy conducted February 2006.

Search Results 8107 matches found

Search query: All: ("elders" or "frailty" or "discharge" or ("disability" and (continuity of care and interface ) and social care)) in "Health Sciences"
Search Results 3720 matches found

Search query: (All: ("elders" or "frailty" or "discharge" or ("disability" and (continuity of care and interface ) and social care)) and All: humans) in "Health Sciences"
Search Results 2769 matches found
Search query: **All**: ("elders" or "frailty" or "discharge" or ("disability" and ( continuity of care and interface ) and social care)) and humans ) in "Health Sciences / Health and Social Care" and **Between**: 01/2000 and 03/2006
Search Results 731 matches found

Search query: **All**: ((All human adults and not children and not infants) and ("elders" or "frailty" or "discharge" or ("disability" and ( continuity of care and interface ) and social care))) in "Health Sciences / Health and Social Care" and **Between**: 01/2000 and 03/2006
Search Results 253 matches found

Search query: **All**: ((All human adults and not children and not infants and not adolescents and not animals) and ("elders" or "frailty" or "discharge" or ("disability" and (continuity of care and interface ) and social care))) in "Health Sciences / Health and Social Care" and **Between**: 01/2000 and 03/2006
Search Results 221 matches found (10 relevant)

Search query: **All**: ( (All human adults and not children and not infants and not adolescents and not animals and not dental) and ("elders" or "frailty" or "discharge" or ("disability" and ( continuity of care and interface ) and social care))) in "Health Sciences / Health and Social Care" and **Between**: 01/2000 and 03/2006
Search Results 46 matches found (2 relevant)

Search query: **All**: ( (All human adults and not children and not infants and not adolescents and not animals and not dental) and ( "elders" or "frailty" or "discharge" or ("disability" and ( continuity of care and interface ) and social care))) in "Health Sciences / Health and Social Care" and **Between**: 01/1995 and 01/2000
Search Results 2 matches found (none relevant)

Search query: **All**: ( (All human adults and not children and not infants and not adolescents and not animals and not dental) and ("elders" or "frailty" or "discharge" or ("disability" and (continuity of care and interface ) and social care))) in "Health Sciences / Health and Social Care" and **Between**: 01/1990 and 01/1995
Search Results 27 matches found (none relevant)

Search query: **All**: ((All human adults and not children and not infants and not adolescents and not animals and not dental) and (continuity of care and interface) and social care)
INTRODUCTION

Good ........ My name is Rosie King from The hospital. May I speak with (say ex-patient's name) please?

Either

1. Get person and repeat introduction
2. If (ex-patient) is home but unavailable, arrange for another suitable time to call.

Date: ___________________________ Time: ___________________________

3. If (ex-patient) is not home, ask if (ex-patient) is likely to be available if I ring in the next couple of days.

Date: ___________________________ Time: ___________________________

Recently you were a patient in The hospital. Do you recall me explaining about the telephone survey while you were in hospital? I gave you an information sheet about the research that I am doing.

We would be most appreciative if you could answer some survey questions about your preparation for going into hospital and for coming home. This will help us to find out things that need to be improved in the hospital and home-care system.

This questionnaire has ?? questions and will take 30 to 40 minutes. I appreciate your willingness to take part and that you have other demands on your time. I also have other surveys to do today, so brief answers would be appreciated.
I can assure you that the information you give will remain confidential. The answers from all people interviewed will be gathered together and presented in a report. No individual answers will be passed on.

Please listen carefully and choose the answer that best describes you.

IF (EX-PATIENT) IS HOME AND STILL WILLING TO PARTICIPATE, PROCEED TO SECTION A.

A. DEMOGRAPHICS

Now to start with some general questions

A.1 Gender (circle) 1. Male 2. Female

A.2 HACC Eligibility:

1. Frail-aged

2. Frail-aged and physically disabled

3. Younger disabled

A.3 Is an interpreter required? 1. Yes ☐ 2. No ☐

A.4 What is the main language you use to communicate?

1. English (……)

2. Greek (……)

3. Italian (……)

4. Russian/Ukrainian (……)

5. Polish (……)

6. Vietnamese (……)

6. Other, please state ...........................................

A.5 What is your post code? ...........................................

A.6 What is your date of birth? / / 19
A.7 Can you tell me which of the following living arrangements describes your household? Do you...

[Read Options. Single Response]

1. Live alone   (......)
2. Live with partner   (......)
3. Live with children   (......)
4. Live with partner and children   (......)
5. Live with parent(s)   (......)
6. Live with parent(s) and siblings   (......)
7. Live with other unrelated adults   (......)
8. Live with other related adults   (......)
9. Other   (......)

A.8 Do you have someone who is looking after you in some way?

[For example, the person could be family members, neighbor or friend]

1. Yes
2. No

B. ENTRY TO HOSPITAL

B.1 What was the reason for your last admission to hospital?

...........................................................................................................................

B.2 How were you admitted to hospital?

[If answer is ‘through outpatients’, response equals unplanned admission. Read options. Single response]

1. Referred by my doctor and my admission was planned [ ] Go to B.3
2. Emergency or unplanned admission [ ] Go to D
3. Transferred from another hospital [ ] Go to D

B.3 Did you attend a pre-admission clinic before you went into hospital?
1. Yes [ ] Go to C

2. No [ ] Go to C

C. PLANNED ADMISSIONS

C.1 Before you went into hospital, was your family (or neighbour or friend who assists you) involved in the planning to go into hospital?

1. Yes [ ]
2. No [ ]
3. Don’t know [ ]

C.2 Did you get written information about going into hospital?

1. Yes [ ] Go to C.3
2. No [ ] Go to C.5
3. Don’t know [ ]

C.3 Do you recall who gave you this information?

[Read Options. Single Response]

1. Your GP [ ]
2. Outpatient Clinic [ ]
3. Domiciliary Care [ ]
4. District Nurse [ ]
5. Other health worker [ ]
6. Other [ ]

C.4 Did someone spend time with you explaining the information?

1. Yes [ ]
2. No [ ]
3. Not needed [ ]

C.5 Before you went into hospital, did you get information about services that you may need when you went home from hospital?

[If the person asks ‘What kind of services?’, explain services that are found in the community, like Domiciliary care, community nursing, meals-on-wheels, household help etc]

1. Yes [ ]
2. No □
3. Don’t know □

C.6 How much information did you get on equipment you might need when you got home from hospital?

1. As much as I needed □
2. Some, but not enough □
3. None □
4. No information needed □

C.7 Before you went into hospital, overall how prepared did you feel for going into hospital?

1. Very prepared □
2. Could have been better prepared □
3. Unprepared □

D. ASSESSMENT OF QUALITY OF LIFE

Now I am going to ask you a number of questions about your health during the last week.

ILLNESS

D.1 Concerning your use of prescribed medicines:

[If the person asks ‘What is a prescribed medicine’, explain that it refers to a medicine prescribed by a doctor, and it does not include over the counter drugs.]

Would you say that:

1. You did not or rarely use any medicines at all.
2. You used one or two medicinal drugs regularly.
3. You needed to use three or four medicinal drugs regularly.
4. You used five or more medicinal drugs regularly.

D.2 In the last week, to what extent have you relied on medical aids, not including your glasses or hearing aid?

[If the person asks for an example explain this refers to a walking frame, wheelchair, prosthesis etc.]

Would you say that:

1. You did not use any medical aids.
2. You occasionally used medical aids.
3. You regularly use medical aids.
4. You had to constantly a medical aid.

D.3 In the last week, did you need medical treatment from a doctor or other health professional?

Would you say:

2. You had some regular medical treatment.
3. You were dependent on having regular medical treatment.
4. That your life was dependent upon regular medical treatment.

INDEPENDENT LIVING

D.4 Did you need any help with personal care in the last week?

[If the person asks ‘what is personal care’, explain this refers to activities such as washing, dressing, personal grooming or going to the toilet.]

Would you say:

1. You needed no help at all.
2. Occasionally you needed some help with personal care tasks.
3. You needed help with the more difficult personal care tasks.
4. You needed daily help with most or all personal care tasks.

D.5 When doing household tasks during the last week, did you need any help?

[For example, preparing food, gardening, using the video recorder, radio, telephone or washing the car]

Would you say:

1. You needed no help at all.
2. Occasionally you needed some help with household tasks.
3. You needed help with the more difficult household tasks.
4. You needed daily help with most or all household tasks.

D.6 Thinking about how easily you got around your home and community in the last week.

Would you say:

1. You got around your home and community by yourself without any difficulty.
2. You found it difficult to get around your home and community by yourself.
3. You could not get around the community by yourself, but you got around your home with some difficulty.
4. You could not get around either the community or your home by yourself.

SOCIAL RELATIONSHIPS

D.7 Were your personal relationships in the last week affected by your health.

[For example: with your friends, partner or parents]

Would you say your relationships:

1. Were very close and warm.
2. Were sometimes close and warm.
3. Were seldom close and warm.
4. You had no close and warm relationships.

D.8 Were your relationships with other people during the last week affected by your health.

Would you say:

1. That you had enough friends, and you were never lonely.
2. That although you have friends, you were occasionally lonely.
3. That you have some friends, but you were often lonely.
4. That you felt socially isolated and lonely.

D.9 Thinking about your health and your relationship with your family in the last week.

Would you say:
1. Your role in the family was unaffected by your health.
2. There were some parts of your family role that you could not carry out.
3. There were many parts of your family role that you could not carry out.
4. You could not carry out any part of your family role.

**PHYSICAL SENSES**

**D.10** Thinking about your vision, in the last week.

*[including when using your glasses or contact lenses if needed]*

Would you say:

1. You saw normally.
2. You had some difficulty focusing on things, or you did not see them sharply.  
   *[For example: small print, a newspaper, or seeing objects in the distance.]*
3. You had a lot of difficulty seeing things and your vision was blurred.  
   *[For example: You saw just enough to get by with.]*
4. You only saw general shapes, or you are blind.  
   *[For example: You need a guide to move around.]*

**D.11** Thinking about your hearing in the last week.

*[Including using a hearing aid if needed]*

Would you say:

1. You heard normally.
2. You had some difficulty hearing or did not hear clearly.  
   *[For example: You asked people to speak up, or turn up the TV or radio volume.]*
3. You had difficulty hearing things clearly.  
   *[For example: Often you did not understand what was said. You usually did not take part in conversations because you could not hear what was said.]*
4. You hear very little indeed.  
   *[For example: You could not fully understand loud voices speaking directly to you.]*

**D.12** When you communicated with others in the last week.

*[For example: by talking, listening, writing or signing]*

Would you say:

1. You had no trouble speaking to others or understanding what they were saying.
2. You had some difficulty being understood by people who do not know you. You have no trouble understanding what others are saying.
3. You were only understood by people who know you well. You had great trouble understanding what others are saying.
4. You could not adequately communicate with others.

**PSYCHOLOGICAL WELLBEING**

**D.13** Thinking about how you slept in the last week.

Would you say:

1. You slept without difficulty most of the time.
2. Your sleep was interrupted some of the time, but you were usually able to go back to sleep without difficulty.
3. Your sleep was interrupted most nights, but you were usually able to go back to sleep without difficulty.
4. You slept in short bursts only. You were awake most of the night.

D.14 Thinking about how you generally felt in the last week.

Would you say:

1. You did not feel anxious, worried or depressed.
2. You were slightly anxious, worried or depressed.
3. You felt moderately anxious, worried or depressed.
4. You were extremely anxious, worried or depressed.

D.15 How much pain or discomfort did you experience in the last week.

Would you say:

1. You had none at all.
2. You had moderate pain.
3. You suffered from severe pain.

Now that we have gone through how your health is now, I want to ask you to think back about how you managed living at home before you went into hospital.

D.16 Before you went into hospital, to what extent did you rely on medical aids, excluding your glasses or hearing aid.

[If the person asks for an example explain this refers to a walking frame, wheelchair, prosthesis etc.]

Would you say that before you went into hospital:

1. You did not use any medical aids.
2. You occasionally used medical aids.
3. You regularly use medical aids.
4. You had to constantly use a medical aid.

D.17 Before you went into hospital, did you need any help with personal care?

[If the person asks ‘what is personal care’, explain this refers to activities such as washing, dressing, personal grooming or going to the toilet.]

Would you say before you went into hospital:

1. You needed no help at all.
2. Occasionally you needed some help with personal care tasks.
3. You needed help with the more difficult personal care tasks.
4. You needed daily help with most or all personal care tasks.

D.18 When doing household tasks during the last week, did you need any help?

[For example, preparing food, gardening, using the video recorder, radio, telephone or washing the car]

Would you say before you went into hospital:

1. You needed no help at all.
2. Occasionally you needed some help with household tasks.
3. You needed help with the more difficult household tasks.
4. You needed daily help with most or all household tasks.

D.19 Thinking about how easily you got around your home and community.
Would you say before you went into hospital:

1. You got around your home and community by yourself without any difficulty.
2. You found it difficult to get around your home and community by yourself.
3. You could not get around the community by yourself, but you got around your home with some difficulty.
4. You could not get around either the community or your home by yourself.

D.20 Thinking about how you generally felt before you went into hospital.

Would you say before you went into hospital:

1. You did not feel anxious, worried or depressed.
2. You were slightly anxious, worried or depressed.
3. You felt moderately anxious, worried or depressed.
4. You were extremely anxious, worried or depressed.

E. INFORMATION GIVEN IN HOSPITAL

We are interested in any information you got in hospital to get you ready for managing at home.

Please tick (✓)

E.1 While you were in hospital, were you given any instructions about the medicines that you were taking home?

1. Yes
2. No
3. Don’t know
4. Not taking any medications
5. Not needed, taking the same medications as before admission

E.2 Did you get any information about the side effects of the medicines that you were taking home?

1. Yes
2. No
3. Don’t know
4. Not enough information
5. Not taking any medications

E.3 Were you given written instructions about your medicines?

1. Yes Go to E.4
2. No Go to E.5
3. Don’t know Go to E.5
4. Not taking any medications Go to E.5

E.4 If YES, did someone spend time explaining these instructions?

1. Yes
2. No  □
3. Not needed  □

**E.5 While you were still in hospital, were you given information about help with managing at home?**
[e.g. shopping, showering, bathing, dressing, toileting, feeding, mobility, transport etc]
1. Yes  □
2. No  □
3. Don’t know  □
4. No information needed  □

**E.6 In hospital, did you get information on services in the community?** [eg. Domiciliary care, community nursing, meals-on-wheels, household help etc]
1. Yes  □
2. No  □
3. Don’t know  □
4. No information needed  □

**E.7 In hospital, did you get information on equipment you can use at home?**
[e.g. rails, shower chair, walking aids etc]
1. Yes  □
2. No  □
3. Don’t know  □
4. No equipment needed  □

**F. PREPARING TO GO HOME**

When you were told that you were going home from hospital....

**F.1 What day of the week were you discharged?**

(Daly, M.)

1. Monday [ ]
2. Tuesday [ ]
3. Wednesday [ ]
4. Thursday [ ]
5. Friday [ ]
6. Saturday  [   ]
7. Sunday  [   ]
8. Don’t recall  [   ]

F.2 Do you recall the time of day when you were discharged from hospital?

[Single response]

1. Between 0700 and 1200  [   ]
2. Between 1300 and 1800  [   ]
3. Between 1900 and 2200  [   ]
4. Between 2300 and 0200  [   ]
5. Between 0300 and 0600  [   ]
6. Don’t recall  [   ]

F.3 How did you get home from hospital?

[Single response]

1. Private car  [   ]
2. Taxi  [   ]
3. Public transport  [   ]
4. Other  [   ]

F.4 Did anyone arrange services for you to use at home? [eg. Domiciliary care, community nursing, meals-on-wheels, household help etc]

1. Yes  □
2. No  □
3. Don’t know  □
4. No-one needed to – services were already in place  □ [Go to F.7]
5. No services needed  □ [Go to F.7]

F.5 How many days did it take after you got home from hospital for you to get these services? [Single response - Please circle]
1. Same day
2. Following day
3. 2 days
4. 3 days
5. 4 or more days
6. Don't recall
7. Services have not arrived

F.6 Did the services that you needed when you got home from hospital take too long to arrive?
   1. Yes
   2. No
   3. If YES, did this delay cause you any problems?

F.7 If you have services already, have they met your needs?
   1. Yes
   2. No
   3. If NO, please tell me more

F.8 Did anyone arrange equipment for you?
   1. Yes [go to F.9]
   2. No [Go to F.10]
   3. Don’t know
   4. No-one needed to – equipment already in place
   5. No equipment needed [Go to F.12]

F.9 If YES, has this equipment arrived yet?
   1. Yes
   2. No
3. If NO, has this delay caused you any difficulty?...........................................................................................................................................................
..........................................................................................................................................................................................................
..........................................................................................................................................................................................................

F.10 Are you using the equipment?
1. Yes ☐
2. No ☐
3. If NO, can you tell me why you aren’t using the equipment?....................................................................................................................................................... 
..........................................................................................................................................................................................................
..........................................................................................................................................................................................................

F.11 If equipment has come, has it met your needs?
1. Yes ☐
2. No ☐
3. If NO, please tell me more ..........................................................................................................................................................................................................................................................
..........................................................................................................................................................................................................
..........................................................................................................................................................................................................

F.12 Was the person who assists you involved in the planning for your discharge from hospital?
1. Yes ☐
2. No ☐
3. Don’t know ☐
4. Nobody assists me ☐

F.13 When you were still in hospital but had been told you could leave, how did you generally feel about managing at home?

Would you say that before you went home from hospital:

1. You did not feel anxious, worried or depressed.
2. You were slightly anxious, worried or depressed.
3. You felt moderately anxious, worried or depressed.
4. You were extremely anxious, worried or depressed.

F.14 Were there any delays in your discharge from hospital?
1. Yes ☐ [go to F.15]
2. No ☐ [Go to G]

F.15 If YES, what was the delay? [Tick as many as needed]
1. Transport ☐
2. Medications
3. Don’t know
4. Other

G. MANAGING AT HOME
Now that you are home from hospital......

G.1 Has anything been worrying you about managing at home?
1. Yes
2. No
3. If YES, please tell me more

........................................................................................................................................
........................................................................................................................................
........................................................................................................................................

G.2 Are you worried about having a fall?
1. Yes
2. No
3. If YES, please tell me more

........................................................................................................................................
........................................................................................................................................

G.3 Can you contact your doctor if you need to?
1. Yes
2. No
3. If NO, please tell me more

........................................................................................................................................
........................................................................................................................................

G.4 Can you contact the services if you need to?
[For example, your local doctor, Domiciliary care, community nursing, meals-on-wheels, household help etc]
1. Yes
2. No
3. If NO, please tell me more

........................................................................................................................................
........................................................................................................................................


G.5 Has anything been done to deal with your worries?

[For example, have you returned to see your GP, seen a counselor, spoken to community services?]

1. Yes □
2. No □
3. Not needed, haven’t had any worries □
4. If YES, please tell me more

…………………………………………………………………………………………………………………………
…………………………………………………………………………………………………………………………
…………………………………………………………………………………………………………………………

G.6 Have there been any unexpected problems?

1. Yes □
2. No □
3. If YES, please tell me more

…………………………………………………………………………………………………………………………
…………………………………………………………………………………………………………………………
…………………………………………………………………………………………………………………………

H. FIRST WEEK HOME
In the week since you have been out of hospital….

H.1 Have you been back to the Emergency Department?

1. Yes □
2. No □
3. How often?............................................................................................................................

H.2 How many times have you seen:-

1. Your local doctor
2. Domiciliary Care
3. District Nurse
4. Chemist
5. Meals on wheels
6. Other health worker
7. Any other people who have helped you
8. Who were they?
H.3 Have you had any of these services help you?

1. Home modifications
2. Help with shopping
3. House cleaning
4. Others
5. Can you tell me what the other services were?

I. PREPARED AND SUPPORTED FOR DISCHARGE HOME

Looking back to the time you left the hospital.....

I.1 Overall how prepared did you feel for coming home?

1. Very prepared
2. Could have been better prepared
3. Unprepared

I.2 Have you had enough support from services since you've been home?

1. Yes
2. No
3. Could have been better supported
4. Not needed

I.3 Do you have anything else that you would like to say?

That concludes the survey. On behalf of The hospital I would like to thank you very much for taking part and for your time.
INTRODUCTION

Intro 1. Good ....... My name is Rosie King from the hospital. May I speak with (say carer’s name) please?

Either

3. Get person and repeat Introduction 1 and 2.
4. If (carer) is home but unavailable, arrange for another suitable time to call.

Date: __________________________ Time: __________________________

3. If (carer) is not home, ask if (carer) is likely to be available if I ring in the next couple of days.

Date: __________________________ Time: __________________________

Recently the person you care for was a patient in the hospital. Do you recall me approaching you and explaining about the telephone survey when the person you care for was a patient in the hospital? I gave you an information sheet about the research that I am doing.

We would be most appreciative if you could answer some survey questions about your involvement when the person you care for went into hospital and then came home again. This will help us to find out things that need to be improved in the hospital and home-care system.

This questionnaire has ?? questions and will take 30 to 40 minutes. I appreciate your willingness to take part and that you have other demands on your time. I also have other surveys to do today, so brief answers would be appreciated.

I can assure you that the information you give will remain confidential. The answers from all people interviewed will be gathered together and presented in a report. No individual answers will be passed on.
Please listen carefully and choose the answer that best describes you.

IF (CARER) IS HOME AND STILL WILLING TO PARTICIPATE, PROCEED TO SECTION A.

A. DEMOGRAPHICS

A.1 Can I just confirm that you are (carer’s name) and are the main person that provides care and support to your (parent, partner, child or friend)?

1. Yes
2. No
3. Don’t know

Now to start with some general questions

A.2 Gender (circle) 1. Male 2. Female

A.3 HACC Eligibility of person being cared for:

1. Frail-aged
2. Frail-aged and physically disabled
3. Younger disabled

A.4 Is an interpreter required? 1. Yes 2. No

A.5 What is the main language you use to communicate?

1. English (……)
2. Greek (……)
3. Italian (……)
4. Russian/Ukrainian (……)
5. Polish (……)
6. Vietnamese (……)
6. Other, please state ………………………………………

A.6 What is your post code? …………………………………

A.7 What is your date of birth? / / 19
A.8 Can you tell me which of the following living arrangements describes your household? Do you...

[Read Options. Single Response]

1. Live alone  (……)
2. Live with partner  (……)
3. Live with children  (……)
4. Live with partner and children  (……)
5. Live with parent(s)  (……)
6. Live with parent(s) and siblings  (……)
7. Live with other unrelated adults  (……)
8. Live with other related adults  (……)
9. Other  (……)

A.9 What is your relationship to the ex-patient?

1. Partner (husband or wife)  (……)
2. Parent (father or mother)  (……)
3. Child (son or daughter)  (……)
4. Relative (excluding 2 or 3)  (……)
5. Friend  (……)
6. Neighbor  (……)
7. Other  (……)

A.9 Are there any other relatives or friends who assist with the care of (ex-patient)?

1. Yes  ❑
2. No  ❑
3. Don’t know  ❑

B. ENTRY TO HOSPITAL

B.1 What was the reason for last admission to hospital of the person you care?

..............................................................................................................................................
B.2 How was __________ admitted to hospital?

[If answer is ‘through outpatients’, response equals unplanned admission. Read options. Single response]

1. Referred by his/her doctor and the admission was planned [ ] Go to B.3

2. Emergency or unplanned admission [ ] Go to D

3. Transferred from another hospital [ ] Go to D

B.3 Did __________ attend a pre-admission clinic before he/she went into hospital?

1. Yes [ ] Go to C

2. No [ ] Go to C

C. PLANNED ADMISSIONS

C.1 Before __________ went into hospital, were YOU involved in the planning for his/her admission into hospital?

1. Yes
2. No
3. Don’t know

C.2 Did YOU get written information about his/her going into hospital?

1. Yes Go to C.3
2. No Go to C.5
3. Don’t know

C.3 Do YOU recall who gave you this information?

[Read Options. Single Response]

1. Your GP
2. Outpatient Clinic
3. Domiciliary Care
4. District Nurse
5. Other health worker
6. Other
C.4 Did someone spend time with YOU explaining the information?

1. Yes  
2. No

C.5 Before ___________ went into hospital, did YOU get information about services that he/she may need when he/she came home from hospital?

[If the person asks ‘What kind of services?’ explain services that are found in the community, like Domiciliary care, community nursing, meals-on-wheels, household help etc]

1. Yes  
2. No  
3. Don’t know

C.6 How much information did YOU get on equipment he/she might need when he/she got home from hospital?

1. As much as I needed  
2. Some, but not enough  
3. None  
4. No information needed

C.7 Before ___________ went into hospital, overall how prepared did YOU feel for him/her going into hospital?

1. Very prepared  
2. Could have been better prepared  
3. Unprepared

D. ASSESSMENT OF CAREGIVER ABILITY TO MANAGE PRE & POST ACUTE CARE

Now I am going to ask you a number of questions about YOUR health and ability to manage during the last week.

D.1 In the last week since ___________ has been discharged; did YOU receive any help with his/her personal care?

[If the person asks ‘what is personal care’, explain this refers to activities such as washing, dressing, personal grooming or going to the toilet.]

Would you say in the last week:

5. You needed no help at all.  
6. Occasionally you needed some help with personal care tasks.  
7. You needed help with the more difficult personal care tasks.  
8. You needed daily help with most or all personal care tasks.

D.2 When doing household tasks during the last week since ___________ has been discharged, did YOU receive any help?
[For example, preparing food, gardening, using the video recorder, radio, telephone or washing the car]

Would you say:

5. You needed no help at all.
6. Occasionally you needed some help with household tasks.
7. You needed help with the more difficult household tasks.
8. You needed daily help with most or all household tasks.

Now I want to ask you to think back about how you managed looking after at home BEFORE he/she went into hospital.

D.3 Before went into hospital, did you need any additional help with his/her personal care?

[If the person asks ‘what is personal care’, explain this refers to activities such as washing, dressing, personal grooming or going to the toilet.]

Would you say before he/she went into hospital:

1. You needed no help at all.
2. Occasionally you needed some help with personal care tasks.
3. You needed help with the more difficult personal care tasks.
4. You needed daily help with most or all personal care tasks.

D.4 When doing household tasks before went into hospital, did you need any additional help?

[For example, preparing food, gardening, using the video recorder, radio, telephone or washing the car]

Would you say before went into hospital:

1. You needed no help at all.
2. Occasionally you needed some help with household tasks.
3. You needed help with the more difficult household tasks.
4. You needed daily help with most or all household tasks.

D.5 Thinking about how you generally felt before went into hospital.

Would you say that before he/she went into hospital:

5. You did not feel anxious, worried or depressed.
6. You were slightly anxious, worried or depressed.
7. You felt moderately anxious, worried or depressed.
8. You were extremely anxious, worried or depressed.

E. CAREGIVER STRAIN INDEX

I am going to read a list of things that other people have found to be difficult. Would you tell me if any of these apply to you? (Give examples)

<table>
<thead>
<tr>
<th>Issue</th>
<th>Yes=1</th>
<th>No=0</th>
</tr>
</thead>
<tbody>
<tr>
<td>Sleep is disturbed (e.g., because is in and out of bed or wanders around at night)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>It is inconvenient (e.g., because helping takes so much time or it’s a long drive over to help)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>It is a physical strain (e.g., because of lifting in and out of a chair; effort or concentration is required)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>It is confining (e.g., helping restricts free time or cannot go visiting)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>There have been family adjustments (e.g., because helping has disrupted</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Routine; there has been no privacy</td>
<td></td>
<td></td>
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<tr>
<td>----------------------------------</td>
<td>--</td>
<td></td>
</tr>
<tr>
<td>There have been changes in personal plans (e.g., had to turn down a job; could not go on vacation)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>There have been other demands on my time (e.g., from other family members)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>There have been emotional adjustments (e.g., because of severe arguments)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Some behavior is upsetting (e.g., because of incontinence; has trouble remembering things; or ________ accuses people of taking things)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>It is upsetting to find ________ has changed so much from his/her former self (e.g., he/she is a different person than he/she used to be)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>There have been work adjustments (e.g., because of having to take time off)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>It is a financial strain</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Feeling completely overwhelmed (e.g., because of worry about and concerns about how you will manage)</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

**Total Score** (Count yes responses. Any positive answer may indicate a need for intervention in that area. A score of 7 or higher indicates a high level of stress.)

---

**F. INFORMATION GIVEN IN HOSPITAL**

We are interested in any information you got in hospital to get you ready for managing ________ at home.

Please tick (√)

**F.1** While ________ was in hospital, were YOU given any instructions about the medicines he/she was taking home?

1. Yes  
2. No  
3. Don’t know  
4. Not taking any medications  
5. Not needed, he/she is taking the same medications as before

**F.2** Did you get any information about the side effects of the medicines that ________ was taking home?

1. Yes  
2. No  
3. Don’t know  
4. Not enough information  
5. Not taking any medications

**F.3** Were you given written instructions about his/her medicines?

1. Yes  

Go to F.4

---

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2. No  ☐ Go to F.5
3. Don’t know  ☐ Go to F.5
4. Not taking any medications  ☐ Go to F.5

F.4 If YES, did someone spend time explaining these instructions?

1. Yes  ☐
2. No  ☐
3. Not needed  ☐

F.5 While ________ was still in hospital, were you given information about help with managing him/her at home? [e.g. shopping, showering, bathing, dressing, toileting, feeding, mobility, transport etc]

1. Yes  ☐
2. No  ☐
3. Don’t know  ☐
4. No information needed  ☐

F.6 In hospital, did you get information on services in the community? [eg. Domiciliary care, community nursing, meals-on-wheels, household help etc]

1. Yes  ☐
2. No  ☐
3. Don’t know  ☐
4. No information needed  ☐

F.7 In hospital, did you get information on equipment ________ could use at home? [eg. rails, shower chair, walking aids etc]

1. Yes  ☐
2. No  ☐
3. Don’t know  ☐
4. No equipment needed  ☐

G. PREPARING TO GO HOME

G.1 Did the hospital staff know that you are the main person that provides care and support to ________?

1. Yes  ☐ (Go to G.2)
2. No  ☐
3. Don’t know  ☐
G.2 How often did you visit__________when he/she was in hospital?

Would you say:

1. You were able to visit every day
2. You visited as much as you could, but not every day
3. You were not able to visit very often at all
4. You were unable to visit at all.

When you were told that__________was going home from hospital....

G.3 What day of the week were he/she discharged?

[Single response]

8. Monday [ ]
9. Tuesday [ ]
10. Wednesday [ ]
11. Thursday [ ]
12. Friday [ ]
13. Saturday [ ]
14. Sunday [ ]
8. Don't recall [ ]

G.4 Do you recall the time of day when__________was discharged from hospital?

[Single response]

1. Between 0700 and 1200 [ ]
2. Between 1300 and 1800 [ ]
3. Between 1900 and 2200 [ ]
4. Between 2300 and 0200 [ ]
5. Between 0300 and 0600 [ ]
6. Don't recall [ ]

G.5 How did__________get home from hospital?
[Single response]

1. Private car  
2. Taxi  
3. Public transport  
4. Other  

G.6 Did anyone arrange services for ________ to use at home? [e.g. Domiciliary care, community nursing, meals-on-wheels, household help etc]

1. Yes  
2. No  
3. Don’t know  

4. No-one needed to – services were already in place  
5. No services needed  

GO TO G.9

G.7 How many days did it take after ________ got home from hospital for him/her to get these services? [Single response - Please circle]

1. Same day  
2. Following day  
3. 2 days  
4. 3 days  
5. 4 or more days  
6. Don’t recall  
7. Services have not arrived

G.8 Did the services that ________ needed when he/she got home from hospital take too long to arrive?

1. Yes  
2. No  

3. If YES, did this delay cause any problems?........................................................................................................................................................  
   ........................................................................................................................................................................  
   ........................................................................................................................................................................

G.9 Did anyone arrange equipment for ________?
1. Yes □ [go to F.8]
2. No □ [Go to F.9]
3. Don’t know □
4. No-one needed to – equipment already in place □
5. No equipment needed □ GO TO G.12

G.10 If YES, has this equipment arrived yet?
1. Yes □
2. No □
3. If NO, has this delay caused any difficulty?
...........................................................................................................................................................
..........................................................................................................................................................................
..........................................................................................................................................................................

G.11 Is _________ using the equipment?
1. Yes □
2. No □
3. If NO, can you tell me why he/she isn’t using the equipment?
...........................................................................................................................................................
..........................................................................................................................................................................
..........................................................................................................................................................................

G.12 Were you involved in the planning for _________ discharge from hospital?
1. Yes □
2. No □

G.13 To what extent were you involved in the planning for _________’s discharge?
(For example, you were invited to meetings or had conversations with medical and nursing staff or were asked for information about _________ home situation)

Would you say:
1. You were not at all involved.
2. You could have been more involved.
3. You were very involved in the planning for discharge.

G.14 When _________ was still in hospital but had been told he/she could leave, how did you generally feel about managing him/her at home?

Would you say that before you went home from hospital:
5. You did not feel anxious, worried or depressed.
6. You were slightly anxious, worried or depressed.
7. You felt moderately anxious, worried or depressed.
8. You were extremely anxious, worried or depressed.

G.15 Were there any delays in discharge from hospital?

1. Yes ☐ [go to G.16]
2. No ☐ [Go to H]

G.16 If YES, what was the delay? [Tick as many as needed]

1. Transport ☐
2. Medications ☐
3. Don’t know ☐
4. Other ☐

H. MANAGING AT HOME

Now that is home from hospital......

H.1 Has anything been worrying you about managing him/her at home?

1. Yes ☐
2. No ☐
3. If YES, please tell me more

…………………………………………………………………………………………………………………………………
…………………………………………………………………………………………………………………………………
…………………………………………………………………………………………………………………………………

H.2 Are you worried about him/her having a fall?

1. Yes ☐
2. No ☐
3. If YES, please tell me more

…………………………………………………………………………………………………………………………………
…………………………………………………………………………………………………………………………………
…………………………………………………………………………………………………………………………………

H.3 Can you contact your doctor if needs medical attention?

1. Yes ☐
2. No ☐
3. If NO, please tell me more
H.5 In looking after __________, can you contact the services if you needed to?

[For example, your local doctor, Domiciliary care, community nursing, meals-on-wheels, household help etc]

1. Yes
2. No
3. If NO, please tell me more

H.6 Has anything been done to deal with your worries?

[For example, have you and __________ returned to see your GP, seen a counselor, spoken to community services?]

1. Yes
2. No
3. Not needed, haven’t had any worries
4. If YES, please tell me more

H.7 Have there been any unexpected problems?

1. Yes
2. No
3. If YES, please tell me more

H.8 If you have services already, have they met the needs of __________?

1. Yes
2. No
3. If NO, please tell me more
H.9 If equipment has come, has it met the needs of__________?

1. Yes  ☐
2. No  ☐

3. If NO, please tell me more ........................................................................................................................................
..............................................................................................................................................................................
..............................................................................................................................................................................

I.  FIRST WEEK HOME
In the week since__________ has been out of hospital....

I.1 Has he/she been back to the Emergency Department?

1. Yes  ☐
2. No  ☐

3. How often?..........................................................................................................................................................................

I.2 How many times has__________ seen:-

1. Your local doctor  
2. Domiciliary Care  
3. District Nurse  
4. Chemist  
5. Meals on wheels  
6. Other health worker  
7. Any other people who have helped  
8. Who were they?

I.3 Have you had any of these services help you?

1. Home modifications  ☐
2. Help with shopping  ☐
3. House cleaning  ☐
4. Others  ☐

5. Can you tell me what the other services were?  

J. PREPARED AND SUPPORTED FOR DISCHARGE HOME
Looking back to the time the person you look after left the hospital…..

J.1 Overall how prepared did YOU feel for coming home?

1. Very prepared ☐
2. Could have been better prepared ☐
3. Unprepared ☐

J.2 Have YOU had enough support from services since has been home?

1. Yes ☐
2. No ☐
3. Could have been better supported ☐
4. Not needed ☐

J.3 Do you have anything else that you would like to say?

........................................................................................................................................................................
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That concludes the survey. On behalf of the hospital I would like to thank you very much for your time and taking part.
APPENDIX 4C

KEY ISSUES: PRE-ADMISSION AND DISCHARGE PLANNING
Interview Questions Domiciliary Care and Community Nursing Practitioners

1. Name of interviewee:
2. Date of interview:
3. From your perspective:

   a) What are the main issues facing an older person BEFORE GOING INTO hospital?

   b) What are the main issues for carers / significant others when the older person they care for goes into hospital?

   c) What are the main issues facing a person with a disability BEFORE GOING INTO to hospital?

   d) What are the main issues for carers / significant others of a person with a disability BEFORE GOING INTO to hospital?

2. From your perspective:

   a) What are the main issues for an older person WHEN LEAVING hospital?

   b) What are the main issues for carers / significant others when the older person they care for leaves hospital?
c) What are the main issues for a person with a disability WHEN LEAVING hospital?

_________________________________________________________________________________________________

_________________________________________________________________________________________________

_________________________________________________________________________________________________

d) What are the main issues for the carer / significant other of a person with a disability when they leave hospital?

_________________________________________________________________________________________________

_________________________________________________________________________________________________

_________________________________________________________________________________________________

4. Process on admission to hospital for your clients – do you know who does what – clerical, nursing & medical responsibilities?

_________________________________________________________________________________________________

_________________________________________________________________________________________________

_________________________________________________________________________________________________

4 a) How do you know who does what during the hospital admission process?

_________________________________________________________________________________________________

_________________________________________________________________________________________________

_________________________________________________________________________________________________

5. Process on discharge from hospital for your clients – do you know who does what – clerical, nursing & medical responsibilities?

_________________________________________________________________________________________________

_________________________________________________________________________________________________

_________________________________________________________________________________________________

5 a) How do you know who does what during the hospital discharge process?

_________________________________________________________________________________________________

_________________________________________________________________________________________________

_________________________________________________________________________________________________

6. How do you learn about hospital admission and discharge of your clients?

_________________________________________________________________________________________________

_________________________________________________________________________________________________

_________________________________________________________________________________________________
7. Does anyone from the hospital notify you of a client’s admission?

8. How does notification occur?

9. What orientation is there for new practitioners of a client’s hospital admission and discharge?

10. Documentation – what is used at your service for hospital admission and discharge planning? Where is it filed & by whom?

11. Is there any electronic admission and discharge planning process between the hospital your service?

12. If there was an electronic admission and discharge process between the hospital and your service:
   - 12a How often should the list be produced?
   - 12b What kind of admission information would be most useful to you?

13. What is the process used in this service following discharge from the hospital – including phone calls to the hospital, fax/letters to other community service providers, GPs?

14. As far as you know, what is the process for discharge planning throughout a patient’s admission – e.g. discharge planning meetings; care plans; case conferences?
15. When was the process and documentation for admission and discharge planning last evaluated in your service e.g. with surveys to practitioners?

16. Given that we have limited resources, which are the most important issues in relation to pre-admission and discharge planning?
   1.
   2.
   3.
   4.
   5.
   6.

16a. Do you have any ideas of how these issues could be improved?

17. What changes would you like to see in the system?

18. Do you have any further comments?

Thank you for your participation
APPENDIX 4D

Hospital hOme Pathways

DISCHARGE PLANNING PROCESS
HOSPITAL NURSES CONSULTATIONS

HOP Information Sheet provided, please tick (✓) □ YES □ NO

Informed consent provided, please tick (✓) □ YES □ NO

Name of ward and core business:
Interviewees name and position:
Date:

1a. Do existing community service providers (including GPs) provide information about a patient who is admitted?


1b. If they do, how is this information provided?


2. Can you explain the process on admission for younger people with a disability, Aboriginal people 45 years and over and persons over 65 years – who actually does what – clerical, nursing & medical responsibilities?


2a. Who notifies existing services of a patient’s admission?


2b. How are existing services notified?


3. How are referrals made to Allied Health?

4. Documentation – what is used for discharge planning? Where is it filed & by whom?

5. Electronic discharge notification – what is the process including letters to existing services, externals consultants, GPs?

6. At what point of the patient’s admission does discharge planning commence?

7. What is the process for discharge planning throughout a patient’s admission – e.g. discharge planning meetings?

8. Do you know of any agencies in the community that assist younger people with disabilities and frail older people to continue to live at home independently?

9. How do you know about these community agencies?
10. Which community agencies are most often used for referrals when a younger person with disabilities or a frail older person is discharged?

11. Which community agencies have been most responsive about receiving and accepting referrals for younger disabled people and frail older people?

11a. Which community agencies have not been responsive about receiving and accepting referrals?

11b. Why was the referral unsuccessful?

12. Are unpaid carers or significant others of younger people with disabilities or a frail older person ever consulted before discharge?

13. How do staff learn about discharge planning processes for this ward? What orientation is there for pool, agency or new staff?
14. When was the process & documentation for discharge planning last evaluated in this ward e.g. with staff and/or patient surveys?


15. What are the types of issues that make some patients particularly difficult to discharge?


16. What discharge planning approaches have been attempted in the past and HAVE NOT worked?


17. What are you doing now that works and would like to maintain, or improve?


17a. Is there any follow-up of patients performed after discharge to ensure that services have been put in place?


17b. If services have NOT been received, do you know why?


18a. What problems have you had when trying to discharge patients?


18b. What problems do patients tell you about when they are being discharged?
19. Given that we have limited resources, from your perspective what are the most important issues with discharge planning?

1. 

2. 

3. 

4. 

5. 

6. 

20. Do you have any ideas of how these issues could be improved?

____________________________________________________________________________________

____________________________________________________________________________________

____________________________________________________________________________________

21. What changes would you like to see in the system?

____________________________________________________________________________________

____________________________________________________________________________________

____________________________________________________________________________________

22. Do you have any further comments?

____________________________________________________________________________________

____________________________________________________________________________________

____________________________________________________________________________________

THANK YOU FOR YOUR PARTICIPATION
APPENDIX 5A

Other Community Services

☐ OTHER SERVICES
  Name of Service: __________________________
  Contact Person: __________________________
  Service(s) provided: ______________________
  Date commenced: __________________________

☐ OTHER SERVICES
  Name of Service: __________________________
  Contact Person: __________________________
  Service(s) provided: ______________________
  Date commenced: __________________________

☐ OTHER SERVICES
  Name of Service: __________________________
  Contact Person: __________________________
  Service(s) provided: ______________________
  Date commenced: __________________________

☐ OTHER SERVICES
  Name of Service: __________________________
  Contact Person: __________________________
  Service(s) provided: ______________________
  Date commenced: __________________________

Your Health and Community Services Record

WHAT IS THIS CARD FOR?
The information on this card can help you and your health and community service providers coordinate your health care between hospital and home. This card is for health and community service providers to complete and it will help you keep track of who is involved in providing health and community care to you. It is most useful if you need frequent health checks and have a number of community service providers assisting you.

Sign and date Your Health and Community Services Record to ensure that you and your health care providers know that it is your property and using it is your decision.

Your name: __________________________
Date: __________________________

Your signature: __________________________

Write this card in Your Health Record for convenience and safety.

Before a health care provider makes a referral to another health or support service for you, they should discuss your needs and the choices available with you and your carer or family. Referrals to community-based services often go to Home and Community Care (HACC)-funded services. These services are targeted at older people and younger disabled people, enabling them to continue to live at home independently. Information needed when making a referral to HACC services:

- Name
- Address
- Age
- Needs
- Special Considerations

[Logo of Department for Families and Communities and HACC]
Hospital staff will tick ✓ in the box when they have contacted a community service provider for you. Community service providers can add their contact details, the date and services provided.

☐ ABORIGINAL HOME CARE PROGRAM
Tel: 8234 8373  Date contacted:  /  /
Contact Person:
Service(s) provided:
Date commenced:  /  /

☐ COMMONWEALTH CARELINK
Tel: 1800 052 222  Date contacted:  /  /

☐ COUNCIL COMMUNITY SERVICES (LOCAL)
City of Charles Sturt  Tel: 8408 1363
Port Adelaide Enfield  Tel: 8405 6600
City of West Torrens  Tel: 8416 6333
Contact Person:
Service(s) provided:
Date commenced:  /  /

☐ DOCTOR (GP)
Name of GP:
Tel:
Address:

☐ ETHNIC LINK SERVICES
Tel: 8241 0201  Date contacted:  /  /
Contact Person:

☐ METROPOLITAN DOMICILIARY CARE
(Metropolitan Access Team - REFERRALS)
Tel: 8193 1234  Date contacted:  /  /
Contact Person:
Service(s) provided:
Date commenced:  /  /

☐ OPTIONS COORDINATION (WEST)
Tel: 8348 6000  Date contacted:  /  /
Contact Person:
Service(s) provided:
Date commenced:  /  /

☐ PHARMACIST
Pharmacist:
Tel:
Address:

☐ ROYAL DISTRICT NURSING SERVICE
Tel: 1300 364 264  Date contacted:  /  /
Contact Person:
Nursing Centre Location:
Date commenced:  /  /

For information on other services not listed above, turn to Page 4.
APPENDIX 5B

Please keep your medication list up to date. Your Doctor or Pharmacist can help you do this.  

<table>
<thead>
<tr>
<th>Medication Name</th>
<th>Strength</th>
<th>Other Names</th>
<th>Purpose of Medication</th>
<th>Number to Take</th>
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<table>
<thead>
<tr>
<th>Other Medications</th>
<th>Strength</th>
<th>Other Names</th>
<th>Purpose of Medication</th>
<th>Instructions</th>
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</table>
MEDICATION ALLERGIES:

<table>
<thead>
<tr>
<th>Medicine</th>
<th>Date</th>
<th>What Happened?</th>
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SPECIAL INSTRUCTIONS

Make sure you understand the medicines you are taking – read the label, including the warnings.

Make sure the medicine is what your doctor ordered for you. Ask about:
- directions for use
- possible side effects or interactions, and
- how long you will need to take it for.

You may need to obtain more medicines to complete or continue your treatment.

You can return medications to your local pharmacy that are no longer needed.

YOUR MEDICINES CARD

This card contains confidential and personal information. It will help you keep a list of all the medicines you are taking. You can include:

- prescriptions, over the counter and complimentary medicines (e.g. vitamins and herbs), and
- information about drug allergies you may have.

Name:__________________________
Address:________________________
Phone:__________________________

Health Contact Information

Local Doctor:____________________
Phone:__________________________
Pharmacist:_____________________ 
Phone:__________________________
Hospital:_____________________
Phone:__________________________

Take this card with you every time you see your Local Doctor, Specialist, Hospital (includes admission, outpatient and Emergency Department) or Community Service Provider.
APPENDIX 5C

SUGGESTIONS FROM REFERENCE GROUP “GOING HOME PACK”

- pack needs to be small, succinct (OPS, meds). MOW number on back, local council’s number. Ethnic Link

- something about medications eg changes in doses or types of medications – maybe where they can get some info re this.
- info on where they can hire equipment
- info on community services esp Day Therapy services post discharge
- info re respite services for self and carers

- carer respite centre
- ethnic link
- case manager of community services

- consumers reference guide and contact numbers and names of key contact personnel
- card so as patients can record services and contact names relevant to current service provision.
- card to record referrals to service providers post separation
- PACK SHOULD BE COMMUNITY BASED AND GENERATED

- useful telephone numbers
- MOW
- Dom Equip Services
- Medication - what medication am I taking? What are the medications for? What are the side effects of these medications? How long do I need to take them for?

- To build on the effectiveness of the info pack and to cater for individual needs could info about hospital SW dept having specialised info / pamphlets about particular needs be included in pack eg SW dept number on patient to ask Ward Staff to contact SW covering the Med/Surg unit that patient has been admitted under
- Info pack for carer

- It may be useful for health professionals to have a checklist of all the info is available / or a pack for health professionals – not all health professionals are aware of services available.
- A regular ?????? to inform health professionals of services available both in the hospital and the community
- Have updated info on hospital Internet on community services for health professionals
- pamphlet for consumers on discharge planning – maybe more simple – give consumers a checklist of things that they need to consider / plan / ensure are planned.

- Supermarkets who deliver cost, contact numbers, days to ring, method of payment.
- Put date on brochures (at least year of publication)
- Organisations who offer fee for service programs
- Make really clear that HACC eligibility is a prerequisite for service provision.
- City of Charles Sturt information number 8408 1375
- Useful numbers: to include indigenous specific agencies. To include a more specific department at the major hospital (eg social work)
- Discharge planning package to be given to patients by the GP when planning admission. To be given to patients during admission if unplanned.
- GP education – focus on the benefits to the GP (and patient). What would motivate the GP to use this package? Promote package with AMA, RACGP and local Division of General Practice.
- Brochure: does not provide understanding – grammar is ambiguous. Dot points need to be (1) very clear and (2) very concise. Does not mention medical transport (ie to outpatient appointments). Needs to promote choices and independence at home.
- Brochures to be NESB and indig specific and tape (cassette) available to visually impaired and illiterate.

- Poisons information – add to folder
- Other pre-existing service involvement – contact details and case coordinator details from organisation and service provided eg personal care, shopping/cleaning, nursing/allied health.
- Hours provided – number of days
- Medication chart – is dosette required, ?PRN and instructions, does pre-existing service require info.
- Special needs – hospital and services be aware of phobias, language barrier, religion, physical problems etc
- Info on obscure disability/disease – Hyper-reflexia for quads, Sanfillipo disease etc. If info not available where can it be accessed. Info for hospital / service.
- GP number
- Family contacts
- Living will / power of medical attorney
APPENDIX 5D

Nominal Group Themes from cards written by participants.

BARRIERS AND LIMITATIONS

1. INFORMATION QUALITY, 10 STICKERS, 8 VOTES
   - Don’t know when to ask for help
   - Lack of communication with client
   - Client already upset and has lost confidence therefore harder for them to work through options rationally
   - Communication: Vulnerable people need a range of communicated instructions to assist with discharge
   - Instructions not clear to client. SPECIALLY IF CALD client!
   - Clients can’t read / understand information provided by hospital
   - Lack of communication between appropriate family, carers and hospital
   - Language issues. Need to use interpreter, if necessary
   - Communication with the carer before discharge and the recipient
   - Absence of formal education, meaning unable to understand most health concepts

2. KNOWLEDGE, 18 STICKERS, 7 VOTES
   - System to ensure referral actually takes place – evidence
   - Lack of knowledge of admission situation of client
   - That all service intervention for positive recovery has been reviewed and coordinated before leave / discharge
   - Lack of: - coordination between Interface, WDC, GP
   - Hospital unaware of previous providers for discharge communication
   - Not knowing person was in hospital
   - Hospitals often don’t do home visits and so are not aware of all the issues for clients
   - Difficulty for hospital staff to access community service information – complexity of service providers
   - Lack of: - coordination between In-patient and Out-patient re needs of interpreters
   - Lack of communication between hospital and service
   - Hospital not interested what happens to patient at home? (carer? no carer?)
   - Not much “follow up” from hospital after discharge
   - Service provider knowing client is hospitalized
   - Hospital staff – knowledge of previous services and provider
   - Clients not have a case manager or out of hours case management
   - Poor communication between hospital, GP and service provider
   - You, as key support agency, were not alerted to client being admitted to hospital nor discharged
   - Communication between hospital staff and provider / case manager of community services

3. SERVICES FLEXIBILITY AVAILABILITY SPREAD, 6 STICKERS, 7 VOTES
   - Waiting lists for certain programs that may be indicated post discharge
   - Hospitals need to have capacity to put services in place while clients are on Agency waiting lists
   - Eligibility criteria for support programs may be issue
   - Inability for services to be flexible and provide more carer, eg initially may need 2 for showering
   - Not enough services
   - Necessary equipment not being immediately available eg electric lifter, hospital bed, pressure mattress

4. SERVICES - RESTRICTED HOURS ETC, 8 STICKERS, 5 VOTES
   - Weekend? timing coming home inconvenient time. No communication from hospital
   - Timing of discharge (on Friday before long weekend)
   - Timing – hospitals need for beds does not consider patient’s social needs
   - After hours support / contacts
- Lack of support on weekend, and public holiday
- Agencies work 9 – 5pm, not after hours
- After hours service: many services “close down” for weekends. Major limitations when hospital attempts to empty bed for weekend
- Phoning you as case manager when you can’t coordinate services which are closed now for weekend

5. COMMUNITY SUPPORTS & LINKS, 5 STICKERS, 4 VOTES
- Support to empower the person returning home
- Financial poverty – if discharged in off-pension week there may not be any $’s to buy food, transport, medication
- Have not bought in “provisions” in time for weekend
- Clients often have not prepared emergency plans eg not come to grips with their potential situation before it happens
- Volunteers need to provide support - at times difficult due to lack of volunteers

SOCIAL ISOLATION, 9 STICKERS

- Living alone
- Clients / carers: Not have anyone to call / contact to discuss / review what to do eg family, friends
- Family can not always be contacted
- Guardianship Board applications lodged without explanation, consultation with clients / family
- Combination of health condition leading to hospitalization and other health issues lead to person being too frail for living alone
- Carer can’t leave the caree alone to go to seek assistance, medications, household items – respite & transport issues
- Socially isolated patients may have no advocate in hospital eg family / friends
- Clients don’t have a support network at home
- No phone available that can make outgoing calls except for 000

6. DISCHARGE, 10 STICKERS, 3 VOTES
- Services to have already been put in place before discharged and before having come home
- Pre-discharge plan
- Planned return home with services
- That the person returning home agrees with the discharge plan
- Lack of written discharge plan for consumer (sometimes others get the info and client doesn’t)
- Some clients should not have been discharged – without proper discharge plan
- Discharged, not well prepared by hospital
- Pressures of hospital to move patients through too quickly
- Understanding: limited understanding of issues faced by ill, vulnerable people by those who make decisions about their discharge
- Not told in advance re discharge day / time

MEDICATION / COMMUNICATION, 4 STICKERS

- Medical plan supported and understood before discharge
- No contact with family pre and post admission to service
- Medication mix ups – client takes hospital medication and medication prescribed by GP leading to double ups
- Medication may be confusing medications and therefore may be at high risk of: eg relapse if not taking or eg overdosing / incorrectly timing it

7. ASSESSMENT, 7 STICKERS, 3 VOTES
- Hospital staff do not know the clients actual living circumstances as well as you do, hence have not known what to plan for
- Assessment of needs in hospital often over-estimates client’s ability to cope. Home assessment not always in place in timely manner
- Medical focus in hospitals – main concern admission medical condition, Ignores previous care needs
- Time: hospital staff appear not to have time to listen to patients stories / service providers histories, which all impact on success of admission and discharge
• Not accepting assessment done by others eg Interface, WDC
• Inadequate assessment (holistic) – client may understate their previous coping
• Lack of copy of ACAT or other assessments done

8. INFORMATION FOR CLIENTS, 6 STICKERS, 1 VOTE
• No Help Line : (not available)
No link with hospital after discharge to reassure, demystify admission and discharge

• Client not having follow-up contact details
• Client not given contact details re equipment use
• Consumers lack of information and consultation about service available
• Carers / clients often don’t have a contact person at hospital
• Knowledge: more accessible information about community services, availability, contact

9. TRANSPORT, 2 STICKERS, 1 VOTE
• Sending home alone in transport (eg cab) does not allow hospital staff to learn from this experience hence barriers self-perpetuate
• No private transport

Other stickers grouped together

• Clients not understand or remember the system of care provision.  
  Who provides what

• Client not given enough information about what has been organized for them
• Carers don’t have enough education to understand discharge information

OPPORTUNITIES

1. DEVELOP BETTER COMMUNICATION / DATA INFO SYSTEM, 13 STICKERS, 10 VOTES
• Extra intense services Better communication between acute care and primary care
• Central data base to include service providers, case manager / contact person and number
• Use modern (email, fax) information systems to inform service providers of hospital admission and discharge information
• Technology: being aware of confidentiality but using technology to ensure that relevant community member / services are aware of hospital plans and actions
• Database of hospitals, govt services and community organizations accessible to all service providers for ongoing liaison
• Communication – HACC services having access to hospital data to check if clients are hospitalized
• Communication – a system to flag patients in hospital who have HACC services in community

ID OF PERSON TO SERVICE

• Patient / client has ID card with contact number for service provider she / he is getting help from
• Information concerning HACC services to be collected as routine hospital admission information

2. POTENTIAL TO IMPROVE, 5 STICKERS, 5 VOTES

• Hospital being aware of patients’ situation
• Volunteers – used to provide in-home support between service providers communication
• Personal responsibility: Pro-active discussion to assist with planning for possible emergencies, focuses on individuals taking charge rather than being “victims” of the system
• Acute care giver to gain insight of patients’ home environment
• Acute care giver to look beyond the 4 walls of the hospital

SERVICE INTEGRATION, 2 STICKERS, 2 VOTES

• To integrate the support at the right time to allow the recovery to be a positive outcome
• For effective client care plans to be developed or reviewed

3. ASSESSMENT, 5 STICKERS, 6 VOTES

• Assessment, 6 STICKERS, 1 VOTE
No link with hospital after discharge to reassure, demystify admission and discharge
• Intervention as great support networks between services and the person and carer
  • Assessment in the home with client post discharge → setting goals (facilitated by health professional) to determine clients motivation / needs etc
  • Better assessment processes in hospital when diagnosing the clients needs, on discharge
• Improved assessment processes. If possible assessment of clients by other agencies pre discharge to allow set up of services
• Process for Guardianship Board application to be discussed with client and family prior to lodgment

4. INCREASE ACCESS / FLEXIBILITY, 5 STICKERS, 4 VOTES
• Access to 24 hour, 7 days / week in home help services for discharged patients
• Flexibility in providing service, i.e. weekend, holidays as well as week days
• Flexibility in amount of service delivered e.g. may need some in first few weeks home
• Extended hours of service: Some services providing after hours: weekend services for clients – Help Lines, Crisis Responses, even libraries (to help read letters)
• For waiting list for services to be reduced / eliminator

5. METHOD OF COLLECTING INFORMATION, 9 STICKERS, 4 VOTES
• For access to the same information by hospitals and agencies e.g. carers, clients, hospital, services
• Notification of admission & contact details to service provider
• Don’t assume / rely on carers to inform service providers
• For improved referral systems between agencies and hospitals
• Client provided list of contact people to support them (i.e. could be certain family member)
• A more thorough referral from GP about the client’s health and needs so that a better referral is made to a service provider. So information is not confused
• A singular case manager to make sure that the client is linked to another service provider (HACC) agency before losing touch with the client
• A more streamlined approach in case management at a formal provider level (i.e. WDC) to review clients who they have referred onwards
• HACC service providers to be kept involved / informed of Outpatient appointments and continuing treatments

6. DISCHARGE, 8 STICKERS, 3 VOTES
• Hospital discharge info sent with clients’ permission to relevant agencies and GP. (GP’s need to carefully monitor and refer and not assume client OK.)
• Provide discharge summary in layman’s language for client to keep
• Discharge detailed to go to appropriate service provider
• Improved communication between agencies and hospital (and vice versa) – inclusion in discharge planning process to facilitate seamless care
• Assist client to take control of discharge information using verbal and written methods and ensuring they understand concepts
• HACC service providers to be involved in discharge planning in hospitals
• Involvement of client in discharge planning
• Adequate information provision to client on discharge with appropriate contact details equip etc

INFORMATION BASES AND COMMUNICATION, 6 STICKERS, 1 VOTE

• Well prepared discharge: medication, discharge letter, transport – all organized
• Take into account timing issues when discharge - ? pension day, ? weekend
• Family involvement and notification
• Recognising the greater individual need to begin with
• Timing!! If patient doesn’t have live in carer – no discharge on Friday !
• For clients to be better linked to their community following discharge

7. CLEAR PROCESS IF CHANGE

(KNOWLEDGE → EMPOWERMENT, CLIENT FOCUS, CONSENT), 3 STICKERS, 1 VOTE
- Encourage the person / client to work toward their needs
- Community responses: ie availability of services, such as local chemist, for longer hours, all weekend
- Education of client to motivate and empower re their health - pre hospital admission - pre discharge

SHARING INFORMATION AND DISSEMINATION, 1 STICKER

- Copy of ACAT or assessment for client (not just others)

8. ASSESSMENT / ENTRY, 2 STICKERS, 1 VOTE

- If patient has a disability – contact key disability service providing agency on admission
- If person has disability - disability service providing agency to give priority to contacts about hospitalization issues

9. RANGE OF SERVICES AND WAYS TO IMPROVE ACCESS, 17 STICKERS

- Collaboration between service providers to ensure "seamless delivery"
- Closer contacts between service providers
- Not too many services – gets too confusing
- Carer Respite Centre
- Local Council, community services
- Community Nursing
- Contact GP
- Better linkages with local government services, which are primarily short term only, and this means client does not have ongoing support
- Improved access to emergency respite or post hospital support packages
- Call Commonwealth Care Link
- Improved processes for contact with GP by hospital
- Carer to contact social worker if available in the primary care services
- Other services
- Acknowledgement that council's business is not about providing high level care support. This is something forgotten
- Better communication between hospital – carer / services
- To develop network of providers to meet quarterly to address ongoing issues
- Pool of equipment for use on discharge or system to acquire it quickly

REFERRAL, 3 STICKERS

- For risk criteria to be developed and service put in place according to risk
- Protocol to ensure that referral actually happens
- Providing information and allowing consumer choices in what they consider most important

COMMUNITY PUBLICITY / PROMOTION OF SERVICES AVAILABLE

4 STICKERS

- Publicity: local newspaper taking up issues related to health can increase community awareness of issues / responses
- Less Brochures – more one to one conversations / communication with client and their families
- Identify services available for client. (They may not know what exists)
- Awareness of services (including eligibility, waiting lists, charges) to facilitate process of discharge back into community

LANGUAGE, 3 STICKERS

- Offer interpreters as a matter of course for people from CALD backgrounds
- Ensure client understands info provided call, interpreter if necessary or community support person
- If language barrier – appropriate referral to eg Ethnic Link Services

Your comments on Your Health Record are welcome and will assist in ensuring ongoing improvements in the provision of health care services. Please answer the following questions and return this form by placing it in Your Health Record and Care’s Info Kit Feedback collection box located in the Clinical Nurse Manager’s office of North 1B or South 2.

1. I am a: □ Ward Nurse
   □ Other health care provider (please specify)

2. Your Health Record has improved communication with my patient and his/her other health care providers in the community.
   Strongly agree □
   Agree □
   Undecided □
   Disagree □
   Strongly disagree □
   Comments: □

3. Your Health Record has improved my knowledge of health care providers in the community.
   Strongly agree □
   Agree □
   Undecided □
   Disagree □
   Strongly disagree □
   Comments: □

4. Your Health Record has improved the continuity of care with my patient and his/her other health care providers in the community.
   Strongly agree □
   Agree □
   Undecided □

5. Your Health Record is a useful tool for patients to use.
   Strongly agree □
   Agree □
   Undecided □
   Disagree □
   Strongly disagree □
   Comments: □

6. Do you think other patients would benefit from being provided with Your Health Record?
   □ Yes □ No
   Comments: □

7. What is the most useful aspect/section of Your Health Record?
   □
   □

8. What is the least useful aspect/section of Your Health Record?
   □
   □

9. Would you recommend any changes/additions to Your Health Record?
   □
   □

10. Do you have any further comments?
    (Please write on the back of this sheet if you need to)

Thank you for taking the time to complete this feedback form. Your comments are valuable in improving Your Health Record. YHR was developed by Hospital hOme Pathways, June 2004. HOP was a collaborative project funded by the Home and Community Care Program (HACC) & auspiced by Domiciliary Care. The record has been prepared for education & information purposes & does not constitute medical advice.
APPENDIX 7F: CARER’S INFO KIT PROVIDER FEEDBACK FORM

Your comments on the Carer’s Info Kit are welcome and will assist in ensuring ongoing improvements in the provision of health care services. Please answer the following questions and return this form by placing it in the Your Health Record and Carer’s Info Kit Feedback collection box located in the Clinical Nurse Manager’s office of North 1B or South 2.

1. I am a: □ Ward Nurse □ Other health care provider (please specify) ……………………………

2. The Carer’s Info Kit improved communication with my patient’s carer.
   Strongly agree ………………… □
   Agree ………………… □
   Undecided ………………… □
   Disagree ………………… □
   Strongly disagree ………………… □

   Comments: …………………………………
   …………………………………………………

3. The Carer’s Info Kit has improved my knowledge of support for carers in the community.
   Strongly agree ………………… □
   Agree ………………… □
   Undecided ………………… □
   Disagree ………………… □
   Strongly disagree ………………… □

   Comments: …………………………………
   …………………………………………………

4. The Carer’s Info Kit has improved the continuity of care with my patient and his/her carer and/or other health care providers in the community.
   Strongly agree ………………… □
   Agree ………………… □
   Undecided ………………… □
   Disagree ………………… □
   Strongly disagree ………………… □

   Comments: …………………………………
   …………………………………………………

5. The Carer’s Info Kit is a useful tool for carers to use.
   Strongly agree ………………… □
   Agree ………………… □

   Undecided ………………… □
   Disagree ………………… □
   Strongly disagree ………………… □

   Comments: …………………………………
   …………………………………………………

6. Do you think other carers of patients would benefit from being provided with the Carer’s Info Kit?
   □ Yes □ No

   Comments: …………………………………
   …………………………………………………

7. What is the most useful aspect/section of the Carer’s Info Kit?
   …………………………………………………
   …………………………………………………
   …………………………………………………

8. What is the least useful aspect/section of the Carer’s Info Kit?
   …………………………………………………
   …………………………………………………
   …………………………………………………

9. Would you recommend any changes/additions to the Carer’s Info Kit?
   …………………………………………………
   …………………………………………………
   …………………………………………………

10. Do you have any further comments?
    …………………………………………………
    …………………………………………………

   Thank you for taking the time to complete this feedback form. Your comments are valuable in improving Your Health Record. YHR was developed by Hospital Home Pathways, June 2004. HOP was a collaborative project funded by the Home and Community Care Program (HACC) & auspiced by Domiiliary Care. The record has been prepared for education & information purposes only & does not constitute medical advice.
PATIENTS GET ‘YOUR HEALTH RECORD’ (YHR) IF:

✔ Aged 65 + or with a disability 18 years +

✔ Lives in the region (check suburb and post code list attached)

✔ ASAP during admission

✔ Discharge HOME

PATIENTS NOT ELIGIBLE:

- not discharged home
- confused or cognitive impairment
- Refuses
- Palliative

CARERS GET CARERS INFO KIT (CIK) IF:

✔ Care for patient who is aged 65 years + or has disability 18 years +

✔ Lives in the region (check suburb and post code list attached)

✔ When care-recipient is discharged HOME

CARERS NOT ELIGIBLE:

- Carers looking after someone not being discharged home
- Refuses
- Looking after someone who is palliative

WHAT DO YOU NEED TO DO?

1. Identify which patient(s) and/or carer(s) are eligible and label YHR on Handover Sheet in ‘Discharge Planning’ (N1B) or ‘Comments’ (S2) column
2. a) Approach patient, and cover the following points:
   ▪ is a trial
   ▪ is free
   ▪ BENEFITS
     o keeps all health information together
     o helps manage your health care in the best possible way
     o belongs to you - you decide what details are included
   ▪ health care providers cannot look at it without your permission
   ▪ is voluntary - if you refuse, health care will continue as usual
   ▪ CAN YOU PLEASE TAKE IT WITH YOU EVERY TIME YOU SEE YOUR LOCAL DOCTOR, SPECIALIST, COMMUNITY SERVICE PROVIDER & WHENEVER RETURNING TO HOSPITAL
2. b) Approach carer, and explain

- Carers often need care and support for themselves, and are often not aware of services in the community that can help
- CIK can put you in touch with services in the community that could help you
- CIK is free

3. For YHR, you need to:

i) Show patient ‘While you are in hospital…plan for your return home’ brochure. Ask patient (and his/her carer, family and friends) to read it. Offer help, if needed.


iii) During discharge planning, start ‘Your Health and Community Services’ pamphlet. Get patient to sign Page 1. On Page 2, tick boxes of service(s) contacted, or add the name if service is not listed, fill in date when contact made.

AND…..

PLEASE fill out as many ‘Your Health Record Provider Feedback Form’(s) and ‘Carer’s Info Kit Provider Feedback Form’(s) as you are able and place in box provided!!!

ONE LAST THING............THANK YOU!!!
APPENDIX 6

Features of Successful Hospital Discharge Planning

Feature of successful discharge planning that hospital nurses wanted to maintain included having a designated ‘discharge planner’ nurse, whose role and responsibility was to plan and organise patients’ discharge. This position needed to be rotated among the nursing staff, as to be effective and efficient discharge planners they needed continuous education about community services. A discharge planner nurse was most needed during the day shift from Monday and Friday, as sometimes there could be 10 discharges and 10 admissions on the same day.

Weekly discharge planning meetings helped with developing discharge plans, and were preferred over piecemeal planning done on a daily basis as this was less efficient. Doctors’ attendance at weekly discharge planning meetings involved them in the discharge plan and the multidisciplinary team, which also included social workers, physiotherapists, occupational therapists and other allied health professionals. Not all the teams that operated in each ward had weekly discharge planning meetings, but those that did made an important contribution to the patient’s transition to their discharge destination. The nurses wanted greater emphasis placed on the making of referrals early, especially those made by doctors. More consultation with family and/or carers and education of family and/or carers was considered as an area that could be improved upon.

An existing nursing admission assessment tool worked well to predict services. Handover sheets, updated every morning and afternoon, were also very useful. However, it was felt that both of these could be improved by providing more detail, especially when discharge was getting closer. A discharge planning checklist was suggested to ‘keep us on track and let us know what needs to be done’.

Community nursing involvement within the hospital via the ‘Community Nursing Liaison Nurse’ played an important and valued role. The nurses thought that this type of position for all the major CSPs would improve discharge planning, the hospital’s linkage into the community and the relationship between the hospital and the community sector. The nurses valued the work done by community sector agencies such as domiciliary care, community nursing and Meals On Wheels, but they also recognised that these agencies were overwhelmed by the ‘demographics of the area and the ageing population’ and understood that it was a case of demand exceeding supply.
Follow-up of patients after discharge to ensure that the services had arrived was generally not the regular practice of nursing staff. They did not consider it was their responsibility to follow-up patients once they had left the hospital. They were aware that follow-up was pursued by some specialised areas from within the hospital, such as social work, or services that the hospital provided for cardiac patients, for example. If a patient had been referred to community nursing or domiciliary care, the nurses believed that it was the job of these services to provide the follow-up. Checking before departure to ensure that all the services were in place was considered sufficient. If services hadn't arrived, the nurses may or may not find out. Some patients rang the ward to let them know if services hadn't arrived.
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